CAREGIVER OUTCOMES AND THE IMPACT OF RESOURCES FOR FAMILY MEMBERS PROVIDING CARE TO COMMUNITY DWELLING OLDER ADULTS

A Dissertation in

Nursing

by

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Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

August 2014
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Abstract

**Background:** Outcomes for family caregivers is an important topic given the aging population, as providing care to a loved one, particularly an older adult, has become a common occurrence. With the growing numbers of people requiring care, family members are increasingly filling the caregiving role. Caregiving experiences can range from those that are relatively easy to manage to those that are burdensome and cause caregiver strain. Caregivers with the heaviest responsibilities are vulnerable to risks such as a decline in mental or physical health. Recent research has begun to address the positive aspects of caregiving including improved well-being and health benefits. What is less well known is how resources, both utilization and perception of adequacy, in the caregiving role may support the family caregiver in providing care to a community dwelling older adult.

**Purpose:** The purpose of this study was to determine if resource utilization and family caregivers’ perception of resource adequacy are associated with caregiver strain and satisfaction, specifically if caregiver outcomes are moderated by resource utilization and adequacy.

**Methods:** To examine caregiver outcomes and the association of resources with those outcomes, a secondary analysis of data from the Informal Caregiver Survey was conducted. Bivariate analysis and hierarchical regression models were used to examine the relationship between caregiving demands and caregiver outcomes of satisfaction and strain. Hierarchical regression with moderation was used to examine if resource utilization and perceptions of resource adequacy moderate the relationship between caregiving demands and caregiver satisfaction and strain.

**Results:** A significant positive relationship was found between caregiving demands and caregiver strain, suggesting that as caregiving demands increase levels of caregiver strain do as well. The utilization of formal resources also has a positive relationship with caregiver strain.
indicating that as resource utilization increases so do levels of caregiver strain. Social support was found to have a positive relationship with caregiver satisfaction and a negative relationship with caregiver strain indicating that perceived levels of higher social support are associated with higher levels of caregiver satisfaction and lower levels of caregiver strain. Family support was found to have a positive relationship with caregiver strain, indicating that as levels of family support increase so do levels of caregiver strain. Finally, the perception of formal resource adequacy was found to have a negative relationship with caregiver strain meaning that higher levels of perceived adequacy are associated with lower levels of strain. Additionally, resource adequacy was found to moderate the relationship between caregiving demands and caregiver strain with individuals reporting the highest levels of resource adequacy experiencing the lowest levels of caregiver strain.

**Conclusion:** Understanding the caregiving experience and the impact it has on family caregivers is a critical consideration given the sheer numbers of caregivers and the invaluable service they provide. This study begins to address the question of how resources in the caregiving role can impact both the positive and negative outcomes for family caregivers. It also highlights that not all resources are equal; different resources are required to support the individual caregiving context. Findings from this study contribute to the importance of providing targeted resources to family caregivers which may be especially salient for those without a supportive family, lack social support or whose needs are unmet in the caregiving role.
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Acknowledgements

Pursuing a PhD is not an individualistic pursuit. It takes a village of supportive people to make it happen. To acknowledge all the support I have had the benefit of receiving, I would like to thank those who helped me get to this point.

Thank you to the Jonas Center for Nursing Excellence and the John A. Hartford Foundation for their generous financial support of my doctoral studies. In addition to financial support, being associated with these foundations has afforded me the opportunity of being part of a large network of scholars and colleagues who provided inspiration throughout my program.

Dr. Janice Penrod, my advisor and dissertation co-chair. Thank you for all your help and guidance. Thank you as well for exposing me to the larger academic community. Being your student has provided me with excellent opportunities and an amazing training experience. Thank you too for always encouraging me to think clearer, dig deeper and not be easily satisfied with the simplest answer.

Dr. Ann Kolanowski, my dissertation co-chair. Thank you for all your encouragement throughout my program. Without your support I would not have pursued a PhD, it is because of you I took that first big step to enroll in the program and it is because of you I stayed in the program. Thank you as well for always helping me to drill down deeper and focus on what was important to my study. You saved me from going down many rabbit holes for which I am very grateful.

Dr. Rhonda BeLue and Dr. Amy Sawyer, my committee members. Thank you for adding your expertise to my committee. Your guidance throughout the dissertation process was invaluable, particularly with the methodological aspects of my study.
Thank you to my friends and colleagues for their support throughout my program. I would especially like to acknowledge and thank Brenda Baney. Your willingness to always listen to me with a gentle patience and resulting wise words of counsel somehow seemed to make me feel better and things seem less daunting.

My family. Thank you for your unwavering belief in me and for always having faith I would get to the finish line even when I didn’t. I am blessed to have you in my life. To my sister Shelley; thank you for always providing comic relief (often at your own expense) when I needed it most. Thank you to my Mom for showing me what a strong woman is and that giving up is not an option. Thank you too Mom for reminding me that sometimes the best thing in life is to be silly and have a good laugh. And a special thank you to my Grannychick. My Granny passed away the first week of my PhD program but remained my guiding light throughout. Her courage and strength of character in being my grandfather’s caregiver for many years while he suffered with Parkinson’s disease was a constant reminder why it is so important to understand and provide support to family caregivers.

And finally to my partner, Deirdre. Words can never express my love and gratitude. Without you I would not have made it through this experience. This is truly a joint success – thank you. You have been my rock, my beacon of calm through some pretty crazy and unsettled times. You have been my biggest cheerleader and the best caregiver anyone could ever hope for. In the words of Jane Austen; my heart is, and always will be, yours.
Chapter I

Introduction

Outcomes for family caregivers is an important topic given the aging population, as providing care to a loved one, particularly an older adult, has become a common occurrence. According to the National Alliance for Caregiving (2011), 65.7 million caregivers constitute 29% of the United States adult population and are found in 31% of all the households.

Caregiving is a complex and variable role requiring multidimensional support that extends across physical, emotional, and financial domains. The complexity of the role can result in a significant amount of strain and poor health outcomes for the caregiver (Christakis & Allison, 2006; Garlo, O’Leary, Van Ness, & Fried, 2010; Pressler et al., 2009; Schulz et al., 1997; Schulz & Beach, 1999). There may also be positive outcomes of the caregiving role that contribute to caregiver satisfaction and well-being such as positive affect (Brown et al., 2009; Ingersoll-Dayton & Raschick, 2004; Poulin et al., 2010; Wilson-Genderson, Pruchno & Cartwright, 2009). In the caregiving role, resources play an integral part in understanding caregiver outcomes and have been hypothesized to be important in examining both caregiver strain and satisfaction (Schultz & Sherwood, 2008; Wakefield, Hayes, Boren, Pak & Davis, 2012). To assist family caregivers, it is important to understand the caregiving experience and how their perceptions of resource adequacy may impact caregiver strain and satisfaction.

In this chapter, discussion of the issues family caregivers face while providing care to an older adult and how resources in the caregiving role may contribute to both positive and negative outcomes for the caregiver is provided to frame the problem addressed in this study. The purpose of the study is explicated by a discussion of the conceptual model providing the
framework for the study. The chapter will conclude with the significance of the study and its anticipated contributions to the caregiving literature.

**Statement of the Problem**

It is well known that the population in the United States is aging, with the number of people aged 60 years or older expected to triple over the next 50 years (U.S. Census Bureau, 2010). Of the 65.7 million people providing care to a family member, almost 49 million are caring for an adult or older adult patient (National Alliance for Caregiving, 2011). As the baby boom generation ages over the next 25 years, the numbers of people needing care will grow. This aging of the population coupled with the moving of institutionalized care into the community has resulted in an increased reliance on family members to provide care (Tooth et al., 2008). In fact, there are many factors that influence the growing numbers of caregivers. The rapidly mounting need for informal caregivers can be attributed to the increasing numbers of individuals growing into older age and often living with chronic illnesses, the constraints on available resources, and older adults preferring community-dwelling to institutionalization alternatives (Lavela & Ather, 2010).

This growing requirement for family caregivers is an important consideration because in order for an older adult with a chronic illness to be cared for at home, there needs to be someone available to provide that care (Stajduhar, Martin, Barwich & Fyles, 2008). The term family caregiver and informal caregiver will be used interchangeably and refers to a wide range of unpaid care services (e.g. assisting with dressing, assisting with getting in and out of bed or a chair, managing medical appointments and routines) provided in response to illness or functional impairment of a chronically ill or functionally impaired older family member, partner, friend, or neighbor that exceeds the support usually provided in family relationships (Schumacher, Beck,
Marren, Stotts & Deitirch, 2006). Most of the care provided to patients with major chronic illnesses or at the end of life is performed by family caregivers with estimates that over 85% of care for patients is delivered by a family member (National Alliance for Caregiving, 2009).

Caregiving experiences can range from those that are relatively easy to manage to those that are burdensome and cause caregiver strain (National Alliance for Caregiving, 2011). Caregivers with the heaviest responsibilities are vulnerable to risks such as a decline in mental or physical health (Christakis & Allison, 2006). Providing care for older adults with a chronic illness is a complex and variable role requiring multidimensional support that extends across physical, psychological, spiritual, and emotional domains (Hornea et al., 2008). Typically, family caregivers are responsible for providing both emotional and physical care to the patient as well as organizing and coordinating health services on behalf of their loved one (Stajduhar et al., 2008). There is little debate that family caregivers experience a significant amount of burden (Jones, Hadjistavropoulos, Janzen, & Hadjistavropoulos, 2011; Tooth et al., 2008; Torres et al., 2010; Zarit, 2004) and reduced quality of life (Tooth et al., 2008) as a result of their caregiver roles. These negative effects of caregiving and the culmination of perceived strain have been associated with premature institutionalization and unmet patient needs (Sullivan, 2007).

Caregivers have a strong influence on a patient’s psychological adjustment and management of illness, including adherence to a treatment regimen and adoption of other health behaviors that promote functioning (Martire, Lutsig, Schulz, Miller, & Helgeson, 2004). Family caregiver behaviors, such as type and hours of care provided, have been linked to a variety of patient physical and mental health outcomes, including psychological well-being, health behaviors, pain severity and physical disabilities (Pinquart & Sorenson, 2003; Schultz & Sherwood, 2009). This is a critical consideration as the support provided by a family caregiver
can impact the patient’s response and adjustment to their illness (Martire et al., 2006).

Additionally, research has shown a positive association between the caregiver’s experience of emotional distress such as depression and anxiety and the patient’s level of distress and physical health (Monin & Schulz, 2009). As the family caregiver can play an integral role in the health of the patient, the importance of highlighting areas of caregiver strain and its impact on not only the caregiver but the patient as well becomes apparent.

In order that caregivers might maintain their own health and provide the best care possible, it is important to perceive this group of people as co-recipients of care in addition to co-providers of formal care with healthcare professionals (Harding & Higginson, 2003; Penrod, Hupcey, Baney & Loeb, 2011). Viewing family caregivers as potential co-recipients of formal care (Penrod et al., 2011) affords the caregiver an opportunity to discuss issues that make the role more difficult and to be offered helpful resources or services (Next Step in Care, 2010) potentially enhancing the quality of care for the patient and the caregiver’s outcomes.

Support for informal caregivers has long been advocated, yet there is a shortage of evidence-based strategies to assess and respond to the caregivers needs (Hudson et al., 2010). Compounding this, support given to family caregivers is often provided in an ad hoc manner with clinical assessment tools generally focusing on the patient rather than the caregiver. This occurs although family caregivers can often experience personal distress, burden, impaired self-care, increased psychological and physical morbidity, and even mortality when the resources they need to carry out their caregiving role are not met (Christakis & Allison, 2006; Monin & Schulz, 2009). The use of resources and the perception of their adequacy play an integral part in understanding both positive and negative caregiver outcomes (Schultz & Sherwood, 2009; Wakefield et al., 2012).
Despite the extensive body of literature examining the negative outcomes of caregiving (Martire et al, 2004; Monin & Schulz, 2009; Northouse, Katapodi, Song, Zhang, & Mood, 2010), not all studies on the effects of caregiving find negative consequences for the caregiver. Recent research has shown positive outcomes of the caregiving role that suggest providing help improves well-being (Poulin et al., 2010) and physical health and may reduce mortality (Brown et al., 2009). Providing care can make caregivers feel good about themselves. Feeling needed may give some older adults a purpose and add meaning to their lives (Schulz & Sherwood, 2009). Other positive outcomes of caregiving are that it may enable the person to learn new skills and strengthen relationships with others (Schulz & Sherwood, 2009).

