

**IMPACT OF MEDICATION STRESSORS ON EMOTIONAL HEALTH OF  
INFORMAL CAREGIVERS OF DEMENTED PATIENTS**

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A dissertation submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Division of Pharmaceutical Outcomes and Policy in the School of Pharmacy.

Chapel Hill  
2007

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## **ABSTRACT**

JOHN E. BYRD: Impact of Medication Stressors on Emotional Health of Informal  
Caregivers of Demented Patients  
(Under the direction of Betsy Sleath, PhD)

**Purpose:** To better understand the medication-related concerns of dementia caregivers, their impact on caregiver emotional health and to identify potential areas for interventions that might assist them with medication management and reduce their overall stress and burden.

**Scope:** Since demented patients lose their cognitive ability to manage their own medications early in the disease process, informal caregivers are involved with this sometimes complex process for an extended period of time which has the potential to cause a great deal of burden, anxiety and frustration.

**Methods:** This research study was conducted using a sample of 139 caregivers of persons with memory problems recruited from caregiver support groups, clinic settings and an online listserv.

**Results:** Caregivers who reported lower levels of social support and had more difficulty handling the medication effects reported higher depression scores. Less than half of the caregivers surveyed believed that their pharmacist was proactive in communicating drug information or that there was a private place within the pharmacy to do this.

**Conclusions:** The findings suggest that medication-related stressors are associated with poorer emotional health outcomes in caregivers. The descriptive analysis of caregiver's attitudes about pharmacists and pharmacy services also suggests that there are things that can be done to assist caregivers to improve the relationship and communication with their pharmacist.

**Key Words:** dementia; caregivers; medications; depression

## **ACKNOWLEDGEMENTS**

Special thanks go out to the following people and organizations who helped me reach out to dementia caregivers within the community. This research would not have been possible without the kindness of all of these people. May God bless each of you for the amazing work that you do! A special thanks to Lisa Gwyther and Kate Barrett who believed in me and my research interest early on. Without your help, I would never have gotten this project off the ground.

Lisa Gwyther, Duke University, Durham NC

Kate Barrett, Orange County Department on Aging, Chapel Hill NC

Blair Barton Percival, Piedmont Triad Council, Greensboro NC

Helen Millison, Randolph Memorial Hospital, Asheboro NC

Sally White, Adult Center for Enrichment, Greensboro NC

Jenna Ivey PharmD, UNC School of Pharmacy, Chapel Hill NC

Heidi Jean Coward MD, UNC Geriatric Clinic, Chapel Hill NC

Heidi Roth, MD, UNC Memory Disorders Clinic, Chapel Hill, NC

Alice Watkins, Eastern North Carolina Alzheimers Association

Beth Croom, Western North Carolina Alzheimers Association

Mark Foreman, The Carillon, Hillsborough NC

Dottie Lyvers, Northwest Piedmont Council on Government, Winston-Salem, NC

Anne Williard, Northwest Piedmont Council on Government, Yadkinville, NC

Christina Jacobs, Alzheimer's Family Support Group, Hendersonville, NC

Susan Caudle, Coltrane LIFE Center, Concord, NC

Andrea Locklear, Alzheimer's Support Group, Greenville, NC

Lesia Henderson, Sampson County Department on Aging, Clinton, NC

Gillie Edwards, Alzheimer's Support Group, Laurinburg, NC

Susan Scurria, Hertford/Edenton, NC

Carolyn Sidwell, Life Center of Davidson County, Lexington, NC

Tom Meuser PhD, Alzheimer's List, Washington University, St. Louis MO

Overall, this was one of the most rewarding experiences of my professional career. There is no way for a researcher to truly understand the burden of a dementia caregiver without taking the opportunity to meet and talk with them. I met many amazing people along the way and I will carry this with me throughout my career as a researcher. While I may never know exactly how it feels to live as a dementia caregiver, I have at least captured a glimpse of that role.

I must extend thanks to my academic and dissertation advisor, Dr. Betsy Sleath, who has been by my side since I entered the doctoral program in the Division of Pharmaceutical Outcomes and Policy in the Fall of 2002. She has the unique ability to know when to provide encouragement and how to do it. Whether it was an issue with school or work or life, Betsy was always there to listen and to help set me back out on the proper path. While she was always quick to praise me for my accomplishments, she also never hesitated to push me when I needed to be pushed. Somehow, she always knew which one I needed. She truly is a wonderful researcher, leader, mentor and friend.

I want to thank all of the other members of my dissertation committee—Drs. Susan Blalock, Elizabeth Clipp, Peggye Dilworth-Anderson, Richard Landerman and Mary Roth. I have learned something from each of you and appreciate your willingness to share your experiences and knowledge with me. There was never a time that I asked for one-on-one help from any of you when I didn't receive more assistance than I had hoped for. One special thanks goes out to Dr. Clipp for an especially impressionable moment. I will never forget the Saturday morning last summer when we sat at your dining room table debating over the wording and presentation of my study questionnaire. I remember that you had many

family responsibilities that day but you managed to take the time to patiently spend a couple of hours with me. I drove away from your house that day thinking that I was truly blessed to have been paired with such experienced researchers who are so interested helping students learn. As I develop into a seasoned researcher, I hope that I will influence the careers of others as you all have done for me.

To other faculty members within the Division of Pharmaceutical Outcomes and Policy (both present and former), I extend my thanks to you, as well. I have learned something from each one of you and have appreciated your openness and willingness to share yourselves. To Dr. Pamela Joyner, a special thanks to you for helping me with my “teaching” experience. Your demeanor and supportive nature always provided a calming effect for me. You taught me how to be confident and professional in the classroom. I would also like to thank the Agency for Healthcare Research and Quality (AHRQ) who was the funding source for this work under an R36 Dissertation Grant. This assistance was of great value in my efforts of primary data collection and analysis. I hope the findings from my work will support your mission of “improving the quality, safety, efficiency, and effectiveness of health care for all Americans.”

I would also like to thank those who are close to me. Christy, you were always supportive of my endeavors and were one of the primary reasons that I was able to leave a full-time job and career to return to school in pursuit of my dream. I know that you made many personal sacrifices for me and they never went un-noticed. Although things have changed for us over time, your love, respect, encouragement and support were vital in helping me get to this point. To my kids—Elizabeth, Alex and Nicholas—you guys are amazing. Each one of you has shown me the meaning of unconditional love. In your own

way, you have helped me get through this long process. I hope that I can give back to you by being a supportive father who lets each of you grow into who you are and who you want to be. You will always have my unconditional love.

Finally, I would like to thank Chris Smith, my partner. You have been steadfastly by my side as I have worked to complete this dissertation. Your patience, love and support have carried me through the final months of this work.



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## **CHAPTER ONE**

### **INTRODUCTION**

Memory problems often referred to as Alzheimer's disease (AD) and dementia is a growing public health concern and caregivers are an integral part of the care process. There are currently over 4.5 million adults who live with dementia in the United States and are being cared for by informal caregivers (e.g., family members, friends) (Alzheimer's Association, 2006). Informal caregivers play a prominent role in the ongoing care of the demented patient. As the cognitive ability and functional status of the demented patient declines over time, the responsibility of obtaining medical care and maintaining the ongoing health status of the patient falls on the primary caregiver(s). On a broad level, this responsibility includes preventative care (e.g., screenings), management of behavioral problems, and recognizing the need for primary, secondary or tertiary care for management and exacerbations of chronic illnesses. On a daily basis, this means that the caregiver must schedule medical appointments and administer medications and other types of treatments and care in order to maintain the demented patient's physical and mental health.

As the responsibilities of the dementia caregiver increase over time with the growing complexity of care, there is the potential for the caregiver to experience increased emotional, physical and financial stress and burden. Caregiver health has been an area of focus for research over the past two decades. Many studies have examined the impact of the caregiving process on both the physical and mental health of the caregiver. Research efforts

have been focused on understanding the cause of stress and burden and developing interventions to alleviate it.

Since demented patients lose their cognitive ability to manage their own medications early in the disease process, informal caregivers are involved with this sometimes complex process for an extended period of time which has the potential to cause a great deal of burden, anxiety and frustration. The overall objectives of this study were to better understand the medication-related concerns of dementia caregivers and to identify potential areas for interventions that might assist them with medication management. The caregiving process is important and ultimately the health of both the care recipient and the caregiver are affected.

This research study was conducted using a sample of caregivers of persons with memory problems recruited from caregiver support groups, clinic settings and an online listserv. Caregivers were administered a self-report questionnaire designed to collect the following information about the caregiving process: caregiver and care-recipient contextual information (e.g, demographics, health status), medication-related stressors (e.g, issues with administering medications, managing effects and side effects of medications, obtaining prescription medications), social support (e.g., pharmacists), and emotional health outcomes.

Studies have already shown that the overall caregiving process causes depressive symptomatology and compromised emotional health in caregivers. This study further contributes to the research of: (1) the overall depression associated with caring for AD patients, (2) specific medication-related stressors experienced by caregivers and their impact on the caregiver's emotional health, and (3) survey instrument development for medication-related issues experienced by caregivers. The study will also identify potential opportunities



for pharmacy interventions for AD patients and their caregivers. This study is one of the first to use an instrument that asks questions related specifically to the medication management responsibilities of the caregiving process in conjunction with a caregiver time activity survey. This study adds to the previous literature because it examines whether these medication-related stressors influence caregiver emotional health. Identifying the medication stressors that impact caregiver-reported health outcomes allows us to make specific recommendations for pharmacist-based interventions. Overall, this study contributes to the growing body of research and literature that explores emotional health of caregivers and continues to help us understand how we can work to alleviate their burden.

This dissertation is organized by beginning with a review of the current literature that will demonstrate the prevalence of dementia in the United States, the role of caregivers, the negative impact of caregiving on the caregivers emotional health status and the role of medication management in the process of caregiving (Chapter 2). The last part of this chapter will outline the conceptual framework that shapes the research. This will be followed by the current study's research hypothesis and specific aims (Chapter 3). In Chapter 4, the rationale and process for developing a self-report study questionnaire for primary data collection will be detailed. The process of developing the questionnaire was closely tied to the conceptual framework. The research methods used to analyze study hypotheses and specific aims are in Chapter 5. This chapter describes the study questionnaire and details the work that was done to access caregivers of persons with memory problems. This is followed by the study results in Chapter 6. Finally, Chapter 7 summarizes the major findings from this research and discusses implications for caregivers, health care professionals (including pharmacists), and health services researchers.

## **CHAPTER TWO**

### **REVIEW OF LITERATURE**

#### **2.1. Overview of Chapter**

This chapter outlines key literature findings related to dementia, caregivers, caregiver emotional health and medication management. The first section provides an overview of dementia which will include its prevalence, the most common diagnostic forms, its anticipated growth in the United States and the impact of the cost of the disease on society. Next, I will discuss the role of caregivers in the provision of care for the person with memory problems and demonstrate how the burden of this responsibility can negatively impact the caregiver's emotional health. Third, the available literature on medication management by caregivers is presented and the limited information that is available on this topic related specifically to caregivers of persons with memory problems is covered. Then, social support and social networks for caregivers is described with a discussion of how pharmacists might play a role in the support system. Finally, the conceptual model used for this research is detailed to demonstrate how a modified version of the Pearlin Stress Process Model of Caregiving (Pearlin et al 1990) was developed.

## **2.2. Dementia**

Dementia is primarily an age-related and irreversible brain disorder that begins with memory loss, which worsens over time and eventually results in functional losses and behavior changes (Cummings JL 2002; Henderson and Jorm, 2000). There is a progressive decline in cognitive ability (e.g, critical thinking, decision-making, speech) and an eventual loss of motor and physical functions (American Psychiatric Association, 1997). “The essential features of dementia are multiple cognitive deficits that include memory impairment and at least one of the following: aphasia, apraxia, agnosia, or a disturbance in executive functioning” (American Psychiatric Association, 1997). The level of cognitive decline and onset of symptoms varies between types of dementia and within patient populations.

Alzheimer’s disease (AD) is the most common form of dementia, accounting for 50 to 75% of all cases, and primarily affects the aging population with prevalence dramatically increasing with age (Alzheimer’s Association, 2006). Another 20 to 30% of dementia cases are typically diagnosed as vascular, or multi-infarct, dementia (Cummings and Beson, 1992). Differential diagnosis between AD and vascular dementia is clinical and based on diagnostic criteria. A small percentage (less than 10% of all cases) of dementia diagnoses are related to other less common causes such as Parkinsons disease, human immunodeficiency virus (HIV), Lewy body disease, Pick disease and frontal lobe disorders (Henderson and Jorm, 2000). For the purposes of this research study, dementia caregivers were those who care for patients who suffer from any form of dementia as there was no method of verifying the cause of the memory problem.

Memory problems are a growing public health concern in the United States because of their impact on individuals, families and the health care system. There are currently 4.5 million elderly persons in the United States living with AD alone and this number is expected to increase with the growth in the elderly population (Alzheimer's Association 2006). If the current population trends continue and no preventative treatment is developed, the number of patients will increase to over 13 million by 2050 (Herbert et al, 2003). Prevalence depends on the type of the dementia diagnosis; however, in all cases, prevalence increases dramatically with age. Dementia affects between 5 to 8% of the population between the ages of 65 and 74, 15 to 20% of the population between the ages of 75 and 84 and it may be as high as 50% in elderly persons over the age of 85 (Evans et al, 1989).

With the growing number of people suffering from dementia and the rising costs of caring for these individuals, there is also a large economic cost associated with this population. It is estimated that the annual costs (both direct and indirect) of caring for these patients may be as high as \$100 billion (Ernst and Hay, 1994; Ernst et al, 1997). In 2001, Moore et al reported that the average annual cost of dementia caregiving was \$18,385 with one-third of that cost attributed to caregiver time and the other two-thirds due to lost wages. In a 2002 report to the Alzheimer's Association on the cost impact of AD, Koppel predicted that the disease would cost American businesses \$61 billion that year which was doubled from the amount in 1998. Over half of these costs, a projected \$36.5 billion, were attributed to caregiver absenteeism from work, decrease in caregiver productivity while at work and replacement costs. The cost impact of caregivers on businesses far exceeds the \$24.6 billion paid for the actual health care expenditures of the person with AD (Koppel, 2002). These figures are expected to continue increasing as more people are diagnosed with this disorder.

### **2.3. Informal Caregivers of Dementia Patients**

While the progression of dementia is highly variable between patients with some experiencing rapid decline in functional status and others who plateau for extended periods of time, the disease is highly dependent on caregivers providing support at some time for help with patient Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Clipp and Moore 1995). Eventually, these caregivers are involved in every aspect of daily life for the demented person as these patients require more hours of support and greater levels of care than physically disabled elders without cognitive impairment. The primary caregivers and family members are often involved in managing the behavioral problems, other chronic health conditions, preventative care and medications of the demented patient. While some of these patients live in institutions (e.g., assisted living facilities, nursing homes), more than half of them live at home where 75% of their care is provided by an informal caregiver who is a spouse, family member, or friend (Alzheimer's Association 2002). These caregivers are usually spouses or children of the demented patient and are also living with their own compromised health and other life stressors (Sleath et al 2005). The majority of informal caregivers are women (Ferrini and Ferrini, 2000).

## **2.4. Caregiver Emotional Health**

As the memory and behavior of the demented patient becomes more impaired, there is a greater dependence on the caregiver that leads to increased emotional, physical and financial stress and burden. While much of the funding for AD research is focused on causes, diagnosis and treatment, more emphasis has been placed on the personal and emotional impact of the disease on families and caregivers during the past decade (U.S. Department of Health and Human Services, 2004). The study of caregiver health-related quality of life is important in understanding the impact of caregiving on caregivers' emotional well-being.

Providing extensive daily care for persons who suffer from AD or other dementing disorders is stressful and many studies have documented the effect of caregiving on both the physical and emotional well-being of informal caregivers (Zarit et al 1996). Caregivers have been shown in research to have poorer physical and mental health outcomes than non-caregivers (Schulz and Beach, 1999; Wilcox and King, 1999). There have been more studies that have documented the psychological impacts of caregiving. Zarit et al (1996) found, in a study of caregivers assisting a relative with AD or other dementia, that 47% demonstrated clinically-significant levels of depression. The prevalence of depression in caregivers is higher than in those who do not have caregiving responsibilities with 30 to 55% of caregivers reporting depressive symptomatology (Schulz and Martire, 2004). A more recent study using the National Longitudinal Caregiver Sample by Sleath et al (2005) has shown that nearly 30% of informal caregivers of demented relatives demonstrate depressive symptoms. Depression is one of the most common consequences of caregiving and can lead to poor

quality of life, functional decline and mortality (Donaldson et al, 1997, Haley WE et al, 1995; Perel VD, 1998; Schulz and Beach, 1999).

This area of research has also been very important to the National Institutes of Health (NIH), as well, over the past decade. Resources for Enhancing Alzheimer's Caregiving Health (REACH) was funded by the National Institute on Aging (NIA) and the National Institute of Nursing Research (NINR) and began in 1995. The goal of this research, conducted at six university sites across the United States was to develop interventions for family caregivers. This project was extended to REACH II in 2001 and was focused on interventions that would reduce depression and burden of the caregiver ([www.edc.gsph.pitt.edu/reach](http://www.edc.gsph.pitt.edu/reach)). Several publications of findings from REACH demonstrate effective intervention strategies that can be used to improve the emotional health outcomes of caregivers of persons with memory problems (Schulz et al, 2003). These interventions range from education, behavioral skills training, use of information technology and environmental skill-building (Burgio et al, 2003; Burns et al, 2003, Eisdorfer et al, 2003; Gitlin et al, 2003). These studies show that ongoing efforts that focus on improving caregiver emotional health can be effective. The current research study contributes to the literature by further reporting the overall depression associated with the caregiving process and identifying possible areas for interventions in the medication management process.

## **2.5. Medication Management by Informal Caregivers**

One of the first cognitive functions lost by the persons with memory problems is their ability to manage their own medication regimens. Since they live, on average, eight years after the onset of symptoms, managing the medications becomes a stressful event for the caregiver that can extend over many years (Alzheimer's Association 2002). Caregiver anxiety and frustration associated with medication management can be attributed to its complexity. The caregiver's medication management responsibilities extends beyond simple administration of the medication and includes managing adverse events, evaluating the effectiveness of the medication regimen, obtaining the medications (which includes physically obtaining from the pharmacy and financially being able to afford them), and gathering information about the medications to ensure that the patient receives optimal therapy and avoids complications.

There have been few studies that have identified specific medication-related stressors and their subsequent impact on the caregiver's emotional well-being. Therefore, it is important to continue doing research that will help us to understand the types and extent of the medication-related stressors, the social support that exists related to medication management and, ultimately, their impact on the emotional health and stress of the caregiver. Francis et al (2002) reported the roles of informal caregivers in the management of medication from their British study of 684 caregivers recruited from 26 pharmacies. The goal of this study was to document and quantify the frequency and range of medication-related tasks assumed by an informal caregiver. They identified ten medication-related tasks and found that they were positively associated with caregiver strain and negatively associated



with social functioning and mental status. All of the medication-related tasks involved ordering and obtaining prescriptions, assisting with medication administration, making clinical judgments about changing doses and noticing, and managing side effects of the medications. Caregiver burden was measured using the Carer Strain Index (CSI). The CSI was positively associated with the number of medication-related activities undertaken by the caregiver after controlling for caregiver age and socioeconomic status and was an important part of the caregiver process. This study did not identify specific intervention opportunities for pharmacists; however, qualitative comments from the survey indicated that pharmacists should be more involved in the medication-management process to help caregivers be more effective in their role.

Ranelli et al (1994) reported medication-related stressors in a descriptive analysis of responses from thirty-one caregivers in Northern Florida. These caregivers identified adverse effects, lack of improvement while on medications, inability of patient to manage medications, compliance problems, and lack of professional advice as the primary stressors. Ranelli et al also found that the caregivers primarily used the same pharmacy and would like more help from the pharmacist in managing medications. Caregivers said they wanted the pharmacists to provide more individualized care, to make recommendations for managing adverse effects, to provide information about home medical equipment and non-prescription purchases that would improve the quality of care for the patient and to explain how the drug therapy works and methods for managing adverse events. This study demonstrated that medication-related stressors exist among caregivers and that there are potential interventions and support from pharmacists that would relieve this burden. However, the Ranelli et al study (1994) was limited by its small sample size.

Neither the Francis et al (2002) nor Ranelli et al (1994) study examined the impact of medication related-stressors on the emotional well-being of dementia caregivers. These studies were conducted in caregivers of elderly patients. Dementia caregivers are more involved in the medication management for the patient than caregivers of other elderly persons. Thus, there is a need to better understand the role of medication management specifically within dementia caregivers. In documented caregiver research, surveys of dementia caregivers, including the National Longitudinal Caregiver Sample conducted in caregivers of veterans with AD and vascular dementia, have only measured the medication-related activities and other caregiving tasks of the caregiver in terms of time spent on the activity. In 1995, Clipp and Moore evaluated caregiver time use in coordination with a clinical trial. The Caregiver Activities Time Survey (CATS) was used to estimate all activities including the administration of medications. This task was a self-report by the caregiver where they were asked to estimate the number of hours and minutes spent in a typical day administering medication. While measuring the time that caregivers spend on helping with ADLS and certain IADLs is important in understanding caregiver burden, managing the patient's medications is a more complex caregiving process with many stressors that should be more clearly defined.

## **2.6. Support of Informal Caregivers**

Caregivers require social support from pharmacists, other health care professionals, support groups and family members in order to manage medications effectively. Therefore, it is important to examine the medication-related issues of dementia caregivers beyond a simple measure of time spent on the activity. It is also critical to understand the prevalence of the individual stressors and examine the support that are currently available to caregivers. The dimensions of social support include network structure and social integration, integrated social support or enacted support, and subjective social support (Miller and Guo 2000). Subjective, or perceived, support has been shown to be the most important type of mediator in the caregiving process (Lubben 1988). Emotional support and help with caregiving activities has been shown to be positively associated with lower incidences of caregiver stress and depression (Creasey et al 2003; Yates et al, 1999). The level of social support is variable between caregivers depending on both the size and the quality of their social network structure. Thus, this variability can lead to different caregiver health outcomes.

There are also formal support systems available to caregivers. Depending on the financial status of either the patient or caregiver, there is formal help available in the form of home health aides and nurses to assist with caregiving activities in the home. Only about 25% of AD patients and caregivers in the United States have the resources to utilize this system (Alzheimer's Association 2006). However, there are support systems in place that could help with caregiving, including medication-related stressors, other than paid caregiving. Caregivers are not always aware of these other formal support systems within

the healthcare system which leads to a strain on their emotional health and an increased feeling of losing control.

Pharmacists, support groups and Internet websites are all sources of information for medication issues. Yet, pharmacists seem to be the most logical source for dealing with the stressors related to medication management based on their knowledge and consistent contact with the patient and/or caregiver give them an advantage over others. The difficulties a caregiver faces when managing their loved one's medications can be reduced with effective communication and education from pharmacists. This research can help in understanding the social support needs of the dementia caregiver that can be mediated by pharmacists. By completing this research, we can outline medication-related intervention strategies that will decrease caregiver burden and subsequently enhance the health outcomes of both the caregiver and the demented patient.

## 2.7. Conceptual Model

Figure 2.1 outlines the basic conceptual framework that shapes this research. This framework was the Stress Process Model of Caregiving and was designed to assess the impact of caregiving on overall caregiver health (Pearlin et al 1981; Pearlin et al 1990). The primary reason for choosing this framework was that the model was initially developed by applying the stress process model to dementia caregivers. This model has been used and cited in numerous studies involving caregiver emotional health and well-being (Morrissey et al 1990; Sisk 2000). As the role of the caregiver changes over time, so does the ability of the caregiver to respond to caregiver-related stressors, defined by Pearlin et al as “problematic conditions or difficult circumstances” (Pearlin et al 1990).

This basic stress process model includes four components: (1) stressors, (2) mediators, (3) outcomes, and (4) contextual factors. Within the conceptual framework presented by Pearlin et al (1990), caregivers experience both primary and secondary stressors. Primary stressors are those that are directly linked to the patient and his/her disability while the secondary stressors are those that arise from the role of caregiving. These primary stressors can be either objective, and include specific care demands, or subjective (e.g., overload, captivity). Examples of secondary stressors are family conflict, loss of self or inability to participate in social activities. The model assumes the primary stressors directly impact emotional health as well as creating secondary stressors (e.g., loss of time for personal activities, financial burden). The caregiving process is complex and there are mediators that can influence the stress process. Social support available to the caregiver as well as their confidence in their abilities are potential mediators of the stress process as they have the

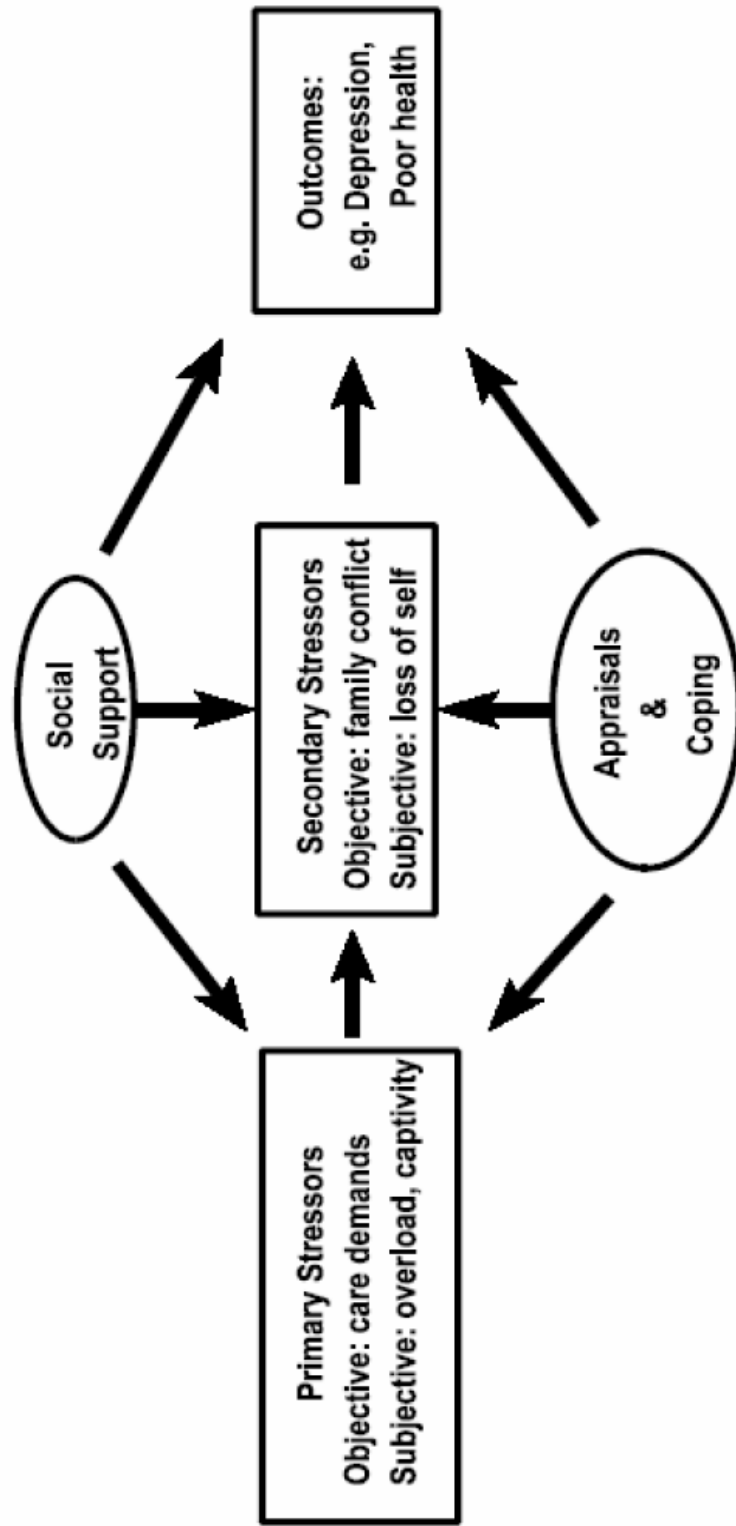
ability to impact both the stressors and patient reported outcome measurements. The contextual factors that are included in this model are ones that refer to the background of the caregiver (e.g., race, gender, education). Finally, the outcome measurement in this model can include both mental and physical health outcomes.

