

Walden University ScholarWorks

Walden Dissertations and Doctoral Studies

Walden Dissertations and Doctoral Studies Collection

1-1-2011

Influence of Coping Styles on Social Support Seeking Among Cancer Patient Family Caregivers

Sandra Renee Rankin Walden University

Follow this and additional works at: https://scholarworks.waldenu.edu/dissertations

Part of the Family, Life Course, and Society Commons, Nursing Commons, and the Social Psychology Commons

This Dissertation is brought to you for free and open access by the Walden Dissertations and Doctoral Studies Collection at ScholarWorks. It has been accepted for inclusion in Walden Dissertations and Doctoral Studies by an authorized administrator of ScholarWorks. For more information, please contact ScholarWorks@waldenu.edu.

Walden University

COLLEGE OF SOCIAL AND BEHAVIORAL SCIENCES

This is to certify that the doctoral dissertation by

Sandra Rankin

has been found to be complete and satisfactory in all respects, and that any and all revisions required by the review committee have been made.

Review Committee

Dr. Leann Stadtlander, Committee Chairperson, Psychology Faculty Dr. Rachel Piferi, Committee Member, Psychology Faculty Dr. Debra Wilson, University Reviewer, Psychology Faculty

Chief Academic Officer

David Clinefelter, Ph.D.

Walden University 2011

ABSTRACT

Influence of Coping Styles on Social Support Seeking Among Cancer Patient Family Caregivers

by

Sandra Renee Rankin

M.A., St. Edwards University, 1996 B.S., Spalding University, 1990 A.A., Spalding University, 1985

Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy Psychology

> Walden University May 2011

ABSTRACT

Family caregivers of cancer patients may enter a predeath grief cycle when their loved one is diagnosed with cancer. The emotional upheaval and accompanying stress that define predeath grief may lead to health problems for the caregiver, and also interfere with their ability to provide care for their loved one. The purpose of the present research was to examine the relationship between coping styles of family caregivers and the tendency of those caregivers to seek social support during active caregiving. This study employed a quantitative approach based on the revised coping theory and the process of bereavement, which is grounded in the transactional theory of stress and coping, to examine coping styles of family members who care for cancer patients. Family caregivers of current cancer patients (n=103) were recruited through e-mails, flyers, the Walden Participant Pool, public social networking sites, and websites to complete the Ways of Coping Questionnaire. A preliminary analysis indicated a normal data distribution and confirmed homoscedasticity and linearity. Through the use of multiple regression, correlations, and t tests, relationships between 7 coping styles and the tendency to seek support were explored. Results indicated that coping styles of confrontive coping, problem solving, and positive reappraisal were positive and significant predictors of the tendency to seek social support during active caregiving. However, coping styles of distancing, self-control, escape/avoidance, and taking responsibility were not significant predictors of seeking social support. Findings from this study can influence social change by promoting appropriate support interventions that appeal to family caregivers, regardless of their coping styles, in order to effectively support the physical and mental health of the caregiver population.

Influence of Coping Styles on Social Support Seeking Among Cancer Patient Family Caregivers

by

Sandra Renee Rankin

M.A., St. Edwards University, 1996 B.S., Spalding University, 1990 A.A., Spalding University, 1985

Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy Psychology

> Walden University May 2011

UMI Number: 3454307

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI 3454307
Copyright 2011 by ProQuest LLC.
All rights reserved. This edition of the work is protected against unauthorized copying under Title 17, United States Code.



ProQuest LLC 789 East Eisenhower Parkway P.O. Box 1346 Ann Arbor, MI 48106-1346

DEDICATION

This dissertation is dedicated to my mom, Marilyn Lyons Brown, who always encouraged me to follow my own path. She died of cancer on March 21, 1981. I also dedicate this dissertation to my dad, Armon Brown, who provided ongoing support and encouragement to finish my research.

ACKNOWLEDGMENTS

First and foremost I want to thank God for not only giving me the strength and determination to finish this process, but also for putting a team of people in my life to support me through this process.

Thank you to my husband, Hugh, for his love and support. He read endless papers to make sure they made sense (especially those written in the middle of the night), brought me food when I forgot to eat because I was doing homework, and took care of various household tasks so all I had to worry about was getting to work and finishing my doctorate. He certainly went above and beyond to support me and I am grateful.

I owe a great deal of appreciation and gratitude to my dog, Teal, who passed away Christmas Day 2010. She spent many hours on the couch keeping me company while I wrote paper after paper. My other dogs, Squirt and Fancy, have tried to fill the gap by lying at my feet or bringing me toys to remind me I need to play.

Others who provided consistent support include Wes, Sherri, Cedric, Bill, Carla, Lucky, Butch, Eileen, Jim, Loretta, Esther, Natalie, Stephanie, Conrad, Susan, and Connie. I am certain they are as relieved as I am that I have finished.

Much gratitude is owed to Dr. Lee Stadtlander who took on the task of chairing my dissertation committee. I deeply appreciate the encouragement, patience, and guidance she has provided throughout this process. I would not have finished had it not been her help and support. I am also very appreciative to Dr. Rachel Piferi and Dr. Debra Wilson who, through their support and comments, were very instrumental in my producing a quality research project.

TABLE OF CONTENTS

LIST OF TABLES	V
LIST OF FIGURES	Vi
CHAPTER 1: INTRODUCTION TO THE STUDY	1
Background	1
Problem Statement	2
Research Design	2
Hypotheses	2
Purpose	5
Theoretical Basis	5
Definitions	6
Assumptions	10
Limitations	10
Scope and Delimitations	11
Significance	11
CHAPTER 2: LITERATURE REVIEW	15
Introduction	
Concepts of Bereavement and Grief	
Five Stages of Grief	
Principles of Grief	
Complicated Grief	
Anticipatory Grief	
Family Caregiver Predeath Grief Cycle	
Diagnosis and Bereavement	
Grief	
Stress and Coping	
Caregiver Health Issues	
Social Support	
Types of Caregiver Support	
Barriers to Support	
CHAPTER 3: RESEARCH METHOD	50
Participants	
Materials	
Procedures	
Data Analysis	
Ethical Concerns	
Luncai Concerns	
CHAPTER 4: RESULTS	56
Overview of Design and Procedures	61

Results	62
Preliminary Analysis	
Major Findings	
Hypotheses	
Discussion	
CHAPTER 5: SUMMARY, CONCLUSION, AND RECOMMENDATIONS	76
Interpretation of Findings	
Theoretical Perspective	
Limitations and Recommendations for Further Study	
Implications for Social Change	
Recommendations for Action	
Conclusion	
REFERENCES	94
APPENDIX A: PERMISSION TO USE WAYS OF COPING	107
APPENDIX B: DEMOGRAPHIC QUESTIONS	108
APPENDIX C: SAMPLE WAYS OF COPING QUESTIONS	111
A DREADING D. DIEGDAGED CONCENTE FOR ONLINE CLIDATEN	110
APPENDIX D: INFORMED CONSENT FOR ONLINE SURVEY	112
ADDENDLY E. EMAIL INVITATION FOR ONLINE CURVEY	112
APPENDIX E: EMAIL INVITATION FOR ONLINE SURVEY	113
APPENDIX F: FLYER FOR ONLINE SURVEY	111
ALLENDIA F. FETER FOR ONLINE SURVET	114
CURRICULUM VITAE	115

LIST OF TABLES

Table 1. Demographic Information for Participant and Loved One with Cancer 58
Table 2. Participant Relationship to Loved One for which they are Providing Care 60
Table 3. Participant Use of Copng Styles
Table 4. Means and Standard Deviations
Table 5. Independent Sample t Tests
Table 6. Correlation Coefficients between Coping Styles and Seeking Social Support 67
Table 7. Correlation Coefficients between Coping Styles and Education
Table 8. Anova Table for the Regression Model
Table 9. Summary of Regression Analysis for Predictors of Social Support Seeking 69

LIST OF FIGURES

Figure 1. Family Caregiver Predeath Grief Cycle25
Figure 2. Data Distribution
Figure 3. Scatterplot Shows Assumptions of Linearity and Homoscedasticity are Met64

CHAPTER 1: INTRODUCTION TO THE STUDY

Background

Prior to the 1900s, it was not unusual for patients to die at home with family members by their side (Kovacs & Fauri, 2003; National Family Caregivers Association, 2009). During the dying process, family members cared for the patient and physicians made home visits to administer treatment (Kovacs & Fauri, 2003; National Family Caregivers Association, 2009). By today's standards, medical care prior to the last century was archaic and the average lifespan was short; therefore, the amount of time spent caregiving between patient diagnosis and death was short. Today, providing care for an ill loved one is quite different. Advances in medical care allow people to live longer with chronic or terminal disease, thus increasing the duration of the caregiving role (Kovacs & Fauri, 2003). Although the experience of caregiving can vary from one caregiver to another, caregiving activities occupy at least 41 hours a week for primary caregivers, making caregiving the equivalent of a full-time job (Evercare, 2006).

The number of family caregivers is growing (Honea et al., 2008) which translates into an increasing number of people experiencing predeath grief triggered by the many losses that occur when a loved one is diagnosed with cancer (Tomarken et al., 2008). Discussed further in chapter 2, predeath grief and the accompanying long term stress can lead to an exacerbation of current health problems or the development of new health issues for the caregiver (Ohio State University, 2003; Talley & Crews, 2007). Increased caregiver health problems due to predeath grief impact an already costly healthcare industry (Evercare, 2006; Honea et al., 2008).

Researchers have verified that caregivers are growing in numbers (Honea et al., 2008) and caregivers experience predeath grief between the diagnosis and death of their loved one (Tomarken et al., 2008). The existing literature also addresses caregiver health issues that result from predeath grief and the associated stress (Dumont, Dumont, & Mongeau, 2008; Ohio State University, 2003; Talley & Crews, 2007) as well as the benefit of grief support groups following the death of the patient (Holtslander, 2008). However, it is not known if the coping styles of family caregivers of cancer patients influence their tendencies to seek social support for the grief and stress experienced between the diagnosis of their loved one and the end of the caregiving role. Details of the current literature which expose this gap in the literature are discussed in chapter 2.

Problem Statement

The problem is that, although family caregivers can use a variety of coping styles and processes to manage emotions brought about by the lifestyle changes that accompany a loved one's cancer diagnosis, it is not known if those coping styles influence the family caregiver's tendency to seek social support between diagnosis and death or remission of their loved one. The present study examined the influence of coping styles on support seeking tendencies of family caregivers of cancer patients.

Research Design

Hypotheses

The hypothesis states that coping styles determine a family member's tendency to seek social support as measured by a survey design using the Ways of Coping Questionnaire ([WOC]; Folkman & Lazarus, 1988). The WOC questionnaire was

administered using an online survey format. Potential participants self-selected by following an Internet link to the survey and answering two qualifying questions. If answers to both qualifying questions met inclusion criteria, the potential participant was automatically taken to the online survey. If the answer to either qualifying question did not meet inclusion criteria, the participant received a screen thanking them for their time and explaining they did not meet inclusion criteria to complete the survey. Participant responses to the WOC questionnaire were anonymous. Chapter 3 includes more detail concerning study participants, materials, and procedures.

H₀1: Attempts by the caregivers to alter their situation, as measured by the Confrontive Coping scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁1: Attempts by the caregivers to alter their situation, as measured by the Confrontive Coping scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_02 : The detachment and minimization of the situation by the caregiver, as measured by the Distancing scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁2: The detachment and minimization of the situation by the caregiver, as measured by the Distancing scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_03 : Exercising self-control over feelings and actions associated with providing care to an ill loved one, as measured by the Self-Controlling scale of the WOC, will be

positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁3: Exercising self-control over feelings and actions associated with providing care to an ill loved one, as measured by the Self-Controlling scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_04 : The belief of the caregiver that they had a part in their loved one's situation, as measured by the Accepting Responsibility scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁4: The belief of the caregiver that they had a part in their loved one's situation, as measured by the Accepting Responsibility scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_05 : Attempts to escape or avoid the problem, as measured by the Escape Avoidance scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁5: Attempts to escape or avoid the problem, as measured by the Escape Avoidance scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_06 : Problem-focused efforts to solve the problem, as measured by the Planful Problem Solving scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁6: Problem-focused efforts to solve the problem, as measured by the Planful Problem Solving scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_07 : A search for positive meaning and personal growth from the situation, as measured by the Positive Reappraisal scale, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_17 : A search for positive meaning and personal growth from the situation, as measured by the Positive Reappraisal scale, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Purpose

The purpose of this study was to examine the relationship between coping styles of family caregivers of cancer patients and the tendency of those family caregivers to seek social support between the diagnosis of their ill loved one and the end of the caregiving role. Researchers have suggested family members do not utilize supportive resources because of various barriers (McConigley, Halkett, Lobb, & Nowak, 2010; Thomas, Hudson, Oldham, Kelly, & Trauer, 2010). The underutilization of support resources may be related to the coping styles of family caregivers which were explored in this study.

Theoretical Basis

The revised coping theory and the process of bereavement (Folkman, 2001), was used to examine relationships between coping styles and tendencies to seek social support. Grounded in the original transactional theory of stress and coping (Lazarus &

Folkman, 1984), the revised theory stresses that one copes with a situation based on how one perceives a situation. Depending on how the caregiver typically perceives life situations, the predeath grief associated with caregiving may be intensified if the caregiver tends to perceive life and life events in a negative manner (Lazarus, 1999). Mentioned but minimized in the original theory, the revised coping theory and the process of bereavement (Folkman, 2001) emphasizes the importance of positive emotions in coping with long term stressful situations. Through the use of an anonymous online survey, participants answered questions about their coping styles and perceptions associated with providing care for their ill loved one. The purpose of this study was to explore coping styles of family members to postulate if those coping styles influence the use of supportive resources between diagnosis of their loved one and the end of the caregiving role.

Definitions

Terminology used to describe caregiving and grief experiences is defined differently throughout the existing literature, thus leading to reader confusion. Because of the variability in definitions the following terms are clarified for their use and purpose in this paper.

Accepting responsibility: According to Folkman and Lazarus (1988), overwhelmingly stressful situations can result in a person accepting personal blame and guilt for causing the stressful situation or problem.

Bereavement: Goodkin et al. (2001) referred to bereavement as shock that accompanies immediate loss. The shock is characterized by fear, anger, disbelief, and the realization that things are going to be different in the future (Goodkin et al., 2001).

Confrontive coping: This coping style refers to the intense active efforts to change the stressful situation (Folkman & Lazarus, 1988). The person utilizing this coping style is often angry and willing to take risks in various areas of their life (Folkman & Lazarus, 1988).

Didactic: Didactic refers to an educational session designed to instruct or provide information (Merriam-Webster Online Dictionary, 2009). References to didactics in this paper refer to sessions designed to convey psychological coping skills and information.

Distancing: Distancing is a coping style in which one cognitively minimizes the stressful situation and its' personal significance, thus enabling one to emotionally detach from the situation (Folkman & Lazarus, 1988).

Escape/Avoidance: This is a coping style in which one psychologically and behaviorally attempts to escape, avoid, or detach from a stressful situation through such methods as fantasizing, using alcohol or drugs, or even denying the situation exists (Folkman & Lazarus, 1988).

Family caregiver: Family caregivers can include family members, partners, close friends, and neighbors who provide care for someone close to them who is disabled or dying as a result of chronic illness (Jeffreys, 2005; National Family Caregivers Association, 2009).

Formal caregiver: Those considered formal caregivers are paid for their services and are healthcare professionals such as physicians, nurses, and hospice workers (Ohio State University Medical Center, 2009a).

Grief: Grief presents as physical, emotional, intellectual, or spiritual pain following some type of loss (Jeffreys, 2005). Grief immediately follows the initial shock referred to as bereavement (Goodkin et al., 2001). The intensity of grief can vary throughout any given day and can present with a variety of symptoms (Goodkin et al., 2001).

Informal caregiver: Informal caregivers are unpaid family or close friends who provide various forms of support for the patient (Honea et al., 2008; Ohio State University Medical Center, 2009a).

Palliative care: This type of care treats only the symptoms of disease as the disease has progressed to the point where a cure is no longer sought (Jeffreys, 2005). Palliative care means making the patient as comfortable as possible by managing pain and discomfort (Jeffreys, 2005).

Positive reappraisal: This is a coping style in which one creates or finds positive meaning in the stressful situation by seeking personal growth as an outcome of the situation (Folkman & Lazarus, 1988). This type of coping may have religious components.

Post death grief: This is grief experienced by caregivers after the death of the patient (Dumont et al., 2008).

Predeath grief: Predeath grief is experienced by caregivers prior to the death of the patient in response to the many losses that accompany the cancer diagnosis of a loved one (Tomarken et al., 2008). This type of grief can be exacerbated by other stressors and lead to various physical and psychological symptoms (Tomarken et al., 2008).

Problem solving: This is a coping style characterized by concentrated efforts to change the situation by viewing the situation as a problem and taking an analytical approach to solve that problem (Folkman & Lazarus, 1988)

Self-control: Efforts to control one's thoughts, feelings, and actions in the midst of stressful situation are characteristic of this coping style (Folkman & Lazarus, 1988). Caregivers utilizing self-control typically present a brave outward response to their loved one's illness to keep others, including the patient, from knowing their true feelings (Mellon, Northouse, & Weiss, 2006).

Seeking social support: This refers to a person's efforts to actively pursue informational, physical, and/or emotional support (Folkman & Lazarus, 1988).

Spousal caregiver: A spousal caregiver is the husband, wife, or significant other who assumes responsibility for all household duties, takes the patient to appointments, mediates communication between healthcare workers and the patient, and manages patient medications (Jeffreys, 2005; Ohio State University Medical Center, 2009a).

Stress: Lazarus and Folkman (1984) defined stress as the interaction of a person and their environment in which the person believes the situation exceeds their resources or threatens their well being.

Support group: Support groups consist of those with a common issue such as caring for a chronically ill loved one (Classen, 2004). Depending on the type of support group, group members can receive emotional and educational support as well as help from each other outside normal group times (Classen, 2004).

Assumptions

Grief and stress associated with caregiving may be intensified if the caregiver tends to perceive life and life events in a negative manner (Lazarus, 1999), but many caregivers do not seek support during active caregiving (McConigley et al., 2010). The current study was based on the revised theory of coping and the process of bereavement (Folkman, 2001), and assumed that various coping styles of family caregivers of cancer patients influence whether or not the caregiver seeks social support.

Limitations

There were several potential limitations for the present study. One such limitation was the use of a convenience sample (n=103). The small sample size decreased the generalizability of the findings to all family caregivers of cancer patients. Participant self-selection was also a limitation that decreased generalizability as only those who received the survey link or had time to answer the questions were included. Additionally, the present study included only family members of cancer patients aged 18 and older, not the patients' teenagers or young children. Although family caregivers were defined in this study as family members, close friends, neighbors, and partners, use of the term family caregiver could have been interpreted by potential participants as relatives only, thus creating another limitation for the study. For example, friends who may be helping care

for the patient in situations where family members must attend to other responsibilities, such as going to work or school, may not have completed the survey because they are not related to the patient.

Researchers have verified the effects of long term stress associated with providing care to a family member with cancer (Aubrecht, Arlington, & Gordon, 2006; Ohio State University, 2003; Talley & Crews, 2007). Although assumptions of the present study included the influence of coping styles on the tendency of family members of cancer patients to seek social support, it only examined a single point in time in the caregiving experience and therefore did not monitor long term changes in caregiver health, responsibilities, or coping styles.

