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### THE EFFECTS OF MULTIPLE GRATITUDE INTERVENTIONS AMONG INFORMAL CAREGIVERS OF PERSONS WITH DEMENTIA AND ALZHEIMER'S DISEASE

by

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy in

Nursing Science

College of Nursing

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#### DEDICATION

I dedicate my work to the loving memory of my grandfather, Donald Edward Wright, who was the one who instilled in me that a positive outlook on life, despite the difficulties, was imperative to happiness. I also dedicate my work to the loving memory of my brother Steve and my Grandmother Clarice. I am thankful for the time I had you here. Save a place for me. To God be the glory.

#### ACKNOWLEDGEMENTS

Once upon a time, I began this journey not truly knowing where it will land or even, at times, how to get there. Completing this dissertation has been a challenging and extensive venture which at times, has felt like an impossible dream. With a heart and soul full of gratitude I wish to acknowledge and thank the many individuals in my life that together nurtured and supported my ideas and efforts throughout my graduate education.

First, I have to thank God for providing and sustaining me, especially in the times I would not have thought this all possible. To my husband Nathan, you have truly been *my rock* during this formidable adventure. You stood by my side constantly encouraging me and praying for me. Your unwavering commitment to our family and our marriage is a constant source of support. Many thanks go to my children who had to put up with me as I know this wasn't always an easy task. To my mother, Carol, who taught me how to selflessly care for others and has always been my cheerleader...thank you for guiding me to the right career choice. I also want to acknowledge and thank the many friends who encouraged me along the way.

I would like to express my deep appreciation for my dissertation committee chair Dr. DeAnne Messias for helping me to make this dissertation more than I could have imagined. I would like to acknowledge Dr. Kathleen Scharer for her guidance and mentorship throughout graduate school and give a heartfelt thanks for the time spent as the chair of my committee before her retirement. I would also like to thank Dr. Abbas

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Tavakoli, and Dr. Scott Huebner for lending me their time, expertise, and patience. To my research assistant, December Bishop, whom I will never forget, thanks for reminding me about the size of this world that we live in. Thanks are also due to the many support group leaders and caregivers who played a huge role in the success of this dissertation. I extend a special thank you to the Alzheimer's Association of South Carolina and to Shiela Lewis, without whom, this project would not have been possible. I would like to thank Dean Peggy Hewlett and the South Carolina Nurses Foundation for their support. You helped to encourage me to pursue my doctorate and you made it all possible.

#### ABSTRACT

The purpose of this group randomized intervention trial was to examine the impact of participation in three telephone-based gratitude interventions on the physical, psychological and social functioning of participants in caregiver support groups who are unpaid family caregivers of persons with dementia and Alzheimer's disease. Fredrickson's (2001) Broaden-and-Build Theory informed the investigation of the effect of three gratitude interventions on participants' levels of gratitude, positive aspects of caregiving, subjective well-being, physical health and mental health. This was a randomized, wait-list controlled study involving informal caregivers involved in support groups. The research questions were:

- How does gratitude contribute to subjective well-being, mental and physical health and the positive aspects of caregiving among caregivers?
- 2.) What is the relationship between gratitude, subjective well-being, physical and mental health and the positive aspects of caregiving?
- 3.) What is the effect of multiple gratitude interventions for the intervention group versus the control group?

The total sample (n=55) included caregivers involved in 12 support groups. Support groups were recruited from existing caregiver support groups in Richland, Lexington, Florence, Horry, and Spartanburg counties within the state of South Carolina. Each support group that had consenting participants was randomized using simple randomization by group to either the intervention or wait-list control group. Intervention group participants (n=-35) continued to attend support group meetings over a 5 week period during which they received three gratitude-based interventions by phone: positive writing about the past, daily gratitude lists, and a letter of gratitude. The wait-listed control group participants (n=20) continued to attend regular support group meetings and had the opportunity to participate in the gratitude activities upon completion of the research. Data collection involved pre-test (baseline) and posttest (2 weeks after last intervention) measures collected by telephone by a trained research assistant using standardized, reliable and valid measures.

The primary dependent variables were gratitude, the positive aspects of caregiving, satisfaction with life, physical health and mental health, measured using the Gratitude Questionnaire (GQ-6), the Positive Aspects of Caregiving Scale, the Satisfaction with Life Scale (SWLS) and the WHOQOL-BREF. Data analysis involved a basic structure of repeated measures analysis with pre (baseline) and post-intervention (2 weeks after last intervention).

The findings indicated gratitude was a significant predictor for positive mental health and there was a positive correlation between satisfaction of life and positive aspects of caregiving. At follow-up, there were no statistically significant differences on any outcome variables between participants in the intervention and control groups. Participants exposed to the gratitude intervention described being grateful for health, God, family, friends, and nature.

These findings suggest the need for further investigations of the role gratitude plays in family caregiving for persons with Alzheimer's disease and dementia. Implications for nursing education and practice include the incorporation of gratitude and

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positive psychology interventions in supporting and educating formal and informal family caregivers of individuals with Alzheimer's and dementia.

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#### CHAPTER 1

#### INTRODUCTION

"There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, those who will need caregivers" (Carter, 1995, p. 3)

Informal caregivers are unpaid individuals such as family members, friends and neighbors who provide assistance with the basic tasks of self-care (Family Caregiver Alliance [FCA], 2005; Stoller & Martin, 2002). Long-term care is needed when illness or trauma limits a person's ability to carry out basic tasks of self-care (FCA, 2005). This type of care can be provided in a variety of settings, including residential care, skilled nursing facilities, and in the home (FCA, 2005). Thompson (2004) reported 78% percent of community-living adults in need of long-term care relied on informal caregivers as their only source of help.

Individuals with Alzheimer's disease often require long-term caregiving support from informal caregivers. An estimated 5.4 million Americans have Alzheimer's disease and in 2011, more than 15 million family members and unpaid caregivers provided care in the home to people with Alzheimer's disease and other dementias (Alzheimer's Association, 2012). The number of persons 65 years old and over is expected to more than double by the middle of the next century (U.S. Census Bureau, 2008). More than 13.5 million people in the United States (US) will have Alzheimer's disease by the year 2050 (Alzheimer's Association, 2012). Despite the fact that informal care accounts for

the majority of long-term care delivered in the US, data on home health care and longterm care usage often exclude informal care (Golberstein, Grabowski, Langa & Chernew, 2009). Yet, the annual contribution of the care provided by unpaid caregivers has been estimated to be more than \$210 billion (Alzheimer's Association, 2012).

A serious and prolonged impairment, such as Alzheimer's disease leads to increasing dependency on others for long-term care. Informal care is an important component of the long-term care system (Wiener, 2009). Given the increasing risk for a growing number of Alzheimer's disease patients, it is essential to provide these caregivers with sufficient support and to further understand the nuances and differences of caregiving for this distinct population of care recipients. In this chapter, I provide an overview of Alzheimer's disease in the United States and the experience of being an unpaid caregiver of a family member with Alzheimer's disease. The theoretical framework is presented. The research aim and purpose, research questions and hypotheses are also included in this chapter.

#### Background

Alzheimer's disease is the sixth leading cause of death in the United States and the fifth leading cause of death in those aged 65 years old and older (Alzheimer's Association, 2012). The most common form of dementia, Alzheimer's disease, involves a loss or malfunction of neurons in the brain resulting in changes in memory, behavior and the ability to think clearly. The most common initial symptom is a gradual worsening in the ability to remember new information; as the disease progresses, the individual eventually loses the ability to perform basic functions such as walking and swallowing (Alzheimer's Association, 2012). As the damage spreads, those affected can

experience such signs as memory loss to the extent that it disrupts daily life, difficulty in planning and solving problems, trouble completing familiar tasks, confusion with time and/or place, trouble understanding visual images and spatial relationships, new problems with language and writing, misplacing things, increasingly poor judgment, withdrawal from social activities and changes in mood and personality. Individuals diagnosed with Alzheimer's disease progress from mild and moderate to severe at different rates, with death the eventual outcome (Alzheimer's Association, 2012).

The cause of Alzheimer's disease is not yet known and no treatment is available to slow or stop the progression of this disease. Medications have been approved to temporarily treat symptoms but their effectiveness varies (Alzheimer's Association, 2012). Out of the top ten causes of death in the United States, Alzheimer's disease has been the only disease for which there are no known methods to prevent, cure, or slow its progression (Alzheimer's Association, 2012). There are seven stages of Alzheimer's disease which provide a general guideline for understanding the progression of the disease (See Table 1.1).

#### **Unpaid Family Caregivers of Patients with Alzheimer's Disease**

Caring for a family member with Alzheimer's disease can be a devastating and challenging experience (Butcher, Holkup & Buckwalter, 2008). Alzheimer's disease is a tragic, debilitating chronic illness with an unpredictable course that averages 10 years from diagnosis to death (Alzheimer's Association, 2012). Caregivers generally experience a combination of grief and loss coupled with the physical and emotional demands of caregiving (Sanders & Corley, 2003). The grief that caregivers experience

does not subside as with other losses, but continues throughout the duration of the disease (2003). Losses associated with Alzheimer's disease are similar to those associated with death (Sanders & Corley, 2003). Caregivers have described their grief as an overwhelming sense of multiple losses felt on a daily basis throughout the entire course of the illness (Sanders & Corley, 2003).

Findings from nationally representative surveys conducted for the Alzheimer's Association (2012) indicated 80% of care for those with Alzheimer's disease is provided at home by an unpaid family caregiver. Many of these caregivers reported high levels of emotional stress and depression. More than 60% of caregivers of those with Alzheimer's disease and other dementias rated the emotional stress of caregiving as high or very high and one-third report depression (Alzheimer's Association, 2012).

Many of these caregivers also reported the physical and emotional toll of caregiving on their own health and had \$8.7 billion in additional health care costs in 2011 (Alzheimer's Association, 2012). Caregivers of people with Alzheimer's disease were more likely to report that their health was fair or poor and said that the greatest difficulty of caregiving was that it exacerbated their own health problems and that they had difficulty maintaining healthy behaviors (Alzheimer's Association, 2012). The type of assistance or help that these caregivers provide depends on the needs of the person with Alzheimer's disease and the stage of the disease (Alzheimer's Association, 2012). Each person with the disease progresses differently as phases overlap, time in each stage varies, and not everyone experiences all symptoms (Alzheimer's Association, 2012). Family members of those with Alzheimer's disease experience a great deal of stress

throughout the illness, but this stress varies and changes depending on the stage of the illness (Alzheimer's Association, 2012).

#### The Experience of Caring for a Family Member with Alzheimer's Disease

The burden of care usually falls upon family members who can become frustrated, frightened, guilty and bitter as the family member with Alzheimer's disease becomes increasingly dependent (Chenoweth & Spencer, 1986). Memory loss is the best known symptom of Alzheimer's disease, but this disease also causes loss of other abilities that can be detrimental to relationships. Personality and behavior can also be affected. The close relationship that involved shared experiences and memories that may have previously existed between the caregiver and the impaired person may be buried by the symptoms as the disease progresses. If the decision is made to move the person with Alzheimer's disease to an assisted living facility or nursing home, caregiving duties often do not end. Many family caregivers continue to provide help with activities of daily living (ADL's), assist with financial and legal affairs, make arrangements for medical care and provide emotional support (Alzheimer's Association, 2012). Family caregivers caring for someone with Alzheimer's disease struggle with this burden and often need help to deal with this situation.

#### **Theoretical Framework**

The theoretical framework guiding this study is the Broaden-and- Build Theory of Positive Emotions (Fredrickson, 2001), which is part of the growing field of positive psychology. The mission of positive psychology is to understand and foster the factors that help individuals, communities and societies to flourish (Seligman & Csikszentmihalyi, 2000). To harness the power of positive psychology, there is a need to

understand the effects of positive emotions and attempt to understand how and why these lead to states of mind and modes of behavior that help to build personal resources. Positive emotions serve as markers of flourishing or optimal well-being. The Broadenand-Build Theory states that positive emotions, such as gratitude, have the ability to help build physical, intellectual, social and psychological resources through an enhanced mindset (Fredrickson, 2001). As a result, these broadened mindsets carry indirect and long-term adaptive benefits and can help to build reserves to be drawn on later to improve coping (Fredrickson, 2001).

Gratitude has been described as being aware of and thankful for the good things that happen, and taking time to express thanks (Emmons & McCullough, 2004; Seligman, Steen, Park & Peterson, 2005). Gratitude interventions consistently demonstrated the most increase in subjective well-being when compared with other positive psychology interventions (Emmons & McCullough, 2004). The diverse benefits of gratitude can be understood through the framework of the Broaden-and-Build Theory.

#### The Broaden-and-Build Theory

The Broaden-and-Build Theory (Figure 1.1) aids in describing the form and function of positive emotions (Fredrickson, 2001). The central idea of this theory is that positive emotions such as joy, contentment, love and gratitude help to broaden an individual's thought-action repertoire. These positive emotions are found to promote the discovery of creative actions, ideas and social bonds which help build personal resources and provide adaptive benefits. The resources built through positive emotions outlast the transient emotional states that helped them to be acquired (Fredrickson, 2004).

Positive emotions may help to fuel resiliency (Fredrickson, 2004). Those people that are considered resilient are said to thrive in difficult circumstances, have faster recovery from stressors and a consistently high level of functioning. Understanding why some people thrive could be very beneficial to informal caregivers of family members with Alzheimer's disease. Psychological thriving may include newly developed skills and knowledge, renewed confidence and the sense of mastery and strengthened personal relations (Fredrickson, 2004). People that have been found to be thriving in the face of adversity cost our health care system less, were less prone to relapse and might even be less vulnerable to new adversities (Carver, 1998).

According to the Broaden- and- Build Theory, interventions cultivating the positive emotion of gratitude will help individuals to increase their sense of well-being, including their physical and mental health (Fredrickson, 2004). The broadened awareness created by gratitude may help individuals recognize the value of the new behaviors presented by the positive psychology interventions, and broadened thought-action repertoires may help them integrate these new behaviors into their daily lives (Cohn & Fredrickson, 2010).

Positive psychology and gratitude may prove to be beneficial components to add to current caregiver support. Current approaches to caregiver support might be enhanced by providing education and support that would help to build and strengthen personal resources. Using gratitude interventions to build caregiver resources could help to increase Alzheimer's disease caregivers' level of functioning and help them to recover more quickly from caregiving stressors.

#### **Research Questions and Hypotheses**

The three research questions were:

- 1.) How does gratitude contribute to subjective well-being, mental and physical health and the positive aspects of caregiving among caregivers?
- 2.) What is the relationship between gratitude, subjective well-being, physical and mental health and the positive aspects of caregiving?
- 3.) What is the effect of multiple gratitude interventions for the intervention group versus the control group?

The first hypothesis was that gratitude will independently predict subjective wellbeing, perceived physical and mental health, and high positive aspects of caregiving. The second hypothesis was that a positive correlation will exist between and among these constructs. The third hypothesis was that the intervention group will have higher scores of gratitude, subjective well-being, mental and physical health, and higher positive of aspects of caregiving post-test scores than the control group who will be attending the support group only.

The results of this study contribute to the body of knowledge of gratitude interventions and their use among caregivers and will help advance caregiver support and promote advocacy for the caregivers of people with Alzheimer's disease and dementia. A greater understanding of how positive psychology in the form of gratitude may be useful in to supporting caregivers. Without this understanding, caregivers will not know the effects of focusing on the positive emotion of gratitude and how it can aid in building their enduring personal resources. The primary focus of most previous research is the negative aspects of caregiving. No recent research has addressed the potential impact of

positive psychology as additional support of caregivers of people with dementia or Alzheimer's disease. The following chapter contains a review of the recent research literature on caregivers with Alzheimer's disease, the positive aspects of caregiving, positive psychology and gratitude.

Table 1.1: The Seven Stages of Alzheimer's Disease
--

Stage	Characteristics
1 No cognitive decline	• No impairment
2 Very mild cognitive decline	Minimal impairment in memory, especially forgetting names and locations of objects
3 Mild cognitive decline	<ul> <li>Can get lost when traveling to a new location, word and name finding becomes more apparent, decreased performance in work and difficulty in social settings</li> <li>Anxiety and depression can begin to be symptoms</li> </ul>
4 Moderate cognitive decline	<ul> <li>May begin to have difficulty with managing complex tasks such as cooking, driving, or managing finances</li> <li>May have reduced memory of recent events and conversations but most still know themselves and their family</li> <li>Social withdrawal may begin at this stage and most become defensive and deny problems</li> </ul>
5 Moderately severe cognitive decline	<ul> <li>Decline is more severe and is no longer able to manage independently</li> <li>Unable to recall important information such as address and phone number and become confused about place and time</li> <li>Severe decline in mathematical abilities and judgment skills</li> <li>Require increased supervision with basic tasks</li> </ul>
6 Severe cognitive decline	<ul> <li>Lack of awareness of recent experiences and difficulty remembering the past</li> <li>Lose ability to independently do activities of daily living</li> <li>Can have agitation and hallucinations especially in evenings and late afternoon; may wander and get lost</li> <li>Dramatic personality changes including suspicion of family members and compulsive, repetitive behaviors</li> <li>May forget the name of their spouse or primary caregiver</li> </ul>
7 Very severe cognitive decline	<ul> <li>Speech becomes severely limited and most lose ability to speak and be understood; swallowing impaired</li> <li>Need help with eating and toileting; general incontinence</li> <li>Lose ability to walk independently and sit without support</li> <li>even Stage Global Deterioration Scale (Reisberg, Ferris, deLeon &amp;</li> </ul>

Adapted from the Seven Stage Global Deterioration Scale (Reisberg, Ferris, deLeon & Crook, 1982)

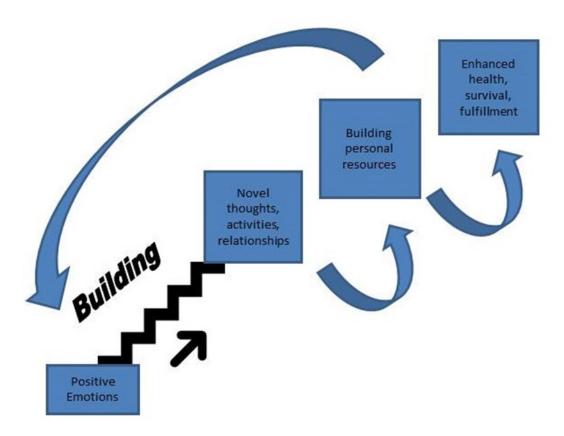


Figure 1.1 The Broaden and-Build Theory of Positive Emotions

Adapted from the Broaden-and-Build Theory of Positive Emotions (Fredrickson & Cohn, 2008, p. 783)

### CHAPTER 2

#### **REVIEW OF THE LITERATURE**

#### **Caregivers of Family Members with Alzheimer's Disease**

Informal family caregivers of family members with Alzheimer's disease may need support through the process of adapting and adjusting to the stress encountered while providing care to their relatives. In this chapter, I provide a review of the current research literature on caregivers of Alzheimer's disease, the positive aspects of caregiving, positive psychology and gratitude.

#### **Informal Family Caregivers**

The empirical literature on informal caregiving has focused on identification of caregiver characteristics (Department of Health & Human Services [DHHS], 1998; American Association of Retired Persons [AARP], 2001; Stoller & Martin, 2002; Family Caregiver Alliance [FCA], 2005; National Alliance for Caregiving [NAC], 2009). The research on caregivers tends to include women, the majority of whom are middle aged (35-64 years of age; 50 years of age on average). Among the U.S. population, it has been estimated the average caregiver was married and working full-time while providing 19 hours of care in an average week (NAC, 2009).

