An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury

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ABSTRACT

Research shows that approximately 12,500 new spinal cord injuries occur each year, which poses a drastic life change for the person who sustained the injury and their closest family members and friends who often times become the ones who care for them in the community. Due to this new, unexpected caregiving role, research shows that many are often unprepared to care for the spinal cord injured person once they are discharged from one of the inpatient settings.

The purpose of this study was to explore and examine the lived experiences of caregivers of spinal cord injury individuals. The results of this inquiry may benefit clinicians, patients, and caregivers with shared experiences and may help educate and guide future caregiver relationships. This study was guided utilizing van Manen’s six research activities of qualitative inquiry. Participants were recruited for this study through purposeful sampling until data saturation occurred. A total of six participants were recruited for this study; five completed the study. Face-to-face, audio-recorded interviews were conducted. Colaizzi’s 7-step approach was used for data analysis. Six main themes and two subthemes were identified during the interviews, which provided the overall essence to this qualitative study.
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CHAPTER 1
INTRODUCTION

Background and Significance

According to the National Spinal Cord Injury Statistical Center (NSCISC) (2015), there are approximately 12,500 new cases of Spinal Cord Injury (SCI) each year. A traumatic SCI is a life-altering injury to the spinal column that causes a paralyzing injury. Common causes of SCI since 2005 are motor vehicle accidents, falls, interpersonal violence (commonly gunshot wounds), and sports (most commonly diving) (Chin, 2015). Depending on the area of the spine that is affected, all four limbs and trunk may be affected (quadriplegia) or only two limbs and trunk (paraplegia). Spinal cord injuries are further classified into complete versus incomplete injury; complete loss of motor and sensory function below the level of the traumatic lesion or partial loss of sensory and/or motor function below the level of injury (Chin, 2015). Patients with complete SCI have a less than 5% chance of recovery, and if after 72 hours of injury, functional recovery is essentially zero if complete paralysis continues (Chin, 2015). This poses a drastic life change for not only the person who sustains the injury, but also to their significant other or closest family members and friends whom often become their caregiver. A person who was once completely independent may now depend on a caregiver to provide basic necessities ranging from cooking and cleaning to intimate personal care such as bowel and bladder programs. This caregiver may experience various emotions from happiness that their loved one survived a traumatic accident to overwhelming stress and burden to now having to unexpectedly provide total care to someone who was once completely independent.
Long-term caregiving can put a strain on any relationship and often times there are many lifestyle adjustments that need to be made to be able to provide long-term care (NSCIA, 2011). Young male individuals account from approximately 80% of new SCI cases (NSCISC, 2015). More than half of SCI patients are single at the time of injury and compared to the general population, divorce rates are slightly higher for those who are married at the time of the SCI (BrainandSpinalCord.org, 2015).

**Problem Statement**

Caregiver health is an important factor for not only the SCI patient but also to the healthcare system (Elliot & Berry, 2009). Persons with spinal cord injury are typically cared for at home by family members. As a caregiver, they may be at a greater risk of negative consequences due to the sole challenges of caring for a SCI person and the extended time of the caregiving career (Schulz, et al., 2009). Caregivers are often sent home with minimal resources and varying degrees of social support placing them at risk. The availability of social support and feelings of control over one’s life were important determinants of caregivers’ well-being (Decker, Schultz & Wood, 1989). These same authors identified that those who spend more time each day assisting the SCI patient feel burdened by these responsibilities and experienced more depression and less life satisfaction. Caregivers are often times unpaid and provide all care within the home. Primary caregivers of SCI patients report a heavy burden of care (Ma et al., 2014). Compared with spouses who were not caregivers, the caregiving spouses reported more physical stress, emotional stress, burnout, fatigue, anger and resentment (Weitzenkamp, et al, 1997).
According to Boschen and Gargaro (2009), based on U.S. statistics, informal caregivers are an integral part of the health care delivery system and two thirds of all home care is provided by family caregivers for SCI individuals. Therefore, we need to think proactively and with a long-term prospective about the quality of life of both the person with the injury and the caregiver (Boschen & Gargaro, 2009).

**Purpose of Study**

The purpose of this study was to explore and examine the lived experiences of caregivers of spinal cord injury individuals. The results of this inquiry may benefit clinicians, patients, and caregivers with shared experiences and may help educate and guide future caregiver relationships.

**Research Question**

The question that guided this study was: What is the meaning and significance of the lived experiences of caregivers as it relates to caring for an individual following a spinal cord injury?

**Chapter Summary**

This chapter provided a brief background of the significance of spinal cord injury and its effect on the caregiver. The purpose of the study and the research question that guided this phenomenological study has been included. Chapter II will provide an in depth analysis of the literature surrounding caregivers of spinal cord injured persons.
CHAPTER II
LITERATURE REVIEW

A computerized review of the literature was conducted utilizing Academic Search Premier, CINHAL, DynaMed, Proquest, Pub Med, and Google™ prior to initiation of the study. Key search words used included spinal cord injury (SCI), spinal cord injuries, SCI abbreviation, lived experience, support, caregiving and caregiver. Articles were reviewed from 1989 to current as they related to the population of interest. The search revealed many qualitative studies as they related to caregivers of spinal cord injured persons.

The research published to date (Appendix A) is focused in two themes designated by this author, which includes psychological well-being and interventions. While there may be commonalities in the content, this author attempted to categorize them into the area in which the majority of the research was performed.

Psychological Well-Being

A spinal cord injury (SCI) has a tremendous impact on not only the person, but also on the caregiver and family. The research demonstrates that the caregiver is expected to know and understand a significant amount of information on how to care for their loved one (Boschen & Gargaro, 2009; Boschen, Tonack & Gargaro, 2005; Dickson, et al., 2010). Additionally, this is expected to be accomplished in a short amount of time in order to care for this person in the home, usually unpaid and with limited resources. After spending time in the home, caregivers soon felt “underserved and unprepared emotionally and cognitively for their new, unanticipated role” (Boschen, Tonack & Gargaro, 2005, p.397). These feelings led to high levels of stress, degeneration of
caregiver health, increased depressive symptoms, and decreased life satisfaction (Boschen, Tonack & Gargaro, 2005). Caregivers of SCI individuals often neglect or ignore their own health problems and needs, and report their health is not as good as compared to non-caregivers (Weitzenkamp, et al., 1997).

Caregivers of those with a SCI are typically informal (spouse or parent) and are not acknowledged by the government or health care system as being an integral part of the care continuum (Boschen & Gargaro, 2009). A caregiver for a person with a SCI (one who is typically male, young, cognitively intact, and previously healthy and active) is likely to be quite different from one who is caring for an older adult with a chronic illness, child with congenital disability, or cognitively impaired brain injury person (Boschen, Tonack & Gargaro, 2005; Boschen & Gargaro, 2009). The caregiver role begins as an “unexpected career” that is defined by new tasks that must be performed for the individual with a SCI, thus changing the relationship (Dickson, et al., 2010). These caregivers enter into a role unprepared and lacking specialized training while attempting to improve the quality of life of the injured person (Dickson, et al., 2010; Boschen & Gargaro, 2009). Consequently, in caring for the SCI person, the caregivers’ health becomes jeopardized secondary to a lack of freedom, financial strain, and role overload (Dickson, et al., 2010). These caregivers are catapulted into this new role with little time to adjust. As the individual with a SCI, functionality does not improve over time; the permanency may compound adjustment or acceptance of the role (Dickson, et al., 2010). Thus, resentment and a sense of inequality in the relationship are common emotions shared by caregivers (Weitzenkamp, et al., 1997) and although the caregiver does not suffer the injury they have to amend to the consequences of the injury (Boschen, Tonack
Caregivers find the provider role difficult, dramatically life altering, and overwhelming as they struggle to reprioritize their goals and daily activities. In addition they have to deal with new personal and social relationships, and accommodate for severe economic constraints (Boschen, Tonack & Gargaro, 2005). Overall, being a caregiver is stressful and involves little positive reinforcement (Boschen & Gargaro, 2009).

As one considers the rehabilitation process for the SCI person, acutely and post-acuteley, many caregivers report the first year after discharge as chaotic. Supporting an individual with a SCI continues to be challenging for several years after that (Boschen & Gargaro, 2009). Caregivers often feel unprepared to deal with their new role following discharge, and the transition from rehabilitation to home can be very difficult (Boschen & Gargaro, 2009). Caregivers who spent more time each day caring for the person with a SCI and feeling burdened by the responsibilities experienced more depression and less life satisfaction (Decker, et al., 1989). Others often described their loss of independence as being chained to the individual with a SCI. There is a struggle to balance competing roles of spouse or mother and caregiver (DeSanto-Madeya, 2006).

Boschen and Gargaro (2009) have identified that the primary stressor of role overload leads to secondary stressors of loss of self. This interplay and influence of coping strategies and social support appears to be the most dynamic in the first year post injury, and the caregivers psychological functioning seems to be related to their coping style (Boschen & Gargaro, 2009). The health and adjustment of the caregiver of a person with a SCI is important to the person with a SCI and the whole service provision system (Boschen & Gargaro, 2009; Boschen, Tonack & Gargaro, 2005). Without the caregiver,
secondary complications and health erosion are expensive and preventable (Boschen & Gargaro, 2009; Boschen, Tonack & Gargaro, 2005). Caregiver health is an important part of the healthcare system as they provide valuable services to community dwelling SCI individuals (Elliot & Berry, 2009).

Interventions

Within the literature there are several suggestions for interventions on how to assist the caregiver following the discharge of one with a SCI; however, few of the studies have been replicated and most suggest additional research in the future. Decker, et al. (1989) suggest developing a support network of family, friends, and possibly healthcare providers that can assist with alleviating some burden of care, while keeping the SCI person in their own home. The availability of social support and the caregiver having a sense of control over one’s life were important determinants of caregiver well-being (Decker, et al., 1989). Understanding that living with someone with a spinal cord injury is a continuous learning experience, the challenges do not disappear after a few years, and life responsibilities shift, which may give a new perspective and appreciation on life (DeSanto-Madeya, 2006). Caregivers should receive training on useful coping strategies and be encouraged to communicate with friends and engage in recreational activities (Ma, et al., 2014).

