5-12-2003

The impact of caregiving: family caregivers of spinal cord injury survivors

Kristine L. Engel

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The Impact of Caregiving:
Family Caregivers of Spinal Cord Injury Survivors

Kristine L. Engel

Cardinal Stritch University
THE IMPACT OF CAREGIVING:
FAMILY CAREGIVERS OF SPINAL CORD INJURY SURVIVORS

By
Kristine L. Engel

A Master’s Project
Submitted to Cardinal Stritch University College of Nursing
in partial fulfillment of the requirements for the degree
Master of Science in Nursing

Cardinal Stritch University
Milwaukee, Wisconsin
May 12, 2003
ABSTRACT

Spinal Cord Injury (SCI) results in a devastating disability that affects not only the individual victim but also the entire family system. Many family members find themselves taking on the role of primary caregiver for their loved one living with SCI. The purpose of this study was to explore the lived experience of family caregivers of SCI survivors. The search for potential stressors affecting caregivers was explored. Findings from this study are intended to provide input into specific nursing interventions that can be used to better prepare the caregiver for that role. This study was conducted using a qualitative research design. Two singular case studies were used to explore the caregiving experience from a holistic approach. Interviews, observations, and a journaling activity comprised a triangular approach to data collection and enhanced the rigor of this study. Multiple recurrent concepts extracted from the literature provided an organizational framework to categorize, present, and interpret the data gathered. Major themes of emotional issues, role changes, and health problems revealed factors influencing the lived experience of family caregivers of SCI survivors. Emotional issues revealed feelings of anxiety, anger, and depression. Role changes witnessed included role ambiguity, role overload, role reversal, and role challenge. Finally, the participants in this study revealed health problems consisting of fatigue, headaches, and neglect in seeking medical attention for other health problems.
Dedication

This thesis is dedicated to family caregivers of spinal cord injury survivors and to the Spinal Cord Injury Center at Froedtert Hospital in Milwaukee Wisconsin, from which I gained the inspiration for this study. To the nursing and support staff working with me while I pursued my graduate studies, they offered me encouragement, recognition of my effort and shared in my celebration upon the completion of this research study. I also dedicate my thesis to my family who provided unconditional love and support.
Acknowledgment

I would like to acknowledge my committee members:

Nancy Cervenansky, PhD, RN, Committee Chair

Vicki Dallmann-Papke, MEd, RN

Raymond Riska, MBA, RN

They provided the guidance, sharing of expertise and continued support I needed to complete my studies.
# Table of Contents

<table>
<thead>
<tr>
<th>Chapter One: Introduction</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Statement of the Problem</td>
<td>9</td>
</tr>
<tr>
<td>Purpose of the Study</td>
<td>11</td>
</tr>
<tr>
<td>Research Question(s)</td>
<td>11</td>
</tr>
<tr>
<td>Significance of the Study for the Discipline of Nursing</td>
<td>12</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>13</td>
</tr>
<tr>
<td>Assumptions of the Study</td>
<td>13</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>13</td>
</tr>
<tr>
<td>Summary</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Two: Review of the Literature</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Issues</td>
<td>16</td>
</tr>
<tr>
<td>Changes in Roles</td>
<td>19</td>
</tr>
<tr>
<td>Health Problems</td>
<td>22</td>
</tr>
<tr>
<td>Summary</td>
<td>23</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Chapter Three: Methodology</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design</td>
<td>25</td>
</tr>
<tr>
<td>Sample/Sampling Plan</td>
<td>26</td>
</tr>
<tr>
<td>Setting</td>
<td>26</td>
</tr>
<tr>
<td>Data Collection Methods</td>
<td>27</td>
</tr>
<tr>
<td>Interviews</td>
<td>27</td>
</tr>
<tr>
<td>Observation</td>
<td>28</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Data Analysis</td>
<td>50</td>
</tr>
<tr>
<td>Interpretation of the Findings</td>
<td>54</td>
</tr>
<tr>
<td>Emotional Issues</td>
<td>54</td>
</tr>
<tr>
<td>Role Changes</td>
<td>57</td>
</tr>
<tr>
<td>Health Problems</td>
<td>58</td>
</tr>
<tr>
<td>Summary</td>
<td>60</td>
</tr>
<tr>
<td>Chapter V: Summary, Conclusion, and Recommendations</td>
<td>61</td>
</tr>
<tr>
<td>Summary of Findings</td>
<td>61</td>
</tr>
<tr>
<td>Conclusions and Recommendations</td>
<td>63</td>
</tr>
<tr>
<td>Recommendations for Clinical Practice</td>
<td>64</td>
</tr>
<tr>
<td>Recommendations for Further Research</td>
<td>64</td>
</tr>
<tr>
<td>Bibliography</td>
<td>66</td>
</tr>
<tr>
<td>Appendix A The Research Participant Interview Questions</td>
<td>70</td>
</tr>
<tr>
<td>Appendix B The Journaling Activity Guiding Questions</td>
<td>71</td>
</tr>
<tr>
<td>Appendix C Informed Consent</td>
<td>72</td>
</tr>
</tbody>
</table>
CHAPTER I

Statement of the Problem

There are approximately 10,000 new cases of spinal cord injury (SCI) each year in the United States. The number of individuals living with SCI at any given time ranges from 183,000 to 230,000 ("Facts & Figures", 2000).

Some of the adverse emotional consequences associated with living with a spinal cord injury include that of depression (Krause, Kemp, & Coker, 2000; Elliot, Witty, Herrick & Hoffman, 1991), anxiety (Kennedy & Rogers, 2000), and loss (Wortman & Silver, 2000), but what is the impact and emotional consequence for the family caregiver of SCI survivors?

Extensive literature exists relating to family caregivers of persons with chronic illness and disability such as Alzheimer's disease, Multiple Sclerosis (MS), and Chronic Obstructive Pulmonary Disease (COPD). How do these findings compare to family caregivers of people living with SCI? Current literature primarily focuses on the perceptions and experiences of family caregivers of SCI survivors from a quantitative perspective (Weitzenkamp, Gerhart, Charlifue, Whiteneck & Savic, 1997; Laing, Chase, Butt, Hulse, & Johnson, 1996; Sherrard, 1995; Foxall, Eckberg, & Griffith, 1986). Further research conducted from a qualitative perspective is needed to enlighten and enrich existing data.

The act of caregiving is known to stimulate feelings ranging from various emotional responses, to health problems, in addition to role changes (Sullivan, 2001; Elliott, Kurylo & Lindsey, 1998; Weitzenkamp et al., 1997; Gillies, 1988). The aim of
this study was to explore and gain a deeper understanding of the lived experiences of family caregivers of SCI survivors through a qualitative research design.

**Background information**

The investigator is a nurse educator of an 18-bed spinal cord injury unit and has greater than 10 years of nursing experience working with SCI survivors and their families. The investigator holds a strong commitment to serving SCI survivors by meeting their healthcare needs from the day of injury, through the rehabilitation process, and finally to discharge. As part of an interdisciplinary team, the investigator has been given the opportunity to assist in preparing SCI survivors and their families for successful re-entry into the community. Those efforts include addressing the needs of the patient, their families, especially those whom have assumed the caregiver role.

Team members include representatives from neurosurgery, physical medicine and rehabilitation, nursing, physical and occupational therapy, social services, psychology, and chaplain services among others. The team is focused on meeting the medical needs of the patient as well as the emotional and spiritual needs of the patient and their families.

The investigator has always personally strived to help patients with SCI and their families to cope with the challenges and struggles of either living with SCI or caring for a loved one with a SCI.

The investigator in collaboration with members of the interdisciplinary team, has developed, implemented, and continues to refine clinical pathways. The aim of a clinical path is to manage the needs of the SCI survivor, including addressing and predicting the needs of family caregivers. The staff in the SCI outpatient program strive to continue to meet the needs of the SCI survivor and their families on an outpatient basis.
The investigator was interested in exploring and examining the lived experiences of family caregivers of SCI survivors.

**Purpose of the Study**

The purpose of this study was to explore the lived experiences of family caregivers of SCI survivors. This study intended to identify actual and potential stressors experienced by family caregivers of SCI survivors. The existing research reveals potential areas of concern such as emotional issues, role changes, and health problems for the caregiver (Sullivan, 2001; Elliott et al., 1998; Weitzenkamp et al., 1997; Gillies, 1988).

Through identification of these stressors, further nursing interventions, including educational strategies may be developed and implemented to better prepare the family caregiver of this patient population, thus improving outcomes.

**Research Question(s)**

It is challenging to meet the needs of patients and their families in today's fast paced ever-changing health care environment. The trends of cost containment and shorter lengths of stay, allow little time for health care providers to develop relationships with the patients much less their family members. This leaves the nurse little time to adequately prepare family caregivers for community re-entry and a life changed.

The primary research question was: "What is the lived experience of family caregivers of SCI survivors?" The following sub questions included:

1. What are the stressors specifically affecting the family caregiver of the SCI survivor?
2. How has the family caregivers’ life changed as a result of their caregiving experience?
3. What challenges are family caregivers of SCI survivors faced with?