The AARP Caregiver Identification Study (2001) found that 69% of respondents said that a caregiver was *a person caring for someone* and 1 in 10 respondents said they were not familiar with the term *caregiver*. Many spouses reported that over time they were providing more and more daily care for their significant other despite not

recognizing themselves as caregivers. In the early stages, many Alzheimer's disease caregivers attributed their spouse's symptoms to *just getting older* (Morgan & Laing, 1991). These data clearly showed there was a possibility that research and intervention efforts may not have captured all of caregiving and the issue of caregiving could be much larger than was reported.

#### **Consequences of Caregiving**

Family caregivers are at risk for physical and psychological health problems (e.g., Schulz, Visintainer, & Williamson, 1990; Schulz, OBrien, Bookwala, & Fleissner, 1995; Schulz & Beach, 1999; Vitaliano, Zhang & Scanlan, 2003; Pinquart & Sorenson, 2003). Historically, research has focused on the negative aspects of care such as burden, strain, stress, and depression (e.g., Zarit, Reever & Bach-Peterson, 1980; Brodarty & Hadzi-Pavlovic, 1990; Dura, Stukenberg & Kiecolt-Glaser, 1991).

Caregiving and its relationship to stress in the face of illness has been the topic of many studies. Caring for a loved one who was experiencing a life-threatening illness wears heavily on caregivers. Schulz, O'Brien, Bookwala, & Fleissner (1995) found evidence suggesting that caregivers were at a high risk for health problems. Schulz et al., (1995) showed that caregivers had higher levels of self-reported health problems than non-caregivers.

In a study reported by Stetz and Brown (2004) comparing cancer and AIDS family caregivers in regard to their physical and emotional health, results demonstrated high levels of stress and depression in the caregivers when compared to community norms. Stetz and Brown (2004) showed that caregivers do indeed have higher levels of

stress than population that were not providing care. Additional insight was gained about the experience of caregiving and its relationship to physical and emotional health.

In evaluating younger caregivers of relatives Gaugler et al. (2005) studied 233 caregivers from an inner-city area and outlying counties and found that younger caregivers were more likely to report emotional fatigue with caregiving responsibilities. This study showed that the potential for competing role responsibilities among younger caregivers in conjunction with other life course roles such as childrearing, fulltime employment and various economic responsibilities exacerbate feelings of exhaustion, fatigue, and overload. Although the focus was on younger caregivers, the importance of competing roles is important, particularly for those caregivers who face various economic challenges.

Caregiver burden has been a key measure in caregiver research. Those who care for a family member experience stress on a daily basis. Caregiver burden, as a manifestation of that stress, has been thoroughly researched, particularly with respect to coping and social support. These feelings of burden may have affected the caregivers' willingness or ability to provide care and may have negatively their physical and mental health (Schulz & Beach, 1999). In a cross sectional study , Campbell and colleagues (2008) examined caregiver burden, relationship quality, caregiver confidence, experience of adverse life events, neuroticism, age and gender for 74 caregivers in England. Through multiple regression analysis, the researcher's findings validated the findings of Schulz and colleagues (1995) reviews of over 50 caregiver studies. The findings indicated that it is not the objective measure of load from the patient that determines burden level, but the subjective interpretations by the caregiver as well as coping efforts.

The literature on caregiver health and well-being has identified multiple factors that affect the outcomes of the caregiving experience. In order to fully address these negative effects, it is also important to identify the financial impact that caregiving has on both the caregivers themselves, their families and the economy.

Social and financial impact of family caregiving. The economic value and impact of informal caregiving often has been overlooked. The contributions of informal caregivers have been the foundation of the long-term care system in the U.S. and an important part of the economy (AARP, 2007). The care that adult-children caregivers provide to their parents has been shown to reduce the likelihood that beneficiaries will have Medicare expenditures for formalized long-term care (VanHoutven & Norton, 2004). Home health expenditures by Medicare and Medicaid have been projected to grow through 2019 due to the continued shift of long-term care from institutional to home settings (Centers for Medicare & Medicaid Services [CMS], 2009). The AARP (2007) reported that the economic value of caregiving has been estimated to be \$350 million. This number was an assumption about the cost of replacing the services that informal caregivers provided, but even a conservative estimate shows the substantial worth of the resources that these caregivers provide. The cost of caring for those with Alzheimer's disease will have an enormous increase as the baby boomer generation ages. Medicare spending will increase and the cost to families will continue to rise. The sandwich generation is a generation of people who care for their aging parent while still trying to raise their own families (Pierret, 2006). As the baby boomer generation ages, many caregivers will find themselves caring for their family members while still trying to raise their own families. This will mean many caregivers will find themselves also employed

in a full-time job outside of the home. The economic impact of caregiving can be profound and is an important issue when determining the value of caregiving and the demands and impact of the caregiving role.

**Employed family caregivers.** Family caregivers who arrange care for loved ones with chronic conditions are often forced to alter their everyday lives to accommodate their family member's health condition (National Academy on an Aging Society, 1999). Employed family caregivers juggle between work and home and elder care responsibilities. An estimated 19% of American adults reported caring for an older relative and at least 15-25% of workforce has been comprised of family caregivers (AARP, 2007). Family caregiving has been costly from the employer's point of view.

The National Alliance for Caregiving (2009) revealed that family caregiving costs the nation's employers more than 33 billion annually in productivity losses. The NAC (2009) study examined a large manufacturing company which looked at the health of family caregivers and the associated health costs to the employer. The family caregivers in this company had a higher incidence of self-reported depression, a greater tendency to engage in poor health habits and showed markedly higher rates of other chronic conditions. This study also estimated that these caregivers cost the employer 8% more in additional health care costs when compared with non-caregivers. According to the 2009 National Alliance for Caregiving study nearly three quarters (74%) of family caregivers have been employed while their helping an older adult friend or relative. A typical family caregiver spent an average of 19 hours a week giving care. Employed family caregivers frequently have to make accommodations at work including going in late/leaving early/taking time off, taking a leave of absence, reducing their work hours or

choosing to take a less demanding job, giving up work entirely and turning down promotions (NAC, 2009). Despite these demands, there are positive outcomes of caregiving. These outcomes have been called the positive aspects of caregiving.

#### **Research on the Positive Aspects of Caregiving**

A review of the positive aspects of caregiving literature acknowledged that the phenomenon does exist, but many questions remain about the significance of the relationship between the negative and positive aspects of caregiving and if there is even a true relationship between them. The following paragraphs will synthesize and discuss the research found and discuss implications for future research.

Despite the negative aspects of caregiving, most caregivers find positive aspects of and meaning in caregiving (Butcher, Holkup & Buckwalter, 2001; Farran, Keane-Hagerty, Salloway, Kupferer & Wilken, 1991). The majority of the research on the positive aspects of caregiving has been done with caregivers of those patients with Alzheimer's disease or dementia. Boerner, Schulz and Horowitz (2004) and Kinney and Stephens (1989) in their research with Alzheimer's disease and bereaved caregivers found as the perceived positive aspects of caregiving increased, these caregivers experienced higher levels of grief. The correlation of these measures to length of caregiving and quality of prior relationship is unknown. Farran et al. (1991) examined 94 family caregivers of patients with Alzheimer's disease. Almost all participants (90%) gave responses that they valued positive aspects of relationships and of caregiving and that these positive experiences helped them to find meaning in the caregiving process. Several studies with bereaved caregivers or those caring for those at the end-of-life report that the positive aspects of caregiving co-existed with the negative aspects but the

positive aspects were independent (Narayan, Lewis, Tornatore, Hepburn & Corcoran-Perry, 2001; Cohen, Colontoni & Vernich, 2002; Sanders, 2005). Those studies that examined caregivers regardless of diagnosis have focused mostly on the characteristics of the caregivers that might be related to positive aspects (Lopez, Lopez-Arrieta & Crespo, 2004; Koerner, Kenyon & Shirai, 2009). Koerner, Kenyon and Shirai (2009) found that the positive aspects of caregiving were associated with two personality traits: agreeableness and extroversion.

Upon review of the literature, several concepts were identified that were positive in nature and related to the caregiving experience. Many studies used the term *positive aspects of caregiving* (e.g., Grant, Ramcharan, McGrath, Nolan & Keady, 1998; Cohen, Colantonio & Vernich, 2002; Boerner, Schulz & Horowitz, 2004; Chen & Greenberg, 2004; Kim, Schulz & Carver, 2007; Bolden & Wicks, 2010). Also used were gain, rewards, and uplifts. The term *positive aspects of caregiving* is not clearly defined and may be interpreted in multiple ways.

Critical to an understanding of research on the positive aspects of caregiving have been issues related to the measurement of this construct. Although a significant amount of research has examined some positive aspect of caregiving, the vast majority of these studies have employed instruments of questionable reliability and validity. In order to determine the value of a study, reliability and validity of instrumentation must be known and reported. Many studies chose to create their own measures that were not tested for reliability (Rapp & Chao, 2000; Cohen, Colontoni & Vernich, 2002). The Positive Aspects of Caregiving Scale was a measure specifically designed for the REACH study which compared a variety of interventions for dementia caregivers (Schulz & Beach,

2000). The REACH (2000) study was a landmark study in caregiver research due to its large sample size and use of multiple sites. Koerner, Kenyon and Shirai (2009) also used the positive aspects of caregiving scale as they examined the positive and rewarding experiences of caregiving to determine if they were a function of personality or other interpersonal factors. Data were collected from 63 family caregivers by mailing this questionnaire to participants.

#### Guiding Theories of Research on Positive Aspects of Caregiving

Theoretical and conceptual frameworks have interrelated roles in the progress of science. Theories allow researchers to draw facts together and link findings to a coherent structure to make evidence more useful (Polit & Beck, 2004). Approximately 25% of the studies reviewed had no mention of a guiding theory or conceptual framework (e.g., Kinney & Stephens, 1989; Scott, Arslanian & Engoren, 2005; Koerner, Kenyon & Shirai, 2009). For many of the studies where a guiding theory or conceptual framework were given, it was not clear how the theory was actually used and few of the authors provided explanations for the meaning and definitions of the theoretical terms used. Original sources were not always cited or accurate and a description of how the theory guided the study was vague (Narayan et al., 2001; Kim, Schulz & Carver, 2007; Bolden & Wicks, 2010). The majority of caregiving research has been used to describe the negative outcomes of the caregiving process on family caregivers and has utilized stress and coping theory as a guide.

Several theoretical frameworks have been used in research on positive aspects of informal caregiving. One example is the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), employed in a study of the influence of positive aspects of

caregiving as a moderator of treatment for Alzheimer's caregivers (Hilgeman, Allen, DeCoster & Burgio, 2007). The researchers utilized the stress and coping framework of Lazarus and Folkman (1984) to explain the differences in the ability of caregivers to manage the stress and to predict physical and emotional outcomes. Hudson (2004) studied the positive aspects and challenges associated with caring for a dying relative at home. The researcher used this model to describe the positive interpretations of the caregiving role by caregivers as a meaning-based coping resource.

In order to better understand how the positive aspects of caregiving relate to the negative consequences of caregiving, Pearlin's (1990) model of caregiver stress was used to examine the association between meaning and psychological well-being. This model was used as a model for incorporating the construct of meaning into the stress process framework (Noonan & Tennstedt, 1997). Pearlin's (1990) model of the caregiver stress process aided in describing some factors as resources that help alleviate some of the negative effects of stress and other factors that magnify the stress. In the next section, I discuss Positive Psychology and gratitude.

#### **Positive Psychology**

The field of positive psychology provides an alternative approach to the study of human behavior by focusing on fostering the positive rather than the repair of the negative (Peterson, 2006). Martin Seligman is known as one of the leading researchers in the field of positive psychology. His insight with his own children led him in his research on flourishing and optimism. Through being a parent, he realized that raising children was not about correcting their weaknesses and whatever is wrong with them, but about identifying and nurturing their strengths. Positive psychology facilitates the

development and display of positive traits, which in turn facilitate positive subjective experiences (Seligman & Csikszentmihalyi, 2000; Peterson, 2006).

The study of positive psychology has been a comprehensive look at describing and understanding the *good life* or what makes life worth living (Peterson, 2006). Positive psychology focus has not been just on happiness, but has encompassed all positive emotions such as joy, interest, contentment, pride, love, and gratitude. From the perspective of positive psychology, gratitude as a positive emotion can help to build psychological, physical and social resources.

Gratitude has been defined in the American Heritage Dictionary ("Gratitude", 2001, p. 371) as simply....*thankfulness* from the Latin word *gratus* which means pleasing. We all have been familiar with the feeling of gratitude when we received a gift and were thankful to the person who gave it to us. This limited definition of gratitude does not begin to reflect the deeper meaning and experience that gratitude represents.

#### Gratitude

Gratitude is defined as being aware of and thankful for the good things that happen, and taking time to express thanks (Peterson, 2006). Gratitude has often been seen as the key or path to the experience of God or a higher power (Emmons & McCullough, 2004). Gratitude has been found to have a high positive correlation with happiness, life satisfaction and subjective well-being. According to the observations of Lyubomirsky (2008), the happiest participants in her research studies had their share of crises and became just as distressed and emotional in such circumstances, but they were also those that were most comfortable expressing gratitude for all they have.

Multiple benefits are associated with gratitude (Emmons & McCullough, 2004). Researchers, theorists, and practitioners have identified social, developmental, biological and personal growth benefits associated with gratitude. Social and developmental benefits of gratitude include the enhancement of dyadic relationships and the promotion of prosocial behavior. The biological benefits of gratitude have not yet fully explored but include benefits to physical health and optimal functioning.

**Social and developmental benefits of gratitude.** There has been a wealth of research which supported the idea that gratitude has a great influence in dyadic relationships and at the societal level. The literature has clearly shown that gratitude has the ability to benefit relationships and social networks. "Providing benefits and creating bonds of gratitude tie people together in society, whatever their place in the social hierarchy" (Emmons & McCullough, 2004, p. 23). Gratitude could be defined as the intangible capital for society.

A dyadic relationship was one where both members performed actions that benefited the other (Algoe, Gable, & Maisel, 2010). As relationships moved through time, some or all of these benefits may have gone unnoticed or become routine. Relationships can be fostered and grown through an emotional response of gratitude. The relationship-building effect of gratitude points to an extension of the traditional thinking about the role of gratitude, expanding it past being merely a reciprocal exchange, to one of constructing and strengthening relationships (Bartlett & DeSteno, 2006; McCullough, Kimeldorf, & Cohen, 2008; Algoe & Haidt, 2009).

In a study by Algoe, Gable and Maisel (2010), romantic partners were asked to complete nightly diaries for 2 weeks to record their thoughts. They were also asked to

record their emotional responses and their interactions with their partners from that day. Increased feelings of satisfaction with the relationships and increased feelings of connectedness were reported by the participants. Gratitude was associated with increased relationship quality for both members of the relationship. Gratitude may help to turn *ordinary daily moments* into opportunities for relationship growth (Algoe, Gable & Maisel, 2010).

Gratitude is discussed as *an other praising emotion* which results in a focus on others (Algoe & Haidt, 2009). Gratitude was found to produce reports of motivation for people to do things to create or strengthen relationships. Gratitude was found to be significantly related to marital satisfaction (Gordon, Arnette, and Smith, 2011). In a marital relationship, expressed gratitude may have benefits such as an outward showing of appreciation to a partner. When a spouse expresses gratitude to a partner, the spouse acknowledges and celebrates the partner, the acknowledgment has the potential to leave the partner wanting to nurture and support the marriage (Gordon, Arnette & Smith, 2011). Appreciation has been found to be one of the easiest positive emotions that can be self-induced and sustained for long periods of time (Emmons & McCullough, 2004).

Further evidence for the implications of gratitude in growing relationships was found in another study which looked at gift-giving in sororities (Algoe, Haidt & Gable, 2008). Gratitude was found to help in initiating a relationship-building cycle. Relationships with others can help us get through periods of difficulty and help us to flourish when times are good. The true aspects of gratitude are thought to lie far beyond that of just reciprocity; gratitude is also thought to build relationships (Lambert, Clark, Durtschi, Fincham, & Graham, 2010; Lambert & Fincham, 2011).

Prosocial behavior has been defined as the act of helping another person or society as a whole (Bartlett & DeSteno, 2006). Grateful people are more likely to behave prosocially (Tsang, 2006). Participants reported being motivated to give to others when they themselves were the recipient of a favor. In the three studies by Bartlett and DeSteno (2006), the ability of gratitude to shape prosocial behavior was examined. All three studies demonstrated that gratitude increased efforts to help others even when it was costly and that the emotion of gratitude increased assistance provided to strangers. This reciprocity aided in building trust and in building social relationships.

Gratitude may foster a sense of connectedness to others, the community and society. Being grateful has been shown to strengthen social bonds and increase the desire to give back to society in adolescents (Froh, Bono, & Emmons, 2010; Froh, Emmons, Card, Bono, & Wilson, 2011). Gratitude predicted social integration in these adolescents and lead to increased well-being which were considered to be essential to successful development and preparation for the demands of adulthood. Upstream generativity or reciprocity (also known as paying it forward, or repaying a kindness paid to you) was found to be initiated and fueled by gratitude which can help to promote the well-being of both the individual and society as a whole (Nowak & Roch, 2007; McCullough, Kimeldorf & Cohen, 2008; Froh, Bono & Emmons, 2010). This principle of reciprocity not only applies to material things, but also to nonmaterial things such as offering help, encouragement or extending an invitation (Emmons & McCullough, 2004). Gratitude has been crucial for every society and culture. Cultivating gratitude at the social level created ties which form mutual trust, a moral basis on which to act and aided in the maintenance of bonds within a community (Emmons & McCullough, 2004).

**Biological benefits of gratitude.** The biological benefits of gratitude would include the effects of gratitude on physiologic health. A holistic view requires that emotion of gratitude would be physically expressed just as other emotions are expressed behaviorally. Emotions may be accompanied by patterns that are characteristic of bodily expression (Freund, 2008). Chronic stressors or emotional responses can have neurohormonal consequences that may negatively affect such bodily functions as blood pressure, immunity, and other physiological functions (2008).

There has been a lot written about the transformative power of positive emotions, but scientific explorations of these experiences have been lacking (Emmons & McCullough, 2004). There is a growing body of research showing positive emotions may be the key to optimal functioning. It was once thought that the emotions were maintained by only the brain, but we now know that the body has a response to emotions. The heart, brain, nervous and hormonal systems make up the components of emotional experience (Emmons & McCullough, 2004). Krause (2006) found that gratitude was positively correlated to better self -reported health and less subjective stress levels. According to Algoe, Haidt and Gable (2008), grateful people tended to take better care of themselves and engaged in more health promoting behaviors. An increase in the number of hours of sleep and a better quality of sleep have also emerged as improvements in health related to gratitude (Nelson & Harvey, 2003; Emmons & McCullough, 2003; Wood, Joseph, Lloyd, & Atkins, 2009). Those that practice activities that promote gratitude regularly have reported a stronger immune system and fewer physical symptoms such as headaches, coughing, nausea or pain (McCullough, Emmons, & Tsang, 2002; Emmons & McCullough, 2003; Sheldon & Lyubormirsky, 2006).

