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Lisa Ann Lumley
LDanLee98531@gmail.com

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EXPLORING THE LIVED EXPERIENCE OF SIGNIFICANT OTHER CAREGIVERS PROVIDING CARE TO PARTNERS SURVIVING A SPINAL CORD INJURY

A Dissertation Submitted to Molloy University
The Barbara H. Hagan School of Nursing & Health
Sciences PhD in Nursing

In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

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by

LISA ANN LUMLEY
Susan Ann Vitale, PhD, RN, PNP, ANP, Dissertation Supervisor

October 2023

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Molloy University

The dissertation committee of the Barbara H. Hagan School of Nursing has examined the dissertation titled

EXPLORING THE LIVED EXPERIENCE OF SIGNIFICANT OTHER CAREGIVERS
PROVIDING CARE TO PARTNERS SURVIVING A SPINAL CORD INJURY

Presented by LISA ANN LUMLEY

A candidate for the degree of Doctor of Philosophy

And hereby certify that the dissertation was read and approved by the committee.

Susan Ann Vitale

Susan Ann Vitale, PhD, RN, PNP, ANP (Chairperson)
Professor, The Barbara H. Hagan School of Nursing & Health Science, Molloy University

Margaret Whelan

Margaret Whelan, Ed.D., APRN, FNP-BC (Committee Member)
Professor, The Barbara H. Hagan School of Nursing & Health Science, Molloy University

Kathleen Maurer Smith

Kathleen Maurer Smith, PhD (Committee Member)
Professor Emerita, Molloy University

Jennifer Mannino

Jennifer Emilie Mannino, PhD, RN, CNE
Professor and Director of the PhD in Nursing Program
The Barbara H. Hagan School of Nursing & Health Sciences, Molloy University

Date: 10/16/2023

ABSTRACT

According to the World Health Organization, 250,000 to 500,000 people worldwide have suffered a spinal cord injury. Significant others may become caregivers responsible for meeting the needs of the dependent partner. The focus of this study is on significant other caregivers' experiences providing care for partners after a spinal cord injury.

The effects of stress from providing care may be detrimental to caregivers' psychological and physical well-being. Psychological distress, such as anxiety and depression in caregivers, is a significant public health issue that affects the quality of life for millions of individuals. There is a lack of studies focusing on the lived experiences of significant other caregivers in committed relationships with partners after a spinal cord injury. It is not known how caregivers navigate changes in their relationships and lives. Hence, a qualitative research study was conducted guided by a descriptive phenomenological methodology.

The purpose of this study was to explore caregivers' experiences. To add to nursing knowledge, the research question is, what is the lived experience of significant other caregivers who provide care to partners surviving a spinal cord injury? Through analysis of in-depth interviews with significant other caregivers via Zoom, a detailed description, and essence of their lived experiences were investigated. Nurses must know the caregivers' lived experiences to adequately provide anticipatory guidance.

Purposive sampling and snowballing were used to recruit participants from online support groups and/or collegial referrals. The online groups were comprised of various significant others who are primary caregivers for partners with a spinal cord injury. Meleis' transitions theory provided a framework for this study. Data analysis was conducted using Colaizzi's method of member checking. Results were reviewed after data collection and analysis.

DEDICATION

This research study is dedicated to all the incredible participants who work through the daily challenges of caring for their partners with a spinal cord injury. Their openness and willingness to share their personal experiences as caregivers were sincerely appreciated. During one of my darkest days, shortly after my husband's accident, my mother gave me a small wooden sign that read, "You never know how strong you are until being strong is the only choice you have." This has become one of my most important life mantras. The participants of this study live this quote every day. They are all truly "Women Warriors."

During my course of studies in Molloy University's doctoral program, an assignment in one of Dr. Margaret Whelan's courses was to create Haiku poems depicting a concept of interest. It is my hope that these two poems will invite readers to ponder what life is like as a caregiver to a partner after a spinal cord injury before reading this dissertation.

Haiku
By Lisa Ann Lumley
Life can change quickly
Caregiving becomes your role
Tough, distressing, love

In sickness and health
Caring is an act of love
Heavy load to bear

PREFACE

My own experience as a caregiver to my husband, who survived a spinal cord injury approximately seven years ago, and as a registered professional nurse fueled my curiosity to explore the lived experiences of other significant caregivers providing care for their partners after spinal cord injuries. After a thorough review of the literature, a significant gap in the body of knowledge specifically aimed at significant other caregivers caring for their partners with spinal cord injuries was identified. Most studies addressed caregivers of aging parents, special needs children, or partners with other diagnoses such as cancer and Alzheimer’s disease. No studies specifically addressed the special population of significant other caregivers who chose to be caregivers to their partners after spinal cord injuries. Thus, my interest was further piqued, and the framework for this research study was created.

I feel honored to have been allowed to hear the experiences of twelve incredible women and explore this phenomenon. I hope this study's findings will add to the body of nursing knowledge and raise awareness of the importance of including significant other caregivers as integral healthcare team members when caring for clients with spinal cord injuries.

The study participants openly shared some of their innermost feelings with me and were truly happy to share their stories. For them, it seemed cathartic to be listened to and have their feelings and experiences somehow validated by this research study. Their strength, resilience, and sense of commitment to their partners and their relationships with their partners were unshakable and remarkable.

For those partners whose lives have been turned upside down by their partners’ spinal cord injuries, I am humbled to have been able to be your confidante. It is my hope that this research will help in some way to enlighten fellow nursing colleagues as to the worth and importance of significant other caregivers. Embracing significant other caregivers as integral members of the healthcare team will not only benefit their well-being but hopefully have a positive effect on the well-being of their partners who have painstakingly survived a life-changing spinal cord injury. Post-injury, the participants' lives will never be the same. Reflecting on this experience, I realize that my life will never be the same since hearing their stories. Their words echo in my head and remind me of the precious nature of life, love, and true commitment to one another. Conducting this study has reinforced for me that despite life's challenges, love conquers all.

ACKNOWLEDGMENTS

First and foremost, I would like to wholeheartedly acknowledge my husband, Daniel C. Lumley, who miraculously survived a traumatic spinal cord injury with less than a one percent chance of living. Dan, you are my Superman and inspiration for this project. A heartfelt thank you for not letting me use you "as an excuse" for not achieving my lifelong dream of pursuing a doctoral degree. You are the strongest, bravest person I have the honor of knowing. I am eternally grateful to God every day for you.

I would like to thank my amazing children, Dean, Emily, Daniel, Lauren, John, and JC, for their support and encouragement. Their unwavering cheerleading kept me going, especially when I felt like quitting. No accomplishment is better than being your mother.

Thank you, my parents, Anna and Victor Morgan, for believing in me and always telling me that if I put my mind to it, I could do anything. I am a strong, fearless woman today because of both of you.

A huge acknowledgment to my dissertation chairperson, Dr. Susan Ann Vitale, who continually fostered my passion for qualitative research. Her wisdom, guidance, and encouragement were integral in completing this dissertation.

I sincerely thank my committee members, Dr. Kathleen Maurer-Smith and Dr. Margaret Whelan. Their time and sharing of their expertise were greatly appreciated. Their feedback and concern for my own well-being were invaluable.

A special thank you to Dr. Jennifer Mannino, Director of Molloy University's Doctoral in Nursing program. Her time and patience were outstanding and greatly valued, especially with editing and formatting.

The journey towards earning a PhD in Nursing is not one I traveled alone. I would like to humbly acknowledge my doctoral cohort, Patricia Brosnan, Blanca Clarfield, Macia Drummond, Victoria Marner, Shaneke Pryce, and Megan Ventrello, also known as Cohort X. You are all brilliant, and it was an honor to have traveled this journey with each of you by my side.

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CHAPTER 1: INTRODUCTION

Surviving a life-altering spinal cord injury is traumatic and may result in lasting issues for the survivor. When there is a dyadic relationship, and a spouse or partner is involved, secondary issues may evolve and subsequently be problematic long after the actual injury. Significant others of partners who suffered a spinal cord injury may be burdened with the responsibility of meeting the physical and psychological needs of their dependent partners. This dynamic often causes psychological distress for caregivers. Effects of distress on significant other caregivers can harm their overall psychological and physical well-being (Geng, Chuang, Yang, et al., 2018).

Background

In 2018, the number of people living with spinal cord injuries in the US was estimated at 288,000 persons, with approximately 17,700 new spinal cord injury cases occurring annually in the United States (National Spinal Cord Injury Statistical Center, 2018). When a spouse or partner survives a life-threatening spinal cord injury, personal needs requiring help are often the result. Significant others become caregivers responsible for meeting the physical and psychological needs of the dependent partner (Adelman et al.,2014).

Traumatic, life-altering spinal cord injuries are unexpected, and those involved are ill-prepared to deal with the aftereffects of the injury. Although victims of spinal cord injuries must bear the burden of suffering, when the injury happens to someone who is married or in a committed relationship, the significant other in the relationship is very likely to shoulder the additional role of caregiver. When partners have physical and/or mental limitations because of the injury, the spouses or partners must rise to the occasion to meet the dependent partner’s needs and to manage family obligations such as work outside the home, finances, overall household demands, and meeting other family members’ needs.

Being a caregiver is a taxing experience where personal needs become secondary. Since their partners may be unable to work due to a spinal cord injury, significant others may need to work outside of the home, adding additional stress to their already stressful lives. The stressful effects of caregiver burden can harm caregivers' psychological and physical well-being. Family caregiver psychological distress is a worrisome issue in today's society. Forty-five percent of caregivers experience anxiety, while forty-two percent suffer from depression (Geng, Chuang, Yang et al., 2018). Caregiving has been identified as "an important public health issue that affects the quality of life for millions of individuals." (Centers for Disease Control and Prevention, 2018) Significant other caregivers are essential in providing quality care for their partners. The overall wellness of their loved ones is at stake if caregivers' physical, psychological, and financial well-being is compromised (Adelman et al., 2014).

Approximately 1 in 5 Americans (21.3%) are caregivers, and caregiving occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations (AARP & NAC, 2020). There are approximately 53 million adult caregivers in the United States today, which is up from about 43.5 million in 2015 (AARP & NAC, 2020). For those who care solely for adults, the prevalence has increased from 16.6% in 2015 to 19.2% in 2020 (AARP & NAC, 2020). The number of caregivers 50 years and older has increased from 14.3% in 2015 to 16.8% in 2020 (AARP & NAC, 2020). One could surmise that spinal cord injuries may be the cause of some of the disabilities requiring care.

Problem Statement

Research has been conducted on caregiver burden, caregiver distress, and other detrimental effects of being a caregiver, but no studies have been located focusing on the lived experiences of significant other caregivers who are in intimate relationships with a dependent partner after a spinal cord injury. The physical changes that occur as a result of a spinal cord injury place a considerable strain on significant other caregivers and may change the couples' relationship overall. It is not known how significant other caregivers navigate changes in their relationships and life after a traumatic spinal cord injury of their partner. Therefore, a qualitative research study guided by phenomenological methodology was conducted. Phenomenological studies seek to describe commonalities in the meaning for individuals of their lived experience of a concept or phenomenon (Creswell & Poth, 2018).

Purpose

The purpose of the study was to reveal issues of concern and to identify coping mechanisms for significant others caring for dependent partners after life-altering spinal cord injuries and to ultimately discover the meanings that caregivers ascribe to their experiences. To enrich one's understanding of a phenomenon, the meanings must come directly from those who are actually experiencing the phenomenon in their own words and descriptions (Van Manen, 2014).

Research Question

To gain insight into the phenomenon of significant other caregivers' experiences, the research question for this study is, 'What is the lived experience of significant other caregivers who provide care to partners surviving a spinal cord injury?' Through the analysis of numerous, in-depth interviews with significant other caregivers, a rich description of their lived experiences was investigated using this qualitative, phenomenological approach.

Significance of the Study and Relevance to Nursing

Psychological distress experienced by caregivers providing care for a dependent loved one who has survived a life-threatening event is a significant issue in today's society. An extensive amount of research has been published about caregiver burden and psychological distress in the last decade (Abreu, et al.,2018; Adelman, et al., 2014; Geng, et al., 2018; Hagedoorn, et al., 2002; Kanmani & Raj, 2018; Zarit, et al., 1986). Despite this literature, there is a lack of published studies that focus on the lived experiences of significant other caregivers in committed relationships with a dependent spouse after a spinal cord injury.

To add to the body of nursing knowledge in this area, a qualitative study rooted in phenomenology was conducted to explore the true essence of significant other caregivers' experiences providing care to their dependent partners after a spinal cord injury. To adequately assess and provide anticipatory guidance, nurses must know various facets of the caregivers' lived experiences. An increased understanding of this phenomenon will provide nurses with a framework to assist caregivers in navigating seamlessly through the complex transition process. A successful transition to the caregiver role may potentially minimize the incidence of psychological distress and its resultant consequences.

This study is important to generate new knowledge for the nursing profession regarding the crucial role of significant other caregivers. When a person sustains a spinal cord injury, the primary focus is on the patient's well-being. However, becoming a caregiver for the injured individual makes one vulnerable to the associated effects of the physical and psychological demands of the role. Providing care to a dependent partner is stressful. Nurses can help ease some of this stress. Ducharme, et al. (2011) posited that "providing proactive nursing assessment and interventions early in the caregiver role transition may support and better prepare a caregiver to make a healthy transition to this newly assumed role." (Ducharme, et al., 2020, p. 1110).

Nurses practicing in hospitals have the unique privilege of being present when clients are admitted after a life-altering event. These nurses may meet clients' partners who may assume care provision after discharge. Nurses must understand that the partners' entire life has been disrupted. They can provide education to help caregivers make a smooth transition. Education can take several forms including skills training such as proper transferring, meeting incontinence needs, and medication administration. Nurses can educate caregivers on warning signs of emotional distress so that they are aware of when to reach out for help if needed. Meleis (2020) discussed the property of awareness in the transition process. Kindarara et al. (2017) explained that "awareness influences engagement." (p. 516). If caregivers are aware of their own feelings, they may seek support if they are experiencing any distress. If caregivers are engaged in their partners' care and well-being, they can be proactive in their approach and feel empowered to provide quality care.

Researcher Assumptions and Biases

To lay bare any assumptions and preconceived biases, it is necessary for this researcher to reveal her situated context. In 2016, my husband sustained a T-3 – T-4 complete spinal cord injury, rendering him a paraplegic paralyzed from the middle of his chest down. I have been his primary caregiver since his discharge from rehabilitation. In addition to being the primary caregiver for my spouse, I have been a Registered Professional Nurse since 1987. To minimize bias, this researcher used bracketing to objectively interview participants. This researcher avoided revealing personal experiences or opinions to avoid having an influence on the participants' responses and redirected the interviews to the participants' experiences as needed.

Method of Inquiry

A descriptive, qualitative, phenomenological research methodology was utilized to explore the lived experiences of significant other caregivers. Phenomenology was utilized to investigate significant other caregivers' lived experiences and attempt to ascribe meaning to their experiences. Van Manen (2014) describes phenomenology as work that is oriented toward lived experiences.

Limitations

An identifiable limitation may be the small number of qualitative versus quantitative study participants. The sample size was determined as the study proceeded, and no new themes emerged. For this study, a total of 12 participants were interviewed.

Another expected limitation was a gender imbalance in the sample since all participants were female. Considering that 78% of all new spinal cord injuries are males (National Spinal Cord Injury Statistical Center, 2018), the sample of significant other caregivers may be largely females. In addition, the recruitment of participants for the study occurred through two private Facebook support groups largely composed of women who are wives and girlfriends of partners with spinal cord injuries.

The sample for this study included significant others caring for partners with any level of spinal cord injury, and selection was not limited by the level of injury or disability of the partner. Experiences differed depending on the location of the dependent partner’s spinal cord injury. Higher levels of injury in the spinal cord yield more physical limitations and thus require a higher level of care.

Delimitations

All participants were adults over the age of 21 years, English-speaking, in a committed relationship with a partner who had sustained a spinal cord injury, and in the role of their partner’s primary caregiver. Participants were enrolled in the study without bias regarding gender identification, ethnicity, religious affiliation, sexual orientation, marital status, and/or socio-economic backgrounds.

Summary

Significant others caring for partners who have sustained spinal cord injuries face unique challenges. There is little known about the transition, as the role of caregiver evolves from the perspective of significant others caring for a partner with a spinal cord injury. Based on what has been learned from the literature review, this researcher believes that exploring the lived experiences of significant others caring for partners with a spinal cord injury may help bridge the existing gap in nursing knowledge. It is hoped that the findings from this research will be utilized to assist significant others in coping with the challenges of being caregivers and in their intimate relationships with their partners after spinal cord injury.

CHAPTER 2: LITERATURE REVIEW

The purpose of this review is to present the literature pertaining to caregivers of partners with significant physical limitations. Although the primary focus is on significant other caregivers of partners paralyzed because of spinal cord injury, relevant publications about caregivers with other limiting conditions are included. This chapter is divided into sections that relate to the research question. Section one provides an overview of a spinal cord injury and the multiple facets involved in this diagnosis. The second section presents the research highlighting caregivers' incidence in the United States. The third section presents the occurrence of psychological distress in caregivers. Section four reviews internet interventions for caregivers. Sections five and six review literature related to Meleis' transitions theory. In section seven, the terms used in this study are described as they are found in the published literature. This chapter will guide the reader through available literature about caregiving and related concepts.

Spinal Cord Injury

The sample for this proposed study included significant others caring for partners with any level of spinal cord injury, and selection was not limited by the level of injury or disability of the partners. The Mayo Clinic (2022) defines a spinal cord injury as “damage to any part of the spinal cord or nerves at the end of the spinal canal (cauda equina) that often causes permanent changes in strength, sensation and other body functions below the site of the injury.” When a spinal cord injury is complete, all sensory feeling and ability to control movement and motor function below the level of injury is lost. With incomplete spinal cord injuries, there are some motor and sensory functions in varying degrees for different injuries (Mayo Clinic, 2022). Spinal cord injuries are classified by degree of injury. Kretzer (2016) explained that “the standard neurological classification of spinal cord injury provided by the American Spinal Injury

Association (ASIA) assigns grades from ASIA A (complete spinal cord injury) through ASIA E (normal sensory/motor), with B, C, and D representing varying degrees of injury between these extremes." (p.S27)

Injuries to the spinal cord may result in paralysis. Tetraplegia or quadriplegia indicates that sensory and motor functions in one's arms, hands, trunk, legs, and pelvic organs are affected. Paraplegia indicates that sensory and motor function is affected in all or part of the trunk, legs, and pelvic organs. Symptoms of spinal cord injury include one or more of the following: loss of movement, loss of or altered sensation, including the ability to feel heat, cold, and touch, loss of bowel or bladder control, exaggerated reflex activities or spasms, changes in sexual function, sexual sensitivity and fertility, pain or an intense stinging sensation caused by damage to the nerve fibers in the spinal cord, difficulty breathing, coughing or clearing secretions from the lungs (Mayo Clinic, 2022).

The causes of spinal cord injury vary and include vehicular crashes, falls, acts of violence, sports, medical/surgical complications, and other causes (NSCISC, 2018). Vehicular crashes are identified as the leading cause of spinal cord injury at 38.3%, with falls the second leading cause at 31.6% (NSCISC, 2018). Kretzer (2016) identified the causes of spinal cord injury as trauma (motor vehicle accidents, sports, violence, falls), degenerative spinal disease, vascular injury (anterior spinal artery syndrome, epidural hematoma), tumor, infection (epidural abscess), and demyelinating processes.

The World Health Organization (WHO, 2013) estimated that 250,00 to 500,000 individuals worldwide suffer spinal cord injuries annually. The estimated annual global incidence is 40 to 80 cases per million population worldwide. Approximately 90% of spinal cord injuries are a result of trauma, although the cases of non-traumatic spinal cord injuries are increasing (WHO, 2013). About 78% of new spinal cord injury cases are male (NSISC, 2018).

Incidence of Caregivers in the United States

The American Association of Retired Persons (AARP) and the National Alliance of Caregiving (NAC) (2020) conducted a quantitative study that presents an overview of unpaid family caregivers. That study notes that approximately one in five Americans (approximately 21.3%) are caregivers and that caregiving occurs among all generations, racial/ethnic groups, income or educational levels, family types, gender identities, and sexual orientations. The report concludes that there are nearly 53 million adult caregivers in the United States today, up from about 43.5 million in 2015 (AARP & NAC, 2020). When examining the incidence of those who care solely for adults, the prevalence has increased from 16.6% in 2015 to 19.2% in 2020 (AARP & NAC, 2020). The number of caregivers 50 years and older has increased from 14.3% in 2015 to 16.8% in 2020 (AARP & NAC, 2020). The Centers for Disease Control (CDC, 2018) identifies caregiving as "an important public health issue that affects the quality of life for millions of individuals." Although that study does not necessarily define why care is needed, considering the large number of spinal cord injuries in the U.S. annually, one could surmise that spinal cord injuries may be the cause for some of the disabilities requiring care.

Caregiver Psychological Distress

An extensive literature review revealed a great deal of information related to the psychological distress of caregivers whose partners have survived a traumatic event (Abreu et al., 2018; Geng et al., 2018; Hagedorn et al., 2002; Kanmani & Raju, 2018; Zarit et al., 1986). It is apparent that caregiver psychological distress is a prevalent phenomenon. Several articles and studies noted that female caregivers are more likely than male caregivers to experience distress.

For those who take on the responsibility of caring for partners with a debilitating or limiting disability from a spinal cord injury, it is often a challenging experience in which personal needs become secondary. Since many persons who suffer a spinal cord injury are young and at their peak earning potential when they become injured, often they may be unable to work for extended periods of time and may not be able to return to work at all after the injury. In addition to being caregivers, many individuals need to work outside of the home to provide financial support, adding additional stress to their already stressful lives. Effects of stress from caregiver burden can be detrimental to caregivers' psychological and physical well-being. Psychological distress in family caregivers is a significant issue plaguing today’s society. Geng et al. (2018) cited that forty-five percent of caregivers experience anxiety, and approximately forty-two percent suffer from depression. Significant other caregivers are essential in providing quality care for their loved ones. If caregivers’ physical, psychological, and financial well-being is threatened, then the overall wellness of their loved ones may be at stake as well (Adelman et al., 2014).

In a quantitative, comparative study review, Ahmad and Khan (2018) aimed to compare the level of distress among male and female caregivers. The authors asserted that caregivers reported experiencing psychological distress and exhibited feelings of loss, grief, uncertainty, shame, guilt, and anger (p. 94). They described caregivers as “secondary patients who need and deserve protection and guidance.” (p. 93). The authors explained that caregiving is stressful and that chronic stress increases the risk of disease, and chronic illness in caregivers is a prevalent problem. The stress associated with being a caregiver initially results in a negative effect on psychological well-being, but as it continues, the stress may negatively affect the caregiver’s physical well-being (Ahmad & Khan, 2018). Caregivers are so busy caring for their loved ones that caring for themselves is not the priority.

Kanmani and Raju (2018) described caregivers as experiencing “physical, emotional, psychological problems, caregiver burden, dissatisfaction and unmet psychological needs.” (p. 54) In that study, caregivers are described as “emotionally disturbed” and demonstrating “crying, sadness, helplessness and hopelessness.” (Kanmani & Raju, 2018, p. 57) These symptoms are in alignment with the symptoms described in Ahmad and Khan’s comparative study (2018) and clearly exhibited the psychological distress experienced by caregivers caring for dependent partners. Being the sole caregiver is emotionally and physically draining, with minimal opportunity to care for oneself.

Hagedorn, et al. (2002) explained how intimate partners of patients surviving life-threatening events deal with “fears, such as losing their loved one, and may have to take an active role in caregiving.” (p.482) They provided evidence that female caregivers report more symptoms of psychological distress than their male caregiver counterparts. The authors explained that often, female caregivers report feeling more competent in the caregiver role than males, but when the role of caregiving becomes overwhelming, the females may suffer more signs of psychological distress. Not being able to adequately care for a loved one in need may cause great distress. Considering the potential physical limitations of dependent partners, caregiving is challenging at best and may result in psychological distress on the part of significant other caregivers. Additionally, it seems feasible that caregivers who have lived through nearly losing an intimate partner may experience fear of losing their loved ones even after the immediate threat is gone. Recollections of a traumatic, life-threatening event may increase the likelihood of psychological distress in caregivers (Hagedorn et al., 2002).

Abreu, et al. (2018) conducted a community-based, cross-sectional study aimed to evaluate the degree of psychological distress in family caregivers of people with dementia. Although this study did not focus on significant others caring for partners with a spinal cord injury, parallels could easily be established among the caregiver roles. The participants included 108 persons who made up dyads that included persons with dementia and family caregivers living in Porto District, Portugal. Variables examined in this study included age, gender, marital status, education level, relationship to the person with dementia, employment, and years of caregiving. Family caregivers completed a tool entitled Brief Symptom Inventory (BSI). The BSI is a 53-item questionnaire covering nine symptoms of depression: somatization, obsession–compulsion, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The completed questionnaire revealed a positive symptom total (PST) as the dependent variable, indicating the level of caregiver distress. The persons with dementia were evaluated using the Clinical Dementia Rating (CDR) to assess the level and severity of dementia. The caregivers showed significant value in psychological distress in six dimensions: somatization, obsessive-compulsive, interpersonal sensitivity, anxiety, hostility, and paranoid ideation. This psychological distress may seriously threaten caregivers' psychological and physical well-being, which could impede the caregivers' ability to care for their dependent family members. The study showed that higher levels of dependency and severity of dementia increase the likelihood of greater psychological distress in caregivers.

Abreu, et al. (2018) noted several limitations making generalization difficult. One limitation was that the caregiver's adjustment to dementia may be shaped by culture, and the study was conducted in Portugal. Another limitation was that the BSI was long and extremely time-consuming. Lastly, the small number of participants in that study limited the use of other statistical analysis methods. The authors concluded that there is a need for a more comprehensive screening tool for psychological distress in the family caregiver and a need for more effective interventions for the caregiver to cope with the effects of psychological distress.

All the reviewed studies of caregivers experiencing psychological distress align with one another and describe similar critical attributes such as depression and anxiety. They describe experiencing similar symptoms of psychological distress while caring for a dependent partner.

Internet Interventions for Caregivers

Kaltenbaugh, et al. (2015) conducted a systematic review including six research studies. A total of 795 articles were found in the literature, but only six studies met the inclusion criteria set by the review's authors. This systematic review focused on exploring the literature to examine the physical, social, psychological, financial, usability, and feasibility outcomes of web-based interventions on caregivers of people with cancer and to identify potential trends. Each study examined in this review involved administering an intervention over the Internet with varied approaches ranging from single to multicomponent modalities. Most of the caregivers in the included studies were middle-aged females caring for spouses who had some college education and a moderate sense of comfort with technology and Internet use. The interventions in these web-based services were either single or multimodal and aimed to reduce negative feelings and moods (Kaltenbaugh, et al., 2015).

One limitation of this systematic review is that it was conducted in 2014. In the six years since the completion of this systematic review, there have been many advances in technology, including face-to-face modalities of socialization such as videoconferencing. This systematic review concluded that web-based interventions are beneficial for providing information and support for caregivers. It was noted that few studies addressed interventional perceptions, needs, and screening for psychological distress in family caregivers. This gap indicates a need for further research in this area.

Theoretical/Conceptual Framework: Meleis' Transitions Theory Overview

Meleis' transitions theory results from over 40 years of clinical work and research (Meleis, 2020, p. 355). The Transitions Theory identifies four distinct situations that trigger a transition. These triggers include a change in health or illness and developmental, situational, and organizational transitions. The Transitions Theory characterizes the transition using several descriptive properties. These properties include time span, process, disconnectedness, awareness, and critical points. Meleis concluded that personal, community, societal, and global factors influence how one responds to a triggering change event. These responses to change can be observed and measured by examining the process and outcome patterns. Meleis further described the process pattern by breaking it down into stages. These stages include engagement, locating and being situated, seeking and receiving support with follow-up, and acquiring confidence. Meleis defined the outcome pattern as a point where the transition process has achieved an endpoint. Five patterns of outcome responses include mastery, fluid and integrative identity, resourcefulness, healthy interaction, and perceived well-being (Meleis, 2020).

Application of Meleis' Transitions Theory to Caregivers

Transitioning from a partner to a caregiver after the other life partner survives a life-altering spinal cord injury is wrought with emotional, mental, and physical challenges. Meleis (2020) explained that transitions occur because of a trigger. With transitioning to a caregiver role, the trigger is a change in health or an illness situation. The role of becoming a caregiver is often abruptly thrust upon those who must make a choice to either stay in the relationship and be a caregiver or leave the situation altogether. This soul-searching process may be difficult for some who may struggle with the harsh reality of caring for a dependent partner and the tremendous shift in the relationship. Some relationships may end, thus relieving the healthy partner of caregiver duties, while those who make a conscious choice to assume the role of caregiver face transitioning into the role and assuming the extra associated responsibilities.

The caregiver transition process begins when a partner has a catastrophic event such as a spinal cord injury. This event creates a situation whereby caregivers describe life as ‘before’ and ‘after.’ Part of the caregiver’s transition process, as described by Meleis, is a sense of disconnectedness. Caregivers may experience a sense of loss in the way things used to be and may grieve the way the partner was before the spinal cord injury. The transition experience totally disrupts caregivers’ lives, and changes preconceived hopes for the future. For effective adaptation to occur, eventually, caregivers need to accept the current situation and let go of what their lives were like before the spinal cord injury. This process is not linear and may take some time.

Based on Meleis’ transitions theory, certain conditions may affect the progression of a caregiver through the transition process. These conditions include personal, community, societal, and global factors, as outlined in Meleis’ transitions theory. One’s own values and meaning of life may be threatened by a major change caused by one's partner becoming disabled because of a spinal cord injury.