Scope and Delimitations

Delimitations defining the bounds of the study included participants who self-selected to complete the online survey. The study was confined to familial caregivers aged 18 and older who were caring for a family member with cancer at the time they completed the survey. Participants had to be able to read, speak, and understand English so they could understand and complete the survey. The study was not specific to income level, gender, number of children in the home, ethnicity, or culture.

Significance

Researchers have addressed the effectiveness of grief support groups following the death of the patient (Adams, McClendon, & Smyth, 2008; Dumont et al., 2008; Kim, Carver, Deci, Kasser, 2008; Kissane et al., 2006; Metzger & Gray, 2008; Sanders & Corley, 2003; Wilsey & Shear, 2007). Researchers have also confirmed the existence of

caregiver grief and stress during active caregiving and recommend ongoing supportive interventions for caregivers between the diagnosis and death or remission of the patient. However, despite what is known and recommended, there are no published studies that specifically address the influence of coping styles on the tendency of family members of cancer patients to seek social support while providing care to their ill loved one. That gap in the literature was filled by the present study.

The professional application of the present study took the form of an online survey which included demographic information about the family caregiver and the cancer patient in addition to the WOC questionnaire. Services aimed at family caregivers actively providing care to cancer patients are currently lacking in the Austin area. Long before the recovery or death of the cancer patient, the family caregiver experiences trauma related to caregiving (Schumacher et al., 2008) that, if ignored, can threaten the caregiver's mental and physical health (Oliver & Brough, 2002). The health of both caregiver and patient can deteriorate if the caregiver is unhealthy and cannot provide good patient care (Evercare, 2006), thus reinforcing the need for caregiver services.

Despite a growing awareness of caregiver stress and health issues, hospitals frequently resist offering any type of predeath grief or social support group (Schneider, 2006). This resistance stems from a belief that grief support groups offered prior to the death of the patient promote death instead of successful treatment and are therefore counterproductive to hospital goals. Unfortunately, this leaves family caregivers to their own devices (Stetz & Brown, 2004) to cope with the unexpected and numerous responsibilities of caring for a chronically ill loved one. The growing awareness should

bring about social change but research is needed to reinforce the awareness. The present study will promote positive social change by increasing awareness of the family caregiving experience within the healthcare and therapeutic professions. The increased awareness can promote the development of effective and appropriate social support interventions as a way to support and maintain family caregiver health and wellness, improve family coping skills, and influence increased support services specifically tailored to the family caregiver. Caregiving has been introduced in chapter 1 through not only a brief history, but an explanation of how advances in medicine have increased the duration and intensity of caregiving for the family. Increased duration and intensity can mean increased stress and health risks associated with the diagnosis, treatment, and care of a family member with cancer (Oliver & Brough, 2002). The purpose of this quantitative survey design is to examine the relationship between coping styles and the tendency to seek social support.

Chapter 2 includes the existing literature on the most common explanations of grief including the five stages of grief, anticipatory grief, and complicated grief. The chapter continues with an explanation of the family caregiver predeath grief cycle. This cycle separates and describes bereavement and grief, discusses stress and the resulting health issues, and discusses how each aspect of the predeath grief cycle impacts the caregiver and the patient. Chapter 2 concludes with a review of research on social support, support groups, barriers to seeking support, and recommendations in the literature for ongoing interventions for family caregivers. Chapter 3 includes the methodology of the present study, including a description of the instrument to be used to

measure coping styles related to social support. This chapter also includes information on the analysis used to determine the number of participants, the population, recruiting methods, design, and ethical considerations. Results of the current study are presented in chapter 4 and chapter 5 contains the results and how the findings might be applied.

CHAPTER 2: LITERATURE REVIEW

Researchers have confirmed the existence of predeath caregiver grief and the connection of this predeath grief to feelings of loneliness, symptoms of depression, and negative thinking (Tomarken et al., 2008). The severity of other stressors in the life of the caregiver has an impact on the severity of predeath grief (Tomarken et al., 2008). Specifically, the severity of predeath grief is in proportion to the severity of a given stressor (Tomarken et al., 2008). In a study of current (n=42) and former (n=49) caregivers, it was found that predeath grief, and the negative effects of that grief, plague the caregiver long after the death of the patient and the end of the caregiving role (Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001).

This project was originated with a plan to explore whether predeath grief could be ameliorated through providing free support groups for cancer patient family caregivers. Only one person signed up for the group, despite extensive advertising. The question was then pursued as to why this was the case: why would family caregivers not take advantage of a free support group? A possible response to this question, which developed through a search of the literature, was that it may be due to how individuals cope with the stress of caregiving. This notion was explored in this study by assessing family caregivers' coping style and their use of supportive services.

This chapter includes current research on familial caregiving, focusing on family caregivers of cancer patients. Aspects of the grief experience are covered, including types and the most common definitions of grief contained in the literature. The caregiving experience is presented from the standpoint of a family caregiver predeath grief cycle

including stress and health risks associated with the act of caregiving, and the purpose of support for caregivers.

The literature review started with a thorough database search using EBSCO, Gale, Ovid, Proquest, and Sage hosts at the Walden University Library. Databases searched included but were not limited to Academic Search Complete, Academic Search Premier, CINAHL Plus with Full Text, eBrary e-book Collections, Health Sciences: A SAGE Full Text Collection, Health and Medical Complete, Journal of the American Medical Association, Nursing & Allied Health Source, MEDLINE, opposing Viewpoints Resource Center, Ovid Nursing Journals Full Text, Proquest Central, PsycARTICLES, PsycBOOKS, PsycINFO, and Psychology: A SAGE Full-Text Collection. Thoreau, the Walden Library Virtual Catalog, was consistently searched for additional articles and ebooks. Secondary sources included books specific to caregiving, the grieving process, or cancer, books that complimented journal articles by the same authors, a large scale family caregiver survey conducted by a healthcare organization, and caregiver research conducted by Ohio State University. Other secondary sources were simply leads to primary sources. Terms used in literature searches included, but were not limited to, caregivers, caregiving, cancer, support groups, stress, stress effects, immunology, grief, loss, family caregivers, chronic illness, psycho-oncology, coping, and caregiver health.

Introduction

The healthcare community has been slow to recognize that the majority of care given to terminally ill patients is provided by family members (Stetz & Brown, 2004).

Often referred to as informal caregiving because no paycheck is involved (Ohio State

University Medical Center, 2009a), family caregiving is no longer an experience reserved for the elderly (Talley & Crews, 2007). Familial caregiving has been classified as a social issue due to the increasing number of family caregivers and the reported number of hours spent providing care (Gibson & Houser, 2007). The last 3 decades have brought an increased awareness (Stetz & Brown, 2004) and understanding of familial caregiving that has revealed the existence of predeath grief, the associated stress, and caregiver health problems resulting from providing care for an ill loved one (Vitaliano, Young, & Jianping, 2004). Despite this increasing awareness, hospitals offer few services to the family caregiver prior to the death of the patient (Schneider, 2006). Consequently, the complex needs of family caregivers are often ignored by the healthcare community as well as the caregiver's own family and friends (Stetz & Brown, 2004) because the primary focus of treatment remains on the patient.

Familial caregivers include the husbands, wives, significant others, close friends, and others close to the patient who cook, clean, shop, drive the patient to appointments, pay the bills, handle business and medical issues, communicate with physicians, oversee medication schedules (Jeffreys, 2005; Ohio State University Medical Center, 2009a) and treatments, and are generally available around the clock for whatever the patient needs (Tsigaroppoulos et al., 2009). They also assist the patient with activities of daily living (ADLs) such as bathing, maneuvering toilets and bedpans, getting in and out of wheelchairs, eating, and dressing. Caregiving and the associated responsibilities are usually forced upon the family when a loved one is diagnosed with a life threatening illness (Evercare, 2006; Zivin & Christakis, 2007). Because their loved one suddenly

needs help, most caregivers believe they have no choice but to take on the caregiving role (Evercare, 2006). This abrupt change in the family brings feelings of anxiety, ambivalence (Linderholm & Friedrichsen, 2010), grief, and loss over the unexpected and numerous lifestyle changes that accompany a life threatening diagnosis (Leithborg, Kissane, & Burns, 2003). Because of new, sudden, and unfamiliar duties, the quality of life for the caregiver is adversely impacted (Talley & Crews, 2007) as what has been familiar and comfortable is replaced with threatening demands and responsibilities, thus causing the caregiver to withdraw and isolate (Lazarus & Folkman, 1984). Family caregivers (n=13) in one study reported a sense of moral duty to provide care which included hiding insecurities, anger, and fear from the patient (Linderholm & Friedrichsen 2010). The suppression of feelings, sudden changes in family duties, and new demands and responsibilities creates internal conflict and increased grief and stress for the caregiver, thus putting caregivers at high risk for illness, disease, and even death (Linderholm & Friedrichsen, 2010; Vitaliano et al., 2004; Zivin & Christakis, 2007) because of the chronic grief and associated stressors that accompany caregiving (Zivin & Christakis, 2007). However, the management of stress and predeath grief experienced during active caregiving influences how families of cancer patients move through the grieving process after the patient dies (Robinson-Whelen et al., 2001).

Concepts of Bereavement and Grief

Grief is a normal response to loss, which can be experienced by both patient and caregiver (Ohio State University Medical Center, 2009b). Although grief is explained in various terms, the emotional and physical symptoms that occur as a result of grief remain

consistent. What follows are the most common explanations of the grief process contained in the literature.

Five Stages of Grief

One of the most famous accounts of the grief experience was by Kübler-Ross (1969) who defined grief according to five distinct stages. Since the 1970s, the stages of denial, anger, bargaining, depression, and acceptance have been commonly used to describe how an individual moves through grief (Friedman & James, 2008). Ohio State University Medical Center (2009b) expanded on Kübler-Ross's five stages of grief by adding shock, physical symptoms, panic, guilt, and trouble with daily routines. Although Kübler-Ross made it clear that a person can bounce between stages versus moving through them in order, the general perception is that grief is comprised of these stages and they are the same for everyone (Friedman & James, 2008), regardless of the type of loss. The reality is that for most people who experience the loss of a loved one, the grief does not fit neatly into predefined stages. Friedman and James (2008) posited that the word "stage" implies one will simply move out of something within a predefined time period. Grief is not so compliant, which is why Friedman and James disputed the five stages of grief by pointing out that grief does not end simply by waiting for the end to come. Additionally, the five stages of grief defined by Kübler-Ross were meant to describe the stages of grief experienced by the dying as the stages were based on experiences of dying patients (James & Friedman, 2009; Kübler-Ross, 1969). The five stages of grief were not intended to describe the grief experience of the family of the

terminally ill loved one, nor were the stages meant to describe grief associated with other types of loss.

Principles of Grief

Jeffreys (2005) explained grief in terms of principles intended to grant permission to grieve to those who have experienced loss. These principles reinforce that a person can grieve in the manner in which they need to, regardless of the type of loss. Meant for caregivers, the principles are intended to normalize the grief process without misleading one to believe grief can be neatly fixed or locked away never to be heard from again (Jeffreys, 2005). According to Jeffreys, even though a person may have thoroughly grieved a specific loss, a portion of that grief will be triggered by the next loss even if that loss occurs years later. Therefore, every loss throughout a person's life brings back feelings of grief from previous losses. Jeffreys also pointed out that one loss is accompanied by multiple other losses. For example, the spouse who learns their partner has been diagnosed with cancer experiences the initial shock which quickly leads to grief over the threat of upcoming losses such as a future that could have been and a loss of freedom because life now revolves around the patient. Along with grief over threatened losses, caregivers experience grief over a loss of their own identity, a loss of what has been normal, and a loss of the ability to choose how they spend their personal time (Jeffreys, 2005). Considering the flood of emotions that can accompany loss, the caregiver can easily and quickly be overwhelmed by grief following the diagnosis of their loved one.

Complicated Grief

Complicated grief, also referred to as pathological grief (Tomarken et al., 2008), presents with unusual and unexpected behaviors (Jeffreys, 2005) such as avoidance and failing to adapt to the loss (Wagner, Knaevelsrud, & Maercker, 2006). Those who experience complicated grief seek to avoid the pain of the loss and the consequential changes or try to hold on to the loved one by remaining stuck in the grief (Jeffreys, 2005). This type of grief usually occurs after the death of a loved one but other factors can influence the onset of predeath complicated grief (Jeffreys, 2005). For example, when a spousal caregiver becomes ill complicated grief can occur prior to the death of the loved one because the illness of the caregiver is unexpected and becomes one more thing for the caregiver to handle. The predeath grief then includes not only the added guilt at not being completely present with the patient, but also anger and fear at being unable to fulfill caregiver responsibilities. A study of 248 caregivers revealed that predeath complicated grief is not specific to a particular age group or influenced by biopsychosocial factors (Tomarken et al., 2008). Instead, predeath complicated grief is predicted by the level of caregiver pessimism with higher levels of pessimism indicating a higher risk for predeath complicated grief (Tomarken et al., 2008).

Anticipatory Grief

Anticipatory grief, the expectation about what will or might happen, the time table of those events, and how to handle the events (Lazarus & Folkman, 1984; Ohio State University Medical Center, 2009b), is common among spousal caregivers. The anticipation in this case is the anticipation of the patient's death (Jeffreys, 2005). Hebert,

Dang, and Schulz (2006) conducted a longitudinal study of 222 grieving caregivers of dementia patients to explore the possibility of grief being eased by having advanced knowledge of a loved one's death. Results indicated that, although diagnosis and caregiving responsibilities started an average of 3 years before the patient died, grief was not lessened by prior knowledge and many caregivers reported being unprepared for the death. Feeling unprepared for the death of the patient also increased mental health issues in the caregiver such as an onset or increase in depression and anxiety (Hebert et al., 2006). Caregivers reported feelings of gratitude for having extra time with their loved ones versus a sudden and unexpected death, but had simultaneous and conflicting feelings of being punished, helpless, and isolated before and after the patient died (Grbich, Parker, & Maddocks, 2001). Such conflicts in feelings have been shown to present as physical symptoms such as stomach problems, disorientation, and frequent tearfulness. Interviews with 30 caregivers indicated that high levels of anxiety and traumatic helplessness were present at the beginning of the disease trajectory and continued beyond the death of the patient (Saldinger & Cain, 2004). These feelings were indicative of immediate and long-term responses to the changing needs of the patient, disruption of normal family routines, child care, and caregiver fear that the patient will have needs the caregiver is ill equipped to meet. Most caregivers in this study reported being unable to manage their feelings and emotions in a way that allowed them to face not only the death of the patient, but life without the patient (Saldinger & Cain, 2004). Despite findings indicating that prior, anticipatory knowledge of the patient's death does not ease grief following the death, these findings were contradicted by Dumont et al.

(2008). The study (n=18) by Dumont et al. identified several factors that appeared to help caregivers through the post death grieving process. These factors included anticipating the death.

Family Caregiver Predeath Grief Cycle

While there are many schools of thought on grief and how a person moves through the experience of grief to handle the loss that triggered the grief, not every breakdown of the grief process can be applied to everyone in every situation. Caregivers are thrown into a cycle of grief that begins with the diagnosis of their loved one and can end with their own diagnosis resulting from the stress of the caregiving role (Goodkin et al., 2001; Grbich et al., 2001; Kübler-Ross, 1969; Marwit & Meuser, 2005; Sanders & Corley, 2003; Zivin & Christakis, 2007). A review of the literature brings to light the caregiver experience and makes it clear that what they go through is not the typical grief experience. What follows is an explanation of the various components of the spousal caregiver predeath grief cycle (see Figure 1).

Diagnosis and Bereavement

Caregivers (*n*=20) who were followed from the diagnosis of their loved one to the loved one's death expressed feelings of shock, anger, disbelief, fear, and depression when they learned their loved one had cancer (Grbich et al., 2001). The fear, anger, and disbelief characterized the shock of immediate loss referred to as bereavement (Goodkin et al., 2001). Bereavement brings the realization that things are going to change, even though the family caregiver is not sure what the change entails. The shock of a cancer diagnosis brings its own form of denial, which spurs a search for other opinions or simply

the denial that such a horrible disease can be in the family (Kübler-Ross, 1969). The distress of bereavement quickly transitions to a state of grief in which the family member experiences a myriad of symptoms including depression, longing for what has been lost, loneliness, and stress.

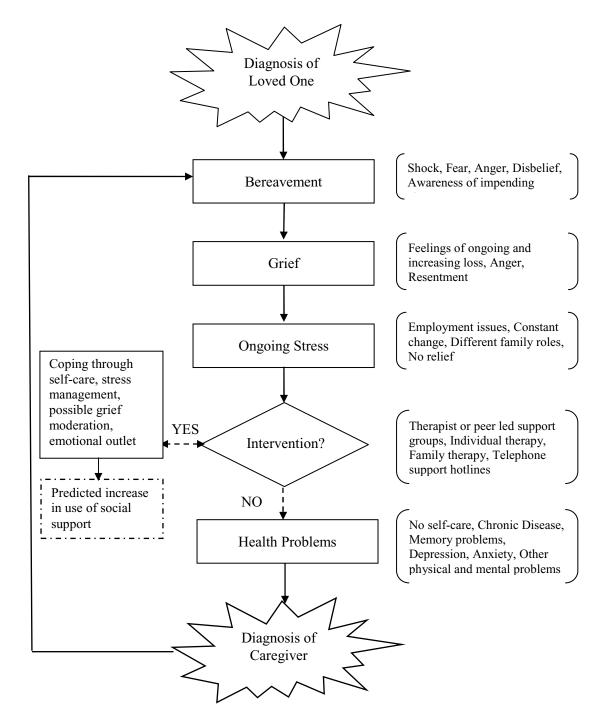


Figure 1. Graphic representation of family caregiver predeath grief cycle as brought to light though the literature.

Grief

Although the intensity and symptoms of grief may vary for each caregiver (Adams et al., 2008), grief becomes the frame of reference for every experience of the caregiver (Marwit & Meuser, 2005). Adams et al. (2008) verified results of an earlier study by Aneshensel, Botticello, and Yamamoto-Mitani (2004) in which responses of caregivers indicated that the grief experience varies based on their own emotional well-being. This means caregiver grief can be as unpredictable as the patient's disease.

Grief centered on losses resulting from the caregiving experience can present as a variety of thoughts and feelings. Saldinger and Cain (2004) found that caregivers had no doubt the patient was going to die, but often fantasized of a miraculous recovery or at least delaying the death. More than half of 253 caregivers reported grief resulting from many losses including the unknown course of the disease and a loss of intimacy (Sanders & Corley, 2003). Families may try to spare each other from the grief by not talking about the situation. Although quality communication has been frequently identified as an issue in caregiver studies (Fried, Bradley, O'Leary, & Byers, 2005; Saldinger & Cain, 2004), families tend to hide their feelings from each other, thus exacerbating the grief (Kübler-Ross, 1969). Grief was further deepened by the expectation that feelings of loss would only increase as the disease progressed (Fried et al., 2005; Saldinger & Cain, 2004).

