

**Caregivers of Family with Alzheimer's Disease and Dementia:  
Well-Being and Meaning in Life**

by

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A dissertation submitted to the Graduate Faculty of  
Auburn University  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

Auburn, Alabama  
December 13, 2014

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## Abstract

Family caregivers of persons with Alzheimer's disease and dementia experience threats to their well-being through the stress of care. There are many factors that can improve the well-being of caregivers, but the present study focused on the existential concept of meaning in life as it relates to the well-being of the caregivers. This study sought to understand the relationship between caregiver well-being (basic needs and activities of daily living) and meaning in life (exciting life, accomplished life, principled life, purposeful life, and valued life) as well as how various demographic factors may impact well-being and meaning in life. A significant, positive relationship was found between caregiver well-being and meaning in life. Significant, strong, positive relationships occurred between accomplished life and basic needs of well-being as well as between valued life and basic needs. Significant, moderate, positive relationships occurred between exciting life and basic needs, principled life and basic needs, purposeful life and basic needs, accomplished life and activities of daily living, and valued life and activities of daily living. Employed participants were the only group to have significantly higher well-being than unemployed participants.

## Acknowledgements

I would like to thank my entire family for their unending encouragement throughout my work as a student and on this dissertation. My husband, David, has provided a great deal of support, and our children have been loving and patient. My parents and other family members have cheered me on throughout this process. I also appreciate my friends and colleagues who have been there for me. My advisor and committee chair, Dr. Suhyun Suh, is appreciated for all of her patience, feedback, and support as a student and during my dissertation. I am also thankful to Dr. Chippewa Thomas and Dr. Melanie Iarussi for their words of wisdom and feedback on my committee as well as each educator instrumental in my instruction and influence on my degree and future. Finally, I dedicate this dissertation to the memory of my grandfather, Robert Coker, who was an inspiration as a great caregiver.

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## **Chapter 1**

### **INTRODUCTION**

Understanding the well-being of caregivers of family members with Alzheimer's disease (AD) and other dementias has been researched throughout recent years, and the positive experiences of caregiving have been a focus (Berg-Weger, Rubio, & Tebb, 2001). Family members make up the majority of caregivers for those with AD and other dementias worldwide (Vellone, Piras, Talucci, & Cohen, 2007). Although an entire family may be involved in the care of the ill family member, generally one family member in particular provides the primary caregiving (Rodriguez-Sanchez et al., 2011). Most often, the caregivers for AD and dementia patients are immediate family members (Black et al., 2010). This primary caregiver faces drastic life changes in the caregiving role, and their families are also greatly impacted. The innumerable families providing care to their relatives with these diseases remind us that the quality of life of the caregivers changes dramatically from what it was before caring for the ill family member, thus impacting the well-being of caregivers. This change in quality of life can have a large impact on the well-being of the family caregiver, and there is need to incorporate interventions to improve the well-being of the caregiver to AD and dementia care recipients (Vellone et al., 2007). Understanding the state of caregivers' well-being and the relationship meaning in life has with this concept of well-being could help improve caregivers' quality of life from an existential perspective.

Caregivers for care recipients diagnosed with dementia or AD face greater stress than those caring for physically frail older adults for many reasons, and this has an impact on the caregiver's well-being (Pinquart & Sorensen, 2004). For example, shifts in the behavior and personality related to dementia in the recipient are often observed. An increased need for supervision arises leaving less time for the caregiver. The caregiver isolates as a result of behavior issues from the recipient. There is lack of gratitude from the care recipient which could be uplifting for the caregiver, and visible rewards are not apparent for the caregiver as the care recipient progressively deteriorates. It is critical to keep these factors in mind when the counselor attempts to understand the well-being of the caregiver as these factors carry a major influence (Pinquart & Sorensen, 2004).

Focus on caregiving behavior has been high (Poulin et al., 2010). For example, the behavior of caregiving was primarily looked at from the aspect of active caregiving and not aspects such as being on call or engaging in other lifestyle activities. Perren, Schmid, and Wettstein (2006) considered dementia caregiving as a process that must demand adaptation to change. The behavior of the care recipient changes and the caregiver must be able to adapt to these changes in behavior. Caregivers are driven by a strong sense of obligation to provide the best care to family members. According to Hwang, Rivas, Fremming, Rivas, and Crane (2009), "inevitable changes to personal life due to the caregiver role, feelings of restriction of personal time and freedom, and the lack of a support network" (p. 260) occur as a result of the sense of obligation to being a caregiver. These are results of adaptation of behavior to meet the demands of the caregiving role.

Providing counseling for caregivers of AD and other dementias is important due to the high levels of stress experienced by caregivers. This stress can lead to increased mortality among caregivers due to the development of anxiety and depression (Granello & Fleming, 2008). The physical health complications that could arise from the impacts of anxiety and depression could lead to the deaths of these caregivers if not addressed; thus, the counselor needs to step in to work with the caregiver on the care of his or her well-being. Popular treatment involves a combination of techniques to manage stress, developing social support, and education that addresses the problems encountered by the caregiver (Granello & Fleming, 2008). The detrimental effects of caregiving have clearly been studied and are documented, but it is important for counselor to be able to understand what benefits the well-being of caregivers. Behavior is not the only aspect of the caregiver's life that is altered with the duties involved. High levels of psychological distress and depression, higher rates of psychological illness, lower rates of preventative health behavior engagement, and other psychosocial problems are exhibited by caregivers (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

Caregivers have demonstrated high levels of health problems, such as physiological illness and suppressed immune responses, and they have engaged in less preventative health behavior (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). It is important for counselors to assist caregivers in understanding the limitations of caring for their physical health just as much as mental health. The growing body of literature on caregiving suggests that caregivers are at risk of developing adverse mental and physical health effects (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). A counselor may be the caregiver's first line of response in seeking outside help, and the

counselor has the potential to recommend seeking medical treatment and to take a holistic approach with the caregiver to address the whole individual. Additionally, understanding how meaning impacts this particular dimension of well-being is indispensable to the counselor's assessment of the health of the caregiving client.

The significance of meaning in life as it relates to caregiving is only one facet of the concept. As a positive variable, identifying meaning in life indicates well-being, which facilitates adaptive coping and growth therapeutically (Steger, Frazier, Oishi, & Kaler, 2006). No one meaning fits everyone's life, but interest lies in which meaningful qualities are most associated with the well-being of caregivers. Less meaning in life has been associated with depression and anxiety, suicidal ideation and substance abuse, and many other negative well-being components (Steger et al., 2006). If counselors were to further explore the satisfaction gained from the caregiving relationship and the meaningfulness of life, the caregiving experience could perhaps be better understood. Highlighting other meaningful areas in the caregiver's life can provide a richer understanding of the overall wellness of the caregiver rather than only a focus on the relationship the act of caregiving has on well-being. Therefore, the benefit of understanding the relationship between meaning in life and well-being is great.

Well-being is a strengths-based perspective that cannot be measured by one observable variable, but it contains subjective and objective dimensions that are multifaceted (Rubio, Berg-Weger, & Tebb, 1999). Research is prevalent on the aspect of the burden of caregiving and depression, but there is much less research on the subjective well-being of caregivers as it is associated with positive affect and life satisfaction

(Pinquart & Sorensen, 2004). Although the phenomenon of well-being can be difficult to precisely define, the counselor can focus on what is working well for the caregiver.

According to Berg-Weger, Rubio, and Tebb (2000), the well-being of caregivers has been explored from many perspectives. The relationship of the caregiver to the care recipient has been studied, and married and adult child caregivers showed higher well-being on measures. The competence the caregiver felt in their role was important; higher perceived mastery in the caregiving role meant increased well-being. Finally, caregivers who reported fewer mental and physical health symptoms scored higher on well-being measures.

The concept of meaning in life for caregivers is suggested as a coping strategy that could be learned or attained through the development of various interventions (McLennon, Habermann, & Rice, 2011). It is likely the research on what is meaningful for the caregiver would be most pertinent in understanding interventions for the client in a counseling setting, but it is likely to be used in the screening or assessment process and in comprehending depression in a more existential concept. Many of the intervention programs available to caregivers focus on their decreased well-being, and there are few that focus on overall wellness. According to Carbonneau, Caron, and Desrosiers (2011), programs promoting leisure between caregiver and care recipient can encourage maintenance of their relationship and strengthen the bond. This can be meaningful intervention for the caregiver. Carbonneau, Caron, and Desrosiers (2011) reveal the following:

by sharing pleasant moments with the care receiver, the meaning of the caregiver's role in daily life develops in a more optimistic perspective. The

caregiver's role takes on a new meaning and ceases to be an existentially difficult and burdening experience. (p. 36)

Finding meaning in caregiving was found to improve caregiver well-being. The use of analyses of narratives of caregivers could provide insight into what is meaningful in caregiving (McLennon, Habermann, & Rice, 2011). Cooper, Katona, Orrell, and Livingston (2008) implied that a need for caregivers to recognize what types of psychological coping strategies works best to reduce depressive or anxious symptoms, and revealing to a caregiver of what is meaningful to him or her on a personal level can be beneficial in therapeutic settings. Counselors would be able to work with clients on the appropriate coping strategies to obtain meaning and thus improve well-being. The aspect of using the existential concept of meaning as a coping skill for caregivers experiencing mental health burden has support (McLennon, Habermann, & Rice, 2011). Interventions can be built to assist caregivers in learning how to develop or enhance their meaning in their caregiving situations.

### **Significance of the Study**

Finding meaning has been found to mediate the effect caregiver burden has on the mental health of the caregiver (McLennon, Habermann, & Rice, 2011). There is little research on the subjective well-being of caregivers and its association with positive affect and life satisfaction, such as meaningfulness (Pinquart & Sorensen, 2004). The mediating effects of meaning in life are significant as they are related to the reactions toward caring for the family member with Alzheimer's disease or dementia. Activities and life experiences found meaningful by the caregiver are reported to be significant in maintaining well-being (Mausbach et al., 2007).

The aspect of helping care recipients has been researched (Poulin et al., 2010), but it is helpful for counselors and counselor educators to understand what else, other than helping the family member with the illness, is meaningful to the caregiver. The results of this study can be used by counselors working with caregivers in helping them determine the most meaningful aspects of life to work on reducing the implications of negative well-being and/or the lack of outside support. The study's relevance to caregiver support groups facilitated by counselors or peers could be quite far-reaching to include meaning-in-life discussion.

Previous research has been criticized for not informing clinicians of the results of stress and coping for caregivers. Knussen and colleagues (2008) called for a need to inform clinicians in such a way that allows for working on early and potentially positive interventions for stress and coping before a downward spiral of mental health and other personal troubles overcomes the caregiver's well-being. The answer to preservation of caregivers' well-being could very well be in the interventions pertaining to growth and development of meaning in life (McLennon, Habermann, & Rice, 2011).

Caregivers for family members can range from typical (spouses and children) to atypical (daughters-in-law, grandchildren, other family members) caregivers (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). This study will examine typical and atypical caregivers of all ages. Most of the caregivers studied have been women in the baby boomer population (Robison et al., 2009). Further studies of other age groups and genders will be significant for helping counselors work with the ever-growing group of caregivers.



## **Purpose of the Study**

With the number of people diagnosed with Alzheimer's disease and other dementias on the rise, the need for caregivers for these patients increases. Family members comprise the majority of these caregivers (Vellone et al., 2007). Numerous studies have discussed the caregiver characteristics that surround caregiver burden, but there is a lack of literature that addresses characteristics that positively influence decreasing caregiver burden. Cooper, Katona, Orrell, and Livingston (2008) suggested future interventions for caregivers to focus on psychological coping strategies such as positively coping with their situation.

The primary purpose of this research study was to examine the relationship of meaning in life of caregivers with well-being when they care for family member with Alzheimer's disease or dementia. Another purpose was to investigate demographic factors contributing to each of the two variables. They included: age, gender, race, marital status, level of education attained, religious preference, employment status, annual household income, relationship to care recipient, and average hours per week of care provided to care recipient. The study also determined the relationship between five subscales of the Meaningful Life Measure (MLM) (Morgan & Farsides, 2008): purposeful life, valued life, accomplished life, principled life, and exciting life, and each subscale of the Caregiver Well-Being Scale (Tebb, 1995). The subscales of the Caregiver Well-Being Scale include two major categories of the basic human needs and the activities of daily living. The basic human needs include: (a) expression of feeling, (b) attendance of physical needs, (c) security, and (d) self-esteem and esteem from others. The activities of daily living include: (a) time for self, (b) household maintenance, (c)

leisure activities, (d) maintenance of functions outside the home, and (e) family support. The exciting life and accomplished life on the MLM refer to the positive affective consequences of a sense of fulfillment. The principled life refers to an individual's worldview or philosophy while purposeful life refers to having goals and clear sense of direction (Morgan & Farsides, 2008).

### **Research Questions**

1. Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients?
2. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being for family caregivers of AD and dementia care recipients?
3. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of activities of daily living of well-being for caregivers of AD and dementia care recipients?
4. How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics?
5. How do family caregivers of AD and dementia care recipients differ in well-being based upon demographic characteristics?

### **Terms Defined**

*Alzheimer's Disease (AD)*: Defined by Langbart (2002) as “a degenerative and irreversible brain disease that may progress over 15 to 20 years, causing a relentless loss of cognitive function and ultimately leading to profound dementia with physical and mental incapacitation” (p. 103).

*Dementia*: Defined by McFadden and McFadden (2013) as “progressive loss of cognitive functions that diminish memory, language, decision-making, abstract thought, and performance of familiar tasks” (p. 6).

*Family caregiving*: Defined by Gaugler, Kane, and Kane (2002) as “the provision of unpaid support by one family member to another who needs assistance because of a disability” (p. 207). In this study, caring family include spouses, children, siblings, sons- or daughters-in-law, grandchildren, or other relatives of the care recipient.

*Meaning in life*: Described by Yalom (1980) as “meaning refers to sense, or coherence. It is a general term for what is intended to be expressed by something. A search for meaning implies a search for coherence” (p. 423). In the current study, meaning in life will be measured by the Meaningful Life Measure (MLM) (Morgan & Farsides, 2008).

*Well-being*: Defined by Beddington et al. (2008) as “a dynamic state that refers to the individuals’ ability to develop their potential, work productively and creatively, build strong and positive relationships with others and contribute to their community” (p.1057). In the current study, well-being will be measured by the Caregiver Well-Being Scale (Tebb, 1995).

## CHAPTER 2

### REVIEW OF THE LITERATURE

As our nation experiences a rise in the population diagnosed with Alzheimer's disease or dementia, the number of informal family caregivers rises. As of 2013, 15.5 million caregivers were providing over 17.7 billion hours of unpaid care for care recipients (Alzheimer's Association, 2014). Furthermore, every 67 seconds someone in the United States develops Alzheimer's (Alzheimer's Association, 2014). The expense and other concerns associated with placing family members diagnosed with those illnesses in nursing home or other facilities often makes caregiving at home more practical. Family caregivers can include anyone from spouses to children to siblings to in-laws; every situation is unique in the caregiving experience. In the general sense, particularly with older adults, helping others may promote the helper's well-being with greater positive affect and satisfaction of life; however, the effects of caring for ill loved ones are in stark contrast as caregivers may experience high stress, poor health, and potential burnout (Poulin et al., 2010). The acknowledgement that caring for or helping others should have a positive impact on well-being brings into fruition the matter of how and if having meaning in life has a substantial impact on the well-being of caregivers to family members with Alzheimer's disease or dementia.

According to Haley, LaMonde, Han, Burton, and Schonwetter (2003), caregivers were more likely to report being depressed if they felt less self-efficacy in their role, felt less satisfaction from the role, or found less meaning in the role as caregiver. Stengard

(2002) found that outcomes of caregivers' well-being were mediated by meaning and emotional support. Individuals with above-average informal support were slightly less likely than those without informal support to experience depressive symptoms, particularly in caring for care recipients with memory and behavioral problems (Sorensen & Pinquart, 2005). A higher level of caregiver burden is associated with caring for older adults with cognitive issues that experience changes in behavior and mood, and caring for family members with dementia has a higher level of burden than caring for family members with physical impairments (Sequeira, 2012). Being able to manage the burden of caregiving can provide relief for the caregiver as well as contribute to the dignity of the care recipient as the caregiver copes with his or her own stress.

### **Meaning in Life**

The existential concept of meaning in life can be quite broad. It arose from Viktor Frankl's work, and research has taken place throughout the years to extend the understanding of the concept. Meaning in life, in itself, is an indicator of well-being as it is a positive variable (Steger, Frazier, Kaler, & Oishi, 2006). A caregiver's meaning in life is very personal and involves the values and judgments of the caregiver; therefore, a more in-depth understanding of the family care values and preferences will improve decision-making skills and the well-being of the caregiver of family member with Alzheimer's disease or dementia (Whitlatch, Feinberg, & Tucke, 2005).

According to Langle (2005), "personal meaning is a complex achievement of the human spirit and is found in the individual's confrontation with the challenges of the world and one's own being" (p. 2). The challenges associated with caregiving are part of the world outside the caregiver as well as within the caregiver; personal meaning is found

through struggles and triumphs with those challenges. Langle (2005) goes on to explain there is a correlation of two given facts: a situation's demand and understanding of one's self, which reflects in the caregiving scenario. Finding existential meaning could have a potential role in the prevention of depression (Mascaro & Rosen, 2008). The authors note that an increased experience of global meaning could lead to a decrease in depressive symptoms. The demands of the situations associated with caregiving have been associated with depression. Existential meaning is associated with greater understanding of one's self, so caregivers could benefit greatly from understanding meaning to decrease depression.

Numerous scales have been developed to study meaning in life and meaning in life while caregiving. The Finding Meaning Through Caregiving Scale (FMTCS), developed by Farran, Miller, Kaufman, Donner, and Fogg (1999), measures factors related to meaning in life for family caregivers of persons with AD. Farran et al. (1999) looked at various types of meaning in the FMTCS studying caregivers caring for family members with Alzheimer's disease. Types of meaning included ultimate meaning, which is the exploration of deeper philosophical or spiritual meaning in life; loss/powerlessness that is associated with loss concerning the caregivers themselves and powerlessness of caregiving; and provisional meaning, which has to do with the day-to-day tasks associated with caregiving. The authors note that provisional meaning could be studied further because the day-to-day experiences and meaning of caregivers' experiences are so important.

The Sense of Coherence Scale (SOC-29) measured five factors with spousal caregivers, which included, consistency of life, contentment, purpose, disappointments,

and interest in life (Välimäki, Vehviläinen-Julkunen, Pietilä, & Pirttilä, 2009). The similarities between having a sense of coherence and sense of meaning in life are similar. This scale was examined in conjunction with caregiver depressive symptoms and distress; therefore, the importance of such information is highlighted. Although a number of scales measure constructs such as meaning in life or sense of coherence, little is known about how judgments of meaning in life are formed. It is unknown if they are personality characteristics, contexts of environments or sociocultural, mood, recent life events, or goal progress (Steger et al., 2006).

Obtaining satisfaction in caregiving involves “subjective” sources of satisfaction, which are essential for the well-being of the caregiver. These positive effects are objective and reflect an objective gain from caregiving, such as “developing new skills and competencies”; ‘growing as a person’ and improving the relationship” (Sequeira, 2012, p. 498). The more meaning a caregiver can understand and identify on a personal, subjective level, the more there will be an objective effect and positive changes others will notice. The foundation for the ability to help caregivers come to terms with the caregiving experience lies within the subjective understanding of what is satisfying and meaningful about being a caregiver and life as a whole.

### **Meaning in Life with Caregiving**

It is evident from literature that being a caregiver can pose a serious threat to one’s quality of life, but it is not concluded that caring for the ailing relative is to blame (Poulin et al, 2010); the authors go on to suggest that providing the help in this role could actually increase well-being. Caregivers who responded to experiencing positive feelings about the caring process were less likely to report experiencing problems with

depression, burden, or poor health (Cohen, Colantonio, & Vernich, 2002). If counselors were to further explore the satisfaction gained from the caregiving relationship and the meaningfulness of life, the caregiving experience could perhaps be better understood. Highlighting other meaningful areas in the caregiver's life can provide a richer understanding of the overall wellness of the caregiver rather than only a focus on the relationship the act of caregiving has on well-being. Therefore, the benefit of understanding the relationship between meaning in life and well-being is great.

According to Whitlatch et al. (2005), caregiving involves an understanding of personal values and preferences as well as what the care recipient values. By gathering a more in-depth understanding of the values and preferences involved in family care, the decision-making skills and well-being of the caregiver and care recipient will be enhanced (Whitlatch et al., 2005). In a counseling scenario, Rossheim and McAdams (2010) suggest the counselor listen carefully and tirelessly to the caregiver's stories. This would allow for the counselor to assist the caregiver in finding personal meaning in the experience of caregiving.

If certain actions did not correct stressful events among caregivers, distress could be alleviated through meaning-based coping, which includes "positive reappraisal, revised goals, positive events, and activating spiritual or other deeply held beliefs" (Ziemba & Lynch-Sauer, 2005, p. 108). These concepts are aligned with meaning from an existential approach. It is suggested that meaning-based coping may take the place of grief and lead to a more positive reappraisal of caring for the care recipient (Ziemba & Lynch-Sauer, 2005). If caregivers attempt to find or obtain meaning and embrace the positive aspects of life or the caregiving experience, well-being could be revived.



Skovdahl, Kihlgren, and Kihlgren (2003) suggests that caregivers working from a poises-oriented type of care, which on how tasks are completed versus the fact that tasks have simply been completed (praxis-oriented), work in a more reflective manner. In the study (Skovdahl et al., 2003), the formal caregivers were divided into Group 1 (less aggressive patients) and Group 2 (more aggressive patients). Those caregivers from Group 1 did seem to attribute aggression to loss of balance and utilize empathy, imagination, and flexibility. Group 2 appeared to feel more neglected and feel unappreciated for their efforts with less social support. Much can be gleaned from this study. Caregivers who find their work more meaningful could find more harmony in their work, or as care recipients become more aggressive, care may become more difficult and arduous, thus leaving the caregiver to feel more underappreciated and finding less time and energy to seek social support. However counselors look at these findings, it is apparent that meaning in life is beneficial to the caregiver, but the counselor needs to take into account the level of aggressiveness of the care recipient in order to understand the caregiver's reality better. The relationship and interactions between the caregiver and care recipient is a highly important consideration.

Reid, Moss, and Hyman (2005) studied reciprocity in the caregiver and care recipient relationship. This type of relationship would entail each party benefitting as much as they contribute to the relationship. In a caregiving relationship, reciprocity is typically quite limited. Reciprocity in the caregiving relationship was shown to decrease caregiver burden; it was explained that love accounted for 16 percent of the variance in the findings (Reid et al., 2005). The potential that caregivers who have great love for their family member they care for is likely. Love and emotional burden were also found to be

stronger for highly intrinsically motivated caregivers. Therefore, it is possible reciprocity is not a type of external reinforcement. These findings are important when looking at caregivers' meaning in life as there are concepts some may find externally meaningful (external purpose) or more internally meaningful (spirituality, etc.). It is important to consider the actual relationship of the caregiver and family member; counselors must also place love in the equation. This love can produce a devotion to the care recipient that means sacrificing.

In one study that looked at female caregivers, meaning could be derived from the burden that meant sacrificing for others could actually be rewarding. Interestingly, the female *marianisma* role in Mexican culture could be related to this phenomenon as the female is often expected to fulfill the role of submission to her husband and perform in self-sacrificing behaviors (Mendez-Luck, Kennedy, & Wallace, 2008). As this role may be present in many Spanish cultures, discovering how this translates into a meaningful aspect related to caregiving would provide vast information on how counselors could be helpful to clients from Spanish cultures.

Religious cultural groups are also relevant to meaning in caregiving. A high predictor of meaning in caregiving for dementia care recipients was high religiosity, which translates to religion and spiritual beliefs helping caregivers cope with caregiving duties (Quinn, Clare, Pearce, & Dijkhuizen, 2012). Research has found prayer to be one of the most frequently cited forms of alternative therapy for dealing with health concerns, especially for African-American women. Research that has looked at African-American daughters as caregivers who reported strong religious faith, determined the women experienced less depression, greater self-acceptance, and possibly a greater threshold for

perceiving caregiver stress (Gwyther, 2006). Religious practice may offer a set of familiar beliefs that offers an interpretation for suffering as well as learning to celebrate in spite of insurmountable loss. The hope that is available through having spiritual or religious meaning could be beneficial through the positive times and times of burden in caregiving.

Along with African-Americans, research has found that Hispanics have found great meaning through religious coping and positive appraisal; however, one study determined that not only African-Americans and Hispanics showed greater resilience with finding positive aspects of caregiving and utilizing religion for coping with burden (Sorensen & Pinquart, 2005). The researchers found that across races and ethnic groups, such as whites, African-Americans, and Latinos, caregivers were able to positively appraise the caregiving experience and find meaning through religion. Other variables possibly mediate the effect of the psychological strengths (Sorensen & Pinquart, 2005). According to Sequeira (2012), “religion can act as an important personal resource in terms of a strategy to find meaning in life” (p. 497). The caregiver’s personal meaning could be a mediating factor in how one appraises the caregiving experience or incorporates that meaning with religious meaning.

Caregivers who reported more positive emotions were less likely to report feelings of depression, burden, or poor health (Cohen, Colantonio, & Vernich, 2002). The focus on the positive aspects could potentially buffer against the more negative consequences of caregiving, but some positive aspects could protect better than others (Cohen et al., 2002). The key for the counselor would be to assess positive, meaningful aspects of the caregiver’s lifestyle and incorporate those into buffering against the

negative. Potentially, these positive perspectives could lead to mastering the caregiving role.