Meleis (2020) described the property of beginning to end of a transition as the time span period and further explained that, although the beginning may be definitive, the end of the process is more fluid. For caregivers, the time span begins when they realize the situation in which their partner will depend on them for care and ends when the skills and attitudes of being able to provide care are mastered, and the caregiver feels competent in the role. The transition typically ends when caregivers have a sense of well-being and feel that their life is one of quality despite being a caregiver.

Conceptual/Operational Definitions and Literature Review

To lay the foundation for this research study, terms and concepts were searched to reveal information in the literature. As part of an overall literature search, these terms are included below.

Caregiver burden: Adelman et al. (2014) pointed out that there is currently no International Classification of Diseases (ICD), Ninth Revision (ICD-9), or ICD-10 code for the concept of caregiver burden. Zarit, et al. (1986) completed a quantitative, longitudinal study of spousal caregivers and proposed a definition of caregiver burden as “The extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning.” (p. 260) The multidimensional tasks associated with providing care for a loved one may be overwhelming and add an undue burden to the caregiver. For this research study, caregiver burden will be defined by terminology and statements offered by participants.

Caregiver psychological distress: A review of the literature provided a more in-depth, healthcare provider-related definition of caregiver psychological distress. Ahmad and Khan (2018) defined a caregiver as “an individual who has the responsibility of meeting the physical and psychological needs of a dependent patient.” (p. 93) Psychological distress is defined as “a state of emotional suffering characterized by symptoms of depression (e.g., loss of interest, sadness, hopelessness) and anxiety (e.g., restlessness, feeling tense).” (Mirowsky & Ross, 2002, p. 152) Furthermore, Ahmad and Khan (2018) defined “distress” as “feeling upset, nervous, depressed or angry.” (p. 94) For the purpose of this study, psychological distress will be defined by individual participants' perceptions and descriptions of their feelings of being a significant other caregiver.

Significant Other: A significant other is defined as "a person who is important to one's well-being, especially a spouse or one in a similar relationship." (Merriam-Webster, 2022) Participants may include those who are in heterosexual or same-sex relationships, married or not married, but identify themselves as being in committed relationships.

Summary

This chapter reviewed the literature pertaining to caregivers of partners with significant physical limitations. Although the primary focus is on significant other caregivers of partners paralyzed because of spinal cord injury, relevant publications about caregivers with other limiting conditions were included. The review included studies on an overview of spinal cord injuries, the incidence of caregiving in the U.S., psychological distress among caregivers, potential interventions for caregivers, an outline of Meleis' Transition Theory, and terms used to describe caregiving.

Meleis' Transition Theory provides a framework for the transition the significant others need to make as they become competent in their role as caregivers to their dependent partners who survive a spinal cord injury. This theory and its applicability to significant other caregivers was examined further after data was collected from participant interviews.

No studies focusing on the lived experiences of significant other caregivers in intimate relationships with a dependent partner after a spinal cord injury were located during the literature review. This qualitative study aimed to explore the lived experiences of significant other caregivers and examined how these caregivers navigate changes in their relationships and life after a traumatic spinal cord injury of their partner.

CHAPTER 3: METHODOLOGY

This chapter provides a comprehensive overview of the methodology used for this research study. It will include the identified problem statement, the purpose or aim of the study, and the developed research question. A structured plan for recruitment of participants, data collection, and data analysis and management will be outlined in this chapter. Inclusion and exclusion criteria, ethical considerations, and the reflexivity of the researcher are also discussed in Chapter 3.

Problem Statement

Currently, no studies have been located focusing on the lived experiences of significant other caregivers who are in intimate relationships with a dependent partner after a spinal cord injury. When a partner survives a spinal cord injury, significant physical changes such as paralysis, sexual dysfunction, and loss of control of bowel and bladder may occur (Mayo Clinic, 2022). These physical changes adversely affect significant other caregivers who are responsible for providing care to their partners. The ways in which significant other caregivers navigate changes in their relationships and life after a traumatic spinal cord injury of their partner have not yet been explored. Thus, a qualitative research study, guided by descriptive phenomenological methodology, was conducted that explored the lived experiences of significant other caregivers providing care for their dependent life partners after a spinal cord injury.

Phenomenology is rooted in a philosophical approach developed by Husserl and Heidegger in the early 1960s (Polit and Beck, 2017). A phenomenological approach seeks to investigate subjective phenomena and believes that the truth lies within the experiences of the people who are living the actual phenomena. Polit and Beck (2017) asserted that a phenomenological approach is especially useful when a phenomenon has been poorly defined or conceptualized. Such is the case with the exploration of the lived experiences of significant other caregivers who are caring for their partners after a spinal cord injury. The literature is rich with studies about caregivers caring for family members with other significant diseases, such as cancer and Alzheimer’s disease, but no studies have been located that directly focus on significant other caregivers who have partners with a spinal cord injury.

Purpose

The purpose of the study was to explore the experiences of significant others caring for dependent partners after life-altering spinal cord injuries. The aim was to ultimately discover the meanings that caregivers ascribe to their experiences in their own words. Phenomenologists believe that lived experience gives meaning to each person’s perception of a phenomenon (Polit and Beck, 2018). Being exposed to the true meaning of other’s lived experiences can help the reader understand how significant other caregivers deal with everyday challenges and issues encountered while caring for their partner with a spinal cord injury.

Research Question

To gain insight into the phenomenon, the research question of this qualitative, phenomenological study was, ‘What is the lived experience of significant other caregivers who provide care to partners surviving a spinal cord injury?’ Through analysis of numerous in-depth interviews with significant other caregivers, a rich description of their lived experiences was investigated.

Qualitative Research Design

The purpose of this research study was to explore the lived experiences of significant others caring for a partner after a spinal cord injury. Considering the topic of this study, a descriptive, qualitative, phenomenological research approach seemed most appropriate to enhance one’s understanding of these lived experiences. Creswell and Poth (2018) posited that a phenomenological research study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon. A phenomenological approach seeks to describe the essence of a phenomenon by exploring it from the perspective of those who are experiencing it. Phenomenology seeks to find a commonality of shared lived experiences of a particular group. For this study, that group included a sample of twelve significant others caring for partners after a spinal cord injury. A phenomenological approach seeks to find meaning in one’s experiences as described by the individual in their own words and descriptions (Van Manen, 2014).

Recruitment Plan/ Sample Selection

Molloy University Institutional Review Board (IRB) approval was obtained prior to the commencement of this study (see Appendix A). Purposive sampling was used to recruit participants from two online support groups using Facebook as a platform. One group consists of wives and girlfriends caring for partners with spinal cord injury (WAGS of SCI). The WAGS of SCI group is a private group comprised of over 2,000 members from various states in the United States and Canada. This private group was created approximately 5 years ago, in 2018.

The second online group is comprised of various significant others who are primary caregivers for a partner with a spinal cord injury. This group is entitled ‘Spinal Cord Injury Spouse Support’ and comprises 552 members and was created approximately 7 years ago in 2016. Members are from various states in the U.S. and Canada.

Both online groups are private and solely inclusive of caregivers. Verbal permission was obtained to recruit participants from the administrators of both groups. This researcher gained access to these groups as a member of both. I am the primary caregiver for my husband who has a complete spinal cord injury with resultant paralysis from the middle chest area down. I was unfamiliar with any of the participants interviewed for this study.

To initially recruit participants, an IRB-approved advertisement flyer (Appendix B) was posted by the administrators within both groups via a social media platform asking for volunteers. Volunteers were asked to send a private message via email or call/text via phone to this researcher so that the study's expectations, purpose, and process could be presented. This researcher provided interested individuals with an IRB-approved letter describing the study by email (Appendix C). Participants were recruited until data saturation was reached, and this researcher believed that the selected sample produced an in-depth portrayal of the phenomenon under study.

Another recruitment strategy that was used for this study was snowballing. Participants were encouraged to tell other significant other caregivers who are caring for their dependent partners after a spinal cord injury about the study and provided them with this researcher’s contact information if they were interested in being a study participant. Colleagues of this researcher were made aware of this proposed study and were asked to provide this researcher’s information to any potential interested participants meeting the inclusion criteria. None of the participants enrolled were a result of participant or collegial snowballing.

Potential Risks

No anticipated physical, psychological, social, or legal risks were associated with participation in this study. All participants volunteered to participate and agreed to share their experiences to whatever degree they chose. Participants were asked to share the experiences that they selected themselves without coercion. Based on the preset inclusion criteria, all participants possessed the legal ability to give their own consent.

Due to the sensitive nature of the explored phenomenon, it was conceivable that the topics participants chose to discuss may be emotional and elicit unpleasant memories. If participants experienced any psychological or medical need during the interview process, an appropriate community referral or activation of the emergency response system via 911 would have been initiated. No referrals were indicated during the interviews.

Potential Benefits

No direct benefits, such as compensation, were derived from participation in this study. It is possible that the participants may have experienced personal benefit in having the opportunity to talk about their situation. They may also have found that by participating in this study, they may have gained a clearer understanding of the phenomenon and that their experiences may potentially help other significant other caregivers in similar situations.

Inclusion Criteria

All participants were adults over the age of 21 years, English-speaking, in a committed relationship with a partner who had sustained a spinal cord injury, and in the role of their partner’s primary caregiver. Participants were enrolled without bias regarding gender identification, ethnicity, religious affiliation, sexual orientation, marital status, and/or socio-economic backgrounds. Participants were not required to participate in the groups to participate in this study.

Exclusion Criteria

Participants were not enrolled if they did not meet the inclusion criteria.

Human Subject Considerations/Ethical Issues

Confidentiality

Human subjects' research requires specific consideration of the ethical rights of participants. In accordance with ethical and legal requirements, Institutional Review Board (IRB) approval was obtained from Molloy University before the start of this study. This researcher obtained permission from the administrators who oversee the online Facebook support groups for significant other caregivers caring for their partners after spinal cord injury to distribute invitational flyers to the support group participants via Facebook posts. The flyer that was created by this researcher was posted by the group's administrators (Appendix A). No personal identifying information such as address, family names, places of employment, and names of care providers/care services were collected during the interviews. Pseudonyms were used for all data collection. Participants chose a pseudonym to use during the interview and were instructed not to use any real names of places, partners, or family names. The participants were asked to change the online screen name that appeared on a Zoom video before the beginning of the recording. Participants were assured of strict confidentiality and guaranteed that all data would be de-identified. All participants were advised numerous times during the recruitment and interview phase that participation was strictly voluntary. Participation or declining participation did not affect their support group status. Additionally, being a member of one of these online support groups was not required to participate in this study.

Consent

All subjects were asked for verbal consent before obtaining written consent. An IRB-approved consent form clearly outlined the purpose of the study and any potential risks/benefits of participation for the participant (Appendix D). The approved consent form was signed by participants and emailed to this researcher before the start of each interview. Participants were encouraged to maintain a copy of the signed consent for their records. Participants were reassured of strict confidentiality and that all data would be de-identified.

Withdrawal or Discontinuation of Study

Participation in this research study was strictly voluntary. Participants were informed of their right to withdraw from the study at any time and could have chosen to withdraw from the study or stop an interview at any point without penalty. Any data obtained before withdrawal or discontinuation of the interview would be discarded and removed from data analysis. None of the recruited participants chose to withdraw at any point during the course of this research study. During the interview, this researcher was continually observant of any cues that the participant may need a break from the interview and offered to stop if the participant became visibly distressed. The participants had the opportunity to take a break or reschedule the interview for a later date and time, but none chose to do so.

Data Collection

The number of subjects in a phenomenological study is generally small, between 10-12 participants (Polit and Beck, 2017). Approximately 10-12 participants were anticipated before this study's start, and 12 participants were interviewed. After completion of the 12th interview, it was determined by this researcher that no new themes were emerging. After an informed consent form was signed, the participant chose to provide a recorded, one-hour interview by Zoom on a day and time of the participant’s choosing. At the start of the interview, participants were asked to answer several demographic questions, including the following (Appendix E):

1. What is your current age?
2. What gender do you identify as?

3. What is your education level?
4. Do you work outside the home, and if so, what is your occupation?
5. What is your relationship with your partner?
6. How long have you been in a committed relationship with your partner?
7. Do you have children together?
8. When and how did your partner's spinal cord injury occur?
9. What is the level of your partner's spinal cord injury such as cervical, thoracic, lumbar region)?
10. Were you in a relationship with your partner before his/her spinal cord injury?

After the completion of the demographic questions, in-depth, semi-structured interviews began. This researcher encouraged participants to share their stories of caring for their partners using open-ended, broad, and probing questions. The participants' subjective views were the aim of this investigation. Participants were asked to share their experiences in a linear manner from when their partners first sustained a spinal cord injury until the current day. Interview questions/probes included but were not limited to the following (Appendix F):

1. Please try to recall when your partner was first injured, and you found yourself in the role of a caregiver. Tell me the story of your experience and what it is like providing care for your loved one.
2. What are your biggest challenges with being a caregiver for your partner?
3. Would you please explain your individual ways of coping with challenges and/or obstacles?
4. What advice would you give other significant others who are faced with being a caregiver for a partner with a spinal cord injury?

5. What advice would you give nurses and other healthcare providers caring for patients with a spinal cord injury and their significant other caregivers?
6. In what ways, if any, has your relationship as a couple changed since your partner's spinal cord injury?
7. In what ways, if any, have you changed since being in the role of a caregiver?
8. Would you have done anything differently regarding caring for your partner if given the opportunity?
9. Please feel free to share anything else that may help me understand your personal experience.

This investigator conducted all 12 interviews. After the initial interview, participants were emailed an overview of this researcher's understanding of key concepts of the interview and offered a chance to add further information for clarification. Two participants emailed additional information, and one other participant texted additional data to this researcher's cell phone. Three participants replied to this researcher's email to validate key concepts, while the others did not respond. The recorded interviews were transcribed by an outside transcription service. Data collection included interview videos, interview transcripts, and field notes written by this researcher to record impressions during and after each interview.

Data Management

Original signed consents and recorded interviews are stored on a flash drive and retained in a double-locked safe in the investigator's home. During data collection and analysis, interview transcripts and written data analysis records are securely stored on this researcher's private, password-protected computer with firewall and anti-virus protection. At the completion of the study and any potential publications or presentations, all computer records related to the study will be printed and transferred to a flash drive and permanently deleted from the computer. The printed copies and backup flash drives will be safely stored in the investigator's private home in a double-locked file cabinet and room. These documents include the signed consents and interview recordings for the period of years as required by Molloy University's IRB.

Data Analysis

To analytically review the interview data, Colaizzi's approach was utilized. Polit and Beck (2017) outlined Colaizzi's method succinctly in several steps. These steps were closely adhered to as the data analysis proceeded. After each interview, this researcher read the entire transcript in its entirety and extracted significant statements with perceived meanings for each statement. This researcher again read all the transcripts to acquire a feeling for them and extract commonalities. The formulated meanings were organized into clusters of themes with references to the original interviews for validation. Discrepancies were noted among interview data and between various clusters of themes to avoid ignoring data that did not fit into perceived categories. Once it was determined that themes were reoccurring and no new themes were identified, this researcher integrated the results into an exhaustive description of the phenomenon using statements to reflect themes. When completed, member checking ensued, and these thematic findings were shared with the participants as a final validating step. Field notes, including researcher observations, were part of the data analysis (Polit and Beck, 2017).

Transcripts from individual participants' interviews were repeatedly read to identify common concepts, themes, and meanings. The transcripts were identified by codes and compared to the audio tapes for accuracy. Shared thematic information that emerged was documented and summarized by this researcher to best reflect the participants' lived experiences caring for a partner with a spinal cord injury. Data analyses of phenomenological research studies conclude with a rich description of the essence of the lived experience for participants, including what they have experienced and how they have personally experienced it (Creswell and Poth, 2018). Since this was a qualitative research study, there were no set measurement tools for data extracted from participant interviews. Interpretation of interview findings resulted from this researcher's best effort to capture the participants' essence of their lived experiences based on their spoken word and responses to interview questions.

Reflexivity of Researcher/Strategies to Enhance Scientific Rigor and Trustworthiness

Before the start of each interview, this researcher revealed her situated context to the participants by explaining that she is also a significant other caregiver to her spouse, who sustained a T-3 spinal cord injury approximately 6 and a half years ago. To enhance the trustworthiness and credibility of the study, this researcher used bracketing to objectively interview participants. This researcher refrained from revealing personal experiences or opinions to avoid influencing the participants' responses and tried to redirect the interview back to the participants' experiences as needed. This researcher put aside any personal experiences to avoid influencing the data collection and analysis. As a part of the audit trail of field notes taken during interviewing, a reflexive journal was maintained by this researcher in an effort to bracket. This reflexive journal included notes on this researcher's self-reflection of preconceived notions and biases and any potential role conflict that may have arisen.

To validate the credibility of this study, member checking was offered to each participant. Creswell and Poth (2018) defined the process of member checking in qualitative research as having participants judge the accuracy and credibility of an account from researcher-provided data analyses, interpretations, and conclusions. After each interview and rigorous data analysis with extraction of formulated themes, the participants were contacted via email to confirm that the themes extracted were congruent with their perspectives. Changes were made based on the participants' feedback. This member checking enhanced confirmability that the themes were from the participants' words and experiences and that no misconceptions by the researcher occurred.

This researcher made every attempt to provide a safe, nonthreatening environment during each of the interviews. It is this researcher's assumption that participants answered questions honestly and to the best of their abilities. The expectation was that participants would share their experiences openly without fear of judgment.

Summary

This chapter offered the reader an opportunity to review the methodology used for a qualitative research study using a descriptive phenomenological approach that explored the lived experiences of significant other caregivers providing care for their partners after a spinal cord injury. The problem was clearly stated with a specific purpose and aim defined. A comprehensive overview of sampling, data collection, analysis, and management were presented including ethical considerations of the study participants. The rigors this study employed to assure trustworthiness, credibility, and authenticity were discussed to guide the reader through the research process.

CHAPTER 4: FINDINGS

The focus of this chapter is to present the findings in terms of the conduct of the study and what emerged from the data. This chapter provides an overview of the descriptive demographics of the participants interviewed for this study and their respective partners. It includes the process for recruitment of participants. The process for data collection and data analysis is clarified. A detailed description of the participants introduces their characteristics and situations as the researcher perceives them. The researcher attempts to clearly describe the unique tone of each interview to provide a contextual framework for the reader. To maintain participants' anonymity and protect their privacy, each participant interviewed was asked to choose a pseudonym that would be used in reporting the findings. Some participants chose words, while others chose to use initials. This chapter concludes with the emergent themes extracted from the interview data. The themes are explored using significant statements derived from the transcribed interviews.

Study Sample

Recruitment for this study was initiated after IRB approval from Molloy University in February 2023. Permission was granted by the administrators of two private online Facebook groups to recruit members of these two groups as participants in this study. The administrators from both groups posted the invitational flyer (Appendix B) on the respective Facebook pages for all members to view. Interested participants contacted the researcher directly via text messaging and email. All interested people were then emailed a copy of the informed consent (Appendix D) to carefully review. They were encouraged to contact the researcher with any questions and with their availability for a one-hour long interview via Zoom. After the signed consent was obtained and a mutually convenient date and time were established, this researcher created a Zoom meeting with an associated link and emailed the participant.

A total of twelve volunteers contacted this researcher, expressing interest in participating in the study within approximately two weeks of the advertisement flyer being posted on Facebook. Fifty percent of the volunteers made initial contact via text message, with the first volunteer texting three days after the advertisement was posted. The other fifty percent initially communicated via email. All twelve volunteers met the inclusion criteria of being adults over the age of 21 years, English-speaking, in a committed relationship with a partner who had sustained a spinal cord injury and was in the role of their partners' primary caregivers. Virtual interviews were arranged and conducted. No further participants were recruited after the twelfth interview since no new themes emerged.

Data Collection

Contact with research participants was initiated using a combination of email and text messaging. A total of twelve interviews were conducted from February 26, 2023, through March 30, 2023. All interviews were conducted virtually via Zoom at a date and time selected by the research participants. The participants were encouraged to find a private place where they felt comfortable speaking freely. Eleven of the participants chose to participate in the virtual interview in their private homes, and one participant chose her car for the interview. The length of the interviews ranged from 46 to 68 minutes, with a mean length of 56 minutes. Each interview began with introductions, an explanation of my role, and the objectives of our meeting. Each participant was asked to choose a pseudonym and for permission to record the interview. The participants were reminded that at any point, they could stop the interview and did not have to answer a question if they did not want to answer it. None of the participants chose to do either.

All twelve interviews were digitally recorded using this researcher’s Microsoft Cloud® via Zoom. Concurrently, all interviews were recorded using the Voice Memo feature on this researcher’s personal iPhone as a backup. Both the researcher’s laptop computer and cell phone were adequately charged, and the recording feature was tested before each interview. The back-up i-Phone® Voice Memos were then deleted.

All interviews began with this researcher asking several scripted demographic questions (Appendix E). Following completing the demographic questions, semi-structured, broad, and probing questions were asked (Appendix F). Participants were encouraged to tell their story in a linear manner from the time of their partners’ spinal cord injury to the present time. Each interview was initiated with the first prompt question: *“Please try to recall when your partner was first injured, and you found yourself in the role of a caregiver. Tell me the story of your experience and what it is like providing care for your loved one.”*

The general flow of the interview depended on the participant’s individual responses and questions from the interview guide (Appendix F) that were used when there was a lull in the interview or to redirect the participant when they went off-topic. Participants were informed that besides recording the interview, this researcher would be taking field notes. All agreed to have field notes taken during the interview. Throughout the interviews, attentive listening by this researcher was employed with frequent nodding of the head and using affirmatory responses such as “okay” and “uh-huh.” Each interview ended with the last question on the interview guide:

“Please feel free to share anything else to help me understand your personal experience.”

At the end of the interview, participants were encouraged to contact this researcher via email, text message, or phone call with any additional information they wished to share. One participant texted, and two emailed additional data that was included in the coding and analysis. Participants were reminded that a follow-up email would be sent by this researcher to clarify perceived themes. This member-checking was done after analysis and coding of the interview transcript to verify that this researcher captured the true meaning of the participant's words. Creswell and Poth (2018) define the process of member checking in qualitative research as having participants judge the accuracy and credibility of an account from researcher-provided data analyses, interpretations, and conclusions. Three participants responded with the affirmation of themes. The others did not return a response. All data obtained, including audio files, transcriptions, consents, and demographic data forms, are stored in a password and firewall-protected personal computer.

Field Notes

Field notes were hand-written by this researcher during the interviews to record significant words or phrases, non-verbal cues, and displays of emotion. Several of the participants started to cry or appeared to be on the verge of crying during certain points in the interviews. When these displays of emotions were apparent, the participants were asked if they needed to take a break. None of the participants wished to take a break during the interviews. Some additional notes were added after the interviews were transcribed, and this researcher carefully reviewed each interview's written transcripts and audio files. The field notes also contained analytic memos documenting this researcher's reflections during the interviews. Deriving meaning from the data using field notes assisted this researcher in coding and developing themes. This researcher's field notes journal is stored in a locked cabinet. All stored data will be retained for the number of years as required by Molloy University Institutional Review Board.

Participant Demographic Data

Demographic data was compiled using the demographic questionnaire (Appendix E) questions for each study participant. The descriptive statistics for the study participants for age, gender, the highest level of education, and employment status are provided in Table 1.

Participants ranged in age from 27 to 72 years, with a mean age of 49. All the participants identified as female. Regarding education level, one of the participants completed trade school, two completed some college, six completed a bachelor's degree, and three completed a master's degree. Seven of the 12 participants work outside of the home, with five working full-time and two working part-time. Two participants were unemployed, and three were retired (see Table 1).

Table 1

Participant Demographic Data

Participants	*n*	Percentage
Age		
27 years to 35 years	3	25%
36 years to 50 years	4	33%
51 years to 66 years	3	25%
67 years to 72 years	2	17%
Caregiver Gender		
Male	0	0%
Female	12	100%
Other	0	0%
Highest Level of Education		
Trade School	1	8%
Some College	2	17%
Bachelor's Degree	6	50%
Master's Degree or higher	3	25%
Employment Status		
Working full-time	5	42%
Working part-time	2	17%
Unemployed	2	17%
Retired	3	25%

All the research participants were in a committed, heterosexual relationship with their partner. Eleven out of 12 participants were married, with one participant being engaged to her partner. The number of years in a relationship with their partners ranged from 4 years to 45 years, with a mean of 19 years. Three participants had no children, two had one child, two had two children, three had three children, one had four children, and one had more than five children. Five of the participants had children with their partners, and four participant’s children were a combination from previous relationships. Ten of the women were in a relationship with their partner before his spinal cord injury, while two did not know their partners before the spinal cord injury (see Table 2).

Table 2

Participant and Partner Relationship Data

Relationship Status	*n*	Percentage
Married	11	92%
Engaged	1	8%
# of Years in Relationship		
Less than 1 year	0	0%
1-10 years	4	33%
11-20 years	3	25%
21-30 years	3	25%
31-40 years	0	0%
41-50 years	2	17%
Number of Children		
0	3	25%
1	2	17%
2	2	17%
3	3	25%
4	1	8%
5 or more	1	8%
Type of Children		
Mutual	5	42%
Combination	4	33%
None	3	25%
In Relationship Pre-Injury		
Yes	10	83%
No	2	17%

All the participants identified as their partners' primary caregivers. The number of years since the participants' partners' spinal cord injury ranged from five months to fifty-four years, with a mean of approximately eleven years. The participants' partners' level of spinal cord injury ranged from cervical level one to thoracic level eleven. One partner had a cervical level one spinal cord injury, seven sustained an injury between cervical level five to seven, and four were injured between thoracic level one to eleven. (See Table 3).

Table 3

Caregivers' Partners' Spinal Cord Injury Data

	n	Percentage
Number of years since partners' spinal cord injury		
Less than 1 year	2	17%
1-10 years	8	67%
11-20 years	0	0%
21-30 years	1	8%
31-40 years	0	0%
41-55 years	1	8%
Level of partners' spinal cord injury		
C-1 - C-4 (cervical)	1	8%
C-5 - C-7 (cervical)	7	58%
T-1 – T-11 (thoracic)	4	33%

Description of Research Participants

A detailed description of each participant is provided to assist the reader in understanding each participant's story, unique situation, and individual differences. These participant descriptions can also enable the reader to envision the researcher's interpretation and understanding of the data analysis used to code information and identify emerging themes. Participant-ascribed pseudonyms are being used for each of the twelve participants to protect their anonymity. What follows is a detailed description of each of the study participants.

KB

KB is a 42-year-old, full-time mental health case manager who has been in a relationship with her partner for four years. They had been dating for over three years and recently got married nine months ago. KB has three children from a previous relationship, but none with her current husband. Her partner sustained a thoracic level 10 spinal cord injury twenty-seven years ago when he fell out of a second-story window while in his college dormitory room.

The interview took place in a private room in her home via Zoom. KB's hair was neatly pulled into a ponytail behind her head. She wore thin-rimmed eyeglasses and a dark-colored hooded shirt. She smiled pleasantly and said she had been cleaning the house before the interview. KB explained that she was in the process of merging two households since, previously, they lived in separate residences. KB described how her home was not wheelchair accessible and that she and her fourteen-year-old son decided to move into her husband's two-bedroom apartment for accessibility reasons. KB has two older daughters who live on their own.

KB described how, up until about one and a half years ago, her husband was essentially independent. This was the first marriage for KB's spouse, and he had no children from any previous relationships. He works full-time as a mental health counselor. He developed several pressure injuries from a serious bout of diarrhea related to C-difficile and was hospitalized for a saddle pulmonary embolism, requiring him to need more care from her. KB spoke articulately and in a matter-of-fact manner. The interview flowed smoothly, with KB laughing at times. She seemed eager to talk and explained how she, her husband, and her son liked to play video games. KB described the acquisition of new caregiving skills as "leveling up." When asked to elaborate, KB explained that she felt that with each new skill she mastered to best care for her husband's physical needs, she went up to a "higher level" as a caregiver, like in a video game.

Amy

Amy is a thirty-one-year-old who works part-time outside of the home as a dispatcher for a local utility company, is attending graduate school, and has a seven-year-old son with her husband of eight and a half years. Six years ago, Amy's husband, who has lupus, "contracted just a regular stomach bug of some sort, and then never really got better from it." Amy describes how the virus "activated his immune system…and attacked his spine." Amy's husband sustained a thoracic level 8 spinal cord injury. Amy's husband is currently able to work full-time and commutes one hour each way to work every day. He can manage most of his own care. However, Amy still assists with transfers, a bowel program, and other personal needs of her husband. Immediately after the injury, Amy provided a higher level of care since her husband couldn't do so. Amy identified as his primary caregiver.

Amy appeared well-groomed, with shoulder-length hair pulled loosely to one side with a hair clip. She had a pale complexion with rosy, red cheeks. She was dressed in a dark-colored, logo-embossed crew neck sweatshirt. She smiled broadly through most of the interview and readily told her story.

Amy explained how a strong sense of faith is their best coping mechanism. She eloquently described how their faith has afforded them "a renewed appreciation for how short life is" and explains that they "long for eternity when they will be in heaven…when we won't have the challenges of this world."

Sunflower

Sunflower is a forty-six-year-old, master's prepared, international educator who lives in Canada and South America. She has been in a relationship with her husband for twenty-three years. They have two children together, who were nine years and thirteen years old at the time of the injury four years ago. Sunflower's husband is also an international teacher who sustained a cervical level six spinal cord injury when he fell while going over a bump while mountain biking four years ago with friends in South America. Sunflower's husband sustained his injury amid the COVID-19 pandemic and was transferred from critical care in South America to rehabilitation in their home state in Canada.