Elliot and Berry (2009) suggest that psychological interventions for caregivers show positive outcomes in areas such as service utilization, including delayed institutionalization, treatment of depression, and in problem solving training are highly valued by caregivers. Programs that provide services, support, information, and skill building with a relative intensity (in terms of frequency and duration) have a greater
positive effect than circumscribed, infrequent, and educationally based programs (Elliot & Berry, 2009). Programs for new caregivers may have a greater benefit within the first year with a combination of problem-solving training sessions and education which can effectively lower caregiver dysfunction problem-solving styles (Elliot & Berry, 2009). Despite being discharged from a facility, continued support, education and training are important for caregivers transitioning into their new role in the community.

Schulz, et al. (2009) conducted a randomized clinical trial designed to improve the quality of life of caregivers of individuals with SCI. The caregiver was taught how to reduce environmental and personal stress, improve health and self-care, enhance access to support systems, and improve emotional well-being through didactic instruction, problem solving and skills training, stress management techniques, and telephone support groups, as well as receiving a notebook of related information (Schulz, et al., 2009). The dual-target intervention included both the caregiver and the SCI person and was designed to enhance the caregiver only intervention. The SCI person also received SCI education and was taught how to improve management of environmental and emotional stress, improve their health and self-care, enhance their access to support groups, and improve their emotional well-being through didactic sessions (Schulz, et al., 2009). Results indicated that the dual-target model, a conceptual model for stress-health processes applied to SCI persons and caregivers, is an effective strategy for improving the quality of life for the caregiver and the dyad as a whole.

**Chapter Summary**

This chapter provided a summary and description of the current literature related to those (non-healthcare providers) who are delivering care to individuals with spinal
cord injuries. Several studies examined interventions and the psychological well-being of the SCI person and caregiver. There is paucity in the literature related to the lived experiences of caregivers in relation to caring for those who have suffered a traumatic spinal cord injury. The literature reviewed by this author provides a starting point for this phenomenological study.
CHAPTER III

METHOD OF INQUIRY: GENERAL

Hermeneutic phenomenology provides the methodological approach for this study. Phenomenology as defined by van Manen (1990) “the study of the lifeworld- the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it” (p. 9). Phenomenology refers to a person’s perception of the meaning of an event, as opposed to the event as it exists externally to (outside) that person. “Phenomenological projects and their methods often have a transformative effect on the researcher… phenomenological research is often itself a form of deep learning, leading to transformation of consciousness, heightened perceptiveness, increased thoughtfulness and tact” (van Manen, p. 163). This same author states that phenomenological inquiry is what people experience in regard to some phenomenon and how they interpret those experiences. Additionally, phenomenological studies question the essence of the experienced phenomenon or identify the meaning of the phenomenon for those experiencing it to assist the researcher in meeting the goal. Hermeneutics utilizes the uniqueness of the individuals’ lived experiences as a means for better understanding the social, cultural, political, or historical context in which the experiences occur (Polit & Beck, 2010).

History of Phenomenology

A philosophical movement originating in the 20th century, phenomenology is the direct investigation and description of phenomena as consciously experienced without theories about their causal explanation and as free as possible from unexamined
preconceptions and presuppositions (Biemel, 2015). German philosopher, Edmund Husserl (1859-1938) is often acknowledged as the founder of phenomenology.

Phenomenology is both a philosophy and a research method defined as the science of pure consciousness. It is the study of experience and how we experience it, as well as studies the structures of conscious experience as experienced from a subjective or first-person point of view (Smith, 2013). This then leads to the analyses of conditions of the possibility of intentionality, conditions involving motor skills and habits, background social practices and, often, language (Mastin, 2008). Husserl’s phenomenological aim is the rigorous and unbiased study of things as they appear, to arrive at an essential understanding of human consciousness and experience (Dowling, 2007). Experience, in a phenomenological sense, includes passive experiences of sensory perception and imagination, thought, emotion, desire, volition and action. It includes everything we live through and perform; yet, we may observe and engage with other things in the world but not actually experience them in a first-person manner (Mastin, 2008). Making an experience conscious is having a certain awareness one has of the experience while living through or performing it. Mastin (2008) describes that Heidegger further pointed out that we are often not explicitly conscious of our habitual patterns of action, and the domain of Phenomenology may spread into semi-conscious and even unconscious mental activity.

Martin Heidegger, a student of Husserl, criticized and expanded Husserl’s phenomenological enquiry to encompass our understanding and experience of being, and developed his theory of “Dasein”, the non-dualistic human being engaged in the world. He believed philosophy is not at all a scientific discipline, but more fundamental than science itself, and just one way, among many, of knowing and understanding the world.
(Mastin, 2008). Heidegger and Husserl contrasted in their views of how lived experience is explored and encouraged the application of hermeneutics as a research method looking at lived experiences as an interpretive process (Dowling, 2007). His focus was the meaning of Being (presence in the world) and uses the phrase “Being-in-the-world” to refer to the way human beings exist, act, or are involved in the world (Dowling, 2007).

Max van Manen appears to combine the descriptive phenomenology of Husserl with an argument that it is also interpretive (Dowling, 2007) and offers a contemporary approach to researching the lived experiences through hermeneutic phenomenology. According to van Manen (1990), “Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences and asks, ‘What is this or that kind of experience like?’ as it differs from almost every other science in that it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it’” (p. 9). The approach to van Manen’s (1990) methodical structure provides discussion into method and methodology, not a mechanistic set of procedures, but to animate inventiveness and stimulate insight. Reduced to the elemental methodical structure, hermeneutic phenomenology research may be seen through a dynamic interplay of six research activities according to van Manen (1990):

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5.
maintaining a strong and oriented pedagogical relation to the phenomenon; (6) balancing the research context by considering parts and whole (pp. 30-31).

These activities further guide this phenomenological study.

**Phenomenological Activities Related to this Study**

As outlined by van Manen (1990), the first activity is *turning to a phenomenon which seriously interests us and commits us to the world* which is the foundation for a researcher interested in understanding human experience. From this phenomenological point of view, one must remind themselves that the question of knowledge always refers back to our world, our lives, and to who we are; however, the problem of this inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much (van Manen, 1990). One does not need to forget about their assumptions, “but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (van Manen, 1990, p. 47). For this student researcher, interest in this subject began with a self-reflection of personal life experiences as a caregiver to one with a spinal cord injury. Caregivers are an important aspect to the wholeness of one with a SCI, yet easily forgotten once discharged from the acute care setting. As a family nurse practitioner it is important to understand not only how to care for one with a SCI, but also how to integrate care and well-being for the caregiver.

The second activity, *investigating experience as we live it rather than as we conceptualize it* suggests that wisdom is sought in the understanding of the nature of the lived experience itself (van Manen, 1990). In regards to collecting data in the human science perspective, methods of conversational interviewing and close observation are
used to collect and gather data, which to some is not quantifiable, but when someone has related a valuable experience then the researcher has gained something (van Manen, 1990). This phenomenological inquiry will examine the lived experiences of caregivers who are providing care for someone with a spinal cord injury to develop an enriched understanding of that experience through conversational interviewing.

The third activity has the researcher *reflect on the essential themes which characterize the phenomenon* (van Manen, 1990) which is “a true reflection on lived experience is a thoughtful, reflective grasping of what it is that renders this or that particular experience its special significance” (p. 32). Setting up situations conducive to collaborative hermeneutic conversations, the researcher is able to encourage participants to reflect on their experiences to determine the deeper meanings or themes of these experiences (van Manen, 1990). By identifying and analyzing the themes found among caregivers of SCI persons, a richer and deeper understanding is revealed about the nature of this lived experience.

The fourth activity, *describing the phenomenon through the art of writing and rewriting*, is the application of *logos* (language and thoughtfulness) to a phenomenon (an aspect of lived experience) to what shows itself precisely as it shows itself (van Manen, 1990). “The phenomenological method consists of the ability, or rather the art of being sensitive- sensitive to the subtle undertones of language, to the way language speaks when it allows the things themselves to speak … an authentic speaker must be a true listener, able to attune to the deep tonalities of language that normally fall out of our accustomed range of hearing, able to listen to the way the things of the world speak to us”
As the caregiver shares their experiences in caring for a SCI person, the individual and unique lived experiences are discovered.

Next, the fifth activity, maintaining a strong and oriented pedagogical relation to the phenomenon is extraordinarily demanding and requires the researcher to remain strong in their orientation to the fundamental question or notion (van Manen, 1990). This researcher has personal knowledge and experience with the phenomenon under study, yet personal biases will be separated and the researcher will maintain openness to each participant’s experience.

Lastly, the sixth activity, balancing the research context by considering parts and whole encourages the researcher to constantly measure the overall design of the study against the significance that the parts must play in the total textual structure (van Manen, 1990). “Human science is a systematic study of human experience. It is difficult sometimes to persist with a theme and systematically explore its meaningful aspects. One must resist the temptation to take a stab at meaning here, and then there, and then drift to another theme, thus producing a description has in some sense a forced quality to it” (van Manen, 1990, p. 168). The power of conversational research is the ability to take each experience and to evaluate and examine each part to then bring it all together to contribute to the overall study. This researcher will utilize this activity to be in the moment with each participant and maintain openness to appreciate each experience.

**Research Plan**

**Participant Selection**

Purposeful sampling was utilized to recruit caregivers of spinal cord injury persons in order to provide detailed descriptions of their unique personal experiences.
(Ayres, 2007). This researcher anticipated that those recruited would provide their story about being a caregiver to one with a spinal cord injury and provide detailed personal experiences. After Institutional Review Board (IRB) approval (Appendix B) participants were recruited after discharge from an acute rehabilitation hospital in Northern Nevada. Participants were English speaking, 18 years of age and older, residing in Nevada, providing in-home care to one with a SCI, and providing care for greater than 6 months. Recruitment continued until data saturation occurred. Data saturation, as defined by Polit & Beck (2010), is “the collection of qualitative data to the point where a sense of closure is attained because new data yield redundant information” (p. 567).