In this research study, the Pearlin model was modified so that the primary and secondary stressors included only the medication management issues of the caregiver. The modifications are shown in Figure 2.2. By doing this, we were able to directly examine the association of medication-stressors on the emotional health outcomes and burden of the caregiver while understanding the role of caregiver/care-recipient contextual factors and caregivers resources (e.g., support). Our analyses controls for other caregiving characteristics and stressors (e.g., time spent on caregiving tasks, patient functional status, comorbidities, and socioeconomic characteristics) that are not specifically outlined in the drawing of the conceptual framework but will be discussed in the modeling methodology (Chapter 5) and results (Chapter 6). The caregiver and care-recipient contextual factors are important to consider as each caregiver/care-recipient combination is different with influences from demographics, relationship and co-habitation status between the caregiver and their loved one and the care-recipient's health and functional status. The caregiver resources are mediator variables in this model as they help to describe the relationship between the independent variables (medication related stressors) and the dependent variable (caregiver emotional health). Figure 2.2 shows the mediated relationship with the path relating stressors to emotional health outcomes mediated by caregiver resources.

In the current research study, the primary medication-related stressors are those concerns that are related to caring for the demented patient's medications (e.g., medication

administration, dealing with medication side effects and effectiveness of medication therapy, acquisition of medications and lack of information). On the other hand, secondary medication-related stressors are encountered as a result of the primary stressors and can be measured as caregiver time missed from work or social activities resulting from the responsibility of medication management. The caregiver resources include the support available to the caregiver as well as their perceptions of their own financial status and health. Social support is measured as the subjective social support and is the extent to which the informal caregiver has developed resources to assist in managing the loved one's medications from either family/friends or pharmacists.

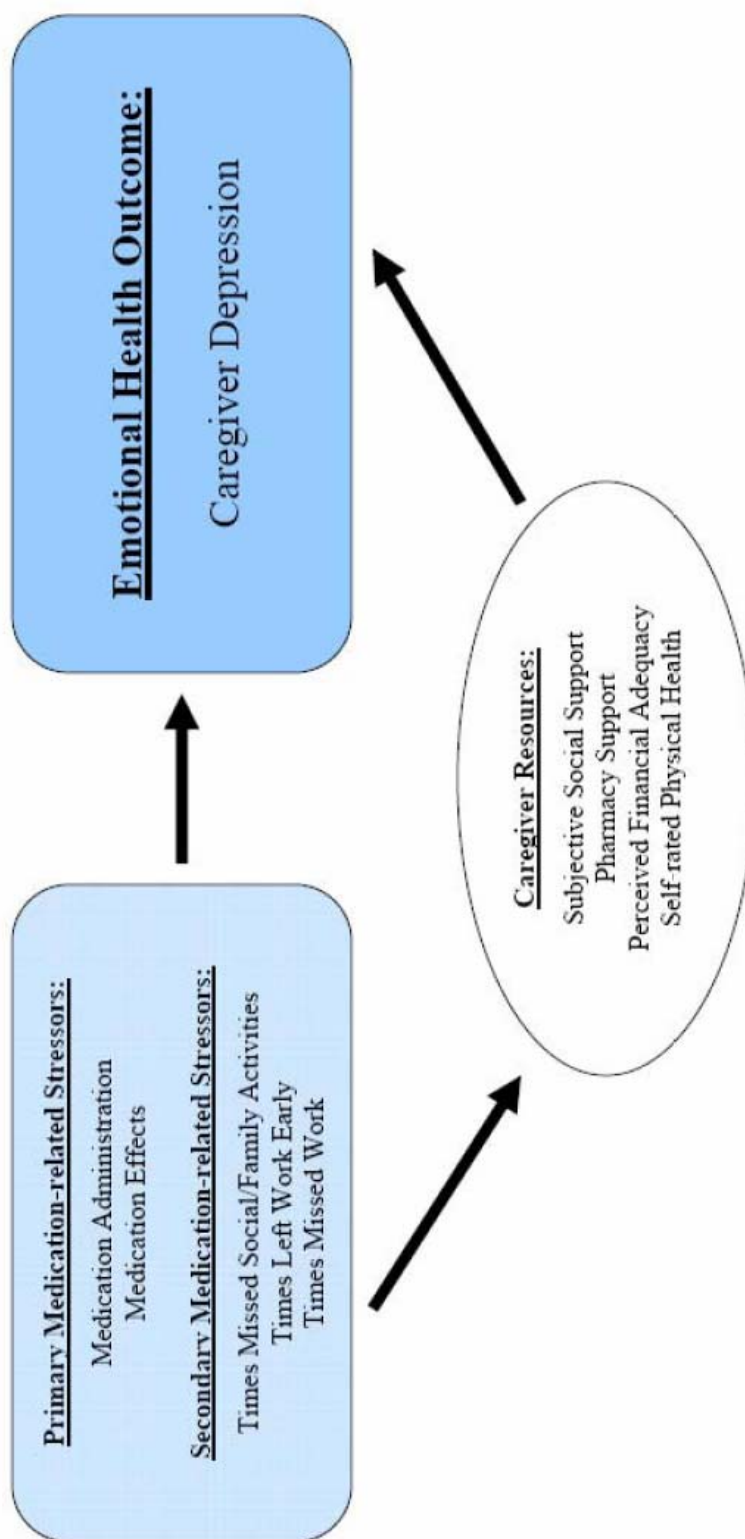
Figure 2.1: Stress Process Model of Caregiving (Pearlin et al 1990)



Adapted from Pearlin et al., 1990



Figure 2.2: Medication Stress Process Model of Caregiving (adapted from Pearlin et al 1990)



## **CHAPTER THREE**

### **RESEARCH HYPOTHESIS AND SPECIFIC AIMS**

The primary research hypothesis was that, among informal caregivers of patients with dementia, those who report more medication-related stressors will have poorer emotional health outcomes (depression) than those caregivers with fewer medication-related stressors.

The **primary aims** of this study are:

**Aim 1:** To examine the relationship between the medication-related stressors experienced by the caregiver and caregiver depression.

H<sub>1</sub>: Caregivers who experience more primary medication-related stressors (e.g., administering medications, managing side effects of medications) will have more depression.

H<sub>2</sub>: Caregivers who miss more time from work, leave work early and miss more social activities and/or family functions (secondary medication-related stressors) due to medication-related problems will have more depression.

H<sub>3</sub>: The relationship between the medication-related stressors and caregiver depression is mediated by caregiver subjective social support.

**Aim 2: To examine the association between the caregiver primary medication-related stressors and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

H<sub>4</sub>: Caregivers of demented patients with lower functional status and more medical comorbidities will have more primary medication-related stressors.

H<sub>5</sub>: Caregivers of demented patients on more prescription medications will have more primary medication-related stressors.

H<sub>6</sub>: Caregivers with less education will have more primary medication-related stressors.

**Aim 3: To examine the association between the secondary medication-related stressors (e.g, time missed from work, social activities and family functions) of the caregiver and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

H<sub>7</sub>: Caregivers of demented patients with lower functional status, more medical comorbidities and more medications will miss more time from work, social activities and family functions.

**The secondary aim of this study is:**

**Aim 4: To describe caregivers attitudes about pharmacists and pharmacy services and determine what caregivers believe can be done to assist them with medication-related stressors.**

## **CHAPTER FOUR**

### **PRELIMINARY FOCUS GROUPS, DEVELOPMENT AND VALIDATION OF THE SURVEY OF CAREGIVER MEDICATION CONCERNS SCALE AND THE RESEARCH STUDY QUESTIONNAIRE**

This chapter will outline several key components that occurred prior to conducting the primary data collection portion of this dissertation research. First, I will discuss the focus groups that were conducted to identify the issues that caregivers face in managing their loved one's medications. Then, I will discuss how we used the information obtained from the focus groups to create a survey instrument for measuring medication-related stressors of caregivers. This will be followed by the scale validation process (item reduction, factor analysis, assessment of reliability) that took place after the collection of primary data. This may seem somewhat out of place organizationally as I will not have discussed the process for collecting the primary data; however, it will help to keep the process of scale development and validation together in one chapter. Finally, I will conclude the chapter by discussing the study questionnaire that was created which includes the survey instrument for medication-related stressors along with other measurements necessary for testing the research hypotheses.

#### **4.1. Preliminary Focus Groups**

In order to measure the medication-related stressors of caregivers for the current research study, it was necessary to perform some preliminary research and analysis. The Survey of Caregiver Medication Concerns (SCMC) and pharmacy support scales were developed from information obtained from focus groups, existing literature, and key opinion leaders to elicit information about medication-related issues. Two focus groups designed to explore the difficulties that dementia caregivers face when managing their loved one's medications were conducted with the assistance of the Orange County Department on Aging located in Chapel Hill, North Carolina. The inclusion criteria were: >18 years of age and primary informal caregiver responsible for medication management for their loved one with memory problems. One week prior to the focus group, reminder postcards were sent to caregivers who had agreed to participate and a courtesy call was made on the day before to confirm. As an incentive to participate, each caregiver was provided lunch and given a twenty-five dollar gift card to Wal-Mart at the end of the session. The purpose of these groups was to identify the medication-related stressors and issues so that the information could be used in instrument development. A script for the focus groups was created based on findings from the literature and questions were asked to help identify potential survey items (Appendix 1). Consent was obtained from each participant prior to the focus group. Caregivers were informed that they could leave the group at any time if they became uncomfortable. This research was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Two focus groups were conducted with a total of eighteen informal caregivers of patients diagnosed with a memory problem. Thirteen white and five black caregivers were recruited with the assistance of the Geriatric Pharmacy Specialist and social workers at the Department on Aging. The majority of the participating caregivers were female (83%). The groups were diverse in terms of the relationship of the caregiver to the care-recipient with spouses (50%), children (22%) and other relatives or friends (28%). Caregivers reported managing, on average, 5.2 prescription medications, for their loved one with memory problems.

There were three primary areas of concern that were identified by the caregivers in the focus groups. First, the caregivers talked about the issues related to administering the medications. The caregivers discussed the difficulties organizing the medications, administering more complex therapies (e.g., eye drops, inhalers), coordinating the medications appropriately with food, water or milk as needed and convincing the demented patient to take the medication. Second, the caregivers were concerned about their ability to both afford and obtain the medications. All of the caregivers reported going to their pharmacy at least three times each month to obtain prescriptions. The caregivers talked about the cost of the prescriptions and that it was becoming increasingly difficult to afford them. One caregiver had not received prescriptions from the physician for her demented loved one in the past due to her inability to pay for the drugs. Eight of the eighteen caregivers had researched having their prescriptions shipped from Canada due to cost considerations. Next, the caregivers discussed the role of side effects and medication effectiveness as a concern. The caregivers were concerned about whether or not the medication was effective, the need for them (as the caregiver) to determine and communicate

effectiveness to the demented patient's physician and their inability to manage side effects (e.g., diarrhea).

Caregivers were also asked questions about pharmacists and pharmacy services. They discussed how their pharmacist helped them manage their loved one's medications and also offered suggestions for ways that they could offer additional support. The primary areas of interest in pharmacist and pharmacy support were (1) the availability of information, (2) the availability of and access to the pharmacist, and (3) the ability of the pharmacist to work closely with their loved one's physicians on medication-related issues.

## 4.2. Scale Development

The focus group sessions were tape-recorded and were then transcribed into text. The audiotapes were erased after transcription. The content of the transcripts were analyzed by the Principal Investigator, a pharmacist, and then reviewed by another pharmacist prior to creating the initial item pool. The item pool was then shared with another group of clinicians and key opinion leaders—2 pharmacists, 1 nurse, 2 social workers— from the University of North Carolina and Duke University for further review. The purpose of this review was to further examine face validity, identify ambiguous content and edit item content. Final revisions were then made to the item pool and the survey instrument was developed to be included in the study questionnaire.

After the final revisions, a 21-item instrument (Survey of Caregiver's Medication Concerns) which would identify the **primary medication-related stressors** was ready for inclusion in the study questionnaire. The instrument was divided into three sections and the 21 items were placed in the most appropriate category: (1) eight items related to medication administration (e.g., giving medications multiple times per day, managing and organizing medications, substitute for performing the task, convincing care-recipient to take medications), (2) five items related to medication effects and side effects (e.g., knowing if medications are working, identifying adverse events and side effects of medications, communicating with patient about medications and problems) and, (3) eight items dealing with obtaining and paying for medications (e.g., ability to afford medications, visits to pharmacy). The categories and specific items that comprised this survey instrument are listed in Table 4.1.



Additional items were added to the study questionnaire to identify *secondary medication-related stressors* and covered time missed from work and social activities and times the caregiver was required to leave work early to handle medication problems. Secondary related stressors differ from the primary medication-related stressors in that they are not directly related to the tasks of managing the medications but are a by-product of the process. For example, managing a side effect (e.g., diarrhea) from the care-recipient's medication regimen is directly related to the medication process (primary medication-related stressor) while missing dinner with friends because the caregiver must stay at home with the care-recipient is a result of the primary stressor (secondary medication-related stressor). These questions address items that were also identified in the focus group conducted in the pilot project phase of this research. Caregivers were asked to recall if they had to miss an entire day from work, leave work early or miss a social activity to deal with problems associated with managing their loved one's medications. Responses were yes/no. If the caregiver responded 'yes' to one these three questions, they were asked to recall the number of times this had happened within the past 30 days. The variables identifying the numbers of times missed for each of these are continuous variables. These items are outlined in Figure 4.1.

Finally, ten items were developed to measure the caregiver's perception of their current pharmacist and pharmacy services to create a pharmacy support scale. As with the primary and secondary medication-related stressors, these items were also created from information obtained during the caregiver focus groups and from a review of the literature. Caregivers were asked to indicate their level of agreement with each statement with

responses ranging from strongly disagree (score=0) to strongly agree (score=4). These items are outlined in Figure 4.2.

**Table 4.1: Primary Medication-related Stressors: *Survey of Caregiver Medication Concerns Scale (SCMC)***

|   | Strongly<br>Disagree | Disagree | Neutral | Agree | Strongly<br>Agree |
|---|----------------------|----------|---------|-------|-------------------|
| <b>Administering Medications</b>  |                      |          |         |       |                   |
| 1. It is hard for me to give my loved one medication more than one time a day.  | 0                    | 1        | 2       | 3     | 4                 |
| 2. It is easy to manage my loved one's medications.   | 0                    | 1        | 2       | 3     | 4                 |
| 3. It is hard to organize all of my loved one's medications.  | 0                    | 1        | 2       | 3     | 4                 |
| 4. It is easier to keep track of my loved one's medications when I use a pill organizer.  | 0                    | 1        | 2       | 3     | 4                 |
| 5. I have trouble convincing my loved one to take medications.  | 0                    | 1        | 2       | 3     | 4                 |
| 6. It is hard to keep the times of day straight when giving my loved one his/her medication.                                      | 0                    | 1        | 2       | 3     | 4                 |
| 7. I worry about who will give my loved one medication if I am not able to do it.   | 0                    | 1        | 2       | 3     | 4                 |
| 8. There has been a time when I had to hide my loved one's medication.  | 0                    | 1        | 2       | 3     | 4                 |
| <b>Effects of Medications</b>   |                      |          |         |       |                   |
| 9. I worry at times that my loved one's medications are not working.  | 0                    | 1        | 2       | 3     | 4                 |
| 10. It is hard for me to know whether my loved one is having a bad reaction to his/her medications.                               | 0                    | 1        | 2       | 3     | 4                 |
| 11. I have trouble managing the side effects (for example, nausea, and diarrhea) from my loved one's medications.                 | 0                    | 1        | 2       | 3     | 4                 |
| 12. I am concerned that my loved one is not receiving the best medications for his/her condition.                                 | 0                    | 1        | 2       | 3     | 4                 |
| 13. I worry that my loved one will not be able to let me know if the medications are causing problems.                            | 0                    | 1        | 2       | 3     | 4                 |
| <b>Obtaining Medications</b>  |                      |          |         |       |                   |
| 14. I have difficulty, on occasion, paying for my loved one's medication.   | 0                    | 1        | 2       | 3     | 4                 |
| 15. I have, on occasion, decided not to fill a prescription for my loved one because money was tight.                             | 0                    | 1        | 2       | 3     | 4                 |
| 16. I have, on occasion, decided not to ask my loved one's doctor for a prescription because money was tight.                     | 0                    | 1        | 2       | 3     | 4                 |
| 17. There have been times when I have not had reliable transportation to the pharmacy to pick up my loved one's medications.      | 0                    | 1        | 2       | 3     | 4                 |
| 18. Each month, I have to make more than one trip to the pharmacy to pick up medications for my loved one.                        | 0                    | 1        | 2       | 3     | 4                 |
| 19. There have been times when my own health has prevented me from giving my loved one medication.                                | 0                    | 1        | 2       | 3     | 4                 |
| 20. I have considered getting my loved one's medications from outside of the United States because they are less expensive there. | 0                    | 1        | 2       | 3     | 4                 |
| 21. I worry that I will not be able to afford my loved one's medications in the future.   | 0                    | 1        | 2       | 3     | 4                 |

Figure 4.1 Secondary Medication-related Stressors

Have you had to miss an entire day of work to deal with problems associated with managing your care-recipient's medications? *(Circle one)*

a. No  
b. Yes

If Yes: How many times have you had missed a day of work entirely in the past 30 days to deal with these problems? \_\_\_\_\_ times

Have you been late to work or had to leave work early to deal with problems associated with managing your care-recipient's medications? *(Circle one)*

a. No  
b. Yes

If Yes: About how many times have these problems caused you to leave work early or be late for work in the past 30 days? \_\_\_\_\_ times

Have you had to miss a social activity (like being with friends or attending church) to deal with problems associated with managing your care-recipient's medications? *(Circle one)*

a. No  
b. Yes

If 'Yes: How many times have you missed a social activity in the past 30 days to deal with these problems? \_\_\_\_\_ times

**Figure 4.2 Satisfaction with Pharmacists and Pharmacy Services for Pharmacy Support Scale**

| 19. Please think about the pharmacy where you usually get your loved one's medications and answer the following questions. |                   |          |         |       |                |
|--|-------------------|----------|---------|-------|----------------|
| <i>(Circle one for each response)</i>  |                   |          |         |       |                |
|  | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
| a. The pharmacist is usually available to answer my questions about my loved one's medications.                            | 0                 | 1        | 2       | 3     | 4              |
| b. The pharmacist warns me about problems that my loved one might have with the medications.                               | 0                 | 1        | 2       | 3     | 4              |
| c. The pharmacist tells me what my loved one's medications are used for.   | 0                 | 1        | 2       | 3     | 4              |
| d. I receive advice from the pharmacist that helps me to manage my loved one's medications.                                | 0                 | 1        | 2       | 3     | 4              |
| e. The pharmacist answers any questions that I have about my loved one's medications.                                      | 0                 | 1        | 2       | 3     | 4              |
| f. I feel like the pharmacist really cares about my overall health and well-being.   | 0                 | 1        | 2       | 3     | 4              |
| g. There is a place at the pharmacy where I can talk in private with the pharmacist.                                       | 0                 | 1        | 2       | 3     | 4              |
| h. I am satisfied with the amount of time that the pharmacist spends with me.  | 0                 | 1        | 2       | 3     | 4              |
| i. I trust the pharmacist to give me the best information about my loved one's medications.                                | 0                 | 1        | 2       | 3     | 4              |
| j. The pharmacist works with my loved one's doctors to provide the best medications possible.                              | 0                 | 1        | 2       | 3     | 4              |

### **4.3. Scale Validation**

For organizational reasons and since both the primary and secondary medication-related stressors and pharmacy support are measures included in the multivariable analysis of the dissertation, the factor analysis results are included here. The domains identified in these scale validation processes will be used in the methods and results chapters that will follow. This may appear to be presented out of order; however, it is important to remember that the scale development was a major portion of this dissertation. For a description of the dissertation study questionnaire and the study population in which the scales were tested, refer to Chapters 5 and 6, respectively.

Data from the Survey of Caregiver Medication Concerns (SCMC) and pharmacy support portions of the dissertation study questionnaire (n=139) were analyzed using descriptive statistics (mean, SD, min, max) to confirm variability among responses. The responses were also examined to verify missing data. Mean imputation was performed for missing values in the medication stressor or pharmacy support items in an effort to preserve the number of observations used in the multiple variable modeling and since the amount of missing data was small with no more than 2.8% missing from any item. Any items that exhibited either a ceiling or floor effect were considered for elimination from instrument validation. Factor analyses (principal component with Promax rotation) was performed to identify the domain structure. Cronbach's alpha was calculated to measure internal consistency reliability.

#### 4.3.1. Survey of Caregiver Medication Concerns Scale

**Item-reduction Analysis:** A descriptive analysis of the original 21-items related to medication stressors revealed that there were several items that were subject to either ceiling or floor effects where the responses were not well distributed. Descriptive statistics (mean, SD, range) are included in Table 4.2. The items examined for potential exclusion because of abnormal distribution were: (1) It is easier to keep track of my loved one's medications when I use a pill organizer (mean=3.00, SD=1.27, range 0-4), (2) I have, on occasion, decided not to fill a prescription for my loved one because money was tight (mean=0.69, SD=0.97, range 0-4), (3) I have, on occasion, decided not to ask my loved one's doctor for a prescription because money was tight (mean=0.63, SD=0.86, range 0-4), (4) There have been times when I have not had reliable transportation to the pharmacy to pick up my loved one's medications (mean=0.59, SD=0.84, range 0-4), (5) There have been times when my own health has prevented me from giving my loved one medication (mean=0.92, SD=1.14, range 0-4), and (6) I have considered getting my loved one's medications from outside the United States because they are less expensive (mean=0.98, SD=1.19, range 0-4). Two other items were identified for possible exclusion as well based on their ambiguity: (1) It is easy to manage my loved one's medications and (2) It is hard to organize my loved one's medications. The responses were fairly well distributed; however, the questions were not as specific as some of the other items and their validity was questioned.

A correlation matrix was then used to determine correlations among these items with ceiling and floor effects to see if there were significant relationships between items that would warrant inclusion in the final instrument analysis. All of the items outlined above were correlated with other items in the instrument except for the question about using a pill

organizer to manage medications. Due to the specificity of this item and its relationship to being a physical task of organizing the medications, it was chosen for exclusion from the factor analysis.

In addition to some of the responses to items related to the affordability of medications not being normally distributed, there was also a concern that the implementation of the Medicare Part D prescription drug benefit during the data collection phase might have created a bias in these questions. During development of the items, there was no prescription drug benefit under the Medicare program and both the focus groups and literature suggested that the cost of medications was a major concern of caregivers. Since several of the items related to affordability were subject to the ceiling and floor effect, we decided to also exclude all five items that asked caregivers about paying for medications or their ability to afford them. The following five items were eliminated from the factor analysis: (1) I have difficulty, on occasion, paying for my loved one's medications, (2) I have, on occasion, decided not to fill a prescription for my loved one because money was tight, (3) I have, on occasion, decided not to ask my loved one's doctor for a prescription because money was tight, (4) I have considered getting my loved one's medications from outside the United States because they are less expensive, and (5) I worry that I will not be able to afford my loved one's medications in the future. Once these items were excluded, along with the one previously mentioned, there were 15 items available for the factor analysis which will be discussed in the next section of this chapter. These items used in the factor analysis are in bold type in Table 4.2.



**Table 4.2: Distribution Properties of Original SCMC Scale Items (n=139)**

| Question  | N          | Mean        | SD          | Min      | Max      |
|---|------------|-------------|-------------|----------|----------|
| <b>1. It is hard for me to give my loved one medication more than one time a day.</b>   | <b>135</b> | <b>1.36</b> | <b>1.18</b> | <b>0</b> | <b>4</b> |
| <b>2. It is easy to manage my loved one's medications.</b>  | <b>136</b> | <b>2.40</b> | <b>1.18</b> | <b>0</b> | <b>4</b> |
| <b>3. It is hard to organize all of my loved one's medications.</b>   | <b>135</b> | <b>1.41</b> | <b>1.12</b> | <b>0</b> | <b>4</b> |
| 4. It is easier to keep track of my loved one's medications when I use a pill organizer.  | 136        | 3.00        | 1.27        | 0        | 4        |
| <b>5. I have trouble convincing my loved one to take medications.</b>   | <b>136</b> | <b>1.34</b> | <b>1.28</b> | <b>0</b> | <b>4</b> |
| <b>6. It is hard to keep the times of day straight when giving my loved one his/her medication.</b>                                 | <b>136</b> | <b>1.14</b> | <b>1.09</b> | <b>0</b> | <b>4</b> |
| <b>7. I worry about who will give my loved one medication if I am not able to do it.</b>  | <b>136</b> | <b>2.27</b> | <b>1.34</b> | <b>0</b> | <b>4</b> |
| <b>8. There has been a time when I had to hide my loved one's medication.</b>   | <b>136</b> | <b>1.46</b> | <b>1.42</b> | <b>0</b> | <b>4</b> |
| <b>9. I worry at times that my loved one's medications are not working.</b>   | <b>136</b> | <b>2.24</b> | <b>1.06</b> | <b>0</b> | <b>4</b> |
| <b>10. It is hard for me to know whether my loved one is having a bad reaction to his/her medications.</b>                          | <b>136</b> | <b>1.92</b> | <b>1.19</b> | <b>0</b> | <b>4</b> |
| <b>11. I have trouble managing the side effects (for example, nausea, and diarrhea) from my loved one's medications.</b>            | <b>136</b> | <b>1.41</b> | <b>1.09</b> | <b>0</b> | <b>4</b> |
| <b>12. I am concerned that my loved one is not receiving the best medications for his/her condition.</b>                            | <b>136</b> | <b>1.58</b> | <b>1.06</b> | <b>0</b> | <b>4</b> |
| <b>13. I worry that my loved one will not be able to let me know if the medications are causing problems.</b>                       | <b>136</b> | <b>2.54</b> | <b>1.22</b> | <b>0</b> | <b>4</b> |
| 14. I have difficulty, on occasion, paying for my loved one's medication.   | 136        | 1.32        | 1.16        | 0        | 4        |
| 15. I have, on occasion, decided not to fill a prescription for my loved one because money was tight.                               | 136        | 0.69        | 0.97        | 0        | 4        |
| 16. I have, on occasion, decided not to ask my loved one's doctor for a prescription because money was tight.                       | 136        | 0.63        | 0.86        | 0        | 4        |
| <b>17. There have been times when I have not had reliable transportation to the pharmacy to pick up my loved one's medications.</b> | <b>135</b> | <b>0.59</b> | <b>0.84</b> | <b>0</b> | <b>4</b> |
| <b>18. Each month, I have to make more than one trip to the pharmacy to pick up medications for my loved one.</b>                   | <b>136</b> | <b>2.13</b> | <b>1.45</b> | <b>0</b> | <b>4</b> |
| <b>19. There have been times when my own health has prevented me from giving my loved one medication.</b>                           | <b>136</b> | <b>0.92</b> | <b>1.14</b> | <b>0</b> | <b>4</b> |
| 20. I have considered getting my loved one's medications from outside of the United States because they are less expensive there.   | 136        | 0.98        | 1.19        | 0        | 4        |
| 21. I worry that I will not be able to afford my loved one's medications in the future.   | 136        | 1.69        | 1.37        | 0        | 4        |

**Factor Analysis:** A factor analysis was performed on the remaining 15 items from the instrument which met the factor analysis requirement of having between 5 to 10 subjects per item as there were 139 caregivers in the study population (Tinsley HE, 1987). Principal component analysis with Promax rotation revealed five factors with Eigenvalues  $>1$ . Eigenvalues of the correlation matrix for this analysis are shown in Table 4.3 and the corresponding scree plot is illustrated in Figure 4.3. The scree plot shows a break between one and two factors. Upon examination of the scree plot, it was determined that two components captured approximately 40% of the variance in the model with 30% and 10% explained by the first and second factors, respectively. While this information helped to guide the decision about how many common factors to retain, I also examined the interpretability of the two factor solution.