Sunflower was dressed neatly in a light-colored cardigan sweater, her long, dark hair loosely falling over her shoulders as she spoke. She appeared to be in an empty classroom and stated she was on a break from work.

Sunflower described her experiences after her husband's injury as going through phases and stated that she, her husband, and their two children have been experiencing the phases at different times. She elaborated on this process, "I feel as though right now, our family is in some stability. For myself, there's some actual deeper processing happening. Where the first year is just survival, and then the second year is growth, and then you start to work into some routines, and now, there's time for me to breathe. And in that breathing, there's the processing." She adamantly agreed when asked if she saw her experiences as a journey or transition.

Jeanie Jo

Jeanie Jo is a sixty-seven-year-old with a master's degree in clinical psychology. She admitted to retiring earlier than planned from an administrative position in clinical research in the field of pharmaceuticals after her husband's injury. She has been married to her partner for the last twenty-one years and has a daughter. Jeanie Jo's partner sustained a cervical level 5 to 7 spinal cord injury when he fell down the stairs in their home after having a hypoglycemic seizure episode related to confirmed diabetes approximately two and a half years ago. His injury was sustained during the COVID-19 pandemic, so Jeanie Jo had limited opportunity to be with him in the acute hospital and rehabilitation phase of his recovery.

Jeanie Jo explained that she does not have a "caregiver personality" and "was dragged, kicking and screaming into the caregiver role." She explained how she felt "angry" and "overwhelmed" when it was expected that she would assume the role of caregiver to her husband post-injury by the healthcare team. She explained that in the immediate period after her husband’s injury, she “felt incompetent for the first time in her life.”

Jeanie Jo differed from the other participants in that she refused to take on certain caregiver tasks and opted to pay out of pocket for caregivers. Additionally, due to pandemic-related constraints, her training was limited to a few hours during the last week that her husband was in a rehabilitation facility. She adamantly stated that she “refused” to learn the catheterization and bowel-related caregiver tasks and planned to hire outside help for these tasks. Jeanie said, “Their [healthcare team] assumption is that you will do it. And especially if a wife will do it. I had to tell the director of nursing many times and tell them to stop asking me about it. Tell them to stop assuming I will do it.”

As a result of her decision to not participate in certain caregiver tasks, Jeanie Jo explained how they have spent a great deal of their retirement savings on outside caregivers. She estimated that they had spent approximately two hundred thousand dollars within the first year on outside caregivers and injury-related costs not covered by insurance. Jeanie Jo sadly described how they “were lucky to have the money we planned…” but had hoped to use their retirement savings for travel.

RJT

As a fifty-five-year-old heavy equipment operator, RJT began the interview in her car while driving home from a full workday. She was wearing her dark blonde hair pulled back from her face in a ponytail with a simple pair of small silver-colored hoop earrings. She was dressed in a black hoodie sweatshirt with a bright yellow reflective utility jacket over the sweatshirt. Her eyeglasses rested atop her head, and bright green, noise-canceling earplugs hung loosely around her neck and apparently were used during her workday. Once she arrived home, RJT exited her car and conducted the remainder of the interview while walking outside the grassed property of her private home. At times during the interview, she purposefully peeked through a window into their home to check on her husband and his caregiver.

RJT and her husband have been in a committed relationship for twenty-eight years including dating for nine years before getting married. They do not have children together; however, RJT has three adult children from a previous marriage. She explained how, approximately nine years ago, her husband sustained a spinal cord injury while they were riding a dune buggy that flipped over while on vacation in Arizona visiting her parents who live there. During the accident, her husband “broke his neck” and sustained a cervical level six spinal cord injury, rendering him a “quadriplegic.” RJT was in the vehicle with her husband and was uninjured.

RJT hires outside caregivers to provide care for her husband while she is at work. She single-handedly manages his care after work, at night, on weekends, and on her days off. The couple spends approximately three thousand five hundred dollars a month for caregivers. RJT’s husband is unable to work, adding to the financial strain. RJT talked about how finding help was difficult, and it was sometimes challenging to manage any at-home issues since she was not permitted to take personal phone calls while at work. She said that when she wants to check on her husband while at work, she uses her cell phone and has “to hide, to try to make sure that my husband's okay.”

When asked what her biggest challenge is, RJT replied, “People understand what it is I'm going through at my job, being that I am a caregiver.” She clearly stated that she doesn’t want anyone to “feel sorry” for her. She clarified her feelings and stated, “When I do have a bad day, they just don't ... They cannot fathom or even try to understand what it is I'm going through.”

Sara

Sara is the youngest of the participants interviewed at twenty-seven years old. She talked about dating her partner for three years and being married for two years. After approximately one year of marriage, the couple decided to move from their home state across the country to another state. The intent of the cross-country move was so that she could complete a master's degree and her husband could pursue a new job opportunity. While on his way to work early one morning, a semi-truck collided with the back of her husband's car at a red light and proceeded to flee the scene of the accident. The hit-and-run accident left her husband in critical condition with a resultant cervical level 1 spinal cord injury and traumatic brain injury. Neither Sara nor her husband work outside of the home. Her husband requires care with transferring, positioning, hygiene, suctioning of his airway, catheterization, and toileting twenty-four hours a day.

The virtual Zoom interview took place in a bedroom in Sara's home. Her pale skin was accentuated by her dark brown hair that was pulled back from her face. Her face and shoulders appeared petite, and she wore large-framed eyeglasses over her dark eyes. She wore a dark, black, and gray speckled sweater.

Sara explained that her mother-in-law is a registered nurse who immediately traveled to be with her son. Throughout the interview, conflict with her partner's mother became apparent. During the initial injury, Sara explains how she felt "ignored" by the nurses and doctors and how they would talk mainly to her mother-in-law. Sara further explained how the healthcare team "would ignore me to talk to my mother-in-law because she was a nurse because a young wife doesn't know…." To alter these dynamics, Sara aimed to learn in-depth medical knowledge regarding spinal cord injury care in an effort for the team to take her seriously. She stated, "I had to get better; I had to be better, faster, smarter, more knowledgeable so that I could talk to the doctors and nurses in a medical way so that they couldn't back down from me when I asked them explicit questions….”

Sara explained that throughout her husband’s course of recovery, the family dynamics and other care-related issues were a constant source of conflict between them. She started to cry as she explained how she and her spouse would argue and how he was “verbally abusive” to her when she wouldn’t advocate for him to have pain medication despite being non-verbal due to his tracheostomy. She cried as she described how he would “silently scream at her.” She described how when her spouse was transferred to a rehabilitation facility, only one visitor was permitted daily due to COVID-19 constraints and how her husband “picked his mom to go with him.”

Sara openly cried as she described how, after her husband’s accident, she “went into a depression,” was having difficulties focusing on her schoolwork, experiencing nightmares, and categorized these feelings as “PTSD.” Sara tearfully stated, “I couldn’t even drive at first.” She expressed feeling her heart race, not sleeping, and having frequent “retriggers” currently. Sara has sought counseling and various support groups and admits that symptoms have improved over time.

When describing her experiences as a significant other caregiver, she used the analogy of “a snow globe.” Sara described this perception: "It's like I'm in a snow globe. You can see that I'm suffering, that I'm drowning, that you can't get me out.” I said, "You're not even on the same plane as me to save me." Sara explained how being a member of a social media group consisting of women and girlfriends with spouses with spinal cord injuries has helped her feel less isolated and stated, “I can see other people in their own snow globes.”

Rebecca

Rebecca is a forty-two-year-old woman who has been married to her husband for seventeen years. They have three children together. Rebecca described how, approximately ten years ago, her husband sustained a traumatic brain injury and cervical level five-six spinal cord injury after colliding with the back of a logging truck on his way to work. Rebecca explained that she is a “crier” and got teary-eyed as she told her story. At the time of the accident, the couple’s children were eight, four, and one-year-old.

During the interview, Rebecca sat in front of a plain, white wall in her private home. She was dressed neatly yet casually in a dark-colored t-shirt. She had a pale complexion and wore large, tortoise-colored framed eyeglasses. Her dark-colored, shoulder-length hair loosely framed her round-shaped face in curly ringlets.

Rebecca vividly revealed a wide range of feelings as she openly described her experiences. She expressed sadness, anger, grief, feeling overwhelmed, “exhausted,” “feeling incapable and unprepared,” as well as guilt. She described the first couple of years after her husband’s accident as a “blur” and recalls being in “soldier mode.” She admitted to “carrying it all” because she didn’t want to burden others. She recalled having to wake up every two to four hours in the early years after her husband returned home from rehabilitation to provide care, such as turning and repositioning to catheterizing him. Rebecca explained how, initially, she hired home health aides to assist with the morning routine so that she could get some sleep but recalled how it was difficult to find qualified help and that they couldn’t afford to pay out-of-pocket.

She vividly described her feelings as a significant other caregiver by using an analogy of being in the ocean. Rebecca stated, “I felt overwhelmed. I felt like, I don't know if you've been in the ocean before, but you can imagine if not that if you're in heavy waves, you struggle to get up.

You stand up, and then another wave knocks you down. I felt like as soon as my feet were on solid ground, I was down again." She recalled feeling like she could "never relax."

Rebecca openly cried numerous times during the interview but refused when offered to take a break. She remembered that the staff in the hospital and rehabilitation encouraged her to "build a community" to help support her and her family. She described family and community support as "vital" to her and her family's lives but sadly explained how some family and friends "dwindled" as the years progressed. She has experienced the loss of many relationships since her spouse's injury. When asked why she thought people left, she explained that "when it got heavy, they left" and how it made her "angry that they wouldn't take the time, especially some of the people who had known him pretty well his whole life and who were like brothers to him." Rebecca explained that she didn't feel angry at them personally but at the situation itself.

Throughout the interview, Rebecca emphasized the feeling of loss for herself, her spouse, and her family. When trying to explain further, Rebecca highlighted the loss of communication between her and her spouse because she tends to hold on to her feelings when she is overwhelmed or stressed. She described a loss of intimacy since the injury and expressed difficulties separating her role as a wife and a caregiver. Rebecca explained how their mutual bedroom is an area where most of his care takes place and how it is difficult to be intimate and surrounded by an abundance of medical equipment. She vividly describes her feelings of ongoing grief and loss by stating, "Nobody can understand mourning the man that you sleep next to every night."

Cloudy

Cloudy is a thirty-five-year-old woman who has been in a relationship with her fiancée for ten and a half years. Her fiancée sustained a cervical level 5-6 spinal cord injury because of a diving incident while they were vacationing out of the country approximately 7 years ago. Cloudy described how, while out of the country in an acute care hospital, the staff depended on her to provide most of his care and how she felt like she was his primary caregiver right from the start. Upon being transferred to their home country after he was somewhat stabilized, she recalled feeling like the staff tried to take over his care and "pushed her away."

Cloudy chose a blurred effect for the background, and the room contents were invisible. She had her dark hair pulled back neatly and tightly from her face. Her face was pale in color, smooth, with perfectly arched eyebrows and full lips. She wore a dark grey crew neck shirt.

Cloudy recalled the first year after the accident as a "whirlwind." She vividly recalled the shock of the accident and the resultant financial strain it thrust upon them. Cloudy explained how they had to sell their townhouse without any capital gain while her partner was still in rehabilitation because it was completely inaccessible for his wheelchair. She recalled "using every penny we had that year on living, on surviving. And very quickly we realized, how can we even do this? We couldn't even afford to buy brand-new catheters. There were times when he was reusing catheters by sanitizing them and using them again." After his return home to a rented, accessible location, Cloudy worked part-time as a waitress in addition to being her partner's primary caregiver. She expressed how she often would get called away from work to tend to caregiving issues, such as when the hired caregiver did not show up due to a bowel accident or when her partner fell out of his chair.

Cloudy remembered telling her partner, "I can't do this," during the first-year post-injury. She explained how she was going to school, had an hour and a half commute each way, and was picking up serving jobs. She described how she stopped attending school and how her partner lost his job during that first year. During the second year, her partner decided to attend school as a recreation therapist, but she did not work. Cloudy explained that her partner was currently being paid an income and was provided more insurance while he was in school, so the financial strain was somewhat lessened.

Throughout the interview, Cloudy was somewhat dismissive of her feelings and seemed to minimize the impact of being a caregiver on her life. She provided such statements as. “I'll just do everything. It's not a big deal” when outside care is unavailable. When asked to describe her feelings about the current situation, she exclaimed:

> After the first couple of years, his, even right away, injury, besides the accidents and whatnot, didn't really phase me. I don't like being in a wheelchair, him being in a wheelchair. I'm not the kind of person where I sit and look at photos of the past and, oh, he used to be able to stand up to hug me.

Regarding having children, Cloudy explained, “That's never been a thing for me. I'm just, I don't know why. I just, I don't know why. It just never happened to me. It hasn't really phased me. Whether we can have kids or not doesn't bother me either.”

Cloudy expressed that self-care was her main way of coping. She described using exercise, massage therapy, acupuncture, hypnosis, cold water therapy, hiking, and gardening on a frequent basis. She said, “If I care for myself, then I can care for others.” She explained how she didn’t want to be “codependent” on her partner and often used “tough love to promote his independence.”

Cloudy explained how she felt that her relationship with her partner had improved since the accident because they needed to communicate more. She elaborated by stating that she sees being a caregiver for her partner as a decision they made and further explained, “…that is a decision that you make in your relationship, that you're willing to do very intimate personal care for your partner, you have to be able to separate it and I think it can be really hard." Cloudy described that at times separating her role as partner and caregiver is difficult but manages to do so by making time to do things as a couple that doesn't involve caregiving tasks.

ADC

ADC is a sixty-four-year-old woman who has been married to her spouse for twelve and a half years and has been in a relationship with him for approximately fourteen years. They have eight children between them from previous relationships. ADC works part-time as an office assistant. ADC's husband sustained a thoracic level 11 spinal cord injury after being involved in a motorcycle accident and does not currently work outside of the home.

The interview took place virtually with ADC in a room in her private home. The room behind her appeared sunny with several white floating shelves lined with coastal-themed, framed pictures and knickknacks. ADC had long, full, silver-colored, stylishly cut hair that flowed softly over her shoulders as she spoke. Her make-up was impeccable, and her bright red lipstick accentuated her wide, friendly smile.

ADC described how she noticed a distinct change in her husband while he was in the hospital after his injury. ADC described how her husband became "very erratic," and was "starting to make poor decisions" after being given "drugs" for his injury. She explained how he "pushed her away" and asked her for a separation while he was in the hospital. She further explained, "I think we had unresolved issues. I think when you go into these things, the issues that you had before you went into them don't go away. If anything, they're amplified." She described tearfully how she felt "indecisive" about her role and overall, she was "shocked". He turned away from her and reached out to his ex-wife and daughters. ADC described several episodes of discord between herself and his family and how her husband’s daughter assumed the role of primary caregiver for her father.

Since the initial conflict, ADC and her spouse have reconciled, and she stated that she is his primary caregiver. She describes how, after their reconciliation, adjustments were necessary for both. She described his behavior after being discharged from rehabilitation as “institutionalized thinking because he had gotten so used to people waiting on him and so used to just being a victim and waiting.” ADC explains how she managed his demanding personality by “pushing him” to do various tasks, refusing to do tasks he could do himself, and setting boundaries. She labeled this behavior as “tough love.”

ADC explained how her partner often perceives his needs as more important than hers. To manage this, ADC illuminated how “part of my journey as a caregiver is to defend my own rights.” In doing so, ADC set one boundary whereby her spouse was not permitted to ask her to do anything for him after ten o’clock at night so that she could get much-needed rest. She has many hobbies, such as writing, painting, and dancing. She explained how doing things for herself is her main coping mechanism.

During the interview ADC described many emotions that she experiences as a caregiver. One such emotion was grief. She clarified this emotion and stated, “I think the grief is ongoing as caregivers; what we lost, I lost an incredible able-bodied man.” When discussing her feelings, ADC expounded on faith. She admitted to currently struggling with faith and clarified by saying. “I used to have faith that life was going to be okay. I don't have that faith right now. I used to have faith that things were going to work out. I don't have that faith right now.”

MW

MW is the oldest of the participants interviewed for this study at seventy-two -years of age. She speaks in a no-nonsense, business-like way; however, at times during the interview, she starts to get emotional, as demonstrated by her teary eyes and crack in her voice. MW has been with her husband for forty-four years, and they share two adult daughters and four grandchildren. MW's husband sustained a thoracic level 6 spinal cord injury approximately five months ago because of transverse myelitis.

The interview took place virtually in a room in MW's private home. The room she was in had numerous quilts that looked handmade. When asked about the quilts, MW replied, smiling that she made them all to relax when she is not too tired from providing care for her husband. While she quilts, she watches her husband, who is in another room, using an electronic camera device and can speak to him through this device if needed. MW has short, white, tightly curly hair and wears tiny stud earrings.

MW admitted to "being terrified" of having to provide total care to her husband upon discharge from the hospital and often felt "guilty" when she was away for any reason from his hospital or rehabilitation facility while he was there. She described feeling isolated and misunderstood by others and used the analogy of an asteroid, stating, "I don't know, but I tell people it's like there's this big universe, and the little hole opened up over here, and we fell in the hole, and it closed up behind us, and we're on this asteroid out here."

Throughout the interview, she repeatedly said, "It is really hard," when referring to being her husband's primary caregiver. She talked of the financial strain as a result of her husband's injury and sadly stated. "We are depleting our retirement funds." She eloquently described a myriad of emotions that she has been experiencing in the last four months, including sadness, frustration, and grief. She tried to explain the reason behind being sad and stated that it is "sadness that this is forever." MW also attributed feelings of sadness and grief to not being able to do certain things like attending a quilting conference or going to Disney with her grandchildren. At this point in the interview, MW became visibly upset and started to cry. However, she refused the offer of a break. She explained that some of the frustration came from others telling her that she needed to take care of herself, and she exclaimed, "How? My needs are secondary." When asked about her grief, she clarified by stating, "…there is loss after loss after loss."

YK

YK is a forty-two-year-old full-time accountant who has been in a committed relationship with her spouse for six years and married for the last two years. They are a blended family and share four children together from previous marriages. At the time of the interview, their children were twenty-one, twenty-one, eighteen, and sixteen years of age.

YK describes the day her husband suffered a rare spinal stroke at cervical level 5 to 6, rendering him completely paralyzed from his nipple line down: "This was literally just one day our lives just got flipped upside down." She teared up as she explained how he went from excruciating pain while heading out to enjoy a cigar night with friends to feeling nothing at the moment he became paralyzed. She sadly recalled their experience as being sent home from a local hospital emergency department and then returning to the hospital shortly after and subsequently being helicoptered to a trauma center in a nearby city.

YK's face against the blurred background was stunningly beautiful. Her pale skin was accentuated with a light blush, and her eyes were outlined with long, full eyelashes. Her long, dark, neatly styled hair framed her face. Her speech was somewhat soft but deliberate throughout the interview, and she willingly shared her experiences without hesitation.

YK talked of “living the facade” since her husband’s injury, whereby she felt forced to smile and not share the challenges of being a caregiver of someone with a spinal cord injury. She elaborated by explaining how when acquaintances who they haven’t seen since the injury see them, they exclaim, “Oh my God, you look so good. Look at you. You must be doing good.” YK doesn’t disagree with people when they make such comments. However, she laughingly retorts how it took her six hours to transfer, position, and perform personal hygiene and bowel program for her husband to make him look presentable. She jokingly explained how she told her husband she wanted a “sash with badges like in Girl Scouts” for all of the roles she plays as a caregiver. “I've become everything. I've become a therapist, I've become a barber, I've become a PT, OT… medical professional, urologist.”

Kelpa

Kelpa, age sixty-four, was the last of the participants to be interviewed for this study. She was also the only nurse in the sample and had been in a committed relationship with her spouse for the longest amount of time, forty-five years. Kelpa was one of two participants who met her partner after his injury and had never known him as able-bodied. She met her spouse approximately ten years after his injury that was sustained in a diving accident. They met while she was working as a rehabilitation assistant in a rehabilitation facility where he was staying. She became a nurse about a year after they were married.

The interview took place virtually, and Kelpa was in her car for approximately one hour. She had short, graying hair and wore eyeglasses and a light-colored winter coat. Her speech was confident, and the dialogue flowed smoothly. She admitted that being a nurse “made it easier” to be her husband’s caregiver, although she graciously attributed much of the credit to her “differently abled” husband. She laughingly stated, “I had solid assessment skills and clinical skills. So, I've told him, and he knows I've saved his life over and over by identifying things early.” When describing her husband, she stated that he is quite independent and “leads with his independence.” She described their relationship as “very imbalanced” regarding tasks and admittedly explained how her husband is “healthier” because she is his “advocate.”

At times, it felt as if she was providing advice about being a significant other caregiver, which seemed to align with her previous profession as a nurse educator. She even went as far as citing research findings from a longitudinal study and stated, “People with spinal cord injury who are married have better outcomes.”

Kelpa described that providing care for her spouse has become more difficult as he has aged. She described how she has suffered numerous health issues that sometimes present a challenge with providing the care her husband needs and attributes these issues “as a combination” of her work as a nurse and her role as a caregiver to her husband. At one point, she described often suffering from “acute overwhelmedness” [sic] because of being a primary caregiver. She explained that when this occurred, she and her spouse “talked through it” and she recognized that this is when she needed respite from her caregiver role.

Overview of Care Provided by Participants

The amount and level of care provided by each of the participants varied based on their partners’ level of spinal cord injury as it affected their physical ability and the time that had elapsed after the injury. A spinal cord injury is “damage to any part of the spinal cord or nerves at the end of the spinal canal (cauda equina) that often causes permanent changes in strength, sensation and other body functions below the site of the injury.” (Mayo Clinic, 2022) The higher the level of injury in the spinal cord, the higher the level of care needed by the participants' partners. Some participants described that as time passed after the initial spinal cord injury, their partners became stronger and able to manage some of their own care within the limitations of their physical abilities.

Overall, participants described various caregiving tasks. As told by the participants, one task was assisting partners in turning and positioning their bodies for comfort and minimizing the risk of pressure injuries. Several participants explained how they would wake up at night approximately every two hours to turn and reposition their partners. For participants whose partners had sustained pressure injuries, detailed descriptions of managing pressure injury care were explained.

In addition to turning and positioning, several participants described assisting their partners with transferring to and from their wheelchairs to beds, toilets and commodes, shower chairs, and other chairs. Depending on their partners' level of injury and access to equipment, participants spoke of using mechanical lifts, transfer boards, and physical lifting with transferring.

Another important caregiving task was assistance with or performing urinary catheterization for their partners on a routine basis. Some of the participants explained that their partners were taught to perform this task for themselves, while other participants described how, due to the level of injury, their partners were physically unable to perform urinary catheterization on their own. In addition to assisting with urinary elimination, participants discussed assisting with bowel elimination. Many of the participants talked of managing bowel programs with or for their partners in which routine use of digital stimulation of the rectum, suppositories, enemas, and transferring to commodes was necessary. Some of the participants' partners had ostomies for bowel elimination, and these participant caregivers described assisting with the management of such devices.

For participants whose partners suffered a cervical spinal cord injury, care of a tracheostomy with subsequent intratracheal suctioning was described. For these participants whose partners lost the use of their arms and hands (quadriplegia), assistance was needed with the consumption of food and drink.

Based on their partners' injury level and physical ability, participants described providing hygiene care such as shaving, showering, changing undergarments, and cleaning their partner after a bowel movement. The above-forementioned care was in addition to managing their partners’ medical care, including arranging doctors’ appointments and medication preparation and administration.

While the physical care for their partners was described to be intense at times, the participants explained how, at the same time, they are supporting their partners’ psychosocial needs. They described making plans for family and friends to visit, arranging social outings, managing the household chores and finances, and providing companionship for their partner. For those participants who had children, they explained how they tended to the needs of their children as well. For seven of the twelve participants, these multiple responsibilities were completed while working part-time or full-time outside the home.

Summary of the Participants

Each of the 12 women who participated in this study had a unique story to tell. The emerging themes will highlight the lived experience of these study participants caring for a partner who has survived a life-altering spinal cord injury. It was evident that each participant shared the desire to tell their personal stories. The next section will describe the process of how the transcripts were analyzed.

Data Analysis

Within twelve to twenty-four hours of each interview, the iterative process of analyzing the data for this study began with listening to each recorded interview. While listening to the recorded interview, notes from this researcher's reflective journal and field notes were reviewed. In this manner of listening to the interview recording while looking at notes taken during the interview, an accurate recall of information was facilitated.

Each audio recording was electronically sent to a professional transcription service immediately after the interview. The interview audio and video recording were saved to this researcher's password and firewall-protected computer. The completed transcript was typically returned to this researcher for analysis within twenty-four to forty-eight hours after being sent. Upon receipt of the transcript, it was first read carefully and checked for any transcription errors. If an error was noted, the audio recording was listened to for clarity, and the error was corrected in the transcript.

The next reading of each transcript was accompanied by carefully listening to the audio recording. While reading and listening, initial impressions were noted in the comments section of the transcript. Coding began with this second reading of the transcript. Paul Colaizzi's (1978) methodology for data analysis served as the framework for this research study. Beck (2021) outlined Colaizzi's methodology as one of four analytic approaches appropriate for data analysis in descriptive, phenomenological, and qualitative research studies. Beck (2021) summarizes

Colaizzi’s strategy in seven to eight steps. These steps were utilized in the data analysis for each transcript in this study as follows:

The transcribed interviews were read and re-read numerous times to acquire each interaction's general tone and feel. Significant statements were selected, highlighted with different colored ink, and organized into categories. The next step was aggregating the categories into clusters of themes. Each theme was then reviewed to confirm the appropriate placement of each sub-theme. Several statements appeared to appropriately fit into more than one theme. Each was thoroughly reviewed and placed in the theme that appeared to be the best fit. Identifying emerging themes was completed after thoroughly reviewing all significant statements from each of the twelve participant interviews. The final emerging themes were collated to best represent the phenomenon of the lived experiences of significant other caregivers providing care for their partners with a spinal cord injury.

Each transcript with color-coded, highlighted statements was emailed to this researcher’s dissertation chairperson for review. The dissertation chairperson was a qualitative research content expert and a secondary, outside reader. Debriefing sessions with the dissertation chairperson were conducted to discuss significant statements and impressions of participant interviews. Commonalities among participant statements were discussed, and findings were validated during these debriefing sessions. Additional notes were entered in this researcher’s journal to record ideas and suggestions discussed at the debriefing sessions. Sessions were held until all interviews had been discussed and significant statements were identified to support the coding and ultimate discovery of the emerging themes. This process yielded the extraction of significant statements from the approximately 679 minutes of audio-recorded narratives.

Findings of significant statements and researcher perceptions were emailed to each participant after the initial interview for their feedback. To member check, participants were encouraged to reply with any further information and to validate findings. The three who replied agreed with the significant statements and main topics, and no inaccuracies were noted. Two participants emailed, and one texted additional data after the initial interview. This additional data was stored with the interview transcript and included in the data analysis.

The next section discusses themes extracted from the previously described data analysis. The themes that emerged were as follows: (1) Women Warriors; (2) Waves of Emotion; (3) Chronic Caregiver Sorrow; (4) The Caregiver Journey; (5) Listen to Us; (6) So Much to Do, So Little Time: The High Cost of Caregiving; (7) Relationship Changes; (8) Caregiver Coping Crisis; and (9) Living the Façade. Selected excerpts from the interview transcripts illuminate the meaning of the themes as the participants described their lived experience as a significant other caring for a partner with a spinal cord injury.

Emerging Themes

Analysis of the interview data resulted in the identification of nine major themes. These themes illustrate the key points of the phenomenon investigated in this study as expressed by the participants. The identified themes portray the lived experiences of significant other caregivers who are providing care to partners who have survived a spinal cord injury. These themes emerged from the participant’s own words and reflected the challenges, complexities, effects on relationships, and coping mechanisms associated with being a significant other caregiver to a partner with a spinal cord injury.

Theme 1: Women Warriors

Regardless of their relationship status (married or engaged), their partners' level of injury, or the length of time since the injury, all the participants described having to advocate for their partner in various ways. They described having to advocate and protect their partners from harm when they were admitted to hospitals and rehabilitation facilities, for coverage with insurance companies, and out in public with interactions with others. The participants frequently used the words "fight, fight for, argue, and protect" when describing their experiences.

KB described two instances when her partner was hospitalized, and she needed to advocate for him. When asked if she felt like she needed to be her partner's protector, she adamantly replied:

> Yes. Very, very, very much so. Then, the first time when he got the C. diff and had to be at the hospital, and it was right there at the tail end of massive COVID, and I couldn't be up there. And we weren't even married at that point. I was calling every shift. "Okay, any updates? Anything going on?" He would call me, 'Oh my gosh. They stuck me back in the teeny tiny room. And I feel like the walls are closing in.' He was almost starting to hallucinate a little bit. And so, I called the nurse, and I'm like, "Look, you've got to get him out of there. He needs a bigger room, blah, blah, blah". And just so yeah.

When sharing the story of another hospitalization, KB described how she had to ask for what her partner needed to keep him free from harm, "He needs this low air loss mattress; otherwise he's going to get pressure wounds…." KB also described how when her spouse ultimately developed a pressure injury while in the hospital, she tried to explain to the staff what worked best for him in the past by stating. "We need to put something on this, and I know exactly what we need, I can tell you." KB felt her suggestions were ignored and the nurses “just blew me off.”