Personal mastery “consists of a general sense of control over one’s life and circumstances” (Mausbach et al., 2007, p. 638). In a caregiving study, it was found that as overload increased and personal mastery was reduced, depressive symptoms increased (Mausbach et al., 2007). However, increased personal mastery was associated with decreased depressive symptoms. The potential effects of increasing personal mastery could be avoidance of negative coping strategies, attempting to actively deal with stressors, and seeking social support in order to encourage improved mental health of the caregiver. Resemblance can be observed between personal mastery and obtaining meaning in life. Individuals who participate in meaningful activities and find meaning in what they do demonstrate a sense of control over their lives. It is suggested that psychoeducational interventions and behavioral activation techniques can be utilized to teach stress management techniques and to encourage pleasurable activities even when stressed (Mausbach et al., 2007). These findings can prompt counselors to implement psychosocial treatments to encourage mastery in caregivers.

In China, caregivers were provided with a psychoeducational intervention called Coping with Caregiving (CWC) that taught CBT strategies to handle stress, and it was determined that the self-efficacy of the caregivers in responding to the recipients’ disruptive behaviors as well as controlling upsetting thoughts had increased (Au et al., 2010). Coping strategies had also improved through the use of this program; rational problem-solving and distancing were both increased. The implications of this study vary as the importance of psychoeducation is highlighted. There is the potential for CBT to be

utilized in the treatment of caregivers and helping them improve their well-being. However, Cooper, Katona, Orrell, and Livingston (2008) found problem-focused strategies were associated with increases in anxiety in caregivers. Culture could play a role in these differences as well as the variety in the studies. Understanding more about how problem-solving or focusing on problems fits into the scheme of working with caregivers will be important to counselors.

Caregiver appraisals that focus on meaning in life or self-efficacy are recommended (Haley et al., 2003). The authors suggested this may help increase social activity or leisure for caregivers, which in turn, enhances their well-being. Meaningfulness has been found to be essentially related to being in contact (Debats, Drost, & Hansen, 1995). This contact was perceived on three levels: with self, with other, and with life or the world. Meaninglessness, on the other hand, had been found to be associated with a lack of contact with the world. Having less meaning is associated with greater psychological distress or greater need for therapy (Steger et al., 2006). Various instruments already measure meaning in life, and correlating these items with measures of well-being could be beneficial to unlocking how meaningful items can be beneficial to the life of the caregiver.

The Purpose in Life Test (PIL) has been one of the most widely used measurements of meaning in life (Mascaro & Rosen, 2008), but it is argued to lack conceptual clarity. Mascaro and Rosen (2008) describe important components of life meaning: personal meaning, Spiritual Meaning, and implicit/informal meaning. These authors describe the Life Regard Index (LRI) as better for measuring personal meaning, Spiritual Meaning Scale (SMS) for assessing Spiritual Meaning, and Personal Meaning

Profile (PMP) for looking at implicit/informal meaning. The Meaningful Life Measure (MLM) was developed through factor analysis to comprehensively and parsimoniously measure a broad range of meaning in life content (Morgan & Farsides, 2009). Items from the PIL, LRI, and Psychological Well-Being: Purpose in Life scale (PWB-P) were analyzed for the MLM. A comprehensive scale such as this can be ideal for assessing a sense of overall meaning in life. According to Mascaro and Rosen (2008), the LRI has been found to prospectively find levels of depression and hope. These are two important aspects to look for in caregivers in counseling, so use of a comprehensive scale such as the MLM could be beneficial in understanding a sense of hope and assessing for depression.

Even without being provided with a scale to measure meaning in life, individuals may engage in self-assessments of their meaning. A major confrontation with a life-altering circumstance or “boundary experience” can elicit an evaluation of one’s meaningfulness in life (Debats, Drost, & Hansen, 1995). Becoming a caregiver for a family member diagnosed with AD or other dementia is surely a confrontation with an experience that surely tests the boundaries of the lifestyle caregivers once led. As the quality of life changes for caregivers, counseling professionals are to be concerned with their changes in well-being. Understanding more about the meaning of life at this critical point can lead to greater understanding of improving well-being of caregivers.

### **Caregivers’ Well-Being**

The examination of the psychological and physical health aspects, such as with regards to health and well-being of a caregiver, have been studied in-depth; however, the caregiver’s subjective overall health, utilization of preventative care, interruptions in

employment status, and social isolation are other facets of caregiving that are part of overall well-being and demand attention (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). Various perspectives of caregiver well-being have been studied and include: the relationship to the care recipient, the caregiver's perception of competence in the caregiving role, and outcomes of physical and mental health (Berg-Weger, Rubio, & Tebb, 2000). The exploration into what is meaningful in life to the caregiver can provide us with greater insight into just how important these key aspects of well-being are construed by the caregiver.

According to literature, married and adult child caregivers report greater well-being on well-being measures; well-being is higher for caregivers who have reported improved mastery, a feeling of being in control, in their caregiving role; and caregivers who reported less mental health symptoms and better health scored higher on well-being measures (Berg-Weger, Rubio, & Tebb, 2000). It is also apparent from research that the more problem behaviors a care recipient presents, the less control caregivers feel they have in their role; therefore, caregivers may be at risk of losing their mastery that helps maintain greater well-being (Sherwood et al., 2007). These findings are critical to keep in mind as the relationship of well-being and meaning in life is examined among caregivers. Counselors can monitor the levels of depression of caregivers by assessing the caregivers' mastery or control they feel they have in their role.

Caregivers have described their experiences in research. In a qualitative study utilizing focus groups, two thematic areas were revealed for caregivers (Lilly, Robinson, Holtzman, & Bottorff, 2012). The two themes were forgotten: abandoned to care, alone, and indefinitely as well as unrealistic expectations for caregiver self-care. Many

caregivers reported feeling like their work was unappreciated and taken for granted by nearly everyone, including the care recipient. The theme included words from caregivers fighting for recognition for their caregiving as well as support from others. The other theme, unrealistic expectations for caregiver self-care, suggests self-care for the caregivers is of utmost importance in order to preserve their own mental and physical health as the daily effort caregivers put forth can be difficult.

The mental and physical well-being of caregivers can be tested daily because family members living with Alzheimer's disease or dementia require much assistance with daily tasks. They experience cognitive, behavioral, and psychological changes that provide challenges to the caregiver. Therefore, the caregiver often experiences reduced psychological well-being, and many studies affirm that caring for the older person with dementia is associated with depressive symptoms and increases a "burden" of caregiving (Au et al., 2009). Caregiver burden is defined by Phillips, Gallagher, Hunt, Der, and Carroll (2009) as "embarrassment, guilt, overload, feelings of entrapment, resentment, isolation from society, and loss of control" (p.336). This "burden" or negative symptoms are often looked at in regards to well-being, but they are not closely examined with the meaningful, positive activities and direction in life. According to Rubio, Berg-Weger, and Tebb (1999), well-being and burden are similar phenomena on the caregiving spectrum, but burden may be more subjective than well-being. Research is prevalent on the aspect of the burden or stress of caregiving and depression, but there is much less research on the subjective well-being of caregivers as it is associated with positive affect and life satisfaction (Pinquart & Sorensen, 2004).



The subjective impact of caregiving on the caregiver is not the only concern for counseling professionals. Since disease or incapacity of a loved one present one of the greatest challenges upon a family, the illness of the loved one has an impact on the entire family system (Rodriguez-Sanchez et al., 2011). It is important to have cohesion among family members in caring for and supporting the care of the ill loved one in order to avoid leaving the primary caregiver with feeling a lack of support from the family. Future policies in Australia are slated to focus on caregivers' mental health by promoting positive social support and minimizing family conflict (Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2010). Caregivers for family members with dementia typically have less social contact than with other caregiving groups; therefore, strain for support from family members is greater (Hoskins, Coleman, & McNeely, 2005). Spousal caregivers are usually older and frailer, and they typically provide more hours of care than non-spousal caregivers; therefore, their social interactions outside the family tend to decrease (Sorensen & Pinqart, 2005). The functional dynamics change with the care of a dependent relative even though the burden usually lies with the primary caregiver.

Primary caregiving duties can result in social isolation and disengaging from activities once enjoyed. If there is an unmet need for long-term care services, the caregiver may experience up to a fourfold increase in social isolation; this is particularly true if the care recipient lives in the home with the caregiver (Robison et al., 2009). The significance of obtaining contacts outside the home is accentuated, however, in order to achieve optimal networking for care services in whatever capacity may be desired in order to enhance well-being. Valimaki, Vehvilainen-Julkunen, Pietila, and Purttila (2009) focused on the construct of sense of coherence of spouse caregivers. Sense of coherence

includes the extent to which the person finds his or her life comprehensible cognitively, manageable instrumentally, and meaningful which is motivational. Purpose was one of the five factors identified in this study. It was found that work may serve as a purposeful venue that allows socialization; whereas retired individuals were more likely to socially isolate. The aspect of socialization is important when it comes to meaningfulness in life.

Social support is generally considered a positive aspect for the caregiver; however, there are three different views on social support. These views are the adjustment to the stresses of caregiving not necessarily occurring because of social support, the type of measurement used to gauge social support not explaining caregiver adjustment, and how decades of research questions the positive depictions of informal social support (Smerglia, Miller, Sotnak, & Geiss, 2007). The potential for incongruent relationships is likely, such as friends or family members who do not attempt to empathize with the caregiver's experience. Furthermore, the lack of supportive relationships could account for the depictions that social support is not very helpful for the caregiver. In one cross-sectional study, social support was found to be negatively related to depression (Phillips, Gallagher, Hunt, Der, & Carroll, 2009).

Grandchildren and in-laws reported receiving the least amount of social support as caregivers (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). The authors discuss that the grandchildren may be younger and not yet realize the importance of support in a caregiver role, and the in-laws may have fewer close family members such as biological children for support, which leaves them in a position to care for an in-law who is ill (Nichols et al., 2011). Regardless of the reasoning behind the type of support inside

or outside the family the caregiver receives, the dynamics and functioning of the family impact the primary caregiver.

According to Rodriguez-Sanchez et al. (2011) the dynamics in families providing care change:

Functional families are those in which the roles of all the members are laid down without critical points of assumed debilities and without positions of either artificial supremacy being held by any of the members and in which they all participate, work, contribute and cooperate on an equal basis and with enthusiasm for the collective welfare. Sometimes several members of the family take care of the dependent relative, but it is more common for the burden of the care to lie with a single person: the main caregiver. This care affects the caregiver significantly in physical, mental, social, and economic aspects. (p. 1)

The demographics of the care recipient appear to have an influence on who provides the care. For older, unmarried, or women care recipients, the caregiver could likely be someone other than a spouse or child (Nichols et al., 2011). Furthermore, the designated caregiver likely would have fewer commitments or family demands. Regardless of the relationship of the caregiver to the care recipient or if the caregiver is considered an atypical caregiver, counselors must pay special attention to the social support the caregiver may or may not be receiving and evaluated regularly for physical and emotional well-being (Nichols et al., 2011). The family support may not be plentiful for atypical caregivers or those considered young.

In a study studying social support, caregivers of physically frail care recipients were provided the short version of the Japanese version of the Zarit Burden Interview

(Makizako, Tsutomu, Shimada, Ohnuma, Furuna, & Nakamura, 2009). Surprisingly, their results showed that having a cooperator (someone to help in caregiving) or spouse caregiver did not have a significant relationship with caregiver burden. Makizako et al. (2009) did note the realization that questions related to social support in their study may not have been clear considering social support had previously been found to increase well-being of caregivers. However, the findings supported having a cooperator, spouse caregiver, and fitness level of caregiver as being related to the well-being of caregivers. These findings authenticate the body of research that social support is quite important, but that caregivers often feel alone or isolated even with family or other cooperation in the caregiving process. Even when burden may not necessarily be decreased, well-being can be increased through receiving help from other or socialization.

Social engagement has been increasingly viewed by physicians to be important to the well-being of caregivers, and physicians recognize churches and congregations as providers of spiritual social support. Churches have started to connect families to resources and fill in gaps with regards to support to caregivers and their families (Gwyther, 2006). Organizations such as churches being helpful in the social support aspect of caregiving can improve the well-being of caregivers even when obtaining social support elsewhere seems impossible. According to Robinson (1990), social skills may be an antecedent to social support. Therefore, it is likely caregivers who have social skills initially may seek more social support than those who do not possess the social skills. On the other hand, caregivers who did not describe themselves as assertive were more likely to experience lower subjective burden; this is possibly a result of less assertive people having a more “go with the flow” personality (Robinson, 1990). It is clear that regardless

of whether or not a caregiver is assertive, gaining and maintaining social support is critical to well-being.

Butterworth et al. (2010) highlighted the effects of lacking social support during caregiving on older adults:

Compared with non-caregivers and those reporting low levels of caregiving activity, older adults involved in substantial caregiving had poorer mental and physical health, greater financial stress, and reported more conflict and less social support from family and spouse. Their odds of experiencing clinically significant anxiety and depression were over 50% greater than non-caregivers, and they reported 25% more depression and anxiety symptoms. Most critically, however, the test of mediation showed that it was the lack of positive support and greater conflict with family/spouse that explained caregivers' poorer mental health relative to non-caregivers. (p. 620)

The body of research increases understanding of how the function of the family taking care of the ill relative changes and places a greater amount of burden on the primary caregiver while impacting other areas of his or her life. According to Makizako et al. (2009), being a spousal caregiver is related to decreased well-being. Women and unmarried individuals who were care recipients were more likely to be cared for by family members who were not spouses (Nichols et al., 2011). Women in the baby boomer population make up the majority of caregivers (Robison et al., 2009).

It was originally noted that wives specifically experienced the greatest burden of caregiving (Etters, Goodall, & Harrison, 2008). In one study (Haley et al., 2003), female gender, health problems of the caregiver, higher stress appraisals and fewer perceived

benefits of caregiving, and limited social activity appeared to predict lower life satisfaction. The authors explain that some of these factors are associated with decreased well-being in non-caregivers as well as depressive symptoms in women. The research highlights the impact caregiving particularly has on women as well as how certain factors are associated with decreased well-being and possible depression even when individuals are not in the caregiver role. In Finland, women caregivers were found to have decreased sense of coherence or a dynamic feeling of confidence in their roles (Välimäki et al., 2009).

One study looked at low income females who were caregivers to older relatives, which took place in Mexico City, Mexico. The study described three themes related to their day-to-day care of the relatives (Mendez-Luck, Kennedy, & Wallace, 2008). These themes analyzed by the researchers included: caregiver burden being *pesado*, referring to physical weight in English or burden in Spanish, that describes situations which were physically or emotionally taxing for the caregiver; *ser carga*, which translates to being a burden to others, as a negative state of being; and burden as a positive sacrifice on behalf of the others. In the interviews, participants described the physically taxing chores, such as doing laundry and carrying the care recipient (Mendez-Luck, Kennedy, & Wallace, 2008). The emotional burden appeared to be related to the intense care and level of attention.

The aspect of *ser carga* did not mean the caregivers found the care recipient to be a burden, but that they were afraid of becoming burdens to future caregivers themselves (Mendez-Luck, Kennedy, & Wallace, 2008). However, the positive theme of burden as a positive sacrifice resonated as “41% and 56% of study participants described caregiving

as a sacrifice of good will and love, respectively” (Mendez-Luck, Kennedy, & Wallace, 2008, p. 275). It is apparent caregivers recognize the burden caregiving entails emotionally and physically as well as the concern future generations may endure the negative aspects of caregiving; however, the positive sacrifice is apparent even when so much is given up to take care of the family member. Although the themes may be explained a bit differently in this Mexican study, we can see similarities to what has been described in American studies and those elsewhere.

The aspect of social support, which “has the strong potential to help us understand the dynamics and interactions between individuals and their social environments” (Au et al., 2009, p. 761), can enhance the caregiver’s self-esteem and sense of belonging. Pillemer and Sutor (2002) described peer support enhancement by which volunteers who are current or were former caregivers were paired with caregivers of family members with Alzheimer’s disease to provide one-on-one support. According to Pillemer and Sutor (2002), artificially enhancing the network did not appear to have direct effects, but finding support from others with similar experiences appeared to be helpful; this could be naturally occurring. The aggressive tendencies and other experiences caregivers often find with their care recipients could encourage social isolation that encourages a need for support from inside and outside the family.

Skovdahl et al. (2003) engaged in a qualitative analysis of 15 formal caregivers who care for recipients with dementia and aggressive tendencies. Two themes were found: the need for balance between demands and competence, and a need for support. According to the research, caregivers felt a need to keep things balanced for the care recipients in order to meet their demands while maintaining competence to care for their

needs and aggressive behavior. Just as caregivers felt the need to support the care recipients, caregivers also felt the need to support each other. This study does not look at informal family caregivers, but it still provides insight into the needs of those caring for this population. It highlights the need for social support and maintaining well-being in order to feel prepared and well-balanced in the role of caregiver. Perhaps the need for support groups could be quite significant in order to facilitate socialization among caregivers who can provide support to one another. Support groups can also address the changes in well-being experienced.

Hayslip, Han, and Anderson (2008) compared active caregivers with not-as-yet caregiving adults. Their results indicated that introverted active caregivers more frequently experienced depressed moods. On the other hand, the potential future caregivers were most concerned about having lack of social support if they were to become caregivers. They also believed their future would be determined by chance or fate, and this belief, in turn, increased depressed mood. This particular study is an example of the influence meaning can have on individuals' outlook on the caregiving process. Finding meaning in socialization or social support appears to be important to alleviating depression. Simply having some type of meaning could reduce chances of depression as well since the not-as-yet caregivers more often believed futures are determined by chance or fate. This suggests lack of meaning prior to caregiving could be detrimental to one's mental health.

Other factors predicted depressive symptoms. According to Robison et al. (2009), these factors were the caregiver living with the care recipient, caring for a younger person, and caring for someone with memory problems. This highlights the additional



stress of caring for someone with Alzheimer's disease or dementia and the importance of counselors learning more about caregivers who care for this population. In a longitudinal study in which caregivers of care recipients diagnosed with Alzheimer's disease in the United Kingdom were given the Hospital Anxiety and Depression Scale, Zarit Burden scale, and the Brief COPE to measure coping strategies, the mediation of coping style was looked at in regards to relationship between caregiver burden, depression, and anxiety (Cooper, Katona, Orrell, & Livingston, 2008). The participants were interviewed twice – one year apart. Coping strategies utilized by individuals studied included emotion-focused, problem-focused, and dysfunctional coping strategies. Emotion-focused strategies include use of acceptance, humor, emotional support, religion, and positive reframing. Problem-focused strategies include active coping, instrumental support, and planning. Dysfunctional strategies include behavioral disengagement, denial, self-distraction, self-blame, substance use, and venting (Cooper, Katona, Orrell, & Livingston, 2008).

According to Cooper et al. (2008), use of problem-focused strategies did not decrease burden or anxiety one year later as hypothesized; instead, individuals were more anxious. Caregivers who used emotion-focused strategies were less anxious one year later in the study, and the dysfunctional strategies were associated with cross-sectional anxiety; those who were anxious at baseline were anxious one year later. Cooper et al. (2008) commented that individuals who were perhaps more anxious in general were more likely to seek out problem-focused strategies which may have frustrated them and been ineffective. In looking at how meaning in life impacts the well-being of caregivers, it would make sense that the emotion-focused strategies present themselves as more

meaningful as individuals using those coping skills have already found enjoyable or anxiety-reducing activities. Problem-focused strategies are potentially less meaningful, and dysfunctional strategies appear to be related to the items which research has shown to decrease the well-being or increase burden of caregivers, such as social isolation, developing difficult relationships with family members, and engaging in behavior which could lead to further depression and anxiety.

In addition to depression and anxiety, caregivers also experience a cycle of loss and grief associated with long-term caregiving (Rossheim & McAdams, 2010). This is referred to as chronic sorrow by Rossheim and McAdams (2010), which differs from depression, but it does not include the impaired function that depression brings. Recognizing the difference between depression and chronic sorrow is imperative for the counseling professional. Studies have indicated the caregiver does not only mourn the loss of the care recipient's life, but prior to death, mourning over "loss of normalcy, loss of self, and aspects of the relationship diminished by the care recipient's illness" occur (Ziemba & Lynch-Sauer, 2005, p. 109). Rossheim and McAdams (2010) explain how caregivers experiencing depression often experience self-neglect and withdrawal, whereas those with chronic sorrow may vigorously engage in advocating for the care recipient. It should be noted that individuals in this position are at risk for depression and anxiety. Caregivers face the loss of the loved one who is afflicted, and in many circumstances with their own aging, personal health crises or loss of other loved ones (Ziemba & Lynch-Sauer, 2005).

Depression and distress were found to be significantly associated with sense of coherence (SOC) and health-related quality of life (HRQoL) in spousal caregivers in

Finland (Välimäki et al., 2009). The timing of the onset of depressive symptoms in caregivers is unclear, according to Välimäki et al. (2009); however, symptoms of depression could remain unnoticed in caregivers when the care recipients were in the early stages of their diseases. A qualitative analysis explored the subjective psychological experience of spouses or partners of individuals with early stages of dementia and produced four themes with three subthemes each (Quinn et al. 2008). These themes and subthemes were related to the difficulties caregivers experienced in attempting to understand the illness, balancing their relationship with the care recipient with changes in lifestyle, strategies for coping with their partner's dementia, and emotional strains experienced by the caregivers. This qualitative study sheds some light on the struggles caregivers face even in the early stages of their loved one's illness. These findings tie into the significance of recognizing depressive symptoms in the early stages of the care recipients' illness as the relationship, social life, emotional well-being, and capacity to understand the gravity of the diagnosis are critically impacted. Early recognition of changes to a caregiver's well-being is crucial in intervening.

In addition to the psychological or emotional well-being of the caregiver, the physical health is critical. There is an association between low physical activity and higher caregiver burden (Hirano, Suzuki, Kuzuya, Onishi, Hasegawa, Ban, & Umegaki, 2011). The limited physical activity of caregivers could be explained by the psychological impact of caregiving eroding the psychological and physical health of the caregiver to the point where they engage in less physical activity. Caregivers may also feel fatigued by the sense of burden of caregiving as well as having less time to exercise due to caregiving duties. Although leisure activities were limited, housekeeping often

continued in households, and long-standing sports, such as playing golf, often continued without being affected by the sense of burden (Hirano et al., 2011). Increasing physical activity could increase well-being, and caregivers could be encouraged to engage in activities which are either necessities or which they have enjoyed for a length of time and are part of a lifestyle.

The health related quality of life (HRQOL) declines for caregivers of care recipients diagnosed with dementia (Arlt et al., 2008). According to a Canadian study from Black et al. (2010), 35 percent of caregivers studied reported their general health had worsened since becoming a caregiver. It is likely individuals who have high mastery over stress and can manage it are more likely to engage in healthy behaviors, whereas individuals who do not master the stress experience an increase in health concerns as they may adopt an attitude of not caring (Mausbach et al., 2007). Among females, Latina caregivers were more likely to eat fewer than two meals per day and gain more than ten pounds in six months, while there was a significantly higher likelihood for Caucasian women to smoke, experience heart conditions, and have gastrointestinal problems (Rabinowitz & Gallagher-Thompson, 2007). White caregivers are older than minority caregivers on average, but health-related decline of minorities may be less due to those groups more often having a secondary person to assist with the caregiving process (Sorensen & Pinquart, 2005).

The significance of nutrition to health is also highlighted. Nutritional changes occur for various reasons related to the stress of caregiving. Body mass index (BMI) of male and female caregivers was checked over the course of 15 to 18 months; both male and female caregivers had significantly higher BMI than the male and female control

groups (Vitaliano, Russo, Scanlon, & Greeno, 1996). Most men with increased weight admitted to decreased control and increased fat intake; women admitted to increased caloric intake and increased anger control. Vitaliano et al. (1996) explained the anger control of women is potentially due to frustration of not having a confidant, such as a spouse who suffers from AD or dementia, with which to discuss frustration. Spousal caregivers in particular responded that they frequently felt anger and resentment as the problems of the care recipient increased (Croog, Burleson, Sudilovsky, & Baume, 2006). Since spouses generally begin living together without such issues as AD or dementia, the changes brought about by such illnesses could potentially bring about the anger-resentment by the spouse left to become a caregiver. It is suggested the morale in the home can be diminished by the daily interactions for both the spousal caregiver and care recipient (Croog et al., 2006).

Moreover, negative coping strategies such as avoidance are associated with higher levels of distress, and active positive coping is associated with positive mental health (Montoro-Rodriguez & Gallagher-Thompson, 2009). Recognizing one's meaning in life could be related to practicing what is positive coping for a particular individual, and thus improves mental health. Both strains of caregiving and rewards of caregiving could predict positive affect. Extrinsic and intrinsic motivations were associated with higher meaning in caregiving, but the findings concluded that only intrinsic motivation significantly predicted meaning (Quinn, Clare, & Woods, 2012). Potentially intrinsic motivation is related more to having some sort of personal meaning in life than extrinsic meaning, which focuses more on external factors. The benefit of both types of motivation

could be linked to positive affect, but as other research has also shown, meaning is quite a personal phenomenon.

Knussen, Tolson, Brogan, Swan, Stott, and Sullivan (2008) researched the distress associated with caregiving by focusing on three coping subscales: maintaining balance, focusing on the caregiver, and avoidance. Data was collected at baseline and six months later with 115 pairs of caregivers and care recipients. Caregivers who put effort into maintaining balance through coping strategies were found to experience less distress at the second measure. The research determined that simply controlling emotions with stress-related variables, which includes use of avoidance and wishful thinking, was associated with no decrease of stress.

Knussen et al. (2008) discussed individual differences which may attribute to maintaining balance in life, such as optimism or neuroticism. The authors went on to discuss that having a break from caregiving responsibilities could also be important for maintaining balance. It is possible the caregivers who have more time for breaks and do not have to more regularly focus on caregiving are able to make time for meaningful pursuits. The Knussen et al. (2008) study focuses on caregivers of the hearing impaired which may not have the severity of behavioral concerns and require as much of a time commitment as with the AD and dementia care recipients. However, this research is helpful in understanding ways in which people cope with stressors and highlights the benefits of taking breaks from caregiving. It would be helpful to understand what meaningful activities could be derived from taking such breaks or if these breaks actually are meaningful in the caregiving process.