Although some studies have shown the positive outcomes of caregiving, the negative consequences on the physical and mental health and mortality of the caregiver have been well documented (Garlo et al., 2010; Pressler et al., 2009; Schulz et al., 1997; Schulz & Beach, 1999). Given the extensive caregiving literature, there is a dearth of studies examining both positive and negative consequences of caregiving using a resource-oriented perspective. There is also a gap in exploring how resource utilization and family caregivers’ perceptions of resource adequacy have the potential to impact the caregivers’ outcomes.

**Purpose of the Study**

The purpose of this study was to determine if resource utilization and family caregivers’ perception of the adequacy of resources are associated with caregiver strain and satisfaction, specifically if caregiver outcomes are moderated by resource utilization and adequacy. This study will add to the existing body of knowledge regarding the importance of resources in the caregiving role and their impact on caregiver outcomes.
Conceptual Framework

Caregiving has often been investigated using the stress and coping (Lazarus & Folkman, 1984) and stress process theories (Pearlin et al., 1981; Pearlin et al., 1990). Here, stress is considered to be the relationship between the person and his/her environment and the cognitive appraisal of that relationship (Lazarus & Folkman, 1984). Cognitive appraisal is an evaluative process that determines why and to what extent a particular interaction between a person and the environment is stressful and is assessed by whether a demand threatens a person’s well being and if there is an ability to meet those demands. The Transactional Model of Stress and Coping originally developed by Lazarus and Folkman (1984) is a framework for evaluating the processes of individual adaptation, such as coping with stressful life events like caring for a loved one with a chronic illness. In this model, coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). The transactional nature of stress is emphasized, that is stress is viewed as an interactive two way process between the stressors produced by the environment and the ways in which the individual copes with these stressors. In other words, stress is a person-situation interaction that is dependent on the interplay between the person and the cognitive appraisal of his/her environment.

In the Stress Process Model (Pearlin et al., 1981, Pearlin et al., 1990) the focus is on the process of stress rather than the individual adaptation to stress. Here the process of social stress combines three major conceptual domains, that of the sources of stress, the mediators of stress, and the manifestations of stress. The process of stress focuses on the relationships among the conditions that lead to stress and the ways these relationships develop and change over time.
The Stress Process Model focuses on stressors, making a distinction between primary and secondary stressors (Pearlin et al., 1990) whereas the Transactional Model of Stress and Coping model gives more attention to coping and appraisal in responding to stress (Lazarus & Folkman, 1984). Both of these models emphasize an individual’s cognitive appraisal of the situation when undergoing a stressful event or circumstance, such as caregiving.

**Conservation of Resources Model**

Another stress model employs a resource-oriented perspective, the Conservation of Resources (COR) Model. Although the COR Model has not been used in the caregiving literature, it has been used to predict stress outcomes in organizational settings, health contexts, following traumatic stressful events, as well as with everyday stressors (Hobfoll, 2001). Rather than placing an emphasis on an individuals’ cognitive appraisal, the COR (Hobfoll, 1989, 1998, 2001) is an integrated stress theory which places equal emphasis on the environmental and internal aspects of the stress process. The basic tenet in COR is that “individuals strive to obtain, retain, protect and foster those things that they value” (Hobfoll, 2001, p. 341). In this model, there is less focus on the factors that create stress and more of a focus on the resources that preserve well-being in the face of stressful situations.

In the COR model, stress is defined as a reaction to the environment in which there is a loss of resources, resources are threatened, or a person invests their resources without a subsequent gain. The COR model proposes that stress is the result of a threat to resources (e.g. the perception that there may be a lack of family support), the actual loss of a resource (e.g. a supportive family member moves far away), or the insufficient gain of additional resources following a significant investment of resources (e.g. the decline in the patient’s health after a significant financial investment into resources aimed at improving health). In a caregiving
context, the stress caused by one of these three pathways can lead to caregiver strain, especially when the caregiving demands that deplete caregiver resources are greater than the rate of resource replenishment (Halbesleben, 2006).

**Types of Resources.**

Resources in the COR model are broadly defined as “those objects, personal characteristics, conditions or energies that are valued in their own right or that are valued because they act as conduits to the achievement or protection of valued resources” (Hobfoll, 2001, p. 339). This is a very inclusive definition with resources being construed as anything that is valued by an individual or helpful to relieve stressful situations. Defining a resource in this way has been criticized as being too vague and lacking in conceptual clarity (Lazarus, 2001). To address this critique, Hobfoll (1998, 2001) developed a list of 74 resources that can be divided into four types: 1) Object resources (e.g. physical resources such as a home or transportation); 2) Condition resources (e.g. employment and personal relationships); 3) Personal resources (e.g. skills and self-efficacy); and 4) Energy resources (e.g. the ability to obtain other resources such as knowledge or money). Examples of resources from the list that are highly relevant to the caregiving role include: “feeling valuable to others” (personal); “personal health” (energy); “spouse/partner’s health” (condition); “feeling that my life has meaning/purpose” (personal); “adequate finances” (energy) and “time for adequate sleep” (objective) (Hobfoll, 2001).

**COR Major Principles.**

In addition to the different types of resources, the COR model has three major principles. The first major principle is that loss of a resource is a primary source of stress. An important aspect of this principle is that resource loss is proportionately more significant than resource gain (Hobfoll, 2001). Given an equal amount of loss and gain, the resource loss will have a much
greater impact. The second principle is that resources act to preserve and protect other resources. That is, to protect against resource loss, recover from resources that have been lost, and to gain resources there must be an investment of resources. A consideration here is people with greater resources are not as vulnerable to resource loss and are more able to engage in resource gain than those with fewer resources. For example, if a caregiver has the resource of self-esteem, they will be more likely to use the resource of social support when confronted with stress whereas the caregiver with low self-esteem may be less likely to engage in social support (Hobfoll, 2001).

The third principle relates to depleted resource pools. In this principle, following a stressful circumstance, such as a stressful caregiving experience, the caregiver will have increasingly depleted resource pools to combat further stress. This depletion impairs the caregiver’s capability of coping with further stress and results in a spiral of losses. When faced with resource loss, individuals experience stress and try to offset the net loss by utilizing other resources. If alternative resources are garnered and used successfully, adaptation occurs; leading to a gain in secondary resources. Conversely, if the person fails to access additional resources unsuccessful adaptation results and secondary losses are incurred (Hobfoll, 1989, 2001). For example, if caregivers encounter losses in terms of time or health they can regain their lost resources by seeking help from their social network or using formal services. This new resource gain can offset their losses from providing care. On the other hand, if they do not gain further resources, the loss can aggravate the stressful caregiving situation.

As a result, the COR model allows for the examination of how environmental factors affect all types of resources available to caregivers as well as how resources in the caregiving role can result in both positive and negative outcomes for the caregiver. This is captured by the conceptual model in Figure 1. In this model, caregiving demands (such as functional
dependency of the older adult care recipient and hours spent caregiving) impact on the available resources (such as social support, finances, respite care, and feelings of self-worth) which in turn can impact the investment of resources; which are then invested in the caregiving role. Here, resource loss (which is not offset by replenishment) is conceptualized as caregiver strain while resource gain is conceptualized as caregiver satisfaction. For successful adaptation, resources are bolstered and these work to offset conditions that produce resource loss. In contrast, unsuccessful adaptation can result in negative outcomes and a loss of invested resources (Hobfoll, 2001).

**Figure 1**: Conservation of Resources Model (Adapted from Hobfoll, 2001)

**Research Questions**

This study addresses the following research questions:

1. A. Are caregiving demands associated with resource utilization by family caregivers?

   B. Are caregiving demands associated with family caregivers’ perceptions of resource adequacy?
2. Are caregiving demands associated with the outcomes of caregiver strain and satisfaction?

3. A. Does resource utilization moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction?
   
   B. Do family caregivers’ perceptions of resource adequacy moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction?

Theoretical Definitions

The following definitions are for the major concepts examined in this study. The literature review in chapter two provides further detail and clarification of these concepts.

1. Caregiver strain: Refers to the perceived difficulty of performing roles or the feelings of being overwhelmed by the tasks that caregivers may experience, which outweigh available resources (Hornea et al., 2008).

2. Caregiver satisfaction: Refers to the positive impact of caregiving and is the “subjectively perceived gains from desirable aspects or positive affective returns from caregiving” (Lawton, Moss, Kleban, & Rovin, 1991, p. 182).

3. Resources in the caregiving role: Using the definition from the COR model, resources can be defined as “those objects, characteristics, conditions or energies that are valued by the individual or that serve as a means for attainment of these objects, characteristics, conditions or energies” (Hobfoll, 2001, p. 339). Resources can be divided into four different types: 1) Object resources (physical resources such as a home or transportation); 2) Condition resources (employment and personal relationships); 3) Personal resources (skills and self-efficacy); and 4) Energy resources (the ability to obtain other resources such as knowledge or money) (Hobfoll, 2001).
4. Caregiving demands: Refers to the activities performed in the caregiving role and includes time spent on caregiving tasks, time spent in the caregiving role as well amount of assistance provided (Schumacher, Stewart, Archbold, Caparro, Mutale & Agrawal, 2008).

See Table 1.1 for an overview of the conceptual and operational definitions used in the study.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Conceptual Definition</th>
<th>Operational Definition</th>
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<tbody>
<tr>
<td>Caregiver Strain</td>
<td>Perceived difficulty of performing roles or feelings of being overwhelmed in the caregiving role</td>
<td>3 item Global Strain Index scale including physical and emotional strain and financial hardship</td>
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<td></td>
<td></td>
<td>7 item Modified Caregiver Strain Index Subscale</td>
</tr>
<tr>
<td>Caregiver Satisfaction</td>
<td>Perceived positive impact of caregiving and its desirable aspects</td>
<td>2 item Caregiver Satisfaction Subscale</td>
</tr>
<tr>
<td>Object (formal) Resources:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Formal resource utilization</td>
<td>The utilization of available resources.</td>
<td>10 item scale with the different categories of formal resources</td>
</tr>
<tr>
<td>Formal resource perception of adequacy</td>
<td>Family caregivers’ perceptions of the benefit or adequacy of available resources.</td>
<td>10 item scale with 3 possible responses</td>
</tr>
<tr>
<td>Condition (informal) Resources:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>The functional characteristics of social networks and their social influence.</td>
<td>8 item Medical Outcomes Study Social Support Survey subscale</td>
</tr>
<tr>
<td>Family Support</td>
<td>Family members who provide assistance as well as social and emotional support.</td>
<td>8 item Family Support Scale</td>
</tr>
<tr>
<td>Caregiving Demands</td>
<td>The range of activities performed in the caregiving role including time spent on caregiving tasks, time spent in the caregiving role as well amount of assistance provided.</td>
<td>Hours spent caregiving per week Length of time caregiving Progression of caregiving responsibilities Functional dependency of older adult care recipient</td>
</tr>
</tbody>
</table>
Significance of the Study

It is well known that the population in the United States is aging, with the number of
people aged 60 years or older expected to triple over the next 50 years (U.S. Census Bureau,
2010). About 80% of all older adults will have at least one chronic condition or illness, with
50% having at least two chronic conditions (Centers for Disease Control and Prevention, 2012).
The most prevalent chronic conditions affecting older Americans are heart disease, cancer,
stroke, diabetes, and Alzheimer’s disease (Centers for Disease Control and Prevention, 2012;
National Alliance for Caregiving, 2009). With the majority of older adults reporting they would
prefer to remain at home (Stajduhar et al., 2008) the need for family caregivers and the
accompanying support required to remain in the caregiving role is clear.