4. What factors impact the experience of caregiving for a SCI family member?

Lazarus' (1984) theory on stress and coping was used to explore these questions and was intended to provide a framework for further understanding of the nature of stress as it relates to the purpose of this study. This theory is explained in further detail in chapter two, the literature review. The investigator has integrated the theory throughout the analysis and interpretation narrative of the study; and compared and contrasted it to the study's findings thus, confirming or challenging tenets of the theory.

Significance of the Study for the Discipline of Nursing

The significance of this study was geared toward providing nurses with additional information regarding the lived experiences of family members caring for persons living with SCI. Through this in-depth study, the investigator was able to identify stressors and challenges facing family caregivers of SCI survivors. The information obtained assisted the investigator to better understand the complexities facing family caregivers. This information was also used to assist the investigator in developing strategies for helping family caregivers develop problem solving and coping skills, thus improving outcomes.

The results of this study also helped the investigator, a nurse educator of a spinal cord injury unit, better prepare families for caregiving roles through education of the unit's nursing staff.

Few studies have been done focusing on family caregivers of SCI survivors. Even fewer using a qualitative research design. This study was conducted using a qualitative case study design to explore the lived experiences of family caregivers of persons living with SCI.
Limitations of the Study

One limitation of the study might have been related to the investigator’s position on a spinal cord injury unit for over 10 years. This position could have potentially created pre-conceived ideas and related biases held by the investigator. The investigator strongly recognized this potential limitation and made every effort to place any pre-conceived notions pertaining to the topic being studied aside in order to present faithful descriptions and interpretations of the participant’s experience. The investigator had an objective third party examine the data as well. The third party member had previous experience working in the field of SCI and served as a content expert. This enhanced the rigor of the study findings.

Assumptions of the Study

One assumption included in this study was that the subjects experienced certain stressors in terms of their role as a caregiver of a family member living with SCI. Another assumption of this study was that the amount of caregiving tasks (completing or providing greater than or equal to 50% of caregiving tasks) provided by the caregiver affected the amount and degree of stress experienced by the caregiver. A final assumption made was that families choosing to care for a family member with SCI could be better prepared for that role. Better preparation may yield better outcomes.

Definition of Terms

**Family.** People connected by blood or marriage- e.g. parents, grandparents, spouses, siblings, (friends or other significant others were not included in this study).

**Caregiver.** A person providing for the physical and emotional needs of another individual.
Role changes. The acquisition of new or different tasks or functions.

Stress. Stress is an emotional response of a person-environment relationship.

Stress encompasses physiological, psychological, and social entities (Lazarus, 1984; 1977).

Stressors. Stressors refer to psychological, social, physical, and environmental stimuli that affect a person’s wellness. Stressors are theorized to cause varying degrees of responses from individual to individual (Blattner, 1981).

Summary

In conducting this study, the investigator’s intent was to discover what the perceptions and experiences were of the family caregiver participants and compare and contrast that information with factors identified in the literature. Findings from this study were helpful in the development of specific interventions that will assist caregivers to adapt to life changes forever. The next chapter is a critical review of the literature and synthesis of the body of knowledge that exists pertaining to the focus of this research study, caregivers of SCI survivors. Specifically, the review describes emotional issues, changes in roles, and health problems.
CHAPTER II

Review of the Literature

SCI affects not only the individual victim but also the entire family system (Laing, Chase, Butt, Hulse & Johnson, 1996). There is a plethora of publications regarding the issues, which surround the caregivers of those living with chronic disabilities such as Alzheimer’s disease and multiple sclerosis (MS). While a SCI creates a “chronic illness” like pattern, comparisons and generalizations cannot be made to other chronic disabilities without extreme research conducted from both quantitative and qualitative perspectives. There is a consensus in the literature that a void exists on the adjustment process and long-term adaptation issues surrounding the families caring for persons living with SCI (Laing et al., 1996; Sherrard, 1995). Research conducted from a qualitative perspective might help explore this void.

Advances in emergency care and surgical intervention have increased the life expectancy following SCI so that in some cases it approaches that of the general population (Shewchuk, Richards & Elliott, 1998). Caring for the needs of a person living with SCI varies depending upon severity of injury and the degree of paralysis. “Forty percent of all individuals with SCI use some assistance, with more than half coming from family members” (Elliott, Kurylo & Lindsey, 1998, p.1). Following the onset of a severe physical disability, such as a spinal cord injury, spouses or other family caregivers become the primary sources of help with activities such as feeding, dressing, transfers, and bowel and bladder care. This type of assistance may be required to various degrees for an undefined period (Shewchuk et al., 1998). If the primary caregiver is the spouse or other family member, the health and well being of the caregiver may erode over time.
The purpose of this review was to explore the existing research regarding the experiences of the caregiver of the SCI survivor. Existing research reveals predictable areas of concern for the family member caring for persons living with SCI. These areas of concern relate to emotional issues, role changes, and health problems for the caregiver.

The theory of stress and coping as conceptualized by Lazarus (1984) provided a framework for further understanding and examination of stress or potential stressors as it relates to case study participant’s experiences of caregiving.

Lazarus (1984) views stress as a relationship between an individual and his environment that is taxing to the person and affects their well-being. Lazarus (1984) uses the term “appraisal” to explain the process of assessing stimuli and evaluation of the stress response. Lazarus (1984) describes “coping” as an individual’s ability to change cognitively and behaviorally to manage stressors. Understanding these processes may help explain how family caregivers of SCI survivors experience and react to stressors and stress stimuli.

Lazarus (1984) refers to stressors or stress stimuli as events impinging on an individual. Exposure to a cataclysmic phenomenon, such as an incapacitating illness, is one type of stressor, according to Lazarus (1984, p. 138). The stress stimuli in this study would be a loved one sustaining a SCI and the sequelae that follows.

**Emotional Issues**

Emotional issues encompass psychological and social stressors. “Social demands refer to normative patterns of expectations about behavior” (Lazarus, 1984, p. 238). According to Lazarus’ theory of stress and coping, individuals exposed to numerous,
shifting, and complex expectations might experience low morale, impaired social functioning, or damage to one's health (p. 238).

Frequently mentioned emotional issues experienced by caregivers of chronic illnesses include feelings of loss, loneliness, and isolation (Sullivan, 2001, pp.81-82; Weitzenkamp et al., 1997). Time spent caregiving might not allow opportunities to engage in other rewarding social activities. Weitzenkamp et al. (1997) studied the added impact of caregiving among spouses of SCI survivors, “Caregivers report relinquishing their own activities in order to provide care, they have decreased social contacts, and they report that former friends and acquaintances often distance themselves”, (p.822).

Elliott, Kurylo, and Lindsey (1998) reported that caregiver stress and anxiety might get worse over the course of the year following the injury. “These findings are contrary to the belief that the anxiety is related to the newness of the injury” (Elliott et al., 1998, p.2). Elliott et al. (1998) reported that if caregivers develop difficulties coping immediately after an injury, it is likely that the caregiver will continue to have coping problems a year later.

Elliott et al. (1998) reported another finding related to both anxiety and depressive behavior. During the first year after injury, the degree of caregiver anxiety and depression were related to an amount of “expressive support”. This means that depression and anxiety increase if the caregiver did not have people with whom they could talk or express their feelings. Caregivers who had someone to talk with and who offered emotional support to them during the rehabilitation period immediately following the injury, reported less anxiety and depression a year after the injury. “It is important for caregivers to have other people with whom they can talk. Without this support the
caregiver is at greater risk of having problems with psychological adjustment” (Elliott et al., 1998, p.2). Rintala, Young, Spencer and Bates (1996) studied family relationships and adaptation to SCI and found the issue of reciprocity was important. “At the same time that the person with SCI needed support, members of his family needed support from him” (Rintala et al., 1996, p.73).

The research of Weitzenkamp et al. (1997) reported a significant amount of emotional stress felt by caregivers. Anger, resentment, and depression were reported among the caregiving spouses of SCI survivors verses non-caring spouses. “Overt depression, feelings of uselessness and not being understood, and insomnia are but a few of the specific documented symptoms” (Weitzenkamp et al., 1997, p.822). Weitzenkamp et al. stated that more spouses of SCI survivors felt more “down in the dumps” than their disabled partners. Weitzenkamp et al. noted a limitation of their study that the status of participants’ pre-injury marriages was not examined in their research. Rintala et al. (1996) also described feelings of anger and resentment among spinal cord injured persons and their family members. Rintala et al. conducted a qualitative study analyzing multiple interviews between a 30 year-old man sustaining a T12 SCI and multiple family members. A quote taken directly from this study is as follows: “At first Russell was grateful that his brother was taking care of everything, but later he resented that his brother tried to make decisions for him and that his brother had become angry about some of the decisions Russell had made” (p.73).

At the time of injury, the average patient sustaining a SCI is approximately 30.7 years-of-age. “Whereas most SCI’s tend to occur in persons aged 16 to 30 years, about 40% of the survivors are over 45 years of age” (Wirtz, LaFavor & Ang, 1996, p.34).
Elliott et al. (1998) reported another interesting finding in their research related to caregiver anxiety and the age of the individual with SCI. Caregiver anxiety was heightened if the individual with SCI was a younger person (than the average of persons living with SCI) or a child. "The younger the patient, the higher the level of anxiety. This may be because the parent/caregiver is thrown into a situation that was not supposed to happen" (Elliott et al., 1998, p.2). Thus, caregivers are placed into a quandary over life plans.

