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Unmet Needs And Service Utilization by Informal Caregivers

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UNMET NEEDS AND SERVICE UTILIZATION BY INFORMAL CAREGIVERS
CARING FOR ADULTS 65 YEARS AND OLDER IN VIRGINIA

by

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ABSTRACT

UNMET NEEDS AND SERVICE UTILIZATION BY INFORMAL CAREGIVERS CARING FOR ADULTS 65 YEARS AND OLDER IN VIRGINIA

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Old Dominion University, 2017
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The number of Americans expected to live into their 80's and 90's is growing at an increased rate in the United States, and the numbers of those aging adults with multiple chronic conditions also continues to grow. It is estimated that by 2050, there will be 89 million adults over the age of 65 years living in the United States. For a variety of reasons, including policy, personal, and financial reasons, many aging adults are choosing to "age in place" or to remain in the community. With the increase in the numbers of aging adults in the community, the ability to locate quality and affordable informal caregiving options has become an essential need. Aging adults with chronic conditions, especially those with a high disease burden, have significant limitations in their ability to carry out day-to-day activities, have higher psychosocial needs, and have a higher mortality rate. Caregivers for aging family members often experience higher levels of burden and stress.

The purpose of this dissertation was to examine health related, community-based service use by informal caregivers caring for aging adults who identify as having an unmet need. Unmet needs in this study included the physical, mental, and/or tangible needs of the informal caregiver. Using a non-experimental, descriptive study design; predisposing, enabling, and need factors that traditionally influence health care service utilization by informal caregivers for aging adults in Virginia was studied. Results showed that demographic factors of the informal caregiver,

willingness of the aging adult to access services, and stress and burden influenced community based, health service use. Findings further showcased a need to explore family dyads and a need for more comprehensive survey research among the informal caregiving population. Overall, this study highlighted the complexities of service utilization among informal caregivers and that use of services is influenced by a variety of complex factors.

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To Brianna, Kyle J., and Baby G.

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This dissertation represents not only a piece of contributory work to the field of Health Services Research, but a milestone in my career and the end of a six-year journey. My experience during this process has been amazing and this work could not have been completed without the guidance and support of those around me, both within and outside the university.

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TABLE OF CONTENTS

	Page
LIST OF TABLES	x
LIST OF FIGURES	xi
Chapter	
I. INTRODUCTION	1
PURPOSE OF THE STUDY	9
RESEARCH QUESTIONS	10
DEFINITIONS OF KEY TERMS	10
SIGNIFICANCE OF STUDY	11
II. THEORETICAL FRAMEWORK	13
LITERATURE REVIEW	16
CONCLUSION	33
III. METHODOLOGY	34
RESEARCH QUESTIONS	38
INSTRUMENTATION	38
READABILITY	40
CONTENT VALIDITY	40
ETHICAL CONSIDERATIONS	42
DATA COLLECTION PROCEDURES	42
DATA ANALYSIS	45
IV. DATA ANALYSIS AND FINDINGS	50
RELIABILITY	52
RESEARCH QUESTIONS	53
POST HOC ANALYSIS	57

DATA ANALYSIS SUMMARY	58
V. DISCUSSION, CONCLUSIONS, RECOMMENDATIONS, AND IMPLICATIONS.....	59
CONCLUSIONS	66
LIMITATIONS	70
RECOMMENDATIONS	72
FUTURE RESEARCH.....	73
IMPLICATIONS.....	74
REFERENCES	76
APPENDICES	
A: ORIGINAL SURVEY	102
B: CAREGIVER BURDEN SCALE	120
C: BRIEF MEASURE OF SOCIAL SUPPORT	122
D: CAREGIVER BURDEN INTERVIEW	124
E: SUBJECT MATTER CONTENT VALIDITY FORM.....	127
F: REVISED SURVEY.....	130
G: PERMISSIONS.....	146
VITA.....	153

LIST OF TABLES

Table

1. Demographic Variables of the Informal Caregiver	35
2. Content Validity Scores	41
3. Research Question Data Analysis Plan.....	48
4. Demographic Variables of the Aging Adult Needing Informal Caregiving Services	51
5. Cronbach's Alpha	52
6. Need for Caregiving Assistance.....	54
7. Willingness to Access Services	54
8. Impact on Service Use	55
9. Social Support, Importance, and Service Use.....	56
10. Impact of Burden	57

LIST OF FIGURES

Figure

1. Andersen Health Care Service Utilization Model 13
2. Adapted Gelberg-Andersen Behavioral Model for Vulnerable Populations 15

CHAPTER I

INTRODUCTION

Problem Statement

The number of Americans expected to live into their 80's and 90's is growing at an increased rate in the United States, and the numbers of those aging adults with multiple chronic conditions also continues to grow (U.S. Department of Health and Human Services, 2013). It is estimated that by 2050, there will be 89 million adults over the age of 65 years living in the United States (Centers for Disease Control and Prevention, 2013). For a variety of reasons, including policy, personal, and financial reasons, many aging adults are choosing to “age in place” or to remain in the community, a decision supported by their families (Callahan, 1992; Mattimore, Wenger et al., 1997; Feldman, Oberling, Simantov, & Gursen, 2004; Benjamin, Matthiak, & Franke, 2000). With the increase in the numbers of aging adults in the community, the ability to locate quality and affordable formal and informal caregiving options (at-home or long-term care for aging adults with chronic health conditions) has become an essential need (Seematter-Bagnoud & Santo-Eggimann, 2007; Donohue, Huskamp, Wilson, & Weissman, 2009).

Aging adults with chronic conditions, especially those with a high disease burden, have significant limitations in their ability to carry out day-to-day activities, have higher psychosocial needs, and have a higher mortality rate (Cohen-Masfield, Shmotkin, & Hazan, 2010; Kellogg & Bricner, 2000). Most aging adults with complex health needs rely on care provided by informal or unpaid caregivers, and most informal caregivers are related to the care recipient, such as a spouse, sister, brother, daughter, and/or son (Stone, Cafferata, & Sang, 1987; Wolff & Roter, 2008; Levin, Halper, Peist, & Gould, 2010). The issue of aging in place and informal caregiving

goes beyond meeting the personal needs of the person requiring care. There are health consequences, as well as social and financial implications, for caregivers, which can be associated with unmet needs of those receiving and providing the care. Unmet needs have been conceptualized by the U.S. Department of Health and Human Services (Jackson, 1991) as the need for someone to assist with Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs) such as bathing, dressing, managing medications, and transportation. Unmet needs can also be defined as support desired or required by the caregiver, but not necessarily received, such as community resources, caregiver education, emotional support, or respite care, that impede the ability to provide adequate care to the aging adult (Black et al., 2013). Unmet needs for both the aging adult and the caregiver can become burdensome or stressful on the caregiver and have been linked to higher levels of physical and psychological ailments, such as headaches, weakened immune systems, depression, and anxiety (Wight, LeBlanc, & Aneshensel, 1998; Shewchuk, Richards, & Elliott, 1998; Zarit, 2006, Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1997; Schulz & Beach, 1999; Pinguart & Sorenson, 2003).

Caregivers for aging family members experience higher levels of burden and stress and, whether actual or perceived, there is a need to explore how to reduce that burden and stress (Garlo, O'Leary, Van Ness, & Fried, 2010). In most cases, the informal care provider is the only source of support for an aging adult, despite the availability of a variety of community services. These services are generally not accessed, either by the care recipient or by the informal care provider (Perlin, Mullan, Semple, & Skaff, 1990).

It is important to address and understand how unmet needs can influence caregiver burden and stress, not only in the experience of that burden and stress, but also in the scope of

the actual needs of the caregiver or of the aging adult and the services that they can or cannot provide or access themselves. While there can be high levels of stress and burden among caregivers, health service utilization (or the inability to access services) may play a broader role in the development of caregiver burden and stress.

Aging Adult Population

The population of aging adults is one of the fastest growing populations in the United States (Werner, 2011). From 2000 to 2010, there was a 15 percent increase in the number of people in the US over the age of 65 years. According to the 2010 US Census, there were over 34 million adults aged 65 years or older, which accounted for 12% of the total population. Of those 34 million adults, the median age was 75 years. Approximately 60% of the population is female, but the gap between female and male adults over the age of 65 years is the closest it has ever been, and the number of men aged 85 to 94 years showed the largest increase in size (Werner, 2011). The Commonwealth of Virginia has over one million adults over the age of 65 years and saw a 30% increase from 2000 to 2010 per the U.S. Census Bureau (Werner, 2011). Since 2011, approximately 10,000 people in the United States have turned 65 years of age every day. It is estimated that by 2030, 20% of the population will be considered to be an aging adult (Taylor et al., 2010; Wan, Velkoff, & DeBarrow, 2005), and many of those persons will present with a chronic health condition.

Aging Adults with Chronic Conditions

Chronic conditions are illnesses that are often preventable, have been present and are expected to be present for at least 1 year or more, and are considered not to be curable. However, such conditions including heart disease, stroke, cancer, diabetes, obesity, depression, and arthritis, are manageable (Hwang, Weller, Ireys, & Anderson, 2001; Anderson & Horvath, 2004;

Pleis, Lucas, & Ward, 2008; Centers for Medicare and Medicaid Services, 2012). The most common chronic health conditions, per the Centers for Medicare and Medicaid Services (2012), are high blood pressure (58%), high cholesterol (45%), heart disease (31%), arthritis (29%), and diabetes (28%). According to the Centers for Disease Control and Prevention (2013), chronic conditions are the cause of 70% of the deaths and account for 86% of the health care costs in the United States (Gerteis et al., 2014).

Chronic conditions amongst aging adults are of great concern, due to the complex nature of treating both the chronic condition and issues of aging (National Alliance for Caregiving, 2005). Approximately 50% of aging adults have one or more chronic conditions and as many as 11 million aging adults have five or more conditions. The number of aging adults with multiple chronic conditions is expected to rise at the same time as the population of aging adults rises. Thorpe and Howard (2006) found that the number of adults age 65 years and older with five or more chronic conditions has increased by 20% since 1987.

There are many reasons for the increase in the number of aging adults with chronic conditions. Advances in medical treatment outcomes for chronic diseases have created a health care system that is capable of better screening, more accurate diagnosing, and more effectively educating patients about chronic diseases. According to Hyre and colleagues (2007), knowledge about high cholesterol increased from 40% in the 1980's to 60% in 2004. The resulting patterns of prevention, diagnosis, and clinical practice have allowed aging adults to live longer and many of them have been able to continue to age within their communities.

While chronic conditions can affect people of all ages and across many sociodemographic levels, some people are more vulnerable to certain chronic conditions. Within the aging adult population, minorities and those living at certain economic levels are more likely

to be affected by certain chronic conditions. For example, aging adults who live below the poverty line are more likely to suffer from kidney disease, congestive heart failure, heart disease, mental illness, and diabetes (Centers for Medicare and Medicaid Services, 2012; U.S. Department of Health and Human Services, 2006). Older adults with chronic health conditions, especially those without the means to care for themselves or to hire a formal caregiver, are at higher risk, and due to their higher risk are in greater need of a caregiver and assistance from community-based services.

Caregivers of Aging Adults

Aging adults with chronic conditions often require more assistance with Activities of Daily Living (ADLs) (i.e. feeding, bathing, dressing) or Instrumental Activities of Daily Living (IADLs) (i.e. preparing meals, managing finances, housework), coordinating and attending doctors' visits; managing medications, wound care, financial support; and attaining resources within the community (Garlo et al., 2010; Schulz, Beach, Cook, Martire, Tomlinson, & Monin, 2012). It is estimated that approximately 34 million adults provide care to assist an aging adult to meet these needs (National Alliance for Caregiving, 2015).

Caregivers are often necessary to allow an aging adult to maintain functionality in society. While formal caregivers are available, prohibitive costs or personal beliefs have shifted much of the care for aging adults to family and friends in the community who provide informal assistance within the aging adult's or the caregiver's home (Norgard & Rodgers, 1997; Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990). Studies show that 78% of aging adults who need caregiving support rely on informal caregiving situations involving family and friends, while 22% use formal caregiver support such as home health aides. The use of informal caregiving has significantly increased since 1994 (Fisher et al., 2011; Reinhard, Hauser, &

Choula, 2011; Schulz, Williamson, Morycz, & Biegel, 1993).

Informal caregivers are broadly defined as the spouses, children, other family members, or friends who provide needed, unpaid care to meet the needs of a person with a chronic condition (Stone et al., 1987). According to the most recent study by the National Alliance on Caregiving (2015), the vast majorities of caregivers are female, approximately 49 years of age, and have been providing care for about four years. Many of them are also employed outside the home (Coughlin, 2010; National Alliance for Caregiving, 2015). The aging adult receiving the care is most likely to be a parent of the informal caregiver, but can also be a spouse or another family member. Approximately 25% of aging adults who receive informal caregiving have a chronic, progressive memory problem or a cognitive impairment such as Alzheimer's or another related form of dementia (National Alliance for Caregiving, 2015).

Cost of Caregiving

As the number of informal caregivers continues to grow, the cost of providing informal caregiving services will also grow. Coughlin (2010) estimates that the number of informal caregivers will double by 2030 – from 31.5 million to 71.5 million. It is also estimated that caregiver services have an estimated value of \$472 billion per year (National Alliance for Caregiving, 2015; Chari, Engbert, Ray, & Mehrotra, 2015). Costs per caregiver vary, but it is estimated that the average informal caregiver cost is \$1,500 to \$35,000 per year (Hu, Huang, & Cartwright, 1986; Moore, Zhu, & Clipp, 2001). This number varies greatly due to the challenges in defining caregiving and caregiver services, as well as the dollar amounts associated with the costs and the types of care being provided. These costs are determined by the diagnoses and/or needs of the aging adult. The varying definitions of caregiving costs may be attributed to the varying needs of the aging adult and the ability for the caregiver to meet those needs. Needs,

whether tangible or intangible, and the ability to obtain those needs may also play a role in the cost of caregiving.

Unmet Needs

Unmet need is broadly defined, and ranges from the adequacy of care received to the need for specific services. The issues surrounding what kinds of needs or services are needed are complex, since no one aging adult or caregiver has the same needs (Hirakawa, Kuzuya, Enoki, & Uemura, 2011; Gaugler et al., 2005; Branch, 2000; Kane & Boult, 1998). Caregivers may define the aging adult's needs as help with ADLs and IADLs, social support, or other tangible or non-tangible needs. Unmet need has been linked to earlier placement into a nursing home or other long-term care facility by the caregiver (Gaugler et al., 2005). Gaugler et al. (2005) found that as the needs of the aging adult increase, the challenge of managing the aging adult's needs along with the caregiver's own needs rise as well, increasing the likelihood for placement in a long-term care facility.

Utilization of Services

Despite the large availability of resources to assist caregivers in caring for an aging adult, use of the services remains low (Hong, 2010). The U.S. Department of Health and Human Services (2004) reported that only 2% of caregivers accessed services. Multiple studies have shown a link between caregiver burden and stress and the utilization of services from within the community (Toseland et al., 1999; Eifert & Eddy, 2012; Hong, 2010; Roelands, Van Oost, & Depoorter, 2008; Friedemann, Newman, Buckwalter, & Montgomery, 2013; Phillipson, Jones, & Magee, 2014; Beeber, Thorpe, & Clipp, 2008; Gaugler et al., 2005; Kelley, Buckwalter, & Maas, 1999). Utilizing services can be important to reduce caregiver burden and stress, as well as to increase the caregiver's mental and physical ability to provide care to the aging adult, which

ultimately impacts the aging adult's overall health and well-being. Despite the evidence that service utilization reduces caregiver burden and stress, many caregivers report that they have unmet needs and that their unmet needs impact their quality of life (Branch, 2000). Gaugler et al. (2005) found that caregivers of aging adults with dementia who had higher levels of unmet needs experienced higher negative health outcomes, including higher levels of mortality.

Another study found that informal caregivers of aging adults reported that it was difficult to attain needed information or referrals, and to access adequate and appropriate in-home services, which led to feeling forgotten and abandoned (Lilly, Robinson, Holtzman, & Bottorff, 2012).

Although there are various models of caregiving and a breadth of literature about unmet needs amongst caregivers, little research has focused on the reasons behind the unmet needs or the factors which influence utilization of caregiving services. Furthermore, most research focuses on one issue or on a limited number of services, and fails to examine service utilization as a whole or as a set of concurrent needs and services (Hong, 2010).

Caregiver Burden and Stress

It has been said that the caregiver is one of the essential keys to good health and to the provision of care to an aging adult (Garlo et al., 2010; Lim & Zebrack, 2004). However, most caregivers do not have the knowledge, training, or support to provide the care necessary to manage the aging adult with a chronic condition within the community setting (Stone et al., 1987; Wolff & Roter, 2008; Levin, Halper, Peist, & Gould, 2010;). This can have a negative effect on the caregiver, especially in the form of perceived or actual burden and stress. In addition to the negative effects of stress and burden on caregivers, the effects of stress and burden can also impact the aging adult by diminishing the caregiver's ability to provide adequate and necessary care.

Even though many persons provide care to aging adults with little hesitation, the toll that informal caregiving has on a person is greater than that experienced by a formal caregiver (Pearlin, Mullan, Semple, & Skaff, 1990; Garlo, O’Leary, Van Ness, & Fried, 2010, Mohamed, Rosenheck, Lyketsos, & Schneider, 2010). Approximately 50% of all caregivers report they had no choice in caring for the aging adult (National Alliance for Caregiving, 2015). Informal caregivers face a host of emotional, financial, social, and health related issues that not only impact the individual caregiver, but also impact the care recipient (Andersen & Newman, 2005; Bradley, Curry, McGraw, Webster, Kasl, & Andersen, 2004; Bookwala, Zdaniuk, Burton, Lind, Jackson, & Schulz, 2004). Caregivers are at a higher risk for depression, anxiety, and illness; and have higher rates of early mortality (Schulz, Beach, Cook, Martire, Tomlinson & Monin, 2012; Bennett, Fagundes, & Kiecolt-Glaser, 2013; Gaugler, Kane, Kane, & Newcomber, 2005). Studies have shown a link between the unmet needs of the aging adult or the caregiver, the level of utilization, and caregiver burden and stress.

Purpose of the Study

Healthy People 2020 identifies two objectives related to this topic: 1) (OA-8) Reduce the proportion of non-institutionalized older adults with disabilities who have an unmet need for long-term services and supports; and 2) (OA-9) Reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiving support services (U.S. Department of Health and Human Services, 2010). Identifying the unmet needs of both the caregiver and the aging adult not only increases knowledge about the needs of caregivers and aging adults, but also contributes to efforts to reduce burden and stress among caregivers.