Despite the importance of family caregiving and its potential for negative consequences
associated with the role, few studies have explored the impact of formal (e.g. respite care)
(Casado, van Vulpen, & Davis, 2010; Houde, 1998; Mast, 2013) and informal (e.g. social and
family support) (Kang, 2006; Lin, Fee, & Wu, 2012; Pot, Deeg, & van Dyck, 2000) resource
utilization on caregiver outcomes such as caregiver strain and satisfaction. Research has been
conducted on the impact of patient cognitive and physical impairment on caregiver outcomes
(Blyth, Cumming, Brnabic, & Cousins, 2008; Monin & Schulz, 2009; Tooth et al., 2008);
however, there is a dearth of literature exploring how resource utilization and the perception of
resource adequacy moderate family caregiver outcomes.

The current focus in the caregiving literature is dominated by examination of caregivers
providing care to patients with dementia and to a lesser extent by studies of caring for patients
with heart disease and diabetes (Schulz, Martire, & Klinger, 2005; Stetz & Brown, 2004). An
area that requires more investigation is that of resources in the caregiving role, particularly the
types of resources that best meet the needs of the family caregiver. Social support is one of many types of caregiving resources. In a systematic review examining how social support can impact the caregiving role while providing care to elderly family members, Smerglia and colleagues (2007) found that previous studies did not distinguish between measuring social support as perceived and available or as already received. This is an important consideration as there is a difference between having received social support and its impact on the caregiving role rather than perceiving that help may be available. This lack of distinction between perceived and received resources may help explain the ambiguity of previous studies finding resources in the form of social support as both helpful (Ownsworth, Henderson, & Chambers, 2010) and at times adding to the stress of the caregiving (Smerglia, Miller, Sotnak, & Geiss, 2007). More attention is required regarding the development and evaluation of services that respond to the resource needs of caregivers as this may not only lead to improved outcomes for the caregivers but also for the older adults for whom they provide care (Tong, Sainsbury, & Jonathan, 2008). Assessing family caregivers’ perceptions of resource adequacy and the impact this has on their outcomes will help to address what the needs of caregivers are and how different forms of resources may address those needs as well as how malleable the different types of resources are.

Chapter Summary

Previous studies have examined the negative consequences of caregiving on the care providers’ health. Recent research has begun to address the positive aspects of caregiving including improved well-being and health benefits. What is less well known is how perceptions of resource adequacy in the caregiving role may support the family caregiver in providing care to an older adult as well as the types of resources that are beneficial. This study used the COR model to address this gap in the literature as it provided the framework for examining how
resources may affect caregiver outcomes of strain and satisfaction. Given the importance of the caregiving role and the growing need for family members to take on the role and remain as caregivers, it is important to understand how best to support them in this crucial role.
Chapter II

Introduction

In the United States there are 65.7 million caregivers that make up 29% of the adult population and they are found in 31% of all households (National Alliance for Caregiving, 2011). Of these family caregivers, almost 49 million are caring for an adult or older adult patient. The number of people needing care will only continue to grow as the population of the United States ages, with the number of people aged 60 years or older expected to triple over the next 50 years (U.S. Census Bureau, 2010). The moving of institutionalized care into the community combined with a rapidly aging population has resulted in an increased reliance on family members to provide care for those with chronic illness (Tooth et al., 2008). Family caregivers supply a wide range of unpaid care services that include providing care in response to illness or functional impairment of a chronically ill or functionally impaired older family member, partner, friend, or neighbor that exceeds the support usually provided in family relationships (Schumacher, Beck, Marren, Stotts & Dietrich, 2006).

This chapter will focus on empirical findings related to family caregiver outcomes and will include an explanation of the search strategy employed. The result of the review will then be organized into the following major sections: Caregiver Outcomes; Caregiving Demands; Caregiver Strain; Caregiver Satisfaction; and Resources in the Caregiving Role. The chapter will conclude with a summary of the literature review.

Search Strategy

An extensive search for relevant research was conducted to examine the current state of the science relevant to family caregivers providing care to an older adult with a chronic illness. Using the databases of Cumulative Index to Nursing and Allied Health Literature (CINAHL), MedLine and PsycINFO the literature was searched using the MeSH terms of “family
caregivers”, and “social support” that encompassed the terms of social networks and support systems. Limits for the search included English language, articles published from 2003 – 2013 and age 65 or over. This resulted in 931 hits to which the search term “caregiver outcomes” was added which brought the results total down to 136 hits. A second search was also conducted that added the term “resources” to the above listed MeSH terms with a total of 97 retrievals. The titles and abstracts of the articles from these searches were read for appropriateness of relevant content area of being family caregivers providing care to an older adult patient. Upon finding relevant studies, the reference lists were then searched to further expand the quest for information. The next section examines caregiver outcomes.

**Caregiver Outcomes**

Family caregivers are often considered the backbone of care in caring for the growing older adult population (Institute of Medicine, 2008). Most of the care provided to patients with major chronic illnesses or at the end of life is performed by family caregivers with estimates that over 85% of care for patients is delivered by a family member (Houser, Gibson, Redfoot, 2010; National Alliance for Caregiving, 2009). With this prevalence of family caregivers, the importance of understanding the impact of caregiving on the family caregiver becomes apparent. Previous studies have examined the negative consequences of caregiving, particularly spousal caregiving, on the physical and mental health and mortality of the caregiver (Garlo, O’Leary, Van Ness, & Fried, 2010; Pressler et al., 2009; Schulz et al., 1997; Schulz & Beach, 1999). Patient cognitive and physical impairment increase caregiver burden (Tooth et al., 2008), negatively influence caregiver emotional experiences (Monin & Schulz, 2009), and decrease caregiver well-being (Blyth, Cumming, Barnabic, & Cousins, 2008). These outcomes are a significant concern as family caregivers are a “critical national health care resource” (Schulz &
Sherwood, 2009, p. 23) and their well-being must be optimized so they may stay in the caregiving role and continue to provide unpaid contributions that had an estimated economic value of approximately $450 billion in 2009 (American Association of Retired Persons, 2012).

Age has been shown to increase impaired self-care, psychological and physical morbidity and even mortality (Christakis & Allison, 2006; Monin & Schulz, 2009) in the caregiving role with older adult caregivers being more negatively impacted than their younger caregiver counterparts. In their seminal study on caregiving as a risk factor for mortality, Schulz and Beach (1999) found that burdened older adult caregivers who reside with the person for whom they are providing care have mortality risks that are 63% higher than age-matched, non-caregivers after 4 years. Other studies report that 21% of older adult caregivers experience a negative change in their self-reported health as a direct result of their caregiving (Keating, Fast, Frederick, Cranswick, & Perrier, 1999) and that caregiver burden is associated with reduced health-related quality of life (Serrano-Aguilar, Bastida-Lopez, & Yanes-Lopez, 2006). Increased levels of depression and stress and low ratings of subjective well-being in caregivers are consistently associated with older caregiver age and relationship with the patient. In fact, spousal caregivers are at particular risk for decreased well-being (Schulz & Sherwood, 2009). Spousal caregivers are often older than other family caregivers and suffer from more health problems, which may contribute to greater perceived stress when providing care (Pinquart & Sorensen, 2011).

Risk factors and the negative outcomes associated with the caregiving role have been extensively studied (Pinquart & Sorenson, 2003, 2007, 2011; Pearlin et al., 1990; Zarit, Reever, & Bach-Peterson, 1980); however, it wasn’t until just over a decade ago that the positive aspects of the caregiving role were examined (Lin, Fee & Wu, 2001; Schulz & Sherwood, 2009). This
was an important shift in research focus because caregivers can experience either positive or negative outcomes. The positive outcomes that have been associated with the caregiving role include the personal gratification of caring for a family member (Ingersoll-Dayton & Raschick, 2004), caregiver satisfaction (Wilson-Genderson, Pruncho & Cartwright, 2009), well-being (Poulin, Brown, Ubel, Smith, Jankovis & Langa, 2010), physical health, and even reduced mortality (Brown et al., 2009). In their study on well-being among spousal caregivers, Poulin and colleagues (2010) hypothesized that like other broadly construed types of helping behaviors (such as volunteering and charitable giving) providing help in the caregiving context could also lead to well-being. For seven days, the 73 study participants completed a form of online surveys to track their emotions several times per day. The control variables included the chronic illness and functional dependency of the patients as well as differentiating between actual caregiving time and what they termed “on-call” or vigilance caregiving. Active caregiving was considered the amount of assistance required with ADLs and IADLs whereas on-call caregiving was considered the amount of supervision the family caregiver was required to provide. This differentiation between active and on-call caregiving were distinguishing characteristics of this study that may account for the findings. When controlling for on-call caregiving, active caregiving resulted in improved well-being particularly for those caregivers who perceived themselves to be interdependent with the person for whom they were providing care (Poulin et al., 2010).

To contribute to the literature, this study will examine the positive and negative aspects of caregiving, namely caregiver satisfaction and strain. This will be accomplished by examining the relationship of caregiving demands with caregiver strain and satisfaction and the moderating effect of resources on the aforementioned outcomes.
Caregiving Demands

Caregiving for older adults with a chronic illness is a complex and variable role requiring multidimensional support that extends across physical, psychological, spiritual, and emotional domains (Honea et al., 2008). Typically, family caregivers are responsible for providing both emotional and physical care to the patient as well as organizing and coordinating health services on behalf of their loved one (Stajduhar, Martin, Barwich & Fyles, 2008). Demands in the caregiving role can range from those that are relatively easy to manage to those that are burdensome and cause caregiver distress (National Alliance for Caregiving, 2011). The general types of care provided can be divided into hands-on care and close supervision, household care, care coordination, and social and emotional support (Scharlach, 2008). Hands on care and close supervision can include demanding physical and emotional responsibilities of care such as assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include helping with basic functions such as bathing, dressing, toileting, eating, and walking; whereas IADLs include helping with functions such as managing money, household care, and coordinating care services (Wakefield et al, 2012). Household care can include basic tasks of transportation, preparing meals, shopping, or housework. Responsibilities for care coordination involve activities such as finding out information about available resources, managing and coordinating care for the patient as well as paying for that care. Providing social and emotional support such as responding to unmet patient needs is done to some extent by most family caregivers (Scharlach, 2008).

On average, family caregivers provide 20 hours per week of care to an older adult with one or more limitations in ADLs (Johnson & Weiner, 2006). More negative outcomes for caregivers have been shown to be related to patients who exhibit more problem behaviors (e.g.,
falling down, making excessive demands, or asking repetitive questions) (Ingersoll-Dayton & Raschik, 2004) and longer hours spent providing ADLs and IADLs (Ingersoll-Dayton & Raschik, 2004; Kang, 2006; Lin et al., 2012).

Health status changes can result in transitional periods of instability and produce significant changes in the lives of patients and their family caregivers and have important implications for well-being and health (Schumacher & Meleis, 1994). Transitions in caregiving include changes in the patient’s health status and the adjustments made by the family caregiver in response to the patient’s illness, emotional and physical needs, and changing symptoms (Blum & Sherman, 2010). In their study on transitions in spousal caregiving, Burton and colleagues (2003) found that as a patient becomes more ill, the caregiving demands increased and those caregivers with the heaviest caregiving demands had more symptoms of depression and poorer self-reported health and health behaviors. Another study on the consequences of transitions into, within, and out of the caregiving role found that the role is highly dynamic and caregiving transitions have conditioning effects on caregivers’ levels of perceived burden (Seltzer & Wailing, 2000). In other words, as caregiving demands escalate caregivers perceive their burden to be higher the longer they have been providing care to the patient. Transitions are an important element to consider when assessing caregiver outcomes as transitions into, out of, and across the illness trajectory have been shown to impact caregiver outcomes (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003; Martire et al., 2006; Penrod et al. 2011; Waldrop, Kramer, Skretny, Milch & Finn, 2005).

**Caregiver strain**

There is little debate that family caregivers experience a significant amount of perceived burden and strain (Jones, Hadjistavropoulos, Janzen, & Hadjistavropoulos, 2011; Tooth et al.,
2008; Torres et al., 2010, Zarit, 2004) and reduced quality of life (Tooth et al., 2008) as a result of caregiving. The caregiving role is complex to define as it is so multifaceted. For patients with a chronic illness, caregiving is a complex role requiring multidimensional support that extends across physical, psychological, spiritual, and emotional domains (Hornea et al., 2008).