Data Generation and Analysis Procedures

Data Generation

“The insight into the essence of a phenomenon involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience” (van Manen, 1990, p. 77). Participants were viewed as experts of their own lived experiences being a caregiver to one with a spinal cord injury and their experiences were shared during in-depth interviews. “Phenomenological themes may be understood as the structures of experience. So when we analyze a phenomenon, we are trying to determine what the themes are, the experiential structures that make up that experience” (p. 79). According to Polit & Beck (2010), using unstructured interviews allows and encourages respondents to be conversational and define important dimensions of the phenomenon, and to elaborate what is relevant to them instead of what is relevant and important to the writer. Allowing open conversation, establishing trust, and creating a safe environment was vital and allowed the interview process to thrive. Participants were
encouraged to choose a location of choice that would allow comfort to share personal experiences. The caregiver was also given the option to include the SCI person or not. While interviewing, active listening was the researchers’ commitment to the caregiver to listen intently and receptively. Conversational interviewing is the “kind of interview where information is exchanged between the informant and interviewer in both directions…the emphasis of the interviewer is on listening to whatever the informant says as opposed to guiding and controlling the conversation” (Cohen et al., 2000, p. 61).

Data Analysis

According to Polit & Beck (2010), the “purpose of data analysis, regardless of the type of data or underlying research tradition, is to organize, provide structure to, and elicit meaning from the data” (p. 463). Three techniques to uncover themes in the data according to van Manen (1990) are, the holistic approach, the selective reading approach, and the detailed reading approach. To characterize phenomena, these essential themes consist of listening and observing during interviews and reading and re-reading the transcripts in order to reflect back on the conversations. As cited in Wojnar and Swanson (2007), Colaizzi’s (1978) method was used to guide the analysis and it consists of seven steps:

1) Reading and rereading the participants’ descriptions of the phenomenon to acquire a feeling for their experience and make sense of their account. As van Manen (1990) suggests, meaningful significances of the phenomena emerged the more readings occurred creating a clearer picture of the phenomena as an experience. Use of audio recordings was used to record and store data appropriately, and then the individual interviews were transcribed for further review by the researcher.
2) Extracting significant statements that pertain directly to the phenomenon. Using the selective reading approach (van Manen, 1990) to read and reread the transcripts several times to identify statements or phrases that seem particularly essential or revealing about the experience being described was conducted.

3) Formulating meaning for these significant statements. The formulations must discover and illuminate meanings hidden in the various contexts of the investigated phenomenon. Every sentence or sentence cluster was evaluated to discover what was revealed about the phenomenon utilizing van Manen’s (1990) detailed reading approach.

4) Categorizing the formulated meanings into clusters of themes that are common to all participants; referring these clusters to the original transcriptions for validation and confirming consistency between the investigator’s emerging conclusions and the participants’ original stories; not giving into the temptation to ignore data which do not fit or prematurely generating a theory which conceptually eliminates the discordance in findings thus far. All participants had different and unique stories and experiences to share, so each were placed into different categories producing explanations for all data received.

5) Integrating the findings into exhaustive description of the phenomenon being studied. Employing a self-imposed discipline and structure to bridge the gaps between data collection, intuition and description of concepts. Describing includes coding segments of text for topics, comparing topics for consistent themes, and bridging themes for the conceptual meanings. Based on this description a prototype of a theoretical model about the phenomenon under investigation is formulated. As suggested by van Manen (1990), the researcher constructs emerging themes as a generative guide for
writing the research study. These themes allowed the researcher to guide the research study moving beyond a description and towards an explanation and understanding of the lived experiences of the caregivers.

6) **Validating the findings by returning to some participants to ask how it compares with their experiences.** Phenomenological research cannot be separated from the practice of writing (van Manen, 1990). The research was discussed with the participants to ensure thoroughness, which captured the true essence of their experiences.

7) **Incorporating any changes offered by the participants into the final description of the essence of the phenomenon.** Together with step 6, this opportunity allowed each participant, if necessary, to elaborate or clarify their lived experiences and reveal any other relevant new data to be worked into the final product. This is an important part to verify that the researcher interpreted and presented each participant’s lived experience accurately.

**Ensuring Trustworthiness**

Earning the trust of the reader is an important role of the researcher in qualitative research (Polit & Beck, 2010). Cohen and Crabtree (2006) discuss Guba’s (1981) recommendations to establish trustworthiness in a research study and evaluate its worth to involve establishing credibility, transferability, dependability, and confirmability.

Credibility incorporates prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member-checking (Cohen & Crabtree, 2006). Prolonged engagement is defined as time spent in the field learning and engaging to understand the phenomenon of interest, and to develop relationships and build rapport to facilitate trust between the researcher and members of
the setting. Persistent observation provides depth and detail to the situation. Incorporating triangulation is by ensuring that an account is rich, robust, comprehensive and well-developed to establish trustworthiness. Peer debriefing asks a fair-minded peer to analyze and offer their perspective for inquiry and feedback that may have otherwise not been thought of by the researcher. Negative case analysis incorporates the search and discussion of data that does not support or contradicts the patterns or explanations that emerge from analysis of the data. Referential adequacy identifies data to be archived and analyzed to develop preliminary findings and test the validity of the findings. Member-checking is a technique used to establish the validity of an account and is argued to be the most crucial technique to establish credibility.

Transferability is used as a way to achieve external validity by describing a phenomenon in detail which one then can evaluate and draw conclusions which may be transferred to other times, settings, situation, and people (Cohen & Crabtree, 2006).

Dependability seeks external auditing to involve one outside the research process to examine the process and product of the study. Evaluating the accuracy and findings allows the interpretation and conclusion to be supported by the data (Cohen & Crabtree, 2006).

Confirmability allows audits and triangulation to incorporate multiple methods to facilitate a deeper understanding and shed light on the phenomenon. Involving multiple investigators and fostering a reflexive dialogue allows a broadened understanding of the study and reveals the researchers beliefs, values, perspectives and assumptions to be contested (Cohen & Crabtree, 2006).

Chapter Summary
This chapter first described phenomenological research and its importance as a methodology for this qualitative research study. The hermeneutic approach of van Manen (1990) was used in this phenomenological study, as well as the incorporation of Colaizzi’s seven-steps of data analysis, data collection and management were outlined and explained. Lastly, ensuring trustworthiness within the study was explained.
CHAPTER IV

METHOD OF INQUIRY: APPLIED

Sample: Participant Recruitment and Selection

Knowledgeable participants about the content of this study were selected through purposeful sampling. Purposeful sampling permitted the researcher to seek participants best capable of adding their experiences for the purpose of understanding the phenomena. The goal was to recruit approximately 5 to 10 participants with recruitment cessation once data saturation occurred. Once narratives revealed no new information and redundancy occurred, data saturation had been achieved (Polit & Beck, 2010).

Inclusion and exclusion criteria for this study included the following: At the time of recruitment, participants had to be English speaking, 18 years of age or older, reside in Nevada, provide in home care to one with a SCI, and have been providing care for greater than 6 months. Anyone not meeting these requirements was excluded from the study.

Participants of this study had to agree to a face-to-face, audio taped interviews, conducted in a mutually agreed upon private location that was convenient for the participant and researcher. In addition, participants were also required and agreed to follow-up communication via face-to-face, telephone, email or mail for review of their narratives. Each participant was provided a copy of their transcription for review, which allowed the participant to make any corrections, clarify points, and ensure accuracy of their experience. At this time, participants were asked to provide any additional thoughts regarding their lived experience.

Gaining Access

Protection of Human Subjects
The Institutional Review Board (IRB) at the University of Nevada, Reno reviewed and approved this research (Appendix B). Permission and approval was also granted from recruitment sites prior to posting recruitment flyers (Appendix E).

**Recruitment**

After IRB approval and approval from selected sites, recruitment flyers were posted in highly visible areas at each location (Appendix D). Additional participants were recruited by word of mouth from other participants who self-selected for this research and met the selected inclusion criteria.

Interested participants contacted the researcher via telephone or email. The researcher determined inclusion criteria, further explained the purpose of the research, interview structures, protection of confidentiality and privacy, consent to audio-taped interviews, verbatim transcription of the data, handling of data, and final reporting of the data following conclusion of the research, as well as, the availability to answer any questions the participant may have regarding the research. All of this information was included in the recruitment flyer (Appendix D) and the informed consent (Appendix F), which was discussed with interested participants prior to the interview. All participants were informed that participation in this research study was completely voluntary and that they may refuse or withdrawal from the research at any time without penalty or risk. All participants who met the inclusion criteria were treated fairly, equally, and without discrimination. Individuals who agreed to participate in this research were contacted and agreed to a date, time and location for the interview to occur.

**Privacy and Confidentiality**
All of the information obtained in this study was and continues to remain confidential. All participants were given a pseudonym and any identifying information was removed from the transcripts to protect privacy and maintain confidentiality. The researcher field notes and transcripts only referred to participants by their pseudonym. The key for participant contact information and recorded interviews were and continue to be stored in a locked cabinet accessible only to the researcher. A confidentiality statement was signed by the transcriptionist who had access to the interview data (Appendix C). Upon completion of the research, all data and materials collected throughout the study will be maintained for three years as in compliance with IRB and then destroyed accordingly.

**Consent**

A consent form was developed to meet the requirements of the participating university’s IRB. The consent form was developed to thoroughly explain the purpose of the research with a discussion of inclusion criteria. The consent form clearly explained that participation in the study was on a voluntary basis and each participant could withdraw from the research at any time without penalty or risk. Research procedures were clearly stated along with details as they relate to privacy and confidentiality. Benefits and risks of the study were explained as well. All participants who met inclusion criteria and chose to participate in this study stated understanding of the consent process prior to beginning the interview and were given a copy of the consent form. According to the IRB, a consent signature was not required for the interview to proceed.

**Data Generation and Analysis Procedures**

**Data Generation**
For this study, data was collected through in-depth, face-to-face guided interviews held with each participant lasting between 10 minutes and 53 minutes. All interviews took place in a mutually agreed upon, private location where confidentiality was maintained throughout the length of the interview. Interview questions were prepared and utilized to help facilitate the discussion between the participant and the researcher (Appendix G). Initial interview questions focused on basic demographic information to categorize specific characteristics of the participants interviewed. The interviews were recorded with a digital voice recorder, transcribed verbatim by a transcriptionist, who signed a confidentiality statement, within two weeks of the interview, and with follow-up review by the researcher. Field notes were also maintained by the researcher to depict aspects of the physical environment, participant body language, demeanor, dress, and other observations not discernible from the transcripts.