After performing a Factor Analysis retaining two factors, I looked at (1) the simplicity of the two factor structure and (2) how well the variables fit together conceptually. The factor loadings (Table 4.4) suggested a simple factor structure with variables having moderate to high loadings (coefficient  $\geq 0.40$ ) on one construct and low loadings on the other construct. Finally, the items within each of the constructs were examined to determine whether or not they were conceptually similar within the same construct and distinctively different from the other construct. The items under each construct followed the original concept introduced and developed in the focus groups and the preliminary analysis. All of the items that were identified previously as concerns with effects and effectiveness of medications were within the medication effects construct of the two factor solution while all of the items related to administering and obtaining medications were within the medication administration construct. Therefore, two domains were identified—medication

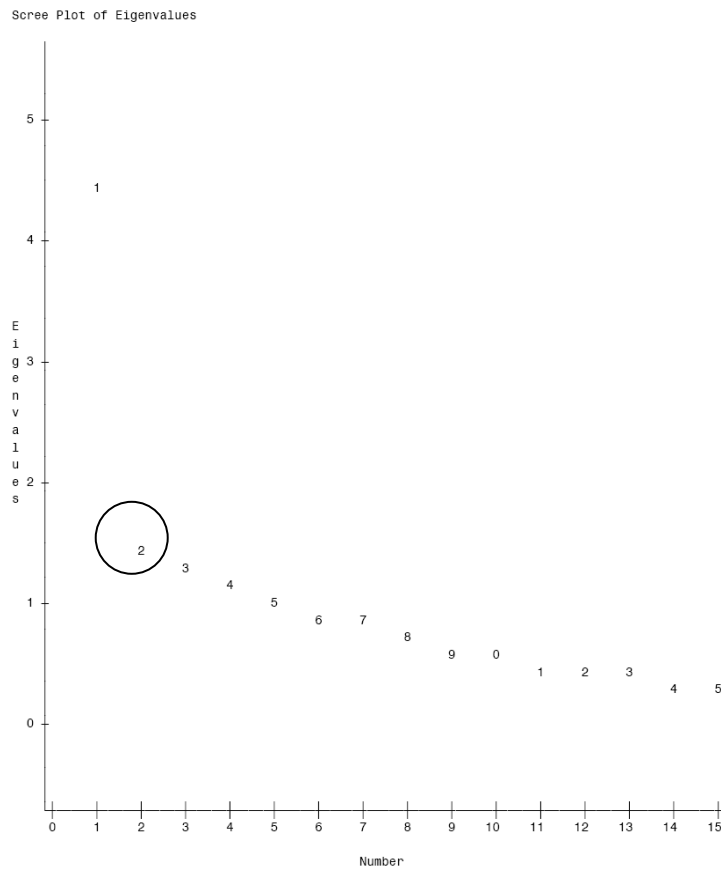
administration and medication effects—to be used for measuring the primary medication-related stressors.

The ten items loading on **medication administration** included: (1) there have been times when my own health has prevented me from giving my loved one medication, (2) it is hard to keep the times of the day straight when giving my loved one his/her medication, (3) there has been a time when I had to hide my loved one's medication, (4) I worry about who will give my loved medication if I am not able to do it, (5) each month I have to make more than one trip to the pharmacy to pick up medications for my loved one, (6) it is hard to give my loved one medication more than one time a day, (7) there have been times when I have not had reliable transportation to the pharmacy to pick-up my loved one's medications, (8) I have trouble convincing my loved one to take medications, (9) It is easy to manage my loved one's medications, and (10) It is hard to organize all of my loved one's medications. The five items loading on **medication effects** were: (1) it is hard for me to know whether my loved one is having a bad reaction to his/her medications, (2) I worry at times that my loved one's medications are not working, (3) I have trouble managing the side effects from my loved one's medications, (4) I am concerned that my loved one is not receiving the best medications for his/her condition, and (5) I worry that my loved one will not be able to let me know if the medications are causing problems. The correlation between the two domains was 0.49 ( $p < 0.0001$ ).

**Table 4.3: Eigenvalues of the Correlation Matrix (Promax Rotation) for SCMC (15 items)**

| Factors | Eigenvalue | Proportion of Variance | Cumulative Variance |
|---------|------------|------------------------|---------------------|
| 1       | 4.42597456 | 0.2951                 | 0.2951              |
| 2       | 1.48593653 | 0.0991                 | 0.3941              |
| 3       | 1.27500592 | 0.0850                 | 0.4791              |
| 4       | 1.13218215 | 0.0755                 | 0.5546              |
| 5       | 1.04695125 | 0.0698                 | 0.6244              |
| 6       | 0.87550258 | 0.0584                 | 0.6828              |
| 7       | 0.81033340 | 0.0540                 | 0.7368              |
| 8       | 0.75356335 | 0.0502                 | 0.7870              |
| 9       | 0.62997767 | 0.0420                 | 0.8290              |
| 10      | 0.59488962 | 0.0397                 | 0.8687              |
| 11      | 0.48276161 | 0.0322                 | 0.9009              |
| 12      | 0.44676983 | 0.0298                 | 0.9307              |
| 13      | 0.40481475 | 0.0270                 | 0.9576              |
| 14      | 0.32703432 | 0.0218                 | 0.9794              |
| 15      | 0.30830248 | 0.0206                 | 1.000               |

**Figure 4.3: Scree Plot of Eigenvalues for SCMC (15 items)**



**Table 4.4: Factors Loadings (Promax) of SCMC Scale (15 items)**

| <b>Item Focus</b>   | <b>FACTOR 1<br/>Medication<br/>Administration</b> | <b>FACTOR 2<br/>Medication<br/>Effects</b> |
|---|---|--|
| Own health has prevented from giving medications.                   | <b>0.674</b>                                      | -0.052                                     |
| Hard to keep the times of day straight for administering.           | <b>0.609</b>                                      | 0.102                                      |
| Had to hide loved one's medications.                                | <b>0.606</b>                                      | -0.176                                     |
| Multiple trips to the pharmacy each month.                          | <b>0.590</b>                                      | -0.235                                     |
| Hard to organize medications.                                       | <b>0.545</b>                                      | 0.240                                      |
| Worry about who will give medications if he/she unavailable.        | <b>0.532</b>                                      | 0.127                                      |
| Hard to give medications more than once per day.                    | <b>0.446</b>                                      | 0.242                                      |
| No reliable transportation to pharmacy at times.                    | <b>0.444</b>                                      | 0.117                                      |
| Trouble convincing loved one to take medication.                    | <b>0.401</b>                                      | 0.263                                      |
| Easy to manage loved one's medications.                             | <b>-0.498</b>                                     | -0.174                                     |
| Hard to identify adverse reactions to medications.                  | -0.116  | <b>0.819</b>                               |
| Worry that medications are not working.                             | -0.056  | <b>0.734</b>                               |
| Trouble managing the side effects of medications.                   | -0.007  | <b>0.646</b>                               |
| Concerned that loved one not receiving best medications.            | 0.072   | <b>0.627</b>                               |
| Worry that loved one can not communicate problems with medications. | 0.069   | <b>0.602</b>                               |

**Internal Consistency:** Cronbach's  $\alpha$  for both factors exceeded the standard criterion for reliability of  $\geq 0.70$  with values for medication administration and medication effects being 0.77 and 0.74, respectively. Table 4.5 shows the reliability estimates along with the distribution of the factors. Since this was a study questionnaire administered at one single point in time with no follow-up surveys, it was not possible to perform test-retest reliability within the scope of this dissertation.

**Table 4.5: Reliabilities and Descriptive Statistics of Factors**

| <b>Factor</b>  | <b>N</b> | <b># of Items</b> | <b>Mean</b> | <b>SD</b> | <b>Range</b> | <b>Cronbach <math>\alpha</math></b> |
|--|----------|-------------------|-------------|-----------|--------------|-------------------------------------|
| <b><i>Factor 1</i><br/>Medication<br/>Administration</b> | 133      | 10                | 14.21       | 6.91      | 0-31         | 0.77                                |
| <b><i>Factor 2</i><br/>Medication<br/>Effects</b>        | 136      | 5                 | 9.68        | 3.91      | 0-20         | 0.74                                |

#### 4.3.2. Pharmacy Support Scale

**Item-reduction Analysis:** A descriptive analysis of the 10-item pharmacy support scale that measured caregiver's perception of pharmacists and pharmacy services revealed that there were no items subject to either floor or ceiling effects. Therefore, all items remained in the scale for factor analysis and the test for reliability. Descriptive statistics for these items are in Table 4.6.

**Table 4.6: Descriptive Statistics for the Pharmacy Support Scale (n=133)**

|   | <b>Mean</b> | <b>SD</b> | <b>Range</b> |
|---|-------------|-----------|--------------|
| <b>The pharmacist is usually available to answer my questions about my loved one's medications.</b> | 2.96        | 0.96      | 0-4          |
| <b>The pharmacist warns me about problems that my loved one might have with the medications.</b>    | 2.29        | 1.21      | 0-4          |
| <b>The pharmacist tells me what my loved one's medications are used for.</b>                        | 2.17        | 1.22      | 0-4          |
| <b>I receive advice from the pharmacist that helps me to manage my loved one's medications.</b>     | 2.21        | 1.17      | 0-4          |
| <b>The pharmacist answers any questions that I have about my loved one's medications.</b>           | 2.88        | 0.96      | 0-4          |
| <b>I feel like the pharmacist really cares about my overall health and well-being.</b>              | 2.37        | 1.14      | 0-4          |
| <b>There is a place at the pharmacy where I can talk in private with the pharmacist.</b>            | 1.81        | 1.22      | 0-4          |
| <b>I am satisfied with the amount of time that the pharmacist spends with me.</b>                   | 2.37        | 1.07      | 0-4          |
| <b>I trust the pharmacist to give me the best information about my loved one's medications.</b>     | 2.67        | 1.05      | 0-4          |
| <b>The pharmacist works with my loved one's doctors to provide the best medications possible.</b>   | 2.10        | 1.05      | 0-4          |

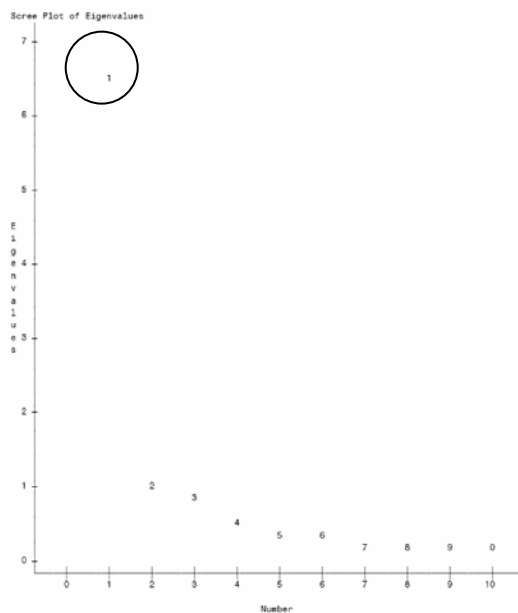
**Factor Analysis:** A factor analysis was performed on the 10-item pharmacy support scale.

As with the SCMC, this instrument met the factor analysis requirement of 5 to 10 subjects per item. Principal component analysis revealed only one factor with an Eigenvalue  $>1$ . Eigenvalues from this analysis are shown in Table 4.7 and the corresponding scree plot is demonstrated in Figure 4.4. The one-factor solution revealed high factor loadings ( $>0.50$ ) with these values shown in Table 4.8.

**Table 4.7: Eigenvalues of the Correlation Matrix for Pharmacy Support Scale (10 items)**

| Factors | Eigenvalue | Proportion of Variance | Cumulative Variance |
|---------|------------|------------------------|---------------------|
| 1       | 6.50804977 | 0.6508                 | 0.6508              |
| 2       | 0.96592009 | 0.0966                 | 0.7474              |
| 3       | 0.79139692 | 0.0791                 | 0.8265              |
| 4       | 0.46387960 | 0.0464                 | 0.87298             |
| 5       | 0.30787003 | 0.0308                 | 0.9037              |
| 6       | 0.25586933 | 0.0256                 | 0.9293              |
| 7       | 0.20984168 | 0.0210                 | 0.9503              |
| 8       | 0.20180943 | 0.0202                 | 0.9705              |
| 9       | 0.16617894 | 0.0166                 | 0.9871              |
| 10      | 0.12918332 | 0.0129                 | 1.000               |

**Figure 4.4: Scree Plot of Eigenvalues for Pharmacy Support Scale (15 items)**



**Table 4.8: Factors Loadings of Pharmacy Support Scale (10 items)**

| Item Focus   | Factor Loading |
|--|----------------|
| Pharmacist cares about caregiver's overall well-being                | 0.899          |
| Receive advice from pharmacist that helps manage medications.        | 0.865          |
| Satisfaction with the amount of time spent with pharmacist.          | 0.860          |
| Pharmacist explains what medications are used for.                   | 0.843          |
| Pharmacist warns about medication problems.                          | 0.830          |
| Trust the pharmacist to give the best information about medications. | 0.827          |
| Pharmacist works with doctor to provide best medications.            | 0.799          |
| Pharmacist answers questions about medications.                      | 0.791          |
| Pharmacist available to answer questions.                            | 0.730          |
| Private place at the pharmacy to talk to pharmacist.                 | 0.575          |

**Internal Consistency:** Cronbach's  $\alpha$  for the one-factor solution was 0.94. Table 4.9 shows the reliability of the scale along with the distribution of the scores. As with the SCMC, it was not possible to perform test-retest reliability with this cross-sectional survey of caregivers.

**Table 4.9: Reliabilities and Descriptive Statistics of Pharmacy Support Scale**

| Factor           | N   | # of Items | Mean  | SD   | Range | Cronbach $\alpha$ |
|------------------|-----|------------|-------|------|-------|-------------------|
| Pharmacy Support | 133 | 10         | 23.79 | 8.94 | 0-40  | 0.94              |



#### 4.4. Research Study Questionnaire

Most surveys of dementia caregivers, including the National Longitudinal Caregiver Sample conducted in caregivers of veterans with AD and vascular dementia, have only measured the medication-related activities of the caregiver in terms of time spent on the caregiver activity using a caregiver activities time survey. There was no public or private dataset available for use in this study that had measured specific medication-related concerns of caregivers of demented patients. In order to achieve the specific aims outlined in this proposal, it was necessary to perform primary data collection. A self-report study questionnaire was designed to collect all of the information to examine the proposed conceptual framework outlined in Chapter 2 (Section 2.7).

Using existing literature, key opinion leaders and results from the SCMC instrument development, a study questionnaire, *Caregivers of Persons with Memory Problems: The Medication Study*, was designed as a caregiver self-report survey to elicit caregiver and care-recipient contextual information (e.g, demographics, health status), medication-related stressors (e.g, issues with administering medications, managing effects and side effects of medications, obtaining prescription medications), social support (e.g., family members, friends, pharmacists) and emotional health outcomes (e.g., depression). The overall process will be outlined in this section and will be followed by sections that detail the data elements collected and the analysis performed.

An initial list of data elements was created that included all of the variables required for analysis (outlined in Chapter 3). For each data element, we determined the number(s) of questions needed to obtain the necessary information and whether or not we would create the

question(s) or use survey instruments that had been proven reliable and valid in previous research. Each of these data elements were grouped into one of four categories based on the conceptual model: (1) caregiver and care-recipient contextual information, (2) caregiver resources, (3) medication-related stressors, and (4) caregiver emotional health outcomes. The source, question/item construction, range of responses, and reliability/validity information for each of the items organized under these four categories are detailed in the Measurement section of Chapter 5 (Section 5.3).

Once all necessary items were identified, a draft questionnaire was circulated to a group of survey experts for feedback. This group included three pharmacists, one nurse, two social workers and a statistician—all who had experience and familiarity with survey research methodology and questionnaire development. The process from this point was an iterative one with adjustments being made to improve the consistency of questions, to enhance the readability and understandability, and to eliminate or correct ambiguous questions. Most of the changes to the survey were minor changes in wording or structure of questions. However, a few key things were done to improve the appeal of the questionnaire and to provide a positive frame of reference for the survey respondent (caregiver). First, the term “loved-one” was eliminated from the questionnaire in as many places as possible and replaced with the term “care-recipient.” This was done because “loved one” often has different meanings to different caregivers. Next, the term “dementia” and “demented patient” were removed from the entire survey and replaced with “memory problems” and “persons with memory problems.” Again, this was done in an effort to soften the tone of the survey. Finally, a blank page was included at the end of the survey that asked the caregiver to share any additional thoughts or ideas that they had about managing the care-recipients

medications or the caregiving process, in general. This opportunity, along with a note of appreciation, helped to leave the caregiver with a positive feeling about their participation. Once all changes had been made, one final draft showing the comments and changes was sent to all reviewers for final approval prior to printing.

This final draft was also shared with three caregivers who had participated in the focus groups to determine the time required to complete the questionnaire. On average, it took these caregivers 16 minutes to answer all of the questions. This seemed appropriate and was not considered too burdensome from a time perspective. The final questionnaire was prepared in a 12-point font for ease of reading and then printed and bound into a booklet format. The final version of the questionnaire is in Appendix 2.

## **CHAPTER FIVE**

### **METHODS**

#### **5.1. Study Population**

Adults who were primary informal caregivers of persons with memory problems were the targeted population for this research study. While there was no medical record review of the care-recipient to confirm the diagnosis of memory problems, caregivers were asked to self-report whether or not the care-recipient had received a formal diagnosis of either AD, vascular dementia or another form of memory problem. In order to participate in the study, the caregivers were required to (1) be  $\geq 18$  years old, (2) be able to read and write in English, (3) be the primary informal caregiver for the demented patient, and (4) be responsible for medication administration and/or management for the care-recipient. Adult caregivers who are the primary caregiver for the demented patient are at highest risk for poorer mental and physical health outcomes (Clipp and Moore 1995). Thus, the targeted population represented an appropriate high-risk group. Caregivers who participated in the pilot phase of this project (focus groups) where the SCMC and pharmacy support scales were developed (outlined in Chapter 4) were not eligible to participate in this formal research study. This research was approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

## **5.2. Caregiver Recruitment and Data Collection**

Caregivers of persons with memory problems were recruited using several partnerships that were developed by the Principal Investigator. There were four primary sources of caregivers: (1) Geriatric and Memory Disorder clinics within the medical center at the University of North Carolina at Chapel Hill, (2) Eastern and Western North Carolina Chapters of the Alzheimer's Association, (3) local, county and regional Departments on Aging and Councils on Governments throughout the state of North Carolina, and (4) an online caregiver support group, "The Alzheimer's List (<http://alzheimer.wustl.edu/adrc2/alzheimerlist/>).” These resources were targeted because they each allowed direct access to a group of primary informal caregivers of persons with memory problems, either through patient/caregiver visits with a physician or in a caregiver support group setting. It was believed that this strategy would also offer diversity and provide access to caregivers from a range of socioeconomic backgrounds.

The Principal Investigator (PI) communicated initially with each key contact at these organizations, either by telephone or electronic mail, to introduce the research study. If the identified contact person was not responsible for interactions with the dementia caregivers, the PI was given the appropriate contact information and approached those individuals. Once the appropriate contact person was identified, more detailed telephone conversations or face-to-face meetings were held to outline the purpose of the research study and develop a strategy for making contact with caregivers. Each support group and organization was structured differently and specific contact strategies were needed for each partnership

opportunity. Certain support groups would allow presentations, others would only permit a brief explanation of the study and others did not allow outside participation at all.

Between December 2005 and August 2006, the Principal Investigator spent time with caregivers during clinic visits, visited eleven caregiver support groups through the state of North Carolina, worked with three other support groups who would not allow personal visits by mailing a packet of surveys and posted two requests (one month apart) on “The Alzheimer’s List” listserv requesting caregivers to participate. The UNC Geriatric and Memory Disorders clinics were visited one day a week for a total of three months (January-March in Geriatric clinic; May-July in Memory Disorders clinic). The caregivers were approached about the research study after the physician or multidisciplinary team had seen the patient. The visits to each clinic were discontinued after three months because of the decrease over time in the number of eligible participants due to earlier participants returning for follow-up visits.

Caregiver support groups were offered an educational program entitled, *Medications and Memory Problems*. The program outlined the basic categories of prescription and over-the-counter medications used in treating patients with dementia and provided useful tips for helping the caregiver better manage the medication process. The Principal Investigator, a pharmacist, presented this program during a scheduled support group in return for the opportunity to introduce the research study and distribute study questionnaires to interested caregivers. Three caregiver support groups were unable to coordinate a meeting time for the program or the facilitator did not allow presentations during their meeting time. For these groups, the caregiver facilitators were sent a packet of surveys to distribute to their caregivers during their meeting.

Using all of these resources, a total of 189 caregivers were contacted and provided with a study questionnaire. As an incentive for completing the study questionnaire and to maximize response, all study caregivers who returned a completed survey were sent a check for fifteen dollars. The initial survey packet (study questionnaire, cover letter, informed consent form and contact card) was distributed to the caregivers in various manners depending on the type of contact with the caregiver. For caregivers who were given the packet during a clinic visit or at support group meeting, the PI collected contact cards and signed informed consent forms at the time of distribution. For the three support groups where the PI was not present at the meeting, the meeting facilitator followed the same distribution process as the PI. Completed contact cards and informed consent forms were mailed to the PI for follow-up. If the caregiver was recruited over the online listserv, the initial packet was mailed to the caregiver with a detailed instruction sheet that asked them to return the signed consent form with their completed survey. Contact information for these caregivers was obtained by electronic mail. All caregiver contact information was loaded into a secure, password-protected database so that the information could be used for follow-up procedures.

To maximize survey response rate, procedures recommended by Dillman was used (Dillman 2000). Each study questionnaire that was initially given to a caregiver was accompanied by a personalized cover letter reinforcing the importance of the study and thanking the caregiver for participating. A self-addressed stamped envelope was included with the study questionnaire. One week after the caregiver was given a study questionnaire; he/she was sent a letter thanking them for participating in the study and reminding them to return the questionnaire, if they have not already done so. If the study questionnaire had not

been returned within three weeks of them receiving it, caregivers were sent a letter encouraging them to complete the questionnaire and return it to us at their earliest convenience. A replacement questionnaire and self-addressed, stamped return envelope was included with the letter. If the questionnaire had not been returned within eight weeks of initially receiving it, caregivers were sent a similar follow-up packet. Caregivers who did not return the questionnaire after the eight-week mailing were contacted by telephone or email, depending on the contact information available, to determine if they were still interested in participating in the study. If the participant was no longer interested in participating, no further follow-up was conducted. If they were interested in participating, a final study questionnaire was mailed to the caregiver. No further contact was made with the caregiver after this mailing. Each letter used throughout the follow-up process is located in Appendix 3.



### 5.3. Measurements

This section will outline the four categories of data collected in the study questionnaire, *Caregivers of Persons with Memory Problems: The Medication Study*. The first category is caregiver and care-recipient contextual information. This category includes sociodemographic variables (background and context) for both the caregiver and care-recipient and medical/functional status of the care-recipient. Next, information about caregiver resources is categorized to describe their subjective social support, their health status, their perceived financial adequacy, and their satisfaction with pharmacists and pharmacy services. Third, the medication-related stressors that were experienced by the caregiver are defined. This category included instrument development as there was no current survey tool available. Complete details of the development of this scale were detailed in Chapter 4. This section will also include the 10 items asked about satisfaction with pharmacist and pharmacy services. Finally, the caregiver emotional health outcome (depression), which is the critical endpoints of the conceptual model, is detailed. This section is inclusive of all items and measures in the study questionnaire regardless of their inclusion in the analyses required for the research study. Specific measures that were modeled in the multivariable analyses are discussed in the Data Analysis section (Section 5.4) of this chapter.

### 5.3.1. Caregiver and Care-recipient Contextual Information

**Sociodemographics:** The following variables were collected for both the caregiver and care-recipient: age, gender, ethnicity (American Indian/Alaskan, Asian, Black/African American, Native Hawaiian or Pacific Islander, White, Hispanic/Latino), marital status (married, separated, divorced, widowed, never married), and education level (less than high school, high school diploma or more). Information was also asked about how long the caregiver had been caring for the care-recipient, cohabitation with the care-recipient (yes=1; no=0), and whether or not he/she was a caregiver for someone else (yes=1; no=0). Age and length of time as a caregiver were continuous variables. The categorical variables for ethnicity and marital status were dichotomized and the caregivers were described as being White or non-White and married or not married.

**Care-recipient Medical Comorbidities:** The number of comorbid conditions was captured using the Older American Resources and Services (OARS) comorbidity scale, which asked the caregivers to indicate the presence (yes) or absence (no) of 25 medical conditions (Haley et al 1996). One additional item (the presence of pain) that was not included in the original survey was added to the list of comorbidities. Comorbid psychosocial symptoms including pain are prevalent in the demented elderly; therefore, we thought that it was important to add this item to the comorbidity scale (Snow A 2005). The caregiver was asked to report the number of conditions for their loved one. The score was summed for a possible range of 0-26 with a higher value indicating the presence of more medical comorbidities.

**Care-recipient Functional Status:** The number of IADLs that could be performed independently by the demented patient was measured using part of the OARS

Multidimensional Functional Assessment questionnaire (Fillenbaum 1988). The OARS IADL instrument consists of seven items that measure the help needed by the demented patient for instrumental activities of daily living. Each item was given a score of 1 to 3 resulting in a possible range of 7 to 21 with higher scores indicating a higher level of assistance needed.

**Care-recipient Medications:** The caregiver was asked to recall the number of prescription medications that the care-recipient was taking at the time of the survey and was directed to retrieve the bottles and count the number of medications, if necessary, in order to provide an accurate count. Instructions were also given to exclude any over-the-counter or herbal medications. The number of medications was a continuous variable. Caregivers were also asked whether or not their care-recipient was covered by prescription drug insurance. The responses (yes=1; no=0) created a dichotomous variable. If the caregiver responded ‘yes’ to this question, they were asked to indicate which type of insurance coverage based on the following categories: private insurance, Medicaid, Veterans Administration, Medicare or other. Caregivers were also asked to indicate the number of pharmacies that they routinely used for obtaining prescription medications and this variable was continuous. The names of the pharmacies used by the caregivers were listed and categorized by the PI into one of three categories: chain, independent, or mail order pharmacy.

Table 5.1 presents a summary of care-recipient and caregiver contextual measurements included in the research study questionnaire.