Laing et al. (1996) reported another source of anxiety and frustration for the caregiver of SCI in regards to financial strains. Many families experience a decrease in income when a family member becomes disabled. Many SCI survivors and their partners choose to remain unmarried in order to protect their benefits. "If an individual with SCI marries, the new spouses' income immediately becomes relevant, and the SCI survivor may be at risk for losing Social Security Income (SSI) or loss of access to other income-eligible programs" (Laing et al., 1996, p.105). Another frustrating financial issue relates to spousal reimbursement for caregiving duties provided. "Many insurance companies will not pay family members for any attendant care they provide but will pay a home health agency. This can send a clear message to the spouse that their services are 'expected' as part of the marriage contract and do not have any financial value" (Laing et al., 1996, p.105).

Changes in Roles

Lazarus' (1984) theory on stress and coping indicates that role conflict, ambiguity, and overload are critical factors in creating stress. Role conflict can arise when attempting to satisfy one role causes another to suffer. Role ambiguity may
indicate stress if an individual is unclear as to what is expected. One is unable to plan effectively or behave in a directed manner without such clarity. Finally, role overload can be stressful if its requirements overextend the individual’s resources (Lazarus, 1984, p. 239).

Physical disability such as SCI may render an individual unable to perform certain roles. Thus, an individual living with a disability and his significant others experience loss of former familial roles and may need to acquire new and unfamiliar ones (Gillies, 1988). “New roles may be learned and familiar roles may be strengthened. One thing is certain however, all family members will experience role inadequacy from time to time” (Sherrard, 1995, p.32).

When a family member is confronted with the task of caring for a loved one with SCI there is major role confusion, role challenge, or feelings of burden (Richards & Shewchuk, 1997: Sherrard, 1995: Foxall, Eckberg & Griffith, 1986). Time spent involved in caregiving activities may not allow the caregiver opportunities for relationships and activities outside the home. If these opportunities become restricted or limited, the family caregiver may experience role restriction (Laing et al., 1996). Foxall et al. (1986) studied spousal adjustment to chronic illnesses. The participants indicated feeling a sense of loss in roles fulfilled at least partially outside the home. These areas included leisure, kin, work, minor affiliate, and friend. The area of role changes tends to overlap with the category of emotional issues. Foxall et al. concluded that unfulfilled roles might partially explain feelings of loneliness. This research demonstrated that feeling lonely was positively correlated with decreased social role activity for the participants.
Similar to role restriction, a family caregiver may experience "role confusion". This occurs when a family caregiver attempts to manage the expectations of several roles. "For example, 'switching hats' from wife to attendant requires an ability to successfully juggle the expectations of both roles without allowing them to overlap in a detrimental manner" (Laing et al., 1996, p.104).

Gillies (1988) studied role insufficiency following SCI. Gillies presented a case study of a 20-year-old male who sustained an incomplete sixth cervical SCI. The primary caregiver in this case was the individual’s mother. Very similar to "role confusion", Gillies found that this particular caregiver experienced "role insufficiency". The caregiver in this instance was very anxious regarding the impending discharge of her son, as she doubted her own abilities to assume the caregiver role. "I don’t think I can take care of him. After all, I’m not a nurse" (Gillies, 1988, p.21).

"Role reversal" is another role change experienced in some relationships and families. In this situation, a female partner of a male with SCI may assume the principal "breadwinner" responsibilities while the spinal-cord-injured partner assumes stay-at-home tasks such as housekeeping and child care (depending upon his level of injury and independence). In other instances, a non-disabled male partner may assume principal child rearing and homemaking tasks secondary to the inability of his disabled female partner to assist in these activities (Laing et al., 1996).

"Role overload" can occur when the caregiver feels burdened with numerous care taking responsibilities. "Role overload may be exacerbated by role confusion and/or role reversal" (Laing et al., 1996, p.104). Decker, Schultz and Wood (1989) studied determinants of well being in primary caregivers of spinal cord injured persons. The
study examined “role restriction” and “role overload” felt by the participants. Perceived burden (role overload) was positively correlated with the number of responsibilities and number of hours spent per day helping the disabled partner.

Health Problems

Lazarus and Monet (1977) discussed the possible link between stress and health problems. Individuals under stress have been known to engage in coping activities that are damaging to health such as heavy use of tobacco or alcohol. Another way stress can lead to health problems is by psychological or social factors leading the person to minimize the significance of their own symptoms. Thus, individuals might avoid seeking medical attention (p. 5). Lazarus and Monet also mention outpourings of hormones during stressful periods, which might create dramatic alterations in bodily processes (p. 5).

Health problems refer to the physiological stressors experienced by the caregiver. Spousal caregivers of persons with chronic illnesses have been shown to ignore or neglect their own health problems and needs. Studies linking arthritis, high blood pressure, heart disease, and cataracts to family caregivers of persons with chronic obstructive pulmonary disease (COPD) have been reported. Wives of partners with MS have reported new issues such as hypertension, insomnia, sore muscles and tingling of their extremities (Weitzenkamp et al., 1997).

On the average, caregivers of persons with SCI report 3 to 4 more physical health problems during the first year of care taking, ranging from sinus problems and colds to body aches and pains (Elliott et al., 1998). Other physiological stressors experienced among family members include sleep disturbances, loss of appetite, weight loss, and
fatigue (Sullivan, 2001, p.80). Weitzenkamp et al. (1997) reported significant fatigue in caregiving spouses of spinal cord injury survivors. Shewchuk et al. (1998) studied health outcomes among caregivers of persons with SCI. Participants reported developing an average of nearly five physical symptoms in the first year of caregiving and that physical symptoms and anxiety were highly interdependent. Deteriorating health of the caregiver can affect the well being of the individual with SCI. Exhausted caregivers unable to provide good care might increase the chances of causing secondary complications for the individuals with SCI. For example pressure sores might develop if the caregiver becomes too fatigued to transfer or reposition the disabled person. Secondary health problems for the individual with SCI might lead to further duties for the caregiver, such as dressing changes and trips to the clinic. These duties might contribute to or exacerbate the deteriorating health of the caregiver.

Summary

SCI is a devastating event affecting the entire family system. Existing literature concurs that predictable areas of concern for caregivers of SCI survivors include emotional issues, role changes, and health problems ("SCI & Aging", 2000; Gill, 1999; Weitzenkamp et al., 1997).

Nurses play a key role in assisting family caregivers to work through the long-term sequelae of SCI surrounding them when a loved one becomes disabled. Support can influence the degree to which caregivers feel a sense of confidence and control in their lives. Still, despite years of research, little is known about the burden of caregiving for SCI individuals from a qualitative perspective. Further research from a qualitative
research perspective is needed to examine the critical factors impacting the experience of caregiving for SCI family members.
CHAPTER III

Methodology

The purpose of this study was to explore the lived experience of family caregivers of spinal cord injury (SCI) survivors using a qualitative research design. In addition to the primary research question, there were several other questions to be examined in this study. The search for potential stressors and challenges affecting caregivers was explored. The final sub-question considered whether the caregiver’s life had changed, and if so, how?

Design

The study used a qualitative research design in an attempt to gain further insight into the caregivers experience as compared to what is currently available in the literature from numerous quantitative sources. The research tradition was phenomenology. The research question, “What is the lived experience of family caregivers of SCI survivors?” was congruent with the domain encompassed by the tradition of phenomenology. The fact that data came directly from the participants demonstrates consistency with the tradition of phenomenology. Thus, the method used to collect data was compatible with the purpose of the research.

The investigator conducted two in-depth case studies to obtain an understanding of the lived experience of family caregivers of spinal cord injury (SCI) survivors. One important component of this case study research design was to collect data under the participant’s natural conditions. The investigator collected data in the participant’s home in order to generate rich descriptive data. The investigator gained a holistic understanding of the participant’s lived experience as a caregiver of family members.
living with SCI through personal observations and through descriptive anecdotes directly from the participants.

Sample/Sampling Plan

The investigator used a purposive sampling plan when selecting participants for the study. The study examined the lived experience of two individuals caring for their family members who are living with a spinal cord injury. The investigator selected participants who were recommended via co-workers (of the investigator) and who met the criteria for inclusion in the study.

The participants were invited to participate after having met the following criteria: (a) must be a minimum of 21 years of age and less than 65 years of age; (b) must have the ability to speak and read English; (c) must have the ability to give informed consent verbally and in writing; (d) must be providing greater than or equal to 50% of caregiving tasks for a family member living with SCI for at least one month. Caregiving tasks include providing physical support measures such as feeding, bathing, dressing and toileting. These tasks are referred to as activities of daily living (ADL’s); (e) must have a desire to participate in the study.

Setting

The investigator gathered data at a location agreed upon by the investigator and the participant. The investigator explained to the participants that an environment, which was quiet, private, and free from distractions, would be desired, allowing the participant to speak freely about their feelings and experiences as a caregiver.

Collecting data in the participants’ home provided the investigator an opportunity to observe the caregiver interact with the individual with a SCI and allow the investigator
to view the participants in their natural setting. Interviews conducted in the participants' homes were appropriate for a qualitative, phenomenological study as the investigator captured the participants' lived experiences.