**Data Analysis**

The initial step of this research consisted of data collection through observation and listening to each participant. Next, data analysis consisted of listening to the recorded interviews of each participant’s experience. The verbatim transcripts were then read and re-read several times to analyze the data. Utilizing this process allowed for an individualized view of each participants text. Also, utilizing van Manen’s (1990) three techniques (the holistic approach, the selective reading approach, and the detailed reading approach) thematic statements were isolated. Through thoughtful reflection and analysis, essential themes yielded to characterize the phenomena. Colaizzi’s (1978) 7-step approach that operationalizes van Manen’s (1990) techniques was utilized in analyzing the data.
1) Read all transcripts to acquire a feeling for them and to make sense out of them. All interviews were conducted in person by this student researcher. After the conclusion of each interview, a transcriptionist who previously signed a confidentiality statement transcribed the audio-taped recordings verbatim. Each transcript was reviewed and listened to multiple times to ensure accuracy and time was allowed for review of field notes and additional notes as taken by the researcher. Utilizing van Manen’s (1990) holistic approach of listening, reading, and re-reading the interviews, this allowed the researcher to immerse oneself into the data in order to gain a sense of the whole content.

2) Review each transcript and extract significant statements from them. Utilization of van Manen’s (1990) selective reading approach which detailed reading the transcripts several times to identify statements or phrases that seem particularly essential or revealing about the experience being described, lent to the beginning discovery of significant phrases. This researcher used paper copies of the transcripts to code by hand through highlighting, underlining, and circling to focus on important declarations.

3) Meanings are formulated from significant statements. The detailed reading approach, according to van Manen (1990), examines every single sentence or sentence cluster to evaluate and identify what was revealed about the phenomenon. The researcher analyzed common words, phrases, and thoughts that were significant to the participants’ experience. This requires the researcher to have creative insight (Colaizzi, 1978) and ensured a deep understanding of each interview.

4) Meanings are organized into themes, these themes evolve into theme clusters, that eventually categorizes them. Steps 1 through 3 were repeated for each transcription,
organized into clusters of themes, and then referred back to the original transcripts in order to validate them.

5) Integrate results into an exhaustive description of the phenomenon under study.

The researcher, according to van Manen (1990), formed emerging themes as a generative guide for writing the research study. These themes allowed the researcher to guide the written research study moving beyond a description and toward an explanation and understanding of the lived experiences of caregivers of SCI persons. Commonalities within various descriptions created a meaningful explanation of the phenomena (van Manen, 1990).

6) Formulate an exhaustive description of the phenomenon under study in as unequivocal a statement of identification as possible. This researcher participated in a dynamic effort to understand and recognize the meanings of the lived experiences through writing the results of this study (Polit & Beck, 2010). Themes and theme clusters were identified as writing began and results of the interviews were studied.

7) As a final step, validation is sought from the participants to compare the researcher’s descriptive results with their lived experiences. All transcripts were provided to the participants for review as to allow the participants the opportunity, if necessary, to clarify and elaborate on their lived experience. This is an important part of verifying that the researcher interpreted and portrayed the participants’ lived experiences accurately.

Ensuring Trustworthiness

Trustworthiness is an important aspect of a qualitative study and qualitative researchers must consider the true value of their study to demonstrate that their study is
credible and valid. Guba (1981) recommend establishing trustworthiness in a research study and evaluating its worth by establishing credibility, transferability, dependability, and confirmability.

**Credibility**

The researcher guided this phenomenological study utilizing the reputable qualitative research methods developed by van Manen (1990). Shenton (2004) states one of the key criteria in evaluating credibility is ensuring that the study measures or tests what is actually intended. As part of this research study, this researcher cited key writers of related works in the literature review; specified particular data analytic methods used, and verified the data analysis with the participants themselves all in an attempt to ensure credibility of the research study.

**Transferability**

Transferability is concerned with the extent to which the findings of one study can be applied to other situations (Shenton, 2004). This study and its findings were specific to the lived experiences of caregivers of SCI persons and while this data cannot be generalized to the entire population; this research does serve as an example of an important segment of the American population. The goal of this researcher was to provide an intense and pronounced description of the phenomena to give readers a deeper understanding of the caregiver’s perspective in caring for one with a spinal cord injury, which include their personal lived experiences.

**Dependability**

Ensuring dependability of qualitative research reflects research findings that must be consistent and accurate which provides reliability of the study (Guba, 1981). In order
to address dependability, the processes within the study should be reported in detail enabling future researchers to repeat the work (Shenton, 2004). To maintain dependability, the processes within this research are described in detail. An in-depth description of the planning process, execution of the study, details of the field experience and evaluation of inquiry are provided.

**Confirmability**

The concept of confirmability is the qualitative researcher’s comparable concern to objectivity (Shenton, 2004). Steps must be taken to help ensure that the findings are the result of experiences and ideas of the participants, rather than the characteristics and preferences of the researcher (Shenton, 2004). To guarantee neutrality in this study, the researcher provided a detailed explanation of the methodology, along with ongoing reflective commentary in the form of an audit trail. In this study, the researcher discussed with the committee chair and committee members, the researchers’ biases based on personal experiences as a caregiver to one with a spinal cord injury before the study began. Recognizing these biases allowed the researcher to produce a text that accurately reflects the participants’ lived experiences of being a caregiver and not that of the researcher.

**Chapter Summary**

This chapter provided the application process of van Manen’s phenomenological approach to research with a description of Colaizzi’s steps for data analysis. The researcher identified specific areas of the study where credibility, transferability, dependability and confirmability were demonstrated to ensure trustworthiness within the research.
CHAPTER V

FINDINGS

The purpose of this study was to explore, describe and gain an overall deeper understanding of the lived experiences of caregivers of spinal cord injury individuals. The question that guided this study was: What is the meaning and significance of the lived experience of caregivers as it relates to caring for an individual following a spinal cord injury? The following accounts come from five caregivers who provide care to one with a spinal cord injury. Their insight provides the reader with a sense of their lived experience.

Description of the Participants

A total of six participants were recruited for this study, five of the participants’ data was utilized for this study. One interview was excluded from the study, as during the interview it was not clear that the person met inclusion criteria. Five caregivers participated in this study; two males and three females. Two male and two female participants were the spouses of a SCI person and one female participant was the parent to a male SCI person. The length of time caregiving ranged from 9 months to 15 years. The length of time for those being married ranged from 2 years to 40 years. Four caregivers worked outside the home in addition to caregiving; one caregiver was employed through an agency as the caregiver to the person with a SCI. Three of the caregivers had children; two caregivers had no children. All SCI persons identified themselves as quadruplegic.

Data Collection
The five participant interviews were conducted between January and February 2016. The researcher did not know two of the participants; two of the participants were known to the researcher having been family of previous patients; one of the participants was known to the researcher through a mutual acquaintance. The participants agreed to face-to-face interviews in a mutually agreed upon convenient location. Three interviews took place in the participants’ private residence, one interview took place at the participants’ place of employment, and one interview took place at the University of Nevada, Reno. All of the chosen interview settings allowed for a private, quiet environment. Two of the interviews were conducted with the female SCI persons present. The male SCI persons were not present for interviews conducted with their female caregivers. For all face-to-face interviews, the digital recorder was placed centrally to both the researcher and the participants. All face-to-face interviews were conducted with the participant and researcher diagonally across from one another in chairs, or conducted sitting on couches next to or across from the researcher.

Each participant was given the consent form for review. The researcher allowed adequate time for the participant to read the consent form, and the researcher reviewed the consent form with each participant to answer any questions the participants might have regarding the consent form. The researcher reminded each participant that involvement in the study was completely voluntary and if they chose, they could withdraw from the study at any time without risk or penalty. The consent form was provided to each participant.

Before each interview, an open dialogue occurred lasting approximately 10 to 15 minutes to assist the participant with being at ease and building rapport before sharing
their personal experience with the researcher. After this initial time period, the researcher announced the formal interview was about to begin and asked if the participant was ready. Once the participant agreed “yes” the recorder was started and the formal interview began. Before ending each interview, the researcher asked, “Is there anything else you’d like to share?” When the participant indicated there was no additional information to share, the researcher thanked the participant and the recorder was turned off.

The participants were asked to review the verbatim transcript for accuracy and to ensure the participant answered the interview questions as they had intended. Time was allowed to add any additional thoughts they had about their lived experiences. Of the six participants recruited for this study, five completed the study.

**Data Analysis**

Following each interview, all of the digitally recorded interviews were transferred to the researcher’s computer and converted to a MP3 file, encrypted and emailed to the transcriptionist’s personal email address within one day of completion of the interview. The transcriptionist produced a verbatim transcript of each interview in a word document that was encrypted and emailed back to the researcher within one to three weeks of the original interview. The data was then hand coded by the researcher using Colaizzi’s 7-step method of data analysis.

**Immersion**

The researcher listened to recorded interviews while the verbatim transcription was completed. Once transcription was complete, the verbatim transcripts were reviewed, as well as, transcript review while listening to each interview to verify
accuracy. Transcripts were read and re-read by the researcher several times to immerse the researcher into each experience and allow more time to become familiar with the data, gaining a deeper understanding of each experience.

**Extraction of Significant Statements and Phrases**

Each verbatim transcript of the five interviews produced 4 to 23 pages of transcription. The researcher then hand coded and identified 132 significant words, statements and/or phrases, describing their lived experiences as a caregiver to one with a spinal cord injury, in detail.

**Identification of Common Meanings and Shared Practices**

The researcher then formulated meanings and shared practices for each significant word, statement or phrase identified in the transcripts. Conscientiousness was taken to ensure that each identified meaning or practice remained associated to the participants’ original statements in their personal interviews.

**Organizing Relationships among Common Meanings and Shared Practices**

The researcher formulated common meanings and shared practices that were then analyzed and organized for resemblance. These meanings and practices emerged as themes, which were then organized into clusters of themes as identified by the researcher. These theme clusters then represented the individual and group experiences of the caregiver experience to those with a spinal cord injury. Validation of these themes occurred by returning to the original transcripts to ensure original data was not lost or not accounted for while identifying clusters of themes.

Part of data analysis includes being aware of discrepancies and contradictions, which are an expected finding in qualitative research (Guba, 1981). Each transcript was
returned to each participant to review and ensure complete understanding by the researcher. Each participant was asked to review the transcript and validate the researcher’s findings. They were encouraged to correct any errors and add any additional thoughts regarding their caregiving experiences. The following statements from the participants were made during this process.

- It looks fine, thank you for showing me. (Shelley)
- Looks good, I say Ummm too much. (Alexa)
- I didn’t realize that I talked so much but everything looks great. (Paul)

Having the participant’s validate the researcher’s interpretations allowed the researcher to acknowledge that the findings were interpreted correctly and were a true account of the participants’ experiences.