Additional evidence of health and physiologic change as it relates to gratitude is an area in need of further research.

**Personal growth related to gratitude.** Gratitude and personal growth appeared to be related. Gratitude has been described as being related to a life that is meaningful and makes a unique contribution to self-acceptance and personal growth (Wood, Joseph, & Maltby, 2008). According to Fredrickson's (1998) Broaden - and - Build theory, gratitude is a positive emotion that creates resources that build upon one another and served as reserves to be drawn on in time of need.

There are several examples of transformational growth in those who were able to express gratitude during times of great difficulty. There has been a growing body of literature on resilience that suggested that negative events can be endured and actually result in positive adaptation despite adversity after difficult events such as the Vietnam War and the attacks of September 11<sup>th</sup>. The relationships among positive emotions and posttraumatic stress disorder (PTSD) for women with trauma histories have been investigated. Post-trauma levels of gratitude were independently negatively associated with PTSD symptom level (Vernon, Dillon and Steiner, 2009).

Many people stated that their life changed positively in response to negative events and gratitude was one emotional response that may have been a part of their cognitive processes. Vietnam War veterans without post-traumatic stress disorder [PTSD] reported higher levels of gratitude and well-being (Kashdan, Uswatte & Julian, 2006). Gratitude in response to trauma has not been fully explored, but it was hypothesized that gratitude stemmed from spiritual deepening or the sense that life was of value as a result of experiencing a traumatic event (Vernon, Dillon, & Steiner, 2009).

The report of positive traits after the September 11<sup>th</sup> terrorist attacks as listed in the Values in Action Classification of Strengths (VIA) questionnaire showed increases 2 months after the attacks and continued to be elevated 10 months after the attack (Peterson & Seligman, 2003). The VIA is much like the DSM-IV but lists positive traits rather than disorders. Gratitude was listed as one of the seven character strengths that increased after the September 11<sup>th</sup>. The researchers stated that people turned more towards others which changed their social worlds and resulted in more personal growth as a result of the traumatic experience.

The existing research suggests that gratitude may be an important part of what people define as a part of life that is positive and good. But the question remains, what are the conditions that result in people becoming grateful? It appears that a recognition of the absence or potential absence of those things or people that were important may result in development of a deep appreciation, or gratitude (King, Hicks, & Abdelkhalik, 2009; Frias, Watkins, Webber, & Froh, 2011). When people are faced with adversity, they may gain new coping skills or use skills that they did not know that they possessed (Krause, 2006). Stressors may also trigger higher levels of self-examination which could lead people to approach their lives from a more positive direction. Stressors may also help people develop a deeper appreciation for others and a deeper sense of meaning in life (Krause, 2006).

Association of gratitude and religion. Most research studies about gratitude have focused on feelings of gratitude without reference to whom or what one was grateful to (Krause, 2006). Gratitude was found to be likely to build and strengthen a sense of spirituality and has also been found to have a strong association with religion (Emmons

& McCullough, 2003). The roots of gratitude can be seen in many of the world's great religions such as Judaism, Christianity and Islam. In all of these religions, the concept of gratitude has been woven throughout texts, prayers and teachings. Gratitude has been the most common emotion that religion seeks to provoke and sustain in believers (Emmons & Crumpler, 2000). In Judaism, thankfulness is everything has been presented as a vital component because all things have been thought to come from God. It has been taught that prayers that praise God should be said in good and bad times in order to keep a divine perspective on life. In the Christian perspective, gratitude has been a main theme. Because humans were believed to have been created by God, Christians have been obligated to praise and thank the source of their life. In Christianity, gratitude shapes emotions, thoughts, actions and deeds and is taught as a way to live with others. God is said to be the ultimate giver (Emmons & Crumpler, 2000). Mature religiosity is said to originate out of feelings of profound gratitude and thankfulness toward God and to also be one of the surest ways to be able to see the Holy Spirit in someone's life (Emmons & Crumpler, 2000; Emmons & Kneezel, 2005). The Islamic tradition of Ramadham is actually a period of fasting said to lead to a state of gratitude. In Islam, gratitude is described in layers, with the first layer being grateful for receiving any gift and the higher layer being attained when one can be grateful in not receiving gifts or being thankful for gifts that are hidden in times of affliction (Emmons & Crumpler, 2000).

In a study of adults with congenital and late-onset neuromuscular diseases, Emmons and Kneezel (2005) found 85% of the sample identified as Christian. The researchers asked the participants to write about a time in their lives when they felt a strong sense of gratitude and to recreate it in their minds. Public and private

religiousness were found to be significantly associated with dispositional gratitude and grateful feelings. The findings suggested that gratitude was also found to be positively related to a nondenominational measure of spiritual transcendence. Grateful people were more likely to see an interconnectedness of all life and feel more of a connection and commitment to others. Those who reported higher levels of gratitude described seeing life in more of a transcendent context and recognized the possibilities of gifts to be found in all things that are a part of life. The research findings suggested that gratitude did not necessarily require a spiritual or religious framework, but that being religious and/or spiritual may facilitate feelings of gratitude.

Prayer is considered as a formalized manner to detach oneself to increase awareness of blessings that are meaningful and valuable. Lambert, Fincham, Braithwaite, Graham, & Beach (2009) examined the relationship between prayer and gratitude in three different studies. Praying was found to predict modest increases in gratitude. In these studies, prayer was found to be reported as a frequent reminder to express gratitude and aided in noticing every day surroundings as gifts from a supreme creator. Prayer was noted as a potential tool for clinicians where culturally appropriate. The benefits of prayer also could occur through a similar process of meditation which would not be based in any one spiritual set of beliefs (Lambert et al., 2009).

The link between gratefulness to God and the effects of stress on health in late life was explored in a study by Krause (2006). The findings of this study included that the effects of stress on health were reduced for older people who felt more grateful to God. There was a stress-buffering property found in gratitude toward God. The findings from the study highlight the potential of gratitude to aid in buffering stress through the

maintenance and growth of a spiritual relationship with God while aiding older adults to age successfully.

## **Gratitude Interventions**

Intervention experiments utilizing gratitude have been found, in general, to have positive effects. It is unknown how long-lasting those effects have been. These interventions have shown that focusing on inducing gratitude can have a beneficial impact on people's lives (Bono & McCullough, 2006). In the following sections I will identify and discuss the current literature on reflecting and journaling, positive writing and gratitude letters. I will also discuss explanations for the effectiveness of gratitude interventions decreasing and summarize my findings.

**Reflecting and journaling.** Counting blessings and being aware of their influence in one's life has been found to be an effective approach for maximizing one's contentment and happiness (Emmons & McCullough, 2003). A concept called hedonic adaptation was mentioned in the literature on gratitude (Lyobomirsky, 2008). This was defined as an adaptation to satisfaction or the ability to become rapidly accustomed to sensory or physiologic changes. It has been found that people show this same adaptation to life events such as marriage or chronic illness (Lyubomirsky, 2008). In order to have the ability to notice, appreciate and savor all the pieces of life, one must overcome this adaptation which requires regular practice of grateful thinking and reflection. This process is not without its share of work. It requires consistency, intention and a great deal of effort (Lyubomirsky, 2008).

In three separate studies, Emmons and McCullough (2003) examined the associations between journal writing and physical and social well-being among samples

of undergraduate students for two of the studies and adults with congenital or adult-onset neuromuscular disorders for one of the studies. The participants wrote a journal of positive and negative affects experienced, coping behaviors, health behaviors, physical symptoms and their overall appraisal of life. In one of the studies participants were asked to look back over the past week and to write down up to five things in life that they were grateful for during a ten week span of time. Two of the studies utilized a *daily experience rating form* which utilized more of a reflection technique in reviewing their reactions and emotions related to daily experiences.

In a 4-week longitudinal study, Sheldon and Lyubomirsky (2006) examined the positive outcomes of practicing and expressing gratitude among a sample of undergraduate students. The participants attended small group sessions were asked to cultivate a sense of gratitude over the next several weeks and to make an effort to think about the many things in life for which they were grateful. The participants received examples of what this might include and then were instructed to write about the things in their life and give detail. The measures used in this study were affect using the Positive and Negative Affect Schedule (PANAS) (Watson, Clark, & Tellegen, 1998) and motivation using the Self-Concordant Motivation Scale (Sheldon & Elliot, 1999). Affect and motivation to continue to do the exercise were measured before the exercise, immediately after the exercise and several weeks after. Performing the gratitude exercise regularly led to reduced negative affect and the exercise had beneficial effects on reducing negative mood. Those participants who continued the exercise reported a higher level of positive mood and positive affect. The act of reflection and contemplation about what things they were grateful for was strengthened by their writing.

A similar intervention was utilized in a study with Chinese school teachers (Chen, 2010). An 8 week gratitude intervention program was implemented in which the participants kept a weekly log of three good things that happened to them during the week using a *count-your-blessings form* in order to enhance their self-awareness through self-reflection. The effects of this intervention showed an increase in scores on satisfaction with life and on positive affect.

Life events recall sheets were utilized by Watkins, Grimm and Kolts (2004) to record memories of events from the last three years of life in undergraduate college students. The sheet also included a rating column for whether the events were considered positive or negative. They were also asked to check a box if while trying to think of positive events, negative events came to mind. The results of this study suggested that pleasant events come to mind easily for grateful individuals. The simple practice of reflection on things that one is grateful for, produced emotional benefits including life satisfaction and optimism. The emotional impact of this intervention also may be suggestive of ways that gratitude could enhance subjective well-being.

In two separate studies, McCullough, Tsang & Emmons (2002) examined the effect of daily reflective/journaling techniques. Participants in this study used 21 daily recording forms to summarize their day as a whole. Daily mood diaries were utilized in the second study. The first study involved patients at a hospital who had neuromuscular disorders and the second study involved undergraduate students. The following scales were used in this study: gratitude was measured using an earlier version of the Gratitude Questionnaire (GQ-6) (McCullough et al., 2002), life satisfaction was measured with the Satisfaction with Life Scale (Diener, Emmons, Larsen & Griffen, 1985) and the

Campbell Well-Being Scale was used to measure well-being (Campbell, Converse & Rodgers, 1976).

Using a sample of early adolescents, Froh, Sefick and Emmons (2008) asked participants to list up to five things they were grateful for since yesterday daily for 2 weeks. This study was important because it showed participants in a different life stage with a similar intervention as other studies, still producing the same benefits. High levels of life satisfaction and subjective well-being were reported by the participants in this study. Regardless of the exact method, all of these interventions clearly demonstrate that focusing on gratitude may help turn ordinary moments into opportunities. Reflections and journaling techniques have been successful in reaching positive outcomes such as higher levels of well-being, improved mood and an increase in satisfaction with life. Gratitude intervention studies using reflection and journaling techniques in general have been done quite extensively using undergraduate students as samples. It is unknown if this technique will be useful in other populations.

**Positive writing and gratitude letters.** Most everyone enjoys being appreciated when someone says thank you, but sometimes our *thank you's* can be construed as casual, quick and meaningless (Froh, Kashdan, Ozimkowski, & Miller, 2009). Students expressed their gratitude by choosing one person that they could meet for a face to face meeting in the next week (Froh et al., 2009). They were to write a gratitude letter to this individual and deliver it in person. The letter had to give specific details about what that person did that had affected their life positively. In a study by Seligman et al. (2005) participants wrote a letter to a living person to whom they were grateful and delivered it in person.

Expressive writing has mainly been focused on writing about traumatic events: however, more recently researchers have explored the effects of writing about topics with a more positive focus (Wing, Schutte, & Byrne, 2006). Positive writing is an intervention that is not widely seen in the literature, but one that could prove to have lasting effects. This type of intervention would differ from that of journal writing or a simple list, in that it would be more detailed and not an intervention that is necessarily done every day, but reflected on often. Watkins, Woodward, Stone and Kolts (2003) in a series of studies investigated whether grateful reflections could enhance positive affect and subjective well-being. The researchers found in several of the studies, participants who just thought about writing a letter of gratitude, wrote a grateful essay or wrote a letter of gratitude all had higher levels of positive affect and subjective well-being after performing these interventions. Participants wrote about their early memories as well as about a time when they felt they were at their best and then reflected on the personal strengths displayed in the story (Seligman et al., 2005). They were to review their story every day for a week. A sample of 60 women who had breast cancer wrote their deepest thoughts and feelings about their experiences with cancer (Low, Stanton, & Danoff-Burg, 2006). The participants engaged in four 20-minute writing sessions over a three week period. They wrote continuously and without worrying about spelling or grammatical structure. This study supports the potential positive health effects produced by written emotional disclosure and benefit finding. The participants reported less somatic symptoms over time and more positive health outcomes. Among participants writing about a positive life experience for 2 minutes a day, Burton and King (2008) had similar findings. These participants reported fewer health complaints at follow-up.

Positive writing was also used as an intervention with college students (Koo, Algoe, Wilson, & Gilbert, 2008). The students wrote about positive events and even focused on how it might never have happened. It was reported that writing about the events and thinking about how they might never have happened deepened their appreciation of the moments and made them feel more grateful. This downward comparison improved their affective states. Positive writing has also been found to increase reported levels of life satisfaction and increase emotional intelligence (Wing et al., 2006). Though these individual interventions have been effective, it was stated that multicomponent interventions yielded more significant results in several studies (Sorenson, Pinquart, Habil & Duberstein, 2002; Gitlin et al., 2003; Finkel, Czaja, Schulz, Martinovich, Harris & Pezzuto, 2007). Multicomponent interventions would be those that include education in addition to counseling or skill building. These multicomponent interventions may be more effective because they help to decrease hedonic adaptation.

### **Explanations for Effectiveness of Gratitude: Decreasing Hedonic Adaptation**

Hedonic adaptation is defined as the general tendency to adapt to emotionrelevant change by winding up back where one started (Brickman and Campbell, 1971; Frederick & Loewenstein, 1999; Sheldon, Boehm, & Lyubomirsky, 2011). Brickman and Campbell (1971) described the *hedonic treadmill* as the sensory adaptation that happened when people experience emotional reactions to life events. They suggested that a person's emotional system adjusted to the current life circumstances and their reactions become relative to prior experiences. They proposed that people react briefly to good and bad events but eventually return to neutrality.

According to Lyubomirsky (2008), gratitude interventions work best when they were not monotonous in nature. New activities have more of a potential to contribute to subjective well-being because they can provide varying experiences. A positive new activity, when kept fresh and interesting can keep a person from going back to where they started, i.e., hedonic adaptation, over a longer period of time (Sheldon & Lyubomirsky, 2007; Sheldon et al., 2011).

Although researchers have made progress in understanding gratitude, few have shown long-term results. Changing the frequency of activities is thought to lead to a more meaningful practice of grateful thinking (Sheldon and Lyubomirsky, 2006). There were more increases in well-being over the course of the study in those that performed the activity several times a week as compared to those participants that performed the activity only once a week. A happiness program that included varying multiple activities on a daily basis was successful over an extended period of time (Fordyce, 1977, 1983). By definition, the adaptation from the hedonic treadmill occurs only in response to constant or repeated activities that have become monotonous in nature, not dynamically varying ones (Frederick & Lowenstein, 1999).

#### **Summary and Conclusion**

This review examined the caregiving literature, identifying issues related to the positive and negative aspects of caregiving and how individuals may respond to caregiving activities and responsibilities. There continue to be unanswered questions related to family caregiving and to interventions aimed at cultivating and enhancing the positive aspects of caregiving. Limitations of the existing research include the wide variance in measures of caregiver stress and the predominance of convenience samples.

There is clearly a need for more studies with populations that are representative of the caregiver population and that examine the positive aspects of caregiving. The strengthsbased approach of positive psychology provides the opportunity to examine caregiving from a different theoretical perspective. Research on gratitude interventions has shown social, developmental, biological and personal growth benefits. More evidence is needed for the application of gratitude and its effect on the caregiver population, especially for caregivers of people with Alzheimer's disease. The following chapter contains a description of the research design and methods.

# CHAPTER 3

## **RESEARCH DESIGN AND METHODS**

The research aim was to examine the effect of participation in three telephone-based gratitude interventions on the physical, psychological and social functioning of participants in caregiver support groups who are unpaid family caregivers of persons with dementia and Alzheimer's disease. The three research questions were:

- 1.) How does gratitude contribute to subjective well-being, mental and physical health and the positive aspects of caregiving among caregivers?
- 2.) What is the relationship between gratitude, subjective well-being, physical and mental health and the positive aspects of caregiving?
- 3.) What is the effect of multiple gratitude interventions for the intervention group versus the control group?

The group randomized intervention trial was a wait-list controlled study involving informal caregivers in caregiver support groups. The 12 caregiver support groups were randomly assigned to the gratitude intervention and wait-list condition. Pre-and post-tests conducted with participants in both groups consisted of semi-structured telephone surveys and interviews. Data analysis included descriptive statistics, regression model and repeated measures analysis with pre (baseline) and post-intervention (2 weeks after third gratitude intervention) measures. I employed general linear model analysis to examine the effect of time, treatment and time by treatment interaction. This chapter describes in detail the research design and methodology. The specific content includes the presentation of my engagement with family caregiving and detailed descriptions of the research setting, support group recruitment process, participant recruitment process, instrumentation, data collection, and data analysis. I also discuss the risks and benefits to human subjects and describe the protection for participant confidentiality

## **Researcher Engagement: Family Caregiving**

My interest in researching the experiences of caregivers is grounded in my own experiences helping to care for my maternal Grandmother and Great Grandmother as I was growing up. I saw and experienced that being a caregiver for an adult was an extremely hard job. I experienced great sadness and grief as I watched my Great Grandmother and Grandmother become new persons who no longer knew me. I will also never forget the day when our family had to say that we were no longer able to safely care for my Grandmother at our home. I cried as we packed her things to move her to a nursing home. I am now experiencing Alzheimer's disease again with my only living grandparent, my paternal Grandmother.

I have extensive nursing experience caring for patients and working with families of those facing dementia and Alzheimer's disease. The majority of my practice has been with older adults. I worked closely with caregivers over 2 years with the VA Hospital system and a home health agency. I also hold a Graduate Certificate in Gerontology and have focused on caregivers in my doctoral education. I became very interested in understanding what it is that makes some caregivers have a positive experience while others continue to struggle and not do well. To increase my knowledge of these issues, I

was fortunate to be able to study Positive Psychology through an independent study in the School of Psychology at the University of South Carolina. My interest in identifying the conditions and situations that enable some people to thrive in difficult circumstances led me to this study of gratitude among family caregivers.

### **Setting and Recruitment Processes**

Existing caregiver support groups in South Carolina served as the research setting. I obtained support group contact information through the Alzheimer's Association South Carolina Chapter and contacted peer and professional leaders of dementia and Alzheimer's disease caregiver support groups in Richland, Lexington, Horry, Florence and Spartanburg counties. Most support groups had varying attendance. The recruitment goal was at least 10 participants from 7 or 8 large groups. Recruitment efforts started with the larger groups and if fewer participants initially responded, other support groups were contacted. Over a six month period (July through December 2013) I personally contacted twenty caregiver support groups in the state of South Carolina. The prolonged recruitment period resulted from the fact that some support group facilitators requested a description of the research study for review prior to giving me permission to present the research opportunity at their support group meeting. The initial telephone contacts with support groups aimed to simulate interest in the research and explain the recruitment presentation. If the support group leader indicated willingness to go ahead and schedule the presentation and no in person meeting was required prior to the presentation, we scheduled the meeting. If the support group leader preferred to meet in person to discuss the details of the study, we made an appointment to discuss the study in person and then proceeded to schedule the recruitment meeting. Only two support group leaders

requested an in person discussion prior to presenting to their support groups. Another factor that contributed to the prolonged group recruitment process was the fact that many support groups did not meet during the summer.