This study had two purposes: 1) to test the reliability and validity of a survey developed to examine service utilization that evolved from three other valid and reliable measures selected

from the literature. Testing reliability and validity of the newly developed survey will ensure that the instrument will measure what it should and that, if used in another setting, the measure would produce similar results; and 2) to examine the utilization of services as it relates to the unmet needs of informal caregivers for adults 65 years of age or older in Virginia. Unmet needs can include the physical, mental, and/or tangible (financial, respite, transportation, etc.) needs of the caregivers.

Research Questions

The following research questions will be addressed in this research study:

1. What is the validity of the newly developed survey measure?
2. What is the reliability of the newly developed survey measure?
3. How is service utilization influenced by need for caregiving assistance?
4. How is service utilization influenced by a caregiver's willingness to access services on the aging adults' behalf, and does burden and social support play a role?
5. How is service use to support the care of an aging adult impacted by demographics and burden?
6. What is the correlation between health service utilization, social support, and burden?
7. How do predisposing, enabling, and need factors impact a person's feelings of burden?

Definitions of Key Terms

Activities of Daily Living (ADLs): Self-care activities such as feeding, bathing, dressing, toileting, transferring and grooming.

Aging adult: An adult, over the age of 65 years

Burden: An idea, task, or concept that causes a person to worry.

Enabling Factors: Factors including the level of care needed by an aging adult, the length of time as an informal caregiver, access to resources, social support, the costs associated with caregiving, and the perceived needs of the aging adult by the informal caregiver.

Instrumental Activities of Daily Living (IADLs): Complex skills needed to successfully live independently, such as managing finances, transportation, preparing meals, shopping, managing medications, and housework.

Informal caregiver: A family member or other person, 18 years or older, who assists in the daily care of a medically frail adult, often without pay.

Need Factors: Factors measuring access to health care services. Need includes time spent providing care, types of caregiving services needed, ability to access health services, and the level of importance of health services for the aging adult to the caregiver.

Predisposing Factors: Factors that influence the likelihood that some individual needs or will use or access a health service. Predisposing factors can include demographic characteristics such as age, gender, education level, income, marital status, and competing responsibilities.

Stress: A state of mental or emotional strain caused by a circumstance or set of circumstances.

Significance of Study

While it is well documented in the literature that informal caregivers care for the majority of aging adults, there is a need to continue the research, especially regarding health care service utilization and how caregiver characteristics and aspects of caregiving influence the use of health-related services. Once the survey instrument is validated and has been shown to be reliable, it can be used to explore the gap between the perceived need for health care services and actual service utilization.

The dynamics of caregiving are not simply about the individual caregiver or the aging

adult's needs, but rather they are about the dynamic combination of caregiver characteristics, community resources, care recipient needs, caregiver life circumstances, and caregiver competence that facilitate successful supports of the caregiver and the aging adult. Information gathered from this study will be useful to describe the needs of informal caregivers, and also to predict future caregiver or aging adult needs.

CHAPTER II

THEORETICAL FRAMEWORK

Andersen Health Care Utilization Model

The Andersen Health Care Utilization Model was developed in the late 1960's to describe or explain why people use health care services, to define health care access, and to assist in developing health care practices and policies that help families, patients, and others access and use health care services (Andersen, 1995). The model originally used the family as the unit of measure. Later developments of the model moved from the family as the unit of measure to the individual as the unit of measure, mostly due to the difficulty in analyzing family dynamics and other factors that impact the whole unit (Andersen & Andersen, 1967; Andersen, 1968; Andersen, 1995). The model fills gaps in the understanding of health care utilization where other models and frameworks are lacking (Mechanic, 1979; Rundall, 1981). Simply put, the Andersen Health Care Utilization Model uses predisposing, enabling, and need factors as a mechanism to explain or predict health care service utilization among families.

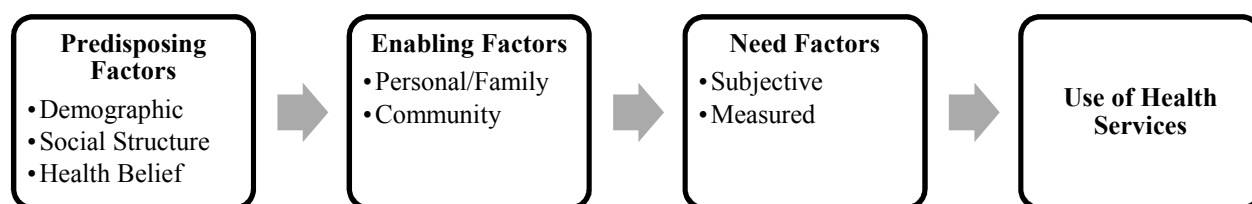


Figure 1: Andersen Health Care Service Utilization Model

Source: Andersen, 1968

Over time, Andersen refined and adapted his model, incorporating the research of others in the field to expand the current uses and definitions of health service utilization. Expanded models include elements such as: policy, resources, and organization; types of services needed; patient satisfaction or patient outcome; and in the most current version, the unique needs of

special or vulnerable populations (Andersen & Aday, 1974; Andersen, 1995; Gelberg, Andersen, & Leake, 2000).

Gelberg-Andersen Behavioral Model for Vulnerable Populations Adaptation

The Gelberg-Andersen Behavioral Model for Vulnerable Populations (Gelberg, Andersen, & Leake, 2000) will serve as the theoretical foundation of this research. This model is an expanded version of the original Andersen Behavioral Model, also known as the Andersen Health Care Utilization Model or the Behavioral Model of Health Services Use (Andersen, 1968; Andersen, 1995), which describes the relationships among predisposing, enabling, and need factors while explaining the relationship between the factors and health services utilization. This model has been used in health services research (Hong, 2010; Padgett, Struening, & Andrews, 1990; Padgett, Struening, Andrews, & Pittman, 1995; Swanson, Andersen, & Gelberg, 2003). The newer, expanded Gelberg-Andersen model can incorporate factors such as age, gender, education, health insurance status, and physical illness, but also incorporates specific vulnerabilities found among populations (Kushel, Gupta, Gee, & Haas, 2006).

Informal caregivers of aging adults represent a vulnerable population due to the burden and stress that they experience in their caregiving role. The mental status, age, gender, education and competing responsibilities of the caregiver, coupled with the complex and changing health needs of the care recipient, influence whether health care services are effectively utilized (Manne & Badr, 2010; Oberst & James, 1989; Gelberg et al., 2000; Touliatos, Perlmutter, & Straus, 2001; Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993). Using an expansion of the Andersen model allows for biological factors to be emphasized, and considers the psychosocial factors and caregiver needs that may influence an aging adult's overall health (Andersen & Newman, 1973; Bradley, McGraw, Curry, Buckser, King, Kasl et al., 2002; Bookwala et al., 2004).

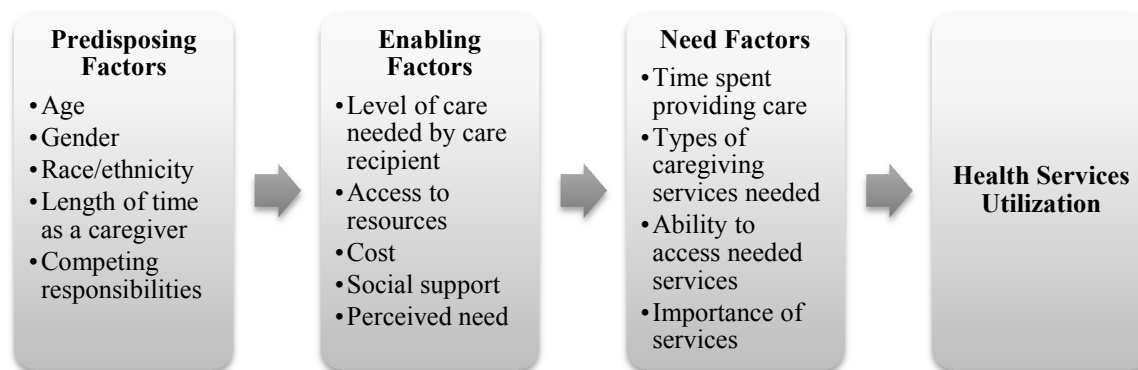


Figure 2: Adapted Gelberg-Andersen Behavioral Model for Vulnerable Populations

Anderson Model and Elderly Populations

The Anderson model of health services utilization and its expanded versions have been used minimally in aging adult research. The research has shown that health service utilization does increase with age, which is a widely known fact. Furthermore, the model includes predisposing, enabling, and need factors that have not been applied to caregivers and care recipients as a combined population. Many studies have focused on the aging adult as either the primary individual care recipient or the primary caregiver; the care recipient and the caregiver have not been viewed together as the driving force behind the use of health care services. Most research done in the 1980's through early 2000's focuses on the health services need of one or the other (Kadushin, 2004; Hong, 2010; Padgett, Struening, & Andrews, 1990; Padgett, Struening, Andrews, & Pittman, 1995; Swanson, Andersen, & Gelberg, 2003; Henton, Hays, Walker, & Atwood, 2002; Branch, Jette, Evashwick, Polansky, Rowe, & Diehr, 1981; Evashwick, Rowe, Diehr, & Branch, 1984; Wilson & Truman, 2005). Comprehensive research on service utilization and use among the aging adult population regardless of role (whether care recipient or caregiver) is lacking.

Literature Review

“Quality of Life” (QOL) is the term used to evaluate the overall well-being of individuals. Standard indicators of QOL include a person’s wealth, employment, environment, physical and mental health, education, hobbies or personal interests, and social interactions (National Cancer Institute, 2010). In the scope of caregiving, the QOL of a caregiver is influenced not only by the predisposing, enabling, and need factors shown above in the Andersen-Gelberg Model, but also by factors related to the aging adult and his or her needs. Informal caregivers have been identified as one of the most vulnerable groups and many report lower QOL as well as higher rates of caregiver burden and stress while providing care (Manne & Badr, 2010; Oberst & James, 1985).

Higher rates of burden and stress are attributed to higher rates of illness, psychological distress such as depression and anxiety, fatigue, indigestion, and the increased severity of preexisting conditions (Smith, Williamson, Miller, & Schulz, 2011; Mastrian, Ritter, & Deimling, 1996; Aranda & Knight, 1997; Haley, West, Wadley, & Ford, 1995; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Schutlz et al, 1987; Colgrove, Kim, & Thompson, 2007; George & Gwyther, 1986; Gwyther & George, 1986; Manne & Badr, 2010; Wagner, Bigatti, & Storniolo, 2006; Oberst & James, 1985). Burden and stress amongst individuals providing care to an aging adult can be attributed to many factors such as age, gender, competing responsibilities, length of time as a caregiver, level of care required by the aging adult, and social support (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Strawbridge, Wallhagen, Shema, & Kaplan, 1997; Song, Beigel, & Milligan, 1997). These factors influence the use of health-related services and other resources found in the community that can assist the caregiver in providing care to the aging adult. Past and current research also suggests that these factors are

predictors of caregiving outcome. As the aging population grows, these factors will become increasingly complex, greatly influencing the caregiving experience (Smith, Williamson, Miller, & Schulz, 2011).

Predisposing Factors

Predisposing factors are those influences that provide a rationale for a behavior (Green & Krueger, 2005). Originally conceptualized as a person's sociodemographic factors, these are the features that would influence the likelihood that one would need or would use health care services (Hulka & Wheat, 1985). Predisposing factors include demographic indicators such as age, gender, ethnicity, etc. However, predisposing factors also encompass an individual's knowledge, attitudes, beliefs, personal preferences, skills, and levels of self-efficacy (Glanz, Rimer, & Viswanath, 2008).

Age

The age of informal caregivers varies, but most research places the majority of caregivers in the middle to older adult years (Reckrey, DeCherrie, Kelley, & Ornstein, 2013). The National Alliance for Caregiving (2015) found that the average age of a person caring for an aging adult is approximately 49 years old. The National Alliance for Caregiving (2015) also reports that 79% of caregivers are between 35 and 65 years of age. Most caregivers are caring for a parent (47%) or a spouse (10%), and 25% are caring for a parent or spouse over the age of 85.

Gender

The National Alliance for Caregiving (2015) reports that 60% of caregivers are female. Previous studies have solidified not only that the role of caregiving is often performed by women, but that caregiving is also expected to be performed by women (Calasanti & King, 2007; Keefe & Medjuck, 1997; Lutzky & Knight, 1994). Higher levels of caregiving burden and stress

that influence service utilization are reported by women. The higher, self-imposed expectations of female caregivers who must assume multiple roles (i.e. caregiver, wife, mother, friend, etc....), the perceived need to spend more time with the aging adult, and limited help with caregiving, personal, and household tasks all contribute to caregiver burden and stress (Wallace, Dilworth-Anderson, & Goodwin, 2003; Zhan & Montgomery, 2003).

Race/ethnicity

Informal caregiving occurs across all races and ethnicities. Race and ethnicity are a driving force behind the use of community-based services (Borrayo, Salmon, Polivka, & Dunlop, 2002; Schaefer, Allwardt, Montgomery, & Karner, 2002). A report issued by the National Alliance for Caregiving (2015) suggests that 66% of caregivers are White, 32% are African American, 35% are Hispanic, and 4% identify as Asian American. This report also suggests that White caregivers are older than their African American, Hispanic, and Asian American counterparts, but that White and Asian Americans are more likely to be caring for an older adult. Reckrey et al. (2013), in a study of health care service utilization and the associations of caregiver burden and use of healthcare services for aging adults, found that 36% of the informal caregivers were White, 32% Hispanic, and 28% were African American, but the higher levels of burden were felt more by non-White caregivers. The non-White caregivers who felt the most stressful effects of caregiving were also those without outside help, whose aging adult in their care needed the most help with their ADLs and IADLs, and who provided over 40 hours of care per week.

Race and ethnicity are also linked to higher levels of burden and stress among caregivers. Hispanics report the highest level of burden, followed by Asian Americans, African Americans, and then Whites (National Alliance for Caregiving, 2015). Cox and Monk (1990) report an

underlying assumption that African-American and Hispanic groups prefer family caregiving over formal caregiving. While this may be true for many families, there is a lack of evidence that suggests informal caregiving is influenced solely by family and cultural values. Healthcare service utilization is also influenced by the knowledge of available services, issues in accessing services, and language barriers (Cox & Monk, 1990)

The associations between burden and stress and the obligation to care for an aging adult were noted in studies by Cicirelli (1993) and Guberman, Maheu, and Maille (1992). Additional research by del-Pino-Casado and Frias-Osuna (2011; 2014) found that caregivers who felt obligated to care for someone in their family had higher levels of burden. In this study, the levels of burden and stress were found to be higher among those caring for spouses or other relatives, such as children or children-in-law, siblings, or other immediate or blood relatives.

Length of time as a caregiver

Being an informal caregiver comes with a large adjustment period and for many, years of navigating a system that is not always user-friendly to either the informal caregiver or the aging adult in their care. Caregivers, on average, provide informal caregiving services to an aging adult for at least three to five years, and those who care for an aging adult over 85 years of age serving in this role for four or more years. Often, caregiving responsibility begins long before one has identified himself or herself as a caregiver (Reckrey et al., 2013).

Most caregivers (49%) report that their becoming a caregiver was not by choice. Rather, they became a caregiver because the aging adult relative became too old or too frail to care for themselves, or had a diagnosed cognitive impairment or mobility issues, and there was not another option for care (National Alliance for Caregiving; Dilworth-Andersen, Goodwin, & Williams, 2004). Those who feel obligated to provide care for an aging adult are usually

providing care to someone close to them, such as a spouse or parent. The decision to provide care is often based on whether other help is available. Even when other help is available, these family caregivers still feel that they have no choice, but to become the caregiver. In addition to feeling obligated or forced into caring for aging adult, there is research that has shown that many caregivers, especially female caregivers, are not psychologically prepared for the role, which influences their caregiving experience (Hayden & Heller, 1997).

Competing responsibilities

Caregivers of aging adults not only have the role of caregiver, but also hold other roles in their social structure and environment, such as employee, spouse, or parent. Many times, these other roles compete or stand in conflict with their role as a caregiver (Barnes, Given, & Given, 1995). Competing responsibilities can create stress and burdensome situations among informal caregivers; feelings of guilt arise for taking time away from the care recipient in order to do something for themselves or their families (Trudeau-Hern & Daneshpour, 2012). Archnold (1982) noted that caregivers often give up their own needs to provide care for others and often this includes scheduling their career and other activities around the care recipient. Caregivers give up much of their time, energy, personal goals, emotional and financial resources to provide care to an aging adult. Several studies have concluded that caregivers who work outside the home and provide caregiving services have poorer work outcomes than those who only provide care or only work outside the home (Shyu, 2000; Scharlach & Boyd, 1989; Scharlach, 1994; Pavalko & Artis, 1997).

Employment

Many caregivers hold employment outside of the home in addition to caring for the aging adult. Approximately 60% of informal caregivers are employed part- or full-time (Navaie-

Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002; Trudeau-Hern & Daneshpour, 2012) and work an average of 35 hours per week (National Alliance for Caregiving, 2015). Employment and caregiving are in conflict for many reasons, mainly due to inflexible work schedules and the need for the income that the employment provides. Income could be needed to supplement the aging adult's finances, or in many instances, the income is needed to keep a household financially stable (Fast, Williamson, & Keating, 1999; White-Means & Rubin, 2004; Stoller, 1983; Warshaw, Barr, & Schachter, 1987). Only 56% of employed caregivers report having a flexible work environment, including telecommuting options (National Alliance for Caregiving, 2015). Employment policies play an influential role in the burden and stress felt by working caregivers. The increasing numbers of working caregivers have prompted employers to examine their employment policies to better accommodate the working caregiver. Workplace policies may or may not include information on access to relevant programs and services available to the employee (Lui, 2012; Krach & Brooks, 1995), but even with this information, employment often creates higher levels of burden and stress for the informal caregiver.

Employment has been linked to higher stress levels among those with caregiving responsibilities. Stress-related illnesses can cause caregivers to be less involved in their jobs and affect their job performance (Azarnoff & Scharlach, 1988; Montgomery, Gonyea, & Hooyman, 1985; Treas, 1977; National Alliance for Caregiving, 2015). Research has shown that primary caregivers who hold outside employment have higher rates of absenteeism, lateness, excessive use of the phone for personal reasons, lack concentration due to the constant strain of trying to care for an aging adult, lack of sleep, and the ability to work fewer hours than needed or wanted (Covinsky, Goldman, & Cook, 1994; National Alliance for Caregiving, 2015; Azarnoff & Scharlach, 1988).