Given the complexity of the caregiving role and its outcomes, it is relevant to distinguish between caregiver burden and strain. Both burden and strain are terms that are used to describe caregiver outcomes when the demands of caregiving outweigh the available resources or resources are not effective (Given, Given, Stommel, Collins, King, & Franklin, 1992). In their systematic review of the literature, Hornea and colleagues (2008) distinguish between strain and burden. Here, strain refers to the perceived difficulty of performing roles or the feelings of being overwhelmed by the tasks that caregivers may experience. Adding to this strain is a lack of resources in the role, such as feeling unprepared in the caregiving role and not having the requisite skills and knowledge to provide care (Archbold, Stewart, Greenlick & Harvath, 1990). Burden can be divided into objective and subjective burden with objective burden referring to events or activities associated with the caregiver role such as delivering physical day-to-day care or managing challenging behavioral changes in the patient (Honea et al., 2008). This is in contrast to subjective caregiver burden which refers to the emotional reactions such as worry, frustration, anxiety, or fatigue (Pinquart & Sorenson, 2003).

As a result of caregiver strain, family caregivers can often experience impaired self-care, increased psychological and physical morbidity, and even mortality (Christakis & Allison, 2006; Monin & Schulz, 2009). Older adult caregivers may be more vulnerable to the negative effects of caregiving if they have their own health issues, leading to feelings of being overburdened.
physically, emotionally, and financially when they are the primary caregiver for a loved one (Parker, Teel, Hobbs Lennerts & Macan, 2011).

These negative effects of caregiving and the culmination of perceived strain have been associated with premature institutionalization and unmet patient needs (Sullivan, 2007). Caregiving outcomes, including strain, are influenced by the interaction between the caregiver and patient (Lin, Fee, & Wu, 2011). Higher functional dependency, such as increased need for assistance with ADLs and problem behaviors of the patient can result in higher levels of strain for the caregiver (Ingersoll-Dayton & Raschik, 2004). This interaction is reciprocal with caregivers having a strong influence on a patient’s psychological adjustment and management of illness, including adherence to a treatment regimen and adoption of other health behaviors that promote functioning (Martire, Lutsig, Schulz, Miller, & Helgeson, 2004). The patient’s physical and mental health outcomes, including psychological well-being, health behaviors, pain severity, and physical disabilities (Pinquart & Sorenson, 2003) have been linked to the manner in which the caregiver role is enacted including the quantity and caregiving experiences (Schultz & Sherwood, 2009). For example, providing care to an older adult that fails to address the care recipient’s needs may lead to frustration and negative outcomes for the caregiver. Conversely, providing care to an older adult that significantly addresses their needs could be an uplifting experience and contribute to positive caregiver outcomes (Schultz & Sherwood, 2009) such as caregiver satisfaction.

**Caregiver Satisfaction**

Rather than focusing strictly on the negative outcomes of caregiving, recent research (Lin et al., 2012; Lopez et al., 2005; MacKenzie & Greenwood, 2012; Poulin et al., 2010; Scharlach, 2008; Schulz & Sherwood, 2009; Wakefield et al., 2012) has started to examine how caregiving
can also contribute to positive outcomes for the caregiver. An early and influential example of this mixed outcomes approach is the Lawton and colleagues (1991) study that suggested that while caregiving can be considered a stressor that competes with other demands in the caregiver’s life and has the potential to exhaust any available resources, it can also be positively affirming to provide care.

In their study on the effects of caregiver burden and satisfaction, Wilson-Genderson and colleagues (2009) used a 2-factor model and hypothesized that a family caregiver committed to the caregiving role, can have an affirming experience that can also be a stress inducing situation that diminishes the caregiver’s resources. That is, caregiving can be positively affirming at the same time that it is a stressor that competes with other demands and causes caregiver strain. For example, providing care to a family member with a chronic illness can increase both caregiver strain and satisfaction. The results of the study highlighted the impact of caregiver burden for the patient and the caregiver while additionally noting the possibility of experiencing satisfaction. The findings from this study could be a reflection of capturing the potential transitory nature of caregiver burden and satisfaction. In this study, there were three time points of data measurement that captured different phases on the illness trajectory in contrast with previous studies that measured outcomes at a single time point (Wilson-Genderson et al., 2009). There was a statistically significant increase in negative affect over the three time points and a statistically significant decrease in positive affect in the same time frame for the family caregivers (Wilson-Genderson et al., 2009).

A different way of examining the caregiving role and accounting for the positive aspects of caregiving is the Healthy Caregiver Hypothesis (Bertrand, Saczynski, Mezzacappa, Hulse, Ensrud & Fredman, 2012). This model proposes that older adults who are healthier than their
counterparts become and remain caregivers, which results in their better health outcomes than non-caregivers of the same age. Using this model as a framework, a cross-sectional study investigated the cognitive function of older women caregivers who had provided care continuously to those who had not provided care. The authors found the continuous caregivers had better verbal memory performance (e.g., immediate and delayed recall of vocabulary) and processing speed (e.g., attention and cognition) than older adults who were not caregivers (Bertrand et al., 2012). These findings are in contrast to previous studies that have shown negative outcomes associated with caregiving.

One reason for the divergent finding could be the sample was high-functioning older women with an average age of 83 which is older than samples from other studies. The women in the study were also classified as a caregiver if they provided help with one or more ADLs or IADLs which could result in underestimating the effect of continuous caregiving on the older female caregiver (Bertrand et al., 2012). This divergent finding could also be due to the study design as it is a secondary analysis of the Caregiver Study of Osteoporotic Fracture parent study. A limitation of the study is the surrogate measures for the patient’s health. The caregiver, rather than the patient, reported on the patient’s health and rated the person’s health on a 4-point scale. This may have impacted the results as other studies have shown there is disparity between what family caregivers and patients report on the health status of the patient (Deshields et al., 2012; Jones et al., 2011). Caregivers have been shown to overestimate levels of pain and health issues of the people for whom they are providing care (Deshields et al., 2012; Jones et al., 2011) which may mean the patients in this study were not as ill and therefore their caregivers provided less intensive levels of care than would be expected. This study may help to explain this divergent
finding as the family caregiver and their care recipient independently rate their own respective health status.

Other studies have had mixed results, with caregivers deriving some mental health benefits from providing care to a spouse but still experiencing caregiver strain resulting in poorer perceived health, an increase in health-risk behaviors, and an increase in anxiety and depression (Beach, Schulz, Yee, & Jackson, 2000). These mixed results could be the result of different instruments being used to measure satisfaction, such as satisfaction from providing care or satisfaction with support services received. Another issue is most studies examining caregiver satisfaction have used a cross-sectional design, homogeneous samples, and controlled for different variables from study to study (Savard, Leduc, Lebel, Beland & Bergman, 2006). In their meta-analysis on the correlates of physical health for family caregivers, Pinquart and Sorenson (2007) found older age, lower socioeconomic status, and lower levels of informal support were related to poorer health outcomes for the caregiver. However, from the 176 included studies, different measures were used for caregiver health including subjective and objective instruments. These factors of using different instruments and controlling for different combinations of confounding variables such as age, education, and socioeconomic status may contribute to the inconsistent findings in caregiver satisfaction. Given the complexity of caregiving, these mixed results are not surprising as many factors and variables contribute to the outcomes for family caregivers including resources within the role. Caregiver strain and satisfaction may be occurring simultaneously as some resources are gained as others are depleted.
**Resources in the Caregiving Role**

Resources may play an integral part in developing an understanding about caregiver outcomes. In fact, resources have been hypothesized to be important in examining both caregiver strain and satisfaction (Schultz & Sherwood, 2009; Wakefield et al., 2012). Current funding for formal caregiving resources (e.g., respite care and home care) represents a significant cost. The Administration on Aging estimated that funding for Family Caregiver Support Services program during 2011 was $153,911,000 (Administration on Aging, 2012). In 2010, more than half of the states reported an increase in demand for community based services such as transportation, respite care and home-delivered meals that would facilitate older adults and their family caregivers remaining in their homes and communities. For example, Areas on Aging have received 67% increase in demands for caregiver support services. During this same time frame, 31 states cut non-Medicaid aging and disability services programs with expected further cuts to community and home based services that will directly impact services and supports for family caregivers (Feinburg, Reinhard, House, & Choula, 2011). With the limited funds available to support family caregivers, it is critical to start to examine which resources family caregivers perceive to adequately meet their needs so that funding is directed to the resources that have the highest potential to be both efficacious for the caregiver and cost effective. Despite the extensive caregiving literature, few studies have examined the positive and negative consequences of caregiving using a resource-oriented perspective and determined how caregiving resources may affect caregiver outcomes. This study addresses this gap by exploring if a gain or loss of resources for caregivers influences the relationships between caregiving demands and caregiver outcomes (i.e. satisfaction and strain).
Resources are “those objects, personal characteristics, conditions or energies that are valued in their own right or that are valued because they act as conduits to the achievement or protection of valued resources” (Hobfoll, 2001, p. 339). As indicated by this definition, the Conservation of Resources (COR) model divides resources into four major categories of: 1) object resources (home-delivered meals, transportation); 2) condition resources (family and social support); 3) personal resources (skills and self-efficacy); and 4) energy resources (the ability to obtain other resources such as knowledge or money) (Hobfoll, 1986, 2001).

Using the COR model as the framework, resources in this study are considered from a broad lens and include object resources (i.e. use of formal resources) and condition resources (family and social support). Resources can take many forms in the caregiving role and can be internal, such as coping skills and knowledge (Schumacher et al., 2000) or external such as social support or income (Given, Sherwood & Given, 2008; Rosland & Piette, 2010). Most studies have focused on the lack of resources such as a lack of someone to take over the caregiving role if required (Mui, 1995), family conflict (Kang, 2006) and lack of support from family or friends (Schulz & Sherwood, 2009) and their relationship to depression. This study expands on previous research by examining not only a lack of resources but how resource utilization and family caregiver perceptions of resource adequacy are associated with caregiver outcomes. Resource utilization examines the total number of resources used. Perception of resource adequacy will deal with whether the resources in the caregiving role met or did not meet the needs of the family caregiver.

**Social Support.**

Social support refers to the functional characteristics of social networks and their social influence (Berkman & Glass, 2000). The concept has been variously defined and can include the
quality and quantity of supportive interactions, as well as the characteristics of the social system and/or the people within those social systems (Hupcey, 1998a). Although social support has been variously conceptualized, it has often been hypothesized to reduce stressful roles and life events (Smerglia, Miller, Sotnak, & Geiss, 2007). Hupcey (1998b) defined social support as “a well-intentioned action that is given willingly to a person with whom there is a personal relationship and that produces an immediate or delayed positive response in the recipient” (p.313). Social support has been used as a predictor of caregiver outcomes and is widely believed to enhance adjustment in the caregiving role (Glasdam, Timm, & Vittrup, 2010; Onsworth, Henderson, & Chambers, 2010).

Findings concerning social support and its relationship to caregiver outcomes such as well-being have had mixed results. One of the issues is the lack of uniformity in the measurement of social support. Some studies assess the satisfaction with the structure of the support (the number of persons in the network) and others assess the function of social support (either the perception of available support or support which has been received) (Ownsworth et al., 2010). That is, caregivers may not have access to many social supports but be highly satisfied with those that they do have or other caregivers may have numerous social supports but not be satisfied with the support received or support that is perceived to be available. The inconsistent findings may also be a reflection of the complexity of social support. A great deal of variation in asking for and receiving support can be the result of the caregiver characteristics, such as the existing relationship between the caregiver and patient as well as the age, gender, and caregiving demands (Pinquart & Sorenson, 2011; Schulz & Sherwood, 2009).

In a cross-sectional study (Onsworth et al., 2010) examining the moderating effect of social support on caregiver psychological well-being, higher levels of patient functional
dependency were associated with poorer caregiver outcomes. In this study, higher functional dependency was defined as increased assistance with ADLs. Here, satisfaction with social support was found to moderate the relationship between patient functional impairment and caregiver psychological well-being, suggesting that when patients become more dependent, satisfaction with social support networks is particularly important for enhancing caregiver well-being (Onsworth et al., 2010).