Mental health and physical health are not the only aspects of well-being impacted by the act of caregiving for a relative with dementia or AD. The financial impact is noteworthy as well. Smith, Piamjariyakul, Yadrach, Ross, Gajewski, and Williams, (2010) studied the caregivers providing home parenteral nutrition (HPN) to family members, which involves 12-hour intravenous infusions daily on the part of the caregiver; they found that economic stress was the most frequent concern described because of out-of-pocket expenses for treatment. Expenditures related to paying for prescriptions and non-prescription medications as well as the costs of transporting care recipients to and from appointments were reported by caregivers; ten percent of respondents indicated they spent more than \$1000 monthly on the family members receiving care (Black et al., 2010). Caregivers also are four times more likely to experience depression when faced with inadequate income (Robison et al., 2009), so it appears the various facets of well-being have great impact on one another in the caregiving process. The caregiver population also faces the costs of increased healthcare for themselves as a result of worsened health (Smith et al., 2010). According to Sorensen and Pinquart (2005), income was positively related to better health; this was more so true for Whites than African-Americans and Hispanics. Formal services and respite care may be more readily available, and caregivers can enjoy activities outside of caregiving (Sorensen & Pinquart, 2005).

The financial impact is harder considering not all caregivers are able to keep steady employment once stepping into the caregiving role. In the Black et al. (2010) study, 71 percent of caregivers experienced disruption to employment of some type, and 14 percent resigned or retired. Sorensen and Pinquart (2005) found the caregiver's racial

or ethnic group played a role in whether or not employment was maintained; African-American and Hispanic caregivers were more likely to maintain employment while caregiving with little opportunity to make adjustments to their work schedule and potentially caring for younger family members at the same time. White caregivers may have access to higher paying jobs, and experience greater emotional well-being as a result of occupational success (Sorensen & Pinguart, 2005). Significant use of vacation or personal leave could jeopardize the caregiver's employment or overall well-being. According to Robison et al. (2009), female caregivers missed work due to caregiving responsibilities twice as often as men, and baby boomers missed work twice as often as older adults. On the other hand, caregivers who are employed also suffer financial costs with caregiving (Wang, Shyu, Tsai, Yang, & Yao, 2013). With the average care of an individual with Alzheimer's disease costing \$174,000 over the course of the illness, caregivers carry much of that financial burden (Wright, Litaker, Laraia, & DeAndrade, 2001).

Caregivers who viewed the physical care as "work" were likely to feel more rewarded by the caregiving process (Sorensen & Pinguart, 2005). The view of providing care as work could be potentially helpful when a caregiver gives up a career or employment in order to care for his or her loved one. Furthermore, the more prepared a caregiver believes he or she is for the demands of work and caregiving, role strain was decreased and mental health was maintained even when the demands of caregiving were high (Wang et al., 2013). The work/caregiving conflict may be a more dynamic variable than employment status alone, and the phenomenon of preparedness for the roles could be better reflected. It appears through the research that the ways caregivers manage



employment vary, and many are able to successfully balance work and caregiving, whereas others may not be able to manage the strain with both roles.

### **Counseling the Caregiver**

The counseling professional must assess problems early on with the idea of adopting coping strategies that minimize burden and promoting satisfaction (Sequeira, 2012). During the assessment of the caregiver's well-being process, the caregiver's perceived family functioning must be taken into account; if the caregiver perceives his or her family as dysfunctional, this could represent significant vulnerability to quality of life (Rodriguez-Sanchez et al., 2011). The counselor can use this information in starting to understand interventions for the caregiver as well as for the caregiver's family if needed. A family-centered assessment is recommended in order to determine the conflict level with the family as well as help clarify expectations, identify support, and help with conflict resolution (Edders, Goodall, & Harrison, 2008). The assessment process also involves measuring negative and positive affect in order to tap into various aspects of well-being and arrive at different correlates (Haley et al., 2003).

Hayslip, Han, and Anderson (2008) studied active caregivers and not-as-yet caregivers; they provided the NEO Five-Factor Inventory to participants. The researchers found that personality traits had direct impact on mental health whereas social support did not. Counselors may be able to use this information in providing personality assessments to clients who are caregivers or have the potential to become caregivers of family members. Instruments that measure meaning in life have some parallels with such a personality inventory. Mascaro and Rosen (2008) found the Life Regard Index (LRI) to prospectively predict levels of depression and hope; the Personal Meaning Profile (PMP)

and Spiritual Meaning Scale (SMS) have some clinical utility with the Big Five. The Big Five and LRI have been found to predict levels of depression and hope as well as happiness and general psychological distress over two longitudinal studies. Depression, anxiety, hope, and antisocial features have been correlated with the PMP and SMS as well as the Big Five. Religiosity, which is related to meaning, has been associated with personality traits such as agreeableness, conscientiousness, and altruism (Quinn, Clare, & Woods, 2012).

The use of personality inventories in understanding meaning could have great utility with caregivers. Further conversation would be able to result from the findings on meaning, and perhaps the counselor would be able to use the results to determine what the caregiver needs to work on in regards to social life, activities or experiences, and aspects of mental health. Furthermore, understanding a caregiver's religiosity is important in the counseling relationship. Herrera, Lee, Nanyonjo, Laufman, and Torres-Vigil (2009) concluded the following regarding religiosity: (a) there needs to be improved conceptualization of religion and spirituality; (b) there is a need for better assessment of the role of religious coping in caregiving; (c) there must be further study of the negative outcomes of religious coping, such as depressive or stress-related disorders that could be warning signs; (d) the long-term efficacy of religious coping on mental and physical health should be assessed; and (e) examination of guilt, forgiveness, and hope for the future as spiritual rewards in caregiver outcomes. It is important to note that spiritual and religious beliefs assist caregivers in coping with mental and physical health problems, but there may be unintended negative effects due to beliefs (Herrera et al., 2009).

In helping the caregiver, the counselor can examine protective factors already in place which can be adaptive. These can include appraisals of one's caregiving, the caregiver's personality, coping resources, social networks and social support (Haley et al., 2003). The appraisals of caregiving are important in how the caregiver views his or her role. This may be viewed as a more negative or positive experience depending on the individual receiving help. Counselors can intervene based upon the framework of the appraisals. Additionally, if psychometric measures are utilized to measure depression in the home or in a non-psychiatric setting, there is "insufficient discriminative capacity to monitor to measure minor changes" (Schoenmakers, Buntinx, & DeLepeleire, 2010, p. 54).

There is argument for the continued use of the Caregiver Strain Index (CSI) to assess caregiver stress levels periodically and to evaluate the efficacy of various interventions (Hoskins, Coleman, & McNeely, 2005). Hoskins et al. (2005) studied various interventions and the results from the CSI assessments determined utilizing respite care helped reduce caregiver stress levels. These findings are particularly important for counselors in order to assist caregiving clients in obtaining resources for respite care if desired. Having day care options available for AD and dementia patients requires further research (Hoskins et al., 2005). It is likely the counselor could be most effective during the assessment or intake process by encouraging the client to discuss their preferences and what may have worked for them in previous circumstances. The counselor assisting the caregiver in painting a picture of their needs and determining a path for further intervention would be beneficial in the counseling process.

Assessing the levels of depression of caregivers at the beginning of the counseling relationship is helpful in further interventions. Caregivers' levels of depression can change based upon the amount of mastery or control over the caregiving situation. According to Sherwood et al. (2009), the problematic behaviors of the care recipients can alter the mastery of the caregiving situation. Counselors can help clients improve the mastery of caregiving by educating on problem behaviors with AD and dementia patients, teaching better ways to cope with situations, and teaching stress-reducing techniques like guided imagery and relaxation (Sherwood et al., 2009). Butterworth et al. (2010) suggest family-centered interventions to improve family functioning, relationship quality, and communication, as well as other strategies to build social support.

While focusing on family is critical, in order to help caregivers adapt to increasing impairment on behalf of the care recipient, psychoeducational groups are likely to be effective (Perren, Schmid, & Wettstein, 2006). The researchers studied the impact of psychoeducational intervention on caregivers and found that the well-being of caregivers stabilized over the course of a year; two years after the intervention, the intervention group did experience a decrease in well-being. However, even though the positive effects from the original psychoeducational intervention appeared to have diminished, the use of support groups seemed to be helpful for both the intervention and control groups in this study. These findings are important for counselors to grasp the impact of their interventions on clients of this nature. It would be beneficial for psychoeducation to be an aspect of therapeutic services perhaps on an ongoing basis and to recommend or provide support groups.

The majority of studies reviewed by Gallagher-Thompson and Coon (2007) were psychoeducational in nature with skill-building components; most studies reviewed included caregivers of dementia patients. The nature of these evidence-based treatment groups included depression management, behavior management, anger management, and how to deal with the progressively lowered stress thresholds in relatives with dementia as well as what were referred to as “mixed” approaches. However, some psychoeducational approaches did not meet the evidence-based criteria, such as teaching caregivers skills for environmental modification to homes for safety of family members (Gallagher-Thompson & Coon, 2007). These types of interventions could be considered for further research, and they may be beneficial for counselors working with caregivers of this population. The aspect of understanding what is meaningful to caregivers could give counselors a better understanding of psychoeducational group topics to pursue. Providing psychoeducational interventions to help improve psychological and physiological health may be beneficial to Latina caregivers, particularly to educate on dietary habits (Rabinowitz & Gallagher-Thompson, 2007). Counselors putting the opportunity out there for caregivers of any ethnic group to receive psychoeducation can encourage positive health behaviors.

One of the major negative health problems for caregivers is anxiety. Out of various interventions researched, CBT and relaxation appeared to be the most effective interventions to target anxiety, but little evidence of any intervention to reduce anxiety was found (Cooper, Balamurali, Selwood, & Livingston, 2007). Counselors utilizing relaxation techniques to help caregivers cope with the anxiety experienced as a result of caregiving appears to offer promising relief. Yoga is also a potential method of relaxation

with a promising preliminary outlook (Cooper et al., 2007). The use of teaching relaxation coping skills can be integrated into appropriate therapy for the client. Understanding the client's needs from an existential framework can potentially assist the counselor in utilizing the most effective techniques.

Psychotherapy yielded the largest average effect size, and cognitive-behavioral treatment seemed to be most efficacious in treating caregivers (Gallagher-Thompson & Coon, 2007). CBT was found to be helpful in reducing depression individually or in small groups. According to Gallagher-Thompson and Coon (2007):

We conclude that programs that target specific components of caregivers' quality of life (such as perceived burden, mood, and perceived stress, as well as coping and self-efficacy) and that include some combination of skill building, education, and support are currently the most effective interventions. (p. 47)

Three components of a specific intervention were provided to an experimental group of spousal caregivers in a New York University Aging and Dementia Research Center study. These included individual and family counseling, participation in support groups, and ad hoc counseling where caregivers and participating family members could contact study counselors with concerns or crises (Gaugler, Roth, Haley, and Mittelman, 2008). The researchers looked at nursing home admissions that occurred among the care recipients in the study and how depressive symptoms were impacted in both the experimental and control groups (which received typical counseling services from the center). According to Gaugler, Roth, Haley, and Mittelman (2008), depressive symptoms did not decrease drastically in caregivers in the experimental group following nursing

home admission; this was likely due to the intensive intervention being effective at managing depressive symptoms consistently.

The consideration of the possibility of nursing home admission for care recipients is important for counselors; however, utilizing effective, meaningful interventions is significant in the counseling process. In the intervention group in the Gaugler, Roth, Haley, and Mittelman (2008) study, individual and family counseling sessions were catered to the needs of the caregivers and/or family as well as worked on behavioral problem management and communication strategies for involved and uninvolved family members . With support groups and ad hoc services from counselors, caregivers appear to be better equipped to cope with ongoing changes with the care recipient. This study lends its findings to counselors working with caregivers. Orienting individual and family sessions to the needs and concerns of the caregiver could allow the caregiver to find meaning in the session and have the ability to discuss meaningful items that relate to his or her well-being. The counselors' recognition of resources, such as support groups, can be beneficial to many clients as well. The ad hoc availability, as described to help decrease depressive symptoms, would be up to the counselor. Just as caregiving at home is an around-the-clock task, having 24-hour availability from the counselor would likely be helpful to manage a crisis or to address significant changes. When intervening with caregivers of color, the effect of the lack of resources, including informal resources, should not be underestimated (Sorensen & Pinquart, 2005). Even formal services may have limited benefits because the services are often not used until the caregiver's stress level is excessively high (Sorensen & Pinquart, 2005).

Wright, Litaker, Laraia, and DeAndrade (2001) noted that caregivers often report a lack of time for gaining education on their roles as caregivers due to the time commitment to the care recipient. For nursing professionals, the use of telecommunications technology (Telehealth) was suggested for communications within the home. Counselors could utilize this type of technology just as nursing professionals in order to meet the needs of the caregivers at home. This could even represent understanding the caregiver's meaning more effectively as the caregiver may feel more comfortable in his or her own home and make it convenient to care for the family member at the same time. The downside to communication technology would be the use of an automatic telephone system where caregivers were only assisted with matters of concern. It is suggested this low-profile type of support could indeed negatively impact caregivers' emotions with its indirect assistance from professionals (Schoenmakers, Buntinx, & DeLepeleire, 2010).

Regardless of the types of services counselors are providing, Hoskins, Coleman, and McNeely (2005) suggest psychoeducation and education on dementia can be helpful for the caregiver. Enhancing the knowledge of counselors is critical to working with this population. Providing education on self-care is not going to be enough for working with this population because caregivers who care for family members with AD and related dementias are enduring unique types of stress and strains on well-being. Counselors must also be prepared to understand the nutritional changes and changes in physical activity of the caregivers.

As Rossheim and McAdams (2010) explained, chronic sorrow does differ from depression; however, helping professionals are often unprepared to treat the chronic



sorrow that occurs with caregiving. They often treat it as anxiety, depression, or grief. These concerns are parts of chronic sorrow, but it is suggested specialized counseling approaches be introduced to help those with chronic sorrow in the caregiving role. Counselors often work on closure with grief counseling, and in the case of caregivers experiencing chronic sorrow, closure is most likely not an option. Counselors may be able to assist caregivers in what is known as an “anticipatory” plan while caregivers experience grief or sorrow (Ziemba & Lynch-Sauer, 2005). Such a plan may include lists of counseling and support groups, strategies to problem-solve, accenting strategies for self-care, and analyzing potentially problematic interactions with the care recipient (Ziemba & Lynch-Sauer, 2005). Counselors who work with caregivers have been provided with a difficult venture that requires much planning and encouraging various treatment modalities. The counselor who utilizes an existential perspective may find many strategies for analyzing the caregiver’s meaning in life as it relates to the caregiver’s well-being.

## **CHAPTER 3**

### **METHODOLOGY**

This chapter discusses the research design and methodology used by the researcher to determine how meaning in life is associated to well-being for caregivers based upon responses from family caregivers of those with Alzheimer's disease or dementia. The chapter includes discussion on the research design, research questions, participants, measures, data collection, procedure, and data analysis.

#### **Research Design**

This study used a cross-sectional survey study with two scales which measure meaning in life and caregiver well-being using the Meaningful Life Measure (MLM), developed by Morgan and Farsides (2008), and The Caregiver Well-Being Scale, developed by Tebb (1995). A demographic questionnaire was also utilized to collect participant data. Participants for this study included caregivers to family members who have been diagnosed with Alzheimer's disease (AD) or other dementias. The surveys were offered to participants via an online survey. Survey links were sent to online support group forums, listservs and social media groups for caregivers of AD and dementia care recipients in order to recruit participants. Data collected was analyzed via descriptive statistics, simple linear regression, bivariate correlation, and t-tests and analysis of variance to determine relationships among variables.

#### **Research Questions**

1. Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients?

2. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being of family caregivers to AD and dementia care recipients?
3. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of activities of daily living of well-being of family caregivers to AD and dementia care recipients?
4. How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics?
5. How do family caregivers of AD and dementia care recipients differ in well-being based upon demographic characteristics?

### **Participants**

The participants for this study were adult family caregivers of those diagnosed with Alzheimer's disease or dementia across the country. Participants were at least 19-years-old, and primary family caregivers to the person diagnosed with AD or dementia. Out of 121 potential participants who began the survey, 61 participants completed all sections of the survey with data collected and analyzed.

### **Measures**

**Demographic questionnaire.** The participants in this study completed a questionnaire (Appendix B) based on demographic information. The following elements were included in the questionnaire: age, gender, race, marital status, level of education attained, religious preference, employment status, annual household income, relationship to care recipient, and average hours per week of care provided to care recipient.

**Meaningful Life Measure (MLM).** The participants completed the Meaningful Life Measure (MLM) (Appendix C) developed by Morgan and Farsides (2008), which was approved for use in this study by the author. This 23-item measure includes five subscales based on (a) purposeful life (e.g. “I have a clear idea of what my future goals and aims are.”); (b) valued life (e.g. “My life is significant.”); (c) accomplished life (e.g. “So far, I am pleased with what I have achieved in life.); (d) principled life (e.g. “I have a personal value system that makes my living worthwhile); and (e) exciting life (e.g. “My life interests and excites me.”). This measure includes a comprehensive composite meaning. The MLM was used in a reliability and validation study only (Morgan & Farsides, 2008).

Responses to the 23 items are on a 7-point Likert scale from one (strongly disagree), two (disagree), three (slightly disagree), four (neither agree nor disagree), five (slightly agree), six (agree), and seven (strongly agree). Males and females were analyzed together in the initial study on the instrument, and all subscales achieved acceptable internal reliability with moderate to high intercorrelations. They ranged from .53 between accomplished life and principled life to .71 between exciting life and accomplished life. Convergent validity was also found. Five predictors in purposeful life accounted for 51% of variance; four predictors of exciting life accounted for 60% of variance; in accomplished life, 72% of variance was explained by six factors; 48% in principled life were accounted for by three predictors; in valued life, 62% of variance was explained by the three predictors.

The five subscales did correlate with established meaning constructs. A review of literature related to the measure produces no study of the measure with any population

besides college students. According to Morgan and Farsides (2008), “further research using multiple and representative samples is necessary to fully investigate the invariance of the MLM’s factor structure” (p. 361).

**Caregiver Well-Being Scale.** The Caregiver Well-Being Scale (CWBS) (Appendix D), developed by Tebb (1995), is a two-section questionnaire with a total of 23 questions in the first subscale and 22 questions in the second subscale. This questionnaire was approved by the author for use in this study. The first subscale contains questions regarding activities of living, and the second subscale contains questions regarding basic needs. The activities of living subscale is based upon five factors, which include: (a) time for self (e.g., “laughing”), (b) household maintenance (e.g., “preparing meals”), (c) leisure activities (e.g., “starting a new interest or hobby”), (d) maintenance of functions outside the home (e.g., “maintaining employment or career”), and (e) family support (e.g., “asking for support from your friends and family”). The basic needs subscale contains four factors, which include: (a) expression of feeling (e.g., “feeling love”), (b) attendance of physical needs (e.g., “getting enough sleep”), (c) security (e.g., “having a home”), and (d) self-esteem and esteem from others (e.g., “feeling good about yourself”). The assessment was developed because most assessments for caregivers do not measure strengths and support systems, but instead focus on burdens and strains (Tebb, 1995).

This 45-item assessment includes a five-point Likert scale, which includes: one (never or almost never), two (seldom, occasionally), three (sometimes), four (often, frequently), and five (almost always). One hundred sixty-five family caregivers of adults and children self-administered the assessment after being examined for face validity by

four individuals familiar with adult caregiving literature (Tebb, 1995). A principal components analysis was conducted on each of the subscales to examine item clusters. The basic needs subscale was based upon Maslow's hierarchy of needs. Items were only considered with a factor loading of .40 or higher (Tebb, 1995).

In order to determine internal reliability and consistency, a coefficient alpha was determined for each subscale and factor within the subscales. Each subscale or factor had a coefficient alpha of at least .70 with activities of daily living at .92 and basic needs at .91. The exceptions were the factors of maintenance of functions outside the home at .51 and family support at .67 (Tebb, 1995). Criterion and construct validity were assessed for this scale. An analysis of variance was performed to determine criterion validity by comparing scores of caregivers with noncaregivers. Significant differences were shown on the basic human needs subscale, but not on the activities of daily living subscale (Tebb, 1995). Items from a standard measure of life satisfaction taken from the Computerized Stress Inventory were compared to the two subscales on the Caregiver Well-Being Scale to determine construct validity. The correlations for the two subscales with the life satisfaction items were significant at .61 for the basic human needs subscale and .47 for the activities of daily living subscale (Tebb, 1995). Tebb reported this instrument was effective for social workers to look at strengths of caregivers, and strong criterion validity was shown for administering this assessment to adults with dementia.

### **Procedure**

After obtaining Institutional Review Board (IRB) approval through Auburn University Institutional Review Board (Appendix A), the researcher contacted various Alzheimer's disease and dementia support groups via email and telephone for assistance

in obtaining participants through web postings or listservs. Groups contacted included the Alzheimer's Association and Caregiver Action Network. Information about the study and links to the study were included on the TrialMatch® website from the Alzheimer's Association and in a forum on the Caregiver Action Network website. The researcher also reached out to individuals via social networking, which included Facebook, Twitter, and Reddit, with the link to the survey. A listserv email message through the Alabama Counseling Association was sent out with the purpose of recruiting participants who met the study's criteria.

Participants received a link via email, the website posted, or the social networking site to take the survey on [www.qualtrics.com](http://www.qualtrics.com). The link to the study took participants to an informed consent page. Consent to participate was indicated by clicking the button to move beyond the consent page and with completion and submission of the survey. The survey began once participants continued past the informed consent page. Following the initial informed consent page, participants were asked to complete the demographic questionnaire, followed by the MLM and the CWBS. The end of the online survey included information on how to access caregiver resources through the Alzheimer's Association. Once participants completed the survey, the researcher donated fifty cents for that survey completion to the Alzheimer's Association. Participants were made aware that all results are anonymous. No identifying information, such as name or address, was collected from participants.

### **Data Analysis**

First, descriptive statistics were collected to determine the demographics of the participants in this study. In order to respond to the five research questions, various

statistical analyses were utilized. Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients? The data for the first research question was analyzed through simple linear regression. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being for family caregivers of AD and dementia care recipients? What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of activities of daily living of well-being for caregivers of AD and dementia care recipients? The second and third research questions were analyzed through bivariate correlations. How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics? How do family caregivers of AD and dementia care recipients differ in well-being based on demographic characteristics? Data pertaining to the fourth and fifth research questions were analyzed with t-tests and one-way analysis of variance.



## CHAPTER 4

### RESULTS

#### Introduction

The primary purpose of this research study was to examine the relationship of meaning in life of caregivers with well-being when they care for family members with Alzheimer's disease or dementia. A secondary purpose was to investigate demographic factors contributing to each of the two variables. Demographic variables of interest included: age, gender, race, marital status, level of education, employment status, and caregiver's relationship to care recipient. The study also investigated the relationship between five subscales (purposeful life, valued life, accomplished life, principled life, and exciting life) of the Meaningful Life Measure (MLM) (Morgan & Farsides, 2008), and each subscale of the Caregiver Well-Being Scale (CWBS) (Tebb, 1995). The subscales of the Caregiver Well-Being Scale include two major categories of the basic human needs and the activities of daily living. The basic human needs include: (a) expression of feeling, (b) attendance of physical needs, (c) security, and (d) self-esteem and esteem from others. The activities of daily living include: (a) time for self, (b) household maintenance, (c) leisure activities, (d) maintenance of functions outside the home, and (e) family support. The exciting life and accomplished life on the MLM refer to the positive affective consequences of a sense of fulfillment. The principled life refers

to an individual's worldview or philosophy. Purposeful life refers to having goals and clear sense of direction (Morgan & Farsides, 2008).

Chapter four is organized by a discussion of the sample demographics, descriptive statistics, data screening, reliability analysis, research questions, and conclusions. The following provides a discussion of the sample demographics. Data were exported to SPSS 20 for analysis.

### **Sample Demographics**

There were a total of 121 participants who started the survey. However, only 61 participants completed the survey. Participants were excluded if they did not complete enough questions for scores to be generated on the scales. Of the 61 remaining participants, their ages ranged from 26-78 ( $M = 52.74$ ,  $SD = 12.46$ ). The majority of participants (86.9%,  $n = 53$ ) were females and 13.1% ( $n = 8$ ) were males. Regarding race, 90.2% ( $n = 55$ ) were white; 3.3% ( $n = 2$ ) were African Americans; 4.9% ( $n = 3$ ) were Hispanics; and 1.6% ( $n = 1$ ) self-identified as "other." Approximately three-fourths (75.4%,  $n = 46$ ) were married; whereas the number of participants who were single, never married (8.2%,  $n = 5$ ) or divorced (8.2%,  $n = 5$ ) were equally distributed. Marital status is presented in Table 1.

Table 1

*What is your current marital status?*

Marital Status	<i>n</i>	%
Single, never married	5	8.2
Married	46	75.4
Living together, not married	3	4.9
Divorced	5	8.2
Separated	1	1.6
Widowed	1	1.6
Total	61	100.0

Regarding educational attainment, 9.8% ( $n = 6$ ) were high school graduates; 21.3% ( $n = 13$ ) had completed some college; and 32.8% ( $n = 20$ ) had college degrees. Educational attainment is presented in Table 2.

Table 2

*What is the highest level of education you have received?*

Educational Attainment	<i>n</i>	%
High school graduate	6	9.8
Some college	13	21.3
College degree	20	32.8
Master's degree	18	29.5
Professional degree (MD, JD)	1	1.6
Other:	3	4.9
Total	61	100.0

Forty-one percent ( $n = 25$ ) were Protestants; 21.3% ( $n = 13$ ) had no preference or no religious affiliation; 16.4% ( $n = 10$ ) were Roman Catholics. Religious preference is presented in Table 3. The largest group of respondents (26.2%,  $n = 16$ ) earned \$50,000 to \$69,999 per year; 24.6% ( $n = 15$ ) earned \$30,000 to \$49,999; and 14.8% ( $n = 9$ ) earned \$100,000 to \$149,999 per year. Annual household income is presented in Table 4.