Increased feelings of grief and loss can interfere with the caregiver's ability to move through the death of the patient. For example, recalling images of a loved one during post death mourning is common but trying to recall memories of the patient before the illness can be difficult following the isolation and engagement of the caregiving role

(Koop & Strang, 2003). Interestingly, interviews of caregivers (*n*=15) following the death of the patient revealed that caregivers totally immersed in the care of the patient are often haunted by images of the disease ravaged patient, the actual death, or even the room where the death occurred (Koop & Strang, 2003). This further exacerbates other problems in the post death grieving process such as the inability of caregivers (*n*=222) to express feelings about losing the patient or their caregiving role (Hebert, Dang et al., 2006). Regardless of casual attitudes toward caregiving, loved ones will still die while their family endures the intensity of providing constant care only to then be left alone (Schneider, 2006) to deal with reorienting not only to life, but life without their loved one.

Stress and Coping

Many aspects of caregiving make it one of the most stressful situations a person can experience because this is not usually a responsibility that is entered into by choice (Zivin & Christakis, 2007). Following the diagnosis of their loved one, the new caregiver quickly learns that the often unfamiliar and conflicting duties involved with caring for a chronically ill family member upset the normal routine of the entire family (Zivin & Christakis, 2007; Hebert & Schulz, 2006). Caregivers of dementia patients believed feelings of grief and loss resulted from a combination of changes within the family system and personal losses (Adams et al., 2008). Providing care to a family member with cancer also interferes with the routine of the caregiver, including sleep loss (Carter, 2003; Waldrop, 2007) and job responsibilities (Swanberg, 2006). Employed caregivers find they must put the needs of their loved one before their job, even though studies indicate

that work provides a break from the stress of caregiving as well as financial security (Given et al., 2004; Swanberg, 2006). Therefore, as patient symptoms intensify, caregiver stress and grief intensify, and working outside the home becomes more difficult and stressful, thus causing work productivity to suffer (National Alliance for Caregiving, 1997; Park et al., 2010). Caregivers with children and a job reported more stress than those with no children, regardless of employment status, thus indicating parental duties significantly increase caregiver stress (Kim, Baker, Spillers, & Wellisch, 2006). This results from the caregiver being in multiple roles within the family. The amount of stress experienced by the caregiver, as indicated by a review of the American Cancer Society Quality of Life Survey, was shown to be influenced by the responsibilities of the caregiver; the more roles the caregiver has, the greater the stress (Kim et al., 2006), resentment, and loneliness (Kübler-Ross, 1969).

All family members experience role changes as the loved one's symptoms and treatment change (Hebert & Schulz, 2006). Managing the stress and fear that accompany a loved one's life threatening illness and the consequential role changes may result in the caregiver detaching from the situation by viewing their loved one as an object (Gillies & Johnston, 2004). Changing how they view their loved one is a coping mechanism as caregivers often witness the intense physical and psychological pain and suffering of their loved one as indicated in a study of 76 hospice-patient family caregivers (Prigerson et al., 2003). Depending on how the caregiver views life situations, the stress associated with caregiving may be intensified as a result of caregiving responsibilities, not the patient's illness (Stetz & Brown, 2004), especially if the caregiver tends to view life and life

events in a negative manner (Lazarus, 1999). This intense stress brings about a variety of emotions, including guilt for depersonalizing the situation (Gillies & Johnston, 2004) in order to handle the rapid changes in the patient's disease trajectory.

A needs assessment completed by 159 female caregivers of late stage cancer patients revealed that the caregiver's environment and needs change as quickly as the disease of cancer (DuBenske et al., 2008). Additionally, the assessment indicated that the rapid and unexpected changes create unique grieving needs. Although predeath grief is present across the disease trajectory, the intensity can change as needs of the patient and caregiver change (Kübler-Ross, 1969; Tomarken et al., 2008). The amount of stress brought about by changes associated with caregiving is based on how one perceives and copes with change (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) defined coping as physical and psychological efforts to manage situations perceived as demanding or exceeding a person's available resources. Effectively managing demanding or overwhelming situations requires problem focused and emotion focused forms of coping.

Problem focused coping occurs when a person perceives and believes a situation is changeable (Lazarus & Folkman, 1984). Caregivers attempt to cause changes in their environment by focusing on changing the pressures, barriers, people, or processes involved in the situation (Lazarus & Folkman, 1984). They may also attempt personal changes including changes in behavior, finding new forms of gratification, changing their view of the situation, or learning new ways of managing the situation (Lazarus & Folkman, 1984). Emotion focused coping is centered on hope and optimism but usually

occurs when a person perceives that a situation is out of their control (Lazarus & Folkman, 1984). This type of coping skill centers on ways to manage the stressors that accompany the situation. Emotion focused coping is concentrated on internal responses to the situation and will often include many reappraisals of the situation in order to justify acting as though the worst case scenario does not matter or will not occur (Lazarus & Folkman, 1984). Ideally, both forms of coping should be used to effectively manage stressors (Lazarus & Folkman, 1984) but in the harried and frightening world of the caregiver, many things are not ideal.

Caregiver Health Issues

Caring for a chronically ill family member creates a significant amount of stress that cannot be quickly resolved, thus opening the door for serious mental and physical illnesses in the caregiver (Aubrecht et al., 2006; Ohio State University, 2003; Talley & Crews, 2007). According to Zivin and Christakis (2007), physical and psychiatric problems often develop or increase as a direct result of caregiving. This is because caregivers are hesitant to take time for self care because of guilt and fear of taking time away from the patient (Jeffreys, 2005). Spousal caregivers in a small focus group (n=6) reported that the sudden onset of the caregiving role and accompanying stress was overwhelming and left them unprepared for the physical and psychological changes that occurred as a result of their caregiving duties (Hudson, Aranda, & McMurray, 2002).

Although most worry about their own health (Tsigaroppoulos et al., 2009), many caregivers forgo their own medical appointments to care for their loved one (Ohio State University Medical Center, 2007) as indicated in the Caregivers in Decline study by

Evercare (2006). Researchers reported that 71% of the 528 participants did not go to the doctor or dentist for new conditions and 55% missed appointments for existing conditions (Evercare, 2006). Additionally, the majority of participants reported eating and exercise habits had deteriorated due to the time involved in caregiving. Part of the problem is that caregivers are notorious for underestimating their need for self care because they are so engrossed in the needs of their loved one (Evercare, 2006). As a result, the negativity silently builds up over the course of active caregiving (Jeffreys, 2005) leading to symptoms indicative of burnout (Evercare, 2008). Such symptoms can include irritability, apathy, changes in eating habits (Evercare, 2006; Ohio State University Medical Center, 2007), increased drug and alcohol use (Evercare, 2006), and emotional and physical exhaustion (Chambers, Ryan, & Connor, 2001). A different study had similar findings in that caregivers (n=49) revealed an increase in prescription drugs, over-the-counter drugs, various medication side effects, and the use of alcohol (Aubrecht et al., 2006). Some caregivers also reported taking the patients' medications to sooth self-diagnosed symptoms they believed were similar to those of the patient. Various stomach problems as well as increased symptoms of arthritis following the diagnosis of the patient were also reported.

Cannon, one of the first to study how the body responds to stress (Jacobs, 2001), developed the theory of homeostasis, which he described as being a point of perfect equilibrium in the body (Vedhara & Irwin, 2006). When this equilibrium is disrupted, such as in periods of high stress, the body reacts with a fight or flight response and inhibits various bodily functions to efficiently defuse the stress and return the body to a

state of balance (Lusk & Lash, 2005). Another pioneer in the study of stress was Seyle who recognized that the physiological systems meant to protect the body during stress can also be damaging (Lusk & Lash, 2005). Seyle defined the stress response as a simultaneous activation of the sympathetic-adrenal-medullary axis and the hypothalamic-pituitary-adrenal axis (Vedhara & Irwin, 2006) which throws the body, and consequently the immune system, off balance (Reiche, Morimoto, & Nunes, 2005). Seyle believed the body goes through three phases (Jacobs, 2001) when attempting to manage stress and balance the body. These phases, referred to as the general adaptation syndrome (Lazarus & Folkman, 1984; Vedhara & Irwin, 2006), include an alarm phase where the body is preparing for fight or flight, followed by a resistance phase where the body is still fighting against the stressor but the fight or flight response has stopped. The last phase, exhaustion, often results in illness because the body is no longer trying to adapt to the stressor. Caregivers often find themselves in the caregiving role for several months or years during which time the stress is overwhelming their body's resources.

The fight or flight response is the body's typical method of self protection (Lusk & Lash, 2005). This protective response causes the body to become sympathetically dominant, in that the sympathetic nervous system takes control and prepares the body for danger (Jacobs, 2001). Ensuring that the body has energy and stamina to fight or run, the sympathetic nervous system sends blood to the heart, lungs, and major muscle groups (Jacobs, 2001) and floods the bloodstream with stress hormones (Lusk & Lash, 2005). The body is an efficient machine that can manage large amounts of stress, but the body cannot remain in fight or flight mode long term without sacrificing health (Caine, 2003;

Selye, 1976) as even efficient machines break down. Short term stressors such as layoffs and marital or financial problems can be traumatic and as such can compromise the immune response until the situation is resolved (Kang et al., 1991). Once the situation is resolved, the parasympathetic nervous system regains control and rebalances the body (Jacobs, 2001; Selye, 1976). Long term stressors can include personal chronic disease, providing care for a loved one with terminal or chronic disease (Ader, 2001; Caine, 2003; Kiecolt-Glaser et al., 2003), the death of a spouse (Ader, 2001), or other stressors that usually have no foreseeable resolution. The chronic nature of long term stressors overwhelms the body and the fight or flight response transitions to defeat, depression, and anxiety (Bjorntorp, 1996; Ohio State University, 2003). Consequently, the immune response is compromised (Bjorntorp, 1996; Kiecolt-Glaser et al. 2003; Ohio State University, 2003) resulting in autoimmune diseases, memory problems, compromised responses to medication, and brain atrophy (Lekander, 2002). Relaxation can return the body to a state of balance (Seaward, 2007), but caregivers rarely have time to relax because of the often overwhelming responsibilities of the caregiving role. The caregiver's health is therefore pushed to, or beyond, its' limits.

A six year longitudinal study of 117 caregivers and 106 non-caregivers found that spousal caregivers had higher levels of proinflammatory cytokine IL-6 compared to non-caregivers (Kiecolt-Glaser et al., 2003). This particular cytokine has been linked to heart problems (Kiecolt-Glaser et al., 2003; Waldrop, 2007), arthritis, cancer (Kiecolt-Glaser et al., 2003), chronic fatigue, and hypertension (Waldrop, 2007). Study results implied that caregiving is a health threat because of the long term stress present in providing care for a

chronically ill loved one (Kiecolt-Glaser et al., 2003). At a minimum, caregivers experience fatigue, physical strain (Waldrop, 2007), and decreased emotional energy (Kovacs & Fauri, 2003) as a result of providing 24 hour care (Waldrop, 2007).

The cognitive functioning of caregivers is an area with little research, but Mackenzie, Smith, Hasher, Leach, and Behl (2007) pointed out that family caregivers often have impaired cognitive abilities as a result of providing care to a terminally ill loved one. A battery of neuropsychological tests completed by a group of family caregivers (*n*=22) indicated this group had trouble learning and recalling new information, focusing their attention, and changing their attention between tasks (Mackenzie et al., 2007). Although the caregivers were able to quickly complete tasks, they made multiple errors (Mackenzie et al., 2007). Mackenzie et al. point out that the impaired memory and attention functioning could be problematic for the patient as caregivers manage and administer medications and provide updated patient information to healthcare professionals. This means medications may be administered incorrectly and symptom information relayed to physicians and healthcare workers may be unreliable.

Psychological implications of caregiving can be just as problematic. Although anxiety and depression are common in caregivers as well as their patients (Tsigaroppoulos et al., 2009), the mental status of the caregiver has an impact on the quality of care provided to the patient (Shaffer, Dooley, & Williamson, 2007). Interestingly, interviews with family caregivers (*n*=1662) widowed within the previous 12 months revealed that when patients were receiving care in a hospital, social and religious needs of the caregivers were largely ignored compared to caregivers of patients

receiving hospice care (Park et al., 2010). These unmet needs resulted in caregivers providing a lower quality of care to the patient (Park et al., 2010). Telephone interviews with caregivers over a one year time frame suggested that caregivers are at risk for clinical depression, with spousal caregivers of patients in late stages of their disease being more depressed than spousal caregivers of patients in earlier stages of their disease (Given et al., 2004). These results remained consistent even when compared to non-spousal caregivers of patients at all stages of disease. Additionally, Miaskowski, Kragness, Dibble, and Wallhagen (1997) found that caregivers of cancer patients with no pain (n=42) had slightly less depression and anxiety compared to caregivers of cancer patients with pain (n=86). Interestingly, the cancer patients being cared for in this study were not terminally ill yet mood states of caregivers were still negatively influenced.

A study by Soothill et al. (2001) found that caregivers and patients share the disease experience, with each influencing the well being of the other. Therefore, as patient symptoms intensify, caregiver anxiety, resentment, and depression also intensify, thus increasing the likelihood of the patient being harmed by the caregiver (Bradley et al., 2009; Given et al., 2004; Waldrop, 2007; Williamson & Shaffer, 2001). Resentment, anxiety and depression have been found to predict harmful or poor patient care (Carter, 2003; Park et al., 2010; Shaffer et al., 2007; Stetz & Brown, 2004; Williamson & Shaffer, 2001). Caregivers who do not guard their own health can easily experience burnout which results in inadequate patient care (Evercare, 2006). According to the Caregivers in Decline study by Evercare (2006), more than half of the 528 participants reported that as their own health declined, their ability to care for their loved one also declined.

Surprisingly, researchers found that caregivers who focused only on the positive aspects of their caregiving role had a more difficult time adjusting to life after the death of the patient (Boerner, Schulz, & Horowitz, 2004). After the patient dies the caregiver not only looses their partner, but also their sense of purpose as they are no longer a caregiver (Boerner et al., 2004). The role of caregiving could require so much mental focus and energy that, once the situation ends, it could take time to sort through the experience, assess what happened, realize the significance of what happened, and decide what to do next (Lazarus & Folkman, 1984).

Social Support

Caregivers who reported unmet social needs during the caregiving experience also reported limited support from family and friends (Evercare, 2006; Soothill et al., 2001; Waldrop, 2007) and feelings of abandonment (Chambers et al., 2001). However, the limited or nonexistent support is often the result of the caregiver not wanting to seem shallow or bore others by talking about the illness as implied in a study of 30 caregivers and their cancer patients (Waldrop, 2007). During the study, some caregivers reported feeling as though they monopolized conversations with friends and family by talking only about the illness and related caregiving responsibilities. These feelings, in addition to the patient's need for constant care and supervision, resulted in the caregiver isolating at home (Chambers et al., 2001), with the isolation increasing with the decline of the health of the patient. A study of 219 cancer patients and their caregiving spouses found that caregivers give up more of their own time and resources when the patient's health declines (Manne, Alfieri, Taylor, & Dougherty, 1999). Consequently, caregivers in the

study by Manne et al. (1999) reported feeling confined and isolated from the support of others, resulting in irritability and resentment toward the patient, the disease, and the patient's ability to cope with the disease. Research by Stetz and Brown (2004) confirmed that as the patient requires more care, the activities of caregiving increasingly interfere with caregivers being able to seek social interaction and support. The isolation and lack of support often leads the caregiver to feel as though no one understands what they are going through (Waldrop, 2007). This social isolation results in negative thoughts and feelings being suppressed and possibly never being appropriately acknowledged and worked through. Soothill et al. (2001), in a study of 32 caregivers, reinforced the idea that caregivers may have greater psychosocial needs than the patient.

According to Lazarus and Folkman (1984), social relationships are needed for a person to survive and thrive. People adapt to situations easier if they believe social support is available to them when and if it is needed, meaning one must actively participate in developing and using social networks (Lazarus & Folkman, 1984). Social support networks are especially useful for helping caregivers cope with the ever changing responsibilities, stress levels, and isolation (Lazarus & Folkman, 1984). However, building such a network can be difficult as reported by former family caregivers of cancer patients (*n*=635) in a study by Spillers, Wellisch, Kim, Matthews, and Baker (2008). Study participants reported that the more guilt they felt during their caregiving experience, the more difficult it was for them to leave the house or reach out to others to build a social support network, thus increasing feelings of being alone (Spillers et al., 2008). The importance of social support in alleviating feelings of being alone was

reinforced in a study by Chambers et al. (2001) in which participants (n=14) in a focus group reported feeling relief at being able to discuss their situation with other caregivers as sharing experiences helped them realize they were not alone. Kübler-Ross (1969) noted that without the chance to express thoughts and feelings noncaregivers may view as socially unacceptable, the myriad of emotions and feelings that make up caregiver grief do not resolve, but trigger physical and emotional illness for the caregiver. Caregivers (n=14) of newly diagnosed colorectal cancer patients reported difficulty maintaining a positive attitude (Houldin, 2007). The caregivers found themselves needing to step back from the situation in order to get emotions under control for the benefit of the patient (Houldin, 2007). As indicated by study participants (n=528), support groups can provide a welcome opportunity to step back from the situation (Evercare, 2006). More than half of bereaved family caregivers (n=45) interviewed by Hudson (2006) placed importance on various types of support in getting through the caregiving experience. However, support groups for spousal caregivers may provide more than an outlet for emotional expression. Using blood samples from participants (n=20) who attended a five session support group, Hosaka and Sugiyama (2003) found an increase in immune function when the five sessions were completed. In contrast, spousal caregivers who reported little or no support had a decline in immune function as long as one year after the death of the patient (Kiecolt-Glaser, McGuire, Robles, & Glaser, 2002).

Types of Caregiver Support

Research has shown that support groups help caregivers manage various aspects of the caregiving experience both during active caregiving (Holtslander, 2008; Honea et

al., 2008) and after caregiving ends (Schneider, 2006) but support groups have expanded beyond the therapy room or community center. Researchers have explored various group formats including online, weekend retreats, telephone, family focused, and traditional support groups with interesting results. Female caregivers (n=38) who participated in an online support group posted a total of 330 messages revolving around hope, constantly changing emotions, and concerns about physiological and psychological issues (Klemm & Wheeler, 2005). Throughout the many messages, participants shared detailed experiences of guilt, decreases in physical strength, exhaustion, and anger at the disease and the effect it was having on their loved one. Wagner et al. (2006) suggested those experiencing post death grief also benefit from online support groups. Wagner et al. examined online support and post death grief by assigning participants with post death grief to treatment or control groups. While the treatment group (n=26) reported fewer grief related symptoms of depression and anxiety at the end of the 5-week study, the control group reported no change (Wagner et al., 2006). Online support groups consist of two types of group members. The first type consists of those who actively post within the group forum (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). The second type is made up of those who are logged on and reading posts but not actively participating in posting (van Uden-Kraan et al., 2008). Comparing the impact of online support groups on those who posted (n=419) and those who did not post (n=109), researchers found that those who did not post were not as satisfied with the actual information exchange as those who posted (van Uden-Kraan et al., 2008). Additionally, those who posted felt supported and part of a community whereas those who did not post

felt alone (van Uden-Kraan et al., 2008). However, both types of group members gained a sense of empowerment in managing their particular situations (van Uden-Kraan et al., 2008).

A unique approach to addressing the mind, body, and spirit of family members of cancer patients involved a weekend retreat. This holistic approach created an environment for participants (n=8) to comfortably express feelings and thoughts associated with the illness of their family member (Arnaert, Gabos, Ballenas, & Rutledge, 2010). The weekend was designed to provide relief from caregiving duties and teach participants coping and self-care skills (Arnaert et al., 2010). Results of this qualitative study indicated the weekend retreat created a feeling of camaraderie among participants that lasted well beyond the weekend, thus reinforcing the importance of support programs for family members of cancer patients.

