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Health Information Seeking as a Coping Strategy to Reduce the Stress of Informal Caregivers of Individuals with Alzheimer’s Disease and Other Forms of Dementia

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HEALTH INFORMATION SEEKING AS A COPING STRATEGY TO REDUCE THE
STRESS OF INFORMAL CAREGIVERS OF INDIVIDUALS WITH ALZHEIMER’S
DISEASE AND OTHER FORMS OF DEMENTIA

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
Agricultural and Mechanical College
in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

in
The Manship School of Mass Communication

by
Nia Francis Mason
M.M.C., Louisiana State University, 2006
May 2018
I dedicate this to my grandparents. You all are the reason my parents were unstoppable in accomplishing their goals – who in turn encouraged me to reach for mine. Although three of you are no longer with me in the physical world, I still strive to become the person you always knew I could be. I am the realization of your hopes and dreams.
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Dr. Francis has not only become a mentor, but she has become a friend. My successes in this program are due in large part to her guidance and stellar academic focus. I greatly admire her as a person, and as a scholar. I will forever be indebted to her for the countless hours of guidance and friendship she has given since we met. Thank you!

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Dr. Tucker may not have known me prior to being placed on my committee, but I could not have asked for a better graduate school representative. He reassured me that my committee
was in place to help, not hinder me. Not only did he speak the words, but he took the extra time to help strengthen my research weaknesses. I am a stronger researcher, and a better person because of his addition to my committee.

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ABSTRACT

This study explored the relationship between information seeking and the perceived stress levels of informal Alzheimer’s and dementia caregivers. An additional component was added to determine whether health literacy and emotional state moderated the relationship. The study involved conducting qualitative interviews followed by collecting survey data to answer the following research questions: 1) What motivating factors lead informal AD caregivers to seek out information? How do their information needs change? Why do informal caregivers choose to utilize certain resources more than others? Is there a correlation between information seeking and resulting stress levels? Does health literacy moderate the association between information seeking and stress? The study also investigated the following hypothesis: Informal caregivers with low health literacy and low self-efficacy will have increased stress levels and those who have high health literacy and high self-efficacy will have decreased stress levels.

Qualitative findings revealed that caregivers tend to rely on mediated resources that they find credible, and interpersonal resources such as people with similar experiences to their own. Many participants were satisfied with information available, but others felt that their interactions with healthcare professionals created more stress and emotional anguish than anticipated. Quantitative results supported qualitative results in showing that participant information needs change based on care recipient needs. Results also showed that overall, there was no correlation between information seeking and perceived stress levels; however, there was a significant difference between low-level information seekers and mid-level information seekers. Additionally, health literacy does not moderate the relationship between information seeking and
perceived stress, but emotional state and self-efficacy were significant predictors of perceived stress.

This study offers an initial step in finding ways that mediated communication can meet the healthcare needs of those who attempt to fill their information needs. The study also reiterated the idea that in many cases, it is necessary to combine the efforts of mediated and interpersonal communication to have the greatest effect.
 CHAPTER 1
INTRODUCTION

Rosalynn Carter, the wife of President Jimmy Carter and former first lady of the United States, was considered a career caregiver. She stood by her words that have often been quoted: “You have either been a caregiver, you are a caregiver, you will be a caregiver or someone will care for you,” (Snelling, 2013). Since leaving the White House in 1981, the former first lady has worked to improve the quality of life for people around the world as a leading advocate for mental health, caregiving, early childhood immunization, human rights, and conflict resolution. Carter is a member of the Board of Trustees for The Carter Center in Atlanta, Georgia, and president of the Board of Directors for The Rosalynn Carter Institute (RCI) of Caregiving. Through research, education, and training, the RCI promotes the mental health and well-being of individuals, families, and professional caregivers; delineates effective caregiving practices; builds public awareness of caregiving needs; and advances public and social policies that enhance caring communities (Rosalynn Carter Institute, 2017; The Carter Center, 2018).

Carter’s interest in caregiving began in her childhood. According to Carter (2017), when she was 12 years old, her father became terminally ill with leukemia. Being the oldest daughter in a group of four children, her 34-year old mother depended on her to aid in caring for her father. She also supported many members of President Carter’s family who died of cancer and helped care for her mother until she died in 2000 at the age of 94. Besides her firsthand knowledge of caregiving, she heard stories from others as she traveled the country speaking about caregiving. She finds that many people giving care to their loved ones feel isolated, inadequate, and despairing. For example, one man she met revealed that he would wait until his terminally ill wife was out of the room to break down and cry (Carter, 2017).
She was deeply influenced by how chronic illness affected and shaped her family and by the heroic and selfless efforts of health care providers (Carter, 2008). She also learned early on, however, that family members also provide the type of assistance health care providers offered. Today, she notes that the backbone of the country's long-term, home-based, and community-based care systems is the family caregiver (Carter 2008).

Caregiving is a significant factor in the lives of many people. People become familiar with informal caregiving — when a person with no professional healthcare training provides unpaid care to someone with whom they have a personal relationship (Carratero, Garges, Rodenas, & Sanjose, 2009; Schulz & Thompkins, 2010) — as they witness others provide care for aging parents, siblings, and friends who wish to remain in their own homes and communities as they age (Office of the Assistant Secretary for Planning and Evaluation, 2003). For example, I witnessed both my maternal grandmother and paternal grandmother become caregivers for my grandfathers when they became ill. My first experience was during my middle school years when my maternal grandfather was diagnosed with pancreatic cancer. Due to his late diagnosis, as well as pancreatic cancer being a fast-spreading form of cancer, his decline was swift. My grandmother kept my grandfather in the home. She took care of him until the day he passed away, and the experience was both emotionally and physically taxing for her.

In my early 30s, that grandmother was diagnosed with Lewy Body dementia. Lewy Body dementia is the second most common type of progressive dementia after Alzheimer's disease dementia (Mayo Clinic). Like others diagnosed with this illness, my grandmother suffered speech loss, hallucinations, difficulty walking, and Parkinson's disease-like symptoms such as rigid muscles, slow movement, and tremors. Being older at the time of her diagnosis, I became a secondary caregiver because my mother lived out of state. My aunt took on the role of primary
caregiver. When needed, I administered medication, aided my grandmother in using the bathroom, and calmed her when she became agitated. Just as my grandmother cared for my grandfather in the home until the day he died, my aunt made it possible for my grandmother to die at home, as requested, with me at her side holding her hand. Through the process, I gained an understanding of the stresses caused by caregiving, but I also developed a great admiration for those who are informal caregivers of their loved ones.

**Brief Overview of the Problem**

Although aging individuals and adults with a chronic or disabling condition may receive care from paid caregivers, most rely on unpaid assistance from family members, friends, and neighbors to provide them with a broad range of assistance (Family Caregiving Alliance, 2009). These individuals are considered informal caregivers and may be primary or secondary caregivers and live with, or separately from, the person receiving care (Family Caregiver Alliance, 2009). Informal caregivers are estimated to reach 37 million by 2050, making them the largest source of long-term care services in the United States (Office of the Assistant Secretary for Planning and Evaluation, 2003).

The Family Caregiver Alliance (2016) notes that on average, informal caregivers spend 13 days each month on tasks such as shopping, food preparation, housekeeping, laundry, transportation, and giving medication. Additionally, they spend six days per month feeding, dressing, grooming, walking, bathing, and assisting the care recipient in using the bathroom; 46% perform nursing tasks. Caregivers also spend 13 hours per month coordinating physician visits, managing financial matters, or researching care services or information on their loved one’s disease (Gallup-Healthways, 2011).
Informal caregiving will remain a staple duty and topic of discussion for the foreseeable future because the aging community is rapidly expanding. Everyone that is a member of the generation known as baby boomers, born approximately between 1945 and 1958, will be 65 or older by 2029 (Colby & Ortman, 2014). With an estimated 21% of the population at least 65 years old by 2030 (Colby & Ortman, 2015), many people face the possibility of becoming caregivers within the next 10 years. The aging population, an increased number of people living with chronic disease, and the lack of a formal support system for caregivers has increased the prevalence of caregiver stress and burden (Adelman, Tmanova, Delgado, & Lachs, 2014). The major effects of caregiver burden on the mental health of a caregiver are depression, anxiety, and high stress levels (Carratero et al., 2009).

**Significance of the Research**

Despite the significant contributions made by informal caregivers, many unmet needs must be addressed, especially obtaining the information and education necessary to care for an adult experiencing a chronic health condition (Washington, Meadows, Elliot, and Koopman, 2011). Werner et al. (2017) found no widely-available mechanism that meets informal caregiver information need. Giving focus to informal caregivers of individuals coping with Alzheimer’s disease and other forms of dementia (collectively referred to as AD) is important because these patients deteriorate over time, and there will likely be a correlation in higher levels of stress for primary caregivers (Carratero et al., 2009).

Research has shown that informal caregivers of persons with AD tend to have higher rates of depression, reduced life satisfaction, and increased physical health problems when compared with control samples (Pinquart & Sorensen, 2003; Roth et al., 2001; Schulz, O’Brien, Bookwala, & Fleissner, 1995). The stress process model (Pearlin et al., 1981, 1990) explains the
numerous social and psychological experiences that can culminate in a degraded quality of life for both the caregiver and the care recipient (Segrin, Badger, Sikorskii, Crane, & Pace, 2018). It is necessary, then, for AD caregivers to use effective coping strategies to deal with the tremendous financial, physical, and psychological stresses that result from providing care (Ashley & Kleinpeter, 2002).

Seeking information about health is increasingly documented as a key coping strategy in health-promotive activities and psychosocial adjustment to factors of illness (Lambert & Loiselle, 2007). Coping refers to how individuals attempt to relieve stress (Endler & Parker, 1990). Although some caregivers demonstrate resilience and coping strategies that help ameliorate the negative experiences that can occur during the caregiving process (Harmell, Chattillion, Roepke, & Mausbach, 2011; Cheng, Mak, Lau, Ng, & Lam, 2015), many find it to be an extremely challenging role in which most have little background or training (National Alliance for Caregiving, 2011). More than 80% of caregivers have reported the need for more information on caregiving topics (AARP & National Alliance for Caregiving, 2015).

Information seeking can be considered a task-focused coping strategy in that one must assess their challenges, and seek information to solve their problems, and in turn, alleviate stress (Endler & Parker, 1990). Research that explores the effectiveness of task-focused coping have been mixed, with some previous studies showing associations between task-focused coping and decreased depression (Compas, Banez, Malcarne, & Worsham, 1991; Mosher & Prelow, 2007), while more recent meta-analyses have failed to show that task-focused coping has any noticeable effect on depression and anxiety among dementia caregivers (Li, Cooper, Bradley, Shulman, & Livingston, 2012; Li, Cooper, Austin, & Livingston, 2013). Although findings have been mixed,
task-focused coping remains common among AD caregivers, including strategic planning and active coping (Sun, Kosberg, Kaufman, & Leeper, 2010).

In addition to traditional sources, individuals, including patients and caregivers, are increasingly using online resources for health information. (Conrad, Bandini, & Vasquez, 2016). Searching for health and health care information is the third most common online activity, with 72% of adult Internet users having sought support and health information on the Internet (Fox & Duggan, 2013). Communication, including interpersonal, online, and other media sources of information, facilitate the dissemination of new information and influence how individuals approach health, ultimately shaping the experience of health and illness (Bell, 2014). It is not difficult to understand why communication researchers and medical professionals alike are interested in understanding how and why individuals obtain health information, where they go to retrieve such information, what types of information they prefer, and how the health information sought is used (Lambert & Loiselle, 2007).

While Pearlin et al. (1981) deemed information seeking a mediating variable between stress and well-being, many other researchers focused on discerning what factors influence information seeking (Talja, Keso, & Pietiläinen, 1999). The current study instead focuses on the outcomes of information seeking. As a coping strategy, information seeking has the potential to moderate caregiver stress levels. Previous research has not sought to determine whether the current information available to AD caregivers meets their needs in a way that reduces the burden that develops as a result of their daily tasks. Having a comprehensive understanding of caregivers’ information needs allows for effective communication strategies to be employed to promote an improved quality of life for patients and caregivers alike (Washington et al., 2011).
Moreover, understanding experiences of and the factors that contribute to information seeking for caregivers of individuals with AD may significantly contribute to reducing caregiver stress.

**Dissertation Guide**

The next section, Chapter 2, first details AD and its prevalence in the aging population. The chapter then focuses on the unpaid caregivers of individuals afflicted with AD, as well as the stress that they incur due to their caregiving tasks. Previous researchers have attempted to understand the role that stress plays in caregiver well-being and factors that mitigate stress. One such variable is information-seeking. This chapter, therefore, assesses the potential of information seeking as an instigating variable that may reduce caregiver stress levels.

Chapter 3 offers a summary of using a mixed method approach to research. The chapter provides an in-depth explanation of the study's interview protocol and survey development, as well as a description of how each method was analyzed.

In Chapter 4, the relevant themes offered by in-depth interviews with current and former informal caregivers are discussed using supportive and illustrative data. The second portion of the chapter details the results from survey data that offers insight regarding health literacy and emotions as moderating variables between information seeking and stress.

Chapter 5 highlights the implications of these results for those who offer information and services to informal caregivers of individuals with AD. Results also suggest the need for continued improvement in both mediated communication and patient-provider communication.
Dementia and Alzheimer’s Disease

**Defined.** Dementia is an overall term for a group of symptoms characterized by a decline in thinking skills, including memory, affecting a person’s ability to perform everyday activities. Alzheimer’s disease is the most common type of dementia (Alzheimer’s Association, 2014; Leonard, 2016). Alzheimer’s is a progressive disease of the brain that slowly causes impairment in memory and cognitive function, and is one cause of dementia (Healthline, 2016). Dementia is diagnosed through a demonstration of cognitive impairment, and decline from a previous level of functioning, in memory and other domains of intellectual function. There should be a demonstration of consequent social or occupational impairment (Martin, Anders, & Maëlenn, 2015). In other words, dementia is diagnosed when an individual shows a visible decline in the way they interact with others and in how they perform routine activities. An additional diagnosis tool is through medical technology. For example, it is possible for brain-imaging scans to show the buildup of specific types of proteins related to Alzheimer's long before visible symptoms emerge (Fifield, 2018).

Although Alzheimer’s disease was identified more than 100 years ago, research of its symptoms, causes, risk factors, and treatment has gained momentum only in the last 30 years (Alzheimer’s Association, 2014). Scientists have learned that dementia is a neurodegenerative illness, meaning that neurons in the brain gradually cease to function or function inappropriately and eventually die (Healthline, 2016). This leads to the eventual impairment of one's ability to carry out essential bodily functions such as walking and swallowing. In the final stages of the disease, the afflicted are bedbound and require around-the-clock care (Alzheimer's Association,
2014). Not for lack of effort, there are currently no drugs available to cure or slow down Alzheimer’s.

**Prevalence and problem.** Although research has revealed a great deal about the disease, there is still not much known about the biological changes that cause Alzheimer’s disease, why it progresses at different rates among affected individuals, and how the disease can be prevented, slowed, or stopped (Leonard, 2016). Without a cure, it is estimated that the number of people with dementia will nearly double every 20 years (Martin et al., 2015). The current number of people living with Alzheimer’s disease is 5.7 million (Alzheimer’s Association, 2018). That number is predicted to increase to 13.5 million by 2050, which would be 16% of the senior population (Alzheimer’s Association, 2015). The 2015 World Alzheimer’s Report estimates that these numbers show one of the biggest global public health and social care challenges facing people today and in the future.

While dementia shortens the lives of those affected, its most significant impact is upon the quality of life, both for individuals living with dementia and for their family and informal caregivers (Martin et al., 2015). Caring for someone with dementia is challenging physically and emotionally due to dementia's influence on a person's behavior, including wandering, depression, anxious or agitated states, hallucinations and false ideas, loss of inhibition, and aggression (Alzheimer's Association, 2011). Dementia can be associated with particularly intense needs for care, exceeding the demands related to other illnesses and conditions (Martin et al., 2015). The degenerative nature of dementia inevitably leads to an increase in the dependent population, where dependency is understood as the state in which a person requires the help of others to perform daily activities (Council of Europe, 1998). The challenges associated with the demographic shift will be exacerbated by the decreasing ability of formal care systems to care
for older adults because of a shortage of nurses and other health care workers and increasing costs of hospitalization and long-term care (Talley & Crews, 2007). Many affected patients prefer to remain in their home for many reasons, including the high cost of formal resources and family customs, resulting in the long-term care burden of dependent people falling upon informal caregivers (Carratero et al., 2009).

**Informal Caregiving**

*Defined.* An informal caregiver, often a family member, typically provides unpaid care to someone with whom they have a personal relationship even though they have no professional training (Carratero et al., 2009; Schulz & Thompkins, 2010). Caregivers provide patients with an array of services, ranging from relatively undemanding tasks to those that considered highly demanding (Rosa et al., 2010). In 2015, approximately 43.5 million caregivers provided unpaid care to an adult or child, with 34.2 million of those providing care to an adult age 50 or older (National Alliance for Caregiving and AARP, 2015). Additionally, about 15.7 million informal caregivers cared for someone with AD that same year (Alzheimer's Association, 2015).

The average age of an informal caregiver is 49.2 years old, with 48% of caregivers between the ages of 18 and 49 years (National Alliance for Caregiving and AARP, 2015). Nearly 35% of caregivers are over the age of 65 (National Alliance for Caregiving and AARP, 2015). More than 75% of all caregivers are female, and they may spend as much as 50% more time providing care than males (Institute on Aging, 2016). Although male caregivers are less likely to provide personal care, when compared to 28% of female caregivers, 24% helped a loved one get dressed; but where 30% of female caregivers help with bathing, only 16% of male caregivers did so (National Alliance for Caregiving and AARP, 2009).
The AARP and the National Alliance for Caregiving (2015) noted that individual adult caregivers in the U.S. identify their race/ethnicity as the following: White: 62%; Hispanic (non-White, non-African-American): 17%; African-American: 13%; and Asian-American: 6%. Hispanic (non-White, non-African-American). African-American caregivers have the highest prevalence of caregiving among racial and ethnic groups, experience higher burdens from caregiving, and spend more time caregiving on average than their White or Asian-American peers (Alzheimer’s Association, 2015).

**The Problem.** The complex nature of providing care to an individual with chronic illness and disabilities is generally viewed as a significant life stressor, and its effects on the health and well-being of the caregiver have been intensively studied over the last three decades (Schulz & Thompkins, 2007). Some caregivers report experiencing some level of physical strain, emotional stress, or financial hardship because of their care-providing activity (Rosa et al., 2010). Caregiving responsibilities experienced by families and friends continue to increase due to recent medical advances, shorter hospital stays, increasing life spans with better management of chronic illnesses, limited discharge planning, a shortage of homecare workers, and the expansion of home care technology (Family Caregiver Alliance, 2009). The chronic nature and lack of time frame associated with AD, is an addition to the conflicting demands of jobs and family, increasing economic pressure, and the physical and emotional demands of long-term caregiving (Family Caregiver Alliance, 2007). The potential negative repercussions in the physical and psychological well-being of caregiver are termed caregiver burden (Carratero et al., 2009).

Psychologically, caregivers show higher levels of depressive symptoms and mental health problems than among their noncaregiving peers (Marks, Lambert, & Choi, 2002; Pinquart & Sorensen, 2003; Schulz et al., 1997). It is estimated that between 40% and 70% of caregivers
have clinically significant symptoms of depression, with approximately one quarter to one-half of these caregivers meeting the diagnostic criteria for major depression (Zarit, 2006). Additionally, higher levels of clinical depression are attributed to people caring for individuals with AD, with studies showing that 30% to 40% of AD caregivers suffer from depression and emotional stress (Covinsky, Newcomer, Dane, Sands, & Yaffe, 2003; Alzheimer's Association & National Alliance for Caregiving, 2004).

