

DISSERTATION

STATISTICAL MODELING OF CAREGIVER BURDEN AND DISTRESS AMONG
INFORMAL CAREGIVERS OF INDIVIDUALS WITH AMYOTROPHIC LATERAL
SCLEROSIS, ALZHEIMER'S DISEASE, AND CANCER

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ABSTRACT

STATISTICAL MODELING OF CAREGIVER BURDEN AND DISTRESS AMONG INFORMAL CAREGIVERS OF INDIVIDUALS WITH AMYOTROPHIC LATERAL SCLEROSIS, ALZHEIMER'S DISEASE, AND CANCER

Caregiver burden and distress have been associated with informal caregivers. Research findings on the specific aspects of the caregiving role that influence burden are mixed. Factors such as amount of time per day giving care and specific characteristics about the disease progression have been linked to caregiver burden and distress. Other findings suggest that caregiver burden and distress may be associated with disease characteristics, but caregiver personality traits are the major factor that influences caregiver burden.

The purpose of this study was to use a variety of instruments to assess the relationship between traits that the caregiver comes into the caring situation with (resiliency, social support, spirituality, hope) and caregiver burden, within different caregiving populations. Caregivers giving care to individuals with Alzheimer's disease, Amyotrophic Lateral Sclerosis, or cancer were the caregiving groups of interest. A convenient sample of 95 informal caregivers completed the battery of instruments through an online survey tool.

Differences between the three caregiving samples were assessed in terms of

burden and distress. Hierarchical regression models were created to understand the roles gender, time giving care, activities assisted with, resiliency, social support, spirituality, and hope play in predicting caregiver burden and distress. Psychometric properties were assessed on all six instruments used in this study. Cluster analytic techniques were used to cluster caregivers based on a number of attributes to better understand the caregiving population.

Results from this research indicate that resiliency, social support, spirituality, and hope significantly predict caregiver burden and distress. Amount of time giving care per day, number of months giving care, and activities that the caregiver assists with did not play a significant role in predicting caregiver burden or caregiver distress. The three caregiving groups were unequal in size, but reported similar levels of burden and distress. Two caregiving clusters were created based on this sample. Caregivers who had higher levels of resiliency, social support, spirituality, and hope (cluster one) were significantly less burdened and distressed than caregivers who reported lower levels of resiliency, social support, spirituality, and hope (cluster two).

This research adds to the body of work within caregiver burden and distress. The findings suggest that burden is a factor of different aspects of the caregiver rather than the disease characteristics and progression of the person receiving care.

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DEDICATION

To Corriann my love, I could not have made it through without you.

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CHAPTER 1: INTRODUCTION

Introduction

An increase in the aging population is a challenge that the United States is currently facing. A national report listed Americans over the age of 65 in 2005 as 12% of the population, and by the year 2020 the percentage is projected to increase to 16% (Federal Interagency Forum on Aging-Related Statistics, 2008). As life expectancy increases, so does the number of mentally and/or physically impaired elderly adults (Arai, 2006). Spillman and Black (2005) asserted that the percentage of disabled Americans aged 65 and over has decreased since the mid-1980s, but the overall number of Americans over the age of 65 has increased dramatically.

Not all impaired/disabled people are elders, and *impaired/disabled* are umbrella terms that can include any undesirable deviations from normal or healthy conditions. For example, people with certain impairments or disabilities are often labeled as chronically ill, or even terminally ill. Chronic illnesses tend to be prolonged and rarely completely cured (Dowrick, Dixon-Woods, Holman, & Weinman, 2005). Some chronic illnesses, such as diabetes or asthma can be treated effectively to minimize progression and discomfort. Other chronic illnesses are distinctly progressive and eventually lead to death, and are otherwise known as terminal illness (Ascension Health, 2007). According to Ascension Health (2007) a terminal illness is used to describe an active disease that cannot be cured or effectively treated. The term *terminal illness* is typically reserved for

progressive diseases, such as Amyotrophic Lateral sclerosis (ALS), Alzheimer's disease (AD), and certain forms of cancer that lead to death rather than impairment or terminal impairment caused by trauma. In the United States alone, 70% of health care spending is on patients with some sort of chronic illness (Dowrick, et al., 2005; Holman & Lorig, 2000).

Terminal illnesses and many chronic illnesses tend to be progressive; therefore, as the impairments worsen, family members often take on the role of the informal caregiver (Crespo, Lopez, & Zarit, 2005). The service of the informal caregiver, according to Spillman and Black, (2005) is the unpaid help, which is considered regular assistance with any activity of daily living, typically provided by spouses, children, or other family members. In contrast, formal caregiving is the care provided from services such as home nursing or care in assisted living and nursing homes. From 1994 to 1999, the percentage of disabled elderly over the age of 65 receiving only informal care increased from 57% to 66% indicating a fairly substantial rise in the percentage of informal family caregivers (Spillman & Black, 2005).

Context of the Problem

According to the Federal Interagency Forum on Aging-Related Statistics (2008), the 65-year-and-older age group is increasing, as is the number of disabled people in that age group who are increasingly receiving regular care from family members (Spillman & Black, 2005). Being a caregiver for a family member comes with increased stress that can lead to greater physical and mental health risks for the caregiver (Vitaliano, Young, & Zhang, 2004). Other findings through longitudinal studies indicate that caregivers of

patients with dementia experience an increased level of emotional distress as the behavioral and cognitive symptoms of the patients worsen (Crespo et al., 2005; Zarit, 2004). These physical and emotional distresses experienced by the caregiver are often referred to as *caregiver burden*. Zarit, Reever and Bach-Peterson (1980) operationally defined caregiver burden as the extent of caregivers' perceived suffering in terms of emotional and physical health, social life and financial status as a result of caring for their family member. The term caregiver distress is often used synonymously with burden, but is typically defined by depression scales (Miller, Berrios, & Politynska, 1996).

Zarit (2004) report that a majority of burden related research on caregivers has been with the caregivers who care for dementia patients, more specifically Alzheimer's disease (AD) patients. Zarit's reasoning is that this is because many terminal illnesses have brief durations, whereas a patient with AD can live for many years. As previously mentioned, caregiver burden seems to increase as the dementia patient's symptoms get worse (Crespo et al., 2005; Zarit, 2004).

The amount of time being a caregiver is a factor that is highly correlated to patient condition. As time increases, so does the severity of the disease symptoms. Grunfeld et al. (2004) investigated caregiving effects with advanced breast cancer patients. This was a longitudinal study where the researchers assessed depression and anxiety in caregivers at the start of the palliative phase, and at the start of the terminal phase. Information on the time periods between the phases was not given, but it is important to note that people progress at different rates even within the same diagnosed population. It is possible to infer from the Grunfeld et al. (2004) article that the palliative time frame started shortly after the diagnosis of advanced breast cancer, and the terminal phase started when the

patient significantly deteriorated. The findings, as reported by Grunfeld et al., indicate that out of their sample of 89 caregivers, 11% were clinically depressed and 30% were clinically anxious at the beginning of the palliative phase. At the beginning of the terminal phase, the percent of caregivers with clinical anxiety increased somewhat, but was not statistically significant, while the depression increase was statistically significant at 30%. Similarly, Zarit (2004) reports that typically between 40% and 70% of all AD caregivers have or had clinical depression. These percentages are slightly higher than Grunfeld et al.'s (2004) findings, yet it is important to note the similarity. Depression in caregivers for terminal breast cancer patients only increased when the person they cared for significantly deteriorated.

Additional research, some with an AD population and some with other terminal populations, indicate that caregiver burden has stronger ties to caregiver traits and characteristics than to patient and disease characteristics (Zanetti, Frisoni, Bianchetti, Tamanza, Cigoli, & Trabucchi, 1998; Cousins, Davies, Trunbull, & Playfer, 2002; Pot, Deeg, van Dyck, & Jonker, 1998). For example, Brazil, Bedard, Willison, and Hode (2003) found that self-esteem, family support, finances, scheduling and health were all major factors that defined caregiver burden for their sample of caregivers of cancer patients.

Family caregivers are increasing in number and are experiencing events that are adversely affecting their mental and physical wellbeing, but research is mixed on the major influences and correlates of caregiver burden (Zarit, 2004; Zanetti, et al., 1998). Another problem is that the majority of available research has looked within similar caregiving populations rather than between/among these populations. For example, the

effects, in terms of emotional health, of being a caregiver for a family member with dementia have been well documented (Matsumoto, Ikeda, Fukuhara, Shinagawa, Ishikawa, Mori, et al., 2007; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Zarit, Reever, & Bach-Peterson, 1980).

Research between different diagnoses is limited, but findings from Ory, Hoffman, Yee, Tenndtedt and Schulz (1999) indicate that dementia caregivers experience more strain than non-dementia caregivers, but this could be because dementia caregivers are involved in caregiving more hours per week, and have been a caregiver longer than non-dementia caregivers. Contradictory findings from Crespo, Lopez and Zarit (2005) showed non-significance in terms of depression and anxiety between caregivers for demented and non-demented patients. A possible explanation for the different findings could be that in both studies one group all had the same diagnosis (dementia) and the other group, termed non-demented, needed informal care but their diagnosis was not indicated. The non-congruent findings could also be due to the variability within the caregivers providing care for non-demented family members.

Statement of the Problem

The caregiving literature is not underdeveloped, but what is lacking is consistent evidence that shows areas of caregiver needs based upon caregiver personal attributes as well as type of care given. On the one hand, burden exists to a greater or lesser extent in every caregiver. On the other hand, there is research looking at the causes of caregiver burden. Some research has suggested that burden is mainly influenced by time and progression of the disease (Crespo et al., 2005; Zarit, 2004), yet other research suggests

that caregiver traits/states, rather than disease characteristics are the major influences of caregiver burden (Cousins et al., 2002; Zanetti et al., 1998). Therefore, in order to discover differences between caregivers dependent upon diagnosis, it is important to assess caregivers giving care to specific conditions. This would then lead to a functional understanding of the effects of caregiving and how those effects are differentiated by personal traits/states and disease type.

Research Questions / Focus of Inquiry

The following research questions are arranged in two sets. The first set of research questions are methodologically driven, and deal with the psychometric properties of the instruments. The second set of questions deal with the overarching focus of the research. Each construct was measured by an existing instrument. The instruments are provided and defined in the methodology section.

Set One: Methods Based Research Questions

1. Do the psychometric properties of the four attribute instruments (resiliency, social support, hope, spirituality) align with findings from previous studies?
2. The Caregiver Distress Scale (CDS) was created and validated by Cousins et al. (2002), using a different caregiving population that is not part of this proposed study (Parkinson's disease). Does the CDS accurately assess distress, using classical test theory, within the sample of this study (AD, ALS, cancer)?
3. The Zarit Caregiver Burden Inventory (Zarit, et al., 1980) was created for use with dementia caregivers and is currently one of the most common inventories for

dementia care. Does the Zarit Caregiver Burden Inventory accurately assess burden, using classical test theory, within the sample of this study (AD, ALS, cancer)?

Set Two: Content Research Questions

4. What are the differences in distress and burden of being a caregiver for a terminally ill family member in terms of three types of care (ALS, AD, cancer)?
5. What are the relationships between caregiver personal attributes (operationalized in method section) and distress and burden?
6. To what degree can distress and burden be predicted from a combination of caregiver personal attributes, while controlling for demographic variables and time (per day giving care and how long they have been giving care)?
7. Can caregiving clusters be formed through the combination of attributes (perceived social support, resiliency, spirituality, and hope as personal attributes)?

Limitations

There are limitations to a non-experimental comparative approach, as well as disadvantages of a self-report survey design. Results from this non-experimental design cannot be inferred as cause and effect because the caregivers were not randomly assigned to different groups (Gliner, Morgan, & Leech, 2009). The type of patient the caregivers are caring for is considered an attribute variable. In other words, it is an attribute that they are coming into the study with. Another potential limitation to the data derived from a battery of surveys is the quantity. Multiple difference statistics can be computed to compare the groups, but open-ended questions will not be included. With this design, it is

not possible to answer the question *why*, or deeply understand the personal experiences of being a caregiver.

The advantages of using a self-report survey method is that it allows for anonymity and the surveys can be administered to a large number of people in a relatively short amount of time (Mitchell & Jolley, 2004). The disadvantages of using self-report surveys are that response rates are typically low and participants are likely to skip questions that they do not understand. There are methods that can attenuate response bias, but they involve interviews (Mitchell & Jolley) of respondents, which will not be feasible for this proposed study. The instruments will be delivered online. This is a low cost way of administration that can lead to a larger number of responses than face to face interviews or surveys. The main limitation with electronic administration of the instruments is that the sample is limited to people that have access to the internet. Research findings on survey administration are mixed. Underwood, Kim, and Matier (2000) argue that mail surveys yield a higher response rate than electronic, but more people can be sampled and the response time is much shorter for electronic surveys (Shannon & Bradshaw, 2002). The aforementioned limitations are fairly minor in nature. Systematic steps within the research design will be taken to reduce error, but there will inevitably be a certain amount of error.

The three groups (ALS, AD, and cancer) can all be seen as terminal, yet these represent three very distinct diseases that do not share many major symptomatic features and, therefore, represent a unique context in which to study caregivers. Other diseases such as stroke could be problematic if selected because a feature of many stroke patients is dementia (Merino & Hachinski, 2002). There are a number of different terminal

illnesses, but it would be difficult to try to include more groups into this study.

Definition of Terms

The following terms and definitions will be used throughout the study.

AD: Alzheimer's disease, a neurodegenerative type of dementia that causes memory loss as well as the inhibition of functioning that leads to death from associated symptoms.

ALS: Amyotrophic Lateral Sclerosis, a neurodegenerative disease that affects the motor neurons causing increased voluntary muscle weakness leading to death, commonly from respiratory failure.

Cancer: A disease noted by uncontrolled cell division leading to abnormal tissue growth.

Caregiving (Formal): Typically referred to as paid help.

Caregiving (Informal): Typically referred to as unpaid help. Informal caregiving is often grouped as primary, secondary and tertiary. A primary caregiver is the person who tends to have the most responsibility when looking after someone's health and wellbeing. A secondary caregiver provides supplemental or intermittent care and support. A tertiary caregiver often provides hands off support by way of helping with tasks like shopping and yard/house work.

Caregiving archetypes: models of caregivers based on selected behaviors, attributes, and traits/states within the context of this study.

Distress and burden: High levels of stress related to giving care to another person.³

Traits/states: There is a distinction between traits and states, with the former being fixed, stable and measurable, while the latter is not fixed and results from interaction with the environment (Wagnild, 2009). The purpose of this dissertation is not to

distinguish the two but rather use them interchangeably. Resiliency, hope, perceived social support, and spirituality could be argued as either traits or states; therefore, within this dissertation the terms are used together.

Researcher's Perspective

Investigating caregiver burden can take different forms. The overarching goal is to understand factors associated with caregiver burden. In order to develop an understanding of caregiver burden, it is important to start with identifying the key units or concepts. This process of developing an understanding of the key units is typically seen as a hypothetico-deductive approach, where theory begins with conceptual development that is used to formulate understanding and description of the research problem (Dubin, 1978). In order to understand and explain caregiver burden, drawing from Dubin's description of the hypothetico-deductive model, it is imperative to first identify and isolate the variables involved. Data collection and interpretation are theory dependent; therefore, a developed understanding of the problem is necessary for the interpretation of data (Willis, 2007).

Understanding of the grounding methodology is important, but a successful study ultimately comes down to using the proper methods to answer the research questions. The postpositive paradigm is a structured and objective framework that guides the empirical researcher (Creswell, 2007). In order to make sense of the world, postpositive researchers use the scientific method to discover and describe human behavior (Mitchell, & Jolley, 2004). It is possible to use empirical methods to find underlying rules and reasons for the occurrence of events, which according to Mitchell and Jolley leads to a better, yet

incomplete understanding of the world. That ontological, or “nature of reality” (Guba, 1990, p. 18), statement can be simplified by saying that reality exists and the effects of caregiving on caregivers are influenced by natural laws, but those laws can never be fully explained or understood.

According to Guba, (1990) coming to know what we know can only be approximated. Epistemologically, research is never complete and a theory is never completely accurate because of uncontrollable error. Practice depends on research, and the ability to generalize findings is how knowledge accumulates and assists in the understanding of human behavior (Creswell, 2007). For example, by using a systematic and structured design, it will be possible to generalize these findings to the sample of caregivers of AD, ALS and cancer patients who participate in this investigation. This knowledge, in turn, will then be assessed and added upon by other researchers in the field of caregiving, advancing knowledge in the field for the betterment of patients.

Significance of the Study

The older population is increasing; therefore, as life expectancy increases, so does the prevalence of disabled people that need some type of intermittent or permanent care. The research within caregiving is quite expansive, yet incongruences with findings leave unexplained knowledge gaps in the caregiving research field. Some researchers, as previously explained, demonstrate that burden is positively related to progression of the disease and how long a person has been giving care (Crespo et al., 2005). Other researchers argue that when you hold time and disease progression characteristics constant, caregiver traits/states become the major factors associated with caregiver

burden and distress (Zanetti et al., 1998).

The caregiving literature is often couched within specific disease domains. For example, the majority of Zarit's (1980; 2006) research and scale development has been with informal caregivers of dementia patients. Other researchers such as Mitsumoto (2001) and Cwik (2001) are neurologists who specialize in ALS drug studies. There are only a few instances in the literature where a researcher investigated multiple diseases within one study.

The proposed study incorporates caregivers from three disease types to help understand differences between them. In order to detect and understand the differences between caregivers, other variables like time and caregiver attributes need to be accounted for. Modeling caregiver burden to better understand caregiver needs is one challenge of the study. The other challenge is to cluster caregivers based on their attributes and burden measures, in order to assess the prevalence of disease type within each cluster and to better understand the role that disease type and attributes play in caregiver burden. On a broader scale this work is significant because it adds to a body of research that focuses on understanding the needs of informal caregivers through the use of novel research methods. It looks at a population that is growing within the health care system and at families across our nation.

CHAPTER 2: LITERATURE REVIEW

Overview of the Chapter

The purpose of the literature review is five-fold. The first purpose is to provide a brief but guided overview of the historical progression and background of home healthcare, and its current state. The second purpose is to distinguish between the concepts of informal and formal caregiving. Third is to provide detailed information about three different diagnosable conditions: Alzheimer's disease (AD), Amyotrophic Lateral Sclerosis (ALS) and cancer. Fourth is to identify traits/states associated with giving care to people who have one of the aforementioned diagnoses. The final purpose of the literature review is to identify the constructs of caregiver burden that are most frequently assessed, and relate those concepts back to the caregiver traits/states.

Introduction and Historical Background

In order to have a deeper understanding of where we are now, in terms of family care and medicine, it is important to look back and reflect on the past that has paved the way for the caregiver and patient conditions explored in this study. In late 18th century America, physicians were not prestigious and there was much debate about the usefulness of medicine (Starr, 1982). Medical advice was limited to colonial newspapers, correspondence through hand written letters, and a few medical almanacs that were

accessible to only a small number of people. Medical care was domestic in nature and seen as a responsibility of the women in the town (Starr, 1982). The end of the 18th and beginning of the 19th century was when medical schools started to become established, and physicians became more prestigious (Starr, 1982).

Throughout history, families have taken care of their sick family members in need. In the 18th, 19th, and even in the beginning of the 20th century, most illnesses were relatively short-lived, so there really were not many instances of long-term care (Zarit, 2006). The increase in technology during the first 25 years of the 20th century ushered in the development of a variety of useful medical tests such as urine and blood analyses (Howell, 1995). Medical machines played, and still play, an important role in diagnosis but are also a factor in the increase of medical costs (Howell, 1995). During the medical technology boom of the 1900s to 1960s, patient care gradually shifted from domestic care to institutional care and the number of institutionalized locations such as hospitals and clinics that were not the home of the physician grew (Starr, 1982). Institutional care provided a centralized location to deliver what patients needed, in terms of diagnostics, treatments, and care.

The shift from domestic to institutional care was necessary for diagnosis and treatment purposes. As medical technology increased, so did life expectancy, but medical care costs also increased (Starr, 1982). During the 1930s, hospital costs dramatically increased because of two reasons. One reason was because services that were once included in the cost of a hospital visit were no longer included, and because of an increase in long hospitalizations starting at the end of the 1920s. (Starr, 1982). There has never been a complete shift from domestic care to institutional care, but the emergence of

medical technology and the cost associated with it has led to the majority of non-critical or recuperative care being given by the informal caregiver (Starr, 1982; Pinguart, & Sorensen, 2003).

Long term institutional and formal care is very costly; therefore, care is given at home, typically by an untrained family member or friend (Donelan, et al., 2002). The progression of medicine and technology has changed the social dimensions of patient care. With advances in medical knowledge, people use a combination of domestic and professional care to support their diagnostic and health restorative needs. The cost of healthcare has also changed the landscape to more domestic care (Starr, 1982). Throughout this process, little attention has been given to the domestic part of modern medicine, more specifically the domestic care of terminally ill family members or friends.

Informal and Formal Caregiving

As a terminal illness progresses, the symptoms get worse. For example, Alzheimer's patients become more demented (Reisberg & Franssen, 1999). Amyotrophic Lateral Sclerosis patients lose the control over their voluntary muscles (Mitsumoto, 2001). Cancer patients become weak because of the disease process as well as the treatment (O'Reilly & Kelvin, 2003). As these symptoms progress across time, more care is needed and that responsibility typically falls on a family member (Crespo et al., 2005). Informal caregivers are characterized as anybody who provides unpaid help to the patient (Spillman & Black, 2005). This unpaid help is generally thought of as assistance that goes beyond normal everyday tasks, such as help with bathing or walking (Cohen, Miller, & Weinrobe, 2001).

Informal caregivers can be defined further as primary and secondary caregivers, where the primary caregiver spends most of every day with the patient and helps him or her with everyday functioning (Donelan et al., 2002). According to caregiver demographics from Donelan et al. (2002), primary informal caregivers (N=1,002) are typically female (64%), age between 45 and 64 (51%), and have an average yearly income of less than \$20,000. Most patient care is provided by an informal caregiver, but some patients also receive help from formal caregivers. Walker, Pratt, and Eddy, (1995) stated that less than twenty percent of family caregivers seek out some type of formal care support.

Formal caregivers receive payment for helping, and are typically not related to the patient; therefore, they do it because it is a paying job. Whereas informal caregivers give care because they often believe that it is their responsibility (Biegel, Sales, & Schulz, 1991). Informal and formal care differs at the relationship (caregiver to patient) level, but more importantly or drastically in terms of setting, professional qualifications, and cost. The focus of this study is with informal caregivers only, but it is important to not only distinguish between informal and formal care, but to also show how they can work together in some instances.

Setting (Caregiving Environment)

Informal caregiving typically refers to a family member or friend who gives care to the person in need at their home (Walker et al., 1995). Formal care at facilities, also termed institutional care, is often perceived as impersonal by family caregivers, therefore home care is preferred (Glazer, 1990). The perceptions of formal care, and income level,

have been reported as two major predictors of the likelihood to seek out some type of formal care (Stommel, Collins, & Given, 1994).

According to Glazer (1990), formal care may be perceived as institutional, but there are services that provide certain types of non-medical formal care, that takes place at the patient's home. For example, two common types of formal home care are homemaker services and home health aide services (Genworth Financial, 2010). Homemaker services are personal care assistants that provide hands-off care. The services that are typically provided by a licensed personal care assistant deal with cooking, cleaning and running errands. Home health aide services are hands-on in terms of helping with transferring, bathing, dressing, toileting. The health aide services are non-medical (Genworth Financial, 2010).