A meta-analysis comparing spousal and adult children caregivers found that the patient’s physical health and informal social support were the strongest predictors of caregiver psychological distress and concluded that increasing the resource of social support is an important intervention for decreasing caregiver strain (Pinquart & Sorenson, 2011). Informal support was defined as the structure of social support (the number of people providing assistance) and the function of social support (the number of hours help was provided). The analysis also found that spousal caregivers report more depression symptoms, greater burden and decreased levels of psychological well-being than their non-spousal counterparts. This could be a result of the spousal caregivers being older on average than non-spousal caregivers and it could also be a reflection that the spouse generally lives with the patient and may as a result be providing more care which could result in greater strain and decreased social support. There may also be a selection bias in that spousal caregivers may be a healthier group of older adults who are physically able to provide care as less healthy caregivers are at an increased risk of giving up the caregiving role (Pinquart & Sorenson, 2011).

In contrast, another meta-analysis on social support and adjustment to caring for an elderly family member found that in 61% of the included 35 studies, social support for the caregiver did not have a significant positive impact on their adjustment to the caregiving role.
(Smerglia et al., 2007). This finding contrasts with previous studies showing positive outcomes for social support. The divergent finding could be the result of the different types of social support measures used in the studies, (e.g., the structure and function of social support as well as feelings toward the actual social network) or the differing caregiver outcomes that were measured such as depression and burden. It may be that in this study, it was not the social support that influenced the divergent findings but rather the extent to which the caregivers were dissatisfied with the social network.

**Family Support.**

A component of social support is the family network, with families playing an essential role in caring for community-dwelling older adults (Kita & Ito, 2012). Family support has been shown to be an important aspect of caregiving (Phillips & Crist, 2008; Scharlach, Li & Dlavi, 2006) and as such is a potential resource. Generally, one family member assumes the primary responsibility for providing care but this is frequently augmented by other family members who provide assistance as well as social and emotional support (Scharlach et al., 2006). As such, providing care to an older adult with a chronic illness can impact the entire family system. The cumulative effect of caregiving has the potential to disrupt the “routine” life of a family as families work as a system (Kita & Ito, 2012). Providing care for an older adult family member requires resources (e.g., money, time, knowledge) that may divert from other aspects of family life (e.g., interactions with family members other than the older adult, caring for other family members) (Given & Given, 1991). In a grounded theory study examining the caregiving process for community-dwelling older adults, families were interviewed to understand caregiving as a family unit (Kita & Ito, 2012). The authors found two key categories that were impacted by providing care to an older adult: “degree of daily life routinisation” and “degree of minimization
of competing demands within the family”. Degree of routinisation included each family’s specific style of activities and minimization of competing demands included minimizing the conflicts or problems among family members (Kita & Ito, 2012).

In a cross-sectional study examining family conflict in caregiving at the end-of-life, Kramer and colleagues (2009) defined family conflict as “interpersonal tension or struggle among two or more persons whose values, needs or expectations are opposing or incompatible” (p. 216). In this study, family conflict was examined as a function of the family context, conditions and contributing factors with 35% of the families reporting some type of conflict. Past conflict was found to be a predictor of future family conflict in the caregiving context as was different family members asserting control over the decision making process (Kramer et al., 2009).

For those families that are able to adjust to the stressors of providing care to an older adult with a chronic illness, they are likely to serve as supports for the primary family caregiver. The assistance of other family members can be a source of support but it can also compound stress for both the caregiver and the patient (Pearlin et al., 1990; Scharlach, 2008). Given the demands of caring for an older adult with a chronic illness are high, there is a pervasive risk of family conflict (Badr & Taylor, 2006) with this conflict adding to the stress of the caregiving role (Schulz & Martire, 2004). As a result of family conflict other family members may be less apt to provide additional social and emotional support which may lead to increased caregiver strain (Scharlach et al., 2006). Family support, similar to social support, may be used as a resource in caregiving when there is harmony within the family but it may also contribute to caregiver strain when there is family conflict.
**Resource Utilization.**

Using the COR model, utilization of available supports is also considered a resource in the caregiving role. This is an area that requires further investigation as despite the growing availability of resources and the identified benefits of using formal services the actual rate of utilization remains low (Hong, 2009; Keith, Wacker & Collins, 2009). For example, the National Alliance for Caregiving found that only 11% of family caregivers utilized support groups and only 9% used respite services (National Alliance for Caregiving, 2004). Although there are a variety of support services for addressing family caregivers’ needs, many of these caregivers either do not access these services or use them late in the course of the patient’s illness (Hong, 2010). Not utilizing available resources could be a result of the caregiver not being aware of the services or due to a host of other complex interconnected factors. These factors could include the type and amount of social and family support, the type of support services (formal or informal) available to the caregiver as well as the caregiver’s confidence in those services, the caregiver’s perception of the need for the resource or even stressed caregivers who do not have time to investigate available support services.

Developing a better understanding of the facilitators and barriers to service utilization were addressed in this study by examining the caregivers’ perceptions of used resources to determine if the resources met the caregivers’ needs. Utilization of available resources is an important consideration as caregivers with higher levels of burden and greater restrictions on their time more likely to seek and engage in formal services (Hong, 2010). Determining if resources are utilized and if resources are perceived as meeting the needs of the family caregiver and how this impacts their outcomes is paramount in an era of cost containment.
In a descriptive cross-sectional study that examined caregiver stress and the moderation effects of social support, the authors found that younger caregivers with paid help had better health outcomes than their older counterparts without paid help (Huang, Musil, Zauszniewski & Wykle, 2006). Based on the study findings, the authors concluded that those with support, such as paid in-home assistance, fare better in the caregiving role than those without support (Huang et al., 2006).

Research is now starting to focus on both the negative and positive aspects of caregiving, with resources impacting two major caregiving outcomes, caregiver strain and satisfaction (Hunt, 2003; Lin et al., 2012; Wakefield et al., 2012). For family caregivers, providing care may interfere with their physical and emotional health which can result in strain (Lin et al., 2012). Caregiving can also provide a sense of satisfaction through helping out a family member. Using the COR model as a framework, caregiver strain can be conceptualized as a stressor and a net loss of resources whereas caregiver satisfaction can be conceived as a resource gain from the positive aspects of providing care. The relationship between resources in the caregiving role and caregiver outcomes is an area that requires further investigation. Understanding how to best support family caregivers in their role through examining the resources used and their perceived adequacy and then providing appropriate resources (either formal or informal services) has the potential to improve the outcomes for both the caregiver and the older adult for whom they provide care.

**Chapter Summary**

Although recent studies have demonstrated the potential for positive outcomes for the family caregiver, the negative consequences of caregiving, particularly spousal caregiving, on the physical and mental health and mortality of the caregiver have been well documented (Garlo
et al., 2010; Pressler et al., 2009; Schulz et al., 1997; Schulz & Beach, 1999). Few studies have examined the impact of resource utilization and perception of resource adequacy on negative and positive caregiver outcomes. Using the COR Model will address this gap and highlight how resources in the caregiving role may influence the outcomes for the family caregiver. Not only is this important for the outcomes of the caregivers but these outcomes can influence their ability and/or decision to remain in the caregiving role, thus affecting the health of the older adult care recipient (Lin et al., 2012).
Chapter III

Methodology

Introduction

To examine caregiver outcomes and the association of resources with those outcomes, the study consisted of a secondary analysis of data from the National Long Term Care (NLTC) Survey and the Informal Caregiver Survey. This survey was sponsored by the National Institute on Aging and conducted by the Duke University Center for Demographic Studies (Grant # U01-AG007198). Due to the nature of the NLTC Survey, conducting a secondary data analysis was an efficient and appropriate way to address the research questions in this study. The sampling design and comprehensiveness of the survey as evidenced in the volume of questions that address all aspects of the caregiving role makes the NLTC Survey and the Informal Caregiver Survey a relevant source for understanding how resource utilization and perception of resource adequacy affect this critical role.

Secondary analysis is simply the reanalysis of existing data (Garmon, 2007) and has both advantages and disadvantages. Advantages to secondary analysis are that it is “a practical, cost-effective, and scientific method and offers ready access to large data sets with multiple variables” (Garmon, 2007, p. 95). Examining informal caregivers’ resource utilization and perceptions of the adequacy of resources for caregiving and how these resources impact their outcomes requires the examination of multiple variables. The NLTC Survey and Informal Caregiver Survey provide data on the variables of interest and facilitated the examination of the relationships between caregiving resources and caregiver outcomes. The fit between the research questions for this study and the variables measured in the Informal Caregiver Study is
strong because numerous questions in the survey address resources, caregiver outcomes, and caregiver demographics.

A disadvantage of secondary analysis is that the validity of the study’s findings is dependent upon the quality of the original study. If the original study was not rigorous, the quality of the secondary analysis will be negatively affected. The NLTC Survey was designed around the principles laid out by the Demographic Surveys Division of the U.S. Census Bureau. In these principles, guidelines have been established following the Information Quality Guidelines (Federal Registry, 2002) to ensure and maximize the quality, objectivity, utility and integrity of disseminated information. These guidelines conceptualize quality as encompassing utility, objectivity and integrity. Utility refers to the usefulness of the information. Objectivity deals with ensuring the information from the survey is accurate, clear, and complete and presented in a reliable and unbiased manner. Finally, integrity involves the security of the information so that it is in no way compromised through corruption or falsification (Federal Registry, 2002).

Another disadvantage of secondary data analysis is fitting the research question to the data that has already been collected. As the investigator conducting the secondary data analysis has no control over the type of data that was originally collected, the data may not adequately operationalize the concepts of interest in the current study. Before initiating a secondary analysis on an existing data set the minimum information that is required includes: what was the study’s purpose, what was the study’s design, what are the variables, what were the sampling procedures, how were the data collected and how much data is missing, and who collected the data (Garmon, 2007).
To address these requirements for secondary analysis, this chapter will provide a description of the NTLC Survey, the supplemental Informal Caregiver Survey and the database constructed from the surveys. This will be followed by a discussion of the study sample and measures, protection of the participants in the original study, and the data analysis plan.

**National Long Term Care Survey**

The National Long-Term Care (NLTC) Survey includes data from a nationally representative sample of randomly selected community-dwelling and institutionalized older adult Medicare enrollees. Following the original 1982 survey, successive waves of data were collected every five years in 1984, 1989, 1994, 1999 and 2004. The 2004 NLTC Survey was the sixth and final round of the longitudinal survey of elderly Medicare enrollees. Field operations for all rounds were handled by the U.S. Census Bureau. The 1982 and 1984 rounds were conducted by Center for Medicare and Medicaid Services. The 1989, 1994, 1999, and 2004 rounds were conducted by Duke University with funding from National Institute of Health/National Institute on Aging. Although the surveys were conducted by two institutions, the field operations did not change. The only major difference was the 1982 NLTCS was restricted to the disabled community-dwelling older adult population whereas in the 1984 and forward surveys the interviews were administered to community-dwelling older adults (initially only the disabled but later extended to nondisabled population) as well as Medicare enrollees living in institutions (Manton et al., 2008).

The purpose of the study was to examine trends in chronic disability across time for elderly people in the United States (Erosheva & White, 2006). To assess the health of older adults, the NLTC Survey used extensive self-reported information about activity of daily living (ADL) functioning, the amount and type of help received, health status, and resources for
obtained health care (such as special equipment and assistive devices). The NLTC survey also tracked health expenditures, Medicare service use, and if there were available family members to provide care (NLTCS, 2012). As noted earlier, field procedures, instruments and organization of the NLTC Survey were based on the Demographic Surveys Division of the U.S. Census Bureau (Manton, Corder & Stallard, 1993). A survey manager for field operations trained and supervised the field coordinators and the research interviewers. All interviewer progress and training as well as regular reports on the progress of the survey was conducted by the same person. Throughout the data collection period, coordinators assisted with research interviewer training. There was also a manager for data reduction who trained and supervised the quality control staff. The data reduction manager supervised all data cleaning activities. The Quality Control Manager assisted in quality control staff training, followed up on missing information and subjected interviews to quality control within a specified time frame (Phillips, Stephens, & Cerf, 1986). In each of the waves of the NLTC Survey, questions about disability and health remained consistent (Clark, 1998). The survey can be considered longitudinal in that once the older adults were screened in to participate they stayed in future waves of the survey. In addition to examining the survey longitudinally, each wave can be analyzed independently which allows for cross-sectional analysis.