A total of 14 support groups gave permission for a presentation of the research project at a group meeting. I began the formal presentations to caregiver support groups in August 2013 and concluded in December 2013. Of the 14 groups that received an orientation to the research, members in 12 support groups consented to participate in the research study.

### **Participant Recruitment Process**

The target population for this study was family caregivers for an individual with dementia or Alzheimer's disease who are consistently attending support group meetings. Caregivers (n=55) were recruited from 12 support groups. Inclusion criteria were: the caregiver had to be a family member 18 years or older, able to speak, write and read English as their primary language, have a telephone, commit to attending scheduled support group meetings for the length of the study and commit to utilize the gratitude interventions as requested for the length of the study if randomized to an intervention group. The care recipient must have been formally diagnosed with either dementia or Alzheimer's disease, per caregiver report.

### Randomization

Group randomization occurred after obtaining information and consent to participate from the 12 support groups and 55 participants. Upon completion of participant enrollment, I assigned each of the 12 support groups a number and using a computer-generated list, randomized the groups to either intervention (n=35) or wait-list

status (n=20). The next phase of the research consisted of conducting the gratitude intervention to participants enrolled in the intervention support groups.

#### Interventions

The individual intervention consisted of 3 gratitude activities presented to participants via telephone contact over a period of 5 weeks. The 3 gratitude activities were a positive writing activity (Appendix A); a daily gratitude list (Appendix B) and a gratitude letter (Appendix C). I made individual telephone contacts with all participants in the intervention group and personally explained each of the three gratitude interventions. In addition, one week prior to each gratitude intervention participants received a tip sheet (Appendices A,B,C) with the directions for the specific activity.

The positive writing activity consisted of identifying people, events, relationships or experiences from the past for which the caregiver was grateful (Appendix A). I instructed participants that they did not have to describe the situation in detail. During the follow-up call I asked them to describe their response to the activity. The second intervention activity consisted of making short and simple lists of at least three good things each day (Appendix B). The instructions were to sit down and reflect on the items on the lists, and to identify what went right or specific things for which they had been grateful during the previous week. During the follow-up telephone call, I asked participants to share some of the items for which they were grateful.

The third intervention was writing a gratitude letter (Appendix C). The participant instructions were to write and deliver, if possible, a letter of gratitude to someone in their life whom they had never properly thanked. The decision to deliver the letter was left to each individual caregiver. During the follow-up telephone call, participants reflected on

the process of writing the letter, discussed the content and focus of their letters, and reported if they were able to deliver it.

#### **Intervention Delivery Format**

The researcher presented the gratitude interventions individually to participants by telephone. Participants had 1 week to complete the first two interventions and 2 weeks for the third intervention, because of the longer time caregivers might need to complete the gratitude letter. It often took multiple phone calls to reach participants and actually set up a time to conduct the intervention teaching. Each follow-up call was made 1 week from the initial teaching for the intervention and 2 weeks after the initial teaching for the gratitude letter intervention.

Participants in the intervention group were asked to comment on the intervention activity and their progress with the activity. In addition, participants in both the intervention and control groups were additionally asked the following questions in follow-up telephone calls: "Have you attended a dementia or Alzheimer's disease caregiver support group meeting in the last 2 weeks (4 weeks for control group)?" and "Did you discuss this research study at the support group meeting?". Participants in the intervention group and the control group were also asked if they have questions pertaining to providing care for the person with dementia or Alzheimer's disease.

Throughout the intervention period, the researcher remained in weekly telephone contact with intervention group participants to reinforce instructions, check on progress and provide support with any difficulties or questions that might arise. Following the telephone call contacts, the researcher made field notes regarding participant questions, concerns, and some of their discussion about the individual activities (i.e. some of the

things they were grateful for, what they were grateful for from the past). The researcher utilized the follow-up and intervention record form to record notes from the conversations (Appendix D).

## **Instruments and Measures**

Measurement included demographic data and standardized, reliable and valid measures of gratitude, subjective well-being, the positive aspects of caregiving, perceived physical and mental health (Appendix F). At recruitment, participants provided personal and care recipient demographic information using a researcher-developed demographic form (Appendix G). The researcher collected support group information via semistructured interviews with group leaders (Appendix H). In the following section I present an overview of each of the measures and instruments.

## **Demographic Data on Caregivers and Care Recipients**

Using a researcher-developed form I collected demographic data for each participant and care recipient. Caregiver participant information included age (in years), gender, income (combined household income), education (years in education, ethnicity, length of time caregiving (in months and years), relationship to care recipient, number of hours spent caregiving, information about support group attendance and employment status (full time, part time, or retired). The participants also provided the following information on the family member for whom they provided care: age (in years), ethnicity, gender, symptoms of Alzheimer's disease exhibited and approximate date of Alzheimer's disease diagnosis.

## Gratitude

The measure of gratitude was the Gratitude Questionnaire (McCullough, Emmons & Tsang, 2002). The GQ-6 consists of six items rated on a 7-point Likert scale. The items measure how frequently gratitude is felt, the intensity of it and the range of events or people that elicit it. The reliability of this scale was reported as  $\alpha$ =0.82. Researchers have reported the validity of GQ-6 scores among adults in multiple studies (i.e. McCullough, Tsang & Emmons, 2004; Kashdan, Mishra, Breen & Froh, 2009; Toussaint & Friedman, 2009).

## **Positive Aspects of Caregiving**

The Positive Aspects of Caregiving Scale measured the rewards and satisfaction derived from caregiving (Tarlow, Wisniewski, Belle, Rubert, Ory & Gallagher-Thompson, 2004). This instrument is composed of nine items rated on a 5-point Likert scale. The items measure the perceptions of caregivers in regards to the positive aspects of caregiving such as their perception of feeling useful, appreciated and finding meaning. The positive aspects of caregiver study with a sample of over 1200 caregivers of Alzheimer's disease patients in the Resources for Enhancing Alzheimer's Caregiver Health Study (Tarlow et al., 2004; Beach, Schulz, Yee & Jackson 2000; Schulz & Williamson, 1997). The reported reliability of this scale was  $\alpha$ =0.89 (Tarlow et al., 2004).

## Subjective Well-Being and Satisfaction with Life

The measure of subjective well-being (SWB) was the Satisfaction with Life Scale (Diener, Emmons, Larsen & Griffen, 1985). This scale is one of the most commonly used

measures of SWB (Pavot & Diener, 1993). Research has identified an affective and a cognitive component to subjective well-being (Andrews & Withey, 1976; Diener & Emmons, 1984, Diener, Emmons, Larsen & Griffen, 1985). The cognitive component is referred to as life satisfaction (Diener et al., 1985). The SWLS is a short 5-item instrument designed to measure the person's perception of satisfaction with one's life. Each item is rated using a seven-point Likert Scale. A score of 30-35 is a very high score, 25-29 is a high score, 20-24 is average, 15-19 is slightly below average, 10-14 is dissatisfied and 5-9 is extremely dissatisfied. The SWLS focuses on a person's positive experience and allows the participant to draw on what he or she finds most important in judging their global life satisfaction which has been found to be a primary factor in the general construct of subjective well-being. This scale has been used in elderly caregivers who had a spouse diagnosed with primary degenerative dementia by Vitaliano, Russo, Young, Becker & Maiuro (1991). It has been used in a wide variety of populations including multiple studies with students and several studies using older adult samples (i.e. Pavot, Diener, Colvin, & Sandvik, 1991) and caregivers of Alzheimer's disease patients (McConaghy & Caltabiano, 2005). The reliability of this scale was reported as  $\alpha$ =0.87 and a test-retest correlation of 0.82 (Diener et al., 1985; Pavot & Diener, 1993).

### **Perceived Physical and Mental Health**

The World Health Organization Quality of Life Assessment–Bref (WHOQOL-BREF) was the measure of perceived physical and mental health (WHO, 1993). WHO defined quality of life as a person's perception of their position in life in the context of physical and psychological health, environment and social relationships). The WHOQOL-BREF was developed with global input from 15 World Health Organization

(WHO) centers around the world. This instrument has been used in a variety of cultural settings with results from multiple different populations and countries.

The WHOQOL-BREF consists of 26 questions that are scored according to a 5point Likert scale. The WHOQOL- BREF utilizes one question from each of the 24 areas in the WHOQOL-100 (a 100 question scale) that belong to each of the domains of physical health (7 items), psychological health (6 items), social relationships (3 items) and environment (8 items). Also included are two general questions in which respondents rate their quality of life and how satisfied they are with their health. The WHOQOL-BREF has been rigorously tested to assess its validity and reliability (Skevington, Lotfy & O'Connell, 2004). The reported reliability of this scale is  $\alpha$ =80 (WHO, 1993). The internal consistency of the domains is as follows: physical health  $\alpha$ =0.82, psychological  $\alpha$ =0.81, environment  $\alpha$ =0.80 and social relationships  $\alpha$ =0.68 (Skevington, Loffy & O'Connell, 2004).

### **Data Collection Processes**

Preparation for data collection included creating a database using an excel spreadsheet for data entry and creating a coding book to aid in entering data for analysis. Preparation for data collection consisted of training data collection staff, obtaining informed consent, obtaining participant contact information and conducting pre-test telephone calls. Training of the data collection staff occurred in December 2013. All research staff completed CITI human subjects training prior to any active involvement with subjects. Training of data collection staff included review of the study questionnaire and a practice data collection session. During this practice session, the researcher conducted mock telephone calls and provided feedback to the graduate student

responsible for data collection. The researcher obtained the support group information by interviewing the support group leader either on the telephone prior to the recruitment meeting or at the recruitment meeting in person.

## **Obtaining Informed Consent and Contact Information**

At the scheduled participant recruitment meetings, support group members listened to a brief presentation by the researcher explaining the study and if they agreed to participate in the research, signed an informed consent form (Appendix I). The consent process varied across support groups. Five of the support group meetings occurred during lunch time and to maximize support group meeting time, the group leaders requested the researcher wait until after the meeting to conduct participant recruitment. Concurrently, the researcher obtained participant contact information was also obtained by the researcher on a separate form at the same time as the informed consent was obtained. Participants were asked to fill out a form with their contact information, emergency contact information and best time of day and days of the week to call them (Appendix E). Because some potential participants were not able to stay after the support group meeting due to having to go back to work, the researcher requested a contact phone number and the research assistant contacted these individuals by phone at a later time to collect further personal information. A study packet which included a tip sheet and three assignment sheets was mailed to all caregivers in December, approximately two weeks before the first intervention began.

## **Pre-and Post-Test Data Collection**

The trained research assistant contacted all participants via telephone after the initial instruction to conduct the pre-test interviews and obtain demographic information.

Similarly, the research assistant contacted participants in both groups by telephone 2 weeks after the implementation of the final intervention. Participants in both the intervention and control group were asked to maintain support group attendance for the length of the study. Support group attendance was likely to occur only once or twice during the time of the study. During follow-up calls the researcher inquired about support group attendance. Control group participants received individual telephone calls once a month (twice during study) to ask if they have attended the support group. If at any time, participants were unable to attend the scheduled support group meeting, they were asked the reason for not being able to attend. Support group attendance was tracked using an Excel Spreadsheet by the researcher.

#### Human Subjects Risks and Benefits

The research protocol was approved by the Institutional Review Board at the University of South Carolina through an expedited review. An initial recruitment meeting was held during regularly scheduled support group meetings. The details of the study were discussed at this meeting. The informed consent procedure was discussed, followed by the subsequent signing of the informed consent form. Participants were assigned a random number upon completion of the informed consent and demographic information utilizing simple random assignment with a computer generated list. Groups were randomly chosen for participation in either the wait-list control or to the intervention group.

There were no identified risks to participants in this research study. All participants continued to receive usual support within the support group. If the caregiver was noted to be a threat at any time to themselves or to the person to whom they are

providing care, the researcher was prepared to instruct the participant to seek professional help according to the intervention plan (Appendix J), but this did not occur during the study. The personal support was hoped to give each participant an outlet for concerns and fears and an expedited referral process for any identified complications.

Participants received up to \$20.00 incentive for participating in this study. Participants received a \$10.00 Gift Card for completing the pre-test questionnaires and a \$10.00 Gift Card for completing the post-test questionnaires. Incentives were either distributed by me personally at the next support group meeting after each questionnaire was completed or mailed to the address they had indicated on their contact information sheet (in situations when the participant was not in attendance or if the researcher was unable to attend the support group meeting).

## Confidentiality

The researcher personnel were responsible for maintaining all information about the participants and their situations strictly confidential. It was explained to the participants that identifying information was not be released without their prior written consent (Appendix I). Names and contact information were kept in a separate, locked cabinet during the course of the study and will be destroyed at the conclusion of the study. All data were kept in a locked private office. Information obtained during the study was not to be shared unless it became medically necessary. No participants were identified as being at risk of harming themselves or others and no information on participants was shared. The participants were told that no information gained from this study would affect current home care or participation in any government assistance programs. Participants were told that records that individually identify them and consent

forms may be inspected by the University's Institutional Review Board. The results of this research study are to be presented at meetings and submitted for publication; however the participants' identities will not be disclosed.

## **Data Analysis**

Data were entered into an excel spreadsheet by the trained research assistant as data collection occurred. To check the accuracy of the data (50%) was printed and verified with the hard copy. Several backup copies were also made.

The analysis design included repeated measures analysis of specific measures taken at two points in time, pre (baseline) and post-intervention (2 weeks after last intervention) among participants enrolled in caregiver support groups randomly assigned to either intervention or control condition. Descriptive statistics were computed on the selected variables, calculated expected mean squares and the appropriate combinations for the hypothesis tests with specific functions of the repeated measures were employed. The sample is described by group since group was the main independent variable. For categorical variables, the univariate constructions included frequency distributions. For continuous variables, statistics included measure of central tendency (mean and median) and measure of spread (standard deviation and range). The descriptive statistics for main variables were done by group. I used SPSS 22 and SAS 9.4 to set up, enter, and analyze the data. Chi square and t-test were used to examine characteristics of sample and scales by group for pre-test. Employing general linear model analysis in SAS (GLM and MIXED procedures) I examined the effects of 1) time, 2) treatment and 3) time by treatment interaction. The regression model was used to examine the pre results and the

difference (post-pre). Given the repeated measures design, the intraclass correlation (RHO) was assumed to be positive and constant across all repeated measures.

**Power analysis.** A power analysis was conducted prior to collecting data to guide the sample size. Effect size delta values are typically in the range of 0-1. Values of effect size = 0.10, 0.25, and 0.40 or greater correspond to small, medium, and large effects (Cohen, 1988). A power analysis calculation indicated that there was at least 80% power for alpha=0.05, medium effect size, Rho ranges from 0 to 0.7 and for n=55 for between subject effects. The power calculation indicated that there was at least 80% power for alpha 0.05, medium effect size with an n=55 for within subject effects and interaction of between-subjects and within-subjects group. The power calculation for regression analysis indicated that there was a 70% power for alpha 0.05, medium effect size with a sample size of 55.

**Content analysis.** In order to gather a deeper understanding of participant responses to the gratitude intervention, I conducted a content analysis of the responses recorded on the intervention teaching and follow-up forms using Krippendorff's (2004) content analysis methodology. Each of the participant interaction forms were read and frequencies of responses were tabulated for each of the gratitude activities.

I began by reading through each participant interaction form, highlighting words and phrases that related to people, places, things and experiences that participants were grateful for. I listed these on a separate form. After tabulating the list, I began to look for similarities and commonalities among the responses. I identified six major categories. Within each major category I rank ordered the responses according to frequency. This resulted in 7 additional sub-categories. The content analysis of the gratitude intervention

responses provided a more in-depth understanding of the responses from the intervention group participants.

## **Summary and Conclusion**

This was a group randomized, wait-list controlled study involving informal caregivers who were involved in support groups. A total of 55 participants were recruited from 12 existing caregiver support groups. Three gratitude interventions were taught over the telephone to participants in the intervention group. To test the effect of the implementation of the three gratitude interventions, compared to the control group, I used general linear model analysis with the pre and post-intervention measures of gratitude, subjective well-being, positive aspects of caregiving, perceived physical and mental health. In the following chapter I present the findings of the analysis.

# **CHAPTER 4**

## RESULTS

The purpose of this research was to examine the effect of three telephone-based gratitude interventions on frequency, intensity and elicitation of gratitude; subjective physical, emotional and well-being; and life satisfaction among adult caregivers of family members with Alzheimer's disease or dementia. The three specific research questions were:

- 1.) How does gratitude contribute to subjective well-being, mental and physical health and the positive aspects of caregiving among caregivers?
- 2.) What is the relationship between gratitude, subjective well-being, physical and mental health and the positive aspects of caregiving?
- 3.) What is the effect of multiple gratitude interventions for the intervention group versus the control group?

The hypotheses were that following receipt of the telephone-delivered gratitude interventions, participants would demonstrate higher levels of gratitude that would be associated with higher levels of the positive aspects of caregiving, subjective well-being and perceived levels of physical and mental health. The conceptual framework guiding this investigation was the Broaden-and-Build Theory (Fredrickson, 2001). Participants were 55 members of 12 caregiver support groups in South Carolina. Data collection occurred though individual in person and telephone interviews. Data were analyzed using the Statistical Package for the Social Sciences (SPSS) version 22 and SAS 9.4 and

content analysis of the participants self-reported responses to the gratitude interventions. In this chapter I present the characteristics of support groups, the demographic characteristics of the sample, a brief summary of participant responses, the results of the data analysis, and the results of the research hypotheses.

## **Characteristics of Caregiver Support Groups**

I collected caregiver support group data for informational purposes only. When contacting caregiver support group leaders, I conducted an informal survey (Appendix H). These data were collected for each of the 14 support groups for which I provided a formal presentation regarding the research. Four support groups were led by health care professionals and 10 were peer-led. Eighty percent of the support group leaders have taken courses specific to Alzheimer's disease such as educational seminars and conferences. The longevity of the support groups ranged from 3 months to over 10 years. Average reported attendance at support group meetings ranged from from 5 to 20 or more participants.

### **Demographic Characteristics of the Sample**

A total of 64 caregivers consented to participate and 55 completed the study protocol, for a retention rate of 86%. Among the nine who did not complete the study, three dropped out due to a recent loss in their family – two of which were the care recipient; two stated they were *too busy* and four did not state a specific reason for not continuing in the study. All participants completed the pre-test questionnaire and completed all three gratitude interventions and 98% (n=54) completed the post-test questionnaire. One participant declined to complete the post- test interview due to personal reasons. Table 4.1 presents the demographic characteristics of the caregivers who participated in the research.

Among the 55 caregivers, the average age 62.7 years of age, with a range from 36 to 85 years of age. The average age of intervention participants was 65 and of control participants was 60 years of age. The study sample (n=55) consisted of 86% female participants and 15% male. Within the intervention group 86% of participants were female and 14% were male, compared to 85% female and 15% male in the control group. In terms of race, the sample was predominantly white (80% total; 71% intervention group; 95% control group) with the remaining 10% self-identifying as African American (26% intervention group; 5% control group). One participant in the intervention group did not provide information on race.