There are forms of medical care that take place at the patient's home, but are typically performed by a licensed practical nurse (LPN). This type of in home medical care is seen as short-term and consists of such tasks as measuring vital signs and administering medications, rather than helping the patient with their activities of daily living (Stoker, 2003). Another form of in-home care that combines both medical and non-medical is in home hospice. Hospice programs are designed for end-of-life care and involve medical staff such as physicians, nurses, nursing assistants, but also include aides, social workers, and counselors (United States Department of Health and Human Services, 2000). Hospice care includes services that help with all aspects of daily living, but also provides medical support in terms of on-call physicians and nurses. This type of care is short-term, because the focus of hospice is on making the patient comfortable during the last few months of life (United States Department of Health and Human

Services, 2000).

Hospice care is reserved for end-of-life care only; therefore, in most circumstances, other forms of care were given before the patient was eligible for hospice. If a patient can no longer be cared for at home or live independently then the patient can move to an assisted living facility or a nursing home to receive formal care (Genworth Financial, 2010). Assisted living facilities provide the hands-on personal care like a home health aide would, but the patient also receives intermittent medical care. Nursing homes, or skilled nursing facilities, provide 24-hour-a-day nurse care, and on-call physician care (Genworth Financial, 2010).

Finally, a recently more common alternative to home formal health care or assisted/nursing home care is adult day care. Adult day care is a service that provides social support to patients in a protected environment (Genworth Financial, 2010). Adult day care programs are not necessarily new, but are becoming increasingly more popular. Within the last year alone (2009 to 2010), the national median rate per day increased by 12% (Genworth Financial, 2010). Adult day care programs provide a place where the caregiver can leave their family member or friend, so they can have a day off or more commonly, so they can go to work.

The setting of formal care is quite different from informal care. When formal care is provided at an institution, the patient receives care from trained professionals in a medical setting. Informal care is typically performed at home, where the caregiver is untrained and provides both hands-on (bathing and toileting), and hands-off (cooking and cleaning) care. It may be becoming more common for some caregivers to seek out extra formal help, in the form of a service aide or an adult daycare program, but the majority of

caregivers perform most care functions without formal help.

Professional Qualifications

Formal care whether in institutions, in assisted/nursing facilities, or given by home health aides, is provided by trained and licensed individuals (Genworth Financial, 2010). In most formal medical settings there is some sort of professional hierarchy. For example, a common hierarchy by medical qualification would be: physicians (MD), physician assistants (PA), registered nurses (RN), licensed practical nurses (LPN), and certified nursing assistants (CNA).

There are different experiential levels within each qualification, but the qualification alone is what differentiates the skill sets and authority level. For example, MDs and PAs can prescribe medication and perform most care procedures, whereas RNs, and CNA's are trained to work directly with the patient (Empowered Patient Coalition, 2010). It has been documented that there are considerable turnover rates within the medical professions, and that increases as patient load and responsibility (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002). There are driving factors that make people choose a medical profession, like prestige and power (Hatem & Ferrara, 2001), but at the same time it is a paying job.

Informal caregivers are not paid for the patient care they provide, so their motive cannot be characterized as monetary gain or means. A caregiver for a family member gives care because they either believe that it is their responsibility (Biegel et al., 1991), or they feel that they can provide better and safer care than in an institutionalized setting (Glazer, 1990). It has been stated that a caregiver's burden or distress is related to personal characteristics or attributes. At the same time, it is possible that these attributes

are also what drives a family member to be a caregiver when formal options exist (Cousins et al., 2002).

Informal caregivers are often not trained in most of the areas of personal care. Family caregiving skills are not typically learned from courses, but rather from experience. Schumacher, Stewart, Archbold, Dodd, and Dibble (2000) explain that many caregivers make adjustments through a trial and error process. What differentiates formal and informal caregiving at the professional qualification level † what motivates the caregiver, and the training involved.

Caregiving Costs

Formal caregiving can be very costly and is not always covered by insurance or Medicare (United States Department of Health and Human Services, 2000). Table 2.1 shows the median national rate for different types of formal care, as well as one year and five year growth rates. The findings indicate that formal caregiving costs are rising at an incremental rate (Genworth Financial, 2010).

Table 2.1

Cost of Formal Care (Genworth Financial, 2010)

Formal Care	National Median Rate (\$)	Increase From 2009 (%)	Five-Year Annual Growth Rate (%)
Homemaker services	18 per hour	3.0	2.4
Home health aide services	19 per hour	2.7	1.7
Adult day health care	60 per day	12	Not collected in 2005
Assisted living facility	105 per day	12	6.7
Nursing home (semi private room)	185 per day	5.7	4.6
Nursing home (private room)	206 per day	5.1	4.5

The median cost associated with having a hands-off personal care assistant (homemaker service), to help with cooking and cleaning averages to over \$140 for one eight hour work day (Genworth Financial, 2010). The cost increases to over \$150 per work day, for a hands-on personal care aide. The largest median costs are associated with assisted living facilities (\$3,185 per month), nursing homes with a semi private room (\$5,550 per month), and nursing homes with private rooms (\$6,180 per month) (Genworth Financial, 2010). Formal caregiving may be obtainable for some people, but with the increasingly high associated costs, this option does not work for everybody.

The associated cost of informal care, from a large nationally representative sample, was derived from the number of hours per week giving some type of informal care to a family member with dementia (Langa et al., 2001). Langa et al., reported that the amount of time giving care (by an informal caregiver) ranged from around five hours per week for mildly demented patients, to over 41 hours per week for severely demented patients. The associated yearly cost ranged from \$3,630 for the mildly demented, to \$17,700 for the severely demented, for a national cost of over \$18 billion per year.

Informal caregiving is typically defined as a situation in which a family member or friend provides more than the normal amount of care to a disabled person (Cohen, Miller, & Weinrobe, 2001). The differences between formal and informal care are not only associated with who is giving the care, but where the care takes place, the skill set that the caregiver has, and the associated costs of care. Because of the previously stated differences between formal and informal caregiving, this study will only assess informal family caregivers. Informal family caregivers are the same in the sense that they are

giving care to someone they personally know, and they are not getting paid for their services. Including formal caregivers into this study could adversely affect the interpretations based on the findings.

Literature Informing Illness and Caregiver Constructs and Attribute Methodology

The systematic review of published research in relation to the outlined illnesses was conducted under these questions: what constructs of burden are most frequently assessed? Are there personal traits/states of the caregiver, other than giving care for a terminally ill family member, that are related to caregiver burden, and if so, what role do these traits/states play? The review consisted of six steps, derived from Needham (2000), for conducting systematic literature reviews, namely: formulating framing questions, exhaustively searching for relevant research articles in terms of the framing questions, assessing quality of the selected articles in terms of personally defined criteria, excluding articles that do not meet the set criteria, explaining overall findings of the included articles, and interpreting the findings.

Articles were selected if they contained relevant data on effects of being an informal family caregiver for an ALS, AD or cancer patient. The initial search only included studies that identified certain aspects of caregiver effects such as burden, stress, strain, and anxiety. The subsequent searches broadened the scope to include any articles that investigated caregiver attributes that could possibly be related to the caregiving effects found in the previous search. Figure 2.1 represents the guiding framework for the literature review informing illness, caregiver constructs and attributes, which ultimately lead to the overarching research design.

Sources for the literature were from the following databases: psycinfo, academic search premier, abstracts in social gerontology, and social work abstracts. The following words were used in different strings and combinations in each database: caregiver effects or affects and terminal illness or chronic illness, caregiver burden and terminal illness or chronic illness, health effects, caregiver traits, caregiver states, caregiver characteristics, and caregiver personality. After the initial search, the articles were grouped by caregiver effect. Then further searches were conducted on the identified caregiver effects to generate significant support for each effect.

Selection of Disease Types

The selection of disease types for this study did not originate through a structured process, but can be seen as the product of social interest, and disease characteristics. Some research suggests that role of an informal (non-paid), AD caregiver is associated with a decrease in emotional and physical well-being (Aneshensel, Pearlin, Mullan, Zarit, & Whitlack, 1995). Other research indicates that caregiving is stressful, but caregiver burden and distress is more related to the personal traits of the caregiver (Zanetti, et al., 1998). The findings from Aneshensel, et al. (1995) and Zanetti et al. (1998) may not seem commensurable, but can be explained. First of all, the populations were different. Aneshensel, et al. (1995) studied AD caregivers, and Zanetti et al. (1998) studied Parkinson's caregivers. Second of all, a combination of disease type, time and caregiver traits/states may explain more variance in caregiver distress and burden than just focusing on just traits/states or time.

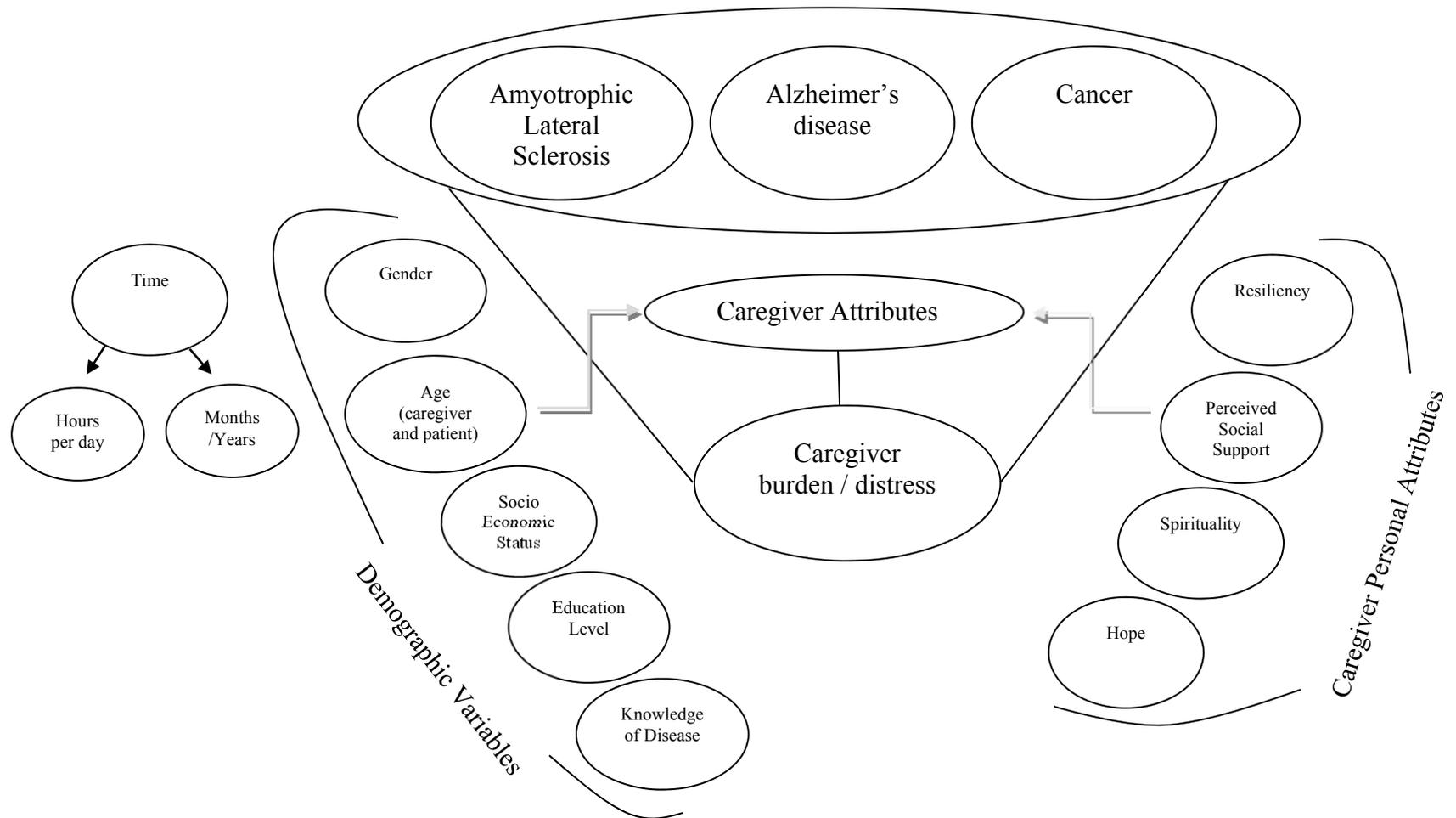


Figure 2.1. Guiding Framework of the Literature Review Informing Illness and Caregiver Attributes

There are a number of disease types that could be investigated, based on the notion that the disease is terminal. Research on Alzheimer's disease and other dementias is receiving more private and government funding because of the social impact of the disease (Hodes, 2006). In 2009, the National Institutes of Health (NIH) and National Institute on Aging (NIA) funded around \$450 million of AD-based research, which was down from the \$643 million mark in 2006 (United States Department of Health and Human Services, 2010). Projections indicate that there are around 5.2 million Americans with AD, and one in every eight baby boomer will be diagnosed with AD (Arnold, 2009). Funding may be decreasing, but prevalence of AD is increasing.

Alzheimer's disease, in 2009, was considered the sixth leading cause of death in the United States, and cancer was the second leading cause of death claiming over 560,000 lives in 2009 (Centers for Disease Control and Prevention, 2010). Cancer is unique for this study, because even though cancer can be considered terminal there is still a chance for remission. Diseases like AD and ALS are death sentences, and hope is in the form of drug research but recently failed drugs have been making the news because they were reportedly making the patients worse (Eli Lilly, 2010).

Outlined below is general information about the three diseases of interest for this study (AD, ALS, and Cancer). Each disease is unique from the others, in terms of progression and disease characteristics. Other diseases would be relevant, but these were chosen because they do not share many major disease characteristics. Alzheimer's disease and cancer may seem more relevant than ALS, because of sheer numbers, but the disease process of ALS is considerably more rapid than AD and most forms of cancer,

and there is no medication currently available to help with the severity of the symptoms (Amyotrophic Lateral Sclerosis Association, 2008).

Alzheimer's Disease (AD)

Historically, according to Khachaturian (2006), it was in the late 1890s and early 1900s when researchers discovered plaques and tangles, which are buildups of protein, in the dissected postmortem brains of demented patients. In 1907, Alois Alzheimer documented a case study where one of his patients displayed strange behavior that included issues with memory. Alzheimer documented his patient's behavior changes and then when the patient died, he linked the behavior changes with abnormalities in the autopsied brain (Khachaturian, 2006). The belief today, according to Whalley (2001), is that AD patients have significantly more plaques and tangles, especially in the hippocampus, than normal aging controls.

Alzheimer's disease, also referred to as dementia of the Alzheimer's type, is considered to be a slowly progressive degenerative brain disease that only can be definitely diagnosed by microscopic examinations of different parts of the brain (Hamdy & Turnbull, 1998). Microscopic brain examinations for a confirmation of diagnosis can only be completed through autopsy, but Hamdy and Turnbull explain that clinicians are able to use different brain images, laboratory tests, and neuro-psychological examinations to accurately diagnose AD.

Alzheimer's disease is the most common cause of dementia in the elderly, and reportedly affects more than 10% of all people over the age of 65, and possibly as much as 50% of all people over the age of 85 (Sambat, 1998). The progression of AD is

represented in stages, but the time frame in each stage is variable, lasting from a year to many years (Reisberg & Franssen, 1999). Table 2.2 helps to organize the seven stages of progression of AD according to Reisberg and Franssen.

Table 2.2

Seven Stages of Alzheimer’s Disease

STAGE	CHARACTERISTICS	DURATION
Stage 1: Normal	Normal mentally healthy person.	
Stage 2: Normal aged forgetfulness	Typical forgetfulness of not remembering where they have placed certain items, and/or not being able to recall names as well as before.	
Stage 3: Mild cognitive impairment	Subtle deficits noted by other people. These include: repeating statements or questions, decline of job performance, and difficulty concentrating. Overt decline over time.	7 years
Stage 4: Mild Alzheimer’s disease	Impairment is evident. Forgetting of major recent events, and problems recalling the day of the week and month. Blunt affect and withdrawal is also noticeable.	2 years
Stage 5: Moderate Alzheimer’s disease	Independence is usually not manageable. Cannot recall events, current president, living address, or the weather.	1.5 years
Stage 6: Moderately severe Alzheimer’s disease	This stage can be broken down into sub stages including: difficulty with activities of daily living like dressing, assistance with bathing, assistance with using the restroom, and by the end of this stage speech ability is compromised.	2.5 years
Stage 7: Severe Alzheimer’s disease	Limited speech of only a few words declines to complete intelligible speech. Continuous assistance with basic activities of daily living.	1.5 years

Adapted from Reisberg & Franssen, 1999

Amyotrophic Lateral Sclerosis (ALS)

Amyotrophic Lateral Sclerosis is a progressive motor neurodegenerative disease that gradually causes paralysis and respiratory failure leading to death typically within two to four years of symptom onset (Mitsumoto, 2001). According to the Robert Packard Center for ALS Research at Johns Hopkins (2010), there are around two people per 100,000 people diagnosed each year, and around 30,000 people living with ALS in the United States at any given time (Mitsumoto). Currently the only medication approved for

ALS improves survival by a few months, but has little effect on lessening the severity of the symptoms; therefore, the symptoms are monitored and treated individually on a case by case basis (Radunovic, Mitsumoto, & Leigh, 2007).

The history regarding ALS is similar to AD in the way that it was a physician in 1874, named Jean Martin Charcot, who established the characteristics of ALS by systematically observing the progression of his housemaid who was suffering from the disease (Cwik, 2001). When his housemaid died, Charcot performed an autopsy and documented the pathological features of ALS, which to this day are considered to be accurate (Cwik, 2001).

There is not a test for ALS, and in many cases the first symptom is muscle weakness (Mitsumoto, 2001). The classifications of the muscle weakness, according to Mitsumoto, are limb onset, and bulbar onset. Limb onset is when weakness is first noted in an arm or a leg, whereas bulbar onset is when weakness is noted in the muscles controlling speech and swallowing (Mitsumoto, 2001). Muscle weakness is not exclusively related to ALS, but marked progression to include multiple body regions, and the use of electrodiagnostic and neurophysiologic examinations allow for a fairly clear diagnosis (Cwik, 2001).

Amyotrophic Lateral Sclerosis is considered a rare but fast-paced disease. On average 50% of people diagnosed with ALS survive for only two years after diagnosis (Robert Packard Center for ALS Research at Johns Hopkins, 2010). Other sources indicate the survival range is around two to four years from symptom onset (Mitsumoto, 2001). Some people progress faster than others, and because breathing is effected by the disease, people who live at higher elevation tend to be closer to the two year mark rather

than the four year mark.

Cancer

Cancer is the unregulated division and growth of cells eventually forming a tumor within an organ, which then indicates the type of cancer (O'Reilly & Kelvin, 2003).

According to Rosenbaum and Rosenbaum (2005), cancer is the number two killer in the United States, accounting for 25% of deaths per year. For men, the most common types of cancer are lung and prostate, where prostate is 90% curable if diagnosed early, but still accounts for over 30,000 deaths per year (Rosenbaum & Rosenbaum, 2005). For women, lung cancer claims over 73,000 lives annually, and it is estimated that on a yearly basis, around 200,000 women are diagnosed with breast cancer, and of that, approximately 40,000 will die of the disease (Rosenbaum & Rosenbaum 2005). With that said, since 1975, the five year survival rate of all cancers combined is on the rise, most likely due to technology and heightened awareness (National Cancer Institute, 2008).

The three selected illnesses are vastly different. Typically referred to as terminal illnesses, ALS and AD do not have and cures, and the treatments that are available for AD only help with the severity of the symptoms. Cancer, on the other hand, has a remission and survival rate. For many cancers, if they are diagnosed early, they can be effectively treated, whereas with ALS and AD, diagnosis tends to be a lengthy process which is not relevant to survival because there is no long term survival for ALS or AD patients.

Literature Findings and how they Inform the Study Method

The extracted components of the literature review are structured in terms of demographic variables, independent variables, and dependent variables. The demographic and independent variable sections include findings in terms of the given variables' impact on caregiver burden and distress. Each section includes a summary table of relevant study findings. Finally, the independent variable and dependent variable sections include a review of the measures used to operationally define the constructs.

Demographic variables

Table 2.3 displays evidence pertaining to the relationships between demographic variables and caregiver burden. Demographic variables are often collected in survey designs because they can be used to find differences within subsamples of the population, but also as controls for model building (Tabachnick, & Fidell, 2007). Part of the literature review method was to identify commonly reported demographic variables in the caregiving literature. The demographic variables identified most often as having a possible association with distress and burden are as follows: age of caregiver, gender, socio-economic status, education level, and knowledge of disease.

Table 2.3

The Relationship Between Caregiver Demographic Variables and Caregiver Burden.

Demographic Variables	Evidence	References
Gender	Women are more likely to be caregivers than men, especially in children who care for a parent. For spousal caregivers, marital happiness did not change for men over time, but as time went on, woman caregivers became less happy in their marriage.	Baek (2005); Stephens, Franks, et al. (1999)
Socio-Economic Status	Caregivers of lower income were more likely to report perceptions of caregiver strain than caregivers of higher income.	Beck (2001); Schulz, Newsom, et al. (1997)
Education Level	People that had higher levels of education were more likely to have a better understanding of the disease, which is related to their outlook.	Schulz, Newsom, et al. (1997)
Knowledge of Disease	Gaining knowledge about the disease was identified as a key coping mechanism for caregivers. Also, caregivers who had a better understanding of the disease were more likely to view their experience as a gain rather than a burden.	Kukeya (2006)

Gender

While most terminal illnesses are not gender-specific, the majority (68%) of informal caregivers are women (Foundation for Accountability (FAACT), & Robert Wood Johnson Foundation (RWJF), 2001). Figure 2.2 displays the breakdown of

informal caregivers regardless of gender, and the corresponding list includes gender to show the hierarchy of who typically gives care (FAACT & RWJF). Children, including children-in-law, tend to be the primary caregivers for a disabled family member. When we look at gender, it appears that there are more daughter in-law caregivers than adult son caregivers.

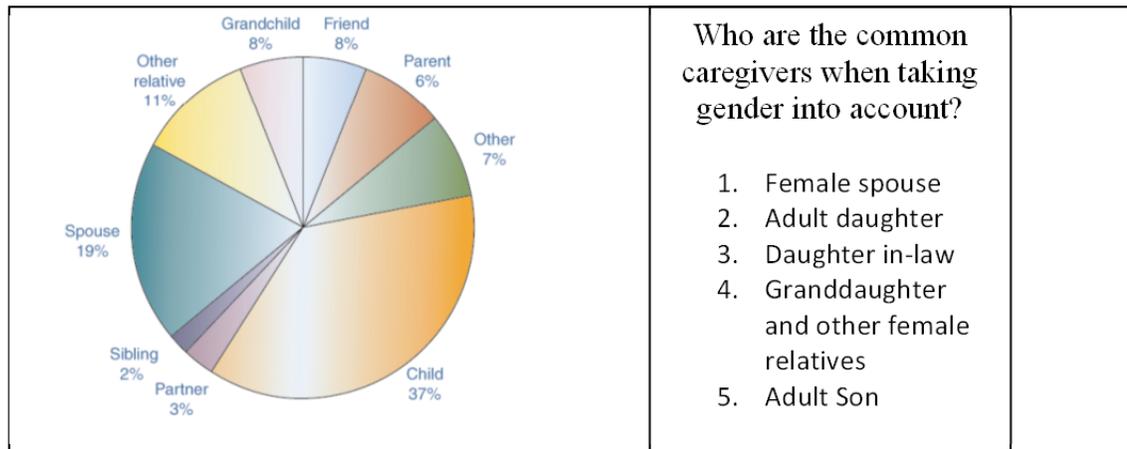


Figure 2.2. Demographics of Primary Informal Caregivers (FAACT & RWJF, 2001)

A Meta-analytic finding among caregiver gender differences is that women have slightly higher levels of reported burden and worse physical health than male caregivers (Pinquart, & Sorensen, 2006). The differences were based on 229 studies, but the effect sizes were very minimal and heterogeneous, therefore the differences could be artificial.