Data Collection Methods

The investigator used a triangulation approach to data collection to enhance the study’s rigor. These approaches included interviews, observations, and journaling, and field notes. The only individual collecting data was the investigator.

Interviews

The investigator conducted a semi-structured interview approach to study the participants’ lived experiences. The interview questions were structured to generate data about the participants’ lived experiences as caregivers. The interview questions were designed around the potential areas of concern outlined in the literature review (role changes, emotional issues or feelings of loss, and health problems). The semi-structured interview process allowed the investigator to guide the discussion, while encouraging the participants to elaborate on what was relevant to them. The investigator used an informal conversational approach to promote a comfortable, secure atmosphere and to allow for spontaneous reflection. The investigator hoped that using an informal conversational approach when interviewing would build rapport with the participant and reduce any potential anxiety that the participant might have. The use of non-directive, open-ended questions was used to minimize any leading behaviors or framing by the investigator. By doing this, the investigator obtained rich data pertaining to the phenomenon under investigation. The investigator attempted to suspend all that was known to her about the topic under study through the process of bracketing. Thus, appropriate for a
phenomenological study, the investigator made an effort to hold in abeyance, preconceived judgment or opinions about the phenomena under study to eliminate bias.

The investigator interviewed each participant three times. All interviews were conducted face-to-face between the investigator and the participants. The first interview lasted approximately one hour and was conducted in a setting agreed upon between the investigator and the participant. The second interview lasted approximately 1-1/2 hours and took place inside the participants' home allowing time for observations (described later in this chapter). The third and final interview lasted approximately one hour and served the purpose of allowing for any final clarification and any contributions or thoughts from the participant. The interviews were audiotaped with prior authorization obtained at the time of the interview. Confidentiality was maintained throughout the study.

The investigator later transcribed the audiotapes interviews verbatim. The investigator will keep all audiotapes, notes, and other transcriptions confidential and secured in a locked area for three years, and then the material will be destroyed. The investigator explained to the participants that confidentiality would be assured and that they may choose not to respond to questions or withdraw from the study at any time.

Observation

In addition to the case study interviews, the investigator gathered further data from observational experiences. Observational experiences included attention to the participant's home environment (wheelchair ramps, adaptive equipment, or other handicap alterations to the home).
The investigator also requested permission in advance to observe an interaction or act of caregiving between the participant and family member living with SCI.

The investigator was attentive to verbal and non-verbal behaviors of the participants (such as communication style between family members, facial expressions and other body language) in the role of caregiver and in the natural setting in which caregiving usually occur. The investigator recorded observations as field notes to assist in understanding the phenomenon under study.

**Journaling**

The investigator also asked the participants to express their thoughts related to caregiving through journaling. The investigator invited the participants to write down on paper their personal thoughts and reflections pertaining to their role as a caregiver. This allowed the participant a different means of self-expression. The participants were provided four sheets of 8.5-x 11 sized paper after the second interview, and were asked to write down any thoughts they might have pertaining to the following statement, "Describe how you imagine your caregiving role five years from now." The participants were informed that they may also write down any other thoughts related to caregiving that they might not have shared verbally.

**Organization/Analysis of the Data**

The goal of conducting in-depth interviews was to obtain rich data from the participants. The investigator examined direct quotes from the participants and from their journals for patterns and overall themes pertaining to the phenomenon under study. Further, the investigator analyzed observational data recorded as field notes to further explore the lived experience of caregivers of spinal cord injury survivors. These data sets
were analyzed, organized, and presented in both narrative and matrix format. Matrix analysis is a useful methodologic tool that provides a structure for systematic and consistent analysis of qualitative data. In addition, it provides a means for the investigator to concisely communicate findings to others (Marsh, 1990).

**Summary**

The investigator conducted in-depth case studies to generate information, which built upon the existing body of knowledge of the lived experience of family caregivers, the research phenomenon under study in this investigation. A triangulation approach was used for data collection that included interviews, observations, field notes, and journaling. All participants were required to meet the same criteria described previously for inclusion in the study.
CHAPTER IV

Findings of the Study

Several recurrent concepts extracted from a review of contemporary literature related to the primary research question and relevant to the sub-questions served two important functions relative to this research. First, phenomena described in the literature assisted in the development of the interview questions used to collect data. The interview questions were constructed to include concepts relative to emotional issues, role changes, and health problems. Second, these concepts provided an organizing framework to categorize, present, and interpret the data generated from the participants. Not all concepts were presented as a category because the data collected did not reflect all of the concepts presented in the literature. Specific themes and sub-themes emerged from the data within each of the specified categories and were used to organize and present the data.

A thematic analysis of the data revealed factors that influence the lived experience of family caregivers of spinal cord injury survivors. The researcher structured the data presentation to guide the reader through the lived experience of the participants who care for a family member living with a spinal cord injury (SCI). The researcher will provide an introduction of the participant including observations made of the participant’s home, in addition to a description of a caregiving task completed by the participant of her disabled partner. This description will be followed by a presentation of the lived experience relative to emotional issues, role changes, and health problems.

The investigator used this structure to present data collected from a reflective journal with emphasis placed on how the participant viewed their caregiving experience
five years into the future. The names of the participants and their disabled partners have been changed for purposes of confidentiality.

**Introduction of Participant One**

Karen is a 61 year-old female caring for her husband Barry, a 62 year-old male, living with a SCI. Barry sustained a fifth cervical (C5) injury to his spinal cord as a surgical complication after undergoing an elective spine surgical procedure in October of 2001. At the time these interviews were conducted, Karen had been caring for Barry for approximately 14 months. Karen and Barry have been married for 39 years. They are the parents of two sons and the grandparents of three grandchildren. Karen works part-time as a registered nurse. She reports that she is in good health but suffers from arthritis. Barry’s elderly mother lives with them. She is fairly self-sufficient but needs direction at times.

**Observation of Home**

Karen and Barry live in a ranch style home, which was fairly spacious as it had an open concept. Barry was observed navigating his wheelchair easily within the kitchen and living room. The home was well kept. There were no signs of adaptive equipment stored in the rooms that the investigator observed. There was a ramp built in the garage to allow Barry to enter and exit the home easily. Karen offered that Barry was able to access all rooms in the home except for the master bedroom. This was due to the doorway to the master bedroom being too narrow for his wheelchair.
Observation of Caregiving Task

Prior to one of the interviews the investigator was able to witness a caregiving task provided by Karen. Karen commented that supper ran late that evening and that they were just finishing up. The investigator was able to observe Karen disassemble a tray that attaches to Barry’s wheelchair for meals, assist Barry with medication administration, and assist him with several position changes in his wheelchair. They spoke politely to one another, although Karen was distracted with assisting Barry, directing his mother who was trying to help in the kitchen, and speaking to me all the while the phone rang, which no one answered. Karen apologized for running late but commented that running late was nothing new to them.

Presentation of the Data

According to previously cited literature, stress results from cataclysmic events impinging on an individual. Dealing with an incapacitating disability, whether it is your own or that of a loved one is one such example. During the first interview, Karen was asked about the steps she took to prepare for her role as a caregiver and whether being a registered nurse assisted in that preparation. Karen commented:

It helped [being a registered nurse] but I don’t have any expertise at all in spinal cord injury...so I had no expertise working with a Hoyer [mechanical lifting device]...no expertise with ranging and no expertise with a bowel program...so being a nurse I guess helped me to recognize some things but they were pretty basic things...a fever.
Karen went onto share:

I think that the education at the hospital definitely helped...I did hands-on at the hospital and yet when he came home I was a fish out of water as far as what I was doing...it wasn't working...I wasn't doing the right thing. You know it just didn't work like it was supposed to work...

**Emotional Issues**

**Anxiety; worrying about things going wrong.**

Emotional issues come in many different categories. This researcher found that many different emotional issues played a role in influencing the lived experience of the caregiver. Examples of this are presented throughout the sub-themes. Evidence of stress and anxiety may persist after many months of caregiving, especially if these feelings were present immediately after the injury (Elliott, Kurylo, & Lindsey, 1998). Karen shared more about her feelings soon after her husband's injury:

I can remember times when he first came home just thinking I can't do this and screaming and hollering. That was very early when he first came home...I was afraid of doing things for fear I would do it wrong.

In this study, anticipation of things going wrong and the anxiety of the unknown remain evident many months after the injury. Evidence of this can be found in the following quote as Karen reflects on recent plans to attend a party:

We were almost ready to leave and I will be darned if he doesn't have a big accident...here we are dressed and ready to go and I have to get him back into bed, get him cleaned up, and worry that he will have an accident at the party. Should we go or not? It's that kind of stuff. It's the unknown.

Karen went on to share that these feelings persist on a day-to-day basis, not only in anticipation of a social event or outing. She shared:
You know when he gets up [awakens in the morning] and isn’t feeling good I am worried...I say to myself should I go to work? I can’t tell you how many times I’ve asked myself that question...Will he call me if he gets sicker? Probably not...then you worry...it’s very draining...so the worry just wears you out, gets you down.

Anger; lack of Initiative of Disabled Partner.