Telephone trees and conference calls are another way for caregivers to stay connected with each other and get support when they need it most. However, in recent years therapy has been offered over the telephone in order to accommodate those who cannot easily leave the house. Donnelly et al. (2000) studied the impact of telephone therapy with the help of 14 cancer patients and 10 partners. Patients participated in an average of 16 sessions and partners participated in an average of 11 sessions, discussing such topics as stressors associated with treatments, conflicts resulting from role changes since diagnosis, and grief experienced by both patient and partner (Donnelly et al., 2000). Although participants were generally satisfied with telephone therapy it was apparent that family members and patients needed support (Donnelly et al., 2000). Interestingly,

despite the need and desire for support, participants often need encouragement to actively participate in group discussions (Donnelly et al., 2000). Regardless of support group participation, caregivers have voiced appreciation for access to 24-hour telephone support for times when their situation is unbearable and the support group is unavailable (Steiner, 2006). Additionally, telephone support can be ideal for those who cannot participate in other forms of support as it respects the independence of the caregiver and easily adjusts to the changing caregiving responsibilities (Radziewicz et al., 2009).

Another unique approach to caregiver support involves educational materials provided by nurses during palliative care home visits (Hudson et al., 2005). This unconventional intervention was part of a controlled trial with family caregivers (*n*=106) caring for terminal cancer patients at home; 52 caregivers received regular palliative care and 54 caregivers received palliative care services as well as a workbook and audiotape containing self-care information and exercises (Hudson et al., 2005). Although differences in anxiety, feeling prepared to provide care, and self-efficacy were nonexistent, caregivers who received the intervention reported a more positive view of their caregiving experience during follow up after the death of the patient (Hudson et al., 2005).

Family focused grief therapy groups include the patient, spouse, and children. Benefits of this type of group, as pointed out by Kissane, Lichtenthal, and Zaider (2007), include improving communication between family members as well as adaptation to the disease trajectory and subsequent family changes. Specifically, the family decides the focus of therapy while the therapist identifies family strengths; the number of sessions

can vary based on family requests. The study by Kissane et al. included 176 individuals from 81 families and found that family focused groups offered from diagnosis through the death of the patient may prevent depression and anxiety in family caregivers.

However, there was little impact on overall family functioning and grief (Kissane et al., 2007).

Holtslander (2008) suggested that traditional grief support groups are beneficial following the death of the patient. However, Wilsey and Shear (2007) studied grieving caregivers (n=22) and found that, although the help and support of others was appreciated after the patient's death, it did nothing to soothe the caregiver's overwhelming grief, anger, and bitterness. The researchers also suggested that the caregiver's grief, anger, and bitterness are exacerbated when family and friends are perceived as intrusive and uncaring, or their efforts to help are simply unwanted. This is because, despite best intentions, attempts to help and comfort sometimes do more harm than good. James and Friedman (2009) concurred, explaining that relatives and friends tend to intellectualize the grief instead of validating the caregiver's emotional response to the death, thus increasing caregiver grief and feelings of not being heard or understood. Other studies have confirmed these results and, contrary to Holtslander, suggested that grief support groups do nothing to soothe caregiver post death grief (Stroebe, Zech, Stroebe, & Abakoumkin, 2005). Surprisingly, less than half of caregivers (n=161) studied, accessed grief support services following the death of the patient because they did not believe the services would be beneficial (Cherlin et al., 2007). However, more spousal caregivers sought support services compared to non-spousal caregivers (Cherlin et al., 2007).

Overall, the literature implies that support groups are needed and useful but there seems to be confusion in tailoring support groups to meet the ongoing needs of any one particular group of caregivers. For example, Hosaka and Sugiyama (2003) developed a support group for caregivers by modifying an existing cancer patient support group. The problem was that all participants (n=20) in the new support group were females who were not caring for a cancer patient (Hosaka & Sugiyama, 2003). Structured educational groups may be aimed at caregivers but focus solely on the patient's disease, physical and psychological symptoms indicating death is close, and the overall disease process (Jones, 2006). Although many support groups include didactics on stress and coping skills (Honea et al., 2008; Langer, Rudd, & Syrjala, 2007) adequate time must also be allowed for discussion so group members can not only process the information learned, but thoughts and feelings associated with their situation. Unfortunately, although group discussion is one of the most beneficial aspects of a support group, many support groups focus the majority of group time on education, allowing minimal or no time for discussion (Honea et al., 2008; Langer et al., 2007).

There are studies that identify specific characteristics of effective support groups, including caregivers becoming aware that they are not alone and providing caregivers with access to new medical information (Butow et al., 2007). Unfortunately, most studies on support group development focus only on the needs of the patient, not the family members who care for them, even when the groups are conjoint with patients and their families. For example, support groups for caregivers of dementia patients tend to focus on disease education, community resources, and ways to manage the behavior of the

patient across the disease trajectory (Adams et al., 2008). One study investigated psychoeducational groups designed for family caregivers (Hudson et al., 2008). Participants (*n*=44) were divided into 16 educational groups with each group meeting for three sessions and covering topics centering on patient care. At the end of the study, caregivers reported feeling more prepared and competent to care for their loved one but, because their own needs were not addressed, they felt just as unsupported, pessimistic, and over burdened at the end of the study as they did when the study began (Hudson et al., 2008). Additionally, in a review of 19 interventions designed to support caregivers, Caress, Chalmers, and Luker (2009) found the majority of the interventions neglected caregiver emotions and fears, focusing instead on symptom management and learning how to care for the patient.

Studies have indicated that family caregivers consistently report a desire to hold groups in a more relaxed setting instead of a clinical setting and to have their own group focusing on their needs instead of the needs of the patient (Butow et al., 2007). The Caregivers in Decline study (Evercare, 2006) indicated that at least half the participants (n=528) wanted to learn how to identify and delegate caregiving tasks to other family members and friends. The study by Evercare (2006) also identified that the majority of participants wanted to learn stress management, how to handle their own personal health, and would like the ability to call nurses with questions as needed. Additionally, participants in a study of hope among caregivers verbalized hope resulting from being around and talking with others going through the same experience (Holtslander, Duggleby, Williams, & Wright, 2005). This was confirmed in a study of 30 caregivers

where Waldrop (2007) found that after the death of the patient, participants who felt support and acceptance from others were able to move through the predeath grief easier than those without a positive support system. This was regardless of the decrease in anxiety and hostility and increase of loneliness, sadness, tearfulness, and overwhelming reminders of the person and the caregiving experience (Waldrop, 2007).

Barriers to Support

Surveys and interviews with family caregivers of cancer patients have consistently supported the need for social support (Evercare, 2006; Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004). This need was also supported by a study of caregivers (*n*=19) who reported that certain topics cannot be discussed with the patient, family, or friends, but can be shared and discussed with other caregivers (Milberg, Rydstrand, Helander, & Friedrichsen, 2005). However, in contrast, a study by McConigley et al. (2010) revealed that caregivers (*n*=21) turned only to family and friends for support instead of seeking formal social support. The conflicting findings suggest that tendencies to seek social support are influenced by more than having an ill loved one.

Thomas et al. (2010) conducted an audit of 87 files and held four focus groups (n=22) to explore possible barriers that prevent caregivers from getting support during active caregiving. Results indicated poor timing of resources, availability of resources, and geographic issues prevented caregivers from getting the help they need. For example, grief support groups were perceived as being offered too late in the caregiving experience because they are not available during active caregiving or are offered for only a few months after the death of the patient (Thomas et al., 2010). Geographic issues were

related to a shortage of resources at hospitals close to the patient's home, which caused the caregiver to spend more time traveling to distant hospitals to visit or transport their loved one (Thomas et al., 2010). Also noteworthy is the finding that many caregivers reported receiving no support services when in fact they had received services from various agencies (Chen, Hedrick, & Young, 2010). This was thought to be because services received were not what the caregiver needed or wanted, thus making the receipt of these services unmemorable.

Many of the services and programs offered to caregivers, including support groups and counseling, do not address the ever changing nature of caregiving (Montgomery & Kosloski, 2009), making it conceivable that caregivers decline much needed services (Kosloski, Montgomery, & Youngbauer, 2001) because services offered are not what they need at a given time. Services must be provided according to what caregivers need, not what service providers want to offer because as duties change, the caregiver may have trouble reconciling who they are as a caregiver within their original role in the relationship with the patient (Montgomery & Kosloski, 2009). For example, a husband may have difficulty maintaining the role of husband when his caregiving role requires him to assist in activities of daily living that may conflict with how he previously viewed himself as a husband. The new role requires the establishment of new behavioral norms, or ways to act, in the caregiver patient role. Following the end of the caregiving role, regardless of how the role ends, identities must again be reconciled. Therefore, services for caregivers need to address the different experiences of caregivers, changes in the caregiving role, and caregiver identity over the course of the disease trajectory.

Consistent with earlier findings by Sharpe, Butow, Smith, McConnell, and Clarke (2005), Thomas, Hudson, Oldham, Kelly, and Trauer (2010) found that caregivers are often the source of their own difficulty in obtaining support. Participants reported creating some of their own barriers by not discussing their concerns or the patient's condition with the patient (Thomas et al., 2010; Tsigaroppoulos et al., 2009). Sharpe et al. (2005) found that caregivers who do not discuss their needs with the patient have less support from other family members. However, caregivers often hide their emotions from the patient because they want the patient to remain hopeful (Mellon et al., 2006).

Patients can also interfere with caregivers seeking help by refusing to allow strangers, such as healthcare workers, into the home (Thomas et al., 2010). However, service providers in Singapore (n=36) reported that finding a competent person to care for their ill loved one is more of an issue than the patient not allowing strangers in the home (Ng, 2009). Additionally, as the disease progresses caregivers are less likely to leave their loved one in the care of someone else (Ng, 2009). A barrier is also created when the patient does not receive or use social support as they do not understand the benefits of such support (Sherman et al., 2008). Consequently, the caregiver receives little or no encouragement from the patient to utilize social support. Compounding the problem of not seeking support is the perception of the family caregiver concerning their caregiving role. Family members who provide care to an ill loved one do not always identify with being a caregiver and will reject support that is offered to them because they, the caregiver, are not the patient (Seale, 2000).

Caregivers are exhausted and therefore do not have the time or energy to search for or use support (Toseland, McCallion, Gerber, & Banks, 2002). A study of dementia caregivers (*n*=164) indicated that only caregivers who do not feel heavily burdened by the tasks of caregiving will attend support groups (Toseland et al., 2002). For the exhausted caregiver, services that do not require leaving home may be most beneficial. However, according to Ng (2009), despite requesting support services such as telephone support, very few caregivers take advantage of this support when it is offered.

Researchers suggest that an increase in caregiver support groups and improved access to palliative care would increase the likelihood of caregivers seeking formal social support. However, based on the research suggesting patients and caregivers are responsible for creating many of their own barriers to support, these suggestions may be overly simplistic without first examining the influence of coping styles on support seeking behaviors. Studies that confirm the physical and psychological need for caregivers of cancer patients to have social support while in the caregiving role as well as the effectiveness of grief support groups after the death of the patient have consistently recommended on-going interventions for caregivers between the diagnosis and death of the patient (Adams et al., 2008; Aubrecht et al., 2006; Dumont et al., 2008; Kim et al., 2008; Kissane et al., 2006; Metzger & Gray, 2008; Sanders & Corley, 2003; Wilsey & Shear, 2007). However, there is a gap in the literature in that there are currently no published studies that address the influence of family caregiver coping styles on tendencies to seek social support while actively providing care to a loved one with

cancer. Using the quantitative research method described in chapter 3, the present study filled the identified gap in the literature.

CHAPTER 3: RESEARCH METHOD

Currently, it is unknown if the coping styles of family caregivers of cancer patients influence the family's tendency to seek social support while providing care for their ill loved one. The present study explores the relationship between coping styles of family caregivers and the use of social support between diagnosis of their loved one and the end of the caregiving role. This chapter contains information on the study participants, recruiting methods, inclusion criteria, rationale for the sample size of 103 participants, and rationale for using a quantitative approach versus other research methods. Methods of data collection for this quantitative study are explained, as well as the role of the researcher in data collection. Potential ethical concerns and strategies to protect the confidentiality of participants are also explained.

Participants

The research population was comprised of family caregivers of cancer patients.

The sample was one of convenience and was recruited through e-mail invitations

(Appendix E), public social networking sites, the Walden University Participant Pool,
and flyers (Appendix F) placed at local cancer treatment centers, hospitals, and
businesses with community bulletin boards in the Austin area. Potential participants were
screened according to their responses to the first two questions in the online survey to
ensure they met inclusion criteria.

Caregivers included in the study were volunteers who were at least 18 years old and currently providing care to a family member who is fighting cancer. Socioeconomic levels, gender, the number of children in the home, ethnicities, and cultures could vary.

Because participation was voluntary, no compensation was given to study participants.

The identity of participants was unknown as no e-mail or IP addresses were stored.

Therefore, responses to the online survey were completely anonymous.

A power analysis was conducted using GPower version 3 (Erdfelder, Faul, & Buchner, 1996) to determine the appropriate sample size. A sample size of 103 was determined to be appropriate based on an alpha of .05, statistical power of .80, and .15 as the anticipated effect size. The anticipated effect size was based on Cohen's d (Cohen, 1992).

A quantitative approach to the present study was most appropriate for examining the influence of coping styles on the tendency to seek social support. This approach allowed the use of an online survey to examine coping styles in an anonymous and nonthreatening manner. For example, caregivers tend to believe no one understands what they are going through (Waldrop, 2007) and, because they are caring for a loved one, they often have guilt associated with any feelings they consider negative (Gillies & Johnson, 2004). The perceived lack of understanding and potential fear of being judged could alter how thoughts and feelings are conveyed through a qualitative or mixed methods approach. Additionally, it was not appropriate to use a mixed methods or qualitative approach for the current study because the variables had already been identified in past research, an existing theory appropriate to the population being studied existed, and the nature of the study was not intended to search for themes within the caregiver population.

Materials

Demographic information (Appendix B) about the caregiver and patient was collected from participants for the purpose of identifying trends but was not included in the analysis. With permission from the developer (see Appendix A), the coping process, specifically the thoughts and actions associated with providing care to a loved one with cancer, was examined using the WOC (Folkman & Lazarus, 1988). The WOC (Appendix C), developed by Folkman and Lazarus (1988), consists of 66 items and is based on the transactional theory of stress and coping which was also developed by Lazarus and Folkman (1984) and is the theoretical basis of this study. Originally, the WOC was a 67item checklist based on early work by Lazarus (Lazarus, 1966; Lazarus & Launier, 1978) but was later revised to the 66-item, four point Likert scale (Folkman & Lazarus, 1988) used in this study. The WOC has been validated with many different populations including those relevant to this study such as caregivers of patients with dementia (Papastavrou, Tsangari, Kalokerinou, Papacostas, & Sourtzi, 2009), formal caregivers in palliative care settings (Timmermann, Naziri, & Etienne, 2009), cancer survivors (Karademas, Argyropoulou, & Karvelis, 2007), and husbands of cancer patients (Wagner, Bigatti, & Storniolo, 2006).

The questionnaire measures the coping process in eight scales: (a) confrontive coping, (b) distancing, (c) self-controlling, (d) seeking social support, (e) accepting responsibility, (f) escape/avoidance, (g) planful problem solving, and (h) positive reappraisal (Folkman & Lazarus, 1988). Responses can also be divided into emotion focused or problem focused coping using 28 and 22 specific items respectively (Folkman

& Lazarus, 1988). Based on Cronbach's alpha, internal consistency and reliability for the scales averaged between 0.61 and 0.79 (Folkman & Lazarus, 1988). Although the alpha scores are low, they are consistent with other coping measures. Use with spouses (*n*=84) of breast cancer patients produced higher results as the internal consistency and reliability for emotion focused coping was 0.83, and 0.84 for problem focused coping (Wagner, Bigatti, & Storniolo, 2006). The WOC has face validity in that each of the 66 items is a commonly used method of coping with stressful situations (Folkman & Lazarus, 1988). Additionally, the questionnaire has construct validity in that it validates the developer's prediction that coping is a process that changes over time based on changes in the stressful situation, and that this coping process includes both emotional and problem focused styles (Folkman & Lazarus, 1988).

The WOC (Folkman & Lazarus, 1988) was utilized in the current study as an online survey to explore the coping processes of family caregivers of cancer patients. Requiring approximately 15 minutes to complete, the WOC is a classic Likert scale format, presenting participants with a choice of four levels of agreement for each of the 66 questions (Folkman & Lazarus, 1988). Levels of agreement range from zero, indicating the activity does not apply or is not used, to three, indicating the activity is used a great deal (Folkman & Lazarus, 1988). Scoring the subscales is accomplished by adding the responses to the questions for each scale to identify the extent to which each type of coping is used in a particular situation. This is the raw score. Relative scores are obtained by calculating the average item score for each individual scale, totaling the average item scores, and then dividing the average item score for an individual scale by

the total average item score. The relative scores reveal any relationships between the scales. When the paper version of the survey is administered, it can be self-scored. However, because the survey was administered online, results were downloaded, scored, and addressed so responses of individual participants remained confidential.

Procedures

The current study is a survey design in which demographic information and responses to the WOC questionnaire were collected online through Survey Monkey. The link to the survey was made available to the public through e-mail invitations, flyers, public social networking sites, and the Walden University Participant Pool. Once a potential participant entered the survey, they were asked two qualifying questions: (a) are you currently taking care of a family member that is fighting cancer? and (b) are you at least 18 years old? If the participant answered "yes" to both questions, they were automatically taken to the demographic information and survey. If the participant answered "no" to either of these questions, they were not allowed to access the demographic information or survey, but instead automatically routed to a screen informing them they did not meet inclusion criteria. Those who met inclusion criteria but did not complete the demographic information or survey were excluded from the analysis.

Data Analysis

Descriptive statistics, including means, frequencies, standard deviations, and percentages, were used to examine participant characteristics. Multiple regression was used to examine relationships between independent variables and the dependent variable

of social support seeking tendencies among caregivers of cancer patients. Comparing means between demographics and predictor variables, such as between coping styles and gender, was done with t tests.

Ethical Concerns

Ethical considerations for this study included confidentiality and informed consent as there is an expectation of both within research studies and therapeutic alliances (American Psychological Association, 2002). The first screen of the survey provided information on study procedures. Participants indicated informed consent (see Appendix D) by clicking "next" at the bottom of the first screen and entering the survey.

Participant confidentiality was protected by adhering to the Health Insurance Portability and Accountability Act (HIPAA) as established by the Department of Health & Human Services (2008). Because the survey was online, participants self-selected to take part in the survey by clicking on the survey link. All data was collected and stored online using Secure Sockets Layer (SSL) encrytion. SurveyMonkey was set to block email and IP addresses so individual computers and participants could not be identified. The data is stored on a flash drive and CD, both of which are password protected.

This chapter has provided an overview of the materials, procedures, data analysis, and ethical concerns for the current study. Chapter 4 includes details on participant demographics, the analysis, major findings, and how each coping style is related to seeking social support.