Depressed caregivers are more likely to have coexisting anxiety disorders, deal with substance abuse or dependence, and suffer from chronic diseases (Caregiver Health, 2006). As a response to increased stress, caregivers are shown to have increased alcohol and other substance use (Rospenda, Minich, Milner, & Richman, 2010). Several studies have shown that caregivers use prescription and psychotropic drugs more than non-caregivers (U.S. Department of Health and Human Services, 1998; National Alliance for Caregiving & Evercare, 2006). Researchers have also found that caregiving can result in feeling a loss of self-identity, lower levels of self-esteem, constant worry, or feelings of uncertainty (Center on Aging Society, 2005; Pinquart & Sorensen, 2003; Marks, Lambert, & Choi, 2002). The higher levels of stress felt by caregivers increases feelings of frustration, anger, guilt, or helplessness during the caregiving process (Pinquart & Sorensen, 2003). There is also the potential for caregivers who are caring for a spouse with significant cognitive impairment and/or physical care needs to more likely to engage in harmful behavior toward their loved one (Beach et al., 2005).

The high rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities of daily living, such as bathing and grooming, put many caregivers at serious risk for poor physical health outcomes (Family Caregiver Alliance, 2006). For example, caregivers are at higher risk
for chronic conditions such as heart disease, cancer, diabetes, and arthritis at nearly twice the rate of non-caregivers (Ho, Collins, Davis, & Doty, 2005; King, Oka, & Young, 1994; Shaw, Patterson, Ziegler, Dimsdale, Semple, & Grant, 1999). They suffer from increased rates of physical ailments such as acid reflux, headaches, and pain/aching (Evercare & National Alliance for Caregiving, 2006). Studies have also shown that caregivers have diminished immune response, which leads to frequent infection and increased risk of cancers (Glaser & Kiecolt-Glaser, 1997; Kiecolt-Glaser, Dura, & Speicher, 1991; Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996).

Most caregivers are ill-prepared; they enter the process of providing care with little or no support (National Alliance for Caregiving & AARP, 2004; National Alliance for Caregiving & AARP, 2009; Family Caregiver Alliance, 2006). Previous research has linked physical and mental health with lack of social support in the general population (Thoits, 1995; Uchino, Bowen, Carlisle, & Birmingham, 2012). Some of that research has specifically focused on the link between physical and mental health among family caregivers (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Roth, Mittelman, Clay, Madan, & Haley, 2005; Thielemann & Conner, 2009). Cranswick (1997) found the needs of informal caregivers are respite care, financial compensation, information, and counseling. However, support needs vary according to the stage of life of the caregiver, length of time they have been a caregiver, and the intensity of the caregiving situation (Norbeck, Chafetz, Skodol-Wilson, & Weiss, 1991). Recent research echoed some of the earlier research and found that informal caregivers identified their needs as falling into four categories: the need for a social life, the need for instrumental support (i.e., caregiver relief, assistance with physical care, reimbursement of financial costs), the need for informational support, and the need for emotional support (Ploeg, Biehler, Willison, Hutchison,
& Blythe, 2016). When informal caregivers do encounter supportive conversations and networks, the positive outcomes suggest the encouragement of healthy behaviors, communication assistance in acquiring health information and seeking, and the potential influence of tangible health support and coping assistance (Goldsmith & Albrecht, 2011).

Managing Caregiver Stress

The Stress Process Model of Caregiving. A recurring theme in the literature regarding caregiving is the individual response to its demands (D'onofrio et al., 2015). Findings are often different, as some studies report that some caregivers are overwhelmed early by care responsibilities and others showing stability or even decreases in the burden over time (Gaugler et al., 2000). This variability in caregiver response has often been explained in terms of the burden models, such as the Pearlin Stress Process Model (D'onofrio et al., 2015; Pearlin, Menaghan, Lieberman, & Mullen, 1981).

The stress process model was originally developed as a way to explain the interrelated conditions that lead to caregivers' health becoming compromised (Segrin et al., 2017); however, since its development, the model has been applied to the burden experienced by caregivers of cancer patients and survivors (Osse et al., 2006; Segrin et al., 2017), to understanding how one's environment and support systems may mitigate stress levels (Raina et al., 2004; Mitrani et al., 2006), and differences in the ways in which various ethnicities and cultures perceive the effects of being a caregiver (Knight & Sayegh, 2009). Caregiver burden, as previously discussed, is the extent to which caregivers perceive the act of caregiving as affecting their emotional, social, financial, physical, and spiritual functioning (Adelman et al., 2014).

In particular, the Pearlin Stress Process Model (Pearlin, Menaghan, Lieberman, & Mullen, 1981), explains why caregiving is more stressful for some than others by specifying risk
factors including primary caregiving stressors, which are those directly related to caregiving, and secondary role strains, such as poor caregiver health and negative social interactions (Ford et al., 1997). Other secondary role strains may arise within work and family roles (Pearlin et al., 1990).

Primary stressors deplete the caregivers' psychological resources, degrade their overall outlook on life, and ultimately influence the way they handle secondary role strains (Pearlin et al., 1981). As Goode, Haley, Roth, and Ford (1998) explain, primary stressors are not unitary, and there appear to be at least two different domains. One type arises from the performance of direct patient care such as helping with tasks that the care recipient is no longer able to perform independently. The second source includes patient behavioral problems and memory impairments.

**Caregiver Perceived Stress.** In previous research, Schulz et al. (1995) found that caregiver mental and physical health outcomes are related to patient and caregiver characteristics, including perceived stress. An individual’s stress can be measured by the number of stressful life events that he or she encounters in the world, but perceived stress refers to how much stress he or she perceives in their experience (Lebois, Hertzog, Slavich, Barrett, & Barsalou, 2016).

In terms of caregiver stress, perceived stress, or subjective burden, refers to how an informal caregiver perceives the impact of stressful life events, such as caregiving tasks and financial problems, they experience while caregiving (Montgomery, Gonyea, & Hooyman, 1985). For example, some informal caregivers may enjoy caring for a loved one, whereas others may find it difficult and overly demanding, leaving them to feel socially isolated (Brouwer et al., 2004). As a result of feeling overwhelmed, some caregivers feel strained, become depressed, and may develop health problems (Schulz & Beach, 1999). This is echoed by later research showing
that objective stressors experienced by caregivers pose challenges, but the extent to which these stressors affect their well-being depends in part on their subjective experience of these problems (Son et al., 2007).

It is equally as important to understand the factors that predict perceived stress as it is to examine perceived stress as a predictor of negative health outcomes (Lebois et al., 2016). Establishing these factors would inform how the perceptions of stress form, and in turn, inspire the creation of interventions or implementation of changes that decrease it (Lebois et al., 2016).

**Information Seeking as a Coping Strategy.** Although seeking information from doctors and nurses is highest among all groups of people (Cotton & Gupta, 2004; Couper et al., 2010), the increase in public access to medical and health information allows health consumers to become more proactive in their healthcare (Lustria et al., 2011; Hall, Bernhardt, & Dodd, 2015). Rees and Bath (2000) noted that information seeking is a problem-focused coping strategy that individuals sometimes adopt as a response to a threatening situation, such as a health crisis. Van der Molen (1999) found that information seeking was used as a strategy to cope with and reduce stress.

Individuals may utilize active or avoidant coping styles, and the differences are associated with psychological vulnerability to stress (Gorka, LaBar, & Hariri, 2016). Researchers and practitioners in the fields of mental health and behavioral medicine recognize that the ways people cope with the demands of a stressful event make a difference in how they feel emotionally (Folkman, Lazarus, Gruen, & DeLongis, 1986). The difference in coping styles can affect the caregiving stress process through an individual’s efforts to adjust the circumstances which increase stress levels, and regulate the emotional distress connected to the situation (Lazarus & Folkman, 1984; Penley, Tomaka, & Wiebe, 2002).
Underlying constructs, such as coping and social support, have the potential to intervene at different points during the caregiving process (Raina et al., 2004). Pearlin et al. (1981) recognized that people differ in their mobilization of resources, actions, and perceptions of how to minimize or avoid distress, and therefore included mediating variables in their model as acting directly on the outcome of caregiving or as intervening at different points in the process. Being well versed in coping and its elements, Pearlin et al. (1981) noted that it is necessary to extend the identification of coping behaviors and to rely more on empirical evaluation than intuition in judging whether behavior that is labeled as coping has coping functions. For example, information seeking, which has been defined as a coping strategy, is purposeful and goal-oriented, and not the result of passive exposure to information (Anker, Reinhart & Freely, 2011). Focusing on this specific coping strategy as a decisive action that may decrease the burden felt by caregivers would greatly contribute to the understanding of whether information seeking is, in fact, a significant coping mechanism to reduce stress in a population that is known to experience considerable amounts stress from various sources.

The stress process model developed by Pearlin et al. (1981) attempts to understand why burden levels are different among caregivers by utilizing stress as an input variable, with well-being as an output variable mediated by coping strategies such as information seeking. In their review of studies that focus on information seeking as an input variable, Anker et al. (2011) found that measures of health information seeking outcomes are mostly concerned with the actions that information seekers take as a result of their information search. These actions include speaking with a doctor about information that has been found and changing treatment decisions based on the information sought (Anker et al., 2011).
Studies have not focused specifically on whether the process of information seeking decreases caregivers' stress levels. To gain a more intricate understanding of the impact information seeking may have on caregiver stress levels, the current study instead focuses on information seeking as an input variable and stress as an output variable, moderated by health literacy and emotional state.

Previous research suggests that certain caregiver resources, including more adaptive coping responses, are associated with lower levels of depression (Haley, Levine, Brown, & Bartolucci, 1987, 1996; Pearlin, Mullin, Semple, & Skaff, 1990; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). Knight and Sayegh (2009) note that people use both social support and coping to avoid, eliminate, or reduce distress. They found that different coping styles can affect the caregiving stress process through efforts to modify the stressful circumstances and regulate the emotional distress connected to the situation (Knight & Sayegh, 2009).

Other studies have shown that active coping may lead to fewer depressive symptoms for caregivers of individuals with AD by aiding in solving problems associated with the caregiving process, as well as reducing caregiver strains (Haley et al., 1987; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985; Knight & Sayegh, 2009). The term active coping may refer to a coping style that is characterized by solving problems, seeking information, seeking social support, seeking professional help, changing environments, planning activities, and reframing the meanings of problems (Li, 2006). Alternatively, when caregivers practice avoidant coping styles, it may lead to worse outcomes because they may engage in denial and disengagement, which individuals use to decrease the emotional consequences of stressors. (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Powers, Gallagher- Thompson, & Kraemer, 2002).
Information Seeking

**Information Needs.** Informal caregivers provide most of the care for people with AD, making them an essential resource for the care recipient and an asset to the healthcare system; therefore, understanding and paying attention to informal caregiver needs and challenges are vital aspects of caring for a person with AD (Steiner, Pierce, & Salvador, 2015). Despite the significant value of informal caregivers, studies report unmet needs among them, particularly regarding obtaining the information and education necessary to care for an adult experiencing a chronic health condition (Washington et al., 2011).

Case (2007) offers the following definitions of information need and information seeking: An information need is a recognition that one's knowledge is inadequate to satisfy a goal. Information seeking is a conscious effort to acquire information in response to a need or gap in one’s knowledge to meet a goal. In other words, people realize that there is a difference between what they know and what they need to know. They constantly compare their current levels of knowledge against goals that they wish to reach and react by seeking information whenever they sense uncertainty (Atkin, 1973). Although the previous definition of information seeking implies that it is a purposive activity, Wilson (1999) offers a broader definition that notes information seeking behavior includes both active and passive information seeking, including face-to-face communication with others, and the passive reception of information as in, for example, watching television advertisements, without any intention to act on the information received.

Many studies have sought to pinpoint the information needs of informal caregivers of those with AD. Earlier researchers, such as Wackerbarth and Johnson (2002), found that informal caregiver’s most important needs were related to legal, financial, and diagnosis and
treatment information. Edelman, Kuhn, Fulton, and Kyrouac (2006) found the top areas of interest were specifics regarding AD stages and symptoms, treatments, genetic aspects, and topics concerning day-to-day care. Washington et al. (2011) found that evidence indicates caregivers have a strong preference for receiving two types of information: general information, which includes facts, explanations, or relevant advice for large numbers of caregivers; and specific information, which is tailored to individual needs. The authors offer that general information can be offered during regular visits with health care providers, and specific information needs can be made accessible through other information channels, such as printed documents or online.

Online resources are noted to be especially helpful for caregivers who are often in the home with the care recipient and find it difficult to attain information in other ways (Smith & Toseland, 2006). Most recently, Werner et al. (2017) identified three critical information needs of informal caregivers: 1) timely access to information, 2) access to information that is tailored or specific to caregiver’s needs and contexts, and 3) usable information that can directly inform how caregivers manage behaviors.

**Information-Seeking Behaviors.** How health information is evaluated, as well as when and where it is sought, are methods and measures associated with information seeking behaviors (Anker et al., 2011). One commonality that can be found across numerous studies about health information seeking behaviors is the finding that people make a conscious choice to seek health-related information (Lambert & Loiselle, 2007). Chisolm (2010) posits that seeking health information online can be considered a behavior like accessing primary care, in that a person recognizes a health-related need in both cases and tries to meet it.
Van der Molen (1999) and Rees and Bath’s (2000) findings, as well as other studies (Dunne, 2002; Griffin, Dunwoody, & Neuwirth, 1999; Holmes & Lenz, 1997; Johnson, 1997; Szwajcer Hiddink, Koelen, & Van Woerkum, 2005; Warner & Procaccino, 2004), indicate that individuals’ health information seeking behaviors are typically initially motivated by an information need. That need is generally defined as a perceived gap between what an individual knows and what he or she wants to know to achieve a certain goal (Case, 2002; Griffin et al., 1999; Johnson, 1997; Loiselle, 1995; Szwajcer et al., 2005).

Although significant, an information need is not enough to prompt information seeking; rather, personal and situational factors influence what type and how much information is sought, what sources are used, and how the information is obtained (Lambert & Loiselle, 2007). Examples of personal factors include individuals’ sociodemographic characteristics and psychosocial variables such as an individuals’ personality traits, expectations, goals, beliefs, values, attitudes, emotions and moods, skills, and/or resources (Borgers et al., 1993; Loiselle, 2001; Matthews, Sellergren, Manfredi, & Williams, 2002). Situational factors refer to the characteristics of an individuals’ environment, source of information, and information seeking context (Allen, 1996; Czaja, Manfredi, & Price, 2003; Dunne, 2002; Loiselle, 2001; Matthews et al., 2002). For example, an accessible information source might be more likely to be used than one perceived as difficult to access (Gallop, 1997).

Additionally, self-efficacy has been widely used as a predictor of individuals' behavior by assessing their confidence or skill level to perform a task or behavior (Bandura, 1997; Grasso & Bell, 2015; Myrick, 2017), and has been shown to contribute positively to information seeking (Brown, Ganesan, & Challagalla, 2001; Griffin et al., 1999; Johnson, 1997). If one has performed a task successfully in the past, this positive experience is likely to enhance one's self-
efficacy (Chen & Feeley, 2014). In the information age, studies have used self-efficacy measures to predict technology-use behaviors and the ability to make informed medical decisions (Cranney et al., 2002; Chu, Mastel-Smith, 2010; Lustria et al., 2011).

Some researchers find that individuals may avoid information, especially if paying attention to it will cause mental discomfort or dissonance (Case, Andrews, Johnson, & Allard, 2005), but as Cotton and Gupta (2004) found in their study, online health information seekers are happier and healthier than those that are offline. In the context of the interpersonal communicative process within a network where one individual is experiencing uncertainty due to a difficult situation, an individual's responses to information received are dependent upon a range of factors, including relational closeness, the context of the message, and the message itself (Feng & Lee, 2010).

It is necessary to understand how information seeking in the growing presence of extended social networks, Internet sources, and online health information may affect health behaviors and health outcomes (Chisolm, 2010). These findings reiterate the idea that information seeking does not occur in a vacuum; interpersonal communication plays an important role in what type of information is sought and how it is received (Anker et al., 2011). For example, effective communication between individuals and their healthcare providers is critical in improving patient outcomes, particularly among patients with chronic diseases (Judson, Detsky, & Press, 2013; Schillinger et al., 2003; Stewart, 1995; Stewart et al., 1999).

Beyond verbal interaction, patients (or caregivers) and providers can now engage in a collaborative communication exchange augmented by using the Internet for direct email communication, use of electronic medical records and access to health information from health-related websites (Gerber & Eiser, 2001). However, this communication can be impeded by
several factors, including but not limited to, lack of appropriate health information seeking behaviors, and inadequate health literacy (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014).

**Health Literacy.** The importance of health literacy for public health is becoming increasingly evident (Beauchampe et al., 2015). The term health literacy is used to describe how literacy skills, such as reading and comprehension, influence an individual's capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Kutner, Greenberg, Jin, & Paulsen, 2006). The 2003 National Assessment of Adult Literacy (NAAL) survey, conducted by the United States Department of Education, found that an estimated 93 million Americans had either below basic or basic health literacy, which is equivalent to the skills of locating, reading, and understanding only easily identifiable health information and using the information to solve simple, one-step problems (Kutner et al., 2006).

Lower health literacy scores, measured as reading ability and numeracy, have been associated with higher avoidable hospitalization rates (Baker et al., 2002), decreased ability to self-care (Riegel et al., 2009), poorer health outcomes, and higher mortality rates (von Wagner, Knight, Steptoe, & Wardle, 2007; Peterson et al., 2011; Sudore et al., 2006). It is worth noting that Osse (2006) found caregivers would benefit from greater health literacy to handle care recipient’s symptoms better, as well as become more adept at informing doctors about changes in the care recipient’s behavior and mental health.

Improving the public’s information-seeking experience has been recommended as an important strategy for promoting public health (Beckjord, Finney Rutten, Arora, Moser, & Hesse, 2008). Giving people greater access to health information and increasing their capacity to use it effectively means enabling individuals to exert greater control over their health and the range of personal, social and environmental determinants of health (Nutbeam, 2008). From this
public health perspective, health literacy represents the skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health (Nutbeam, 2008).

**Affective Component of Information Seeking.** There is an assumption among some scholars that affective factors also can significantly motivate people’s ways of accessing, seeking and using information sources in diverse contexts (Savolainen, 2014). Lee and Kim (2014) noted that previous work revealed many antecedents of health information seeking, but few have sought to tie the psychological processes and effects of information seeking to behavioral outcomes. Myrick (2017) helped to fill that gap by experimentally testing the relationships between searching behavior and post-search outcomes. The study found that discrete emotions and social cognitive variables predict important post-search outcomes, from attitudes toward the search engine to health-related behavioral intentions and information sharing intentions. The results underscore the importance of understanding emotional reactions to online health information to predict better the attitudinal and behavioral outcomes of using the Internet for acquiring health information (Myrick, 2017). Although information seeking is often studied from a cognitive perspective, the emotional state of individuals is an important part of the information seeking process (Kuhlthau, 1991).

The affective component (i.e., emotions) of health information seeking can motivate a search but also impact the outcomes of that search because the emotions and related goals of the information seeker change (Myrick, 2017). Previous research shows that viewing health information elicits multiple emotions in audiences (e.g., Carrera, Munoz, & Caballero, 2010; Dillard, Plotnick, Godblod, Freimuth, & Edgar, 1996; Myrick & Oliver, 2015). For example, when health information is fused with positive affect, it can attract attention, foster receptiveness,
prompt reconsideration of an issue, facilitate recall, and improve attitudes (Monahan, 1995). Experiencing positive emotions after an online health information search may encourage Internet users to continue learning about ways to prevent health threats and may also lead them to share information, building relationships with others (Myrick, 2017). The process of seeking health information online has also been found to help searchers fill information voids and enhance their coping abilities, indicating that searching may result in gratification and positive emotions for some users (Morahan-Martin, 2004). These findings highlight the probability that during an online health information search, multiple discrete emotions are evoked in users (Myrick, 2017).