The NLTC survey sample consisted of adults 65 years of age and older, which had their names randomly selected from the Health Insurance Master file and were sent a pre-survey letter inviting participation in the study. These people were then screened either by telephone or personal visit to determine if they had impairment in their ADL or IADL that lasted or was anticipated to last at least 90 days. Based on the participants’ responses they were placed in one of three categories: non-disabled (who were subsequently screened out of the survey); disabled
but living in the community (that is, they had impairment in either ADL or IADL); and the disabled living in an institution. For the participants screened into the survey (approximately 8,500 people), a detailed residential (approximately 5,500 people) or institutional interview (approximately 3,000 people) was conducted either over the telephone or in person (Manton, Gu, & Lowtimore, 2008). The survey gathered information on medical diagnosis, functional status (the presence of ADL, IADL or other functional impairments and the equipment they themselves or their caregivers used to deal with these impairments), income, health service use, use of federal services, housing and living arrangements (Manton & Liu, 2012).

The segment relevant to this study is the community-dwelling older adults from the NLTC Survey as this group determined the selection of participants for the Informal Caregiver Survey. See Table 3.1 for a listing of the types of questions asked in the older adult screening interview, the community-dwelling older adult interview and the informal caregiver interview.
Table 3.1 NLTC Survey Questionnaires

<table>
<thead>
<tr>
<th>Screening Questionnaire</th>
<th>Questionnaire for Community Dwelling Older Adults</th>
<th>Informal Caregiver Survey</th>
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</thead>
</table>
| • Date, time and place of interview  
• Respondent's current address  
• Proxy information (if appropriate)  
• Questions on 6 ADLs  
• Questions on 9 IADLs  
• Selected demographic and residential status information | • Condition list  
• ADL status (detailed questions on 6 ADLs)  
• IADL status (detailed questions on 9 IADLs)  
• Source, type and amount of informal help  
• Source, type, amount and payor for formal help  
• Questions on range of motion and impairment  
• Activity list  
• Nutrition  
• Social activities  
• Alcohol consumption and smoking  
• Other functioning (mental, emotional, behavioral)  
• Housing and neighborhood characteristics  
• Health insurance  
• Medical providers and prescription medicines  
• Cognitive functioning  
• Military service, ethnicity, income, assets | • Caregiver name, address  
• Basic demographics  
• Relationship to sample member  
• Amount and kinds of help provided  
• Information on care provided by others  
• Caregiver's living situation  
• Caregiver's work situation  
• Caregiver's health and functional status |

Listed below are the procedural steps for administering the survey to the over 20,000 Medicare enrollees in the screening sample and subsequently identifying the informal caregiver to be interviewed:

1. An introductory letter was sent to each Medicare enrollee to acquaint him/her with the survey.
2. A short screening interview was conducted by telephone to screen out those who had no functional limitations in ADL or IADL, who had died, or who had entered an institution.

3. A second introductory letter about the NLTC Survey was sent to persons whose responses to the screen indicated that they had functional limitations.

4. Demographic information was collected and recorded all contacts within the household.

5. The detailed interview was conducted with persons living in the community with (according to the screen) functional limitations.

6. The informal caregivers who were identified from those community-dwelling older adults with functional limitations were interviewed over the telephone in a later survey (Clark, 1998). The older adult named his/her primary informal caregiver.

Disabled, community-dwelling older adults (i.e. aged 65 and older) with one or more limitations in instrumental activities of daily living (IADLs) or ADLs constituted the sample for the community portion of the survey. In the original and subsequent surveys, disability for the community-dwelling older adult was defined as:

…the inability to perform IADLs (e.g. cooking, doing laundry) due to health or aging, or the inability to perform at least one ADL (e.g. bathing, dressing) without using personal assistance of special equipment…To be identified as chronically disabled when initially selected for a detailed interview a sample person had to have at least one ADL or IADL disability that lasted, or was expected to last, >90 days. Disability was grouped into four categories, i.e., those with ≥ 1 IADL impaired (but no ADL impaired), those with 1-2, 3-4, or 5-6 ADLs impaired (Manton, Corder, & Stallard, 1997, p. 2594).

As part of the inclusion criteria the limitations in IADLs and/or ADLs needed to be present for either 90 days or expected to persist for 90 days (Ingersoll-Dayton & Raschick,
Once screened into the survey, participants remained in the survey. In 1982, over 30,000 people representing both community-dwelling and institutionalized older adults were drawn from the national Medicare beneficiary enrollment files with a response rate of over 90% for all waves of the survey (Manton et al., 2008). Participants who received a detailed interview in one survey year were automatically interviewed in all subsequent years until their death (Manton et al., 1997). In this population, there is the potential for a high attrition rate due to mortality. This was offset by refreshing the data in each wave from 1984 onwards by adding a sample of 5,000 Medicare enrollees who had turned 65 since the last survey (Lin et al., 2012; NLTCS, 2012). The refreshed sample was screened into the survey in the same fashion as the original survey. After the original survey in 1982, this addition of 5,000 participants aged 65-69 for the subsequent waves facilitated maintaining the sample size of approximately 20,000 people for the entire data set (Manton et al., 2008). The addition of “replacements” also helped to ensure that the entire Medicare population (those 65 and older) was adequately represented in each of the NLTC Survey waves. This adequate representation was maintained because the new group of participants would age and thus continually represent the older age categories (70 and older) for each successive wave of the survey.

The sample for the survey was established in April and data collection for each wave occurred from June to October of the respective year. To promote consistency and allow for longitudinal analysis, sampling and data collection procedures remained largely unchanged for all the waves of the survey (Manton et al., 2008). Sampling units from the first survey in 1982 until the last survey in 2004 remained unchanged so that the same people in the same sampling units could continue to be interviewed (U.S. Census Bureau, 2006). The original and subsequent sampling design came from the Primary Sampling Units (PSUs) design (U.S Census Bureau,
PSUs consist of a large number of aggregate units that are contained in a well-defined geographic area (Murphy, 2008). In the sampling frame for the NLTC Survey, these PSUs consist of a county or group of contiguous counties from which all counties in the United States were grouped into a total 376 units (or counties). For the NLTC Survey, these units were further collapsed resulting in 176 PSUs from which the list of Medicare enrollees was drawn (Manton et al., 2008). See Table 3.2 for the sample size for each wave of the NLTC Survey (NLTC Survey, 2012).

Table 3.2 Sample Size for Each Wave of NLTC Survey

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<tbody>
<tr>
<td>Sample Size</td>
<td>20,485</td>
<td>25,401</td>
<td>17,565</td>
<td>19,171</td>
<td>19,907</td>
<td>20,474</td>
</tr>
</tbody>
</table>

In the 2004 NTLC Survey, the total sample size was 20,474 (U.S. Census Bureau, 2006). Screening interviews and the subsequent community or institutional surveys were conducted by telephone or in person. Trained interviewers from the U.S. Census Bureau administered the surveys. The response rate was continually above 95% for all waves of the survey until the 2004 wave. Due to the difficulty of locating and tracking individuals aged 65-74 with low levels of Medicare service use, the response rate dropped to 91% in 2004 (Manton et al., 2008).

Informal Caregiver Survey.

The community-dwelling participants of the NLTC Survey were screened to identify those that reported receiving unpaid help and who also identified a primary caregiver. The result was a sample of primary caregivers who were all contacted to participate in the Informal Caregiver Survey. The Informal Caregiver Survey was conducted in 1982, 1989, 1999 and 2004 (NLTC Survey, 2012) and is linked to the respective NLTC Survey. For example, informal
caregivers participating in the 2004 Informal Caregiver Survey were identified from the community-dwelling older adults participating in the 2004 NLTC Survey.

After identifying the primary caregiver, the Informal Caregiver Survey was conducted by the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation and the Research Triangle Institute (NLTC, 2012). Trained interviewers were employed to perform the telephone surveys. During the telephone survey that lasted approximately 30 minutes, the informal caregivers were asked questions on a variety of topics. Questions focused on demographics, the nature and intensity of the help that was provided, self-rated health, types of available resources, perceptions of challenges and rewards in the caregiving role, as well as living arrangement (Hong, 2010; Wolff, Dy, Frick, & Kasper, 2007; Wolff & Kapser, 2006). See Appendix B for the Informal Caregiver Questionnaire Flowchart.

For the 2004 Informal Caregiver Survey, less than 10% of the observations had missing values (Hong, 2010).

**Sample and Sample Size for the Study**

For this study, the data source was the 2004 wave of the Informal Caregiver Survey. The NLTC Survey and Informal Caregiver Survey data were last collected in 2004. As a result they could be critiqued as being outdated or irrelevant to today’s informal caregivers. To determine how relevant the data were for use in this study an examination of the changes that may have occurred in the caregiving role since the data were collected and if these changes would impact the relevance of the data to caregiving today was conducted.

It is well known that the population is aging and as a result there will be an ever increasing reliance on families to provide care for their aging parents, relatives and friends for extended periods of time (Family Caregiving Alliance, 2012). As the pressures on these family...
caregivers mount, information and support services are required to help them in their critical role but often it is not known where or what help is available. These issues have not changed since the 2004 surveys were conducted. In fact, as the population continues to grow older with the aging of the baby boom generation, it has become even more important to examine and evaluate the impact resources in the caregiving role have on the family caregiver. The “typical” family caregiver in the U.S. is a married woman in her forties who provides more than 20 hours of unpaid care (Family Caregiving Alliance, 2012); this is also borne out in the 2004 survey demonstrating that the profile of the typical caregiver today, in 2014, is consistent with the caregiver participants in the 2004 survey. Although the data for this study were analyzed from a survey that is now ten years old, the information that was originally collected remains relevant to addressing questions related to informal caregivers providing care to community-dwelling older adults. As such, the 2004 wave of the Informal Caregiver Survey remains an appropriate dataset to examine the impact of resource utilization and perception of resource adequacy on caregiver outcomes.

**Inclusion Criteria.**

Inclusion criteria for this sample included community-dwelling adults 65 years of age and older who had any limitations in IADLs or ADLs of at least three months duration who identified an informal caregiver (Wolff & Kasper, 2006). Informal caregiver eligibility criteria included those caregivers who were unpaid relatives or nonrelatives of the older adult. To be included in the survey, the caregiver must have reported providing one or more hours of help to participants in the 2004 NLTC Survey within the week prior to the community interview (Wolff & Kasper, 2006). If the older adult identified more than one caregiver, the person providing the most hours of help with ADLs or IADLs was selected for the community interview. To be included in the
sample for the Informal Caregiver Survey, the caregiver must have completed the survey and be an unpaid caregiver (NLTC, 2012). As a result, informal caregivers were included in the survey regardless of the care recipients’ type of chronic illness. This is in contrast to other studies that have focused on caregivers for older adults for specific illnesses and resulted in a sample representative of the general U.S. population of caregivers (Lin et al., 2012).

**Sample Size.**

The sample size of older adults that were randomly selected to participate in the 2004 NLTC Survey was 20,474 (NLTCS, 2012). From this total number, 5,201 of the community-dwelling older adults met the criteria for disability and were screened for a detailed community interview. Of the 5,201 participants, 2,300 responded that they received unpaid help and identified their primary informal caregiver. These informal caregivers were then contacted with 1,923 of the 2,300 caregivers (84%) completing the Informal Caregiver Survey (Lin et al., 2012; NLTCS, 2012).

The sample size of 1,923 is appropriate for this study. Using the software G*Power a required sample size for the study was calculated. The parameters included an effect size of .02, an alpha of .05 and a power level of .95, and a total number of predictors of 15 (to include all the predictor variables and covariates) resulting in a required sample size of 1,401. When detecting moderation, the most common effect size test is $f^2$ with 0.02, 0.15, and 0.35 being considered small, medium, and large respectively (Cohen, 1988; Kenny, 2013). A 30-year review of effect size in moderation suggests even these numbers may need to be lower (Aguinis, Beaty, Boik, & Pierce, 2005); hence the chosen effect size of 0.02 for this study.
Sample Characteristics.

In this sample of 1,923, the care recipients (the older adults from the 2004 NLTC Survey) ranged in age from 65 – 107 with a mean age of 80. Most of the care recipients were female (65%) and either married (46%) or widowed (44%). The care recipient sample was primarily white (88%) with 8% being African American. Most of the care recipients had less than a high school education (44%) or were a high school graduate (28%).