Amy passionately expressed how each time her husband needed to be hospitalized, she made arrangements for their young son’s care so that she could stay in the hospital with her partner. She recalled:

> …every time that my husband has had to go to the hospital, because of our great support system, I was always able to go with him and stay with him at the hospital. And if I had not been able to do that, I do not know that my husband would still be alive. Because every time that we have gone, that he's had to go to the hospital and be admitted or anything like that, the medical staff is always wonderful about monitoring him and making sure he doesn't die and all of those things like getting in fluids or medication or those things that he needs. But all of his other care, when he's in the hospital, I did. Any turning, positioning, pillows, boots, getting him an alternating pressure mattress, I always had to really fight for that.

Amy explained her role as an advocate for her partner when dealing with members of the health care team and stated:

> I would have to be like, "You don't understand. I trust you as a medical professional, but you do not know as much about this patient as I do because I care for him all the time." And usually, when my husband was really sick, it was very difficult for him to speak or explain lots of things. He doesn't have a memory problem, but his memory is just not that great. Also, when he's sick, you don't feel good, you don't want to be talking to people you don't want, so I did most of the advocating.

Sunflower vividly recalled several instances in which she needed to advocate for her husband’s care and well-being while in the hospital. For instance, she felt he was in danger of being injured when the staff attempted to transfer him using a bed sheet. She further explained that his acute care was in South America and that they did not have equipment such as lifts, and the staff was of small stature. She recalled, “There was definitely a couple times in that I'd had to be like, “Whoa, you need to stop.” Sunflower explained how she would stay with her husband while he was in the hospital and felt that she needed to be there “to help supervise the care.”

Jeanie Jo, who has a degree in psychology, recalled having to advocate for her husband’s psychological well-being after his spinal cord injury while in the hospital and rehabilitation facility. She feared that her spouse would not verbalize his feelings to anyone and remembered advocating by stating:

> I insisted, when he was still in the hospital, I said, he needs to see a psychiatrist. I want him started on an antidepressant immediately, even though he will say he's not depressed, you can't tell me he's not going to be depressed. So, they did that in the hospital at the trauma unit, on the step down. And he started on Lexapro low dose. And then when he got to the rehab, I said, well, where's the support? I need him to see a psychologist, a psychiatrist, a clinical social worker, someone who could help him accept what this is.

As experienced by several other participants, Jeanie Jo recalled having to be assertive and had to request special equipment for her spouse during his hospitalizations. She excitedly described this scenario:

> I went all the way up the chain, all the way up the chain. And every time he was in the hospital his wounds got worse or he got a new one. They act like, well, this is what happens. I said, no, at home he doesn't get wounds. So, when we come in through the ER and I talk to the nurse in the ER that's handling him for the day. When we move him

> upstairs, he must have the specialty bed. I say it when we get upstairs. I didn't see anything about that. Two days later we might get the bed. That's ridiculous. I said it and I said, put it in the chart. Let me see you put it in the chart. It's all electronics. So put it in the chart.

RJT explained how she wrote numerous letters of medical necessity to the insurance company to get the vast number of medical supplies and equipment covered to ensure proper care for her husband at home. She vehemently explained:

> I had to write letters of medical necessity for him, type of thing. And then, I had to fight for a shower chair. I had to fight for a standing frame. I had to fight for his second wheelchair. And I would tell them, "My husband doesn't have a broken leg. He has a spinal cord injury."

As with many of the other participants, RJT explained how she would stay with her husband whenever he was hospitalized:

> I've always, anytime that he has been in the hospital, I stayed with him, because, even though they are doctors and nurses, they don't deal with a spinal cord injury. And I've had arguments with them to get an air mattress. They don't know how to transfer him from his seat to the chair. They don't know the caregiving aspect of that.

Sara told a story of when her husband was in the hospital after his spinal cord injury and how the family was instructed by the neurosurgeon to provide minimal stimulation so he could recover from his brain trauma. She angrily explained how one day, she entered his hospital room; the nurse had the television tuned to a football game and had the sound turned all the way up and the remote lying right next to her husband’s ear. Sara explained how her husband could not communicate his needs then and appeared visibly agitated. Sara tearfully described how her husband had blood dripping from the side of his mouth because he had bitten through his tongue. In response to this situation, Sara stated she “called her out on it” and how the nurse was not permitted to care for her husband moving forward.

Rebecca described how she, too, stayed with her partner any time he was hospitalized to oversee his care and advocate for his needs. She eloquently described one admission:

> But anyway, when he's there, I am caring for him because they don't understand. Like I carry with us anytime we go to a hospital, I carry with us a four-inch-thick gel foam mattress. And I have to explain to every single one of them why it's important for him to have that down. They don't want to deal with it because it's harder to change the sheets. It's blah, blah, blah. I don't back down. This is what's best for him, so this is what we're going to do. But they don't understand.

Rebecca went on to describe her role as her spouse’s advocate in the hospital:

> If he's not capable of doing it himself, which he most of the time is, he needs to be turned at least every three to four hours so that he doesn't develop a pressure ulcer. He can't lay on his sacrum for more than 30 minutes. He needs to be one way or the other because he had a sacral flap surgery. He is very prone to something happening to that site. So, I take care of him when he is in the hospital and it's not as easy to take care of him when he's in the hospital because it's not our setup that we're used to.

Cloudy explained how she felt the need to watch over and protect her partner from harm even when he was home. She talked of being fearful that something would happen to him while she was gone:

> I couldn't leave him at home for more than, I don't know, 20 minutes because he needed things like his leg bag drained. Or if he had a spasm, his foot, his feet would go behind his foot plate and he would be trapped or he would... Something would happen if I left.

ADC laughingly referred to herself as a “Mama bear” when referring to being a caregiver for her spouse. ADC explained that her husband doesn’t typically advocate for his needs and that she feels compelled to do so for him. She recalled feeling protective when they were out in public and described one situation:

> Oh my God, I am such a Mama bear. Do not piss me off. Do not piss me off. Oh my God. And he's a very gentle man. So, he'll sometimes be like, “It's okay. It's okay.” I'm like, "It is so not okay. It is so not okay." 100%. I want to protect him. He's already had so much pain. You don't get to treat him that way. You don't get to treat him that way. I mean I've gone off on people who park in the handicap spot, and they park on the stripes.

She passionately explained her perceived need to protect her spouse:

> I have gone off on people because they have parked there. I stop now, I just call the cops. But I'm so protective of him and so protective of his, you don't get to treat him this way. That's disrespectful. And that is not acceptable to me.

MW explained how she actively and continually managed her spouse’s electronic patient portal and communicated his needs to their primary care provider using this patient portal. She explained how she does “100 percent of the writing on his behalf.” MW explained how her husband is in pain most of the time and how if she feels something “is off base,” she reaches out to their provider with requests and for advice to best manage her partner’s care.

YK described how she became an “instant advocate” when her spouse became injured. She used the word “fight” numerous times throughout the interview to describe situations in which she needed to advocate for the needs of her partner. She explained how the insurance company wanted her partner to be discharged after only twenty days in intensive care even though she felt he was still critically ill. She wistfully described how she felt she needed to advocate for her husband because he was unable to do so for himself at the time:

> I fought to keep him there for two months with insurance until they absolutely were like, “He can go to a SNF or you can get him home.” And so in between all of learning how to care, what does this mean for our lives, taking care of our home, our kids, legal aspects like financial, becoming a power of attorney because he couldn't sign anything, just advocating for that.

YK went on to further elaborate:

> I had to become a medical expert and fight with insurance companies on just the humanity of what somebody needs in a crisis situation, where you pay for insurance for 24 years of your life, and when you need it, they argue your healthcare. Because they wanted to send him home because they said he had met the minimum requirement necessary to leave and I'm like, "Is that breathing? He can't do anything independently." He couldn't even have moments of therapy because he was having medical crisis and we had a horrible situation where we were sent to the ER. And thank God I was with him the entire time. I advocated to stay with him as a person with disabilities because he couldn't function.

Kelpa described being an advocate for her husband and explained how her experience as a nurse helped her in this role. She described having a positive impact on his well-being by being a nurse and his advocate, “I've saved his life over and over by identifying things early.” She vividly recalled one instance in which he was hospitalized, and she noticed his blood pressure increasing dangerously and proudly admitted that she was the one who advised his nurse to call a rapid response.

Each of the 12 participants discussed protecting and/or advocating for their partners somehow. This emerging theme was evident and numerous significant statements were identified to validate this theme. Since all of the participants communicated that advocating and protecting their partner was an integral component of their lives, the term “Women Warriors” seemed to best illuminate this as an overarching theme in this research study.

Theme 2: Waves of Emotion

A myriad of emotions was expressed by participants throughout all twelve interviews. Although the participants admitted to feeling these emotions at different points in time after their partners’ injury, many of the emotions were similar in nature. The participants incorporated these emotions as they told their stories of being caregivers to their partners with a spinal cord injury. Eight distinct feelings emerged from the interviews, including frustration, sadness/depression, anxiety, feeling overwhelmed, feeling misunderstood by others, envy, anger/resentment, guilt, and isolation. These emotions often overlapped with one another as the participants told their stories. The next section will illustrate these feelings in the participants’ own words.

KB described how, during one of her spouse’s hospitalizations, she felt anxious, fearful, and frustrated that he wasn’t going to receive the care he needed to keep him safe from the healthcare team. Despite her advocating for his needs, she expressed that these feelings surfaced and were troublesome for her. She described how she needed to take an anti-anxiety medication to help relieve these feelings.

> I cried. I had an anxiety attack. I cried. I legit had to take, I have a PRN and that I don't use very often, because I was trying to be strong for him and because he was so sick, and

> I was scared, and I was upset and frustrated and just don't blow me off like that. This is somebody's life. And I understand you're coming in here and doing this every day, and you know what you need to do. I don't know that you know this. And you're basically pushing me out of the way and telling me to shut up. So, this guy, the nurse, and I lost respect for him. I don't know that you can take care of my husband the way it needs to be done right now. And we're at a pretty critical stage. He had two-digit blood pressure. We are in the trauma unit. It was scary.

She went on to further explain her feelings of frustration with being a caregiver to her partner and stated, “I get really frustrated with advocating and stuff like that…” and “…but it is tiring and it's frustrating.”

When discussing her children’s role in assisting her with their stepfather’s care, she admitted to feeling conflicting feelings. She described feeling proud of them but at the same time guilty that they were exposed to this situation:

> I'm mixed. I think it's great because again, this is their stepdad, right? So, they don't necessarily have to do all these things. They could absolutely choose not to. And that's okay. At the same time, I feel a little bit of guilt that they feel that they have to do that. But at the same time, we've talked about it and they have said they want to. They love him and they will do just whatever they can to help. And so, I feel a little bit of mom guilt with that, but at the same time I'm like, "Wow, I raised some pretty decent humans that want to do that, and they don't have to."

Amy described how in the months after her husband’s spinal cord injury, she experienced a great deal of anger at the situation she was put in as his caregiver:

> I had taken on so much responsibility on myself and was trying to carry the weight of the world and just take care of everything else while my husband was trying to get better and learn how to live in a wheelchair, and it was too much. And it was not something that anybody else put on me. I just decided that that was my job. And so that kind of turned me into a really angry person.

Amy went on to explain her feelings of anger and sadness, “I was really angry because I was not letting myself grieve what we had lost. And so, I was really sad….” She described how she tried to ignore her feelings so that she could do what needed to be done for her husband and family:

> I was far too busy to be sad, because when I was sad, I couldn't do all the things that I needed to do to take care of my family. And so, I just had to power through it. I felt like I just had to power through it to take care of my family. And so, I was just kind of stuffing all of that down, and it just kind of came out in anger.

Amy repeatedly referred to feeling angry throughout the interview, and each time anger was mentioned, she tried to explain its source. For instance, she openly stated, “I think mostly my anger was just that our life was so hard and that I wasn't letting myself feel the other emotions. And so, it was just all coming out as anger.”

Sunflower angrily described going through “stages of being bitter,” in which others would comment on how “amazing” her husband was doing but didn’t recognize her role as a caregiver and how she contributed to his well-being. She explained how she felt frustrated and angry that his injury was taking precedence over other important aspects of their family:

> Even I had to, probably about a year-and-a-half in, have a pretty serious conversation with him as well. The kids and I are living this with you. Every time we see a person, we

> don't want to go through this again. There does become a little bit of that balance of, "What about the achievements of your children? What about what I've done?" This has become monopolizing.

Sunflower described how there were times in which she needed to experience her feelings and how, at other times, she didn’t allow herself to do so. She further explained this concept, “I think sometimes you need to be allowed to be angry, and you need to be allowed to be sad. Yeah. And sometimes it's not.” She elaborated that she realized that not allowing oneself to experience feelings may have negative consequences, “…if you just bury it, it's going to manifest itself somewhere else, physically, mentally, or later.”

Jeanie Jo described feeling “angry” and “overwhelmed” after her husband’s injury and explained how she resisted being in the role of his caregiver from the start, “I was dragged, kicking and screaming into the caregiver wall. Not something I ever wanted to do.”

Jeanie Jo admitted to having a long history of depression and anxiety prior to her husband’s injury. She frankly admitted that because of her husband’s injury and taking on the role of caregiver, her issues with depression and anxiety have been “blown up.” She expressed “feeling sad” that many of their friends are at the age where they are retired and traveling. When explaining her sadness, Jeanie Jo stated, “I'm sad because we can't do it, and we won't be able to do some of these things.”

When interviewing RJT, she seemed to be somewhat uncomfortable talking about her feelings and often referred to how her husband was feeling when asked about her own feelings. At one point, she willingly admitted that she felt “sad and angry” during the first year or so after the injury. She calmly expressed how she would ask, “Why? Why did this happen to us? Why?”

Sara cried openly several times during the interview but refused a break when offered. She described how she and her husband suffered from depression after his injury and had difficulties focusing. She elaborated on this situation, “We both went into a depression. I couldn't focus on school even without taking care of him in the hospital”.

Sara described how she was experiencing nightmares, and her therapist identified that she had post-traumatic stress disorder. She openly told of her experiences and described the manifestations of her feelings:

> It's mostly anxiety, it's depression, definitely PTSD. The PTSD is a lot better. Before I couldn't even drive, because after the accident and seeing what his car looked like, it's no wonder he died on scene because there's no way that he should be alive at all. And so, there was PTSD with driving, there's PTSD with hospitals. My mom going in the hospital, my heart rises after my mom was in the hospital this last week with all of her stuff. I don't sleep well. I'm lucky if I fall asleep at 2:00 AM. I can't focus. I've been really clumsy because I haven't been getting good sleep. And it re-triggers me for a couple of more weeks until it's, "Okay, we're not going to the hospital, it's okay."

She further explained how her mental health has deteriorated since her spouse’s injury. Sara recalled a statement her mother made when describing her to others. This statement was made to help get some respite relief from Sara’s in-laws, “She is not okay. She is a shell of who she was.” She used the analogy of living in a snow globe to describe her feelings of isolation and being misunderstood by others. “It's like I'm in a snow globe. You can see that I'm suffering, that I'm drowning, that you can't get me out.” And I said, “You're not even on the same plane as me to save me.”

Sara also described feeling “incredibly angry” at the driver of the motor vehicle who hit her husband and caused his spinal cord injury. She angrily described how the accident was a hit and run and that the driver didn’t turn himself in to the police until twenty-four hours later.

Rebecca described feelings of guilt, isolation, anger, and being overwhelmed throughout the interview. She said she felt guilty asking anyone for help caring for her partner because she “didn’t want them to be burdened.” She mentioned that she often did not express her feelings to her spouse because she “didn’t want to burden him.” She explained how she felt guilty if she left her husband home when she needed respite from being his caregiver:

> I have guilt because when I leave to go to the grocery store or meet a friend for lunch or something like that, I'm away from the injury, from what is required of me to help my husband. But he can’t. There's no getaway for him.

She went on to further explain the feelings of guilt and stated, “Why should I be able to escape the heaviness and he can't?”

When describing her feeling of isolation, Rebecca became visibly upset as she tried to elaborate on this emotion. She tearfully described how she didn’t want to share her feelings with others for fear that they would leave:

> I felt very alone. I felt alone. I wasn't ever alone physically. I was either with my husband, my kids, with my mom sometimes or my friend. But I felt alone in that. Nobody else understood what I was carrying. And even if I did explain it, they weren't going to get it. I noticed that when people felt things were heavy, they would leave. So, I didn't want to talk about heavy stuff to people because I was afraid that would be it.

Rebecca recalled how when her partner was in rehabilitation, she felt angry when the therapists advised her to “stop doing things” for her husband. To promote independence, the therapist reasoned that the more she did for her spouse, the less he would try to do for himself. She laughingly recalled this feeling of anger and stated, “I wanted to punch him [the therapist] in the face!”

In describing her feelings of being overwhelmed as a primary caregiver to her spouse, Rebecca used the analogy of being in the ocean. She explained how caring for someone with a spinal cord injury meant dealing with many complications and setbacks. She described this analogy in detail:

> Overwhelmed. I felt overwhelmed. I felt like, I don't know if you've been in the ocean before, but you can imagine if not that if you're in heavy waves, you struggle to get up. You stand up, and then another wave knocks you down. I felt like as soon as my feet were on solid ground, I was down again.

When describing her feelings, Cloudy said, “Carrying everything on your shoulders can be a bit much sometimes.” Cloudy talked about how she often managed her partner’s care alone, didn’t always ask for help, and would not express her feelings, only to have her feelings come out later. She stated, “I think by the time I ask for help for things, I'm so kind of bubbling over…” and “I would say sometimes I try to sort of say, "Oh, it doesn't bother me. It's fine. I'll just do it." And then later on it comes up.”

Cloudy shared her feelings of isolation and being misunderstood by others:

> You have somebody who depends on you. And it's not their fault, and they can't help it, and you know they can't help it, and you know you're the only person here. But it can feel a little bit isolating because I feel like none of our friends or family, not even his family, nobody really gets it.

ADC described frustration and feeling overwhelmed in the following excerpt:

> I was getting really resentful and so exhausted that I was not handling things well. I was not proud of the meltdowns that I would have after 10 o'clock at night because he would be asking me for things, and I had nothing left to give. Because once again, I am working. Now I'm working three days a week, but I'm still working and I'm in my sixties and I have a life.

ADC described the myriad of emotions she feels as a caregiver, including peace, envy of others, and sadness, by using the word "waves":

> I'm in waves. I go through waves of being very at peace and waves... I'm in a not at peace wave right now. I feel envious of other people. I feel envious of their lives and how easy it is for them to get up and go and travel. And I feel like at this point in my life, my life should be easier and not harder. So, all of those things that I used to have, those "It's going to be fine," I don't have that right now. So, it's changed me in a way that has made me, I don't know, more depressed.

MW described feelings of guilt when she would leave her husband to go home while he was hospitalized. She explained, "…a couple of times, I would feel guilty driving home like, "I don't have to take care of him tonight. They can take care of them."

MW eloquently described her feelings of isolation using an analogy of the universe and an asteroid. She explained this analogy, "I tell people it's like there's this big universe and the little hole opened up over here and we fell in the hole, and it closed up behind us, and we're on this asteroid out here."

MW talked of feeling "emotionally tired." When asked how she would define this term, MW clarified:

> It just means you just can't cope with what's going on, and crying doesn't save it, or it doesn't fix it. I would say it's sadness and frustration, and just sadness about that this is going to be forever. That's really hard.

During her interview, YK tried to explain the magnitude of being a caregiver to her partner and openly expressed feelings of being misunderstood by others. She stated:

> …you don't have any inkling what it takes to care for another adult human being in its full capacity every single day and then all the medical things that go with it. And so, it's hard because people don't necessarily want to hear the sad side of this, the medical problems, they just don't understand.

Kelpa recalled how when she is experiencing “acute overwhelmedness” [sic] as a caregiver, she is able to recognize that she needs respite time. She also vividly described her feelings of envy of others regarding bearing children:

> Envious at times just with, I was envious back when I was younger and my friends and my sisters and brothers were starting families and I didn't know that I necessarily wanted to have kids, but when people around you are having it's like, maybe we should see what we can do.

Theme 3: Chronic Caregiver Sorrow

Dialogue that described feelings of grief and loss of their spouse as a partner emerged as a distinct theme throughout five of the interviews. These participants depicted the loss related to the affected partner’s lack of intimacy, shattered dreams and expectations of their future together, and the loss of an able-bodied partner. Another dominant theme was losing a partner they could depend on for help with household chores and finances. One distressing issue that emerged was the acknowledgment that although their partners were still physically present, they were different than they were before the spinal cord injury. All five of the participants who brought up feelings of loss, sadness, and grief had been in a relationship with their partner prior to his injury. Interestingly, neither of the two participants who entered relationships after their partners' injury identified having feelings of loss or grief.

The participants described a "sadness" that was ongoing. The term "chronic sorrow" was first introduced by Olshansky (1962) to describe the distress parents felt after having a child with a disability. Roos (2002) defined chronic sorrow as "a unique grief reaction that occurs when loss is not final but continues to be present in the life of the griever." Roos (2002) also refers to chronic sorrow as a "living loss."

Amy poignantly described how she felt that her expressed anger was a result of grief. She explained, "I kind of figured out, through the course of a lot of counseling that I was really angry because I was not letting myself grieve what we had lost. And so, I was really sad."

Amy tearfully described how her spouse and her expectations of parenting have been lost because of the spinal cord injury. When discussing her spouse's interactions with their young son, she recalled:

> My husband always thought that he would be the dad to get down on the floor and play with his child and all of that, and he's not really able to do that. Floor transfers are really difficult. They can be kind of dangerous. And so, he doesn't prefer to get down onto the floor just because it can be so difficult to get out. So yeah, I think that's probably the biggest con, is that he just misses out on some stuff. It makes me sad because it just is, that's something that we lost.

Sunflower described how she, her partner, and their children experienced the process of grief at different times since the injury. She concluded that they all had a loss and needed to be able to feel sadness and grieve the loss at their own pace:

> Those first two years, I'm not totally sure they got to be kids through some of that. I think, again, it's the recognition and the recognition, I think, of society sometimes of, it's okay to mourn the loss and acknowledge what the trade-offs are, but let's acknowledge it. I almost think you have to grieve it to come out on the other side. I think you need to go through the cycle of grief. I think my husband went through the cycle of grief between his second and third year. My son went through it just recently. I think my daughter did it really early, and I'm just hitting it now. I think that's actually been important in our family. And it's something that working with a counselor has really helped with, though, is acknowledging it is lost. And if you just bury it, it's going to manifest itself somewhere else, physically, mentally, or later.

Jeanie Jo labeled her feelings of loss and sadness as “a chronic, complicated grief that will never go away.” She tearfully described the process of grief during her interview. She shared:

> Let me tell the process. After the initial acute phase, I'll call it that, then it's grief. You go through the stages of grief. You can't believe that your life has been turned upside down and this is what it's going to be… So, the grief was very real. And it was just such a loss. Such a loss of the life that we thought we were going to have.

Sara succinctly defined her feelings of loss after her spouse’s spinal cord injury using legal terminology. She used the term “loss of consortium” to explain the situation in which she lost the spouse she married:

> Loss of consortium is [not] having a spouse that can care for me emotionally, physically. He was the primary and sole income while I was going to school, so we lost that. He needs 24/7 assistance. He can't be left alone. So, it's like, where are you going to get a job that's going to pay me enough to still pay taxes, pay everything else, and pay for caregivers...

Rebecca described a "deep, deep, deep sense of loss and grief" not only for herself but for their three children. She explained how one of their sons angrily made the comment, "Well, if my dad had never been injured, then he would've taught me how to do this kind of thing."

Rebecca explained that she feels they have been "robbed." When describing one of their daughters, Rebecca explained that her daughter is very athletic and that she would enjoy sports with her father prior to his injury. She elaborated on this feeling when she stated, "She's our sports kid, and so she feels very robbed. Her dad was an athlete, and he was a good athlete. So, she feels robbed of him."

To further describe this sense of loss and "being robbed," Rebecca poignantly stated:

> I have my faith in God, and I firmly believe that we are on this path for a reason, but that does not change my human emotions. I feel robbed. This could go back a little bit to the wife-caregiver thing and my feelings of loneliness. Nobody can understand mourning the man that you sleep next to every night.

Rebecca described how her husband's physical appearance has changed drastically since the injury. Before the injury, she described her spouse as muscular and fit and explained how he had lost muscle mass and a great deal of weight and is now "skin and bones." Adding to the concept of "being robbed," Rebecca explained, "So yeah, you feel robbed. They feel robbed of the experiences they would've had with him able-bodied. I feel robbed of the same thing."

ADC self-identified feelings of grief and loss in her interview. She explained how she was dealing with “emotional challenges” and identified grief as a main challenge. She vividly recalled being able to do pleasurable things together prior to his injury and is now unable to have these same experiences:

> I think the grief is ongoing as caregivers, what we lost, I lost an incredible able-bodied man. We used to take bike rides together. We used to hike together. We used to go sailing together, canoeing together. We were very active and traveled. And so much of that is lost. So, my biggest challenge is dealing with the grief. I’m not having enough fun in my life. It’s not like we can just pop in the car and say, “Let's go do this.” Friends my age are retired and they’re traveling the world and I’m not having enough fun. My daily life is I’m a caregiver, I work, that's my daily life.

MW described how she and her husband seek to find happiness in the “small victories.” She described their situation after her husband’s injury as one of continual loss and stated, “…there is loss after loss after loss.”

Theme 4: The Caregiver Journey

Several of the participants described the transition into their role as a significant other caregiver as a process or journey. They talked of being in different phases or stages at different points in time after their partners’ injury. The process they described was fluid without a distinct timeline or endpoint, although they each described certain stages using similar terms. The following select excerpts will illustrate the journeys each participant told as part of their stories.

KB talked about how she would “level up” whenever she could master a new skill as a caregiver. When asked to explain this term, KB laughingly described how her husband and son like to play video games and that when playing these games, players go to a higher level each time the level below is mastered. She further explained that since her partner was injured before they met, he was essentially independent. However, most recently, his health has been declining, and she has had to take on more caregiving tasks.

KB further explained her transition to becoming her partner’s caregiver: she needed to set “boundaries” even if she mastered a skill. She described how she had to learn to be cognizant of when to step back and permit him to be independent. She described how she often assisted her partner even when he didn’t need assistance. She compared this to when able-bodied people in public see a person in a wheelchair, and they often ask if assistance is needed. She described how she felt that others would judge her if she wasn’t aiding, and part of her transition into the caregiver role was learning to deal with these situations:

> I see people talk about all the time, if we're out in public and he's struggling with something, getting over a little bump or having trouble loading himself into the van or something like that. And it was a matter in the beginning like, "Oh, I can help you, I can help you, I can help you." And he's like, "No, I got it. I got, don't worry about it, I got it." But it was that expectation. I think that outside expectation from others that were like, "Well, why aren't you helping him?" So, it's just that getting over that pressure from the outside sources of why aren't you helping, why aren't doing this?

Amy told her story of becoming a caregiver and how she needed to learn how to “meld” her role as a wife and her role as her husband’s caregiver. She described how she needed to learn to safely perform certain caregiver skills so as to not injure him and how she experienced some difficulties transitioning to a caregiver role:

> So, with your spouse or if you're in a committed relationship, your partner or your serious significant other, whenever you're caring for them, it can be really difficult to transition

> different parts of your relationship or to meld them together. So, we have the caregiving side of the relationship where he needs help with things, and so I need to help him with things, and that's not always something that... The activity itself is not always something that I want to do, but it's something that he needs. That's how it feels now. And like I said, that took some melding into, I guess, because at first, it was very difficult to transition into those things. Because to me, I know that it's not this way for everyone because not everyone will choose to be a caregiver.

In telling her story, Sunflower described transitioning from survival to growth to working in routines to “breathing and processing” and “reality mode.” When asked if she saw her experience after her husband’s spinal cord injury as a journey or transition, she adamantly agreed. The select excerpt from the interview with Sunflower depicts this process:

> I feel as though right now, our family is actually in some stability. Actually, for myself, there's some actual deeper processing happening. Where the first year is just survival and then the second year is growth, and then you start to work into some routines and now, there's time for me to breathe. And in that breathing, there's the processing

With tears in her eyes, Sunflower further explained her current state, “I would say I'm in a reality mode. It's like, whoa, this is our life. What does this mean going forward? How does this impact us, big picture…?”

At the beginning of the interview, Jeanie Jo described “feeling incompetent for the first time in my life” after her husband’s injury. Towards the end of the interview, Jeanie Jo described how, upon mastering certain caregiving skills, she felt more “competent” to handle her role as a caregiver, and the acquisition of these skills put her in a calmer state of mind.

> I have become competent at the caregiving tasks. Doesn't mean I want to do them, but I can do them. I never thought I could do that. I thought I'll never get that Hoyer lift right and I couldn't figure out how to do this or that. You feel better then. You feel like, okay, I can do this. And now I know that I can do it. So, if a caregiver called out, I could do it. It's not like, oh my God, oh my God, what are we going to do? You're going to have to stay in bed. So that is how I've changed. I mastered some skills that I didn't want, but now I have them. And I've also, because of this situation, I believe I have gotten better at managing my own emotions, and I'm calmer.

Rebecca described being in "survival mode" in the weeks following her husband's injury. She went on to explain how she transitioned from "survival mode" to "soldier mode" when her husband came home from the hospital. Rebecca told of how, after being in "soldier mode," they "fell into a routine" and adapted to their situation. She eloquently described her journey and how, through their faith, she has currently come to a point of "acceptance":

> I see it very much as a journey. I'm very strong in my family Christian, and I'm very strong in my faith there. And I believe that this was the path we were put on and that we have a purpose to serve because of it. And so, I try to be very intentional about doing that, about sharing my story and the ways that God has provided for our family, in the ways that he has rescued me at times. And so that's the perspective that I have. And because of that, I think that I have gotten myself to a point now to where, yeah, I feel like I still live somewhat in survival mode, but I have gotten to the point of acceptance. I have accepted this, that this is our life and I've accepted that we will, or I could say I'm determined that we will live this out to the best of my ability.