Karen described the fact that Barry lacked the use of his upper extremities all together when he initially came home from the hospital. Over the course of the past year, Barry re-gained some arm function. This allows him to do simple tasks such as feed himself after set up and use the phone. Karen shared some of her frustration regarding her perception of Barry’s poor initiative to assist with tasks.

...I will get to the point where I will get so tired. I will say dammit all anyway [speaks forcefully], you can make the call [refers to Barry’s ability to make a phone call]. I want you to do what you can...I know you [referring to Barry] get frustrated because you can’t do a lot but would you please do what you can to take the load off of me!

Karen went on to share an example after a day at work. She remembered feeling tired and hungry and hoping that Barry would take the initiative to make her a sandwich. She shared:

...I came home and there was no sandwich...no nothing. That is the frustrating part. He knows that it bothers me. He knows that I come home hurting...but yet the thought process to say that she [refers to self] might be hungry and tired when she comes home, I will make her a sandwich so she can just sit down and eat just doesn’t seem to happen.

Depression; lack of Expressive Support.

Elliott, Kurylo, and Lindsey (1998) reported that the degree of caregiver depression may be related to the amount of “expressive support” the caregiver has.
available to them, meaning the degree of psychological adjustment relates to whether the
caregiver has people with whom they can talk to and express their feelings. During the
interviews, Karen shared the fact that she had few people with whom she felt she could
talk to and share feelings with. She did share the fact that she remembered feeling
rapport with her husband’s case manager at the hospital at the time of his discharge.
Karen shared her thoughts:

You know what would be an ideal world? In my mind it would be to have
somebody like Lynn [referring to case manager] out to your house once a
week...just sit and talk...to ask how are you doing and can I help
you...that would be an ideal world...

Karen continued to reflect for a few moments longer. She commented, “I don’t
think there is enough emphasis on the needs of the caregiver...the psychological needs of
the caregiver”. Karen continued to emphasize this point by stating:

You know you really do need somebody to talk to. You really do need
somebody to tell your frustrations to and have the caregiver cry. At least
it [frustration] is getting out. You are getting those emotions out and you
are getting those fears out...

Role Changes

Role Ambiguity.

As described in the literature review, the area of role changes tends to overlap
with the category of emotional issues (Foxall, Eckberg, & Griffith, 1986). During the
first interview Karen described the roles she holds as those of wife, mother, grandmother,
and caregiver. She reflected on her experience as a caregiver when her husband first
came home and described various role changes she has been through. As previously
cited, Karen verbalized not having any SCI experience despite being a nurse, which led to
feelings of role ambiguity. She felt unclear as to what would be expected when she commented, “I was a fish out of water as far as what I was doing...”.

**Role Overload.**

Karen went on to share that when she was preparing to take her husband home from the hospital, she thought that she could handle all of the caregiving responsibilities alone. She described thinking that she could continue to work, maintain the home, and care for her husband. She soon realized that she had overextended herself and was experiencing symptoms of role overload. She commented:

> When he first came home from the hospital I probably turned into a crazy woman. It was very overwhelming...When he came home it was so much more work than I expected...I got so tired and overwhelmed...

**Role Reversal.**

Karen went on to explain that she resisted hiring help, as she was very concerned about their finances. Karen described signs of role reversal as she was faced with the situation of being the sole breadwinner. Karen described:

> I didn’t want to think about spending the money for help. He [Barry] wasn’t getting any disability at that point so we were living completely on my income...so I said to myself I can do this myself. As a result, I just went wacko.

**Role Challenge.**

Karen described symptoms of role challenge as she spent all of her time working and caring for Barry. She had little time for herself. She commented:

> The part that really got me is there was never, ever, ever time to sit down and never, ever time for me. There was never time to watch even a half-hour show on television...never time to do anything in terms of relaxing...
As time passed Karen realized that she needed help and has since hired some help. The additional assistance has helped to lessen the symptoms of role ambiguity and role challenge but she still expressed symptoms of role overload. As previously cited, Karen had verbalized her frustration with her perception of Barry’s lack of initiative. She verbalized that she wishes Barry would take the initiative to do the things that he can to take the load off of her. She described an example of the fact that her husband is capable of making phone calls and feels that he should take the initiative to order his own supplies. She shared:

That is his job [ordering supplies] and I should not have to think about any of it. This is totally his job...I told him that if you don’t order it we won’t have it...too bad.

Health Problems

Neglecting Own Health Needs.

Spousal caregivers have been shown to neglect their own health problems and needs (Weitzenkamp et al., 1997). During the first interview, Karen stated the fact that she has arthritis and is in need of knee replacement surgery. She explained that she has put the surgery off because she has had to tend to Barry’s needs. She explained:

I have very bad arthritis and so I am always in pain...I was taking care of him [Barry] and coping with the fact that I needed to have my other knee done and I couldn’t have it done because he was always sick. So there was no getting my knee done...

Karen went on to explain that she doesn’t eat as well or as much as she should. She maintained that this is partly due to caring for Barry, working at the hospital, in addition to the fact that she takes pills for her arthritis pain and doesn’t feel hungry. She shared:
...I don’t think I am eating enough or eating right. I don’t think I eat enough at home and then I get to work and I have a very stressful job...We are so busy at work I don’t get to eat...

She commented on how the pain pills she takes for her arthritis affects her appetite:

...I started taking more pain pills for the knee. I have to live with it somehow and then of course the pain pills decrease your appetite and you don’t feel like eating that much.

Fatigue.

A common health problem seen in caregiving spouses of SCI survivors is fatigue (Weitzenkamp, 1997). As already cited, Karen described feeling fatigued when she first started her caregiving role. She stated, “When he first came home...it was so much more work than I expected it would be. I got so tired...”. She also maintained that prior to hiring more help she had to cut back on the amount of hours she worked at the hospital due to fatigue. She stated, “…as time progressed and I became more and more tired and I started cutting back” [refers to hours worked at the hospital].

The researcher asked Karen to reflect on the most challenging aspect of being a caregiver. She reflected while appearing to find it difficult to decide between the emotional issues or the physical challenges of caring for someone who is virtually immobile related to paralysis. She shared:

I don’t know which is worse. Probably in my case which wouldn’t be true for alot of people...the physical work is probably most draining because there are times when I hurt and I say to myself I just want to sit down…I say to Barry...I am sitting here for 20 minutes and I will be okay but I have to do this [sit down and rest].
Introduction of Participant Two

Brandi is a 36 year-old female caring for her husband, Steve, a 37 year-old male living with a SCI. Steve sustained a 4th cervical (C4) injury to his spinal cord leaving him without the use of all four extremities while on the job working as an operations engineer in January 2001. At the time these interviews were held, Brandi had been caring for her husband for nearly two years. Brandi and Steve have been married for 15 years and have two children, a son age 16 and a daughter age 11. Both children live at home. Brandi who previously worked as a patient care assistant, quit working outside the home when her husband was injured and currently provides 24-hour care for Steve in their home.

Observation of Home

Brandi and Steve’s home was a very small ranch style home in what appeared to be a poor neighborhood. Brandi and Steve’s home was in need of maintenance as evidenced by chipped exterior paint, cracked pavement, and untrimmed shrubbery. There was a wheelchair ramp in the back of the house off a deck, which led into the kitchen. The house had a detached garage.

The interior was well kept but very small. The investigator was able to view the entire home, which included two bedrooms, a kitchen, bath, and living area. The living room was full of wheelchairs and other adaptive equipment. Brandi commented that they used this room for storage, as there wasn’t another room large enough for storage. Brandi commented that the one narrow hallway connecting the living area and kitchen to the rest of the house was barely wide enough for Steve to fit through in his wheelchair.
Observation of Caregiving Task

Prior to one of the interviews, the investigator was able to observe several caregiving tasks. Brandi invited the investigator to talk with Steve while she administered his medications, repositioned him in bed, and prepared a tube feeding. As she did this, the investigator observed Brandi interact with Steve. She was very attentive. Both she and Steve spoke very politely to one another initially. Steve proceeded to make comments directed to the investigator relative to how difficult it was to live life as a paralyzed individual. Brandi reminded Steve that they had to “do what we gotta do”. Brandi appeared to have a slightly stern tone to her voice, which indicated that she was annoyed with his comments. While she was assisting Steve, Brandi was also directing the children and answering the phone.

Presentation of the Data

Brandi reported that she learned how to care for someone living with a spinal cord injury from the staff caring for Steve while he was in the hospital after his injury. Although she had previous experience working as a patient care assistant, she did not have any prior exposure to caring for individuals living with SCI. Prior to Steve’s discharge from the hospital, Brandi arranged for home care staff to help her care for Steve. She was working outside the home and her children were still young and in school. Brandi quickly became discouraged with the home care services she hired as she felt that they were unreliable. Brandi described:

The people didn’t show up. They didn’t know who was supposed to come and I was stuck doing everything...
Brandi went on to describe the fact that she tried several home care services which unleashed multiple problems. Brandi shared:

It was horrible. It was a nightmare. People didn’t show up [refers to home care staff]...different personalities, different smells and some people had hygiene problems...I did it for a month [utilized home care services] and I couldn’t take it anymore...so I just washed my hands of it...I didn’t want to deal with these people...

A month after taking Steve home, Brandi made different arrangements to quit her job and was being paid through worker’s compensation to be Steve’s full-time caregiver.