Table 3

*What is your religious preference?*

Religious Preference	<i>n</i>	%
Protestant (e.g. Baptist, Methodist, etc.)	25	41.0
Jewish	1	1.6
Roman Catholic	10	16.4
Mormon	2	3.3
Other Christian	8	13.1
No preference/no religious affiliation	13	21.3
Other (Episcopal, Anglican)	2	3.3
Total	61	100.0

Table 4

*What is your annual household income?*

Annual Income	<i>n</i>	%
Less than \$10,000	1	1.6
\$10,000 to \$29,999	8	13.1
\$30,000 to \$49,999	15	24.6
\$50,000 to \$69,999	16	26.2
\$70,000 to \$99,999	6	9.8
\$100,000 to \$149,999	9	14.8
Over \$150,000	4	6.6
Total	59	96.7
Not Answered	2	3.3
Total	61	100.0

Approximately one-third (34.4%,  $n = 21$ ) of participants were employed full-time (over 32 hours per week); 21.3% ( $n = 13$ ) were employed part-time (less than 32 hours per week; and 44.3% ( $n = 27$ ) were unemployed. Twenty-three percent ( $n = 14$ ) of participants were spouses or partners of family members who were diagnosed with

Alzheimer’s disease or dementia; 37.7% ( $n = 23$ ) were children; and 18% ( $n = 11$ ) as presented in Table 5.

Table 5

*What is your relationship to your family member diagnosed with Alzheimer’s disease or dementia who receives your care?*

Relationship	<i>n</i>	%
Spouse/Partner	14	23.0
Child	23	37.7
Grandchild	4	6.6
Daughter- or son-in-law	5	8.2
Parent	11	18.0
Other:	4	6.6
Total	61	100.0

On the average, 31.1% ( $n = 19$ ) of respondents spent over 80 hours per week caring for their family members with Alzheimer’s disease or dementia; and 21.3% ( $n = 13$ ) spent 26-40 hours per week. See Table 6.

Table 6

*On average, how many hours per week do you spend caring for your family member diagnosed with Alzheimer’s Disease or dementia? This includes time spent during the day and night.*

Hours Spent	<i>n</i>	%
10 or less hours per week	10	16.4
11-25 hours per week	9	14.8
26-40 hours per week	13	21.3
41-80 hours per week	10	16.4
Over 80 hours per week	19	31.1
Total	61	100.0

### **Descriptive Statistics**

Scores on the MLM were derived by computing the mean on each of the five subscales. Scores on the MLM could range from 1-7, with 7 representing the greatest

extent of meaning in life. The highest rated subscale on the MLM was valued life ( $M = 5.76$ ,  $SD = 1.28$ ), whereas the lowest rated subscale was exciting life ( $M = 4.03$ ,  $SD = 1.28$ ) with an overall score of 5.14 ( $SD = 1.12$ ) for meaning in life.

On the CWBS, scores were also derived by computing the mean on each of the two subscales. Scores on the CWBS could range from 1-5, with 5 representing the highest degree of well-being. Scores for activities of daily living ( $M = 3.26$ ,  $SD = 0.61$ ) and basic needs ( $M = 3.15$ ,  $SD = 0.67$ ) did not deviate considerably from the overall score of 3.20 ( $SD = 0.59$ ). Descriptive statistics are presented in Table 7.

Table 7

*Descriptive Statistics*

Variable	<i>N</i>	<i>Minimum</i>	<i>Maximum</i>	<i>M</i>	<i>SD</i>
Exciting Life	61	1.00	7.00	4.03	1.28
Accomplished Life	61	1.60	7.00	5.10	1.31
Principled Life	61	1.80	7.00	5.50	1.25
Purposeful Life	61	2.25	7.00	5.32	1.17
Valued Life	61	2.00	7.00	5.76	1.28
Meaning in Life	61	1.81	6.79	5.14	1.12
Activities of Living	61	2.09	4.70	3.26	0.61
Basic Needs	61	1.55	4.41	3.15	0.67
Well-Being	61	1.84	4.42	3.20	0.59

**Data Screening**

Data were screened for normality with skewness and kurtosis statistics and histograms. Skewness and kurtosis values less than the absolute value of 2 were considered to be normal. Skewness values ranged from -0.03 to -1.09. Kurtosis values ranged from 0.02 to 0.63. Therefore, the distributions approximated normality based on

the skewness and kurtosis coefficients. Skewness and kurtosis coefficients are presented in Table 8.

Table 8

*Skewness and Kurtosis Coefficients*

Variable	N	Skewness		Kurtosis	
	Statistic	Statistic	Std. Error	Statistic	Std. Error
Exciting Life	61	-0.24	0.31	0.02	0.60
Accomplished Life	61	-0.77	0.31	-0.07	0.60
Principled Life	61	-0.99	0.31	0.50	0.60
Purposeful Life	61	-0.82	0.31	0.34	0.60
Valued Life	61	-1.09	0.31	0.63	0.60
Meaning in Life	61	-1.03	0.31	0.61	0.60
Activities of Living	61	-0.03	0.31	-0.51	0.60
Basic Needs	61	-0.44	0.31	-0.31	0.60
Well-Being	61	-0.32	0.31	-0.43	0.60

In addition, the distributions were inspected visually with histograms. A normal curve is a symmetrical, bell-shaped curve. The histogram for exciting life was a symmetrical bell-shaped curve as illustrated in Figure 1.

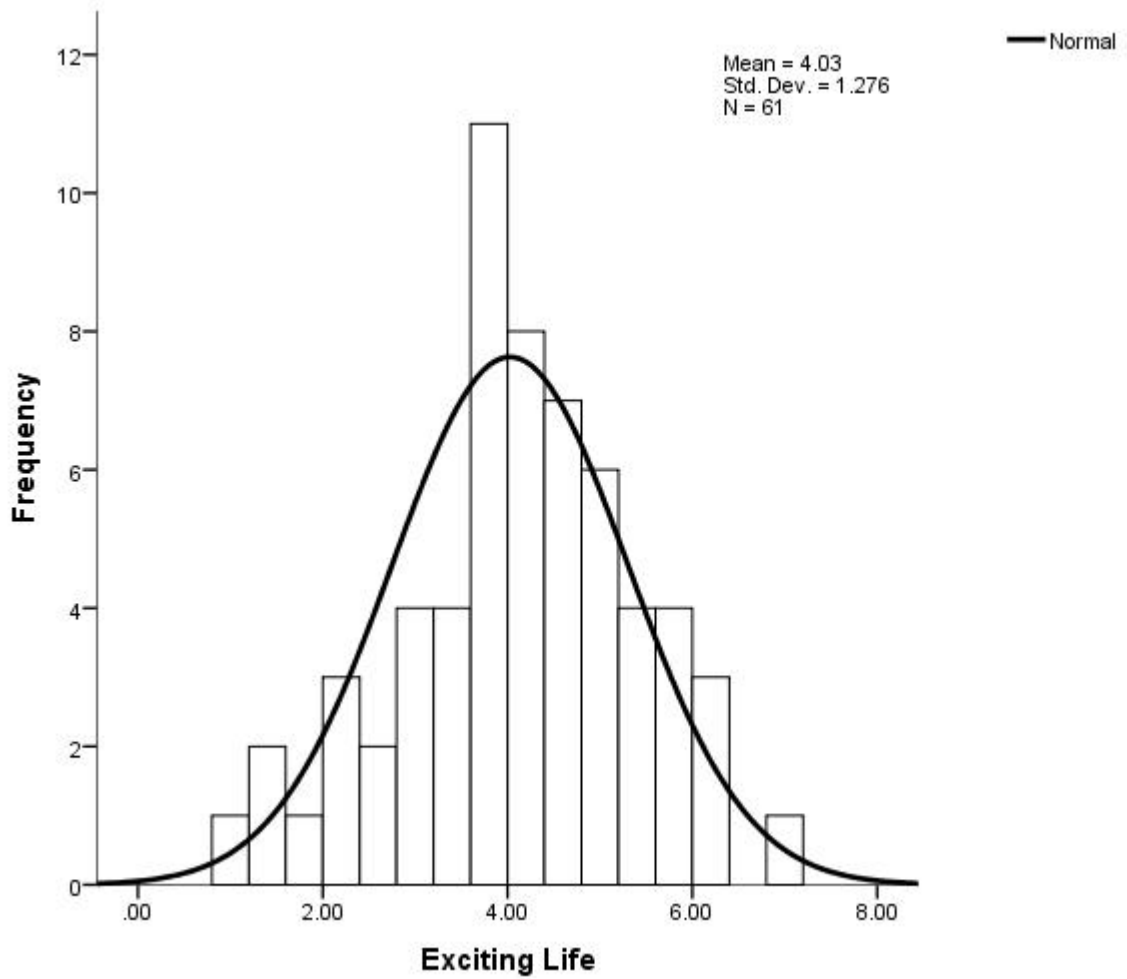


Figure 1. Histogram for Exciting Life



The histogram for accomplished life was approximately normal. See Figure 2.

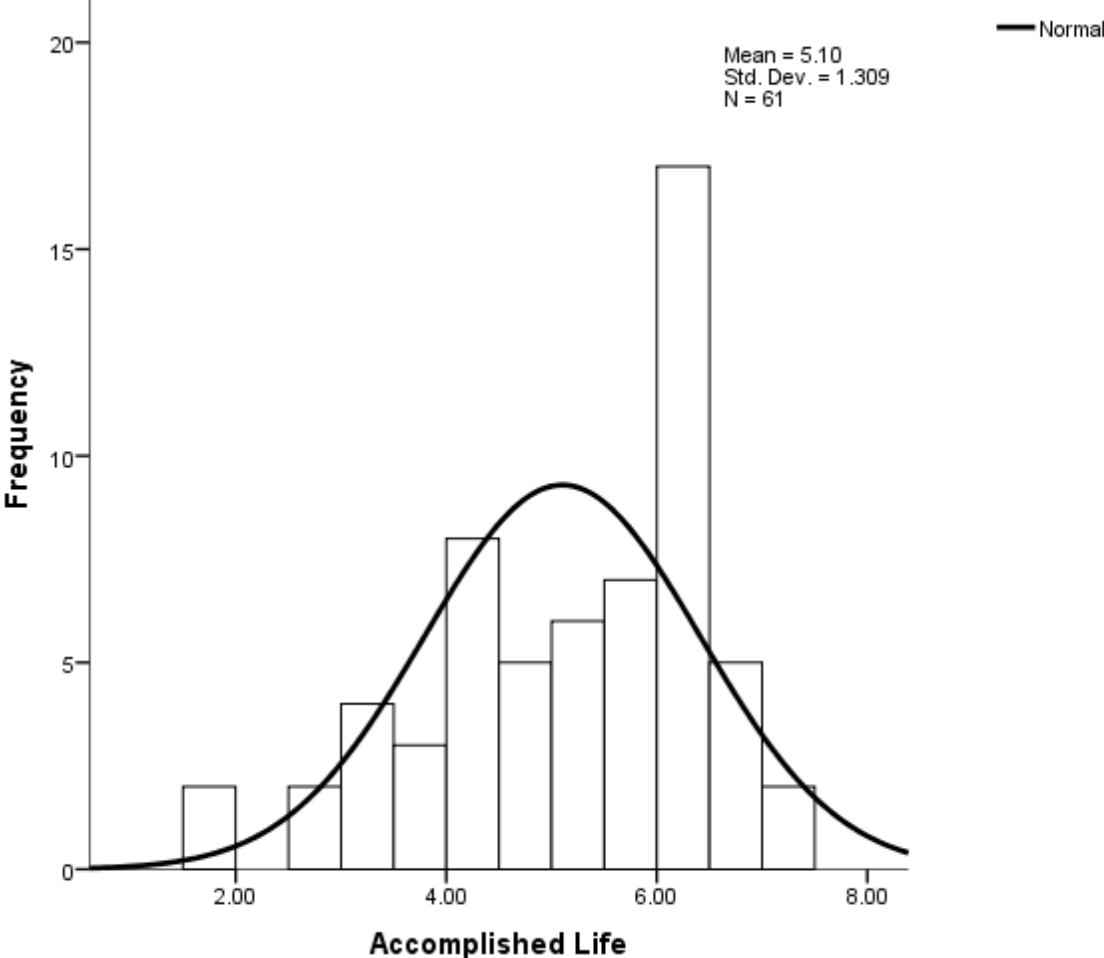


Figure 2. Histogram for Accomplished Life

The histogram for principled life was approximately normal. See Figure 3.

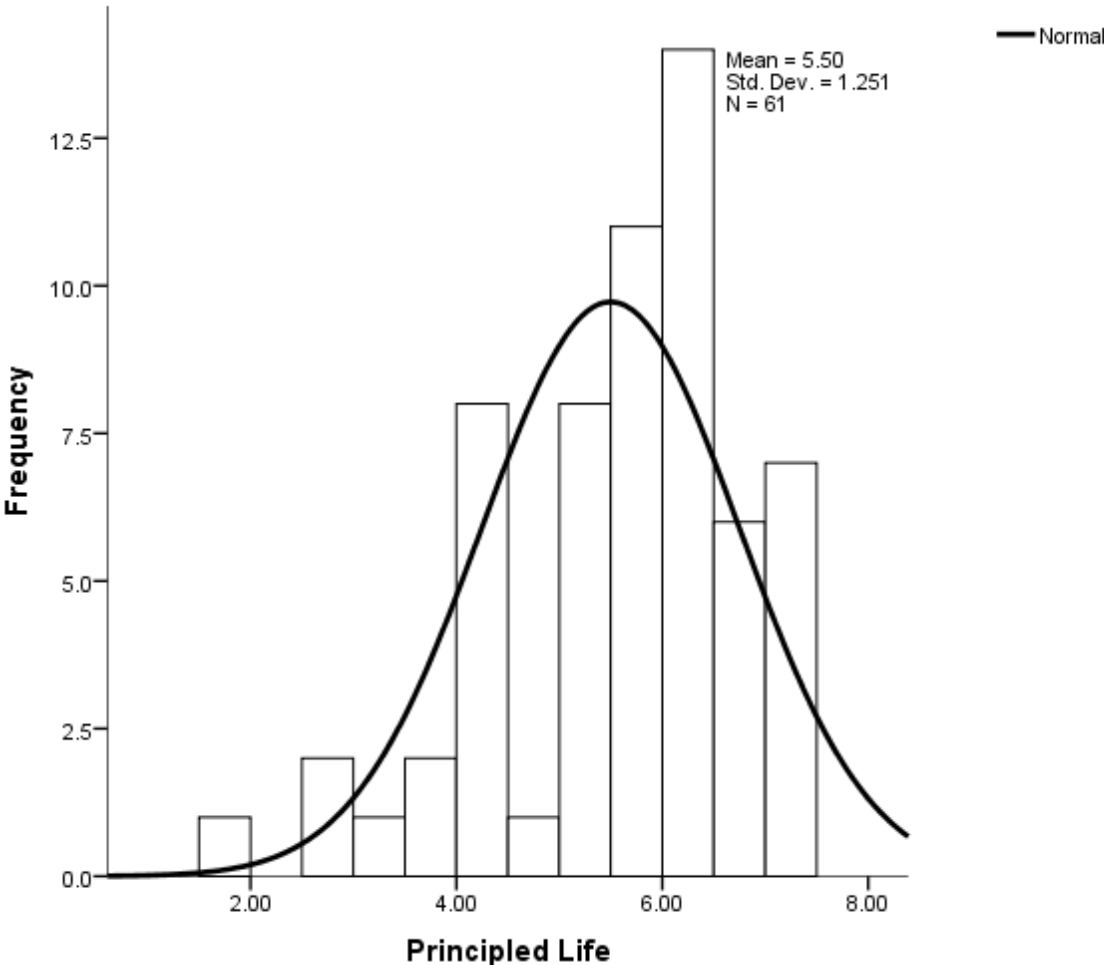


Figure 3. Histogram for Principled Life

The histogram for purposeful life was approximately normal. See Figure 4.

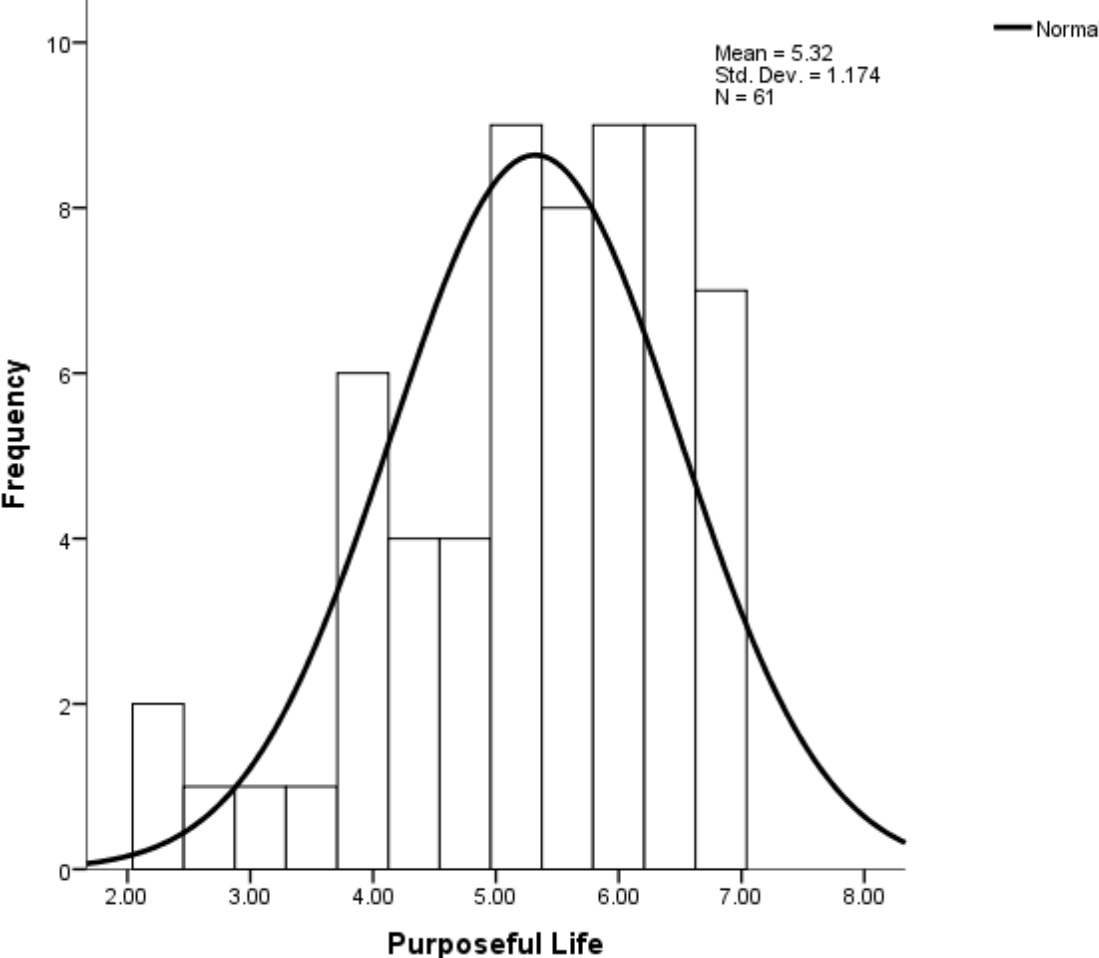


Figure 4. Histogram for Purposeful Life

The distribution for valued life was approximately normal. See Figure 5.

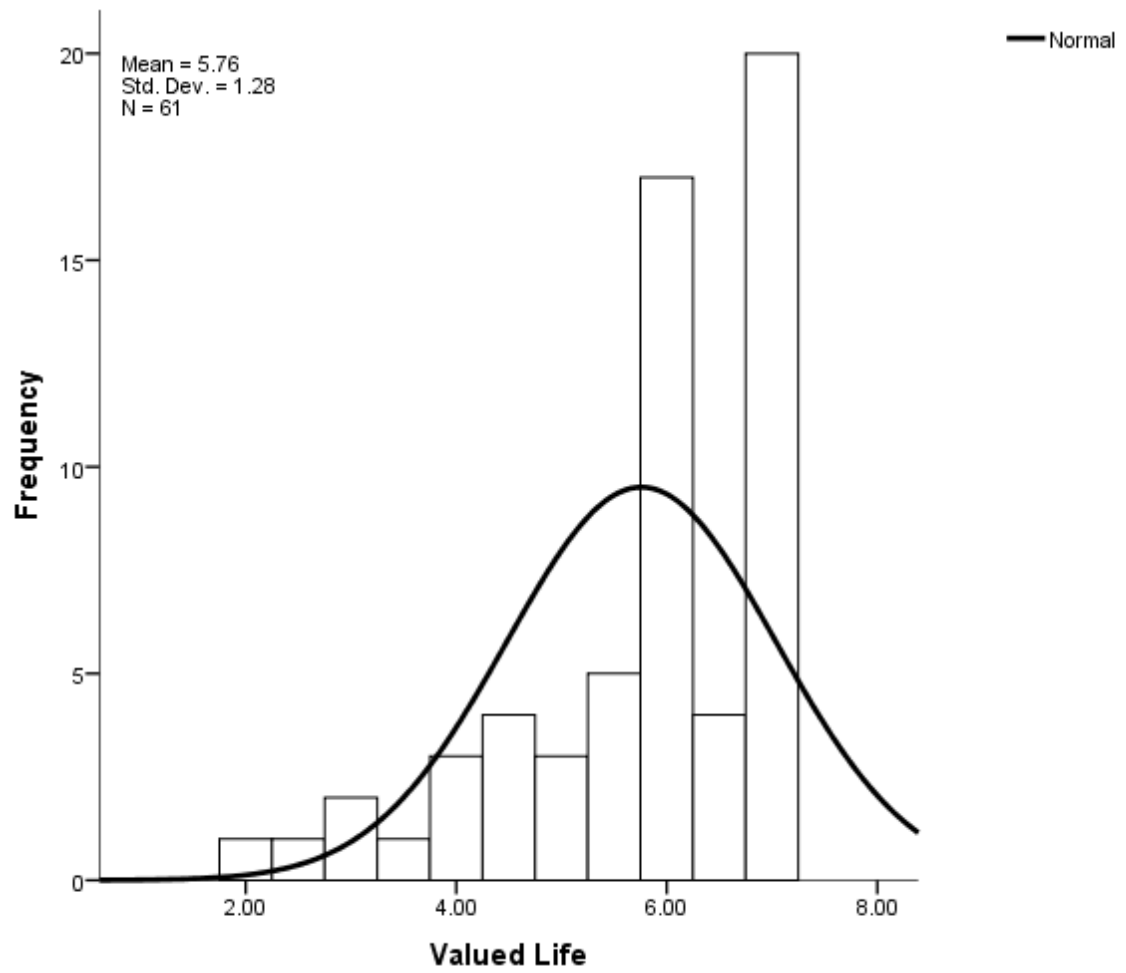


Figure 5. Histogram for Valued Life

The histogram for meaning in life was approximately normal. See Figure 6.

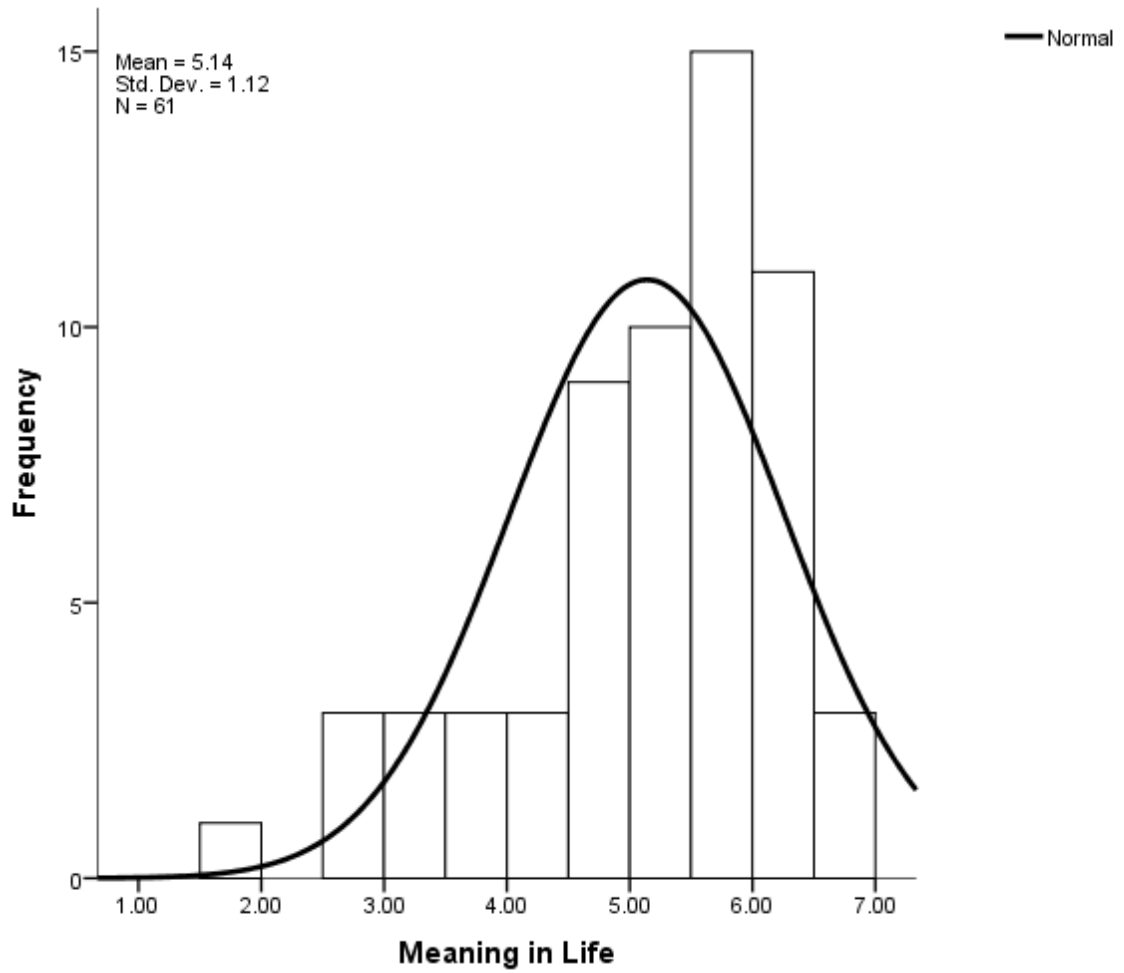


Figure 6. Histogram for Meaning in Life

The histogram for activities of living was approximately normal. See Figure 7.