Three-fourths of sample participants reported they were currently married. Participants who identified themselves as not married (either single or divorced) were equally represented in the intervention (n=9; 25.7%) and control groups (n=5; 25%). The sample was highly educated, with 87% having completed college degrees or education beyond a college graduation. Within the intervention group 83% of participants completed either a college education or more compared to 90% of the control group.

Almost half of the caregivers were the spouse of the care recipient (n=24, 44%). The next largest group was composed of those family members caring for their parent (n=24, 44%), followed by those caring for other relatives (n=7, 12%). Within the intervention group, the majority (63%) of care recipients were diagnosed with Alzheimer's disease in contrast to the care recipients in the control group (40%), 60% of whom had a diagnosis of another dementia.

Table 4.2 presents additional data on the caregiving activities reported by study participants. Across the entire sample, the most frequent types of assistance needed were

emotional support (n=53; 96%) and assistance with health care including visits to the doctor and managing medications (n=52; 95%). Other common care needs included personal care tasks (n=31; 56%), homemaker chores (n=38; 69%), providing transportation (n=47; 85%), managing finances (n=47; 85%) and supervision (n=41; 75%).

In addition to Alzheimer's and dementia, the care recipients had other health conditions that could impact caregiving needs. Among care recipients in the intervention group, many had also been diagnosed with diabetes (n= 10; 29%), hypertension (n=17; 49%) or arthritis (n=9; 26%). Among control group care recipients there were concurrent diagnoses of hypertension (n=10; 50%), heart disease (n=5; 25%) and arthritis (n=4; 20%).

The average length of time participants had been providing care for their family member was 4 years, with a range from 5 months to 15 years. The majority (52%) were providing care for 24 hours a day. The remaining 48% of participants estimated they currently spent between 3 to 56 hours a week providing care to their family member with Alzheimer's disease or dementia. Chi-square tests were used to examine the relationship of variables at pre-test by group. There were no statistically significant differences between groups for any of the variables.

#### **Content Analysis of Gratitude Intervention Data**

Most participants seemed to put forth a great deal of time, effort and thought into all three gratitude activities. This was evidenced by detailed discussion of the activities during the follow-up conversations. Only three participants chose to actually deliver their letter of gratitude to the person it was addressed. Seven participants

chose to address their letter of gratitude to a person that was deceased or no longer a part of their lives. The gratitude letter was the activity with the most negative feedback. Several participants were not ready to discuss the activity when the follow-up call was initiated and requested additional time. Many participants minimally discussed the gratitude letter and it should be noted that several letters seemed to be more of a letter of apology to someone rather than a letter of gratitude. The gratitude lists had the most positive feedback and detailed discussion. Most of the participants wrote more than three grateful responses per day, despite the directions of only being asked to think of three responses.

The analysis of the content of self-reported participant responses to the three gratitude interventions (i.e., positive writing, daily gratitude list, and gratitude letter) resulted in the identification of six major content categories: health, God, family, friends, nature and other. Further analysis resulted in identification of sub-categories within each major category. The health category included gratitude for the ability to be independent, being alive and medical technology/medication. Gratitude for God included church family and prayer and family gratitude consisted primarily of children and grandchildren.

Health was the most frequently discussed category and was mentioned by almost every caregiver. It comprised 30% of the content of the analyzed participant interaction forms. Most participants identified specific aspects of their health. Most frequently mentioned were examples of feeling grateful for overcoming different types of cancer and examples of feeling grateful for their physical functioning. For example, many participants stated that they were *just happy to be alive* and *grateful to be able to walk and breathe*.

Nature was another commonly identified theme. Many participants noted they were grateful for aspects of nature including weather (sun and rain), the joy of gardening and ability to do yard work and the ability to take walks. Some respondents exhibited a few unique individual themes within their follow-up discussions for the gratitude activities. For example, several participants discussed *gratitude for retirement* and *no alarm clocks to wake them up*.

### **Results of Pre- and Post-Intervention Data Analysis**

The following analysis examined the means for all scales used in the pre-test and post-test measurement of gratitude, positive aspects of caregiving, satisfaction with life, physical health and psychological health. Pearson Correlation Coefficients were also examined to determine the relationships between the variables of interest. Scale reliability is also reported in this section.

Table 4.3 shows mean, standard deviation and the minimum/maximum for all of the scales used in the pre-test. The mean for the measure of gratitude at pre-test for the sample was 37.0 (36.7 intervention group; 35.7 control group). A gratitude score of 6-35 is a low score, 36-40 is moderate and 41-42 is high. Both groups had moderate levels of gratitude measured at pre-test. The mean for the measure of positive aspects of caregiving for the sample was 39.2 (41.3 intervention group; 35.5 control group). A score of 55 would report the highest levels of positive aspects of caregiving. The mean for satisfaction with life for the sample was 22.1 (22.6 intervention group; 21.2 control group). A score of 30-35 is a very high score, 25-29 is a high score, 20-24 is average, 15-19 is slightly below average, 10-14 is dissatisfied and 5-9 is extremely dissatisfied. The mean for physical health for the sample was 24.4 (24.3 intervention group; 24.5 control group). A score of 35 on the WHOQOL-Bref for the physical health domain would

signify the highest level of physical health. The mean for psychological health for the sample was 22.5 (22.6 intervention group; 22.2 control group). A score of 30 on the WHOQOL-Bref for the psychological health domain would signify the highest level of physical health. T-tests were used to examine differences between groups for scales at pre-test. T-test findings revealed only a significant difference at pre-test for positive aspects of caregiving (p=0.0405).

The results indicate similar means for both the intervention and control groups at pre-test measurement for gratitude, satisfaction with life, physical health, psychological health. There was a difference between groups for the means at pre-test measurement for positive aspects of caregiving and social relationships. The intervention group reported higher levels of positive aspects of caregiving at pre-test measurement and the control group reported a higher score for social relationships.

Table 4.4 shows mean, standard deviation and the minimum/maximum for all of the scales used in the post-test. The mean for the measure of gratitude at post-test for the sample was 37.4 (36.8 intervention group; 38.4 control group). Both groups had moderate levels of gratitude measured at pre-test and those means were similar at posttest. The mean for the measure of positive aspects of caregiving for the sample was 41.9 (42.6 intervention group; 40.7 control group). The intervention group showed a slight decrease and the control group showed an increase in positive levels of caregiving from pre-test to post-test measures. The mean for satisfaction with life for the sample was 23.4 (24.2 intervention group; 22.1 control group). The intervention group showed a slight increase and the control group showed a slight decrease in satisfaction of life scores. Both the intervention and the control group scores were in the average range for

satisfaction of life. The mean for physical health for the sample was 24.8 (25.0 intervention group; 24.7 control group). The results indicate similar means for both the intervention and control groups at post-test measurement for physical health. The intervention and control groups showed similar means at pre-test for the measure of physical health. The mean for psychological health for the sample was 22.9 (23.1 intervention group; 22.4 control group). The intervention and the control group showed similar measures of psychological health at pre-test.

To determine the correlation between caregiver self-reported gratitude and the other variables of interest, Pearson Correlation and reliability for all measures were computed (Table 4.5) The result indicated there are positive linear relationships between gratitude and psychological health (r=0.48, p=0.0002), social relationships (r=0.39, p=0.0027), and environment (r=0.44, p=0.0006). There were positive linear relationships between the positive aspects of caregiving and satisfaction with life (r=0.45, p=0.0004), psychological health (r=0.37, p=0.0053), social relationships (r=0.48, p=0.0002), and environment (r=0.39, p=0.0030). The results also indicated that there is a positive linear relationship between satisfaction with life and psychological health (r=0.49, p=0.0001), social relationships (r=0.52, p=<0.0001) and environment (r=0.47, p=0.0002).

Scale reliability was assessed using Cronbach alpha coefficient. The reliability coefficients were 0.69, 0.88, 0.86, 0.74, 0.59, 0.73, and 0.48 for gratitude, positive aspect of caregiving, satisfaction with life scale, physical health, psychological health, social relationships, and environment; respectively. The reliability for Positive Aspects of Caregiving Scale, Satisfaction with Life Scale, BREF/Physical Health and BREF/Social

Relationships were acceptable. The Gratitude Questionnaire, BREF/Psychological Health and BREF/Environment did not have acceptable internal consistency.

## **Results of Hypothesis Testing**

The first hypothesis stated that gratitude would independently predict subjective well-being, perceived physical and mental health, and high positive aspects of caregiving. To test the impact of gratitude on subjective well-being, perceived physical and mental health and high positive aspects of caregiving, regression analysis for the effects of group and gratitude and the effects of group and gratitude difference post to pre were conducted.

Table 4.6 shows the regression results for effects of group and gratitude on subjective well-being. The results indicate overall the model is significant ( $F_{2,52}$ =6.66; p=0.0027). Twenty percent of the variability of subjective well-being is explained by group and gratitude. The result did not reveal any relationship for group (p=0.3715) but there was a significant relationship between gratitude and subjective well-being (p=0.0007).

Table 4.7 shows the result of regression for the difference (post-pre) for group and gratitude on difference (post-pre) subjective well-being. The results indicate overall the model is not significant ( $F_{2,51}$ =1.23; p=0.3016). Five percent of the variability of subjective well-being changes from post to pre is explained by group and gratitude. The result did not reveal any significant effect for group (p=0.3902) or for the difference of gratitude (p=0.1706) and the difference of subjective well-being post-pre.

Table 4.8 shows the regression results for group and gratitude on mental health. The results indicate overall the model is significant ( $F_{2,52}$ =8.87; p=0.0005). Twenty-five

percent of the variability of mental health is explained by group and gratitude. The result did not reveal any significant relationship for group (p=0.3103) but there was a significant relationship between gratitude (p=0.0001) and mental health.

Table 4.9 shows the regression results for the difference (post-pre) for group and gratitude on difference (post-pre) mental health. The results indicate overall the model is not significant (F  $_{2,51}$ =2.40; p=0.1007). Nine percent of the variability of mental health changes from post to pre is explained by group and gratitude. The result did not reveal a significant effect for group (p=0.4000) but there was a significant relationship for the difference of gratitude (p=0.0407) and the difference of mental health post to pre.

Table 4.10 shows the regression results for group and gratitude on physical health. The results indicate overall the model is not significant ( $F_{2,52}=0.51$ ; p=0.6027). Two percent of the variability of physical health is explained by group and gratitude. The result did not reveal any significant relationship for group (p=0.7946) or gratitude (p=0.3421) and physical health.

Table 4.11 shows the result of regression for the difference (post-pre) for group and gratitude on difference (post-pre) physical health. The results indicate overall the model is not significant ( $F_{2,51}$ =0.42; p=0.6604). Two percent of the variability of physical health changes from post to pre is explained by group and gratitude. The result did not reveal any significant effect for group (p=0.3704) or for the difference of gratitude (p=0.8138) and the difference of physical health post to pre.

Table 4.12 shows the regression results for group and gratitude on positive aspects of caregiving. The results indicate overall the model is significant ( $F_{2,52}$ =5.20; p=0.0087). Seventeen percent of the variability of the positive aspects of caregiving is

explained by group and gratitude. The result did reveal a significant relationship for group (p=0.0282) and gratitude (p=0.0183) and the positive aspects of caregiving.

Table 4.13 shows the result of regression for the difference (post-pre) for group and gratitude on difference (post-pre) positive aspects of caregiving. The results indicate overall the model is not significant ( $F_{2,51}=2.04$ ; p=0.1399). Seven percent of the variability of positive aspects of caregiving changes from post-test to pre-test is explained by group and gratitude. The result did not reveal any significant effect for group (p=0.0833) or for the difference of gratitude (p=0.4324) and the difference of positive aspects of caregiving post to pre.

Two regression models were examined, one for the effects of group and gratitude on each variable for pre-test and the other for the effects of group and difference of gratitude post to pre on difference of outcomes (subjective well-being, mental health, physical health and positive aspects of caregiving). There was a significant relationship for gratitude and subjective well-being for the pre-test but the result for the effects of the difference of gratitude and the difference of subjective well-being post-pre was not significant. There was a significant relationship for gratitude and mental health for the pre-test and the results for the effects of the difference of gratitude and the difference of mental health post-pre was significant. The regression results indicated a significant relationship for gratitude and positive aspects of caregiving for the pre-test but the result for the effects of the difference of gratitude and the difference of caregiving post-pre was not significant. Therefore, the hypothesis that these constructs can be reliably predicted by gratitude is partially supported. Gratitude was found to be a

significant predictor for mental health (p=0.0407) and not a significant predictor for subjective well-being, positive aspects of caregiving or physical health.

In the second hypothesis, it was predicted that a positive correlation would exist between and among the constructs of gratitude, subjective well-being, perceived physical and mental health and the positive aspects of caregiving. To test the relationship of the positive aspects of caregiving with subjective well-being, and perceived physical and mental health, regression analysis for effects of the variables on positive aspects of caregiving and for the effects of the difference of variables (post-pre) on the difference of positive aspects of caregiving (post-pre) were conducted.

Table 4.14 shows the result of regression for group, gratitude, satisfaction with life, physical health and mental health on positive aspects of caregiving. The results indicate overall the model is significant ( $F_{7,47}$ =5.66; p=<0.0001). Forty-six percent of the variability of positive aspects of caregiving is explained by group, gratitude, satisfaction with life, physical health and mental health. The result revealed a significant relationship for group (p=0.0167) and physical health (p=0.0478) and the positive aspects of caregiving.

Table 4.15 shows the result of regression for gratitude (post-pre), satisfaction with life (post-pre), physical health (post-pre) and mental health (post-pre) on difference (post-pre) for positive aspects of caregiving. The results indicate the overall model is significant ( $F_{7,46}$ =5.14; p=0.0002). Forty-four percent of positive aspects of caregiving changes from post to pre are explained by group, gratitude, satisfaction with life, physical health and mental health. The result revealed a significant relationship for effect of group

(p=0.0022) and for the difference of satisfaction with life (p=0.0011) and the difference of positive aspects of caregiving post to pre.

Analysis revealed that positive aspects of caregiving were significantly related to physical health. The Pearson Correlation Coefficient did not show the relationship between these two variables. Analysis revealed that positive aspects of caregiving were positively correlated with satisfaction with life (r=0.44, p=0.0011). The difference post-pre was found to be significant for positive aspects of caregiving and satisfaction with life. Therefore the hypothesis that there will be a positive correlation between and among the constructs and the positive aspects of caregiving is partially supported. A positive correlation was found only between satisfaction with life and positive aspects of caregiving.

The third hypothesis stated that the intervention group will have higher scores of gratitude, subjective well-being, perceived physical health, perceived mental health and the positive aspects of caregiving. To test the impact of the three gratitude interventions on gratitude, subjective well-being, perceived mental health, perceived physical health and positive aspects of caregiving, mixed procedure in SAS with repeated measures on one factor (outcome) was used.

Table 4.14 indicates the P values for mixed model for scales. The results did not reveal any significant interaction effects for time\*group for all outcomes (gratitude, positive aspects of caregiving, satisfaction with life, physical health, psychological health, social relationships or environment). Also, the result did not indicate that there was any significant difference in group for all outcomes. The time effect was only

significant for the positive aspects of caregiving (p=0.0005) and environment (p=0.0007). The time effect was borderline significant for satisfaction with life (SWLS) (p=0.0530)

Results indicated that there was no significant difference in gratitude scores in participants assigned to the intervention group in comparison to participants assigned to the control group at post-test. When reviewing the means and standard deviations for both groups pre-test scores, they are similar and for post-test there was a slight difference between the control and intervention groups. The intervention group did not have higher scores of gratitude, subjective well-being, perceived physical and mental health or positive aspects of caregiving for post-test.

## **Summary and Conclusion**

This chapter presented the findings from a group randomized intervention trial to examine the impact of three telephone-based gratitude interventions conducted with unpaid family caregivers of persons with Alzheimer's disease and dementia as additional support to those who were attending caregiver support groups. Participants (n=55) included family caregivers recruited through community support groups in five South Carolina counties. All participants completed pre-tests measures of gratitude, subjective well-being, positive aspects of caregiving, physical health and mental health. Using a group randomized design, caregivers in the intervention group received three gratitude assignments via telephone over a five week period. Following the completion of the intervention, 54 participants completed post-test assessments. Statistical analyses included descriptive statistics and general linear model analysis with repeated measures. Findings indicated a significant relationship for gratitude and mental health. There was a positive correlation between the constructs of satisfaction of life and positive aspects of

caregiving. The intervention group did not have any statistically significant differences in gratitude, subjective well-being, physical health, mental health or positive aspects of caregiving from pre-test to post-test measurements.