**Table 5.1: Summary of Care-recipient and Caregiver Contextual Information Measurements**

| <b>Variable</b>                    | <b>Type/Range</b> |
|------------------------------------|-------------------|
| <b>Care-recipient</b>              |                   |
| Number of patient comorbidities    | 0-26; discrete    |
| Patient IADLs                      | 7-21; discrete    |
| Age                                | Continuous        |
| Gender                             | Dichotomous       |
| Ethnicity                          | Dichotomous       |
| Number of prescription medications | Discrete          |
| <b>Caregiver</b>                   |                   |
| Age                                | Continuous        |
| Gender                             | Dichotomous       |
| Ethnicity                          | Dichotomous       |
| Education                          | Dichotomous       |
| Marital Status                     | Dichotomous       |
| Caregiver for Others               | Dichotomous       |
| Lives with care-recipient          | Dichotomous       |
| Length of time as caregiver        | Continuous        |

### 5.3.2. Stressors

The concerns with medication management were measured in two ways—primary and secondary medication-related stressors. *Primary medication related-stressors* were measured using the two factors identified in the SCMC scale development (Chapter 4). Those two factors were medication administration (10 items) and medication effects (5 items). Each item within the two factors was scored from 0-4 with a range of 0-40 for medication administration and 0-20 for medication effects. A higher score represented a greater level of concern or burden within that domain. These scales were found to be reliable as presented in Chapter 4 (Section 4.3.2) with a Cronbach's alpha of 0.77 for medication administration and 0.74 for medication effects.

*Secondary medication-related stressors* were measured by asking three questions that inquired about missing an entire day of work, leaving work early, or missing a social activity within the past 30 days to deal with problems associated with managing the care-recipient's medications. Responses were yes/no and the variables were dichotomous. If the caregiver responded 'yes' to one of these questions, they were asked to report the number of times within the past 30 days that this had occurred.

*Caregiver Activity Survey:* While it is important to understand the specific medication-related stressors of caregivers, it remains important to evaluate the time that caregivers spend on their caregiving tasks. This study questionnaire included the Caregiver Activity Survey (CAS) that measured the time spent caring for the person with memory problems (Davis et al 1997). The instrument covers six areas of caregiving activities—communicating with the person, using transportation, dressing, eating, looking after one's appearance and supervising the person—and asks the caregiver to anticipate, on average, the

time spent performing the task in a typical 24-hour period. The reports of time spent on the activities were summed to create one 'time' variable that represented the total time spent on caregiving. If caregiver responses yielded a total time measurement that exceeded the 24 hour period, the total time was capped at 24 hours for the purposes of modeling. The six-item CAS total score has high test-retest reliability, with ICC = 0.88 between weeks 1 and 3 (Davis et al 1997). Convergent validity was also tested by Davis et al in 1997 by assessing the correlation between the CAS and other AD measures—Alzheimer's Disease Assessment Scale Cognitive Subscale (ADAS-Cog), Mini Mental State Exam (MMSE), and Physical Self Maintenance Scale (PSMS). The CAS total time scores were found to be positively correlated with ADAS-Cog and PSMS with  $r=0.69$  ( $p<0.0001$ ) and  $r=0.51$  ( $p<0.0001$ ), respectively. The total time scores were found to be negatively correlated with the MMSE ( $r=-0.63$ ;  $p<0.0001$ ).

### 5.3.3. Caregiver Resources:

**Social Support:** Caregiver social support was measured using a modified, 11-item version of the Duke Social Support Index (DSSI) that measures subjective social support (Koenig et al 1993). The seven items that are related to subjective social support of the caregiver were summed to create the support measure. Items were scored on a scale of 1 to 3 resulting in a total score range of 3-21 with higher scores indicating a higher level of subjective social support. One question, related to the satisfaction of the caregiver with their kind of relationships with their family and friends, required reverse scoring; otherwise, all other questions were scored based on the caregiver's responses in the study questionnaire. There were no weights required for items when scoring. Internal consistency, using Cronbach's alpha, has been reported in different types of populations and ranges between 0.71 and 0.81 (Koenig, 1993).

**Caregiver Self-reported Health:** Caregiver perceived health status was measured using the SF-12 Health Survey. The short version was used to limit respondent burden and it provides a reliable estimate of caregiver perceived health status. This instrument has been proven to be both valid and reliable with Cronbach's alpha of 0.91 (Ware et al 1996). The SF-12 includes a physical component (e.g., physical functioning, bodily pain, general health) and a mental component (e.g., vitality, social functioning, emotional and mental health) and two scores were reported with a range from 0 to 100 for each where a higher score indicates better health. Scoring was performed using the online scoring software for SF12-v2 (QualityMetric, Inc.) and the accompanying scoring algorithms. This scoring tool includes algorithms that handles missing responses and computes the scale and summary scores without deleting observations.

**Perceived financial adequacy:** This was measured using three questions that assess the degree to which bills are burdensome, the degree to which money meets their basic needs and the adequacy of income to buy extras (Fillenbaum 1998). Responses were measured on a 3-point scale with a possible range from 1 (low financial well-being) and 3 (high financial well-being). The items were summed for a range of scores from 3-9. There was no weighting or reverse scoring required for this measurement. This variable was used to indicate the caregiver's perceived financial adequacy.

**Pharmacy Support:** Ten items were included in the study questionnaire to assess the caregiver's perceptions of their pharmacist and pharmacy. The primary areas covered by 8 of the 10 questions included availability of and communication and interaction with the pharmacist. The other two questions focused on the privacy of consultation within the pharmacy and the pharmacist's relationship with their care-recipient's physician(s). Each of these items were scored on a scale of zero (strongly disagree) to 4 (strongly agree) with higher scores representing a higher level of perceived satisfaction with their current pharmacy and pharmacy services. All ten items were shown to be highly correlated to one another which resulted in a one-factor solution in the scale validation process described previously (Section 4.3.2). The scale was reliable with Cronbach's  $\alpha=0.94$ . All ten items were summed to create a continuous variable with a possible range from 0 to 40.



#### 5.3.4. Caregiver Emotional Health Outcome

The standardized instrument included in the questionnaire to measure the emotional health outcome of the caregiver was the abbreviated version of the Patient Health Questionnaire (depression presence and severity).

**Depression:** The abbreviated version of the original Patient Health Questionnaire (PHQ-9) was included to assess depression presence and severity. The PHQ is a self-administered depression module of the PRIME-MD diagnostic instrument for common mental disorders. This version consists of the actual criteria upon which the diagnosis of the Diagnostic and Statistical Manual of Mental Disorders, Fourth Editions (DSM-IV) depressive disorders is based. The module presents nine depressive symptoms. Respondents were asked to recall the past two weeks and score the presence of each symptom on a scale from 0 to 3 (0=not at all; 1=several days; 2=more than half the days; 3=nearly every day). The scores for each item of the nine items are summed to create an overall score range of the PHQ-9 is 0 to 27. Higher scores represent a greater level of depression presence and severity. None of the items require reverse scoring nor are there any weights applied to any of the items. Using this instrument, depression presence and severity can also be categorized as minimal (score 0-4), mild (score 5-9), moderate (10-14), moderately severe (15-19) and severe (score  $\geq 20$ ) (Kroenke, 2001).

This shorter version of the PHQ was used since it has been shown to be equally valid and reliable as the longer version to measure depression severity (Kroenke, 2001). Criterion validity has been performed by using an independent Mental Health Professional (MHP) interview as a standard. For PHQ-9 scores greater than or equal to 10 (indicating at least moderate depressive severity) there was a sensitivity of 88% and a specificity of 88% for

major depression using the MHP as the criterion standard (Kroenke, 2001). Cronbach's alphas ranging from 0.86 to 0.89 have been reported in studies within a variety of practice settings (Spitzer, 1999; Spitzer, 2000).

In order to obtain information about things that the caregivers were currently doing to alleviate depressive feelings or symptoms, a series of questions were developed. First, one general question, "In the past 2 weeks or so, have you been feeling sad or depressed or no interest in things," was asked. This question was not included to either replace the PHQ-9 measurement or to be used in conjunction with it. It was only included to solicit information about strategies being employed by caregivers to manage their feelings of being "sad, depressed or no interest in things" and is used for descriptive purposes only for this study and for purposes of future research. If the caregiver responded 'yes' to this question, they were then asked what types of things they were currently doing to help them get over these feelings. The following options were given to solicit this information from the caregiver: (1) nothing, (2) taking an antidepressant medication, (3) taking herbal medicines or natural supplements, (4) getting counseling from a mental health professional, (5) getting counseling from a health care provider, (6) going to a support group, and (7) talking with someone at church.

## **5.4 Data Analysis**

### **5.4.1. Preliminary Analysis**

All data analysis was performed using SAS Version 9.1 (Cary, North Carolina) after converting the dataset from the SPSS program where the data were entered. Preliminary analysis was performed to clean the data, assess violations of assumptions, and identify potential confounders. Descriptive analyses were performed to describe the sample. The distributions of variables to be used in the primary analyses were also examined.

Frequencies and percents were used to summarize categorical measures, and means, standard deviations, ranges and frequency plots were used to describe continuous measures. Bivariate relationships were assessed using t-tests, correlations, and chi-square statistics.

#### **5.4.2. Outliers/Missing Data**

Steps were taken to (1) ensure data integrity and appropriateness and (2) to understand the missing data patterns and impute missing data. The first step to ensure the integrity and appropriateness of the data was to check the accuracy of the data coding and the entry into the computer program (SPSS). This was done by pulling a random sample of 25% of the original study questionnaires (n=35) and comparing the data that was entered into the computer database to the responses that were on the hard copies. There were no discrepancies identified. The entire dataset was then scanned for values that were outside of the ranges for the variables. There were a 3% error in cases (4 out of 139 questionnaires) where a data point was outside of the appropriate range. The hard copy questionnaires were pulled to examine the responses. In each one of the cases, the data had been entered incorrectly into the database. Each of the errors was corrected and the final data was found to lie within the necessary parameters.

Following the test for integrity and accuracy, the data was then scanned for missing data and it was determined that the proportion of missing data for any of the dependent or independent variables that were being modeled was less than 5%. The data was also scanned to determine if there were trends in the missing data that indicated that an item was subject to refusal of reporting. The majority of the data that was missing was done by the respondent not completing an entire page of the study questionnaire or not finishing the questionnaire. Before deciding on the method for handling the missing data, it was necessary to determine if the data were missing at random. In order to test this, the respondents were divided into two groups: (1) those with missing responses (n=40) and (2) those without missing responses (n=99). A t-test of mean differences on all key independent and dependent variables

(outlined in Sections 5.3.1-5.3.4) was performed to establish that the two groups did not differ significantly. None of these mean differences between groups were found to be significant at  $p \leq 0.05$ . Although a listwise deletion method of dropping the observations with missing values could be used for a small amount of missing data (<5%) and data found to be missing at random, we decided to use an imputation method which allowed us to keep all observations (n=139) in each multivariable analysis. Missing values for any variable—including continuous, discrete and categorical variables—were substituted with the mean value for that variable. All substitutions were made prior to regression analyses and before any of the multi-item scales were created.

### 5.4.3. Analysis by Aims

**Aim 1: To examine the relationship between the medication-related stressors experienced by the caregiver and caregiver depression.**

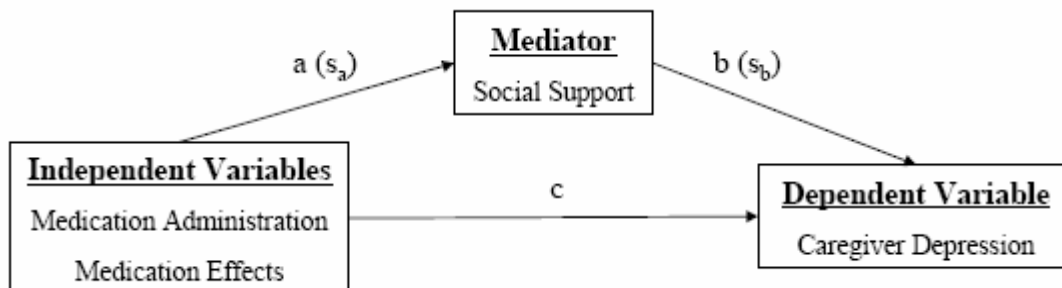
Caregiver emotional health—depression presence and severity—was the dependent variable used in this analysis. Because the distribution of the depression scores was skewed to the right, this variable was transformed by taking the square root of the score. A frequency plot verified that this transformed variable was normally distributed. Therefore, the dependent variable for depression was the square root of the caregiver's PHQ-9 depression score and it was modeled as a continuous variable. The independent variables that were modeled included the caregiver and care-recipient contextual factors, caregiver resources, and medication related stressors that were outlined in the conceptual model (Chapter 2) and measurement (Chapter 5) sections.

All caregiver sociodemographic variables (age, gender, race, marital status, and education) were included in the model. In addition, a bivariate analysis using t-tests was performed to determine the association between the emotional health outcome and the other independent variables which were measured under caregiver and care-recipient contextual factors (Section 5.3.1), medication-related stressors and caregiver resources. Only independent variables that were statistically significant in the bivariate analysis were modeled in the multivariable analysis. Both the caregiver sociodemographic variables and the significant variables from the bivariate analysis were added in stages during the multivariable analysis. First, the caregiver and care-recipient contextual factors were added. In the second stage, the stressors were added. Finally, the caregiver resources were added to the model. Tolerance statistics were also calculated with the PROC GLM procedure in SAS

to measure the strength of the interrelationships between the independent variables. In order to test the assumptions of the model, residuals were also calculated and examined for the model. A histogram of the residual values was plotted to test for a normal distribution. The residuals were also plotted against the predicted values to ensure that their distribution was scattered randomly around zero.

A Sobel test was conducted to test for the size and significance of the indirect effect of social support as a mediator between the medication-related stressors and caregiver depression (Baron and Kenny, 1986). This was done to test whether social support, the mediator, carries the influence of medication-related stressors (independent variables) to caregiver depression (dependent variable). Two tests were conducted with medication administration and medication effects both tested as the independent variable. The mediation, path coefficients (a, b and c) and standard errors of the path coefficients ( $s_a$  and  $s_b$ ) are illustrated in Figure 5.1. The test of the indirect effect was calculated using the formula,  $ab/\sqrt{b^2s_a^2 + a^2s_b^2}$ , and treating the ratio as a Z test. The Z statistic was test at the 0.05 significance level.

**Figure 5.1: Illustration of Mediator Model**



**Aim 2: To examine the association between the caregiver primary medication-related stressors and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

The primary stressors were the factors identified in the SCMC scale validation and factor analysis. Each domain—medication administration and medication effects—were measured using continuous variables and modeled with ordinary least square (OLS) regression. A bivariate analysis using t-tests was performed to determine the association between the medication-related stressors and the caregiver and care-recipient contextual variables (except for the caregiver sociodemographics). Then, both the caregiver sociodemographic variables and the significant variables from the bivariate analysis were modeled simultaneously in the multivariable analysis. Tolerance statistics and residuals were measured as in Aim 1.



**Aim 3: To examine the association between the secondary medication-related stressors (e.g, time missed from work, social activities and family functions) of the caregiver and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

Initially, caregiver secondary medication-related stressors were measured as three separate dependent variables—number of times missed work, number of times left work early/got to work late, and number of missed social activities. Multivariable modeling to predict either missing work or leaving work early was designed to be run using only caregivers who reported being employed on either a part or full-time basis; however, only 53 caregivers (39%) were employed at the time of the survey. This resulted in too small of a sample size for a valid regression model that would have also required controlling for the level of employment (e.g., part-time versus full-time). Therefore, this analysis was dropped from the study and will not be reported as originally planned. The variable for number of times a caregiver missed social activities was analyzed and it was modeled as a continuous variable in this analysis. Again, a bivariate analysis using t-tests was performed to determine the association between the number of missed social activities and the caregiver and care-recipient contextual variables (except for the caregiver sociodemographics). Then, both the caregiver sociodemographic variables and the significant variables from the bivariate analysis were modeled simultaneously in the multivariable analysis. Tolerance statistics and residuals were measured as in Aims 1 and 2.

**Aim 4: To describe caregivers attitudes about pharmacists and pharmacy services and determine what caregivers believe can be done to assist them with medication-related concerns.**

Both quantitative and qualitative analyses were performed for this Aim. A descriptive analysis is presented to demonstrate the caregiver's satisfaction with their current pharmacy care delivery system and whether or not they view pharmacists as a current and potential mechanism of support for medication-related concerns. At the end of the questionnaire the caregivers were asked to, "Please use this space to share with us any other thoughts or ideas that you have about managing your loved one's medications or about caregiving, in general." A qualitative analysis of these free-form comments (Appendix 4) that referred to pharmacists and pharmacy services is also incorporated.

## CHAPTER SIX

### RESULTS

#### 6.1. Study Population

##### 6.1.1. Caregiver Demographics

A total of 189 caregivers were recruited and provided with a study questionnaire for the research, *Caregivers of Persons with Memory Problems: the Medication Study*.

Completed questionnaires were received for 139 caregivers for an overall response rate of 74%. The demographics of the participating caregivers are outlined in Table 6.1. The responding caregivers were older adults with an average age of 61.4 years (SD=12.2) and a range from 29 to 87 years. The majority of the caregivers were female, 102 (74.8%), and White, 113 (82.7%). About 38% (n=53) reported to still be employed, either on a full or part-time basis. Approximately 58% (n=80) of the caregivers reported an annual income of greater than \$30,000. The majority of the caregivers (79%) had received formal education beyond high school with 107 of the 139 caregivers having at least some level of college education.

There was a wide range in the length of time the respondents reported having been a caregiver with a low of 0.25 years to a high of 20 years, with an average of 5 years (SD=3.5). The relationship of the caregiver to the care-recipient was well distributed with 66 (47.5%) being the spouse of the care-recipient, 49 (35.3%) being a child, and 21 (15.1%) reporting

another relationship. The majority of the caregivers (70.5%) currently resided in the same household as the care-recipient for whom they were responsible. The average subjective social support score for the caregivers was 12.5 (SD=2.7) with a range of 3 to 18.

Cronbach's alpha for the subjective social support score was 0.73 which is within the range of 0.71-0.81 that has been reported in previous studies (Koenig 1993). Perceived financial adequacy mean scores were 6.1 (SD=1.1) with a range of 3 to 8. Both the support and perceived financial adequacy scores were near the middle of the possible range for these measures.

**Table 6.1: Caregiver Demographics (n=139)**

|                                |              |
|--------------------------------|--------------|
| <b>Age (years)</b>             |              |
| Mean (SD)                      | 61.42 (12.3) |
| Range                          | 29-87        |
| <b>Gender—n (%)</b>            |              |
| Male                           | 32 (23)      |
| Female                         | 104 (74.8)   |
| Missing                        | 3 (2.2)      |
| <b>Race—n (%)</b>              |              |
| White                          | 115 (82.7)   |
| Alaskan/American Indian        | 2 (1.4)      |
| Black/African American         | 19 (13.7)    |
| Hispanic/Latino                | 2 (1.4)      |
| <b>Education—n (%)</b>         |              |
| Less than high school          | 5 (3.6)      |
| High school diploma            | 24 (17.3)    |
| Some college                   | 33 (23.7)    |
| College degree                 | 37 (26.6)    |
| Graduate/professional degree   | 37 (26.6)    |
| Missing                        | 3 (2.2)      |
| <b>Employment Status—n (%)</b> |              |
| Working full-time              | 35 (25.2)    |
| Working part-time              | 18 (12.9)    |
| Retired                        | 60 (43.2)    |
| Unemployed                     | 9 (6.5)      |
| Disabled                       | 6 (4.3)      |
| Other                          | 8 (5.8)      |
| Missing                        | 3 (2.2)      |
| <b>Marital Status—n (%)</b>    |              |
| Currently married              | 108 (78.4)   |
| Separated                      | 1 (0.7)      |
| Divorced                       | 9 (6.5)      |
| Widowed                        | 6 (4.3)      |
| Never married                  | 9 (6.5)      |
| Other                          | 2 (1.4)      |
| Missing                        | 3 (2.2)      |

| <b>Annual Income—n (%)</b> |           |
|----------------------------|-----------|
| Less than \$9,000          | 7 (5)     |
| \$9,001-\$18,000           | 17 (12.2) |
| \$18,001-\$30,000          | 28 (20.1) |
| \$30,001-\$40,000          | 22 (15.8) |
| \$40,001-\$50,000          | 14 (10.1) |
| \$50,001-\$60,000          | 12 (8.6)  |
| Above \$60,000             | 32 (23)   |
| Missing                    | 7 (5)     |

| <b>Length of Time as Caregiver (years)</b> |            |
|--|------------|
| Mean (SD)                                  | 5.02 (3.5) |
| Range                                      | 0.25-20    |

| <b>Live with Care-recipient—n (%)</b> |           |
|---------------------------------------|-----------|
| Yes                                   | 98 (70.5) |
| No                                    | 38 (27.3) |
| Missing                               | 3 (2.2)   |

| <b>Relationship to Care-recipient—n (%)</b> |           |
|---|-----------|
| Spouse                                      | 66 (47.5) |
| Child                                       | 49 (35.3) |
| Other relative                              | 18 (12.9) |
| Other                                       | 3 (2.2)   |
| Missing                                     | 3 (2.2)   |

| <b>Caregiver for others—n (%)</b> |            |
|-----------------------------------|------------|
| Yes                               | 30 (21.6)  |
| No                                | 106 (76.2) |
| Missing                           | 3 (2.2)    |

| <b>Subjective Social Support</b> |            |
|----------------------------------|------------|
| Mean (SD)                        | 12.5 (2.7) |
| Range                            | 3-18       |

| <b>Perceived Financial Adequacy</b> |           |
|-------------------------------------|-----------|
| Mean (SD)                           | 6.1 (1.1) |
| Range                               | 3-8       |

### 6.1.2. Caregiver Emotional Health Outcome

Emotional health outcomes for the caregivers are presented in Table 6.2. The majority of caregivers in the study population reported low levels of depression presence and severity with 70.5% (n=98) having none to mild depression with PHQ-9 scores between 0 and 9. Forty-one caregivers (29.5%) did report moderate to severe depression with PHQ-9 scores of 10 or greater. The average PHQ-9 score among all caregivers was 7.00 (SD 5.34) and a range of 0-26 and presented a distribution curve that was skewed to the right. Cronbach's alpha in this population of caregivers was 0.88 which was consistent with the range (0.86 to 0.89) that has previously been reported in studies within a variety of practice settings (Spitzer, 1999; Spitzer, 2000).

**Table 6.2: Caregiver Reported Emotional Health (n=139)**

| <b>Depression (PHQ-9)</b>                  |             |
|--|-------------|
| Mean (SD)                                  | 7.00 (5.34) |
| Range                                      | 0-26        |
| <b>Depression (PHQ-9) Categories—n (%)</b> |             |
| None to mild (score 0-9)                   | 98 (70.5)   |
| Moderate to severe (score 10-27)           | 41 (29.5)   |

### **6.1.3. Medication-related Stressors**

The summary of the findings of medication-related stressors can be found in Table 6.3. Both primary medication stressors—medication administration and medication effects were normally distributed average scores near the middle of the scoring range. The average medication administration burden was 15.1 (SD 5.9) with a range of 0-29. Medication effect burden scores averaged 9.7 (SD 3.9) with a range of 0-20. There were a significant number of caregivers, however, who responded to having missed social or family activities to handle medication problems. Over 38% (n=51) of the caregivers responded ‘yes’ to this item. Of those respondents who had missed social or family activities, they reported that it had occurred on average 3.1 times (SD 2.4, range 1-14) within the past 30 days.

As mentioned in the caregiver characteristics, there were only 53 caregivers who reported being employed on either a full or part-time basis. Of those caregivers who were employed, only 13 (24.5%) caregivers responded that they had missed an entire day of work while 20 (37.7%) said that they had been forced to leave work early. For those caregivers who did respond ‘yes’ to these items, the average number of times that the caregiver reported missing an entire day of work within the past 30 days was 3.9 (SD 6.1, range 1-20) and leaving work early within the past 30 days was 2.7 (SD 3.0, range 1-10). Table 6.3 shows the number of caregivers who missed or left work early as a percentage of the caregivers who were employed (n=53). Due to the small number of caregivers who were employed, no further analysis was performed on work-related variables/responses.



**Table 6.3: Summary of Medication-related Stressors**

| <b>Primary Medication-related stressors</b>                |            |
|--|------------|
| <b>Medication Administration (n=139)</b>                   |            |
| Mean (SD)  | 15.1 (5.9) |
| Range  | 0-29       |
| <b>Medication Effects (n=139)</b>                          |            |
| Mean (SD)  | 9.7 (3.9)  |
| Range  | 0-20       |
| <b>Secondary Medication-related stressors</b>              |            |
| <b>Missed Social/Family Activities—n (%) (n=139)</b>       |            |
| Yes  | 53 (38.1)  |
| No   | 82 (59)    |
| Missing  | 4 (2.9)    |
| If 'Yes', number of times                                  |            |
| Mean (SD)  | 3.1 (2.4)  |
| Range  | 1-14       |
| <b>Missed Work—n (%)—of those who were employed (n=53)</b> |            |
| Yes  | 13 (25.5)  |
| No   | 40 (74.5)  |
| If 'Yes', number of times                                  |            |
| Mean (SD)  | 3.9 (6.1)  |
| Range  | 1-20       |
| <b>Left Work Early—n (%)</b>                               |            |
| Yes  | 20 (37.7)  |
| No   | 33 (62.3)  |
| If 'Yes', number of times                                  |            |
| Mean (SD)  | 2.7 (3.0)  |
| Range  | 1-10       |

#### 6.1.4 Care-recipient Medication Management

Caregivers reported managing 6.5 prescription medications (SD=3.7, range 0-21). The majority of the care-recipients, over 87%, were covered by a prescription drug plan with over half being covered by a private insurance plan (n=51) or a Medicare Part D plan (n=37). The remaining caregivers were covered by either Medicaid (n=20), the Veterans Administration (n=12), or an 'Other' plan (n=3). Caregivers used 1.4 pharmacies (SD=0.61, range 1-4), on average. The caregivers listed the pharmacies that were used and each of them was categorized into one of three categories—chain, independent, or mail-order pharmacy. Chain pharmacies were the most frequent type of pharmacy used for obtaining medications with 87 caregivers reporting their use. Independent and mail-order pharmacies were used by 45 and 44 caregivers, respectively. These findings are summarized in Table 6.4.

**Table 6.4: Summary of Medication Management (n=139)**

|  |            |
|--|------------|
| <b>Number of medications</b>                     |            |
| Mean (SD)  | 6.5 (3.7)  |
| Range  | 0-21       |
| <b>Prescription Drug Insurance—n (%)</b>         |            |
| Yes  | 121 (87.1) |
| No   | 16 (11.5)  |
| Missing  | 2 (1.4)    |
| <b>Type of Prescription Drug Insurance—n (%)</b> |            |
| Private Insurance                                | 51 (36.7)  |
| Medicaid   | 20 (14.4)  |
| VA   | 12 (8.6)   |
| Medicare   | 37 (26.6)  |
| Other  | 3 (2.2)    |
| <b>Number of Pharmacies Used</b>                 |            |
| Mean (SD)  | 1.4 (0.61) |
| Range  | 1-4        |
| <b>Types of Pharmacies Used—n (%)</b>            |            |
| Chain Pharmacy                                   | 87 (62.6)  |
| Independent Pharmacy                             | 45 (32.4)  |
| Mail Order Pharmacy                              | 44 (31.7)  |

### **6.1.5. Care-recipient Demographics**

The care-recipients were older adults with an average age of 79.5 years (SD=8.9) with a range of 55 to 95 years old. The distribution of males to females was relatively equal with 46.8% and 51.8%, respectively. As was the case with the caregivers, the care-recipients were primarily White (84.2%). Of the non-White care-recipients, 10.1% were Black. The level of formal education among the care-recipients was well-distributed with 48.2% having a high school diploma or less and the remainder having some college education. The majority (n=76) were still married and living with their spouse or partner (n=69). While the caregivers reported a range of zero to 13 living children for the care-recipients, the average number was 2.9 children (SD=1.9) and the distribution of the responses were skewed to the right. As was expected with the elderly care-recipient population, the average number of medical comorbidities using the OARS instrument was 4.7 (SD=2.6) with a range of 1 to 15. The majority of the care-recipients were also highly reliant on their caregivers for assistance with IADLS based on the average score of 17.1 (SD=3.2) and range of 8 to 21 with a distribution of scores that was skewed to the right. These findings are outlined in Table 6.5.