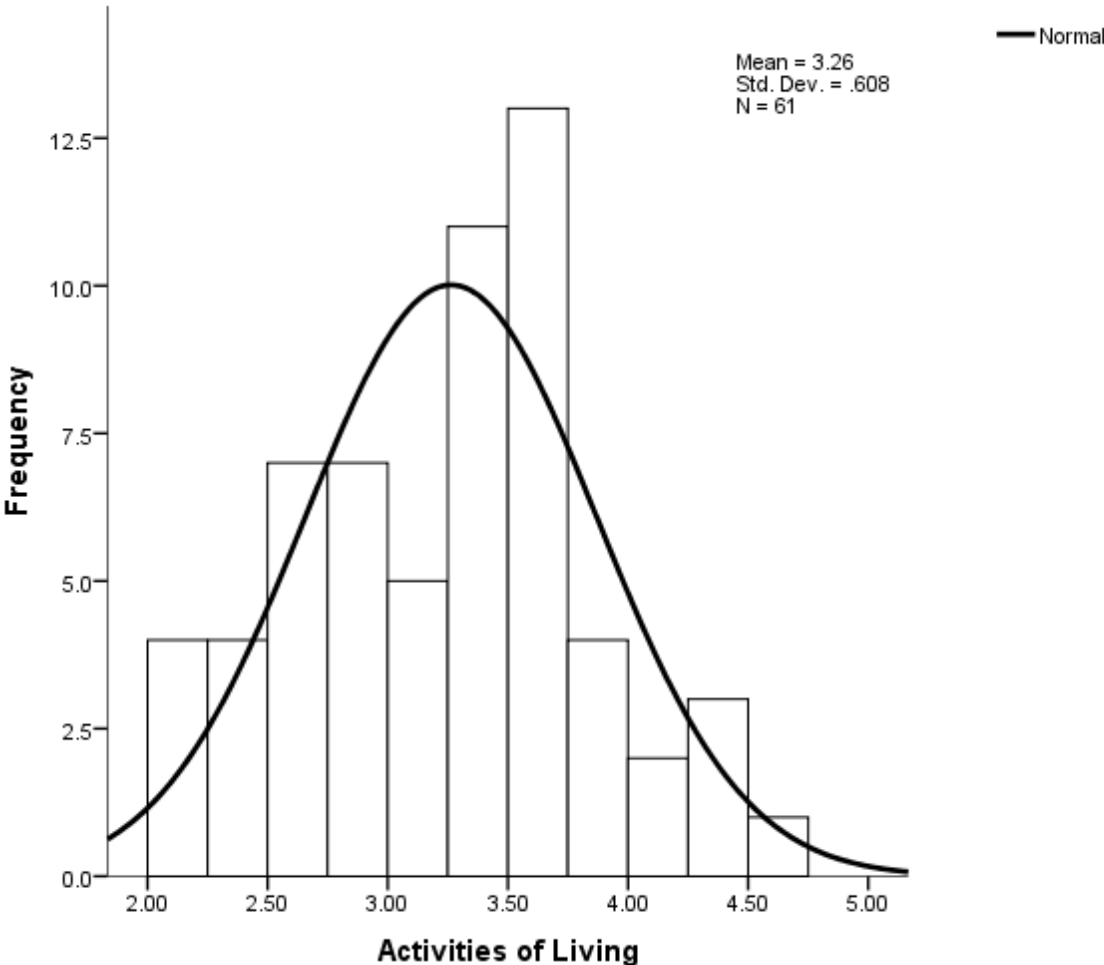


Figure 7. Histogram for Activities of Living

The histogram for basic needs was approximately normal. See Figure 8.

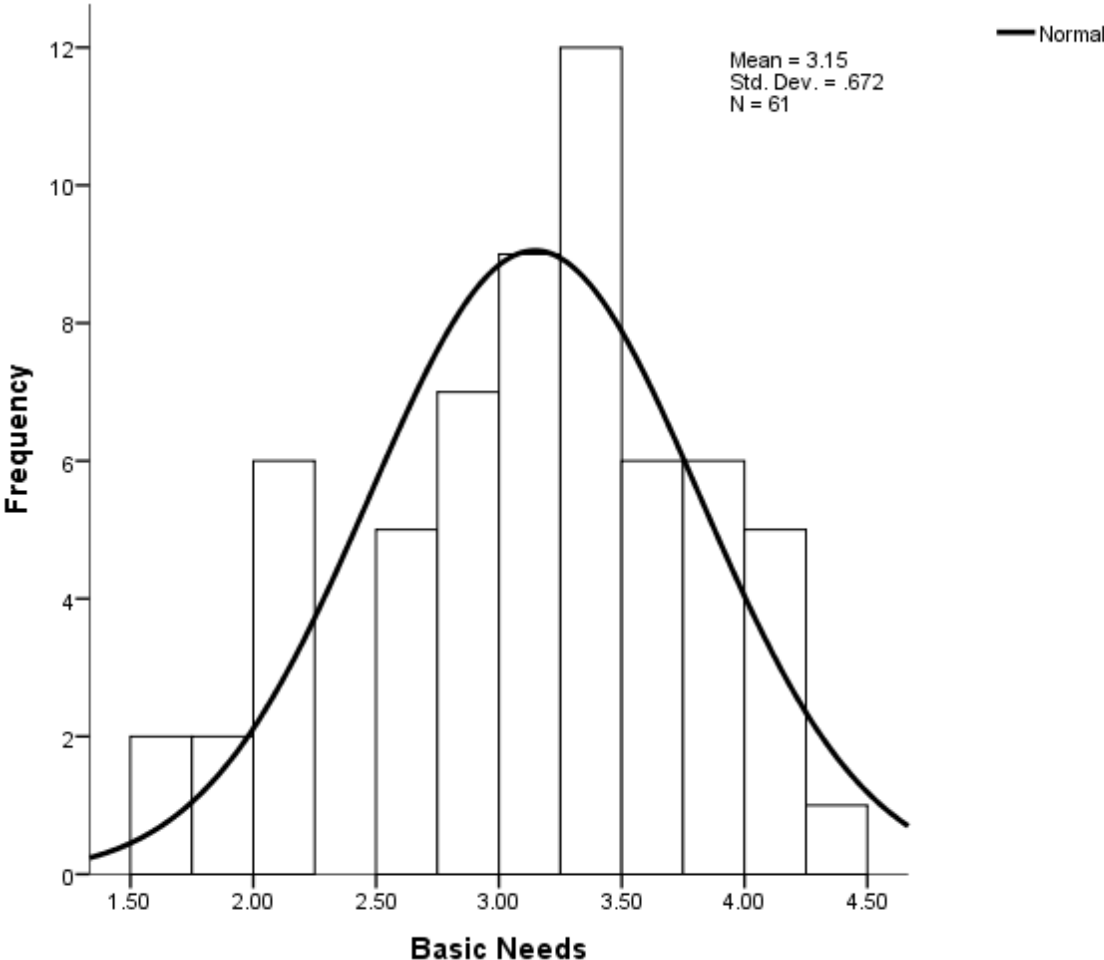


Figure 8. Histogram for Basic Needs

The histogram for well-being was approximately normal. See Figure 9.

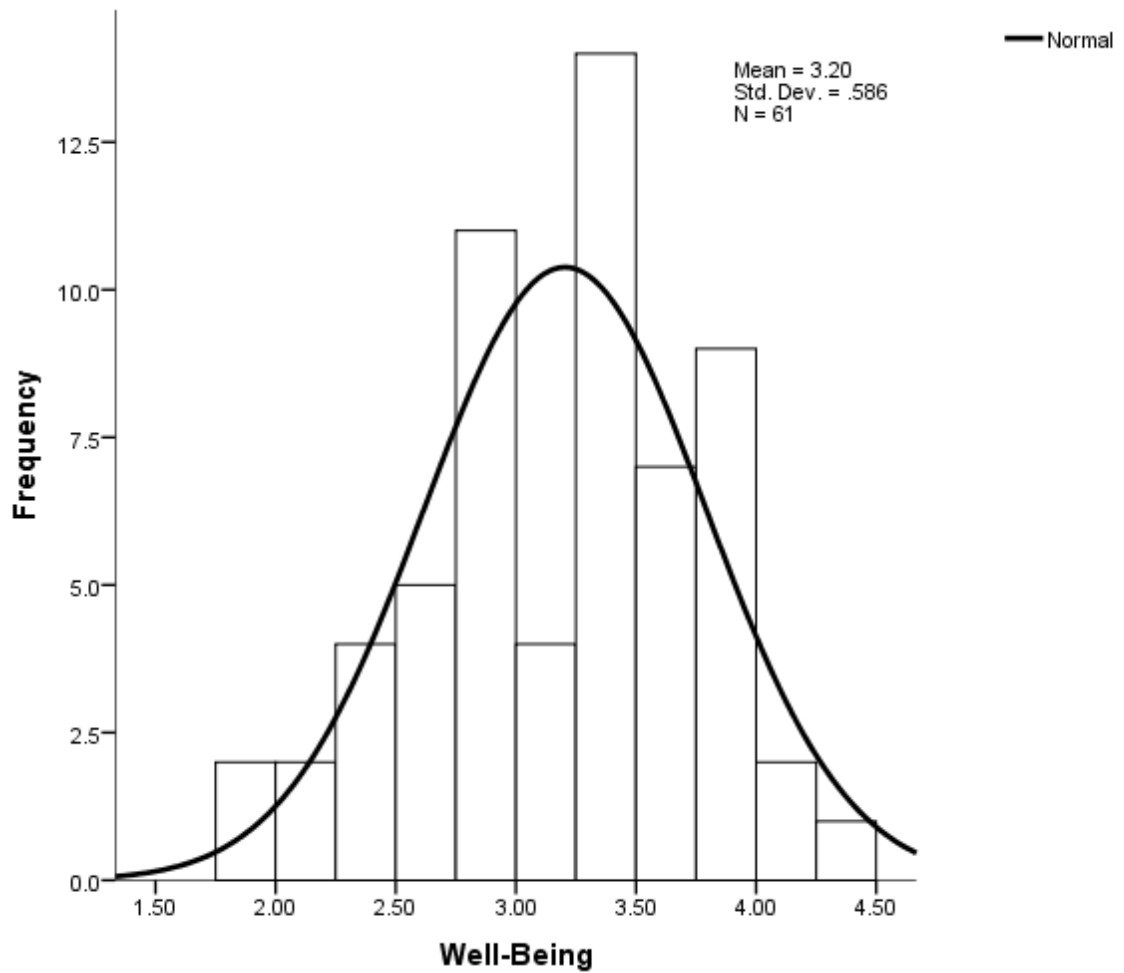


Figure 9. Histogram for Well-Being

The skewness and kurtosis statistics and histograms confirmed that the data were normally distributed. Therefore, the analyses proceeded as planned.

### Reliability Analysis

Instrument reliability for the sample was investigated with Cronbach's alpha. The internal consistency of the MLM ranged from  $\alpha = .704$  for valued life to  $\alpha = .934$  for principled life with an overall internal consistency of  $\alpha = .963$ . On the CWBS, the internal consistency was  $\alpha = .873$  for activities of living and  $\alpha = .918$  for basic needs with



an overall internal consistency of  $\alpha = .934$ . Reliability coefficients are presented in Table 9.

Table 9

*Reliability Coefficients*

Variable	N of Items	Cronbach's alpha
Exciting Life	5	.796
Accomplished Life	5	.913
Principled Life	5	.934
Purposeful Life	4	.881
Valued Life	4	.704
Meaning in Life	23	.963
Activities of Living	23	.873
Basic Needs	22	.918
Well-Being	45	.934

### Research Questions

Five research questions were formulated for investigation. They were as follows:

1. Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients?
2. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being for family caregivers of AD and dementia care recipients?
3. What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of activities of daily living of well-being for caregivers of AD and dementia care recipients?

4. How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics?
5. How do family caregivers of AD and dementia care recipients differ in well-being based upon demographic characteristics?

**Research question one.** Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients? Research question one was investigated with simple linear regression. Meaning in life was significantly and positively related to well-being, ( $B = 0.33$ ,  $t = 6.32$ ,  $p < .001$ );  $R^2 = .40$ . For every increase in meaning in life by one unit, there was a corresponding increase in well-being by 0.33 units. Regression coefficients are presented in Table 10.

Table 10

*Regression Coefficients*

Predictor Variable	<i>R</i>	<i>R</i> <sup>2</sup>	Adj. <i>R</i> <sup>2</sup>	<i>B</i>	SE <i>B</i>	$\beta$	<i>t</i>
	.635	.404	.394***				
Meaning in Life				.332	.053	.635	6.32***

*Note.* Dependent variable = Well-being; \*\*\* $p < .001$ ;  $F(1, 59) = 39.96$ ,  $p < .001$ .

**Research question two.** What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being for family caregivers of AD and dementia care recipients? It was initially anticipated that research question two would be investigated with multiple linear regression. Due to the small sample size, however, it was investigated with bivariate correlation. Specifically, the Pearson  $r$  was conducted. Table 11 provides the criteria governing the interpretation of the correlation coefficients.

Table 11

*Criteria for Interpreting Correlation Coefficients*

Value of the Correlation Coefficient	Magnitude of the Correlation
0.70 or higher	Strong
.40 to .60	Moderate
.10 to .30	Weak
< .10	Zero

Table 12 provides the correlations between the variables of interest.

Table 12

*Correlation Coefficients for Basic Needs and Meaning in Life Variables*

	Exciting Life	Accomplished Life	Principled Life	Purposeful Life	Valued Life
Basic Needs	.46	.70	.54	.63	.71

*Note.*  $p < .001$ , two-tails,  $N = 61$ .

There was a significant, moderate, positive relationship between exciting life and basic needs of well-being,  $r(59) = .46, p < .001$ , two-tails. As exciting life increased, there was a corresponding increase in basic human needs of well-being. The coefficient of determination ( $r^2$ ) = .21, which means that 21% of the variance in basic needs of well-being can be explained by exciting life. A scatterplot of this relationship is presented in Figure 10.

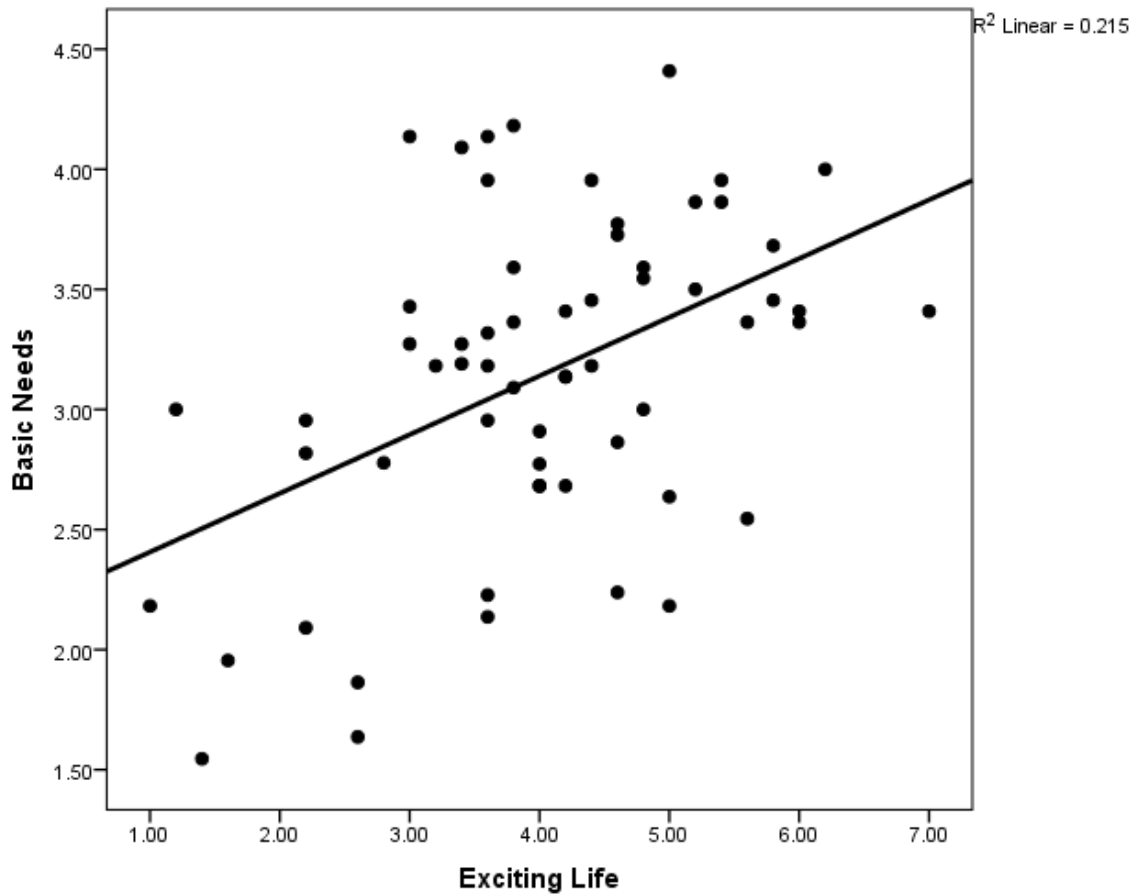
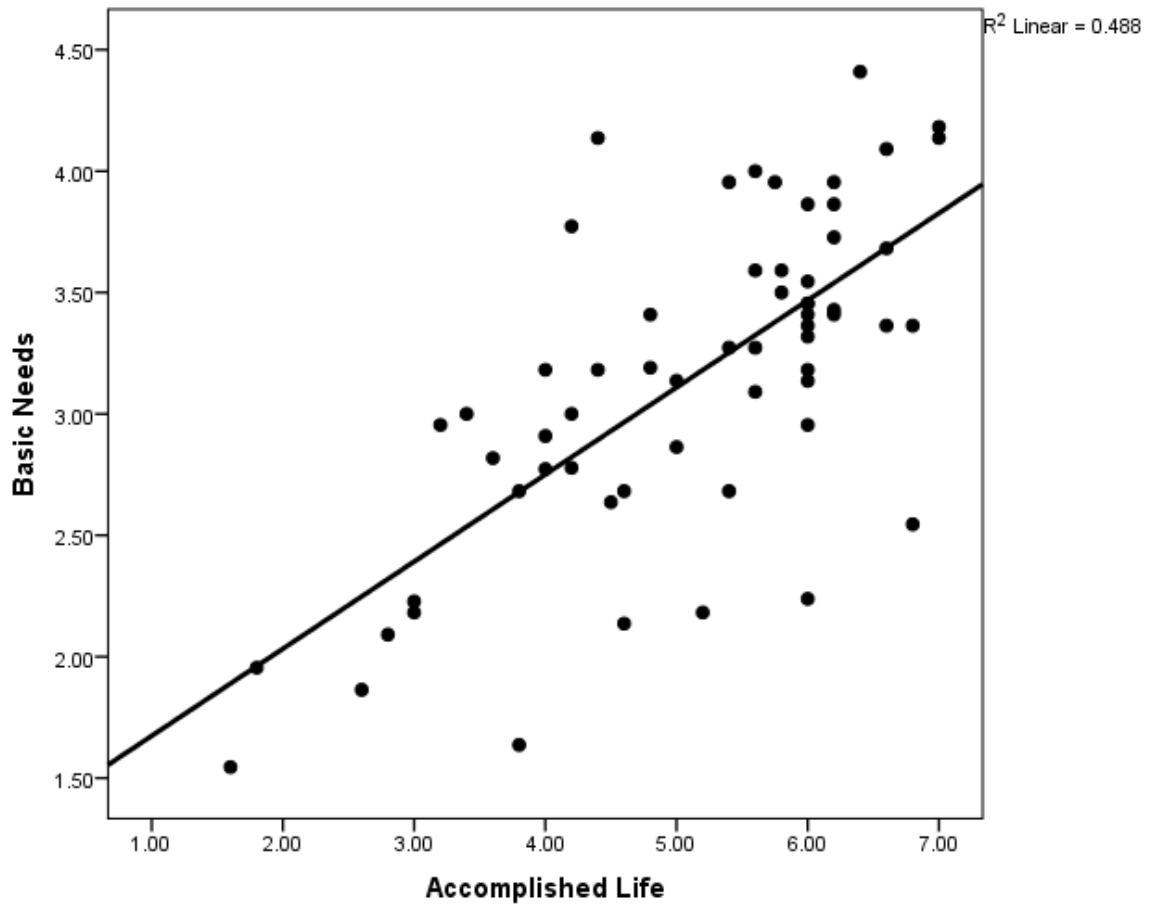


Figure 10. Exciting Life and Basic Needs of Well Being

There was a significant, strong, positive relationship between accomplished life and basic needs of well-being,  $r(59) = .70, p < .001$ , two-tails. As accomplished life increased, there was a corresponding increase in basic human needs of well-being. The coefficient of determination ( $r^2$ ) = .49, which means that 49% of the variance in basic needs of well-being can be explained by accomplished life. A scatterplot of this relationship is presented in Figure 11.



*Figure 11.* Accomplished Life and Basic Needs of Well Being

There was a significant, moderate, positive relationship between principled life and basic needs of well-being,  $r(59) = .54, p < .001$ , two-tails. As principled life increased, there was a corresponding increase in basic human needs of well-being. The coefficient of determination ( $r^2$ ) = .29, which means that 29% of the variance in basic needs of well-being can be explained by principled life. A scatterplot of this relationship is presented in Figure 12.

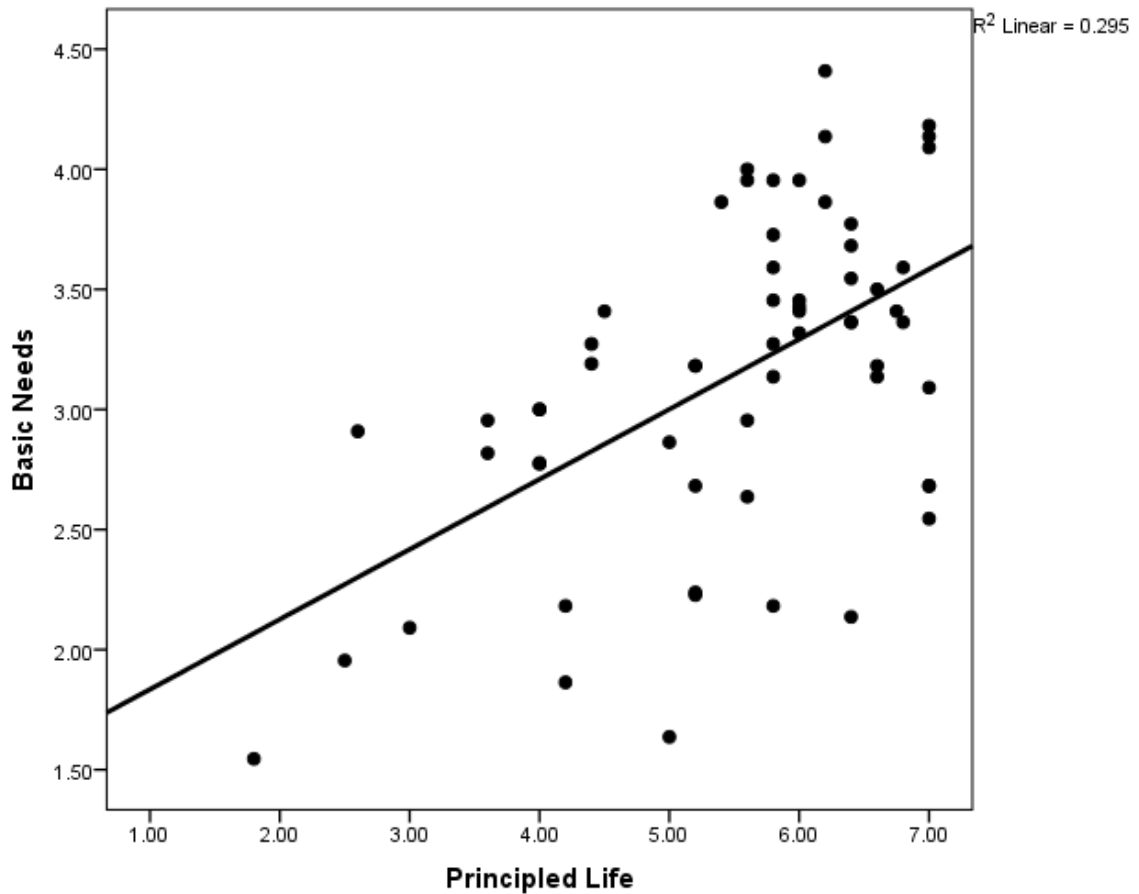


Figure 12. Principled Life and Basic Needs of Well Being

There was a significant, moderate, positive relationship between purposeful life and basic needs of well-being,  $r(59) = .63, p < .001$ , two-tails. As purposeful life increased, there was a corresponding increase in basic human needs of well-being. The coefficient of determination ( $r^2$ ) = .40, which means that 40% of the variance in basic needs of well-being can be explained by purposeful life. A scatterplot of this relationship is presented in Figure 13.