Cloudy described the first year after her partner’s injury as a “whirlwind.” She explained how her spouse went back to college in the second year after his injury and how they could find “more balance.”

YK told us how she learned to “be more patient” and “really see outside of yourself” throughout her journey of becoming her husband’s caregiver. She explained how she has transitioned from thinking that she needed to “do it all” to learning to accept outside help. She also described how she has learned to stay in the moment, deal with issues day to day instead of looking too far into the future, and move on from difficult days:

> I think in the beginning, if I could say anything it's, I thought I could do it all, I thought I could manage everything, keep my shit together, hold it all in, when in truth, I can't. I need support in that. And I think that's probably been the harder thing for me to accept is that I can't do it all and I can't fix this and there's no amount of what I'm going to do to make it better that will make it better. So, I just focus on where we are today is not where we're going to be tomorrow, where we're three years down the road, we don't know what that looks like. I try not to dwell on where we'll be, but just know that we won't be here. Whether today's a good day, we won't always have good days, or if today's a shitty day, we won't always have shitty days, but we won't be here.

Theme 5: Listen to Us

When asked what advice they would give nurses and other healthcare providers caring for patients with a spinal cord injury and their significant other caregivers, the participants overwhelmingly replied that they would advise the team to “listen” to caregivers and patients. The participants felt “ignored” and “not heard” and often felt “dismissed” by nurses and healthcare providers when in an acute care hospital, rehabilitation facility, or a private office.

The excerpts below and the comments of the participants will illustrate their frustration and desire to be heard by the healthcare team.

KB recalled her feeling of frustration during one hospital admission for her husband, in which the nurses claimed to not know how to do digital stimulation as part of her spouse's daily bowel regimen. KB simply stated, "Listen to family members. Listen." She remembered trying to explain the procedure to the staff and felt that her instructions were not being heeded. KB described some of the nurses as being "closed off" to her suggestions and "blew her off." When one nurse was performing digital stimulation, her spouse told her that he felt "pounded like a gorilla" and was very uncomfortable when the nurse was performing this task. KB stated that she felt like it was "an us against them mentality" when referring to herself and her partner and the nurses, doctors, and other healthcare team members.

In addition to not listening, KB felt that the healthcare team "lacked knowledge and training" on caring for a spinal cord injury patient. She expressed feelings of anxiety as she recalled that she needed to explain many facets of his care to them. KB refers to a spinal cord injury as a "completely different animal" and felt that most of the staff were unprepared to care for a patient with a spinal cord injury. KB laughingly recalled one experience, "I can't tell you how many people came in, and they were like, "Oh, can you feel this? They didn't even read any information when they touched his toes."

Amy's advice to the healthcare team caring for patients with spinal cord injuries echoed KB's advice. Amy also simply stated, "Probably the biggest advice that I would give is to actually listen to your patient and their caregiver." Amy vividly recalled her experiences during her spouse's hospitalizations in which she didn't feel that she was being heard.

> Whenever we went to the hospital, we would go in, I would talk to the doctor, usually it was an admittance through the emergency department, and I would talk to the doctor and tell them all the things that they needed to know, and they would just be like, "Mm-hmm. Okay, yep." And they'd be glancing at the chart and trying to check their boxes and get out of the room. And I would have to be like, "You don't understand. I trust you as a medical professional, but you do not know as much about this patient as I do because I care for him all the time."

Amy described how often her husband's physical needs were not met by the nursing and medical team. Her words depicted feelings of being "ignored" by nurses and doctors. She stated, "…it was just like oftentimes, it's just his needs are ignored, or he's asking for something or I'm asking for something, and that's ignored."

Sunflower described differences in the relationships with the healthcare team in South America versus that experienced in their home country. She recalled feeling "listened to" by the team while in South America. While in a hospital in her home country, she expressed that the doctors and nurses didn't perceive her as an "an intelligent member [of the team]." She recounted her positive experience in South America in the following excerpt.

> With all of the doctors, if I asked a question, I felt listened to and I got a response. Or with the nurses or the physiotherapist or whatever, I felt like there was dialogue that went back and forth."

Sunflower provided additional advice to healthcare members caring for a patient with a spinal cord injury to consider the patient, caregiver and family members as a "unit."

> I think that piece, just that they're a unit. There's two people impacted by this, and to maybe actually ask what the caregiver ... You know what I mean? What are the

> circumstances of the caregiver? Because I think sometimes if you know they have three children, or maybe they do have really good support, or they don't have any family in the area, I think having just that understanding may help with a little bit more empathy and less judgment.

In her interview, Jeanie Jo provided similar advice to the healthcare team and stated, “listen to the caregiver.” She described her experiences when her spouse was hospitalized and felt “not listened to” and powerless. She recalled these perceptions, “I was not being listened to. And I felt for the first time in my life that I really had no power. I could not affect a change.” Her advice echoed participant Amy’s, and she stated, “Please listen to the family because they know more than anything about what's really going on with this patient.”

As with the other participants, RJT felt “unheard” when advocating for her husband while he was hospitalized. She poignantly described feeling dismissed by the doctor and described these feelings as, “…they walk in, and they say, "Okay, I'm the doctor I know best." She told of how she viewed spinal cord injuries as a “specialty” that most healthcare members are not familiar with and how a different approach is needed to adequately diagnose and treat patients with spinal cord injuries. She described having to miss days at work when her husband is hospitalized because she feels she needs to stay with him to ensure he is provided proper care. She explained, “I'm left with missing days of my job because I'm afraid that if I leave him in the hospital, their care would be insufficient because they're not knowledgeable.”

Sara described feeling “disrespected” by the healthcare team when the nurse “absolutely ignored” her and spoke to her mother-in-law, a fellow nurse. She sadly recalled, “…nurses and the doctors especially, would ignore me to talk to my mother-in-law because she was a nurse, because [the] young wife doesn't know.”

Sara shared how she felt “judged” and disliked by the nurses and doctors while her husband was hospitalized. She angrily described her experience and perceptions, “They didn't like me. His nurse made no hiding the fact that she did not really like me. She thought I was a little prissy upstart….”

Sara recommended that members of the healthcare team display kindness when caring for patients with spinal cord injuries. She recalled her experiences, “Just be kind because I could tell when doctors and nurses got annoyed with me because I was just a concerned wife that was just trying to piece together what had just been exploded of our lives. Just being kind.”

Rebecca pleadingly advised the healthcare team to attentively listen to the patient who has survived a spinal cord injury and the patient’s caregiver. She agreed with other participants that many nurses and doctors have limited knowledge and experience with patients with spinal cord injuries. Her statements illustrate this advice.

> Listen to them. Listen to them. They are living it… most of the doctors we have, all of the doctors we have encountered are not super knowledgeable on spinal cord injury. Same for the nurses. They just don't experience it a whole lot. So, when I am saying to you, his body will not tolerate that or he had a bad reaction to that medication or whatever, listen, because we are living it every single day and a lot of doctors and nurses want to just do their routine thing.

Rebecca described how some hospitals are not wheelchair accessible and that this setup becomes troublesome when trying to provide quality care. Rebecca described how this inaccessibility could result in negative feelings for the patient with a spinal cord injury. She recalled such an experience when her spouse was hospitalized.

> We had one circumstance, one of our major hospitals …, his wheelchair would not fit through the bathroom door. So, we had to do his bowel program, I had to bring my toilet seat from home, his toilet seat from home, put it over a trashcan up against the wall. Can you imagine how degrading that is for a person?

Cloudy concurred with several of the other participants in her interview that there is a serious lack of knowledge and training for nurses, doctors, and other healthcare team members regarding spinal cord injury patients and how to manage them. As her partner’s caregiver, she expressed that oftentimes, she is educating the healthcare team about the unique characteristics of spinal cord injury and its resultant medical sequelae. She explained how when her partner needs to go to the hospital with autonomic dysreflexia symptoms, their questions are not always answered.

> I would say there needs to be a lot more education around spinal cord injury. There is a tremendous lack of knowledge and education and training in something like spinal cord injury. I feel like sometimes we're just sort of shooting in the dark, trying to figure out what's going on. And a lot of the time going to the ER because you have AD symptoms is extremely not beneficial because you just end up being sent home with no answers. Right? There's really very limited information. And I've heard this over and over from medical staff, from nurses, from doctors sort of saying, "I don't really know." So, I think I don't think it's their fault. I think it's a training overall that really needs to change.

ADC recalled how when her husband was in the hospital and she felt he was not cognitively competent to make sound decisions, she “was not taken seriously” by the healthcare team. Her advice to nurses, doctors, and other healthcare team members is also to “listen.” She passionately explained this in the below excerpt.

> Take the spouse seriously. Listen to the caregivers. I know him best and if I tell you he is not of sane mind and body, how would you know? You've never met him before. How would you know? So, I think that the medical community needs to expand their vision of caregiving of people, take us more seriously.

YK shared a story of a home care nurse who told them her husband had a rash when he had the beginning stage of a pressure injury. YK expressed that she felt the nurse did not have enough training in caring for patients with spinal cord injuries. Her advice to healthcare members is to become more knowledgeable about spinal cord injury and to explore each patient's situation individually since not all spinal cord injuries are the same. She expressed not being heard by some of the healthcare team while her spouse was in the hospital. When referring to the healthcare team, she described, "60% who listened and would be really like, "Really sorry, we'll do better." or "Let me show you how we do this, or here's a suggestion." But we also had 40% who just couldn't care less."

As a longtime nurse and caregiver for her spouse, Kelpa also advised healthcare team members to listen to the patient and their caregiver when providing care. She emphatically stated, "I'd say you need to listen to the patient. I mean, that's advice regardless of spinal cord injury. But listen to the caregiver."

Theme 6: So Much to Do, So Little Time: The High Cost of Caregiving

In telling their stories, the participants recounted the challenges and intricacies involved with being primary caregivers to partners who survived a spinal cord injury. Their powerful narrative resonated with weariness as they poignantly described their experiences. Some participants told of the ill effects of caregiving on their outside job performance. They vividly described having little or no assistance with caregiving tasks. Several participants openly discussed the financial impact of their partner's injury and their resultant need to be caregivers. Furthermore, participants spoke of threats to their physical and psychological well-being because of being caregivers to their partners and the strain of "carrying it all." The effects of caregiving on the participants' lives were multi-dimensional and thus were divided into subthemes to best portray their lived experiences. These subthemes overlapped at times during the interviews.

Subtheme 1: Effects on Outside Work Performance

KB, who is a full-time mental health case worker, told of how she provides care to her spouse before work, after working a full day, and on weekends when she is off from her outside job. She explained how being a caregiver affects all aspects of her life. She expressed that one of the biggest challenges in her life is having enough time for all her obligations. When asked to explain her biggest challenge with being a caregiver, KB tearfully answered, "Time. Spreading myself between my kids and being here for him. Also, my work has suffered. What I have to do after this is, I'm two and a half weeks behind in my notes for work." She goes on to tell her story of being a caregiver, "…it [caregiving] takes a toll on everything, our relationship, my work, my relationship with my kids, and just finding that norm again."

As with KB, Amy described not having enough time to do all that needs to be done on a daily basis. She described how both she and her husband work outside of the home and that managing work, providing care before and after work, and commuting leaves little time for anything else. She told of their typical day and the challenges they encountered.

> So, with how long it takes just with getting ready in the morning, and then getting ready for bed in the evening, he has the very long days, and we don't have very much family time. We don't have a lot of just time to relax. And so that has been really challenging, just because it's always rushed to get everything done, all of his care done, and also to

> spend time as a family, which is very important to us. And that has been one of the biggest challenges. And also getting enough sleep.

Subtheme 2: Financial strain

Jeanie Jo described how her partner's injury has impacted them financially. Because of his injury, her husband can no longer work, and thus, his income has been lost. Jeanie Jo explained how they spent "nearly two hundred thousand dollars for caregivers in the first year alone." She further explained that this money came from their retirement funds and how they did not have long-term care insurance and were not eligible for any assistance because "we have too much money." She sadly went on to tell how this was not how they intended to spend their retirement savings but was glad that they had the money available.

In explaining the financial strain of paying for outside caregivers, Jeanie Jo stated that they currently spend approximately "five thousand dollars a month" on caregivers. She further explained that in the beginning, when her husband needed more help, the cost of outside caregivers was approximately "twenty thousand dollars a month."

RJT openly shared her experiences and explained how her spouse requires care twenty-four hours daily. RJT works full-time and provides care when she is off from work. However, they pay a caregiver to provide care while she is at work. She estimated that they spend approximately "three thousand five hundred dollars a month" on caregiving expenses. At certain times, her job requires overtime hours, and she needs to find additional caregivers and pay additional wages adding to the already high cost of care. She also described how she finds it difficult to balance work and caregiving, especially if her husband has a problem while she is at work. RJT wistfully recalled how her husband was a supervisor prior to his injury and how he is no longer able to work to contribute to their joined income. She labeled this as a “huge strain financially.”

YK sadly described how her spouse’s employment was terminated after twenty-four years of service since he was unable to perform his job duties due to his injury. She explained how she would like to hire outside help, however they do not currently have the financial capacity to do so. Since her husband’s injury, YK has eliminated her commute to work by working from home. She works full-time as an accounting manager, provides care for her spouse and children, and handles all the other household chores. YK explained how they need to be “conscientious about where they spend their money” since the injury. She commented on her conversation with her husband, “I want to make sure we have it so that we can buy you what you need medically. We know we’re not going on vacation, so that cost goes there.”

Cloudy told of how her husband’s injury put a financial strain on them from the beginning. She described having to pay approximately “five hundred dollars a month” to supplement their insurance for caregiving costs even though neither could work outside the home. She recalled how they had to sell their home at a capital loss because it was not wheelchair accessible. She described their situation and hardships eloquently.

> We used every penny we had that year on living, on surviving. And very quickly we realized, how can we even do this? We couldn’t even afford buying brand new catheters. There were times where he was reusing catheters by sanitizing them and using them again.

MW shared the financial strain of her husband’s spinal cord injury and recalled how difficult it has been to be able to afford all the supplies needed for his care. She explained how they were depleting their retirement savings to fund the medical necessities for her spouse.

> We were not affluent, but we had retirement in our minds. And in fact, we've said to each other multiple times, "You have to be not affluent, but you have to be comfortable to be able to afford this." I have lubricant coming and I have gloves coming and I have pads coming, and I have all different kinds of things to put on the sore spots to try to make it get better. I have a hospital bed in there that I'm renting for $300 a month. I have one from the hospital in our garage that's probably a $20,000 one they gave me for free, but we can't figure out how to get it in the bedroom. And the wheelchair van, I just bought it with cash.

Subtheme 3: Threats to Caregivers' Physical and Psychological Well-being

Amy described the first year after her husband's injury and how she managed the challenges of caregiving.

> It was very stressful, and we also had this baby that we had to take care of as well. And even though we had such a great support system, I was still the one trying to manage our home. And I felt like there was too much for me to do to take care of my husband and my child, to think about taking care of myself or think about being really sad about what we had lost. And there were times when I would cry, but most of the time, just out of necessity. I had to keep going. I just had to keep doing all of the things that needed to be done.

Sunflower told how her husband's injury and her role as a caregiver have affected her physical and psychological state. She openly described her feelings.

> I'm also a middle-aged human being who had to have perimenopause strike full force because of the stress and stuff. Which is, I think, another piece of that whole caregiver piece is your own physical. Not just your emotional wellbeing, your physical wellbeing.

Sunflower explained how others tell her to take care of herself and described how she doesn’t have the time for self-care due to all of her other obligations. She jokingly commented on her desire to respond to others, “Right. Are you going to come cook dinner for me those three days so I can do that?”

Jeanie Jo told of the threat to her physical and psychological well-being. She described having a previous history of depression and anxiety and how her husband’s injury has “blown it up.” She vividly told of numerous back, neck, and shoulder injuries that were a direct result of her transferring her husband. She stated that her shoulders “hurt all the time” and how she tried to minimize injuries to herself by using proper body mechanics in transferring; however, she felt that her physical stature was limiting. She explained these limitations.

> I try so hard to do all this kind of stuff the right way, but it’s just a lot. I’m not tall, so when I get him in the chair, I have to do this to make sure he is in place. I’m not a strong tall woman. I’m 67 years old.

RJT described her usual taxing routine at night. She described how she isn’t able to sleep an adequate number of hours because she is up periodically during the night to turn and position her spouse and assist with his bowel program. She explained how she tries to “catch up” with sleep by sleeping whenever she can at different times.

Sara described the effects of being a caregiver to her spouse after his injury on her physical and mental state. She vividly revealed that she has “PTSD and nightmares.” She explained how she doesn’t sleep well and only manages to get about four hours of sleep a night. She stated that she tries to nap during the day when he sleeps but tends to wake up at the sound “of any little thing.” Sara explained her current physical state and situation.

> I don’t feel like a 27-year-old. My body feels like I'm more closer [sic] to 40 than I do 20. I don’t feel good. Physically, I’m tired. My back constantly aches. I have to get massages monthly just to try to not be cramped up like I am. I literally have no time or energy to even think about hanging out with friends. And I’ll sit down and he'll call me to go fix something and it’s just never ending.

Rebecca told of how their insurance provided outside help with caregiving for a short period of time. She admittedly stated that they didn’t have the finances to pay out-of-pocket for assistance once the insurance coverage ended. Rebecca recalled “sacrificing everything” to be able to afford the cost of hourly wages for a caregiver to come to help in the morning. She explained how when the caregiver came; she would sleep because she had been up every two to four hours during the night to turn and catheterize her husband. Rebecca stated that she was in a continual state of hypervigilance, worrying about what would happen next and how, for years, she couldn’t relax.

Cloudy recounted instances in which she herself was injured while transferring her husband. She recalled a couple of times lifting him off the floor when he fell and how she was in a state of “sheer panic” and wasn’t using proper body mechanics. She explained how she is currently working through these injuries with various forms of therapy.

ADC described experiencing intense depression and anxiety after her partner’s injury. She described how these feelings were perpetuated by being a caregiver and how she had changed psychologically since the injury.

MW further described her experience as a caregiver and stated that she is often “emotionally tired.” She tells how she sometimes has to choose between doing something she finds pleasurable, like reading or sleeping. She also described how she is affected physically since she doesn't have time to exercise as she did prior to her spouse's injury.

YK described the negative effects of being a caregiver on her physical well-being. She explained how she injured herself and had to make adaptions to her footwear and home to be able to prevent injury and best care for her husband.

> Being home the first month I was running around my house barefoot because I've always run around barefoot. And I was on my feet 16 hours a day and I had to get nursing shoes, buy nursing shoes, that I have to wear during the day now because I literally just jacked up my legs so bad from... We have hardwood floors. So, it wasn't like that's the smartest idea. And then I was sleeping on an air mattress next to his medical bed every night because we have a three-story colonial, and our room was on the third floor. He's never going to be able to get up there. So, we had to rearrange our house, turn a dining room into a bedroom and we had to order a bed and we had to get a medical bed.

YK described how she is trying to manage her own psychological well-being and found herself trying to manage her husband's psychological needs as well. This seemed to be causing her distress and she recalled how she told her husband, "Listen, I don't have the capacity to be your cheerleader and mine. I'm struggling to keep shit together, so I need you to figure out a way to keep shit together."

YK described how she has taken on multiple responsibilities since her husband's spinal cord injury. She explained how she joked with her husband that she wanted "a sash with badges like in Girl Scouts" for all of the roles she plays as his caregiver. She stated, "I've become everything. I've become a therapist, I've become a barber, I've become a PT, OT… medical professional, urologist."

Kelpa described having numerous physical ailments that created challenges in providing care for her husband when needed. She talked of having arthritis and joint issues in her wrist and shoulders that made it painful to transfer her husband. She described how they “created workarounds” to manage transfers and care without her using her affected parts. She described how she needed a hip replacement last year and how they purchased a ceiling lift to prevent her from having to do “pivot lifts” which she identified were a contributing factor leading to her hip issues.

Theme 7: Relationship Changes

Throughout the interviews, many of the participants shared various changes that had occurred after their partners’ spinal cord injury. They described both positive and negative changes in their relationship as a couple. Several spoke of role reversal between them as a couple and between their spouse and children. Those participants with children described how the injury affected parent-child relationships and the feelings that their children were experiencing. Some spoke of the loss of relationships with friends and family members after the injury. Since the theme of relationship changes is multilayered, this section will be divided into subthemes.

Subtheme 1: Partner Relationship Changes

KB explained how her partner struggled with role conflict. She mentioned that her husband was frustrated and had comments such as, "I should be providing” and "I'm not providing; I'm not being that man that you need me or want me to be.” She elaborated and stated, “It is affecting the relationship a little bit, just because he wants to be that independent provider. He prides himself in providing.”

Since KB and her spouse met after his spinal cord injury, it is not possible to examine their relationship before and after the injury. KB stated that she felt that they had a strong sense of communication because of her role as a caregiver. Due to some recent health issues, KB’s spouse went from being mostly independent in his care to needing her assistance on a regular basis. She explained, “A good thing actually is we're communicating better because we have had to lean on each other so much the last couple of months. And so, we've actually communicated better, and we are more, I hate to say, we're more of a team.”

Amy recalled how she felt angry and sad after her husband’s injury. She described in detail, “I was trying to take so much on myself, and it really changed me because I was angry, I was sad about what we had lost, but I wasn't letting myself be sad, I wasn't grieving the things that we lost, and I was trying to do far too much.” She went on to explain how the anger and “circumstances of our lives” changed her personality into “something not desirable.” Amy explained how her anger and personality change seriously affected her relationship with her husband. She poignantly explained, “And then because of that, it was more my husband responding to that, because there's only so much you can take being around somebody who's not very nice before you start being not very nice back to them.” Amy admitted that the change in herself and their overall relationship happened slowly over time without them recognizing the shift in their relationship.

Amy further described how she found it challenging to shift from a caregiver to a wife role.

> That seems like a very different part of my brain than he is my husband, and so I want to do these other things for him as well, whether that's sexual intimacy, emotional intimacy, just spending time together and hanging out and doing some of... If we want to snuggle on the couch, I have to shift from, okay, I'm your caregiver, so I have to help you safely

> get on this couch to I'm your wife, and I just want to snuggle for a minute. So that part is really what's so different.

Amy spoke of a "shift in the balance" in the relationship between herself and her partner and how their "roles kind of shifted." She described how, prior to his injury, her husband was the one who used to do household tasks such as replacing a lightbulb, hanging Christmas lights, and hanging a picture. She told of how they used to work together as a couple to do things such as making dinner and cleaning the house and how he is now unable to do so now. Although she spoke of physical limitations, Amy described this further and stated that the "emotional dynamic of helping each other just has changed."

Jeanie Jo talked of other changes in the relationship with her husband after his injury. She explained that issues that they had prior to the injury have been "amplified or magnified by this crisis." She described how her husband has always been one to keep his feelings to himself and that since his injury, this aspect of his personality has become "worse." She described herself as very emotional and finds it challenging when her spouse doesn't share his feelings with her.

Similarly, RJT described how some of the same relationship issues they had pre-injury are still present and come to the surface more often. She explained, "If you think that you had problems before, during your marriage, before this, they're going to even be more manifested."

She expressed that she has difficulty separating her caregiver and wife roles. She shared one of her husband's comments to support this statement, and she recalled him saying, "Don't treat me like you're my mom." She further described this conflict in the below excerpt.

> But the biggest, hardest thing for me is, once you become a caregiver role, I often don't want to be that caregiver all the time type of a position. And sometimes, it happens, where being that I'll have to kind of get after him about what it is and making sure that he

> doesn't get depressed or making sure that he's doing his things. And sometimes, he doesn't like it because I have to re-question him.

Sara described how some of the unpleasant personality traits her husband exhibited prior to his spinal cord injury have worsened. She described how he expresses his frustration and makes comments such as “This happened to me…you can walk.” Although Sara described the worsening of some personality traits, she also told of how she perceived that her partner had changed since the injury. She described that he used to be “more caring” and looked after her needs, but since the accident, this has changed, and it is all about her taking care of him.

Sara expressed that she found it challenging to separate her caregiver and wife roles. She vividly described her experiences and her internal conflict.

> I feel like I have a toddler, a child, and a teenager, but I still have the responsibilities to a husband that you would expect a wife and husband to have, of I can't just tell him to do something or not do something 'cause I'm his wife, it needs to be a conversation. But there's the mentality of the toddler or the teenager of, "I want what I want when I want it, and if you don't give it to me, I give you a pissy attitude back."

Rebecca animatedly described how communication between her spouse and herself has suffered since the injury. She explained that when she is stressed or overwhelmed, she goes inward to try to figure things out, and this is distressing for her spouse, who wants to be involved. Because of this stated communication gap, Rebecca feels that they have lost a sense of connection with each other. She openly explained these relationship changes in her interview:

> Our communication has definitely changed, has suffered, I guess I could say that. And of course, that results in other things, just sort of that ripple effect. I guess sometimes that we don't feel probably as connected because I'm kind of over here doing this stuff and I'm

> in this lane and I just got to keep going. He's over there and he's just trying to catch up, figure out what I'm doing and where the kids are supposed to be and all that kind of thing. So, I would say we don't feel as connected probably overall.

As several of the other participants expressed, Rebecca described having difficulties separating her role as caregiver and wife at times. She explained, “I'm going to say after nine years, unless I'm just missing something huge, it's impossible to separate wife and caregiver.”

ADC described experiencing drastic changes in the relationship with her spouse while he was initially hospitalized for the injury. She described how he “pushed her away” and actually asked for a separation while he was still in the hospital. ADC described feeling “indecisive” about their relationship for many months afterward. She explained this indecisiveness in further detail, “This disaster happened that I thought we were going to be drawn together. We exploded. We completely exploded.” While discussing their relationship, ADC stated that they had some issues prior to the injury and how they worsened post-injury. She explained, “I think we had unresolved issues. I think when you go into these things, the issues that you had before you went into them don't go away. If anything, they're amplified.”

MW described how, since becoming her husband’s caregiver, she doesn’t feel as if he acknowledges her role in his care enough. She described their relationship before the injury as “not being incredibly warm” and feels that he “takes her for granted.” Although MW explained how she hears him acknowledging her help to others, he doesn’t always say “thank you” to her. She described that this lack of acknowledgment made her feel “frustrated.” She further explained this situation and how it made her feel, “When he says thank you, I take it to heart. I've gotten better at it. I think he's into himself a lot because he's trying to manage his pain.”

Kelpa met her husband after his accident thus a comparison between their relationship prior to and after the injury was not feasible. Kelpa described her and her spouse as having “a very imbalanced relationship as far as the work put in.” When discussing how she managed to separate being a caregiver from her role of being a wife, Kelpa explained that self-awareness and communication is necessary. She described, “Mostly it is kind of me being aware of when I'm feeling like a roommate, caregiver, and not a wife and that I bring it to his attention. And then he's really good at, he's not quite self-correcting because I have to prompt him.”

Subtheme 2: Effects on Family Dynamics

Sunflower concurred with Amy that they had partnered on all tasks before her husband's injury, and now he can no longer do so. She described how she takes care of all the household chores with help from her children. She described how the children take on chores and some of the care for their father but described feeling conflicted with this situation. She explained how the “family dynamic changed drastically.” Sunflower described this conflict and explained, “…my son, the younger one, actually did a lot of physio with his dad, which was adorable and heartbreaking….” She further elaborated on her feelings regarding the children helping with caregiving tasks.

> When I look at my kids taking on a caregiver role, I'm just very aware of the pieces where they're taking on an adult role. That's heavy in trying to balance that. I think that's another thing when people say, “Oh, it's so great that they help.” I'm like, “Yeah, it is, but they also shouldn't have to.”

YK described how their children have had to adapt to their father’s injury. She sadly described how her husband was unable to attend their daughter’s college graduation and their son’s high school graduation because he was hospitalized at the time. She tearfully explained how it was emotionally difficult for all of them that their father wasn’t physically present at these two milestones. She described how their celebrations are different than what they were pre-injury. She went on to explain how so much thought has to go into whether a venue is accessible and the immense amount of preparation that is needed before a family outing.

YK told of how their children have had to help more with household chores since their father’s injury since he cannot do many of the chores that he did prior to his injury. She explained how this was a cause of anxiety for the children since they were trying to balance their own life obligations. Furthermore, YK explained that she and her husband do not want them to participate in his care because they didn’t want to “burden” them with it. She stated, “Our opinion is then, we want them to be adults and do their lives; he [her spouse] doesn't want them caring for him.”

Subtheme 3: Loss of Family Member Relationships and Friendships Post-Injury

Sunflower sadly recalled how some other relationships have ended since her husband’s injury. She recalled how her brother was no longer involved in their lives since the accident. In trying to explain the reasoning behind the loss of relationships Sunflower explained, “I think we've all had people disappear in our lives too, who just can't handle it. Some actual literature about that, that it isn't about you and it's about them.”

Jeanie Jo wistfully described how she had more independence before her husband’s injury. She labeled herself as social and stated that her husband wasn’t as social. Prior to the accident, if an invitation was extended to them and he didn’t want to go, she would go alone. Jeanie Jo explained how, since the injury, this has changed, and she feels she needs to stay home with him. She further described these feelings during her interview.

> That's the life that we had before. And what happened for me was that was taken away from me. All of a sudden, I was expected to hang out all day with him. I was like, I can't do that. I need that social interaction. So that was very difficult. And I think I'm reestablishing my independence now.