**Table 6.5: Care-recipient Demographics (n=139)**

|                                       |            |
|---------------------------------------|------------|
| <b>Age (years)</b>                    |            |
| Mean (SD)                             | 79.5 (8.9) |
| Range                                 | 55-95      |
| <b>Gender—n (%)</b>                   |            |
| Male                                  | 65 (46.8)  |
| Female                                | 72 (51.8)  |
| Missing                               | 2 (1.4)    |
| <b>Race—n (%)</b>                     |            |
| White                                 | 117 (84.2) |
| American Indian/Alaskan               | 3 (2.2)    |
| Black/African American                | 14 (10.1)  |
| Hispanic/Latino                       | 2 (1.4)    |
| Other                                 | 1 (0.7)    |
| Missing                               | 2 (1.4)    |
| <b>Education—n (%)</b>                |            |
| Less than high school                 | 32 (23)    |
| High school diploma                   | 35 (25.2)  |
| Some college                          | 31 (22.3)  |
| College Degree                        | 22 (15.8)  |
| Graduate/Professional degree          | 17 (12.2)  |
| Missing                               | 2 (1.4)    |
| <b>Marital Status—n (%)</b>           |            |
| Currently married                     | 76 (54.7)  |
| Separated                             | 1 (0.7)    |
| Divorced                              | 8 (5.8)    |
| Widowed                               | 50 (36)    |
| Never married                         | 2 (1.4)    |
| Missing                               | 2 (1.5)    |
| <b>Number of Children</b>             |            |
| Mean (SD)                             | 2.9 (1.9)  |
| Range                                 | 0-13       |
| <b>Living Arrangements—n (%)</b>      |            |
| Spouse/partner                        | 69 (49.6)  |
| Other relatives                       | 40 (28.8)  |
| Unrelated individuals                 | 17 (12.2)  |
| Alone                                 | 10 (7.2)   |
| Missing                               | 3 (2.2)    |
| <b>Number of Comorbidities (OARS)</b> |            |
| Mean (SD)                             | 4.7 (2.6)  |
| Range                                 | 1-15       |
| <b>IADL Functional Status (OARS)</b>  |            |
| Mean (SD)                             | 17.1 (3.2) |
| Range                                 | 8-21       |

## 6.2 Bivariate Analysis and Correlations

Bivariate analyses were performed for each dependent variable included in Aims 1-3 and the independent variables of interest—caregiver/care-recipient contextual factors, stressors and caregiver resources. Only significant bivariate relationships were included in the multivariable models with the exception of caregiver sociodemographics (age, gender, race, marital status, education) which were included in each model as control variables. Table 6.6 details the bivariate relationships between the dependent and independent variables. A correlation matrix was also run to examine the relationships between the independent variables. These findings are in Table 6.7.

**Contextual to Contextual (Caregiver and Care-recipient):** Caregiver age was positively correlated with being male ( $r=0.2708$ ,  $p=0.0015$ ), being married ( $r=0.2877$ ,  $p=0.0007$ ), having no more than a high school education ( $r=-0.2070$ ,  $p=0.0160$ ), being the primary caregiver for another person ( $r=0.3438$ ,  $p<0.0001$ ), reporting a longer period of time as a primary caregiver ( $r=0.2684$ ,  $p=0.0016$ ) and caring for a loved one with fewer medical comorbidities ( $r=-0.2019$ ,  $p=0.0188$ ). Caregivers were more likely to be caring for a loved one of the opposite sex ( $r=-0.2799$ ,  $p=0.0010$ ) while male caregivers were more likely to be caring for a loved one with more medical comorbidities. White caregivers were more likely to have been a primary caregiver for a longer period of time ( $r=0.1758$ ,  $p=0.0414$ ). Being a married caregiver was positively correlated with being a primary caregiver for another loved one ( $r=.1798$ ,  $p=0.0362$ ) and negatively correlated with their care-recipient's age ( $r=-0.2364$ ,  $p=0.0058$ ). Caregivers with formal education beyond a high school diploma

were more likely to be employed ( $r=0.2401$ ,  $p=0.0044$ ). Caregivers who were primary informal caregivers for another loved one were more likely to be caring for a male loved one with memory problems ( $r=0.2529$ ,  $p=0.0030$ ). The length of time that the caregiver has been caring for their loved one was positively correlated with higher functional impairment ( $r=0.2955$ ,  $p=0.0005$ ). Male care-recipients were more likely to be younger ( $r=-0.2794$ ,  $p=0.0010$ ). Care-recipient age was positively correlated with poor functional status ( $r=0.2406$ ,  $p=0.0049$ ) and negatively correlated with the number of medications that they were taking ( $r=-0.2056$ ,  $p=0.0163$ ). Male care-recipients were more likely to have less functional impairment ( $r=-0.2157$ ,  $p=0.0117$ ). Greater functional impairment was positively correlated with the number of their medical comorbidities ( $r=0.1903$ ,  $p=0.0265$ ). The number of medical comorbidities of the care-recipient was positively correlated with the number of medications that they were taking ( $r=0.4765$ ,  $p<0.0001$ ). Those caregivers who reported spending less time on caregiving activities were more likely to have formal education beyond high school ( $r=-0.2421$ ,  $p=0.00614$ ) and be employed ( $r=-0.2683$ ,  $p=0.0023$ ) while time spent on caregiving activities was positively correlated with care-recipient functional impairment ( $r=0.4248$ ,  $p<0.0001$ ).

**Contextual to Caregiver Resources:** The age of the caregiver was negatively correlated with their self-reported physical health ( $r=-0.3040$ ,  $p=0.0004$ ) but positively correlated with their satisfaction with their pharmacy services ( $r=0.3018$ ,  $p=0.0004$ ). White caregivers reported better physical health ( $r=0.2383$ ,  $p=0.0055$ ). Caregivers who were married were more likely to report higher scores for perceived financial adequacy ( $r=0.2167$ ,  $p=0.0116$ ). Caregivers with formal education beyond high school were more likely to report

better physical health ( $r=0.2397$ ,  $p=0.0053$ ). The amount of time spent on caregiving activities was negatively correlated with caregiver physical health ( $r=-0.2038$ ,  $p=0.0232$ ) and perceived financial adequacy ( $r=-0.2475$ ,  $p=0.0052$ ). The age of the care-recipient was positively correlated with both caregiver social support ( $r=0.2055$ ,  $p=0.0168$ ) and satisfaction with pharmacy services ( $r=0.1716$ ,  $p=0.0491$ ). Poor functional status of the care-recipient was negatively correlated with caregiver social support ( $r=-0.1783$ ,  $p=0.0386$ ), caregiver physical health ( $r=-0.2210$ ,  $p=0.0106$ ) and perceived financial adequacy ( $r=-0.2144$ ,  $p=0.0128$ ). The number of care-recipient medical comorbidities was negatively correlated with caregiver social support ( $r=-0.1797$ ,  $p=0.0386$ ) and caregiver physical health ( $r=-0.2604$ ,  $p=0.0024$ ). Finally, the number of care-recipient medications was negatively correlated with caregiver social support ( $r=-0.2662$ ,  $p=0.0017$ ), perceived financial adequacy ( $r=-0.1798$ ,  $p=0.0369$ ) and satisfaction with pharmacy services ( $r=-0.1894$ ,  $p=0.0290$ ).

**Contextual to Medication-related Stressors:** The time spent on caregiving activities was positively correlated with caregiver concerns about medication administration ( $r=0.2508$ ,  $p=0.0048$ ). The level of care-recipient functional impairment was positively correlated with caregiver concerns with medication effects ( $r=0.2616$ ,  $p=0.0022$ ). The number of care-recipient medical comorbidities was positively correlated with caregiver concerns with both medication administration ( $r=0.2328$ ,  $p=0.0070$ ) and effects ( $r=0.2414$ ,  $p=0.0122$ ). Finally, the number of care-recipient medications was positively association with medication administration concerns ( $r=0.2377$ ,  $p=0.0059$ ).

**Caregiver Resources to Caregiver Resources:** Caregiver social support was positively correlated with all other caregiver resources: physical health ( $r=0.3440$ ,  $p<0.0001$ ), perceived financial adequacy ( $r=0.2842$ ,  $p=0.0008$ ) and satisfaction with pharmacy services ( $r=0.2453$ ,  $p=0.0044$ ). In addition to social support, caregiver physical health was positively correlated with perceived financial adequacy ( $r=0.3256$ ,  $p=0.0001$ ).

**Caregiver Resources to Medication-related Stressors:** Caregiver social support was negatively correlated with both medication administration ( $r=-0.3018$ ,  $p=0.0004$ ) and effects ( $r=-0.2811$ ,  $p=0.0009$ ). Caregiver physical health was negatively correlated with medication effects ( $r=-0.1831$ ,  $p=0.0342$ ) and the number of social activities missed by the caregiver ( $r=-0.2326$ ,  $p=0.0068$ ). Caregiver perceived financial adequacy was negatively correlated with all three medication-related stressors: administration ( $r=-0.1816$ ,  $p=0.0371$ ), effects ( $r=-0.1808$ ,  $p=0.0359$ ) and number of missed social activities ( $r=-0.1885$ ,  $p=0.0285$ ). Satisfaction with pharmacy services was only correlated (negatively) to medication effects ( $r=-0.2781$ ,  $p=0.0012$ ).

**Medication-related Stressors to Medication-related Stressors:** Caregiver concerns with medication administration was positively correlated with their concerns about medication effects ( $r=0.4871$ ,  $p<0.0001$ ).



Table 6.6: Bivariate Analysis of Dependent and Independent Variables Identified for Aims 1-3 (n=139)

| Independent Explanatory Variables             | Caregiver Depression<br>(Square Root PHQ-9) |          | Medication<br>Administration |          | Medication<br>Effects |          | Number of Missed<br>Social Times |          |
|---|---|----------|------------------------------|----------|-----------------------|----------|----------------------------------|----------|
|   | <i>b</i>                                    | <i>p</i> | <i>b</i>                     | <i>p</i> | <i>B</i>              | <i>p</i> | <i>b</i>                         | <i>p</i> |
| <b>Caregiver Contextual Factors</b>           |   |          |                              |          |                       |          |                                  |          |
| Age   | -0.00590                                    | 0.4519   | 0.02380                      | 0.6815   | 0.01423               | 0.6032   | 0.01937                          | 0.1663   |
| Gender (1=male; 0=female)                     | -0.10963                                    | 0.6268   | 0.56106                      | 0.6826   | 1.18990               | 0.1286   | 0.39124                          | 0.3310   |
| Race (1=white; 0=non-white)                   | 0.40907                                     | 0.1006   | 2.84524                      | 0.0605   | 0.87478               | 0.3154   | -0.67899                         | 0.1276   |
| Marital Status (1=married; 0=not married)     | -0.28069                                    | 0.2407   | -0.53245                     | 0.7512   | -0.53313              | 0.5234   | -0.03717                         | 0.9309   |
| Education (1= $\geq$ HS graduate; 0=<HS grad) | 0.27778                                     | 0.2153   | -1.13172                     | 0.4075   | 0.31826               | 0.6846   | 0.55578                          | 0.1651   |
| Caregiver for Others (1=yes; 0=no)            | -0.00303                                    | 0.9895   | 1.08239                      | 0.4403   | 0.62075               | 0.4398   | -0.07178                         | 0.8618   |
| Length of time as caregiver                   | 0.00386                                     | 0.0913   | -0.00633                     | 0.6504   | 0.01439               | 0.0707   | 0.00290                          | 0.4790   |
| <b>Care-recipient Contextual Factors</b>      |   |          |                              |          |                       |          |                                  |          |
| Age   | -0.02547                                    | 0.0166   | -0.08345                     | 0.2007   | -0.05001              | 0.1805   | 0.00018                          | 0.9925   |
| Gender (1=male; 0=female)                     | -0.01549                                    | 0.9353   | -1.50068                     | 0.1951   | -0.08099              | 0.9031   | 0.01864                          | 0.9564   |
| Functional Status                             | 0.03076                                     | 0.2992   | 0.25633                      | 0.1545   | 0.31434               | 0.0020   | 0.07893                          | 0.1354   |
| Number of comorbidities                       | 0.07583                                     | 0.0355   | 0.59567                      | 0.0063   | 0.31621               | 0.0116   | 0.12768                          | 0.0478   |
| Number of medications                         | 0.08598                                     | 0.0007   | 0.43226                      | 0.0052   | 0.12336               | 0.1685   | 0.07999                          | 0.0810   |
| <b>Stressors</b>                              |   |          |                              |          |                       |          |                                  |          |
| Medication Administration                     | 0.04988                                     | 0.0003   | --                           | --       | 0.27646               | <0.0001  | 0.03450                          | 0.1684   |
| Medication Effects                            | 0.10656                                     | <0.0001  | 0.84247                      | <0.0001  | --                    | --       | 0.06338                          | 0.1471   |
| Social Activities Missed                      | 0.05784                                     | 0.2258   | 0.39999                      | 0.1684   | 0.24111               | 0.1471   | --                               | --       |
| Caregiver Activity Time                       | 0.00019                                     | 0.0777   | 0.00186                      | 0.0036   | 0.00046               | 0.2131   | 0.00030                          | 0.1121   |
| <b>Caregiver Resources</b>                    |   |          |                              |          |                       |          |                                  |          |
| Subjective social support                     | -0.19084                                    | <0.0001  | -0.65704                     | <0.0001  | -0.35838              | 0.0002   | -0.02875                         | 0.5708   |
| Self-rated Physical Health (SF-12)            | -0.02062                                    | 0.0103   | -0.07619                     | 0.1221   | -0.06005              | 0.0327   | -0.03920                         | 0.0063   |
| Financial Adequacy                            | -0.32940                                    | 0.0001   | -1.12952                     | 0.0353   | -0.65360              | 0.0334   | -0.34848                         | 0.0269   |
| Pharmacy Support                              | -0.03816                                    | 0.0003   | -0.09517                     | 0.1483   | -0.12054              | 0.0012   | 0.00103                          | 0.9578   |

Statistically significant variables are in BOLD



### **6.3. Analysis by Aims**

Each stage of every multivariable model was tested by (1) running tolerance statistics to test the interrelationships between explanatory variables and (2) calculating residuals and predicted values for each of the models and plotting them against one another to ensure that the distribution was scattered randomly around zero. The tolerance statistics for the variables in each model were all above 0.55; so, there was no concern of collinearity between the independent explanatory variables in the models. The frequency plot of residuals for each model confirmed a normal distribution. The plot of residual values against the predicted values also confirmed that the assumptions of the models were met as the distribution of the points was scattered randomly around 0.

**6.3.1. Aim 1: To examine the relationship between the medication-related stressors experienced by the caregiver and caregiver depression.**

Multivariable analysis results are shown in Table 6.8. The multivariable analysis of caregiver emotional health is presented in the stages outlined in the Methods (Chapter 5). First, all caregiver sociodemographic variables along with caregiver and care-recipient contextual variables that were significant in the bivariate analysis were added. This was followed by caregiver stressors and caregiver resources added in Stage 2 and Stage 3, respectively. In the last two stages, only variables with significant bivariate relationships (Table 6.3) were added. In Stage 1, care-recipient age was the only variable that remained significant in the multivariable model ( $p=0.0098$ ). Care-recipient age and caregiver depression were negatively associated with caregivers who were caring for younger loved ones reporting higher levels of depression. After adding medication-related stressors, both care-recipient age ( $p=0.0441$ ) and medication effects ( $p=0.0044$ ) were significant. As in Stage 1, care-recipient age remained negatively associated with depression. However, medication effects were positively associated with the emotional health of caregivers.

In the final stage of the model (Stage 3) which added the caregiver resources, caregiver depression was associated with only subjective social support and medication effects and was no longer associated with care-recipient age. Caregivers who reported having more difficulty handling the medication effects reported higher depression scores ( $p=0.0480$ ). Subjective social support was also associated with depression among this group of caregivers. Caregivers with less subjective social support also reported higher depression scores ( $p<0.0001$ ) than caregivers who reported feeling more supported.

We notice that the path from the medication-related stressors to the emotional health outcome measure—caregiver depression—becomes either less significant (medication effects) or insignificant (medication administration) when social support is added to the model. Thus, when adding subjective social support as a predictor variable, it carries the weight of the regression model and mediates the pathway between the stressors and the emotional health outcome. This finding supports the conceptual framework outlined in Chapter 2. Care-recipient age became statistically insignificant when social support was added to the regression model in Stage 3. This occurred because care-recipient age ( $p=0.0166$ ) and subjective social support ( $p<0.0001$ ) are positively related to the dependent variable—caregiver depression—and they are positively related to one another. So, once the model is controlled for social support, the association between care-recipient age becomes less significant.

The Sobel test results demonstrated statistically significant indirect effects with social support as a mediator between both medication-related stressors and caregiver depression. The Sobel test statistic for medication administration was 3.61598 with  $p=0.0030$  while the test statistic for medication effects was 3.46341 with  $p=0.00053$ . This supports the original hypothesis that the relationship between the medication-related stressors and caregiver depression is mediated by caregiver subjective social support.

There were two findings in this regression modeling that were not consistent with the original hypotheses. There was no association between the medication administration stressor or the secondary medication-related stressor—number of times missed social/family activities. Although there was a bivariate relationship, there was no statistically significant association between depression and medication administration—after controlling for

caregiver and care recipient contextual factors and caregiver resources. The number of times a caregiver missed social/family activities was not significant in the bivariate analysis ( $p=0.2258$ ) and, thus, was not included in any of the stages of the multivariable modeling. As additional variables were modeled in stages, the R-squared increased from 0.1738 in Stage 1 to 0.2621 in Stage 2 to 0.4489 in Stage 3. So, within the final stage of modeling, nearly 45% of the variation in caregiver depression is explained by the independent variables included in the model.

Table 6.8: Multivariable analysis of Caregiver Depression with Caregiver and Care-recipient factors

**CAREGIVER DEPRESSION—PHQ-9 square root (N=139)**

| Characteristic                                      | STAGE ONE<br>Model Contextual Factors<br>Only |               | STAGE TWO<br>Add Caregiver<br>Stressors |               | STAGE THREE<br>Add Caregiver<br>Resources |                   |
|---|---|---------------|---|---------------|---|-------------------|
|   | <i>b</i>                                      | <i>p</i>      | <i>B</i>                                | <i>p</i>      | <i>b</i>                                  | <i>p</i>          |
| <b>Caregiver Contextual Factors</b>                 |   |               |   |               |   |                   |
| Age   | 0.00442                                       | 0.5972        | 0.00171                                 | 0.8313        | -0.00155                                  | 0.8244            |
| Gender (male=1;female=0)                            | -0.07981                                      | 0.7209        | -0.14031                                | 0.5183        | -0.17426                                  | 0.3604            |
| Race (1=white;0=non-white)                          | 0.44816                                       | 0.0620        | 0.31882                                 | 0.1701        | 0.31665                                   | 0.1432            |
| Marital Status (1=married;0=not married)            | -0.44545                                      | 0.0747        | -0.32456                                | 0.1760        | -0.00350                                  | 0.9874            |
| Education (1= $\geq$ HS graduate;0= $\leq$ HS grad) | 0.37809                                       | 0.0870        | 0.34041                                 | 0.1092        | 0.34919                                   | 0.0664            |
| <b>Care-recipient Contextual Factors</b>            |   |               |   |               |   |                   |
| Age   | <b>-0.02924</b>                               | <b>0.0098</b> | <b>-0.02194</b>                         | <b>0.0441</b> | -0.01180                                  | 0.2234            |
| Number of comorbidities                             | 0.05539                                       | 0.1809        | 0.01805                                 | 0.6553        | -0.01859                                  | 0.6194            |
| Number of medications                               | 0.05547                                       | 0.0620        | 0.05466                                 | 0.0559        | 0.04062                                   | 0.1129            |
| <b>Stressors</b>                                    |   |               |   |               |   |                   |
| Medication Administration                           |   |               | 0.01531                                 | 0.3085        | 0.00218                                   | 0.8713            |
| Medication Effects                                  |   |               | <b>0.07518</b>                          | <b>0.0044</b> | <b>0.04727</b>                            | <b>0.0490</b>     |
| <b>Caregiver Resources</b>                          |   |               |   |               |   |                   |
| Subjective social support                           |   |               |   |               | <b>-0.12913</b>                           | <b>&lt;0.0001</b> |
| Self-rated Physical Health (SF-12)                  |   |               |   |               | -0.01326                                  | 0.1049            |
| Financial Adequacy                                  |   |               |   |               | -0.09321                                  | 0.2428            |
| Pharmacy Support                                    |   |               |   |               | -0.00758                                  | 0.4496            |
| <b>R-squared</b>                                    |   | <b>0.1738</b> |   | <b>0.2621</b> |   | <b>0.4489</b>     |

Statistically significant variables are in BOLD.

**6.3.2. Aim 2: To examine the association between the caregiver primary medication-related stressors and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

The multivariable findings are outlined in Table 6.9 and 6.10. After multivariable modeling of caregiver and care-recipient contextual factors against both domains of primary medication-related stressors—administration and effects—some associations were identified. Caregiver race were the only statistically significant predictor for medication administration. More problems with medication administration were reported by caregivers who were White ( $p=0.0255$ ). For the medication effects domain, both care-recipient predictor variables—care-recipient IADL functional status ( $p=0.0134$ ) and the number of care-recipient comorbidities ( $p=0.0343$ )—that were significant in bivariate analysis remained significant in the multivariable model. These were both positive associations with the higher the IADL score (greater functional impairment) and the more care-recipient comorbidities, the higher the stressor scores for medication effects. None of the caregiver sociodemographics were associated with the medication effects stressor in either the bivariate or multivariable model. Nearly 15% of the variation in medication administration was explained by the regression model ( $R\text{-squared}=0.1490$ ) while about 12.5% of the variation in medication effects was explained the model ( $R\text{-squared}=0.1256$ ).



**Table 6.9: Multivariable Analysis of Medication Administration with Caregiver and Care-recipient factors**

| <b>MEDICATION ADMINISTRATION (N=139)</b>     |  |               |
|--|--|---------------|
| <b>Characteristic</b>                        | <b>STAGE ONE<br/>Model Contextual Factors<br/>Only</b> |               |
|  | <i>b</i>   | <i>p</i>      |
| <b>Caregiver Contextual Factors</b>          |  |               |
| Age  | -0.00430   | 0.9344        |
| Gender (male=1;female=0)                     | -0.41683   | 0.7652        |
| Race (1=white;0=non-white)                   | <b>3.37646</b>   | <b>0.0255</b> |
| Marital Status (1=married;0=not married)     | -0.21969   | 0.8827        |
| Education (1= $\geq$ HS graduate;0=<HS grad) | -0.32535   | 0.3369        |
| <b>Care-recipient Contextual Factors</b>     |  |               |
| Number of comorbidities                      | 0.41567  | 0.0964        |
| Number of medications                        | 0.30275  | 0.0846        |
| <b>R-squared</b>                             |  | <b>0.1490</b> |

Statistically significant variables are in BOLD.

**Table 6.10: Multivariable Analysis of Medication Effects with Caregiver and Care-recipient factors**

| <b>MEDICATION EFFECTS (N=139)</b>            |  |               |
|--|--|---------------|
| <b>Characteristic</b>                        | <b>STAGE ONE<br/>Model Contextual Factors<br/>Only</b> |               |
|  | <i>b</i>   | <i>p</i>      |
| <b>Caregiver Contextual Factors</b>          |  |               |
| Age  | 0.02189  | 0.4641        |
| Gender (male=1;female=0)                     | 0.80804  | 0.3126        |
| Race (1=white;0=non-white)                   | 1.09074  | 0.2012        |
| Marital Status (1=married;0=not married)     | -0.89467   | 0.2893        |
| Education (1= $\geq$ HS graduate;0=<HS grad) | 0.62038  | 0.4256        |
| <b>Care-recipient Contextual Factors</b>     |  |               |
| Functional status                            | <b>0.25789</b>   | <b>0.0134</b> |
| Number of comorbidities                      | <b>0.27190</b>   | <b>0.0343</b> |
| <b>R-squared</b>                             |  | <b>0.1256</b> |

Statistically significant variables are in BOLD.

**6.3.3. Aim 3: To examine the association between the secondary medication-related stressors (e.g., time missed from work, social activities and family functions) of the caregiver and (a) the caregiver contextual factors and (b) the care-recipient contextual factors.**

The multivariable findings are outlined in Table 6.11. There were three variables associated with the number of missed social activities—caregiver age ( $p=0.0255$ ), caregiver education ( $p=0.0201$ ), and the number of care-recipient comorbidities ( $p=0.0195$ ). Older caregivers and caregivers with a high school education or greater missed more social activities. Caregivers with less than a high school education missed an average of 0.59 (adjusted mean) social activities compared to caregivers with at least a high school education who missed 1.14 (adjusted mean) social activities, on average. Caregivers who reported caring for a loved one with a higher number of comorbidities missed more social activities than those who reported fewer comorbidities. About 10% of the variation in the number of missed social activities was explained by this regression model ( $R\text{-squared}=0.1023$ ). As discussed in Chapter 5, the number of caregivers who worked was too small of a sample size ( $n=53$ ) for a valid regression model that would have also required controlling for the level of employment (e.g., part-time versus full-time). Therefore, this analysis was dropped from the study and not reported.

**Table 6.11: Multivariable Analysis of Social-related Stressor with Caregiver and Care-recipient Factors (n=129)**

**SOCIAL MISS TIMES (N=139)**

| Characteristic                                   | STAGE ONE<br>Model Contextual Factors<br>Only |               |
|--|---|---------------|
|  | <i>b</i>                                      | <i>P</i>      |
| <b>Caregiver Contextual Factors</b>              |   |               |
| Age  | <b>0.03545</b>                                | <b>0.0225</b> |
| Gender (male=1;female=0)                         | 0.10076                                       | 0.8059        |
| Race (1=white;0=non-white)                       | -0.76952                                      | 0.0822        |
| Marital Status (1=married;0=not married)         | -0.30832                                      | 0.4798        |
| Education (1= $\geq$ HS graduate;0= $<$ HS grad) | <b>0.85752</b>                                | <b>0.0344</b> |
| <b>Care-recipient Contextual Factors</b>         |   |               |
| Number of comorbidities                          | <b>0.15253</b>                                | <b>0.0195</b> |
| <b>R-squared</b>                                 |   | <b>0.1023</b> |

**6.3.4. Aim 4: To describe caregivers attitudes about pharmacists and pharmacy services and determine what caregivers believe can be done to assist them with medication-related concerns.**

There were both quantitative and qualitative findings for this Aim. First, I will discuss the quantitative results from the Pharmacy Support Scale which covered the caregiver's perception of the availability of and communication and interaction with the pharmacist. Next, I will present the qualitative results which are from the free-form comments that were included by the caregivers at the end of the study questionnaire. At the end of the questionnaire the caregivers were asked to, "Please use this space to share with us any other thoughts or ideas that you have about managing your loved one's medications or about caregiving, in general." The comments that were specifically related to medication management or their thoughts about pharmacists/pharmacy services were categorized and presented below under Qualitative Findings.

**Quantitative Findings:** The distribution of responses to the questions about caregiver's perceptions of pharmacists and pharmacy services are in Table 6.12 while the descriptive statistics for these items are presented in Table 6.13. The most favorable responses regarding pharmacists was both their availability and ability to answer questions about medications with caregivers, 79.5% and 81.3%, respectively, responding that they agreed or strongly agreed with those statements. Items that related to the pharmacist being proactive in their communication were not viewed as positively by caregivers with 'agree' or 'strongly agree' responses from 51.5% (n=69) regarding the pharmacist warning them about problems, 48.8% (n=65) regarding the pharmacist telling them what the medication is used

for, and 49.3% (n=66) regarding the pharmacist giving advice that helps the caregiver to manage the loved one's medications. Sixty-six caregivers (49.3%) responded favorably (agree/strongly agree) to the pharmacist caring about their overall health and well-being while 89 caregivers (66.4%) did trust the pharmacist to give them the best information about medications.