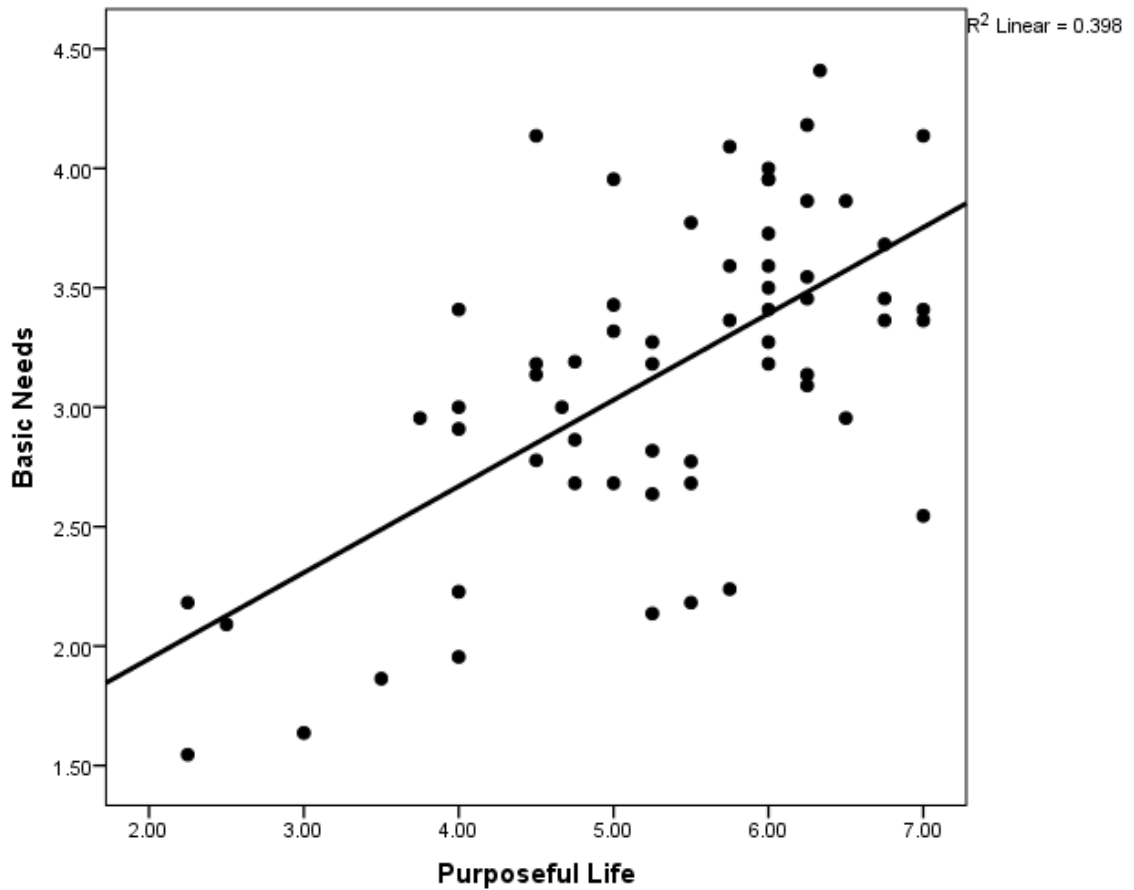


Figure 13. Purposeful Life and Basic Needs of Well Being

There was a significant, strong, positive relationship between valued life and basic needs of well-being,  $r(59) = .71, p < .001$ , two-tails. As valued life increased, there was a corresponding increase in basic human needs of well-being. The coefficient of determination ( $r^2$ ) = .50, which means that 50% of the variance in basic needs of well-being can be explained by valued life. A scatterplot of this relationship is presented in Figure 14.

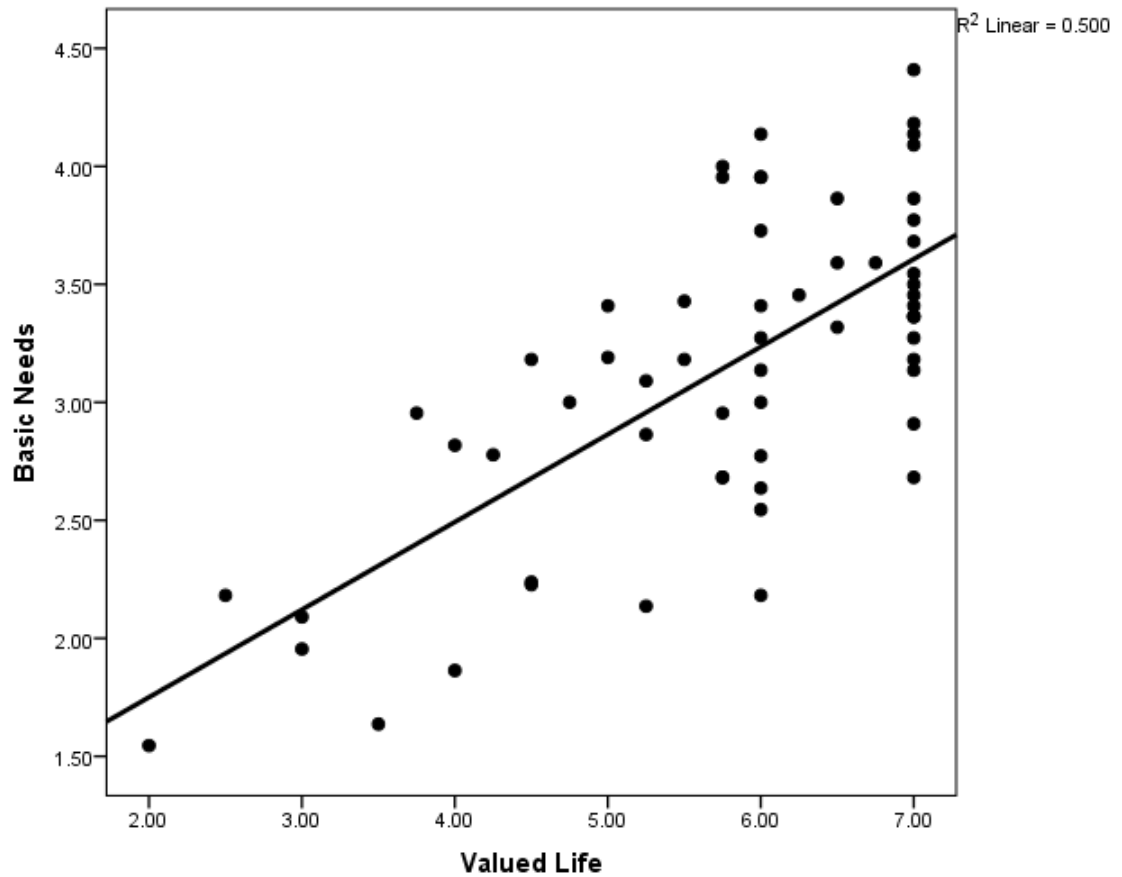


Figure 14. Valued Life and Basic Needs of Well Being

**Research question three.** What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of



activities of daily living of well-being for caregivers of AD and dementia care recipients?

Table 13 provides the correlations between the variables of interest.

Table 13

*Correlation Coefficients for Basic Needs and Meaning in Life Variables*

	Exciting Life	Accomplished Life	Principled Life	Purposeful Life	Valued Life
Activities of Living	.37**	.48***	.32*	.40**	.51***

*Note.* \* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ , two-tails,  $N = 61$ .

There was a significant, weak, positive relationship between exciting life and completion of activities of daily living of well-being,  $r(59) = .37, p = .003$ , two-tails. As exciting life increased, there was a corresponding increase in completion of activities of daily living of well-being. The coefficient of determination ( $r^2$ ) = .14, which means that 14% of the variance in completion of activities of daily living of well-being can be explained by exciting life. A scatterplot of this relationship is presented in Figure 15.

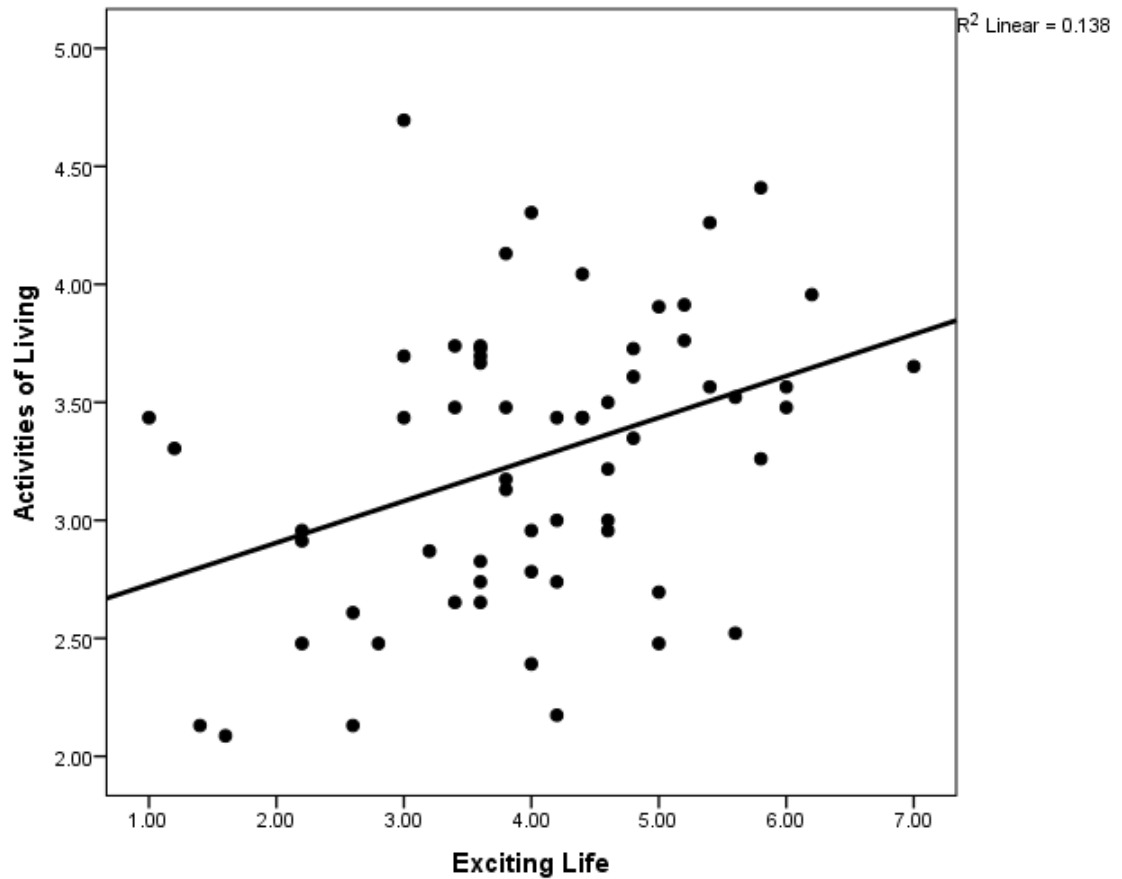


Figure 15. Exciting Life and Completion of Activities of Daily Living

There was a significant, moderate, positive relationship between accomplished life and completion of activities of daily living of well-being,  $r(59) = .48, p < .001$ , two-tails. As accomplished life increased, there was a corresponding increase in completion of activities of daily living of well-being. The coefficient of determination ( $r^2$ ) = .23, which means that 23% of the variance in completion of activities of daily living of well-being can be explained by accomplished life. A scatterplot of this relationship is presented in Figure 16.

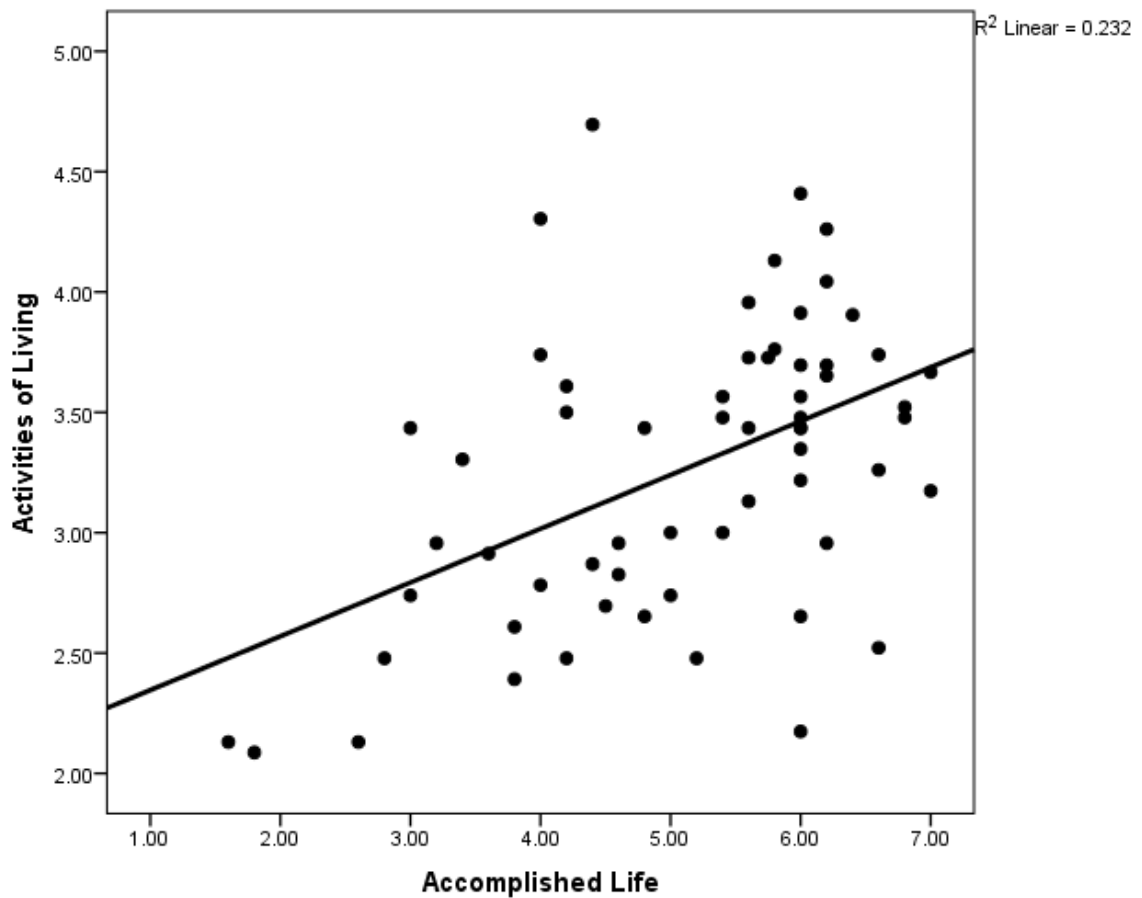


Figure 16. Accomplished Life and Completion of Activities of Daily Living

There was a significant, weak, positive relationship between principled life and completion of activities of daily living of well-being,  $r(59) = .32, p = .012$ , two-tails. As principled life increased, there was a corresponding increase in completion of activities of daily living of well-being. The coefficient of determination ( $r^2$ ) = .10, which means that 10% of the variance in completion of activities of daily living of well-being can be explained by principled life. A scatterplot of this relationship is presented in Figure 17.

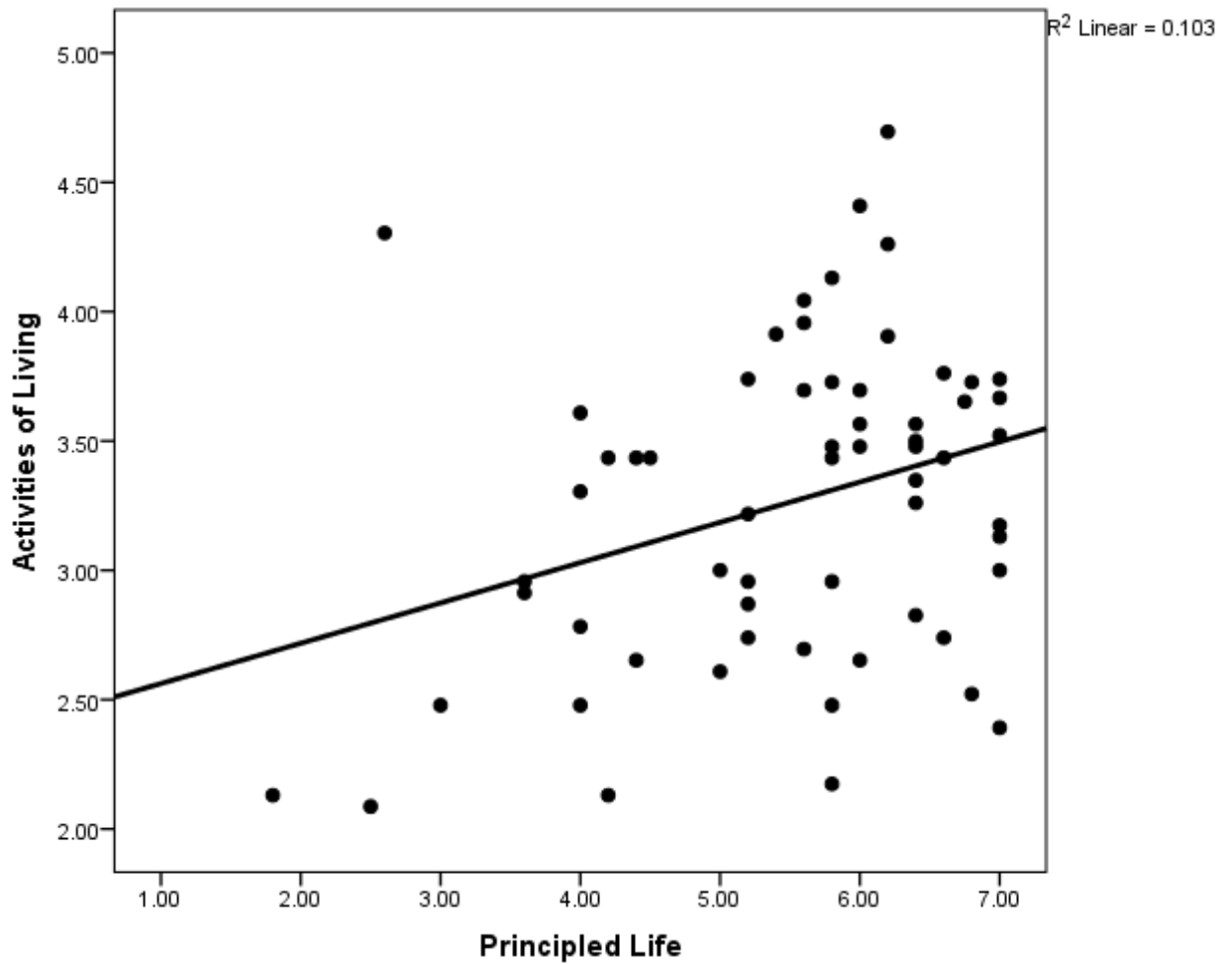


Figure 17. Principled Life and Completion of Activities of Daily Living

There was a significant, weak, positive relationship between purposeful life and completion of activities of daily living of well-being,  $r(59) = .40, p = .001$ , two-tails. As purposeful life increased, there was a corresponding increase in completion of activities of daily living of well-being. The coefficient of determination ( $r^2$ ) = .16, which means that 16% of the variance in completion of activities of daily living of well-being can be explained by purposeful life. A scatterplot of this relationship is presented in Figure 18.

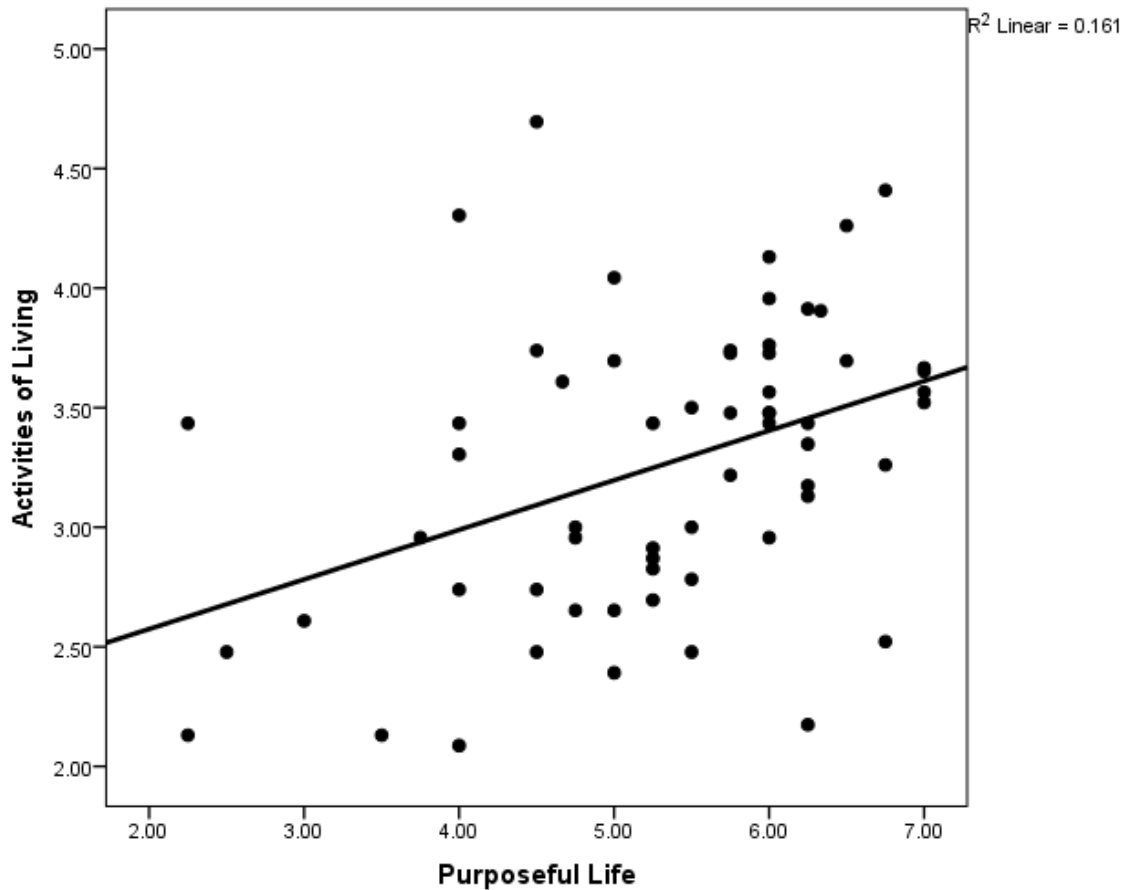


Figure 18. Purposeful Life and Completion of Activities of Daily Living

There was a significant, moderate, positive relationship between valued life and completion of activities of daily living of well-being,  $r(59) = .51, p < .001$ , two-tails. As valued life increased, there was a corresponding increase in completion of activities of daily living of well-being. The coefficient of determination ( $r^2$ ) = .26, which means that 26% of the variance in completion of activities of daily living of well-being can be explained by valued life. A scatterplot of this relationship is presented in Figure 19.

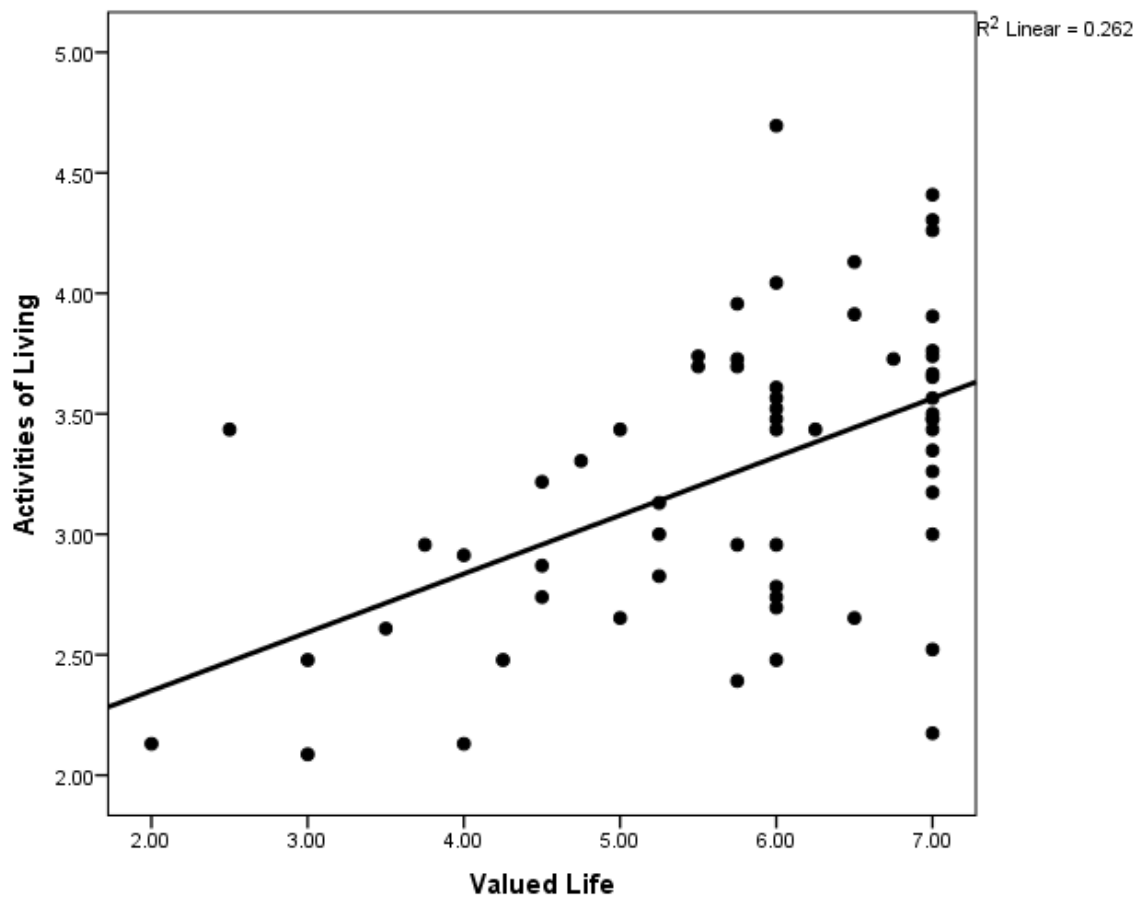


Figure 19. Valued Life and Completion of Activities of Daily Living

**Research question four.** How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics? Due to the small sample size, some categories of variables had to be combined when warranted. When conducting statistical tests involving mean group

differences, groups were combined so that no subgroup had less than 10 participants. Therefore, gender differences were not tested since there were only eight males in the sample. Demographic variables tested for this research question included age, marital status, educational attainment, religious preference, employment status, household income, and relationship status to ill family member.