**Essence, Themes and Subthemes**

The researcher identified six main themes and two subthemes revealing the caregiver experiences and life satisfaction caring for a person with a spinal cord injury. The themes include: 1) the reality of unanticipated change, 2) adjustment, 3) health, 4) flexibility, 5) lack of caregiver support, and 6) individuality. The theme lack of caregiver support was further divided into two subthemes: 1) professional support and 2) knowledgeable support. These themes and subthemes provided guidance to the overall essence of the lived experiences of caregivers to one with a spinal cord injury. The identified themes and subthemes influenced an overall essence of desired wellness for caregivers as they attempted to balance the care they provide to one with a SCI and care they provide to themselves. The caregiving career is complex and unknown and is often
a career that one is not prepared to do. There are various obstacles that may impede overall wellness, but it is important to understand they exist.

**Theme: The Reality of Unanticipated Change**

The reality of unanticipated change was evident in each interview. Aside from one couple, each couple went from living life as two able bodies to living life with the change that one needed to be taken care of and was no longer completely able. One couple married after the injury had occurred, so she understood the way their life would be together. The mother went from looking at her son standing in his graduation picture to providing total care to him after his accident. When asked the question, “Tell me about your experience,” the reality of unanticipated change was a clear theme in their responses, including:

It was scary at first but now we’re starting to get into a rhythm of things but before it was pretty scary. (Scott)

The participant continued to elaborate on his statement.

You know it’s pretty tough you know. Cause when I first, when she first came home and I was like okay, there’s nobody here to help me, and then I started thinking about what did the doctors do, what did the nurses there do at the time, the therapists, what did they do? You know. And there’s times where I’ll be doing uh motion, leg motions with her, range motions and she’ll correct me, you know, no it’s… you know she remembers too how they did it, you know, and she will tell me I’m doing it wrong. So we correct it and you know try to do it that way. Yeah, so there’s nobody here when I came home, it was just her and I. (Scott)

Other participants contributed.

At that time he was very newly injured and so I met him fairly early on in his injury and so kind of where we were then versus where we are now, he’s a lot more independent in his day-to-day care so when I first met him he was you know having to use a slide board to transfer into the front seat of the car and he wasn’t
very independent in some of his day-to-day activities of daily living. But where we are now um, he is able to do a lot more on his own. (Alexa)

It has been hard, but I still feel very blessed. I still feel very fortunate and grateful for my life. There are days where you know I’m irritated and tired and um, and there’s been years that have been a struggle um especially when the children were younger. Um and especially in the beginning when I was first learning how to take care of him and he was also adjusting, it was very challenging. But um overall I’d say it has been a good life. You know and in spite of it all, he’s a very resilient kind of guy. (Shelley)

It was very, very tough to um, to watch your child. It’s a whole new change. (Patty)

The participant continued her response.

In the beginning it was very emotional, you know a struggle for me, because it just was um the daily watching him struggle to move, watching him struggle to eat, um you know I mean still I, I don’t cry in front of him, but I cry. It’s tough on a mom, it’s tough on his dad too you know to watch him struggle just to, just to get to what he’s wanting to do, what he, you know, just watching him struggle on a daily basis is – is very hard. (Patty)

**Theme Summary**

The first theme “the reality of unanticipated change” identifies the beginning of this life experience for the caregiver and the person with a spinal cord injury. This is an unimagined change in routines, relationships and life. SCIs are abrupt, unplanned, and unexpected, throwing even a stable life/relationship into crisis and chaos. What normal was is now a different normal, so these caregivers have learned to adapt.

**Theme: Adjustment**

This theme became apparent when participants were asked, “Has your relationship changed after the injury?” Even years after the initial injury, caregivers and the person with the SCI continue to adjust. The following are responses provided.

I think our relationship got even tighter because like I told her, I’ll be her arms, her hands, and her feet. Um, a lot of people you hear ‘em talk to you like, injury
pulls people apart. Our injury seemed to pull us closer together and you know, more than 100% I care for her now. (Scott)

This participant continued to say.

Yeah, we adjust a lot in our life since the injury. Um, like, um going to do different things. Like before we used to go out and do everything, now it’s like, it’s all based on her. If she, her body, is up to it we’ll go do something, if not, it can wait. (Scott)

Other participants responded.

I still sometimes get frustrated more than I used to. See when she, she never had any time, she was never sick. She had a couple of doctor’s appointments … she was more or less looking after me. I mean not physically, but I mean she’s been looking out for me. She’d have whatever was in the house, it was, it was her house. I mean I just went to work and came home, but she ran the house and everything, so when all that, yeah there was a big change. I had to, I had to learn how to do the laundry. I’d never done the laundry, ever. You know, and uh there were a lot of changes like that. And then sometimes you’d think it was her, but sometimes, I’d get a little bit depressed. You know, but not, not for the worst. I mean I was glad I was able to, I am really, really glad cause I, I’ve done things that I didn’t know I could do. (Paul)

I guess like him getting more comfortable with himself as an individual with a spinal cord injury he realized like in some instances it’s easier for me to just do something cause it makes our day go by faster, but at the same time, there are instances I notice that he is just being lazy, and he could totally do it on his own. So we have that kind of dynamic back and forth of, okay is it easier just for me to do it and we move on with our day, or are you just being lazy and you could totally do that yourself. He is consciously looking at, you know, am I putting a burden on me in any way um, and so he makes a conscious decision to try to do as much as he can on his own um, so you know I think we have a good relationship in that we try to kind of have a balance of you know in a relationship. You don’t want to be viewed as the caregiver, you’re a spouse first, and so I think what I, in my profession when I work with people or you meet individuals with new spinal cord injuries, you see that the spouse turns into the caregiver and not remain the spouse and I think that’s kind of the ultimate demise of some relationships. Um because it takes away—you’re almost like in a role that you—you—you have to do something and you don’t feel like you still have that relationship part of it. Um, so I don’t—um often don’t think of myself as a caregiver cause um, I’m a spouse first and so I think I have a different outlook on it just because of my background. (Alexa)
It was almost like the husband I was married to for 9 years before the injury was gone. And now I had a different husband—I mean same—same man, same personality and what not, but not the same situation, so it was almost like starting completely over. (Shelley)

**Theme Summary**

The theme of adjustment describes the caregiver having to adjust to their new role. As described, adjustment takes place on a daily basis at times and the participant and the SCI person have learned to adjust to making daily adjustments.

**Theme: Health**

The theme of health evolved while talking to participants about their personal self-care as it relates to taking on a caregiving role. Some felt as though there was no change to their health, while others felt there had been a change. All participants seem to be resistant to acknowledge that changes in their health may have had anything to do with being a caregiver. The following dialogues were offered in this discussion related to self-care.

I would say my health got better, but then I gained a lot of weight too, cause I spend more time at home. But, um, I have been trying to watch my back, cause if I hurt myself at work, I have to come home and who is going to take care of her? I mean, you know, I try to figure out a different way to lifting her and I’m probably doing damage to my back, you know, but I try to make things more comfortable through our movements and stuff like that. But health wise and mentally it’s – it’s all good, but its just I had to adapt, make a big turnaround to adapt to her needs and the way I can move her and, you know, move her around and all that. (Scott)

Probably, yeah, I’m taking a lot more pills than I used to. And my blood pressure’s gone up. I take nerve pills now, never used to before. Depression at times, um yeah, it’s – I’ve changed – and I don’t know how much of that is because of her and how much of that is because of my age, you know, I’m getting older. There’s a difference in my health in the last 5 years definitely. (Paul)

Yeah, I think so. Um, gosh, my self-care, I tend to, I think and it’s not just because of being a caregiver, I think it’s the mom and wife role I tend to put
myself on the back burner. Um, a lot and even though you know he’ll say, no I encourage you to that, it’s, it’s still just you know, sometimes when I actually have the time, I am just so exhausted, I just don’t want to do anything. Um, but I try to uh have other interests and do things too and you know get out and do stuff. (Shelley)

Well my health has been going downhill since I turned 30. No, my self-care, no it hasn’t changed at all. But my health I think – it doesn’t have anything to do with him, its just I’ve become a diabetic in this – well I was actually a diabetic before, I had just learned that I was a diabetic right before his accident. I have always had uh, um, degenerative disc disease in my back and as I get older it just gets worse. So, no, it doesn’t - my problems don’t have anything to do with him. Yeah I take care of myself just as – just as well as I would have if he was not hurt. (Patty)

**Theme Summary**

The theme of “health” discussed how participants reflected upon their current health status and if caregiving had any affect on it. Caregivers were often resistant to acknowledge any change to their health and seemed to deny that caregiving resulted in some of the health changes.

**Theme: Flexibility**

The theme of flexibility took shape as caregivers described advice that they would give to other caregivers new to the role. Learning to adapt and adjust to daily changes, at times, requires one to be flexible and patient. The theme flexibility was discovered by the following expressions.

Yeah we go through a lot you know. And you know we were told too at the hospital there will be days when you guys may even argue you know, mood swings. Well I try to keep her out of depression mode. You know, try to if something else comes up, we sort of try to laugh about it and you know, people that might be caregivers you know, have any feedback about them, I don’t want them around, cause I don’t want her in a depressed mode. But like I say, every day is something different, you know. Yeah we have fun, you know, experience, a really big experience. (Scott)
Don’t be afraid to ask for help or advice. I mean, as I said, I came into this not even knowing – literally didn’t even know how to switch on the dishwasher or the laundry machine. I’ve never done it. So, just if you had to do what’s needed to be done you know, um, in my case I was just glad to be getting her home so I didn’t care what I had to do. I was just glad to get her home, honestly. And um, just patience, you need a lot of patience you know. (Paul)

**Theme Summary**

Being a caregiver to one with a spinal cord injury involves flexibility to be able to care for daily life challenges with ease and creativity. Participants often described having compassion and patience, which was also necessary in facing daily obstacles.

**Theme: Lack of Caregiver Support**

The theme lack of caregiver support was a strong theme during each participant interview. Each caregiver stated dissatisfaction with the lack of support while caring for one with a SCI. Two subthemes emerged as participants described the types of caregiver support that were lacking and are important to them. The participants desired caregiver support in the realms of 1) professional support and 2) knowledgeable support.