CHAPTER 4: RESULTS

The present study was conducted to examine the relationship between certain coping styles and the tendency of family members of cancer patients to seek social support between the diagnosis of their loved one and the end of the caregiving role. Specifically, confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem focused, and positive reappraisal coping styles were assessed. A total of 137 people participated in the study, but only 103 completed the survey and are included in the analysis. Those excluded from the analysis (n=34) consisted of 3 participants who completed only personal demographic information, 3 participants who completed personal and patient demographic information before exiting the survey, and 28 who were not given access to the survey because they answered "no" to one of the qualifying questions and therefore did not meet inclusion criteria. Participants (n=103) consisted of 35 males and 68 females with a mean age of 49.57 (SD = 12.43) from 26 different states who were providing care for a family member with cancer at the time of the study.

Participants completing the survey reported having spent an average of 20.94 (SD = 19.96) months providing care for their loved one, with 1 month being the minimum amount of time reported and 96 months being the maximum. Loved ones receiving care from their family members had a mean age of 57.07 (SD = 15.44). Most participants were married and working full-time. Table 1 contains details of the marital, employment, and educational status of participants and their loved ones. Table 2 provides the relationships of participants to the loved ones for whom they were providing care. Interestingly, not

including their spouses or life partners, male caregivers provided care for more male (n=11) than female patients (n=1), and female caregivers provided care for more female (n=35) than male (n=0) patients. Those who completed the study (n=103) provided the type of cancer their loved one had been diagnosed with; a total of 32 different types of cancer were reported, with breast cancer being the most frequently reported.

Using descriptive statistics, participant coping styles in relation to education were examined. Results revealed that participants with less than a masters degree relied on the escape/avoidance coping style, while participants with a masters degree or higher relied on the problem focused coping style. Considering the majority of participants in this study, specifically 78.7%, reported having less than a master's degree, and overall results of this study indicated those using problem focused coping are more likely to seek social support than those using escape/avoidance coping, the majority of participants in this study are not likely to seek social support. However, upon examination of which coping style participants used most, results indicated participants in this study do not rely on only one coping style (see Table 3).

Table 1

Demographic Information for Participant and Loved One with Cancer

Participant Loved One Characteristic NNPercent Percent Gender Male 35 34.0 52 50.5 Female 68 66.0 51 49.5 Marital Status Married 72 69.9 60 58.3 Single 19 19 18.4 18.4 Widowed 3.9 3.9 4 4 Life Partner 7 6.8 7 6.8 Common Law 1 1.0 1 1.0 Age < 18 0 0.0 1 1.0 5.8 3 2.9 20 - 296 30 - 399 12 11.7 8.7 40 - 4917.5 36 35.1 18 50 - 5925.1 23.3 26 24 60 - 6925.2 17 16.5 26 70 - 796 5.8 15 14.6 80 - 890 0.0 6 5.8 > 90 0 0.0 1.0

Employment				
Employed Full-time	56	54.4	7	6.8
Employed Part-time	10	9.7	5	4.9
Retired	15	14.6	29	28.2
Family Medical Leave	4	3.9	18	17.5
Unemployed (not retired)	11	10.7	42	40.8
Student	4	3.9	1	1.0
Employed Full-time and Student	1	1.0	0	0.0
Employed Part-time and Student	1	1.0	0	0.0
Employed Full- and Part-time 1	1.0	1	1.0	
Education				
High School/GED	27	26.2	46	44.7
Did Not Complete High School	1	1.0	5	4.9
Some College	25	24.3	15	14.6
Associates Degree	6	5.8	4	3.9
Bachelors Degree	22	21.4	22	21.4
Masters Degree	15	14.6	7	6.8
Doctorate/Professional	3	2.9	4	3.9
Certification (no degree)	4	3.9	0	0.0

Table 2

Participant Relationship to Loved One for Which they are Providing Care

			Caregiver Gender				
Caregiver Rel	Caregiver Relationship to Patient			<u> 1ale</u>	<u>Fer</u>	<u>nale</u>	
	N	Percent	N	Percent	N	Percent	
Spouse	49	47.6	18	17.5	31	30.1	
Life Partner	7	6.8	5	4.9	2	1.9	
Daughter	16	15.5	0	0.0	16	15.5	
Son	5	4.9	5	4.9	0	0.0	
Sister	7	6.8	0	0.0	7	6.8	
Brother	1	1.0	1	1.0	0	0.0	
Mother	7	6.8	0	0.0	7	6.8	
Step-Daughter	2	1.9	0	0.0	2	1.9	
Grandson	1	1.0	1	1.0	0	0.0	
Son-in-law	1	1.0	1	1.0	0	0.0	
Mother-in-law	1	1.0	0	0.0	1	1.0	
Daughter-in-law	2	1.9	0	0.0	2	1.9	
Grandmother	1	1.0	1	1.0	0	0.0	
Father	3	2.9	3	2.9	0	0.0	

Table 3

Participant use of Coping Styles

Positive Reappraisal

Coping Style	N	Percent	
Confrontive	12	11.7	
Distancing	27	26.2	
Self-control	78	67.9	
Responsibility	12	11.6	
Escape / Avoid	77	74.7	
Problem Focused	55	53.5	

Overview of Design and Procedures

60.2

62

Participants completed an online survey consisting of demographic information and the WOC by Folkman and Lazarus (1988). The WOC consists of 66 questions in a four point Likert scale format and measures a total of eight coping styles; seven of the coping styles (confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem focused, and positive reappraisal) are used as predictor variables and one, seeking social support, is used as the dependent variable. The means and standard deviations for the seven predictor variables are reported in Table 4.

Demographic information was collected about the participant and their loved one for whom they are providing care. Although reported, the demographic information is not included in the analysis.

Table 4

Means and Standard Deviations

Measure	Mean	SD
Confrontive	3.27	2.03
Distancing	3.68	3.14
Self-Control	8.33	3.77
Responsibility	2.29	1.93
Escape/Avoid	7.45	4.23
Problem Focused	6.43	2.63
Positive Reappraisal	5.98	4.25

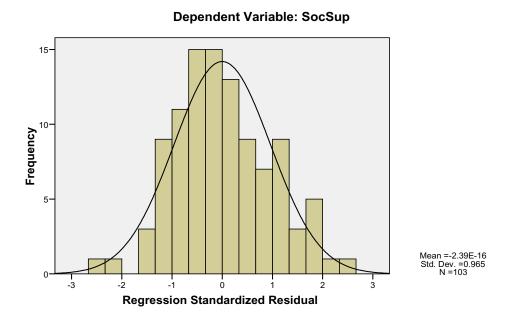
Results

Preliminary Analysis

Data analysis was conducted using the SPSS 15 software package. An exploratory data analysis using the Kolmogorov-Smirnov test for normality revealed a normal distribution for confrontive coping (p = .054) and problem solving (p = .084) at the .05 significance level; the other variables had a nonnormal distribution (p < .05). However, a histogram was run to visually examine the data and displayed an overall normal distribution (Figure 2).

Figure 2

Data Distribution

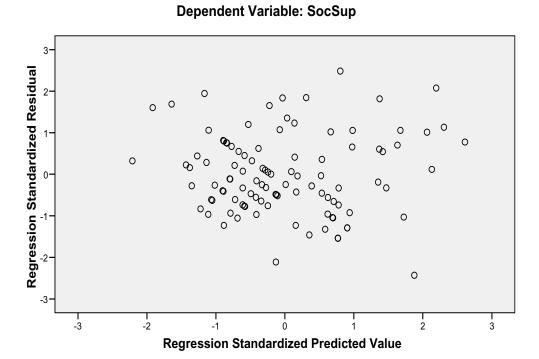


No univariate outliers were identified using criteria of \pm 0.58 standard scores (Field, 2005) on and of the measures. An examination of Mahalanobis distances was computed from the regression of seeking social support on confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem-focused, and positive reappraisal coping skills. Results failed to identify any significant multivariate outliers at the .05 significance level (M = 6.93, SD = 4.22).

Collinearity between the seven predictor variables (confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem focused, positive reappraisal) was assessed and "ruled out" based on the Tolerance statistic (T > 0.10). Additionally, Variance Inflation Factors (VIF) were between 1.28 and 3.08, substantially below the threshold of 10, and therefore within an acceptable level (Field, 2005) showing

there is no collinearity within the data. Homoscedasticity and linearity were confirmed through an examination of a scatterplot of the standardized residuals (Figure 3). As shown in Figure 3, standardized residual scores were evenly distributed over predicted standardized social support scores.

Figure 3
Scatterplot Shows Assumptions of Linearity and Homoscedasticity are Met



Independent sample *t* tests were performed to examine the means of each variable according to gender as there were more female than male participants. Table 5 shows the *t* test results.

Table 5

Independent Sample t Tests

	<u>Me</u>	<u>ean</u>	p	Levene's Equality
	Male (n=35)	Female (n=68)		of Variances
Confrontive	2.80	3.51	.091	.688
Distancing	3.43	3.81	.564	.933
Self-Control	8.49	8.25	.765	.934
Responsibility	2.31	2.28	.931	.407
Escape/Avoid	7.94	7.19	.402	.424
Problem Focused	6.37	6.46	.878	.192
Positive Reappraisal	5.77	6.09	.722	.988

According to Levene's test for Equality of Variances, there is no significant difference between males and females so equal variances were assumed. Additionally, results indicated that the means of each measure do not differ significantly between males and females who participated in the study. Because there was no significant difference between genders on any of the measures, the *t* test suggested men and women have similar coping styles when providing care for a family member with cancer.

Major Findings

Simple bivariate correlations between confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem-focused, positive reappraisal, and seeking social support were computed using Pearson's r. Based on the correlations

appearing in Table 6, seeking social support was significantly, positively, and strongly related to confrontive coping (r = .550, p < .01, $r^2 = .303$), problem-focused (r = .629, p < .01, $r^2 = .395$), positive reappraisal (r = .625, p < .01, $r^2 = .390$), and self-control (r = .423, p < .01, $r^2 = .179$). Additionally, distancing (r = .300, p < .01, $r^2 = .090$) was significantly, positively, and moderately related to seeking social support.

Bivariate correlations using Pearson's r were also computed between confrontive, distancing, self-control, accepting responsibility, escape/avoidance, problem-focused, positive reappraisal, and education. Correlations appearing in Table 7 indicated a significant but negative correlation between education and the escape/avoidance (r = -2.218, p < .05, $r^2 = .047$) coping style, thus indicating the use of escape/avoidance coping decreased as participant education increased. These findings also reinforced results of the descriptive statistics.

The direct impact of confrontive coping, distancing, self-control, accepting responsibility, escape/avoidance, problem-focused coping, and positive reappraisal on seeking social support was examined using a multiple regression analysis. Using the Enter method to ensure all variables remain in the model and are controlled for (Field, 2005), the seven predictor variables were entered into the regression simultaneously. Tables 8 and 9 display the results of the analysis. The multiple correlation (R = .772) was large and differed significantly from zero (F(7, 102) = 19.96, p < .01). The R^2 equaled .595 (adjusted $R^2 = .565$) and indicated the variables are strong predictors of seeking social support with the model accounting for 56.5% of the variance in seeking social

support. See Table 8. The ANOVA, detailed in Table 8, indicates the overall regression model is significant (p < .05).

Table 6 Correlation Coefficients between Coping Styles and Seeking Social Support (n=103)

Measure	Support	Confront	Distanc	SelfCntl	Respon	EscAvoid	ProbFocus	PosApprais
Support		.550**	.300**	.423**	.058	.214*	.629**	.625**
Confrontiv	e		.321**	.346**	.323**	.164	.537**	.368**
Distancing				.774**	.402**	.650**	.410**	.239*
Self-Contro	ol				.408**	.612**	.490**	.375**
Responsibi	lity					.303**	.289**	.145
Escape/Ave	oid						.178	.154
Problem Fo	ocused							.600**
Positive Re	appraisal							

^{*} p < .05, ** p < .01

Table 7

Correlation Coefficients between Coping Styles and Education (n=103)

Measure	Education	Confront	Distanc	SelfCntl	Respon	EscAvoid	ProbFocus	PosApprais
Education		.176	157	119	052	218*	.125	.039
Confrontiv	/e		.321**	.346**	.323**	.164	.537**	.368**
Distancing	Ţ,			.774**	.402**	.650**	.410**	.239*
Self-Contr	rol				.408**	.612**	.490**	.375**
Responsib	ility					.303**	.289**	.145
Escape/Av	oid						.178	.154
Problem F	ocused							.600**
Positive Re	eappraisal							

^{*} p < .05, ** p < .01

Table 8

Anova Table for the Regression Model

	SS	df	MS	F	R^2	p
Regression						
Model	846.00	7	120.86	19.96	.595	.00
Residual	575.20	95	6.05			
Total	1421.20	102				

An examination of the regression weights appearing in Table 9 indicates that several predictor variables are positive and significant predictors of social support seeking. The standardized regression coefficient for confrontive coping ($\beta = .31$, p < .01, $sr^2 = .066$), positive reappraisal ($\beta = .33$, p < .01, $sr^2 = .065$), and problem focused coping ($\beta = .27$, p < .01, $sr^2 = .033$) indicated these variables are positive and significant predictors of seeking social support. Interestingly, confrontive coping (r = .176, p > .05, $r^2 = .031$), positive reappraisal (r = .039, p > .05, $r^2 = .001$), and problem focused coping (r = .125, p > .05, $r^2 = .016$) are the same coping styles shown to have a positive but nonsignificant correlation to education (see Table 7).

Table 9
Summary of Regression Analysis for Predictors of Social Support Seeking

Measure	b	SE B	β	sr ²	t	p
Confrontive	.58	.15	.31	.066	3.96	.00
Distancing	09	.13	08	.002	70	.49
Self-Control	.16	.11	.16	.008	1.42	.16
Responsibility	44	.14	23	.040	-3.08	.00
Escape/Avoid	.07	.08	.09	.003	.95	.34
Problem Focused	.38	.14	.27	.033	2.78	.01
Positive Reappraisal	.29	.07	.33	.140	3.91	.00
Constant	-1.02	.81			-1.26	.21

Hypotheses

This quantitative study was centered on the hypothesis that coping styles determine a family member's tendency to seek social support between the diagnosis of their loved one and the end of the caregiving role. Although results of the overall regression analysis suggested the hypothesis is true, not all coping styles examined were significant predictors of the tendency to seek social support.

H₀1: Attempts by the caregivers to alter their situation, as measured by the Confrontive Coping scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_11 : Attempts by the caregivers to alter their situation, as measured by the Confrontive Coping scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Correlations using Pearson's r indicated that confrontive coping (r = .550, p < .01, $r^2 = .302$) has a large, positive, and significant effect on the tendency to seek social support. Although causality (Field, 2005) cannot be claimed, confrontive coping accounts for approximately 30% of the variance in seeking social support. Additionally, the regression analysis indicated confrontive coping ($\beta = .31$, p < .01, $sr^2 = .066$) is positively related to seeking social support. Based on the presence of a positive relationship, the null hypothesis is retained.

 H_02 : The detachment and minimization of the situation by the caregiver, as measured by the Distancing scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁2: The detachment and minimization of the situation by the caregiver, as measured by the Distancing scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Although distancing (r = .300, p < .01, $r^2 = .09$) has a medium and significant effect on seeking social support, the regression analysis indicated distancing ($\beta = -.08$, p = .49, $sr^2 = .002$) is negatively related to seeking social support and is not a significant predictor of the tendency to seek social support. Because the regression analysis found distancing to have a negative relationship with seeking social support, the null hypothesis is rejected.

 H_03 : Exercising self-control over feelings and actions associated with providing care to an ill loved one, as measured by the Self-Controlling scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁3: Exercising self-control over feelings and actions associated with providing care to an ill loved one, as measured by the Self-Controlling scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Although self-control (r = .423, p < .01, $r^2 = .19$) has a medium and significant effect and accounts for 19% of the variance in seeking social support, it is not, according to the regression analysis, a significant predictor of seeking social support. The regression analysis indicated self-control ($\beta = .16$, p = .16, $sr^2 = .008$) has a positive relationship to seeking social support and therefore the null hypothesis is retained.

 H_04 : The belief of the caregiver that they had a part in their loved one's situation, as measured by the Accepting Responsibility scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁4: The belief of the caregiver that they had a part in their loved one's situation, as measured by the Accepting Responsibility scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

According to Pearson's r, accepting responsibility (r = .058, p > .05, $r^2 = .003$) had no significant effect on seeking social support. Additionally, the regression analysis indicated that accepting responsibility ($\beta = -.23$, p < .05, $sr^2 = .040$) is a significant negative predictor of, and therefore has a negative relationship with, seeking social support. The null is rejected.

 H_05 : Attempts to escape or avoid the problem, as measured by the Escape Avoidance scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁5: Attempts to escape or avoid the problem, as measured by the Escape Avoidance scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Pearson's r revealed that escape/avoidance has a small but significant effect (r = .214, p < .05, $r^2 = .046$) on seeking social support. However, the regression analysis indicated that escape/avoidance ($\beta = .09$, p = .34, $sr^2 = .003$) has a positive relationship with seeking social support but is not a significant predictor of the tendency to seek social

support. Because the null hypothesis in this study is simply looking for a positive relationship, the null is retained.

H₀6: Problem-focused efforts to solve the problem, as measured by the Planful Problem Solving scale of the WOC, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

 H_16 : Problem-focused efforts to solve the problem, as measured by the Planful Problem Solving scale of the WOC, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Correlations using Pearson's r indicated that problem focused coping (r = .629, p < .01, $r^2 = .395$) has a large, positive, and significant effect on the tendency to seek social support, accounting for 39.5% of the variance in seeking social support. Additionally, the regression analysis indicated problem focused coping ($\beta = .27$, p < .05, $sr^2 = .033$) is positively related to, and a significant predictor of, seeking social support. Based on the presence of a positive relationship, the null hypothesis is retained.

 H_07 : A search for positive meaning and personal growth from the situation, as measured by the Positive Reappraisal scale, will be negatively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

H₁7: A search for positive meaning and personal growth from the situation, as measured by the Positive Reappraisal scale, will be positively related to seeking social support as measured by the Seeking Social Support scale of the WOC.

Pearson's r indicated that positive reappraisal $(r = .625, p < .01, r^2 = .391)$ has a large, positive, and significant effect on the tendency to seek social support. The bivariate

correlation also indicated positive reappraisal accounts for approximately 39% of the variance in seeking social support. Additionally, the regression analysis indicated positive reappraisal ($\beta = .33$, p < .01, $sr^2 = .140$) is positively related to, and a significant predictor of, seeking social support. Because the null hypothesis states a negative relationship will exist when in fact there is a positive relationship, the null is rejected.

Discussion

The primary hypothesis, that coping styles are related to a family member's tendency to seek social support, was examined in the current study. Descriptive statistics for the sample as well as information on the WOC (Folkman & Lazarus, 1988) were included, with statistical details on the WOC provided in chapter 3. Described in chapter 4 are the regression analysis, correlations, and variables used to examine the relationship between predictor variables and the dependent variable of seeking social support. All hypotheses were evaluated with decisions to retain or reject the null being made according to regression analysis results.