Employment is a competing responsibility for working caregivers that is associated with higher levels of stress. This stress is more likely to lead to the caregiver quitting his or her job, due to the demands of caring for their aging adult. It is reported that approximately 18% of informal caregivers report quitting their job, 15% have taken a leave of absence, and 4% have retired early (Trudeau-Hern & Daneshpour, 2012; Gibeau & Anastas, 1989; National Alliance for Caregiving, 2015). Moreover, it is reported that caregivers who have decided to forgo employment or to quit their job were caring for more dependent and incontinent people and on average, and were engaged in more ADL and IADL tasks than those with less needy care recipients (Barnes, Given, and Given, 1995).

Spouse and children

One of the largest growing subpopulations of informal caregivers is early to late middle-aged adults with spouses and children of their own. Younger caregivers are more likely not only to work, but also to have children at home (Stoller & Pugliesi, 1989; National Alliance for Caregiving, 2015). Approximately 74% of informal caregivers report being married (National Alliance for Caregiving, 2015; Lai, 2012; Navaie-Waliser, et al., 2002). Furthermore, 48% of informal caregivers have children under the age of 18 years living at home (National Alliance for Caregiving, 2015; Barnes, Given, & Given, 1995; Trudeau-Hern & Daneshpour, 2012; Lai, 2012). This subpopulation is often called the “sandwich generation.” Most of the people who provide care to both aging adults and their spouses and children are women. Historically, societal practices and beliefs have led to the assumption that caregiving is a task to be assumed by women (Chappell & Kuehne, 1998). However, in recent years, more men than women (33% vs. 67%) have become informal caregivers (National Alliance for Caregiving, 2015). The change in who is providing the services or the shared roles of caregiving between men and women can be

attributed to changes in gender roles, changes in family structures, and longer lifespans (National Alliance for Caregiving, 2009; Kramer & Thompson, 2002).

Enabling Factors

Enabling factors are those factors that allow for a motivation to be realized and precede environmental change. These factors include programs, services, and resources (Green & Kreuter, 2005; Glanz, Rimer, & Viswanath, 2008).

Level of care needed by care recipient

The top three problems or illnesses that lead to the need for caregiving are “old age”, cognitive impairment, and mobility issues. Approximately 24% of aging adults have a cognitive impairment, according to their caregivers (National Alliance for Caregiving, 2015). Many aging adults who receive care from an informal caregiver have difficulty performing Activities of Daily Living (ADLs) and Independent Activities of Daily Living (IADLs) (Deai, Lentzner, & Weeks, 2001; Manton, Corder, & Stallard, 1993; Verbrugge, Rennert, & Madans, 1997). Informal caregivers perform a variety of tasks ranging from assistance with transportation to bathing and dressing (Trudeau-Hern & Daneshpour, 2012; Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). In a study by Trudeau-Hern & Daneshpour (2012), study participants reported helping their care recipient with note-taking at appointments, navigating the insurance systems, distributing medications, scheduling appointments, and being the spokesperson to family and friends. Providing care to an aging adult is an evolving process in which the level of need required of the aging adult moves from low to high needs, based on the person’s ability to function. For example, a patient with early onset dementia or cognitive impairment may need to be reminded to take his or her medications, but as time moves on and the disease progresses, these patients could need help with everything including bathing,

dressing, toileting, and moving from location to location (Sorrell & Cangelosi, 2009; Navaie-Waliser et al., 2002). The most assistance is needed for those who are 85 years of age and older, who have two or three chronic conditions, and who need help with one to four ADLs (Desai, Lentzner, & Weeks, 2001).

Research has indicated that level of assistance required by the aging adult is one of the strongest indicators of service need and utilization (Tennstedt, McKinlay, & Kasten, 1994) and has some of the largest impacts on aging adult health (Allen & Mor, 1997; Desai et al., 2001). A study by Desai et al. (2001) found that people needed the most help with eating, toileting, dressing, transferring from location to location, getting outside, bathing, and walking. Of those who needed help with these tasks, approximately 20% did not receive the help needed or required, and 48% of this group suffered a negative outcome.

Access to resources

Approximately 69% of adults aged 65 years of age and older require or would benefit from community-based services (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011) provided by paid medical providers, social workers, adult day care centers, home health aides, and others (Bass, Noelker, & Rechlin, 1996). Services performed include direct care provided to the aging adult such as adult daycare, respite care, and counseling, as well as indirect care provided to the caregiver such as support groups, telephone support, and online support through chat groups, discussion boards, and blogs (Robinson, Buckwalter, & Reed, 2013). While many resources in the community are available to aging adults and their caregivers, efforts to access these services can be difficult due to constraints within a fragmented delivery system, lack of resources in a particular geographic location, and knowledge about the available services within a community (Robinson et al., 2005, Kemper, 1992). One-third of caregivers have reported that

they have spoken with a health care provider (doctor, nurse, social worker) and have been asked what the care recipient needs, but only 16% reported the care recipient directly expressed what was needed (National Alliance for Caregiving, 2015). Several studies have indicated that caregivers need health care providers to assist them in exploring and obtaining services to meet the needs of the aging adults (Beach, 1993; Nkongho & Archbold, 1996; Pavalko & Artis, 1997). Even with advanced technology, caregivers continue to carry out the task of locating and arranging services within a system that lacks adequate information or cannot support the needs of either the caregiver or the aging adult (Robinson et al., 2005; Beeber, Thorpe, & Clipp, 2008). Two of the biggest barriers to technology use are the inability for caregivers to access patient health information and their unfamiliarity with programs or websites that help facilitate health service utilization (Zulman, Piette, Jenchura, Asch, & Rosland, 2013).

Social support

Early research displays evidence that personal adjustment and social behavior, as well as health outcomes, can be influenced by a person's access to others who can support them or can provide a supportive environment (Brown & Harris, 1978; Edwards & Scheetz, 2002). Social support has been shown to have a buffering effect on the effects of the caregiving burden, lowering the burden for those who obtain more social support (Edwards & Scheetz, 2002). Social support is categorized into two groups: perceived and received social support. Perceived support is the support that someone feels he or she has or has available, whereas received social support is tangible social support that a person receives (Ergh, Rapport, Coleman, & Hanks, 2002). Varona, Saito, Takahashi, and Kai (2007) report that the most needed form of social support is the ability to talk and confide in a person openly (85%) followed by receiving advice and

information from others (84%), mainly from those imbedded in the community organizations in which they participated.

Furthermore, research has shown that, since women are traditionally the caregivers of aging adults, more support is need for female caregivers. Service providers need to consider the specific challenges as they relate to gender when they are designing programs (Lui, 2012), especially for younger and/or employed women and/or women with children (Hayden & Heller, 1997; Orel, Landry-Meyer, & Spence, 2007; Stoller & Pugliesi, 1989). Social support or lack of social support for the informal caregivers of aging adults has been linked to the overall health and well-being of both the caregiver and the aging adult. The benefits of social support include lessened feelings of distress and loneliness, reduced stress levels, and less depressive symptoms (Corna & Cairney, 2005; de Jong, Gierveld, & Dykstra, 2008; Antonucci, Lansford, & Akiyama, 2001). Although there is research about the importance of social support, there is little evidence that the existence of social support influences burden, thus influencing service utilization (Smerglia, Miller, Sotnak, & Geiss, 2007; Vrabec, 1997).

Cost

When considering cost and informal caregiving, it is important to note that there are two costs in the caregiving equation. One is the economic value of informal caregiving or the value of the services that informal caregivers provide at no cost to aging adults. The second cost in caregiving is the cost of services provided by others to an aging adult in addition to the informal caregiver's services or in place of the services provided by the caregiver. In 1999, the economic value of unpaid caregiving services to aging adults was estimated at \$196 billion dollars (Arno, Levine, & Memmott, 1999). Eight years later, the value of unpaid caregiving rose to \$375

billion, and it jumped again in 2009 to \$450 billion (Feinberg, Reinhard, Hauser, & Choula, 2011).

These costs can be for medical care, respite care, or other related health services offered by an organization or by individuals, and may have a cost attached to them that is paid by the care recipient or by the caregiver. Most caregiving costs are not covered by insurance companies (Arno, Levine, & Memmott, 1999). In a recent study, approximately 37% of caregivers indicated that caring for an aging adult was expensive (National Alliance for Caregiving, 2015). Informal caregivers often report financial strain due to the lack of compensation for caregiving services being provided or the loss of wages due to changes in work hours in order to provide caregiving services. Lui (2012) found that financial costs are one of the highest predictors of burden and stress, which could influence the use of services for aging adults.

Perceived need

Results of a study by Casado (2008) found that the informal caregiver is the driving force behind the use of health care services. Casado's results indicated that a caregiver's perception of the care recipient's need for services determined whether community-based services were sought out. The growing need for long-term care due to the rising number of aging adults has resulted in the development of more community-based programs that can be accessed by either the caregiver or by the aging adult in need of the services. These programs are intended to alleviate the burden on the informal caregiver and to reduce expensive institutionalization of the aging adult (Gaugler et al., 2005). An example is the Program for All-Inclusive Care for the Elderly (PACE), which is a Medicare and Medicaid program that helps aging adults meet their health care needs in the community. Eligible participants who are enrolled in the program access services such as adult day centers (respite); physician and specialty services; nursing care,

medical social work services; and physical, occupational, and speech therapy; as well as psychiatric services. Other services that the caregiver can access through the PACE program are respite care services, home health care services, home-delivered meals, and homemaker/chore services, if the aging adult lives on his or her own (<http://riversideonline.com/pace/benefits-and-coverage.com>, accessed 08/02/2017). Other aging adult services that may be available in the community are services to help transition from the hospital or from a rehabilitation facility to home, senior companionship programs, personal care services, and medication management services (<http://www.ssseva.org/services/index.html>, accessed 08/02/2017). Evercare® (2006) reported from its study that programs with the most support and that provide the most to informal caregivers are those that save caregivers time, provide relief from caregiving through respite care, reduce stress levels, and make the caregiver feel cared about and valued.

Need Factors

Need has been identified as one largest key factors in determining health care service utilization (Coulton & Frost, 1982; Gilbert, Branch, & Longmate, 1993; Mechanic, 1979; Wolinsky & Johnson, 1991). Andersen conceptualized need as perceived and actual needs. Perceived need is the how an individual perceives his or her health status, functional ability, and symptoms, and the importance that a person or persons place on their need and whether it is important enough to warrant getting services or treatment (Andersen, 1995). Actual needs can be measured by a person with knowledge or expertise in a specific area or who can weigh in with their own judgments based on actual factors. Among these are medical professionals or, in the case of this research, caregivers (Andersen, 1995).

Time spent providing care

The amount of time that an individual spends providing services as an informal caregiver varies, but most research indicates that the average informal caregiver spends 24 to 41 hours providing care per week (Navaie-Waliser et al., 2002; National Alliance for Caregiving, 2015). Caregivers who live with the aging adult spend an average of 40 hours per week providing care (National Alliance for Caregiving, 2015). Race and ethnicity have a role in the number of hours that service is provided by informal caregivers. The National Alliance for Caregiving (2015) reports that Hispanic caregivers spend more time caring for an aging adult than do White caregivers (32 hours vs. 21 hours). When compared to Whites and Asian Americans, 32% of Hispanics and 27% of African Americans provide approximately 41 hours of care each week, while only 18% of Whites and 22% of Asian Americans provide the equivalent number of hours. Findings from a qualitative study conducted by Evercare® (2006) found that caregivers reported higher levels of health decline, especially as the aging adult in their care required more help. Caregivers who provided more than 41 hours of caregiving services have been found to have less energy, get less sleep, and have more stress and anxiety, more instances of pain from unknown sources, higher levels of depression, and weight gain. Significant health effects can be felt by caregivers who provide as little as 20 hours of care per week (Evercare®, 2006).

Additionally, there are some differences in ideology among races and ethnicities that affect caregiving, use of services, and overall burden and stress levels. For example, Miller, Campbell, Farran, Kaufman and Davis (1995) found more physical ailments among non-White aging adults, which in turn created higher levels of need, especially with ADLs and IADLs.

Several studies have shown that aging adults from more disadvantaged ethnic and racial groups have poorer health and greater impairments in ADLs and IADLs (Aranda & Knight,

1997; Hayward & Heron, 1999). Further complicating this issue is that many ethnic and racial groups put more emphasis (self-imposed or familial) that caregiving is the responsibility of the family and that help from the outside the family is not necessary or needed. Several studies report that, compared with White caregivers, African-American and Hispanic caregivers feel that the care of the aging adult in their family is their responsibility (Lawton, Rajagopal, Brody, & Kleban, 1992; Cox & Monk, 1993; Luna, de Ardon, Lim, Phillips, & Russell, 1996).

Types of caregiving services needed

According to Reckrey, DeCherrie, Kelley, and Ornstein (2013), higher levels of burden and stress and the utilization of health care services are influenced by how much assistance an aging adult needs with their ADLs and IADLs. Functionality, which influences service needs, is associated with informal caregiver burden and stress (Pinquart & Sorensen, 2011; Bergvall et al., 2011). The National Alliance for Caregiving (2015) estimates that 60% of aging adults need help with at least one ADL, with mobility being the most needed service (45%). They also found that 57% of informal caregivers help with IADLs such as transportation, shopping, and housework, and strongly influence whether or not aging adults request and receive services based on their needs (Evans, Connis, Bishop, Hendricks, & Haselkorn, 1994; Glass, Matchar, Belyea, & Feussner, 1993). The type of services requested and received is also based on what the caregiver needs. For example, respite care is one of the most requested services; this is most likely due to the benefits it provides for both the caregiver and the care recipient (Beeber, Thorpe, and Clipp (2008).

Most caregivers provide support beyond the help needed with ADLs and IADLs. Over two-thirds of caregivers monitor the condition of and advocate for the aging adult in their care through interactions with providers, agencies, and other professionals. In addition, 60% of

informal caregivers assist with nursing tasks, of which 43% report not having had any prior medical or nursing experience and thus have difficulty performing these tasks (National Alliance for Caregiving, 2015). One in five caregivers reports having difficulty helping the aging adult with ADL and IADL care activities (National Alliance for Caregiving, 2015). Caregivers who provide support for more than one ADL or IADL report having the most difficulty. The most difficult tasks for caregivers are reported to be those involving personal care, such as toileting, incontinence, and bathing (National Alliance for Caregiving, 2015).

Ability to access needed services

Research has shown that most informal caregivers have had no prescribed training and no access to professional caregiving or related health information, which creates a burdensome situation for the informal caregiver (Navaie-Waliser et al., 2002). One in five caregivers of an aging adult reports some difficulty in coordinating care (National Alliance for Caregiving, 2015). Coordinating or accessing care is reported as being most difficult for the caregiver who does not live near their aging adult or who cares for a person with multiple conditions (National Alliance for Caregiving, 2015). Coordinating care issues are also compounded by other factors such as being the only caregiver to an aging adult, the high burden caused by the number of hours required for providing care, competing demands such as work and/or children, and being of a lower socioeconomic status (National Alliance for Caregiving, 2015).

Not only do informal caregivers play a vital role in aging adults use of services, but Hinojos et al., (2009) found that caregivers were more likely to use health care resources if other agencies or persons helped them achieve access. Reaching out for support services does not necessarily indicate that the aging adult has more disability or a change in health status; rather, it

suggests that service utilization is more likely when help is made available to facilitate access (Clark, Sander, Pappadis, Evans, Struchen, & Chiou-Tan, 2010).

Importance of services

There are many reasons driving a caregiver's decision to access services in the community for the aging adult in their care. The literature indicates that community-based services are underutilized, and, in many cases, the use of the service is delayed until the informal caregiver's burden and stress levels rise to a point of higher intensity at which they no longer feel that they can do the work or provide the service themselves (Leutz, Capitman, & Green, 2001). Research has also shown that there are several programs available to caregivers to assist them with caring for an aging adult. There is also evidence to suggest that the importance of the service to the caregiver can play a role in the use of the service (Parker, Mills, & Abbey, 2008; Elliott, Burgio, & DeCoster, 2010; Gallagher-Thompson & Coon, 2007; Alma, Man-Kin, Kam-Mei, Pey-Chyou, Lam, Thompson, & Gallagher-Thompson, 2009). The perceived need and importance of the service go together to determine whether the service will be requested and utilized. There are many reasons why an informal caregiver will not access a service or will feel that it is not important. According to Betts-Adams (2006), denial is linked to necessity, and the denial about the need for the service decreases the importance of the service. The importance of keeping the aging adult's issues private is also linked to service use. Literature has indicated that caregivers often keep the aging adult's diagnoses to themselves and only divulge the information on a need-to-know basis, even to other family members (Dorfman, Berlin, & Holmes, 1996; 1997). Lack of knowledge about the available services, worries about the costs of services, and the perceived benefit of the services desired are also linked to importance and use of services (Liken & King, 1995).

Conclusion

It has been reported that there is a “need gap” between what aging adults need and what informal caregivers need to care both for the aging adult and for themselves (National Alliance for Caregiving, 2015). A multitude of caregiving studies have investigated service use, but findings have been inconclusive and have only showcased that services are not being utilized. The literature fails to show conclusive reasons why an informal caregiver does or does not access a particular community-based service (Casado, 2008). Even when available, community services that could be used to alleviate the strain of caregiving are underused (Caserta, Lund, Wright, & Redburn, 1987; Zarit, Todd, & Zarit, 1986). This research is intended to address the “need gap” by examining how predisposing, enabling, and need factors influence the request and the use of community-based services for aging adults and subsequently, how service use impacts informal caregivers’ stress and burden levels.

CHAPTER III

METHODOLOGY

Study Design

A non-experimental, descriptive study design was used to examine predisposing, enabling, and need factors that influence health care service utilization by informal caregivers for aging adults in Virginia. This was a pilot study.

Pilot Studies

Pilot studies are useful because they are smaller versions of larger, full scale studies that allow for the testing of an instrument or methodology and the elimination of “best guesses” that can have impact on the study results (Baker, 1994; Polit, Beck, & Hungler, 2001; van Teijlingen, Rennie, Hundley, & Graham, 2001; van Teijlingen & Hundly, 2002; Kezer, 2000). Despite the literature showing pilot studies as an important aspect of research, few pilot studies are discussed in detail or in training, and therefore, they are an underutilized research technique (Thane, Ma. Chu, Cheng, Ismaila, Rios, Robson, et al., 2010; Kezer 2000).