Rebecca told of feeling “heartbroken” by the loss of family and friends they have experienced since her husband’s spinal cord injury. When asked why she thought certain relationships ended after the injury, she replied, “I noticed that when people felt things were heavy is when they would leave” and “I also think part of it too is people don't know how to handle something that they're not familiar with.” Although Rebecca described feeling sad and sounded seemingly understanding of the friends and family who are no longer a part of their lives, she also expressed feeling angry at them. She elaborated on her feelings of anger and stated, “It makes me angry in a sense that they wouldn't take the time, especially some of the people who had known him pretty well his whole life and who were like brothers to him.” She vividly described how some people don’t know how to interact with or help her husband since the injury, so they just avoid it. She explained how it takes effort to learn about the intricacies of traumatic brain and spinal cord injury and that some people don’t want to put the effort in to learn about these components.

When discussing other relationships and how her husband’s injury has affected these relationships, Cloudy described how she no longer has a relationship with her “best friend.” She explained how this friend told her a couple of weeks after her spouse’s injury that “it was too stressful” for her to be in their lives. Cloudy further explained how, although some relationships faltered, she has developed stronger ones with others since the injury:

> I think that perhaps it challenges people to reflect within and maybe challenge their mortality. I'm not sure. I think that a lot of relationships expire or have seasons. And yeah, I think it's all purposeful. I think everything happens for a reason. I've gained a lot stronger and more powerful relationships since closing the doors on some of the others.

ADC described how some of their family relationships have been “fractured” since her husband’s injury. She went on to explain how her husband said some hurtful things to her brother and how her brother no longer deals with him. In addition to her brother, ADC described how her spouse’s family, including his children from another relationship, no longer talk to her since the injury. She went on to state that they have made many new friends in their community and that these friends have become a support system for them.

YK described how, since her husband’s injury, they have seen a change in their social circle of friends. She explained that in the beginning, many family members and friends came to help with his care, help with home modifications, and visit, but approximately one year later, these visits have “petered out.” She described how most people don’t truly understand how difficult it is to go out socially. She explained how her husband has physical limitations with his hands and how he is uncomfortable being seen eating in public. She explored this further in the below excerpt:

> It's hard because people don't necessarily want to hear the sad side of this, the medical problems, they just don't understand. And because he can move his right arm fairly well, with adaptive tools, he can feed himself, but he doesn't necessarily want to do that in public right now. It's more of a comfort level. It's all fresh for him. It's not that he's opposed to it and two, for me to help, it's like he doesn't necessarily want to be fed in

> public. Absolutely understandable, totally valid. But nobody else sees it that way. They don't think about it.

YK described how some friends would say “Yeah, yeah, I'm going to come up, let's get together" and how these outings would not come to fruition. She eloquently described how when they did make plans, she had to be cognizant of whether the meeting place was wheelchair accessible and frankly admitted that this was something neither she nor her husband ever thought of prior to his injury. She sadly described how they “have seen most relationships just drop” since her husband’s injury.

Subtheme 4: Loss of or Changes in Partner Intimacy

RJT sadly expressed her feelings regarding changes in intimacy between her and her husband since the injury.

> It's hard to be a caregiver, like the intimacy with him, being that it, either it's very little, or he can't have intimacy as it used to be. That's very difficult. But we still hug a lot, hold hands, that type of thing, go to the movies. We'll try to go to the movies and have date nights, that stuff. But those are the biggest, I would say the biggest difficulties for me, is the intimacy, that type of thing, being close to each other.

Rebecca tells of a lack of intimacy and how their bedroom used to be the place for intimate moments, but now it is filled with medical supplies and equipment for his toileting needs. She described how this modification has further contributed to their issue with intimacy:

> It's very hard to just be his wife. Our bedroom, our master bathroom is his, I call it his bathroom because it's got his whole set up. We had it redone, modified to where he can use it. It's called a 101 in the medical world, but it's a raised toilet seat that he uses. Nobody's going to take that on and off to go to the bathroom. It's like suction cup to the

> floor. So, we all use the front bathroom. So that's his bathroom, but that's in our bedroom. You know what I mean? So, you have all this equipment and everything around your space.

MW briefly described that since the injury, their level of intimacy has been affected. She explained that he is unable to “initiate” intimate acts and that now she needs to be the one to initiate. She explained how she understood that since he is in constant pain since the injury intimacy is “not the first thing on his mind” and described having difficulties separating her role as his caregiver and that of his wife.

YK described how, since their marriage was a second marriage for both of them, they had discussed that someday, when they got older, their sexual relationship would change. She described how they developed a meaningful, fulfilling connection and had healthy communication as a couple. She tearfully described how she didn’t realize at the time of their conversation that this change in intimacy would happen so soon. She described how her husband’s injury occurred soon after they were married and described the struggle:

> We were of the mindset, it was more important to us, we have a great connection, we have a great partnership, we have great communication. He is ultimately my absolute best friend. The part that sucks is we just didn't know it was going to happen two years into being married. So having that ripped away is a struggle. And for him too, his love language is touch and he can't touch, and he can't feel. So that's a struggle.

Theme 8: Caregiver Coping

Upon being interviewed, participants described various coping mechanisms. Participants admitted that they often found it challenging to take care of their own physical and psychological needs; however, all agreed that self-care was an essential component of effectively managing the complex life they all shared as caregivers to their dependent partners after a spinal cord injury.

KB explained how she coped with challenges in their lives by remaining optimistic and “counting the small successes.” She shared one of these “small successes” in that although she is behind in her outside work, she revels in that she can still work outside the home and contribute financially. She also described “finding little bits of time” to care for herself. She joined a trivia league and finds being a part of this team pleasurable. She described how sometimes she would “have a beer” or “take prn medications” to cope. Additionally, she described herself as an “emotional eater” and sometimes used this mechanism to cope.

KB described “finding those intimate moments” with her husband to manage their relationship. She described holding hands and sitting together to watch television as some of these intimate moments. She lovingly told a story of how when her husband was hospitalized, he would order an orange sherbet or ice cream on his dinner tray and give it to her as an act of him taking care of her.

Amy explained that faith in God was her primary coping mechanism. She repeatedly spoke of faith and its impact on her life. Amy explained how faith, in combination with the support of church members and family, helped them all cope with her partner’s injury and the tragic changes in their lives. Amy eloquently described her feelings:

> I'm a Christian, and so my faith was a huge part of that for how I cope and deal with our challenges, relying on my faith in God. And we attend a church where I grew up, so I know almost everyone there. And so, I got a ton of help from everyone that we go to church with as well. They just kind of rallied around us and held us up during a really difficult time.

Amy further explained her devotion to God and how faith changed her everyday life. She stated that when she doesn’t take time to pray, she senses a difference in herself.

> My faith is probably the biggest thing. I spend time every day reading my Bible and praying and spending time with God. And I know a lot of people who don't have faith in God will spend time in meditation, and that really helps. But I spend my meditation time with God, and so that is really extremely beneficial. And I definitely notice a change in myself when I don't make time for that.

In addition to faith, Amy explained how going to formal counseling sessions with her husband helped them to be able to communicate better with the changes in their lives after the injury. She described how she attends individual counseling and that through counseling, she was able to better understand her feelings of anger.

When asked what advice she would give to other significant other caregivers whose partner survived a spinal cord injury, Amy quickly replied, “It is really important to take care of yourself.” Some of the self-care advice included drinking enough water, getting enough sleep, going for a manicure or massage, and reading. She explained how she struggled to find time for these activities but understood self-care's importance to her well-being. To sum it up, Amy stated, “…hold onto the things as best you can that you enjoy.”

Sunflower explained how she and her husband had participated in marriage counseling prior to his spinal cord injury and how, approximately a month after the injury, they both agreed that marriage counseling was necessary. Sunflower explained how going to counseling together taught them the tools needed to help improve their communication. She explained how these tools got her and her husband through the tragic accident; she stated, “I think we wouldn't have gotten through without them.”

Sunflower described how it has been three years since her partner’s injury and how she is now able to cope by exercising, setting boundaries, and participating in activities to promote professional growth. She explained how exercise gave her “dopamine releases” that helped her mental state immensely. She described how she has learned to “say no” in a nonconfrontational manner and further explained this coping mechanism, “…getting to the saying no of just like, "No thanks, I don't have the capacity for that," and being okay with that.” In regard to professional growth, Sunflower excitedly described how she was presenting at an international conference soon.

When describing other coping mechanisms, Sunflower laughingly stated, “I ate a lot of fudgesicles, a lot” and “I have read a lot of Kindle Unlimited smut in the last two years.” She jokingly stated that she sometimes wished she was a drinker so that she could “just shut down” and further explained “it’s not me.”

Regarding giving advice to other significant other caregivers providing care to their partner after a spinal cord injury, Sunflower advised, “I think it's just, find someone who will listen. Find someone who will just listen and keep that person close, man. Especially if they can listen without judgment.” She explained how, although she rarely posted on social media, she found reading posts of other significant other caregivers on a social media group created specifically for wives and girlfriends with partners who have survived a spinal cord injury was very helpful. She explained how reading other caregiver’s posts and stories made her feel less isolated and helped her know that other caregivers were experiencing similar “frustrations.”

In telling of her experiences, Jeanie Jo explained how she regularly sought professional counseling prior to her spouse’s spinal cord injury and that continuing to attend individual counseling sessions after the injury helped her cope effectively. She explained how her therapist continually advised her to take care of herself. She explained how she told her husband, “I have to take care of myself, or I can't take care of you.”

Jeanie Jo described using “mindful meditation” daily and practicing gratitude to manage stress. She openly explained this coping mechanism:

> We don't have control over life. That's the truth. But we all think, I can do it. I can solve every problem, blah, blah, blah. And so, I sort of came to this Buddhist attitude, really, of it is what it is. Don't live in the past, don't live in the future, live right now. Everybody deals with suffering. Suffering is part of life. You have whatever you're doing, somebody else has whatever they're doing, but it's not your whole life. And find joy where you can find it, live in the moment and have a gratitude thing.

She further described how their daughter gave her and her husband a gratitude journal and how they would write down one thing each day that made them happy. She described such things as the sun being out and laughing at a television show. Jeanie Jo explained how practicing gratitude helped her to cope with the challenges of her life as a caregiver to her husband and helped them both deal with the life-altering injury they experienced.

Jeanie Jo expressed how being a part of caregiver support groups helped her to cope. She described being a member of an online social media group with other wives and girlfriends caring for partners with spinal cord injuries was beneficial to her well-being. She described attending a four-day caregiver’s retreat organized by another group where she was able to find support and respite from her caregiving duties.

Jeanie Jo explained how she managed to find a respite from her caregiving duties by enlisting the help of family and friends. She advised other significant other caregivers to “ask for and accept help” as a way of coping. She explained how she would go away overnight every two months or so and have family members and a paid caregiver stay with her husband while she was gone. She laughingly explained how she told them not to call her and that if there was an emergency to “call 911.”

RJT explained how she enjoys gardening and how this helps her to cope with stressors in her life. She stated, “I try to go out and do things for myself.” She described her struggle with gaining weight and how she sometimes coped by overeating. She told how she has seen her weight “go up and down” since her husband’s injury. However, she stressed the importance of self-care. She stated, “I think it's very important, you have to be an advocate for your own care, not only for yourself, but for your loved one. And doing little things for yourself.”

RJT explained how she copes by staying connected with other couples whose partner has suffered a spinal cord injury. She stated, “Reaching out to other people that are having the same experiences as you, makes you feel like you're not alone.” She described how being a member of a social media group for women and girlfriends with spinal cord injuries has been quite beneficial to her well-being and how she has connected with many other caregivers in similar situations through this venue.

As with several other participants, RJT described how she and her spouse have benefited from attending counseling sessions together. She further explained that it is important to find the “right” therapist and if a therapist is not a good fit how it can be “detrimental” to both partners’ overall “health.”

Sara explained how she coped by attending individual counseling and by being a member of spousal caregiver support groups. She described her experiences in one social media support group called WAGS (Women and Girlfriends of Spinal Cord Injury):

> The WAGS Facebook group has been one of the best things because even when I couldn't attend virtual meetings with people because he was in the room, just being able to talk about experiences, talk to other people, see other people posting thoughts that I thought or concerns that I've had like, "Hey, if this happens, this is what you need to watch out for." Those all made me feel a lot better.

Sara further described how she has learned to cope by “setting boundaries” to protect her well-being. She further explained, “I think the next big thing is I think setting firm boundaries and limits where partners or even their family can abuse the care and love that you have for that person to make you do more than is actually fair on you.”

She described seeking respite from her caregiving duties by having her husband’s family take him out on Saturday. Although she is happy to have time to herself, Sara described how her spouse and his family “get mad at her” when they take him out on Saturdays because they feel like she is “foisting” his care on them. She explained how she struggled with this perception but greatly needed respite time to be able to cope effectively in her life.

Rebecca recalled being given good advice while her husband was rehabilitating after his injury. The healthcare team advised them to “Build your community now. Don't let those people go. Continue to give them something to do, even if it's the littlest thing, so that they remain connected to you because you'll need them when you get home.” Rebecca explained how this community has been built since the injury and how the support of family and friends has helped her cope with the demands of being a caregiver. Although she has found support in their “community,” Rebecca admitted that it is “exhausting” trying to explain their needs to others. She explained, “I got to the point where I just didn't ask because I didn't feel like it was fair for them to carry.” She explained how the number of people in their community has “dwindled” since the early stages of her husband’s injury.

In her story, Rebecca advised other significant other caregivers to find someone in whom to confide their feelings. She further explained, “I would encourage them to be honest, at least with one person in their life and say, this is how I'm feeling.” Furthermore, she explained how telling her story to others is a helpful coping strategy. She described using an online website to chronicle their story after her husband’s injury. She explained how it has helped them cope when they go back and read past entries. She described how reading their past entries helped them to see how much they have grown and adapted to the challenges in their lives.

Cloudy expressed that “a lot of self-care” was her primary coping mechanism. She vividly described swimming, hiking, gardening, doing pottery, and going to the gym as some of the self-care activities in which she participated. She explained how this self-care helped her cope with feelings of being overwhelmed. She further described her strategy:

> I try to sort of say to myself, if I can put one even half an hour aside in one day, do my breathing, my Heart Math® or I listen to, read a book or something. Just try to get myself back into my own body so I'm not feeling overwhelmed. I challenge myself to do a little bit each day.

ADC described being able to cope with life challenges as her partner’s caregiving by setting boundaries with him. She described how she explained to him that she needed her rest and how he couldn’t ask her for anything, including non-emergent care after a certain time at night. She further explained her strategy:

> Part of my journey as a caregiver is defend my own rights. So, one of the things that I learned to do was say, "Look, I'm exhausted at night, so you have until 10 o'clock to ask me anything you need to ask me."

Regarding self-care as a coping mechanism, ADC described how she likes to dance, travel with friends, pray, meditate, and journal her feelings. Additionally, she explained how she makes time to quietly drink her coffee and paint in the morning. She vividly explained this routine:

> Every day I get up probably two hours before I have to be anywhere, and I have coffee by myself. I paint in the morning. I get up and I do abstract art or my waves, which you can see in the background. It's one of the ways that I release a lot of emotions onto that paint, and it calms me and it soothes me and it gives me a feeling of accomplishment. And it has nothing to do with him.

MW described how she coped by swimming and quilting. She described how she incorporates her hobby of quilting by setting up a camera monitor in the room so she can view her husband while she is in another room. She explained how she likes to read; however, she finds it difficult to read when there is time because she feels that she should be sleeping when there is an opportunity.

MW mentioned attending individual counseling sessions. She explained how she is on a “different little planet” and how the therapists don’t really understand her unique challenges as a caregiver. She described how she learned a relaxation breathing technique during one of the sessions that she found helpful when she is feeling anxious.

MW advised other significant other caregivers to join an online spousal support group. She admitted that she found it helpful knowing that other caregivers have overcome challenges that she encounters. She further explained the benefits of online support groups:

> I would definitely try to have them reach out to the WAGS group. Definitely. Even though you feel like you're on this asteroid where no one, there's no communication, seriously, there's a ton of folks out there. Maybe we're all on our different asteroids, but people have solved some of the problems, or at least there's answers out there. I have learned so much from them, way more than I learned from the hospital.

YK described how she enjoyed doing fifteen minutes of yoga each night and getting massages every two weeks to cope with the stress in her life. She explained that yoga and massages provided an outlet for her.

Another outlet YK described was counseling sessions both individually and as a couple. She explained how she and her spouse attend couples' counseling and how it helped to improve their communication.

Kelpa openly explained how she and her spouse cope with life challenges by having an active social life. She described how, early in their relationship, they built their own community of "able-bodied, disabled, and differently-abled" couples with whom they frequently socialize. She insightfully described how every marriage has challenges and that their challenges just happen to be of a physical nature. She told of how she and her partner practice having a grateful and positive attitude:

> So mostly it is just appreciating what we have that is so good between us and recognizing that, yeah, it would be great if we had more options for travel and if I didn't have to be caregiver, but it's really not been that bad. So, it's probably attitude and just choosing how

> to view it in a way that really doesn't give the caregiving more weights than really what it is. It's part of our story. We make it work.

Kelpa described effectively coping by being self-aware and recognizing when respite time was needed from her caregiving duties. She described knowing she needed a break when she experienced a sense of “acute overwhelmedness [sic].” She further explained her ability to reflect and stated, “You need to be able to be honest about when you're feeling like you need a break.”

Theme 9: Living the Façade

In telling their stories, several of the participants spoke of concealing their struggles and challenges to others regarding their role as a caregiver to their spouses. It was repeatedly stated that others who were not in the same situation had a lack of understanding about the true essence of their lives as significant other caregivers providing care to partners with a spinal cord injury. These brave women described that they often did not express their feelings to partners and other family members to spare their feelings. Some participants simply stated that it was sometimes easier to remain quiet than to explain their lives' challenges. The following significant statements and excerpts will further illustrate the theme of living the façade.

KB described a situation in which her supervisor at work was having a discussion with her to ascertain why she was falling behind in some of her work. In trying to explain her and her partner's recent struggles, the supervisor asked, “Do you always have this much drama in your life?” KB described feeling surprised and “taken aback” by this comment; however, she smiled and continued to try to explain their situation. In doing so, she came to the realization that no matter how much she tried to explain, this person would never fully comprehend her life challenges. She understandingly stated that from her supervisor's perspective it probably appeared that her life was "full of drama."

Amy spoke of having to "stuff down" her feelings of anger and sadness because she needed to "power through" all of the caregiving tasks placed upon her. She recalled not being able to display her feelings and stated, "…there were times when I would cry, but most of the time, just out of necessity, I had to keep going. I just had to keep doing all of the things that needed to be done." Amy poignantly described how she and her husband had differing views and approaches to his injury. She stated that her husband was "very okay mentally and emotionally, and spiritually" with his injury and approached their situation by trying to figure out how to manage their life-altering challenges. She explained that, because her husband was coping effectively, she felt that she needed to have the same approach although she felt differently. She further explained, "He was fine. I did not think that that was possible for him to be fine, but he really was. I was not, but I thought that I should be because he was fine, if that makes sense."

Sunflower described finding someone outside her circle of family and friends with whom she could be authentic about her feelings. She explained that this particular person listened to her "without judgment." Sunflower spoke of how she didn't feel that she could always be genuinely honest about her feelings to other people with whom she was close. She explained her perspective about being able to reveal her feelings and stated, "I think sometimes you need to be allowed to be angry, and you need to be allowed to be sad. Yeah. And sometimes it's not."

Rebecca openly described how, although she had her mother and friend by her side as a support system after her husband's injury, she didn't feel as though she could authentically tell them how she was feeling or ask them for help. She kept many of her feelings inside and did not share them with the people closest to her. She stated, "I wasn't really honest with them about the things I needed help with because I didn’t want them to be burdened.” She described being fearful that if she tried to explain to them how she was really feeling they wouldn’t understand her situation. She further explained, “Nobody else understood what I was carrying. And even if I did explain it, they weren’t going to get it.” Rebecca elaborated and stated, “I noticed that when people felt things were heavy is when they would leave. So, I didn’t want to talk about heavy stuff to people because I was afraid that would be it.”

Cloudy described feeling “isolated” at times and unable to describe to others not in a similar situation what it is like to be a caregiver to her spouse. She stated, “…nobody really gets it.” She explained how often she hid her true feelings from others and proceeded to do all that needed to be done as a caregiver. However, she admitted that eventually, her feelings came out. She explained, "Oh, it doesn't bother me. It's fine. I'll just do it." And then later on it comes up.”

Cloudy described how she found it difficult and time-consuming to explain to others what needs to be done to care for her spouse, so rather than taking the time to instruct others, she does what needs to be done herself. She admitted that this is something she is currently working on changing. She elaborated on this feeling by stating, “A lot of the time, I think one of the personality types of a caregiver in general is, "Oh, I'll just do it. It's just faster. I'll just get it done." So, I'm working on that.”

In telling of her experiences as a significant other caregiver, YK described how others misunderstood her role as a caregiver. She explained how her real-life experiences are quite different than what others perceive and see on the surface. She vividly explained this phenomenon:

> I don't know that you could prepare anybody for this role. I think you could tell people, you could talk to them, and until you're truly living it, people will never quite understand

> or if they know somebody or are intimate with somebody with a spinal cord injury.
>
> Unfortunately, it's like the facade of what they see.

YK described how she has taken on many roles as her husband’s primary caregiver. She jokingly told of how she told her husband she wanted a sash like in Girl Scouts with badges for all of her varying roles. She told of these roles and stated, “I've become everything. I've become a therapist, I've become a barber, I've become a PT, OT. I told [my spouse] I want a badge, like a sash, like Girl Scouts and I want badges. I want badges for everything I've earned, medical professional, urologist.” She further described her current situation as “Groundhog’s Day” and explained how she doesn’t tell others of all the complexities of her life as a caregiver and how she puts on “a smiling face” to others. She further described living a “façade” and stated, “I find that I do it when people who don't know what it takes behind the scenes, because they don't know. It doesn't matter what you tell them, or they don't want to hear your sad story.”

Kelpa described having a good support system in their friends. When asked if she felt that their friends understood her real-life experiences as a primary caregiver to her spouse, Kelpa admittedly stated “no.” She explained how she didn’t feel comfortable discussing her role in her husband’s care, especially with tasks like his bowel program. She explained how instead of describing all that goes into their morning routine she will avoid these topics and vaguely explain that she and her husband are not available until a certain time in the morning. She further explained this strategy:

> I don't talk about bowel care or that kind of stuff, so that's the stuff we just don't go into, if a friend wanted to schedule something early, now that we're retired, we generally sleep till about 07:30 or so, but that still means we're not up and around and doing much until sometimes 10:30 or 11. So I've learned to just, I tell them I'm available after 11. And

> yeah, some of our friends know that it takes a couple hours to get [spouse] up and get going, but they don't know the specifics of that. And that's fine. I don't want... [spouse] wouldn't be comfortable with that, and I don't need people to know that.

Conclusion

The 9 themes derived from the transcribed interviews of the 12 participants in this study illustrate the meaning of the lived experiences of significant other caregivers providing care to partners who have survived a spinal cord injury. Table 4 provides a concise summary of the themes, sub-themes, and summative in-depth descriptions of each of the nine themes, including select significant participant statements.

Table 4 Emerging Themes and Subthemes

Themes	Subthemes	In-Depth Description of Themes
Overarching Theme: **Theme 1:** Women Warriors	1. Need to protect partners 2. Need to advocate for partners 3. Mistrust of healthcare team	Caring for a partner with a spinal cord injury has many challenges. The needs of a person with a spinal cord injury are sometimes not fully comprehended by those outside of the situation such as healthcare providers, insurance companies, and other relations. One participant described her partner are being “vulnerable” since being confined to a wheelchair. The participants frequently used the words “fight”, “fight for”, “argue”, and “protect” when describing their experiences.
Theme 2: Waves of Emotion	1. Frustration 2. Sadness/Depression 3. Anxiety 4. Feeling overwhelmed 5. Misunderstood by others 6. Envy 7. Anger/Resentment 8. Isolation 9. Guilt	Diverse emotions exist simultaneously and are triggered by the demands of assuming the role of caregiver. Caregivers go back and forth between these emotions at varying times. “I go through waves of being very at peace and waves... I'm in a not at peace wave right now”.

Theme 3: Chronic Caregiver Sorrow	1. Complex and complicated process 2. Ongoing mourning 3. Multiple losses	Multiple losses characterize the lived experiences of significant other caregivers providing care to partners after a spinal cord injury. “a chronic, complicated grief that will never go away” “deep, deep, deep sense of loss and grief” “Nobody can understand mourning the man that you sleep next to every night.” “there is loss after loss after loss”.
Theme 4: The Caregiver Journey	1. Initial shock 2. Survival mode 3. Skills acquisition 4. Acceptance 5. Fluid process	From the time of the initial injury to present, a fluid process exists to describe the transition from a partner in a relationship to being a primary caregiver without a definitive endpoint identified. “survival mode” “soldier mode” “breathing and processing” “reality mode”
Theme 5: Listen to Us	1. Feelings of not being heard by healthcare team 2. Feeling dismissed by healthcare team 3. Not being identified as an integral part of healthcare team 4. Feeling misunderstood by healthcare team	Partners surviving a spinal cord injury need to be admitted to acute care hospitals and rehabilitation centers at varying times. Frequently, caregivers feel “ignored” and plead for members of the healthcare team to “listen” to their partners and themselves. Caregivers and their partners with a spinal cord injury know the daily care best since they live it every day. “just listen to us”
Theme 6: So Much to Do, So Little Time: The High Cost of Caregiving	1. Effects on outside work performance 2. Financial strain 3. Threats to caregivers’ physical and psychological well-being including lack of sleep	Being a caregiver to a partner with a spinal cord injury is wrought with threats to other aspects of caregivers’ lives including work performance, finances, and physical/psychological well-being. “carrying it all” “huge strain financially” Caregiver needs tend to become “secondary” to partners’ needs and take on multiple responsibilities. “I've become everything. I've become a therapist, I've become a barber, I've become a PT, OT… medical professional, urologist”

Theme 7: Relationship Changes	1. Partner relationship changes – partner role reversal, positive and negative, personality changes 2. Effects on family dynamics 3. Loss of family member relationships and friendships post injury 4. Loss of or changes in partner intimacy	Caring for a partner with a spinal cord injury has a significant impact on a couple's relationship. Relationships described as "healthy" prior to the injury may help in the transition from partner to caregiver. "I think when you go into these things, the issues that you had before you went into them, don't go away. If anything, they're amplified"
Theme 8: Caregiver Coping	1. Need for self-care and respite 2. Setting boundaries 3. Building a supportive community 4. Need for individual and couple counseling 5. Need for support of other caregivers in similar situations	Significant other caregivers identified many coping strategies although most admitted to finding it challenging to find a "balance". "It is really important to take care of yourself" "I can't take care of you if I don't take care of myself"
Theme 9: Living the Facade	1. Pretending everything is good 2. Concealing the struggle	Comprehending the intricacies and challenges of being a caregiver to a partner with a spinal cord injury is difficult for those who are not in similar situations. Caregivers described holding back their feelings and putting on a "smiling face" to others. "nobody really gets it". "it's like the facade of what they see"

The 9 emerging themes presented here provide a rich illustration of the lived experiences of the twelve significant other caregivers providing care to their partners after a spinal cord injury. Their words tell their own personal story and allow one to vividly imagine their challenges, successes, and heartfelt feelings. Understanding these caregivers' experiences may allow nurses and healthcare providers to implement interventions to best support their unique needs and possibly promote better outcomes for the caregivers and their partners.

CHAPTER 5: DISCUSSION

This study illuminated the experiences of twelve women providing care for their partners after a spinal cord injury. The functional changes that occur because of the partners' spinal cord injury place a considerable demand on the significant others who are in a committed relationship with their partners. Data from the interviews provided an opportunity to view the lived experience of significant others caring for a partner with a spinal cord injury. The caregivers' perceptions may lead to developing strategies where healthcare providers can offer support and guidance.

Links to Theoretical Framework

Transitioning from an equal partner to a caregiver after a partner survives a life-altering spinal cord injury is wrought with emotional, mental, and physical challenges. The participants of this study described their journey, personal and relationship changes, and various "phases" they experienced after assuming the role of caregiver. They articulated their experiences using words such as "shock," "reality mode," "soldier mode," "survival mode," "breathing and processing," and ultimately "acceptance." The participants' journey and phases can be linked to Meleis' Transition Theory. This section will provide insight into the correlation of the experience of the participants with Meleis' middle-range theory of transition (Meleis et al., 2000).

Change Trigger

"Transitions are both a result of and result in change in lives, health, relationships, and environments" (Meleis et al., 2000, p. 13). Meleis (2020) explained that transitions occur because of a trigger. When transitioning to a caregiver role, the trigger is the actual spinal cord injury. The role of becoming a caregiver was abruptly thrust upon the participants of this study, who consciously chose to stay in relationships and be caregivers to their injured partners. They described transitioning into the role and assuming the extra associated responsibilities.

The caregiver transition process begins when a partner has a catastrophic event such as a spinal cord injury. This event creates a situation whereby caregivers describe life as ‘before’ and ‘after.’ That part of the caregiver’s transition process is described as a sense of disconnectedness (Meleis, 2000). Caregivers may experience a sense of loss in the way things used to be and may grieve the way the partner was before the spinal cord injury. The participants describe this sense of before and after as they told their stories. They described how, prior to the injury, their partners were able-bodied, equal partners in their relationships. Their partners were no longer physically able to perform certain household chores and acts of intimacy. Many of the injured partners either changed careers or could not work outside the home after their injuries. This transition experience totally disrupted the lives of the caregivers and changed the couples’ preconceived hopes and expectations for the future. For effective adaptation to occur, eventually, caregivers needed to accept the current situation and let go of what their lives were like before the spinal cord injury. Meleis described this process as not linear and something that may take some time. This fluid process was described as the participants of this study told their personal stories.