The lowest responses from caregivers about pharmacy services were related to the privacy at their local pharmacy, the time spent by the pharmacist and their perception that the pharmacist worked closely with their loved one's doctor. Only 45 caregivers (33.6%) believed that there was a place at the pharmacy where they could talk in private with their pharmacist and just 68 caregivers (51%) were satisfied with the amount of time spent by the pharmacist. Finally, only 51 caregivers (38.1%) felt as if their pharmacist worked with their loved one's doctors to provide the best medications possible.

**Qualitative Findings:** The free form comments related to medication management included by caregivers at the end of the study questionnaire were collated and grouped into five categories: (1) support for medication management, (2) organizing medications, (3) affording medications, (4) scheduling medication fills/refills, and (5) pharmacist/pharmacy experiences. A summary of the qualitative findings are in Table 6.14. There were many other comments that were related to the overall burden and stress of caregiving; however, those were not categorized as that was outside the scope of this research study. The majority of the comments related to medication management that were included by caregivers were consistent with the questions that were included in the SCMC scale and its two domains—medication administration and medication effects. The comments under organizing medications, affording medications and scheduling medication fills/refills were all included

in the medication administration items while the majority of the comments under pharmacist/pharmacy experiences were included in the medication effects items. However, there were two comments under pharmacist/pharmacy experiences that were not addressed in the SCMC and those were issues around mail order pharmacy delays and the difficulties associated with prescription bottles (e.g., problems with bottle caps and small print). One other issue raised in the comments that was not addressed in the study questionnaire was level of support available to the caregiver from family, friends or others specifically for medication management. The two handwritten comments referred to having either hired help (e.g., home health aide) or a family member (e.g., sister) help administer or organize the medications. The concept of substitution and the availability of others to help with the process and its subsequent impact on the medication management process were captured in the qualitative analysis but not in the quantitative one.

**Table 6.12: Response Distribution for Satisfaction with Pharmacist and Pharmacy Services—n (%) (n=139)**

|  | <b>Strongly Disagree</b> | <b>Disagree</b> | <b>Neutral</b> | <b>Agree</b> | <b>Strongly Agree</b> |
|--|--------------------------|-----------------|----------------|--------------|-----------------------|
| The pharmacist is usually available to answer my questions about my loved one's medications. | 4<br>(3.0)               | 9<br>(6.7)      | 13<br>(9.7)    | 70<br>(52.2) | 38<br>(27.3)          |
| The pharmacist warns me about problems that my loved one might have with the medications.    | 13<br>(9.7)              | 24<br>(17.9)    | 28<br>(20.9)   | 49<br>(36.6) | 20<br>(14.9)          |
| The pharmacist tells me what my loved one's medications are used for.                        | 14<br>(10.5)             | 30<br>(22.6)    | 24<br>(18.0)   | 49<br>(36.8) | 16<br>(12.0)          |
| I receive advice from the pharmacist that helps me to manage my loved one's medications.     | 12<br>(9.0)              | 29<br>(21.6)    | 27<br>(20.1)   | 51<br>(38.1) | 15<br>(11.2)          |
| The pharmacist answers any questions that I have about my loved one's medications.           | 7<br>(5.2)               | 5<br>(3.7)      | 13<br>(9.7)    | 81<br>(60.4) | 28<br>(20.9)          |
| I feel like the pharmacist really cares about my overall health and well-being.              | 12<br>(9.0)              | 14<br>(10.4)    | 42<br>(31.3)   | 45<br>(33.6) | 21<br>(15.7)          |
| There is a place at the pharmacy where I can talk in private with the pharmacist.            | 22<br>(16.4)             | 37<br>(27.6)    | 30<br>(22.4)   | 34<br>(25.4) | 11<br>(8.2)           |
| I am satisfied with the amount of time that the pharmacist spends with me.                   | 10<br>(7.5)              | 14<br>(10.4)    | 42<br>(31.3)   | 52<br>(38.8) | 16<br>(11.9)          |
| I trust the pharmacist to give me the best information about my loved one's medications.     | 8<br>(6.0)               | 9<br>(6.7)      | 28<br>(20.9)   | 63<br>(47.0) | 26<br>(19.4)          |
| The pharmacist works with my loved one's doctors to provide the best medications possible.   | 15<br>(11.2)             | 22<br>(16.4)    | 46<br>(34.3)   | 36<br>(26.9) | 15<br>(11.2)          |

**Table 6.13: Descriptive Statistics for Satisfaction with Pharmacist and Pharmacy Services (n=139)**

|   | <b>Mean</b> | <b>SD</b> | <b>Range</b> |
|---|-------------|-----------|--------------|
| <b>The pharmacist is usually available to answer my questions about my loved one's medications.</b> | 2.96        | 0.96      | 0-4          |
| <b>The pharmacist warns me about problems that my loved one might have with the medications.</b>    | 2.29        | 1.21      | 0-4          |
| <b>The pharmacist tells me what my loved one's medications are used for.</b>                        | 2.17        | 1.22      | 0-4          |
| <b>I receive advice from the pharmacist that helps me to manage my loved one's medications.</b>     | 2.21        | 1.17      | 0-4          |
| <b>The pharmacist answers any questions that I have about my loved one's medications.</b>           | 2.88        | 0.96      | 0-4          |
| <b>I feel like the pharmacist really cares about my overall health and well-being.</b>              | 2.37        | 1.14      | 0-4          |
| <b>There is a place at the pharmacy where I can talk in private with the pharmacist.</b>            | 1.81        | 1.22      | 0-4          |
| <b>I am satisfied with the amount of time that the pharmacist spends with me.</b>                   | 2.37        | 1.07      | 0-4          |
| <b>I trust the pharmacist to give me the best information about my loved one's medications.</b>     | 2.67        | 1.05      | 0-4          |
| <b>The pharmacist works with my loved one's doctors to provide the best medications possible.</b>   | 2.10        | 1.05      | 0-4          |



**Table 6.14 Qualitative Findings Related to Potential Areas of Assistance with Medications**

| <b>Support for Medication Management</b> |   |
|--|---|
|  | <ol style="list-style-type: none"> <li>1. We are now considering getting a home health person to come daily to give her morning medications and help with taking care of laundry, light household chores.</li> <li>2. I don't live with or too near her (30 minutes away), so, my sister occasionally has to fill in--packing them if I get in a bind and can't get home, or if we are waiting on a refill with the pharmacy.</li> </ol>  |
|  |   |
| <b>Organizing Medications</b>            |   |
|  | <ol style="list-style-type: none"> <li>1. I have responsibility for packing my mother's pill packer.</li> <li>2. I fill 2 weeks of pills for husband and me. It's a chore and I need quiet time to do it.</li> <li>3. Because giving the right medicine in the right dose at the right time is so important, I have always used a pill box.</li> <li>4. Difficulty in keeping up and planning for trips, emergencies, etc.</li> <li>5. I have to fill pill containers for myself plus four other people.</li> <li>6. We do use a pill divider on a weekly basis. It is very helpful.</li> <li>7. I have a separate container for morning and evening meds.</li> <li>8. Because she has trouble swallowing or understanding what to do with meds, her meds are all liquid and administered or included in a shake, mixed with jelly or inserted by oral syringe in the mouth then encourage swallowing. I use a checklist now instead of the boxes I used when she could take pills.</li> <li>9. The meds are relatively easy for me to handle with a pill reminder. I do set up her meds and assist her with taking them but it has posed no serious problems thus far.</li> <li>10. Recently, she was disoriented and I found she had taken 2 days of medicine one morning. I don't know if she was disoriented and forgot and took the medicines OR if she took all the meds and that caused the disorientation. Now I hide the meds and give them to her to take morning and evening. It is something else that I have to remember to do!</li> <li>11. I do use the pill box and love it.</li> </ol> |
|  |   |

### Affording Medications

1. It is hard to afford medication for my spouse and myself. I spend most of my time worrying about affording medication.
2. We had trouble for years paying for meds. Then Gov Easley paid 90% on our meds for a year. Now my husband has qualified for VA meds and I am working on a Medicare plan.
3. My answers about obtaining medications will change dramatically when Lucent drops his drug plan.
4. As a veteran, we are very fortunate to have Tricare coverage with a very low copayment. I cannot imagine what our financial situation would be without it.
5. I have to spend money I need for my future and that we had hoped to travel with to pay for the part of the medications with big deductibles. I am on 10 prescriptions and have the same situation with Medicare. I already feel like I am drowning. Everyone seems to think that seniors are wealthy but we are living off savings that won't last forever.
6. My husband has been very stable in the last 2 years since his diagnosis. Meds, so far, seem to be working; however, I am concerned and afraid about our future and financial matters.
7. The new Medicare prescription plan with is "doughnut hole" is a terrible deception on the elderly.

### Scheduling Medication Fills/Refills

1. I would love to figure out a way to get prescriptions scheduled together so that I don't need to go to the pharmacy every week. I cannot figure out how to accomplish this.
2. It would be helpful if the pharmacy was able to give all prescriptions at once instead of at different 30 day periods according to date prescribed.
3. It would be a lot more helpful if all his medications could be renewed on the same date. Because they are renewable at different times, it seems I am always either ordering prescriptions or going to the drug store to pick them up.
4. One of the most frustrating things about medications is that they all seem to need refilling at different times which calls for many trips because you can only get a 30 day supply.
5. It is a great job to keep up with ordering refills and staying ahead of my 21 pills a day as well as his.
6. We order 90-day supply but with 15 prescriptions I have had to use an Excel spreadsheet to keep track of the meds. Giving the meds with the help of a pill organizer is a snap. Keeping the supply coming is a challenge.
7. It is stressful keeping up with prescription renewal.

### Pharmacist/Pharmacy Experiences

1. It is very helpful and mind-easing to be able to visit a clinic like the ACC. Although my mom has a regular doctor, he doesn't seem to be in touch with the elderly person's problems. Having us sit in one room with the physician, pharmacist, OT cuts down on some confusion and anxiety that may have occurred if we had to go office to office.
2. I was dismayed to learn that Detrol LA can counteract the results of Aricept. My husband took Detrol LA for 5 months before I found that "high risk" on CareMark's website. The prescribing doctor and his neurologist were both aware of the Aricept for 5 or 6 years before the Detrol was prescribed and neither warned me. The pharmacist at CareMark said his info did not show that risk but their website's medicine interaction feature warned of "high risk." My husband's MMSE had stayed at 29 for one year, then dropped to 26 in 6 months; the next 6 months it dropped to 24; during the 6 month period he took Detrol LA, it dropped to 18.
3. At Rite Aid, the pharmacist would make sure I signed a form saying I had refused advice from them. They never offered to give me advice; they just made sure their backs were covered. I think there are so many other issues in regards to medications: what do you do when they can't swallow, drug interactions, and diarrhea.
4. A big problem occurred with Medco when they would require additional paperwork from the MD for both of Dad's medications. The MD felt she should not have her judgement questioned and procrastinated in filling out the forms. As a result, shipment of medications was delayed. This was very stressful.
5. Managing my mother's medications has changed in the eight years I have been her caregiver. She had a number of crises in the beginning—one drug gave her hallucinations, others gave her severe diarrhea. I did not know she was allergic to sulfa drugs. Now her condition has been stabilized by correct medicines. Pharmacists and doctors need to be aware that not everyone coming on board as a caregiver is necessarily equipped with the skills to do it.
6. Medicine bottle caps are difficult. Insurance is a pain. The print on medicine bottles is too small.

## **Chapter 7**

### **DISCUSSION**

This dissertation research produced four major findings: (1) as hypothesized, there was an association between the medication-related stressors of dementia caregivers and their own emotional health, (2) the presence of depression among these dementia caregivers and the association with social support were consistent with the previous literature that has reported poor emotional health outcomes in this population, (3) a reliable instrument, the Survey of Caregiver Medication Concerns, for measuring medication-related stressors was developed, and (4) caregivers' reported perceptions of pharmacists and pharmacy services suggest that there are opportunities for pharmacists to improve their communication, education and practice environments.

## **7.1. Medication-related Stressors**

As hypothesized, there was some association between caregiver emotional health and the medication-related stressors of the dementia caregivers. The caregiver's stress related to the effects and effectiveness of medications was associated with higher levels of depression presence and severity. There was no association, however, between the other primary medication-related stressor—medication administration—and caregiver emotional health. One possible explanation for these findings is that the medication effects are not as clearly defined from a task perspective and require mastering communication skills and interpreting both verbal and non-verbal responses from their care-recipients. The five items included in the medication effects domain of the primary medication-related stressors were related to how well the medications are or are not working and how the caregiver communicates with the care-recipient. This can be challenging for caregivers and could negatively impact their own emotional health.

On the other hand, the items included in the medication administration stressor are related to the task of obtaining and giving the medications. Over time, caregivers develop strategies to manage the many tasks of caregiving by developing routines and this likely carries over to handling the tasks of managing medications. By developing these systems to handle the tasks of caregiving, the disruptions for the care-recipient are minimized and this likely alleviates some of the caregiver burden, as well.

Another possible explanation for the association between the medication effects is that the items within this domain also carry an emotional tone and ask more about caregiver's "feelings." Therefore, these questions may be tapping into the caregiver's anxiety or

depression and it may be unclear whether the medication-related stressor is causing the poor emotional health outcomes or if the poor emotional health is contributing to the negative feelings related to the medication-related concerns.

In addition to the association of medication effects and caregiver emotional health, there was also a statistically significant association between caregiver subjective social support and depression. Caregivers with lower levels of support were more depressed. While this is an important finding for this study as it did demonstrate a mediating effect between the medication-related stressors and the emotional health outcome, it is also consistent with other studies of the role of social support in caregiver depression. These findings continue to highlight the importance of dementia caregiver support. Caregivers can feel as if they must care for their loved one twenty-four hours a day, seven days a week; however, it is important for the caregiver to understand their co-existence with the demented patient and to have outlets and assistance with friends and family.

The one secondary medication-related stressor—missing social activities to handle medication problems—that was analyzed was not found to be associated with poorer caregiver emotional health. Those caregivers who missed more social activities for medication-related issues did not report being more depressed than those who missed fewer social activities. There are possible shortcomings in these items within this specific group of caregivers and the study questionnaire. The recall period might have been too short. Caregivers were asked to recall within the past 30 days whether they had one of these occurrences. It is likely that the event might have occurred at some point within the past few months to a year but not specifically within the past 30 days. So, lengthening the recall period would likely have increased the responses for these questions. It remains important to

understand how managing medications impacts work and social activities because keeping the caregiver active in employment and social/family support systems is important.

However, work needs to be done to improve the method for assessing this problem. Based on the results from this research study, we do know from a descriptive perspective that caregivers are being forced to miss time from work and other activities to deal with medication problems. Because we were unable to model this as we originally planned, it still remains unclear if absence from work has a negative impact on caregiver emotional health.

There were also some associations between caregiver and care-recipient contextual factors and the medication-related stressors that should be noted. Caregivers' concerns with medication effects were associated with the care-recipient's functional status and the number of comorbid conditions. As hypothesized, a caregiver caring for a loved one who is more dependent on their caregiver and has multiple conditions will have more concerns about the effects and effectiveness of the medications being given to the care-recipient. A demented person with poor functional status has more compromised cognition than those with higher levels of functioning. Therefore, they are less likely to be able to communicate effectively with their caregiver about their medications and how they are either working or causing them problems. A care-recipient with more comorbid conditions is more likely to be taking more medications than those with fewer comorbidities. In this study population, there was a statistically significant correlation between the number of medications and the number of care-recipient comorbidities ( $p < 0.0001$ ). Older adults who take several medications at one time are at risk for drug-related problems (Lim 1999). These problems can be a result of either adverse drug reactions due to the way drugs act differently in compromised elderly

(e.g., renal disease, liver disease) or due to drug-drug interactions from the concomitant use of medications.

When examining predictors of missing social activities because of medication-related stressors, caregivers who were older and more educated and those who were caring for a loved one with more medical comorbidities missed more social activities. Older caregivers in this study were probably less likely to be as active as their younger counterparts. Caregivers who were caring for a loved one with more medical comorbidities were likely to be dealing with a more complex situation than other caregivers and there may have been other contributors in their decision to miss social/family activities.

The major conclusion related to medication-related stressors from this research is that we have learned that there is an association between some of the medication-related stressors and self-reported depression measure of caregiver emotional health. These findings provide some support of the modified conceptual model and the Stress Process Model (Pearlin et al, 1981) which suggests that caregiver stressors are directly linked to their emotional health outcome and that the process is mediated by the subjective social support of the caregiver.

The associations between the caregiver emotional health outcomes and the medication-related stressors outlined in this research should continue to be evaluated. Future research should be done to refine the medication-related stressors that were identified in this research. This can be initiated by taking the SCMC instrument and qualitative findings from this research study and using in other dementia caregiver studies. Further investigation of the support available for the medication management process is also needed. Future studies should ask questions related to the availability and quality of friends/family who can be substitutes for medication management. If we continue to use and refine this model, we will



be able to better understand the role of medication management in the overall stress process of dementia caregivers.

## **7.2. Emotional Health Outcomes of Caregivers**

We were also able to identify the presence of depression among this group of dementia caregivers which has been reported in other research. While the mean PHQ-9 score was in the mild depression category, 41 caregivers, approximately 30%, reported having moderate to severe depression. This finding was consistent with recent studies by Schulz and Martire (2004) that documented 30 to 55% of caregivers reporting depressive symptomatology and Sleath et al (2005) showing that 30% of informal caregivers of demented relatives demonstrating depressive symptoms. The presence and severity of depression may actually be higher in other caregiver settings where the majority of the caregivers are not recruited from a support group setting. By being involved in support groups, the caregivers in this study have at least one outlet and mechanism for managing the burden of the caregiver process. This likely has a certain level of positive impact on the caregiver's emotional health.

This research adds to the large body of existing literature that has documented the effect of caregiving on the emotional well-being of informal caregivers (Zarit et al, 1996; Schulz and Beach, 1999; Wilcox and King, 1999; Sleath et al, 2005). These findings, along with ongoing research of caregiver emotional health, will allow us to continue to focus on the both the personal and emotional impact of dementia on families and caregivers.

### **7.3. Development of the Survey of Caregiver Medication Concerns Scale**

An important underlying objective of this research was to create a reliable measure of the impact of medication management on dementia caregivers and that was accomplished. Prior to the development of this instrument, there was no standardized method for measuring specific medication-related stressors of caregivers. Other researchers have measured medication stressors of caregivers but a reliable instrument has not been developed and published to date (Ranelli, 1994; Smith, 2003). Analysis of medication tasks could be done by examining the time burden as time spent on the activity of managing medications with a Caregiver Activity Survey; however, this method has limitations and does not address the many facets of medication management.

Through this study we were able to take qualitative responses obtained from caregivers in focus groups and transfer that information into specific questions for a study questionnaire. Although item reduction analysis trimmed our available items for factor analysis from 21 to 15, there were two very distinct domains—medication administration and medication effects—that emerged from the factor analysis. The factor structure was simple with items loading on one of two specific constructs. The factors that were identified were also consistent with the primary areas of concern that were identified in the focus groups and literature review (Ranelli, 1994; Smith, 2003). The Cronbach's  $\alpha$  coefficient for each of the domains was above the acceptable value of 0.70 which showed a good measure of internal consistency reliability.

Five of the eight items that were excluded in the item-reduction analysis were related to the cost of prescription medications. The majority of the qualitative research and original item development was done six to nine months prior to the implementation of Medicare Part

D. There was no way to anticipate the impact that the new prescription drug coverage would have on the elderly population, including those with memory problems. However, based on the caregiver responses from this study, the burden of prescription drug costs was lessened with Part D and was not a major concern of caregivers. Caregiver perceptions of cost may have also been different with continued research later in the calendar year of 2006, as well, as Medicare Part D recipients hit the “doughnut hole” in their coverage. This was also a population where nearly 37% of the care-recipients were covered by private insurance. So, this provides further support that, at least in this population, the cost of prescription medications was less of concern than we had originally thought.

The major accomplishment from this portion of the research is that a validated scale was created to measure concerns that dementia caregivers face when managing their loved one’s medications. There are some obvious limitations with the instrument in its current form; therefore, researchers should take the findings from this scale and use them to continue developing a strong and useful measure of medication-related stressors of caregivers. The instrument was initially developed from a small number of caregivers (n=18) who were either female (n=15) or White (n=13). The instrument was then used for the first and only time in this research study which again lacked diversity with the majority of the caregivers being White middle-class. However, based on the findings from this study, continued revisions of the items related to administering and obtaining medications should be made to strengthen them based on future research in more diverse caregiver populations. The “medication effects” domain of the SCMC scale was associated with caregiver emotional health. So, these relationships should be further explored. The “medication administration” domain needs continued work on item development to ensure that we are capturing the

appropriate stressors in the part of the medication management process. Further pilot testing in more diverse caregiver populations would help researchers understand if there are issues or concerns that were missed in the initial development of the items. It will also be important to capture the qualitative findings provided from this study and incorporate them into the scale items. Two issues raised by caregivers in their comments on the questionnaire were: (1) mail order pharmacy delays and (2) difficulties associated with prescription bottles (e.g., problems with bottle caps and small print). The development of this scale is the first step for researchers in creating a valid and reliable instrument to measure medication-related stressors in dementia caregivers.

#### **7.4. Opportunities for Pharmacists, Pharmacy Practice and Drug Information**

The research also identified an opportunity for the practice of pharmacy and the provision of drug information. First, there were associations between the stress of dealing with medication effects and effectiveness and caregiver depression. Targeted education for pharmacists and pharmacy-based interventions could be developed. Second, caregiver perceptions of pharmacists and pharmacy services were distributed over all response categories indicating that there was a varying degree of satisfaction. These findings create an opportunity for pharmacists to assist dementia caregivers by providing support and education and by creating an environment that is more conducive to effective communication.

Pharmacists are likely to work with caregivers of demented patients in almost every pharmacy practice setting. Therefore, it is important for pharmacists to understand the current treatments for memory problems, the research being done in this therapeutic area, and the issues faced by the patient and caregiver. So, before developing specific pharmacy or pharmacist-based interventions for dementia caregivers, it will be necessary to understand pharmacist knowledge of dementia, its treatment and the caregiving process. There is currently no published literature with this information. A survey of pharmacists should be done that examines their current knowledge about: (1) pathophysiology and epidemiology of dementia, including the types, stages and risk factors, (2) impact of dementia on the patient and caregiver, (3) available treatments (prescription and over-the-counter) for memory loss, (4) common adverse reactions with medication treatments, and (5) the resources available to dementia caregivers. This research will allow us to understand the current gaps in pharmacist knowledge and identify areas of continuing education that is needed in order for

pharmacists to be a resource to dementia caregivers. This research could be done in conjunction with local, state or national pharmacist organizations that have contact information and access to practicing pharmacists. Follow-up continuing education programs could be coordinated through these same organizations.

Based on the findings from this current research study regarding the association between medication effects concerns and caregiver depression, there is a particular need for pharmacists and other healthcare professionals to provide information to caregivers about monitoring the effectiveness and side effects of medications. This is further supported by the perception of pharmacists in this study, where only about 50% of the caregivers agreed that their pharmacist warned them about potential problems their loved one might have with their medication, told them what the medications are used for or gave them advice about how to better manage the medications. Pharmacists can help caregivers by monitoring the patient's medication profile for potential drug-drug interactions, contraindications and adverse events. By providing information to caregivers proactively, they will assist the caregiver in monitoring their loved one's medications which should lead to a decrease in caregiver burden with medication management.

This caregiver education could be done in retail pharmacy settings by using the drug information leaflets currently generated with each prescription. Pharmacists could identify caregivers within their pharmacy setting and set a flag in their pharmacy computer system. When caregivers come to pick-up refills or new prescription fills, the pharmacist should proactively approach the caregiver to determine if they are having any medication problems or have had any questions since their last visit. Longer-term solutions to educating and supporting dementia caregivers could be to (1) develop specific medication-related resources

for medications used by persons with memory problems and (2) provide local resources for the caregivers which might include either a flyer with local contacts or flyers/brochures supplied to the pharmacy by local agencies.

While many retail pharmacies have been focusing on a pharmacy structural design where there is an area for patient consultation and promoting clinical pharmacy services, there remains opportunity for improvement in this area. Only about 34% of the caregivers in this study believed that there was a place in the pharmacy where they could talk with their pharmacist in private. Pharmacists should continue working to promote an environment where patients feel comfortable talking with them about medication-related issues. Another opportunity within the retail setting is to increase the amount of time a pharmacist is available to provide clinical services and to continue to have pharmacy technicians performing the technical functions. This is important for many patient populations but especially for caregivers who are dealing with their own medications and the medications of their loved ones.

Finally, pharmacists must demonstrate empathy toward the dementia caregiver by understanding the challenges that they face and suggesting resources for them when appropriate. From the information provided by caregivers in this study about pharmacist perceptions, only half of the caregivers believed that their pharmacist cared about their own health and well-being. Pharmacists must understand that assistance extends beyond drug treatment for the person with dementia and drug information for the caregiver. Pharmacists can provide caregivers with strategies for managing the medication process but they should always be reminding the caregiver to take care of themselves and to not forget their own physical and emotional well-being.



Managing the health outcomes of anyone, including dementia caregivers, requires a multidisciplinary approach to optimize care. There are many health professionals (e.g., physician, nurse, social worker) who work with caregivers. However, since this research focused on medication-related stressors and needs of dementia caregivers related to medication management, is important to consider pharmacy-based solutions. Pharmacists can take an active role within their pharmacy practice as outlined above by identifying these caregivers and providing information and support to them. Pharmacists are in a unique position and possess the necessary skills to improve the medication process for dementia caregivers. By closing the gaps in pharmacist knowledge about dementia and caregiving through continuing education support, pharmacists can be an instrumental support for the caregiver.

## 7.5. Limitations and Future Studies

**Limitations:** This research has several notable limitations. One of the major limitations of this research study is that it was cross-sectional in design and, thus, only captures the medication management process for these caregivers at one point in time. Without information on temporal relationships between medication-related stressors and other factors (e.g., caregiver and care-recipient contextual, caregiver resources), we have limited information in understanding how changes in either the stressors or other factors over time impact the emotional health of caregivers. In addition to the caregiving process being complex, depressive disorders have a natural history and change (either progressing or regressing) over time. So, there is the possibility that the responses of the caregivers were biased by their current caregiving situation. Also, the cross-sectional design makes it difficult to determine whether the modeled variables (e.g., stressors, contextual factors, resources) influence the emotional health of caregivers or if the emotional health status of the caregiver influences those other variables. Longitudinal studies are needed to perform more detailed analysis of cause and effect relationships and should be considered for future research.

Although questionnaires that are self-administered are a cost-efficient means of collecting data, self-report bias is also a concern when using survey data. Another limitation is that the sample size is not sufficient for path analysis. An adequate sample size is required to test the significance of linear relationships. Kline (1998) recommends that there be 10 to 20 times as many subjects as there are estimated parameters. In the regression models predicting emotional health outcomes there were only about 7 times as many subjects as

modeled parameters which would be insufficient for significance testing of the model effects according to Kline's rule of thumb.