***Age and meaning in life.*** A one-way ANOVA investigated meaning in life relative to age group. Group means are presented in Table 14.

Table 14

*Group Means for Age and Meaning in Life*

Age	N	M	SD
<= 48	22	4.93	1.29
49 - 60	20	5.06	1.03
61+	19	5.47	0.97
Total	61	5.14	1.12

There was no significant difference in meaning in life relative to age group,  $F(2, 58) = 1.30, p = .279$ .

***Marital status and meaning in life.*** The categories for marital status were combined into two categories; married ( $n = 46$ ) and not married ( $n = 15$ ). Group differences were investigated with an independent samples t-test. Married couples ( $M = 5.18, SD = 1.05$ ) did not differ significantly in what they found meaningful in life from non-married couples ( $M = 5.02, SD = 1.35$ ),  $t(59) = .48, p = .633$ , two-tails.

***Educational attainment and meaning in life.*** A one-way ANOVA investigated meaning in life relative to educational attainment. Group means are presented in Table 15.

Table 15

*Group Means for Educational Attainment and Meaning in Life*

Educational Attainment	<i>N</i>	<i>M</i>	<i>SD</i>
High School Degree to Some College	19	4.84	1.26
Undergraduate Degree	20	5.11	1.30
Master's Degree or higher	22	5.43	0.73
Total	61	5.14	1.12

There was no significant difference in meaning in life relative to educational attainment,  $F(2, 58) = 1.42, p = .249$ .

***Religious preference and meaning in life.*** The categories for religious preference were combined into two categories; Protestant ( $n = 25$ ) and non-Protestant ( $n = 36$ ). Group differences were investigated with an independent samples t-test. Protestants ( $M = 5.28, SD = 1.06$ ) did not differ significantly in what they found meaningful in life from non-Protestants ( $M = 5.04, SD = 1.17$ ),  $t(59) = .81, p = .421$ , two-tails.

***Employment status and meaning in life.*** The categories for employment status were combined into two categories; employed ( $n = 27$ ) and unemployed ( $n = 34$ ). Group differences were investigated with an independent samples t-test. Employed participants ( $M = 4.92, SD = 1.37$ ) did not differ significantly in what they found meaningful in life from unemployed participants ( $M = 5.32, SD = 0.86$ ),  $t(59) = -1.41, p = .163$ , two-tails.

***Annual household income and meaning in life.*** The categories for annual household income were combined into two categories; \$49,999 or less ( $n = 24$ ) and \$50,000 or higher ( $n = 35$ ). Group differences were investigated with an independent samples t-test. Respondents with household incomes of \$49,999 or less ( $M = 5.15, SD = 1.11$ ) did not differ significantly in what they found meaningful in life from those with household incomes of \$50,000 or higher ( $M = 5.13, SD = 1.18$ ),  $t(57) = 0.07, p = .949$ , two-tails.



***Relationship status to ill family member and meaning in life.*** A one-way

ANOVA investigated meaning in life relative to relationship status to ill family member.

Group means are presented in Table 16.

Table 16

*Group Means for Relationship Status to Ill Family Member and Meaning in Life*

Relationship Status	<i>N</i>	<i>M</i>	<i>SD</i>
Spouse/Partner	14	5.11	1.11
Child	23	5.01	0.99
Other	24	5.28	1.26
Total	61	5.14	1.12

There was no significance difference in meaning in life relative to relationship status to ill family member,  $F(2, 58) = 0.34, p = .716$ .

**Research question five.** How do family caregivers of AD and dementia care recipients differ in well-being based upon demographic characteristics?

***Age and well-being.*** A one-way ANOVA investigated well-being relative to age group. Group means are presented in Table 17.

Table 17

*Group Means for Age and Well-Being*

Age	<i>N</i>	<i>M</i>	<i>SD</i>
<= 48	22	3.20	0.66
49 - 60	20	3.14	0.58
61+	19	3.28	0.52
Total	61	3.20	0.59

There was no significant difference in well-being relative to age group,  $F(2, 58) = 0.29, p = .748$ .

***Marital status and well-being.*** Group differences were investigated with an independent samples t-test. Married couples ( $M = 3.20, SD = 0.49$ ) did not differ significantly in well-being from non-married couples ( $M = 3.23, SD = 0.83$ ),  $t(59) = -.19, p = .853$ , two-tails.

***Educational attainment and well-being.*** A one-way ANOVA investigated well-being relative to educational attainment. Group means are presented in Table 18.

Table 18

*Group Means for Educational Attainment and Well-Being*

Educational Attainment	<i>N</i>	<i>M</i>	<i>SD</i>
High School Degree to Some College	19	3.13	0.54
Undergraduate Degree	20	3.21	0.65
Master's Degree or higher	22	3.26	0.59
Total	61	3.20	0.59

There was no significant difference in well-being relative to educational attainment,  $F(2, 58) = 0.26, p = .775$ .

**Religious preference and well-being.** Group differences were investigated with an independent samples t-test. Protestants ( $M = 3.18$ ,  $SD = 0.50$ ) did not differ significantly in well-being from non-Protestants ( $M = 3.22$ ,  $SD = 0.65$ ),  $t(59) = -.31$ ,  $p = .755$ , two-tails.

**Employment status and well-being.** Group differences were investigated with an independent samples t-test. Employed participants ( $M = 3.34$ ,  $SD = 0.53$ ) had significantly higher well-being than unemployed participants ( $M = 3.03$ ,  $SD = 0.62$ ),  $t(59) = -2.08$ ,  $p = .042$ , two-tails.

**Annual household income and well-being.** Group differences were investigated with an independent samples t-test. Respondents with household incomes of \$49,999 or less ( $M = 3.26$ ,  $SD = 0.59$ ) did not differ significantly in well-being from those with household incomes of \$50,000 or higher ( $M = 3.18$ ,  $SD = 0.59$ ),  $t(57) = 0.51$ ,  $p = .613$ , two-tails.

**Relationship status to ill family member and well-being.** A one-way ANOVA investigated well-being relative to relationship status to the ill family member. Group means are presented in Table 19.

Table 19

*Group Means for Relationship Status to Ill Family Member and Meaning in Life*

Relationship Status	<i>N</i>	<i>M</i>	<i>SD</i>
Spouse/Partner	14	3.14	0.59
Child	23	3.08	0.56
Other	24	3.36	0.60
Total	61	3.20	0.59

There was no significant difference in well-being relative to relationship to the ill family member,  $F(2, 58) = 1.44$ ,  $p = .245$ .

## **Conclusions**

Meaning in life was significantly and positively related to well-being. Purposeful life, valued life, accomplished life, principled life, and exciting life were significantly and positively related to the basic human needs of well-being for family caregivers of AD and dementia care recipients. Purposeful life, valued life, accomplished life, principled life, and exciting life were positively and significantly related to completion of activities of daily living of well-being for caregivers of AD and dementia care recipients. Family caregivers of AD and dementia care recipients did not differ significantly in what they found meaningful in life based upon demographic characteristics. Employed caregivers of AD and dementia care recipients had significantly higher well-being than unemployed caregivers of AD and dementia care recipients. With the exception of employment status, family caregivers of AD and dementia care recipients did not significantly differ in well-being based upon demographic characteristics. Implications of these results will be discussed in Chapter Five.

## **CHAPTER 5**

### **DISCUSSION**

This chapter addresses the implications of the findings presented in Chapter 4, discusses the limitations of this study, and presents suggested areas for future research as well as clinical applications of the results. As previously mentioned, the primary purpose of this research study was to examine the relationship of meaning in life of caregivers with well-being when they care for family member with Alzheimer's disease or dementia. The demographic factors of age, gender, race, marital status, level of education completed, religious preference, employment status, annual household income, caregiver relationship to person diagnosed with Alzheimer's disease or dementia, and average hours of care per week provided were intended to be investigated for relationships to caregiver well-being and meaning in life. The study design included descriptive statistics along with simple linear regression, bivariate correlation, t-tests, and analysis of variance in order to investigate the research questions.

#### **Implications of Findings**

*Research Question 1: Does having a meaning in life relate with well-being for family caregivers of AD and dementia care recipients?*

In this study, meaning in life was found to be significantly and positively related to caregiver well-being. According to McLennon, Habermann, and Rice (2011), six different studies found having meaning in life to improve caregiver well-being. The present study and past studies do indicate the importance of pursuing the aspect of

meaning in life with caregivers in order to increase their well-being. Meaning in life is a personal matter, but the existential benefit in decreasing depression could have far-reaching implications. The possibilities for practitioners in assisting caregivers with meaning are quite extensive by working individually or in groups.

*Research Question 2: What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and basic human needs of well-being for family caregivers of AD and dementia care recipients?*

According to the data, a significant, moderate, positive relationship was found between exciting life and the basic human needs of well-being of family caregivers. Understanding that caregivers' needs moderately increases with having an exciting lifestyle can be helpful to counseling professionals. By gathering information on what can increase excitement, counselors may be able to assist caregivers in finding activities or situations that increase or improve excitement or decrease the routines caregivers may describe as dull or without change. Links between excitement and happiness could potentially be discovered, as maintaining happiness can lessen the chances of negative mental health problems, such as depression or anxiety.

Accomplished life as part of meaning in life and the basic human needs of well-being of caregivers had a strong, significant, positive relationship. The area of accomplished life focused on achievements and successes in life. Perhaps many caregivers believe they have already accomplished much in their lives in order to provide care to their family members in need, and in turn, they are able to attend to their own basic needs. Women in the baby boomer population make up the majority of caregivers (Robison et al., 2009). Since the majority of caregivers are older adults, there is potential

to have experienced more accomplishments and to feel meaning in those accomplishments. Individuals who feel more accomplished can engage in personal interests and possibly take time out of hectic schedules to take care of personal needs.

A significant, moderate, positive relationship occurred between principled life and the basic human needs of well-being. Having a principled life includes having values, philosophy, and a belief system about the world. For example, doing what is considered in the best interest for the family member with AD or dementia by honoring their integrity and personal story was frequently accomplished by family caregivers (Elliott, Gessert, & Peden-McAlpine, 2009). This research reflects living a principled life with regards to the care recipient, which could imply a more principled life for the caregiver; this leaves more time for the effort put into taking care of the caregiver's own basic needs.

Purposeful life and the basic human needs of well-being were represented by a significant, moderate, positive relationship. Purpose, goals, and direction as part of a purposeful life are indicated in the MLM (Morgan & Farsides, 2008). Välimäki, Vehviläinen-Julkunen, Pietilä, and Pirttilä (2009) described sense of coherence as including purpose. Furthermore, sense of coherence was related to a health-related quality of life and lower reports of depression. Taking care of basic human needs, including health-related tasks, feeling appreciated, and feeling good about oneself, can be linked to healthier quality of life with fewer mental health concerns and overall improved well-being. A large body of research indicates how having purpose in life can contribute to less depressive symptoms and increased hope.

A significant, strong, positive relationship occurred between valued life and the basic human needs of the well-being measurement. The valued life component indicates value of the caregiver's own life considering one's life significant. Consideration for the value of one's own life would lead to care of basic needs. When one feels loved and appreciated by others or even makes time for recreation and other activities, a higher value on life is likely. A caregiver's values are reflected in having meaning in life, and decision-making skills and well-being are improved when this increases (Whitlatch, Feinberg, & Tucke, 2005). Personal meaning in the duties associated with caregiving can also be discovered by the counselor assisting with understanding personal values of the caregiver.

*Research Question 3: What is the relationship between purposeful life, valued life, accomplished life, principled life, and exciting life and completion of activities of daily living of well-being for caregivers of AD and dementia care recipients?*

Exciting life and completion of activities of daily living of well-being yielded a significant, weak, positive relationship found in the data. Although the relationship is weak, it is still important to promote excitement and newness in order to improve activities that take place on a daily basis, such as housework, outside work, and taking time for oneself. Various pleasurable activities can be encouraged even when caregivers report feeling stressed, particularly through psychoeducational and behavioral activation techniques to teach stress management (Mausbach et al., 2007). The decreased stress level could leave more time for emphasis on exciting life as well as completion of activities of daily living. One study determined that activities such as housekeeping and



long-standing sports continued regularly even under the burden of caregiving, but further leisure activities were limited (Hirano et al., 2011).

The relationship between accomplished life and activities of daily living of well-being was significant, moderate, and positive. Caregivers who feel they are already accomplished may be able to better complete activities of daily living and add activities that may inspire them or allow them to socialize and spend time with others. Individuals who already having coping skills are typically able to find enjoyable activities (Cooper et al., 2008). The achievements and accomplishments may have led to satisfactory coping skills gained previously to allow increased engagement in old and new activities of daily living.

Principled life and activities of daily living of caregiver well-being was found to have a significant, weak, positive relationship. The principled aspect of meaning in life may not have much association with the activities of daily living of caregivers. The beliefs and philosophies one has constructed about life appear to have little in common with making choices to engage in routine or new activities, but they are still significant. There was also a significant, weak, positive relationship between purposeful life and activities of daily living. Having purpose, goals, or mission appeared to have minimal contribution in completing daily activities. The significance of a social outlet, such as work, can serve as a purposeful venue, according to Valimaki et al. (2009); however, the purpose found in a meaningful life may vary from the purpose of a having a duty to complete.

A significant, moderate, positive relationship occurred between valued life and activities of daily living in well-being. A valued life aligns with positivity regarding life

and viewing life as worthwhile, and a life that is valued and less-depressed can leave time and energy for routine activities as well as increased social engagements, fun, and hobbies. Whitlatch et al. (2005) indicated that caregiving in itself involves an understanding of personal values and preferences. The value placed on the caregiver's personal life might lead to time for respite from the caregiving experience, which could lead to more time for meaningful activities for the caregiver.

*Research Question 4: How do family caregivers of AD and dementia care recipients differ in what they find meaningful in life based upon demographic characteristics?*

Research question four pertains to the varying demographic variable information gathered in the Demographic Questionnaire (Appendix B). Since there were only eight males in the sample, the gender demographic was not measured with an ANOVA or t-test as was the remainder of the variables, including age, marital status, educational attainment, religious preference, employment status, household income, and relationship status to family member with AD or dementia. Data was arranged so that none of the subgroups contained less than ten participants. Regarding race, 90.2% of the sample was Caucasian, which left less than ten participants who identified as African-American, Hispanic, or other.

The analysis of the subgroups of age (Table 14), marital status (married versus unmarried), educational attainment (Table 15), religious preference (Protestant versus non-Protestant), employment status (employed versus unemployed), annual household income (\$49,999 or less versus \$50,000 or higher), and relationship status to the ill family member (Table 16) yielded no significant differences in finding meaning in life. Research has indicated Hispanic and African-American caregivers utilized religion in

meaning in life (Sorensen & Pinquart, 2005); however, these groups were not represented in this study to determine if differences in meaning regarding religion exist.

*Research Question 5: How do family caregivers of AD and dementia care recipients differ in well-being based upon demographic characteristics?*

Similar to research question four, research question five is based upon the subgroups of demographic variables and differences in caregiver well-being. As in the previous research question, gender and race were not measured due to the sample sizes of the groups. The subgroups of age (Table 17), marital status (married versus unmarried), educational attainment (Table 18), religious preference (Protestant versus non-Protestant), annual household income (\$49,999 or less versus \$50,000 or higher), and relationship status to the ill family member (Table 19) did not yield significant differences in caregiver well-being. Income as a factor can likely reflect on well-being; however, perceived income inadequacy could be linked with increased psychological distress instead of responding to an objective annual income on a scale (Sun, Hilgeman, Durkin, Allen, & Burgio, 2009).

Employment status was the only variable with participants differing in well-being. Employed participants had significantly higher well-being than unemployed participants. Work may serve as a purposeful venue to allow for socialization, and those retired or unemployed may not have that social outlet (Valimaki et al., 2009). Socialization is an aspect of activities of daily living for caregiver well-being, so it is likely no additional time must be made for socializing outside of the focus on the care provided for the care recipient. Employment in general may be jeopardized by taking on caregiving. The interruptions in employment status once placed into the caregiver role could account for

any decrease in well-being. When a caregiver feels prepared for the caregiving role and balancing work, they may be able to manage these two roles better (Wang et al., 2013). Employment also may allow the caregiver to be more financially secure. Self-worth and the fulfillment or satisfaction that comes with employment may also occur. The implications of this balance as well as income could be results of better maintenance of the caregiver's own well-being.

### **Limitations**

The main limitation of this study was sample size. Only 61 participants completed this study, which makes it difficult to generalize these results to the population being studied. The population of caregivers is so vast, there would likely be no external validity. It is possible the low response rate could be attributed to lack of time from caregivers to participate in the study due to stress and the demanding work involved. Even though significant relationships were found through this research, it would be difficult to infer whether or not these results would be applicable to a population of caregivers. Although the results of the present study are helpful, the researcher did not wish to over-estimate the magnitude of such associations. Potentially due to sample size, the demographic variables included in the study yielded small subgroups. Out of the 61 participants, only 13.1% of them were males ( $n = 8$ ). This did not allow enough male participants to analyze separately from the female participants; therefore, it is unknown if any differences in meaning in life or caregiver well-being would have existed between the genders. Additionally, race was another variable that yielded small groups that could not be measured. Only 3.3% ( $n = 2$ ) were African Americans; 4.9% ( $n = 3$ ) were Hispanics; and 1.6% ( $n = 1$ ) self-identified as "other." This left 90.2% ( $n = 55$ ) as self-

identifying as White. The results from this study would not be generalized to include racial groups outside of Caucasian individuals. Therefore, this relatively small sample size data could be limited to Caucasian females. There is no external validity for populations outside of Caucasian females.

Another methodological limitation to this study was the use of self-report data in the questionnaire format. The potential bias of self-report could involve exaggeration of responses or attribution of the items in question to external circumstances, or external circumstances (mood, events, etc.) may have contributed to the responses registered. The measures utilized in this study could have presented an issue for participants as well. Following the demographic questionnaire, two other measures, the Meaningful Life Measure (Morgan & Farsides, 2008) and Caregiver Well-Being Scale (Tebb, 1995), were provided to participants. Both measures utilized Likert-style questions, but it is possible participants could have become confused with the 7-point Likert scale of the Meaningful Life Measure and the 5-point Likert scale of the Caregiver Well-Being Scale as some participants did begin the study and dropped out. Social desirability bias may have also occurred as caregivers who responded may not want to respond in a negative manner or make their personal life not appear positive.

The researcher utilized the Internet to gather data on the questionnaires, and there were also limitations in this approach. Approximately half of the participants who started the survey did not complete it, resulting in lower response rates. Since participation was voluntary, participants could choose to proceed with responding or drop out at any time. Participants were encouraged to reach out to the researcher via email, but there could have been confusion regarding questions, and the researcher did not have known access

to the participants completing the survey. Utilizing the Internet as a location to gather data could be limiting as many participating in research out of their home may have not been compelled to start or complete such research. The mean age of participants in this study was 52. There could be potential limitation for older adults without access to the Internet who were not able to participate in this particular study. Using only an online survey could be quite limiting and not as far reaching as a hard copy version or in-person interview.

### **Future Research and Clinical Applications**

The body of research on the well-being and aspects related to meaning in life of family caregivers of persons with AD or dementia is already vast and growing. With a person getting AD every 67 seconds (Alzheimer's Association, 2014), this research on caregiving becomes increasingly critical. By the year 2050, AD in individuals 65 and older may nearly triple from 5 million to as many as 16 million (Alzheimer's Association, 2014). It is very likely formal care facilities and professionals will increase along with these numbers; however, due to cost and many other personal reasons, the amount of family and friend caregivers will also increase. The research conducted now on caregiving and related issues may have a vast impact in later years.

Some of the benefits of research in understanding well-being and meaning in life of caregivers may include increased qualitative research. Various case studies of caregivers could be utilized in understanding how their well-being and meaning in life actually are impacted or impact their lifestyles. Researchers may be able to utilize physicians' office waiting rooms for data collection as caregivers escort their care recipients to appointments. The use of focus groups may also be quite meaningful in this

type of research. Support groups are a major source of support already for caregivers, and it would appear a research-led focus group might be a way caregivers would share their experiences and perceptions with peers. The lack of social isolation associated with interacting in this format could be helpful in understanding meaning and well-being. Additionally, further phenomenological studies are ways to increase personal experiences of caregiving meaning in life and ways well-being is impacted in the relationship. There could also be benefits in mixed-methods studies. Longitudinal studies, although potentially short-term, may have some benefit in understanding the changes in relationships between meaning in life and well-being from caring for a person in the earlier stages of AD or dementia until closer to or at the end of life of that person diagnosed. Further research should include more diverse groups with larger sample sizes. Collecting data in-person might include visiting a variety of areas for a more diverse sample. The empathy of the researchers themselves will be useful in recruiting participants as many of the population may not feel understood and cared for in what they endure day after day.

Important clinical implications are raised through this research. Counseling professionals who work with caregivers are more likely to incorporate the existential aspect of meaning in life to understand how the well-being of caregiver clients is impacted. The incorporation of measures like the MLM or CWBS may also assist professionals in understanding specific areas of strengths or needs among clients and being able to hone in on those particular areas when engaging in interventions. Enhancement in group and individual practice can be influenced by such work, and psychoeducational strategies can include more information on meaning in life and well-

being. The psychoeducational approaches may be expanded for community outreach for caregivers and other professionals. Counselors themselves may benefit from the increased awareness of the daily concerns their caregiving clients' experience. Even when utilizing various meaning in life or well-being measures, counselors would be able to go through items and discuss the implications with clients. It will be significant for counselors to have a greater understanding of working with caregivers and understanding the reasons for decreases or increases in well-being in order to better diagnose and treat.

Future research could expand upon the findings from this study. Understanding caregiver satisfaction with life may be helpful in studying well-being. A longitudinal study may permit a broader picture. Other areas to consider in the future could be self-care versus focus on caring for others, finding balance between caregiving and other areas of life, and guilt and the anxiety that can come with the guilt. Since socialization is a major theme throughout this research, further research expanding upon socialization and its impact on guilt could be of interest.

## **Conclusions**

This study did find a relationship between having meaning in life and caregiver well-being. Although meaning in life is personal and will vary from person to person, understanding this relationship exists will assist counselors in better working with caregivers individually. A caregiver's meaning in life is very personal and involves his or her own values and judgments (Whitlatch et al., 2005). The basic needs of caregiver well-being had a strong relationship with both accomplished life, valued life, and exciting life of meaning in life. Being able to understand what makes a caregiver feel valued, accomplished, or that life is exciting on some level would be beneficial in the counseling



profession in order to help caregivers meet the basic needs of everyday life. Perhaps beginning with a values assessment could help the counselor approach these areas. The moderate relationships between purposeful life and principled life with basic needs are also noteworthy in that understanding the guiding principles of caregiving and the purpose of the caregiver's life and what he or she is doing can be vital in the counseling process. Activities of daily living of caregiver well-being had a moderately positive relationship with valued life and accomplished life. The more positive mental health with individuals who report a valued or worthwhile existence and feelings of accomplishments can broaden the spectrum of working with caregivers who may or may not report as much positivity in their lives. Employed caregivers had significantly higher well-being than unemployed caregivers. The exact reason for this is unknown, but the relationship highlights the importance of maintaining relationships and socialization outside the home as well as having a balance of life outside caregiving to complete activities of daily living and tend to one's basic needs.

This study does suggest a relationship between meaning in life and well-being of caregivers. It will be critical for further research as the caregiving relationships are not going to diminish in the future, and the use of larger and varying samples to study these relationships will be critical to understanding such populations. More than 60 percent of caregivers are women (Alzheimer's Association, 2014), so this study is somewhat representational of the vast amount of women who do care for relatives. African-American and Hispanic caregivers account for much of the caregiving population (Sorensen & Pinquart, 2005), and this study is unable to represent that. However, with the relationships that were found, there may be greater utilization of existential intervention

associated with meaning in practice, even if it includes working with a caregiver's values alone. The various techniques that are already in place may be enhanced by implementing strategies discussed through this study or related studies that may take place on caregiving.

## References

- Alzheimer's Association. (2014). *2014 Alzheimer's disease facts and figures*. Retrieved from [http://www.alz.org/documents\\_custom/2013\\_facts\\_figures\\_fact\\_sheet.pdf](http://www.alz.org/documents_custom/2013_facts_figures_fact_sheet.pdf)
- Arlt, S., Hornung, J., Eichenlaub, M., Holger, J., Bullinger, M., & Petersen, C. (2008). The patient with dementia, the caregiver and the doctor: Cognition, depression and quality of life from three perspectives. *International Journal of Geriatric Psychiatry, 23*, 604-610. doi:10.1002/gps.1946
- Au, A., Lai, M., Lau, K., Pan, P., Lam, L., Thompson, L., & Gallagher-Thompson, D. (2009). Social support and well-being in dementia family caregivers: The mediating role of self-efficacy. *Aging & Mental Health, 13*(5), 761-768. doi:10.1080/13607860902918223
- Au, A., Li, S., Lee, K., Leung, P., Pan, P., Thompson, L., & Gallagher-Thompson, D. (2010). The Coping with Caregiving group program for Chinese caregivers of patients with Alzheimer's disease in Hong Kong. *Patient Education and Counseling, 78*, 256-260. doi:10.1016/j.pec.2009.06.005
- Beddington, J., Cooper, C. L., Field, J., Goswami, U., Huppert, F. A., Jenkins, R., ... Thomas, S. M. (2008). The mental wealth of nations. *Nature, 455*, 1057-1060. doi:10.1038/4551057a
- Berg-Weger, M., Rubio, D. M., & Tebb, S. S. (2000). Living with and caring for older family members. *Journal of Gerontological Social Work, 33*(2), 47-52.