Overall, the regression model was statistically significant with the variables accounting for 56.5% (adjusted $R^2 = .565$) of the variance in seeking social support. The results indicated that the tendency to seek social support was significantly, positively, and largely related to confrontive, problem focused, and positive reappraisal coping styles. Descriptive statistics indicated that caregivers with education beyond a bachelor's degree primarily use problem focused coping, thus suggesting those with advanced degrees are more likely to seek social support. However, results also indicated caregivers vacillate between coping styles, suggesting there are many factors influencing caregiver coping

styles and therefore the tendency to seek social support. Independent *t* tests indicated no significant difference in coping styles between males and females who participated in this study, suggesting that men and women employ similar coping strategies when actively providing care for a loved one with cancer.

Summarized in Chapter 5 are suggestions for further research, and a description of limitations for the current study. Implications for social change and recommendations for action are also addressed.

CHAPTER 5: SUMMARY, CONCLUSION, AND RECOMMENDATIONS

The present study was conducted to explore coping styles of family caregivers of cancer patients and the possible influence of those coping styles on the family caregiver's tendency to seek social support. Although family caregivers can use many coping styles to manage the emotions and trauma that can accompany the cancer diagnosis of a loved one, it is not known which, if any, of those coping styles have any bearing on social support seeking. Addressed in the literature are various types of support groups (Arnaert et al., 2010; Donnelly et al., 2000; Klemm & Wheeler, 2005; Langer et al., 2007; Wagner et al., 2006), barriers to seeking support (McConigley et al., 2010; Thomas et al., 2010), risks of not seeking support (Carter, 2003; Evercare, 2006; Kiecolt-Glaser et al., 2003; Park et al., 2010; Shaffer et al., 2007; Stetz & Brown, 2004; Williamson & Shaffer, 2001), and health benefits of attending support groups (Holtslander, 2008). However, the literature lacks information concerning how family caregiver coping styles may predict or be related to seeking social support.

Study participants self-selected by clicking on a link and completing an anonymous online survey composed of the WOC by Folkman and Lazarus (1988) and demographic questions about the participant and loved one for whom they were providing care. The demographic information was used for descriptive purposes only. Research findings detailed in chapter 4 suggested those participants who utilized confrontive coping, problem focused coping, and positive reappraisal were more likely to seek social support compared to those who employed the styles of distancing, escape/avoidance, self-control, and taking responsibility.

Interpretation of Findings

Explained in chapter 2, there is a gap in the literature concerning how coping styles of family caregivers of cancer patients influence the caregiver's tendency to seek social support. This gap was addressed by using multiple regression and correlations, detailed in chapter 4, to examine seven different coping styles and the relationship of each to the tendency to seek social support.

The first hypothesis addressed the confrontive coping style which is defined by the caregiver's attempt to change their situation, often using their anger at the situation or engaging in risky behaviors as tools to facilitate that change. Correlations using Pearson's r indicated that confrontive coping has a large, positive, and significant effect on the tendency to seek social support. Additionally, the regression analysis indicated that confrontive coping has a significant positive relationship to seeking social support. Based on the presence of a positive relationship, the null hypothesis is retained. This is consistent with the literature which suggests family caregivers seeking social support want access to health professionals, education on the disease, and education on self-care as well as how to provide good care to their loved one (Evercare, 2006; Holtslander, Duggleby et al., 2005).

The second hypothesis was concerned with comparing the caregiver's detachment and minimization of the situation to the tendency to seek social support. Although the coping style of distancing was shown to have a medium and significant effect on seeking social support, the regression analysis indicated distancing is negatively related to seeking social support and is not a significant predictor of the tendency to seek social

support. These seemingly conflicting results indicated that, although distancing has a significant effect on seeking social support, the effect is that it causes caregivers to resist seeking support, thus creating the negative relationship between distancing and the tendency to seek support. For example, if a caregiver uses the coping skill of distancing, they may minimize and detach from their situation and their loved ones' illness by acting as though nothing has changed (Folkman & Lazarus, 1988) or that the loved one is not actually ill (Chung, Easthope, Chung, & Clark-Carter, 2001). Caregivers may also use distancing behaviors such as viewing their loved one as an object (Gillies & Johnston, 2004), or overusing humor to forget the seriousness (Kuiper, Martin, & Olinger, 1993) of their loved one's illness. Consequently, if the caregiver is minimizing, detaching, or trying to forget their situation, they will avoid any type of supportive intervention that may focus on emotions (Berzonsky, 1992) or losses associated with their loved one's disease (Chesla, Martinson, & Muwaswes, 1994). The null hypothesis was rejected. This is consistent with the literature which explains that caregivers may experience denial concerning the life threatening nature of their loved one's illness (Kübler-Ross, 1969). Additionally, distancing may be necessary to reconcile the dual role and internal conflict of being both family member and caregiver. For example, it may be difficult for a husband to maintain the role of a spouse when the role of caregiver requires him to assist in activities of daily living. This may conflict with how he previously viewed himself as a husband and therefore require husband wife behaviors to be redefined as within a caregiver patient relationship (Montgomery & Kosloski, 2009).

The tendency to seek social support by those who refrain from an outward show of emotions associated with providing care to an ill loved one was tested with the third hypothesis. The findings of this study indicated self-control has a medium and significant effect on, and a positive relationship with seeking social support. The null hypothesis was retained. However, the regression analysis indicated self-control is not a significant predictor of seeking social support. Researchers have suggested that caregivers do not discuss emotions, feelings, or certain topics with the patient in an effort to keep the patient from losing hope (Mellon et al., 2006), thus requiring caregivers to exercise emotional control through frustration, stress, and fear that accompany the caregiving role (Fried et al., 2005; Milberg et al., 2005). Seeking social support goes against the caregivers' need to protect the patient and often increases personal guilt for having feelings toward their loved one they consider negative (Gillies & Johnson, 2004).

Hypothesis four was concerned with the coping style of accepting responsibility, which, according to Folkman and Lazarus (1988), means a person takes responsibility for causing the stressful situation. The data indicated this coping style has no significant effect on seeking social support. Additionally, the regression analysis indicated that accepting responsibility for a loved one's illness is a significant negative predictor of, and therefore has a negative relationship with, seeking social support. It is not surprising that the null is rejected as nowhere in the literature is it suggested that caregivers take personal responsibility for causing their situation or the patient's illness. Actually, caregivers often feel guilty for depersonalizing the situation (Gillies & Johnston, 2004) in order to handle the stress and rapid changes in the patient's symptoms.

Attempting to escape or avoid the situation through fantasizing, alcohol, drugs, or excessive sleep was the focus of the fifth hypothesis. Results of the study suggested escape/avoidance has a small but significant effect on seeking social support. However, the regression analysis indicated that escape/avoidance has a positive relationship with seeking social support but is not a significant predictor of the tendency to seek social support. Because of the positive relationship, the null is retained. This is not surprising as many caregivers find it difficult to maintain a positive attitude and need to step away from the situation to get their emotions under control so the patient is not upset (Houldin, 2007). Evercare (2006) suggested support groups can provide the perfect opportunity to temporarily escape the caregiving role. Another form of escape and avoidance includes fantasizing the patient will make a sudden and unexpected recovery, even though the caregiver is fully aware that the patient is terminal (Saldinger & Cain, 2004).

The sixth hypothesis focused on using a problem-solving approach to manage, or fix, the problem. Correlations using Pearson's r indicated that problem focused coping has a large, positive, and significant effect on the tendency to seek social support.

Additionally, the regression analysis indicated problem focused coping is positively related to, and a significant predictor of, seeking social support. Based on the presence of a positive relationship, the null hypothesis is retained. This is consistent with the literature. According to Lazarus and Folkman (1984), problem focused coping is utilized by caregivers who attempt to change aspects of the situation such as stressors, barriers, people, or processes. These attempts to change the situation can take the form of altering personal behaviors and perspectives, finding new forms of personal satisfaction, and

learning new ways to manage what the caregiver cannot change. Problem focused coping could be associated with confrontive coping in that, with both coping styles, family caregivers look for solutions to not only provide good patient care, but also good self-care. However, problem focused support groups often fall short of meeting caregiver emotional needs by focusing solely on patient care (Caress et al., 2009; Hudson et al., 2008), thus giving an impression that caregiver needs are secondary to the needs of the patient which then enables caregiver self-neglect.

The last hypothesis focused on caregivers reaching out for social support when the primary coping style is positive reappraisal. This coping style typically involves some form of spirituality to find positive meaning and obtain personal growth from the situation. According to the data, the positive reappraisal coping style not only has a large, positive, and significant effect on the tendency to seek social support, but is a significant predictor of seeking social support. Because the null hypothesis states a negative relationship will exist, the null is rejected. Results of the analysis are somewhat inconsistent with the literature. While the literature does address the use of positive reappraisals by caregivers, it suggests that positive reappraisal does not always produce a positive outcome for the caregiver long term. According to Lazarus and Folkman (1984), this coping style may revolve around internal responses to the loved one's illness and include many reappraisals of the situation to justify acting as though the worst case scenario does not and will not exist. However, should the worst case scenario occur, the caregiver's sense of purpose will change as abruptly as it did when the loved one was initially diagnosed, thus requiring a reappraisal of the caregiver's identity as the

caregiving role has ended. Consequently, caregivers using the positive reappraisal coping style may have more difficulty adjusting to life after caregiving (Boerner et al., 2004).

Theoretical Perspective

Relationships between coping styles and tendencies to seek social support were examined from the theoretical perspective of the revised coping theory and process of bereavement by Folkman (2001). The revised coping theory and process of bereavement (Folkman, 2001) emphasized the importance of positive emotions in coping with ongoing stress, stating that coping with a situation is based on how one perceives that situation. Therefore, predeath grief associated with caregiving may be intensified if the caregiver tends to perceive a situation in a negative manner (Lazarus, 1999). The results of this study were consistent with the theory on which the study was based in that confrontive coping, problem focused coping, and positive reappraisal are styles in which the caregiver is involved in the process and looking for solutions to improve patient care and self-care. Coping styles of distancing, escape/avoidance, self-control, and taking responsibility imply a negative perception of the situation, which acts as a deterrent to seeking social support. Previous studies focusing on the caregiving experience have examined and identified caregiver coping styles (Chambers, Ryan, & Conner, 2001; Jeffreys, 2005; Houldin, 2007; Lazarus & Folkman, 1984) as well as various types, characteristics, and benefits of caregiver social support (Holtslander, 2008; Honea et al., 2008; Klemm & Wheeler, 2005; Langer, Rudd, & Syrjala, 2007; Steiner, 2006; Waldrop, 2007). However, coping styles and social support have been addressed separately, typically for the purpose of identifying and verifying their existence versus identifying

potential relationships between coping styles and social support. Therefore, because the current study examines the relationship between coping styles and the tendency of the family caregiver to seek social support while providing care for a cancer patient, the current study adds to the existing literature.

Limitations and Recommendations for Further Study

There are several limitations to this study which make it difficult to generalize the results to the general population of family members actively providing care to loved ones with cancer. Discussed in chapter 1, the study is limited in that it does not follow the caregiver across the loved one's disease trajectory, therefore only measuring the caregivers coping style at one moment in time. It is conceivable that coping strategies could shift depending on the effects of long term stress (Aubrecht et al., 2006; Ohio State University, 2003; Talley & Crews, 2007), actual caregiving duties being performed, and the severity of the loved one's symptoms.

Cultural differences in coping styles were not considered in the current study nor did the demographic information request cultural information. Approaches to caregiving can vary between cultures and possibly require support interventions to be cultural specific. For example, a study of Chinese caregivers (n=24) suggested that in this culture, death was viewed as a natural process so it was natural for family members to be a part of the dying process (Mak, Chan, Chan, & Yeung, 2003). Caregiving was not viewed as burdensome. Additionally, caregivers in this study did not seek social support because they did not want to impose their problem on friends and neighbors as this would establish an expectation of reciprocation to those friends and neighbors (Mak et al.,

2003). A study by Kalnins (2006) had similar findings in that Latvian caregivers (*n*=18) participating in the study revealed they took on the caregiving role because it was expected of them as a family member. Interestingly, Latvian caregivers expressed a desire for support but preferred the support to center on caring for the patient as they did not believe it was appropriate to share their personal grief with others (Kalnins, 2006).

Demographic information was requested about the participant (caregiver) and the loved one (patient) with cancer with each set of demographic information being a separate section of the survey, followed by the WOC (Folkman & Lazarus, 1988) in the third section. Responses to all questions were required before the participant was automatically taken to the next section. Participants were not given an option to skip the demographic information for the patient. One participant who did not finish the survey reported being the 30 year old parent of the patient, thus implying the patient was a child. Although no information was requested or captured that would identify participants or patients, any distrust or discomfort with providing demographic information on younger patients may have deterred potential participants from completing the survey.

Discussed in chapter 1, the use of a convenience sample (n=103) and participant self-selection decreased the generalizability to all family caregivers of cancer patients and were therefore limitations. Additionally, the present study did not include teenagers under the age of 18 or younger children that may also be providing care to the cancer patient. Friends, neighbors, partners, and coworkers could also be providing care to the cancer patient but, use of the term family caregiver could have suggested only immediate family members could participate in the study.

While this study was a good beginning for the study of coping styles among family caregivers of cancer patients, future research should build on this study by exploring the finer details of coping styles related to seeking social support. For example, as stated earlier, this study did not distinguish between cultures. According to the literature, coping styles can vary across cultures and subcultures, meaning if this study was conducted within a specific culture it might yield different results. Without cultural specific information, it is difficult to develop appropriate and effective support interventions. Additionally, regardless of culture, different age groups should be explored through different studies and possibly different research methods as not all age groups experience grief, including predeath grief, the same way (Jeffreys, 2005) so support seeking behaviors and attitudes could also vary. For example, teenagers are full of emotions that are part of being a teenager. Caregiving duties resulting from the parent's life threatening illness adds to the normal teenage emotional confusion and creates conflict between wanting to be with family, especially the ill parent, and wanting autonomy (Jeffreys, 2005). Teenagers are often not mature enough to understand the true nature of losses due to caregiving requirements until they are much older. A spouse, in contrast, fully understands what they have lost due to their loved one's illness and struggles with the conflict of being a spouse and a caregiver (Montgomery & Kosloski, 2009).

Future research should be conducted with larger samples to increase the generalizability of the findings. Having co-researchers in different cities may help facilitate a larger study with participants more evenly distributed across the country.

Although the current study had participants from 26 different states, 44.7% of participants were from Texas as this is where the study originated.

Longitudinal research across the patient's disease trajectory would be beneficial for exploring if or how coping styles change when patient symptoms or care needs change. Because the current study suggested caregivers vacillate between coping styles, longitudinal research would also allow any changes in coping to be monitored according to life events outside the patient's illness as well as changes in the mood or health of the caregiver. The timing of support services was one of the barriers discussed in chapter 2, as reported by caregivers that did not seek support. According to Montgomery and Kosloski (2009), support services tend to ignore the constantly changing needs of the caregiver, causing many caregivers to decline support services because what is offered is not what they need at a given time. Improving the understanding and awareness of these changing needs would allow support services to be more flexible and accommodating to caregivers. For example, a support program offering various levels and types of support may be more appropriate than the traditional ongoing support group. Such a program could take the form of a support center that offers educational classes on nutrition, stress management, meditation, exercise, disease education, alternative and conventional treatments, and other wellness oriented topics. Healthcare professionals with various specialties, including therapists, physicians, psychologists, exercise instructors, and counselors, would provide the classes so information could be offered at basic, intermediate, or advanced levels, thus meeting the ever changing needs of the caregiver across the patient's disease trajectory. Support center staff would recommend classes

based on an initial assessment, such as the WOC (Folkman & Lazarus, 1988), to identify one's initial coping style. The variety of educational and counseling services would allow caregivers who use confrontive or problem solving coping styles to participate in classes that provide a sense of control over their situation by offering information or approaches that promote some form of change. Caregivers using the coping styles of self-control, escape/avoidance, and distancing could attend classes they perceive as a nonthreatening distraction from their situation. However, all caregivers would interact with each other in some way, regardless of classes chosen, meaning defenses could drop and coping styles could begin to shift. For this reason, support and therapy groups, family counseling, individual counseling, and a non-denominational chapel with spiritual guidance would be available.

Implications for Social Change

The present study will promote positive social change by increasing awareness of the family caregiving experience within healthcare and therapeutic professions. As mentioned in chapter 1, this increased awareness can promote appropriate support interventions tailored to the family caregiver to support and maintain caregiver health and wellness. However, results of this study, as detailed in chapter 4, indicate that family caregivers of cancer patients not only use different coping styles, but some of these coping styles may influence self reliance and detachment instead of seeking social support. Therefore, a one-size-fits-all approach to support groups is not effective for all caregivers. The question then becomes how can the healthcare community not only

provide appropriate support services to all caregivers, but get caregivers, regardless of coping style, to understand the importance of and use those services?

Discussed in chapter 1, this study originally involved a free support group but attempts to recruit participants were futile. The direction of this study then changed to pursue an answer as to why family caregivers did not take advantage of a free support group, suspecting the answer would be consistent with the literature and related to how individuals cope with the stress of caregiving. According to the results of this study, caregivers whose coping style is to have a positive outlook and approach caregiving as a problem to be solved are most likely to seek social support. Those using other coping styles are less likely to seek social support and are therefore without appropriate interventions. These results make it clear why no one attended the free support group. Advertising for the original caregiver support group was developed to appeal to the caregiver's emotional response to their new responsibilities and their loved one's illness. Results of this study suggested family caregivers approach caregiving from either an intellectual or denial perspective so it is not surprising that efforts to recruit participants for the support group were unsuccessful. Support group advertising was aimed at the very thing caregivers in this study indicated they avoid: emotions.

The unsuccessful attempts to recruit for the free support group, when analyzed according to the findings of this study, support the need for healthcare professionals to do their homework before assuming a need exists and offering an intervention to meet that assumed need. Surveying family caregivers of cancer patients before recruiting for the support group would have allowed the researcher to determine if a support need existed

and, if appropriate, determine the nature of the need and design a support group and recruiting process around that need. For example, advertising for the initial free support group was done through flyers left at and mailed to cancer treatment centers and local businesses and therapeutic practices that cater to or support cancer patients and their caregivers. Advertisements were also placed in city and local newspapers, and a website was developed specifically for the support group which gave details of the group and provided online registration. Because the advertising, including the website, focused on the emotional response to caregiving, and distribution of the advertising was focused on places and people most familiar with cancer patients and their families, the advertising was not only ineffective but too narrowly focused. In contrast to the emotional focus of previous support group advertising, results of this study suggested that those caregivers more likely to attend a support group approach their situation as a problem to be solved or changed. Therefore, it is possible these caregivers are already attending individual counseling, exercise classes, self-help sessions offered through local holistically oriented pharmacies, and reading medically oriented magazines and websites in search of useful information. Possible recruiting strategies for reaching those most likely to attend a support group could include providing public informational sessions through appropriate pharmacies, providing brown bag lunch sessions at hospitals and cancer treatment centers to familiarize staff with not only the group being offered but also the need served by the group, and sending electronic and/or hardcopy flyers to mental health counselors and therapists, physical therapists, and exercise instructors and gyms. Advertising to a broader market coupled with advertising language focused on possible solutions instead

of emotional upheaval caused by caregiving, could result in participant recruitment for a free support group being more successful.

Recommendations for Action

There are several actions that can be taken to disseminate the results of the current study to those in the best position to use the information to improve lives of family caregivers of cancer patients. The results need to be made available to the healthcare community, beginning in Austin Texas where the study originated.