**Emotional Issues**

**Stress; inability to trust others to help.**

Brandi is Steve’s full-time caregiver. Due to Steve’s level of injury, he requires 24-hour care and cannot be left alone. Brandi describes:

...my frame of mind is he’s a baby and I would not leave a baby here unless someone was here...

Brandi described that her children are able to help with some cares. Her daughter helps with meal preparation and feeding. Her son helps with numerous other tasks including transfers, which provides some relief for Brandi on occasion. Brandi described:

...without him [refers to her son] I don’t know what I would do...my son is my reliever. He’s my reliever. He gives me my day off on Sundays...

When asked if the help that her children provide is enough to take some of the load off of her, Brandi discussed how she wanted her children to lead as much of a normal life as possible and that caregiving was her job and not theirs. She discussed the
fact that Steve relies on her specifically and that she wasn’t able to rely on the other people to care for him. She shared:

I am his security blanket and he doesn’t like me being away from him...I don’t trust people. It’s not that I can’t have people coming in, it’s my choice...I feel uncomfortable with other people caring for him...

Anger; disabled partner’s depression.

Brandi frequently made comments throughout the interviews such as “You do what you have to do”, when describing her experience. She did describe feeling frustrated over Steve’s depression as she described it. She described the fact that Steve frequently says, “…I wanna die. It’s not worth it...should I live or should I die?” Brandi shared that her response is; “What kind of a thing is that to say?” Brandi went on to share:

“It kind of wears on me sometimes. I yell at him because you know day in and day out it is like stop it! [raises her voice] you are not dying! But then I can’t really do that [yell] because he is entitled to his depression...I have to be understanding.

Brandi went on to share her perception of the most challenging aspect of being a caregiver:

Dealing with his stress....that is a challenge...He says things sometimes that just kind of go through you and just piss you off. I try to just keep my head and not get really mad at him because his circumstances are what is causing him to be the way he is sometimes.
Role Changes.

Role Reversal

Although Brandi clearly articulated that her current financial situation was comfortable because all facets of worker's compensation were in place, she reflected upon the time when her husband was first brought home. She described signs of role reversal when she recalled facing the fact that she was the sole breadwinner of the family. She had been recently been fired from her job, and had a multitude of bills to pay. She recalled:

...My income dropped because I got fired from my job because I took too much time off work because Steven was so sick...his income dropped...I still got all the bills flowing, my kids are in private school, I still got my truck note, my car note...my bills was just piling up...I just cut out everything, anything I could to cut out of my budget because I wasn’t getting much money in the house...

Role Overload.

When Brandi was asked to describe the roles she holds, she described feeling solely responsible for the success of the family unit. She described her responsibilities in relation to caring for Steve, the children, and their home:

I am the caregiver. I’m the heart of the whole thing. If I break the whole situation, system falls apart. I guess I’m the main conjunction to this machine.

Brandi spent time reflecting on the time Steve spent in the hospital and how there were multiple staff providing for all of Steve’s needs. She described that in the hospital
setting, there are people “...who care for him, provide medications, and even clean his room...”. She added, “I’m doing all these jobs. I’m doing four peoples jobs”.

**Health Problems**

**Fatigue.**

Brandi described how her life revolves around a strict 24-hour schedule. She stated how she frequently feels tired related to lack of sleep due to keeping up with Steve's requests for care. She shared:

> It is always broken [referring to sleep] because he is always on the same schedule...It’s a challenge to get up at the drop of a dime...I mean he wants me to do what I gotta do and snaps his fingers...all those demands. It can be a challenge sometimes especially if your tired, and you are like a machine. I am constantly going.

Brandi went on to describe an average nights sleep as “Normally I am up like every two hours and sometimes every three”. When asked if that was enough sleep at night she commented, “I guess. I don’t know. I try to take a vitamin everyday, you know like an energy pill”.

Brandi went on to describe how she spent each hour of an average day caring for Steve. She commented, “I am constantly running”. She described how she feels by the end of the day around 10 o’clock pm, “...I was so tired. I was so bent over. I was just deadbeat tired. My body just shut down”.

She recalled feeling thankful that her son was able to “pitch in” so that she could lay down as she knew she had another “long day” ahead of her the next day and had to do it [care for Steve] all over again.
Headaches.

Besides feeling fatigued at times, Brandi described often during the interviews that she suffers from headaches. She commented, "I get headaches. I had one last night. Oh man, that migraine was killing me". Brandi commented that she started experiencing headaches soon after his injury and "...when he came home from the hospital". She shared:

In a week...three to four days of the week I have real bad ones [headaches]. I am taking some type of headache pills. Last night I popped three.

Brandi shared the fact that her doctor told her that her headaches were a result of "stress". She shared that her headache medication only helped her some of the time. She commented that sometimes her headaches are so intense that she is forced to stop what she is doing and lie down and just "pray" that the headache subsides. She stated:

...when I can't take it anymore, when it starts hitting me so bad I just lay down. That's all I can do. Just pop a couple of pills and lay down and pray to God that it goes away. So that is what I did last night.
Introduction to the Reflective Journal

In addition to the case study interviews and observations, the participants were asked to keep a journal. A questionnaire was used to guide the journal entry. The investigator organized these data using the major categories and some of the relevant themes that guided the presentation of the data for the singular case studies.

The idea of keeping a journal was received with varying levels of enthusiasm but with a willingness to try. Karen shared her thoughts related to the journaling questions in a couple of short paragraphs. Throughout the interview process, Brandi mentioned to the investigator that she was completely willing to participate in the journaling activity but that she was not one that has ever kept a journal and was more expressive verbally, yet she was willing to try. After the third and final interview with Brandi, she stated that she had pondered the journaling questions and asked to respond to them on tape and journal “verbally” as that was the method she was more comfortable with. Therefore, the investigator gave the tape recorder to Brandi who freely spoke in response to the journaling questions. Both Brandi and Karen shared with the investigator that they felt that they had shared all that they could think of during the lengthy sets of interviews with the investigator but still had a few comments to share in response to the journaling questions.

The following is a presentation of the essential commentary shared by the participants in response to the journaling questions.
Presentation of the Data

Emotional Issues

Anxiety related to personal health deterioration.

The participants were asked to reflect on how they viewed their caregiving experience five years into the future. Karen shared:

I see myself retired...however I may be more physically compromised due to arthritis and not be able to provide all of Barry’s care...I may not be able to provide all of Barry’s care from a physical standpoint. I hope we will still be able to live independently in our home.

Stress, inability to trust others.

Brandi shared the fact that at some point in the future she may need to consider hiring caregiving assistance as she anticipates that her son will attend college out of state. She shared some reservations regarding accepting the help of others to assist her in caring for Steve. Brandi commented:

It is something we have to work out but I think what I am going to do is hire someone to come in for a couple of hours to give me a break...but I am not going to be sitting there waiting for them to show up...[pauses]...I’ll just do it myself. I’ll keep my money in my pocket and do what I need to do.
Analysis of the Data

Theoretical Framework

The investigator had originally chosen the theory of stress and coping as conceptualized by Lazarus (1984) to provide a framework for this study comparing and contrasting the theory to the participant’s lived experiences. Prior to the study, the investigator viewed the lived experience of the family caregiver of a SCI survivor as having a stressful influence on the caregiver, which the literature supports for caregivers of SCI survivors as well as for other types of chronic disabilities.

According to Lazarus (1984; 1977) stress is viewed as an individually determined varied response of a person-environment relationship encompassing physiological, psychological, and social entities. Findings from this study correlate with key concepts extracted from the literature review as well as with the same physiological, psychological, and social entities described in Lazarus’ stress theory.

The investigator found that those choosing to engage in the caregiving role have experienced months and years of challenging stimuli in everyday living. Lazarus’ theory helped the investigator understand and explain the cognitive and behavioral stressors as experienced by the participants.

Determination to manage health problems, multiple roles and emotional issues as well as the drive to remain independent in their homes all played key roles in demonstrating successful community re-entry for family members caring for loved ones with SCI.
Data Analysis

The investigator used a thematic approach to analyze and synthesize the data generated from this study. In addition to the narrative presentation of the data, a descriptive matrix was developed and integrated to "tease-out" data collected by the investigator that answered the primary and secondary research questions.