For the purposes of this study, and based on the literature, pilot testing was conducted to determine the reliability and validity of a survey instrument designed to answer the research questions. This was a necessary process, since the measure was a compilation of other reliable and valid surveys gleaned from the literature review. Conducting this research allowed for: 1) removal of all unnecessary, difficult, and ambiguous questions; 2) assessment of the response rates to each of the questions asked; 3) a revision of the scale; and 4) testing the assumptions of the research questions posed in the earlier chapter.

Sample

Demographics such as age, gender, race, marital status, and income were collected from

the participants. Data such as number of children, age of the aging adult, work status, and living arrangements were also collected. Almost 75% of the respondents were female, with the majority of them identifying as White (54.8%) or Black (22.6%), and being married (64.5%). The average age of the respondent was 61.4 years. Over 50% of the respondents reported that they had attended college obtaining an Associate's (12.9%), Bachelor's (22.6%), or Master's (19.4%) degree. It was an equal split between working and non-working informal caregivers, with 48.1% of respondents reporting working outside the home and reporting an average income of \$40,000-\$69,999 per year. Seventy-one percent of respondents reported having children, but only a small number (less than 1%) reporting having children who lived at home or who were under the age of 18 years.

Table 1

Demographic Variables of the Informal Caregiver

		N	Percentage
Gender	Male	4	12.9
	Female	23	74.2
Race	White	17	54.8
	Black	7	22.6
	Hispanic	1	3.2
	Other	1	3.2
Marital Status	Single	2	6.5
	Married	20	64.5
	Divorced	2	6.5
	Widow/Widower	3	9.7
Education	High School Diploma or GED	10	32.3
	Associates degree	4	12.9
	Bachelor's degree	7	22.6
	Master's degree	6	19.4

Table 1 Continued

		N	Percentage
Employment			
	Yes	13	41.9
	No	14	45.2
Income			
	Under \$19,999	1	3.2
	\$30,000-\$39,999	3	9.7
	\$40,000-\$49,999	7	22.6
	\$50,000-\$59,999	4	12.9
	\$60,000-\$69,999	2	6.5
	\$70,000-\$79,999	1	3.2
	\$80,000-\$89,999	1	3.2
	\$100,000 and above	4	12.9
Average Number of children		3	
Children living in the home		<1	
Children under the age of 18			
years		<1	
Mean Age		61.4	

Limiting the age of the adult care recipient

Careful consideration was given to limiting the age of the adult care recipient to 65 years of age or older. Roebuck (1979) defined an aging adult as anyone over the age of 50 years, but over the course of time, this threshold has risen to 60 years of age (Thane, 1978; 1989; Roebuck, 1979) and is now 65 years of age and older (Centers for Medicare and Medicaid Services, retrieved September 10, 2015). Of those 65 years of age and older, population subgroups have been created to further define the aging population. Those 65 to 74 years of age are classified as “early elderly” and those 75 years of age and older as “late elderly” (Orimo, Ito, Suzuki, Araki, Hosoi, & Sawabe, 2006). This study focused on caregivers of aging adults 65 years of age and older because these are the individuals who qualify for Medicare, which helped to standardize the aging adult pool and caregivers. Additionally, most aging adult research is conducted with those aged 65 years of age and older, since this group shows the greatest increases in the need for

services in the present and in the future. It is estimated that the number of aging adults will increase to 80 million in 2050, up from 35 million in 2000 (U.S. Census Bureau, 2000).

Furthermore, adults over the age of 65 years of age are the largest users of services and are the most impaired, requiring help with more ADLs and IADLs (Brault, 2012; U.S. Department of Health and Human Services, 2012; Manton, Corder, & Stallard, 1997).

Statistical Significance

There is little guidance about how large a response a pilot study requires to be statistically significant. Several studies discussing pilot studies report that sample size calculations are not required for pilot studies, with the general rule being to ensure that the pilot study is large enough to provide useful information, but not so large that statistical significance is hard to detect (Lenth, 2001; Yin, 2002; Wittes & Brittain, 1990). The literature suggests that, to achieve significance in a large-scale study, there should be 5-10 participants for each item on the survey, up to a total of 300 (Tabachnick & Fidell, 2007; Comrey & Lee, 1992; Flynn & Percy, 2001). To achieve statistical significance in a pilot test, the literature suggests using the 10% rule, meaning that, in order to ensure statistical significance, the pilot study response rate should be 10% of the total number of responses calculated for the larger study (Baker, 1994; Hertzog, 2008).

Using this calculation, a response rate of 215-430 surveys was calculated based on a survey instrument that contains 43 items among the 3 scales. The 10% rule was then applied. Thus, the minimum number of completed surveys needed to achieve statistical significance in the pilot study was 21-43.

Research Questions

1. What is the validity of the newly developed survey measure?
2. What is the reliability of the newly developed survey measure?
3. How is service utilization influenced by need for caregiving assistance?
4. How is service utilization influenced by a caregiver's willingness to access services on the aging adults' behalf, and does burden and social support play a role?
5. How is service use to support the care of an aging adult impacted by demographics and burden?
6. What is the correlation between health service utilization, social support, and burden?
7. How do predisposing, enabling, and need factors impact a person's feelings of burden?

Instrumentation

An extensive literature review was completed to find and evaluate survey instruments used in other studies to examine caregiver utilization of services. The review of the relevant literature uncovered multiple reliable and valid survey instruments including: The Caregiver Burden Scale (Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993), which measures the tasks that informal caregivers may or may not perform and whether or not the caregiver feels burdened by the task; the Zarit Caregiver Burden Interview (Zarit, Reever, & Bach-Peterson, 1980) which measures the overall level of burden felt by an informal caregiver providing care to a person; and the Brief Measure of Social Support (Sarason, Sarason, Shearin, & Pierce, 1987), which measures perceptions of social support. These three instruments provide the initial framework for the 43-items developed for this study (Appendix A). Permission to reference these instruments for use in the development of the instrument in this study has been provided by the "gratis reuse" policy.

Permission to publish these surveys in the appendices was collected from the authors or from the agency that holds the copyright (Appendix G).

Demographic questions

Demographic questions such as age, gender, race and ethnicity, income, and marital status were included across multiple measures and were included in the survey instrument developed for this research. Based on the review of literature, questions about the number of children in the home, as well as about the respondents' work schedules, were also included as demographic variables and were used to describe the population, as well as to inform other statistical analyses.

Caregiver Burden Scale

The Caregiver Burden Scale (Appendix B) was developed to examine perceived burden among caregivers who provide care to a family member. This measure was found to allow for the narrowing of the source of a caregiver's stress, which could lead to more effective interventions. The Caregiver Burden Scale (Macera et al., 1993) has a Cronbach's alpha of 0.87. For this study, the original index was used as a guide and, using the literature as the reference, questions were developed to include variables that measured whether the caregiver needed help with a particular task, and received help for the task, and whether the help was from a community agency. If help was not received, what was the reason behind the lack of help, and what was the relative importance of the task?

Zarit Caregiver Burden Interview ©

The Zarit Caregiver Burden Interview (Appendix C) has a Cronbach's alpha of .92 (Hébert, Bravo, & Prévile, 2000) and has been widely used in caregiving research domestically and abroad (Bonin-Guillaume, Durand, Yahi, Curiel-Berruyer, Lacroix, Cretel et al., 2015;

Hirono, Kobayashi, & Mori, 1998). The Zarit Caregiver Burden Interview is considered a “gold standard” in the caregiver burden literature (Schreiner, Morimoto, Arai, & Zarit, 2006; Van Durme, Macq, Jeanmart, Gobert, 2011).

Brief Measure of Social Support ©

The Brief Measure of Social Support (Appendix D) is a survey designed with the intention of measuring perceptions of social support and satisfaction with the social support received from others. The Brief Measure of Social Support has been shown to be valid and reliable. In test-retest measures, the survey was found to be significant at the 0.01 level, with correlations of 0.80 and a Cronbach’s alpha of .75 to .97 ($p < 0.01$) (Sarason, Sarason, Shearin, & Peirce, 1987).

Readability

The Flesch-Kincaid readability test was completed to ensure that the survey could be understood by the respondents. This test was designed to assess how easy or difficult text is to understand by weighting word and sentence lengths to generate a score (Kincaid, Fishburne, Rogers, & Chissom, 1975). A score of 60-70 or a grade level of 8 or less is considered the standard. The survey developed for this study scored a 64.3, with a corresponding grade level of 6.1.

Content Validity

Prior to the survey’s being disseminated, content experts were secured and the survey was given to them for the purpose of reviewing it and ensuring that the instrument represented the purpose and scope of the study (Anastasi, 1988; Messick, 1993; Walsh, 1995). The three subject matter experts were asked to rate the survey using a Likert scale (5=Strongly Agree,

4=Agree, 3=Neither Agree or Disagree, 2=Disagree, 1=Strongly Disagree). Overall, they rated the survey highly, without reporting any significant issues.

Table 2

Content Validity Scores

Content Question	N	Aggregate Likert Score
The instructions for completion are clear and can be easily understood.	3	5
The content of the survey is appropriate for informal caregivers of aging adults.	3	5
The length of the survey is appropriate.	3	3
The survey relates to caregivers of aging adults and the caregivers' needs.	3	5
The survey addresses needs of caregivers.	3	5
The survey addresses stress and burden.	3	5
The survey adequately addresses social support.	3	5
The survey addresses the importance of services for aging adults and the caregivers' ability to access them.	3	5

Based on the validity score given by the experts about length, the determination was made that it would be beneficial to remove some of the survey items in order to reduce the length of the survey.

Ethical Considerations

This study was submitted to the Institutional Review Board at Old Dominion University for approval. After the initial approval, the study was amended to include different methods for participant recruitment. There were very few known risks to this study, beyond what could normally be expected from usual and regular conversation about caring for an aging adult. There was no guarantee that participants would personally benefit from taking part in this study.

Data Collection Procedures

The study utilized an online survey available at www.seniornavigator.org and a paper-based survey handed out to attendees of a local caregiving conference and at a local adult day care program, to collect data for analysis. Both distribution methods were used to assure an adequate response rate for this study.

Data Collection

Online collection

Over the past 30 years, the internet has rapidly grown as the host of online or Web surveys (Couper, 2000). Prior to the mass acceptance of computers for personal use, surveys were collected in three ways: face-to-face, via telephone interviews, and via the mail (Tourangeau, Couper, & Conrad, 2013). Across the globe, people spend much of their time online, doing everyday tasks, which makes the evolution of online survey research more applicable, manageable, useful, and appealing to respondents (Tourangeau, Couper, & Conrad, 2013; Dillman, 2000; Schmidt, 1997). From 1995 to 2006, users of the Internet grew from 16 million users to over a billion users, and that number continues to grow (Internet World Stats, 2006). In the United States alone, there are 310 million users of the Internet (Internet World Stats, 2014). Using the Internet as a mechanism for disseminating survey tools and collecting

data allows for a greater number of people to be reached, but also lowers costs, which enables more people to conduct research (Couper, 2000; Clayton & Werking, 1998; Dillman, 2000; Gjestland, 1996; Palmquist & Stueve, 1996). Online surveys also allow for the standardization of the tool, since code can be written to reduce giving alternative answers or skipping questions (Couper, 2000).

While there are many upsides to using the Internet as a means of distributing survey tools and collecting data, there are issues that should be considered. Internet surveys should be held to the same standards as face-to-face or other in-person data collection methods (Gurney, Chambers, Grant, Shah, & Sullivan, 2004; Schaeffer & Presser, 2003; Simsek & Veiga, 2001; Yeaworth, 2001). Researchers need to consider how the sample will be collected in order to ensure that a non-biased sample can be procured, that the sample reaches a variety of individuals, and that participants are able to complete the survey if interested (Couper, Traugott, & Lamias, 2001; Heerwegh, Vanhove, Matthijs, & Loosveldt, 2005).

In-person, paper-based collection

With the growing popularity of internet-based surveys, the use of paper-based surveys has dwindled (Birnbaum, 2004); however, there is evidence that supports survey participants respond similarly on both versions. Several studies have shown that when the same survey is given and the results are compared, they produce similar mean scores, reliability scores, and factor structures (Buchanan & Smith, 1999; Miller, Neal, Roberts, Baer, Cressler, Metrick, & Marlatt, 2002; Fouladi, McCarthy, & Miller, 2002; Slaughter, Norman, & Schneiderman, 1995; Taylor, 2000; Yun & Trumbo, 2000). Literature shows that, while web-based surveys are able to reach a broader network of respondents, response rates are higher with paper-based surveys (Handwerk, Carson, & Blackwell, 2000; Matz, 1999; Tomsic, Hendel, & Motross, 2000; Underwood, Kime,

& Matier, 2000), although depending on the audience, this fact is variable. In order to combat response issues, Rogers (1987), Sudweeks and Simoff (1999), and Smith (1997) recommend using multiple methods to improve response rates.

While there are documented benefits to using paper-based surveys, as with any distribution method, there are downsides. Threats to the usefulness of paper-based surveys include randomization issues, errors in distribution, and comparison of the results to other studies (Buchanan & Smith, 1999, Fouladi, McCarthy, & Moller, 2002; Im, Chee, Bender, Cheng, Tsai, Kang et al, 1999; Meyerson & Tyron, 2003).

The benefits of conducting this research online outweighed the downside of using internet surveys reported in the literature, but to ensure that all audiences were able to complete the survey, a traditional paper-based survey was given out at various locations throughout Virginia. The web version and the paper-based version mirrored each other to ensure that all participants received the same items, regardless of their response method.

SeniorNavigator.org

Permission was granted by SeniorNavigator to post the survey instrument for this study on their website for dissemination. SeniorNavigator is a non-profit organization with goals to “provide helpful, free health and aging information to seniors, caregivers, and people with disabilities via an accessible high-tech/high-touch approach” (<http://www.seniornavigator.org/>, accessed 06/10/2017). According to SeniorNavigator’s Content Manager, the website receives approximately 1 million “hits” per year from those seeking senior and caregiving information. A link to the web survey was placed on the SeniorNavigator website for approximately 9 months. The survey link and a description of the study were also included in web-based mailings. Approximately 5,000 list-serve members were emailed about the survey, which included

announcements in newsletters and programmatic materials developed and monitored by SeniorNavigator.

Senior Services Caregiver Symposium

A paper version of the survey was created and handed out to interested participants at a one-day local caregiver symposium hosted by Senior Services of Southeastern Virginia. The day-long symposium had an estimated attendance of over 300 caregivers. Interested participants were handed a survey and were provided space to complete it on-site, or were provided a flyer with instructions to complete the survey online. Surveys completed onsite were returned to a member of the research team. Responses then were entered into Qualtrics and were combined with data from surveys completed online.

Adult Day Program

The paper version of the survey was handed to interested participants at a local adult day care program. Those interested were given the option to complete the survey on-site and return it to a member of the research team, to take it home to complete and return it to a staff member the next day, or to complete the survey online (for which they were provided instructions). Responses from paper surveys completed were entered into Qualtrics.

Data Analysis

At the completion of the study period, the data from the survey were downloaded into a file for analysis. The dataset was cleaned and reviewed for accuracy. Once the dataset was clean, it was analyzed using IBM SPSS Statistics ® (V22, 2013), a software package used to perform statistical analyses.

Frequencies and Descriptive Statistics

Data were analyzed to determine the means, medians, standard deviations, and summary statistics for all continuous variables. Frequency and descriptive calculations of demographic variables allowed for features of the study participants to be categorized and described. Frequency calculations of specific study variables enabled a description of the relative occurrence of caregiving service needs. Descriptive statistics summarized a dataset and were used to calculate central tendency for variables, such as age. The summary of caregiving services utilized by caregivers was necessary in order to calculate multivariate statistics in order to describe the relationships between variables and to understand the service needs. Also, this calculation gave a range of services that were used in order to quantify high and low users of services.

Cronbach's alpha

Cronbach's alpha is a measure of internal consistency. A Cronbach's alpha computes the correlation coefficient for two sets of data from the same participant. The more correlated the sets of data are, the more reliable the data are said to be (Cravetter & Wallnau, 2000; Field, 2009). This measure was used to measure the reliability of the three scales: social support, service utilization, and caregiver burden. Cronbach's alpha was also used to calculate the overall reliability of the survey instrument and to remove questions from the survey in order to reduce its length. Numerous studies (Hair, Black, Babin, & Anderson, 2010; Francis & White, 2002; Kim & Stoel, 2004) suggest using the Corrected Item-Total Correlation as a method of removing questions, with .50-.60 being the threshold for exclusion when a factor analysis is not feasible. Total item correlation is the correlation between an item and the remaining survey. When the correlation is low, then the survey is not measuring the same items as the rest of the exam. Since

factor analysis would not be a valid statistic to use in this study due to its low sample size, Corrected Item-Total Correlation was used to remove questions, since it was the most applicable method for this research.

Pearson Correlation

A Pearson Correlation is the measure of linear correlation or the relationship between two variables. It has a value of +1 and -1, and the closer to 1 the outcome is, the more positive the correlation (SPSS Tutorials, accessed 06/20/2017).

Multiple Regressions

A multiple regression is when there is a single and continuous dependent variable and two or more independent variables. It is a statistical technique that develops a mathematical relationship between two or more independent variables and a continuous dependent variable. More specifically, a multiple regression analysis explains how the value of the dependent variable is changed with the addition or deletion of independent variables (Freedman, 2005).