Socio Economic Status

Socio economic status is a touchy sensitive subject, because if it is asked as a fill-in-the-blank question, response rates are very low (Vaske, 2008). Response rate can be increased if income is given in representable ranges. A few studies have shown a negative relationship with income level and perceived burden (Beck 2001; Schulz, et al.,

1997). This indicates that as income decreases perceived burden increases. Income level's effect on burden may be moderated by resources or support, because not having the money to purchase available resources or obtain paid help could affect burden.

Education Level and Knowledge of Disease

Education level and knowledge of the disease are positively correlated (Schulz et al., 1997). The more educated the caregiver, the more the caregiver will reach out to learn about the disease, and have access to the applicable resources. According to Kukeya (2006), as caregiver knowledge and information needs were met, their outlook on their caregiving experience became more positive.

Caregiver Personal Attributes

Table 2.4 displays evidence pertaining to the relationships between personal attributes (constructs) and caregiver burden. Personal attributes are characteristics of the caregiver. A major deductive part of the literature review was to identify the most commonly reported caregiver attributes. In some cases the attributes were termed as traits, or more commonly personality traits (Zanetti et al., 1998; Cousins et al., 2002). The literature search was opened up to include any key word that was associated with caregiver attributes, traits and personal characteristics.

Table 2.4

The Relationship Between Caregiver Personal Attributes and Caregiver Burden.

Personal Attributes	Evidence	References
Resiliency	Resiliency was positively correlated with successful coping mechanisms to reduce perceived burden.	Ross, Holliman, et al. (2003); Wilks (2004); Wilks & Vonk (2008)
Perceived Social Support	Caregivers who reported higher levels of social support were less likely to report symptoms of stress and anxiety.	Faber (2005); Kirschling (1986); Monahan & Hooker (1997); Waldrop (2006)
Spirituality	Overall, as caregiving stress increases, caregiver mental functioning decreases, but the correlation is not as strong with highly spiritual caregivers. Burden is mediated through prayer, and prayer is positively correlated with resiliency.	Colgrove, Kim, et al. (2007); Wilks (2004); Wilks & Vonk (2008)
Hope	As hope increases so does levels of personal control, intimacy, safety and trust.	Borneman, Stahl, et al. (2002); Chauhan (2008); Elliott & Olver (2007); Herth (1993)

Resiliency

Resilience was fittingly described by Wilks and Croom (2008) as a survival mechanism that everybody has, and thus it is not unique to any one person. In general, resiliency is as simple as recovering from adversity (Wagnild, 2009). Research on resiliency gained popularity in during the 1980s, but focused mainly on children who were living in adverse situations (Werner, 1984; Byrne, Love, Browne, Roberts, & Steiner, 1986; Beardslee & Podorefsky, 1988). During the 1990s, research on adult resiliency became more common within certain populations like burn victims (Holaday & McPhearson, 1997), AIDS patients (Rabkin, Remien, Williams, & Katoff, 1993), and

people living in long-term care facilities (Beaton, 1991).

Many studies that investigate resiliency tend to sample people that are affected by a disease, rather than the people who care for the patients. One of the few studies that focused on caregivers found a negative relationship between resiliency and burnout, indicating that if the caregiver is more resilient then they are less likely to become burnt out (Egan, 1993). Resiliency has been shown to be positively correlated with spirituality (Wilks & Vonk, 2008) and social support (Wilks & Croom, 2008), but negatively correlated with stress (Wilks & Croom, 2008). In other words, a more resilient caregiver tends to have more social support and spiritual beliefs, and less stress. Ultimately, resiliency may be a product or influence of multiple variables.

Finding ways to successfully deal with caregiving demands is resiliency. Ross, Holliman and Dixon (2003) found that the most resilient caregivers were people who had been caregivers at a young age. Other factors associated with resilient caregivers, according to Ross et al. (2003), were the ability to take personal time, physical exercise, having hobbies, and (once again) social support and spirituality. If resiliency is made up of a number of other attributes, then it may not account for unique variance within caregiver burden.

The 14-Item Resilience Scale (RS-14). The original Resilience scale was constructed through a multiple step process (Wagnild & Young, 1990). Using a grounded theory approach, Wagnild and Young identified five underlying characteristics of resiliency (i.e., self-reliance, meaning, equanimity, perseverance, and existential aloneness). Fifty, seven point items were initially developed, but after a preliminary

analysis ($n = 24$ older women) the scale was reduced to 25 items. Psychometric properties of the 25 item scale were assessed in terms of concurrent construct validity with positive correlations between resiliency and both life satisfaction and morale, and a negative correlation with depression (Wagnild & Young, 1993). With the data from their 1993 study ($n = 782$), Wagnild and Young suggested that even though their instrument was based on five factors, a principal components analysis indicated two distinct factors (personal competence, and acceptance of self and life).

The short 14-item version of the resilience scale (Appendix A) was created using similar questions to the 25-item resilience scale that reflected the five characteristics of resiliency (Wagnild, 2009). Wagnild (2009) reported that the shorter version was one-dimensional, even though it contained similar items that made up parts of the two factors from the 25-item resilience scale. Also, data from the 14-Item Resilience scale showed strong internal consistency (Cronbach's alpha = .93), and strongly correlated with the 25-item resilience scale ($r = .97$). Finally, data from the 14-item Resilience Scale was positively related to healthy lifestyle, life satisfaction and morale, and negatively related to depression (Wagnild & Young, 1993).

Perceived Social Support

Social support has different meanings to different people and can take different forms. Social support is often related to spirituality (Wilks & Vonk, 2008), and is a subsection a common spirituality inventory (Holland et al., 1998). Social support is intertwined with spirituality because people that are spiritual tend to go to spiritual gatherings (church), therefore their church becomes a social support unit.

Increased social support is not only related to increased resiliency (Wilks &

Croom, 2008), but is also negatively correlated with anxiety and depression (Zimet, Dahlem, Zimet, & Farley, 1988). According to Waldrop (2006), caregivers reported that social support was crucial through the caregiving process, but became even more important during the final stages of the disease process. The role that social support plays in the caregiving process is important because it is strongly related to positive and negative caregiving outcomes.

Multidimensional Scale of Perceived Social Support (MSPSS). The initial validity studies with the MSPSS instrument (Appendix B) were not with caregivers. It was initially validated with undergraduate students (Zimet et al., 1988). Cronbach's alpha was .88 for the entire scale and ranged from .85 to .91 for the subscales. Of the initial 275 undergraduate students, 69 were retested three months later, and the reliability for the entire scale was .85 (Zimet et al., 1988). Perceived family social support (subscale) was negatively related to both anxiety and depression.

In a later validation study, Zimet, Powell, Farley, Werkman, and Berkoff (1990) investigated the psychometric properties of the MSPSS with samples of three different populations (pregnant woman, adolescents, and pediatric residents). A principal components factor analysis confirmed the three factor model (Zimet et al., 1988). Cronbach's alphas were consistently high ranging from .84 to .92 for the three samples.

Zimet et al.'s (1988; 1990) findings were also supported by Dahlem, Zimet and Walker (1991), who used the MSPSS with 154 college students. This measure has been used with different populations but there is a lack of supporting evidence that this scale is valid for caregivers.

Spirituality

The role spirituality plays in caregiving has been explained in previous paragraphs because it is closely tied to social support and resiliency (Wilks & Croom, 2008). Not all spiritual people go to church, yet high levels of spirituality have been associated with lower stress and higher mental functioning (Colgrove, Kim, & Thompson, 2007). Social support may also be contributing to the findings, but Colgrove et al. (2007) explains that spirituality helps a caregiver find meaning in his or her role; therefore, that derived meaning lessens the severity of caregiver stress.

A longitudinal study with patients who had terminal cancer demonstrated that religious beliefs did not change over time and were not related to survival rate but levels of religious activity were positively correlated with happiness, life satisfaction and negatively correlated with pain (Yates, Chalmer, St. James, Follansbee, & Mckegney, 1981). In terms of religiosity and caregiving, burnout rates of paid caregivers who considered themselves highly religious were significantly lower than burnout rates of their non-religious counterparts (Kash & Holland, 1990).

Systems of Belief Inventory (SBI-15R). The Systems of Belief Inventory (SBI-15R) is a four point (strongly disagree to strongly agree) shortened version of the validated SBI-54 (Holland et al., 1998). The SBI-15R was highly correlated with the SBI-54 ($r = .98$). In the initial study using the 15-item SBI, Holland et al. (1998) suggested a two factor substructure with an explained variance of over 65%. Internal consistencies of the SBI-15R and its sub-factors have been consistently strong, with Cronbach's alpha

above .90 (Holland et al., 1998; Baider, Holland, Russak, Kaplan De-Nour, 2001; Ripamonti, et al., 2010).

The SBI-15R was highly correlated with the Religious Orientation Inventory (ROI) and the Index of Core Spiritual Experiences (INSPIRIT), which shows support for convergent construct validity (Baider et al., 2001). Stability (test re-test) estimates demonstrated correlations above .85 for both subscales of the SBI-15R (Ripamonti et al., 2010). Appendix C shows the items of the SBI-15R and the substructure.

Hope

The concept of hope, for the purposes of this study, is interesting. Patients within two of the three groups (AD and ALS), will die from complications of the disease process. Late stage cancer patients will most likely die from their disease process as well, but they still could go into remission. The cancer group is unique in the sense that they have built-in hope, whereas AD and ALS patients will continue to decline until death.

The difficulty with having hope as a variable is that it is multidimensional, yet not easy to define (Herth, 1991). Hope is also similar to spirituality. Borneman, Stahl, Ferrell, and Smith (2002) explained that caregivers often mentioned that the future is in God's hands. Caregivers also reflected on the idea that hope shifted from hoping for a cure to hoping for a peaceful death (Borneman et al., 2002). Hope has different meanings to different people. The cancer group is inherently different because they can still have hope for remission. The AD and ALS groups may also have hope but that could be dependent on their realistic outlook of the future.

The Herth Hope Index (HHI). The Herth Hope Index (HHI) is a 12-item version of the 30-item Herth Hope Scale (HHS) (Herth, 1992). The HHI was correlated with the HHS ($r = .92$), as well as the Nowotny Hope Scale ($r = .81$), which demonstrates convergent construct validity (Herth, 1992). Discriminant construct validity was also assessed by correlating the HHI with a hopelessness scale ($r = -.73$).

Stability over time was demonstrated by administering the HHI to the same group of participants at two different testing times ($r = .91$) (Herth, 1992). Three factors were identified (inner sense of temporality and future, inner positive readiness and expectancy, and interconnectedness with self and others), which accounted for 61% of the variance within the model. The overall Cronbach's alpha was .97 with all items positively contributing (Herth, 1992). Appendix D displays the items of the HHI, as well as the items associated with each proposed factor. Note that two of the items (3 and 6) are negatively-worded items, so they are reversed when scored.

Outcome Measures

Zarit Burden Interview (ZBI)

The Zarit Burden Interview, also called the Zarit Burden Index, was first published in a 29 item, five point scale format (Zarit, et al., 1980). Appendix E shows the original 29 items, along with the more common 22 item format. The ZBI is widely used and data obtained from various studies demonstrate internal consistency, with Cronbach's alphas above .80 (Arai, Kudo, Hosokawa, Washio, Miura, & Hisamichi, 1997; Schulz, Tompkins, & Rau, 1988).

Construct evidence is mixed because some studies suggest a relationship between

the ZBI and the patient's disease characteristics (Uttl, Santacruz, Litvan, & Grafman, 1998), while other studies did not find similar correlations (Zarit, et al., 1980). Factorial evidence is also mixed. A few studies suggest two factors from 12 items (Hebert, Bravo, & Preville, 2000; O'Rourke & Tuokko, 2003), while other studies suggest three factors (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Knight, Fox, & Chou, 2000).

The ZBI was created by researchers that specialized in dementia research (Zarit et al., 1980). It has grown in popularity, and has been used with multiple populations. The variability in the differing populations and the sampling procedures could play a major part in why there is mixed evidence.

Caregiver Distress Scale (CDS)

Cousins et al. (2002) created a caregiver distress scale (Appendix F) based on four validated scales (Burden 2, Impact of Caregiving Scale, Care-giving Burden Scale, and the Frustration Scale). The process consisted of two phases. In phase one, 80 Parkinson's disease caregivers completed the four validated burden measures. All four measures were internally consistent with Cronbach's alphas over .70. A cluster analysis was used to create groupings of survey questions, followed by an exploratory factor analysis to confirm the loadings and reduce the items. Phase two was completed at a later date with a sub-sample of 56 caregivers from the original 80 from phase one. The same four measures were administered, and the analysis was completed in the same manner as in phase one. Internal consistency (Cronbach's alpha) for each measure remained similar between phase one and phase two.

Cousins et al. (2002) accepted items if the loadings were greater than .45 on the factor, and at least .15 higher than the item loading on any other factor. Also, Cousins et

al. (2002) indicated that each item that was retained needed to have its highest loading on the same factor for phase one and phase two. In addition, items that were highly correlated ($r^2 > .5$) were reduced to one item.

The final caregiver distress measure that was created by Cousins et al. (2002) included 17 items divided into five sub-constructs (relationship distress, emotional burden, social impact, care-receiver demands, and personal cost). After the final items were selected, Cousins et al. (2002) correlated the phase one and phase two items, to demonstrate test retest (stability) reliability. The phase one to phase two sub-construct correlations ranged from .47 to .82, all five of which were statistically significant. Cronbach's alphas for the finalized items were .87 for phase one and .88 for phase two.

The CDS is a measure that was created through a structured statistical process based on data from four validated measures. The sample was with Parkinson's disease caregivers, but a more recent study used the CDS with caregivers of stroke patients (Piggin et al., 2008). To date, The writer has not found any published articles where the CDS was used with AD, ALS, or cancer.

Summary

The aging population is increasing. People are living longer, and that alone increases chances of being diagnosed with a disease. It is becoming more common that when individuals have a terminal illness, they want to be taken care of in their home rather than in a hospital. With health care costs rising, it is not feasible for many families to have home health care for a family member with a terminal illness. Nursing homes, assisted living homes, and even adult day care centers are fairly expensive. The

caregiving then becomes the family's responsibility.

Having to take care of a family member on a daily basis is not only time consuming, but it can become an unhealthy situation for the caregiver. The caregiver may have to limit his/her hours at his/her paying job, or quit all together. At this point, caregiver burden seems inevitable. As indicated earlier, some researchers link increased burden to the amount of time being a caregiver, and other researchers link burden to caregiver personality factors. It is important to understand caregiver burden, and investigate its correlates. Having a better understanding of caregiver burden and being able to identify factors associated with burden will be beneficial to not only the caregiver, but also to the patient. If it is known that increased social support leads to less caregiver burden, then appropriate steps can be taken to ensure that every caregiver has some kind of support system.

Disease characteristics may also play a role in burden, so it is important to investigate different disease types in terms of burden. Having a working model that predicts caregiver burden is an important goal to work towards. If we know all of the major correlates, then burden could be minimized.

CHAPTER 3: METHODS

General Approach

A non-experimental research design, more specifically the comparative approach, includes only attribute variables and oftentimes a battery of surveys (Gliner, et al., 2009). Survey research methods do not answer the question *why*; rather, these methods are used to answer questions pertaining to *what* a person is feeling or thinking (Mitchell, & Jolley, 2004). Surveys give the researcher the ability to understand what the participant is thinking, which is different than observing what the participant is doing (Mitchell, & Jolley, 2004). Using survey methods with a comparative approach will allow for comparisons, in terms of the surveys used, between different groups.

The overarching research question for this study is: what are the measurable differences between three groups of caregivers (AD, ALS, cancer)? Truth can only be approximated; therefore, reality can be measured but generally with error. The ontological (nature of reality) and epistemological (what we can know about reality) viewpoints, as stated in the previous sentence, lead to a more structured and objective research approach. More importantly, the research questions were based on what was missing in the caregiver literature rather than being based on metaphysics of inquiry.

Participants

There are basically two types of caregivers, formal and informal. Formal caregivers are paid aides, whereas informal caregivers are the unpaid help, typically in the form of a family member or a friend (Spillman & Black, 2005). The participants for this study will be informal caregivers to a family member or friend that has been diagnosed with AD, ALS or cancer. The caregiver can be the primary or secondary caregiver, as indicated through how much time they give care per day.

Sampling

There are a number of different ways to access a population of informal caregivers. The sample was obtained through the help of the Muscular Dystrophy Association (MDA) ALS branch, ALS Association, Alzheimers Association, Radiant Research, Urban Media Group, Cancer Support Center, Rocky Mountain Cancer Center, Eldercare, Ann Togher, and the Johnson Adult Day Program. The instruments were online. The caregivers received links to the instruments where they could anonymously complete the different questionnaires. The links were given by the divisional representatives of the previously mentioned associations. No identifier information was obtained.

The sampling was non-probabilistic because the probability of being selected was not known (Gliner, et al., 2009). This was a convenience sample because the representatives of the associations distributed the survey link to applicable caregivers. For this study, caregivers were selected if they provided regular unpaid care to a friend or family member who had AD, ALS or cancer. Figure 3.1 displays the sampling process.

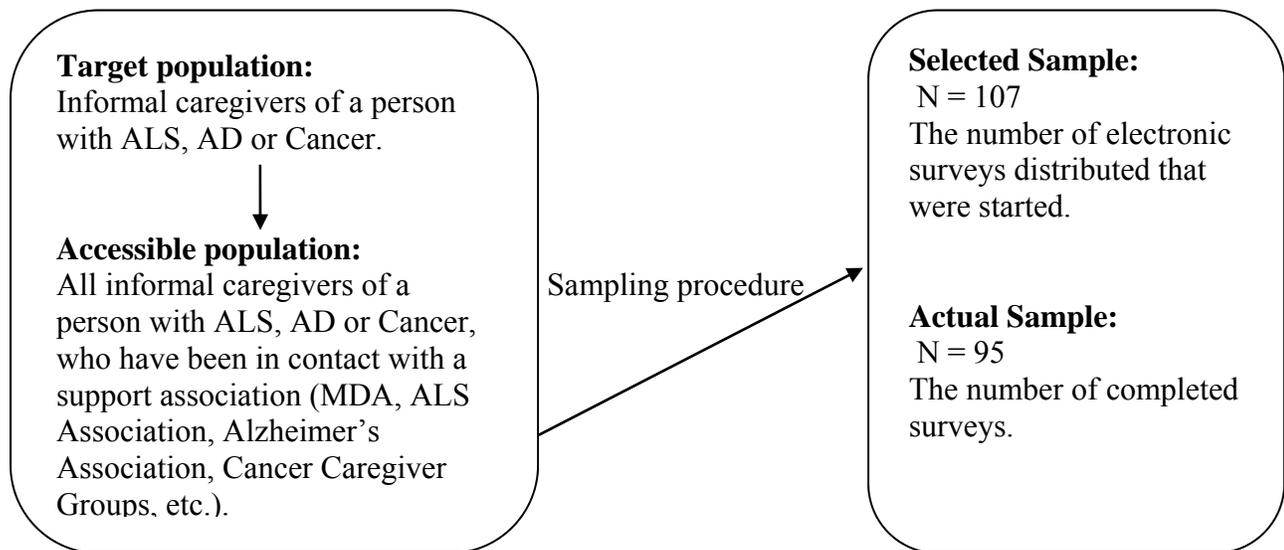


Figure 3.1. Sampling process, diagram format adapted from Gliner, et al. (2009).

The goal was to get a large enough sample size, because some of the analyses require large n 's (factor analysis, hierarchical regression, and cluster analysis). Also, with a larger n , error is reduced and generalizing to the target population is not as problematic, as it is with a small sample. The ALS caregiving population is much smaller than the AD and cancer caregiving population so it was necessary to oversample ALS caregivers, by contacting every major ALS organization (MDA and ALS association's nationwide). The selected sample was the number of caregivers who went to the online questionnaire site. The contacts from the different associations talked with the caregivers before the link was given, so the actual sample was fairly close to the selected sample.

Measures

A variety of validated measures were used to define the various constructs related caregiver traits/states, distress and burden. The independent variables (attributes) were

scores on the following measures: The Resilience Scale (one-dimensional), Multidimensional Scale of Perceived Social Support (three subscales of family, friends, and significant other), Systems Belief Inventory (two subscales beliefs/practices and social support), and the Herth Hope Index (three subscales of inner sense of temporality and future, inner positive readiness and expectancy, and interconnectedness with self and others). The Dependent variables were scores on the following measures: Zarit Burden Interview (two subscales of personal strain and role strain), and the Caregiver Distress Scale (five subscales of relationship distress, emotional burden, care-receiver demands, social impact, and personal cost).

Measurement Validity and Reliability for the Attribute Variables

Multiple pre-existing validated measures were used. Evidence for each measure has summarized in Table 3.1. Instruments were selected based on prevalence in the literature, and accessibility. Authors of the instruments were contacted prior to the study and agreed to the use of their instruments for the purposes of this research.

The measures, outlined in Table 3.1, have different scale points. The first two (RS-14 and MSPSS) have seven-point scales while the last two (SBI-15R and HHI) have four-point scales. Refer to Figure 3.2 for the scale points and dimensionality of each measure. The aforementioned measures were not altered in any way before administration. Some of the analyses reported in chapter four used standardized transformations of the data.

Table 3.1

Evidence for Measurement Validity and Reliability of Caregiver Personal Attributes

Scale	Evidence of validity	Reference(s)
The 14-Item Resilience Scale (RS-14)	Factor structure of the original 25 item scale indicated five factors (eigenvalues greater than 1). Loadings were consistent but 25 items was determined to be too long, so a one-dimensional 14-item instrument was developed. A reported Cronbach's alpha of .93 demonstrates strong internal consistency. Positive correlation with morale and life satisfaction, negative correlation with depression. Depressed participants scored significantly lower than non-depressed healthy participants.	Wagnild & Young, 1990, Wagnild & Young, 1993; Wagnild & Collins, 2009; Wagnild, 2009
Multidimensional Scale of Perceived Social Support (MSPSS)	Multidimensional scale with strong internal consistency (Cronbach's alpha = .88) for the entire scale, and sub scales ranged from alphas of .85 to .91. Factorial evidence has demonstrated a consistent three factor loading through multiple studies, along with consistently high Cronbach's alphas. Discriminant construct validity evidence was demonstrated by negatively correlating with anxiety and depression.	Zimet, Dahlem, Zimet, & Farley, 1988; Zimet, Powell, Farley, Werkman, & Berkoff, 1990; Dahlem, Zimet, & Walker, 1991
Systems Belief Inventory (SBI-15R)	The 15 item SBI is a short version of the 54 item form, which it correlates $r = .98$. The 15 item short form consists of two subscales (beliefs/practices and social support), both with strong internal consistency (Cronbach's alpha = .92 and .89 respectively). Test retest reliability was above .85 for both subscales, and spiritual churchgoers scored significantly higher than spiritual non-churchgoers who scored significantly higher than the non-spiritual group.	Holland et al., 1998; Baider et al., 2001; Ripamonti et al., 2010,
Herth Hope Index (HHI)	Internal consistency ranging from .78 to .97, in varying samples. Positively correlates with self-esteem, self-confidence, self-transcendence and quality of life. Three factors have been proposed, but not agreed upon. Evidence has recently suggested that a one factor solution may be more appropriate than a three factor solution.	Herth, 1991; Herth, 1992; Phillips-Salimi et al., 2007)

Having a larger number of points does increase precision, but also increases the chance of extreme response sets which inflate reliability (Komorita & Graham, 1965). According to Chang (1994), variance increased with a six-point scale, but when that was factored out, the correlation and reliability was reduced. When items appear to be homogenous, through factor analytic techniques, then a smaller point scale can be as reliable as a larger point scale (Komorita & Graham, 1965). Stability and internal consistency are types of correlations, so a smaller range affects the strength of the correlation (Nunnally, 1970).