This research, as many others involving the recruitment of caregivers, focused on partnering with community organizations and clinics where caregivers come for support or information about caring for their loved one. There is the possibility of selection bias as the caregivers who participated in the study may have different characteristics than those caregivers who were not identified through the study selection methods. The availability of community support, either by structured support groups or multidisciplinary clinical teams, may have confounded the findings. The challenge in caregiver research continues to be identifying and reaching out to those caregivers who have not yet established themselves within a supportive setting within the community. I did contact and attend caregiver support groups across the state of North Carolina to include both rural and urban communities. This did help balance the sociodemographics of the overall caregiver sample but it did not completely address the issue of recruiting non-White participants. Attempts were made to contact African-American churches and communities. This strategy, however, is one that takes time and relationship-building. Therefore, this research is limited in that it was done primarily in a White middle class population of caregivers. Future research should continue to address strategies to reach the non-White caregivers as they remain under-represented in this type of research.

The 74% response rate was relatively higher than other postal research (Billinghurst, 1993; Salisbury, 1997) and resulted in an acceptable sample size. The multi-faceted strategy of reaching out to caregiver support groups, medical clinics and online support groups was successful with the resources that were available within the scope of this dissertation.

However, a research study conducted over a longer period of time with more resources may have yielded an even greater amount of participation. Connecting with community-based organizations and medical facilities requires time to establish relationships and rapport. I was able to do that within those organizations and clinics where I was involved; however, it is possible that a research study with more human resources could have reached out to more people within the same amount of time which would have increased the number of caregivers who were contacted.

This study also did not collect enough detailed information about the extent and quality of social support available to these dementia caregivers. We measured social support with only one instrument that assessed the caregiver's subjective social support. There was no assessment of direct support available to caregivers for medication-related responsibilities. Caregivers need to be surveyed in future research about the types of people available to them to help with medications (e.g., friends, family, paid help, home health), the availability of that help (e.g., daily, occasionally, rarely) and what types of medication-related responsibilities the substitutes can handle. Since there is limited research in this area, this information would best be obtained through caregiver interviews or focus groups where caregivers could respond and elaborate on these issues.

The limitations of the study questionnaire were outlined in Section 7.3 of this chapter. However, it is important to emphasize the fact that more work should be done to refine the scale that was created to assess medication-related stressors in dementia caregivers. The scale was developed using two focus groups in one community. A more focused effort on collecting qualitative information through focus groups and/or surveys among caregivers from different communities and with different socioeconomic backgrounds should be done.

This will allow for further refinement and testing of this instrument in this population and allow us to confirm and expand on the results found within this study.

We were also not able to completely understand the impact of medication-related problems on those caregivers who are employed. There was instability in some of the variables when modeling due to the low number of respondents within a specific category (e.g., non-Whites, not living with the care-recipient). Therefore, this analysis was not able to be completed to test the original hypothesis and aims of this research. From conversations in support group meetings with caregivers and based on hand-written comments on the study questionnaire in this research, there are concerns from caregivers about the impact that medication management has on their employment and job performance. However, we were unable to draw any conclusions from this research study.

**Future Research:** There are several specific suggestions for future research. First, we should use the findings from the development of the Survey of Caregiver Medication Concerns scale and continue to rigorously examine and refine the instrument so that it can be used in future research of dementia caregivers. The refined instrument should be tested in a larger and more diverse population. This will allow us to describe in greater detail the impact of medication management on the emotional health of caregivers and will offer greater generalizability.

Second, we should further examine the role of a pharmacist in assisting caregivers of persons with memory problems. This study offers feedback from caregivers about their perceptions of pharmacists and pharmacy services. Surveying pharmacists about their knowledge of dementia and the role of caregivers would be an important next step. Using

gaps in knowledge that are identified from this type of survey along with the perceptions of caregivers outlined in this current study, it would be possible to make recommendations for pharmacy-based interventions that might include pharmacist education or pharmacy-based services for caregivers. Pharmacists are in a unique position to provide information and support to these caregivers and the findings from this study demonstrate that, as a profession, they are not currently meeting this need.

The next step should be an intervention study with a longitudinal design so that caregivers can be surveyed at several points in time. The intervention could be based on information taken from this current research study. We learned that the concern of medication effectiveness and side effects is associated with poorer emotional health in these caregivers. So, an educational intervention should be considered that is targeted at providing drug information on (1) the use of the care-recipients medications, (2) potential contraindications, (3) potential drug-drug interactions, and (4) adverse events that might be expected.

Finally, more research should be performed to understand the differences between caregivers who use mail order pharmacies and those who use a local chain or independent pharmacy. One would expect that the relationship between the caregiver and their pharmacist and the level of pharmacy support would be different based on where they receive their loved one's prescription medications. Other research that was outside the scope of this dissertation research is to perform further bivariate and multivariable analyses in order to understand the impact of the individual pharmacy satisfaction items on caregiver emotional health. This would also help to guide a framework for pharmacy-based interventions.

## **CHAPTER EIGHT**

### **CONCLUSION**

This research was a step in beginning to understand the impact that managing medications has on dementia caregivers. Our findings suggest that medication-related stressors are associated with poorer emotional health outcomes in caregivers. Our descriptive analysis of caregiver's attitudes about pharmacists and pharmacy services also suggests that there are things that can be done to assist caregivers to improve the relationship and communication with their pharmacist. Help with medication-related stress can, however, be accomplished in many settings and by a host of informed professionals in addition to pharmacists including physicians, nurses, social workers, and support group facilitators. Hopefully, findings from this dissertation research will be one more step in the process of identifying areas of concern for dementia caregivers and designing interventions that will ultimately improve their emotional health outcomes.

## **Appendix 1**

### **Focus Group Script**



## **Focus Group Question Guide**

### **Impact of Medication Management on Caregivers of Demented Patients**

Introduction: Tell us your first name and how long you have been a primary caregiver.

When you think about managing your loved one's medications, what comes to mind?

What are the most stressful parts of managing your loved one's medications?

How has managing your loved one's medications impacted your relationship with him/her?

How has managing your loved one's medications impacted other activities (work, social events, family time, etc)?

Where do you typically receive information about medications?

Where do you currently receive your loved one's medications (e.g. chain pharmacy, community pharmacy, mail order)?

How does your pharmacist help with managing the medications?

How could your pharmacist help with managing the medications?

Ending: We want to try to better understand the role of caregivers in medication management. What advice would you give us?

## **Appendix 2**

### **Study Questionnaire**

#### **Caregivers of Persons with Memory Problems: The Medication Study**

ID Number: \_\_\_\_\_

## **Caregivers of Persons with Memory Problems: The Medication Study**

### **STATEMENT OF CONFIDENTIALITY**

The identification number at the top of the page allows us to keep track of the questionnaires as they are returned. Any information that would permit identification of an individual will be held strictly confidential, will be used only for the purposes of this study, and will not be disclosed to others.

Conducted by:



**Division of Pharmaceutical Outcomes and Policy**

This research has been reviewed and approved by the Committee on the Protection of the Rights of Human Subjects (Medical IRB) at the University of North Carolina at Chapel Hill.

## Caregivers Medication Study Questionnaire

Thank you very much for filling out every question on this survey.  
We know how busy you are as a caregiver.

### SECTION ONE: Patient Information

This section includes questions about your loved one with memory problems. Throughout this survey, we will refer to this person as the "care-recipient" (or your "loved one").

1. How old is the care-recipient?

\_\_\_\_\_ years

2. How many years of schooling has he/she completed? *(Circle one)*

- a. Less than high school
- b. High school diploma or equivalent
- c. Some college
- d. College degree
- e. Graduate or professional degree

3. Is the care-recipient male or female? *(Circle one)*

- a. Male
- b. Female

4. What is his/her race or ethnicity? *(Circle one)*

- a. American Indian or Alaskan Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White
- f. Hispanic or Latino
- g. Other *(specify)*: \_\_\_\_\_

5. What is his/her current marital status? *(Circle one)*

- a. Currently married
- b. Separated
- c. Divorced
- d. Widowed
- e. Never married
- f. Other *(specify)*: \_\_\_\_\_

6. How many living children does he/she have?

\_\_\_\_\_

7. Does he/she live alone or with other people? (Circle one)

- a. Lives with spouse or partner
- b. Lives with other relatives
- c. Lives with friends
- d. Lives with other unrelated individuals (for example, paid help)
- e. Lives alone

8. Please indicate whether or not the care-recipient has the following medical conditions by circling either Yes or No for each question.

| Example: Asthma                                     | Yes | No |
|---|-----|----|
| a. Anemia   | Yes | No |
| b. Arthritis or rheumatism                          | Yes | No |
| c. Asthma   | Yes | No |
| d. Cancer or leukemia                               | Yes | No |
| e. Circulation trouble in arms or legs              | Yes | No |
| f. Depression, anxiety or emotional problems        | Yes | No |
| g. Diabetes   | Yes | No |
| h. Effects of Polio                                 | Yes | No |
| i. Effects of stroke                                | Yes | No |
| j. Emphysema or chronic bronchitis                  | Yes | No |
| k. Epilepsy   | Yes | No |
| l. Glaucoma or blindness                            | Yes | No |
| m. Heart disease                                    | Yes | No |
| n. High blood pressure                              | Yes | No |
| o. Kidney disease                                   | Yes | No |
| p. Liver disease                                    | Yes | No |
| q. Memory problems (Alzheimer's or memory disorder) | Yes | No |
| r. Multiple sclerosis                               | Yes | No |
| s. Stomach/intestinal disorders                     | Yes | No |
| t. Urinary tract disorders                          | Yes | No |
| u. Parkinson's Disease                              | Yes | No |
| v. Skin disorders                                   | Yes | No |
| w. Thyroid or other glandular disorders             | Yes | No |
| x. Tuberculosis                                     | Yes | No |
| y. Ulcers (of the stomach)                          | Yes | No |
| z. Chronic Pain                                     | Yes | No |

**9. The following questions will help determine the functional capability of the care-recipient.**

For each item, check ☒ the one response that best describes his/her ability.

**a. Using telephone**

- ☐<sub>1</sub> Able to look up numbers, dial telephone, and receive and make calls without help.
- ☐<sub>2</sub> Able to answer telephone or dial operator in an emergency, but needs special telephone or help in getting numbers and/or dialing.
- ☐<sub>3</sub> Unable to use telephone.

**b. Traveling**

- ☐<sub>1</sub> Able to drive own car or to travel alone on buses or in taxis
- ☐<sub>2</sub> Able to travel, but needs someone to travel with
- ☐<sub>3</sub> Unable to travel

**c. Shopping**

- ☐<sub>1</sub> Able to take care of all food and clothes shopping with transportation provided
- ☐<sub>2</sub> Able to shop, but needs someone to shop with
- ☐<sub>3</sub> Unable to shop

**d. Preparing meals**

- ☐<sub>1</sub> Able to plan and cook full meals
- ☐<sub>2</sub> Able to prepare light foods, but unable to cook full meals alone
- ☐<sub>3</sub> Unable to prepare any meals

**e. Housework**

- ☐<sub>1</sub> Able to do heavy housework (e.g. scrub floors)
- ☐<sub>2</sub> Able to do light housework, but needs help with heavy tasks
- ☐<sub>3</sub> Unable to do any housework

**f. Taking medicine**

- ☐<sub>1</sub> Able to prepare and take medications in the right dose at the right time
- ☐<sub>2</sub> Able to take medications, but needs reminding or someone to prepare them
- ☐<sub>3</sub> Unable to take medications

**g. Managing money**

- ☐<sub>1</sub> Able to manage buying needs (i.e. write checks, pay bills)
- ☐<sub>2</sub> Able to manage daily buying needs, but needs help managing checkbook and/or paying bills.
- ☐<sub>3</sub> Unable to handle money

**10. The following questions will ask you to determine how much time you have spent on caregiving activities.**

**a. Communicating with the care-recipient**

Please consider the following examples of activities:

- Answering the same question again and again
- Trying to make sense of what the care-recipient says
- Leaving reminders for the care-recipient

Thinking back over the past day, how much time did you spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

**b. Using transportation**

Please consider the following examples of activities:

- Reminding the care-recipient about means of transportation
- Taking the care-recipient to various places (other than shopping) by car or public transportation or taxi

Thinking back over the past day, how much time did you spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

**c. Dressing**

Please consider the following examples of activities:

- Reminding the care-recipient to dress
- Choosing what to wear
- Laying out clothes
- Helping the care-recipient to dress or undress
- Supervising the care-recipient dressing
- Keeping the care-recipient from undressing at the wrong time

Thinking back over the past day, how much time did you spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

**d. Eating**

Please consider the following examples of activities:

- Reminding the care-recipient to eat
- Setting up utensils and food
- Cutting or arranging food on the plate
- Supervising or encouraging the care-recipient to eat
- Cleaning the care-recipient after eating

Thinking back over the past day, how much time did you spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

**e. Looking after one's appearance**

Please consider the following examples of activities:

- Reminding the care-recipient to brush his/her teeth, brush his/her hair, apply cosmetics, shave or care for nails
- Helping the care-recipient to groom
- Setting out items for grooming activities
- Supervising grooming activities
- Maintaining the care-recipient's appearance over the course of the day

Thinking back over the past day, how much time did you spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes

**f. Supervising the care-recipient**

Please consider the following examples of activities:

- Keeping an eye on the care-recipient to be sure that they do not wander off or get into some kind of difficulty
- Looking out for the care-recipient
- Preventing the care-recipient from getting lost
- Finding the care-recipient if they get lost

Thinking back over the past day, how much time did you and others spend in the last 24 hours (day and night) doing these types of activities?

\_\_\_\_\_ hours \_\_\_\_\_ minutes



## SECTION TWO: Medication Management

11. How many prescription medications does your loved one currently take?

\_\_\_\_\_

If you cannot remember the exact number, please get the prescription bottles and count the number of different medications. Please do not count over-the-counter medications or herbal medicines.

12. Does your loved one have insurance, or drug coverage, that pays for his/her prescription drugs? *(Circle one)*

- a. Yes
- b. No

12.1 If Yes: What type of insurance does your loved one have for prescription drugs?

*(Check ☒ all that apply)*

- ☐ a Private Insurance
- ☐ b Medicaid
- ☐ c VA
- ☐ d Medicare
- ☐ e Other \_\_\_\_\_

13. How many pharmacies do you use? *(Circle one)*

- a. One
- b. Two
- c. Three
- d. Four or more

14. What is the name of the pharmacy or pharmacies that you currently use?

\_\_\_\_\_  
\_\_\_\_\_

**15. Think about managing your care recipient's medications and indicate your level of agreement with each statement below.**

*(Circle one for each response)*

|  | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|--|-------------------|----------|---------|-------|----------------|
| <b>a. Administering Medications:</b>   |                   |          |         |       |                |
| 1. It is hard for me to give my loved one medication more than one time a day.                                   | 0                 | 1        | 2       | 3     | 4              |
| 2. It is easy to manage my loved one's medications.  | 0                 | 1        | 2       | 3     | 4              |
| 3. It is hard to organize all of my loved one's medications.   | 0                 | 1        | 2       | 3     | 4              |
| 4. It is easier to keep track of my loved one's medications when I use a pill organizer.                         | 0                 | 1        | 2       | 3     | 4              |
| 5. I have trouble convincing my loved one to take medications.   | 0                 | 1        | 2       | 3     | 4              |
| 6. It is hard to keep the times of day straight when giving my loved one his/her medication.                     | 0                 | 1        | 2       | 3     | 4              |
| 7. I worry about who will give my loved one medication if I am not able to do it.                                | 0                 | 1        | 2       | 3     | 4              |
| 8. There has been a time when I had to hide my loved one's medication.   | 0                 | 1        | 2       | 3     | 4              |
| <b>b. Effects of Medications:</b>  |                   |          |         |       |                |
| 1. I worry at times that my loved one's medications are not working.   | 0                 | 1        | 2       | 3     | 4              |
| 2. It is hard for me to know whether my loved one is having a bad reaction to his/her medications.               | 0                 | 1        | 2       | 3     | 4              |
| 3. I have trouble managing the side effects (for example, nausea, and diarrhea) from my loved one's medications. | 0                 | 1        | 2       | 3     | 4              |

|   | Strongly<br>Disagree | Disagree | Neutral | Agree | Strongly<br>Agree |
|---|----------------------|----------|---------|-------|-------------------|
| 4. I am concerned that my loved one is not receiving the best medications for his/her condition.      | 0                    | 1        | 2       | 3     | 4                 |
| 5. I worry that my loved one will not be able to let me know if the medications are causing problems. | 0                    | 1        | 2       | 3     | 4                 |

|  | Strongly<br>Disagree | Disagree | Neutral | Agree | Strongly<br>Agree |
|--|----------------------|----------|---------|-------|-------------------|
| <b>c. Obtaining Medications:</b>   |                      |          |         |       |                   |
| 1. I have difficulty, on occasion, paying for my loved one's medication.   | 0                    | 1        | 2       | 3     | 4                 |
| 2. I have, on occasion, decided not to fill a prescription for my loved one because money was tight.                             | 0                    | 1        | 2       | 3     | 4                 |
| 3. I have, on occasion, decided not to ask my loved one's doctor for a prescription because money was tight.                     | 0                    | 1        | 2       | 3     | 4                 |
| 4. There have been times when I have not had reliable transportation to the pharmacy to pick up my loved one's medications.      | 0                    | 1        | 2       | 3     | 4                 |
| 5. Each month, I have to make more than one trip to the pharmacy to pick up medications for my loved one.                        | 0                    | 1        | 2       | 3     | 4                 |
| 6. There have been times when my own health has prevented me from giving my loved one medication.                                | 0                    | 1        | 2       | 3     | 4                 |
| 7. I have considered getting my loved one's medications from outside of the United States because they are less expensive there. | 0                    | 1        | 2       | 3     | 4                 |
| 8. I worry that I will not be able to afford my loved one's medications in the future.   | 0                    | 1        | 2       | 3     | 4                 |

|   | Strongly<br>Disagree | Disagree | Neutral | Agree | Strongly<br>Agree |
|---|----------------------|----------|---------|-------|-------------------|
| <b>d. Information about Medications:</b>  |                      |          |         |       |                   |
| 1. I am satisfied with the <u>written</u> information I receive about my loved one's medications.                 | 0                    | 1        | 2       | 3     | 4                 |
| 2. I am satisfied with the <u>verbal</u> information I receive about my loved one's medications.                  | 0                    | 1        | 2       | 3     | 4                 |
| 3. It is easy to understand the <u>written</u> information about my loved one's medications.                      | 0                    | 1        | 2       | 3     | 4                 |
| 4. There have been times when I have not understood the medical terms that are used by my loved one's doctor.     | 0                    | 1        | 2       | 3     | 4                 |
| 5. There have been times when I have not understood the medical terms that are used by my loved one's pharmacist. | 0                    | 1        | 2       | 3     | 4                 |

16. Have you had to miss an entire day of work to deal with problems associated with managing your care-recipient's medications? *(Circle one)*

- a. No
- b. Yes

16.1 If Yes: How many times have you had missed a day of work entirely in the past 30 days to deal with these problems?

\_\_\_\_\_ times

17. Have you been late to work or had to leave work early to deal with problems associated with managing your care-recipient's medications? *(Circle one)*

- a. No
- b. Yes

17.1 If Yes: About how many times have these problems caused you to leave work early or be late for work in the past 30 days?

\_\_\_\_\_ times

18. Have you had to miss a social activity (like being with friends or attending church) to deal with problems associated with managing your care-recipient's medications? (Circle one)

- a. No
- b. Yes

18.1 If 'Yes: How many times have you missed a social activity in the past 30 days to deal with these problems?

\_\_\_\_\_ times

19. Please think about the pharmacy where you usually get your loved one's medications and answer the following questions.

(Circle one for each response)

|   | Strongly Disagree | Disagree | Neutral | Agree | Strongly Agree |
|---|-------------------|----------|---------|-------|----------------|
| a. The pharmacist is usually available to answer my questions about my loved one's medications. | 0                 | 1        | 2       | 3     | 4              |
| b. The pharmacist warns me about problems that my loved one might have with the medications.    | 0                 | 1        | 2       | 3     | 4              |
| c. The pharmacist tells me what my loved one's medications are used for.                        | 0                 | 1        | 2       | 3     | 4              |
| d. I receive advice from the pharmacist that helps me to manage my loved one's medications.     | 0                 | 1        | 2       | 3     | 4              |
| e. The pharmacist answers any questions that I have about my loved one's medications.           | 0                 | 1        | 2       | 3     | 4              |
| f. I feel like the pharmacist really cares about my overall health and well-being.              | 0                 | 1        | 2       | 3     | 4              |
| g. There is a place at the pharmacy where I can talk in private with the pharmacist.            | 0                 | 1        | 2       | 3     | 4              |
| h. I am satisfied with the amount of time that the pharmacist spends with me.                   | 0                 | 1        | 2       | 3     | 4              |
| i. I trust the pharmacist to give me the best information about my loved one's medications.     | 0                 | 1        | 2       | 3     | 4              |
| j. The pharmacist works with my loved one's doctors to provide the best medications possible.   | 0                 | 1        | 2       | 3     | 4              |

### SECTION THREE: Caregiver Information

The next questions are about YOU, the caregiver (NOT your loved one).  
Please answer every question as it applies to YOU.

20. How long have you been a primary caregiver for your care-recipient?

\_\_\_\_\_ years    \_\_\_\_\_ months

21. What is your relationship to the care-recipient? *(Circle one)*

- a. Spouse
- b. Child
- c. Other relative
- d. Friend
- e. Other

22. Do you live with the care-recipient? *(Circle one)*

- a. Yes
- b. No

23. Are you the primary caregiver for anyone else? *(Circle one)*

- a. Yes
- b. No

24. Are your expenses so heavy that you cannot meet your bills, you can barely meet your bills, or bills are no problem? *(Circle one)*

- a. cannot meet my bills
- b. barely meet my bills
- c. bills are no problem

25. How well does the money you have take care of your needs? *(Circle one)*

- a. very well
- b. fairly well
- c. poorly

26. How adequate is your income to buy those little "extras"—that is, those small luxuries?

*(Circle one)*

- a. not at all adequate
- b. somewhat adequate
- c. very adequate

The following questions ask you about views of your health. Please circle the one answer that best applies to your health.

27. In general, would you say your health is: *(Circle one)*

- a. Excellent
- b. Very Good
- c. Good
- d. Fair
- e. Poor

28. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

a. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. *(Circle one)*

- 1. Yes, limited a lot
- 2. Yes, limited a little
- 3. No, not limited at all

b. Climbing several flights of stairs. *(Circle one)*

- 1. Yes, limited a lot
- 2. Yes, limited a little
- 3. No, not limited at all

29. During the past 4 weeks, how much of the time have you:

a. Accomplished less than you would like as a result of your physical health?  
*(Circle one)*

- 1. All of the time
- 2. Most of the time
- 3. Some of the time
- 4. A little of the time
- 5. None of the time

b. Were limited in the kind of work or other activities as a result of your physical health? *(Circle one)*

- 1. All of the time
- 2. Most of the time
- 3. Some of the time
- 4. A little of the time
- 5. None of the time

c. Accomplished less than you would like as a result of your emotional health (such as feeling depressed or anxious)? *(Circle one)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

d. Done work or other activities less careful than usual as a result of your emotional health (such as feeling depressed or anxious)? *(Circle one)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

30. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the house and housework)? *(Circle one)*

- a. Not at all
- b. A little bit
- c. Moderately
- d. Quite a bit
- e. Extremely

31. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

a. Have you felt calm and peaceful? *(Circle one)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

b. Did you have a lot of energy? *(Circle one)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time

c. Have you felt downhearted and depressed? *(Circle one)*

1. All of the time
2. Most of the time
3. Some of the time
4. A little of the time
5. None of the time



32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

(Circle one)

- a. All of the time
- b. Most of the time
- c. Some of the time
- d. A little of the time
- e. None of the time

These questions ask you about your feelings and thoughts during the last two weeks. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

33. Over the last 2 weeks, how often have you been bothered by any of the following problems?

(Circle one for each response)

|  | Not at all | Several Days | More than half the days | Nearly every day |
|--|------------|--------------|-------------------------|------------------|
| a. Little interest or pleasure in doing things.  | 0          | 1            | 2                       | 3                |
| b. Feeling down, depressed or hopeless.  | 0          | 1            | 2                       | 3                |
| c. Trouble falling or staying asleep, or sleeping too much.  | 0          | 1            | 2                       | 3                |
| d. Feeling tired or having little energy.  | 0          | 1            | 2                       | 3                |
| e. Poor appetite or overeating.  | 0          | 1            | 2                       | 3                |
| f. Feeling badly about yourself—or that you are a failure or have let yourself or your family down.  | 0          | 1            | 2                       | 3                |
| g. Trouble concentrating on things, such as reading the newspaper or watching television.  | 0          | 1            | 2                       | 3                |
| h. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual. | 0          | 1            | 2                       | 3                |
| i. Thoughts that you would be better off dead or of hurting yourself in some way.  | 0          | 1            | 2                       | 3                |

**34. Some additional questions about your feelings:**

*Circle Yes or No*

- |  |     |    |
|--|-----|----|
| a. Do you wake up feeling fresh and rested most mornings?                                    | Yes | No |
| b. Is your daily life full of things that keep you interested?                               | Yes | No |
| c. Does it seem that no one understands you?   | Yes | No |
| d. Do you feel weak all over much of the time?   | Yes | No |
| e. Are you troubled by headaches?  | Yes | No |
| f. Do you sometimes have difficulty in keeping your balance while walking?                   | Yes | No |
| g. Are you sometimes troubled by your heart pounding or shortness of breath?                 | Yes | No |
| h. Do you sometimes suddenly feel hot all over?  | Yes | No |
| i. Do you sometimes have periods of great restlessness where you cannot sit still very long? | Yes | No |
| j. Are you the worrying type?  | Yes | No |
| k. Are you sometimes bothered by nervousness or tenseness?                                   | Yes | No |
| l. Do you ever have trouble getting or staying asleep?                                       | Yes | No |
| m. Are you bothered by acid stomach?   | Yes | No |
| n. Are you occasionally bothered by "cold sweats"?   | Yes | No |

|  |     |    |
|--|-----|----|
| o. Are you occasionally bothered by feelings of guilt?                         | Yes | No |
| p. Do you sometimes feel overwhelmed by responsibility?                        | Yes | No |
| q. Do you have personal worries that are getting you down physically?          | Yes | No |
| r. Do you feel somewhat alone, even among friends?                             | Yes | No |
| s. Do you sometimes find yourself wondering if anything is worthwhile anymore? | Yes | No |

**34.1 Taking all things together, how would you say that you find life these days?**  
(Circle One)

- a. Not satisfying
- b. Fairly satisfying
- c. Very satisfying

**35. The following questions are about the people that are in your life. (Circle one response for each item)**

**a. How satisfied are you with how often you see your friends and relatives?**

- 1. Satisfied
- 2. Somewhat dissatisfied
- 3. Very dissatisfied

**b. When you are with your family and friends how often do you feel lonely?**

- 1. Hardly ever
- 2. Some of the time
- 3. Most of the time

**c. How often does it seem that your family and friends understand you?**

1. Hardly ever
2. Some of the time
3. Most of the time

**d. Is there at least one person with whom you have a close, lasting relationship?**

1. Yes
2. No

**e. How often do you feel useful to your family and friends?**

1. Hardly ever
2. Some of the time
3. Most of the time

**f. How often do you know what is going on with your family and friends?**

1. Hardly ever
2. Some of the time
3. Most of the time

**g. How often, when talking with your family and friends, do you feel you are being listened to?**

1. Hardly ever
2. Some of the time
3. Most of the time

**h. How often do you feel you have a definite role (place) in your family and among your friends?**

1. Hardly ever
2. Some of the time
3. Most of the time

i. In times of trouble, how often can you count on at least some of your family and friends?

1. Hardly ever
2. Some of the time
3. Most of the time

j. How often can you talk about your deepest problems with at least some of your family and friends?

1. Hardly ever
2. Some of the time
3. Most of the time

k. How satisfied are you with the kinds of relationships you have with your family and friends?