One method of educating the healthcare community on the findings of this study is through continuing education workshops for therapists, counselors, physicians, and nurses. All licensed healthcare professionals must have continuing education credits to renew their license. These workshops should not be limited to those working solely with cancer patients and their families as anyone in the healthcare field could interact with this population at any time. Although not every licensed healthcare professional can or will attend the same session, workshops could be offered through conferences and as a series of standalone workshops. Regardless of times and frequencies of workshop offerings, some professionals will not attend. Publishing the results in professional journals as well as local newspapers or organizational newsletters may get the information to the workshop resistant.

Ensuring healthcare professionals have access to the information is only the first step as simply having the information, or using it to develop supportive interventions, is not enough. There is still the issue of getting the information to the caregiver and persuading them to take action. Ultimately, the cancer patient's treatment team must

become the treatment team for the entire family as cancer is a family disease and caregiving is a social issue (Gibson & Houser, 2007). Healthcare providers develop treatment plans and timelines for their patients before beginning medical procedures and processes. Support services for the family should be included in those plans as family members may be more likely to seek out social support if the recommendation is from their patient's medical team versus a flyer on a bulletin board or a newspaper advertisement.

Conclusion

Family caregivers include husbands, wives, significant others, brothers, sisters, children, and close friends of the patient who provide assistance to the patient in areas where cancer treatments have impaired their ability for self-care (Jeffreys, 2005; Ohio State University Medical Center, 2009a). The concept of family caregiving is not new, as there was a time in history when it was common for family members and physicians to care for the patient at home, often being at the bedside when the patient died (Kovacs & Fauri, 2003; National Family Caregivers Association, 2009). Because the typical lifespan was shorter at that time, the stress associated with caregiving was also short. This is no longer the case. Advancements in medical science now allow patients to live longer, thus increasing the duration of the caregiving experience (Kovacs & Fauri, 2003), including the predeath grief and stress associated with caregiving. The existing literature confirms that caregiving is a health risk because of the long term and often unrelenting predeath grief and related stress (Dumont et al., 2008) that occurs between the diagnosis of the patient and the end of the caregiving role. There is also an awareness of this predeath

grief within the healthcare community but little is being done to address the issue (Schneider, 2006).

Caregiving for a family member with a terminal or chronic illness can be one of the most stressful events a person will experience over the course of their lifetime (Zivin & Christakis, 2007). The nature of this stress is long term with no quick resolution, thus increasing the caregiver's vulnerability to mental and physical illness (Aubrecht et al., 2006; Ohio State University, 2003). Exacerbating that vulnerability is the caregiver's lack of self care because patient needs tend to overshadow the caregiver's needs which can, over time, cause resentment (Jeffreys, 2005) and symptoms of burnout (Evercare, 2006) for the caregiver. As described in chapter 2, anxiety, depression (Tsigaroppoulos et al., 2009), irritability toward the patient (Manne et al., 1999), changes in eating habits, substance use, emotional and physical exhaustion (Ohio State University Medical Center, 2007), and immune system changes (Kiecolt-Glaser et al., 2003) are common among caregivers. In short, caregiving is a health threat.

Support groups help minimize the health threat by providing an outlet for caregivers to discuss their concerns and emotions (Evercare, 2006), learn how to care for the patient, learn self-care (Arnaert et al., 2010), have access to new medical information, and realize they are not alone (Chambers et al., 2001). According to Kiecolt-Glaser et al., (2002), having social support during active caregiving has a positive effect on the health of the caregiver. However, there are many barriers to seeking support.

Barriers to support services can include patient demands or needs, not enough support services available that are convenient for the caregiver (Thomas et al., 2010), and

services offered not being what is needed at a given time during the caregiving experience (Montgomery & Kosloski, 2009). However, the coping style used to manage responsibilities and stress associated with caregiving can validate or negate perceived barriers to seeking social support. As indicated by the results of the current study, those who employ confrontive coping, problem focused coping, and use positive reappraisal are more likely to seek social support to connect with other caregivers and gain education about the disease, patient care, and self care. In contrast, those who use distancing, escape/avoidance, self-control, and take responsibility for causing the illness are less likely to take advantage of social support services. Reinforced by this study is the need for support programs to meet the ever changing needs of family caregivers of cancer patients and accommodate all coping styles because the general approach to social support does not bring about personal change.

REFERENCES

- Adams, K. B., McClendon, M. J., & Smyth, K. A. (2008). Personal losses and relationship quality in dementia caregiving. *Dementia*, 7(3), 301-319.
- Ader, R. (2001). Psychoneuroimmunology. *Current Directions in Psychological Science*, 10(3), 94-101.
- American Psychological Association. (2002). *Ethical principles of psychologists and code of conduct*. Retrieved from http://www.apa.org/ethics
- Aneshensel, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004). When caregiving ends: The course of depressive symptoms after bereavement. *Journal of Health and Social Behavior*, 45(4), 422-440.
- Arnaert, A., Gabos, T., Ballenas, V., & Rutledge, R. D. H. (2010). Contributions of a retreat weekend to the healing and coping of cancer patients' relatives. *Qualitative Health Research*, 20(2), 197-208.
- Aubrecht, V., Arlington, R., & Gordon, H. (2006). Family caregivers: Health-related changes following patients' cancer diagnosis. *Oncology Nursing Forum*, 33(2), 417-418.
- Berzonsky, M. D. (1992). Identity style and coping strategies. *Journal of Personality*, 60(4), 771-788.
- Bjorntorp, P. (1996). Behavior and metabolic disease. *International Journal of Behavioral Medicine*, 3(4), 285-302.
- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive aspects of caregiving and adaptation to bereavement. *Psychology and Aging*, 19(4), 668-675.
- Bradley, S. E., Sherwood, P. R., Kuo, J., Kammerer, C. M., Gettig, E. A., Ren, D., Rohrer, W. M., Donovan, H. S., Hricik, A., Newberry, A., Given, B. (2009). Perceptions of economic hardship and emotional health in a pilot sample of family caregivers. *Journal of Neuro-Oncology*, *93*(3), 333-342.
- Butow, P. N., Kirsten, L. T., Ussher, J. M., Wain, G. V., Sandoval, M., Hobbs, K. M., Hodgkinson, K., & Stenlake, A. (2007). What is the ideal support group? Views of Australian people with cancer and their carers. *Psycho-Oncology*, *16*(11), 1039-1045.
- Caine, R. M. (2003). Psychological influences in critical care: Perspectives from psychoneuroimmunology. *Critical Care Nurse*, 23(2), 60-67.

- Caress, A. L., Chalmers, K., & Luker, K. (2009). A narrative review of interventions to support family carers who provide physical care to family members with cancer. *International Journal of Nursing Studies*, 46(11), 1516-1527.
- Carter, P. A. (2003). Family caregiver's sleep loss and depression over time. *Cancer Nursing*, 26(4), 253-259.
- Chambers, M., Ryan, A. A., & Conner, S. I. (2001). Exploring the emotional support needs and coping strategies of family carers. *Journal of Psychiatric and Mental Health Nursing*, 8(2), 99-106.
- Chen, Y.-M., Hedrick, S. C., & Young, H. M. (2010). A pilot evaluation of the family caregiver support program. *Evaluation and Program Planning*, 33(2), 113-119.
- Cherlin, E. J., Barry, C. L., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., Kasl, S. V., & Bradley, E. H. (2007). Bereavement services for family caregivers: How often used, why, and why not. *Journal of Palliative Medicine*, 10(1), 148-158.
- Chesla, C., Martinson, I., & Muwaswes, M. (1994). Caregiving: Continuities and discontinuities in family member's relationships with Alzheimer's patients. *Family Relations*, 43(1), 3-9.
- Chung, M. C., Easthope, Y., Chung, C., & Clark-Carter, D. (2001). Traumatic stress and coping strategies of sesternary victims following an aircraft disaster in Coventry. *Stress & Health: Journal of the International Society for the Investigation of Stress*, 17(2), 67-75.
- Classen, C. (2004). Support groups and health. *Encyclopedia of Health and Behavior*. Retrieved from http://www.sage-ereference.com/behavior/Article_n205.html
- Cohen, J. (1992). A power primer. Psychological Bulletin, 112(1), 155-159.
- Department of Health and Human Services. (2008). *HIPAA*. Retrieved from http://www.hhs.gov/ocr/hipaa/
- Donnelly, J. M., Kornblith, A. B., Fleishman, S., Zuckerman, E., Raptis, G., Hudis, C. A., Hamilton, N., Payne, D., Massie, M. J., Norton, L., & Holland, J. C. (2000). A pilot study of interpersonal psychotherapy by telephone with cancer patients and their partners. *Psycho-Oncology*, *9*(1), 44-56.

- DuBenske, L. L., Wen, K. Y., Gustafson, D. H., Guarnaccia, C. A., Cleary, J. F., Dinauer, S. K., & McTavish, F. M. (2008). Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliative Support Care*, 6(3), 265-272.
- Dumont, I., Dumont, S., & Mongeau, S. (2008). End-of-life care and the grieving process: Family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qualitative Health Research*, 18(8), 1049-1061.
- Erdfelder, E., Faul, F., & Buchner, A. (1996). GPOWER: A general power analysis program. *Behavior Research Methods, Instruments, & Computers*, 28, 1-11.
- Evercare. (2006). Evercare study of caregivers in decline: A close-up look at the health risks of caring for a loved one: Top line findings. Retrieved February 20, 2009, from http://evercarehealthplans.com/pdf/TopLineFindings_EvercareCaregiversStudy.pdf
- Evercare. (2008). *Caregiver burnout*. Retrieved February 20, 2009, from http://evercarehealthplans.com/caregiver_burnout.jsp
- Ferrario, S. R., Cardillo, V., Vicario, F., Balzarini, E., & Zotti, A. M. (2004). Advanced cancer at home: Caregiving and bereavement. *Palliative Medicine*, 18(2), 129-136.
- Field, A. (2005). *Discovering statistics using SPSS*. Thousand Oaks, CA: Sage Publications.
- Folkman, S. (2001). Revised coping theory and the process of bereavement. In M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.). *Handbook of bereavement research: Consequences, coping, and care* (pp. 563-584). Washington, DC: American Psychological Association.
- Folkman, S., & Lazarus, R. S. (1988). Ways of coping questionnaire, sampler set, manual, test booklet, scoring key. Palo Alto, CA: Consulting Psychologists Press.
- Fried, T. R., Bradley, E. H., O'Leary, J. R., & Byers, A. L. (2005). Unmet desire for caregiver-patient communication and increased caregiver burden. *Journal of the American Geriatrics Society*, *53*(1), 59-65.
- Friedman, R., & James, J. W. (2008). The myth of the stages of dying, death, and grief. *Skeptic*, 14(2), 37-41.

- Gibson, M. J., & Houser, A. (2007). Valuing the invaluable: A new look at the economic value of family caregiving. *AARP Public Policy Institute Issue Brief*, Retrieved March 22, 2009 from http://www.aarp.org/research/ppi/health-care/health-costs/articles/ib82_caregiving.html
- Gillies, B., & Johnston, G. (2004). Identity loss and maintenance: Commonality of experience in cancer and dementia. *European Journal of Cancer Care*, 13(5), 436-442.
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., & Rahbar, M. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum*, 31(6), 1105-1115.
- Goodkin, K., Baldewicz, T. T., Blaney, N. T., Asthana, D., Kumar, M., Shapshak, P., Leeds, B., Burkhalter, J. E., Rigg, D. Tyll, M. D., Cohen, J., & Zheng, W. L. (2001). Physiological effects of bereavement and bereavement support group interventions. In, M. S. Stroebe, R. O. Hansson, W. Stroebe, & H. Schut (Eds.), *Handbook of bereavement research: Consequences, coping, and care*, (pp. 671-703). Washington, DC: American Psychological Association.
- Grbich, C., Parker, D., & Maddocks, I. (2001). The emotions and coping strategies of family members with a terminal cancer. *Journal of Palliative Care*, 17(1), 30-36.
- Hebert, R. S., Dang, Q., & Schulz, R. (2006). Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia: Findings from the REACH study. *Journal of Palliative Medicine*, *9*(3), 683-693.
- Hebert, R. S., & Schulz, R. (2006). Palliative Care review: Caregiving at end-of-life. *Journal of Palliative Medicine*, 9(5), 1174-1187.
- Holtslander, L. F. (2008). Caring for bereaved family caregivers: Analyzing the context of care. *Clinical Journal of Oncology Nursing*, 12(3), 501-506.
- Holtslander, L. F., Duggleby, W., Williams, A. M., & Wright, K. E. (2005). The experience of hope for informal caregivers of palliative patients. *Journal of Palliative Care*, 21(4), 285-291.
- Honea, N. J. Brintnall, R., Given, B., Sherwood, P., Colao, D. B., Somers, S. C., Northouse, L. L. (2008). Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden. *Clinical Journal of Oncology Nursing*, 12(3), 507-516.

- Hosaka, T., & Sugiyama, Y. (2003). Structured intervention in family caregivers of the demented elderly and changes in their immune function. *Psychiatry and Clinical Neurosciences*, *57*(2), 147-151.
- Houldin, A. D. (2007). A qualitative study of caregivers' experiences with newly diagnosed advanced colorectal cancer. *Oncology Nursing Forum*, *34*(2), 323-330.
- Hudson, P., Quinn, K., Kristjanson, L., Thomas, T., Braithwaite, M., Fisher, J., & Cockayne, M. (2008). Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care. *Palliative Medicine*, 22(3), 270-280.
- Hudson, P. L. (2006). How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support?. *Journal of Palliative Medicine*, *9*(3), 694-703.
- Hudson, P. L., Aranda, S., & Hayman-White, K. (2005). A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomized controlled trial. *Journal of Pain and Symptom Management, 30*(4), 329-341.
- Hudson, P., Aranda, S., & McMurray, N. (2002). Intervention development for enhanced lay palliative caregiver support the use of focus groups. *European Journal of Cancer Care*, 11(4), 262-270.
- Jacobs, G. D. (2001). The physiology of mind-body interactions: The stress response and the relaxation response. *The Journal of Alternative and Complementary Medicine*, 7(6), 83-92.
- James, J. W., & Friedman, R. (2009). *The grief recovery handbook*. New York: Harper-Collins.
- Jeffreys, J. S. (2005). *Helping grieving people: When tears are not enough*. New York: Brunner-Routledge.
- Jones, M. B. (2006). A guide for hope: A psychoeducational program for family caregivers of newly diagnosed stage IV colon cancer patients (Doctoral dissertation, The Chicago School of Professional Psychology, 2007). (Proquest No. AAT 3287161)
- Kalnins, I. (2006). Caring for the terminally ill: Eperiences of Latvian family caregivers. *International Nursing Review*, *53*(2), 129-135.

- Kang, D., Davidson, R. J., Coe, C. L., Wheeler, R. E., Tomarken, A. J., & Ershler, W. B. (1991). Frontal brain asymmetry and immune function. *Behavioral Neuroscience*, 105(6), 860-869.
- Karademas, E. C., Argyropoulou, K., & Karvelis, S. (2007). Psychological symptoms of breast cancer survivors: A comparison with matched healthy controls and the association with cancer-related stress and coping. *Journal of Psychosocial Oncology*, 25(3), 59-74.
- Kiecolt-Glaser, J. K., McGuire, L., Robles, T. F., & Glaser, R. (2002). Emotions, morbidity, and mortality: New perspectives from psychoneuroimmunology. *Annual Review of Psychology*, *53*(1), 83-107.
- Kiecolt-Glaser, J. K., Preacher, K. J., MacCallum, R. C., Atkinson, C., Malarkey, W. B., & Glaser, R. (2003). Chronic stress and age-related increased in the proinflammatory cytokine IL-6. *Proceedings of the National Academy of Sciences*, 100(15), 9090-9095.
- Kim, Y., Baker, F., Spillers, R. L., & Wellisch, D. K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology*, 15(9), 795-804.
- Kim, Y., Carver, C. S., Deci, E. L., & Kasser, T. (2008). Adult attachment and psychological well-being in cancer caregivers: The mediational role of spouses' motives for caregiving. *Health Psychology*, *27*(2), S144-S154.
- Kissane, D., Lichtenthal, W. G., & Zaider, T. (2007). Family care before and after bereavement. *OMEGA*, 56(1), 21-32.
- Kissane, D. W., McKenzie, M., Bloch, S., Moskowitz, C., McKenzie, D. P., & O'Neill, I. (2006). Family focused grief therapy: A randomized, controlled trial in palliative care and bereavement. *American Journal of Psychiatry*, 163(7), 1208-1218.
- Klemm, P., & Wheeler, E. (2005). Cancer caregivers online. *CIN: Computers, Informatics, Nursing, 23*(1), 38-45.
- Koop, P. M., & Strang, V. R. (2003). The bereavement experience following home-based family caregiving for persons with advanced cancer. *Clinical Nursing Research*, 12(2), 127-144.
- Kosloski, K., Montgomery, R. J. V., & Youngbauer, J. (2001). Utilization of respite services: A comparison of users, seekers, and nonseekers. *Journal of Applied Gerontology*, 20(1), 111-132.

- Kovacs, P. J., & Fauri, D. P. (2003). Formal and informal caregiving at the end of life. *Handbook of death & dying*. Retrieved from http://sageereference.com.ezp.waldenulibrary.org/death/Article_n49.html?searchQuery=y% 3D10%26quickSearch%3Dformal%2Band%2Binformal%2Bcaregiving%26x%3 D23
- Kübler-Ross, E. (1969). On death and dying. New York: Simon & Schuster.
- Kuiper, N. A., Martin, R. A., & Olinger, L. J. (1993). Coping humour, stress, and cognitive appraisals. *Canadian Journal of Behavioral Science*, 25(1), 81-96.
- Langer, S., Rudd, M., & Syrjala, K. (2007). Protective buffering and emotional desynchrony among spousal caregivers of cancer patients. *Health Psychology*, 26(5), 635-643.
- Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw Hill
- Lazarus, R. S. (1999). Stress and emotion. New York: Springer Publishing Company.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing Company.
- Lazarus, R. S., & Launier, R. (1978). Stress-related transactions between person and environment. In L.A. Pervin & M. Lewis (Eds.), *Perspectives in interactional psychology* (pp. 287-327). New York: Plenum.
- Leithborg, C. E., Kissane, D., & Burns, W. I. (2003). It's not the easy part: The experience of significant others of women with early stage breast cancer at treatment completion. *Social Work in Health Care*, *37*(1), 63-87.
- Lekander, M. (2002). Ecological immunology: The role of the immune system in psychology and neuroscience. *European Psychologist*, 7(2), 98-115.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen. *Cancer Nursing*, 33(1), 28-36.
- Lusk, B., & Lash, A. A. (2005). The stress response, psychoneuroimmunology, and stress among ICU patients. *Dimensions of Critical Care Nursing*, 24(1), 25-31.
- Mackenzie, C. S., Smith, M. C., Hasher, L., Leach, L., & Behl, P. (2007). Cognitive functioning under stress: Evidence from informal caregivers of palliative patients. *Journal of Palliative Medicine*, 10(3), 749-758.