The following chapter presents the discussion and implications of these findings for nursing research, practice, and education.

		otal mple	Co	ntrol	Inte	rvention
Variables			(n	=20)	(1	n=35)
	(n	=55)	``	,		,
	n	%	n	%	n	%
Sex						
Male	8	14.5	3	15.0	5	14.3
Female	47	85.5	17	85.0	30	85.7
Race						
White	44	80.0	19	95.0	25	71.4
African-American	10	18.2	1	5.0	9	25.7
Marital Status						
Married/Living with Other	41	74.6	15	75.0	26	74.3
Not Married	14	25.4	5	25.0	9	25.7
<b>Religious Affiliation</b>						
Christian	29	52.7	11	55.0	18	51.4
Other	26	47.3	9	45.0	17	48.6
Educational Level						
Less than High School	3	5.0	1	5.0	2	5.7
High School	5	9.0	1	5.0	4	11.4
College or more	47	86.0	18	90.0	29	82.9
Employment Status						
Part-time	10	18.0	4	20.0	6	17.1
Full-time	11	20.0	6	30.0	5	14.3
Retired	27	49.0	8	40.0	19	54.3
Unemployed	7	13.0	2	10.0	5	14.3
Relationship to Care Recipient						
Child	24	44.0	8	40.0	16	45.7
Spouse	24	44.0	10	50.0	14	40.0
Other relative	7	12.0	2	10.0	5	14.3
Diagnosis of Care Recipient		-		-		
Alzheimer's disease	30	54.6	8	40.0	22	62.9
Other dementia	25	45.4	12	60.0	13	37.1

 Table 4.1 Frequency Distributions for Characteristics of the Sample

Variables	Sa	otal mple =55)		ntrol =20)	Intervention (n=35)	
	n	%	n	%	n	%
Assistance needed						
Emotional support	53	96.4	19	95.0	34	97.1
Health care (doctor visits, medications)	52	94.6	18	90.0	34	97.1
Transportation	47	85.5	15	75.0	32	91.4
Managing finances	47	85.5	16	80.0	31	88.6
Supervision	41	74.6	15	75.0	26	74.3
Homemaker chores (IADL's)	38	69.1	13	65.0	25	71.4
Personal care tasks (ADL's)	31	56.3	11	55.0	20	57.1
Symptoms displayed by care recipient						
Confusion	52	94.6	18	90.0	34	97.1
Anxiety, suspiciousness, agitation	41	74.6	17	85.0	24	68.6
Problems speaking	35	63.6	13	65.0	22	62.9
Loss of bladder and/or bowel control	33	60.0	10	50.0	23	65.7
Sleep disturbances	31	56.4	12	60.0	19	54.3
Difficulty recognizing family and friends	29	52.7	8	40.0	21	60.0
Repetitive movements	29	52.7	9	45.0	20	57.1
Inability to recognize objects	25	45.5	7	35.0	18	51.4
Wandering	23	41.8	9	45.0	14	40.0
Loss of appetite	23	41.8	5	25.0	18	51.4
Difficulty recognizing caregiver	19	34.6	7	35.0	12	34.3
Other health conditions of care recipient						
Hypertension	27	49.1	10	50.0	17	48.6
Arthritis	13	23.6	4	20.0	9	25.7
Diabetes	13	23.6	3	15.0	10	28.6
Heart Disease	10	18.2	5	25.0	5	14.3
*COPD	4	7.3	2	10.0	2	5.7
Heart Failure	2	3.6	2	10.0	0	0

Table 4.2 Caregiving Demands and Care Recipient Symptoms

\*COPD = Chronic Obstructive Pulmonary Disease

	Total Sample (n=55)		Control (n=20)			Intervention (n=35)		
Mean	SD	Min- Max	Mean	SD	Min- Max	Mean	SD	Min- Max
37.0	5.0	16-42	37.4	4.8	24-42	36.7	5.2	16-42
39.2	10.6	11-55	35.5	9.4	16-55	41.3	10.7	11-55
22.1	7.9	5-35	21.2	8.9	5-34	22.6	7.3	7-35
24.4	3.2	16-31	24.5	3.5	16-29	24.3	3.0	19-31
22.5	2.5	17-28	22.2	2.7	17-26	22.6	2.5	17-28
10.3	2.8	4-15	11.0	2.8	7-15	9.8	2.7	4-15
29.0	3.7	19-35	28.6	3.4	22-35	29.2	3.9	19-35
	Mean 37.0 39.2 22.1 24.4 22.5 10.3	Mean         (n=55) SD           37.0         5.0           39.2         10.6           22.1         7.9           24.4         3.2           22.5         2.5           10.3         2.8	MeanSDMin-Max37.05.016-4239.210.611-5522.17.95-3524.43.216-3122.52.517-2810.32.84-15	Mean         SD         Min- Max         Mean           37.0         5.0         16-42         37.4           39.2         10.6         11-55         35.5           22.1         7.9         5-35         21.2           24.4         3.2         16-31         24.5           22.5         2.5         17-28         22.2           10.3         2.8         4-15         11.0	Mean         SD         Min- Max         Mean         SD           37.0         5.0         16-42         37.4         4.8           39.2         10.6         11-55         35.5         9.4           22.1         7.9         5-35         21.2         8.9           24.4         3.2         16-31         24.5         3.5           22.5         2.5         17-28         22.2         2.7           10.3         2.8         4-15         11.0         2.8	Mean         SD SD SD SD SD Min- Max         Mean Max         SD SD SD SD Min- Max           37.0         5.0         16-42         37.4         4.8         24-42           39.2         10.6         11-55         35.5         9.4         16-55           22.1         7.9         5-35         21.2         8.9         5-34           24.4         3.2         16-31         24.5         3.5         16-29           22.5         2.5         17-28         22.2         2.7         17-26           10.3         2.8         4-15         11.0         2.8         7-15	MeanSDMin- MaxMeanSDMin- MaxMean $37.0$ $5.0$ $16-42$ $37.4$ $4.8$ $24-42$ $36.7$ $39.2$ $10.6$ $11-55$ $35.5$ $9.4$ $16-55$ $41.3$ $22.1$ $7.9$ $5-35$ $21.2$ $8.9$ $5-34$ $22.6$ $24.4$ $3.2$ $16-31$ $24.5$ $3.5$ $16-29$ $24.3$ $22.5$ $2.5$ $17-28$ $22.2$ $2.7$ $17-26$ $22.6$ $10.3$ $2.8$ $4-15$ $11.0$ $2.8$ $7-15$ $9.8$	MeanSDMin- MaxMeanSDMin- MaxMeanSDMin- SD $37.0$ $5.0$ $16-42$ $37.4$ $4.8$ $24-42$ $36.7$ $5.2$ $39.2$ $10.6$ $11-55$ $35.5$ $9.4$ $16-55$ $41.3$ $10.7$ $22.1$ $7.9$ $5-35$ $21.2$ $8.9$ $5-34$ $22.6$ $7.3$ $24.4$ $3.2$ $16-31$ $24.5$ $3.5$ $16-29$ $24.3$ $3.0$ $22.5$ $2.5$ $17-28$ $22.2$ $2.7$ $17-26$ $22.6$ $2.5$ $10.3$ $2.8$ $4-15$ $11.0$ $2.8$ $7-15$ $9.8$ $2.7$

Table 4.3 Means, Standard Deviation and Minimums/Maximums for Pre-test

a. t-test p value = 0.0485

Coolog		Total Sample (n=55)		Control (n=20)			Intervention (n=34)		
Scales	Mean	SD	Min-	Mean	SD	Min-	Mean	SD	Min-
			Max			Max			Max
Gratitude	37.4	3.8	27-42	38.4	3.6	31-42	36.8	3.8	27-42
Questionnaire (GQ-6)									
Positive Aspects of	41.9	9.9	18-55	40.7	9.2	22-53	42.6	10.3	18-55
Caregiving Scale									
Satisfaction with Life	23.4	6.9	5-35	22.1	7.4	5-35	24.2	6.6	10-35
Scale (SWLS)									
<b>BREF/Physical Health</b>	24.8	3.1	16-32	24.7	3.6	16-30	25.0	2.8	19-32
BREF/Psychological	22.9	2.6	15-28	22.4	3.0	15-27	23.1	2.4	19-28
Health									
<b>BREF/Social</b>	10.7	2.3	6-15	11.1	2.6	6-15	10.5	2.1	6-15
Relationships									
BREF/Environment	30.0	3.2	24-35	29.9	3.1	24-35	30.1	3.4	24-35

Table 4.4 Means, Standard Deviation and Minimums/Maximums for Post-test

		1	2	3	4	5	6	7
1.	The Gratitude	(0.69)	0.29	0.43	0.13	0.48	0.39	0.44
	Questionnaire		0.03	0.0008	0.33	0.0002	0.0027	0.0006
	(GQ-6)							
2.	Positive Aspects of		(0.88)	0.45	-0.15	0.37	0.48	0.39
	Caregiving Scale			0.0004	0.25	0.0053	0.0002	0.0030
3.	Satisfaction with Life			(0.86)	0.00	0.49	0.52	0.47
	Scale (SWLS)				0.98	0.0001	< 0.0001	0.0002
4.	BREF/Physical Health				(0.74)	0.32	0.00	0.44
	2					0.02	0.97	0.0007
5.	BREF/Psychological					(0.59)	0.35	0.59
	Health						0.0087	< 0.0001
6.	BREF/Social						(0.73)	0.52
	Relationships							< 0.0001
7.	BREF/Environment							(0.48)

 Table 4.5 Pearson Correlation Coefficients and Reliability for Scales (n=55)

Note: Diagonally are the reliability coefficients for scales

Table 4.6 Regression Results for Effects of Group and Gratitude on Subjective We	ell-
Being (Pre)	

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	684.49	342.25	6.66	0.0027
Error	52	2673.22	51.41		
Corrected Total	54	3357.71			
	DF	Parameter	Mean	t Value	$\mathbf{D}_{\mathbf{N}} >  \mathbf{t} $
Label	Dr	Estimate	Square	t value	rr~ u
Intercept	1	-6.69	8.15	-0.82	0.4159
Group	1	1.82	2.01	0.90	0.3715
Total scale/ Gratitude Questionnaire	1	0.70	0.19	3.58	0.0007

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	52.69	26.35	1.23	0.3016
Error	51	1094.64	21.46		
Corrected Total	53	1147.33			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	-0.53	2.24	-0.24	0.8143
Group	1	1.14	1.31	0.87	0.3902
Total scale/ Gratitude Questionnaire $R^2$ : 0.05	1	0.23	0.17	1.39	0.1706

**Table 4.7** Regression Results for Effects of Group and Gratitude Difference (Post-Pre) on Subjective Well-Being (Post-Pre)

Table 4.8 Regression Results for	or Effects of Group and Gratitude o	n Mental Health (Pre)
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Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	1639.05	819.52	8.87	0.0005
Error	52	4805.06	92.40		
Corrected Total	54	6444.11			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	24.41	10.93	2.23	0.0299
Group	1	2.77	2.70	1.02	0.3103
Total scale/ Gratitude Questionnaire R <sup>2</sup> : 0.25	1	1.08	0.26	4.14	0.0001

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	402.62	201.31	2.40	0.1007
Error	51	4274.21	83.81		
Corrected Total	53	4676.83			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	-2.22	4.43	-0.50	0.6180
Group	1	2.20	2.59	0.85	0.4000
Total scale/ Gratitude Questionnaire $R^2$ : 0.09	1	0.69	0.33	2.10	0.0407

**Table 4.9** Regression Results for Effects of Group and Gratitude Difference (Post-Pre) on Mental Health (Post-Pre)

**Table 4.10** Regression Results for Effects of Group and Gratitude on Physical Health (Pre)

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	140.91	70.46	0.51	0.6027
Error	52	7165.20	137.79		
Corrected Total	54	7306.11			
		Parameter	Standard		

		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	52.45	13.35	3.93	0.0003
Group	1	-0.86	3.30	-0.26	0.7946
Total scale/ Gratitude Questionnaire	1	0.31	0.32	0.96	0.3421
$R^2: 0.02$					

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	62.73	31.37	0.42	0.6604
Error	51	3824.30	74.99		
Corrected Total	53	3887.04			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	-2.24	4.19	-0.54	0.5944
Group	1	2.22	2.45	0.90	0.3704
Total scale/ Gratitude Questionnaire $R^2$ : 0.02	1	0.07	0.31	0.24	0.8138

Table 4.11 Regression Results for Effects of Group and Gratitude Difference (Post-Pre) on Physical Health (Post-Pre)

Table 4.12 Regression Results for Effects of Group and Gratitude on Positive Aspects of Caregiving (Pre)

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	1000.97	500.48	5.20	0.0087
Error	52	5005.87	96.27		
Corrected Total	54	6006.84			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	4.97397	11.15635	0.45	0.6576
Group	1	6.21999	2.75545	2.26	0.0282

1

0.64943

0.26648

2.44 0.0183

 $R^2: 0.17$ 

Total scale/ Gratitude Questionnaire

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	2	178.51	89.25	2.04	0.1399
Error	51	2226.47	43.66		
Corrected Total	53	2404.98			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	8.31	3.20	2.60	0.0121
Group	1	-3.31	1.87	-1.77	0.0833
Total scale/ Gratitude Questionnaire $R^2$ : 0.07	1	0.19	0.24	0.79	0.4324

**Table 4.13** Regression Results for Effects of Group and Gratitude Difference (Post-Pre)on Positive Aspects of Caregiving (Post-Pre)

**Table 4.14** Regression Results for Effects of Selected Variables on Positive Aspects of Caregiving (Pre)

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	7	2748.52	392.65	5.66	< 0.0001
Error	47	3258.31	69.33		
Corrected Total	54	6006.84			
		Parameter	Standard		

		Parameter	Standard		
Label	DF	Estimate	Error	t Value	Pr >  t
Intercept	1	10.31	11.04	0.93	0.3554
Group	1	6.40	2.58	2.48	0.0167
Total scale/ Gratitude Questionnaire	1	0.04	0.28	0.15	0.8843
Total scale/Satisfaction with Life Scale	1	0.12	0.19	0.60	0.5525
BREF: Physical Health	1	-0.24	0.12	-2.03	0.0478
BREF: Mental Health	1	0.16	0.14	1.15	0.2578
R <sup>2</sup> : 0.46					

Source	DF	Sum of Squares	Mean Square	F Value	<b>Pr &gt; F</b>
Model	7	1055.60	150.80	5.14	0.0002
Error	46	1349.38	29.33		
Corrected Total	53	2404.98			
		Parameter	Standard		
Label	DF	Estimate	Error	t Value	$\Pr >  t $
Intercept	1	9.77	2.77	3.53	0.0010
Group	1	-5.26	1.62	-3.25	0.0022
Total scale/ Gratitude Questionnaire	1	-0.09	0.20	-0.44	0.6600
Total scale/Satisfaction with Life Scale	1	0.61	0.18	3.49	0.0011
BREF: Physical Health	1	0.56	0.33	1.73	0.0905
BREF: Mental Health R <sup>2</sup> : 0.44	1	0.01	0.38	0.02	0.9804

**Table 4.15** Regression Results for Effects of Selected Variables on Difference (Post-Pre)

 for Positive Aspects of Caregiving (Post-Pre)

# Table 4.16 P value for Mixed Model for Scales

Effect/Outcomes	GQ-6	Positive Aspects of Caregiving	SWLS	BREF Phys	BREF Psych	BREF Social	BREF Environment
Group	0.3388	0.1377	0.3600	0.9667	0.3796	0.2275	0.6774
Time	0.2798	0.0005	0.0530	0.2913	0.2513	0.1162	0.0007
Time*Group	0.4135	0.0616	0.4940	0.6154	0.5948	0.1666	0.4547

## CHAPTER 5

## DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

## Introduction

Family caregiving for persons with Alzheimer's disease and dementia is a growing phenomenon. Nurses need to understand both the burdens and the benefits of family caregiving in order to support both caregivers and care recipients. According to the Alzheimer's Association, in 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias. These numbers are expected to increase as the baby boomer generation continues to age (US Census Bureau, 2008). These caregivers lend a considerable amount of support to the long-term, home and community based care system (Alzheimer's Association, 2013). Many caregivers are at risk for negative health outcomes related to the responsibilities of their caregiving (Schulz & Beach, 1999). However, family caregiving roles may also have benefits that may reveal possibilities and opportunities related to the experience (Roth, Haley, Hovater, Perkins, Wadley & Judd, 2013).

This research examined the impact of gratitude interventions on family caregivers of individuals with Alzheimer's disease or dementia. The intent of the gratitude interventions was to add a positive component to the support they receive in caregiver support groups. Past research has indicated that gratitude interventions can improve subjective well-being (Froh, Sefick & Emmons, 2008; Emmons & McCullough, 2003;

McCullough, Emmons & Tsang, 2002) and decrease the risk of depression (Lambert, Fincham & Stillman, 2012; Seligman, Rashid & Parks, 2006). Using gratitude interventions to build caregiver resources could help to increase Alzheimer's disease caregivers' level of functioning and help them to recover more quickly from caregiving stressors (Fredrickson, 2001). The research questions were:

- 1.) How does gratitude contribute to subjective well-being, mental and physical health and the positive aspects of caregiving among caregivers?
- 2.) What is the relationship between gratitude, subjective well-being, physical and mental health and the positive aspects of caregiving?
- 3.) What is the effect of multiple gratitude interventions for the intervention group versus the control group?

This research contributes to efforts to expand the current literature on informal caregivers, specifically in relation to the role of gratitude and positive psychology, an area of research that has not been considered in the past. This chapter includes a discussion of the findings, implications, limitations, and recommendations for future nursing research, practice and education.

#### Discussion

The present study represents the first attempt to examine the effect of gratitude interventions on unpaid family caregivers of persons with Alzheimer's disease and dementia. This research included a series of three different gratitude interventions taught over the telephone. Though the findings were not statistically significant for the gratitude interventions, the present results may still be useful not only towards examining the use of gratitude specifically but as a useful model upon which to build positive psychology

interventions and consider how this framework might be used to better serve this important population of caregivers. The proposed interventions offer a foundation for further refinement. The findings of this research further highlight and describe the positive aspects of caregiving identified by family caregivers of persons with Alzheimer's disease and dementia.

In this study, satisfaction with life was used as a measure of subjective wellbeing. Previous research has shown that gratitude has been repeatedly linked with subjective well-being. The findings of this study are consistent with previous research. McCullough et al. (2002) found that measures of gratitude using the GQ-6 were correlated with scores on multiple measures of life satisfaction, subjective happiness, and subjective well-being. Several studies have shown that the relationship between gratitude and well-being continues even when controlling for other variables (Froh et al., 2009; Wood, Joseph & Maltby, 2008). Although a causal link between the gratitude intervention and subjective well-being among this sample was not observed, there was a correlational link between gratitude and subjective well-being which is consistent with the previous literature. The positive association between gratitude and subjective wellbeing highlights the vital contribution of gratitude to an unpaid family caregiver's wellbeing.

Gratitude has been reported to be negatively correlated to depression and anxiety (Kashdan & Breen, 2007; Lyubomirsky, Sheldon & Schkade, 2005; McCullough, Emmons & Tsang, 2002; Seligman et al., 2005). Part of the reason for this study was to examine if high levels of gratitude were associated with high levels of physical and mental health. McCullough, Emmons and Tsang (2002) found that gratitude was linked

to lower feelings of anxiety and depression. Because I was interested in the potential association between gratitude and mental health, I did not include measures of anxiety or depression in this study. This finding supports the relationship between gratitude and mental health, specifically that family caregivers of persons with Alzheimer's disease and dementia appear to be inclined to be grateful.

The results of this study did not support a correlation between gratitude and physical health and that is not consistent with previous research. Other researchers have begun to examine the positive health outcomes related to gratitude (Bono, Emmons & McCullough, 2004, Emmons & McCullough, 2003; Emmons and Shelton, 2005; Fredrickson & Joiner, 2002). Emmons and McCullough (2003) found that participants who were in the gratitude groups reported fewer physical symptoms and spent more time exercising than those participants in the control group. Wood and Joseph et al. (2009) examined the relationships between gratitude and sleep, and gratitude was found to be related to total sleep quality. Given these recent findings of associations between gratitude and a wide variety of physical and psychological variables, further research is needed in this area. Potential research questions include: What factors predispose family caregivers to more frequent and intense daily gratitude experiences? Can the induction of gratitude offer resilience against mental and physical health problems in family caregivers?

The results from the present study help to paint a portrait of the grateful caregiver. Consistent with the hypothesis, grateful people appear to also have a high satisfaction with life, high perceived mental health and are more inclined to experience higher levels of the positive aspects of caregiving. These preliminary findings may provide the

impetus for more detailed investigations of the possibility that gratitude plays a role in caregivers having more positive experiences.

This study provides useful information about the perception of caregiving; specifically the positive perception in the population of unpaid family caregivers of persons with Alzheimer's disease and dementia. This study contributes to a further understanding of establishing a standard way of measuring positive aspects of caregiving through the Positive Aspects of Caregiving Scale (Tarlow et al., 2004).

The task of providing care to a family member with Alzheimer's disease or dementia may place a burden on the caregiver, but it can also involve rewarding components, enabling the caregiver to feel useful, needed and competent (Boerner et. al., 2004; Tarlow et al., 2004; Cohen et al., 2002; Kramer, 1997). Positive aspects of caregiving have been identified as having positive correlation with caregiver health (Cohen, Colantonio & Vernich, 2002). Caregivers who reported more positive feelings associated with their caregiving responsibilities were less likely to report depression (Boerner, Schulz & Horowitz, 2004; Cohen et al., 2002; Roff, Burgio, Gitlin, Nichols, Chaplin & Hardin, 2004). Caregivers who were able to describe more positive aspects of caregiving may be buffered from negative consequences such as depression and mortality (Haley, Gitlin, Wisniewski, Mahoney, Cohen et al., 2002; Schulz & Beach, 1999; Kinney & Stephens, 1989). Cohen et al. (2002) found that when caregivers felt positively about caregiving, they were less likely to report depression or poor health.