In the Informal Caregiver Survey sample of family caregivers (n=1,923), 80.8% of the family caregivers were white and 9.4% were African American. Sixty-six percent were female. Thirty-two percent were married to the person for whom they were providing care and 32.5% had at least a high school education with 47.3% having some type of post-secondary degree.

This sample of family caregivers is representative of the family caregiver population within the United States. Over 43.5 million adults over the age of 18, or 19% of the adult population in the United States provide care to family member over the age of 50 which has not significantly changed since 2004 (National Alliance for Caregiving, 2009). Of these family caregivers, approximately 75% are white, 10% are African American and 10% are Hispanic (National Alliance for Caregiving, 2009). The average family caregiver is a female in her late 40’s, with about 51% of the caregivers being between the ages of 18 and 49 (National Alliance for Caregiving and AARP, 2009). According to the National Alliance for Caregiving (2009) survey, older adult caregivers are more likely to care for their spouse or partner than their younger age counterparts who are more likely to care for an elderly parent. Many family caregivers who are caring for a patient 65 years of age or older are themselves older adults with the average age for this group of caregivers being 63 (Administration on Aging, 2005). Family caregivers provide, on average, 20 – 25 hours of care per week with caregivers 65 and over
providing 31 hours of care and younger caregivers reporting about 19 hours per week (Johnson & Wiener, 2006; National Alliance for Caregiving, 2011) with the intensity of the help based on the functional dependency of the patient. Spouses, women, caregivers living with the patient, and caregivers who provide care to patients with dementia and at the end of life typically provide help with the greatest intensity and frequency (IOM, 2008).

**Study Measures and Variables**

The predictor variable was caregiving demands in the caregiving role and included the functional dependency of the older adult care recipient, hours spent caregiving per week, time in the caregiving role, and progression of caregiving responsibilities. Covariates for the study included demographic information for the family caregiver including gender, relationship to the older adult care recipient, race, education well as the caregiver’s and older adult’s self-rated health. The moderators were resource utilization and the perception of resource adequacy. The study’s main outcome variables were caregiver strain and caregiver satisfaction. See Figure 2 for a conceptual diagram of the study and Table 3.3 for additional information on the variables examined in the study.
Caregiver strain in this study was measured using two scales; the Global Strain Index (Casado, 2008; Lin et al., 2012) and the Caregiver Strain Index Subscale (Robinson, 1983). The Global Strain Index included three items that globally measure the physical, emotional, and financial strain the informal caregiver has experienced as a result of their caregiving role. The questions in the Informal Caregiver Survey are: “How much of a physical strain would you say caring for (SAMPNAME) is for you?”; “How emotionally stressful would you say caring (SAMPNAME) is for you?” and “How much financial hardship would you say that caring for (SAMPNAME) is for you?” All items in the scale are based on a 5-point Likert scale with 0 = no strain and 5 = very much strain. Cronbach alpha for caregiver strain in this study (α= .782) was consistent with that found in previous research (Lin et al., 2012; Scharlach, Li, & Dalvi, 2006).

In addition to the Global Strain Index, strain in this sample was also measured using a subscale of the Caregiver Strain Index (Onega, 2008; Robinson, 1983). The Caregiver Strain Index was originally developed in the early 1980s by Robinson (1983) to screen for caregiver

**Figure 2**: Conceptual Diagram of the Study Variables

**Outcomes Variables.**
strain after hospital discharge of an elderly family member and is appropriate to use with caregivers of any age (Sullivan, 2007). Using 13 items, this tool measures strain related to care provision and includes the major domains of financial, physical, social, and time constraint concerns and has been used to assess family caregivers who have assumed the role of caring for an older adult. The internal reliability of the entire 13 item scale is good ($\alpha = .86$) (Onega, 2008; Wakefield et al., 2012).

As not all the questions from the scale were asked in the Informal Caregiver Survey, a subscale using 7 of the 13 questions was used for this study. As with the original Caregiver Strain Index, the questions are dichotomous with false = 0 and true = 1. The questions that make up the subscale include: 1) “As a caregiver you have had less time for other family members than before”; 2) “As a caregiver you have had to give up vacations, hobbies, or your own activities”; 3) “I don’t have as much privacy when I take care of (SAMPNAME)”; 4) “Taking care of (SAMPNAME) limits my social life or free time”; 5) “I have to give (SAMPNAME) almost constant attention”; 6) “Taking care of (SAMPNAME) has caused my health to get worse”; and 7) “Taking care of (SAMPNAME) costs more than I can really afford”. Cronbach alpha for caregiver strain in this study ($\alpha = .825$) is consistent with that found in previous research using the entire scale (Onega, 2008; Wakefield et al., 2012). See Table 3.4 for a comparison of questions from the original Caregiver Strain Index and the Caregiver Strain Index subscale used in this study.

The second major outcome variable was caregiver satisfaction. A 5 item caregiver satisfaction scale (Wakefield et al., 2012) was developed from the Caregiving Appraisals Scale (Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Lawton, Moss, Kleban, Glicksman & Rovine, 1991). Measured by a set of 47 items taken from earlier questionnaires, the Caregiver
The Caregiver Satisfaction Scale was grouped into five different dimensions with the five items expressing positive aspects of caregiving being conceptualized as representing Caregiving Satisfaction ($\alpha = 0.71$) (Lawton et al., 1991). The five item Caregiver Satisfaction Scale is one of the most frequently used measures of caregiver satisfaction as it has good internal reliability (Lopez, Lopez-Arrieta & Crespo, 2005; Wakefield et al., 2012), with Cronbach’s alphas ranging from 0.79 (Jensen, Ferrari & Cavanaugh, 2004) to 0.89 (Tarlow, Wisniewski, Belle, Rubert, Ory & Gallagher-Thompson, 2004). The Informal Caregiver Survey asked the following two questions from the Caregiver Satisfaction Scale using a 5-point Likert scale (with 1 = disagree a lot and 5 = agree a lot): “Providing help to (SAMPNAME) has made me feel good about myself” and “Providing care to (SAMPNAME) has enabled me to appreciate life more”. Cronbach alpha for caregiver satisfaction using these two questions in this study ($\alpha = 0.777$) was consistent with other studies using the same two global caregiver satisfaction questions ($\alpha = 0.78$) (Ingersoll-Dayton, & Raschick, 2004; Kang, 2006; Lin, Fee, & Wu, 2011). See Table 3.5 for the instrument properties for the variables.

**Moderator Variables.**

The moderator variable for this study was resources in the caregiving role. Specifically, family caregivers’ perceptions of resource adequacy (whether or not they meet the needs of the caregiver) and their utilization were examined to determine their association with caregiver outcomes. Using the Conservation of Resources (COR) Model (Hobfoll, 1989, 1998, 2001) as a framework, resources can be conceptually broken down into object and condition resources. Among those resources reported, object or formal resources included the range of formal services that offer support to the family caregiver (Hong, 2010). Condition or informal resources included social and family support.
**Object Resources.** The object or formal resources in the Informal Caregiver Survey were categorized as follows: 1) respite care; 2) caregiver support groups; 3) adult day care and senior centers; 4) personal care or nursing care within the home; 5) help with housework; 6) meal delivery services; 7) outside transportation services; 8) household modifications; 9) assistive devices; and 10) information on financial help. Formal resources in the caregiving role was measured using a dichotomous item to assess the level of service utilization (0 = no service used and 1 = service utilized; summing the scores created a formal resource range from 0 to 10) (Hong, 2010). If the family caregiver utilized one of the above formal services, the next question asked whether the service did not meet their needs; partly met their needs; or fully met their needs. This question assessed the perceived adequacy of the formal resources.

**Condition Resources.** The second type of resource to be analyzed using the COR model (Hobfoll, 1989, 1998, 2001) as a framework was condition resources. Informal resources fall within the condition resources category and are the emotional support received by the family caregiver. A subscale of the Medical Outcomes Study Social Support Survey (Moser, Stuck, Silliman, Ganz & Clough-Corr, 2012; Sherbourne & Stewart, 1991) was used to measure social support for the family caregivers. The Medical Outcomes Study Social Support Survey consists of 19 items that measure the four subscales of emotional/informational support, tangible support, affectionate support and positive social interaction (Sherbourne & Stewart, 1991). The measure has been used with family caregivers of patients with pulmonary arterial hypertension and demonstrated a high internal consistency with $\alpha = 0.92$ for affectionate support and $\alpha = 0.97$ for the other three subscales (Hwang, Howie-Esquível, Fleishmann, Stotts & Dracup, 2011).

In the Informal Caregiver Survey 8 of the 19 Medical Outcomes Study Social Support Survey items were used to measure the perception of social support in the caregiving role. The
items were: 1) “There is really no one who understands what you are going through”; 2) “The people close to you let you know that they care about you”; 3) “You have a friend or relative in whose opinion you have confidence”; 4) “You have someone whom you feel you can trust”; 5) “You have people around you who help keep you spirits up”; 6) “There are people in your life who make you feel good about yourself”; 7) “You have at least one friend or relative you can really confide in”; and 8) “You have at least one friend or relative you want to be with when you are feeling down or discouraged”. Item 1 is reverse coded so that all items reflect the same directionality. Cronbach alpha for social support using these eight questions in this study ($\alpha = .919$) is consistent with other studies using the same eight Medical Outcomes Study Social Support questions (Hong, 2010) and is similar to studies using all 13 questions (Sherbourne & Stewart, 1991).

Family support as a potential resource was also measured in the Informal Caregiver Survey. Previous studies conducting secondary analysis of the Informal Caregiver Survey have measured the caregiver’s perception of family support by examining the amount of agreement or disagreement concerning eight different aspects of the caregiving role and situation (Casado, 2008; Casado et al., 2011; Hong, 2010). The Family Support scale in Casado’s (2008) study had good internal reliability ($\alpha = 0.94$). The eight questions that address the aspects of family support include the following that begin with the statement “How much disagreement have you had with anyone in your family because they”: 1) Do not spend enough time with (patient name); 2) Do not do their share in caring for (patient name); 3) Do not show enough respect for (patient name); 4) Lack patience with (patient name); 5) Do not visit or telephone you enough; 6) Do not give you enough help; 7) Do not show enough appreciation of your work as a caregiver; and 8) Give you unwanted advice. The questions are measured on a 4-point Likert scale with $1 = no
disagreement and 4 = quite a bit of disagreement. Cronbach alpha for family support using these eight questions in this study ($\alpha= .931$) is consistent with other studies using the same eight questions (Casado, 2008).

**Predictor Variables.**

Empirical evidence has highlighted a potential relationship between caregiving demands and caregiver outcomes. Information regarding caregiving demands included hours per week spent providing care to the patient in a typical week (DeSalvo et al., 2005; Hong, 2010; Ingersoll-Dayton & Raschick, 2004; Kang, 2006; Kim & Schulz, 2008; Schulz & Sherwood, 2008) length of time in the caregiving role, (Hong, 2010; Kim & Schulz, 2008; Schulz & Sherwood, 2008), progression of responsibilities in the caregiving role (Hong, 2010; Ingersoll-Dayton & Raschick, 2004) and functional dependency of the patient (Casado, 2008; Casado et al., 2011; DeSalvo et al., 2005; Hong, 2010; Ingersoll-Dayton & Raschick, 2004; Kim & Schulz, 2008; Manton et al., 2008; Scharlach et al., 2006; Schulz & Sherwood, 2008; Wakefield et al., 2012). Functional dependency was based on a scale developed by the Duke University Center for Demographic Studies (Manton, Corder, & Stallard, 1993; Manton et al., 1997; Manton et al., 2008). The categories of responses ranged from does not require any help with IADLs or ADLs to requires help with 5 or 6 ADLs and up to 9 IADLs (Ingersoll-Dayton & Raschick, 2004).