The matrix, Table 1, incorporated data analysis through a thematic approach citing brief participant narrative and journal data exemplars related to the participant's experiences in the thematic categories of emotional issues, role changes, and health problems. The data exemplars chosen are also substantiated by themes found in the literature.
TABLE 1. Factors Affecting the Family Caregiver of the SCI Survivor

<table>
<thead>
<tr>
<th>Subjects</th>
<th>Emotional Issues</th>
<th>Role Changes</th>
<th>Health Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Participant One-</td>
<td>Anxiety: “I can remember times when he first came home just thinking I can’t do this and screaming and hollering...I was afraid of doing things for fear of doing them wrong.”</td>
<td>Role Ambiguity: “I was a fish out of water as far as what I was doing...”</td>
<td>Fatigue: “...The physical work is probably most draining because there are times when I hurt and I say to myself I just want to sit down...”</td>
</tr>
<tr>
<td>“Karen’s narrative”</td>
<td>Anger: “I will say dammit all anyway...I want you to do what you can...would you please do what you can to take the load off of me!”</td>
<td>Role Overload: “…When he came home it was so much more work than I expected...”</td>
<td>Neglecting Own Health Needs: “…I needed to have my other knee done and I couldn’t have it done because he was always so sick...”</td>
</tr>
<tr>
<td>“Journal Entry”</td>
<td>Depression: “You know you really do need somebody to talk to...to tell your frustrations to and have the caregiver cry...”</td>
<td>Role Reversal: “…He wasn’t getting any disability at that point so we were living completely on my income...”</td>
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<tr>
<td></td>
<td>Anxiety: “I may not be able to provide all of Barry’s care from a physical standpoint. I hope we will still be able to live independently in our home.”</td>
<td>Role Challenge: “…There was never ever a time to sit down and never time for me...”</td>
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<td>2. Participant Two-</td>
<td>Anger: “It kind of wears on me...I yell at him because you know day in and day out it is like stop it! You are not dying! But then I can’t really do that because he is entitled to his depression...”</td>
<td>Role Overload: “I am the caregiver...if I break the whole situation, system fall apart.”</td>
<td>Fatigue: “It can be challenging sometimes especially if you are tired and you are like a machine. I am constantly going.”</td>
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<td>“Brandi’s narrative”</td>
<td>Anxiety: “…I don’t trust people...it’s my choice...I feel uncomfortable with other people caring for him...”</td>
<td>Role Reversal: “My income dropped...his income dropped...my bills was just piling up...I cut anything I could out of my budget because I wasn’t getting much money in the house...”</td>
<td>Headaches: “I get headaches...three to four days of the week I have real bad ones...”</td>
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<td>“Journal Entry”</td>
<td>Anxiety: [referring to hiring caregiving help in the future] “...I am not going to be sitting here waiting for them to show up...I’ll just do it myself...”</td>
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<td>Subjects</td>
<td>Emotional Issues</td>
<td>Role Changes</td>
<td>Health Problems</td>
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<td>3. Observation of Caregiving Task</td>
<td>Anger: Brandi was observed using a slightly stern voice (appearing annoyed) when responding to her husbands’ comment regarding how difficult it was to be paralyzed. Brandi stated, “We do what we gotta do”. Emotional issues/stressors were not obvious to the investigator upon observing Karen’s caregiving task.</td>
<td>Role Overload: Karen was observed assisting disabled partner while stopping to answer phone multiple times as well as assisting and directing mother-in-law. Brandi was observed assisting disabled partner while stopping to answer the phone and directing children with tasks (making dinner).</td>
<td>Not directly observed.</td>
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Interpretation of Findings

Emotional Issues

As stated earlier the investigator applied Lazarus’ (1984) stress theory to explain the stressors experienced by family caregivers of SCI survivors. Research supports that family caregivers of SCI survivors experience emotional stressors such as anxiety, anger, and depression. The emotional issues experienced by the participants in this study confirm the notions expressed in Lazarus’ theory (1984) in that stressors encompass psychological entities.

Anxiety

Both participants in this study experienced feelings of anxiety. The investigator found evidence of anxiety related to “worrying about the unknown” and related to “feeling others are untrustworthy”. According to the literature, evidence of anxiety may be present even after many months of caregiving if those feelings were present soon after the caregiving role began (Elliot, Kurylo, & Lindsey, 1998). Anxiety related to worrying (Karen) and anxiety related to not be able to trust people (Brandi) were feelings that were present early in their caregiving experience as was evident during the time of the interviews.

Karen exhibited feelings of anxiety related to things going wrong immediately after returning home from the hospital with Barry as evidenced by the following quote: “I can remember times when he first came home just thinking I can’t do this and screaming and hollering. That was when he first came home…I was afraid of doing things for fear I would do it wrong”.

Further evidence that those same feelings of anxiety related to things going wrong after many months of caregiving can be found in the following quote as Karen discussed plans that she and Barry had to attend a party:

...Here we are dressed and ready to go and I have to get him back into bed, get him cleaned up, and worry that he will have an accident at the party. Should we go or not? It's that kind of stuff. It's the unknown.

Brandi also experienced anxiety early in her caregiving role as evidenced by her comments related to hired caregivers who didn't show up for work, which left her responsible for her husband's cares. Brandi still expressed anxiety related to the trustworthiness of others at the time the interviews took place as evidenced by the following data exemplar:

...I don't trust people. It's not that I can't have people coming in, it's my choice...I feel uncomfortable with other people caring for him...

Although the specific stressors behind the anxiety differ between the participants, each participant evidenced signs of anxiety at the time their caregiving role began, which remained evident many months later. These findings concur with the literature of Elliot, Kurylo, and Lindsey, 1998, supporting the fact that the amount of anxiety felt does not necessarily relate to the newness of the injury of their disabled partner.

**Anger**

Feelings of anger have been reported among family caregivers of SCI survivors according to previously cited literature (Weitzenkamp et. al., 1997). The specific stressors behind the anger experienced by both participants in this study appear very similar.
Karen expressed anger relative to the lack of initiative she perceived her husband to hold in the following quote:

…I will get to the point where I will get so tired. I will say dammit all anyway...I want you to do what you can...would you please do what you can to take the load off of me!

Brandi expressed anger related to her disabled partners’ depression and frequent comments he makes about wanting to die. Evidence of this is found in the following quote:

…I yell at him because you know day in and day out it’s like stop it! You are not dying...but then I can’t really do that (yell) because he is entitled to is depression...

While Karen didn’t state that she felt Barry’s lack of initiative was specifically related to “depression” as clearly as Brandi did, the feelings of anger expressed by both participants appears related to very similar causes as one might argue that Barry’s lack of initiative may be related to feeling depressed.

**Depression**

Karen experienced feelings of depression relative to a lack of expressive support and indicated that she desired having someone to talk to in order to vent frustrations. Although Brandi did not express feelings indicative of caregiver depression, the depression experienced by Karen does correlate with the literature. Depression is often experienced by the caregiver and is related to the amount of “expressive support” the caregiver has (Weitzenkamp et. al., 1997).
Role Changes

Another significant finding of this study was related to the role changes experienced by the participants. Between the participants, the feelings of role overload, role ambiguity, and role reversal were demonstrated. Lazarus' (1984) theory on stress indicates that role overload and role ambiguity are critical factors in creating stress.

Role Overload

According to Lazarus (1984) role overload can be stressful if its requirements overextend the individuals' resources. Karen articulated that she felt overwhelmed by the care her husband required because she was faced with more than she expected. Brandi also described symptoms of role overload when she discussed the care Steve required consisted of four peoples' jobs (personal cares, housekeeping duties, etc.) when she stated, "I'm doing all these jobs. I'm doing four peoples jobs".

Role Reversal

This study captured additional role changes experienced by the participants. Early in Karen's and Brandi's experience, they evidenced signs of role reversal, which correlate with the literature review describing the female partner of a male with SCI assuming the principle breadwinning responsibilities in the family (Laing, 1996). Karen demonstrated symptoms of role reversal when she stated, "...He wasn't getting any disability at that time so we were living completely on my income..." Brandi revealed that her husband's and her own incomes dropped and she was faced with a multitude of bills to pay.
Role Ambiguity

Karen also evidenced signs of role ambiguity early in her caregiving experience. She had described feeling unclear as to what was expected of her when she initially brought Barry home from the hospital when she commented, “I was a fish out of water as far as what I was doing…” Brandi did not indicate symptoms of either role reversal or role ambiguity during the interviews.

Another distinction to be made regarding the role changes of role reversal and role overload is that both of these role changes were expressed by Karen at the initial onset of her caregiving role and were not described as a current stressor for her at the time the interviews took place. Nonetheless, all role changes experienced by the participants were expressed as significant to them and are important to recognize as components of the overall caregiving experience.

Health Problems

According to Lazarus and Monet (1977) there is a possible connection between health problems and stress. A common physiological stressor experienced among caregivers is that of fatigue (Sullivan, 2001; Weitzenkamp et. al., 1997). Both participants in this study expressed feeling fatigued. Karen described feeling fatigued throughout her experience as a caregiver. Karen summarized her feelings relative to feeling fatigued throughout her caregiving experience; from the time she brought her husband home from the hospital until the time the interviews took place. Karen summarized her feelings relative to fatigue when she described feeling that the most challenging and draining aspect of being a caregiver was the physical work.
Brandi verbalized feeling fatigued as well when she compared herself to a machine that is "constantly going". Commentary related to feeling fatigued supports the literature findings reporting significant fatigue among caregiving spouses of SCI survivors (Weitzenkamp et. al., 1997).

Headaches

Brandi reported that experiencing headaches has been a health problem that she has been experiencing since her caregiving role began. She explained, "I get headaches...three to four days of the week I have real bad ones". The literature reports that caregivers of SCI survivors experience body aches and pains although headaches was not specifically mentioned. Karen did not express experiencing headaches.

Neglecting Own Health Needs

Lazarus and Monet (1977) stress theory expresses the notion that caregivers experiencing stress may minimize the significance of their own health problems and therefore may avoid seeking medical attention in a timely fashion. Brandi reported seeking medical attention for her headaches and described taking medication to treat the headaches. Karen had described the fact that she has a lot of pain related to her arthritic condition and is in need of knee replacement surgery. She stated that she has had to put off taking care of her own health needs due to the fact that she has had to focus her attention toward her husbands' needs and illnesses. This point was clearly stated by the following quote, which supports the notion described by Lazarus and Monet's' (1977) theory.