However, not all search outcomes are positive. Myrick (2017) also found that people who felt afraid after searching were less inclined to think that future searches would have positive outcomes, but they were more likely to have intentions of taking health-related action. This finding may be viewed as positive, but the researcher notes that negative expectations could dissuade individuals from seeking health information in the future. They may rely on friends’ or doctors’ advice instead, with some sources being more accurate and trustworthy than others. A study in which Dutch university students were surveyed found that when the participants were anxious during the information seeking process, they had negative responses to searching, such as feeling overwhelmed, confused, and frustrated (Baumgartner & Hartmann, 2011). Another study, which surveyed Microsoft employees, found that 38% of respondents reported that online health information seeking made them feel more anxious than they felt before their search (White & Horvitz, 2009). These findings note that the Internet has the potential to increase the anxieties of people who have little or no medical training (White & Horvitz, 2009).

Both the negative and positive emotions experienced during information seeking must be considered in research studies to understand and fully support the needs of informal caregivers.
(Autio, 2017). Understanding emotion is crucial because emotions are an important factor when studying the act of coping with life challenges (Lazarus, 1993). As previously discussed, caring for persons with AD is complex and burdensome, and emotions communicate how people react to such stressors (Autio, 2017). The emotions attached to caregiving can be termed ‘basic emotion,’ which is often attached to descriptions that emphasize the value of emotions in coping with fundamental life tasks (Ekman, 1992; Finucane, Dima, Ferreira, & Halvorsen, 2012). Emotions such as happiness, sadness, anger, fear, and disgust are defined as basic emotions (Finucane et al., 2012). Positive emotions, which can be described with words such as happiness, joy, loving and cheerfulness, reflect the appraisal that progress towards a valued goal is being made (Finucane et al., 2012). Similarly, Lazarus and Folkman (1984) discovered that positive emotions, such as happiness or relief, appear when one succeeds in resolving a situation.

Most informal caregivers of people with AD provide care without the necessary information needed to cope with the cognitive, behavioral and physical changes that occur with disease progression (Gitlin, Kales, & Lyketsos, 2012). These caregivers are often left to manage the progressive symptoms on their own (Gitlin et al., 2012). Resolving the lack of initial knowledge can be solved through information seeking, yet the information needs of family caregivers are not always met to the extent that they can effectively manage the behavioral symptoms of the care recipient (Steiner et al., 2016). The information age, however, has exponentially increased in the amount of information potentially available (Vakkari, Savolainen, & Dervin, 1996). As more information has become available, it is necessary to gain a greater understanding of how acquiring that information affects informal caregivers of people with AD. Although existing models of information seeking place information seeking as the primary
outcome variable while focusing on motivations for, or antecedents of, the process, less research has developed models of what happens after a search (Myrick, 2017).

**Uncertainty Management, Stress Reduction, and Information Seeking.** In general, there are four outcomes or consequences of health information seeking behavior: 1) cognitive, which is increased knowledge, informed decision making and coping; 2) behavioral, which includes discussing information with a professional, increased self-care, and adherence to treatment; 3) physical, meaning an increased quality of life; and 4) affective, which includes decreased anxiety, fear, distress, and increased hope and empowerment (Lambert & Loiselle, 2007). Many of these consequences may be explained due to information seeking being a coping strategy that is important in managing one’s uncertainty about a situation (Rains & Tukachinsky, 2015).

According to uncertainty management theory, one of the biggest challenges in one’s life is coping with the various uncertainties one experiences in social relationships (Van den Bos & Lind, 2002). Uncertainty exists when details of situations are ambiguous, complex, unpredictable, when information is unavailable or inconsistent, or when people are insecure in their knowledge (Rains & Tukachinsky, 2015). Uncertainty is an aversive and alarming experience (Van den Bos et al., 2008), which makes people worry about the amount of control they have in their life, as well as the quality of outcomes that could occur from their experiences (Van den Bos & Lind, 2002; Tangirala & Alge, 2006). Uncertainty is a common characteristic of health experiences such as illness and caregiving (Brashers et al., 2000; Han, Klein, & Arora, 2011). For patients and caregivers, medical sources of uncertainty can include the diagnosis, treatment options, or aspects of medical decision making (Martin, Stone, Scott, & Brashers, 2010; Oprescu, Campo, Lowe, Andsager, & Morcuende, 2013; Stone & Jones, 2009; Vevea &
Miller, 2010). Moreover, when information is insufficient, inaccurate, inconsistent, ambiguous or excessive, it can also contribute to uncertainty and confusion (Brashers, 2001; Caiata-Zufferey, Abraham, Sommerhalder, & Schulz, 2010; DeLorme and Huh, 2009; Han et al., 2011; Martin et al., 2010; Stone & Jones, 2009).

Uncertainty affects people’s cognitions, perceptions, feelings, and behaviors (Van den Bos & Lind, 2002), and threatens one’s general sense of self (Hogg, 2001). Several communication scholars assume that humans have a drive to manage uncertainty to make the world more predictable (Affifi & Weiner, 2004; Berger & Calabrese, 1975; Bradac, 2001; Brashers, Goldsmith, & Hsieh, 2002). The notion of utilizing information to manage one’s uncertainty dates to at least the nineteenth century (Morowitz, 1991). By the 1970s, managing uncertainty had become common in scholarly dialogue about motivations for information seeking (Case, 2007). In many discussions of information seeking, uncertainty is tied to feelings of anxiety, leading to the idea that acquiring information is desired for its instrumental and emotional value (Case et al., 2005). Managing uncertainty through information seeking may impact future health outcomes (Myrick, 2017), and help individuals guard against emotional stress (Lambert & Loiselle, 2007; Shiloh, Ben-Sinai, & Keinan, 1999). Positive occurrences of uncertainty management through information seeking may change one's health behavior, improve social cognitions such as self-efficacy and outcome expectancies, and decrease the anxiety associated with health information seeking by offering reliable and likable sources of information (Myrick, 2017).

Information seeking has been portrayed as one of several active coping strategies that one may use to manage uncertainty in one’s environment and has been applied to both mass media use and as a goal in face-to-face interactions (Brashers 2001; Brashers, Goldsmith, & Hsieh,
It has been suggested that interpersonal social support with elements of gathering, examining and evaluating information can assist with uncertainty management (Brashers, Neidig, & Goldsmith, 2004). Additionally, web-based resources such as online communities may also provide an interpersonal communication platform which can be utilized to cope with health-related uncertainty.

The Internet provides health information seekers with a convenient, cost-effective and private means of managing their uncertainty through access to health knowledge, diagnostic tools, information about specific treatments, or others with a similar health concern (Fox & Duggan, 2013). However, researchers have raised doubts about the quality, accuracy, and reliability of various online health information resources (Zhang, Sun, & Xie, 2015). To counter that concern, it is also noted that information seekers may place greater value on the credibility and reliability of health information and adapt their search behaviors accordingly because health uncertainty often causes an emotional response such as anxiety or distress (Quinn, Bond, & Nugent, 2017). Studies have suggested that when individuals seek information for salient health concerns online, they may undertake a more exploratory searching approach, performing multiple searches, examining various sources to compare and verify information, and placing greater significance on the reliability of the information source (Best, Gil-Rodriguez, Manktelow, & Taylor, 2016; Mendes, Abreu, Vilar-Correia, & Borlido-Santos., 2016; Pang, Verspoor, Chang, & Pearce, 2015; Powell, Inglis, Ronnie, & Large, 2011; Rozmovits and Ziebland, 2004).

**Explanation of Overall Conceptual Model**

A commonly shared view is that information seeking studies aim to build models of information behavior which show how different factors or variables influence information
seeking (Talja, Kesö, & Pietiläinen, 1999). A conceptual model, integrating Pearlin’s Stress Process Model (Pearlin et al., 1981) and prior research on health information seeking (Johnson, 1997; Leckie, Pettigrew, & Sylvain, 1996; Wilson, 1999) guides the current study. As with other models of information seeking, this conceptual model does not embody a fully formed theory but may be considered a framework for thinking about a problem that may develop into a statement that attempts to describe an information-seeking activity, the causes and consequences of that activity, or the relationships among stages in information-seeking behavior (Wilson, 1999).

Information seeking models are narrowly focused along some dimension—usually by task, discipline, or job (Case, 2007). The proposed model focuses on the task of being an informal caregiver of an individual with AD.

**The Conceptual Model.** The independent variable depicted in the model is the act of information seeking. Previous researchers (Leckie et al., 1996) offer that the act of information seeking may be affected by the sources utilized. Sources of information vary. This can refer to mediated, traditional, or face-to-face communication. Additional operationalizations of sources, as described in the Leckie et al. (1996) model include trustworthiness, packaging, quality, and accessibility. Access to reliable health-related information has been linked to reduced anxiety, increased feelings of self-efficacy, and decreases in utilization of ambulatory care (Ybarra & Suman, 2006). However, Peterson et al. (2016) found that most caregivers currently receive insufficient information even though they are open to many information sources, settings, and technologies, including referrals to other healthcare professionals, print material, and community and Internet resources.

The proposed model also includes one moderating variable: health literacy. The conceptual model leads to an outcome variable of stress levels. (Figure 1) Although Lambert and
Loiselle (2007) identify three outcomes or consequences of health information seeking behavior in addition to stress, this study focuses on the stress outcome because it has been identified as one of the major public health issues in this century (Heber, 2017) and can lead to severe psychological and physical implications, including depression (Hammen, 2005), sleep problems (Akerstedt, 2006), neck and shoulder disorders (Kraatz, Lang, Kraus, Münster, & Ochsmann, 2013), an increased risk of coronary heart disease events (Richardson, et al., 2012), and related mortality (Steptoe & Kivimäki, 2012). Substantial economic costs of stress and stress-related psychological disorders arise as a result of absenteeism, presenteeism, productivity loss, and high staff turnover (Hassard, 2014). Additionally, the act of information seeking, as previously discussed, may be considered a coping mechanism used to increase one’s knowledge.

Figure 1: Conceptual Model

As with other components of research, models have strengths and weaknesses. One strength is that models depict key elements of the investigator's approach and selection of
explanatory factors (Case, 2007). The strength of a model to simplify one phenomenon can also be considered a weakness when it is overgeneralized to another, dissimilar phenomenon (Case, 2007). As with the Leckie et al. (1996) model, this model’s main limitation is to a range of people, meaning it is limited to the population of informal caregivers of people with AD.

**Antecedents to the Conceptual Model.** Although not included in the model, previous research notes that numerous variables influence information seeking (Baker & Pettigrew, 1999; Brashers, Goldsmith, & Hsieh, 2002; Leydon et al., 2000; Miller, 1995; Savolainen, 2016; Stavri, 2001). Three variables are: (1) the information need of informal caregivers, (2) self-efficacy in information seeking, and (3) emotional state. In his essay describing debates over the nature of “needs” that have taken place among political philosophers and social policy advocates, Green (1990) identifies four general conclusions about the concept of need; need is always instrumental and involves reaching a desired goal; needs are usually contestable, which makes them different than human wants; need is related to the concept of necessity, leading one to ask whether the need is a primary need, and; need is not necessarily a state of mind, and it is possible to be unaware of one’s true needs. Patients, their families, and their friends often seek out subjective, informal information about the realities of coping with illness in daily life (Brashers, Neidig, & Goldsmith, 2004; Forsythe, 1996; Ewing 2003; Kleinman, 1988.) Research shows, however, that caregivers may not access publicly available caregiving information, and caregiver education programs are not widely implemented clinically (Peterson, Hahn, Lee, Madison, & Atri, 2016).

Self-efficacy refers to "beliefs in one's capabilities to organize and execute the courses of action required to produce given statements” (Bandura, 1997, p. 3), which determine people's feelings, thoughts, motivations, and behaviors (Bandura, 1986). Based on this idea, Bronstein
(2014) finds that success in performing a task is not only based on the possession of the necessary skills, but it requires the confidence to use these skills effectively. Pajares (2002) argued that individuals with high self-efficacy perception expect to succeed and will persevere in an activity until it is completed. Contrarily, individuals with low self-efficacy anticipate failure and will be less likely to persist in doing an activity they perceive as challenging.

As was previously discussed, the emotional state of individuals is an important part of the information seeking process (Kuhlthau, 1991) due to the potential for motivating a search or impacting search outcomes (Myrick, 2017). Recent research has explored how integral feelings (good and bad feelings experienced about a stimulus) and incidental feelings (positive and negative feelings, such as mood states that are stimulus-independent but may be misattributed to it) are used to predict and explain how people react to things they encounter (Peters, 2011). These emotions influence the decisions of patients, physicians and other health care providers, and communicators (Lerner & Keltner, 2001). For example, individuals who are negatively impacted by emotion, becoming overcome with fear or grief, would not be able to make sound decisions (Peters, 2011).

Additionally, two groups of antecedent factors must be taken into consideration. The first group is background factors, including socioeconomic status (SES) and demographic variables such as age, gender, and race. Given that this model is restricted to a specific group of informal caregivers, and that it integrates the Pearlin Stress Process Model (Pearlin et al., 1981), the second group of factors is primary stressors related to caring for someone with Alzheimer's or other dementias. This includes the tasks the care recipient needs help with, as well as the level of burden felt by the caregiver.
Research Questions and Hypotheses

Information seeking is a recursive process involving many factors during a complicated process. This study seeks to examine a sliver of that process. Previous research has defined overall caregiver information needs (e.g., Edelman et al., 2006; Wackerbath & Johnson, 2002; Washington et al., 2011), but greater focus should be given to how these needs may be met. This study builds on previous work by using a more comprehensive, mixed-methods approach to identify these caregiver information needs, resources they utilize during the information seeking process, and potential outcomes. The first questions will focus on the health information needs of informal caregivers of individuals with AD to better understand how their needs may change during the process of caregiving. That information may range from the need to understand the illness to the caregiver's desire to take care of their health during the caregiving process. The subsequent question will seek to discern the different resources they utilize during the information seeking process.

The varying ideas about information needs can be illustrated on a continuum that reflects assumptions about the nature of information, why people seek it, and what they use it for; one end of the spectrum can be considered the Objective pole and the other the Subjective pole (Case, 2007). Atkin (1973) best illustrate the Objective view, which holds that information reflects an objective reality, and that information seeking as driven primarily by a rational judgment that some uncertainty exists that would be resolved by specific information, and emotional motivations of the search process are set aside. In contrast, the Subjective pole represents the view that most searches for information are prompted by a feeling of unease, a sense of having a gap in knowledge, or by anxiety about a situation (Case, 2007). With these
varying ideas regarding information needs and information seeking behaviors, this study seeks to identify:

RQ1: What motivating factors lead informal caregivers of people with AD to seek out information?

In a similar vein, needs and motivations may change over time. Harter (1992) argues that to talk about an individual's information need is virtually the same as describing his or her current psychological state because needs shift as new pieces of relevant are encountered. One bit of knowledge may raise questions, lead to another fact, or to a new conclusion, which may change one's knowledge state and what one finds relevant and worth seeking (Case, 2007); therefore, this study seeks to answer the following two research questions.

RQ1a: How do informal caregiver information needs change over time that they are a caregiver?

RQ2: Why do informal caregivers choose to utilize certain resources more than others during their information seeking process?

The Pearlin Stress Process Model (Pearlin et al., 1981), as previously discussed, is designed to understand how the caregiving process causes more burden for some caregivers than it does for others. As research has shown, the difference in coping styles can affect the caregiving stress process through efforts to adjust the circumstances which increase stress levels (Lazarus & Folkman, 1984; Penley, Tomaka, & Wiebe, 2002). It is possible that utilizing any form of information seeking, which has been defined as a purposeful and goal-oriented coping strategy (Anker, Reinhart & Freely, 2011), has the potential to alter caregiver stress levels. Additionally, much of the literature on uncertainty reduction emphasizes either the benefits of having new information or the potential negative outcomes of information seeking without
considering both costs and benefits in their examples (Case, Andrews, Johnson, Allard, 2005). Based on this information, I pose the following research question.

RQ3: Is there a correlation between information seeking and resulting stress levels?

Although there are expansive opportunities to seek health information, the potential for increased stress levels is bolstered by the numerous challenges that exist. For example, both patients and their families have expressed reluctance to intrude on the busy schedules of health professionals by asking questions regarding their situation (Kristjanson & Aoun, 2004). Another challenge, as discussed, is lack of health literacy, which can negatively impact health outcomes by affecting consumers’ ability to function and make informed health-related decisions in both the health care environment and everyday life (McCray, 2005; Burkell, 2004). In some instances, such as under conditions of personal stress, people can be motivated to pursue salient technical material that may be above their normal level of health literacy (Tetzlaff, 1997), or they may rely on others who can translate medical terminology for them (Stavri, 2001; Tetzlaff, 1997; Dervin, 2003). Although there are more avenues for individuals to seek information related to health inquiries, there is not an expanse of information about how this behavior and information affects health behaviors (Ybarra & Suman, 2006). With these previous studies in mind, I propose the following research questions and hypothesis:

RQ4: Does emotional state moderate the association between information seeking and stress?

RQ5: Does health literacy moderate the association between information seeking and stress?

H1: Informal caregivers with low health literacy and low self-efficacy will have higher stress levels than those who have high health literacy and high self-efficacy.
CHAPTER 3
METHODS

Early on, researchers found the value of mixed methods research in the idea that all methods had biases and weaknesses, therefore utilizing both qualitative and quantitative research methods neutralized the weaknesses in each form of data collection (Creswel & Creswell, 2017). Examples of mixed method research design has been applied to caregiving studies of ALS caregivers (Galvin et al., 2016), male caregivers (Kato-Wallace, Barker, Eads, & Levto, 2014), grief in terminal illness (Waldrop, 2007), and Mexican-American female caregivers (Cagle & Wells, 2008). Regarding AD caregivers, mixed method approaches were used to learn about their unmet service needs (Stirling et al., 2010), differences in their experiences of loss and grief (Adams & Sanders, 2004), and caregiver hope, transitions, and quality of life (Duggleby, Swindle, Peacock, & Ghosh, 2011). To my knowledge, the subject of information sources for AD caregivers has been explored using either qualitative or quantitative research methods, not a mixed method approach. Information sources were studied in large quantitative surveys (National Alliance for Caregiving, 2011; AARP and National Alliance for Caregiving, 2015), as well as qualitative semi-structured interviews (Peterson, Hahn, Lee, Madison, & Atri, 2016).

This study incorporates both quantitative and qualitative research methods not only to discern caregivers' perspectives, impressions, and opinions of caregiving and resources available to them but to understand whether the information-seeking process affects their stress levels due to reasons which the caregivers may not even be aware. Although both methods were instrumental in guiding the findings, this study may be viewed primarily as a qualitative study supported and expanded upon by quantitative research. Being that this research utilizes both quantitative and qualitative research methods, this chapter has been divided into two sections.
The first section will explain the qualitative research method, and the second section will describe the quantitative research method used in this study.