Table 3

Research Question Data Analysis Plan

Study questions	Variables	Analysis
How is service utilization influenced by need for caregiving assistance?	<p><u>Dependent Variable:</u></p> <ul style="list-style-type: none"> • Health Service Utilization <p><u>Independent Variables:</u></p> <ul style="list-style-type: none"> • <u>Predisposing Factors</u> <ul style="list-style-type: none"> ○ Employment ○ Children • <u>Enabling Factors</u> <ul style="list-style-type: none"> ○ Social support ○ Perceived need • <u>Need Factors</u> <ul style="list-style-type: none"> ○ Time spent providing care 	<ul style="list-style-type: none"> • Multiple Regression
How is service utilization influenced by a caregiver's willingness to access services on the aging adults' behalf and does burden and social support play a role?	<p><u>Dependent Variable:</u></p> <ul style="list-style-type: none"> • Health Service Utilization <p><u>Independent Variables</u></p> <ul style="list-style-type: none"> • Willingness • Burden • Social Support 	<ul style="list-style-type: none"> • Multiple Regression
How is service use to support care of an aging adult impacted by demographics and burden?	<p><u>Dependent Variable:</u></p> <ul style="list-style-type: none"> • Health Service Utilization <p><u>Independent Variables:</u></p> <ul style="list-style-type: none"> • <u>Predisposing Factors</u> <ul style="list-style-type: none"> ○ Age ○ Gender ○ Race ○ Marital Status ○ Employment ○ Income ○ Education level • <u>Enabling Factors</u> <ul style="list-style-type: none"> ○ Burden 	<ul style="list-style-type: none"> • Multiple Regression

Table 3 Continued

Study questions	Variables	Analysis
How is service use to support care of an aging adult impacted by demographics and burden?	<p><u>Dependent Variable:</u></p> <ul style="list-style-type: none"> • Health Service Utilization <p><u>Independent Variables:</u></p> <ul style="list-style-type: none"> • <u>Predisposing Factors</u> <ul style="list-style-type: none"> ○ Age ○ Gender ○ Race ○ Marital Status ○ Employment ○ Income ○ Education level • <u>Enabling Factors</u> • Burden 	<ul style="list-style-type: none"> • Multiple Regression
What is the correlation between health service utilization, social support, and burden?	<p><u>Variables</u></p> <ul style="list-style-type: none"> • Social Support • Burden • Health service utilization 	<ul style="list-style-type: none"> • Pearson Correlation
How do predisposing, enabling, and need factors impact a person's feelings of burden?	<p><u>Dependent Variable:</u></p> <ul style="list-style-type: none"> • Burden <p><u>Independent Variables</u></p> <p><u>Predisposing Factors</u></p> <ul style="list-style-type: none"> ○ Length of time as a caregiver ○ Employment ○ Children ○ Marital Status <ul style="list-style-type: none"> • <u>Enabling Factors</u> <ul style="list-style-type: none"> ○ Social support • <u>Need Factors</u> <ul style="list-style-type: none"> ○ Time spent providing care ○ Types of caregiving services needed ○ Number of hours a week providing care 	<ul style="list-style-type: none"> • Multiple Regression •

CHAPTER IV

DATA ANALYSIS AND FINDINGS

In this chapter, the results of the data are presented. The data were collected and analyzed in response to the following research questions:

1. What is the reliability of the newly developed survey measure?
2. How is service utilization influenced by need for caregiving assistance?
3. How is service utilization influenced by a caregiver's willingness to access services on the aging adults' behalf, and does burden and social support play a role?
4. How is service use to support the care of an aging adult impacted by demographics and burden?
5. What is the correlation between health service utilization, social support, and burden?
6. How do predisposing, enabling, and need factors impact a person's feelings of burden?

Response Rate

Thirty-seven surveys were gathered via online submission through www.seniornavigator.org or by paper form at the Senior Services Symposium or at the adult day program. Of the 37 surveys submitted, six surveys were eliminated and deemed unusable because they were blank or because only the screening questions were answered. Of the usable surveys, 14 were collected online, 10 were collected at the senior services symposium, and 7 were collected from the adult day program. The response rate falls within the established guidelines of statistical significance determined for this study, which suggested collecting 21-43 total surveys based on the survey having 43 items to be answered within 3 scales.

Respondents reported that they were caring for their mother (58.1%) or their spouse (25.8%) who was approximately 80 years of age without a diagnosis of Alzheimer's disease or

other cognitive impairment. Most reported having provided care for approximately 3-5 years and spend an average of 54.5 hours per week providing the informal care. Less than 50% lived with the aging adult in their care, with most aging adults living alone in the community (29%).

Table 4

Demographic Variables of the Aging Adult Needing Informal Caregiving Services

	N	Percentage
Relation of aging adult		
Spouse	8	25.8
Mother	18	58.1
Father	3	9.7
Sibling	2	6.5
Number of years providing care		
Less than 6 months	3	9.7
1-2 years	3	9.7
3-5 years	14	45.2
6-8 years	3	9.7
8-10 years	3	9.7
More than 10 years	5	16.1
Aging adult lives with caregiver		
Yes	13	41.9
No	18	58.1
Aging adult's home if not with caregiver		
With another relative	1	3.2
Alone	9	29
With a spouse	1	3.2
Assisted living facility	1	3.2
Nursing home	3	9.7
Primary diagnosis is Alzheimer's disease or other cognitive impairment		
Yes	11	35.5
No	20	64.5

Reliability

Multiple Imputation Method

Imputation is the process of replacing missing data with estimated values in order to perform tests such as reliability (Rubin, 1987). Not only can certain statistical analyses such as the Cronbach's Alpha not run with missing data, but missing data creates a substantial amount of bias (Barnard & Meng, 1999). For this study, approximately 15% of the data was missing, requiring the use of an imputation method. A Multiple Imputation Analysis was completed in SPSS in order to be able to calculate the Cronbach's Alpha of the newly developed measure.

Cronbach's Alpha

Based on literature that states that a survey is considered reliable when the value is greater than 0.70 (Nunnaly, 1978), this survey is highly reliable. Each scale had a calculated alpha score of .70 or above, and combined, the entire survey had a calculated alpha score of 0.781, which again is well in line with the published literature on the topic.

Table 5

Cronbach's Alpha

Scale	Cronbach's Alpha
Social Support	0.729
Service Utilization	0.760
Burden	0.855

Since factor analysis would not be a valid statistic to use in this study due to the survey's low sample size, Corrected Item-Total Correlation was used to remove questions with low reliability. Questions with a value below .50 were removed, with the exception of questions

asking about the IADL and ADL needs of the care recipient, service use, and importance in order to understand informal caregivers' use of community-based services to meet those needs.

Questions related to ADLs and IADLs were retained, since the study was designed to elicit responses about service utilization, including which services informal caregivers used, their willingness to access services from a community-based agency, and the level of perceived importance of having help from a community-based agency who provides assistance with the activity. Removing those questions, despite their low Corrected Total-Item Correlation scores, would create a survey that would be irrelevant to the research questions explored and would invalidate the need for a study beyond this pilot study.

Corrected Item-Total Correlation resulted in removing 10 items from the survey and reducing the number of total questions from 43 to 33 (Appendix C). Common characteristics of the removed items revolved around the concepts of social support and burden. They also included influencing variables, such as spirituality, on informal caregivers' decisions about service needs and service utilization.

Research Questions

How is service utilization influenced by need for caregiving assistance?

Need was not a significant factor in whether a caregiver accessed services for the aging adult in their care, $\beta=1.01$, $t(1.44)$, $p=.209$. Models do depict that as more variables are added, such as levels of social support and the amount of time spent providing care, the significance factor does rise, but not to a level that would deem this finding statistically significant.

Table 6

Need for Caregiving Assistance

		B	t	Sig.
1	Outside Employment	1.625	.629	.547
	Children under the age of 18	-1.500	-.375	.717
2	Outside Employment	1.664	.598	.569
	Children under the age of 18	-1.140	-.210	.839
	Social Support	.103	.108	.917
3	Outside Employment	.148	.054	.959
	Children under the age of 18	-3.063	-.599	.575
	Social Support	-.737	-.750	.487
	Time spent providing care	.004	.148	.888
	Perceived Need	1.018	1.442	.209

How is service utilization influenced by a caregiver's willingness to access services on the aging adults' behalf and does burden and social support play a role?

Service utilization was significantly impacted by a person's willingness to access services $\beta=.655$, $t(7.022)$, $p<0.05$. Burden did not have a significant impact on the service utilization, $\beta=.038$, $t(.148)$, $p=.884$. Social support also did not have a significant impact on their willingness, $\beta=0.82$, $t(.439)$, $p=.665$.

Table 7

Willingness to Access Services

		B	t	Sig.
1	Willingness	.660	7.424	.000
2	Willingness	.655	7.022	.000

Table 7 Continued

	B	t	Sig.
Burden	.038	.148	.884
Social Support	.082	.439	.665

How is service use to support care of an aging adult impacted by demographics and burden?

Demographics and burden were not a significant factor in whether or not an informal caregiver accessed services to assist with caring for an aging adult, $\beta=.611$, $t(.840)$, $p=.417$.

Table 8

Impact on Service Use

	B	t	Sig.
1			
Gender	.193	.091	.929
Age	-.018	-.269	.792
Race	-.725	-1.449	.171
Education Level	-.783	-.874	.398
Outside employment	.166	.131	.898
Income	.150	.468	.647
Marital Status	-.362	-.525	.609
2			
Gender	.520	.239	.815
Age	-.026	-.383	.709
Race	-1.137	-1.614	.133
Education Level	-.719	-.790	.445
Outside employment	.634	.453	.659
Income	.090	.272	.791
Marital Status	-.163	-.221	.829
Burden	.611	.840	.417

What is the correlation between health service utilization, social support, and burden?

There was a significant correlation between service utilization and burden, $r=1.00$, p (two-tailed) <0.5 and the importance of a service and a person's burden level, $r=1.00$, p (two-tailed) $<.05$. There was a negative correlation between a person's social support levels and burden, $r=-.476$, p (two tailed) $<.05$.

Table 9

Social Support, Importance, and Service Use

		Social Support	Importance	Burden	Current Use
Social Support	Pearson Correlation	1	-0.473	-.476*	0.151
	Sig. (2-tailed)		0.686	0.014	0.418
	N	31	3	26	31
Importance	Pearson Correlation	-0.473	1	1.000*	-1.000*
	Sig. (2-tailed)	0.686		0.019	0.019
	N	3	3	3	3
Burden	Pearson Correlation	-.476*	1.000*	1	0.032
	Sig. (2-tailed)	0.014	0.019		0.878
	N	26	3	26	26
Service Use	Pearson Correlation	0.151	-1.000*	0.032	1
	Sig. (2-tailed)	0.418	0.019	0.878	
	N	31	3	26	31

How do predisposing, enabling, and need factors impact a person's feelings of burden?

Marital status, $\beta=-.646$, $t(-2.58)$, $p<0.05$, the length of time during which someone provides care, $\beta=.330$, $t(2.99)$, $p<.05$, and social support, $\beta-.430$, $t(-3.21)$, $p<0.05$ were all

significant impacts on a person's feelings of burden. There was no significant impact from competing responsibilities such as employment or children, types of caregiver services needed, need for services, or how many hours someone provided care.

Table 10

Impact of Burden

	B	t	Sig.
Employment	-.631	-1.549	.140
Marital Status	-.646	-2.585	.019*
Children	-1.261	-1.700	.107
Length of time providing care	.330	2.999	.008*
Social Support	-.430	-3.210	.005*
Types of caregiving services needed	-.098	-.834	.416
Perceived Need	-.022	-.277	.785
Number of hours per week providing care	.005	1.132	.274

Post Hoc Analysis

Since many of the findings were non-significant and because this study is a pilot study, post hoc analyses were performed to explore the data further. Post hoc analyses for this study consisted of reviewing the data and calculating additional frequencies and descriptive statistics after all the planned analyses were completed to look for patterns in the data that could explain the non-significant findings. Post hoc testing is common and usually unplanned (Fields, 2013), as was the case in this study.

Post hoc analyses showed that while the informal caregiver identified a need and that they were willing to use a community agency to provide the service to the aging adult, they were limited because the aging adult would not allow the agency to provide the service to them.

Almost one-quarter (21%) of caregivers identified that the aging adult would not use the service. This was considered to be a significant finding and one that needs further exploration.

Data Analysis Summary

In summary, the above analysis depicts:

- The survey is reliable, with a 3-scale average of .781.
- Need was not a significant factor in whether or not a caregiver used services to assist an aging adult.
- Service utilization was significantly impacted by a person's willingness to access services, but burden and social support did not have an impact.
- Age, race, education level, outside employment, income, marital status, and burden were not significant factors in whether or not an informal caregiver accessed services to assist with caring for an aging adult.
- There was a significant correlation between service utilization and burden, the importance of a service and a person's burden level.
- Marital status, the length of time someone provided care, and social support were all significant impacts on a person's feelings of burden. There was no significant impact from competing responsibilities such as employment or children, types of caregiving services needed, need for services, or how many hours someone provided care.
- Post hoc analyses showed that service utilization was linked to aging adult preferences, despite the aging adult needing assistance and the informal caregiver being willing to use a community based agency to provide the service.

CHAPTER V

DISCUSSION, CONCLUSIONS, RECOMMENDATIONS, AND IMPLICATIONS

This pilot study explored the gap in service utilization that occurs when informal caregivers desire or need assistance to care for an aging adult (National Alliance for Caregiving, 2015). Service use can be described as concepts related to utilization, need, willingness, importance, and how social support and burden may influence an informal caregiver's choices regarding use of community-based services. Questions from three surveys: 1) The Caregiver Burden Scale (Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993); 2) the Zarit Caregiver Burden Interview (Zarit, Reever & Bach-Peterson, 1980); and 3) the Brief Measure of Social Support (Sarason, Sarason, Shearin, & Pierce, 1987) were used to develop a comprehensive measurement tool aimed at exploring the concepts related to an informal caregiver's use of services and the factors that influence their decisions to use or not use community-based services when caring for an aging adult.

Recruitment and Response Rate

The pilot study proved to be an advantageous mechanism not only for testing the reliability and validity of the survey and the assumptions of the research questions, but also as a mechanism for testing the distribution of the survey to potential respondents. The survey was available in two formats (online and paper) and was distributed in three venues: 1) via www.seniornavigator.org; 2) at the Senior Services Caregiver Symposium; and 3) at a local adult day program for older adults. Initially, survey participants were recruited via the SeniorNavigator website. The survey, along with information about the study, was posted on the home page of the organization. The website is estimated to receive one million "hits" per year. The available survey link was also sent via SeniorNavigator newsletters and list-serves to

approximately 5,000 registered members. Despite posting the survey on the website over a period of 9 months and sending it out to approximately 5,000 registered members, only 14 surveys were collected from the website during a nine-month period, resulting in an estimated response rate of 0.001%.

Issues with recruitment were also significant at the caregiver symposium where ten surveys were collected from an estimated pool of 300 attendees (3.33% response rate). At the adult day center, only seven completed surveys were collected from a potential pool of 65 (10.76% response rate). Overall, the paper distribution elicited a higher response rate than the web-based survey, which is in line with the literature and justified the use of two recruitment methods (Handwerk, Carson, & Blackwell, 2000; Matz, 1999; Tomsic, Hendel, & Matross, 2000; Underwood, Kim, & Matier, 2000).

Overall, researchers report a steady decline in survey response rates across all populations. The Pew Research Center (2012) found that the average response rate in 2012 was 9%, a 27% decrease since 1997. Other studies have shown a negative relationship between the age of respondents and survey response rates (Herzog & Rogers, 1988; Murphy, Eyerman, & Kennett, 2004). The mean age for the respondents in this study was 61.4 years, which could have been a factor in lower response rates. Murphy and colleagues (2008) found that survey responses start to heavily decline after the age of 50 years and, as adults move closer to 80 years of age, there are severe drops in response rates. Some of the decline at 50 years and above could be due to trust issues, lack of time to complete a survey, perceived value, and how intrusive the survey appears to the respondent (Murphy et al, 2008). This study was quite long, so time to complete the survey could very well have been a barrier to its completion. Other issues could be related to their physical and mental ability to complete the survey, such as cognitive impairment

or access to reliable internet, and to the overall burden levels felt by the informal caregiver (Norten, Breitner, Welsh, & Wyse, 1994; Newburger, 2001).

Validity and Reliability

Despite a low response rate, the reliability and validity of the survey was high. Internal reliability statistics showed that the three scales of the survey: 1) Social Support; 2) Service Utilization; and 3) Burden were reliable with average alpha scores from the Cronbach's Alpha reliability test being above 0.70, which is the standard acceptable result (Streiner & Norman, 1989; Nunnally & Bernstein, 1994; Bland & Altman, 1997; DeVellis, 2003).

Content validity, or the extent to which the survey represents the constructs, was also high. The average construct score given by the three subject matter experts was five (5), with the exception of the question about length that had an average score of three (3), suggesting that reviewers neither agreed nor disagreed that the survey was appropriate in length. Written comments did highly suggest shortening the survey. Throughout this study, there was concern that the survey length could be a barrier to completion. However, the items included in the pilot testing of the survey were deemed necessary to collect the appropriate data to make conclusions about service utilization and to determine the most appropriate questions for coming to those conclusions.

Reliability testing resulted in the removal of several questions which shortened the survey, and shortening the survey was in line with the comments made by the subject matter experts. The subject matter experts did not have recommendations as to which questions to remove, but they did highly suggest that the survey be shortened, which occurred through reliability testing. The strong reliability and validity scores for this survey suggest that, with

minor modifications, it could be executed to a larger network of individuals and yield the same results.

Service Utilization

Literature identifies “need” as one of the most important factors in determining health service utilization (Coulton & Frost, 1982; Gilbert, Branch, & Longmate, 1993; Mechanic, 1979; Wolinsky & Johnson, 1991) but in this study, service utilization was not significantly influenced by caregiver need or perceived need. Furthermore, service utilization was also not significantly impacted by a caregiver’s demographics such as age, gender, race, education level income, work status, or children living in the home. Service utilization was correlated to the importance that an informal caregiver placed on a particular service. This is in line with the literature, that suggests that the importance of a service to the caregiver correlates to their use of the service (Parker, Mills, & Abbey, 2008; Elliott, Burgio, & DeCoster, 2010; Gallagher-Thompson & Coon, 2007; Alma, Man-Kin, Kam-Mei, Pey-Chyou, Lam, Thompson, & Gallagher-Thompson, 2009).

The most common services that informal caregivers identified as being extremely or very important were the personal care activities needed by the aging adult such as bathing, dressing, and toileting (75%), meal preparation (70%), housekeeping (68.8%), help with home repairs and landscaping (62.5%), transportation (58.3%), medication management (56.2%), medical decision making (55.6%), shopping (50%), and adult day programs or respite programs (50%). These findings are similar to the findings of the National Caregiving Study (2015).

Influences on Service Utilization

Service utilization was impacted by a caregiver’s willingness, which very well could be influenced by the aging adult’s opinions, not by the informal caregiver’s level of perceived burden or need, when accessing a service provided by a community agency. Willingness to

access services could also be influenced by the level of care needed by the aging adult, by cultural values, by type or severity of illnesses, and by an understanding of the benefits of services for older adults, which was not explored in this study (Yang & Kirshchling, 1992; Kim & Shulz, 2008; Guarino, Guarino, Koch, & Beams, 2016; Deai, Lentzner, & Weeks, 2001; Manton, Corder, & Stallard, 1993; Verbrugge, Rennert, & Madans, 1997). Willingness could also be influenced by how much usefulness an informal caregiver puts on the health service or their level of fatigue in their caregiver role. (Leutz, Capitman, & Green, 2001).