- Mak, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong King. *Cancer Nursing*, 26(4), 267-275.
- Manne, S., Alfieri, T., Taylor, K., & Dougherty, J. (1999). Spousal negative responses to cancer patients: The role of social restriction, spouse mood, and relationship satisfaction. *Journal of Consulting and Clinical Psychology*, 67(3), 352-361.
- Marwit, S. J., & Meuser, T. M. (2005). Development of a short form inventory to assess grief in caregivers of dementia patients. *Death Studies*, 29(3), 191-205.
- McConigley, R., Halkett, G., Lobb, E., & Nowak, A. (2010). Caring for someone with high-grade glioma: A time of rapid change for caregivers. *Palliative Medicine*, 24(5), 473-479.
- Mellon, S., Northouse, L. L., & Weiss, L. K. (2006). A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nursing*, 29(2), 120-131.
- Merriam-Webster Online Dictionary. (2009). *Didactic*. Retrieved from http://www.merriam-webster.com/dictionary/didactic
- Metzger, P. L., & Gray, M. J. (2008). End-of-life communication and adjustment: Preloss communication as a predictor of bereavement-related outcomes. *Death Studies*, 32(4), 301-325.
- Miaskowski, C., Kragness, L., Dibble, S., & Wallhagen, M. (1997). Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer-related pain. *Journal of Pain and Symptom Management*, 13(3), 138-147.
- Milberg, A., Rydstrand, K., Helander, L., & Friedrichsen, M. (2005). Participants' experiences of a support group intervention for family members during ongoing palliative home care. *Journal of Palliative Care*, 21(4), 277-284.
- Montgomery, R. J. V., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Journal of the American Society on Aging*, 33(1), 47-52.
- National Alliance for Caregiving. (1997). *The Metlife study of employer costs for working caregivers*. Retrieved February 19, 2009 from http://www.caregiving.org/data/employercosts.pdf

- National Family Caregivers Association. (2009). What is family caregiving. Retrieved February 19, 2009 from http://www.nfcacares.org/who_are_family_caregivers/what_is_family_caregiving .cfm
- Ng, G. T. (2009). Support for family caregivers: What do service providers say about accessibility, availability and affordability of services. *Health and Social Care in the Community*, 17(6), 590-598.
- Ohio State University. (2003). *Mechanism found that weakens caregiver's immune status*. Retrieved February 19, 2009 from http://researchnews.osu.edu/archive/glaserpnas.htm
- Ohio State University Medical Center. (2007). *Tips for preventing and dealing with caregiver stress*. Retrieved February 19, 2009 from http://medicalcenter.osu.edu/patiented/materials/pdfdocs/health-p/tips-dealing-caregiver-stress.pdf
- Ohio State University Medical Center. (2009a). *Being a caregiver*. Retrieved February 19, 2009 from http://medicalcenter.osu.edu/patientcare/healthcare_services/senior_health/home_healthcare_overview/being_caregiver/pages/index.aspx
- Ohio State University Medical Center. (2009b). *Grief and loss*. Retrieved February 19, 2009 from http://medicalcenter.osu.edu/patientcare/healthcare_services/senior_health/grief_loss/Pages/index.aspx
- Oliver, J., & Brough, P. (2002). Cognitive appraisal, negative affectivity and psychological well-being. *New Zealand Journal of Psychology*, 31(1), 2-7.
- Papastavrou, E., Tsangari, H., Kalokerinou, A., Papacostas, S. S., & Sourtzi, P. (2009). Gender issues in caring for demented relatives. *Health Science Journal*, *3*(1), 41-53.
- Park, S. M., Kim, Y. J., Kim, S., Choi, Y. S. Lim, H., Choi, Y. S., Hong, Y. S., Kim, S., Heo, D. S., Kang, K. M., Jeong, H. S., Lee, C. G., Moon, D. H., Choi, J., Kong, I. S., & Yun, Y. H. (2010). Impact of caregivers' unmet needs for supportive care on quality of terminal cancer care delivered and caregiver's workforce performance. *Supportive Care in Cancer*, 18(6), 699-706.

- Prigerson, H. G., Cherlin, E., Chen, J. H., Kasl, S. V., Hurzeler, R., & Bradley, E. H. (2003). The stressful caregiving adult reactions to experiences of dying (SCARED) scale. *The American Journal of Geriatric Psychiatry*, 11(3), 309-319.
- Radziewicz, R. M., Rose, J. H., Bowman, K. F., Berila, R. A., O'Toole, E. E., & Given, B. (2009). Establishing treatment fidelity in a coping and communication support telephone intervention for aging patients with advanced cancer and their family caregivers. *Cancer Nursing*, 32(3), 193-202.
- Reiche, E. M. V., Morimoto, H. K., & Nunes, S. O. V. (2005). Stress and depression-induced immune dysfunction: Implications for the development and progression of cancer. *International Review of Psychiatry*, 17(6), 515-527.
- Robinson-Whelen, S., Tada, Y., MacCallum, R. C., McGuire, L., & Kiecolt-Glaser, J. K. (2001). Long-term caregiving: What happens when it ends?. *Journal of Abnormal Psychology*, 110(4), 573-584.
- Saldinger, A., & Cain, A. C. (2004). Deromanticizing anticipated death: Denial, disbelief, and disconnection in bereaved spouses. *Journal of Psychosocial Oncology*, 22(3), 69-92.
- Sanders, S., & Corley, C. S. (2003). Are they grieving? A qualitative analysis examining grief in caregivers of individuals with Alzheimer's disease. *Social Work in Health Care*, *37*(3), 35-53.
- Schneider, R. M. (2006). Group bereavement support for spouses who are grieving the loss of a partner to cancer. *Social Work with Groups*, 29(2/3), 259-278.
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effects of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum*, *35*(1), 49-56.
- Seale, C. (2000). Changing patterns of death and dying. *Social Science & Medicine*, 51(6), 917-930.
- Seaward, B. L. (2007, Winter). The stress of life: Selye, Jung, Taylor & you. *Beginnings*, 27(1), 4-5.
- Selye, H. (1976). The stress of life. NY: McGraw-Hill.

- Shaffer, D. R., Dooley, W. K., Williamson, G. M. (2007). Endorsement of proactively aggressive caregiving strategies moderates the relation between caregiver mental health and potentially harmful caregiving behavior. *Psychology and Aging, 22*(3), 494-504.
- Sharpe, L., Butow, P., Smith, C., McConnell, D., & Clarke, S. (2005). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology*, *14*(2), 102-114.
- Sherman, A. C., Pennington, J., Simonton, S., Latif, U., Arent, L., & Farley, H. (2008). Determinants of participation in cancer support groups: The role of health beliefs. *International Journal of Behavioral Medicine*, 15(2), 92-100.
- Soothill, K., Morris, S. M., Harman, J. C., Francis, B., Thomas, C., & McIllmurray, M. B. (2001). Informal carers of cancer patients: What are their unmet psychosocial needs? *Health and Social Care in the Community*, *9*(6), 464-475.
- Spillers, R. L., Wellisch, D. K., Kim, Y., Matthews, B. A., & Baker, F. (2008). Family caregivers and guilt in the context of cancer care. *Psychosomatics*, 49(6), 511-519.
- Steiner, C. S. (2006). Grief support groups used by few Are bereavement needs being met? *Journal of Social Work in End-of-Life & Palliative Care*, 2(1), 29-53.
- Stetz, K. M., & Brown, M. A. (2004). Physical and psychosocial health in family caregiving: A comparison of AIDS and cancer caregivers. *Public Health Nursing*, 21(6), 533-540.
- Stroebe, W., Zech, E., Stroebe, M. S., & Abakoumkin, G. (2005). Does social support help in bereavement? *Journal of Social and Clinical Psychology*, 24(7), 1030-1050.
- Swanberg, J. E. (2006). Making it work: Informal caregiving, cancer, and employment. *Journal of Psychosocial Oncology, 24*(3), 1-18.
- Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *The American Journal of Public Health*, 97(2), 224-228.
- Thomas, K., Hudson, P., Oldham, L., Kelly, B., & Trauer, T. (2010). Meeting the needs of family careers: An evaluation of three home-based palliative care services in Australia. *Palliative Medicine*, 24(2), 183-191.

- Timmermann, M., Naziri, D., & Etienne, A. M. (2009). Defense mechanisms and coping strategies among caregivers in palliative care units. *Journal of Palliative Care*, 25(3), 181-190.
- Tomarken, A., Holland, J., Schachter, S., Vanderwerker, L., Zuckerman, E., Nelson, C., Coups, E., Ramirez, P. M., & Prigerson, H. (2008). Factors of complicated grief pre-death in caregivers of cancer patients. *Psycho-Oncology*, *17*(2), 105-111.
- Toseland, R. W., McCallion, P., Gerber, T., & Banks, S. (2002). Predictors of health and human services use by persons with dementia and their family caregivers. *Social Science & Medicine*, *55*(7), 1255-1266.
- Tsigaroppoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I., & Deliveliotis, C. (2009). Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practice*, 15(1), 1-6.
- van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*, *10*(2), e18. Retrieved from http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2483925
- Vedhara, K., & Irwin, M. R. (2006). *Human Psychoneuroimmunology*. New York: Oxford University Press.
- Vitaliano, P. P., Young, H. M., Jianping, Z. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science*, 13(1), 13-16.
- Wagner, B., Knaevelsrud, C., & Maercker, A. (2006). Internet-based cognitive-behavioral therapy for complicated grief: A randomized controlled trial. *Death Studies*, 30(5), 429-453.
- Wagner, C. D., Bigatti, S. M., & Storniolo, A. M. (2006). Quality of life of husbands of women with breast cancer. *Psycho-Oncology*, 15(2), 109-120.
- Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed-methods study. *Health & Social Work, 32*(3), 197-206.
- Williamson, G., & Shaffer, D. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: How were then, how we are now. *Psychology and Aging*, 16(2), 217-226.

- Wilsey, S. A., & Shear, M. K. (2007). Descriptions of social support in treatment narratives of complicated grievers. *Death Studies*, *31*(9), 801-819.
- Zivin, K., & Christakis, N. A. (2007). The emotional toll of spousal morbidity and mortality. *The American Journal of Geriatric Psychiatry*, 15(9), 772-779.

APPENDIX A: PERMISSION TO USE WAYS OF COPING

For use by Sandra Rankin only. Received from Mind Garden, Inc. on September 17, 2010



www.mindgarden.com

To whom it may concern,

This letter is to grant permission for the above named person to use the following copyright material;

Instrument: Ways of Coping Questionnaire

Authors: Susan Folkman, Ph.D. and Richard S. Lazarus, Ph.D.

Copyright: 1988 by Consulting Psychologists Press, Inc.

for his/her thesis research.

Five sample items from this instrument may be reproduced for inclusion in a proposal, thesis, or dissertation.

The entire instrument may not be included or reproduced at any time in any other published material.

Sincerely,

Vicki Jaimez Mind Garden, Inc. www.mindgarden.com

APPENDIX B: DEMOGRAPHIC QUESTIONS

About you

- 1. What state do you live in? (drop down box)
- 2. What is your gender?
 - a. Male
 - b. Female
- 3. What is your current age?
- 4. How old were you when you starting proving care for your ill loved one?
- 5. How long have you been providing care for your ill loved one?
- 6. What is your current marital status?
 - a. Married
 - b. Single
 - c. Widowed
 - d. Life Partner
 - e. Common Law
- 7. What is your relationship to the cancer patient for whom you are providing care?
 - a. Spouse
 - b. Fiancé
 - c. Life Partner
 - d. Daughter
 - e. Son
 - f. Brother
 - g. Sister
 - h. Daughter-in-law
 - i. Son-in-law
 - j. Mother
 - k. Father
 - I. Other (text box)
- 8. What is your current employment status?
 - a. Full-time
 - b. Part-time
 - c. Retired

- d. Family medical leave (FMLA)
- e. Unemployed (not retired)
- f. Student
- 9. What is the highest level of education you completed?
 - a. High School/GED
 - b. Did not complete high school
 - c. Some College (no degree)
 - d. Associates
 - e. Bachelors
 - f. Masters
 - g. Doctorate/Professional
 - h. Certification (no degree)

About the Cancer Patient (your loved one)

- 10. What is your loved one's gender?
 - a. Male
 - b. Female
- 11. How old is your loved one?
- 12. What type of cancer is your loved one fighting? (text box)
- 13. When was your loved one diagnosed with cancer? (text box)
- 14. Where does your ill loved one live?
 - a. Their own home with spouse or other family member
 - b. Alone in their own home
 - c. With me in my home
 - d. Assisted living
 - e. Nursing home
 - f. Moved in with other family member
 - g. Hospice
 - h. Other (text box)
- 15. What is the employment status of the cancer patient for whom you are providing care?
 - a. No unemployed
 - b. No medical leave
 - c. Part-time

- d. Full-time
- e. Retired
- f. Volunteer
- g. Student
- 16. What is the highest level of education your ill loved one completed?
 - a. High School/GED
 - b. Did not complete high school
 - c. Some College (no degree)
 - d. Associates
 - e. Bachelors
 - f. Masters
 - g. Doctorate/Professional
 - h. Certification (no degree)
 - i. Do not know
- 17. What is the current marital status of your ill loved one?
 - a. Married
 - b. Single
 - c. Widowed
 - d. Life Partner
 - e. Common Law

APPENDIX C: SAMPLE WAYS OF COPING QUESTIONS

- 1. I just concentrated on what I had to do next the next step
- 2. I tried to analyze the problem in order to understand it better
- 3. I turned to work or another activity to take my mind off things
- 4. I felt that time would have made a difference the only thing was to wait.
- 5. I bargained or compromised to get something positive from the situation

APPENDIX D: INFORMED CONSENT FOR ONLINE SURVEY

My name is Sandra Rankin and I am a doctoral student at Walden University. I am requesting your help in a research study that examines the caregiving experience of family members of cancer patients. While there is no direct benefit for the participant, participating in the study will greatly help professionals to understand the experience of caregiving and how best to help and support the caregiver.

The study involves completing the online survey which will take approximately 15 minutes to complete. Your participation in this study is voluntary. By completing and submitting this online survey you are giving your consent to participate in this study. You may withdraw your consent and terminate participation at any time without consequence. This page serves as your informed consent. Therefore, you should print a copy of this page for your records.

If you believe you know the researcher, be assured the researcher will unable to identify you. This study is totally anonymous. There will be no way to identify participants after they have submitted their answers.

If you have questions or concerns you may contact the researcher at XXX-XXXX. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is X-XXX-XXXX, extension XXXX. Walden University's approval number for this study is 02-19-10-0342113 and it expires on February 18, 2011.

If several family members are involved in providing care for your ill loved one, all family members are welcome to complete this survey. If you are currently a caregiver and willing to participate in the study, click on the "NEXT" button below.

APPENDIX E: EMAIL INVITATION FOR ONLINE SURVEY

Dear XXXXX:

You are invited to take part in a study to understand the experience of caregiving and help to determine the best way to support family members who are caring for a loved one with cancer. The survey is online and will take approximately 15 minutes to finish. All of your information is anonymous and there will be no way to identify you after you submit your answers.

If you are willing to participate, simply go to the link below and answer the questions.

http://www.surveymonkey.com/s/rankinsurveyentrance

If you have trouble with the link, you can copy and paste this into your browser: http://www.surveymonkey.com/s/rankinsurveyentrance

If several family members are involved in providing care for your ill loved one, all family members are welcome to complete this survey. If you know of someone who is currently a caregiver for a cancer participant, please forward this email to him or her.

Sincerely,

Sandra Rankin, MA, LPC Doctoral Candidate Walden University

APPENDIX F: FLYER FOR ONLINE SURVEY

Does Your Loved One Have Cancer?

Are you helping care for them? Then we need your input!

You are invited to take part in a study to understand the experience of caregiving and help to determine the best way to support family members who are caring for a loved one with cancer.

If several family members are involved in providing care for your ill loved one, all family members are welcome to complete this survey.

If you are willing to participate, simply go to the link below and answer the questions.

http://www.surveymonkey.com/s/rankinsurveyentrance

The survey is online and will take approximately 15 minutes to finish.

All information that you provide is anonymous: there will be no way to identify you after you submit your answers.

CURRICULUM VITAE

Sandra R. Rankin, MA, LPC

Education

Walden University, Minneapolis, MN <i>Ph.D., Health Psychology</i>	Currently Enrolled
St. Edwards University, Austin, TX M.A., Human Services, Counseling	1996
Spalding University, Louisville, KY B.S., Computer Information Systems	1990
Spalding University, Louisville, KY <i>A.A., Computer Studies</i>	1985

License

Licensed Professional Counselor Texas License # 14867 Current/Active

Professional Experience

La Hacienda Treatment Center, Austin, TX

2007 to present

Senior Program Counselor

Oversee outpatient program for adult groups, provide group and individual therapy, provide educational lectures for adult patients and their and families, provide CEU workshops; fill in when Program Director is out of the office.

Mental Health Network, Austin, TX

2006 to 2006

Case Manager

Managed patient cases for various insurance companies, providing precertification/denial of inpatient stays based on medical necessity criteria. Position involved collaborating with Medical Directors, frequent utilization reviews, triage, crisis calls and explaining member benefits. Company downsized at the end of 2006.

Austin Community College, Austin, TX

2004 to 2005

Online Counseling Continuing Education Instructor

Developed and managed online continuing education courses aimed at therapists, social workers, and counselors; Responded to questions from students. Contract discontinued at end of 2005.

Executive Growth & Counseling, Inc., Round Rock, TX Owner/VP Education

2001 to 2004

Owner/operator of online continuing education business for therapists, social workers, and counselors in 5 states.

- Partnered with Austin Community College as continuing education vendor
- Provided access for professionals to purchase and complete CEU courses online, 24/7 with minimal human intervention
- Gained board approval as continuing education provider in 5 states
- Developed all online courses, tests, and evaluations

Texas Workforce Commission, Austin, TX

2000 to 2005

NT Administrator/Programmer V

Executive Growth & Counseling, Austin, TX

1999 to 2000

Private Practice Therapist

Provided psychiatric and chemical dependency counseling for adults.

• Developed cognitive restructuring therapy model (Rankin's Corporate Model, copyright, 2000)

Charter Behavioral Health Systems, Austin, TX Lead Therapist & Case Manager, Adult In-Patients

1997 to 2000

Responsible for quality, consistency, scheduling, and timeliness of adult inpatient services; provided individual, group and family counseling sessions; coordinated support services and after-care program placement with state and federal assistance programs.

- Developed/managed Counselor Intern Training Program, including supervision, scheduling, and instruction
- Trained therapists on properly completing Psychosocial Assessments
- Developed/coordinated program for providing weekend therapy for patients and families
- Reorganized and managed adult outpatient psychiatric program for one year
- Facilitated and supervised evening outpatient chemical dependency groups Developed/taught methods for working with psychiatric intensive care patients
- Employee of the Quarter, Spring 1998

Early Experience

Texas Guaranteed Student Loans, Austin, TX Instruction Specialist / Operations Analyst	1992 to 1997
Catapult, Inc., Austin, TX Instructor Manager	1992 to 1992
Austin Community College, Austin, TX Adjunct Instructor	1990 to 1994

Publications

Rankin, S. R. (1999, July). Controlling stress will increase productivity. *Austin Business Journal*, 19(22), 8.

Memberships

American Counseling Association American Psychological Association Texas Counseling Association Psi Chi (National Honor Society in Psychology)

Texas Board of Examiners of Professional Counselors approved CEU provider # 1368 Texas State Board of Social Workers Examiners approved CEU provider # 5805

Additional Information

Co-taught Abnormal Psychology to master's level students at St. Edwards University, Fall 1999.

Experienced in providing public workshops/seminars on assertiveness, stress management, team building and various other self-improvement and business skills.