The problems addressed within the social and health sciences are complex, and the use of either quantitative or qualitative approaches by themselves is inadequate to address this complexity (Creswell, 2017). There are, however, both advantages and disadvantages to using a mixed methods approach. Researchers have noted reasons for using mixed methods in both health studies and communication research. For example, Weitzman and Levkoff (2000) offer a variety of merits in utilizing mixed methods in health studies. The authors found that qualitative data was useful in ensuring that quantitative data was culturally appropriate, as well as in confirming the results related to the causal relationships found by analysis of the quantitative data. Benoit and Holbert (2008) highlight several examples of studies in communication that use multiple methods. For instance, they note how a combination of quantitative content analysis, survey research, and experiments contributed to the development of research-based in cultivation theory. Kreps and Maibach (2008) argue in support of a mixed methods approach from a health communication perspective. The researchers argue that the sharing of ideas across disciplines can lead to influential transdisciplinary theoretical frameworks that allow for the in-depth study of communication in health contexts.

Mixed method designs, therefore, offer tools that are necessary to integrate theories to offer a more nuanced understanding of social reality, allowing for the further development of theories that explain complex phenomena across multiple levels of analysis (Creswell, Klassen, Plano Clark, & Smith, 2011). There is a richness added to the data, and depth provided to the results, that would not have been possible using a single research method (Tashakkori &
Creswell, 2007). Additionally, qualitative data is useful in theory building and in overcoming reliability problems that are associated with quantitative analysis (Weitzman & Levkoff, 2000). More insight and a greater understanding of research problems can be gained by combining qualitative and quantitative research methods than from either form by itself (Creswell, 2017).

Using a mixed method approach also has its disadvantages. There is a need for extensive data collection (Creswell, 2017), requiring more time and effort because the researcher is technically conducting two studies (Wimmer & Dominick, 2014). There is also a requirement for the researcher to be familiar with both quantitative and qualitative forms of research, which might make data analysis more difficult, particularly if the methods yield conflicting results (Creswell, 2017; Wimmer & Dominick, 2014). Mixed methods researchers may also find it difficult to combine, or integrate, their quantitative and qualitative findings (Bryman, 2007). A lack of integration suggests that the researcher may not be making the most of the data collected, or that they may have experienced barriers or practical difficulties that impede integration of their results, including separate timelines of the quantitative and qualitative components, and an observation that one set of results is more significant or enlightening than the other (Bryman, 2007).

As Bryman (2007) points out, however, bringing quantitative and qualitative findings together has the potential to offer insights that could not otherwise be assembled. Outside of such observations regarding a mixed methods approach, the rationale for using both quantitative and qualitative research methods for this study was motivated by the use of a sequential exploratory strategy, which involves a first phase of qualitative data collection and analysis, followed by a second phase of quantitative data collection and analysis that builds on the results of the first qualitative phase (Creswell, 2017). Creswell (2017) offers that the purpose of this strategy is to
use quantitative data and results to assist in the interpretation of qualitative findings, which is well-suited for exploring a phenomenon.

The intent of this design is to explore with a sample first so that a later quantitative phase can be tailored to meet the needs of the population being studied (Creswell & Creswell, 2017). It can be used to generalize qualitative findings to different samples (Morgan, 1998), and to determine the distribution of a phenomenon within a chosen population (Morse, 2003). As discussed earlier in the chapter, little is known about utilizing a mixed method approach in understanding the effect of AD caregiver information seeking. In combining qualitative and quantitative data, there is an opportunity to develop a complete understanding of changes that may be needed to reduce stress levels of AD caregivers.

**Interviews**

Intensive interviews, also termed in-depth interviews, are a qualitative research technique that involves conducting intensive individual interviews with respondents to explore their perspectives on an idea, program, or situation (Boyce & Neale, 2006). The interviews offer a wealth of detail and rich responses on sensitive issues (Wimmer & Dominick, 2014). They are useful when seeking detailed information about a person's thoughts and behaviors and when exploring new issues in depth (Boyce & Neale, 2006). The researcher can engage in a sustained and intensive experience with study participants (Creswell & Creswell, 2017).

According to Charmaz (2014), intensive interviewing is a way to generate data through a gently guided, one-sided conversation that explores a person’s substantial experience with a research topic. Charmaz (2014) further notes that during the interview, the participant talks while the interviewer encourages, listens and learns. Interviews allow for a more relaxed atmosphere in which to collect information because people may feel more comfortable having a conversation.
with a person about certain topics as opposed to filling out a survey or participating in a focus group (Boyce & Neale, 2006). Additionally, the interviewer can shift the conversation and follow hunches, going beneath the surface of ordinary conversation to examine earlier events and views (Charmaz, 2014).

There are also limitations to conducting in-depth interviews. For example, interviews are a time-intensive activity and are not necessarily generalizable (Boyce & Neale, 2006; Wimmer & Dominick, 2014). Generalizability is usually not an expected attribute because most qualitative research studies focus on a specific issue or phenomenon in a certain population or specific location in a certain context (Leung, 2015). However, instead of generalizability, the development of rich descriptions and themes is the hallmark of good qualitative research (Creswell & Creswell, 2017; Greene & Caracelli, 1997).

Being that caregiving has been studied in various areas, interpretation of the qualitative data in this study can confirm past information or diverge from it. Interviews are appropriate because they allow the participants to share their thoughts and ideas freely without being constrained by pre-determined scales or instruments (Creswell & Creswell, 2017). Neglecting to document AD caregivers’ perspectives and opinions would leave this study lacking in context and missing connections among the data.

Sample. This study utilized a convenience sample of current and former informal caregivers of people with AD \((n = 15)\). The interviews were conducted between March and November 2018 via telephone and face-to-face conversation. Participants who were interviewed face-to-face reviewed, signed, and returned the IRB-approved written consent form before the interview proceeded (See Appendix D). Those interviewed via telephone were read the consent form and agreed to participate in the study verbally. Consent to audio record the interview was
required to participate. All interviews were recorded and transcribed by a professional transcription service. The original audio recordings will be destroyed upon completion of this project. The average length of time for the interviews was 35.5 minutes.

**Interview Instrument.** Intensive interview guides facilitate conducting an open-ended, in-depth exploration of an area in which the interviewee has substantial experience (Charmaz, 2014). The interview instrument (see Appendix B) included 15 main questions, with additional follow-up questions to many of the main questions. All participants were asked questions referring to their experiences as an informal caregiver (What event precipitated you starting the caregiving process?), challenges about finding information related to caring for someone with AD (What are some examples of information that you were unable to find?), sources of that information (Where did you look for information?), forms of support (Do you have an online support system?), and their health as it relates to caregiving (How has your health changed during your time as a caregiver?). However, the method of interviewing allowed for the interviewer and participants to deviate from the interview guide when an additional topic of interest emerged. As Charmaz (2014) suggests, collecting a wealth of information allows for the researcher to look beneath superficial layers of data and captures a range of contexts, perspectives, and timeframes.

**Analysis.** The interviews were analyzed using thematic analysis. Thematic analysis is a method for systematically identifying, organizing, and offering insight into patterns of meaning, or themes, across a data set. This allows the researcher to see and make sense of collective or shared meanings and experiences (Braun, Clarke, & Terry, 2014). Two main reasons noted for using thematic analysis are accessibility and flexibility. It offers a way into qualitative research that explains the mechanics of coding and analyzing qualitative data systematically, which can
then be linked to broader theoretical or conceptual issues (Braun & Clarke, 2012). The thematic analysis was conducted by applying Braun and Clarke’s (2006) recursive process which guides researchers through the six phases of analysis: 1) Familiarizing yourself with the data; 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; 5) Defining and naming themes, and; 6) Producing the report.

Thematic analysis is a search for themes that emerge as being important to the description of the phenomenon by carefully reading and re-reading the data (Daly, Kellehear, & Gliksman, 1997; Rice & Ezzy, 1999). The transcribed audiotaped interviews were reviewed for initial broad themes or codes. A theme captures something important about the data concerning the research question and represents some level of patterned response or meaning within the data set (Braun and Clarke, 2006). Although it is ideal for there to be some instances of the theme across the data set, more instances do not necessarily mean the identified theme is more crucial (Braun and Clarke, 2006). Themes then were grouped and reviewed for emerging patterns, and variability and consistency.

Thematic analysis allows a researcher to determine themes, and their prevalence, in many ways, but it is important to be consistent throughout an analysis (Braun & Clarke, 2012). Thematic analysis tends to be driven by the researcher’s theoretical or analytic interest in the area and provides a more detailed analysis of some aspect of the data (Braun & Clarke, 2006). The researcher’s recognition of patterns within the data is the impetus for creating emerging themes that become the categories for analysis (Fereday & Muir-Cochrane, 2006). For this study, transcribed interviews were reviewed to classify and code common themes, which were identified by shared words and similar meanings contained within the responses. Similar meanings could have been explicit or inferred.
The first step was the production of initial codes from the data. Codes identify a feature of the data that appears interesting to the researcher and refer to the most basic segment, or element, of the raw data that can be assessed in a meaningful way (Boyatzis, 1998). Codes were not predetermined for the analysis of this data but were identified through recognition of specific phenomena within the transcribed interviews. Although some codes were expected, based on previous literature and common sense (Creswell & Creswell, 2017), others were highlighted due to their conceptual interest and relevance to the study. The initial coding highlighted 47 distinct codes (See Appendix A). Following is an example of codes developed for this study.

The code of “emotional response” consisted of descriptions of participant emotions or feelings as a result of their caregiving experience. The code of “lack of time” included any reference that participants made to their having limited time to take care of their personal needs outside of the tasks required of them as being a caregiver. The code “belief that they do not need information” referred to participant responses that offered details of the reasons that they do not need to seek out information regarding AD or being a caregiver.

The next phase of analysis re-focuses the analysis at the broader level of themes, rather than codes, and involves sorting the different codes into potential themes, and organizing all the relevant coded data within the identified themes (Braun and Clarke, 2006). In other words, codes are combined to form overarching themes. The data were examined for differences and commonalities both within and across code categories. Once themes were identified, the results of the qualitative analyses were interpreted for their significance to the communication field regarding caregiver stress levels.

The primary objective for qualitative data collection was to represent the subjective viewpoint of caregivers who shared their experiences and perceptions of caring for their loved
one while navigating their own lives. Data offered a greater understanding of the lived experiences of informal AD caregivers and how those experiences may influence their information-seeking tendencies. The interviews were also utilized to capture as many elements of their information-seeking experiences as possible. The qualitative interview data was revisited after the completion of the quantitative analysis to explore further points of interest that emerged.

In total, 15 in-depth qualitative interviews were conducted with 12 female caregivers and three male caregivers. Of that group, three cared for a spouse, two cared for an in-law, and 10 cared for a parent (See Table 1). As was discussed, a thematic analysis was used to develop themes that appropriately spotlight the information-seeking experiences of informal caregivers.

The first three research questions posed in this study refer to such experiences. Of particular interest were the themes of “sources of information and preferences,” and “responses to information seeking.” Both themes spoke to discerning how forms of communication help or hinder caregivers while both caring for an individual with AD and attempting to maintain an otherwise normal lifestyle. Utilizing this exploratory sequential mixed methods approach allows for the development of an instrument that best fits the sample under the study (Creswell & Creswell, 2017).

Materials and methods used in the process of developing the interview guide for this study were approved by the institutional review board of Louisiana State University (IRB ID: # E10913), on February 26, 2018. The application was updated before proceeding with the survey portion of the research project and approved on October 22, 2018 (See Appendix E).

Survey

The addition of a quantitative component, such as a survey, allows for correlations and the strength of relationships to be determined. Fowler (2009) offers that the utilization of the
consistent standard measurement provided by the survey method ensures that one has comparable information about everyone involved, and without that information, analyzing distributions or patterns of association is not meaningful. The survey will offer both theoretical and practical implications for the communication field.

Wimmer and Dominick (2014) offer advantages for using survey research that are directly related to this study. First, a large amount of data can be collected from a variety of people with relative ease. Second, surveys are not constrained by geographic boundaries. They can be conducted almost anywhere. The utilization of the Internet, telephone, and mail allow researchers to contact participants in nearly any location. Third, surveys provide a standardized measurement that is consistent across all participants, ensuring that the researcher has comparable information. It would be difficult to offer a numeric description of the trends, attitudes, or opinions of a population without such information (Creswell & Creswell, 2017).

There are, however, disadvantages to survey research as well. Most importantly, independent variables cannot be manipulated the way in which they can be in laboratory experiments (Wimmer & Dominick, 2014). Additionally, inappropriate wording or placement of questions within a survey instrument can bias results, the wrong respondents may be included in the survey population, and respondent rates for survey research is steadily declining (Wimmer and Dominick, 2014). The participant recruitment methods and instrument development, which directly address these problems are discussed herein.

**Sampling and Recruitment.** This study used nonprobability sampling to collect survey data. Nonprobability sampling does not allow a researcher to calculate the amount of sampling error present in a research study (Wimmer & Dominick, 2014). Nonprobability sampling does
have merit for this study because the survey was designed to collect exploratory data and investigate relationships within a constrained amount of time (Wimmer & Dominick, 2014).

The survey was generated and administered online using Qualtrics software (Qualtrics, 2017). The data were collected between November 2018 and February 2019. Various resources were utilized to recruit participants both locally and outside of Louisiana. The Board of Alzheimer’s Services of Baton Rouge approved the dissemination of the survey to people that utilize their services. The survey was sent out to 500 randomly selected individuals from their list serve via standard mail services on January 18, 2019. Second, Our House of Respite, a business that specifically offers respite care to families of people with AD, disseminated the survey to their clientele. Our House of Respite has two facilities in Louisiana; one facility in Baton Rouge, and another in Plaquemine. A third resource, Monica Lauren Willis-Parker, an Assistant Professor in the Department of Neurology at Emory University, forwarded the survey to caregivers who utilize the services at the Emory Alzheimer’s Disease Research Center. Additionally, having had past success in recruiting participants via posting the survey hyperlink to personal social media accounts and sending it via email to personal contacts, this was utilized as an additional recruitment method.

**Predictor Variables.** Information seeking was measured by creating a variable from participant indication of how many topics they researched while caregiving (e.g., hereditary nature of the illness, managing care recipient behavior, proper diet nutrition), as well as at which point during the care recipient's illness they researched those topics (e.g., early stage). This variable will be discussed in greater depth in Chapter 4.

Information self-efficacy was adapted from Bronstein's (2014) 27-item Information Seeking Self-Efficacy Scale (IRES). The IRES was adapted from the Internet Self-Perception
Scale (ISPS) developed by Hinson et al. (2003). Bronstein (2014) changed references regarding Internet use to references regarding information seeking and removed four items intended for small children. Using a 5-point Likert scale, participants indicated how much they agreed or disagreed with statements regarding information seeking (e.g., When seeking information, I can solve most problems if I invest the necessary effort.) (9 items; $\alpha = .91$).

A modified differential emotion scale was used to address the emotional state experienced by participants during the information seeking process (Fredrickson, Tugade, Waugh, & Larkin, 2003). Participants used a 14-item, 5-point Likert scale to address the extent to which they felt positive and negative emotions (i.e., I felt stressed, nervous, overwhelmed) ($\alpha = .88$). Seven items were reverse-coded.

**Outcome Variable.** The participant’s perceived stress level was measured using an adapted version of the Perceived Stress Scale (PSS). The 10-item PSS was developed as a sound global measure of perceived stress that specifically measured the degree to which an individual appraises situations in their life as stressful (Cohen, Kamarck, & Mermelstein, 1983). Four items were reverse-coded, and one item was removed to increase the internal consistency of the measure. Using a 5-point Likert scale, participants answered questions about how often they had feelings and thoughts during the previous month (e.g., In the past month, how often have you been upset because of something that happened unexpectedly?) (9 items; $\alpha = .87$).

**Moderating Variable.** The moderating variable included in the study’s conceptual model is health literacy. The health literacy scale included in the survey was adapted from the Ishikawa, Takeuchi, and Yano (2008). The scale, originally developed for individuals with chronic conditions, includes questions regarding functional health literacy, communicative health literacy, and critical health literacy. Two items from the original scale were reverse-coded, and
one was removed to increase the internal consistency of the measure. This survey included eight items from the original scale and used a 5-point Likert scale which asks participants to rate how strongly they agreed or disagreed with statements like "When I talk to a doctor or nurse, I ask questions that I need to ask.” (α = .70).

**Additional Measures.** Participants were asked questions regarding their caregiver status, level of caregiver burden, preparedness for caregiving, and source utilization. Each participant was asked to indicate whether they were a current or former caregiver. Anyone indicating they had never been a caregiver was directed to the end of the survey without answering any additional questions. Next, each participant was asked how long they were a caregiver and for whom the care was given. Additionally, participant information needs were recorded by allowing them to indicate which items among a list of 13 topics searched for by caregivers (Hinojosa & Rittman, 2007), and participants were asked to indicate which tasks they perform as a caregiver. The 15 items were developed by Macera, Eaker, Jannarone, Davis, and Stoskopf (1993). Examples include transportation, cooking, yard work, and toileting.

Preparedness for caregiving, which includes the things which a person feels motivated to learn about, is a general concern of health matters (Becker, 1974). For this study, an adapted version of The Preparedness for Caregiving Scale was used to test participant salience of issues dealing with caring for a person with AD. The 12-item scale (α = .88), which included an option for the participant to include an additional topic that is relevant to caring for someone with AD, was measured using a 5-point Likert scale asking participants to indicate the extent to which they agreed or disagreed with the importance of learning about each item. Topics included “Financial resources available to you and/or your loved one,” “Facilities to place your loved one in the future,” and “End of life care.”
Additionally, participants were asked to indicate what sources of information they utilized. The list included 13 items, which were adapted from a survey of health information trends survey (National Cancer Institute, n.d.). Items included newspapers, television, and religious organizations. Lastly, each person was asked to answer a list of demographic questions. (see Appendix C).
CHAPTER 4
RESULTS

Findings from Interviews

In-depth interviews were conducted with fifteen caregivers to hear their perspectives and gain insights about their lived experiences providing care to a loved one with AD (Table 1). These interviews focused on their experiences in general and how those experiences might have influenced their information seeking and reception. Although many issues arose in these interviews, only the most relevant findings for this study will be reported here. As was discussed in Chapter 3, a thematic analysis was used to develop themes that appropriately spotlight the information-seeking experiences of informal caregivers.