It is interesting that need, both actual or perceived, did not have a strong impact on service utilization; however, need appeared to be influenced by importance. While literature explains the influence of competing responsibilities such as children living at home or employment, it did not, in this study. It could be due to the fact of the mean age of the respondents (61 years) and the fact that less than one percent of the respondents had children under the age of 18 years or who lived at home. Furthermore, fewer than 50% of the respondents held outside employment, so there were most likely fewer demands on their time, thus reducing their need for outside help. Also, someone who does not have employment or children taking up their time could also have more time to explore strategies for caring for an aging adult and could find ways to meet the person's needs without using a community-based agency, especially if the aging adult does not want to use a particular service.

Preferences of the Aging Adult

While this study showed that caregivers found importance or need for these services and were willing to use a community-based agency for assistance, this opinion did not influence service utilization. Rather, preferences of the aging adult who would receive the help from the community agency was the largest indicator of use, as noted in secondary data analyses in

Chapter 4. Caregivers indicated that they would like to use a particular service provided by a community agency, but the aging adult would not allow it (20.8%). This leads to two important questions: 1) How much say does an aging adult have in whether their informal caregiver accesses a service? 2) How does the aging adult's need for autonomy influence the choices that are made?

Burden and Stress

When comparing the overall impact of predisposing, enabling, and need factors on feelings of burden, marital status (predisposing), social support (enabling) and the length of time a person provided care (need) were found to have the greatest impact. Other factors, such as employment and children, had a limited impact on respondent's reported level of burden.

Most respondents (74%) reported feeling low to medium levels of burden, with less than 25% reporting that they felt extremely burdened caring for an aging adult. Levels of burden in this population could very well be lower due to the fact that they did not have as many influencing variables as other study participants in the literature. Many participants were married, older, did not have competing responsibilities, and reported higher levels of social support. These are all factors that positively contribute to a lessening of feelings of burden (Edward & Scheetz, 2002; Brown & Harris, 1978; Cornia & Cairney, 2005; de Jong, Gierveld, & Dykstra, 2008).

Gelberg-Andersen Behavioral Model for Vulnerable Populations

The Gelberg-Andersen Behavioral Model for Vulnerable Populations (Gelberg, Andersen, & Leake, 2000) was the theoretical foundation of this research. It was appropriate for this study because informal caregivers of aging adults represent a vulnerable population, due to the burden and stress experienced in their caregiving role, the role they play in making decisions

of for older adults, and the complexities of informal caregiving (Manne & Badr, 2010; Oberst & James, 1989; Gelberg, et al., 2000; Touliatos, Perlmutter, & Straus, 2001; Macera, Eaker, Jannarone, Davis, & Stoskopf, 1993). The findings of this study confirm the presence of the concepts of predisposing, enabling, and need factors and their relationship to health service utilization for aging adults by their informal caregiver.

Predisposing Factors

Predisposing factors such as marital status and the length of time someone has been a caregiver were all significantly correlated to burden, which could impact service utilization. However, predisposing factors such as age, gender, competing responsibilities, income, and outside employment did not impact service use. This could be due to the fact that less than half of respondents reported having outside employment, thus making them more available to provide informal care without the additional complication of work. Furthermore, less than 1% of respondents reported having children living in the home or having children under the age of 18.

Enabling Factors

Social support, categorized as an enabling factor, was also significantly correlated to service utilization. High levels of social support were reported by respondents. Informal caregivers in this study reported that they have someone to talk to when they are stressed (71.0%), someone to help them care for the aging adult when they need assistance (67.7%), someone to help them with their stress levels (61.3%), and someone to ask for suggestions about caregiving (77.4%). Higher levels of social support have a buffering effect, which could have been the case for this study (Gellert, Hausler, Suhr, Gholami, Rapp, Kuhlmeier et al, 2016; Edwards & Scheetz, 2002; Varona, Saito, Takahashi, & Kai, 2007). Most respondents reported receiving social support from their spouse, a friend, a member of the clergy, and/or their

children. It appears that they have a support network, which would very well negate their need for caregiving services, especially due to the high number of caregivers who reported having someone to help them.

Need Factors

Need factors were not a significant factor in health service utilization. The overall concept of need was not a significant indicator of an informal caregiver's use of services for an aging adult, but the concept of the aging adult's willingness to have a service used for their care, as a subset of need, was a significant factor.

Conclusions

Despite a large number of studies on the topic of informal caregiving, there are few studies on the factors influencing how or why informal caregivers access services for aging adults. For this study, there was discord with the published literature, especially related to need, burden, and the willingness to access services. This could have very well have been due to the fact that this was a small sample size and was not representative of the larger caregiver population. To further explore this concept, a larger study must be completed, and the results between this pilot study and the larger study need to be compared.

Service use was not influenced by a caregiver's need for caregiving assistance. Competing responsibilities such as children, time spent providing care, and social support were not significant findings. This outcome could have been influenced by the fact that less than 12% of respondents reported needing help with caring for the aging adult across a multitude of ADL and IADL services. While there were individual differences in the number of services an aging adult needed assistance with, reported by their informal caregiver, the aggregate total was low. The need for assistance appears to be very personal and individual, which could have led to some

of the non-significance in the findings. Also, few respondents had outside employment (<50%), had children at home (<1%), and reported higher levels of perceived social support. Also, 20% of respondents reported that the aging adult lived with another relative or in a facility. This could influence the level of need one has for caregiving assistance, because the aging adult's needs are taken care of, by someone else, lessening the need for the informal caregiver. While the general idea of an informal caregiver is one who cares for someone, in many cases, caregivers provide the financial support or manage an aging adult's care, but do not do direct caregiving services.

Informal caregivers were generally open to using community-based services, but accessing them was a barrier. In the case of this study, the aging adult who is the care recipient was the barrier to service use. Over 20% of informal caregivers reported the aging adults in their care would not use at least one of the services listed on the survey. This result was not expected, since it was expected that the informal caregivers would be the one to make the decision, based on their perception of the needs of the aging adults. It was also expected that factors such as cost, knowledge about a service, or access to the needed service would be the limiting factor in utilization, but instead it appears that the aging adults in this study hold a lot of power in the caregiving dynamic, thus becoming the influencing factor.

Levels of caregiving vary by family and by situation and in this case, they could very well have been the case for this population. Ideas of family, culture, or even perceptions of appearing weak could play a role in service use or in willingness to use a service. Children who feel an obligation to care for their aging parent, or a spouse who feels that they should care for their spouse as part of the vows they took when they married, could play a role in service use. They may not want to make the aging adult in their care feel inferior or that he or she is losing

independence, so they do not seek services or challenge the aging adult to use a service due to their inability to care for themselves. Also, feelings of pride set out by the aging adult also could be playing a role in service utilization. Many older adults struggle with losing the ability to care for themselves and refuse services. They also do not typically want people in their home and see community agencies as intruders into their space, interrupting their routine or changing their routine, which is a struggle for them. Accepting that they are aging and that they need assistance could very well be a limiting factor for service use. Adapting their routines, accepting outsiders into their home, and accepting that they are losing their independence are all struggles they face, and those feelings must be overcome in order to increase service use among this population. These were not concepts explored in the study, but they do raise important questions about what influences people to use community-based services or even to acknowledge that they need assistance.

Caregiving Dyads

Historically, services have been underutilized due to people not knowing which services were available. In this study, respondents appeared to be aware of the services available to them, but they did not access a service, even when identified as a need because of the aging adult's willingness or lack of willingness to use the service. In order to address the issue of willingness, caregivers and care recipients need to discuss at what point the informal caregiver should have more of a say in how much care or what care is provided by them and which care they, the informal need caregiver will require assistance with, in order to provide the care to the aging adult. What is the breaking point on the plane of care? When are the needs or wants of the aging adult care recipient superseded by the needs and wants of the informal caregiver? This relates back to culture and family and to the idea of parenting the parent by the grown child or parenting

the spouse instead of being an equal partner. The relationship between informal caregiving and service use is extremely dynamic; it is a relationship that has many layers. That is why there have been years of research on the subject, but there has been very little movement in finding concrete contributing factors or solutions for aging adults and their informal caregivers. When should one step in and take over for an aging adult? The answer could be this: at the point at which the aging adult can no longer make informed decisions. Thirty-five percent of the aging adults in this study had a diagnosis of cognitive impairment or Alzheimer's disease, but whether or not that changed their level of need or willingness to access services, coupled with the level of impairment, was not explored. Due to the varying levels of impairment and the sometimes slow decline in health status that can hide the deficiencies, there is often not a solid line that points to when a caregiver needs to step in. Forgetfulness is often a characteristic of cognitive impairment, but forgetfulness is also a very human factor that many people face, so whether or not it is due to something more severe is not easy to flush out.

Despite reported low levels of need and issues with willingness to access services, burden and service utilization were highly correlated; those that access the most services showed higher levels of burden, which is more in line with the literature. This could also be linked to the predisposing, enabling, and need factors explored. The predisposing, enabling, and need factors linked to burden were marital status, time spent providing care, and social support, leading to the conclusion that those who have more supportive environments are less likely to access care since they have the people in their family or friend circles to support them. It is also quite possible that the aging adults who won't use a service could be refusing because they have someone inside their own community to help them.

Overall, this study shows not only the complexities of service utilization among informal caregivers, but the complexities of collecting the data to answer the questions. There are no simple answers regarding service utilization. Rather, the data analyzed in this study suggest that service utilization by informal caregivers is quite circular; there is no single variable that appears to influence usage, and depending on the circumstances, the variables may answer the questions in different ways, depending on how the question is asked.

Limitations

This study was designed to be a pilot test, and thus was meant to evaluate the utility of the survey instrument to provide answers to the research questions. Pilot testing is an effective method that is able to be carried out in the same methodological fashion, but with a smaller sample size. The information gathered from this study was not intended to make strong conclusions about the data, but rather to provide reliable evidence to support use of the survey instrument in a larger study. Several limitations impacted this study; their significance to the findings reported is explored.

Response Bias

This research was solely based on self-report and on the perceptions of the participant. Steps were taken, such as participation by choice and forced-choice responses, to ensure that there was limited impact from study participants responding because they felt a need to answer questions. Furthermore, surveys were completed anonymously and no personally identifying information (name, date of birth, or email address) was collected. It is unknown if people responded in a particular way in order to appear more stable and independent and thus better able to refute the need for assistance from the community, for fear that it would make them incapable of caring for the older adult in their care.

Sample Size

This study is limited by its sample size. Due to the nature of pilot testing, it was not possible to collect or create a large mass of empirical data. Instead predisposing, enabling, and need factors influencing service use were explored in a limited fashion in order to inform a future study. This study was designed to test the reliability and validity of a survey measure, to test the research questions in order to inform hypothesis development, and also to assess the efficacy of conducting a survey in a population that is traditionally harder to navigate.

Response Rates

Despite multiple efforts, neither online nor in person survey collection was highly successful, although collecting the survey in person proved to be the better method. Multiple research articles have discussed non-response bias in informal caregiving populations (Gorey, Rice, & Brice, 1992; Groves, 2006; MacDonald, Newburn-Cook, Schopflocher, & Richter, 2009; Grovers & Peytcheva, 2008; de Winter, Oldehinkel, Veenstra, Burnnekreef, Verhulst, & Ormel, 2005; Boshuize, Viet, & Botterwick, 2006) and they have concluded that response to a survey is related to likelihood to respond, exposure to the survey, and how strongly the respondent feels the outcome of the survey will have an impact on them or on the person they care for.

Low response rates most likely occurred for several reasons, among them the length of the survey, the time it took to complete the survey, or the informal caregiver's perception of the value of completing the survey. Many people who were approached at the caregiving conference and at the adult day center would take a survey to complete and return later, but many of them did not return the survey. Anecdotal explanations from subject matter experts in the field of geriatrics include: time, burden, perception of the value of giving information about informal caregiving, and whether or not the outcome of the survey will benefit the informal caregiver or

the aging adult they are providing care to. Further research needs to be conducted to address these issues, in order to fully understand the issues surrounding informal caregiving.

Recommendations

Caregiving and Service Utilization

Based on the results of this study, more exploratory research needs to be done regarding why informal caregivers do not access services, beginning with the influence of the care recipient. Since many of the typical factors such as demographics, burden, and access did not appear to have a significant impact on service use, research needs to focus on the care recipient and then link back to the informal caregiver. Removing the influence of the person receiving the informal caregiver's services would allow for more comprehensive research about service utilization and caregiving.

In the context of caregiving and service utilization, the desired services of the informal caregivers and the aging adults need to be explored. This study showed that the aging adult's needs superseded the informal caregiver's wants or needs, but what was not explored was whether the lack of service use was linked to the types of services available. Use of assistive services could very well be bolstered by taking into account what services are actually needed or wanted, based on the people using them. This research used a common list of ADL and IADL services, but with changing times could come changing needs. Transportation services were a service that was often stated as a need and a want, but the aging adult would not use the service. There are many reasons for this, such as cost, transportation radius, availability of services, and the fact that often those who need transportation are left waiting at a location for an extended time due to limited drivers and group transportation models. Additionally, there are high rates of no-shows from transportation companies due to high turnover and limited driver availability,

thus rendering the service useless to a person, even if they need it. Asking about what aspects of transportation are needed could be more helpful than just asking about transportation.

The impact on caregivers as part of service utilization also needs to be explored. This study did not implicitly study how service utilization impacts the caregiver's levels of burden or how burden influences informal characteristics such as their marital status and employment. It could be hypothesized that informal caregivers who have strife in their life from issues related to marriage, family, finances, etc. could be more likely to use services because the use of those services could impact their life and alleviate stress and burden in other areas. This study only explored informal caregiver demographics and burden, but the extra step of whether or not burden influences those factors, and thus service utilization, should be explored.

Future Research

While the data were limited due to the small sample size and the limitations associated with the distribution of the survey instrument, this research does showcase a need for continued research in the area of informal caregiving into the ways in which services for aging adults are chosen and utilized.

First and foremost, research should be done with informal caregivers to learn about issues surrounding response rates and ways to increase the rate of response by gathering insight from informal caregivers. This study did not address issues response rates due to its being a pilot study, but in conducting a full-scale study, the barriers to survey completion should be explored first in order to understand and, if needed, to revise distribution methods. There is not much in the literature that discusses response rate issues among informal caregivers and this suggests a secondary reason for this type of work, prior to a full-scale study.

Additionally, qualitative studies need to be completed in order to understand service use

and service needs. With the growing aging adult population, it is imperative to understand how informal caregivers care for the aging adult in their care, and what resources they need in order to complete that care effectively. As the aging population grows, one can surmise that more services will be needed, but it should be understood what services people will or want to access, and that cannot be done without more comprehensive research. Understanding how to survey informal caregivers could be the gateway to more meaningful discoveries, program implementation, and a furthering of the understanding of aging adults and the informal caregivers who are assisting them.

Future research should also explore disease-specific service needs and informal caregiving patterns based on a disease. This was an all-encompassing study, and its only question about disease was about cognitive impairment, but future studies could use this survey tool to study aging adults with particular diseases in order to better understand the issues and to lay a framework for service providers. Services provided to aging adults are often marketed to all, despite the severity of disease or the type of disease. This fact could also influence a caregiver's need or willingness to access a service. This could also be based on whether or not the need is short (ex. a fall with limited complications), or long term (ex. Alzheimer's disease or complications due to stroke). It has been assumed in the literature and by this study that patterns of caregiving don't vary across illness or disease, but that could be a confounding variable that needs exploration.

Implications

The overriding purpose of this study was to examine how informal caregivers access services for adults over the age of 65 years and to determine their willingness to access those services on the aging adult's behalf. Furthermore, there was interest in learning about how

service utilization is influenced by an informal caregiver's perceived importance of a service, need, and level of burden. To accomplish this, it was necessary to pilot test the survey instrument, and also to test the assumptions of the research questions. Overall, this study sought to: 1) to test the reliability and validity of the survey measure developed from three other valid and reliable measures selected from the literature; and 2) to examine the utilization of services as it relates to the unmet needs of informal caregivers for adults 65 years of age or older in Virginia.

The findings of this study showcase that there is a large need for research in this area, but in order to collect comprehensive and appropriate data, there needs to be a better understanding of how to conduct research within the caregiving population. There is limited research on the topic and none is explanatory enough regarding conducting effective research with caregivers. This study provides evidence of the need for qualitative studies to better describe the dynamics between informal caregivers and their care recipients, and hopefully opens up a new stream of research that takes into account caregivers' needs, perceptions of research, and mechanisms for how achieve higher response rates.

This study also points to the need for work on service needs and the relationship of caregiver's needs versus their aging adult willingness to use a service. Until the dynamics influencing a person's decisions are fully understood, whether at the micro or macro level, this reach will not be able to be used in a valuable manner. To put it simply, future research needs to be narrower in focus to fully understand the influencing factors related to service use among informal caregivers for aging adults, especially considering psychosocial factors and the characteristics of the informal caregiver/aging adult relationship. These appear to be the driving forces in the willingness to use a service or the actual use of a service.

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APPENDIX A: ORIGINAL SURVEY*NOT FOR DISSEMINATION***Unmet needs and service utilization by informal caregivers for adults 65 years and older in Virginia**

The purpose of this study is to examine the use of services as it relates to the unmet needs of informal caregivers for adults 65 years of age or older living in Virginia. Unmet needs can include physical, mental, and/or tangible (financial, respite, transportation, etc.) needs of informal caregivers. This research will examine factors affecting the utilization of services by you, an informal caregiver, as well as explore the relationship between service use and caregiver burden and stress.

In order to participate in this study, you need to be:

- A. 18 years of age or older
- B. The primary caregiver or a person aged 65 years or older and the care recipient must live in the state of Virginia.
- C. You should also be able to read English and complete the questionnaire.

RISKS AND BENEFITS:

RISKS: There are very few known risks to you, beyond what we would normally expect from usual and regular conversation about caring for an aging adult. There is a risk associated with discussing certain information. Although we deem other risks unlikely, there also may be some that are unknown and we cannot predict.