- Berg-Weger, M., Rubio, D. M., & Tebb, S. S. (2001). The Caregiver Well-Being Scale revisited. *Health and Social Work, 25*, 255-263.
- Black, S. E., Gauthier, S., Dalziel, W., Keren, R., Correia, J., Hew, H., & Binder, C. (2010). Canadian Alzheimer's disease caregiver survey: Baby-boomer caregivers and burden of care. *International Journal of Geriatric Psychiatry, 25*, 807-813.
- Butterworth, P., Pymont, C., Rodgers, B., Windsor, T. D., & Anstey, K. J. (2010). Factors that explain the poorer mental health of caregivers: Results from a community survey of older Australians. *Australian and New Zealand Journal of Psychiatry, 44*, 616-624. doi:10.3109/00048671003620202
- Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*, 184-188. doi: 10.1002/gps.561
- Cooper, C., Balamurali, T. B. S., Selwood, A., & Livingston, G. (2007). A systematic review of intervention studies about anxiety in caregivers of people with dementia. *International Journal of Geriatric Psychiatry, 22*, 181-188. doi: 10.1002/gps.1656
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929-936. doi:10.1002/gps.2007
- Covinsky, K. E., Newcomer, R., Fox, P., Wood, J., Sands, L., Dane, K., & Yaffe, K. (2003). Patient and caregiver characteristics associated with depression in

- caregivers of patients with dementia. *Journal of General Internal Medicine*, 18, 1006-1014. doi:10.1111/j.1525-1497.2003.30103.x
- Croog, S. H., Burleson, J. A., Sudivlovsky, A., & Baume, R. M. (2006). Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging & Mental Health*, 10(2), 87-100. doi:10.1080/13607860500492498
- Daire, A. P., Torres, J., & Edwards, N. N. (2009). Family caregivers: Psychosocial impacts and clinical needs. *Adultspan Journal*, 8(2), 67-80.
- Debats, D. L., Drost, J., & Hansen, P. (1995). Experiences of meaning in life: A combined qualitative and quantitative approach. *British Journal of Psychology*, 86, 359-375.
- Edders, L., Goodall, D., & Harrison, B. E. (2008). Caregiver burden among dementia patient caregivers: A review of the literature. *Journal of the American Academy of Nurse Practitioners*, 20, 423-428.
- Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23(2), 251-258. doi:10.1111/j.1471-6712.2008.00613.x
- Gallagher-Thompson, D., & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adult. *Psychology and Aging*, 2(1), 37-51. doi:10.1037/0882-7974.22.1.37
- Gaugler, J. E., Kane, R. L., & Kane, R. A. (2002). Family care for older adults with disabilities: Toward more targeted and interpretable research. *International Journal of Aging and Human Development*, 54(3), 205-231.

- Gaugler, J. E., Roth, D. L., Haley, W. E., & Mittelman, M. S. (2008). Can counseling and support reduce burden and depressive symptoms in caregivers of people with Alzheimer's disease during the transition to institutionalization? Results from the New York University caregiver intervention study. *Journal of the American Geriatrics Society, 56*(3), 421-428. doi:10.1111/j.1532-5415.2007.01593.x
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health, 15*, 271-283.
- Granello, P. F., & Fleming, M. S. (2008). Providing counseling for individuals with Alzheimer's disease and their caregivers. *Adulthoodspan, 7*(1), 13-25.
- Gwyther, L. P. (2006). Spirituality and caring for older family members. *Southern Medical Journal, 99*(10), 1180-1181.
- Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine, 6*, 215-224. doi:10.1089/109662103764978461
- Hayslip Jr., B., Han, G., and Anderson, C. L. (2008). Predictors of Alzheimer's disease caregiver depression and burden: What noncaregiving adults can learn from active caregivers. *Educational Gerontology, 34*, 945-969. doi:10.1080/03601270802016481

- Herrera, A. P., Lee, J. W., Nanyonjo, R. D., Laufman, L. E., & Torres-Vigil, I. (2009). Religious coping and caregiver well-being in Mexican-American families. *Aging and Mental Health, 13*(1), 84-91. doi:10.1080/13607860802154507
- Hirano, A., Suzuki, Y., Kuzuya, M., Onishi, J., Hasegawa, J., Ban, N., & Umegaki, H. (2011). Association between the caregiver's burden and physical activity in community-dwelling caregivers of dementia patients. *Archives of Gerontology and Geriatrics, 52*, 295-298. doi:10.1016/j.archger.2010.04.011
- Hoskins, S., Coleman, M., & McNeely, D. (2005). Stress of carers of individuals with dementia and community mental health teams: an uncontrolled evaluation study. *Journal of Advanced Nursing, 50*(3), 325-333. doi:10.1111/j.1365-2648.2005.03396.x
- Hwang, J. E., Rivas, J. G., Fremming, R., Rivas, M. M., & Crane, K. R. (2009). Relationship between perceived burden of caring for a family member with Alzheimer's disease and decreased participation in meaningful activities. *Occupational Therapy in Health Care, 23*(4), 249-266. doi:10.3109/07380570903214788
- Knussen, C., Tolson, D., Brogan, C. A., Swan, I. R. C., Stott, D. J., & Sullivan, F. (2008). Family caregivers of older relatives: Ways of coping and change in distress. *Psychology, Health, & Medicine, 13*(3), 274-290. doi:10.1080/13548500701405483
- Langbart, C. (2002). Diagnosing and treating Alzheimer's disease: A practitioner's overview. *Journal of the American Academy of Nurse Practitioners, 14*(3), 103-109.

- Langle, A. (2005). The search for meaning in life and the existential fundamental motivations. *Existential Analysis, 16*, 2-14.
- Losada, A., Marquez-Gonzalez, M., Knight, B. G., Yanguas, J., Sayegh, P., & Romero-Moreno, R. (2010). Psychosocial factors and caregivers' distress: Effects of familism and dysfunctional thoughts. *Aging & Mental Health, 14*(2), 193-202. doi:10.1080/13607860903167838
- Lilly, M. B., Robinson, C. A., Holtzman, S., & Bottorff, J. L. (2012). Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health and Social Care in the Community, 20*(1), 103-112. doi:10.1111/j.1365-2524.2011.01025.x
- Makizako, H., Tsutomu, A., Shimada, H., Ohnuma, T., Furuna, T. & Nakamura, Y. (2009). Combined effects of factors associated with burdens on primary caregiver. *Geriatrics and Gerontology International, 9*, 183-189. doi:10.1111/j.1447-0594.2009.00523.x
- Mascaro, N. & Rosen, D. H. (2008). Assessment of existential meaning and its longitudinal relations with depressive symptoms. *Journal of Social and Clinical Psychology, 26*(6), 576-599.
- Mausbach, B. T., Patterson, T. L., Von Kanel, R., Mills, P. J., Dimsdale, J. E., Ancoli-Israel, S., & Grant, I. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging & Mental Health, 11*(6), 637-644. doi:10.1080/13607860701787043



- McFadden, S. H., & McFadden, J. T. (2013). Living longer, often with dementia. *Phi Kappa Phi Forum*, 93(1), 4-7.
- McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging and Mental Health*, 15(4), 522-530. doi:10.1080/13607863.2010.543656
- Mendez-Luck, C. A., Kennedy, D. P., & Wallace, S. P. (2008). Concepts of burden in giving care to older relatives: A study of female caregivers in a Mexico City neighborhood. *Journal of Cross Cultural Gerontology*, 23, 265-282.  
doi:10.1007/s10823-008-9058-6
- Morgan, J., & Farsides, T. (2009). Measuring meaning in life. *Journal of Happiness Studies*, 10, 197-214.
- Nichols, L. O., Martindale-Adams, J., Burns, R., Graney, M. J., & Zuber, J. (2011). Typical and atypical dementia family caregivers: Systematic and objective comparisons. *International Journal of Aging and Human Development*, 72(1), 27-43. doi:10.2190/AG.72.1.b
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136, 257-301. doi:10.1037/a0018301
- Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging and Mental Health*, 10(5), 539-548.  
doi:10.1080/13607860600637844

- Phillips, A. C., Gallagher, S., Hunt, K., Der, G., & Carroll, D. (2009). Symptoms of depression in non-routine caregivers: The role of caregiver strain and burden. *British Journal of Clinical Psychology, 48*, 336-346.  
doi:10.1348/014466508X397142
- Pillemer, K. & Suitor, J. J. (2002). Peer support for Alzheimer's caregivers: Is it enough to make a difference? *Research on Aging, 24*(2), 171-192.
- Pinquart, M. & Sorensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: A meta-analytic comparison. *Aging and Mental Health, 8*(5), 438-449. doi:10.1080/13607860410001725036
- Poulin, M. J., Brown, S. L., Ubel, P. A., Smith, D. M., Jankovic, A., & Langa, K. M. (2010). Does a helping hand mean a heavy heart? Helping behavior and well-being among spouse caregivers. *Psychology and Aging, 25*, 108-117.
- Quinn, C., Clare, L., Pearce, A., & van Dijkhuizen, M. (2008). The experience of providing care in the early stages of dementia: An interpretive phenomenological analysis. *Aging and Mental Health, 12*, 769-778.  
doi:10.1080/13607860802380623
- Quinn, C., Clare, L., & Woods, R. T. (2012). What predicts whether caregivers of people with dementia find meaning in their role. *International Journal of Geriatric Psychiatry, 27*, 1195-1202. doi:10.1002/gps.3773
- Reid, C. E., Moss, S., & Hyman, G. (2005). Caregiver reciprocity: The effect of reciprocity, carer self-esteem and motivation on the experience of caregiver burden. *Australian Journal of Psychology, 57*, 186-196.  
doi:10.1080/00049530500141022

- Robinson, K. (1990). The relationships between social skills, social support, self-esteem and burden in adult caregivers. *Journal of Advanced Nursing, 15*, 788-795.  
doi:10.1111/1365-2648.ep8531899
- Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: Effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journal of Gerontology: Social Sciences, 64B*, 788-798. doi:10.1093/geronb/gbp015
- Rodriguez-Sanchez, E., Perez-Penaranda, A., Losada-Baltar, A., Perez-Arechaederra, D., Gomez-Marcos, M. A., Patino-Alonso, M. C., & Garcia-Ortiz, L. (2011). Relationships between quality of life and family function in caregiver. *Biomed Central Family Practice, 12*, 1-7. Retrieved from <http://www.biomedcentral.com/1471-2296/12/19>.
- Rosshem, B. N., & McAdams, C. R. (2010). Addressing the chronic sorrow of long-term spousal caregivers: A primer for counselors. *Journal of Counseling and Development, 88*, 477-482.
- Rubio, D. M., Berg-Weger, M., & Tebb, S. S. (1999). Assessing the validity and reliability of well-being and stress in family caregivers, *Social Work Research, 23* (1), 54-64.
- Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*, 495-523. doi:10.1080/07481180802138845

- Schoenmakers, B., Buntinx, F., & DeLepeleire, J. (2010). Supporting the dementia family caregiver: The effect of home care intervention on general well-being. *Aging and Mental Health, 14*(1), 44-56. doi:10.1080/13607860902845533
- Sequeira, C. (2012). Difficulties, coping strategies, satisfaction and burden in informal Portuguese caregivers. *Journal of Clinical Nursing, 22*, 491-500. doi:10.1111/jocn.12108
- Sherwood, P. R., Given, B. A., Given, C. W., Schiffman, R. F., Murman, D. L., von Eye, A.,... Remer, S. (2007). The influence of caregiver mastery on depressive symptoms. *Journal of Nursing Scholarship, 39*(3), 249-255. Doi:10.1111/j.1547-5069.2007.00176.x
- Skovdahl, K., Kihlgren, A. L., & Kihlgren, M. (2003). Different attitudes when handling aggressive behaviour in dementia – narratives from two caregiver groups. *Aging and Mental Health, 7*(4), 277-286.
- Smerglia, V. L., Miller, N. B., Sotnak, D. L., & Geiss, C. A. (2007). Social support and adjustment to caring for elder family members: A multi-study analysis. *Aging and Mental Health, 11*, 205-217. doi:10.1080/13607860600844515.
- Smith, C. E., Piamjariyakul, U., Yadrach, D. M., Ross, V. M., Gajewski, B., & Williams, A. R. (2010). Complex home care part III: Economic impact on family caregiver quality of life and patients' clinical outcomes. *Nursing Economics, 28*, 393-414.
- Sorensen, S., & Pinquart, M. (2005). Racial and ethnic differences in the relationship of caregiving stressors, resources, and sociodemographic variables to caregiver depression and perceived physical health. *Aging and Mental Health, 9*(5), 482-495. doi:10.1080/13607860500142796

- Steger, M. F., Frazier, P., Kaler, M., & Oishi, S. (2006). The meaning in life questionnaire: Assessing the presence of and search for meaning in life. *Journal of Counseling Psychology, 53*(1), 80-93. doi:10.1037/0022-0167.53.1.80
- Stengard, E. (2002). Caregiving types and psychosocial well-being of caregivers of people with mental illness in Finland. *Psychiatric Rehabilitation Journal, 26*, 154-164.
- Sun, F., Hilgeman, M. M., Durkin, D. W., Allen, R. S., Burgio, L. D. (2009). Perceived income inadequacy as a predictor of psychological distress in Alzheimer's caregivers. *Psychology and Aging, 24*(1), 177-183. doi:10.1037/a0014760
- Tebb, S. (1995). An aid to empowerment: a caregiver well-being scale. *Health and Social Work, 20*(2), 87-92.
- Välimäki, T. H., Vehviläinen-Julkunen, K. M., Pietilä, A. K., & Pirttilä, T. A. (2009). Caregiver depression is associated with a low sense of coherence and health-related quality of life. *Aging and Mental Health, 13*(6), 799-807. doi:10.1080/13607860903046487
- Vellone, E., Piras, G., Talucci, C., & Cohen, M. Z. (2007). Quality of life for caregivers of people with Alzheimer's disease. *Journal of Advanced Nursing, 61*, 222-231. doi:10.1111/j.1365-2648.2007.04494.x
- Vitaliano, P. P., Russo, J., Scanlon, J. M., & Greeno, C. G. (1996). Weight changes in caregivers of Alzheimer's care recipients: Psychobehavioral predictors. *Psychology and Aging, 11*(1), 155-163.
- Wang, Y. N., Shyu, Y. -I. L., Tsai, W. -C., Yang, P. -S., & Yao, G. (2013). Exploring conflict between caregiving and work for caregivers of elders with dementia: a

cross-sectional, correlational study. *Journal of Advanced Nursing*, 69(5), 1051-1062. doi:10.1111/j.1365-2648.2012.06092.x

Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist*, 45, 370-380.

Wright, L. K., Litaker, M., Laraia, M. T., & DeAndrade, S. (2001). Continuum of care for Alzheimer's disease: A nurse education and counseling program. *Issues in Mental Health Nursing*, 22, 231-252. doi:10.1080/01612840152053084

Yalom, I. D. (1980). *Existential psychotherapy*. New York, NY: Basic Books.

Ziemba, R. A. & Lynch-Sauer, J. M. (2005). Preparedness for taking care of elderly parents: "First, you get ready to cry." *Journal of Women and Aging*, 17, 99-113. doi:10.1300/J074v17n01\_08

Appendix A  
CONSENT FORM

**(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS IRB APPROVAL INFORMATION WITH CURRENT DATES HAS BEEN ADDED TO THIS DOCUMENT.)**

**INFORMATION LETTER  
for a Research Study entitled**

**“Caregivers of Family with Alzheimer’s Disease and Dementia:  
Well-Being and Meaning in Life”**

**You are invited to participate in a research study** to examine how having meaning in life impacts your well-being as a caregiver. The study is being conducted by Sarah Littlebear, a Ph.D Counselor Education student, in the Auburn University Department of Special Education, Rehabilitation, and Counseling under the direction of Dr. Suhyun Suh, associate professor. You are invited to participate because you identified yourself as family primary caregiver of a person or persons diagnosed with Alzheimer’s disease or dementia and are age 19 or older.

**What will be involved if you participate?** Your participation is completely voluntary. If you decide to participate in this research study, you will be asked to complete a series of survey questions via the link below. Your total time commitment will be approximately 20 minutes.

**Are there any risks or discomforts?** The risks associated with participating in this study minimal and could include slight emotional discomfort. To minimize these risks, contact information for caregivers is included at the end of the survey.

**Are there any benefits to yourself or others?** If you participate in this study, fifty cents will be donated to the Alzheimer’s Association for research. The research may also help counselors understand more about counseling family caregivers of persons diagnosed with Alzheimer’s disease and dementia.

**Will you receive compensation for participating?** You will be offered no compensation for your participation.

**If you change your mind about participating,** you can close your browser window at any time to end your session. If you choose to withdraw, your data can be withdrawn as long as it is identifiable. Once you’ve submitted anonymous data, it cannot be withdrawn since it will be unidentifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University, the Department of Special Education, Rehabilitation, and Counseling.

**Any data obtained in connection with this study will remain anonymous.** We will protect your privacy and the data that you provide by having all survey responses stored on a secure server. Your responses will not be linked to a name or email address. All electronic survey responses will be stored on a password-protected system. Only researchers directly associated

with this study will have access to the responses. Information collected through your participation will be used to fulfill a dissertation requirement for the researcher's doctoral degree and may be published in a professional journal and/or presented at professional meetings.

**If you have any questions about this study,** please contact Sarah Littlebear at srl0006@auburn.edu or Dr. Suhyun Suh at suhsuhy@auburn.edu.

**If you have questions about your rights as a research participant,** you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone (334) 844-5966 or e-mail at IRBadmin@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION ABOVE, YOU MUST DECIDE IF YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, PLEASE CLICK ON THE LINK BELOW. YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

\_\_Sarah Littlebear\_\_ 3/17/14 \_\_  
Investigator Date

***The Auburn University Institutional Review Board has approved this document for use from***

***\_\_March 7, 2014\_\_ to \_\_March 6, 2017\_\_. Protocol #\_ 14-087 EX1403\_\_***

[https://auburnoira.qualtrics.com/SE/?SID=SV\\_2h5NPZaHENHiIx7](https://auburnoira.qualtrics.com/SE/?SID=SV_2h5NPZaHENHiIx7)



Appendix B  
DEMOGRAPHIC QUESTIONNAIRE

Demographics Questionnaire

Caregivers of Family with Alzheimer's disease and Dementia: Well-Being and Meaning in Life

1. What is your age? \_\_\_\_\_
  
2. What is your gender? \_\_\_\_\_
  
3. What is your race?
  - a. White
  - b. African-American
  - c. Hispanic
  - d. Native American
  - e. Multi-racial
  - f. Asian
  - g. Other
  
4. What is your current marital status?
  - a. Single, never married
  - b. Married
  - c. Living together, not married
  - d. Divorced
  - e. Separated
  - f. Widowed
  
5. What is the highest level of education you have received?
  - a. Less than high school
  - b. Some high school
  - c. High school graduate
  - d. GED
  - e. Some college
  - f. College degree
  - g. Master's degree
  - h. Doctoral degree
  - i. Professional degree (MD, JD)
  - j. Other: \_\_\_\_\_
  
6. What is your religious preference?
  - a. Protestant (e.g. Baptist, Methodist, etc.)
  - b. Jewish
  - c. Roman Catholic

- d. Muslim
- e. Mormon
- f. Other Christian
- g. No preference/no religious affiliation
- h. Other: \_\_\_\_\_

7. Are you employed?
- a. Unemployed
  - b. Employed Part-time (less than 32 hours per week)
  - c. Employed Full-time (over 32 hours per week)
8. What is your annual household income?
- a. Less than \$10,000
  - b. \$10,000 to \$29,999
  - c. \$30,000 to \$49,999
  - d. \$50,000 to \$69,999
  - e. \$70,000 to \$99,999
  - f. \$100,000 to \$149,999
  - g. Over \$150,000
9. What is your relationship to your family member diagnosed with Alzheimer's disease or dementia who receives your care?
- a. Spouse/Partner
  - b. Child
  - c. Sibling
  - d. Grandchild
  - e. Daughter- or son-in-law
  - f. Parent
  - g. Other, Please specify: \_\_\_\_\_
10. On average, how many hours per week do you spend caring for your family member diagnosed with Alzheimer's Disease or dementia? This includes time spent during the day and night.
- a. 10 or less hours per week
  - b. 11-25 hours per week
  - c. 26-40 hours per week
  - d. 41-80 hours per week
  - e. Over 80 hours per week

Appendix C  
MEANINGFUL LIFE MEASURE (MLM)

Please read each of the following statements carefully and then circle the appropriate number to indicate your opinion. Please answer according to the scale below, unless otherwise stated

			Neither			
Strongly disagree	Disagree	Slightly disagree	disagree or agree	Slightly agree	Agree	Strongly agree
1	2	3	4	5	6	7
1. Life to me seems: ...completely routine (1); ...always exciting (7).						
2. Every day is: ...exactly the same (1); ...constantly new and different (7).						
3. Facing my daily tasks is: ...a painful and boring experience (1); ...a source of pleasure and satisfaction (7).						
4. My life interests and excites me.						
5. My daily living is dull and routine.						
6. I find it satisfying to think about what I have accomplished in life.						
7. So far, I am pleased with what I have achieved in life.						
8. I have been very successful in achieving certain things.						
9. I have failed to accomplish much in life.						
10. I feel good when I think of the things I have accomplished in life.						
11. I have a system or framework that allows me to truly understand my being alive.						
12. I have a philosophy of life that really gives my living significance.						
13. I have a personal value system that makes my living worthwhile.						
14. The beliefs I hold about the world enable me to make sense out of my existence.						
15. I hold certain values which I feel greatly enrich my life with significance.						
16. In my life I have: ...no goals or aims at all (1); ...very clear goals and aims (7).						
17. I have discovered: ...no mission or purpose in life (1); ...clear-cut goals and a satisfying life purpose (7).						
18. I have a clear idea of what my future goals and aims are.						
19. I tend to wander aimlessly through life, without much sense of purpose or direction.						
20. My life is worthwhile.						
21. My life is significant.						
22. I really value my life.						
23. I hold my own life in high regard.						

Syntax to create MLM subscales: reverse-scored = 5, 9, 19; exciting Life = 1–5; accomplished life = 6–10; principled life = 11–15; purposeful life = 16–19; valued life = 20–23.

Used with Permission from Morgan, J. & Farsides, T. (2009). Measuring meaning in life. *Journal of Happiness Studies*, 10, 197-214.

Appendix D  
CAREGIVER WELL-BEING SCALE

**ACTIVITIES OF LIVING**

Below are listed a number of activities of living that each of us do or someone does for us. For each activity listed, think over the past three months. During this period of time, to what extent do you think each activity of living has been met. Circle the appropriate number on the scale provided below. You are being asked to rate the extent to which each activity of living has been taken care of by or for you in a timely way.

	1. Never or almost never	3. Sometimes	4. Often, frequently	
	2. Seldom, occasionally			5. Almost always
1. Buying food			1 2 3 4 5	
2. Preparing meals			1 2 3 4 5	
3. Getting the house clean			1 2 3 4 5	
4. Getting the yard work done			1 2 3 4 5	
5. Getting home maintenance done			1 2 3 4 5	
6. Having adequate transportation			1 2 3 4 5	
7. Purchasing clothing			1 2 3 4 5	
8. Washing and caring for clothing			1 2 3 4 5	
9. Relaxing			1 2 3 4 5	
10. Exercising			1 2 3 4 5	
11. Enjoying a hobby			1 2 3 4 5	
12. Starting a new interest or hobby			1 2 3 4 5	
13. Attending social events			1 2 3 4 5	
14. Taking time for reflective thinking			1 2 3 4 5	
15. Having time for inspirational or spiritual interests			1 2 3 4 5	
16. Noticing the wonderment of things around you			1 2 3 4 5	
17. Asking for support from your friends or family			1 2 3 4 5	
18. Getting support from your friends or family			1 2 3 4 5	
19. Laughing			1 2 3 4 5	
20. Treating or rewarding yourself			1 2 3 4 5	
21. Maintaining employment or career			1 2 3 4 5	

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 22. Taking time for personal hygiene and appearance | 1 | 2 | 3 | 4 | 5 |
| 23. Taking time to have fun with family or friends  | 1 | 2 | 3 | 4 | 5 |

### BASIC NEEDS

Below are listed a number of basic needs. For each need listed, think about your life over the past three months. During this period of time, indicate to what extent you think each need has been met. Circle the appropriate number on the scale provided below.

- |                          |              |                      |
|--------------------------|--------------|----------------------|
| 1. Never or almost never | 3. Sometimes | 4. Often, frequently |
| 2. Seldom, occasionally  |              | 5. Almost always     |
- 
- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 1. Having enough money                        | 1 | 2 | 3 | 4 | 5 |
| 2. Eating a well-balanced diet                | 1 | 2 | 3 | 4 | 5 |
| 3. Getting enough sleep                       | 1 | 2 | 3 | 4 | 5 |
| 4. Attending to your medical and dental needs | 1 | 2 | 3 | 4 | 5 |
| 5. Having time for recreation                 | 1 | 2 | 3 | 4 | 5 |
| 6. Feeling loved                              | 1 | 2 | 3 | 4 | 5 |
| 7. Expressing love                            | 1 | 2 | 3 | 4 | 5 |
| 8. Expressing laughter and joy                | 1 | 2 | 3 | 4 | 5 |
| 9. Expressing sadness                         | 1 | 2 | 3 | 4 | 5 |
| 10. Enjoying sexual intimacy                  | 1 | 2 | 3 | 4 | 5 |
| 11. Learning new skills                       | 1 | 2 | 3 | 4 | 5 |
| 12. Feeling worthwhile                        | 1 | 2 | 3 | 4 | 5 |
| 13. Feeling appreciated by others             | 1 | 2 | 3 | 4 | 5 |
| 14. Feeling good about family                 | 1 | 2 | 3 | 4 | 5 |
| 15. Feeling good about yourself               | 1 | 2 | 3 | 4 | 5 |
| 16. Feeling secure about the future           | 1 | 2 | 3 | 4 | 5 |
| 17. Having close friendships                  | 1 | 2 | 3 | 4 | 5 |
| 18. Having a home                             | 1 | 2 | 3 | 4 | 5 |
| 19. Making plans about the future             | 1 | 2 | 3 | 4 | 5 |
| 20. Having people who think highly of you     | 1 | 2 | 3 | 4 | 5 |

21. Having meaning in your life

1 2 3 4 5

22. Expressing anger

1 2 3 4 5

Reverse score #9 & 22

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