Measurement Validity and Reliability for the Dependent Variables

Caregiver burden and distress are similarly defined by Zaret et al. (1980) and Cousins et al. (2002), respectively. Some argue that burden is perceived psychological distress (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). Others argue that distress is simply depression (Miller, Berrios, & Politynska, 1996).

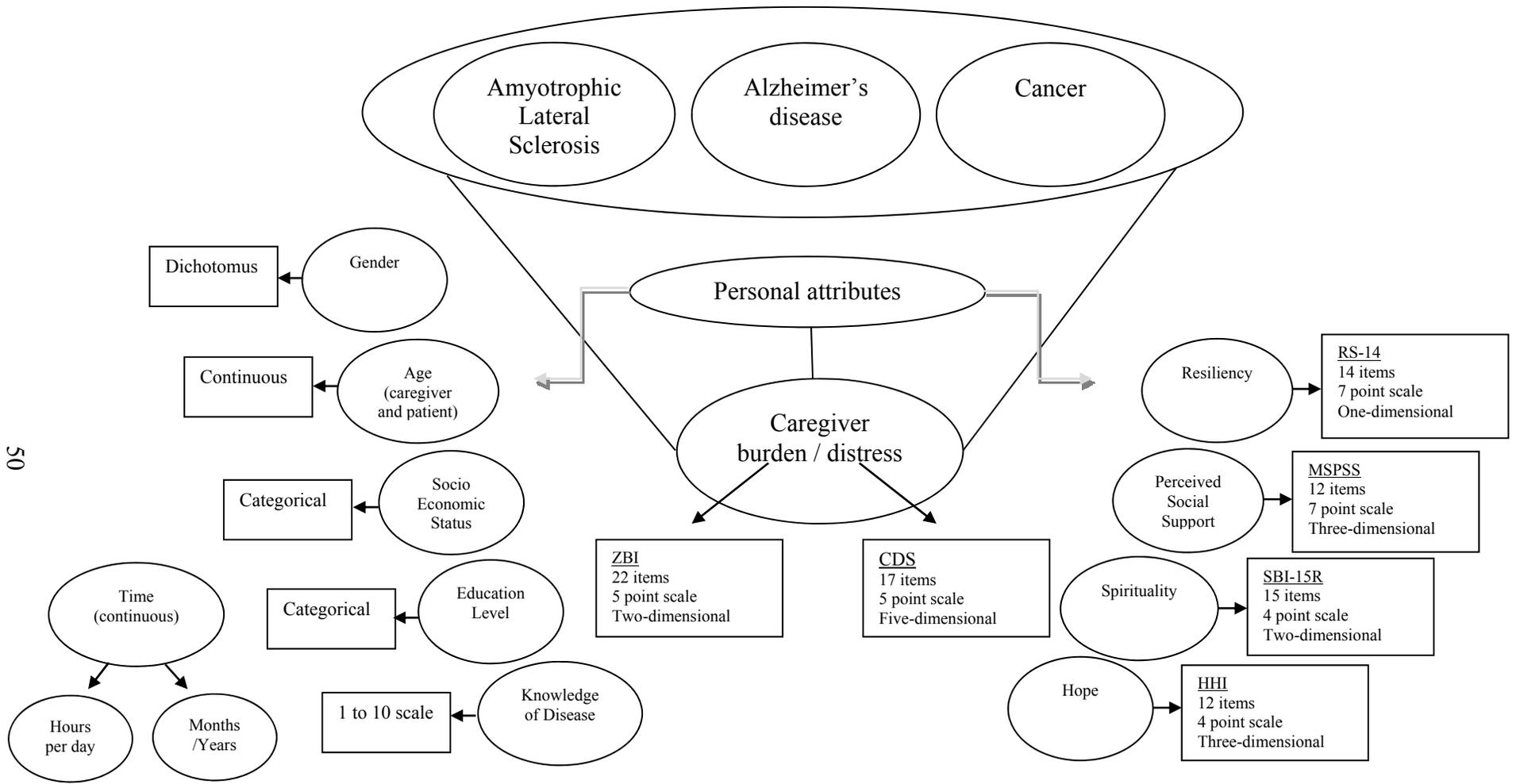


Figure 3.2. Instrumentation

The Zarit Burden Interview (ZBI) is one of the most common burden measures, but was developed with data from informal caregivers of AD patients (Zarit, et al., 1980). On the one hand, a majority of recent published research using the ZBI is with caregivers of dementia patients (Ankri, et al., 2005, Hebert, et al., 2000; Knight, et al., 2000; O'Rourke & Tuokko, 2003). On the other hand, the Caregiver Distress Scale (CDS), was developed with informal caregivers of Parkinson's patients (Cousins, et al., 2002), and most recently used with informal caregivers of stroke patients (Piggin, et al.). Table 3.2 provides evidence for the ZBI and the CDS.

Investigating the psychometric properties of the ZBI and the CDS within each caregiving type (AD, ALS, cancer) could provide convergent construct validity evidence for the measures within each disease type. Using both measures provided cross validation evidence and extracted factors could then be compared. Finally, having three different samples demonstrated the usefulness of the ZBI and CDS within specific disease types that had not previously been assessed.

Table 3.2

Evidence for Measurement Validity and Reliability of Caregiver Distress and Burden

Scale	Evidence of validity	Reference(s)
Zarit Burden Interview (ZBI)	The more recent 22 item format has shown fairly strong internal consistency (Cronbach's alpha = .80), but conclusions on the number of factors and what sub-construct they measure are mixed. Many studies report two factors (personal strain and role strain), but some have found these two factors with only 12 items, and others have found these two factors with all 22 items. Three factors have also been reported, some using 14 items and others using all 22 items. Recently, the ZBI was psychometrically evaluated with informal caregivers of brain injury patients, and evidence from Rasch and Confirmatory Factor Analysis supports the two factor (personal and role strain) model, but used 19 of the 22 items.	Zarit, Reever, & Bach-Peterson, 1980; Arai, Kudo, Hosokawa, Washio, Miura, & Hisamishi, 1997; Schulz, Tompkins, & Rau, 1988; Uttl, Santacruz, Litvan, & Grafman, 1998; Hebert, Bravo, & Preville, 2000; O'Rourke & Tuokko, 2003; Ankri, Andrieu, Beaufiles, Grand, & Henrard, 2005; Knight, Fox, Chou, 2000
Caregiver Distress Scale (CDS)	The CDS is a composite of four validated distress and burden scales. All four scales demonstrated strong internal consistency (Cronbach's alphas above .7). Clustering techniques were used to group survey items. Five clusters formed and redundant items within clusters were removed. The final scale with five sub-constructs consisted of 17 items with strong internal consistency (Cronbach's alpha = .88).	Cousins, Davies, Turnbull, & Playfer, 2002; Piggan, Davies, Thornton, Sharma, Kumar, et al., 2008

Procedure

The measures that were used in this study were recreated electronically using the Qualtrics program. Qualtrics is an online survey program that allows the researcher to create any type of scaled question. Each measure had a separate response box with clear

directions. The caregivers were able to see their progress on a scale of zero to 100 percent complete. The beginning page was the consent form, which explained the type of questions (resiliency, social support, hope, spirituality, and burden), as well as investigator contact information and the IRB approval number. There were no participant identifiers and all responses remained anonymous. The final screen thanked participants for their time, and once again gave investigator contact information. A number of participants contacted the investigator asking if they could send out the survey link to other caregivers. This was encouraged because the initial response rate was lower than expected.

The measures that were used were all previously published. Permission from the authors to use the instruments was solicited over email. All of the authors gave permission to use non-modified (author original) versions of their instruments. Each email correspondence was submitted to the IRB with the original proposal.

The first steps of the data collection phase involved communicating with different associations and research centers. Caregivers were contacted through a third party. Some of the third party contacts were the Alzheimer's Association, the ALS Association, the MDA, Radiant Research, Toghers, Johnson Adult Day Center, Rocky Mountain Cancer Center, and Gilda's Club.

The third-party contacts were given a study outline as well as a copy of the IRB approval cover page. The contacts then distributed the survey link to caregivers that were willing to participate. After one week, the contacts would remind the caregivers about the study, if they had not yet responded. Most associations do not give out membership information, so the third party contact was the only direct link to the participants.

Investigator information and contact details were provided with the survey link.

Initially, participants had to be a member of one of the stated organizations or research centers. This was problematic not only because they receive services from these associations, but some association chapters were not comfortable sending out a study link to their caregiving clients. Information about the study was posted on two caregiver forums and also given to leaders of various caregiver support groups.

Data Analysis

For the three methods-based research questions, exploratory factor analyses was conducted with all six instruments. There are arguments for and against analyzing total variance (principal components) rather than analyzing common variance (principal axis) (Tabachnick & Fidell, 2007). With principal components the decisions about factor loadings include error. With principal axis it adjusts or actually takes out error variance. Principal axis is more appropriate when the focus is on validity of underlying structures because the analysis is focused on shared or common variance, rather than focusing on unique error of the measures. In other words, principal components analysis is useful when the goal is to reduce the number of items, and exploratory factor analysis (principal axis factoring) is useful when the goal is to understand or verify the structure of a given instrument.

Varimax (orthogonal) rotation is commonly used in the literature, mainly because it is the first choice in SPSS. An oblique (oblimin) rotation does not force orthogonality, like with varimax (forcing factors to be uncorrelated). With varimax rotation, it is forcing potentially correlated factors to be uncorrelated which could lead to the loss of important

information (Tabachnick & Fidell, 2007). For the multidimensional instruments in this study, it is not logical to think that factors (within instruments) would not be correlated; therefore, oblique rotations were used within each exploratory factor analysis.

In order to identify the number of factors with exploratory factor analysis, decisions are commonly based on eigenvalues greater than one, but I also used other information like total variance accounted for by the factors and the scree plot, (Tabachnick & Fidell, 2007). Exploratory factor analysis (principal axis extraction) with number of factors indicated was used for each instrument that had supported factor structure. When the factor structure from this study was not congruent with previous findings (CDS and ZBI for questions two and three), principal components analyses were conducted to reduce items into a more succinct instrument to be used for other analyses. Internal consistency estimates were conducted for each instrument as well as for each factor of each instrument.

Instrument model fitting (confirmatory factor analysis) for questions two and three was completed for the two outcome measures (ZBI and CDS). Models were fit initially by what had been reported in the literature then re-analyzed using findings from previous exploratory factor analyses within this study.

The fourth research question, was essentially the overarching question which pertained to differences between diagnoses, was investigated through difference statistics. The three levels of care type (AD, ALS, cancer) was the independent variable and caregiver distress and burden were the dependent variables. Two one-way ANOVAs were used to assess burden differences between the caregiving groups, even though sample sizes were not equal between the groups. Further ANOVAs were calculated to

assess group differences in terms of caregiver attributes (resiliency, social support, hope, and spirituality).

The fifth research question investigated the relationships between each variable, and then was expanded upon for the sixth research question, which investigated the predictive relationship between the caregiver attributes and perceived distress and burden. Caregiver distress was regressed on the caregiver attributes. This was conducted in a hierarchical manner, with time and ADL variables in the first block, and the construct variables in the second block. The same approach was used for regressing caregiver burden on the caregiver attributes.

The seventh research question was what type of caregiver groupings could be formed through the combination of all variables. This research question involved clustering the data from the four personal attribute measures, in order to classify groups of caregivers. The idea behind cluster analysis was to classify a set of objects into homogeneous groupings based on object similarities (Hair, Anderson, Tatham, & Black, 1998). Discernable clusters formed and they were not dependent upon type of disease; therefore, further analyses were not conducted to assess differences in caregiver burden in terms of caregiver grouping and disease type.

The goal of cluster analysis was to form clusters that had minimal variation within the cluster, but larger variations between clusters (Kachigan, 1991). Cluster formations can be mutually exclusive from one another, or in a hierarchical formation (Kachigan, 1991). For many statistical techniques, existing groupings are used. The key characteristic that differentiates cluster analysis from other analyses is that in cluster

analysis the groups are undifferentiated at first and the goal is to form sub-groups with the given variables.

The problem with cluster analysis is that measures of similarity are used for cluster formation, but understanding what the different clusters mean and why we obtained a certain number of clusters can be difficult to interpret, so a structured six stage approach was utilized. Hair et al. (1998) proposed a six stage model-building approach to cluster analysis (objectives, research design, assumptions, derivation of clusters and overall fit, interpretation of clusters, and validation of the clusters). Within each stage there are guidelines to follow, but ultimately it came down to researcher judgment in terms of what made the most logical sense based on literature and theory.

Summary

Multiple demographic, attribute, distress and burden measures were used to assess the impact of informal caregiving between three different diagnoses (AD, ALS, and cancer). Detecting caregiver attributes was an important aspect to adequately model caregiver burden. Analysis techniques included descriptive statistics, difference tests, regression for model building, cluster analysis, and multiple types of factor analyses. The psychometric properties of each scale were assessed to understand functionality and give evidential support within the disease types of this study.

CHAPTER 4: RESULTS

Introduction

The purpose of this study was to explore caregiver characteristics associated with distress and burden. Caregiver characteristics included demographic variables (age, gender, education, income), disease characteristics (hours per day giving care, number of months giving care, activities of care given, knowledge of disease), and caregiver personal traits/states (resiliency, hope, spirituality and social support).

The variables were initially investigated using exploratory data analytic approaches (Morgan, Leech, Gloeckner, & Barrett, 2011). The psychometric properties of all six instruments were evaluated through various factor analytic procedures. The factor structures that were used in further analyses (regression and cluster analysis) were initially based on literature, and then re-computed based on factor and internal consistency results from this particular sample. Correlations were used to assess relationships between all variables, then hierarchies of variables were used within regression in order to model caregiver burden. Differences between caregiver groups (AD, ALS, and cancer) were assessed using ANOVAs and MANOVAs.

Treatment of the Data

The data were exported from Qualtrics to the Statistical Package for the Social Sciences (IBM SPSS) version 19. The initial dataset consisted of 107 responses (cases).

There were 12 cases that were thrown out due to large amounts of missing data (no questions completed, or only demographic questions completed). There were also five cases where some entire sections were skipped (the spirituality items for example). These cases were not thrown out because all of the other questions were completed. Data was replaced for seven individual questions. The group mean solution was used to replace missing data (Vaske, 2008). The sample was sorted into caregiving groups (AD, ALS, cancer) then the mean for the missing questions was calculated. The missing data were replaced with the group means for the given question. Further exploratory statistics were mainly used to assess normality, but also to determine if the major assumptions were met for factor analysis, regression, cluster analysis, and difference statistics.

Demographic Data

After eliminating 12 cases, data from 95 caregivers were used. As Table 4.1 shows, the majority of the caregivers were female (87.4%), caring for a male (65.3%) diagnosed with ALS (62.1%). Income levels ranged widely, but 59.6% of the sample earned over \$50,000 per year. The caregivers were highly educated with everybody having at least completed high school. Furthermore, over 50% had completed at least a bachelor's degree. The age of the caregivers ranged from 19 to 88, with a mean of 52, while the average patient age was 66. As expected the AD patients were the oldest group ($M = 80.66$, $SD = 9.16$), while the ALS patients ($M = 60.36$, $SD = 12.54$) were the youngest group with cancer patients in the middle ($M = 62.83$, $SD = 19.82$). The age (in years) of the AD and ALS caregivers was similar ($M = 52.59$, $SD = 18.76$ and $M = 53.66$, $SD = 12.32$ respectively), while the cancer caregivers were typically much younger ($M = 43.83$, $SD = 14.55$).

Table 4.1

Study Sample Demographics

Demographic Variable	N	Percent
Disease Type		
Alzheimer's disease	29	30.5%
Amyotrophic Lateral Sclerosis	59	62.1%
Cancer	7	7.4%
Caregiver Gender		
Female	83	87.4%
Male	12	12.6%
Patient Gender		
Female	33	34.7%
Male	62	65.3%
Caregiver Average Yearly Income		
Less than \$10,000	6	6.4%
\$10,000 to \$19,000	9	9.6%
\$20,000 to \$29,000	11	11.7%
\$30,000 to \$39,000	6	6.4%
\$40,000 to \$49,000	6	6.4%
\$50,000 to \$59,000	12	12.8%
\$60,000 to \$69,000	6	6.4%
\$70,000 or more	35	37.2%
Not Applicable	3	3.2%
Caregiver Highest Level of Education		
Completed high school	15	15.8%
Some college	20	21.1%
Completed a two-year degree	12	12.6%
Completed a Bachelor's degree	31	32.6%
Completed a Master's degree	12	12.6%
Completed a Doctorate	5	5.3%

Time and Disease Characteristics

Amount of time was measured in two ways. The first measure of time was the number of hours per day giving care. The second measure of time was how long a caregiver had given care to the current individual (years and months). In terms of hours

per day giving care, ALS caregivers reported the most ($M = 13.75$, $SD = 8.23$), followed by AD caregivers ($M = 10.17$, $SD = 8.55$), and cancer caregivers ($M = 7.33$, $SD = 1.21$). The range for AD and ALS caregivers went from 1 to 24 indicating that some caregivers were not yet deeply involved while other caregivers gave some type of care all day every day.

The number of months giving care aligned well with typical length of disease course. Caregivers for a person diagnosed with AD had been giving care, in months, the longest ($M = 50.86$, $SD = 54.10$) followed closely by cancer caregivers ($M = 48.71$, $SD = 8.38$). Typically, ALS caregivers had been giving care for the shortest amount of time ($M = 39.51$, $SD = 40.60$). As indicated by the standard deviations, the ranges of time giving care in months were quite large for the AD and ALS caregivers. Some of the caregivers had just started giving regular care, while one AD caregiver had been taking care of her mother for over 20 years.

Receiving some kind of paid help was similar for the AD caregivers (41.4%) and the ALS caregivers (47.5%), but only 28.6% of the cancer caregivers reported that they currently were receiving paid help. It is important to keep in mind that these sample sizes were low and not equal between groups. These characteristics may not be representative of the larger caregiving population.

Knowledge of the disease was measured on a scale of zero to 10, with zero meaning no knowledge of the disease and 10 meaning very knowledgeable. The actual range of scores went from .5 to 10, with the highest variability within the ALS caregiver group (exclusive range = 9.5). The mean for all groups was very high (AD, $M = 8.15$, $SD = 1.6$; ALS, $M = 7.83$, $SD = 1.83$; cancer, $M = 8.61$, $SD = 1.95$), indicating that either this

sample of caregivers were all very educated about the disease or asking perceived knowledge is not a good way to assess actual disease knowledge.

The type and intensity of care tasks were assessed through 17 modified activities and instrumental activities of daily living (Lawton & Brody, 1969; Lawton, 1971). Table 4.2 displays the 17 activities and instrumental activities of daily living. Activities of daily living (ADL) are basic self-care tasks like bathing, grooming and dressing (numbers 1 through 9). Instrumental activities of daily living (IADL) are basic life functioning tasks such as shopping, housekeeping and cooking (numbers 10 through 17). For each activity, the caregiver indicated *independent* if the person they care for could complete the activity without help, *needs some help* if the activity could only be completed with help, *dependent* if the caregiver had to completely perform the activity for the person, or *not applicable* if the activity was not part of the normal daily living experience. The items were scored as follows: *independent* and *not applicable* were scored as 1, *needs some help* was scored as 2, and *dependent* was scored as 3; therefore, the possible range was 17 to 51.

A statistically significant difference was found among the three caregiving groups in terms of intensity of care tasks, $F(2, 90) = 4.81, p = .010, \eta = .31$ Table 4.2 shows that the mean activities of daily living score was 41.22 for ALS caregivers, 36.28 for AD caregivers, and 35.17 for cancer caregivers. While ALS caregivers indicated more activities of care than the other caregiving groups, a conservative post hoc test (Bonferroni) indicated that the significant difference was between ALS and AD caregivers ($p = .019$) with an effect size of $d = .62$. On average, ALS caregivers assisted with every activity while AD caregivers assisted more with the IADL's. These findings

relate to the nature of the disease progression with ALS patients, because they lose the ability to use voluntary muscles, so all activities of daily living are impacted. With AD, the disease progression is different in the sense that the patient can be impaired but still be able to dress, bathe and feed, but not able to plan through instrumental activities like cooking, shopping and managing finances. The means for the cancer caregivers were similar to the AD caregivers. For the most part, the cancer caregivers in this study assisted/performed most of the IADL's but not the ADL's, except for the mobility type tasks (walking, climbing up stairs, and transferring).

Table 4.2

One-way Analysis of Variance Summary Table Comparing Disease Type on Activities of Daily Living that the Caregiver Helps Perform

Factor index	AD		ALS		Cancer		<i>F</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Total ADL's	36.28	8.18	41.22	7.69	35.16	6.43	4.81	.010
1) Bathing	1.93	.75	2.58	.65	1.83	.75		
2) Grooming	2.03	.68	2.56	.62	1.83	.41		
3) Dressing	1.76	.74	2.61	.67	1.67	.82		
4) Toileting	1.79	.77	2.39	.81	1.83	.75		
5) Oral Hygiene	1.79	.73	2.27	.81	1.50	.55		
6) Walking	1.62	.68	2.05	.84	2.00	.63		
7) Climbing Stairs	1.79	.68	1.95	.94	2.33	.82		
8) Mobility/ Transferring	1.83	.71	2.42	.72	2.17	.75		
9) Eating	1.45	.69	2.36	.74	1.33	.52		
10) Meal Planning/ Cooking	2.69	.54	2.29	.91	2.33	.52		
11) Shopping	2.69	.60	2.63	.72	2.67	.52		
12) Using the Phone	2.17	.71	2.00	.82	1.33	.82		
13) Managing Medications	2.66	.61	2.46	.77	2.17	.75		
14) Doing Laundry	2.59	.68	2.73	.64	2.83	.41		
15) Household Chores	2.45	.63	2.74	.61	2.83	.41		
16) Managing Finances	2.66	.67	2.53	.70	2.00	.63		
17) Driving	2.38	.90	2.42	.88	2.50	.84		

Methods Based Research Question Number One: Psychometric Properties of the Attribute Instruments

1. Do the psychometric properties of the four attribute instruments (resiliency, social support, hope, spirituality) align with findings from previous studies?