**Subtheme: Professional Support**

This subtheme described the significance of support for the caregiver and person with a spinal cord injury. Often times it was a struggle to find support that was able to meet the needs of the caregiver and the SCI person.

I would research more into better resources for us. Cause right now we’re just picking and grabbing, and you know um, I wish from the very get go they would have let me experience all of this at the hospital, but they didn’t. You know, they always had me step out of the room and now – you’re not going home with her, I am going home with her so from the very get go I wish I had learned more hands on contact… I would go as far back as her injury to learn how to cope with it and how to handle her, clean her and take care of her. You know, like right now, we’re just coming up with different ideas and what we hear [from other caregivers] to try to cope with the same thing and you know, yeah, I wish I had of
known more, that they would have let me learn more at the hospital. (Scott)

This participant went on to add.

If you’re going to go out and seek help, be sure of who you get. Some people I have gone to, different companies I’ve gone through, where the people who come over sleep instead of work, cause if she was sleeping, this lady figured she could sleep too. But um, there’s a lot of resources out there and like I said, you are going to go through a lot of trying to get help, and if you’ve got family, get them involved and they can help, you know. (Scott)

Other participants responded.

If we had been able to afford professional help a bit more, cause the thing was – we’re always broke but they said I earned too much to have the help – help you know where it wouldn’t cost us, you know, for those services. So like it was uh, I earned too much but I never had enough to pay a professional. (Paul)

But we do – we have actively seeked help and we have not accomplished that yet, and it’s been this long. And the reason is – and maybe you can help with this too, to figure it out, is that we’ve looked at different uh, you know, uh companies and different, um, whatnot through the hospital and um, the story is always that well they either want to do it permanently on a regular basis – so part time help is really hard to get. Or they don’t do bladder and bowel care. You know, they will come give him his medicine or help him dress or help him shower or fluff his pillows, and we don’t really need that, cause he’s pretty capable of doing some of those things himself. (Shelley)

This participant further went on to add.

So it’s been a challenge to find somebody that actually says, Oh yes I do that and I’ll be happy to do it part time, or you know, we just have not had any luck with that. And I’m like; well you’re really not going to be able to help us. You know? So yeah, it’s been a challenge. (Shelley)

**Subtheme Summary.** The subtheme “professional support” accounts for caregivers needing support systems in place who knew how to take care of one with a spinal cord injury, specifically, quadriplegia, as they were hired to do. Oftentimes,
participants in this study were unable to find support and resources competent in the care of quadriplegics.

**Subtheme: Knowledgeable Support**

This subtheme described the frustration participants felt when they were lead to believe they were getting the support and resources they needed, yet soon found out this was not the case.

We’ve gone through – since we’ve been home, we’ve been through about 5 companies and each people they try – they’ve been trained to do this and to do that, they get here and they go – well we’ve seen that in a movie. (Scott)

This participant went on further to add.

I’ll be at work and we had one lady laugh at her because she had an accident, which she can’t help. So I came home, called up the company and – ‘cause I don’t want nobody to put her in a depression mode you know. And so I had to eliminate that company, get another person or switch to another company, which we have been doing quite a bit to find the right help. And now we finally found a good company and we are getting a lot of good help. (Scott)

Other participants added.

I’d like to find a caregiver to allow for time with my husband … he wants to go on a cruise but understands that I am uncomfortable with leaving him for a long period of time with someone that doesn’t know how to care for him. My mom can come but only for a couple days and she has helped me out in the past take care of him when I needed it. (Patty)

Maybe I would really set out to find somebody to help. Uh, just to have maybe one weekend a month or one whatever kind of schedule um, and start that from the beginning, but other than that, I don’t know – I don’t really think of anything that I can say I would do different. (Shelley)

**Subtheme Summary.** The subtheme “knowledgeable support” addresses the inconsistencies of care from outside agencies. Participants in this study were aware of
the need of respite time outside of caring for one with a SCI person, yet found it challenging to find someone able to complete the job in a trusting and competent manner.

**Theme Summary**

The lack of caregiver support theme sets the stage for burnout. Fortunately, the participants in this study have continued to provide care to one with a SCI with or without additional support. A financial burden is also added to possible caregiver burden when having to care for one with a SCI. Again, the participants in this study have been able to keep their loved one in their own home and care for them while meeting other obligations.

**Theme: Individuality**

Individuality as a theme evolved as some of the participants who have been providing care to one with a spinal cord injury for several years spoke about remembering themselves as part of the equation. For instance, one participant stated, “definitely remember yourself, um so don’t – don’t get into that role um where you start to re-label yourself as a caregiver versus a spouse” (Alexa). As a caregiver, one may feel as though they start to lose their personal identity. Long time caregivers acknowledge the need to maintain their individuality as evidenced by some of the responses.

To be around other individuals that are in the same boat who have gone through that course of learning how to do their own activities of daily living is huge. And so like having that caregiver give that individual who has been newly injured that opportunity to be around other people will save them as a couple so much time in the world and trying to navigate that on their own. So I think that is really important to kind of get around others and – and try not to label yourself as a caregiver um, and try to kind of work through it together where the balance still exists. (Alexa)

This participant went on to add.
I think just making sure that I – like we still have our own interests and things that we like to do and we have a balance of doing those things, so I think that’s really important in keeping that balance. Um, and still having your – kind of own identity and activities and interests um, but you know I don’t think it’s really changed over the course of our relationship that we have always had that as our priority. (Alexa)

Other participants added.

I think our faith played a major part in that we are Christians and um, I think just having a higher power to lean on and having faith in something greater than myself has helped me a great deal when I feel like I just can’t – I – you know – I’ll often pray for strength and people in the church and also the – the military were wonderful in – in helping us. Um, you know but as the years go by that lessens and lessens because they figure you got it. (Shelley)

Just the everyday living and you know, I mean, I’ve had to – I’ve had to let go you know with him being in college, and, um, I have had to learn to let go as I normally would have if he hadn’t of had that accident, you know. I’ve had to learn to cope with that you and – and – and be – be stronger as a person on my own because I’m very – very emotional person, very tender hearted, and so is he, but I’ve had to – he gets onto me because – because I help too much. It takes a lot for me not to um, you know, to learn to let go. You know, to be able to let him do on his own and become independent. (Patty)

**Theme Summary**

Caregiving has become a huge part of each of these participants’ lives. The theme “individuality” is important for the caregiver to recognize and maintain some self-identity for personal wellbeing. This part of caregiving is often forgotten though as it is easy to forget to care for oneself and utilize all energy to provide care for the SCI person.

**Chapter Summary**

This chapter provided the lived experiences of caregivers to a person with a spinal cord injury and was explained through six themes and two subthemes, as collected through participant interviews. The themes and subthemes contributed to an overall essence of desired wellness.
CHAPTER VI

DISCUSSION AND INTERPRETATION

The purpose of this phenomenological inquiry was to explore, describe, and gain a deeper understanding of the lived experiences of caregivers of spinal cord injury individuals and life satisfaction. In this research six themes and two subthemes resulted from each participant’s personal experience uncovering the essence of attempting to achieve wellbeing as a person and caregiver to one with a traumatic spinal cord injury.

With each personal story shared by each participant, common themes emerged intersecting experiences. While each story was unique, the experiences shared love for the person they were caring for and dissatisfaction with respite care. The themes and subthemes were essential in understanding the participant’s experiences. The thick, rich descriptions provided by the participants offer insight into what it is like to be a caregiver to one with a spinal cord injury following a traumatic spinal cord injury.

Findings as They Relate to the Current Literature

The current literature, in relation to qualitative research, focuses on the caregiver role stressors and offers some interventions in dealing with this new unanticipated role. There is paucity in the literature that solely concentrates on individual caregiver experiences. With this in mind, the results of this qualitative, phenomenological inquiry may support or expand on the current findings in the literature; however, the stories and experiences in this study are unique to this particular cohort of caregivers.

Participant Demographics

A total of six participants were recruited for this study and five participated and completed the study; three women and two men. Four participants cared for their
spouses in their personal residences, and the remaining participant cared for her son in his personal residence. The ages of the participants ranged from approximately 35 to 65 years.

**Main Theme: The Reality of Unanticipated Change**

The findings of this study reveal that the caregiver has learned to adapt to what now may be called their new “normal”. Aside from one participant who married an individual with a SCI, all others were living able-bodied lives. Those participants who have become caregivers have learned or are learning a new daily routine of normal. Dickson, et al. (2010) suggests that the caregiver role begins as an “unexpected career” that is defined by new tasks that must be performed for the individual with a SCI; changing the relationship. Four of the caregivers continue to work outside of the home in addition to their caregiving responsibilities. One caregiver followed policy and procedure of a specific agency to be paid as the caregiver for the person with a SCI. One caregiver spoke about wanting to term employment; however, after recognizing the costs of living and the inability of the person with the SCI to work, the caregiver learned to adapt and adjust the work schedule as needed to be able to provide care.

According to Feinberg, et al. (2011), family caregivers with the most intense level of caregiving (providing 21+ hours a week), high burden of care, or living with the care recipient are highly likely to report having to make workplace accommodations, which could lead to financial hardships including loss of earnings and benefits. This is a challenge, and as identified by Boschen and Gargaro (2009), caregivers are typically informal (spouse or parent) and are not acknowledged by the government or health care system as being an integral part of the care continuum. Essentially, informal in-home
caregivers are not compensated for care they provide to keep the person with the SCI out of the hospital and out of extended care facilities.

**Main Theme: Adjustment**

The caregivers in this study learned to adjust to the daily life stressors. They understood that each day was different and what happened yesterday could be different from what happens today. DeSanto-Madeya (2006) describes the numerous trials encountered by those who live with someone who has suffered a SCI. The emotional, social, psychological, spiritual, and economic ramifications can seem insurmountable. Caregivers recognized that their lives have changed and that things are different after the spinal cord injury, but also have come to the realization that they continue to love the person with the SCI and will do what it takes to care for that person and adjust to these changes. Changes occur in social roles, along with health problems and psychological adjustment to a new body image, produce difficult challenges for all involved (DeSanto-Madeya, 2006). As one caregiver pointed out, life before injury was a little simpler, they could get in the car and go. Now, life after the injury takes more time and one must take into account how the person with the SCI is feeling that day.