...I needed to have my knee done and I couldn't have it done because he was always sick, so there was no getting it done.
Summary

The literature is full of articles referring to the stressors facing caregivers of SCI survivors and caregivers of other debilitating illnesses from a quantitative perspective. Data from this research study supports the stressors outlined in the literature, those being emotional issues, role changes, and health problems from a qualitative perspective.

The data from this research presented the lived experiences of two family caregivers of SCI survivors. Stressors specifically affecting the family caregiver supported the themes outlined in the literature and notions described in Lazarus' (1984) theory of stress and coping. While some stressors were shared between the participants in this study (e.g. anxiety, anger, role overload, fatigue), others differed, which indicates that the lived experiences among caregivers remain unique.
CHAPTER V
Summary, Conclusions, Recommendations

The purpose of this study was to explore the lived experiences of family caregivers of SCI survivors and determine the stressors specifically affecting the caregiver role. These stressors were identified through themes found in the literature, participant interviews, and through a journaling activity. The combination of the identified stressors was thought to impact the experience of caregiving. This chapter presents a summary of the findings, draws conclusions regarding the findings, and suggests implications for clinical practice and further research.

Summary of Findings

The study used a qualitative research methodology to explore the lived experience of family caregivers of SCI survivors. A triangulation approach to data collection included interviews, observations, and journaling. The interviews provided rich insights into the lived experience of a family member caring for a loved one living with a SCI. Observations of the home and caregiving task validated the story told by the participants in relation to how their lives have changed as a result of their caregiving role.

The journaling data provided still another means to validate the stressors experienced by the caregivers as expressed in the interviews. Each of the participants clearly articulated in response to the journaling questions that they anticipated experiencing the same stressors five years into the future.

Themes extracted from the literature were used to categorize and present the data. The investigator was able to compare and contrast the lived experiences of the caregivers to relevant literature. The in-depth narrative of the participants' experiences allows the
readers to encounter some of the stressors and challenges experienced throughout the participants' world. The matrix analysis of the data provided an additional summary presentation of the findings. Themes common to the current literature and expressed by the participants were reflected in the matrix identified as Table 1.

Lazarus' conceptual framework provided a means to further understand and validate the nature of stressors as it related to the purpose of this study. The internal rigor of this study was established through the discussion of the journaling data, which validated concerns expressed through the interviews. In addition, the observation of the caregiving tasks validated the stressors shared during the participant interviews.

The primary strategy used in this study to examine external rigor was the rich detailed description of the caregiving experience as told by the participants. The vast detailed data presentation provided a solid framework for further comparison and transferability of the findings. Rigor was further strengthened by the data examination via an objective third party with previous SCI experience.

Furthermore, the qualitative methodology in this study provides a vehicle for conducting additional research in any of the categories described (e.g. emotional issues, health problems, role changes).

Some of the findings in this study suggest that preparation for the caregiving role is a factor that may contribute to the level of stress experienced by the caregiver. Preparation appeared to influence the amount of stress exhibited related to anxiety and role changes. It is assumed that not every caregiver is as well prepared to cope with the caregiving role.
Conclusions and Recommendations

As previously stated, this study focused on the lived experiences of caregivers of SCI survivors. Lazarus’ theory of stress and coping provided the conceptual framework for this study.

Findings of this study suggest that there are multiple stressors affecting caregivers of SCI survivors, which include emotional issues, health problems, and role changes. The findings of this study support current literature regarding the phenomenon under study, however further research regarding the preparation caregivers receive is needed to examine this phenomenon and to draw conclusions concerning the relationship among stressors.

Family members faced with the challenge of caring for a loved one with SCI benefit from educational material and individual instruction. Both participants in this study indicated that they received instruction regarding the care of an individual living with SCI prior to taking their loved one home. Some of the findings in this study suggest that the amount of preparation is a factor that contributes to successful outcomes. Also, the amount of expressive support that caregivers have appears to be a factor relating to the amount of stress felt.

This research supported a need for nurses to take a holistic approach in caring for individuals undertaking the caregiving role for a family member living with SCI. The nurse is central to providing instruction and support for the caregiver as well as the individual living with SCI. Support and instruction that nurses provide may be a significant factor in preparing the caregiver for that role after discharge.
This study suggests a need for more in-depth teaching and preparation for those individuals caring for a family member living with SCI. Further studies are needed to examine the effectiveness of how healthcare providers are preparing caregivers for that role.

**Recommendations for Clinical Practice**

Healthcare providers need to recognize that a stronger emphasis needs to be placed on preparing the caregiver for what that role will entail. Emotional support and resource management should be part of that preparation. Providing caregivers with as much information as possible regarding the technical care spinal cord injuries require in addition to scenarios of what to expect while providing emotional support may assist the caregiver in developing the coping and anxiety reduction skills needed to positively transition to the caregiving role.

**Recommendations for Further Research**

In summary, attempts to replicate this study should be done with a larger sample. Further research examining the experience of male family members caring for a female loved one with SCI will assist in drawing conclusions between the lived experiences between genders. Both of the participants in this study had experience working in a healthcare environment caring for people with injury and/or disability. Thus, examining whether or not there are different stressors for caregivers without prior experience might assist healthcare providers prepare family members for the caregiving role.
The stressors identified from this study were reflective of a single point in time during the caregiving experience. A longitudinal study examining the caregivers' experience from the initial time of their loved ones injury to perhaps months or years post injury might identify different stressors. Caregivers may identify or focus on different stressors at different points during their caregiving experience. Data from such a study would be helpful to healthcare providers in identifying areas of education to focus on when initially preparing the caregiver for their new role. In addition, healthcare providers such as those facilitating support groups may have long-term caregivers participating, of whom may be focusing on other stressors.

Further research can provide information on the preparation, teaching methodologies, and coping strategies that work best in preparing the caregiver for that role in caring for someone living with a SCI.
Bibliography


Appendix A

The research participant interview questions

The first interview

1. Describe your family and your role/s within the family.
2. What is an average day like for you?
3. Describe your caregiving tasks/role.
4. How did you prepare for your role as a caregiver?
5. In reflecting back, describe your feelings in anticipation of becoming a caregiver.

The second interview

6. Describe your relationships with friends.
7. What are your hobbies?
8. Describe your relationship with (family member living with SCI).
9. Describe how this relationship may or may not be different since you began providing caregiving tasks.
10. How would you describe your health? If your health changed since you began providing caregiving tasks, in what ways?

The third interview

11. What is the most challenging aspect of being a caregiver? The most rewarding?
12. In reflecting back on your caregiving experience, describe any nursing interventions, nursing care, or others who have impacted your ability to become a caregiver.
13. What type of education, if any, would have helped you carry out your caregiver role more easily, confidently, or effectively?
14. Describe your feelings now about your caregiving experience.
Appendix B

The research questions guiding the journaling experience

The journal

1. Describe how you imagine your caregiving role five years from now.

2. Feel free to write down any other thoughts or feelings you have regarding your caregiving experience.
Appendix C

Consent to Participate Form

Kristine L. Engel is conducting a research project to study The Impact of Caregiving: Family Caregivers of Spinal Cord Injury Survivors. Participants will include two individuals providing caregiving tasks for family members living with a spinal cord injury (SCI).

The procedure for collecting information about the experience of caregiving for family members living with a spinal cord injury includes:

(a) A series of three audio-taped interviews, two of which will take place at a location determined between the participant and the investigator, and the third will take place in the participant’s home, (none of the interviews will take place in the presence of the individual living with SCI),

(b) Observation of the participant providing at least one caregiving task,

(c) A journaling experience, which provides the participant another means of communicating the impact of caregiving.

Participation is voluntary and written permission will be obtained prior to the interviews and observation. Both participants will be asked a series of questions to stimulate discussion centering around feelings and experiences associated with the caregiving experience. If either participant wishes to withdraw from the study at any time, one may do so without prejudice or penalty, and the information collected up to that point would be destroyed upon request.

There will be no risk or discomfort to the participants caused by the interviews, observations, or journaling experience. All information collected will be recorded in
confidential form and the results will not be released in any way that could identify the participants. All documents will be kept locked and secured for a period of three years after the study, at which time all audio-taped and written information will be destroyed upon the request of the participants. Should the results of this study be published, anonymity of the participants will be maintained.

If you have any questions regarding this research, please call or write:

Kristine L. Engel RN, BSN
South 76 West 19776 Prospect Drive
Muskego, Wisconsin 53150
(414) 805-2879

If you have any complaints about your participation in this study, please call or write:

Sr. Gabrielle Kowalski
Chair, Institutional Review Board, Cardinal Stritch University
6801 North Yates Road
Milwaukee, Wisconsin 53217
(414) 410-4109

I have received an explanation of the study and agree to participate. I understand that participation in this study is voluntary.

_________________________________    _______________________
Name of Participant                        Date

_________________________________    _______________________
Name of Investigator                       Date
Cardinal Stritch University Institutional Review Board has approved this research for the protection of human participants for a period of 18 months.