The psychometric properties were initially investigated through exploratory factor analyses (EFA) to understand the underlying structure of the instrument, followed by Cronbach's alphas to assess the internal consistency of the items. The assumptions for factor analysis were examined for all instruments prior to conducting the EFAs. For every instrument, each item was correlated, $r > .3$, with at least one other item. Sphericity tests (Bartlett) were significant for each instrument, indicating that the items were correlated enough for analysis (correlation matrix was statistically different than a zero correlation matrix). Having an adequate number of items for each predicted factor (sampling adequacy) was also reached through large Kaiser-Meyer-Olkin values ($KMO > .70$), for each instrument. Finally, the communalities (within instruments) for each item were all above .3 which indicates at least a moderate amount of shared variance between the items.

The purpose of this research question was not only to address construct validity, but also to assess the underlying latent factors of each instrument. The goal was not data reduction. Therefore, EFA with principal axis extraction was chosen over principal components analysis (PCA). While PCA is the more common approach, default in SPSS, it is not necessarily the most appropriate approach. The seemingly minuscule, but not trivial, difference between EFA and PCA is that with PCA, ones are used on the diagonal

of the correlation matrix, and for EFA, the communalities are used on the diagonal which tend to lead to smaller structure and communality coefficients, but effectively excludes error variance (Thompson, 2004). Oblique (Oblimin) rotation, as opposed to orthogonal rotation (Varimax) was used for each analysis because the literature did not suggest that the factors would be uncorrelated. Oblique rotations can produce stronger estimates of the true factors because they are not forced to be orthogonal or uncorrelated (Fabriger et al., 1999).

The Resilience Scale (RS-14)

The RS-14 was created from a larger 25 item five-factor instrument (Wagnild & Young, 1990). Later validation studies of the RS-14 indicated that even though it was derived from five factors it appeared to be more of a one-dimensional instrument of resiliency (Wagnild & Young, 1993). A specific number of factors were not indicated prior to analysis; therefore, extracted factors were assessed if their eigenvalues were greater than one.

After rotation, the first factor accounted for 54.28% of the variance, which is similar to what Wagnild (2009) reports in her Resilience Scale instrument manual. The second factor accounted for 8.59% of the total variance with an eigenvalue at 1.2. The two factors accounted for 62.87% of the total variance. Table 4.3 displays the items of the RS-14, the rotated factor loadings, and the communalities.

The first factor, which accounted for most of the explained variance, included four of the five items that were initially drawn from the *self-reliance* factor of the 25-item RS scale. The second factor only had three strong loadings ($> .6$) from items that

originally indexed *equanimity*. The second factor had a loading above 1 but only accounted for 8.59% of the total variance, and was highly correlated with the first factor (.71). Overall, a one-dimensional model appears to work well, but further analyses could be conducted to identify questions that could be eliminated to better strengthen the scale.

Internal consistency for each factor, as well as the entire instrument, was assessed. Cronbach's alpha for the items loading on factor one was .91, and for the items associated with factor two it was .85. The overall Cronbach's alpha for the RS-14 was .93 with all items contributing to the strong alpha, indicating internally consistent data. The RS-14 was used as a one-dimensional scale in further analyses discussed later in this chapter.

Table 4.3

Factor Loadings for the Rotated Factors – RS-14 (Note Loadings < .40 are omitted)

Item	Factor Loading		Communality
	Factor 1	Factor 2	
14) When I am in a difficult situation, I can usually find my way out of it.	.88		.76
8) I have self-discipline.	.82		.61
7) I can get through difficult times because I've experienced difficulty before.	.75		.46
12) In an emergency, I'm someone people can generally rely on.	.75		.70
6) I am determined.	.65		.71
5) I feel that I can handle many things at a time.	.62		.55
11) My belief in myself gets me through hard times.	.52		.49
2) I feel proud that I have accomplished things in life.	.49		.68
13) My life has meaning.	.44	.40	.67
4) I am friends with myself.		.97	.75
3) I usually take things in stride.		.77	.65
10) I can usually find something to laugh about.		.67	.71
1) I usually manage one way or another.		.49	.44
9) I keep interested in things.		.46	.62
Eigenvalues	7.60	1.20	
% of variance	54.27	8.59	

Scale of Perceived Social Support (MSPSS)

The MSPSS was developed and validated with samples from undergraduates (Zimet et al., 1988), pregnant women, adolescents, pediatric residents (Zimet et al., 1990), and older adults (Stanley, Beck, & Zebb). Three subscales of the MSPSS (friends, family, and significant other) have been consistent with findings from young adults to older adults, as well as between different cultures (Basol, 2008). However, no study has examined the psychometric properties of the MSPSS with informal caregivers.

Three factors were requested because the instrument was created to assess five aspects of perceived social support (friends, family, and significant other). The first factor accounted for 52.43% of the variance, 19.66% for the second factor and 12.83% for the third factor. The three factors accounted for 84.92% of the variance. Table 4.4 displays the items of the MSPSS, the rotated factor loadings, and the communalities.

The extracted factors aligned exactly with what had been described in the literature (Zimet et al., 1988; 1990). The first factor (family) had all four loadings above .7. The second factor (significant other) also had strong loadings for each proposed item, while the third factor (friends) showed strong negative loadings with each item.

Internal consistency was strong for all scale items (Cronbach's alpha = .92). Each factor's internal consistency was individually assessed with consistent findings of Cronbach's alphas > .92. Internal consistency findings from this study were consistent with other studies from various populations.

Table 4.4

Factor Loadings for the Rotated Factors – MSPSS (Note Loadings < .40 are omitted)

Item	Factor Loading			Communality
	Family	Sig Other	Friends	
4) I get the emotional help and support I need from my family.	.97			.87
3) My family really tries to help me.	.95			.89
8) I can talk about my problems with my family.	.86			.83
11) My family is willing to help me make decisions.	.75			.87
2) There is a special person with whom I can share my joys and sorrows.		.97		.74
1) There is a special person who is around when I am in need.		.95		.86
5) I have a special person who is a real source of comfort to me.		.87		.86
10) There is a special person in my life who cares about my feelings.		.73		.79
7) I can count on my friends when things go wrong.			-.94	.77
6) My friends really try to help me.			-.84	.71
9) I have friends with whom I can share my joys and sorrows.			-.83	.66
12) I can talk about my problems with my friends.			-.81	.63
Eigenvalues	6.29	2.36	1.54	
% of variance	52.43	19.66	12.83	

Systems Belief Inventory (SBI-15R)

The SBI-15R is a shortened version of the two-factor SBI-54 which was initially assessed using cancer patients. The two factors of the SBI-54 were *spiritual beliefs/practices* and *social support* related to a religious community. The SBI-15R contains 10 items from the *spiritual beliefs/practices* factor and five items from the *social support* factor of the SBI-54. The SBI-15R contained two proposed factors from previous studies (Holland et al., 1998), therefore two factors were requested during analysis. After rotation, the first factor accounted for 73.5% of the variance, while the second factor had a small eigenvalue (.97) and only accounted for 6.4% of the total variance. Table 4.5 displays the items, rotated factor loadings, and communalities for each item of the SBI-15R.

The extracted factors were mostly consistent with the literature. The beliefs factor had loadings above .4 for all ten of the proposed items, but numbers 1 and 8 crossloaded slightly higher on the second (religious social support) factor. The second factor had loadings above .75 from the five proposed items, but only accounted for a small percentage of the total explained variance. Internal consistency was assessed for the total instrument, and then re-assessed for each factor individually. Cronbach's alpha for the entire scale was .97, which is strong but consistent across other studies (Baider et al., 2001; Holland et al., 1998). The two factors or sub-scales were also internally consistent with a Cronbach's alpha of .97 for the *spiritual beliefs/practices* sub-scale, and .94 for the *social support* sub-scale. The two sub-scales were also strongly correlated (.82); therefore, further analyses discussed later in this chapter use the SBI-15R as a total score rather than scores from the two subscales, which reduces chances of multicollinearity.

Table 4.5

Factor Loadings for the Rotated Factors – SBI-15 (Note Loadings < .40 are omitted)

Item	Factor Loading		Communality
	Beliefs	Support	
6) I believe God will not give me a burden I cannot carry.	.94		.76
14) I believe God protects me from harm.	.94		.84
12) One's life and death follows a plan from God.	.86		.82
15) I pray for help during bad times.	.83		.74
4) I feel certain that God in some form exists.	.77		.79
2) Prayer or meditation has helped me cope during times of serious illness.	.66		.72
10) I have experienced a sense of hope as a result of my religious or spiritual beliefs.	.65		.87
11) I have experienced a sense of hope as a result of my religious or spiritual beliefs.	.49	.43	.88
9) When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.		.94	.85
13) I seek out people in my religious or spiritual community when I need help.		.94	.75
3) I enjoy attending religious functions held by my religious or spiritual group.		.80	.76
5) When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.		.78	.69
7) I enjoy meeting or talking often with people who share my religious or spiritual beliefs.		.76	.79
8) During times of illness, my religious or spiritual beliefs have been strengthened.	.48	.52	.91
1) Religion is important in my day-to-day life.	.46	.48	.84
Eigenvalues	11.03	.97	
% of variance	73.54	6.4	

Herth Hope Index (HHI)

The Herth Hope Index is shortened scale that had been derived from the longer Herth Hope Scale. The initial validation study of the HHI was conducted with 172 adults that were acutely, chronically or terminally ill (Herth, 1992). Initial factorial findings suggested a three factor model with four items supporting each factor. The bottom of table 4.6 lists the proposed items of Herth's initial work. Her factors were distinct in terms of inter-factor correlations ($r < .25$), partially because an orthogonal rotation (varimax) was used. In Herth's proposed model, the three factors accounted for only 41% of the total variance, but all of the individual items were acceptably correlated ($r > .4$) together.

Three factors were requested for this study, based on Herth's (1992) findings. The first factor (items: 1, 2, 4, 5, 10, 11, and 12) accounted for 48.41% of the variance. The second factor (items: 3 and 6) accounted for 9.88% of the total variance, which was problematic because those were the only two negatively worded items. The third factor (items: 7, 8, and 9) had an eigenvalue of .86 and only explained 7.15% of the total variance, but all three factors together explained 65.43% of the total variance. Table 4.6 displays the items and loadings, which are very different than what had been proposed in the literature.

An additional exploratory factor analysis was conducted to assess factorial loadings when questions three and six were eliminated from the analysis. Only one factor was extracted and accounted for 54.36% of the total variance. This suggests that a one-factor solution may be the best fit for the HHI, which has been consistent with current research (Phillips-Salimi, Haase, Kintner, Monahan, & Azzouz, 2007).

Internal consistency was assessed for Herth's (1992) three proposed factors, as well as for all items and then for only the positively worded items. Cronbach's alphas for the three factors, containing the items proposed for the literature were .68, .81, and .60 respectively. The first and the third factor demonstrate further problems with the proposed factors. Cronbach's alpha for all items was .88 and .90 when items three and six were removed. The alphas did not change drastically when the two negatively worded items were removed; therefore, further analyses with the HHI used all items as a one-dimensional scale.

Table 4.6

Factor Loadings for the Rotated Factors – HHI (Note Loadings < .30 are omitted)

Item	Factor Loading			Communality
	Factor 1	Factor 2	Factor 3	
1) I have a positive outlook toward life.	.74			.65
4) I can see possibilities in the midst of difficulties.	.63			.55
12) I feel my life has value and worth.	.59		-.38	.70
5) I have faith that gives me comfort.	.57			.26
10) I have a sense of direction.	.57			.61
2) I have short and/or long range goals.	.54			.44
11) I believe that each day has potential.	.47		-.32	.55
6) I feel scared about my future.		.88		.34
3) I feel all alone.		.38		.30
9) I am able to give and receive caring/love.			-.93	.60
7) I can recall happy/joyful times.			-.56	.46
8) I have deep inner strength.	.34		-.37	.48
Eigenvalues	5.81	1.19	.86	
% of variance	48.41	9.88	7.15	
Proposed items from the literature with loadings above .5 (Herth, 1992):				
Inner sense of temporality and future — Items 1, 2, 6, 11				
Inner positive readiness and expectancy — Items 4, 7, 10, 12				
Interconnectedness with self and others — Items 3, 5, 8, 9				

**Methods Based Research Questions Numbers Two and Three: Psychometric
Properties of the Outcome Measures**

2. *The Caregiver Distress Scale (CDS) was created and validated by Cousins et al. (2002), using a different caregiving population that is not part of this proposed study (Parkinson's disease). Does the CDS accurately assess distress, using classical test theory, within the sample of this study (AD, ALS, cancer)?*

3. *The Zarit Caregiver Burden Inventory (Zarit, et al., 1980) was created for use with dementia caregivers and is currently one of the most common inventories for dementia care. Does the Zarit Caregiver Burden Inventory accurately assess burden, using classical test theory, within the sample of this study (AD, ALS, cancer)?*

Caregiving Distress Scale (CDS)

The Caregiving Distress Scale (CDS) was initially created with Parkinson's disease caregivers, and has not been widely used with caregivers of other diagnoses. The formation of the CDS occurred in multiple stages, first by combining items from previously validated instruments, followed by multiple stages of clustering factor analyses (Cousins et al., 2002). The original research has suggested a 17-item five factor solution. Further research has not yet confirmed the five factor solution, nor suggested a different solution. The initial step for this study was to run an exploratory factor analysis in order to assess the underlying dimensionality of the instrument. The initial five factor solution is presented in table 4.7.

Table 4.7

Factor Loadings for the Rotated Factors - CDS (Note Loadings < .30 are omitted)

Item	Factor Loading					Communality
	1	2	3	4	5	
4) I feel frustrated with caring for __	.90					.78
9) Caring for __ has made me nervous	.83					.73
5) My relationship with __ depresses me	.70					.79
15) I feel overwhelmed by caring for __	.50		-.34			.76
3) I take part in other social activities less		.90				.85
2) I visit my family/friends less		.90				.84
1) I take part in organized activities less		.86				.75
10) I feel __ can only depend on me			-.90			.87
12) I feel helpless in caring for __	.34		-.51		.33	.80
6) I feel pressured between giving to __ and others in the family				.63		.77
7) I feel that my own health has suffered because of __				.63		.77
16) __ makes more requests than necessary					.94	.76
14) __ tries to manipulate me					.88	.87
13) My relationship with __ no longer gives me pleasure			-.42		.54	.78
11) I feel resentful towards __	.40				.50	.78
17) I feel that my personal life has suffered because of __					.46	.69
8) My relationship with __ is strained	.40				.45	.77
Eigenvalues	8.44	2.37	1.10	.77	.67	
% of variance	49.66	13.97	6.46	4.51	3.94	
Proposed Items from Cousins et al., 2002:						
Relationship distress — Sum of items 5, 8, 11, 13						
Emotional burden — Sum of items 4, 9, 12, 15						
Care-receiver demands — Sum of items 6, 14, 16						
Social impact — Sum of items 1, 2, 3						
Personal cost — Sum of items 7, 10, 17						

Five factors were requested based on the literature, but none of the proposed factors contained all of the suggested items. The five factors accounted for 78.52% of the total variance, which is about 10% more than in Cousins et al. (2002) original study, but the factors are problematic. Only three of the factors have eigenvalues above 1 and the structure is not interpretable; therefore, further exploratory factor analyses were conducted to discover a different factor structure with items removed.

The second exploratory factor analysis was a re-run of the first but only extracting factors with eigenvalues greater than 1, presented in Table 4.8. All of the items remained in the model for this analysis but loaded in a much different order than the previous analysis because only three factors were extracted. The first factor contained 13 items and accounted for 49.66% of the total variance. The second factor contained three items that solely loaded on the second factor, and accounted for 13.97% of the total variance. Factor three was made up of three items, but all three items were dually loaded on another factor, providing evidence that they could be removed because all three items loaded higher than .4 on more than one factor. In regards to removing other items, number 7 dually loaded, but its highest loading was only .49. The four dual loading items were removed and the analysis was re-computed.

The final exploratory factor analysis procedure involved running the analysis with only 13 of the 17 CDS items. Four items from the previous analysis were removed based on either low loadings ($< .5$), or high dual loadings ($> .4$). Factors were extracted based on eigenvalues greater than one, and then reconfirmed by visually assessing the scree plot.

Table 4.8

Factor Loadings for the Three Rotated Factors - CDS (Note Loadings < .30 are omitted)

Item	Factor Loading		
	1	2	3
11) I feel resentful towards __	.90		
5) My relationship with __ depresses me	.87		
13) My relationship with __ no longer gives me pleasure	.86		
8) My relationship with __ is strained	.85		
12) I feel helpless in caring for __	.82		
14) __ tries to manipulate me	.82		.46
15) I feel overwhelmed by caring for __	.77		
17) I feel that my personal life has suffered because of __	.73		
9) Caring for __ has made me nervous	.71		
4) I feel frustrated with caring for __	.71		
6) I feel pressured between giving to __ and others in the family	.69		
16) __ makes more requests than necessary	.66		.54
7) I feel that my own health has suffered because of __	.49	.38	
3) I take part in other social activities less		.93	
2) I visit my family/friends less		.91	
1) I take part in organized activities less		.87	
10) I feel __ can only depend on me	.42		-.67
Eigenvalues	8.44	2.37	1.10
% of variance	49.66	13.97	6.46

Table 4.9 shows the two factor solution in which factor one explained 52.57% of the variance, and factor two explained 17.14% of the total variance. The two factor solution explained a total of 69.72% of the total variance which is similar to the previous model, but also similar to Cousins et al. (2002) findings. The first factor, of the 13 item two factor solution, contained 10 items that appeared to index relationship and emotional distress. The second factor contained only three items, but they were the original three designed to index social impact.

Internal consistency was assessed for all 17 items together as well as for the items within the two factors of the newly proposed 13 item solution. With all 17 items, Cronbach's alpha was .95. By removing the four previously mentioned items (numbers 7, 10, 14, 16) Cronbach's alpha dropped to .92. The first factor (10 items) of the new solution had a Cronbach's alpha of .94, while the second factor (3 items) was .88. Cronbach's alpha far exceeded the acceptability criteria for each factor, indicating an internally consistent instrument.

Table 4.9

Factor Loadings for the Two Rotated Factors - CDS (Note Loadings < .30 are omitted)

Item	Factor Loading	
	1	2
11) I feel resentful towards __	.89	
5) My relationship with __ depresses me	.88	
8) My relationship with __ is strained	.84	
13) My relationship with __ no longer gives me pleasure	.84	
12) I feel helpless in caring for __	.80	
15) I feel overwhelmed by caring for __	.77	
17) I feel that my personal life has suffered because of __	.71	
4) I feel frustrated with caring for __	.70	
9) Caring for __ has made me nervous	.70	
6) I feel pressured between giving to __ and others in the family	.65	
3) I take part in other social activities less		.94
2) I visit my family/friends less		.86
1) I take part in organized activities less		.73
Eigenvalues	6.84	2.23
% of variance	52.57	17.14

The final step for assessing the psychometric properties of the CDS, involved conducting a confirmatory factor analysis (CFA) on the 13 item version, and comparing the model fit indices to that from the original five factor model.

The initial confirmatory analysis was to evaluate the overall fit of the original

model and the fit for the 13-item model. All 17 items were entered into SAS according to their proposed loadings from Cousins et al (2002). A variety of indices are used to assess overall fit of a model. A good model fit is typically indicated through a Goodness of Fit Index (GFI) greater than .9, root mean square residual (RMSR) less than .05, and a non-significant chi-square with a χ^2/df ratio around 1.

The initial model (17-items with five factors) with orthogonal dimensions did not fit the data, $\chi^2(119) = 451.24, p < .0001$, GFI = .63, and RMSR = .66. The first CFA forced the dimensions (factors) to be uncorrelated; therefore a second analysis using the same model, but with oblique dimensions (correlated factors) was conducted. This model fit the data better than the previous model according to the RMSR = .12, but did not fit well according the other indices, $\chi^2(109) = 172.97, p < .0001$, GFI = .82. Also, the personal cost factor was highly correlated with three other factors: *relationship distress* ($r = .86$), *emotional burden* ($r = .85$), and *care-receiver demands* ($r = .73$), indicating that some factors were not accounting for additional variance within the model.

The 13-item two factor version proposed earlier, was developed through a series of steps which involved multiple EFA's in order to reduce items without losing explained variance. The first CFA with this model forced orthogonal dimensions that did not fit the data $\chi^2(65) = 106.49, p = .0009$, GFI = .86, and RMSR = .17. Finally, A second CFA, that did not force orthogonality, was conducted on the same model. This was the best fitting model for the data, $\chi^2(64) = 99.28, p = .0031$, GFI = .86, and RMSR = .08. The two factors (*relationship/emotional distress* and *social impact*) were marginally correlated ($r = .30$), indicating that the two factors explained unique variance. Even though the χ^2 indicated a lack of fit to the data, an acceptable fit could be assumed

through the two other fit indices (GFI = .86, and RMSR = .08).

The psychometric properties of the CDS were examined through a multi-step process. Exploratory factor analysis was initially used to understand the underlying latent variables of the scale. Loadings were assessed and items were removed based upon high dual loadings or low single loadings. The next EFA produced two factors (with 13 items), that explained the same amount of variance as the original EFA (requesting five factors). The final steps were to assess how the different models fit the data. Cousins et al. (2002) model, fit according to some indices but had multiple high correlations (above .7) between the factors. The 13-item version adjusted for the high correlations by removing four items to condense the instrument into two factors. The two factors within the final CFA were not highly correlated, and the model fit the data reasonably well according to the GFI and RMSR, but the χ^2 was still significant.

Zarit Burden Interview (ZBI)

The ZBI has been one of the most widely used instruments, to assess caregiver burden, over the last 30 years. The initial design of the ZBI was with 29, five point scale items (Zarit et al. 1980). Limited psychometric evidence was given in that first article, but later studies either presented or used a 22-item version of the ZBI (Zarit, 1992; Zarit, 1994). The 22-item version has been widely used, but the multidimensionality has not been consistent. In the 1990 instrument manual, Zarit and Zarit described two factors (*personal strain* and *role strain*), with four unassigned items (items 7, 10, 15, and 22). Additional studies, with caregivers of dementia patients, verified the two factor model with all items (Whitlach, Zarit, & von Eye, 1991; Bedard, Molloy, Squire, Dubois, Lever,

& O'Donnell, 2001), or with only 12 items (O'Rourke & Tuokko, 2003). Other studies have suggested three factors with a modified number of items (Ankri et al., 2005; Knight et al., 2000).

The initial exploratory factor analysis extracted factors based on eigenvalues above 1. Five factors were extracted, but the pattern was not consistent with the literature, and three of the factors combined only accounted for less than 17% of the total variance. The second step was to re-run the analysis but request only three factors. The eigenvalues and variance accounted for was not important for this step, because it would have been the same as the previous EFA. The goal was to investigate the structure of three factors, which has been suggested in the literature, rather than five factors. Table 4.10 indicates that the first factor had an eigenvalue of 9.56 and explained 43.43% of the total variance. Multiple items had their highest loading below .5 (numbers 3, 11, 17, 22), and two items (2 and 10) had marginal dual loadings above .3. The three factors explained a total of 58.93% of the total variance.