**Main Theme: Health**

The theme “health” described participants’ experiences as they consider themselves as part of the dynamic. The findings suggest that the caregivers often deny that changes in their personal health have anything to do with providing care for someone else. The participants acknowledged that there had been changes to their health since taking on a caregiving role, yet denied changes in their health were due to the caregiving responsibilities. Elliot and Berry (2009) recognized that caregiver health is an important
part of the healthcare system as they provide valuable services to community dwelling SCI individuals. Spouses who take on the role of a caregiver have been shown to ignore or neglect their own health problems and needs (Weitzenkamp, et al., 1997). Due to limited free time, family caregivers frequently experience social isolation from a loss of social contacts or from difficulties in trying to identify and navigate practical community services to help them in their caregiving (Feinberg, et al., 2011). The participants of this study admit to health decline, yet are resistant to give the credit to the unanticipated role of a caregiver as the cause. The participants often acknowledged that their health decline was due to aging.

**Main Theme: Flexibility**

DeSanto-Madeya (2006) state that understanding that living with someone with a spinal cord injury is a continuous learning experience, the challenges do not disappear after a few years, and life responsibilities shift, which may give a new perspective and appreciation on life. Similar findings were identified in this study. The participant caregivers have learned to be flexible and resilient to living with a person after having suffered a traumatic spinal cord injury. Aside from one caregiver, the other caregivers did not “sign up” for this job, but have learned or are learning how to take care of the SCI person and utilize available resources when the answer is not immediately available.

**Main Theme: Lack of Caregiver Support (Subthemes: Professional Support and Knowledgeable Support)**

The findings of this study highlight an area of opportunity to care for the informal caregivers. Interviews revealed the participants needed a “weekend off” or “a vacation” alone, yet are resistant to give themselves this time away due to the lack of respite care
support within the community. Decker, et al. (1989) acknowledged that the availability of social support and the caregiver having a sense of control over one’s life were important determinants of caregiver well-being. This study’s participants struggled with obtaining care from outside agencies on an as needed basis and struggled to find someone who could or would perform bowel and bladder care. Persons with spinal cord injury require very personal care as it relates to self-catheterization or care of the catheter and digital stimulation to completely evacuate their bowels during the bowel program. It was evident from personal accounts that community resources are uncomfortable with providing these services to those who are unable to complete them themselves. Due to the struggle of finding outside help, the participants lack opportunity to provide themselves with personal time away from their caregiving duties. Another struggle identified was the lack of ability to find qualified outside agency caregivers. Often the outside caregivers confessed that their knowledge of spinal cord injury was lacking, which did not instill confidence in the participant to relinquish care.

**Main Theme: Individuality**

The theme “individuality” supports the need for caregivers to continue to recognize themselves as a wife and husband, or mother and father. The duty of being a caregiver has overwhelmed some participants and their identity has been relabeled as a caregiver rather than a spouse or parent. This identity struggle may be complicated by the inability to obtain respite care; allowing for individual activities. Decker, et al. (1989) suggest developing a support network of family, friends, and possibly healthcare providers that can assist with alleviating some burden of care, while keeping the SCI person in their own home. One participant suggested participating in activities within the
community that enables the caregiver and SCI person to be around others with similar injuries, to share personal experiences, and develop relationships to provide support to one another.

**Implications for Nursing**

The findings from this study offer various implications for nursing. First, as a nurse and having a personal experience as being a caregiver to one with a traumatic spinal cord injury, this researcher recognized the lack of support and resources in the community for those with a SCI and their caregiver(s). This recognition is what prompted this phenomenological study. The findings of this study confirmed previous assumptions held by this researcher regarding that this community doesn’t have the adequate resources to prepare individuals to return to their personal lives being fully prepared to care for one with a SCI.

As nurses and healthcare providers, it is essential to have some knowledge of spinal cord injuries and include the caregiver in as much hands on care as possible during the rehabilitative process and adequately equip them with necessary resources to be successful in the community. Boschen, Tonack and Gargaro (2005) recognized that after spending time in the home, caregivers soon felt “underserved and unprepared emotionally and cognitively for their new, unanticipated role”. It is also evident that the community needs to understand the care that is needed to care for this population of people and offer respite services to informal caregivers to avoid negative consequences such as burnout or divorce. Family support is also a key driver in remaining on one’s home (Feinberg, et al., 2011) and not in a long-term care facility. These agencies need to equip their caregivers
with the necessary knowledge and skills to perform care that may be personally uncomfortable but necessary for caring for one with a spinal cord injury.

Secondly, this research contributes to the science of nursing and the current literature related to the care of the SCI individual and their caregivers, by offering stakeholders a better understanding of the meaning and significance of the lived experience of this population. Investing in sufficient resources, according to Feinberg, et al. (2011), to lessen the strain in the daily lives of caregivers will yield positive return on investment, containing healthcare costs and long-term services by delaying or preventing the use of nursing home care, hospital inpatient care, and unnecessary rehospitalization. Of relevance, is the need for support systems for both the individual afflicted with the SCI and those that provide their care outside of the inpatient acute care and rehabilitation settings.

Finally, this research provides a view of the experiences of those who provide care for individuals who have sustained a traumatic SCI. Understanding the experience from these participant’s perspectives provides opportunities for the development of support groups.

**Limitations**

Findings of this study are limited to one geographical region of the United States in Northern Nevada. This region does not have a designated spinal cord injury program, so placing recruitment flyers was a challenge to attract eligible participants. Several of the participants had been providing care for many years and have adapted to the changes, so this may have offered a distorted view due to the longevity of caregiving. Two
interviews took place with the SCI person present. This may have limited some of the caregiver’s responses.

**Recommendations for Further Research**

With any phenomenological inquiry, the descriptions and interpretation of the lived experience is that of the individual researcher. With that knowledge, van Manen (1990) notes that the human experience of the phenomenon may offer another yet a potentially richer or complementary description when studied by another. Thus, it is the hopes of this researcher that the findings from this study will encourage dialogue among healthcare providers, caregivers of those with a SCI, and even those with the injury themselves. The themes uncovered in this study could be expanded and tested upon other groups, such as bedside nurses who care for SCI individuals at different stages of hospitalization and rehabilitation. This would enhance the trustworthiness and validity as well as provide comparisons for the present study.

**Chapter Summary**

This chapter offered discussion and interpretation of the themes identified in this phenomenological inquiry. Some of the produced findings support and contribute to the current reviewed literature, but also provides insight and new information into the lived experiences of caregivers and life satisfaction following traumatic spinal cord injury. Lastly, implications for nursing and recommendations for further research are included.
CONCLUSION

Six participants voluntarily participated in interviews and five participants experiences were included in this research. The findings from this research yielded six main themes and two subthemes that contributed a thick, rich description of caregiver experiences as it relates to care provided after a traumatic spinal cord injury. Findings were validated through participant review and provide the experiences that contributed to the overall essence of caregiver experiences. Understanding the meaning and significance of these experiences has significant implications for individuals who care for one with a spinal cord injury, the SCI person, along with nurses, other healthcare providers, and future researchers. The research produced supports and contributes to current literature regarding caregivers of spinal cord injured persons. Lastly, while this research provides one interpretation of the phenomena, it lends opportunity for further investigation into an important segment of our population.
## APPENDIX A

### LITERATURE REVIEW

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<tr>
<th>Reference</th>
<th>Description of Study</th>
<th>Results/Conclusions</th>
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</thead>
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<td><strong>Psychological well-being</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Boschen et al., 2005</td>
<td>Mixed methodology</td>
<td>More attention, understanding, and service directed to support providers are required to reduce trial-and-error learning and emotional and physical burden.</td>
</tr>
<tr>
<td>Boschen, K. &amp; Gargaro, J., 2009</td>
<td>Qualitative, mixed methodology</td>
<td>Respondents underserved and unprepared, emotionally and cognitively, for their new unanticipated role.</td>
</tr>
<tr>
<td>Dickson et al., 2008</td>
<td>Phenomenological study</td>
<td>Role change and emotional impact of spinal cord injury in relation to the caregiver.</td>
</tr>
<tr>
<td>Dickson et al., 2010</td>
<td>Interpretative phenomenological analysis</td>
<td>A distinct change in role from spouse and lover to care provider was reported and this ultimately contributed to relationship change and a loss of former identity.</td>
</tr>
<tr>
<td>Weitzenkamp et al., 1996</td>
<td>Survey</td>
<td>Spouses of long-term SCI survivors who fulfill a caregiving role report more symptoms of stress and depression than their partners with disabilities and other spouses who are not caregivers.</td>
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<tr>
<td><strong>Interventions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decker et al., 1989</td>
<td>Questionnaire</td>
<td>The availability of social support and feelings of control over one’s life were important determinants of caregiver’s well-being.</td>
</tr>
<tr>
<td>Desanto-Madeya, S., 2006</td>
<td>Phenomenological study</td>
<td>Study findings may be</td>
</tr>
<tr>
<td>Study</td>
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<td>Details</td>
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<tr>
<td>Elliot, T.M. &amp; Berry, J.W., 2009</td>
<td>Randomized controlled trial</td>
<td>Intervention for new caregivers featuring brief problem solving training, education, and contact may be associated with lower dysfunctional problem-solving styles over time and may promote certain aspects of caregiver quality of life.</td>
</tr>
<tr>
<td>Ma et al., 2014</td>
<td>Convenience sampling method questionnaire</td>
<td>Primary caregivers report a heavy burden of care and medical providers should encourage caregivers to make more use of these coping styles to promote physical and mental health themselves, their patients and their family, as well improve the quality of care provided.</td>
</tr>
<tr>
<td>Schulz et al., 2009</td>
<td>Randomized controlled trial</td>
<td>Caregivers are in need of and can benefit from interventions that can help them manage the medical and functional limitations of the care recipient. Intervention strategies that target both the caregiver and care recipient are particularly promising strategies.</td>
</tr>
</tbody>
</table>
APPENDIX B
IRB APPROVAL, UNIVERSITY OF NEVADA, RENO

DATE: December 29, 2015
TO: Stephanie DeBoor, PhD, APRN, CCRN
FROM: University of Nevada, Reno Institutional Review Board (IRB)
PROJECT TITLE: [846037-1] An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury
REFERENCE #:
SUBMISSION TYPE: New Project
ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: December 29, 2015
EXPIRATION DATE: N/A No expiration Date for Exempt Categories
NEXT STATUS REPORT DATE: N/A None
REVIEW CATEGORY: Exempt category #2

The UNR IRB reviewed this project and has determined it is EXEMPT FROM IRB REVIEW according to federal regulations. Please note, the federal government has identified certain categories of research involving human subjects that qualify for exemption from federal regulations. The IRB is authorized by the federal government to determine whether studies determined by the principal investigator (PI) to be exempt from federal regulations actually qualify for exemption criteria.