Kramer (1997) stated that exploring the positive aspects of caregiving will be an important determinant of quality of care provided to the care recipient. The findings of this study suggest that the relationship among gratitude, subjective well-being, physical

health, mental health and the positive aspects of caregiving should be examined with greater specificity. This is an important area of research given that the ability for caregivers to persevere in their role while maintaining their own health may be influenced by subjective well-being. Additionally, gratitude and positive aspects of caregiving may present a buffering effect for caregiver well-being (Cohen et al., 2002; Cohen, Gold & Shulman, 1994).

## **Gratitude Interventions**

In the literature, there is strong evidence for the daily practice of gratitude exercises. It was found that adults who practiced daily gratitude exercises had increased gratitude and positive outcomes (Emmons & McCullough, 2003; Watkins et. al., 2003). In a series of studies, Emmons and McCullough (2003) demonstrated that a focus on things for which one is grateful is linked to greater subjective well-being. A sample of college students was randomly assigned to one of three conditions: gratitude, hassles and events. In a study that compared the frequency of performing gratitude lists daily, adults who contemplated what they are grateful for once a week enjoyed the task more and gained increased positive benefits when compared to adults who completed exercises more often (Lyubomirsky et. al., 2005). Lyubomirsky et al. (2005) suggested that participants who wrote gratitude lists several times a week may have led people to find the activity to become less meaningful over time. Hedonic adaptation was explained to affect the potency of the interventions. This study sought to reverse that effect by performing 3 successive and different interventions over time. There evidence is unclear as to the correct frequency of administration of gratitude interventions. More evidence is

needed as to how frequently and for what exact time period the intervention must be practiced in order to produce results.

One modification for the intervention which included a letter of gratitude was in the duration of the exercise. Instead of composing a gratitude letter over several weeks as in Seligman's (2002) study or a gratitude letter exercise over a week (Seligman, Steen, Park & Peterson, 2005), participants in the present study were asked to write a letter over a span of two weeks. Two weeks was suggested for the letter writing interventions in the present study because of the cognitive process that might be involved in planning, organizing the letter, and possibly delivering the letter that may not be needed in the previous two gratitude activities. Thus, the duration of the gratitude letter intervention was different in the current study than those previously reported in the literature.

Seligman's (2002) original gratitude exercise asked participants to take the letter to the person for whom they wrote it and read it in person. In the modified intervention employed in this study, participants were allowed to write the letter to anyone whom they felt they had never properly thanked in their life, including friends and family members who were deceased. Several participants did chose to write their letter to deceased individuals. Participants in the current study were also allowed to choose whether or not they actually delivered the letter and were not required to read their letter to the person to whom it was addressed.

There are other methodological considerations to be addressed because of the lack of a benefit from the gratitude interventions which is contrary to other findings reported in the literature. The difference in results between the current study and Watkins et al.'s (2003) study where the effect of gratitude interventions reported might be due to the time

lapse between intervention and outcome measurements. The post-test was performed two weeks after the last intervention and unfortunately no longer-term follow-ups of the effects were conducted to determine whether gratitude might have a delayed effect on outcomes. The time lapse between the final intervention and post-test measurement was two weeks in the current study, but was immediately after the intervention in Watkins et al.'s (2003) study. Similarly, outcome measurements were taken right after the gratitude exercise in Jackson, Lewandowski, Fleury & Chin's (2001) study.

It is worth noting that there was strong evidence that emerged during the discussion of the interventions during follow-up with the intervention group to suggest that one of the gratitude strategies was more enjoyable than the others. Almost every participant stated that they enjoyed doing the gratitude lists and this intervention was the only one of the interventions that was consistently discussed in detail by almost every participant.

#### Limitations

There are several limitations to address in the present study. For example, it is necessary to consider the demographic makeup of the sample, including race and educational status. This study enrolled more women than men and minority groups were not well represented. The sample lacked ethnic diversity, as the majority of the participants were reported to be Caucasian (80%). Also when examining the socioeconomic status of participants, approximately 88% reported they were college graduates or had more education beyond college such as graduate school or more. Fifty-five percent of the caregivers in the study reported a household income of \$50,000 + annually. The majority of the participants came from middle class to upper-middle class

households. Based on these factors, this sample does not appear to be representative of the general population of family caregivers.

Overall sample size and unequal samples present another limitation of this study. The overall sample size (n=55) was small, and the small size (n=20) of the control group, as compared to the intervention group (n=35) could contribute to a lack of statistical power. Support groups were utilized to recruit participants and possible differences may exist between those individuals who were willing to participate and those who chose to decline. Those individuals who attend support groups may be more inclined to a positive attitude and high levels of gratitude, indicating a higher measure of these initially.

It is also possible that gratitude interventions lends its effects only in people who are predisposed to be grateful as reflected in their high gratitude scores in the pre-test. Perhaps already highly grateful people are more open to engage in gratitude activities compared to people who are less inclined to feel grateful. They might also benefit more from the exercise because the interventions involved engagement in gratitude, which is consistent with their overall tendency to be grateful. This study involved 55 participants that were participating in support groups. These individuals are very likely different from those who provide care for a family member without formal support. Further research should incorporate caregivers who do not attend support groups.

Another limitation is that the current study used data that was self-reported to measure each of the variables. Self-report data should be interpreted with caution as many factors can influence the responses, including social desirability. When administering a psychometric questionnaire, it is hoped that participants will respond in a manner that is honest and adequate to answer the proposed questions. The reliance on

self-report measures could impact reliability because it is difficult to determine how a caregiver who self-reported high levels of the variables actually compared to those who rated themselves lower. Another caveat that should be considered is the current mood of the caregiver while answering the questionnaire and the challenges associated with studying the caregiver population.

The limitations of method of delivery may have influenced results of the study. Due to the limited time available on the telephone due to caregiver responsibilities, it was difficult to fully discuss some of the interventions. Many caregivers reported being very busy and they may not have been able to adequately reflect on the activities. Lack of ongoing interaction between the researcher and participants may have also affected the outcomes of this study. Past research suggests that higher rates of compliance in completing assignments at home require ongoing (at least weekly) interaction between the participants and the researcher (Jakicic, Polley & Wing, 1998). A future study might include a different method of delivering these interventions to increase compliance and achieve a more regular method of follow-up while still taking into account the busy schedules that caregivers may have.

Another limitation to this study is the manner of follow-up for the gratitude interventions. Caregivers were asked to read their activities and reflect on how they felt upon reading the activity. Caregivers were also asked at the beginning of the activity to take time to reflect on the activity even after it is completed. Sometimes long amounts of time occurred between follow-up and the next activity. Reflecting upon the experiences of these activities is an integral part (Chen, 2010). Some caregivers appeared reluctant to discuss their personal experience, which may have meant that they may not have

completed the activity as assigned or that their response to the activity was very personal. In addition to the above considerations, it is important to address that the procedure in the current study allowed the participants to keep their completed gratitude interventions with the only investigator access to the actual contents was through a follow-up discussion of the activities over the telephone.

## **Implications for Practice**

Although the negative aspects of caregiving for have been widely studied, few researchers have investigated the effect of positive psychology interventions on caregivers. This is a fascinating and growing topic in the literature. There is an absence of studies of positive psychology interventions that focus on family caregivers. Similarly, there is little research that has evaluated gratitude interventions on caregivers. Specific evidence-based gratitude interventions have potential relevance for nurses who work with family caregivers. The results of this study could have potential implications for researchers, health care providers, and those individuals working with caregivers that are interested in incorporating positive psychology into a laboratory or practical setting. These gratitude interventions could easily be infused into already existing interventions or used independently. A simple gratitude activity similar to the gratitude lists could be used as part of a support group exercise but may not be particularly useful in the acute phase when clients and families are struggling to understand and make sense of the new situation. It is important to match the caregiver and their unique situation to the interventions chosen. Individualization might involve assessing strengths and discussing positive aspects of caregiving and then involving caregivers in thinking about and acting upon their strengths in order to personalize their learning experience. Introducing

activities like the gratitude list early in the nursing encounter would communicate the dynamic process of finding positive experiences in caregiving that will be an important aspect of adjusting to the role of family caregiver. Another practical approach to individualizing the activities utilized could involve the nurse providing several options for how strengths, like gratitude, can be practiced, allowing caregivers to select the intervention that most appeals to them. It is recommended that nurses familiarize themselves with the various positive psychology interventions that have been utilized in previous research.

Implications for practice should further include that the positive aspects of caregiving are an important part of the caregiving experience despite the negative view that caregiving is burdensome and stressful. It is important for nurses to know that not all caregivers feel burden and strain in their caregiving role. It is important for nurses to encourage and support those caregivers who may view their roles as stressful and burdensome to explore their strengths and potentially see caregiving as an opportunity to learn and grow as individuals. Caregivers would benefit from the positive reinforcement that gratitude interventions and other evidence-based positive psychology interventions could provide. It is important for health care providers to assess strengths and resources rather than limit their assessments to problems and deficits.

#### **Implications for Nursing Education**

The education of nurses needs to include opportunities to gain some understanding of family caregiving for persons with Alzheimer's disease and dementia. Student nurses at all levels need to understand the issues that impact family caregivers in this unique situation. Student nurses should be taught that there are positive aspects of

family caregiving. This further education may help to impact the quality of care provided and help student nurses to take on a leadership role in promoting positive aspects of caregiving and to better discuss the negative attitudes of caregiving that new family caregivers may have. The process of teaching nursing students to work with family caregivers would involve educators teaching students how to discover and apply their own strengths and also to help them guide their patients to develop and apply their strengths as well.

#### **Implications for Further Research**

Although the present study attempted to provide insight into the relationship between gratitude, the positive aspects of caregiving, subjective well-being and physical and mental health, many questions still remain unanswered. Specific to this study, examining gratitude and the use of positive psychology in supporting family caregivers of those with Alzheimer's disease or dementia is a promising area to explore. Patients rarely come to treatment in health care settings with the goal of wanting to be more grateful or have a more positive view of caregiving. It will be important for future research to create empirical evidence that reveals effective ways to bring positive psychology concepts to our encounters with family caregivers in the health care setting. Future research could expand upon the quantitative and qualitative aspects of the use of gratitude and positive psychology with caregivers. Qualitative research in this area would also lend a rich, description that would allow for a more thorough examination of the impact of positive psychology in family caregivers. I suggest that research continue to use both reliable and valid self-reported measures in additional to more concrete observable or biophysical measures to determine the impact of positive emotions.

Further identification and understanding of the moderating variables in gratitude research would also be important. In terms of future research for gratitude interventions, a significant contribution could be made in order to better understand the role of time and frequency of the interventions. An area of research could explore what factors might influence the motivation of caregivers to continue practicing and using different gratitude interventions. It would be interesting to examine the moderating role of effort which could be conceptualized as an indicator of how seriously participants appeared to be practicing the interventions. The quality of the assignments could play a role in the effect of the gratitude interventions.

Future research regarding the gratitude interventions should investigate the longitudinal effects of caregivers performing the activities over a more expansive period of time. Other initiatives should attempt to replicate and extend this initial examination of gratitude interventions among family caregivers of individuals with Alzheimer's and dementia. To the extent that we can understand why and how these interventions may work to improve outcomes, researchers and practitioners may be able to optimize the conditions under which these strategies are ultimately practiced in real-world settings. When performing multiple gratitude interventions, the time on each task and the frequency of the gratitude interventions are necessary to inspect. The unique component of gratitude that was present within the interventions may take longer to internalize in order to produce the expected results. An additional round of data collection (long term follow-up) in three or six months may eventually result in more significant increases among some of the variables. Once the intervention and posttest data collection ended, several participants expressed that they were starting to really think

more about things they were grateful for and for the importance of expressing that gratitude. It could be for some individuals, the possible changes resulting from reflecting and practicing gratitude take time.

Similar to the manner in which new material is taught over time in a more education-based environment, this type of activity might be incorporated into face-to-face educational interventions or web-based learning. Most crucial to the study of utilizing gratitude interventions as a component of caregiver support, is the necessity in which future research examine how these interventions can be better adapted to specific people and times. Choosing an intervention that is easy to incorporate into a person's daily life and lifestyle is fundamental toward its success. It would be important to utilize interventions that mirror a realistic change individuals can make in their own lives.

### **Summary and Conclusion**

One aim of this research was to further understanding of the effects of structured gratitude interventions among family caregivers of those with Alzheimer's disease and dementia. Although the three gratitude interventions were unrelated to any increases in standardized measures of gratitude, positive aspects of caregiving, satisfaction with life or self-reported physical and mental health, additional research is needed in this area. Utilizing positive psychology as an additional method of supporting caregivers is a new area of research. Specifically, results indicated that caregivers were very interested in learning about and practicing these interventions. It may be that the methods of delivery and the exact mix or type of gratitude intervention need to be tailored to the caregiver.

Given the importance of research on the positive and negative aspects of caregiving and the impact of those on caregiver physical and mental health, this study

affords researchers insight into the valuable resource of positive psychology, which may be targeted and refined as a means of developing more holistic programs and educational materials tailored to the specific needs of the growing population of unpaid family caregivers of person's with Alzheimer's disease and dementia. In addition, this contribution reinforces the acknowledgement of the important role that the positive aspects of caregiving and gratitude may have in influencing a caregiver's well-being. Despite the various limitations noted earlier, the current study represents a valuable contribution to the literature. Researchers and healthcare providers may possibly utilize this information to adapt these interventions that focus on gratitude as an avenue to support caregivers. Given that this is the first research study, to my knowledge, to focus on the use of gratitude in unpaid family caregivers of person's with Alzheimer's disease and dementia, future research can help to identify, recognize and use various interventions based in positive psychology to capitalize on the strengths of family caregivers rather than focusing of problems and deficits. Using a more positive approach with family caregivers of persons with Alzheimer's disease and dementia may help them to identify and build resources and further aid them in identifying their unique challenges as opportunities rather than problems and burden.

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## APPENDIX A: POSITIVE WRITING – SCRIPT AND PARTICIPANT WORKSHEET

#### Gratitude Activity #1

#### **Telephone Script – Positive Writing**

*Researcher:* You are being asked to write about your past. We all have positive and negative things in life when we reflect on the past. If your thoughts are usually negative, positive writing forces you to consciously recognize the positive things that have happened to you or that you remember. Write only positive things. You can write about the good things you have done, good experiences that you have had that are precious to you or good memories about the person that you provide care for. If you begin to feel sad or think negatively, take a deep breath and refocus your thinking on only the positive experiences.

*Researcher:* What questions do you have about the activity? (the word activity will be used in place of intervention during discussions with participants)

(Allow time to respond to questions)

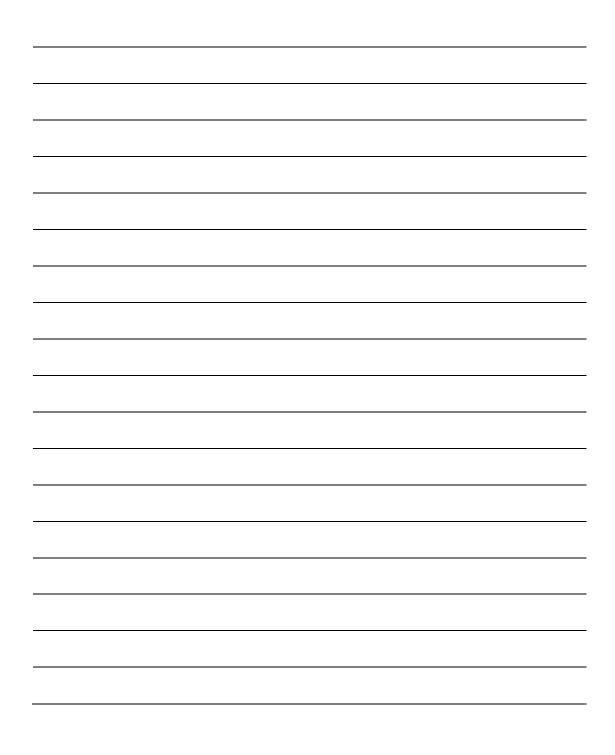
*Researcher:* You do not have to write every day. It is recommended that you complete your writing in one week and reflect and re-read what you have written during the second week. (Give dates for completion and recommend writing on calendar.)

*Researcher:* At this time during the call I would like for you to ask any questions you might have about Alzheimer's disease or caregiving. If there is anything that I don't know or am unable to answer right away, I will call you back. What questions do you have?

(Allow time to respond to questions)

Researcher: Thank you so much for your participation in this study. If you have any questions or problems about this activity before I call you again, please don't hesitate to contact me. I will not be collecting your writing, but I will be calling on (give date) to discuss the activity with you and check on you again. Thank you for taking your time to do this. Gratitude Activity #1

Participant Worksheet – Positive Writing



## APPENDIX B: GRATITUDE LIST – SCRIPT AND PARTICIPANT WORKSHEET

#### Gratitude Activity #2

#### **Telephone Script – Gratitude Lists**

*Researcher:* This activity will require you to think about gratitude on a daily basis. This activity is designed to help you to focus on the positive events that happen every day. For two weeks you are asked to reflect on your day each day and identify three good things that you did, that happened to you, or that you are grateful for. These do not have to be detailed. The activity is meant for you to be able to do relatively quickly.

You have been provided with a worksheet where you will record your daily lists. You will not be required to turn these in, but will be asked to discuss the activity when I call you on (give date).

What questions do you have about the activity?

(Allow time to respond to questions)

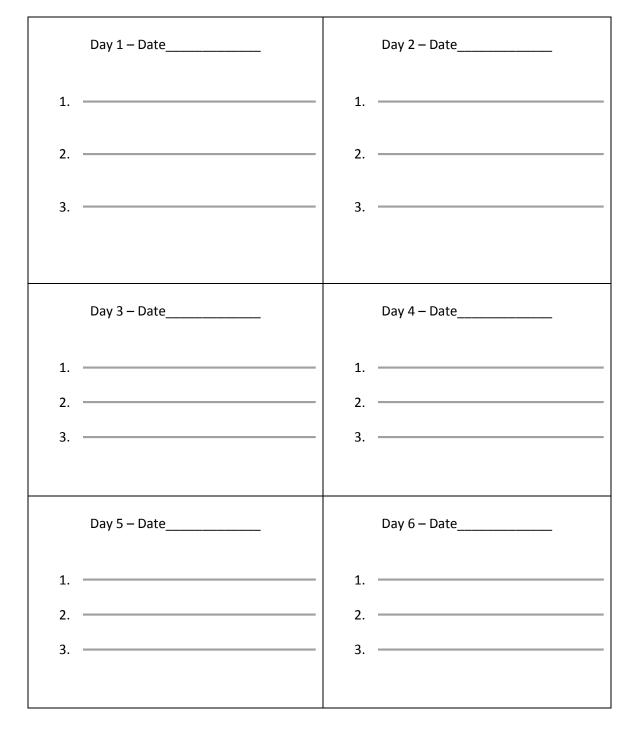
*Researcher:* Now is our time to discuss any questions you may have about Alzheimer's disease or caregiving. What questions do you have? How has everything been going?