Properties

Meleis (2000) identified the essential properties of transition experiences as awareness, engagement, change and difference, time span, and critical points and events. These transition properties can be related to the insights of the significant others in this study.

“Awareness is related to perception, knowledge, and recognition of a transition experience (Meleis et al., 2000, p. 18).” The participants expressed awareness that their roles, relationship with their partners, and lives overall changed after their partners' spinal cord injury. The level of awareness varied amongst participants, but it was most clearly communicated that life as they knew it pre-injury was quite different. They vividly described changes in themselves, their partners, and their relationships with their partners. One participant used the term "reality mode" to describe the point in time when she realized that permanence and the gravity of their changed life situation post-injury.

Engagement is defined by Meleis et al. (2000) as the degree to which a person exhibits involvement in the processes inherent in the transition, such as seeking out information, using role models, learning new skills, actively preparing, and proactively modifying activities. All of the participants described seeking information on how to best manage their partners' care even when adequate information was not provided by the healthcare. Many of the participants used the advice and guidance of other significant other caregivers providing care to their partners with spinal cord injuries and connected with these individuals through social media. They all expressed gratitude for being a member of WAGS (Women and Girlfriends of Spinal Cord Injury) Facebook group and found support from the other members' posts and suggested resources.

The concepts of change and difference were present in the caregivers' transition described by each study participant. Several of the caregivers expressed having difficulties separating their caregiver role from that of being a wife or fiancée. This change in role frequently impacted the couples' intimacy. A lost sense of identity was noted as some participants struggled with disillusioned expectations of what their lives would be like at this stage of life.

Meleis (2020) described the concept of beginning to end of a transition as the time span and further explains that, although the beginning may be definitive, the end of the process is more fluid. For the study participants, the time span began when they realized their partner would depend on them for care and progressed towards an end when the skills and attitudes of being able to provide care were mastered and they felt competent in their assumed roles. Meleis (2020) concluded that one's transition typically ends when there is a sense of well-being, and a positive quality of life is experienced. Regarding well-being and life quality, participants whose partners were injured more than a year ago described "falling into a routine" and "feeling more competent" in their caregiver roles. For those participants whose partners were injured less than a year ago, they articulated having difficulties "finding balance" and often felt "overwhelmed and anxious."

Many participants described critical points and events that helped bolster their confidence and assist them in making the transition to caregivers. Many of these critical points revolved around acquiring skills such as transferring, managing the complications of immobility and pressure on the skin, and successfully venturing out in public.

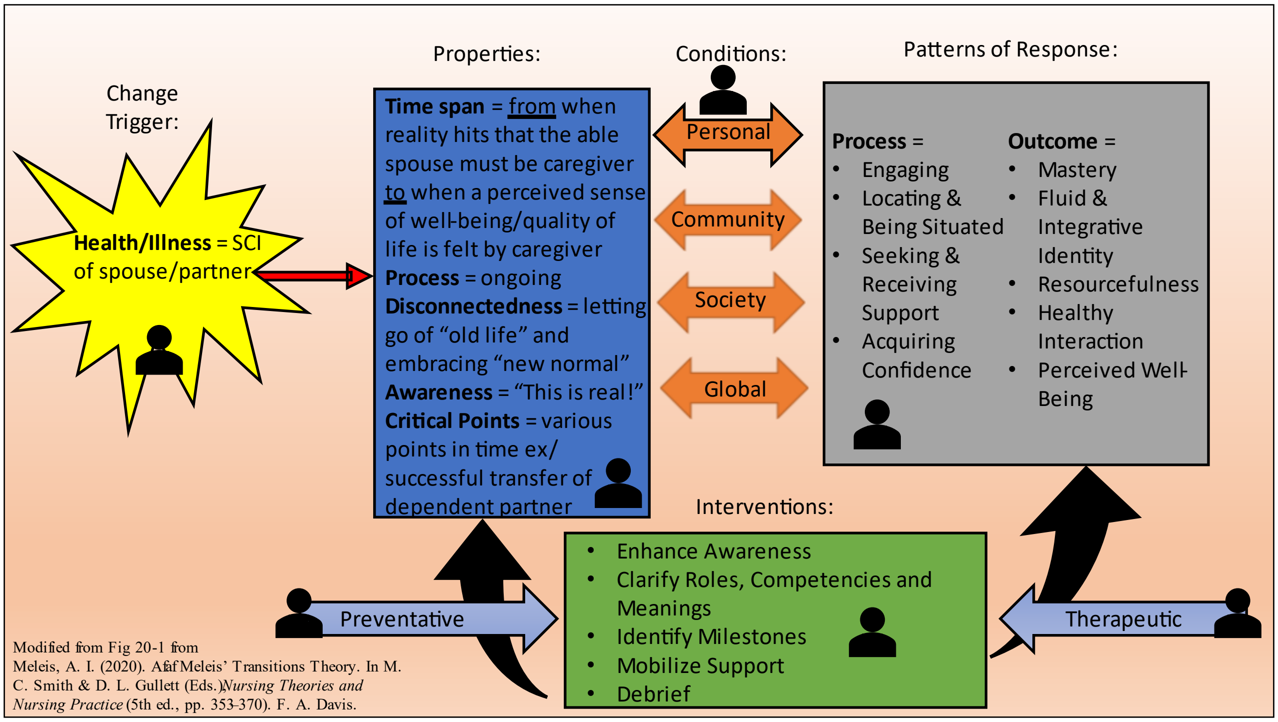
Conditions

Meleis indicated that certain conditions may affect a caregiver's transition, including personal, community, societal, and global factors. One's own values and meaning of life may be threatened by a major change. The participants described these various personal, community, and societal conditions and how they affected their transition in a positive or negative manner. They felt depression, anxiety, frustration, envy of others, and anger. This myriad of emotions had a negative effect on their transition to the caregiver role and made their journey more difficult to accept.

The participants described the effects of either having a supportive community of others to assist in their caregiver role or not having community support. Several participants told of “building a community” to help them succeed in their roles as significant other caregivers. Throughout the interviews, participants spoke of societal and global conditions that affected their transition to the role of caregivers. These conditions included inaccessibility issues when they went out in public with their wheelchair-bound partners. They described situations in which the perception of accessibility of others in society had not been accurate and how one small step could render a location inaccessible for their injured partners in wheelchairs. They told of societal misconceptions of the mental capacity of their injured partners when they went out in public or went to a healthcare facility with their wheelchair-bound partners. For example, they mentioned that people would talk directly to them and not address their partners. They also described issues regarding insurance coverage and governmental benefits for their injured partner and for themselves as care providers, which proved to be a monumental stressor. They had to “fight” with insurance companies, employers, and governmental agencies for appropriate coverage and reimbursement. As described in Meleis’ Transition Theory, these unfavorable personal, community, societal, and governmental conditions inevitably created barriers to a seamless transition into the caregiver role.

Meleis’ Transitions Theory and Implications for Nursing

Nurses often provide care to clients and families experiencing transition after a life-altering spinal cord injury. Numerous opportunities exist for nurses to assist significant others in transitioning to caregivers for their injured partners. The person icon in Figure 1 illustrates when nursing interventions can assist significant others as they transition to caregivers.



Modified from Fig 20-1 from Meleis, A. I. (2020). Afaf Meleis' Transitions Theory. In M. C. Smith & D. L. Gullett (Eds.), *Nursing Theories and Nursing Practice* (5th ed., pp. 353-370). F. A. Davis.

Figure 1 Nursing Interventions

When a spinal cord is sustained, the injured person is typically admitted to an acute care hospital setting. Nurses in acute care hospitals usually provide the bulk of the patient care and thus have ample opportunity to connect with clients' significant others who will later serve as their primary caregivers. Nurses, at this point, may provide emotional support not only for the clients but for the clients' significant others. Nurses may start to introduce some of the skills needed to provide care for clients with spinal cord injuries to their significant others, so they have time to process what needs to be done to care for their injured partners. Caregivers should be repeatedly instructed to perform the skills to feel more comfortable doing them independently once their loved ones are discharged from the hospital and sent home. In addition, the acute care hospital is an optimal place to educate significant other caregivers on the importance of their own self-care and the recognition of signs of caregiver psychological distress. The timing of the delivery of this important information must be carefully assessed by nurses since immediately after the injury caregivers may not be ready. Personal self-care may not seem important to caregivers while they are consumed with the life-altering impact of their partners' injury.

The stories shared by the participants depict how being a partner caregiver makes one vulnerable to the associated effects of the physical and psychological demands of the role. Providing care to a dependent partner is stressful. Nurses can help ease some of this stress. Ducharme, et al. (2011) posited that "providing proactive nursing assessment and interventions early in the caregiver role transition may support and better prepare a caregiver to make a healthy transition to this newly assumed role." (p. 1110) Nurses practicing in hospitals have the unique privilege of being present when a patient is admitted after a life-altering event or diagnosis. These same nurses may meet partners of patients who may assume the provision of care after discharge. An important goal of nurses is to understand that both clients and their partners' entire lives have been disrupted and will change unequivocally. Nurse educators need to be cognizant of Meleis' transitions theory so that they can then transfer this knowledge to nurses who are caring for these patients. With knowledge of Meleis' transitions theory, nurses can educate significant others to help make their transition to a caregiver role smooth. Education can take several forms and may comprise training such as proper transferring, meeting incontinence needs, and medication administration. Nurses can also educate caregivers about warning signs of emotional distress in themselves so they know when to reach out for help if needed. Meleis (2020) discussed the property of awareness in the transition process. As related to Meleis' Transition Theory, Kindarara et al. (2017) explain that "awareness influences engagement." (p. 516). If caregivers are aware of their own feelings, they may seek support if they are experiencing any distress. If caregivers are engaged in their partners' care and well-being, then they can be proactive in their approach and feel empowered in their ability to provide quality care (Kindarara, et al, 2017).

Nurses should aim to understand these transition properties to be therapeutic in their relationship with caregivers. Nurses need to be mindful of their spoken words as well. Phrases such as “it’s your new normal” or “things could be worse,” although true, may leave caregivers feeling as if the nurse does not understand what they are going through. This perception may lead caregivers to disregard any future, potentially beneficial interventions offered by nurses. Nurses can also help partner caregivers identify milestones in the transition process. For example, nurses can provide positive feedback to caregivers for safely transferring a dependent partner into a wheelchair. The nurses’ constructive feedback and positive reinforcement may help caregivers gain confidence in their ability to care for loved ones and consequently help them master the skills needed to make a smooth transition.

Nurses with adequate knowledge of Meleis’ transitions theory understand that certain conditions can affect the progression of caregivers through the transition process. These conditions include personal, community, societal, and global factors, as outlined in Meleis’ transitions theory. Caregivers’ values and meaning of life may be threatened by a major life change, such as a partner becoming disabled. For example, they may lose their sense of security knowing that their partner may not have the physical or mental ability to work as they did before the event or diagnosis, and now the financial responsibility will be transferred to them. Caregivers may fear being stigmatized by being with a disabled partner and losing friends because of the disability. These feelings were expressed by several of the participants of this study. Nurses can provide caregivers with resources for community support and can help caregivers connect to those who can help. For instance, nurses could suggest that caregivers join a support group to meet other caregivers who can serve as role models and help them identify the obstacles involved in being a partner caregiver. With this action, nurses are embracing one intervention in Meleis Transitions Theory and are mobilizing support.

Many of the participants mentioned that nurses and other healthcare providers did not seem to understand the unique challenges that caregivers experience when caring for their partners after a spinal cord injury. This perceived lack of understanding often led to the participants feeling "ignored" or "not listened to" by nurses, doctors, and other healthcare team members. This perception led to mistrust, resulting in their concern that their loved ones would not receive adequate care from the healthcare team.

An increased nursing understanding of Meleis' theory provides a sound framework for nurses to assist caregivers in navigating seamlessly through the complex transition process and thus may decrease the incidence of caregiver emotional distress. Nurse educators are pivotal in educating nurses of Meleis' transitions theory. With a working knowledge of the theory, nurses can incorporate its key tenets into practice and provide effective nursing assessments and interventions for partner caregivers.

Integration of Findings with Previous Literature Review

None of the studies specifically examined significant other caregivers providing care to partners who survived a spinal cord injury. The themes that emerged from this study shared some common threads with selected studies in the literature review and revealed several findings not found in a review conducted before data collection. The commonalities and dissimilarities will be discussed in this section.

Waves of Emotion and Caregiver Coping

An extensive amount of research has been published about caregiver burden and psychological distress in the last decade (Abreu, et al., 2018; Adelman, et al., 2014; Geng, et al., 2018; Hagedoorn, et al., 2002; Kanmani & Raju,2018; Zarit, et al., 1986). Several of the participants of this study expressed feelings of depression and anxiety. This is consistent with the findings of the study completed by Geng et al. (2018), in which forty-five percent of family caregivers providing care for dependent family members experienced anxiety, and approximately forty-two percent suffered from depression. The participants in this study described feelings of sadness and feeling overwhelmed and anxious at various times in their experiences. Several openly cried or got teary while telling their stories. Many of the participants described seeking professional counseling for emotionally distressing feelings, and one participant described taking anti-anxiety medication as needed to ease her symptoms of anxiety.

In a quantitative, comparative study by Ahmad and Khan (2018), the participants' family caregivers providing care to family members with chronic, debilitating illnesses reported experiencing psychological distress and exhibited feelings of loss, grief, uncertainty, shame, guilt, and anger (p. 94). The participants of this study reported exhibiting the same emotions and described feelings of loss, grief, guilt, and anger while telling of their experiences. Ahmad and Khan (2018) described caregivers as “secondary patients who need and deserve protection and guidance.” (p. 93). The authors explained that caregiving is stressful and that chronic stress increases the risk of disease and chronic illness in caregivers (Ahmad & Khan, 2018). The stress associated with being a caregiver initially results in a negative effect on psychological well-being, but as it continues, the stress may negatively affect the caregiver’s physical well-being (Ahmad & Khan, 2018). Similarly, the participants of this study described various physical ailments that they directly attributed to their role as caregivers. The participants verbalized that their needs often became secondary to the needs of their partners, and many expressed struggling to find time to take care of themselves.

Kanmani and Raju (2018) conducted a mixed methodology research study exploring family caregivers' psychosocial concerns and psychological distress while providing care to their loved ones with traumatic brain injury in an emergency and trauma care setting. Kanmani and Raju (2018) described these family caregivers as experiencing "physical, emotional, psychological problems, caregiver burden, dissatisfaction, and unmet psychological needs." (p. 54) In this study, caregivers are described as "emotionally disturbed" and demonstrating "crying, sadness, helplessness, and hopelessness." (Kanmani & Raju, 2018, p. 57) Although many of the participants of this researcher's study cried and expressed feelings of sadness, none expressed feeling helpless or hopeless nor did they describe themselves as "emotionally disturbed." On the contrary, the participants of this researcher's study described continually utilizing various coping mechanisms such as counseling, painting, quilting, exercising, and other activities to deal with their unpleasant feelings.

Literature Review After Data Analysis

Several findings in this research study were not found in the initial review of the literature for this study. Therefore, an additional literature search was conducted after data collection to seek information. The review revealed studies and/or articles that examined chronic sorrow in spousal caregivers, adjustment and coping in spousal caregivers following a traumatic spinal cord injury, financial strain, relationship changes, and caregiver advocacy. The findings of these studies support this study's findings. The topics of chronic caregiver sorrow, relationship changes including loss of intimacy, financial strain experienced after a spinal cord injury, caregiver advocacy, and living the facade will be discussed and compared to findings in other pertinent research studies.

Women Warriors

Throughout the interviews in the data collection phase of this study, caregiver participants described situations in which they felt they needed to be their partner's advocate. The participants used words such as "fight, argue, and protect" as they told their stories of encounters with healthcare providers, insurance companies, and members of the general public.

A review of the literature was done using the key terms caregiver advocate and family advocate. The review revealed a conference abstract from the 1st North American Conference on Integrated Care that was held in Toronto, Canada, in October 2021. The authors of this abstract, Keresteci et al. (2021), concluded that the importance of family caregivers was accentuated during the Covid-19 pandemic. They discussed gaps that were identified in care coordination and cited that the role of caregivers in caring for their loved ones was "misunderstood and often undervalued." (p.1) The conference led to a grassroots committee of family caregivers whose collective voices were being used to prompt necessary social reform and improve the continuum of care for their family members.

The findings of this conference abstract substantiated the words of the significant other participants who often "felt ignored, not listened to," and felt the need to advocate for their partners. Study participant KB stated that while her partner was hospitalized, it felt like "us against them." The study participants discussed deficits in their partners' care because their input wasn't considered important. Several participants discussed "fighting for" specialty hospital beds while their partners were hospitalized to prevent pressure injuries. Many of the participants told of staying with their partners while hospitalized so that they could oversee their care and advocate for their needs.

Chronic Caregiver Sorrow

Many of the participants described feelings of grief as they told their stories. Their words echoed with the sorrow they expressed. Jeanie Jo spoke of “a chronic, complicated grief that will never go away.” Rebecca described her feelings as a “deep, deep, deep sense of loss and grief” and stated, “Nobody can understand mourning the man that you sleep next to every night.” MW articulated her perception of life after her spouse’s spinal cord injury as one of continual loss. She stated, “There is loss after loss after loss.”

A review of the literature was conducted using the terms caregiver, grief, chronic sorrow, sadness, and depression. Chronic sorrow was first introduced by Olshansky (1962) to describe the distress parents felt after having a child with a disability. Roos (2002) defined chronic sorrow as “a unique grief reaction that occurs when loss is not final but continues to be present in the griever's life.” Roos (2002) also called chronic sorrow a “living loss.”

Rossheim and McAdams are members of the Counselor Education Program of The College of William and Mary in Virginia. They published an article addressing the chronic sorrow of long-term spousal caregivers as an introduction for counselors. Rossheim and McAdams (2010) describe chronic sorrow as “grief, chronic sorrow is a realistic response to sustained loss….” (p. 478). In their article, the authors explained chronic sorrow as it relates to long-term spousal caregivers. Although their article does not specifically address significant other caregivers providing care to their partners after spinal cord injury, parallels to their experiences can be made. The authors explained that “For both patients and caregiving spouses, there is no moving on from grief in the case of chronic sorrow—only moving with it, as each new problem offers an inescapable reminder that the losses will continue.” (Rossheim and McAdams, 2010, p. 479). Such is the case for significant other caregivers managing the care of their loved ones with a spinal cord injury.

In this study, participant Rebecca described “feeling robbed” by her partner’s spinal cord injury. She explained further that she married an able-bodied man who no longer was able to do what he could do before the injury. She felt that their children “were robbed” of having a father who was once athletic, and post-injury in a distinctly different physical state.

The loss and chronic sorrow expressed by the participants of this study were palpable throughout the interviews. They described loss in many areas of their lives after their partners’ spinal cord injury. The ten participants who knew their partners prior to their injuries described mourning the loss of the man that they knew pre-injury. The participants spoke about ‘before’ and ‘after’ the injury. They described the loss of familiar acts of intimacy, loss of income, loss of an equal partner who was physically able to help with various household chores, and the loss of a future they envisioned prior to their partners’ injury. Since their partners had not succumbed to their injuries, the participants described how they were faced with multiple losses continuously in their day-to-day lives. They described feelings of sadness related to these multiple losses and explained how even though their spouses were physically present in their lives, their feelings of grief and sorrow were real and emotionally painful to deal with at times.

Rossheim and McAdams (2010) explained how chronic sorrow may result in depression and anxiety. However, depression and anxiety because of chronic sorrow typically present differently than depression and anxiety as a psychiatric disorder. They explained that often clients with a diagnosed psychiatric disorder of depression and or anxiety present with symptoms of helplessness and impaired functioning. However, spousal caregivers experiencing depression and anxiety from chronic sorrow tend not to be diminished in their capacity to perform their caregiving functions and "may actually become more active and decisive" as they maintain responsibilities for their partners' care (Rossheim and McAdams, 2010, p. 479). This seems to be the case with the participant caregivers interviewed for this study. None of them discussed being incapacitated by their depression or anxiety, and all stated that they continued to provide their partners with care despite their feeling depressed or anxious.

Relationship Changes and Loss of Intimacy

Data collected from participant interviews revealed relationship changes and issues with couple intimacy. The participants reported role reversal with their partners, mounting tensions related to caregiving, and overall changes in intimacy. Several of the participants reported seeking professional help from marriage and/or individual counselors. Some participants reported consciously improving communication between themselves and their partners to maintain stability in their relationships.

The participants expressed their frustrations and challenges in caring for their partners after spinal cord injury. These feelings may lead to negative consequences and make the couple's relationship vulnerable. Journalist for *U.S. News and World Report* Anthony Cirillo wrote an article examining the impact of caregiving on couples' relationships (2019). Cirillo (2019) reported that eighty percent of caregivers providing care to their loved ones admit to feeling the strain on their relationships. He estimates that the divorce rate for couples in which one has a chronic illness such as spinal cord injury is as high as seventy-five percent. One of the relationship issues that participants described was a loss of intimacy after their partner's injury. The Caregiver Action Network (CAN) is one of the nation's leading family caregiver organizations. It serves a broad spectrum of family caregivers. It is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge. The Caregiver Action Network (2023) described loss of intimacy as the “hidden cost of caregiving.”

The participants of this study described various strategies to manage the strain in relationships with their partners. KB described “finding those intimate moments” with her husband to manage their relationship. She described holding hands and sitting together to watch television as some of these intimate moments. Participant Cloudy described making a conscious effort for couple time. She explained:

> I think just sort of making time to do other things that are really fun that we can connect on outside of the care, like going for date nights or playing games or laughing or going for nice walks and just really enjoying doing activities that make us really feel good and make us laugh and enjoy life. Because the caregiving pieces are still going to forever be there. It's not going to go away anytime soon. So, you want to sort of, at least in my perspective, I want to do all the fun things while we can. So, then they outweigh all the caregiving things that happen sporadically.

Several of the participants described having difficulties separating being caregivers from being their partners’ wives or fiancée. They spoke of self-awareness and having to consciously reframe their way of thinking for different situations. Several of the participants described that their communication as a couple improved after their partners’ spinal cord injury since they were forced to talk about many things that they didn’t need to talk about pre-injury. This perceived improvement in communication seemed to help these vulnerable dyads stay connected as a couple.

The High Cost of Caregiving: Financial Strain

Many of the study participants reported having financial issues after their partners' spinal cord injury. In some cases, the participants described a significant decrease in their household income since their partners could no longer work outside the home. Other participants explained how the expenses related to the care of their partners caused a financial strain, and some of the participants exhausted their personal savings and/or retirement funds. These expenses included medical equipment and supplies not covered by insurance, hiring outside caregivers to assist in their partners' care, purchasing wheelchair-accessible vehicles, and the cost of home modifications.

A review of the literature was completed using the terms caregiver, finances, income, and financial strain. Lee and Zurlo (2014) conducted a cross-sectional, quantitative study examining whether spousal caregivers face difficulties in meeting their basic household expenses compared to non-spousal caregivers and whether social support mechanisms decrease the financial strain. Their study was conducted in Canada and was not specific to significant other caregivers providing care for their partners after a spinal cord injury. They examined data collected from caregivers in a national Canadian community health survey with a large sample size of 5,067 caregivers who were forty-five years or older. Lee and Zurlo (2014) concluded that "spousal caregiving is associated with a 35% increase in the likelihood of experiencing difficulties in meeting basic expenses compared to other types of caregiving." (p. 302) They concluded that social support services significantly lessened financial strain on spousal caregivers and that spousal caregivers were more likely to experience financial strain than other caregivers.

The findings of Lee and Zurlo (2014) support the findings in this researcher's study, in which several participants reported significant financial strain associated with caregiving.

Several of the participants reported spending anywhere from three thousand to five thousand dollars monthly on outside caregivers and/or medical equipment and supplies. Cloudy described how, at one point in time, she and her partners were “sanitizing” and reusing urinary catheters because they were unable to afford the cost of new, sterile ones. This is a huge concern since using unsterile catheters increases the risk of acquiring catheter-related urinary tract infections and possibly sepsis. Jeanie Jo explained how they spent “nearly two hundred thousand dollars for caregivers in the first year alone.” She further explained that this money came from their retirement funds and how they did not have long-term care insurance and were not eligible for any assistance because “we have too much money.”

Living the Façade

Several of the caregiver participants of this study described suppressing or “stuffing down” their true feelings and “living the facade” for the sake of other people. Although they described feelings of sadness, anxiety, feeling overwhelmed, and exhaustion, the participants explained that they would often not share these feelings with others. Study participant Rebecca stated that she “didn’t want to burden others,” while study participant Cloudy explained that “it took too much time to try to explain.”

A review of the literature on this phenomenon using the terms caregiver façade, caregiver suppression, caregiver and concealing feelings, and caregiver front revealed no results. There were several studies on caregiver compassion fatigue, but none related specifically to significant others and their suppressed emotions. This interesting finding warrants further investigation in future nursing research to better understand the significant others’ lived experiences.

Implications of Findings

Need for Policy Reform

The findings of this study and that of Lee and Zurlo's research (2014) on spousal caregiving and financial strain among middle-aged and older adults support the need for more social, policy development or reform and governmental support for significant other caregivers. The important role of significant caregivers presents many challenges since most caregivers simultaneously care for loved ones while working outside the home to provide a family income. Caregiver psychological distress has a significant financial impact that can influence society. An estimated $25.2 billion is lost in caregiver productivity at work, and caregivers miss up to 6 days of work on average annually due to caregiving issues (Witters, 2011). These staggering statistics reflect the significance and impactful ramifications of caregiver psychological distress. Regulatory and legislative policies are necessary to address the issue of significant other caregiving and its associated psychological distress to provide resources, including education and screening, to minimize the detrimental effects of being a caregiver.

Key Policy Events: Scope and Severity of Problem to be Solved by Policy

In 2014, the Caregiver Advise, Record, Enable (CARE) Act was enacted in Oklahoma to support family caregivers. The Caregiver Advise, Record, Enable (CARE) Act became law in 40 states in four years, with additional states initiating the legislative process (Reinhard, Ryan, Young, et al., 2019). The quick adoption of this act indicates that policymakers recognize the importance of support for family caregivers and the challenging role they must undertake to adequately care for their loved ones. It identified a tremendous gap in the support and guidance available to family caregivers, including significant other caregivers. Significant others assuming care of their partners are thrust into providing complex care at home, typically provided by nurses in the hospital. The CARE Act supports family-centered care and is intended to involve family members in caring for a loved one during hospitalization so they are better prepared to provide care after discharge. This is much needed for significant other caregivers who plan to provide care for their partners after life-altering spinal cord injuries.

On January 22, 2018, Public Law 115–119 115th was enacted by the Senate and House of Representatives of the United States of America in Congress to establish and maintain a Family Caregiving Strategy. This Act was entitled the ‘‘Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017’’ or the ‘‘RAISE Family Caregivers Act’’. This act established a Family Caregiver Advisory Council with the goal of making recommendations and providing support for family caregivers. Although the enactment of this act is remarkable, one distinct gap has been identified by this researcher. The RAISE Family Caregivers Act fails to recognize caregiver psychological distress, nor does it adequately address screening or the provision of resources for those experiencing psychological distress. Based on recommendations in the RAISE Act, expansion is needed to address this issue.

Policy Alternatives and Recommendations: Proposition for Expansion of the RAISE Family Caregiver Act

The CDC (2018) suggests training healthcare providers about the important role of family caregivers and providing information and support to implement health-promoting strategies for caregivers. Not only does the CDC recognize a need for increased awareness of the health issues associated with family caregiving but several other influential organizations have expressed supportive views of family caregivers and a call for action in policy. In 2017, a summit hosted by the National Institutes of Nursing Research was conducted entitled “The science of caregiving bringing voices together” to open discussion of the state of family caregiving and the policy implications (Nursing Outlook, 2018). That summit platform was supported by numerous stakeholders for family caregiving support including the American Association of Retired Persons (AARP), the National Alliance for Caregiving (NAC), the American Nurses Association (ANA), the American Academy of Nursing, the National Cancer Institute, the National Institute on Aging, the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the National Institute on Minority Health and Health Disparities, the National Center for Advancing Translational Sciences' Office of Rare Diseases Research, the National Institute of Health (NIH) Office of Behavioral and Social Sciences Research, the National Institute of Health (NIH) Office of Disease Prevention, and the National Institute of Health (NIH) Office of Research on Women's Health. These organizations' websites and resources are instrumental in recognizing the need for policy changes to address family caregiver psychological support.

Several states have enacted policies and programs enabling monetary compensation for providing care to a dependent loved one to ease the stress of working outside of the home for family caregivers. Eligibility to be a paid family caregiver depends on several factors, such as one's state of residence, income and financial assets, insurance, and whether the caregiver or their spouse is a veteran (Paying for Senior Care, 2021). Currently, only fifteen states in the United States provide state-based public assistance services providing monetary compensation for family caregivers who care for their loved ones. One such program is the Consumer Directed Personal Assistance Program (CDPAP). This is a Medicaid program for chronically ill or physically disabled individuals with a medical need that allows them to choose their own caregiver, including a family member. However, this program does not permit spouses to be paid caregivers to dependent spouses (American Council on Aging, 2021). Medicare does not pay spouses to provide personal care or assistance with activities of daily living for their husbands or wives. Medicare does not cover personal (non-medical) care for any of its beneficiaries (Paying for Senior Care, 2021). This is an enormous gap since many family caregivers are spouses caring for dependent spouses whose care often involves assisting in activities of daily living not deemed medical care.