Table 4.10

Factor Loadings for the Three Rotated Factors - ZBI (Note Loadings < .30 are omitted)

Item	Factor Loading		
	1	2	3
13) I feel uncomfortable about having friends over because of him/her.	.91		
18) I wish I could leave the care of this person to someone else.	.84		
5) I feel angry when I am around the person I care for.	.80		
9) I feel strained when I am around the person I care for.	.71		
16) I feel that I will be unable to take care of him/her much longer.	.70		
6) I feel that he/she currently affects my relationship with other family members or friends in a negative way.	.69		
19) I feel uncertain about what to do about the person I care for.	.62		
4) I feel embarrassed over his/her behavior.	.58		
21) I feel I could do a better job in caring for him/her.		.86	
20) I feel I should be doing more for him/her.		.85	
7) I am afraid of what the future holds for the person I care for.		.62	
15) I feel that I do not have enough money to support this person in addition to the rest of our expenses.		.61	
3) I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work.		.49	.44
17) I feel that I have lost control of my own life since this person's illness.	.35	.48	
14) I feel that this person expects me to take care of him/her as if I was the only one he/she could depend on.			.75
8) I feel he/she is dependent upon me.			.68
1) I feel that the person I care for asks for more help than he/she needs			.63
12) I feel that my social life has suffered because I am caring for this person.			.63
2) Because of the time I spend with him/her, I do not have enough time for myself		.36	.61
10) I feel that my health has suffered because of my involvement with the person I care for.		.31	.57
11) I feel that I do not have as much privacy as I would like because of the person I care for.	.32		.49
22) Overall, how burdened do you feel in caring for this person?	.42		.44
Eigenvalues	9.56	2.00	1.42
% of variance	43.40	9.07	6.43

Three more EFA's were conducted in order to have factors that contained items with high loadings that did not dually load. Many items were removed based on either dual loadings or overall low loadings. Items 20 and 21 had consistently loaded together because they were highly correlated ($r = .73$). These two items had been reported to make up a third factor of guilt, but caused problems in this analysis due to high commonalities. The final solution included 10 items, Table 4.11. The first factor contained seven personal strain items while the second factor contained only three *role expectation* items. The overall explained variance of the two factors was 61.17% was acceptable, but many items were removed to reach this point.

The EFA process to reach a solution containing only 10 of the 22 items involved a number of decision points in terms of what items to remove. Research using the ZBI, in terms of derived factors has not been consistent. In order to understand the fit of the 10 items, a confirmatory factor analysis was conducted.

Two CFA models were computed using SAS. The first model specified the two factors (7 items for factor 1 and 3 items for factor 2), but forced the two factors to be orthogonal. The chi-square was significant $\chi^2(35) = 59.29, p = .0063$, indicating that the model did not fit the data, but the other fit indices were acceptable GFI = .86, and RMSR = .08. The second CFA allowed for the two factors to be correlated, $\chi^2(34) = 34.10, p = .3282$, GFI = .92, and RMSR = .06, indicating that the model fit the data. The important piece is that the model fit when the factors were allowed to correlate. The two factors were highly correlated ($r = .60$) which means that these two factors may be underlying one sub-construct rather than two (*personal strain* and *role strain*)

The 10 item ZBI was derived through multiple factor analyses, which involved

the deletion of items based on researcher set criteria. With that said, the overall ZBI (22 items) demonstrated strong internal consistency (Cronbach's alpha = .93). The 22-items were used as a summed index outcome measure for a number of other analyses within this study.

Table 4.11

Factor Loadings for the Two Rotated Factors - ZBI (Note Loadings < .30 are omitted)

Item	Factor Loading	
	1	2
13) I feel uncomfortable about having friends over because of him/her.	.88	
18) I wish I could leave the care of this person to someone else.	.79	
6) I feel that he/she currently affects my relationship with other family members or friends in a negative way.	.73	
16) I feel that I will be unable to take care of him/her much longer.	.69	
9) I feel strained when I am around the person I care for.	.62	
5) I feel angry when I am around the person I care for.	.62	
4) I feel embarrassed over his/her behavior.	.43	
14) I feel that this person expects me to take care of him/her as if I was the only one he/she could depend on.		.75
1) I feel that the person I care for asks for more help than he/she needs		.62
8) I feel he/she is dependent upon me.		.47
Eigenvalues	4.80	1.32
% of variance	48.00	13.17

Content Research Question Number Four

4. *What are the differences in distress and burden of being a caregiver for a terminally ill family member in terms of three types of care (ALS, AD, cancer)?*

Inferential statistics were used to assess the differences between the three caregiver groups in terms of distress and burden, but also with regards to resiliency, social support, spirituality and hope. For each analysis, the total score on the given instrument was treated as the dependent variable and diagnosis was the independent variable. The assumptions related to ANOVA were assessed and met prior to analysis.

In terms of differences between disease in reference to burden and distress, Table 4.12 shows that AD caregivers scored slightly higher than ALS and cancer caregivers on both the ZBI (possible range of 22 to 110), and the CDS (possible range of 17 to 85, with 51 as the neutral point). With that said, Table 4.13 indicates that there were no statistically significant differences between disease type in terms of caregiver burden, $F(2, 86) = .39, p = .681$, and caregiver distress, $F(2, 86) = .40, p = .672$. The ZBI contained 22 items that were scored from one being *never* to five being *nearly always*. Most caregivers in this sample ($M = 58.46, SD = 17.07$) would not have been considered highly burdened. The same is true for the results on the CDS. The CDS contained 17 items that were scored from one being *strongly disagree* to five being *strongly agree*, with higher scores indicating higher degrees of distress. The caregivers in this sample ($M = 49.13, SD = 14.86$) were not highly distressed. The differences between the groups were ultimately trivial, on average the caregivers were not highly burdened or distressed.

Table 4.12

Means and Standard Deviations Comparing Three Disease Types on Caregiver Burden (ZBI) and Caregiver Distress (CDS)

Disease Type	<i>n</i>	<u>Burden</u>		<u>Distress</u>	
		<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Alzheimer's disease	26	59.27	19.56	51.15	18.56
Amyotrophic Lateral Sclerosis	58	58.65	15.99	48.50	13.40
Cancer	5	52.00	17.89	46.00	10.07
Total	89	58.46	17.07	49.13	14.86

Table 4.13

One-Way Analysis of Variance Summary Table Comparing Three Disease Types on Caregiver Burden (ZBI) and Caregiver Distress (CDS)

Source	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
ZBI					
Between groups	2	227.74	113.87	.39	.681
Within groups	86	25406.50	295.42		
Total	88	19432.38			
CDS					
Between groups	2	178.50	89.25	.40	.672
Within groups	86	19253.89	223.88		
Total	88	25634.24			

Further analyses were conducted to assess the differences between caregivers of the three disease types in regard to the four attribute characteristics (resiliency, social support, spiritual beliefs, and hope). For each analysis, the total score on the given instrument was treated as the dependent variable and diagnosis was the independent variable. Note that some instruments had multiple sub-factors. Analyses were also computed with the sub-factors, but the differences were minimal; therefore, the summed indices for each instrument were used. The purpose of these analyses was not to show that disease type influences these characteristics, but rather to understand the caregiving groups prior to modeling caregiver burden (research question six). Assumptions related to ANOVA were assessed and met for all instruments except the RS-15. The RS-15 was severely negatively skewed because one caregiver responded with all ones (*strongly disagree*) indicating low levels of resiliency. This case was not dropped from the analysis because it appeared to be a valid response based on responses to the other scales. An ANOVA and a nonparametric version (Kruskal-Wallis) were computed with a similar outcome; therefore, results from the ANOVA rather than the Kruskal-Wallis have been presented.

The instruments for the following analyses were scored slightly differently. For resiliency (RS-15), there were 15 items that were scored from one (*strongly disagree*) to seven (*strongly agree*), with higher scores indicating higher levels of resiliency (possible range of 15 to 105, with 60 as the neutral point). The scale measuring perceived social support (MSPSS) included 12 items scored from one (*very strongly disagree*) to seven (*very strongly agree*), with higher scores indicating higher levels of perceived social support (possible range of 12 to 84, with 48 as the neutral point). Spiritual beliefs (SBI-

15R) were measured with 15 items, scored from one (*strongly disagree*) to four (*strongly agree*), with higher scores indicating higher levels of spiritual beliefs (possible range of 15 to 60, with 37.5 as the technical middle point). Finally, for hope (HHI), there were 12 items that were scored from one (*strongly disagree*) to four (*strongly agree*), with higher scores indicating higher levels of hope (possible range of 12 to 48, with 30 as the technical middle point).

There were slight differences between the three caregiver groups in terms of the four scales previously described. Table 4.14 shows that none of the three caregiving groups were consistently high or low on all of the scales. The overall averages, as well as the average by disease type, were well over the middle point for each scale. In general, these caregivers were resilient, had social support, were spiritual, and hopeful.

The differences between the three groups of caregivers were not statistically significant for resiliency, $F(2, 88) = .37, p = .694$, social support, $F(2, 86) = 1.87, p = .160$, spirituality $F(2, 86) = .59, p = .554$, or hope $F(2, 84) = .67, p = .514$. Table 4.15 displays the full ANOVA summary table for each analysis. Ultimately, the three caregiving groups were similar in regards to resiliency, social support, spirituality, and hope.

Table 4.14

Means and Standard Deviations Comparing Three Disease Types on Resiliency (RS-15), Social Support (MSPSS), Spirituality (SBI-15R), and Hope (HHI)

Disease Type	RS-15			MSPSS			SBI-15R			HHI		
	<i>n</i>	<i>M</i>	<i>SD</i>									
Alzheimer's disease	27	81.30	10.55	26	62.12	13.80	26	42.15	16.60	25	37.44	5.86
Amyotrophic Lateral Sclerosis	59	78.82	13.65	58	66.72	10.20	58	45.69	12.76	57	38.95	5.56
Cancer	5	80.00	1.58	5	69.60	4.67	5	43.20	13.55	5	39.00	2.00
Total	91	79.62	12.39	89	65.54	11.30	89	44.52	13.95	87	38.52	5.51

Table 4.15

One-Way Analysis of Variance Summary Table Comparing Three Disease Types on Resiliency (RS-15), Social Support (MSPSS), Spirituality (SBI-15R), and Hope (HHI)

Source	<i>df</i>	<i>SS</i>	<i>MS</i>	<i>F</i>	<i>p</i>
RS-15					
Between groups	2	114.48	57.24	.37	.694
Within groups	88	13707.26	155.76		
Total	90	13821.74			
MSPSS					
Between groups	2	468.67	234.34	1.87	.160
Within groups	86	10777.44	125.32		
Total	88	11246.12			
SBI-15R					
Between groups	2	233.63	116.81	.59	.554
Within groups	86	16902.60	196.52		
Total	88	17136.23			
HHI					
Between groups	2	41.05	20.53	.67	.514
Within groups	84	2569.38	30.59		
Total	86	2610.43			

Additional difference tests were conducted to investigate differences between caregiver gender on the two outcome measures of burden and distress. Two independent samples *t*-tests were computed to investigate whether males or females differ in regards to burden and distress. Findings from previous studies have indicated that females are typically the primary caregivers and males tend to be secondary or tertiary caregivers.

In this sample of caregivers who filled out both the ZBI and CDS, females ($n = 77$) outnumbered males ($n = 12$), but did not differ in terms of hours per day giving care (females = 12.02, males = 13.58), number of months giving care (females = 43.18, males = 47.67) and assisting with activities of daily living (females = 39.26, males = 39.50). The female caregiver group was much larger than the male caregiver group, so the analyses were run using parametric and non-parametric tests. The findings were not different; therefore, results from the independent *t*-tests rather than the Mann-Whitney test are presented here.

Table 4.16 shows that males indicate significantly less burden than females, $t(87) = 2.52, p = .014, d = .79$, but not distress $t(87) = 1.66, p = .101, d = .49$. There was a statistically significant difference between males and females in terms of caregiver burden, with a relatively large effect size. Further inspection of the practical significance indicated a large confidence interval, which did not include zero (2.73 to 23.18). The difference between males and females on the ZBI is interesting, but neither group was overly burdened. Females on average were close to the middle point (sometimes feeling burden) while males typically answered either never or rarely feeling burden.

Table 4.16

Comparison of Males and Females on Caregiver Burden (ZBI) and Caregiver Distress(CDS)

Variable	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>	95% confidence interval	
							Lower	Upper
Burden			2.52	87	.014	.79	2.73	23.18
Males (<i>n</i> = 12)	47.25	16.18						
Females (<i>n</i> = 77)	60.26	16.63						
Distress			1.66	87	.101	.49	1.50	16.65
Males (<i>n</i> = 12)	42.58	14.29						
Females (<i>n</i> = 77)	50.16	14.78						

Content Research Question Number Five

5. What are the relationships between caregiver personal attributes and distress and burden?

The relationships between each variable were assessed through correlations to understand their associations before a regression model was built. The variables were relatively normal in distribution, but two variables (*caregiver gender* and *receiving paid help*) were dichotomous. The dichotomous variables were included based on previous descriptive information (caregiver gender being associated with burden levels). Pearson correlations were computed (Spearman rho was used to confirm *r*s for the dichotomous variables) to examine the intercorrelations of all variables. Table 4.17 shows that 12 of the 15 pairs of variables related to the measured constructs (resiliency, social support, spirituality, hope, distress and burden) were significantly correlated.

The two dependent measures (CDS and ZBI) were strongly correlated, $r(87) = .85, p < .001$, which demonstrates evidence for convergent construct validity for the two outcome measures. The relationships of the independent attribute measures were consistent between both the CDS and the ZBI. In regards to caregiver burden (ZBI), the strongest relationships were with hope (HHI), $r(85) = -.52, p < .001$, and social support (MSPSS), $r(87) = -.45, p < .001$, which suggests that as hope or social support increases burden decreases, and vice versa. Burden (ZBI) was also moderately correlated with resiliency (RS-15), $r(87) = -.29, p = .006$, indicating that with this sample, caregivers that reported higher levels of resiliency reported lower levels of burden, and vice versa. Caregiver distress (CDS) relationships were very similar to the ZBI in regards to the HHI, $r(85) = -.48, p < .001$, the MSPSS, $r(87) = -.46, p < .001$, and the RS-15, $r(87) = -.24, p = .022$.

Table 4.17

Pearson Product Moment Correlations for Measured Variables

Variable	M	SD	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. RS-15	79.62	12.40	-	.29**	.22*	.51**	-.24*	-.29**	.12	.10	.02	.08	.05	-.01	.11	.15
2. MSPSS	65.54	11.30	-	-	.18	.52**	-.46**	-.45**	.06	.04	-.28**	-.01	.22*	-.00	-.17	.03
3. SBI-15R	44.52	13.95	-	-	-	.34**	-.06	-.15	-.02	.18	-.07	-.02	-.19	.15	.09	.04
4. HHI	38.52	5.51	-	-	-	-	-.48**	-.52**	.12	.15	-.17	.04	.04	-.03	-.14	.12
5. CDS	49.13	14.86	-	-	-	-	-	.85**	.00	-.03	.03	-.08	-.06	-.01	.18	-.03
6. ZBI	58.46	17.07	-	-	-	-	-	-	-.00	-.05	.00	-.11	-.05	.07	.26*	-.15
7. ADL's	39.29	8.10	-	-	-	-	-	-	-	.27*	.12	-.09	-.01	.03	-.01	.42**
8. Hours per day giving care	12.22	8.30	-	-	-	-	-	-	-	-	.05	-.01	-.04	.30**	-.06	.07
9. Months giving care	43.76	45.94	-	-	-	-	-	-	-	-	-	.15	-.27**	.23*	-.03	.16
10. Knowledge of disease	8.02	1.75	-	-	-	-	-	-	-	-	-	-	.13	-.01	-.06	.13
11. Caregiver education level	5.23	1.45	-	-	-	-	-	-	-	-	-	-	-	.20	-.23*	.01
12. Caregiver age	52.70	14.76	-	-	-	-	-	-	-	-	-	-	-	-	-.33**	.02
13. Caregiver gender			-	-	-	-	-	-	-	-	-	-	-	-	-	-.05
14. Receiving paid help			-	-	-	-	-	-	-	-	-	-	-	-	-	-

Note: RS-15 = resiliency, MSPSS = social support, SBI-15R = spiritual beliefs, HHI = Hope, CDS = caregiver distress, ZBI = caregiver burden, Male = 1 Female = 2, Receiving paid help No = Yes = 1.

* p<0.05. **p<0.01.

Spiritual beliefs (SBI-15R) were not related to either the ZBI, $r(87) = -.15, p = .152$, or the CDS, $r(87) = -.06, p = .594$ suggesting that spirituality does not play a role in terms of burden or distress. With that said, spirituality was significantly related to resiliency, $r(87) = .22, p = .035$, and hope, $r(85) = .34, p = .001$. Caregivers in this study who were more spiritual tended to also have higher levels of resiliency and hope than their unspiritual caregiver counterparts. Interestingly though, spirituality was not significantly related to social support, $r(87) = .18, p = .097$. Spirituality, as measured by the SBI-15R, is not necessarily characterized by churchgoing; therefore, it is possible for a caregiver to be highly spiritual but not be involved with other spiritual/religious people.

The time and ADL variables were correlated with the other attribute measures to assess possible relationships. The literature had indicated amount of time giving care (hours per day and length in months) has an influence on caregiver burden. With this sample, it was found that hours per day giving care was not significantly correlated with any of the attribute (RS-15, MSPSS, SBI-15R, HHI) or dependent (ZBI and CDS) measures. Months giving care was only correlated with social support, $r(87) = -.28, p = .007$. This means that caregivers who were new to caregiving were more likely to have social support than the caregivers who had been caring for a number of years. In other words, support is prevalent after diagnosis, but as time progresses the support tends to fade away. Finally, the ADLs were not significantly correlated to any of the attribute or dependent measures. As expected, caregivers who gave care for longer amounts during the day and who had been giving care for a number of years tended to assist with more activities of daily living than newer caregivers.

Other relationships included a positive correlation between caregiver education level and social support, $r(87) = .22, p = .039$, and positive correlation between caregiver age and the two time variables. Caregiver knowledge of the disease (scale of 1 to 10) was not related to any other variable, most likely due to a ceiling effect ($M = 8.02, SD = 1.75$). Receiving paid help was only related to ADLs, $r(91) = .42, p < .001$. This may be a trivial relationship because it indicates that caregivers who assist with more activities of daily living tend to receive more paid help. That finding seems backwards, but could be an artifact of sampling and/ or bad variable items.

The constructs that were measured with existing items were all related to each other in some way. The time variables were unrelated to all of the other variables of interest suggesting that time does not play a role in caregiver distress and burden, or the error could be with the way time was measured. Activities of daily living were similar to the time measures in regard to being uncorrelated with all of the other factors of interest. The error for ADL measurement could be with item wording or non-understanding of what the answer categories meant (independent, needs some help, and completely dependent). Gender was related to caregiver burden with females scoring higher (more burden) than males, but both means were close to the middle point of the scale.

Based on the intercorrelations, the two models regressed data from one outcome measure (ZBI and CDS) on the four attribute measures (RS-15, MSPSS, SBI-15R, and HHI). In addition, the model included gender because of its relation to the ZBI, as well as time and ADLs, because of the literature support. Findings of the models are outlined in the following section.

Content Research Question Number Six

6. *To what degree can distress and burden be predicted from a combination of caregiver personal attributes, while controlling for demographic variables and time (per day giving care and how long they have been giving care)?*

Hierarchical regression was conducted to assess the model derived from a combination of the literature and the intercorrelations of the measured variables. Assumptions of linearity, normal distribution and uncorrelated errors were checked and met. Two models were assessed. The predictor variables stayed consistent within each level for both models. The only change between models was the dependent variable. For the first model, caregiver burden (ZBI) was the dependent variable regressed upon caregiver gender (first level); hours per day giving care, months giving care, and ADLs (second level); and resiliency, social support, spirituality and hope (third level).

The means, standard deviations and intercorrelations were previously explained, but are presented again in Table 4.18. Individual beta weights (Table 4.19) suggest that hope and social support contributed most to predicting caregiver burden. For a .4 unit increase in hope, burden decreases one unit. For social support, a .3 unit increase leads to a unit decrease in burden. The overall model significantly predicted caregiver burden (ZBI), $F(8,77) = 5.60, p < .001$, with only hope and social support significantly contributing to the model. The adjusted R^2 value was .3, indicating that 30% of the variance in caregiver burden was explained by the model. Table 4.20 shows that the model is significant at the first hierarchy, but does not improve with the addition of time and ADLs. With adding the measures at the third hierarchy, the model significantly improved and accounted for a majority of the explained variance, R^2 change = .29.

Table 4.18

Means, Standard Deviations, and Intercorrelations for Caregiver Burden and Predictor Variables

Variable	M	SD	1	2	3	4	5	6	7	8	9
1. ZBI	58.09	17.17	-	.27	-.02	.00	.01	-.52	-.29	-.13	-.45
2. Caregiver gender	.87	.34	-	-	-.02	-.07	-.06	-.14	-.11	.10	-.20
3. Hours per day giving care	12.16	.8.21	-	-	-	.11	.27	.14	.13	.19	.05
4. Months giving care	42.14	44.98	-	-	-	-	.12	-.16	-.00	-.11	-.31
5. ADL's	39.31	8.15	-	-	-	-	-	.12	.14	-.03	.04
6. HHI	38.54	5.54	-	-	-	-	-	-	.51	.35	.53
7. RS-15	79.76	12.58	-	-	-	-	-	-	-	.21	.29
8. SBI-15R	44.90	13.72	-	-	-	-	-	-	-	-	.17
9. MSPSS	65.67	11.44	-	-	-	-	-	-	-	-	-

Note: RS-15 = resiliency, MSPSS = social support, SBI-15R = spiritual beliefs, HHI = Hope, ZBI = caregiver burden, Female = 0 Male 1.

Table 4.19

Hierarchical Regression Analysis Summary for Caregiver Gender, Hours Per Day Giving Care, Months Giving Care, Activities of Daily Living (ADL), Hope (HHI), Resiliency(RS-15), Spirituality (SBI-15R), and Social Support (MSPSS) Predicting Caregiver Burden (ZBI)

Hierarchy	Variable	B	SE B	β	t	p
1	Caregiver gender	8.58	4.98	.17	1.73	.089
2	Hours per day giving care	.09	.20	.04	.44	.658
2	Months giving care	-.05	.04	-.14	-1.4	.164
2	Activities of Daily Living (ADL)	.19	.20	.09	.94	.348
3	Hope (HHI)	-1.17	.39	-.38	-3.03	.003
3	Resiliency(RS-15)	-.09	.15	-.06	-.57	.569
3	Spirituality (SBI-15R)	.023	.13	-.02	.18	.856
3	Social Support (MSPSS)	-.37	.17	-.25	-2.21	.030

Table 4.20

Model Summary by Hierarchy

Hierarchy	R	Adjusted R ²	R ² Change	F Change	p of F Change
1	.27	.06	.07	6.57	.012
2	.27	.07	.00	.05	.984
2	.61	.30	.29	8.94	< .001

Note. R² = .37; F(8,77) = 5.60, p < .001

Gender moderately contributed to the ZBI prediction model, but the time variables and ADLs did not play a predictive role. Taking these variables out of the prediction equation would produce a more parsimonious model but would reduce the overall R^2 slightly. Other factors and a larger sample size could contribute to a better predictive model. The time variables did not contribute to the model but have been said to relate to caregiver burden. Ultimately time is probably related to burden but measuring time is problematic.