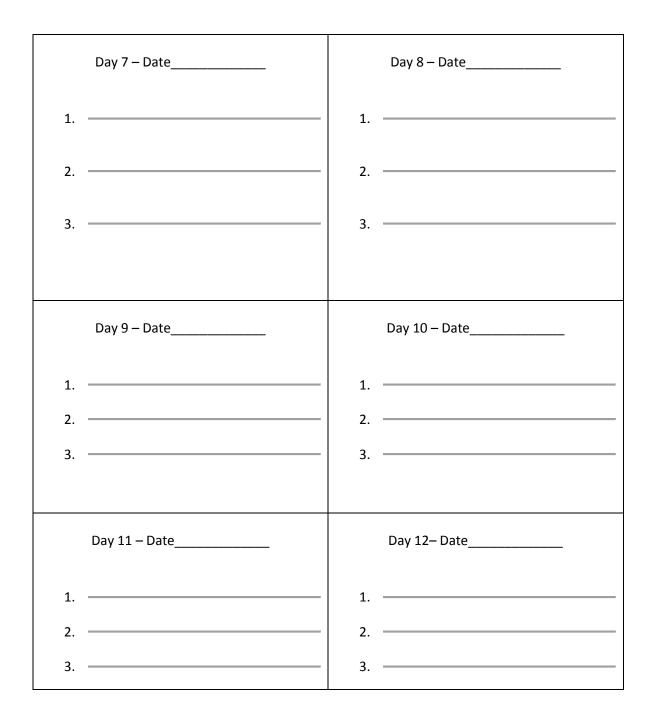
(Allow time to respond to questions)

*Researcher:* Thank you so much for your participation in this study. I appreciate you taking your time to speak with me as well as the time it takes for you to complete the activities. If you have any questions or problems about this activity before I call you again, please don't hesitate to contact me. Thank you so much and I hope you have a good week!

#### Gratitude Activity #2







1	Day 13 – Date		Day 14 – Date
1. –		1.	
2. –		2.	
3. –		3.	
1 2 3		2.	
3		3.	

## APPENDIX C: GRATITUDE LETTER – SCRIPT AND PARTICIPANT WORKSHEET

#### Gratitude Activity #3

#### **Telephone Script – Letter of Gratitude**

*Researcher:* This is the third and final activity. For this activity you are being asked to write a letter of gratitude to someone whom you feel you have never properly thanked. This person can be anyone you wish. Depending on who you write, you may be able to deliver the letter after you have written it. It is recommended that you do this if you are able to. This letter can be any length. You have been provided with pages to write on. You may choose to use additional pages. You do not have to write it in one day. You may use the next 2 weeks to write the letter and reflect on the contents. You will not be required to deliver this letter or to turn it in, but you will be asked to discuss the activity when I call you on (give date).

What questions do you have about the activity?

(Allow time to respond to questions)

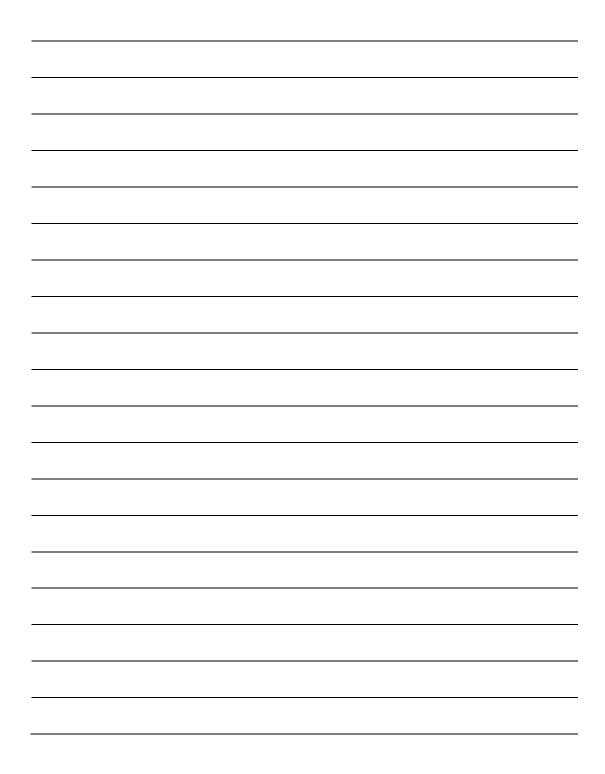
*Researcher:* Now is our time to discuss any questions you may have about Alzheimer's disease or caregiving. What questions do you have? How has everything been going?

(Allow time to respond to questions)

*Researcher:* Thank you so much for your participation. I appreciate you taking your time to speak with me and taking your time to do the activities that I have asked. If you have any questions or problems about this activity before I call you again, please don't hesitate to contact me. Thank you so much and I hope you have a good week!

Gratitude Activity #3

Participant Worksheet – Letter of Gratitude



### APPENDIX D: PARTICIPANT INTERACTION FORM

PARTICIPANT ID	
----------------	--

ME:
l

TELEPHONE NUMBER CALLED:

INTERVENTION #\_\_\_\_ OR FOLLOW-UP #\_\_\_\_ (PLEASE CIRCLE ONE)

Description of what was discussed (progress or concerns):					
Follow-up needed:					
Follow-up notes:					
Referral needed:					
Referral Notes:					

Have you attended an Alzheimer's disease caregiver support group meeting in the last 2

weeks? Yes or No (please circle)

Did you discuss this intervention at the support group meeting? Yes or No (please circle)

## APPENDIX E: PARTICIPANT CONTACT INFORMATION

## Participant Contact Questionnaire

Your Contact Information					
Your name	Your date of birth				
Your home address	Home phone number	Work phone number			

Care Recipient's Emergency Contact Information						
Relationship:						
Physician's phone number:						

Your Emergency Contact Information	
In emergency, please contact	Relationship
Home phone number:	Work phone number:
Alternate contact:	Relationship:
Home phone number:	Work phone number:
Your primary care physician:	Physician's phone number:

What day(s) of the week are best to contact you by telephone?:

What time of day is best to contact you by telephone?:

## APPENDIX F: PRE AND POST TEST QUESTIONNAIRE

#### Pre and Post Test Interview

#### The Gratitude Questionnaire – Six Item Form (GQ-6)

On a scale of 1-7, with 1 being that you strongly disagree and 7 is that you strongly agree, score each statement to indicate how much you agree with it. I will read each statement and you will assign each statement a score.

		Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree
1.	I have so much in life to be thankful for.	1	2	3	4	5	6	7
2.	If I had to list everything that I felt grateful for, it would be a very long list.	1	2	3	4	5	6	7
3.	When I look at the world, I don't see much to be grateful for.	1	2	3	4	5	6	7
4.	I am grateful to a wide variety of people.	1	2	3	4	5	6	7
5.	As I get older, I find myself more able to appreciate the people, events and situations that have been a part of my life history.	1	2	3	4	5	6	7

6.	Long amounts of time can go by before I feel grateful to something or someone.	1	2	3	4	5	6	7	
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#### Positive Aspects of Caregiving Scale

Some caregivers say that, in spite of all the difficulties involved in giving care to a family member with memory or health problems, good things have come out of their caregiving experiences too. I'm going to go over a few of the good things reported by some caregivers. I would like you to tell me how much you agree or disagree with these statements.

#### Providing help to (care recipient) has...

		Disagree a lot	Disagree a little	Neither agree nor disagree	Agree a lot	Unknown	Refused
1.	made me feel more useful.	1	2	3	4	5	6
2.	made me feel good about myself.	1	2	3	4	5	6
3.	made me feel needed.	1	2	3	4	5	6
4.	made me feel appreciated.	1	2	3	4	5	6
5.	made me feel important.	1	2	3	4	5	6
6.	made me feel strong and confident.	1	2	3	4	5	6
7.	enabled me to appreciate life more.	1	2	3	4	5	6
8.	enabled me to develop a more positive attitude toward life.	1	2	3	4	5	6
9.	strengthened my relationships with others.	1	2	3	4	5	6

#### Satisfaction with Life Scale (SWLS)

I will read five statements that you may agree or disagree with. Using the 1-7 scale below,

indicate your agreement with each item. Please be open and honest in your responding.

		Strongly Agree	Agree	Slightly Agree	Neither Agree nor Disagree	Slightly Disagree	Disagree	Strongly Disagree
1.	In most ways my life is close to my ideal.	7	6	5	4	3	2	1
2.	The conditions of my life are excellent.	7	6	5	4	3	2	1
3.	I am satisfied with my life.	7	6	5	4	3	2	1
4.	So far I have gotten the important things I want in life.	7	6	5	4	3	2	1
5.	If I could live my life over, I would change almost nothing.	7	6	5	4	3	2	1

#### WHOQOL-BREF

The following questions will ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate**. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks**.

		Very poor	Poor	Neither poor not good	Good	Very Good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5

9.	How healthy is your	1	2	3	4	5
	physical					
	environment?					

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you	1	2	3	4	5
	able to get around?					

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your	1	2	3	4	5

		1				1
	ability to perform					
	your daily living					
	activities?					
18.	How satisfied are	1	2	3	4	5
	you with your					
	capacity for work?					
19.	How satisfied are	1	2	3	4	5
	you with yourself?					
20.	How satisfied are	1	2	3	4	5
	you with your					
	personal					
	relationships?					
21.	How satisfied are	1	2	3	4	5
	you with your sex					
	life?					
22.	How satisfied are	1	2	3	4	5
	you with the					
	support you get					
	from your friends?					
23.	How satisfied are	1	2	3	4	5
	you with the					
	conditions of your					
	living place?					
24.	How satisfied are	1	2	3	4	5
	you with your					
	access to health					
	services?					
25.	How satisfied are	1	2	3	4	5
	you with your					
	transport?					

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

# **DO YOU HAVE ANY ADDITIONAL COMMENTS ABOUT THIS QUESTIONNAIRE?** (PLEASE LIST HERE):

## APPENDIX G: PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE

#### Demographic Questionnaire

Participant ID Code:

Group ID Code:

Do you currently live with the care recipient (family member with Alzheimer's disease that you provide care to)?:

- 1. Yes
- 2. No

What is your relationship to the care recipient?:

- 1. Child
- 2. Grandchild
- 3. Spouse
- 4. Sibling
- 5. Partner
- 6. Other relative\_\_\_\_\_

What is your age?:

Are you:

- 1. Male
- 2. Female

Are you:

- 1. Caucasian
- 2. African American
- 3. Hispanic/Latina
- 4. Other
- 5. Declined to respond

Are you:

- 1. Married
- 2. Not married

#### What is your religion?:

- 1. Baptist
- 2. Catholic
- 3. Methodist
- 4. Lutheran
- 5. Jewish
- 6. Other\_\_\_\_\_
- 7. No specific religion

#### Which of the following best describes your educational level?:

- 1. Did not graduate from high school
- 2. High school graduate
- 3. Some college
- 4. College graduate
- 5. Attended graduate school
- 6. Other:\_\_\_\_\_

#### How many children (under the age of 18) live in your house with you? (Write "0" if none)

\_\_\_\_\_

#### What is your current occupation?:

- 1. Employed part-time
- 2. Employed full-time
- 3. Unemployed

#### Who is the main wage earner in your house?:

- 1. Self
- 2. Spouse
- 3. Partner
- 4. Parent
- 5. Other relative
- 6. Friend/roommate
- 7. None

#### What was your household income last year before taxes?:

- 1. 0 \$4,999
- 2. \$5,000 \$9,999
- 3. \$10,000 \$19,999
- 4. \$20,000 \$29,999

- 5. \$30,000 \$49,999
- 6. \$50,000 +

Do you currently live with the care recipient (family member with Alzheimer's disease that you provide care to)?:

- 1. Yes
- 2. No

What is the gender of the care recipient?:

- 1. Male
- 2. Female

What is the age of the care recipient?:

What is the race of the care recipient?:

- 1. Caucasian
- 2. African American
- 3. Hispanic/Latina
- 4. Other
- 5. Declined to respond

## What is the specific diagnosis that the family member that you provide care for has been diagnosed with?

- 1. Alzheimer's disease
- 2. Vascular dementia
- 3. Dementia with Lewy Bodies
- 4. Mixed dementia
- 5. Frontotemporal dementia
- 6. Other\_\_\_\_\_

How long have you been providing care to your family member with dementia or Alzheimer's disease?:

\_\_\_\_\_ (months/years)

What is the approximate date (month/year) that the care recipient was diagnosed with dementia or Alzheimer's disease by a healthcare provider? \_\_\_\_\_ (month/year)

Which of the following tasks do you assist the care recipient with? (check all that apply):

- a) Personal care tasks (ADL's)
- b) Homemaker chores (IADL's)
- c) Transportation
- d) Managing finances
- e) Health care (doctor visits, medication monitoring)
- f) Supervision
- g) Emotional support
- h) Other\_\_\_\_\_\_

Number of hours per week spent caregiving:\_\_\_\_\_

#### During the last 30 days, which symptoms has the care recipient regularly displayed?:

- a) Anxiety, suspiciousness, agitation
- b) Confusion
- c) Difficulty recognizing family and friends
- d) Difficulty recognizing you
- e) Inability to recognize objects
- f) Loss of appetite
- g) Loss of bladder and/or bowel control
- h) Problems speaking
- i) Repetitive movements (such as pacing or wringing of hands)
- j) Sleep disturbances
- k) Wandering

## Which of the following other health conditions have (has) the care recipient been diagnosed with?:

- a) Diabetes
- b) Heart Failure
- c) Chronic Obstructive Pulmonary Disease (COPD)
- d) Hypertension
- e) Heart Disease
- f) Arthritis
- g) Other\_\_\_\_\_

#### Are you also providing care to any other individuals?:

- 1. yes
- 2. no

How long have you attended this support group?

If you have previously attended this support group, in what ways do you feel this support group has helped you?

Have you ever attended any other caregiver support group related to dementia or Alzheimer's disease including online (please specify if online or in person)?

Have you attended any classes or educational sessions about dementia or Alzheimer's disease?

#### APPENDIX H: SUPPORT GROUP DEMOGRAPHIC QUESTIONNAIRE

- 1. Support group location:
- 2. Day and time of scheduled meeting:
- 3. How many people typically attend your support group?
- 4. How long has this group been in existence?
- 5. How long have you been the leader of this support group?
- Are you a healthcare professional or have you received any medical training? Please elaborate on this.
- 7. Have you taken any courses specific to dementia or Alzheimer's disease?
- 8. Which courses or conferences have you attended?
- 9. Do you have any family members with dementia or Alzheimer's disease?
- 10. Are you currently a caregiver of someone with dementia or Alzheimer's disease?
- 11. Have you been a caregiver of someone with dementia or Alzheimer's disease?
- 12. What additional comments do you have?

## APPENDIX I: INFORMED CONSENT

#### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

## THE EFFECT OF MULTIPLE GRATITUDE INTERVENTIONS ON CAREGIVERS OF ALZHEIMER'S DISEASE PATIENTS IN SUPPORT GROUPS

Principal Investigator: Cristy DeGregory, RN, PhD (c), Gerontologist (803-319-6167)

#### INTRODUCTION

You are invited to participate in a research study. The Institutional Review Board of the University of South Carolina has reviewed this study for the protection of the rights of human participants in research studies, in accordance with federal and state regulations. However, before you choose to be a research participant, it is important that you read the following information and ask as many questions as necessary to be sure that you understand what your participation will involve. Your signature on this consent form will acknowledge that you received all of the following information and explanations verbally and have been given an opportunity to discuss your questions and concerns with the principal investigator.

#### PURPOSE

The purpose of the study is to gain a greater understanding of the role of positive psychology and its role in the support of caregivers who are caring for a family member with dementia or Alzheimer's disease. I am seeking to identify new methods to strengthen the support that we currently offer caregivers by examining the role of gratitude in supporting caregivers. This consent form explains what you will be asked to do if you decide to participate in this study. Please read it carefully and feel free to ask any questions you like before you make a decision about participating. I am conducting this study as part of the dissertation requirements for the University of South Carolina, College of Nursing.

#### PROCEDURES

You are being asked to participate in this study because you currently provide care to a family member with dementia or Alzheimer's disease. You will be asked to participate in 2 separate interviews over the telephone. The first interview will conducted during the next week following this support group meeting and the second interview will be in 8 weeks. You may also be asked to complete 3 activities that you will be taught how to do over the telephone. You will be mailed a form with directions and you will receive a phone call at the beginning of each activity during which I will briefly explain how to do the activity. You will have

2 weeks to perform each activity. The activities are brief writing assignments and there are no right or wrong answers. Only your personal thoughts and opinions are required. You complete these activities at home and they will not be collected or turned in. During a weekly telephone call, you will be asked to discuss the activities and will be allowed time to ask questions.

#### **POSSIBLE RISKS**

There are no known risks associated with participating in this research except a slight risk of breach of confidentiality, which remains despite steps that will be taken to protect your privacy. Some of the interview questions are of a personal nature and may be uncomfortable to answer. If this occurs, you may refuse to answer the question or end the discussion at any time.

#### **POSSIBLE BENEFITS**

It is not possible to know whether or not you may benefit from participating in this study. You understand that the information gained from this study may be used scientifically and may be helpful to others.

#### **INCENTIVES FOR PARTICIPATION**

You may receive up to a total of \$20.00 for participating in this study. You will receive a \$10.00 Wal-Mart Gift Card for the pre-test interview and a \$10.00 Wal-Mart Gift Card for the post-test interview. You will not receive reimbursement for any interviews that are not attended or completed. Incentives will be hand delivered to the next support group meeting after the pre-test is completed and again when the post-test is completed. If you are not in attendance at the meeting, the gift card will be mailed to the address you have identified on your contact information form.

#### **VOLUNTARY PARTICIPATION**

Participation in this study is completely voluntary (your choice). You may refuse to participate or to withdraw at any time, for whatever reason, without negative consequences. If you refuse to participate or withdraw from the study, you will not be penalized. Your decision will not affect your relationship with your current caregiver support group. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner.

#### **CONFIDENTIALITY OF RESEARCH RECORDS**

Participation will be confidential. A number will be assigned to each participant at the beginning of the project. The only document with your name on it will be this consent form, and it will be stored separately from your study information. This number will be used on project records rather than your name and no one other than the researcher will be able to link your information with your name. Study records/data will be stored in locked filing cabinets and protected computer files at the office of the primary researcher. The results of this study may be published or presented at professional meetings, but your identity will not be revealed. While we will make every effort to protect your privacy, it cannot be absolutely guaranteed. There are two exceptions to this confidentiality. The first is if you reveal that you may harm yourself or someone else and the second is if you reveal current child or elder abuse. If you reveal that you are in danger of harming yourself or others, we will intervene to prevent any harm and arrange for you to receive appropriate professional care. By law, we also have to report any current suspected abuse to the appropriate agencies.

#### **CONTACT FOR QUESTIONS**

For more information concerning this study and research-related risks or injuries, or to give comments or express concerns or complaints, you may contact the primary investigator, Cristy DeGregory (803)319-6167.

#### CONSENT TO PARTICIPATE

The study investigator, Cristy DeGregory, has explained the nature and purpose of this study to me. I have been given the time and place to read and review this consent form and I choose to participate in this study. I have been given the opportunity to ask questions about this study and my questions have been answered to my satisfaction. After I sign this consent form, I understand I will receive a copy of it for my own records. I do not give up any of my legal rights by signing this consent form.

Printed Name of Participant

Signature of Participant

Date

Signature of Witness

Date

## APPENDIX J: CRISIS INTERVENTION PLAN FOR CAREGIVERS