BENEFITS: If you do take part in this study, there may or may not be direct benefit to you. There is no guarantee that you will personally benefit from taking part in this study. We hope the information learned from this study will benefit you and other people caring for an aging adult.

CONFIDENTIALITY:

The very nature of survey research assures that your responses will be confidential and anonymous. Thus, you will not be asked for personal information that could identify you as a participant in this study. Responses will be analyzed collectively, rather than individually, and data will be kept in a secure location with access available only by the researchers. After the information is evaluated, the material will be destroyed in a way that is unrecoverable.

COSTS AND PAYMENTS: There are no costs for you to participate.

VOLUNTARY CONSENT: Your participation in this survey is voluntary. Completion of the entire survey, which should take less than 45 minutes, will serve as informed consent to act as a subject in this research study.

QUESTIONS OR CONCERNS?

If you have any questions, you may contact the principal investigator, Dr. Karen Karlowicz at the following phone number, 757-683-5262. If at any time you feel pressured to participate, or if you have any questions about your rights, then you should call the ODU Office of Research at 757-683-3460, or Dr. George Maihafer, the current IRB chair, at 757-683-4520

If you agree to participate in this study, please proceed to the questionnaire.

- I agree to continue with this survey.
- I do not agree to continue with this survey.

IF YOU ANSWER NO TO QUESTIONS Q1-Q4, STOP THE SURVEY

Q1. Are you 18 years of age or older?

- Yes
- No

Q2. Are you the primary caregiver of a person aged 65 years of age or older?

- Yes
- No

Q3. Does the person you are caring for live in the state of Virginia?

- Yes
- No

Q4. Have you completed this survey in the last 3 months?

- Yes
- No

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOUR CAREGIVING EXPERIENCE

Q1. How is the aging adult in your care related to you?

- Spouse
- Mother
- Father
- Sibling
- Grandparent
- Child
- Friend/Neighbor

Q2. How old is the aging adult in your care? _____ **(WHOLE NUMBER ONLY)**

Q3. How long have you been providing care?

- Less than 6 months
- 6 months to 1 year
- 1-2 years
- 3-5 years
- 6-8 years
- 8-10 years
- More than 10 years

Q4.9 How many hours per week do you provide care to the aging adult? _____
(WHOLE NUMBER ONLY)

Q5. Does the aging adult in your care live with you in your home? **IF NO, SKIP TO QUESTION 6**

- Yes
- No

Q6. Do you live in their home?

- Yes
- No

Q7. If they do not live with you and you do not live with them, where do they live?

- With another relative
- Alone
- With a spouse
- In an assisted living facility
- In a nursing home

Q8. Does the person in your care have a primary diagnosis of memory loss, dementia, or Alzheimer's disease?

- Yes
- No

SOCIAL SUPPORT:

Q9. Do you have someone you can really count on to listen to you when you need to talk?

- Yes
- No

Q9a. Who is this person? **(CHECK ALL THAT APPLY)**

- Spouse
- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

Q10. Do you have someone you can count on to help you when you need help caring for the aging adult in your care?

- Yes
- No

Q10a. Who is this person? **(CHECK ALL THAT APPLY)**

- Spouse
- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

Q11. Do you have someone you can count on to help you feel more relaxed when you feel stressed about caring for the aging adult in your care?

- Yes
- No

Q11a. Who is this person? **(CHECK ALL THAT APPLY)**

- Spouse
- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

Q12. Do you have someone you can count on to give you useful suggestion for caring for the aging adult in your care?

- Yes
- No

Q12a. Who is this person? **(CHECK ALL THAT APPLY)**

- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

SERVICE USE AND SERVICE NEEDS:

Q13. Does the aging adult need help with transportation? **IF NO, SKIP TO QUESTION 14**

- Yes
- No

Q13A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q13B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q13C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q13D. Do you currently receive help from a community agency?

- Yes
- No

Q13E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q14. Does the aging adult need help with housekeeping? **IF NO, SKIP TO QUESTION 15**

- Yes
- No

Q14A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q14B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q14C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q14D. Do you currently receive help from a community agency?

- Yes
- No

Q14E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q15. Does the aging adult need help with meals? **IF NO, SKIP TO QUESTION 16**

- Yes
- No

Q15A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q15B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q15C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q15D. Do you currently receive from a community agency?

- Yes
- No

Q15E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q16. Does the aging adult need help with shopping for themselves? **IF NO, SKIP TO QUESTION 17**

- Yes
- No

Q16A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q16B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q16C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q16D. Do you currently receive help from a community agency?

- Yes
- No

Q16E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q17. Does the aging adult need help with medical decision making? **IF NO, SKIP TO QUESTION 18**

- Yes
- No

Q17A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q17B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q17C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q17D. Do you currently receive help from a community agency?

- Yes
- No

Q17E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q18. Does the aging adult need help handling their finances? **IF NO, SKIP TO QUESTION 19**

- Yes
- No

Q18A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q18B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q18C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q18D. Do you currently receive help from a community agency?

- Yes
- No

Q18E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q19. Does the aging adult need help with taking care of their home (lawn services, home repairs, etc....) **IF NO, SKIP TO QUESTION 20**

- Yes
- No

Q19A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q19B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q19C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q19D. Do you currently receive help from a community agency?

- Yes
- No

Q19E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q20. Does the aging adult need help with managing their medications (administering, filling prescriptions, understanding what medications go with disease or ailment)? **IF NO, SKIP TO QUESTION 21**

- Yes
- No

Q20A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q20B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q20C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q20D. Do you currently receive help from a community agency?

- Yes
- No

Q20E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q21. Does the aging adult need help with personal care activities (bathing, dressing, toileting)?

IF NO, SKIP TO QUESTION 22

- Yes
- No

Q21A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q21B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q21C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q21D. Do you currently receive help from a community agency?

- Yes
- No

Q21E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q22. Does the aging adult need to attend a respite program (adult daycare or senior services)?

IF NO, SKIP TO QUESTION 23

- Yes
- No

Q22A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q22B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q22C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q22D. Do you currently receive help from a community agency?

- Yes
- No

Q22E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

BURDEN AND STRESS:

How often do you feel:

	Never	Rarely	Sometimes	Often	Always
Q23. That the aging adult in your care asks for more help than he or she needs?					
Q24. That because of the time you spend caring for the aging adult in your care, you do not have enough time for yourself?					
Q25. Stressed between caring for the aging adult in your care and trying to meet other responsibilities for your family or work?					
Q26. Embarrassed about the aging adult's behavior(s)?					
Q27. Angry when around the aging adult in your care?					
Q28. The aging adult in your care affects the relationships you have with family and/or friends?					

How often do you feel:

	Never	Rarely	Sometimes	Often	Always
Q29. Afraid of what the future holds for the aging adult in your care?					
Q30. The aging adult in your care is dependent on you?					
Q31. Strained when you are around the aging adult in your care?					
Q33. Your health has suffered because of your involvement with the aging adult in your care?					
Q34. You lack privacy because of the aging adult in your care?					
Q35. Your social life has suffered because of the aging adult in your care?					
Q36. Uncomfortable having your friends over or being around your friends because of the aging adult in your care?					

How often do you feel:

	Never	Rarely	Sometimes	Often	Always
Q37. The aging adult in your care expects you to take care of him or her, as if you were the only one they could depend on?					
Q38. You do not have enough money to care for the aging adult in your care?					
Q39. Unsure about how to care for the aging adult in your care?					
Q40. You should be doing more for the aging adult in your care?					
Q41. You could be doing a better job caring for the aging adult in your care?					

Q42. Overall, to what extent do your spirituality or religious beliefs influence your ability or willingness to access services?

- Not at all
- A little
- Somewhat
- Quite a bit
- Extremely

Q43. Overall, how burdened do you feel in caring for the aging adult in your care?

- Not at all
- A little
- Somewhat
- Quite a bit
- Extremely

DEMOGRAPHICS: PLEASE TELL US A LITTLE ABOUT YOURSELF:

Q1. What is your gender?

- Male
- Female
- Other

Q2. What is your age? _____ **(WHOLE NUMBERS ONLY)**

Q3. What is your race or ethnicity?

- Black
- White
- Hispanic
- Asian or Island Pacific
- Native American
- Other, please specify: _____

Q4. What is the highest degree you have completed?

- Less than high school degree
- High school diploma or GED
- Associates degree
- Bachelor's degree
- Master's degree
- Doctorate degree (PhD, MD, JD, etc...)
- Other, please specify: _____

Q5. Do you have outside employment? **IF NO, SKIP TO QUESTION 34**

- Yes
- No

Q5A. How many hours per week do you work? _____ **(WHOLE NUMBERS ONLY)**

Q6. What is your yearly household income?

- Under \$19,999
- \$20,000-\$29,999
- \$30,000-\$39,999
- \$40,000-\$49,999
- \$50,000-\$59,999
- \$60,000-\$69,999
- \$70,000-\$79,999
- \$80,000-\$89,999

- \$90,000-\$99,999
- \$100,000 and above

Q7. What is your marital status?

- Single
- Married
- Divorced
- Widow/Widower

Q8. Do you have children? **IF NO, SKIP TO THE END OF THE SURVEY**

- Yes
- No

Q8A. How many total children do you have? _____

Q8B. How many children still live at home? _____

Q8C. How many children under the age of 18 years old? _____

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

APPENDIX B: CAREGIVER BURDEN SCALE

SAMPLE COPY, DO NOT USE WITHOUT PERMISSION

Someone with Alzheimer's disease or a related disorder may need assistance in some of the following areas. For each characteristic for which the patient needed assistance DURING THE PAST MONTH, indicate if you have provided this assistance and if doing so added to your stress level, and why. All questions must be answered with a yes/no response; leave blank if not applicable. If no or blank, go to the next item.

Characteristic	Patient Needs Assistance?	Do You Provide Assistance?	Does it Add to Your Stress Level?	Why?
Transportation	Y N	Y N	Y N	
Housekeeping	Y N	Y N	Y N	
Cooking	Y N	Y N	Y N	
Shopping	Y N	Y N	Y N	
Decision Making	Y N	Y N	Y N	
Financial Record ...Keeping	Y N	Y N	Y N	
Walking	Y N	Y N	Y N	
Making House ...Repairs	Y N	Y N	Y N	
Farming/Yard ...Work	Y N	Y N	Y N	
Administering ...Medication	Y N	Y N	Y N	
Dressing	Y N	Y N	Y N	
Bathing	Y N	Y N	Y N	
Eating	Y N	Y N	Y N	
Toileting	Y N	Y N	Y N	

Leaving Patient ...Unattended	Y N	Y N	Y N	
----------------------------------	--------	--------	--------	--

Scoring

Three domains are measured from this scale. The first one, defined as *patient needs*, is a sum of the 15 items providing a range of 0-15. The second one, defined as *caregiver tasks*, is the sum of the tasks for which the caregiver provided assistance. The range could be 0-15, but cannot be higher than the sum of the patient needs. The third domain, *caregiver burden*, is a sum of the items for which the patient needed assistance AND the caregiver provided assistance AND the caregiver reported that providing this assistance was stressful. The possible range was 0-15 but could not be higher than the number of caregiver tasks.

APPENDIX C: BRIEF MEASURE OF SOCIAL SUPPORT

SAMPLE COPY, DO NOT USE WITHOUT PERMISSION

Sarason, I.G., Sarason, B.R., Shearin, E.N., & Pierce, G.R. (1987)
 A brief measure of social support: Practical and theoretical implications,
Journal of Social and Personal Relationships, 4, 497-510.

Social Support Questionnaire (Short Form)

SSQSR

INSTRUCTIONS:

The following questions ask about people in your environment who provide you with help or support. Each question has two parts. For the first part, list all the people you know, excluding yourself, whom you can count on for help or support in the manner described. Give the persons' initials, their relationship to you (see example). Do not list more than one person next to each of the numbers beneath the question.

For the second part, circle how satisfied you are with the overall support you have.

If you have had no support for a question, check the words "No one," but still rate your level of satisfaction. Do not list more than nine persons per question.

Please answer all the questions as best you can. All your responses will be kept confidential.

EXAMPLE:

Who do you know whom you can trust with information that could get you in trouble?

No one	1) T.N. (brother)	4) T.N. (father)	7)
	2) L.M. (friend)	5) L.M. (employer)	8)
	3) R.S. (friend)	6)	9)

How satisfied?

6 - very satisfied	5 - fairly satisfied	4 - a little satisfied	3 - a little dissatisfied	2 - fairly dissatisfied	1 - very dissatisfied
-----------------------	-------------------------	---------------------------	------------------------------	----------------------------	--------------------------

2

1. Whom can you really count on to be dependable when you need help?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
2. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
3. Whom can you really count on to help you feel more relaxed when you are under pressure or tense?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
4. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
5. Who accepts you totally, including both your worst and your best points?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
6. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
7. Whom can you really count on to care about you, regardless of what is happening to you?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
8. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
9. Whom can you really count on to help you feel better when you are feeling generally down-in-the dumps?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
10. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
11. Whom can you count on to console you when you are very upset?
- | | | | | | |
|--------|----|--|----|--|----|
| No one | 1) | | 4) | | 7) |
| | 2) | | 5) | | 8) |
| | 3) | | 6) | | 9) |
12. How satisfied?
- | | | | | | |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|
| 6 - very satisfied | 5 - fairly satisfied | 4 - a little satisfied | 3 - a little dissatisfied | 2 - fairly dissatisfied | 1 - very dissatisfied |
|--------------------|----------------------|------------------------|---------------------------|-------------------------|-----------------------|

TO SCORE SSQSR:

- Count the total number of people for each of the odd-numbered items. Add the totals together (Max. = 54). Divide by 6 for per item SSQ Number Score, or SSQN.
- Add the total Satisfaction scores for the 6 even-numbered items (Max. = 36). Divide by 6 for per item SSQ Satisfaction score or SSQS.
- You can also compute a Family score and a Non-Family score by using the method in #1 for all people described as family members, or not described as family members respectively.

APPENDIX D: CAREGIVER BURDEN INTERVIEW

BURDEN INTERVIEW ©
Mapi Research Trust, Lyon, France

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INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behavior?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
10. Do you feel your health has suffered because of your involvement with your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

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APPENDIX E: SUBJECT MATTER CONTENT VALIDITY FORM**Content Expert Name:** _____**Date:** _____

Thank you for agreeing to evaluate the attached survey tool, titled: Health Care Service Use among Informal Caregivers Providing Care to an Aging Adult. As a person with direct knowledge and experience within the field of geriatrics and caregiving, your input is greatly appreciated. After completed the evaluation, please return to me via email at rdu001@odu.edu.

Directions: Using the questionnaire below, please rate the following questions on a scale of 1-5, being *Strongly Disagree* or the lowest score and being *Strongly Agree* or the highest score.

1. The instructions for completion are clear and can be easily understood?
 1. Strongly Disagree
 2. Disagree
 3. Neither Agree or Disagree
 4. Agree
 5. Strongly Agree

Comments:

2. The content of the survey is appropriate for informal caregivers of aging adults.
 1. Strongly Disagree
 2. Disagree
 3. Neither Agree or Disagree
 4. Agree
 5. Strongly Agree

Comments:

3. The length of the survey is appropriate.
 1. Strongly Disagree
 2. Disagree
 3. Neither Agree or Disagree
 4. Agree
 5. Strongly Agree

Comments:

4. The survey relates to caregivers of aging adults and the caregivers needs.

1. Strongly Disagree
2. Disagree
3. Neither Agree or Disagree
4. Agree
5. Strongly Agree

Comments:

5. The survey addresses needs of caregivers.

1. Strongly Disagree
2. Disagree
3. Neither Agree or Disagree
4. Agree
5. Strongly Agree

Comments:

6. The survey addresses stress and burden.

1. Strongly Disagree
2. Disagree
3. Neither Agree or Disagree
4. Agree
5. Strongly Agree

Comments:

7. The survey addresses the importance of services for aging adults and the caregiver's ability to access them.

1. Strongly Disagree
2. Disagree
3. Neither Agree or Disagree
4. Agree
5. Strongly Agree

Comments:

8. The survey adequately addresses social support.
 1. Strongly Agree
 2. Agree
 3. Neither Agree or Disagree
 4. Disagree
 5. Strongly Disagree
 6. Comments

9. The survey can be easily understood by a variety of people with different backgrounds, education levels, etc...
 1. Strongly Agree
 2. Agree
 3. Neither Agree or Disagree
 4. Disagree
 5. Strongly Disagree
 6. Comments:

10. Comments: **Please enter your additional comments here. If you have survey specific questions, please place them directly on the survey and return with this evaluation form.**

APPENDIX F: REVISED SURVEY*NOT FOR DISSEMINATION***Unmet needs and service utilization by informal caregivers for adults 65 years and older in Virginia**

The purpose of this study is to examine the use of services as it relates to the unmet needs of informal caregivers for adults 65 years of age or older living in Virginia. Unmet needs can include physical, mental, and/or tangible (financial, respite, transportation, etc) needs of informal caregivers. This research will examine factors affecting the utilization of services by you, an informal caregiver, as well as explore the relationship between service use and caregiver burden and stress.

In order to participate in this study, you need to be:

- D. 18 years of age or older
- E. The primary caregiver or a person aged 65 years or older and the care recipient must live in the state of Virginia.
- F. You should also be able to read English and complete the questionnaire.

RISKS AND BENEFITS:

RISKS: There are very few known risks to you, beyond what we would normally expect from usual and regular conversation about caring for an aging adult. There is a risk associated with discussing certain information. Although we deem other risks unlikely, there also may be some that are unknown and we cannot predict.

BENEFITS: If you do take part in this study, there may or may not be direct benefit to you. There is no guarantee that you will personally benefit from taking part in this study. We hope the information learned from this study will benefit you and other people caring for an aging adult.

CONFIDENTIALITY:

The very nature of survey research assures that your responses will be confidential and anonymous. Thus, you will not be asked for personal information that could identify you as a participant in this study. Responses will be analyzed collectively, rather than individually, and data will be kept in a secure location with access available only by the researchers. After the information is evaluated, the material will be destroyed in a way that is unrecoverable.

COSTS AND PAYMENTS: There are no costs for you to participate.

VOLUNTARY CONSENT: Your participation in this survey is voluntary. Completion of the entire survey, which should take less than 45 minutes, will serve as informed consent to act as a subject in this research study.

QUESTIONS OR CONCERNS?