The previous steps were used to model caregiver distress. Caregiver distress and burden were highly correlated ($r = .85$), so differences in the models was not expected. The means, standard deviations and intercorrelations are presented in Table 4.21 and individual beta weights in Table 4.22. The beta weights once again suggest that hope and social support contributed most to predicting caregiver distress. Furthermore, a .4 unit increase in hope decreases distress by one unit. For social support, a .3 unit increase leads to a one unit decrease in distress. The overall model significantly predicted caregiver burden (ZBI), $F(8,77) = 4.97, p < .001$, with only hope and social support significantly contributing to the model. The adjusted R^2 value was .3, indicating that 30% of the variance in caregiver burden was explained by the model. Table 4.23 shows that the model was not significant at the first hierarchy, and did not improve with the addition of time and ADLs. By adding the attribute measures at the third hierarchy, the model significantly improved and accounted for a majority of the explained variance, R^2 change = .30. A more parsimonious model using just the measures of resiliency, spirituality, social support and hope would be appropriate because those were the only variables to contribute to the overall predictive model.

Table 4.21

Means, Standard Deviations, and Intercorrelations for Caregiver Distress and Predictor Variables

Variable	M	SD	1	2	3	4	5	6	7	8	9
1. CDS	58.09	17.17	-	.19	-.00	.04	.03	-.48	-.24	-.01	-.46
2. Caregiver gender	.87	.34	-	-	-.02	-.07	-.06	-.14	-.11	.10	-.20
3. Hours per day giving care	12.16	.8.21	-	-	-	.11	.27	.14	.13	.19	.05
4. Months giving care	42.14	44.98	-	-	-	-	.12	-.16	-.00	-.11	-.31
5. ADL's	39.31	8.15	-	-	-	-	-	.12	.14	-.03	.04
6. HHI	38.54	5.54	-	-	-	-	-	-	.51	.35	.53
7. RS-15	79.76	12.58	-	-	-	-	-	-	-	.21	.29
8. SBI-15R	44.90	13.72	-	-	-	-	-	-	-	-	.17
9. MSPSS	65.67	11.44	-	-	-	-	-	-	-	-	-

Note: RS-15 = resiliency, MSPSS = social support, SBI-15R = spiritual beliefs, HHI = Hope, CDS = caregiver distress, Female = 0 Male 1.

Table 4.22

Hierarchical Regression Analysis Summary for Caregiver Gender, Hours Per Day Giving Care, Months Giving Care, Activities of Daily Living (ADL), Hope (HHI), Resiliency(RS-15), Spirituality (SBI-15R), and Social Support (MSPSS) Predicting Caregiver Distress (CDS)

Hierarchy	Variable	B	SE B	β	t	p
1	Caregiver gender	2.27	4.36	.05	.52	.605
2	Hours per day giving care	.05	.18	.03	.29	.774
2	Months giving care	-.04	.03	-.11	-1.12	.266
2	Activities of Daily Living (ADL)	.19	.18	.10	1.05	.299
3	Hope (HHI)	-1.07	.34	-.40	-3.16	.002
3	Resiliency(RS-15)	-.01	.13	-.00	-.04	.971
3	Spirituality (SBI-15R)	.17	.11	.16	1.57	.120
3	Social Support (MSPSS)	-.39	.15	-.30	-2.64	.010

Table 4.23

Model Summary by Hierarchy

Hierarchy	R	Adjusted R ²	R ² Change	F Change	p of F Change
1	.19	.02	.02	3.01	.086
2	.20	-.01	.00	.12	.951
2	.58	.27	.30	8.81	< .001

Note. R² = .34; F(8,77) = 4.97, p < .001

Content Research Question Number Seven

7. *Can caregiving clusters be formed through the combination of attributes (perceived social support, resiliency, spirituality, and hope as personal attributes)?*

Cluster analytic techniques were used in order to segment caregivers based on scores from the personal attribute measures: resiliency (RS-15), social support (MSPSS), spirituality (SBI-15R), and hope (HHI). The scales were not consistent between measures, so potential groups were clustered based on raw scores from the attribute measures and then re-clustered using standardized (z) scores. The groupings were similar enough, but 11 of the cases were classified differently from the raw scores to the z scores. Raw scores are easier to interpret because the values relate back to the instrument, whereas with z scores the values are transformed to standardized scores with a mean of 0 and a standard deviation of 1. Because the measures used different scales and the groupings did not match, z scores were used for the cluster analysis.

Non-hierarchical clustering was used even though there was no theoretically based information on the probable number of clusters. Therefore, three different cluster solutions were computed (two cluster, three cluster, and four cluster). The two cluster solution was easiest to interpret, because caregivers were essentially clustered by way of low scores on all attribute items versus high scores on all attribute items. The three cluster solution was computed to assess a third, possibly neutral, group, but converged with only one case representing a cluster. The same problem occurred for the four cluster solution.

Thus, the two cluster solution was the most interpretable. Therefore, additional analyses were computed to assess the differences between the two clusters in terms of the variables that were used in the cluster analyses. As expected, the differences were statistically significant because the clusters were created by maximizing the differences between clusters.

Table 4.24 displays the means and standard deviations for each cluster in terms of the attribute variables, as well as the *t*-test summary table. The significant difference between the two clusters indicates that there are two discernable clusters of caregivers in this sample. Cluster 1 is made up of caregivers who had high levels of each measured attribute, while cluster 2 is caregivers who had low levels of each measured attribute.

Table 4.24

Comparison of Clusters on Hope (HHI), Resiliency (RS-15), Spirituality (SBI-15R), and Social Support (MSPSS)

Variable	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>	95% confidence interval	
							Lower	Upper
HHI			7.90	85	< .001	1.69	.97	1.64
Cluster 1 (<i>n</i> = 47)	.60	.68						
Cluster 2 (<i>n</i> = 40)	-.70	.85						
RS-15			5.50 ^a	56.81 ^a	< .001	1.21	.68	1.45
Cluster 1 (<i>n</i> = 47)	.50	.58						
Cluster 2 (<i>n</i> = 40)	-.56	1.10						
SBI-15R			6.34	85	< .001	1.35	.76	1.46
Cluster 1 (<i>n</i> = 47)	.54	.75						
Cluster 2 (<i>n</i> = 40)	-.56	.88						
MSPSS			5.95	85	< .001	1.27	.73	1.45
Cluster 1 (<i>n</i> = 47)	.52	.72						
Cluster 2 (<i>n</i> = 40)	-.57	.98						

^aThe *t* and *df* were adjusted due to unequal variances.

Two additional *t*-tests were computed to answer the following two questions:

1. Does the low attribute level group (cluster 2) score significantly higher on burden (ZBI) than the high attribute level group (cluster 1)?
2. Does the low attribute level group (cluster 2) score significantly higher on distress (CDS) than the high attribute level group (cluster 1)?

A statistically significant difference was found among the two caregiving clusters on burden, $t(85) = 3.35, p = .001, d = .72$, and distress, $t(85) = 2.67, p = .009, d = .57$.

Table 4.25 displays the means, standard deviations and the *t*-test summary for each cluster in terms of caregiver burden and distress. Caregivers who scored higher on the scales measuring resiliency, social support, spirituality and hope generally had lower scores on both the burden and distress scales.

Table 4.25

Comparison of Clusters on Caregiver Burden (ZBI) and Caregiver Distress (CDS)

Variable	<i>M</i>	<i>SD</i>	<i>t</i>	<i>df</i>	<i>p</i>	<i>d</i>	95% confidence interval	
							Lower	Upper
ZBI			3.35	85	.001	.72	4.74	18.56
Cluster 1 (<i>n</i> = 47)	52.82	16.66						
Cluster 2 (<i>n</i> = 40)	64.48	15.54						
CDS			2.67	85	.009	.57	2.06	14.19
Cluster 1 (<i>n</i> = 47)	45.00	13.44						
Cluster 2 (<i>n</i> = 40)	53.13	14.99						

The final analysis with the clusters investigated whether caregivers for somebody with AD, ALS or cancer differed on being in cluster 1 or cluster 2. Assumptions were checked for a 2X3 Pearson chi-square, but expected cell counts were less than 5 for the two cancer caregiving cells, which was expected. Table 4.26 indicates that clustering was not dependent upon disease type, $\chi^2 = 1.45$, $df = 2$, $n = 87$, $p = .485$, Cramers V = .13. Each caregiving disease type was closely split between the two clusters indicating that having high or low levels of resiliency, social support, spirituality and hope are not dependent on the disease type.

Table 4.26

Chi-square Analysis of Disease Type by Caregiving Cluster (Cluster 1 = High Attribute Levels, Cluster 2 = Low Attribute Levels)

Variable	<i>n</i>	Cluster		χ^2	<i>p</i>
		Cluster 1	Cluster 2		
Disease type				1.45	.485
AD	25	13	12		
ALS	57	23	34		
Cancer	5	3	2		
Total	87	39	48		

Summary of Results

Psychometric properties were investigated for six instruments. All of the instruments were internally consistent. The factor structures for all instruments were assessed through EFA's and two (CDS and ZBI) were additionally assessed with CFA's. Based upon the factor analyses, new structures were suggested for two instruments (CDS and ZBI), and factors from two instruments were similar to the structures from the literature (MSPSS and RS-15R).

The caregivers in this sample were asked to participate because they identified as a caregiver for a family member or friend who had been diagnosed with AD, ALS or cancer. The sample was not divided evenly between the three disease types, with ALS caregivers accounting for half of the sample. Differences in caregiver burden and distress were not found between disease types but there was a statistically significant difference between the gender of the caregiver on caregiver burden.

Caregiver burden and caregiver distress were highly correlated, as expected. Resiliency, social support and hope were negatively correlated with caregiver burden and caregiver distress. Spirituality was not correlated with burden or distress, but was

positively correlated with hope and resiliency. Amount of time giving care per day, number of months giving care, and activities of daily living were not related to caregiver burden or distress. Caregiver burden and caregiver distress were significantly predicted from a linear combination of resiliency, social support, hope and spirituality. Gender of the caregiver contributed to the burden prediction model, but time and activities of daily living were not significant predictors.

Caregiving clusters were created using non-hierarchical clustering techniques. Caregivers were grouped into two clusters of fairly equal size. The first cluster included caregivers who had higher levels of resiliency, social support, hope and spirituality, while the second cluster included caregivers with generally lower levels of resiliency, social support, hope and spirituality. In general, caregivers in the first cluster had lower levels of burden and distress than caregivers in the second cluster, which suggests that resiliency, social support, hope and spirituality play a role in caregiver burden and distress.

CHAPTER 5: DISCUSSION

Overview of the Problem

Recent trends have indicated that the number of unpaid caregivers has been steadily increasing over the last few years, and in 2011 the number of caregivers giving care to an individual with AD was estimated at 14.9 million (Alzheimer's Association, 2011). A report from the National Alliance on Caregiving (2011) indicated that one in three caregivers report that caregiving has had more of a positive than negative impact on their lives. That means two out of every three caregivers reported negative or neutral impacts due to caregiving.

Caring for an individual with AD, or other diseases such as ALS or cancer, can be rewarding because you are helping somebody in need, but is ultimately linked to increased stress and burden (Crespo et al., 2005). Longitudinal findings have recently indicated that caregivers for a spouse with dementia were six times more likely to also develop dementia than non-caregivers (Norton et al., 2010).

Research with caregivers is very common; therefore, the amount of literature on the topic is vast but with disagreements. Giving care to an individual with a terminal illness plays a role in decreasing mental and physical health of the caregiver (Matsumoto et al., 2007; Schulz et al., 1997). This is not an absolute because not all caregivers have mental or physical health problems, but the rates are increased (Norton et al., 2010).

The physical and mental distress that a caregiver experiences is commonly referred to as burden (Zarit et al., 1980). Caregiver distress is a similar term that is often measured by depression and anxiety instruments (Miller et al., 1996). It has been reported longitudinally that depression and anxiety increase as the cared-for individual gets worse (Grunfeld et al., 2004), which is logical. Within AD, researchers have indicated that anywhere from 40% to 70% of all caregivers are clinically depressed (Zarit, 2004).

The research problem that this study focused on was what influences caregiver burden and distress. A large body of research indicates that the characteristics of the disease are not as important in terms of caregiver burden as what the caregiver brings (personality, attributes, traits, states) to the caregiving situation (Cousins et al., 2002; Zanetti et al., 1998). Other research has suggested that the main influences of caregiver burden are amount of time giving care and the care tasks associated with the progression of the disease (Crespo et al., 2005; Zarit, 2004). A variety of instruments measuring different constructs were used in order to better understand these variables relationship to caregiver burden and distress within a sample of informal caregivers for individuals with AD, ALS or cancer.

Findings from the First Research Question

1. Do the psychometric properties of the four attribute instruments (resiliency, social support, hope, spirituality) align with findings from previous studies?

The psychometric properties of each instrument were assessed to provide evidence for validity and reliability, but also to ensure that the data derived from the instruments could be used in further analyses. Each instrument was assessed using the

same steps. Exploratory factor analysis (EFA) with principal axis extraction and oblique rotations were conducted on each instrument. If the literature had agreed upon a structure, then the number of factors was requested. If the structure had not been defined or agreed upon, then items were initially extracted based on eigenvalues greater than one. Reliability coefficients were calculated for the entire instrument as well as for the extracted factors.

Resiliency was measured using the RS-14. This instrument had been previously validated but was more commonly used with patients rather than caregivers (Wagnild, 2009). The RS-14 was derived from a 25-item resiliency scale that contained five validated sub-constructs. The RS-14 contained items from each sub-construct but there has not been any factorial evidence suggesting that the RS-14 is multidimensional.

Two factors were extracted in this study with a total explained variance of 62.87%. The first factor contained nine items and accounted for most of the explained variance. Three items had loadings below .5, which accounts for why more variance was not explained. The reliability for the two extracted factors as well as the entire instrument were all well over .7, which is similar to what has been reported in the literature (Wagnild & Young, 1990, 1993; Wagnild, 2009). The RS-14 was used as a one-dimensional measure of resiliency by totaling all 14 items. Further analyses could be conducted with the RS-14, in order to reduce items to explain more variance.

Social support was measured using the MSPSS. This instrument was created and validated with healthy individuals (Zimet et al., 1998). It has been used with samples of pregnant women, adolescents, and older adults, but not with caregivers. The MSPSS has been consistently reported as a three factor instrument, with subscales of friends, family

and significant other. Three factors were extracted, which accounted for almost 85% of the total variance, providing additional evidence of construct validity.

Internal consistency was well above .7 for the entire instrument, but also for each factor. Because the factors were cohesive and had high internal consistency, they could be used individually. For this study, the MSPSS was used as a total score because the factors were somewhat correlated. No items were removed from this instrument, but a confirmatory analysis is needed to assess overall fit of the model to the data.

Spiritual beliefs were defined by the SBI-15R. This instrument included questions pertaining to the belief in a higher power, but also questions about religious support in terms of the community. The SBI-15R is an adapted instrument from a much larger version. Hollend et al. (1998) proposed two sub-factors of beliefs and support. The findings from this study aligned with others in terms of extracting two factors that contained the appropriate items proposed from the original study. However, the beliefs factor explained around 74% of the variance while the support factor only explained 6% of the total variance. In addition, the two factors were highly correlated, which suggests that there are probably not two sub-constructs associated with the SBI-15R.

Internal consistency was over .7 for the entire measure, which is consistent with the literature (Baider et al., 2001; Holland et al., 1998). Two of the items had loadings below .5, which justifies elimination, but because the Cronbach's alpha was large, all items were used to calculate a sum score. Confirmatory factor analysis would be the next plausible step in order to assess the model fit with all items included.

Hope was measured using the Herth Hope Index (HHI). This index is a shortened version from a larger three factor instrument. The HHI contained 12 items, four from

each sub-construct from the original instrument. The initial study using the HHI (Herth, 1992), verified the three factor structure but explained only about 40% of the total variance.

This study did not find the same factor structure as previous work has indicated. In fact, three factors were extracted but did not replicate the proposed structure. Two items were negatively worded and loaded together on a single factor. The negatively worded items were scored correctly, indicating a possible problematic response pattern. The factor structure did not make sense in terms of the literature, but all factors were moderately correlated. This instrument could be strengthened by reducing items and confirming fit, but because Cronbach's alpha was above .7 for all of the items together, a sum score was used as the measure of hope.

Findings from the Second Research Question

2. The Caregiving Distress Scale (CDS) was created and validated by Cousins et al. (2002) using a different caregiving population that is not part of this proposed study (Parkinson's disease). Does the CDS accurately assess distress, using classical test theory, within the sample of this study (AD, ALS, cancer)

The caregiving distress scale (CDS) is a five factor measure of distress. The instrument was created using items from previously validated instruments and assessed with a sample of caregivers who cared for individuals with Parkinson's disease. The CDS has mainly been used with caregivers of the Parkinson's population but the items were designed to assess any caregiver.

The goals of this research question were to assess the CDS using EFA, then remove items based on loadings, then finally assess the new model in terms of best fit of the data. The initial EFA extracted five factors with only three of the factors having eigenvalues above 1. The EFA was re-run with forcing loadings into three factors. Multiple items loaded poorly on more than one factor and were subsequently removed. The final EFA extracted two factors from 13 items. The first factor contained items indexing emotional and relationship distress, while the second factor contained the original three items indexing social impact. The two factor model explained around 70% of the total variance, which is more than in Cousins et al. (2002)'s original study, but that is partially due to the number of items in the model.

Confirmatory factor analysis was computed on the two factor model as well as the original five factor model. The best fit was with the two factor solution, but the chi-square was still significant indicating a poor fit. The two other fit indices, GFI and RMSR, were acceptable for the two factor model, but not acceptable for the five factor model. The reason why the fit was poor for the five factor model was because three of the five factors were highly correlated. The two factor model eliminated a number of items to form two sub-constructs which make logical sense but also fit the data better.

Internal consistency was demonstrated through a Cronbach's alpha above .9, which was consistent with previous findings (Cousins et al., 2002). The exploratory and confirmatory analysis not only helped identify a sub-section of the CDS that could be used to assess distress in caregivers, but also demonstrated that most of the items were directed toward emotional and relationship distress. The CDS did contain three items indexing social impact that consistently loaded together, which provides some support for

that sub-construct within the CDS. As indicated previously, Cronbach's alpha was acceptable and the items were moderately correlated, so all items were used as a sum score of caregiver distress with higher values indicating higher levels of distress.

Findings from the Third Research Question

- 3. The Zarit Caregiver Burden Inventory (Zarit, et al., 1980) was created for use with dementia caregivers and is currently one of the most common inventories for dementia care. Does the Zarit Caregiver Burden Inventory accurately assess burden, using classical test theory, within the sample of this study (AD, ALS, cancer)?*

The Zarit Burden interview is a widely used instrument to assess caregiver burden, which was originally created and used with caregivers of individuals with dementia. It is not clear if the instrument was designed as one-dimensional (Zarit et al., 1980), but the 1990 manual indicates that there are two sub-constructs (personal strain and role strain) (Zarit & Zarit, 1990). Recently, studies have debated about the dimensionality of the ZBI. Some have suggested three factors, with the third factor being two questions that assess guilt (Ankri et al., 2005; Knight et al., 2000). Others have verified the two factor structure but often eliminate the last item which asks about overall feelings of burden (Bedard et al., 2001).

The findings from this study partially supported some of the previous research. Initial EFAs produced solutions that were not justified by the literature. Items were reduced through a series of EFAs and items were removed if they had low loadings or dually loaded. A 10-item two factor version had the best solution in terms of variance

explained and interpretability. A final CFA confirmed that the model adequately fit the data, but the two factors were moderately correlated, which indicates personal strain and role strain may not be unique sub-constructs. Internal consistency was above .7 for all of the items together; therefore, sums of all items were used to measure caregiver burden.

Findings from the Fourth Research Question

4. What are the differences in distress and burden of being a caregiver for a terminally ill family member in terms of three types of care (ALS, AD, cancer)?

Cross-sectional caregiving studies by disease type are uncommon. If your beliefs are that burden is a product of personality then there would be no reason to assess different samples of caregivers. Caregivers of individuals with dementia have been compared to caregivers of individuals who did not have dementia, and burden was the same between both groups (Crespo et al., 2005). Research has indicated increased depression with AD caregivers, but not with ALS caregivers. The progressions of the three diseases explored in this study are vastly different. Patients can live for decades with AD, but only two to five years with ALS. Also, caring for an individual who does not know who you are poses different caregiving challenges than caring for somebody who is weakened due to chemotherapy.

Differences between caregivers based upon the disease of the individual they care for was expected but not supported. The underlying reasons why differences were not found between caregivers may have to do with sampling, sample size, or the idea that maybe burden and distress are independent of disease type. The sampling procedure was a limitation to the study because all participants were affiliated with a disease related

association (Alzheimer's Association, ALS Association). Associations typically provide support by way of caregiver support groups as well as assist needs of the caregiver and care receiver.

Sample size was problematic with this study because the ALS group was overrepresented. More ALS associations were contacted because ALS is considered rare next to AD and cancer. The three caregiving groups were not close to being equal, and the overall sample size was around 90 for most analyses. The lack of power was a concern, but on average the caregivers in this study were not overly burdened or distressed.

Male caregivers were significantly less burdened than female caregivers. Analyses were used to control for activities assisted with as well as time, but the difference remained significant. Male and female caregiving differences are assessed, but oftentimes, as was the case with this study, the male caregiving sample was less than half of the female caregiving sample.

Findings from the Fifth Research Question

5. What are the relationships between caregiver personal attributes and distress and burden?

Caregiver burden was highly correlated with caregiver distress, as expected, but does provide evidence for convergent construct validity for both instruments. Burden and distress were negatively correlated with resiliency, social support, and hope, but not correlated with spirituality. A resilient caregiver tended to be less burdened which

supports previous work where resiliency was correlated with positive coping mechanisms to reduce burden (Ross et al., 2003).

Social support was strongly negatively correlated with burden and depression, but positively correlated with hope. In the literature, high levels of social support have been associated with low stress and anxiety (Monahan & Hooker, 1997; Faber, 2005). Social support not only provides the caregiver with assistance, but they can also serve simply as someone to talk with. Many of the caregivers in this study scored high on the family items of the social support instrument, indicating that other family members are an important element in terms of managing burden and distress.

Hope had a strong negative relationship with burden and distress, indicating that a caregiver who identified as more hopeful tended to have less burden and distress. In previous research, hope has been associated with personal control and trust (Borneman et al., 2002; Chauhan, 2008). In the present study, hope was positively correlated with resiliency, social support and spirituality. A caregiver who has hope in a sometimes hopeless situation is likely to also be resilient, and because of that, burden is reduced.

Spirituality was not directly associated with burden or distress, but it was highly correlated with resiliency and hope. This type of mediated relationship between spirituality and burden through resiliency and hope has been documented (Colgrove et al., 2007; Wilks & Vonk, 2008). Interestingly, spirituality was not related to social support. It makes sense to think that a more spiritual person would go to more organized religious events than a non-spiritual person, which would lead to possible support by the church, but this was not supported in the present study.

The two time variables, as well as the activities of daily living variables, were not related to burden or to any of the previously mentioned constructs. This supports an earlier argument by Cousins et al. that the variables that the caregiver brings to the caregiving situation play a bigger role in terms of burden than do disease progression and time. Activities of daily living could be related to other outcomes that were not assessed. For example, an ALS caregiver often has to do transfers of the individual which can cause physical problems like back aches and strained muscles. An AD caregiver may not have to do transfers until the very end stages of the disease process. Cognitive functioning has been argued to decrease with some caregivers (Norton et al., 2010), but that was not assessed within this study.