The incidence of psychological distress and financial strain in significant other caregivers responsible for caring for dependent loved ones is a significant issue today. The psychological distress experienced by caregivers can have major negative effects on their physical and psychological health. Significant financial implications may result from the loss of productive workdays or the inability of caregivers suffering from psychological distress to work outside the home. Great strides have been made over the last decade in policy with the creation and adoption of the CARE and RAISE Act. However, a thorough analysis of current policy regarding family caregiving reveals a huge gap. There is a need to include a section in the RAISE Act regarding required screening, recognition of psychological distress in significant other caregivers, and subsequent availability of resources to assist in minimizing the effects of such distress. Based on recommendations noted in the RAISE Act, expansion is necessary to further assist significant other caregivers. If caregivers are physically and mentally healthy, they will be best suited to care for their loved ones. Such an expansion can be seamlessly adopted as part of the existing RAISE Family Caregivers Act. Jurisdiction for this expansion falls under the umbrella of the U.S. Congress and should not be state-specific since the threat to the welfare of caregivers is currently an issue across the entire United States.

Nursing Practice Interventions

One feasible, low-cost recommendation would be to require nurses working in healthcare facilities to amend discharge instructions available to significant other caregivers in the electronic medical record to include recognition of the signs and symptoms of psychological distress. The discharge instructions could suggest that caregivers contact their healthcare providers if unmanageable signs of psychological distress are noticed. On discharge of dependent partners, nurses should provide caregivers with verbal and written discharge instructions regarding the recognition of psychological distress and various resources they could access to seek support. Websites from numerous organizations could be included in the written discharge instructions for significant other caregivers. Many of these organizations offer resources for family caregivers at no cost.

Another feasible addition to the RAISE Family Caregivers Act would be requiring nurses and primary healthcare providers to utilize a standardized screening tool to assess for signs and symptoms of psychological distress in patients caring for dependent family members. This screening tool could be required by nurses and other healthcare providers at all points of care, similar to the depression, suicidal ideation, and domestic violence screening tools currently being utilized in practice. Documentation of this screening tool for caregivers could be tied to reimbursement as are other screening tools. Early recognition of distress may minimize the cascading effects on caregivers' physical and psychological health.

Opposing views may question the allocation of funds for said resources. Questions from insurance providers may arise asking who will be responsible for paying for the recommended screening, education, and resources needed to support family caregivers. Organizations such as the Centers for Medicaid and Medicare and private insurance sectors may potentially oppose the expansion recommendations to the RAISE Family Caregivers Act for financial reasons. An unexpected outcome of an expansion of the RAISE Family Caregivers Act could be a significant increase in the identification of depression and anxiety overall. This increase in the incidence of such disorders may require medical interventions such as medications and/or psychotherapy. These interventions would increase the cost of healthcare and may be highlighted by those opposing the expansion of the RAISE Act. One could argue that the output of funds for support and treatment counteracts the significant financial ramifications of unrecognized and untreated psychological distress.

Nurses, nurse leaders, and other providers must be knowledgeable about the lived experiences of significant other caregivers providing care to their partners after spinal cord injuries. Nurses must advocate for practice, assessment, and policy changes to best meet the caregivers' needs. Organizations such as the American Nurses Association, with its vast number of nurse members, could provide a collective voice to promote support and change. A public health policy must be created or revised to provide necessary resources for significant other caregivers, including screening for their potential physical and psychological health issues. This policy must include provisions for monetary compensations for spouses and life partners responsible for the care of their dependent partners after spinal cord injuries.

Nursing Education

The field of nursing and educational preparation for future nurses is ever evolving. Changes in the preparation of nurses are essential due to health care system challenges and family-centered care. To provide quality, family-centered care to clients, nurses must listen attentively to clients and their family caregivers. Many of the participants of this study reported feeling "ignored," and their advice to nurses and other healthcare team members was a resounding “listen to us.” The participants reported that nurses and doctors did not have a clear understanding of the unique facets of clients with spinal cord injuries.

The importance of family-centered care must be stressed at the undergraduate and advanced nursing provider education level. Learning basic nursing care must be accompanied by learning to care for the family. The role of significant other caregivers as members of the health care team must be continually reinforced in didactic and clinical learning settings. It is imperative that nurses remember that clients with spinal cord injuries are going home with their partner caregivers in most cases. A therapeutic relationship with the healthcare team must be established to promote optimal client care upon discharge. Significant other caregivers know the client better than anyone, including their unique characteristics and preferences. Participant Amy recalled how she would have to say to nurses and doctors, "You don't understand. I trust you as a medical professional, but you do not know as much about this patient as I do because I care for him all the time."

A focus on patient and family-centered care is a crucial component in delivering health care and, therefore, must be an integral component of nursing education. Nurses must be educated on nursing care delivery models, including clients and their significant others, in developing the care plan. The plan must be based on the values and beliefs of clients and their families. Fostering an understanding of a care delivery system that is client and family-centered advances competencies that are essential in supporting significant others in providing care for partners with spinal cord injuries. Taking the time to listen to the voices of significant others who are living with the unique challenges associated with spinal cord injuries and incorporating their knowledge into the plan of care is of the utmost importance.

The study participants reported that most nurses they had encountered had limited knowledge of the intricacies of spinal cord injury. Lifelong learning is essential to providing quality client care. Nursing faculty at undergraduate and graduate levels must continually reinforce lifelong learning to bridge the gap between curriculum and actual nursing practice. Nurses need to take the time to assess the client’s cognitive and physical abilities based on their level of spinal cord injury and implement interventions appropriate to meet their individual needs. Listening to clients and their significant other caregivers is one way to learn more about clients. The information these caregivers and their partners provide can broaden the nurses’ knowledge base regarding spinal cord injuries. Nursing faculty in undergraduate and graduate programs could incorporate case scenarios or utilize simulation scenarios to familiarize students with the care of clients with spinal cord injuries. It is imperative that these teaching scenarios include the clients’ significant other caregivers as well to reinforce family-centered care delivery.

Future Nursing Research

Considering the statistics that show that approximately seventy-eight percent of those who sustain spinal cord injuries are male (NSCIS, 2018), recruiting male caregiver participants was challenging. Most caregivers to clients with spinal cord injuries are female unless the male client is in a homosexual relationship. Future research studies could perhaps focus on male significant other caregivers providing care to their partner who has survived a spinal cord injury. It would be interesting to see how the lived experiences of male significant other caregivers compare to their female caregiver counterparts.

Another suggestion for future research studies could be to interview the children whose parents have survived a spinal cord injury to examine their lived experiences. Data collected from children of spinal cord injury survivors could then be compared to the data collected from this study.

The need for assessing the knowledge level of all interdisciplinary team members about spinal cord injury and their significant other caregivers is imperative. This would serve to raise the awareness level and help with the implementation of screening tools in inpatient and outpatient settings to potentially decrease the incidence of caregiver psychological distress and optimize outcomes for clients with spinal cord injuries. This may also lead to developing interventions and services to meet their unique needs. Conducting studies to broaden the understanding of what the experience means to each couple member is imperative. This could be accomplished through focus groups, interviews with each member of the dyad separately and then jointly, and a case study approach including all members of the family. This knowledge is essential in the creation of services that could provide support and guidance and potentially improve the quality of life for individuals with spinal cord injury and their significant other caregivers.

Since several of the participants expressed concern that nurses did not have adequate knowledge of how to care for clients with a spinal cord injury, another potential future research study would be to examine the lived experiences of staff nurses who have had the opportunity to care for such clients and to interact with their significant other caregivers. It would be interesting to explore their perceptions of the significant other caregivers and whether they were perceived as healthcare team members. Such a study could potentially explore nurses’ preconceived notions, biases, knowledge levels, and beliefs about clients with spinal cord injuries and their caregivers.

Limitations and Recommendations

While this study was not designed to be gender specific, all twelve participants were women. Ninety-two percent of the participants were married to their spouses in heterosexual relationships. The homogeneity of the participants in this study is a limiting factor. Therefore, it is recommended that studies be conducted on the lived experience of significant others of both genders, diversity in ethnicity, religion, socio-economic status, and same-sex relationships.

An additional recommendation would be to conduct a study that includes individuals with spinal cord injuries to broaden the understanding of perceptions and lived experiences of both members of the couple. A study designed to include all members of the family living in the home with individuals with spinal cord injury may enhance the understanding of the families' lived experience. As the lived experience of family units managing life after a spinal cord injury is better understood, research instruments can be developed for quantitative studies that may aid in the development of strategies to help support caregivers, other family members, and individuals after life-altering spinal cord injury.

Conclusion

Links to Meleis' Transition Theory and related nursing implications for significant other caregivers have been discussed in detail. The integration of this study's findings has been examined using the literature that was reviewed before and after data collection. The implications of the findings of this study have been discussed concerning policy reform, changes in nursing practice, potential revision of nursing education, and future nursing research recommendations. The limitations of this research study and this researcher's personal reflections have been highlighted.

This study explored the experiences of twelve women providing care for their partners after a spinal cord injury. In their own words, these participants described life-altering changes that occurred because of the partners’ spinal cord injury. Being caregivers to their injured partners placed considerable demand on their daily lives and relationships, yet they persevered. Data from the interviews provides an opportunity to view the lived experience of significant others caring for a partner with a spinal cord injury through their unique lens. Increased awareness regarding the participants’ perceptions may lead to the development of effective strategies in which healthcare providers can support and guide significant other caregivers who are providing care to their partners with a spinal cord injury.

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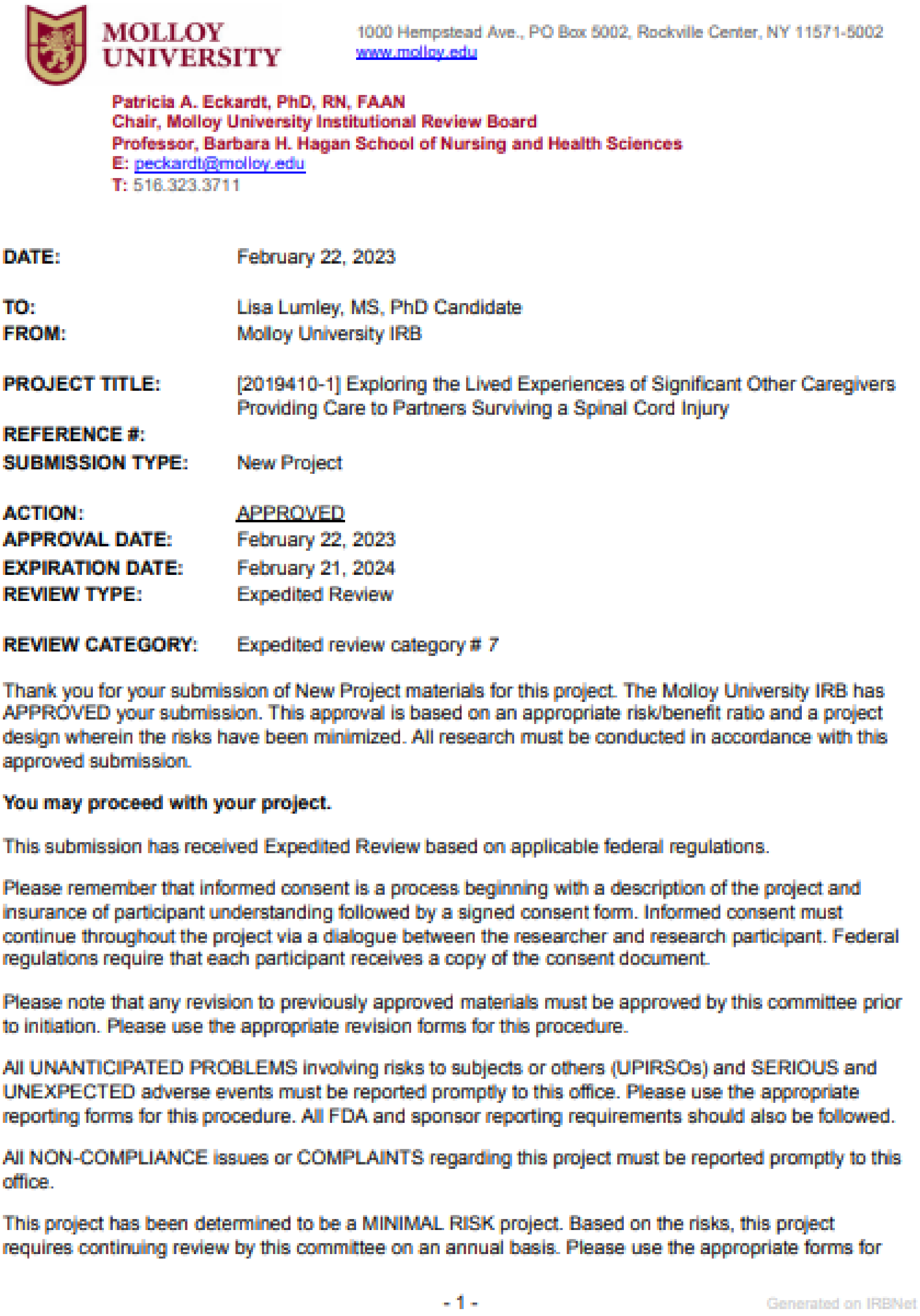
APPENDIX A: IRB APPROVAL LETTER



MOLLOY UNIVERSITY

1000 Hempstead Ave., PO Box 5002, Rockville Center, NY 11571-5002
www.molloy.edu

Patricia A. Eckardt, PhD, RN, FAAN
Chair, Molloy University Institutional Review Board
Professor, Barbara H. Hagan School of Nursing and Health Sciences
E: peckardt@molloy.edu
T: 516.323.3711

DATE: February 22, 2023

TO: Lisa Lumley, MS, PhD Candidate
FROM: Molloy University IRB

PROJECT TITLE: [2019410-1] Exploring the Lived Experiences of Significant Other Caregivers Providing Care to Partners Surviving a Spinal Cord Injury
REFERENCE #:
SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: February 22, 2023
EXPIRATION DATE: February 21, 2024
REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The Molloy University IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

You may proceed with your project.

This submission has received Expedited Review based on applicable federal regulations.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a MINIMAL RISK project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for

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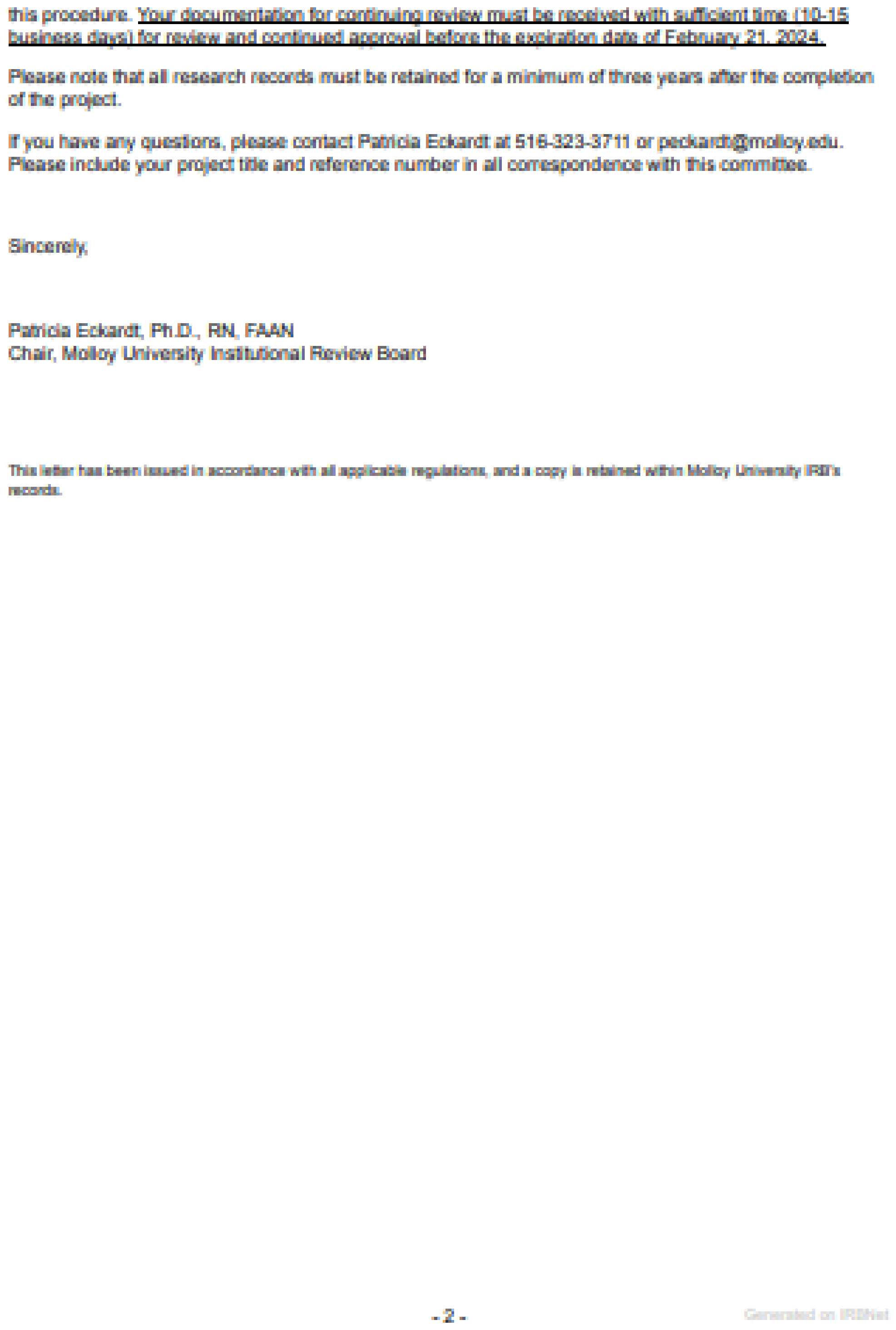

this procedure. Your documentation for continuing review must be received with sufficient time (10-15 business days) for review and continued approval before the expiration date of February 21, 2024.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN
Chair, Molloy University Institutional Review Board

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Molloy University IRB's records.

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APPENDIX B: ADVERTISING FLYER

Would you like to share your story about caring for a partner with a spinal cord injury?

As a Registered Nurse and primary caregiver for my husband who sustained a complete T3-T4 spinal cord injury, I am interested in gaining insight into the lived experiences of other significant other caregivers. I am conducting a nursing research study to gain a deeper understanding of how significant others caregivers experience day-to-day living with a partner with a spinal cord injury.

Are you:

- Over the age of 21 years and speak English as your primary language?
- Currently living with someone as a close couple, in a committed relationship such as with a significant other, spouse, life partner, girlfriend/boyfriend who has sustained a spinal cord injury?
- Interested in sharing your thoughts and feelings about living with a partner with a spinal cord injury?

If you answered 'YES' to all of the questions, you are invited to participate in a nursing research study being conducted by Lisa A. Lumley, RNC, a spousal caregiver, a Registered Nurse, and student in the PhD in Nursing Program at Molloy University in Rockville Centre, NY.

- If you agree to participate, you will be asked to meet virtually via Zoom for approximately one hour to share your experience as a significant other living with a partner with a spinal cord injury. Your identity will be kept confidential.
- The purpose of this study is to explore the unique experience of being a care partner for a significant other with a spinal cord injury. This information may help health care professionals develop strategies to support and provide resources for significant other caregivers.

If you are interested in participating in this study or have any questions, please contact:

Lisa A. Lumley: 631-258-4925 or email: LLumley1@.molloy.edu

APPENDIX C: PARTICIPANT LETTER

MOLLOY
UNIVERSITY
The Barbara H. Hagan
School of Nursing
& Health Sciences

Letter/Statement to Potential Participants

Date________________

Dear_________________,

Thank you for your interest in participating in this qualitative research study. The purpose of the study is to explore issues of concern and coping mechanisms for significant others caring for partners after life-altering spinal cord injuries. The aim is to ultimately discover the meanings that caregivers ascribe to their experiences in their own words. Currently, there are no studies focusing on the lived experiences of significant other caregivers who are in intimate relationships with a dependent partner after a spinal cord injury. Therefore, it is not known how significant other caregivers navigate changes in their relationships and life after a traumatic spinal cord injury of their partner.

Volunteers will participate in an individual recorded interview with the investigator lasting approximately 1 hour. The interview will be scheduled at your convenience and will be via Internet technology Zoom.

An optional follow-up contact can be scheduled for you to clarify and/or validate the analyzed interview in which you participated. You may choose to do this by email, telephone/text, Zoom or Facetime. It would take less than 30 minutes.

You will be provided with a consent form. After all your questions are answered and you agree to participate in the study, you will sign the consent and return it by email or postal mail to the investigator. You will be given a signed copy of the form to retain for your records.

Please contact me if you have any questions. Thank you for your consideration to participate in this study. Your input and perspective on this important topic are appreciated.

Sincerely,

Lisa A. Lumley

Lisa Ann Lumley, PhD Doctoral Student
Barbara H. Hagan School of Nursing and Health Sciences
Molloy University
1000 Hempstead Ave., Rockville Centre, NY 11571
LLumley1@molloy.edu
(631) 258-4925

APPENDIX D: LETTER OF INFORMED CONSENT

MOLLOY
UNIVERSITY
The Barbara H. Hagan
School of Nursing
& Health Sciences

INFORMED CONSENT

Molloy University
Barbara H. Hagan School of Nursing and Health Sciences
1000 Hempstead Ave.
Rockville Centre, NY 115711
(516) 323-3000

Title of the Study: Exploring the Lived Experience of Significant Other Caregivers Providing Care to Partners Surviving a Spinal Cord Injury

This study is being conducted by:

Investigator: Lisa Ann Lumley, MS, RNC-NIC, NPD-BC, PhD Doctoral Student, Molloy University

Barbara H. Hagan School of Nursing and Health Sciences,

Email: LLumley1@molloy.edu

Phone: (631) 258-4925

Doctoral Dissertation Chairperson/Faculty Advisor: Susan Ann Vitale PhD, RN, PNP, ANP,

Professor, Molloy University Barbara H. Hagan School of Nursing and Health Sciences

Email: svitale@molloy.edu

Phone: (516) 323-3000

Key Information about this study:

This consent form is designed to inform you about the study you are being asked to participate in. Here you will find a brief summary about the study; however, you can find more detailed information later on in the form.

- The purpose of the study is to reveal issues of concern and coping mechanisms for significant others caring for dependent partners after life-altering spinal cord injuries and to ultimately discover the meanings that caregivers ascribe to their experiences. The aim is to ultimately discover the meanings that caregivers ascribe to their experiences in their own words. Currently, there are no studies focusing on the lived experiences of significant other caregivers who are in intimate relationships with a dependent partner after a spinal cord injury. It is not known how significant other caregivers navigate changes in their relationships and life after a traumatic spinal cord injury of their partner.

- You may participate in this study if they over the age of 21 years, English-speaking, in a committed relationship with a partner who has sustained a spinal cord injury and serving in the role as their partner's primary caregiver. Participants will be enrolled without bias with regard to gender identification, ethnicity, religious affiliation, sexual orientation, marital status, and/or socio-economic backgrounds.
- You will participate in a recorded interview with the investigator which will take place via Internet technology such as Zoom, for approximately 1 hour. An optional follow-up interview (approximately 30 minutes) can be scheduled for you to add information as desired, and clarify our understanding of your information. This may be by telephone, Zoom, Facetime, or email (your choice).
- Privacy and confidentiality will be maintained. Pseudonyms are used instead of your real name as well as those of partners, families, workplace, or other identifiers.
- There are no anticipated risks or benefits to participation.
- Your participation is completely voluntary. You may choose to not provide any information requested or have what you said deleted. You may choose to not participate in this study or choose to withdraw from it at any time without penalty.

Why am I being asked to take part in this study?
You are being asked to share your experiences as a significant other caregiver providing care to your partner after a spinal cord injury. The goal is to explore how you manage your daily life, relationship with your partner, face challenges, and cope as a caregiver.

What will I be asked to do?
After signing an informed consent form, you will schedule an interview lasting approximately1 hour via Internet technology such as Zoom. You may choose the date and time for your convenience. There are interview questions designed to help you discuss your experiences. The topics include your story, challenges, coping mechanisms, relationship changes, and any other details you would like to share. You may choose to discuss as many of the topics as you wish and may refrain from discussing any of the topics included in the interview.

An optional follow-up interview (approximately 30 minutes) can be scheduled for you to add information as desired, and clarify my understanding of your information. This maybe by telephone, Zoom, Facetime, or email (your choice).

I will record interview conversations and take notes. Video/audio Zoom recordings will be destroyed at the end of the study.

Where is the study going to take place, and how long will it take?
The study interviews will be conducted via Zoom. Your time commitment will involve one interview that will take approximately 1 hour with an optional 30-minute interview via telephone, email, Zoom or Facetime (method of your choice) within 1 to 2 weeks after the initial interview.

What are the risks and discomforts?
There are no research-related risks or psychological discomforts anticipated. It is possible that you may feel tired from talking or become busy with other tasks at the time of your interview.You may stop the discussion at any time or reschedule it.
Every reasonable effort will be made to maintain confidentiality; however, your identity will not be anonymous to the researcher. I will minimize any risks of confidentiality breach by coding written data from interviews and using pseudonyms (not your real name or the real name of partners or locations). In this manner, while information will not be anonymous, it will be coded decreasing risk to your data confidentiality.

What are the expected benefits of this research?
There are no direct benefits for participating in this study.

Do I have to take part in this study?
Your participation in this research is your choice. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled.

Will it cost me anything to participate?
There are no costs for participating in this study.

What are the alternatives to being in this study?
Instead of being in this research, you may choose not to participate.

Who will have access to my information?
You will be identified only by a pseudonym (another name for yourself). Your personal information and signed consent will be kept confidential. Your real name will not be reported in any publication or presentation of the study.

Only the group data obtained as a result of your participation in this study will be made public. Personal identifiers such as partner's names, addresses, workplace, or health care providers will not be used in any publications. Email communication will be kept confidential and deleted after having been read and transcribed to secure study files in a doubly password protected computer without any of your personal identifiers.

How will my information be used?
All the study participants' information will be analyzed as a group and summarized into a written document for the purpose of sharing the research analysis with health professionals and the academic (university) community.

Any future publications related to this research may then help to inform nurses, doctors, and other professionals as to the central issues that need to be addressed in providing support to significant other caregivers providing care to partners with a spinal cord injury. Your information collected as part of this research will not be used or distributed for future research studies.

To ensure that this research activity is being conducted properly, Molloy University's Institutional Review Board (IRB), whose members are responsible for the protection of human subjects' rights for all Molloy-approved research protocols, have the right to review study records, but confidentiality will be maintained as allowed by law.

Can my participation in the study end early?
Your decision to continue with the study is completely voluntary. You may withdraw anytime without penalty. Any information you have contributed may also be excluded if you choose.

Will I receive any compensation for participating in the study? No

What if I have questions?
Before you decide whether you'd like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact the investigator: Lisa Ann Lumley at LLumley1@molloy.edu or (631) 258-4925 and/or the Doctoral Dissertation Chairperson/Faculty Advisor: Dr. Susan Ann Vitale at SVitale@molloy.edu or (516) 323-3000.

What are my rights as a research participant?
You have rights as a research participant. All research with human participants is reviewed by a committee called the *Institutional Review Board (IRB)* which works to protect your rights and welfare. If you have questions about your rights, an unresolved question, a concern or complaint about this research you may contact the IRB. Contact the Molloy IRB office at irb@molloy.edu or the IRB CHAIR: Dr. Patricia A. Eckardt peckardt@molloy.edu call 516-323-3000.

Documentation of Informed Consent:

You are freely making a decision whether to be in this research study.
Signing this form means that:

1. **You have read and understood this consent form**
2. **You have had your questions answered, and**
3. **After sufficient time to make your choice, you have decided to be in the study.**

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

Your signature ________________________________ Date ________________________

Your printed name______________________________ Date _________________________

I also consent to audio tape recording of my interview(s) if conducted by telephone or Facetime ® or video/audio recording if conducted by Zoom.

Your signature ________________________________ Date ________________________

Your printed name______________________________ Date _________________________

Signature of researcher explaining study_________________________ Date____________

Printed name of researcher explaining study ________________________Date____________

APPENDIX E: DEMOGRAPHIC QUESTIONS

Study Focus: What is the lived experience of significant other caregivers who provide care to dependent partners surviving a spinal cord injury?

Demographic Questions

At the start of the interview, participants will be asked to answer several demographic questions including the following:

1. What is your current age?
2. What gender do you identify as?
3. What is your education level?
4. Do you work outside the home and if so, what is your occupation?
5. What is your relationship to your partner?
6. How long have you been in a committed relationship with your partner?
7. Do you have children together?
8. When and how did your partner's spinal cord injury occur?
9. What is the level of your partner's spinal cord injury (such as cervical, thoracic, lumbar region)?
10. Were you in a relationship with your partner prior to his/her spinal cord injury?

APPENDIX F: INTERVIEW QUESTIONS

Study Focus: What is the lived experience of significant other caregivers who provide care to dependent partners surviving a spinal cord injury?

Potential Topics/Questions to Consider

Participants will be asked to share their experiences in a linear manner from when their partners first sustained a spinal cord injury until the current day. Interview questions/probes may include but are not limited to the following:

1. Please try to recall when your partner was first injured and you found yourself in the role of a caregiver. Tell me the story of your experience and what it is like providing care for your loved one.
2. What are your biggest challenges with being a caregiver for your partner?
3. Would you please explain your individual ways of coping with challenges and/or obstacles?
4. What advice would you give other significant others who are faced with being a caregiver for a partner with a spinal cord injury?
5. What advice would you give nurses and other healthcare providers caring for patients with a spinal cord injury and their significant other caregivers?
6. In what ways, if any, has your relationship as a couple changed since your partner's spinal cord injury?
7. In what ways, if any, have you changed since being in the role of a caregiver?
8. If given the opportunity, would you have done anything differently in terms of caring for your partner?
9. Please feel free to share anything else that may help me understand your personal experience.