Table 1. Interview Participant Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Caregiver Status</th>
<th>Relationship to Care Recipient</th>
<th>Years as a Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>F</td>
<td>African American</td>
<td>Current primary</td>
<td>Daughter to mother</td>
<td>3</td>
</tr>
<tr>
<td>Natalie</td>
<td>M</td>
<td>White</td>
<td>Current secondary</td>
<td>Daughter-in-law to mother-in-law</td>
<td>10</td>
</tr>
<tr>
<td>Sarah</td>
<td>F</td>
<td>African American</td>
<td>Former primary</td>
<td>Daughter to father</td>
<td>3</td>
</tr>
<tr>
<td>Betty</td>
<td>F</td>
<td>African American</td>
<td>Current primary</td>
<td>Daughter to mother</td>
<td>5</td>
</tr>
<tr>
<td>Daisy</td>
<td>F</td>
<td>White</td>
<td>Current primary</td>
<td>Wife to husband</td>
<td>6</td>
</tr>
<tr>
<td>Olivia</td>
<td>F</td>
<td>White</td>
<td>Current primary</td>
<td>Wife to husband</td>
<td>18</td>
</tr>
<tr>
<td>Tracy</td>
<td>F</td>
<td>White</td>
<td>Former primary</td>
<td>Daughter to father</td>
<td>About 10</td>
</tr>
<tr>
<td>Matthew</td>
<td>M</td>
<td>Hispanic</td>
<td>Current primary</td>
<td>Son to mother</td>
<td>10</td>
</tr>
<tr>
<td>Rose</td>
<td>F</td>
<td>African American</td>
<td>Former primary</td>
<td>Daughter to mother</td>
<td>About 5</td>
</tr>
<tr>
<td>Stan</td>
<td>M</td>
<td>White</td>
<td>Former primary</td>
<td>Husband to wife</td>
<td>15</td>
</tr>
<tr>
<td>Logan</td>
<td>M</td>
<td>White</td>
<td>Current secondary</td>
<td>Son to father</td>
<td>About 6</td>
</tr>
</tbody>
</table>

Table 1 (continued)
<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Race/Ethnicity</th>
<th>Caregiver Status</th>
<th>Relationship to Care Recipient</th>
<th>Years as a Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sophia</td>
<td>F</td>
<td>African American</td>
<td>Current primary</td>
<td>Daughter to mother</td>
<td>About 3</td>
</tr>
<tr>
<td>Emily</td>
<td>F</td>
<td>African American</td>
<td>Former primary</td>
<td>Daughter to mother</td>
<td>11</td>
</tr>
<tr>
<td>Lily</td>
<td>F</td>
<td>White</td>
<td>Current primary</td>
<td>Daughter to mother</td>
<td>5</td>
</tr>
<tr>
<td>Theresa</td>
<td>F</td>
<td>White</td>
<td>Current primary</td>
<td>Daughter-in-law to mother-in-law</td>
<td>About 2</td>
</tr>
</tbody>
</table>

Four themes emerged from the data that aid in answering the posed research questions: (1) caregiver perceptions of care and its effects, (2) information needs and seeking intentions, (3) sources of information and preference, and (4) responses to information seeking. Three of these themes were broken down into subthemes. Caregiver perceptions of care and its effects included three subthemes: (1) caregiver experience, (2) support systems, and (3) physical and emotional impact of caregiving. Information need and seeking intentions included three subthemes: (1) what is known, (2) what is not known, and (3) caregiver need to fill the gap in knowledge. Responses to information seeking included two subthemes: (1) positive responses to information seeing, and (2) negative responses to information seeking (See Figure 2). Each theme described herein is accompanied by supportive and illustrative data found within the compiled interviews.

Disentangling the care recipient's illness from the caregiver's experience is difficult. Their lives have been intimately intertwined, and a diagnosis of AD does not sever that connection. Discussing the caregiver experience theme first offers a pathway into the motivating factors that lead informal caregivers of people with AD to seek out information and the resources that they utilize.
Figure 2. Thematic Map
Caregiver Perceptions of Care and its Effects

All fifteen of the participants described experiences that were filled with difficulty and that were somewhat unpredictable. Although each experience was unique, participants offered details that showed similarities in how caregiving can affect informal caregivers. Due to the difficulty in navigating the complicated nature of caring for someone with AD, participants experienced both emotional and physical effects.

Caregiver experience. About a third of the participants stated that no one would care for their loved one in the same way that they could. The level of care they provided required hours of their time, leaving little personal time for other activities. As caregiving demands changed during the course of the illness, participants reported adapting to these escalating needs, further reducing the time and energy they had for other activities. For example, Natalie recounts that in the early stages of her mother-in-law’s illness, she and her husband, Matthew, were forced to juggle the responsibilities of starting a family, and constantly worrying about her mother-in-law’s care and safety. Initially, Natalie’s mother-in-law lived in her own home. Matthew, an only child, worked full time, checked on his mother after work, and tried to be home before his daughter went to bed. Even after having a second child, Matthew continued visiting his mother as many days a week as possible, including most Saturdays. This not only added to the stress Natalie already felt, but it also limited the amount of time Matthew spent with his growing family. Another participant, Emily, quit her job so that she could be a full-time caregiver for her mother.

Stan cared for his wife over the course of 15 years. There was never a question that he would make sure she was given proper care. To meet her ever-changing needs, Stan implemented a plan of trial and error:
I put up a rail that led to the bathroom. I knew she would need help walking. I knew she was independent. And when she couldn’t do that, I thought well that didn’t help. So, I bought a portable commode. She put up some resistance at first, but it was a life saver. At night, I did not have to peel out and take her to a bath. When that was no longer possible, I made it possible. Made her get up and go to the toilet bowl. She was sad. I bought her a walker later to keep her from falling. She did fall with that a couple of times. But she didn’t like that, but I bought a really nice one; it folded down very easily, and she grew to like it. Some of the things I tried that didn’t work are reading in bed, and lights and her books and that sort of thing. They didn’t work. So, I was always trying stuff like that....

**Support systems.** Even with the active role that all participants played in their loved one’s care, it was obvious that none of them were able to carry the burden of care alone. They sought help with tending to the physical needs and well-being of their loved one as well as emotional support for themselves as caregivers. To address the critical needs of their loved one, some participants hired outside help, either to give them respite, help them with medical care, or to be an additional set of eyes when care recipients lived in facilities. For example, Tracy described her father’s aide as her “spy” that would make sure he was being treated well at the nursing home. Matthew also considered his mother’s aide as an additional set of eyes at her care facility. His mother is an immigrant whose first language is Spanish; therefore, he felt more comfortable with his mother having a Spanish-speaking companion to keep her company during the day.

In addition to hiring aides, participants that could rely on family to take on some of the care responsibility found the experience more manageable. Examples were Betty and Tracy, whose siblings discussed care needs and shared care responsibilities. Tracy said the following about how she and her siblings work together to care for her father:

We were realistic and all on the same page, the siblings, me and my brother and sister about the financial impact. We all felt the same way about my father, which was he came first and everything else was
secondary. I think because we were consistent in our approach as a family, I think that made things much, much easier, it that it was easy.

However, not all families shared caregiving needs. For example, although Sarah has many siblings, she said, “I didn’t know that the load was going to be totally mine.” She added, “I felt like some of the responsibilities would be distributed among my family, but a lot of people backed out when the need got greater.” Much like caregivers that lack family support, Sarah reported higher levels of stress.

While care for their loved ones was a primary focus of their efforts, participants also addressed the challenges of taking care of themselves while in these demanding roles. At times participants said they would vent to friends to relieve some of the stress. Others found that they needed friends and family to make them feel as though they were making proper decisions in their loved one's care. For example, Theresa noted that she would talk to her sister or others that have been through similar situations. She would ask people for feedback when she questioned her actions as a caregiver. This helped to reassure her that she was acting appropriately and taking good care of her mother-in-law.

**Physical and emotional effects of caregiving.** Theresa’s need for reassurance, as well as the need for all caregivers to seek out support in one way or another, for some, foreshadowed the ways caregiving affected them emotionally. All participants described numerous emotions related to caregiving, none of which were positive. They included feeling obligated and stuck; feeling stressed, frustrated, and overwhelmed; feeling like a failure or like the “bad guy”; and feeling hurt, angry, and sad. Lily described the situation as “very stressful, the whole situation is stressful. But it’s also painful because you see your loved one going through so many changes and losing so much of their life.”
Stress, as illustrated by the previous quote, was the term used most often. Participants said that they were stressed for many reasons, including not having a life outside of being a caregiver and having trouble maneuvering the personality changes of the care recipient. Both hiring additional aid and gaining insight from individuals who had similar experiences, as discussed above, offered caregivers the means to address these issues. However, the effects of caregiving also manifested in physical ways.

When asked if their health had changed due to caregiving, the participants readily identified some of the changes that had occurred. The most noted changes were weight gain and lack of sleep. Participants like Laura and Matthew found that they had much less time to exercise since becoming caregivers, and Teresa admitted to eating more junk food since her mother-in-law moved into her home. Some of the more serious effects included Theresa grinding her teeth at night to the point of cracking one of her teeth and needing a root canal.

Even those participants who denied that caregiving affected their health offered details that countered those statements. For example, Tracy said that she did not believe her health had deteriorated since taking over her father’s care but sought a doctor’s help when she believed she was having a heart attack. She underwent three stress tests on different occasions. Another participant, Daisy, did not believe that caring for her husband had affected her health, but shortly after placing him in a facility she suffered a heart attack.

**Information Need and Seeking Intentions**

As was discussed in Chapter 2, people regularly realize that there is a difference between what they know and what they need to know. Participants were asked if they had any previous experience with or knowledge of AD that would offer them insights into what being a caregiver would be like. Responses indicated that previous experience and knowledge did not necessarily
equate to being prepared for caregiving. With few exceptions, participants did make a conscious effort to acquire information in response to their need or gap in knowledge.

**What is known.** Roughly half of the participants expressed that they knew about AD and caregiving before becoming caregivers themselves. The knowledge they held came from having a family member who was previous caregivers or having AD, prior employment where they bore witness to AD, or knowledge of organizations that deal with AD in some fashion. Theresa, for instance, once worked for a grocery store that required her to deliver groceries to an Alzheimer’s institute. As a caregiver, she often tries to incorporate some of the activities she witnessed with her mother-in-law. Theresa also mentioned her familiarity with the resources offered by the Council on Aging in her city. Another participant, Emily, learned about the financial benefits of having long-term care insurance for her mother through her previous employment as a licensed insurance agent.

Some of the participants had additional relatives who had AD years before them becoming caregivers. Sophia, currently caring for her mother, was close to a grandmother who had AD, and her mother-in-law had AD. Having the previous experience with AD helped her recognize symptoms of the illness with her mother. Tracy’s parents cared for her grandmother in the home for as long as they could. When the symptoms of her AD become too difficult to care for in the home, she was moved to a facility with a ward that specifically cares for individuals with AD.

**What is not known.** All but two of the caregivers addressed a range of topics that they were unfamiliar with before becoming a caregiver. The topic most readily discussed was medical care. Unfamiliarity with navigating some of the more complicated medical issues care recipients have would be difficult for most people who are not trained in the medical field. Examples of
problems that needed to be addressed included cleaning bed sores, identifying cuts that needed stitches, and inserting a PICC line when needed. Participants were able to meet this need by speaking with doctors, friends who were medical professionals, and home health and hospice workers.

Slightly more than two-thirds of participants noted that the financial issues involved with care were unknown to them. Stan and Tracy, although financially secure, said that others needed to be aware of how expensive care can be for a family caring for someone with a long-term illness. About a third of the participants were aware that they did not have a great understanding of the financial situation. For example, Rose was unsure that Medicare and Social Security benefits would be enough to cover all the costs of her father’s care. She contacted a representative at the U.S. Department of Veterans Affairs to find out if he was entitled to benefits as a veteran. Matthew’s greatest concern was that he would not be able to afford long-term care for his mother. He sought legal advice from a geriatric attorney who provided beneficial information about paying for a facility for an indefinite amount of time.

More than a third of the participants also were unaware of the potential changes in personality that their loved one could possibly undergo. This was even the case for Sophia, who believed she was adequately prepared because of previous experiences with AD:

She would always tell me in the beginning, please forgive me, please forgive me and I love you no matter what mistake I make, I'm sorry…. I keep that in the back of my mind, and when you're angry in the moment, it's kind of hard not to be angry, and I asked her, why are you treating me like this and I'm trying hard to help you.

Participants also recognized that it may be difficult for them to know what their information needs might be because it was not necessarily clear to them what they did not know about caregiving and care recipient needs. Theresa and Stan noted that it is sometimes difficult to
know what information is available to you when it is unclear what information is needed. There is the potential that the information you are seeking does not exist. A great deal of the gap in participant knowledge was filled during the information seeking process. Caregivers learned from the hands-on nature of caregiving and learned what their needs were during the process.

**Caregiver need to fill the gap in knowledge.** All but one participant agreed that they proactively sought out help in learning ways to meet the specific needs of their loved ones, like wound care and proper nutrition. More than two-thirds of the participants spoke of wanting to learn about facilities and the potential of hiring individuals to help with care. Participants such as Sarah searched for home health aides or agencies that could provide her with respite care. Natalie and Sophia searched for facilities that catered to individuals with AD because they knew that they would be unable to have their loved ones live with them full time. Two participants discussed their concern with finding information about interacting with the care recipient. For example, Logan wanted to know how to interact with his father.

Other participants did not believe that their gap in knowledge could be filled through information seeking. About a third of the participants believed they did not need to seek out much information about AD because their previous lived experience was adequate in preparing them to become caregivers. Participants like Sophia and Stan were the most vocal about having little need to do research. Sophia was adamant that she learned everything necessary to be a caregiver from having direct experience or having lived with other relatives diagnosed with AD, but also admitted that she does not take the time to do research anymore because it depresses her to know that there is no cure. Stan admitted that one of his least endearing traits is thinking he can learn anything on his own without asking for help or doing much research. This is one of the
reasons he did little research; however, he also admitted that he most likely avoided seeking information when his wife was first diagnosed because he was in denial.

Regarding their need to find information to help alleviate the emotional effects of caregiving, about two-thirds of the caregivers sought emotional support from others. A significant subset did not. Six of the participants were somewhat different than the other participants in that they were encouraged to seek support strictly to learn to provide better care for their loved ones. They mostly referred to the physical things that needed to be addressed. Their emotions were secondary to the care of their loved one, whereas other participants discussed their emotions in tandem with being a caregiver. Therefore, although these participants found the situation to be as stressful as other participants, they were not in search of emotional support. In both instances, however, a need was addressed.

**Sources of Information and Preference**

Participants offered nine sources of information that they tended to utilize when they were seeking information: looking for information on the internet, talking to medical professionals, talking to family or friends, reading books, reading magazines, newspapers, and articles, watching informational videos/movies/TV, obtaining information from organizations, calling for info/help, and obtaining info passively. The sources that were used most often are highlighted next.

Nearly every participant mentioned utilizing the internet for a specific or general search at one point during their time as a caregiver. Only one participant, Daisy, never utilized the Internet. She noted that she could ask others for information if needed. For a general search, Natalie noted that she initially did all her research online. When referring to her search for a care facility to place her mother-in-law, Natalie said that once she had accumulated enough
information from the Internet, she would call specific facilities for additional information or make appointments. When utilizing the Internet, participants tended to visit websites that they found to be credible. Emily, Lily, and Logan mentioned they would use medical websites like the Alzheimer's Association, the National Institutes of Health and Mayo Clinic, or websites that ended in .org. Not only did they utilize these sites because they found them credible, but it was also a way to reduce the amount of information they had to sift through. Logan noted that there was an incredible amount of information online related to the topic, so he visited certain websites to make it easier to find pertinent and credible information.

The Alzheimer's Association not only was an online resource utilized often, it also was a good source for informational workshops, emails, and pamphlets. Betty mentioned that she receives daily emails from the Association. Emily said that after her mother was diagnosed with AD, she began attending the Alzheimer’s Association for their “Lunch and Learn at Noon” to hear guest speakers, watch informational films, and attend classes.

Although television and movies were not the most sought-after source of information, it did offer some participants insight into the illness. For example, Stan mentioned two occasions when watching television was beneficial to his situation. He said that he and his wife watched TV together often, and she enjoyed a show entitled “Midwife.” There was an episode about a nun having AD. He found that he learned as much from the nun’s treatment on television as he learned from anything else. Stan also mentioned a commercial for a dementia medication:

I’ll never forget there was a commercial on, and I think it was for dementia medication, uh, and the husband’s being interviewed and he, and he says, tears in his eyes, ‘We know we didn’t argue more than two or three times the whole time we were married. We argue every day.’
In reflecting on his relationship with his wife as her caregiver, he said that the commercial was meant to be “informative,” but for him, it was "reassuring" because their relationship changed as his wife’s illness progressed.

Speaking with other people appeared to be a preferred source of information. As previously mentioned, participants received a substantial amount of information from medical professionals. For example, Rose said that she was always there to ask doctors questions. This not only allowed her to find out pertinent information, but she was able to ensure that her mother received the best care possible, despite her age and diagnosis. She also followed up with her friend, a doctor, to make sure other medical professionals were appropriately caring for her mother.

Like Rose, others utilized friends and family members in the healthcare industry as resources. For example, one participant had a sister who was a nurse. Another would speak to friends, who were counselors by profession, for advice about his anger regarding the situation. Family and friends who were not medical professionals, but had personal experience caring for someone with AD, were also utilized for information. Lily relies on advice from others:

Talking to someone who lives it every day and has been there from day one – how can you not trust that? You know what I mean? What do they gain from telling you anything that’s not true?

Participants were also able to obtain helpful information from others when they were not actively in search of it. For example, Stan found additional help for his wife by word of mouth. An acquaintance told about someone they felt would be helpful to him in caring for his wife. Daisy learned about a product from her daughter. The product allowed Daisy to worry less about her husband falling while attempting to get out of bed. Although she would never have thought
to research such a product on her own, it allowed her to relax more often and gave her more independence to move around the house without constantly worrying about her husband.

In contrast, at least one participant did not find all passively gained information helpful. Olivia noted that although the hour and a half she spends at a support group does help, at times she is offered information that she was not seeking, nor is she happy to learn. She noted that others offer information so that you will have a better understanding of how to handle certain situations as they arise in the future. This is, at times, problematic for Olivia because she would prefer not to know of some of the problems she may encounter while caring for her husband. Learning about problems that may or may not occur in the future created unnecessary stress for Olivia.

**Responses to Information Seeking**

This theme directly relates to answering research question four, which asks whether information seeking adds to caregiver stress levels. In discussing their information-seeking experiences, participants had both positive and negative responses regarding their experiences in information seeking. Some participants found comfort in what they learned, but others had less than positive experiences. Some of the more problematic experiences discussed were due to poor interactions with human resources.

**Positive responses.** Both Stan and Emily found that information was helpful in that they were able to learn practical things to aid the care recipient. Other participants also felt as though they either found or were given information that made them feel more prepared and capable of caring for their loved one. For example, Matthew found that meeting with the geriatric attorney was most helpful in starting the process of gaining long-term care for his mother. Stan noted that although there were moments when he felt as though he was failing at caring for his wife, he
would also find happiness in the evidence that he was learning skills to better care for her. Overall, addressing task-related information needs was reported as positive because they were able to find answers to their questions.

Other participants offered similar sentiments to Stan. Both Lily and Logan stated that being able to find the information you need is comforting. They noted that it makes you feel better to acquire additional skills for caregiving, but you also discover that others are going through similar experiences. Logan added that it made him feel optimistic and encouraged to know that people are working on finding a cure for AD. Therefore, finding information on practical matters helped them to feel more competent in their roles as caregivers, addressing their own emotional needs.

**Negative responses.** The wealth of information available to caregivers also has negative connotations. In general terms, some participants noted that knowing what information is relevant may be difficult. For example, Logan and Lily believed that the amount of information can be overwhelming, and because every case is different, it is difficult to know what information may pertain to your situation. Logan also noted that some information may be difficult for some people to understand.

Outside of having difficulty seeking information from mediated resources, many participants relayed negative experiences when information came via human interaction. Some participants described poor patient-provider communication. It is unclear if the caregivers had difficulty communicating their needs, or if provider communication style needs to be adjusted in order to be empathetic during such a stressful experience as caring for someone with AD.

Natalie, in her search for a facility in which to place her mother-in-law, was frustrated by what she considered to be a lack of communication on the part of facility employees. Although
Natalie said she clearly communicated the fact that her mother-in-law had AD, the representatives were only concerned with scheduling her and her husband for a tour of the facility. Instead of understanding what Natalie’s needs were and informing her that they were not able to meet those needs, Natalie said that the little time she had was wasted on touring facilities that were not a good fit.

In other instances, participants described what they considered a lack of empathy. Sarah and Stan both commented on the negative interactions they had when seeking information. When Sarah asked the Department of Veteran’s Affairs to complete an assessment of her father in order to receive benefits for his medical expenses, she was shocked by some of the questions. She was asked, "Do you sometimes feel like you wish the person you are taking care of would die?" She described that question as being "cruel." The interaction, which she deemed callous, reinforced her decision that no one would care for her father the way that she could. Stan, who was already leery of seeking outside help, recalled interactions with a neurologist, who specializes in dementia:

The process of diagnosing and talking about dementia to my wife… almost as if, I would say, they didn't know how to deal with it. They haven't learned. They were a little flippant, especially him, the doctor. They offered help mainly medical… And then when we went to Houston, to find out if the surgery could be done. And they put her through the same sort of thing and naturally far more extensive. ...and then the first person you see is a resident and then you get to see an expert, and she tells you that you can't have the surgery and doesn't say a word about dementia. So she knows...none of which was any help. And, uh, so and Judy was certainly cognizant enough to be really angry about the whole experience. She didn’t go back to Baylor Medical Center ever again.