If you have any questions, you may contact the principal investigator, Dr. Karen Karlowicz at the following phone number, 757-683-5262. If at any time you feel pressured to participate, or if you have any questions about your rights, then you should call the ODU Office of Research at 757-683-3460, or Dr. George Maihafer, the current IRB chair, at 757-683-4520

If you agree to participate in this study, please proceed to the questionnaire.

- I agree to continue with this survey.
- I do not agree to continue with this survey.

IF YOU ANSWER NO TO QUESTIONS Q1-Q4, STOP THE SURVEY

Q1. Are you 18 years of age or older?

- Yes
- No

Q2. Are you the primary caregiver of a person aged 65 years of age or older?

- Yes
- No

Q3. Does the person you are caring for live in the state of Virginia?

- Yes
- No

Q4. Have you completed this survey in the last 3 months?

- Yes
- No

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOUR CAREGIVING EXPERIENCE

Q1. How is the aging adult in your care related to you?

- Spouse
- Mother
- Father
- Sibling
- Grandparent
- Child
- Friend/Neighbor

Q2. How old is the aging adult in your care? _____ **(WHOLE NUMBER ONLY)**

Q3. How long have you been providing care?

- Less than 6 months
- 6 months to 1 year
- 1-2 years
- 3-5 years
- 6-8 years
- 8-10 years
- More than 10 years

Q4.9 How many hours per week do you provide care to the aging adult? _____
(WHOLE NUMBER ONLY)

Q5. Does the aging adult in your care live with you in your home? **IF NO, SKIP TO QUESTION 6**

- Yes
- No

Q6. Do you live in their home?

- Yes
- No

Q7. If they do not live with you and you do not live with them, where do they live?

- With another relative
- Alone
- With a spouse
- In an assisted living facility

- In a nursing home

Q8. Does the person in your care have a primary diagnosis of memory loss, dementia, or Alzheimer's disease?

- Yes
- No

SOCIAL SUPPORT:

Q9. Do you have someone you can really count on to listen to you when you need to talk?

- Yes
- No

Q9a. Who is this person? **(CHECK ALL THAT APPLY)**

- Spouse
- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

Q10. Do you have someone you can count on to help you feel more relaxed when you feel stressed about caring for the aging adult in your care?

- Yes
- No

Q10a. Who is this person? **(CHECK ALL THAT APPLY)**

- Spouse
- Mother
- Father
- Sibling
- Friend
- Other relative
- Counselor/Therapist
- Doctor
- Other: _____

SERVICE USE AND SERVICE NEEDS:

Q11. Does the aging adult need help with transportation? **IF NO, SKIP TO QUESTION 12**

- Yes
- No

Q11A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q11B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q11C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q11D. Do you currently receive help from a community agency?

- Yes
- No

Q11E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q12. Does the aging adult need help with housekeeping? **IF NO, SKIP TO QUESTION 13**

- Yes
- No

Q12A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q12B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q12C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service

- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q12D. Do you currently receive help from a community agency?

- Yes
- No

Q12E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q13. Does the aging adult need help with meals? **IF NO, SKIP TO QUESTION 14**

- Yes
- No

Q13A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q13B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q13C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q13D. Do you currently receive from a community agency?

- Yes
- No

Q13E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q14. Does the aging adult need help with shopping for themselves? **IF NO, SKIP TO QUESTION 15**

- Yes
- No

Q14A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q14B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q14C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q14D. Do you currently receive help from a community agency?

- Yes
- No

Q14E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q15. Does the aging adult need help with medical decision making? **IF NO, SKIP TO QUESTION 16**

- Yes
- No

Q15A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q15B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q15C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q15D. Do you currently receive help from a community agency?

- Yes
- No

Q15E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q16. Does the aging adult need help handling their finances? **IF NO, SKIP TO QUESTION 17**

- Yes
- No

Q16A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q16B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q16C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q16D. Do you currently receive help from a community agency?

- Yes
- No

Q16E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q17. Does the aging adult need help with taking care of their home (lawn services, home repairs, etc....) **IF NO, SKIP TO QUESTION 18**

- Yes
- No

Q17A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q17B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q17C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q17D. Do you currently receive help from a community agency?

- Yes
- No

Q17E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q19. Does the aging adult need help with managing their medications (administering, filling prescriptions, understanding what medications go with disease or ailment)? **IF NO, SKIP TO QUESTION 20**

- Yes
- No

Q19A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q19B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q19C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q19D. Do you currently receive help from a community agency?

- Yes
- No

Q19E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q20. Does the aging adult need help with personal care activities (bathing, dressing, toileting)?

IF NO, SKIP TO QUESTION 21

- Yes
- No

Q20A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q20B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q20C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q20D. Do you currently receive help from a community agency?

- Yes
- No

Q20E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

Q21. Does the aging adult need to attend a respite program (adult daycare or senior services)?

IF NO, SKIP TO QUESTION 22

- Yes
- No

Q21A. Do you provide or are you able to provide the assistance?

- Yes
- No

Q21B. Are you willing to request help with providing this assistance from a community agency?

- Yes
- No

Q21C. If you are unwilling to accept help from a community agency, why not?

- Cost is too high
- Services are not available in my area
- I do not know where to find this service
- The person I provide care for will not use this service
- The person I provide care for does this activity themselves

Q21D. Do you currently receive help from a community agency?

- Yes
- No

Q21E. How important is it that a community agency provides assistance with this activity?

- Extremely Important
- Very Important
- Moderately Important
- Slightly Important
- Not important at all

BURDEN AND STRESS:

How often do you feel:

	Never	Rarely	Sometimes	Often	Always
Q22. Angry when around the aging adult in your care?					
Q23. The aging adult in your care affects the relationships you have with family and/or friends?					
Q24. Afraid of what the future holds for the aging adult in your care?					
Q25. The aging adult in your care is dependent on you?					
Q26. Strained when you are around the aging adult in your care?					

Q27. Your health has suffered because of your involvement with the aging adult in your care?					
Q28. You lack privacy because of the aging adult in your care?					
Q29. Your social life has suffered because of the aging adult in your care?					
Q30. The aging adult in your care expects you to take care of him or her, as if you were the only one they could depend on?					
Q31. You do not have enough money to care for the aging adult in your care?					
Q32. You could be doing a better job caring for the aging adult in your care?					

Q33. Overall, how burdened do you feel in caring for the aging adult in your care?

- Not at all
- A little
- Somewhat
- Quite a bit
- Extremely

DEMOGRAPHICS: PLEASE TELL US A LITTLE ABOUT YOURSELF:

Q1. What is your gender?

- Male
- Female
- Other

Q2. What is your age? _____ **(WHOLE NUMBERS ONLY)**

Q3. What is your race or ethnicity?

- Black
- White
- Hispanic
- Asian or Island Pacific
- Native American
- Other, please specify: _____

Q4. What is the highest degree you have completed?

- Less than high school degree
- High school diploma or GED
- Associates degree
- Bachelor's degree
- Master's degree
- Doctorate degree (PhD, MD, JD, etc...)
- Other, please specify: _____

Q5. Do you have outside employment? **IF NO, SKIP TO QUESTION 34**

- Yes
- No

Q5A. How many hours per week do you work? _____ **(WHOLE NUMBERS ONLY)**

Q6. What is your yearly household income?

- Under \$19,999
- \$20,000-\$29,999
- \$30,000-\$39,999
- \$40,000-\$49,999
- \$50,000-\$59,999
- \$60,000-\$69,999
- \$70,000-\$79,999
- \$80,000-\$89,999
- \$90,000-\$99,999
- \$100,000 and above

Q7. What is your marital status?

- Single
- Married
- Divorced
- Widow/Widower

Q8. Do you have children? **IF NO, SKIP TO THE END OF THE SURVEY**

- Yes
- No

Q8A. How many total children do you have? _____

Q8B. How many children still live at home? _____

Q8C. How many children under the age of 18 years old? _____

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

APPENDIX G: PERMISSIONS

Permission to use the Caregiver Burden Scale

From: Caroline Macera <cmacera@mail.sdsu.edu>

To: Ryan Marie Diduk <rdidu001@odu.edu>

Subject: Re: Permission to use caregiver burden scale for dissertation

Yes, it would be fine for you to use the caregiver burden scale. If you can, let me know how it works in your population.

Thanks,
Caroline A. Macera, Ph.D.

Professor Emeritus in Epidemiology
San Diego State University

Permission to use the Brief Measure of Social Support

From: Irwin Sarason
isarason@u.washington.edu>

To: Ryan Marie Diduk
<rdidu001@odu.edu>

Subject: Re: Permission to use Brief Measure of Social Support

Permission granted.
Irwin Sarason

Sent from my iPhone

Permission to use the Zarit Burden Interview

Zarit Burden Interview_UserAgreement_March2016_5.0

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as “MRT” and the User, as defined herein, (each referred to singularly as a “Party” and/or collectively as the “Parties”), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
PROVIDE™
27 rue de la Villette
69003 Lyon
France
Telephone: +33 (0)4 72 13 66 66

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership. The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1. In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User Section 1.01 Identification of the User

User Name Ryan Diduk-Smith
Legal Form Student

Section 1.02 Identification of the Questionnaire

Zarit Burden Interview_UserAgreement_March2016_5.0

© Mapi Research Trust. The unauthorized modification and use of any portion of this document is prohibited.

Title Zarit Burden Interview (ZBI)

Author(s) Zarit Steven H

Owner

Zarit Steven H and Zarit Judy M

Copyright Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit

Original bibliographic references

ZBI-22

Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *Gerontologist*. 1980;20(6):649-55

Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985

Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990

Article 2. Rights to Use Section 2.01 Context of the Use of the Questionnaire

The User undertakes to only use the Questionnaire in the context of the Study as defined hereafter.

Context of Use Other project

Title: Informal Caregivers and Service Utilization

Section 2.02 Conditions for Use

The User undertakes to use the Questionnaire in accordance with the conditions for use defined hereafter.

(a) Rights transferred

Acting in the Owner's name, MRT transfers the following limited, non-exclusive rights, to the User (the "Limited Rights")

- (i) to use the Questionnaire, only as part of the Study; this right is made up exclusively of the right to communicate it to the Beneficiaries only, free of charge, by any means of communication and by any means of remote distribution known or unknown to date, subject to respecting the conditions for use described hereafter; and
- (ii) to reproduce the Questionnaire, only as part of the Study; this right is made up exclusively of the right to physically establish the Questionnaire or to have it physically established, on any paper, electronic, analog or digital medium, and in particular documents, articles, studies, observations, publications, websites whether or not protected by restricted access, CD, DVD, CD-ROM, hard disk, USB flash drive, for the Beneficiaries only and subject to respecting the conditions for use described hereafter; and the unauthorized modification and use of any portion of this document is prohibited.

- (iii) Should the Questionnaire not already have been translated into the language requested, the User is entitled to translate the Questionnaire or have it translated in this language, subject to informing MRT of the same beforehand by the signature of a Translation Agreement indicating the terms of it and to providing a copy of the translation thus obtained as soon as possible to MRT.

(b) Specific conditions for the Questionnaire

- Use in Individual clinical practice or Research study / project The User undertakes never to duplicate, transfer or publish the Questionnaire without indicating the Copyright Notice.

- Use in a publication or on a website with unrestricted access:

In the case of a publication, article, study or observation on paper or electronic format of the Questionnaire, the User undertakes to respect the following special obligations:

- not to include any full copy of the Questionnaire, but a protected version with the indication “sample copy, do not use without permission”
- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: <https://eprovide.mapi-trust.org/>
- to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.

- Use for dissemination:

- On a website with restricted access:

In the case of publication on a website with restricted access, the User may include a clean version of the Questionnaire, subject to this version being protected by a sufficiently secure access to only allow the Beneficiaries to access it. The User undertakes to also respect the following special obligations:

- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire
- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: <https://eprovide.mapi-trust.org/>
- to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected..

- On promotional / marketing documents

In the case of publication on promotional/marketing documents, the User undertakes to respect the following special obligations:

- to indicate the name and copyright notice of the Owner
- to include the reference publications of the Questionnaire

- to indicate the details of MRT for any information on the Questionnaire as follows: contact information and permission to use: Mapi Research Trust, Lyon, France – Internet: <https://eprovide.mapi-trust.org/>
 - to provide MRT, as soon as possible, with a copy of any publication regarding the Questionnaire, for information purposes
 - to submit the screenshots of all the Pages where the Questionnaire appears to MRT before release to check that the above-mentioned requirements have been respected.
- For any other use not defined herein, please contact MRT for the specific conditions of use and access fees (if applicable).

Article 3. Term

MRT transfers the Limited Rights to use the Questionnaire as from the date of delivery of the Questionnaire to the User and for the whole period of the Study.

Article 4. Beneficiaries

The Parties agree that the User may communicate the Questionnaire in accordance with the conditions defined above to the Beneficiaries involved in the Study only, in relation to the Study defined in section 2.01.

Article 5. Territories and Languages

MRT transfers the Limited Rights to use the Questionnaire on the following territories and in the languages indicated in the table below:

Questionnaire Language

ZBI-22 Afrikaans for South Africa
 ZBI-22 Arabic for Israel
 ZBI-22 Bengali for Bangladesh
 ZBI-22 Bulgarian for Bulgaria
 ZBI-22 Czech for Czech Republic
 ZBI-22 Danish for Denmark
 ZBI-22 Dutch for Belgium (Flemish)
 ZBI-22 Dutch for the Netherlands
 ZBI-22 English for Australia
 ZBI-22 English for Canada
 ZBI-22 English for South Africa
 ZBI-22 English for the UK
 ZBI-22 English for the USA
 ZBI-22 Finnish for Finland
 ZBI-22 French for Belgium
 ZBI-22 French for Canada
 ZBI-22 French for France
 ZBI-22 Georgian for Georgia
 ZBI-22 German for Austria
 ZBI-22 German for Germany
 ZBI-22 Greek for Greece
 ZBI-22 Gujarati for India

ZBI-22 Hebrew for Israel
ZBI-22 Hindi for India
ZBI-22 Hungarian for Hungary
ZBI-22 Italian for Italy
ZBI-22 Japanese for Japan
ZBI-22 Kannada for India
ZBI-22 Korean for Korea
ZBI-22 Latvian for Latvia
ZBI-22 Lithuanian for Lithuania
ZBI-22 Malay for Malaysia
ZBI-22 Malay for Singapore
ZBI-22 Malayalam for India
ZBI-22 Mandarin for China
ZBI-22 Mandarin for Malaysia
ZBI-22 Mandarin for Singapore
ZBI-22 Mandarin for Taiwan
ZBI-22 Marathi for India
ZBI-22 Nepalese for Nepal
ZBI-22 Norwegian for Norway
ZBI-22 Polish for Poland
ZBI-22 Portuguese for Brazil
ZBI-22 Portuguese for Portugal
ZBI-22 Punjabi for India, Punjabi for
India
ZBI-22 Romanian for Romania
ZBI-22 Russian for Israel
ZBI-22 Russian for Latvia
ZBI-22 Russian for Russia
ZBI-22 Russian for Ukraine
ZBI-22 Serbian for Serbia
ZBI-22 Slovak for Slovakia
ZBI-22 Spanish for Argentina
ZBI-22 Spanish for Chile
ZBI-22 Spanish for Colombia
ZBI-22 Spanish for Mexico
ZBI-22 Spanish for Peru
ZBI-22 Spanish for Spain
ZBI-22 Spanish for Uruguay
ZBI-22 Spanish for the USA
ZBI-22 Swedish for Finland
ZBI-22 Swedish for Sweden
ZBI-22 Tamil for India
ZBI-22 Telugu for India
ZBI-22 Thai for Thailand
ZBI-22 Turkish for Turkey
ZBI-22 Ukrainian for Ukraine

ZBI-22 Urdu for Pakistan
ZBI-22 Vietnamese for Canada

Article 6. Price and Payment Terms

The User undertakes in relation to MRT to pay the price owed in return for the availability of the Questionnaire, according to the prices set out below, depending on the languages requested and the costs of using the Questionnaire, in accordance with the terms and conditions described in section 6.02 of the General Terms included in Appendix 1.

ROYALTY FEES*

Commercial users

Cost per study 1 000 €

Cost per language 500 €

Funded academic research

Cost per study Free

Cost per language Free

Not funded academic users

Cost per study Free

Cost per language Free

**DISTRIBUTION
FEES***

Commercial users

Cost per study 1 000 €

Cost per language 500 €

Funded academic research

Cost per study 300 €

Cost per language 50 €

Not funded academic users

Cost per study Free

Cost per language Free

Agreed and acknowledged by
Ryan Diduk-Smith

VITA

Ryan Marie Diduk-Smith

Old Dominion University, College of Health Sciences
Norfolk, VA 23529

EDUCATIONAL BACKGROUND

PhD, Health Services Research, **2017**, Old Dominion University, Norfolk, VA

Certificate, Modeling and Simulation in Healthcare, **2014**, Old Dominion University, Norfolk, VA

MPH, Community Health Education, **2006**, East Stroudsburg University, East Stroudsburg, PA

BA, Psychology, **2003**, Russell Sage College, Troy, NY

PUBLICATIONS

Submitted, **Diduk-Smith, R.**, Bluestein, D., & Early, M. (2017). Using clinical simulations in medical student and resident physician education, *Family Practice Management*

Bluestein, D. & **Diduk-Smith, R.**, (2017). Integrating Geriatrics in Primary Care: Progress and Prospects. *Age in Action*

Bluestein, D.A., **Diduk-Smith, R.**, Brown-Hughes, T., & Jordan, L. (2016). The Medicare Wellness Visit: Solving the Recruitment Conundrum. *Family Practice Management*

Winterbauer, N., & **Diduk, R.** (2013). The ten essential public health services model as a framework for correctional health care. *Journal of Correctional Health Care*, 19(1), 43-53. doi: 10.1177/1078345812458248

PRESENTATIONS

Bluestein, D.A., **Diduk-Smith, R.M.**, Hughes, TB., Early, M.T. & Mazzurco, L. (2017). IAGG: San Francisco, CA. The Medicare Wellness Visit: An underutilized path to excellence in geriatric primary care.

Diduk-Smith, R.M., Bluestein, D.A., Brown-Hughes, T. Early, M., & Mathur, S. (2016). American Public Health Association Annual Meeting: Denver, CO. Improving Use of Medicare Wellness Visits in Family Medicine Practices.

Diduk-Smith, R.M., Bluestein, D.A., Early, M., & Hughes, T. (2015). Old Dominion Graduate Research Day: Norfolk, VA. Caregiver burden and stress amongst caregivers providing care to adults in the EVMS Geriatric Navigator Program: A qualitative study.