Only the IRB has been designated authority through the University to make a determination that a study is exempt from federal regulations. The above-referenced protocol was reviewed and the research deemed eligible to proceed in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46.101 paragraph [b]).

If you have any questions, please contact Nancy Moody at 775.327.2367 or at nmoody@unr.edu.

NOTE for VA Researchers: You are not approved to begin this research until you receive an approval letter from the VASHC Associate Chief of Staff for Research stating that your research has been approved by the Research and Development Committee.

Sincerely,

Richard Bjur, PhD Janet Useinger, PhD
Co-Chair, UNR IRB Co-Chair, UNR IRB
University of Nevada Reno University of Nevada Reno

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Nevada, Reno IRB’s record.
APPENDIX C

CONFIDENTIALITY STATEMENT SIGNED BY TRANSCRIPTIONIST

Transcriber's Confidentiality Agreement

Title of the Study: An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury

Principle Investigator: Stephanie DeBoor, PhD, RN, CCRN

Student Investigator: Ashley McCoy, RN, BSN

Contact Phone Number: 775-224-3225

As a transcribing typist of this research study, I understand that I will be hearing recordings of confidential interviews. The information on these recordings has been revealed by research participants who participated in this project on good faith that their interviews would remain strictly confidential. I understand that I have a responsibility to honor this confidentiality agreement:

I hereby agree not to share any information on these recordings with anyone except the principal investigator and student researcher of this project. Any violation of this agreement would constitute serious breach of ethical standards and I pledge not to do so.

This acknowledgement is governed by HIPAA as well as other applicable Federal, state, university, and local laws and regulations.

Signature

Date 14/16

Printed Name of Transcribing Typist
Do you care for someone at home with a Spinal Cord Injury?
Are you interested in participating in a research study?

- My name is Ashley McCoy and I am a Registered Nurse pursuing a Master’s Degree at the University of Nevada, Reno.
- I am researching the experiences of caregivers who provide care at home to one with a traumatic spinal cord injury.
- The title of my study is *An Exploration of the Lived experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury*.
- Would you like to share your story with me?
- Inclusion criteria: English speaking, 18 years of age and older, residing in Nevada, providing in home care to one with a traumatic SCI (quadriplegia or paraplegia), and providing care for greater than 6 months.
- Participants will agree to a face-to-face audio-taped interview to be conducted at a private location of your choice.
- A follow-up interview will be conducted so you can clarify your experience and add any additional remarks.
- All information will be kept strictly confidential and you will be given an alias for the research study results.

I hope you consider being part of this research. If you would like to participate or have additional questions, please contact me at:

(775) 224-3225 or ashleyconroy555@gmail.com or Dr. Stephanie DeBoor (faculty chair) deboors2@unr.edu
Physiatry Outpatient Clinic
10085 Double R Blvd
Reno, NV 89521

December 17, 2015

University Nevada Reno
c/o Office of Human Research Protection
Ross Hall, Room 205, Mail Stop 0331
Reno, Nevada 89557

Please note that Mrs. Ashley McCoy, UNR Graduate Student, has sought the permission of Dr. Humphries, through the physiatry outpatient clinic, to recruit participants for her study, “An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury”.

Mrs. McCoy will post flyers to recruit participants who, if interested to participate, are directed to contact the researcher directly using the contact information on the flyer. Each potential subject will be contacted by the researcher to ensure inclusion criteria, to explain the purpose of the research, maintenance of confidentiality, pre-screening questionnaire, handling of data, reporting of data at the end of the research and to answer any additional questions. Mrs. McCoy’s research activities will be finished by 4/1/16.

Mrs. McCoy has agreed not to interfere with any appointments or impede on normal proceeding of the organization. Mrs. McCoy has also agreed to provide a copy of the University of Nevada IRB approved, stamped consent document before she recruits participants at the hospital, and will also provide a copy of the research obtained.

I, Stefan Humphries, give permission to Ashley McCoy to utilize the outpatient clinic to recruit participants for her research.

Signed, 

[Signature] 01/07/16
Renown Rehabilitation Hospital
1495 Mill St
Reno, NV 89502

December 17, 2015

University Nevada Reno
e/o Office of Human Research Protection
Ross Hall, Room 205, Mail Stop 0331
Reno, Nevada 89557

Please note that Mrs. Ashley McCoy, UNR Graduate Student, has sought the permission of Renown Rehabilitation Hospital to recruit participants for her study, "An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury”.

Mrs. McCoy will post flyers to recruit participants who, if interested to participate, are directed to contact the researcher directly using the contact information on the flyer. Each potential subject will be contacted by the researcher to ensure inclusion criteria, to explain the purpose of the research, maintenance of confidentiality, pre-screening questionnaire, handling of data, reporting of data at the end of the research and to answer any additional questions. Mrs. McCoy’s research activities will be finished by 4/1/16.

Mrs. McCoy has agreed not to interfere with any appointments or impede on normal proceeding of the hospital. Mrs. McCoy has also agreed to provide a copy of the University of Nevada IRB-approved, stamped consent document before she recruits participants at the hospital, and will also provide a copy of the research obtained.

Melodie Osborn gives permission to Ashley McCoy to utilize the Renown Rehabilitation Hospital to recruit participants for her research.

Signed,

Melodie Osborn, CA
APPENDIX F

INFORMED CONSENT, UNIVERSITY OF NEVADA, RENO

UNIVERSITY OF NEVADA, RENO INSTITUTIONAL REVIEW BOARD

TITLE OF STUDY: An Exploration of the Lived Experiences of the Caregiving Role and Life Satisfaction in Caregivers Following Traumatic Spinal Cord Injury

INVESTIGATOR(S): Stephanie DeBoor, PhD, RN, CCRN 775-682-7156; Ashley McCoy, RN BSN, Primary Investigator (775) 224-3225

PURPOSE

You have been asked to participate in a research study. The purpose of this study is to achieve a better understanding of what caregivers of spinal cord injured individuals experience being a primary caregiver to one with a traumatic injury. Understanding your experience might help healthcare providers to better support caregivers with similar experiences.

PARTICIPANTS

You are being asked to participate because you are: 1) 18 or older, 2) English speaking, 3) residing in Nevada, 4) providing in home care to one with a spinal cord injury, and 5) have been providing care for greater than 6 months. Approximately 4 to 12 participants will be enrolled in this study.

PROCEDURES

If you volunteer to participate in this research study, you will be asked to take part in a face-to-face, audio-taped interview, with the student researcher, lasting approximately one hour. The interview will be held at a mutually agreed upon, convenient location. This location will be private to ensure confidentiality of the participant and the information collected. During the interview you will be asked questions related to your caregiving experiences following the traumatic spinal cord injury. Following the initial interview, you will be asked to read the transcript from the interview and the student researcher’s interpretation to make sure it is a good description of your experience. Follow-up communication will be conducted either by telephone, post office mail or face-to-face. Review and discussion of the transcript is expected to take no more than one additional hour of your time. It is important for you to remember that your participation in this study is voluntary and all information shared will be kept confidential.

DISCOMFORTS, INCONVENIENCES, AND/OR RISKS

There are risks involved in all research studies. This study may include only minimal risks. There may be some discomfort answering questions related to caring for one with a spinal cord injury. You may take a break, refuse to answer any question that makes you
feel uncomfortable, or end the interview. You may withdraw from the study at any time. There are no risks for refusing to participate.

**BENEFITS**

You may not experience any direct benefits from participating in this study other than the satisfaction of having participated in research. However, we hope that learning about your caregiving experiences following a traumatic spinal cord injury will help health care providers to better understand how to support other caregivers with similar experiences.

**CONFIDENTIALITY**

All information gathered during this research study will be kept completely confidential. All participants will be given an alias (pseudonym) to keep all material confidential. In field notes, recordings, and transcription, participants will be referred to by their pseudonym to protect anonymity and confidentiality of shared information. Interviews will be audio taped and transcribed by a private, professional transcriptionist who has signed a confidentiality statement. Your identity will be protected to the extent allowed by law. You will not be personally identified in any reports or publications that may result from this study.

The Department of Health and Human Service (HHS), other federal agencies as necessary, the University of Nevada, Reno Social Behavioral Institutional Review Board may inspect your study records. The study records will be securely stored in a locked file cabinet in the researcher’s office and destroyed in accordance with the granting IRB specifications.

**COSTS/COMPENSATION**

There will be no cost to you nor will you be compensated for participating in this research study.

**DISCLOSURE OF FINANCIAL INTERESTS**

The researcher has no financial interest in this study.

**RIGHT TO REFUSE OR WITHDRAW**

You may refuse to participate or withdraw from the study at any time and still receive the care you would normally receive if you were not in the study. If the study design or use of the data is to be changed, you will be so informed and your consent re-obtained. You will be told of any significant new findings developed during the course of this study, which may relate to your willingness to continue participation.

**QUESTIONS**

If you have questions about this study or wish to report a research-related injury, please contact Ashley McCoy, RN, BSN at 775-224-3225 or Dr. Stephanie DeBoor, PhD, RN, CCRN at 775-742-7732 at any time.

You may ask about your rights as a research subject or you may report (anonymously if you so choose) any comments, concerns, or complaints to the University of Nevada,
Reno Biomedical Institutional Review Board, telephone number (775) 327-2368, or by addressing a letter to the Chair of the Board, c/o UNR Office of Human Research Protection, 205 Ross Hall / 331, University of Nevada, Reno, Reno, Nevada, 89557.
APPENDIX G

INTERVIEW QUESTIONS

Interview Questions

1. How long have you been a caregiver to one with a spinal cord injury? Tell me about your experience.

2. Has your relationship changed after the injury? Please elaborate. What coping skills do you have or have you developed along the way in helping to adapt/adjust to the changes?

3. Has your self care/health changed since taking on a care giving role? Please elaborate.

4. After being a caregiver for X amount of time, looking back, would you do anything differently if you had to do it all over again?

5. What advice would you give to other caregivers new to the role?
References