Stan found that getting information related to dementia was “the most stressful.” He said it was important for him and his wife to learn how to deal with each other, but that type of information
was difficult to find. When he realized there was no information available that would help him
deal with his wife’s emotional anguish, he stopped looking altogether.

**Turning a negative into a positive.** Many participants reiterated the concept of being
persistent in seeking information to provide the best possible care for their loved one. Thus, one
participant was able to turn a negative experience into positive results through perseverance in
information-seeking. Lily offered an anecdote that best described this concept. She received two
coupons from a doctor for a three-month trial of a new blood-thinning medication for her mother.
She attempted to use the coupon code online but made an error and was told that she could not
receive the medicine. Lily initially panicked because of the medication’s high cost. Instead of
choosing to stop at that point, she called the company and was able to speak with a person she
found to be helpful. In the end, she was able to obtain the medicine for far less than the initial
cost. Lily said, “So don’t take no for an answer.”

**Summary of Findings**

Being an informal caregiver of someone with AD is a challenging experience. Meeting
the needs of the care recipient requires caregivers to process an abundance of information. At
times, having previous experience with AD meets some of those information needs, but often it
does not. As caregivers continue to go through the various experiences of caregiving, they not
only recognize what their information need is regarding care, but also regarding their own
physical and emotional health. Not everyone believes that information is available to meet those
information needs, but those that do turn to information resources for help are met with an
abundance of information. Caregivers must determine what information is relevant to their
situation, and relevance may change during the timeframe that care is provided. Responses to
information are as varied as the number of resources available. While some participants found
comfort in knowing that there was information available to help them provide better care for their loved ones, others felt that the professionals who were supposed to provide help and information created more stress and emotional anguish than anticipated.

Many of the topics explored in this qualitative analysis were used as a guide to develop the quantitative survey, which is discussed next. Exploring the topics with the survey potentially allows greater generalizability of the qualitative findings. As such, the quantitative results will not only seek to answer the remaining RQs and hypothesis, they will also be used to compare with the qualitative findings.

**Findings from the Survey**

As was discussed in Chapter 3, a survey was conducted to assist in the interpretation of qualitative findings. Some survey questions were included to explore the subject matter among a larger number of the population, as well as directly address certain questions this study sought to answer. The survey specifically sought to answer RQ1a, RQ3, RQ4, RQ5, and the posed hypothesis. This following section will first address the characteristics of those who participated.

**Participant Characteristics**

A total of 74 participants completed the survey. Participants ranged in age from 30-87 years, with a mean age of 61.13 (SD = 12.08). Slightly more than 85% were women, and nearly 73% were white. Additionally, roughly 35% obtained a master’s degree or higher (Table 2). All participants were current or former informal caregivers, with participants being equally distributed between the two groups. The average number of years that participants were caregivers was 5 (SD = 3.73). Adult children accounted for about 43% of the participants, with a spouse or partner making up the second largest group at 28.2% (Table 3).
Table 2. Survey Participant Characteristics
Total N=63

<table>
<thead>
<tr>
<th>Age</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean years (SD)</td>
<td>61.13 (12.08)</td>
<td></td>
</tr>
<tr>
<td>Median years (range)</td>
<td>62 (30-87)</td>
<td></td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>Percent</th>
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<tr>
<td>Female</td>
<td>54</td>
<td>85.7</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>14.3</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Educational Background</th>
<th>N</th>
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<tbody>
<tr>
<td>Less than a high school diploma</td>
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<td>1.2</td>
</tr>
<tr>
<td>High school diploma</td>
<td>9</td>
<td>14.3</td>
</tr>
<tr>
<td>Associate degree</td>
<td>2</td>
<td>3.2</td>
</tr>
<tr>
<td>Some college</td>
<td>10</td>
<td>15.9</td>
</tr>
<tr>
<td>4-year college degree</td>
<td>19</td>
<td>30.2</td>
</tr>
<tr>
<td>Master’s degree or higher</td>
<td>22</td>
<td>34.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race or Ethnic Identity</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African American</td>
<td>10</td>
<td>16.1</td>
</tr>
<tr>
<td>White</td>
<td>45</td>
<td>72.6</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>3</td>
<td>4.8</td>
</tr>
<tr>
<td>Native American or American Indian</td>
<td>1</td>
<td>1.6</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>4.8</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>5</td>
<td>7.9</td>
</tr>
</tbody>
</table>

Table 3. Relationship of Caregiver to Care Recipient
Total N=78

<table>
<thead>
<tr>
<th>Relationship to Care Recipient</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Child</td>
<td>34</td>
<td>43.6</td>
</tr>
<tr>
<td>Spouse / Partner</td>
<td>22</td>
<td>28.2</td>
</tr>
<tr>
<td>Parent</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Grandchild</td>
<td>4</td>
<td>5.1</td>
</tr>
<tr>
<td>Friend</td>
<td>3</td>
<td>3.8</td>
</tr>
<tr>
<td>Sibling</td>
<td>3</td>
<td>3.8</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>6.4</td>
</tr>
</tbody>
</table>
Participant Information Needs and AD Stage

Participants were given a list of 13 items related to AD. AD presents in three stages: mild (early stage), moderate (middle stage), and severe (late stage). Participants were instructed to indicate at which point during their loved one’s stages of illness they may have sought information about each topic. Clinical aspects of AD, prescriptions/medications, and changes in the care recipient's personality were the topics for which participants sought information the most frequently. Taking care of one's health and getting financial assistance were the two topics with the fewest times being researched. Additionally, participants sought information for the most topics during the moderate stage of AD. The stage with the second most topics searched was the mild stage, followed by the severe stage with the fewest searches (Table 4).

<table>
<thead>
<tr>
<th>Caregiving Topic</th>
<th>Mild (Early Stage)</th>
<th>Moderate (Middle Stage)</th>
<th>Severe (Late Stage)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Aspects of AD</td>
<td>37 (43.5)</td>
<td>43 (50.6)</td>
<td>16 (20.0)</td>
<td>96 (9.2)</td>
</tr>
<tr>
<td>Hereditary nature of AD</td>
<td>30 (35.3)</td>
<td>32 (37.6)</td>
<td>12 (14.1)</td>
<td>74 (7.1)</td>
</tr>
<tr>
<td>Help communicating with your loved one</td>
<td>22 (25.9)</td>
<td>40 (47.1)</td>
<td>19 (22.4)</td>
<td>81 (7.8)</td>
</tr>
<tr>
<td>Managing care recipient behavior</td>
<td>28 (32.9)</td>
<td>43 (50.6)</td>
<td>17 (20.0)</td>
<td>88 (8.5)</td>
</tr>
<tr>
<td>Prescriptions/medications</td>
<td>38 (44.7)</td>
<td>39 (45.9)</td>
<td>13 (15.3)</td>
<td>90 (8.7)</td>
</tr>
<tr>
<td>Safety at home</td>
<td>28 (32.9)</td>
<td>45 (52.9)</td>
<td>13 (15.3)</td>
<td>86 (8.3)</td>
</tr>
<tr>
<td>Managing your emotional ups and downs</td>
<td>18 (21.2)</td>
<td>40 (47.1)</td>
<td>18 (21.2)</td>
<td>76 (7.3)</td>
</tr>
<tr>
<td>Taking care of your health</td>
<td>14 (16.5)</td>
<td>32 (37.6)</td>
<td>17 (20.0)</td>
<td>63 (6.1)</td>
</tr>
<tr>
<td>Getting financial assistance</td>
<td>12 (14.1)</td>
<td>34 (40.0)</td>
<td>16 (18.8)</td>
<td>62 (6.1)</td>
</tr>
<tr>
<td>Changes in your loved one’s Personality</td>
<td>27 (31.8)</td>
<td>47 (55.3)</td>
<td>20 (23.5)</td>
<td>94 (9.1)</td>
</tr>
</tbody>
</table>

Table 4 (continued)
Sources of Information and Preference

Participants were given a list of 11 resources that they may have utilized when seeking caregiver information. They chose all the resources that they used and had the option of adding a source that was not on the list. Of the 11 given resources, medical professionals ($n = 67, 90.54\%$) and family and friends ($n = 59, 79.73\%$) were the most frequently used. The resources least utilized were smartphone apps ($n = 5, 6.76\%$), television ($n = 8, 10.81\%$), and religious organizations ($n = 9, 12.16\%$). Eleven (14.86\%) participants specified other resources that they utilized which were not listed in the survey. Examples included an insurance company, health fair, hospice, caregiver agency, own education, and YouTube (Table 4).

Table 5. Resources Utilized when Seeking Caregiver Information

<table>
<thead>
<tr>
<th>Medical Professionals</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family and Friends</td>
<td>59</td>
<td>79.7</td>
</tr>
<tr>
<td>Illness-specific Websites</td>
<td>43</td>
<td>58.1</td>
</tr>
<tr>
<td>Books and Magazines</td>
<td>35</td>
<td>47.3</td>
</tr>
<tr>
<td>Support Groups (online or face-to-face)</td>
<td>33</td>
<td>44.6</td>
</tr>
</tbody>
</table>

Table 5 (continued)
<table>
<thead>
<tr>
<th>Source</th>
<th>N</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness-specific Organizations (in person)</td>
<td>28</td>
<td>37.8</td>
</tr>
<tr>
<td>Social Media</td>
<td>16</td>
<td>21.6</td>
</tr>
<tr>
<td>Newspapers</td>
<td>13</td>
<td>17.6</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
<td>14.9</td>
</tr>
<tr>
<td>Religious Organizations</td>
<td>9</td>
<td>12.2</td>
</tr>
<tr>
<td>Television</td>
<td>8</td>
<td>10.8</td>
</tr>
<tr>
<td>Smartphone App</td>
<td>5</td>
<td>6.8</td>
</tr>
</tbody>
</table>

**Information Seeking and Stress**

Participants were divided into three groups (low, medium, high) to understand better their information seeking behaviors. There was a potential for each participant to have completed 14 information searches, one for each topic during each stage of illness. If the participant completed 1-5 searches, they were labeled as a low-level information seeker (n = 7, 9.6%). If they consulted 6-10 sources, they were labeled as a medium-level information seeker (n = 14, 19.2%). If they consulted 11-14 sources, they were labeled a high-level information seeker (n = 52, 71.2%).

Initially, a Pearson correlation was calculated examining the relationship between participants’ level of information seeking and perceived stress. A weak correlation that was not significant was found (r (49) = .153, p > .05). Information seeking does not appear to be correlated to caregiver’s perceived stress levels.

Although there was no correlation, the groups were then included in an analysis of variance (ANOVA) to test whether there was a difference among levels of information seeking and perceived stress levels. This analysis revealed a significant effect for perceived stress levels, $F(2, 48) = 3.90, p < .05$, partial $\eta^2 = .14$. As Table 6 shows, participants with low levels of information seeking were significantly less likely to have perceived stress than medium level information seekers. Significant differences in means are indicated by using different subscripts.
Multiple variables have been considered as factors in the relationship between information seeking and perceived stress levels. Specifically, this study seeks to find whether emotional state or health literacy moderate the relationship between information seeking and perceived stress levels. To test these relationships, first a multiple linear regression was calculated to predict participants’ perceived stress level based on information seeking level, health literacy, emotions while seeking information, and self-efficacy in information seeking. The results of the regression analysis indicated the four predictors generate a significant regression equation, \( R^2 = .56, F(5,41) = 10.21, p < .001 \). Of the four variables, emotional state \((\beta = .52, SE = .11, p < .001)\) and self-efficacy \((\beta = -.34, SE = -.21, p < .01)\) were found to significantly predict participants’ perceived stress level (Table 7).

Table 7 also shows that an interaction term, health literacy, was included in the regression model to further explore the relationship between information seeking and perceived stress levels. Health literacy, which was positioned as a moderator between information seeking and perceived stress fell short of statistical significance, \((\beta = 1.08, SE = .31, p > .05)\).
Next, a 2 (Health Literacy) x 2 (Self-efficacy) ANOVA was conducted to test hypothesis 1, which posited that informal caregivers with low health literacy and low self-efficacy would have increased stress levels and those who have high health literacy and high self-efficacy would have decreased stress levels. The hypothesis was partially supported. The analysis revealed no main effect for health literacy, as participants with low health literacy ($M = 3.05$, $SE = .16$) did not significantly differ from participants with high health literacy ($M = 2.91$, $SE = .22$) in their levels of perceived stress, $F(1. 44) = .243$, $p>.05$, partial $\eta^2 = .01$. However, a main effect for self-efficacy was revealed. Participants with high self-efficacy ($M = 2.63$, $SE = .11$) were significantly more likely to have lower perceived stress levels than participants with low self-efficacy ($M = 3.33$, $SE = .25$), $F(1. 44) = 6.48$, $p<.05$, partial $\eta^2 = .13$. There was no significant interaction between health literacy and self-efficacy, $F(1. 44) = .884$, $p>.05$, partial $\eta^2 = .02$.

**Summary of Findings**

A total of 74 current and former informal caregivers completed the survey. Participants averaged five years as a caregiver, and they sought the most amount of information during the moderate stage of AD. Medical professionals and family and friends were their preferred source of information. Findings showed no correlation between information seeking and perceived stress.
stress levels, but there was a significant difference between the perceived stress levels of low-level information seekers and medium-level information seekers.

Among four variables, including information seeking level, health literacy, emotional state, and self-efficacy, only emotional state and self-efficacy were significant predictors of perceived stress. The inclusion of the interaction term, health literacy, showed that it was not a significant moderating variable between information seeking and perceived stress levels. A factorial ANOVA was then used to test H1, which showed a significant difference between participants with low and high self-efficacy.
CHAPTER 5
DISCUSSION

The initial intent of this assessment was to discern whether information seeking is an effective coping strategy of informal caregivers of individuals with AD that reduces their stress levels. As Washington et al. (2011) noted, obtaining the information and education necessary to care for an adult experiencing a chronic health condition is an unmet need that must be addressed. By utilizing a sequential exploratory strategy, a broad range of data were collected from AD informal caregivers which covered a wide variety of topics related to the effects of caregiving and the information-seeking strategies the participants used. A survey instrument was generated to investigate further the themes found in the exploratory qualitative data, as well as directly address the research questions and hypothesis that would best be addressed using quantitative analyses.

This chapter will address findings from the study in relation to previous research, and to directly address posed research questions and hypothesis. To do so, the discussion of key findings is organized in line with the study’s research questions and hypothesis. Following the discussion, implications and recommendations, limitations of the study, and suggestions for future research.

Motivating Factors of Information Seeking

Qualitative results of this study confirm findings from previous research regarding information seeking. Lambert and Loiselle (2007) found that information need is not enough to prompt information seeking. They, as well as others, noted that the type and amount of information sought are prompted by need just as much as by personal and situational factors. It was apparent that interview participants were influenced by their personality traits, expectations, goals, attitudes, emotions, skills, and resources. Additionally, although the participants were
demographically different, they shared a similar situational factor – caring for someone with AD. In general, learning how to deal with the diagnoses of AD prompted information seeking.

The topics participants searched for the most were clinical aspects of AD, changes in your loved one's personality, help communicating with your loved one, and prescriptions/medications. The qualitative findings support these results. Interview participants who cared for their loved ones in the home constantly sought information regarding medical topics. None had a medical background, making it necessary to learn about caring for the clinical aspects of AD. Additionally, personality changes were of concern to interview participants.

Participants easily identified the information need they had regarding the practical nature of care. For example, they discussed the need for wound care, financial assistance, and toileting. The emotional element of caregiving was less recognizable as an overt impetus for seeking information, but it was no less a factor. Participants readily expressed the emotional effects of caregiving, and information seeking was used to minimize those negative emotions. For example, hiring home health aides offered an extra level of care for the care recipient, but it also had the potential to relieve caregiver stress levels. Additional help allows for caregivers to have time away from home and may offer an additional resource for learning caregiving skills.

Personality traits, attitudes, and goals also influenced caregiver information seeking. Personality traits and attitudes produced a dichotomy of information-seeking intentions. Participants who felt that they had enough previous experience or could learn most things on their own were less inclined to look for information than others. As with the other participants, they would seek out information if they were trying to meet a goal, but otherwise, they tended to believe that searching for information would not be helpful. Research has termed this phenomenon mastery goals, which is when individuals are motivated to become competent in a
skill, leading them to purposefully seek out new knowledge in order to meet this goal (Barron & Harackiewicz, 2001). When choosing not to seek information, participants’ attitude was that the difficult answers, like a cure for AD or how to help with unexpected personality changes, did not exist. The second school of thought was that all answers were available if one was persistent in searching for them. Often this attitude was applied to meeting a certain goal. For example, participants were motivated to look for home health aides or facilities when care became too difficult.

Other times participants would attend caregiver meetings or sign up for daily emails in case they would learn something helpful they were not aware they needed to know. One participant kept articles about caregiving and AD that she came across even if they were not applicable at the time in case it was information that would be helpful in the future. The nature of AD leads to uncertainty in what can be expected because as some participants noted, each situation is different. Obtaining as much information as possible may point to information seeking being a coping mechanism to attempt to maintain control, because as uncertainty management theory posits, uncertainty makes people worry about the amount of control they have in their life, as well as the quality of outcomes that could occur from their experiences (Van den Bos & Lind, 2002; Tangirala & Alge, 2006).

**Changes in Information Needs**

The qualitative analysis showed that participant information needs change based on care recipient needs. It was apparent that what information was needed and relevant from one day to the next could change. Although there is a three-step progression of AD, that progression is different for each care recipient. Additionally, the length of time for which they need care is different.
Based on the quantitative analysis, there was a need to search for each of the 13 topics listed on the survey during each stage of AD. Among the stages, however, there was a difference in the amount of information seeking as well. Participants searched for the most information during the middle stage and the least during the late stage. It would be fair to assume that as care recipient needs increase, information need would increase as well. There would be a greater potential for caregivers to come across situations and care needs with which they have not had prior experience. As the illness progresses into the late stage, caregivers like those in the study may no longer be able to provide adequate care. As such they may choose to place their loved ones in facilities that can better meet their needs. Locating such a facility would require seeking information, but once the care recipient is placed in an adequate facility, caregiver information needs would decrease due to less hand on care.

**Source Preference**

The interview participants were clear in the reasons why they chose to utilize certain resources. Although not definitively stated, the most significant reason was that they had trust in some resources more than others. Nearly every participant visited Internet sites at one point, and they geared their searches toward sites that they deemed credible. Many mentioned government and hospital websites. For a variety of resources and information, many visited their local Alzheimer’s Association, either online or in person. It offered them informational workshops, videos, emails, and pamphlets. Participant’s continued use of specific resources can be supported by the explanation Leckie et al. (1996) offer about an individual’s awareness of information sources and/ or the content they offer. They found the variables that need to be considered when exploring information seeking include familiarity and prior success, trustworthiness, packaging (convenience, usefulness, and others), timeliness, relative cost-effectiveness, and accessibility.
(relative ease of access). Regarding the nine resources listed above, it can be inferred that the participants were pleased with each of these variables. For instance, using a trustworthy website can be done at a convenient time and costs no more than a monthly subscription. Repeated use of a source speaks to participants having prior success, potentially due to easy access and site navigation.