1. Satisfied
2. Somewhat dissatisfied
3. Very dissatisfied

**IF YOU ARE EMPLOYED**, answer this question. If you are not employed, skip this question and go to the next page.

**36. On your job how often do you talk with other people?** *(Circle one)*

- a. Very often
- b. Sometimes
- c. Rarely
- d. Never

37. In the past 2 weeks or so, have you been feeling sad or depressed or no interest in things?

(Circle one)

- a. No
- b. Yes

35.1 If Yes: what are you currently doing to help you get over feeling sad or depressed or not having interest in things?

(Please circle Yes or No)

- |   |     |    |
|---|-----|----|
| a. Nothing  | Yes | No |
| b. Taking an antidepressant medication                                    | Yes | No |
| c. Taking herbal medicines or natural supplements (e.g., St. John's Wort) | Yes | No |
| d. Getting counseling from a mental health professional                   | Yes | No |
| e. Getting counseling from a health care provider                         | Yes | No |
| f. Going to a support group   | Yes | No |
| g. Talking with someone at my church                                      | Yes | No |
| h. Other: _____   | Yes | No |

38. How old are you?

\_\_\_\_\_ years

39. How many years of schooling have you completed? (Circle one)

- a. Less than high school
- b. High school diploma or equivalent
- c. Some college
- d. College degree
- e. Graduate or professional degree

40. Are you male or female? (Circle one)

- a. Male
- b. Female

41. Do you live alone or with other people? (Circle one)

- a. Live with spouse or partner
- b. Live with other relatives
- c. Live with other unrelated individuals (for example, friends or paid help)
- d. Live alone

42. What is your race or ethnicity? (Circle one)

- a. American Indian or Alaskan Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White
- f. Hispanic or Latino
- g. Other (specify): \_\_\_\_\_

43. What is your current marital status? (Circle one)

- a. Currently married
- b. Legally separated
- c. Divorced
- d. Widowed
- e. Never married
- f. Other (specify): \_\_\_\_\_

44. What is your current employment status? (Circle the ONE that best describes you)

- a. Working full-time
- b. Working part-time
- c. Retired
- d. Attending school
- e. Unemployed
- f. Disabled
- g. Other

45. Please select the range that most closely approximates your total yearly household income, before taxes, from all sources, including social security. (Circle one)

- a. Less than \$9,000
- b. \$9,001 - \$18,000
- c. \$18,001 - \$30,000
- d. \$30,001 - \$40,000
- e. \$40,001 - \$50,000
- f. \$50,001 - \$60,000
- g. Above \$60,000

46. Please use this space to share with us any other thoughts or ideas that you have about managing your loved one's medications or about care giving, in general. Your comments will be very valuable to us!

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**This research aims to help caregivers. We will never understand the challenges faced by caregivers without the assistance of people like you.**

**Thank you for completing this survey.**

Before putting this questionnaire in the enclosed postage paid envelope, **PLEASE** go through each page and make sure that you answered all questions other than those which you were directed to skip.



Division of Pharmaceutical Outcomes and Policy



## **Appendix 3**

### **Follow-Up Procedure Letters**

## INITIAL COVER LETTER



Division of Pharmaceutical Outcomes and Policy

Dear Caregiver:

I wanted to take the opportunity to thank you for your interest in completing the questionnaire, Dementia Caregiver Medication Study, that you received. We do believe that your responses will help us better understand the overall stress and burden associated with medication management for dementia patients. It is our hope that the study will identify potential opportunities for pharmacy interventions for AD patients and their caregivers.

I am a fourth-year doctoral student in the School of Pharmacy at the University of North Carolina. I have been a practicing pharmacist for over 13 years and I am moving into a research career upon completion of my PhD later this year. My work experience and research interests are in the aging population and in mental health. I have been involved for several years now in research of caregivers and persons with memory problems. During that time, I have met many wonderful people who care for a loved one on a daily basis and the work has been extremely fascinating and rewarding. I am convinced that we will never understand the real challenges of caregivers unless we reach out to you and allow you to share your experiences. I know how busy you are as caregivers but would appreciate you taking the time to answer the questions on the enclosed study questionnaire.

Thanks for your contribution to this dissertation research effort. Should you have any questions, you can reach me by telephone at 919-674-2535 or by email at [jbyrd@unc.edu](mailto:jbyrd@unc.edu).

Kind regards,

John Byrd, RPh MBA  
Study Coordinator

## FIRST FOLLOW-UP—THANK YOU LETTER



Division of Pharmaceutical Outcomes and Policy

Dear Caregiver:

I appreciate your interest in completing the questionnaire, Dementia Caregiver Medication Study, that you received last week. We do believe that your responses will help us better understand the overall stress and burden associated with medication management for dementia patients. It is our hope that the study will identify potential opportunities for pharmacy interventions for AD patients and their caregivers.

Thanks for your contribution to this research effort. Should you have any questions, you can reach me by telephone at 919-674-2535 or by email at [jbyrd@unc.edu](mailto:jbyrd@unc.edu).

Kind regards,

John Byrd, RPh MBA  
Study Coordinator

## SUBSEQUENT FOLLOW-UP LETTER



Division of Pharmaceutical Outcomes and Policy

Dear Caregiver:

I wanted to take the opportunity to thank you again for your interest in completing the questionnaire, Dementia Caregiver Medication Study. We have not received a completed questionnaire from you and are sending you another copy along with a self-addressed stamped envelope. If you have already mailed it, disregard this mailing and thank you for your response.

We do believe that your responses will help us better understand the overall stress and burden associated with medication management for dementia patients. It is our hope that the study will identify potential opportunities for pharmacy interventions for persons with memory problems and their caregivers.

Thanks for your contribution to this research effort. Should you have any questions, you can reach me by telephone at 919-674-2535 or by email at [jbyrd@unc.edu](mailto:jbyrd@unc.edu).

Kind regards,

John Byrd, RPh MBA  
Study Coordinator

## **Appendix 4**

### **Caregiver Handwritten Comments**

I have responsibility for packing my mothers pill packer. I don't live with or too near her (30 minutes away), so, my sister occasionally has to fill in--packing them if I get in a bind and cant get home, or if we are waiting on a refill with the pharmacy. Although we have done this around two years now, my sister has just told me my mother doesn't take it as regularly as I had thought. We are not considering getting a home health person to come daily to give her morning medications and help with taking care of laundry, light household chores. So, we are at a transition point.

It is hard to afford medication for my spouse and myself. I spend most of my time worrying about affording medication. I have very little help taking care of my spouse. It is mostly my responsibility. Her doctors suggested she quit taking her Alzheimer's medications. She has truly improved and I had to convince them not to. I would love get her on the newly tested medication but I'm not sure how to do this. I worry about getting my pain medication so i can continue to care for my wife properly.

I would love to figure out a way to get prescriptions scheduled together so that I don't need to go to the pharmacy every week. I cannot figure out how to accomplish this.

You should ask about anger, annoyance, irritability, how time is divided into tiny segments that make sustained effort difficult. Also, I have some household help and some caregiver help. Otherwise, I would be in constant back pain and probably on the psych ward.

It would be helpful if the pharmacy was able to give all prescriptions at once instead of at different 30 day periods according to date prescribed.

Because my husband took no medications for the first 47 years of our marriage, it has been difficult for me to adjust to any schedule past the first thing in the morning.

Especially it has been difficult to give meds near dinner time if we are out for unplanned dinner. I forget, but only rarely. Still, I feel bad about it. We both have great love for God and experience the miracle of his constant care and provision and smiles. We have close

family and friends and neighbors who also love and care for us. The Support Group led by Kate Barrett has been a tremendous blessing to me.

I take care of 2 seniors in my home. I find it important to stay in touch with their doctor-- read and understand all medicines. I give them their meds at the same time every day. I use the same pharmacy all the time.

I wish that my parents had planned earlier to move to an assisted living home. I understand that they want to be "at home," but at this stage, they are unable to do the things they could even last year--housekeeping and cooking and bathing. Falls are beginning and that concerns me greatly for I am not with them 24 hours. My parents do not wish to talk about end-of-life issues, and that concerns me, as well as the house and its maintenance. So, we take one day at a time and continue to count our blessings.

It is very helpful and mind-easing to be able to visit a clinic like the ACC. Although my mom has a regular doctor, he doesn't seem to be in touch with the elderly person's problems. Having us sit in one room with the physician, pharmacist, OT cuts down on some confusion and anxiety that may have occurred if we had to go office to office. It was a pleasant experience with kind and caring people.

I have had no problems with medications. Doctors have been very willing to change any that show adverse problems. It is difficult to have to care for a six foot man who displays many childlike behaviors. You change your way of thinking and dealing with situations at home and in public. It is hard to deal with an adult and child which can change in a second.

We are learning to be happy. I still have trouble on 'pill day.' I fill 2 weeks of pills for husband and me. It s a chore and I need quiet time to do it. I do all the shopping, cooking, finances, laundry and doctor visits for him and me. He does not drive. We have 2 or our 5 children here in Greensboro and they are very helpful in checking on us and doing for us. One daughter is in Texas and calls us for her sibs weekly. 2 daughters are 50 minutes drive from us and come as often as they can. We had trouble for years paying for meds. Then Gov

Easley paid 90% on our meds for a year. Now my husband has qualified for VA meds and I am working on a Medicare plan. My biggest job is trying to stay healthy and cheerful for our last years together.

The business of caring for my husband, giving attention to my mother who is in assisted living, managing our finances, selling our home, finding a place to live, working part time, and trying to maintain a relationship with seven in-town grandchildren, makes managing all's medications a nightmare. I am overwhelmed with responsibility, but I am also blessed with wonderful support from family and friends and a deep faith in loving and sovereign God.

My answers about obtaining medications will change dramatically when Lucent drops his drug plan.

The occasional feeling of being overwhelmed seems to come from a sense of having total responsibility for not only the care of my husband but all other aspects. The low feelings pass fairly quickly and have not needed outside intervention. When he has a bad day with his vertigo, I tend to be more anxious and depressed. Outside activities help.

The role of caregiving is the most difficult thing I have ever faced in my life. Being a caregiver for your spouse involves so many different problems. The feeling of loss is so great and is hard to deal with. It would be good to have someone to talk to about it.

At times it is hard for my wife to take her medicines.

Because giving the right medicine in the right dose at the right time is so important, I have always used a pill box. When my dad could no longer remember what day of the week it was, I put a red dot using nail polish on the lid for Sunday telling him this is God's day and the red dot represented the blood of Jesus shed for us. That kept him straight for a long time. Thank you for caring enough to do this study.



Hendersonville has an outstanding adult day care and I take my wife there 5 days a week. I have to attend to my wife nights and weekends. Without this facility, both my wife and myself would be in institutions because I can not care for her 24/7. My wife is in the late stages of Alzheimer's.

Concerns: 1. Forgetting to give 2. Forgetting to order. 3. Not know all various names of same med. 4. Difficulty in keeping up and planning for trips, emergencies, etc. Medications are easiest of caregiving but still a constant sole responsibility of caregiving. It is impossible to imagine without organizer, money and insurance. Outside help is often more trouble than help. There is no free lunch.

The hardest thing about caregiving is being patient, and not getting frustrated. No one understands.

The most difficult time was when I recognized my husband's severe memory loss and he continued to deny it and would not seek help. After 3 years, he came to me for help and I took him to a neurologist who ordered an MRI of his brain and determined it was shrinking rapidly. He also did a 4 hour neuropsychological test to let us know where he was mentally at this point. Very helpful information and began him on 5mg of Aricept and later increased to 10mg. Switched to a geriatrician who have been invaluable. My husband has not known what medicines he has taken for years. I put them in a cup for him and he takes them. He is very trusting which is good.

My father does not like to do very much. He spends a lot of time in bed and resists many efforts to encourage him to spend more time up and around. He avoids bathing or showering. He also seldom washes his hands. Every day, I wake him up to take his pills, do exercises and take a walk. He is not much of a bother but his extreme lack of initiative can not be healthy for him.

Support groups are great! Caregiver conferences are great.

I became a caregiver for my mother-in-law and she moved in with us in December 2005 as we lived in North Carolina and she was in Ohio. We felt her health was going downhill and we needed to get physicians here to help her. She had pneumonia reoccurring. When she didn't eat, her memory got very bad.

I have no problem preparing my husband's medications or going to the pharmacy to pick them up. As for my feelings about my feelings as a caregiver, I feel that I am where God wants me to be. I feel abandoned and alone. I am with Fred 24/7 but I can do it. I miss volunteering and working. I enjoy working and being with people. I go to a support group meeting once a month if there is someone to relieve me. I miss being able to go to the hairdresser or to shop.

I am providing the best care that I can to sick husband. I am glad I have strength to care for him. He is not a complainer.

At this time, my Dad has Medicaid and is on CAP. I have help Monday through Friday. CAP aide stays during this time.

I listen to their concerns and give them the best answer possible. Assure they get the correct medicine at the right time.

I wish that you could get a deduction on tax for expenses for caregiving.

Always give your loved one the medicine he or she needs. I have looked after my husband for many years because he has Alzheimer's. My mother also has Alzheimer's. I also have to look after my son who is a bad diabetic and has had open heart surgery because of bacterial endocarditis caused by infected teeth.

Try to be patient. Put meds in their hands. Try to make them like a bath. Try to get them outside some. Try to fix meal that is good for them. Pray all the time for yourself as well as your mate. Try not to feel guilty.

Finding the right medication for someone with depression/anxiety can be hard sometimes. She seems to get immune to them after a certain period of time. I have to fill pill containers for myself plus four other people.

We do use a pill divider on a weekly basis. It is very helpful. It would be a lot more helpful if all his medications could be renewed on the same date. Because they are renewable at different times, it seems I am always either ordering prescriptions or going to the drug store to pick them up. As a veteran, we are very fortunate to have Tricare coverage with a very low copayment. I cannot imagine what our financial situation would be without it.

I was dismayed to learn that Detrol LA can counteract the results of Aricept. My husband took Detrol LA for 5 months before I found that "high risk" on CareMark's website. The prescribing doctor and his neurologist were both aware of the Aricept for 5 or 6 years before the Detrol was prescribed and neither warned me. The pharmacist at CareMark said his info did not show that risk but their website's medicine interaction feature warned of "high risk." My husband's MMSE had stayed at 29 for one year, then dropped to 26 in 6 months; the next 6 months it dropped to 24; during the 6 month period he took Detrol LA, it dropped to 18. Somebody needs to do a regulated study about this.

I sometimes feel that she is not really sick and does not want to do for herself. I just guess I don't want her to be sick. She likes to talk to people she doesn't know and just stays and stares them up and down and then says "you have a good day."

Usually obtain medications through a mail order service through patient's retirement plan. Stress in caregiver's life relates to a lot of other stuff in addition to dealing with Alzheimer's patient.

My husband has just started not wanting to take his medication. We take it in the morning after breakfast and we just play a little game to coach him to take it. Usually after coaxing, he would take it. I have found that love and kindness helps more than anything. Lots of

prayer and patience. I hope the information I filled out will be of help to you. No one knows what it is like until you are in the role of caregiver.

The cost of nursing care is phenomenal. One needs to be a millionaire to afford the monthly costs.

Caregiving is: necessary, demanding, satisfying, overwhelming, physically draining, at times invigorating because it requires creativity and problem-solving, a source of worry.

Caregiving is about loving.

I guess one of the hardest things to do was to take control of my mother's medications. It was a challenge but I have learned as a caregiver you have to become tough. You have to take a lot of verbal abuse. You have to always remember how the person was before they got sick. You have to remind yourself daily that this is not my mother; this is the Alzheimer's disease that has robbed her of all the things she used to be. It is hard to watch a loved one lose their independence, their memory, their dignity and their sense of well-being. Thank you for choosing this research field about memory loss. Hopefully one day there will be a cure for this disease. As a caregiver, I face a lot of challenges. It is hard to work, care for a loved one and still manage things with your own family. The juggling of things is not always easy. Sometimes this stress is almost overwhelming and hard to bear. Prayer and my faith in God is what keep me going. May God bless you!

It would be nice to have all the doctors get together to see if any or all of the medications are working together, against each other or are okay.

Family members do not offer help of call to ask how I am doing. I don't want to lose friends by complaining about my situation. If they have never been a caregiver, they have no idea what it is like. My husband and I saved for our retirement and have long term care insurance. However, there is no financial aid for middle income people. I have to spend money I need for my future and that we had hoped to travel with to pay for the part of the medications with big deductibles. I am on 10 prescriptions and have the same situation with Medicare. I

already feel like I am drowning. Everyone seems to think that seniors are wealthy but we are living off savings that won't last forever.

Medications at this point are not a problem for me but managing all of the issues is very hard for me. The one major problem is communication. This makes everything a very serious problem. As well as having to do 99% of all things, I can not understand what my wife is saying or what she may want. I just try to work with her and do the best I can.

I doubt that things would be as organized as they are if I was not retired. I do have a good support system with other siblings and my husband. Even so, being a caregiver is mentally straining and because I must use my own money to help for my mother's care, I wonder what will be left for me. I prepare my mother's medications including insulin needles which help greatly. My siblings and I pay others to help with my mother's care and that, too, relieves me more. My mother is mentally alert but wheel-chair bound.

The caregiving responsibility is on my shoulders all day, every day--it never ends or goes away. One of the most difficult things is dealing with my father's memory deficits and his total lack of awareness or insight that anything is wrong. I have never been a patient person. You have to have great patience and empathy. It becomes very frustrating. He is very slow. I miss the father I used to know and being able to have a meaningful conversation with him. I have to constantly remind myself he is not doing this intentionally--his brain is no longer working the way it used to. I do take it personally when he yells or tells me I am lying. Thank you for wanting to know. I hope your career will help caregivers.

I dealt with the emotional/mental/psychological impact on my life for many years. The wake-up call for me was the physical impact. When my blood pressure went sky high and I had heart palpitations, joint pain and depression, I went to my Doctor. I was a MESS! Thankfully, he steered me to therapy, meds for my joint pain and now, I know, I must take care of myself so that I can take care of my husband. I am in therapy, I am taking meds for my RA and I am back at the Y, back with friends playing bridge and putting myself first,

which is very difficult for mothers and teachers. I teach Kindergarten and care for my husband. I am finally letting go.

Thank you, John, for coming to our meeting in Yadkinville. It was good to meet you. Hope this helps in your study.

I am fortunate that my husband enjoys generally good physical health. Therefore, he takes a limited number of meds. All his meds but one are taken at night. I have a separate container for morning and evening meds.

My husband's MRIs have come back normal but one-on-one testing has a diagnosis of beginnings of dementia. His memory falters slightly but his logic/reasoning skills have slipped considerably more. We moved to North Carolina as younger retirees. My health insurance is free for both of us with meds being \$5/\$10/\$20, office visits \$5 through my NJ State Employee pension. My biggest problem is dealing with all this emotionally. He constantly misinterprets, thus causing emotional conflict.

One of the most frustrating things about medications is that they all seem to need refilling at different times which calls for many trips because you can only get a 30 day supply.

My mother was able to live alone with some assistance until October 2005 at which point I took family medical leave and went to live with her. I moved her to my home in December 2005. When Mom began getting up during the night, I found I couldn't manage during the day without sleep. Mom doesn't take much medication. I have to admit that I can not care for her myself.

My friends and my religious community are better to me than my family. Health care beauracracy in America is difficult to navigate.

I moved back into my Father's home in order to care for him. Eventually, I had to stop working too. So, when you ask how many times did I miss work or was late for work or

could not participate in social activities, I don't know how to give a meaningful answer. My entire life was disrupted. A big problem occurred with Medco when they would require additional paperwork from the MD for both of Dad's medications. The MD felt she should not have her judgement questioned and procrastinated in filling out the forms. As a result, shipment of medications was delayed. This was very stressful. At Rite Aid, the pharmacist would make sure I signed a form saying I had refused advice from them. They never offered to give me advice; they just made sure their backs were covered. I think there are so many other issues in regards to medications: what do you do when they can't swallow, drug interactions, and diarrhea.

Meds management isn't all that hard if you are organized about it.

We manage his and my medications together since Oct 2005. We don't have funds for all necessities except with great care. I handle all finances. He is given money which helps him feel he is in control. It is a great job to keep up with ordering refills and staying ahead of my 21 pills a day as well as his. He fell last night.

Sometimes for seemingly no reason he changes moods and has a flare of anger. It hurts my feelings. Normally he is very nice. It is exhausting. I can't begin to tell all here.

My sister has Downs Syndrome with dementia. I find it easy to organize meds but do find it hard to remember all the names and generics. Complicated keeping track of side effects of meds, I think.

One of the hardest things to realize was that my Mom could no longer manage her meds. Now the issue is to get her to take them. A major issue is if she is on an antibiotic and has to take it three times a day. Morning and night is doable since I live next door; however, the lunch dose means that I have to leave work to ensure that she gets her meds.

I also have a 14-year old son. While he can be very helpful, the situation is very difficult for him to deal with day in and day out. We have only had one break in the last 5 years and that was for 4 days.

Seems that the caregiver has to be on "red alert" at all times. The memory deficient patient cannot be expected to keep track of medications and even if you pared down only one doctor, they are overloaded and busy. The caregivers carry most of the burden in making sure that the meds are ordered, refilled, given and re-ordered. We order 90-day supply but with 15 prescriptions I have had to use an Excel spreadsheet to keep track of the meds. Giving the meds with the help of a pill organizer is a snap. Keeping the supply coming is a challenge.

The most stressful part of medications for me has been regulating meds that treat agitation and sleep disorders. Our GP wasn't up on the latest and tried to just sedate the patient rather than treat for agitation. So with new doctor, we had to experiment with different things before we found something that didn't make her unstable if she did get up during the night yet settle her enough to reduce night time rising to once or twice a night, rather than every hour or half hour.

Caregiving is a very hard job.

Always remember to do the best that you can according to your ability in all that you learn or by experiences and do it to the fullest.

It is very hard to care for my mother and work but I know she is better off at home. Unfortunately, there isn't enough help or money to keep her at home indefinitely.

Caregivers need respite regardless of their income. The cost of providing aide to the caregiver in their home would be far less than placing the patient in a skilled nursing facility. Also, noted that no question addressed whether or not meds ever administered incorrectly, which I have done. And I have learned to manage repeated questions by placing a dry erase board on wall in front of patient's chair with day of week, appointments, meds, etc. listed on it. One last thing, I keep a photo album near patient with photos and notes regarding family and friends.



My husband has been very stable in the last 2 years since his diagnosis. Meds, so far, seem to be working; however, I am concerned and afraid about our future and financial matters.

Wife has Alzheimer's; soon she will not be able to take meds oral without putting in food. Son is MD. Always good have a doctor available 24/7. I am depressed but dealing with it. Will have to place wife in nursing home in the next year, probably.

Because the meds are limited to 3 meds some of which are administered night and morning, I have not experienced any problems except remembering at nighttime when I am very tired. If caregiving was all that I had to do, life would be much better for me. I am trying to organize and prepare to sale a used book business that belongs to my husband in addition to working another part-time job. The book store 5 days a week and working the part-time job. My home is in disarray because I have no time to clean it up. I take my husband with me to the bookstore during the day. My day starts at 3am and I get to bed about 830 or 900 at night. My husband is in early stages. I am already exhausted from everything.

Because Mother sleeps most of the time now and refuses to communicate much of the time, care sometimes seems routine. Because she has trouble swallowing or understanding what to do with meds, her meds are all liquid and administered or included in a shake, mixed with jelly or inserted by oral syringe in the mouth then encourage swallowing. I use a checklist now instead of the boxes I used when she could take pills.

Without the assistance of my husband, this would not be possible. Between the two of us, we provide 24 hour care and supervision for my mother. He is a saint!

My wife can not speak, walk, or take care of herself in any way. We have a "live-in" aide who does much of the work of caring for my wife. My doctor told me about two years ago that my health was at risk if I continued to be the sole caregiver for my wife. So, I hired the aide who now does most of the work.

My mood and stress levels are greatly dependent on my Dad. Currently, he is somewhat stable, physically and emotionally.

I have only recently stepped in as the primary caregiver. My Dad managed the care for the past 5 years. He passed suddenly in December leaving me to this task. I have no idea how he managed so well. I am exhausted!

I am a full-time caregiver for my wife with AD. I currently have 10-20 hours/week of assistance. Full-time care has been required since AD was discovered in 2000. She refuses to take pills many times but will most times after a period of time. Will not take medication crushed or mixed or with food. I attempt to have the doctor write the prescription with the smallest number of pills.

The most difficult part of caregiving is the lack of respite time, the freedom to enjoy time to do the things I like to do, and the physical toll that I have paid. My mother-in-law has lived with us for almost 9 years. Although I have lost touch with many of my friends, I do not feel they have abandoned me. Rather, I feel that sometimes as caregivers we abandon our friends because we do not have the time or energy to nurture those friendships. That is the greatest feeling of sadness for me.

My mother does a lot for herself. I help with all detailed things like her medications. She forgets things, gets lost at times. She is depressed. I am on antidepressants. I keep going and I am the "hub" of my family. Good luck in your research.

It is stressful keeping up with prescription renewal.

I have an almost ideal situation. My mother-in-law came to live with us last August. We have thoroughly enjoyed her stay with us. She has always been in good physical health as she was a walker and a swimmer. The meds are relatively easy for me to handle with a pill reminder. I do set up her meds and assist her with taking them but it has posed no serious problems thus far. I am blessed and I know it...Thank God!

Recently, she was disoriented and I found she had taken 2 days of medicine one morning. I don't know if she was disoriented and forgot and took the medicines OR if she took all the meds and that caused the disorientation. Now I hide the meds and give them to her to take morning and evening. It is something else that I have to remember to do!

This journey is an overwhelming task and I often wonder if I am up to it. My two greatest fears: 1. I will not be able to care for my husband as long as I should. 2. I will kill myself trying. He has been an incredibly wonderful husband for nearly 40 years carrying much of the weight. Can I carry all of it? We shall see...

Managing medications is difficult because of ways some of it is given. One is supposed to be taken alone before breakfast. One day a week a medication has to be taken sitting or standing for 1/2 hour before eating. Have pretty much given up giving first medication because of Mom's sleep habits and my schedule.

With so much aid out there for pregnant, unwed girls and people who won't work, it is a shame that the only aid that I can get is 50 hours a year! It is rewarding taking care of my mother who is 75 with Alzheimer's but the most stressful I have ever had. My mental health has suffered so much along with my marriage. There should be more ways to help caregivers.

I do use the pill box and love it.

I try to be very calm and observant. I take deep breaths and concentrate on what I am doing. Safety is my first goal. I do not rush or hurry.

Managing my mother's medications has changed in the eight years I have been her caregiver. She had a number of crises in the beginning--one drug gave her hallucinations, others gave her severe diarrhea. I did not know she was allergic to sulfa drugs. Now her condition has been stabilized by correct medicines. Pharmacists and doctors need to be aware that not

everyone coming on board as a caregiver is necessarily equipped with the skills to do it. The new Medicare prescription plan with its "doughnut hole" is a terrible deception on the elderly.

Medicine bottle caps are difficult. Insurance is a pain. The print on medicine bottles is too small.

I find giving her meds more challenging as her swallowing problems increase. I now crush most of them and mix them in applesauce or pudding. I was the one who initiated switching to liquid forms of any of her meds when possible. I worry with crushing them that she is not getting the full dose. I also care for my father who has dementia but he is able to dress, feed himself, etc. I have a teenage son still in the home that is impacted by all of this. I cut back to part-time work for about 3 years until finally I realized I needed to quit altogether in order to care for her. My family was uprooted and moved to a different state so we could all live in one house. Good luck with your study. I hope it helps other caregivers!

It is very depressing to take care of my mother like she is a child. She is quite a load at times but I deny myself to take care of her. I spend most of my day around her with not much sleep at times.

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