Living with the individual and knowledge of the disease were not related to any of the observed measures. The knowledge of disease variable was problematic because of a ceiling effect. It was scored from 1 to 10, but the overall average was over 8. Education level was correlated with social support, indicating that the caregivers who had higher levels of education had higher levels of social support. That finding has not been produced in the literature, and seems like a trivial relationship.

Findings from the Sixth Research Question

6. To what degree can distress and burden be predicted from a combination of caregiver personal attributes, while controlling for demographic variables and time (per day giving care and how long they have been giving care)?

Caregiver burden and distress (in individual models) were regressed on gender (first level); number of hours giving care per day, number of months giving care, and ADLs

(second level); and resiliency, social support, spirituality, and hope (third level). Gender moderately contributed to the prediction model. With the addition of time and ADLs the models did not improve. Amount of time per day giving care is not a good measure because that means different things to different caregivers. Just being with the individual because they cannot be left alone is time giving care to some, but others only indicated the amount of time it had taken them to perform the ADLs with the person they care for.

The prediction models for burden and distress were not significant with only gender, time and ADLs in the equation. When the observed measures (resiliency, social support, spirituality, and hope) were entered, the overall F changed significantly. Both models explained around 30% of the variance of burden and distress. This supports the findings from the correlations in regards to the items that significantly impacted the prediction. Time and ADLs were not correlated with burden or distress, but they were included in the model, based on arguments from the literature. Explaining 30% of the total variance is a good start, but other variables need to be identified in order to build a stronger prediction model.

Findings for the Seventh Research Question

7. Can caregiving clusters be formed through the combination of attributes (perceived social support, resiliency, spirituality, and hope as personal attributes)?

Cluster analytic techniques are used to group people based on different criteria. For this study, caregivers were clustered based on the four observed variables (resiliency, social support, spirituality, and hope). Scores from each instrument were standardized and then entered into the equation. Two distinct clusters were formed using non-

hierarchical (K-Means) clustering. The two clusters were significantly different on the four items that they were clustered from, which was expected. Cluster one had higher levels of the four observed variables while cluster two had lower levels. There were also differences between the two clusters in terms of burden and distress. Cluster one reported lower levels of burden and distress than cluster two.

The findings from the cluster analysis align well with previous correlations and regression analyses. These four observed variables were all significantly correlated with burden and distress, except spirituality. Spirituality does play a role because it was strongly correlated with resiliency and hope. These two clusters represent the two ends of the spectrum. Caregivers who had generally higher levels of the observed variables were different than their lower level counterparts, but there was not an observed neutral category. Further research is needed on the concept of clustering caregivers based on their personal attributes.

Implications for the Conceptual Model

Within this sample of caregivers, distress and burden was largely influenced by attributes that the caregiver brings into the caregiving situation. Figure 5.1 demonstrates how the model of burden and distress is simple in comparison to the original model framework from the literature review. People have differing levels of hope, resiliency, social support, and spirituality before a life-changing event takes place. The levels or appearance of these attributes are dynamic entities in the sense that they can change based on the situation. For example, a religious person may have less faith after a spouse or family member gets diagnosed with a terminal illness at a very young age, but then becomes more active in his or her religion when the care-receiver nears death.

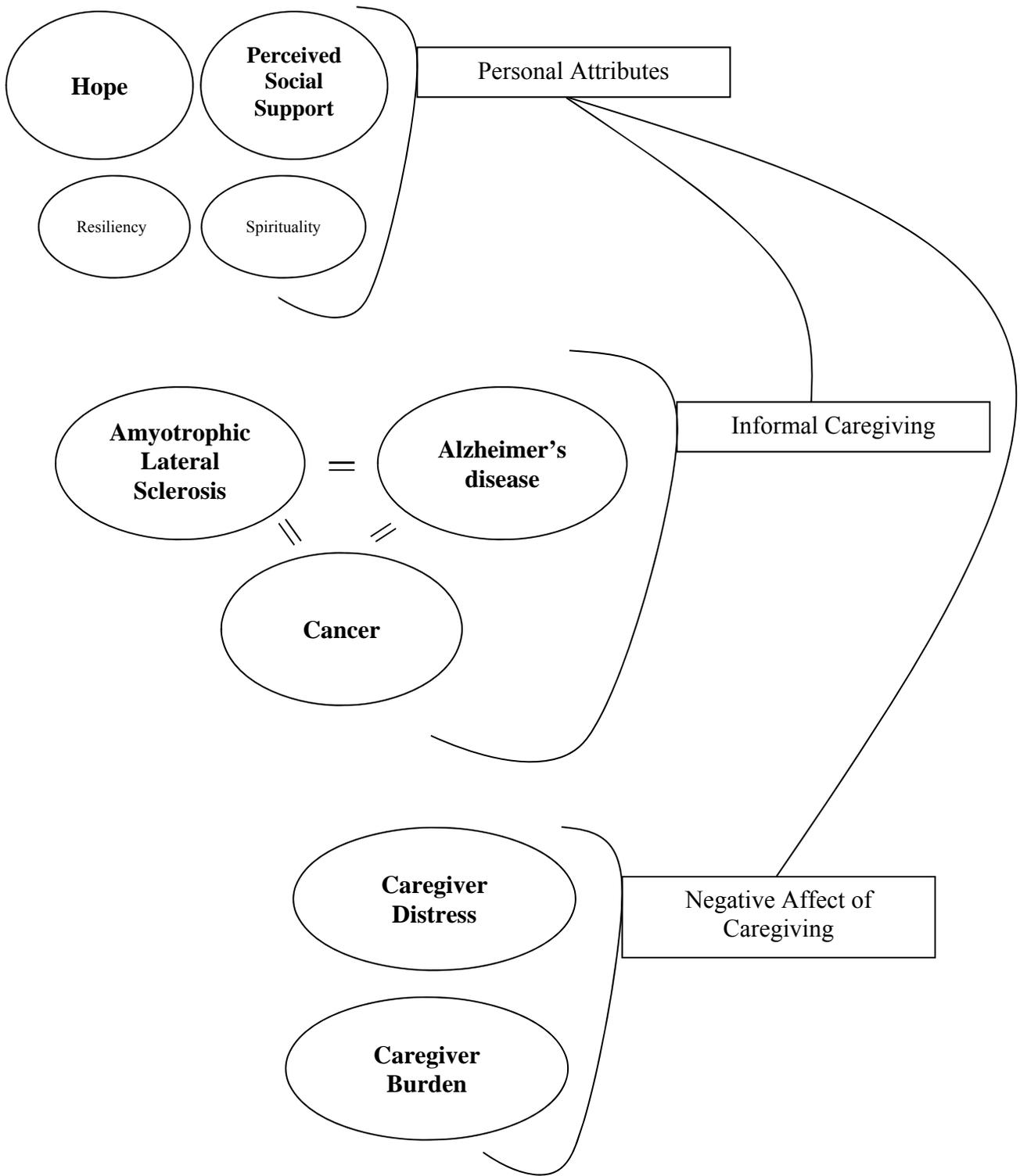


Figure 5.1. Final model of caregiver burden and distress among informal caregivers

The purpose of this research was not to track caregivers over time to assess changes in these attributes, but to measure these attributes and demographic characteristics at one point in time to assess their relationship to distress and burden. Hope and perceived social support were most influential in terms of caregiver burden and distress. The research questions were answered using summed scores for each instrument. Sub-factors associated with two instruments (MSPSS – social support, and SBI-15R – spirituality) were analyzed separately for the regression and cluster models, but the findings did not differ extensively from the models using the total instrument scores.

Implications for Future Research

There were a number of limitations to the present study. First, various associations gave out the survey link to their caregiving clients. All of the associations in Colorado were contacted, but because the response rate was low additional associations throughout the country were contacted. The caregivers who participated in this study had reached out to an association in some way or another; therefore, they were systematically different than caregivers who are not part of a disease or caregiving association.

The sample size was low, and the three caregiving groups were unequal. A larger sample would allow for further analyses by group that were not accomplished in this study (factor analysis by each caregiving group). A larger sample would also increase power in order to assess caregiver differences by disease type.

Future studies should continue to assess time giving care as a variable. Directions and parameters need to be set in order for all caregivers to indicate an accurate amount of time that they give care. The relationship between the caregiver and the care-receiver was

not assessed within this study but could play a moderating role in burden and distress. However, it may also be substantially different between disease types. For example, AD is associated with the aging population so caregivers tend to be spouses or adult children. On the other hand, ALS has been diagnosed in some individuals who are in their mid-twenties; therefore, their caregivers may include parents or friends.

Activities of daily living did not play a role in caregiver burden, but were different between the three caregiver groups. Longitudinal methods would also be useful to assess burden and distress over time, while at the same time assessing amount of time giving care and ADLs.

Other factors influence caregiver burden and distress. Future studies should assess other caregiver attributes, such as altruism, and self-efficacy. Other outcome measures may be useful in addition to measures of burden and distress.

Having multiple disease types within one study is beneficial because the caregivers can be compared within studies rather than trying to make generalizations between different studies. The three disease types for this study were chosen because the three diseases progressed at very different rates. Other caregiving situations may also be important to investigate. For example, using the model from this study with informal caregivers of individuals with traumatic brain injury (TBI) would be important because they become caregivers overnight.

Lastly, the proposed model and cluster solution from this study were based on instruments measuring resiliency, social support, spirituality, hope, burden, and distress, but others could be added for a stronger prediction model.

Implications for Professional Practice

Caregivers are often overlooked when it comes to healthcare because the emphasis tends to be on the care-receiver. Not all caregivers are burdened or distressed, but many experience negative emotional effects that are more tied to what they bring into the caregiving situation (outlook in terms of hope, resiliency, spirituality, and social support) than the tasks and time associated with caregiving.

The intriguing piece is that these attributes (e.g., hope, resiliency, spirituality, and social support) that are related to burden and distress are not fixed. For instance, perceived social support could be enhanced through support or discussion groups. Caregiver therapy is becoming more accepted and typically covered through many insurances or disease-specific associations. Therapy has the ability to help reshape caregiver outlook, which includes hope and resiliency.

Finally, learning about the specific disease process and what to expect as a caregiver was not explicitly assessed with this research, but knowing the disease characteristics is helpful for the caregiver care-receiver relationship. For example, having a more than novice understanding of dementia can help the caregiver know that confusion, flat affect, and temper outbursts are part of the disease process, not the care-receivers personality.

Conclusion

Informal caregiving is becoming more common due to the cost of formal caregiving and the recent trends of terminally ill people wanting to die at home. Being a caregiver for a family member or friend can be rewarding, but can also negatively affect

the caregiver. The caregiving literature was slightly divided, with some researchers believing that caregiver burden is mainly associated with personality characteristics, and other researchers believing burden to be a product of the duration and amount of care provided.

The model that was tested in this study contained caregiver personal attributes (e.g., hope, resiliency, social support and spirituality) as well as time and task variables (activities and instrumental activities of daily living) in order to predict caregiver burden and distress. The results showed that burden and distress tend to stem from caregiver personal attributes rather than from time and task characteristics. These findings supported the literature, but also added a new conceptual model to assess caregiving outcomes.

The majority of caregivers in this study were females caring for individuals with either ALS or AD. Two mathematically-based clusters were formed using caregiver attributes. The two clusters were significantly different in terms of caregiver burden and distress, but cluster assignment was fairly equal between ALS and AD caregivers.

Caregiver burden and distress can be modeled, but appears to be closely linked to attributes that the caregiver has before the caregiving process starts. A person who is resilient, hopeful and socially supported in some way will likely have less burden when caregiving than an individual who is less resilient and hopeful.

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APPENDIX A. THE RESILIENCE SCALE

The 14-Item Resilience Scale (RS-14) (Wagnild, 2009).

Instructions: Please read each statement and circle the number to the right of each statement that best indicates your feelings about the statement. Respond to all statements.

Circle the number in the appropriate column	Strongly Disagree						Strongly Agree
1. I usually manage one way or another.	1	2	3	4	5	6	7
2. I feel proud that I have accomplished things in life.	1	2	3	4	5	6	7
3. I usually take things in stride.	1	2	3	4	5	6	7
4. I am friends with myself.	1	2	3	4	5	6	7
5. I feel that I can handle many things at a time.	1	2	3	4	5	6	7
6. I am determined.	1	2	3	4	5	6	7
7. I can get through difficult times because I've experienced difficulty before.	1	2	3	4	5	6	7
8. I have self-discipline.	1	2	3	4	5	6	7
9. I keep interested in things.	1	2	3	4	5	6	7
10. I can usually find something to laugh about.	1	2	3	4	5	6	7
11. My belief in myself gets me through hard times.	1	2	3	4	5	6	7
12. In an emergency, I'm someone people can generally rely on.	1	2	3	4	5	6	7
13. My life has meaning.	1	2	3	4	5	6	7
14. When I'm in a difficult situation, I can usually find my way out of it.	1	2	3	4	5	6	7

One-dimensional but based on five aspects of resiliency:

Self-reliance — Items 1, 5, 7, 12, 14

Meaning — Items 2, 9, 13

Equanimity — Items 3, 10

Perseverance — Items 6, 8

Existential aloneness — Items 4, 11

APPENDIX B. SCALE OF PERCEIVED SOCIAL SUPPORT

Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, et al., 1988)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

- 1 = **Very Strongly Disagree**
2 = **Strongly Disagree**
3 = **Mildly Disagree**
4 = **Neutral**
5 = **Mildly Agree**
6 = **Strongly Agree**
7 = **Very Strongly Agree**

- | | |
|---|-------|
| 1. There is a special person who is around when I am in need. | (SO) |
| 2. There is a special person with whom I can share my joys and sorrows. | (SO) |
| 3. My family really tries to help me. | (Fam) |
| 4. I get the emotional help and support I need from my family. | (Fam) |
| 5. I have a special person who is a real source of comfort to me. | (SO) |
| 6. My friends really try to help me. | (Fri) |
| 7. I can count on my friends when things go wrong. | (Fri) |
| 8. I can talk about my problems with my family. | (Fam) |
| 9. I have friends with whom I can share my joys and sorrows. | (Fri) |
| 10. There is a special person in my life who cares about my feelings. | (SO) |
| 11. My family is willing to help me make decisions. | (Fam) |
| 12. I can talk about my problems with my friends. | (Fri) |

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

APPENDIX C. SYSTEMS BELIEF INVENTORY

Systems Belief Inventory (SBI-15R) (Holland et al., 1998)

- 1* Religion is important in my day-to-day life.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 2* Prayer or meditation has helped me cope during times of serious illness.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 3** I enjoy attending religious functions held by my religious or spiritual group.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 4* I feel certain that God in some form exists.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 5** When I need suggestions on how to deal with problems, I know someone in my religious or spiritual community that I can turn to.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 6* I believe God will not give me a burden I cannot carry.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 7** I enjoy meeting or talking often with people who share my religious or spiritual beliefs.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 8* During times of illness, my religious or spiritual beliefs have been strengthened.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 9** When I feel lonely, I rely on people who share my spiritual or religious beliefs for support.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 10* I have experienced a sense of hope as a result of my religious or spiritual beliefs.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 11* I have experienced peace of mind through my prayers and meditation.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 12* One's life and death follows a plan from God.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 13** I seek out people in my religious or spiritual community when I need help.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 14* I believe God protects me from harm.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
- 15* I pray for help during bad times.
1—Strongly disagree; 2—Somewhat disagree; 3—Somewhat Agree; 4—Strongly Agree
-

* Denotes items loading on Subscale I (Beliefs and practices).

** Denotes items loading on Subscale II (Social support).

APPENDIX D. HERTH HOPE INDEX

Herth Hope Index (HHI) (Herth, 1992)

Instructions: Listed below are a number of statements. Read each statement and place an X in the box that describes how much you agree with that statement right now.

	Strongly Disagree	Disagree	Agree	Strongly Agree
1) I have a positive outlook toward life.				
2) I have short and/or long range goals.				
3) I feel all alone.				
4) I can see possibilities in the midst of difficulties.				
5) I have faith that gives me comfort.				
6) I feel scared about my future.				
7) I can recall happy/joyful times.				
8) I have deep inner strength.				
9) I am able to give and receive caring/love.				
10) I have a sense of direction.				
11) I believe that each day has potential.				
12) I feel my life has value and worth.				

Inner sense of temporality and future — Items 1, 2, 6, 11

Inner positive readiness and expectancy — Items 4, 7, 10, 12

Interconnectedness with self and others — Items 3, 5, 8, 9

APPENDIX E. ZARIT CAREGIVER BURDEN INTERVIEW

Questions on the 29 and 22 Item Zarit Caregiver Burden Interview (Zarit et al., 1980).

	Zarit et al. 1980 original version		More common shortened version
1	I feel resentful of other relatives who could but who do not do things for my spouse.	1	I feel that the person I care for asks for more help than he/she needs
2	I feel that my spouse makes requests which I perceive to be over and above what s/he needs.	2	Because of the time I spend with him/her, I do not have enough time for myself
3	Because of my involvement with my spouse, I don't have enough time for myself.	3	I feel stressed between caring for him/her and trying to meet other responsibilities for my family or work.
4	I feel stressed between trying to give to my spouse as well as to other family responsibilities, job, etc.	4	I feel embarrassed over his/her behavior.
5	I feel embarrassed over my spouse's behavior.	5	I feel angry when I am around the person I care for.
6	I feel guilty about my interactions with my spouse.	6	I feel that he/she currently affects my relationship with other family members or friends in a negative way.
7	I feel that I don't do as much for my spouse as I could or should.	7	I am afraid of what the future holds for the person I care for.
8	I feel angry about my interactions with my spouse.	8	I feel he/she is dependent upon me.
9	I feel that in the past, I haven't done as much for my spouse as I could have or should have.	9	I feel strained when I am around the person I care for.
10	I feel nervous or depressed about my interactions with my spouse.	10	I feel that my health has suffered because of my involvement with the person I care for.
11	I feel that my spouse currently affects my relationships with other family members and friends in a negative way.	11	I feel that I do not have as much privacy as I would like because of the person I care for.
12	I feel resentful about my interactions with my spouse.	12	I feel that my social life has suffered because I am caring for this person.
13	I am afraid of what the future holds for my spouse	13	I feel uncomfortable about having friends over because of him/her.
14	I feel pleased about my interactions with my spouse.	14	I feel that this person expects me to take care of him/her as if I was the only one he/she could depend on.
15	It's painful to watch my spouse age.	15	I feel that I do not have enough money to support this person in addition to the rest of our expenses.
16	I feel useful in my interactions with my spouse.	16	I feel that I will be unable to take care of him/her much longer.
17	I feel my spouse is dependent.	17	I feel that I have lost control of my own life since this person's illness.
18	I feel strained in my interactions with my spouse.	18	I wish I could leave the care of this person to someone else.
19	I feel that my health has suffered because of my involvement with my spouse	19	I feel uncertain about what to do about the person I care for.
20	I feel that I am contributing to the well-being of my spouse.	20	I feel I should be doing more for him/her.
21	I feel that the present situation with my spouse doesn't allow me as much privacy as I'd like.	21	I feel I could do a better job in caring for him/her.
22	I feel that my social life has suffered because of my involvement with my spouse.	22	Overall, how burdened do you feel in caring for this person?
23	I wish that my spouse and I had a better relationship.		
24	I feel that my spouse doesn't appreciate what I do for him/her as much as I would like.		
25	I feel uncomfortable when I have friends over.		
26	I feel that my spouse tries to manipulate me.		
27	I feel that my spouse seems to expect me to take care of him/her as if I were the only one s/he could depend on.		
28	I feel that I don't have enough money to support my spouse in addition to the rest of our expenses.		
29	I feel that I would like to be able to provide more money to support my spouse than I am able to now.		

Note. Five point response scale: never, rarely, sometimes, quite frequently, and nearly always.

APPENDIX F. CAREGIVING DISTRESS SCALE

Caregiving Distress Scale (Cousins et al., 2002).

Instructions: Specific aspects of family life are affected by the demands of caregiving. With respect to your current situation as caregiver for _____, please indicate whether **YOU personally** disagree or agree with the following statements using the five-point scale below.

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

1. I take part in organized activities less
2. I visit my family/friends less
3. I take part in other social activities less
4. I feel frustrated with caring for _____
5. My relationship with _____ depresses me
6. I feel pressured between giving to _____ and others in the family
7. I feel that my own health has suffered because of _____
8. My relationship with _____ is strained
9. Caring for _____ has made me nervous
10. I feel _____ can only depend on me
11. I feel resentful towards _____
12. I feel helpless in caring for _____
13. My relationship with _____ no longer gives me pleasure
14. _____ tries to manipulate me
15. I feel overwhelmed by caring for _____
16. _____ makes more requests than necessary
17. I feel that my personal life has suffered because of _____

Relationship distress — Sum of items 5, 8, 11, 13

Emotional burden — Sum of items 4, 9, 12, 15

Care-receiver demands — Sum of items 6, 14, 16

Social impact — Sum of items 1, 2, 3

Personal cost — Sum of items 7, 10, 17

APPENDIX G: COLORADO STATE UNIVERSITY IRB APPROVAL LETTER



Research Integrity & Compliance Review Office
Office of the Vice President for Research
321 General Services Building - Campus Delivery 2011
Fort Collins, CO
TEL: (970) 491-1553
FAX: (970) 491-2293

NOTICE OF APPROVAL FOR HUMAN RESEARCH

DATE: December 07, 2010
TO: De Miranda, Michael, 1588 School of Education
Cumming, John, 1588 School of Education, Lehmann, Jean, 1588 School of Education
FROM: Barker, Janell, CSU IRB 1
PROTOCOL TITLE: Modeling Caregiver Burden Among Informal Caregivers of Patients' with Amyotrophic Lateral Sclerosis, Alzheimer's Disease, and Cancer
FUNDING SOURCE: NONE
PROTOCOL NUMBER: 10-2309H
APPROVAL PERIOD: Approval Date: December 07, 2010 Expiration Date: November 18, 2011

The CSU Institutional Review Board (IRB) for the protection of human subjects has reviewed the protocol entitled: Modeling Caregiver Burden Among Informal Caregivers of Patients' with Amyotrophic Lateral Sclerosis, Alzheimer's Disease, and Cancer. The project has been approved for the procedures and subjects described in the protocol. This protocol must be reviewed for renewal on a yearly basis for as long as the research remains active. Should the protocol not be renewed before expiration, all activities must cease until the protocol has been re-reviewed.

If approval did not accompany a proposal when it was submitted to a sponsor, it is the PI's responsibility to provide the sponsor with the approval notice.

This approval is issued under Colorado State University's Federal Wide Assurance 00000647 with the Office for Human Research Protections (OHRP). If you have any questions regarding your obligations under CSU's Assurance, please do not hesitate to contact us.

Please direct any questions about the IRB's actions on this project to:

Janell Barker, Senior IRB Coordinator - (970) 491-1655 Janell.Barker@Research.Colostate.edu
Evelyn Swiss, IRB Coordinator - (970) 491-1381 Evelyn.Swiss@Research.Colostate.edu

Barker, Janell



Research Integrity & Compliance Review Office
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321 General Services Building - Campus Delivery 2011
Fort Collins, CO
TEL: (970) 491-1553
FAX: (970) 491-2293

Barker, Janell

Includes:

Approval is for a maximum of 250 participants using the approved electronic cover letter to obtain consent. Documentation of consent is waived through 117(c)(2). No changes may be made to the protocol and its documents without prior IRB review and approval.

Approval Period:	December 07, 2010 through November 18, 2011
Review Type:	EXPEDITED
IRB Number:	00000202

e-protocol