Aside from mediated forms of communication, interview participants received an abundance of information through speaking with others. The findings support Anker et al. (2011) in their notion that information seeking does not occur in a vacuum. The participants found the information that they received through interpersonal communication just as helpful, if not more so than the information they received from mediated resources. This could be due in part to time and proximity. Ease of access was previously noted by Gollop (1997) who found that accessible information sources might be used more often than ones perceived as difficult to access (Gollop, 1997). Smith & Toseland (2006) found that online resources are especially helpful for caregivers who are often in the home, but it was clear that participants are in contact with healthcare professionals, family, or friends on a regular basis. The practical information that many of them received from home health aides and others who have had similar experiences offered them additional skills and comfort like what they received from visiting websites.

Speaking with others also offered a level of support that cannot be received from most forms of mediated communication. In some cases, interpersonal communication acted as a form of checks and balances to assure caregivers they were giving the best care possible. There was an element of trust that interview participants found in speaking with people who knew them, or who could speak to their personal experiences. Although participants routinely asked healthcare professionals for information, it did not always come from a place of trust. In fact, poor patient-
provider communication led to more than one participant to feeling angry or disappointed, or removing their loved one from a facility's care.

Television shows with realistic portrayals of people caring for others with AD, such as the Handmaid's Tale, were the closest form of mediated communication that was described as offering some comfort. At least one interview participant felt as though he learned from the care someone with AD was given on a television show, and he also found reassurance in a commercial that portrayed the changes in a marital relationship after the wife was diagnosed with AD. There could be many reasons for this finding, many of which have not been discussed in relation to this study. For example, he may have found the commercial reassuring because it reinforced ideas that he had regarding the changes in his marital relationship. Selective perception research indicates that people tend to avoid information that challenges their existing schemata and hence are more likely to interpret messages in accordance with their prior beliefs (Vidmar & Rokeach, 1974). He also may have felt he learned a lot from the episode on television because he perceived it as realistic. Corner (1992) pointed out that audiences often perceive a program as realistic if it deals with “real” issues even if it does so through fantasy.

**Information Seeking and Resulting Stress Levels**

Based on the quantitative data, no correlation was found between information seeking and perceived stress levels; however, the groups were then included in an ANOVA, revealing a significant effect for perceived stress levels, $F(2, 48) = 3.90, p < .05$, partial $\eta^2 = .14$. The relationship showed a significant difference between participants with low levels of information seeking ($M = 2.02$, $SE = .30$) and medium level information seekers ($M = 2.85$ $SE = .21$).

Although there was no overall correlation, it is possible that the amount of information seeking a caregiver undertakes may have an effect. Based on this analysis alone, one can not
speculate as to why low-level information seekers chose to search for information less than others, but one can speculate as to why they had significantly lower perceived stress levels than medium level information seekers. For instance, they may have had a smaller gap in their knowledge about caregiving, leaving them better prepared for caregiving. Another potential reason is that the care recipient did not have as great a need, lessening the burden felt by the caregiver. Alternatively, if these participants had lower levels of information seeking due to practicing avoidant coping, these findings are contrary to previous research. As previously discussed, Papastavrou et al. (2007) and Powers et al. (2002) found that when caregivers practice avoidant coping styles, it may lead to worse outcomes. If these participants did avoid information, it led to lower perceived stress levels than others.

The qualitative analysis both supported the quantitative findings and offered an alternative viewpoint not available from survey responses. Many interview participants easily found the information for which they searched. Some took comfort in knowing that there was information available to them that helped them become better caregivers. They also found relief in the support they received from friends and family. On the other hand, multiple participants noted the frustration they had in receiving information from some professional resources, such as doctors, and facility employees and administrators. Participants seemed to expect a level of empathy and consideration of their situation that they did not receive from some of these resources. These interactions added to caregiver frustration and stress, leading to one participant feeling like her time had been wasted, and another to stop visiting one doctor altogether. Additionally, receiving unwanted information through passive interaction was found to cause unnecessary stress.
These findings point to the possibility that the correlation between information seeking and stress levels is not as cut and dry as the quantitative analysis assumes. The way in which information is received may influence caregiver stress levels. This dynamic was not investigated in the survey.

**Health Literacy as a Moderating Variable**

Health literacy was not found to moderate the relationship between information seeking and stress. On the other hand, doing research on topics such as health information has the potential to increase the anxieties of people who have little or no medical training (White & Horvitz, 2009).

It is worth noting that interview participants did utilize various resources for information seeking, but they tended to rely on home health aides and other medical professionals for medical topics. They were able to receive hands-on experience while learning from others. This may have negated the anxiety that would be caused by trying to learn medical techniques from mediated sources. However, as the discussion section for RQ3 shows, poor interactions with medical providers could lead to increased stress.

**Health Literacy and Self-efficacy as Predictors of Perceived Stress**

It was hypothesized that informal caregivers with low health literacy and low self-efficacy would have increased stress levels and those who have high health literacy and high self-efficacy will have decreased stress levels. In general, the relationship was not significant, but there was a significant difference between participants with high and low self-efficacy.

Although an estimated 93 million Americans have either below basic or basic health literacy (Kutner et al., 2006), the amount of information available to consumers offers an array of outlets from which to find information that can be easily comprehended. Additionally, findings
showed that participants utilized many sources multiple times, suggesting trust and satisfying experience. Self-efficacy in information-seeking, on the other hand, may hinder someone from beginning a search or being persistent in finding alternative resources when one does not meet a need.

Although not originally hypothesized as a significant predictor of perceived stress, this was in fact the case for emotional state. The fewer negative emotions participants experienced while seeking information predicted lower perceived stress levels. These findings support previous research regarding health outcomes related to emotions and information seeking. As was discussed in Chapter 2, experiencing positive emotions after a health information search may encourage individuals to continue learning about ways to prevent health threats and may also lead them to share information, building relationships with others (Myrick, 2017).

Implications and Recommendations

It is important to keep in mind the population for this study: informal caregivers. In 2015, approximately 43.5 million caregivers provided unpaid care to an adult or child in 2015, with 34.2 million of those providing care to an adult age 50 or older (National Alliance for Caregiving and AARP, 2015). The number of individuals caring for someone over the age of 50 will only increase because an estimated 21% of the population will be at least 65 years old by the year 2030 (Colby & Ortman, 2015). Meeting the needs of those who care for others will not only help them provide better care, but it will go towards keeping themselves healthy in the process. Because obtaining the information and education necessary to care for an adult experiencing a chronic health condition is of the utmost importance to this population, this study offers significant contributions to the mass communication field, medical professionals, and those who cater to the aging community and their loved ones.
Mass communication professionals, especially those who relay health-related topics, have the burden of maintaining accurate and up-to-date information. When they fail to do so, the consequences can be more detrimental than under other circumstances. Participants seemed to be aware of what resources were more trustworthy than others, but the potential for seeking out alternative, less trustworthy resources exists when people are not able to find information that applies to their situation. Health communicators should willingly communicate new findings and information that may be deemed helpful to others. Health communicators should also continually network with each other in order to offer other trustworthy resources to those in search of information.

Additionally, as was illustrated in the qualitative analysis, realistic and accurate portrayals of illness on television and in the movies has the potential to be utilized as a learning tool. Even those who rely on newspapers, magazines, and trustworthy websites are privy to media representations. When the mass media is wise and responsible in representing specific phenomena, it helps people learn about health and minimizes the influence of unhealthy and unrealistic media portrayals (Pre, 2017). This is not a new concept in mass communication theory. Agenda setting, which refers to the idea that there is a strong correlation between the emphasis that mass media place on certain issues and the importance attributed to these issues by mass audiences (McCombs & Shaw, 1972), has been studied since it was introduced. Agenda setting theory implies that the mass media can shape the considerations that people make about health issues by making them more salient in people’s mind (Scheufele & Tewksbury, 2006).

For those who work in the medical profession, this study emphasizes the continued need for enhancing patient-provider communication. Although the e-health technology offers patients multiple opportunities for finding information and communicating with doctors, interpersonal
communication should remain a focus of doctors and others who encounter care recipients and their families. Medical professionals were the resource used most often by participants in this study, which is typical of most people. Unfortunately, this resource was also the one that caused the most frustration and stress.

Lack of empathy and miscommunication were reasons cited for the negative interactions. Participants described a desire for professionals to listen to their needs and act accordingly. They also expressed a feeling that doctors and other professionals lack empathy when asking questions and relaying pertinent information. Professionals who service this population, as well as any other population which experiences things of a sensitive nature, should take such concerns seriously. Effective communication is crucial to the success of any encounter. This is especially true in health care encounters because without it, patient concerns are not heard, proper diagnoses and decisions cannot be made, recommendations cannot be shared, and patients will be dissatisfied with their care (Pre, 2017).

Participants relied heavily on home health aides and hospice workers to help them learn better ways of providing medical care to their loved ones. This should encourage agencies and companies that provide these services to hire individuals who are adequately trained and who are effective communicators themselves. If either factor is not taken seriously, there could be negative consequences for the caregiver, the care recipient, or even the company for whom the aide works.

Illness-specific organizations, such as the Alzheimer’s Association, were spoken of highly. For those participants who utilized such services found them to be highly beneficial. Although this is a positive finding, it should be noted that each city has its own Alzheimer’s Association. Sometimes there are several in the same city. If a local organization is not diligent
in offering information to the population they serve, it would deprive that population of a reputable and rich source of information.

Finally, as previously discussed, a common aim of information seeking studies is to build models of information behavior which show how different factors or variables influence information seeking (Talja, Keso, & Pietiläinen, 1999). This study integrated Pearlin’s Stress Process Model (Pearlin et al., 1981) and prior research on health information seeking (Johnson, 1997; Leckie, Pettigrew, & Sylvain, 1996; Wilson, 1999). The study's moderation analysis showed no significant relationships, but health literacy and emotional state were significant predictors of perceived stress. Although neither variable is included among the six groups of variables used to predict outcomes in the Pearlin Stress Process Model, they should be taken into consideration when attempting to predict caregiver stress. Additionally, it has been well established that all caregivers experience burden, even if at varying levels. Giving focus to potential coping strategies, such as information seeking, would perhaps be of greater benefit to this population instead of focusing on stress as an input variable.

Health information seeking models would benefit from including emotional state. Other models refer to the characteristics of the information carrier (Johnson, 1997), the awareness one has of a resource based on previous experience (Leckie et al., 1996), and satisfaction and non-satisfaction with information sources (Wilson, 1999). By incorporating emotional state, researchers may gain a greater understanding of how negative affective responses to information resources, when added to burdensome situations, may affect health outcomes.

**Limitations and Suggestions for Future Research**

Execution of this research study posed inherent limitations. Given the qualitative nature
of the first portion of data collection, the findings are not generalizable to the greater population of individuals. However, generalizability was not the objective of the qualitative portion of the research. The intent was to obtain an overall view of the experiences and information-seeking tendencies of informal caregivers of individuals with AD.

A second important limitation was time, especially regarding the quantitative portion of data collection. Although the process to gain approval for collecting survey data was done in a timely manner, the actual collection of survey data began later than expected, limiting the length of time available to collect data. Wimmer and Dominick (2014) however, note that when research is done as a preliminary search for general concepts, a large sample size is not required.

This study is also limited in its selection of participants and focus on information regarding a specific illness. A convenient sample of participants was chosen during all stages of data collection, thereby neglecting to capture the experiences and tendencies of a more representative number of informal caregivers. The nature of AD makes each caregiver and care recipient’s experience different; therefore, the hope was to give an initial assessment of whether the information available to this population is adequate in helping them navigate the stressors of caregiving. The findings offer many opportunities for future research and evaluation in understanding how information seeking affects caregivers.

As described above, deeper investigation into the information-seeking tendencies of caregivers not only highlights their need for information and the resources they use but also offers insight into the important role of interpersonal communication and the implications of ineffective communication. Additional qualitative research regarding the effects of ineffective communication within the caregiving population would be beneficial. Consequences of such communication not only affects caregivers, but it affects care recipients as well. Findings would
offer further insights into best practices for those in the healthcare industry when dealing with such populations.

Although this study looked at a small sample of the caregiving population, it highlighted the potential effect of emotional responses to information seeking on information-seeking intentions and potential health outcomes. Future research may further investigate how emotional responses to varying resources and information motivate future health information seeking. Future research of this type may apply an experimental method or a larger sample size for a quantitative survey to gain a better understanding of the relationship.

Additionally, this study pointed to the potential of entertainment media as an educational tool for health-related issues. Future research in this area could potentially go in varying directions. For example, researchers can compare the accuracy of portrayals of different portrayals of AD. Such research would point toward both the level of understanding mass media has of different illnesses, as well as how that understanding and subsequent portrayals affect audiences. An additional way in which this phenomenon can be studied is through the lens of media effects to decipher whether incorporating more accurate portrayals of caring for someone with an illness is an effective learning tool for caregivers.

The qualitative results indicate the significant role that home health aides play during the caregiving process. Greater attention can be paid to the reliance that caregivers have on this population. Aides are not only treating the patient, but they are treating family members as well. Determining the practical and emotional benefits of utilizing home health aides, and the potential differences in their communication style compared with other health care providers may go a long way in pinpointing ways of reducing caregiver stress.
Finally, it would be beneficial for future researchers to analyze the composition of individuals who work for organizations such as the Alzheimer's Association. Because such organizations are a main resource of information for informal AD caregivers, understanding more about those who relay the information, and how they do so, would be beneficial to many. For example, if most employees of such organizations have not had first-hand experiences with AD, are they taught ways to empathize in order to communicate effectively? Such findings would offer tips on effective communication styles and optimal organizational development.

Conclusion

This study explored the lived experiences of informal AD caregivers, how those experiences motivate their information-seeking strategies, and whether the information-seeking experience helps in reducing their stress levels. An additional component was added to determine whether health literacy and emotional state moderated the relationship between information seeking and their perceived stress levels. A sequential exploratory strategy, which involved conducting qualitative interviews that were reviewed with thematic analysis, followed by a second phase of collecting survey data. This mixed method approach was used to answer the following research questions: 1) What motivating factors lead informal caregivers of people with AD to seek out information? 2) How do informal caregiver information needs change over the course of time that they are a caregiver? 3) Why do informal caregivers choose to utilize certain resources more than others during their information seeking process? 4) Is there a correlation between information seeking and resulting stress levels? 5) Does emotional state moderate the association between information seeking and stress? 6) Does health literacy moderate the association between information seeking and stress? The study also sought to investigate the following hypothesis: Informal caregivers with low health literacy and low self-efficacy will
have increased stress levels, and those who have high health literacy and high self-efficacy will have decreased stress levels.

Qualitative interviews were conducted with 15 current and former caregivers of individuals with AD. After identifying four emergent major themes (caregiver perceptions of care and its effects, information need and seeking intentions, sources of information and preference, and responses to information seeking), with accompanying sub-themes, the findings were used as a guide to develop the quantitative survey, which is discussed next. Exploring the topics with the survey potentially allow for greater generalizability of the qualitative findings.

In short, qualitative findings reveal that as caregivers navigate the various challenging experiences of caregiving, they recognize what their information need is regarding care, but also regarding their own physical and emotional health. Not everyone believes that resources are available to meet their information needs, but those caregivers who actively sought out information are met with an abundance of information. They must sort through that information to determine its relevance at the time. They tended to rely on mediated resources that they found to be credible, and interpersonal resources such as people who had similar experiences to their own. Many participants were satisfied with information available to help them provide better care for their loved ones, but others felt that their interactions with healthcare professionals created more stress and emotional anguish than anticipated.

Quantitative results supported qualitative results in showing that participant information needs change based on care recipient needs, meaning that information need could change from one day to the next. The greatest information need, however, was during the middle stage of the illness. Results also showed that overall, there was no correlation between information seeking and perceived stress levels; however, there was a significant difference between low-level
information seekers and mid-level information seekers. Additionally, neither health literacy nor emotional state moderated the relationship between information seeking and perceived stress, but emotional state was a significant predictor of perceived stress.

While stress process models deemed information seeking a mediating variable between stress and well-being, this study instead focused on the outcomes of information seeking. In the caregiving population, information seeking is a coping strategy that may reduce caregiver stress levels. Previous research has not sought to determine whether the current information available to this population meets their needs in a way that reduces the burden that develops as a result of their daily tasks. It is necessary to develop communication strategies that improve the quality of life for everyone, but the needs of specific populations differ. Having a comprehensive understanding of caregivers’ information needs can promote an improved quality of life for patients and caregivers alike (Washington et al., 2011).

This study offers an initial step in finding ways that mediated communication can meet the healthcare needs of those who attempt to fill their information needs. The study also reiterated the idea that in many cases, it is necessary to combine the efforts of mediated and interpersonal communication to have the greatest effect. By studying the information needs of the caregiving population, those who work in the healthcare industry, creators of mediated health communication, and organizations that directly deal with the aging population and their caregivers will be more knowledgeable about the relationship between information and stress. Considering the certain increase of the aging population, healthcare professionals and mass communicators alike must broaden their efforts to adequately provide the information and education necessary to care for an adult experiencing a chronic health condition.
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### Theme: Information Need and Seeking Intentions

**Subtheme: What is Known**
- Having prior knowledge/experience of illness
- Having knowledge of organizations/resources

**Subtheme: What is not known**
- Things CGs want to know
- Learning about financial info/Insurance
- Alternative treatment
- Not having prior knowledge/experience

**Subtheme: CG Need to fill the Gap**
- Not wanting/avoiding info
- Persistence in looking/asking for info
- Belief that they don’t need info/can do and learn on own

### Theme: Responses to Information Seeking

**Subtheme: Positive responses to Information Seeking**
- Feeling optimistic
- Believing that having information is important/comforting
- Having trust in people as sources
- Understanding the importance of knowledge and support
- Feeling prepared because of info
- Finding comfort in the doctor
- Finding comfort/benefit in info
- Finding info helpful

**Subtheme: Negative responses to Information Seeking**
- Not knowing what info is relevant/what to look for
- Finding that info can be overwhelming / difficult to understand
- Perceived disconnect with services/medical professionals
- Not knowing where to look for info

### Theme: Sources of Information and Preference

- Watching informational videos/movies/TV
- Obtaining info from orgs (meetings/ mail/ email)
- Calling for info/help
- Looking for info on the Internet
- Talking to a medical professional for info
- Talking to family or friends for info
- Reading books
- Reading magazines/newspapers/articles
- Obtaining info passively
- Having a source preference
- Having trust in people as sources

### Theme: Caregiver Perceptions of Care and its Effects

**Subtheme: CG Experience**
- Having additional duties outside of CG/ needing to prioritize
- Financial concerns/experiences
- Lack of time
- Not prepared for illness/progression
- Effects on relationships
- Difficulty in care
- Lacking emotional capacity

**Subtheme: Support Systems**
- Hiring/needling assistance/outside help
- Organizational support
- Family/friend support

**Subtheme: Physical and Emotional Effects**
- Negative emotional responses
- Physical responses
- Need for self-care
- Need to make sacrifices
APPENDIX B
INTERVIEW PROTOCOL

1) What is your relationship to the person you care for?
   a. What is their diagnosis?
   b. Are you their sole caregiver, or do you have additional help with their care?

2) What have been your experiences with caregiving?
   a. What event precipitated you starting the caregiving process?
   b. How long have you been a caregiver?
   c. What did you expect the experience to be like?
   d. What has it actually been like?

3) Have you sought out information regarding:
   a. Your loved ones’ illness?
   b. How to care for them?
   c. Other?

4) Can you describe why you decided to start seeking out information?
   a. How did it make you feel?
   b. What words would you use to describe the information seeking process as you have experienced it?

5) When your loved one was first diagnosed, what was the first information that you wanted to know?
   a. What was the first information source you utilized?
   b. How did the information you wanted to know change over time?

6) Where did you look for the information?
   a. Online?
   b. Medical professional?
   c. Friends?
   d. Social organization?

7) Do you have an online or offline support system?
   a. Is it helpful?
   b. How often do you communicate?
   c. What advice have you received?
   d. What advice have you shared?

8) Which resources have you found to be the most/least helpful, and why?

9) Did your method of information seeking change over time?
10) Explain why you feel that you have or have not been successful in finding the information that you have looked for during your time as a caregiver.
   a. Give examples of what information you were unable to find.
   b. What resources did you use?

11) Do you tend to seek out certain information from different sources?
   a. Why?
   b. Have you found some to be more trustworthy than others?

12) How would you classify your current health status?
   a. How has your health changed during your time as a caregiver?
   b. Do you find that your health status may be related to your caregiver status at times?

13) What do you do when your health declines?
   a. Have you ever sought out information about how to take better care of yourself as a caregiver?
   b. If you were offered such information, would it be of benefit to you?
   c. Do you think that caregivers, in general, would benefit from receiving information that specifically targets their health and well-being?

14) Did finding /not finding the information you were seeking reduce/increase your stress?

15) What other information would be helpful to you that you have not been able to find?
APPENDIX C
SURVEY INSTRUMENT

Thank you for your interest in participating in this survey. Nia Mason, a doctoral student at Louisiana State University’s Manship School of Mass Communication, is conducting the survey as part of her dissertation research, entitled: Assessment of Health Information Seeking as a Coping Strategy to Reduce the Stress of Informal Caregivers of Individuals with Alzheimer’s Disease and Other Forms of Dementia. This survey is designed to learn about the information needs of informal caregivers of individuals with Alzheimer’s disease and other forms of dementia. The study also is designed to learn about the resources used to meet those needs and how the process makes caregivers feel. Your information will be kept confidential and your name will not be associated with any of the answers in the study. There are no risks involved in the study, and you can stop participation at any time or refuse to answer any questions in the survey, without penalty or loss of any benefit to which you might otherwise be entitled.

This study has been approved by the LSU IRB. For questions concerning participant rights, please contact the IRB Chair, Dr. Dennis Landin, 578-8692, or irb@lsu.edu. If you have any additional questions about the content of this study, please direct them to Nia Mason at nmaso11@lsu.edu or Diane Francis at diane.francis@uky.edu.

Additionally, if you are seeking support or help with caregiving, contact the AARP at 877—333-5885 or Family Caregiver Alliance at 800-445-8106. For mental health services, contact The National Alliance on Mental Illness (NAMI) Helpline at 800-950-NAMI (6264), or the Substance Abuse and Mental Health Services Administration (SAMHSA) National Helpline at 800-662-HELP (4357).

You must be 18 years of age or older to complete the survey. By continuing, you are giving consent to participate in this study. If you are interested in participating, please answer the questions below and click "next" to begin the survey.

Do you agree to participate in this study?
No
Yes
Because this survey is designed for informal caregivers of individuals with Alzheimer’s disease and other forms of dementia (referred to as AD for the remainder of the survey), I would first like to ask you about your experiences as a caregiver. An informal caregiver is any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care.

Q1. How would you describe your caregiver status?
A) I am a current informal caregiver of someone with AD
B) I am a former informal caregiver of someone with AD
C) I have never been an informal caregiver of someone with AD

Q2. Complete the following question: The person I care(d) for would consider me their _____.
A) Spouse/partner
B) Parent
C) Sibling
D) Child
E) Grandchild
F) Cousin
G) Friend
H) Neighbor
I) Other (please specify) _________________________________

Q3. How many years have you been a caregiver for your loved one? (In years, please specify) __

The next set of questions inquire about experiences related to your relationship with the care recipient.

Q4. For each of the following tasks, indicate which you have assisted with DURING THE PAST MONTH. (Mark all that apply)
A) Transportation
B) Housekeeping
C) Shopping
D) Cooking
E) Decision making
F) Financial record keeping
G) Walking
H) Making house repairs
I) Yard work
J) Dressing
K) Bathing
L) Eating
M) Toileting
N) Administering medicine
O) Other (please specify) _________________________________
Q5. With regard to your situation being a caregiver, indicate to what degree you agree with each of the following statements: (1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) My activities are centered around care for my loved one  
B) I must stop in the middle of my work or activities to provide care  
C) I have removed things from my schedule since caring for my loved one  
D) The constant interruptions make it difficult to find time for relaxation  
E) I visit family and friends less since caring for my loved one  
F) Financial resources are adequate  
G) It is difficult to pay for caring for my loved one  
H) Caring for my loved one put a financial strain on me  
I) My family works together at caring for my loved one  
J) Since caring for my loved one, I feel my family has abandoned me  
K) It is very difficult to get help from my family members in caring for my loved one  
L) Others have dumped caring for my loved one onto me  
M) My family (brothers, sisters, children) left me alone to care for my loved one

Q6. Additionally, to what degree do you agree with the following statements? (1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) I am healthy enough to care for my loved one  
B) It takes all my physical strength to care for my loved one  
C) My health has gotten worse since I've been caring for my loved one  
D) Since caring for my loved one, it seems like I am tired all the time  
E) Caring for my loved one is important to me  
F) I enjoy caring for my loved one  
G) Caring for my loved one makes me feel good  
H) I feel privileged to care for my loved one  
I) I really want to care for my loved one  
J) I will never be able to do enough caregiving to repay my loved one
The next set of questions inquire about caregiver information needs regarding caring for an adult experiencing a chronic health condition.

Q7. To what degree do you think it is important to learn about the following topics? (1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) Taking care of your loved one's physical well-being
B) Taking care of your loved one's emotional well-being
C) The services that are available to you and/or your loved one
D) How to set up services for him or her
E) The stress and burden of caregiving
F) How to make caregiving activities pleasant for both you and your loved one
G) The best way to respond to and handle emergencies that involve him or her
H) The different types of help and information you need from the health care system
I) Medication's available for your loved one's symptoms
J) Financial resources available to you and/or your loved one
K) Facilities to place your loved one in the future
L) End of life care
M) Other (please specify)

Q8. To what degree do you agree with each of the following statements regarding looking for information? (1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) I can usually find the information I need
B) Searching form information is easier for me than it used to be
C) When I search form information, I know the difference among the information sources available to me
D) I understand how to search for information better than I did before
E) If I can't find what I'm looking for, I keep trying until I find it
F) I am confident that I can choose relevant information from the results of my search
G) When seeking information, I can solve most problems if I invest the necessary effort
H) I can usually come up with alternative search strategies if I am confronted with a problem during an information search
I) I keep trying to find what I'm looking for, even if it takes a while
Take a moment to read the following information before moving forward with the survey: AD, which refers to Alzheimer’s disease and other forms of dementia, typically progresses slowly in three general stages — mild (early stage), moderate (middle stage), and severe (late stage). Since it affects people in different ways, each person will experience symptoms - or progress through stages – differently. During the early stage, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects. Friends, family or others close to the individual will notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. During the middle stage, which is typically the longest stage and can last for many years, will require a greater level of care. The care recipient may have greater difficulty performing tasks such as paying bills, but they may still remember significant details about their life. You may notice them confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe. In the late stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation, and eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive help with daily activities.

Q9. Regarding the list of topics below, indicate at which point during your loved one's stages of illness you may have sought information about each topic. Choose all that apply.

(1) Mild (Early Stage) (2) Moderate (Middle Stage) (3) Severe (Late Stage)

A) Clinical aspects of AD
B) Hereditary nature of illness
C) Help communicating with your loved one
D) Managing care recipient behavior
E) Prescriptions/medications
F) Safety at home
G) Managing your emotional ups and downs
H) Taking care of your health
I) Getting financial assistance
J) Changes in your loved one's personality
K) Resources available to your loved one
L) Resources available to caregivers
M) Diet/proper nutrition
N) Other (please specify)
People may seek out information from a variety of resources. For example, they may speak with a doctor, do research on the internet, or talk to their friends. The following questions ask about resource utilization when seeking caregiver information.

Q10. Which of the following resources have you utilized when researching information about caregiving? (Select all that apply)
A) Family and friends
B) Support groups (online or face-to-face)
C) Medical professionals
D) Illness-specific organizations (in person)
E) Religious organizations
F) Television
G) Books and magazines
H) Newspapers
I) Illness-specific websites
J) Social media
K) Smartphone apps
L) Other (please specify) ________________________________________________

Q11. Based on your response to the last set of questions regarding the sources you’ve consulted regarding caregiving, how much do you agree or disagree with the following statements?
(1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) The sources I use provide truthful information
B) The information provided by the sources I use is believable
C) My interactions with the sources I use occur as I expect
D) The sources I use offer the information that I expect
E) I believe that there could be a negative consequence from using these sources
F) I trust sources I use
G) I use the same sources frequently
H) Most resources I use are complicated to use
I) The sources I use are easy to understand
Q12. Additionally, since becoming a caregiver for someone with AD, Alzheimer’s disease or other form of dementia, how much do you agree or disagree with the following statements regarding your experiences in seeking the information related to your loved one’s illness? (1) Strongly disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Strongly agree

A) I have often needed someone to help when I am given information to read by the doctor, nurse, or pharmacist
B) When I need help, I can easily get a hold of someone to assist me
C) I need help to fill in official documents
D) When I talk to a doctor or nurse, I ask the questions that I need to ask
E) When I talk to a doctor or nurse, I make sure they explain anything that I do not understand
F) I am someone who likes to find out lots of different information about health
G) I often think carefully about whether health information makes sense in my situation
H) I often try and work out whether information about health can be trusted
I) I am the sort of person who might question my doctor or nurse’s advice based on my own research

Q13. Viewing health information can cause multiple emotions. The next set of questions asks about how seeking information about caregiving makes you feel. The following list consists of several words that describe different feelings and emotions. Read each group of words and indicate to what extent you generally feel this way when seeking information about caregiving. (1) Not at all (2) A little (3) Moderately (4) Quite a bit (5) Extremely

A) angry, irritated, annoyed
B) ashamed, humiliated, disgraced
C) scared, fearful, afraid
D) content, serene, peaceful
E) embarrassed, self-conscious, blushing
F) glad, happy, joyful
G) grateful, appreciative, thankful
H) hopeful, optimistic, encouraged
I) inspired, uplifted, elevated
J) interested, alert, curious
K) proud, confident, self-assured
L) repentant, guilty, blameworthy
M) sad, downhearted, unhappy
N) stressed, nervous, overwhelmed
Sandra Day O’Connor, the first woman to serve as a justice on the United States Supreme Court recently announced that she has dementia and decided to withdraw from public life as the disease advances.

Q14. Did you hear about Justice O’Connor’s announcement?
A) No
B) Yes

Q15. Since hearing about Justice O’Connor’s announcement, have you sought out any information about her life or health issues?
A) No
B) Yes

Q16. What topics have you sought additional information about? (Check all that apply)
A) Her life accomplishments
B) Her health
C) Her political opinions
D) Her career
E) Alzheimer's or dementia
F) Other (please specify)

Q17. What media did you use to seek out this information (check all that apply)
A) Facebook
B) Twitter
C) Other social media (e.g., Instagram, Youtube)
D) TV
E) General online search (specify websites found during search) ________________
F) Print news (e.g., newspapers, magazines)
G) Email
H) Text message - someone texted you
I) Other (please specify) ____________________________________________

Q18. How satisfied were you with the information you found?
A) Extremely satisfied
J) Somewhat satisfied
K) Neither satisfied nor dissatisfied
L) Somewhat dissatisfied
M) Extremely dissatisfied

Q19. Since Justice O’Connor’s announcement, have you talked with anyone about Alzheimer's disease or other forms of dementia?
A) No
B) Yes
Q20. Who have you talked with? (Choose all that Apply)
A) Friend(s)
B) Significant other/spouse/sexual partner
C) Family member(s) besides significant other
D) Co-worker(s)
E) Health care provider(s)
F) Other (please specify) ____________________________________________________

Q21. Next, read the following statements. During the past month, how often have you:
(1) Never (2) Rarely (3) Sometime (4) Very often (5) Nearly always
A) been upset because something happened unexpectedly?
B) felt that you were unable to control the important things in your life?
C) felt nervous and "stressed"?
D) felt confident about your ability to handle your personal problems?
E) felt that things were going your way?
F) found that you could not cope with all the things that you had to do?
G) been able to control irritations in your life?
H) felt that you were on top of things?
I) been angered because things were out of your control?
J) felt things were piling up so high that you could not overcome them?

Lastly, please answer the following demographic questions.

Q22. Which best describes your sex?
A) Male
B) Female
C) Other (please specify) ____________________________________________________

Q23. What is your race or ethnic identity?
A) Black/African American
B) White
C) Asian or Pacific Islander
D) Native American or American Indian
E) Other (please specify) ____________________________________________________

Q24. Are you Hispanic or Latino?
A) No
B) Yes

Q25. How old are you? Please respond with a whole number. ________________
Q26. What is the highest level of education that you have attained?
A) Less than a High School Diploma
B) High School Diploma
C) Associate's Degree
D) Some College
E) 4-year College Degree
F) Master's Degree or higher

Q27. What best fits your household income?
G) Less than $20,000
H) $20,000 to $34,999
I) $35,000 to $49,999
J) $50,000 to $74,999
K) $75,000 TO $99,000
L) Over $100,000
CONSENT FORM FOR SOCIAL SCIENCE RESEARCH

Louisiana State University

Title of Project: Information Seeking Behaviors and Support Needs of Informal Caregivers

Persons in Charge: Nia Mason
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(504) 715-5522

Dr. Diane Francis, Assistant Professor
249 Hodges Hall
Manship School of Mass Communication
Louisiana State University
Baton Rouge, LA 70803
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dianefrancis@lsu.edu

Purpose of the Study: The purpose of this study is to determine what information and support systems are available to informal caregivers that focus on their health, encouraging them to take care of themselves while they are caring for their loved one.

Subject Inclusion: Individuals aged 18 and older who have been or currently are informal caregivers.

Number of subjects: Interviews, 15
Survey, 400

Procedures to be followed: This study will be conducted in two parts.

Interviews: The first part of the study will consist of conducting interviews with current informal caregivers. The interviews will be conducted in person or via telephone, and will cover six areas of inquiry, including:

1) Current information seeking practices, including what type of information do they seek, when do they seek it, and from what resources.
2) The type of information they need but are not able to find, whether it be because of where they are seeking it, their lack of health literacy, or that the information is simply not available.
3) The type of support received, including social groups, medical and educational.
4) Trust of resources, including which resources they trust the most and/or find most credible.
5) Current health status of the caregiver and how it relates to caregiving.
6) The ways in which they maintain their own health while caring for someone else.

Survey: The second portion of the study will be a survey developed from interviews conducted in the first part. They survey will determine whether there are statistically significant relationships among these variables that will help organizations better promote both information seeking and health interventions among informal caregivers. Study participants will complete a self-report questionnaire via Qualtrics or using pen and paper.

Duration: The interview will take about 30 – 60 minutes to complete.

Discomforts and Risks: There are no risks in participating in this research beyond those experienced in everyday life.

Benefits:
- a. You might learn more about yourself by participating in this study. You might have a better understanding of your overall health and information seeking practices.
- b. You may gain insight into the kind of information that is most beneficial to caregivers as well as efficient ways of finding that information.

Statement of Privacy: No identifying information will be included on any of the answers that you provide. If this research is published, no information that would identify you will be included since your name is in no way linked to your responses. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by third parties.

Compensation: Participation is purely voluntary, and no compensation will be provided for participation.

Voluntary Participation: You do not have to participate in this research nor do you have to answer any questions you do not want to answer. You can stop your participation at any time.

You must be 18 years of age or older to consent to participate in this research study.

The study has been discussed with me and all my questions have been answered. I may direct additional questions regarding study specifics to the investigator. If I have questions about subjects' rights or other concerns, I can contact Dennis Landin, Institutional Review Board, (225) 578-8692, irb@lsu.edu, www.lsu.edu/irb. I agree to participate in the study described above and acknowledge that by continuing with the survey I am providing consent.

Signature: _______________________________ Date: ____________________
APPENDIX E
IRB APPROVALS

ACTION ON EXEMPTION APPROVAL REQUEST

TO: Nia Mason
Mass Communication

FROM: Dennis Landin
Chair, Institutional Review Board

DATE: February 26, 2018

RE: IRB# E10913

TITLE: Information Seeking Behaviors and Support Needs of Informal Caregivers


Review Date: 2/26/2018

Approved X Disapproved

Approval Date: 2/26/2018 Approval Expiration Date: 2/25/2021

Exemption Category/Paragraph: 2a

Signed Consent Waived? No

Re-review frequency: (three years unless otherwise stated)

LSU Proposal Number (if applicable):

Protocol Matches Scope of Work in Grant proposal: (if applicable)

By: Dennis Landin, Chairman

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING – Continuing approval is CONDITIONAL on:

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU’s Assurance of Compliance with DHHS regulations for the protection of human subjects*
2. Prior approval of a change in protocol, including revision of the consent documents or an increase in the number of subjects over that approved
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins); notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants, including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
8. SPECIAL NOTE: When emailing more than one recipient, make sure you use bcc. Approvals will automatically be closed by the IRB on the expiration date unless the PI requests a continuation. The survey must be approved by the IRB before that phase can begin.

* All investigators and support staff have access to copies of the Belmont Report, LSU’s Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb
ACTION ON EXEMPTION APPROVAL REQUEST

TO: Nia Mason
Mass Communication

FROM: Dennis Landin
Chair, Institutional Review Board

DATE: October 22, 2018

RE: IRB# E10913

TITLE: Information Seeking Behaviors and Support Needs of Informal Caregivers

New Protocol/Modification/Continuation: Modification

Brief Modification Description: Added a survey.

Review date: 10/18/2018

Approved X Disapproved ______

Approval Date: 10/22/2018 Approval Expiration Date: 2/25/2021

Re-review frequency: (three years unless otherwise stated)

LSU Proposal Number (if applicable):

By: Dennis Landin, Chairman

PRINCIPAL INVESTIGATOR: PLEASE READ THE FOLLOWING – Continuing approval is CONDITIONAL on:

1. Adherence to the approved protocol, familiarity with, and adherence to the ethical standards of the Belmont Report, and LSU’s Assurance of Compliance with DHHS regulations for the protection of human subjects*
2. Prior approval of any adverse event affecting a participant or any request for participant information from the study.
3. Obtaining renewed approval (or submittal of a termination report), prior to the approval expiration date, upon request by the IRB office (irrespective of when the project actually begins) notification of project termination.
4. Retention of documentation of informed consent and study records for at least 3 years after the study ends.
5. Continuing attention to the physical and psychological well-being and informed consent of the individual participants including notification of new information that might affect consent.
6. A prompt report to the IRB of any adverse event affecting a participant potentially arising from the study.
8. SPECIAL NOTE: Make sure you use bcc when emailing more than one recipient. Approvals will automatically be closed by the IRB on the expiration date unless the PI requests a continuation.

*All investigators and support staff have access to copies of the Belmont Report, LSU’s Assurance with DHHS, DHHS (45 CFR 46) and FDA regulations governing use of human subjects, and other relevant documents in print in this office or on our World Wide Web site at http://www.lsu.edu/irb
VITA

Nia F. Mason is a native of New Orleans, Louisiana. She completed a Bachelor of Arts degree in English from The George Washington University in 2003. She returned home to Louisiana, earning a Master of Mass Communication degree from Louisiana State University in 2006, where her research focused on minority recruitment practices at Universities in Louisiana and Mississippi. Nia gained a decade of experience in program planning and support, program administration, and volunteer recruitment and management prior to beginning her doctoral studies. She completed her Doctor of Media and Public Affairs degree in 2019 at Louisiana State University with a focus on health communication research to heighten health awareness in disadvantaged and hard to reach populations.