**Covariates.**

Based on their theoretical and statistical relationship with the outcome and predictor variables, covariates in this study were also measured. Previous research has highlighted the potential relationship between caregiver demographic characteristics and caregiver outcomes of strain and satisfaction (Casado, 2008; Casado et al., 2011; DeSalvo et al., 2005; Hong, 2010; Hwang et al., 2011; Ingersoll-Dayton & Raschick, 2004; Kang, 2006; Kim & Schulz, 2008; Lin
et al., 2012; Lopez et al., 2005; Scharlach et al., 2006; Schulz & Sherwood, 2008; Wakefield et al., 2012). Caregiver demographic characteristics for this study included gender, race/ethnicity, relationship to the patient (spouse or non-spouse), level of education, and self-rated health. The care recipient demographic characteristics included age and self-reported health. Self-reported health of the caregiver and care recipient was assessed using one question that asks the caregivers, when compared to other people of the same age, would they rate their health as excellent, good, fair or poor. This single-item measure has been previously used and shown to correlate with objective measures of health status and mortality (Beach, Schulz, Yee & Jackson, 2000; DeSalvo, Fan, McDonell & Fihn, 2005; Schulz et al., 1994; Silliman, 1993; Wakefield, Hayes, Boren, Pak & Davis, 2012). See Table 3.3 for further details on the study’s variables.

**Protection for Study Participants**

This study is a secondary analysis of an existing dataset. The data from the original study was recorded using anonymous identifiers to protect the confidentiality of the participants; therefore it is eligible for exemption under the DHHS human subject regulations. Specifically, Category 4, research involving existing data, applies as the data was provided for the study with no identifying information being attached to the participants. For the purposes of this study, no further contact with participants was required. As such, The Penn State Office of Research Protection has declared the study exempt as it has been classified as Non-Human/Non-Research and does not meet the definition of “human participant research”. (See Appendix A).

**Data Analysis**

Statistical analysis for this study was conducted using SPSS 22.0 software. Before beginning the data analysis, data recoding and screening were completed. The data was assessed for influential outliers, missing data and departures from distributional normality such as
univariate skewness or kurtosis. No influential outliers were identified. All the variables fell within ±1 for skewness and kurtosis with the following exceptions: ADLs performed, perception of resource adequacy, caregiver satisfaction and caregiver strain (Global). These variables did fall within ±2 which is acceptable in large sample sizes (George & Mallery, 2007). The family support variable did exceed the ±2 (2.39 for skewness and 5.55 for kurtosis). This variable was not transformed again due to the large sample size.

The amount and pattern of the missing data was also assessed. For those variables that had less than 2% missing cases, listwise deletion was used (Graham, 2009; Kline, 2011). Listwise deletion is an acceptable procedure for handling missing data if the cases are small as biases and loss of power are thought to be inconsequential (Graham, 2009). Variables using listwise deletion included the predictor variables and the covariates. For missing data that had more than 2%, (Kline, 2011), or were developed scales (Graham, 2009) the patterns of missingness were assessed to determine if the data was missing at random or missing not at random. Multiple imputation was used to estimate the missing data values as this has been shown yield reasonably unbiased b-weights in multiple regression and is an acceptable way of reducing the errors of estimated parameters (Graham, Cumsille, & Shevock, 2013) and has been shown to be robust in departures from normality assumptions and provides unbiased results with high rates of missing data (Graham, 2009).

In assessing the pattern of missingness for the imputed variables, resource utilization, caregiver satisfaction, caregiver strain (MCSI) and caregiver strain (global) were found to be missing completely at random (MCAR). Social Support, family support and formal resource adequacy were found to be missing not at random (MNAR). These three variables had a skip pattern which resulted in missing data but it may not necessarily have been MNAR but more
likely missing at random (MAR) (Schafer & Graham, 2002). There has been some debate regarding using multiple imputation for MNAR variables. In their work on the state of art on missing data, Schafer and Graham (2002) argue that multiple imputation may be used with MNAR and argue that “nothing in the theory of MI requires us to keep the MAR assumptions” (p. 170). There are however, procedures for decreasing the estimation bias for the MNAR variables. Covariates were kept in each of the models to add variance to the imputation models (Graham et al., 2013). Scales for the imputed variables were used and this solution allows for the estimation of the scale score based on the variables that were observed (Graham et al., 2013). In large sample sizes, MNAR imputated variables are also less susceptible to departures from the assumptions of MCAR (Graham, 2009, Graham et al., 2013) which was the case in this study.

Upon completion of the data coding and screening preliminary, data analysis commenced. During preliminary data analysis descriptive statistics, such as means, standard deviations, and frequency distributions were computed to assess the overall sample characteristics.

To examine research question 1 A. (Are differences in caregiving demands related to resource utilization by family caregivers?) and 1 B. (Are differences in caregiving demands related to family caregivers’ perceptions of resource adequacy?) and determine the strength of the associations between caregiving demands and resources bivariate analysis using Pearson’s correlation coefficient was used (Field, 2009).

To examine research question two (Are caregiver demands related to the outcomes of caregiver strain and satisfaction?) hierarchical regression models were built based on the bivariate analysis. Hierarchical multivariate regression was chosen as it allows for variables to be added into the model in a sequential order based upon their importance in predicting the
outcome variable (Field, 2009). It also allows for the examination of multiple predictors while controlling for covariates (Tabachnick & Fidell, 2007). The association between caregiving demands and caregiver outcomes was adjusted for potential confounding variables by including the identified covariates. Each of the caregiver outcomes (strain and satisfaction) were tested separately in the model. The equations for research question 2 were as follow:

\[ Y_1 = [b_0 + b_1(\text{hours}) + b_2(\text{length}) + b_3(\text{progression}) + b_4(\text{ADLs performed}) + b_5(\text{IADLs performed})] + e \]

Where:

\[ Y_1 = \text{Caregiver strain} \]
\[ b_0 = \text{Mean of caregiver strain} \]
\[ b_1 = \text{Hours spent per week providing care} \]
\[ b_2 = \text{Length of time in caregiving role} \]
\[ b_3 = \text{Progression of responsibilities in the caregiving role} \]
\[ b_4 = \text{Number of ADLs performed} \]
\[ b_5 = \text{Number of IADLs performed} \]
\[ e = \text{error} \]

\[ Y_2 = [b_0 + b_1(\text{hours}) + b_2(\text{length}) + b_3(\text{progression}) + b_4(\text{ADLs performed}) + b_5(\text{IADLs performed})] + e \]

Where:

\[ Y_2 = \text{Caregiver satisfaction} \]
\[ b_0 = \text{Mean of caregiver satisfaction} \]
\[ b_1 = \text{Hours spent per week providing care} \]
\[ b_2 = \text{Length of time in caregiving role} \]
To test the moderating effects of resources on the relationship between caregiving demands and caregiver outcomes (Research question 3A: Does resource utilization moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction? And 3B: Do family caregivers’ perceptions of resource adequacy moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction?) hierarchical models with moderation were built. To examine the potential moderating effects of resource utilization and perception of resource adequacy on caregiver outcomes, steps outlined by Baron and Kenny (1986), Aiken and West (1991) and Jose (2013) were followed. That is, the main effects between caregiving demands and caregiver outcomes as well as the main effects between resource utilization and caregiver outcomes were assessed. Additionally, the interaction effects between caregiving demands and resource utilization (caregiving demands X resource utilization) on caregiver outcomes were assessed to highlight any moderating effects of resource utilization. The same steps outlined for assessing the moderating effect of resource utilization were used to examine the moderating effects of perceived resource adequacy for social support, family support and formal resources. The equations for research question 3 A&B are as follows:

**Question 3A: Resource Utilization**

**Equation 1:** \( Y_1 = [b_0 + b_1(\text{caregiving demands}) + b_2(\text{resource utilization}) + b_3(\text{caregiving demands} \times \text{resource utilization})] + e \)
Where:

\[ Y_1 = \text{Caregiver strain} \]
\[ b_0 = \text{Mean of caregiver strain} \]
\[ b_1 = \text{Caregiving demands} \]
\[ b_2 = \text{Resource utilization} \]
\[ b_3 = \text{Interaction term of caregiving demands X resource utilization} \]
\[ e = \text{error} \]

Equation 2: \[ Y_1 = [b_0 + b_1(\text{caregiver demands}) + b_2(\text{resource utilization}) + b_3(\text{caregiver demands X resource utilization})] + e \]

Where:

\[ Y_2 = \text{Caregiver satisfaction} \]
\[ b_0 = \text{Mean of caregiver satisfaction} \]
\[ b_1 = \text{Caregiver Demands} \]
\[ b_2 = \text{Resource Utilization} \]
\[ b_3 = \text{Interaction term of caregiver demands X resource utilization} \]
\[ e = \text{error} \]

Question 3B: Perception of Resource Adequacy for Social Support, Family Support and Formal Resources. For this question each of the three perceptions were examined separately using the equations 3 and 4.

Equation 3: \[ Y_1 = [b_0 + b_1(\text{caregiving demands}) + b_2(\text{perception of resource adequacy}) + b_3(\text{caregiving demands X perception of resource adequacy})] + e \]

Where:

\[ Y_1 = \text{Caregiver strain} \]
\( b_0 = \text{Mean of caregiver strain} \)

\( b_1 = \text{Caregiving demands} \)

\( b_2 = \text{Perception of resource adequacy} \)

\( b_3 = \text{Interaction term of caregiving demands} \times \text{perception of resource adequacy} \)

\( e = \text{error} \)

Equation 4: \( Y_2 = [b_0 + b_1(\text{caregiving demands}) + b_2(\text{perception of resource adequacy}) + b_3(\text{caregiving demands} \times \text{perception of resource adequacy})] + e \)

Where:

\( Y_2 = \text{Caregiver satisfaction} \)

\( b_0 = \text{Mean of caregiver satisfaction} \)

\( b_1 = \text{Caregiving demands} \)

\( b_2 = \text{Perception of resource adequacy} \)

\( b_3 = \text{Interaction term of caregiving demands} \times \text{perception of resource adequacy} \)

\( e = \text{error} \)

**Chapter Summary**

This chapter has provided an overview of the methodology used in this study. The chapter began with an overview of the dataset that was analyzed. To address the steps to take when completing a secondary analysis on an existing dataset, the procedure for the original NLTC Survey and the Informal Caregiver Survey was outlined and details provided on the data collection methods and survey design. This was followed by a discussion on the measures for the outcome and predictor variables as well as the covariates. Reliability measures for each of the scales in the study were discussed. Based on the type of variables and the research questions to be answered, a data analysis plan was formulated using both bivariate and hierarchical
regression with moderation analysis techniques. The comprehensiveness of the Informal Caregiver Survey made this a relevant source for understanding how resource utilization and perception of resource adequacy impact this critical role.
Chapter IV

Results

Sample Characteristics

As previously discussed, 1,923 family caregivers of community dwelling older adults participated in the Informal Caregiver Survey. Descriptive statistics for the baseline variables of the family caregiver are shown in Table 4.1. For this sample, 66% were female and 32.3% were the spouse of the older adult receiving care. The majority of the participants were white (80.8%) and well-educated (47.3% had greater than a high-school education). For self-rated health, 73.3% of the family caregivers considered their health either good or excellent. Descriptive statistics for the baseline variables of the older adult care recipients are shown in Table 4.2. The older adult care recipients had a mean age of 80, with 46.7% being 85 or older. For the older adults, 49.9% considered their health good or excellent.

Sixty-three percent of the family caregivers provided between 0-20 hours of care per week, 51.3% had provided care for 4 years or more and 51.3% of the participants were providing more care than they had initially. Descriptive statistics for the baseline variables of the caregiving demands are shown in Table 4.3.
Table 4.1 Baseline Characteristics for Family Caregiver

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>%</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>34</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>66</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Relationship to Older Adult</td>
<td>Non-spouse</td>
<td>67.7</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td>Spouse</td>
<td>32.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>White</td>
<td>80.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Black</td>
<td>9.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Hispanic/Latino</td>
<td>6.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>1 = Less than High School</td>
<td>20.2</td>
<td>2.27</td>
<td>.776</td>
</tr>
<tr>
<td></td>
<td>2 = High School</td>
<td>32.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = More than High School</td>
<td>47.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min= 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Max = 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Self-rated Health</td>
<td>1 = Poor</td>
<td>5.8</td>
<td>2.93</td>
<td>.829</td>
</tr>
<tr>
<td></td>
<td>2 = Fair</td>
<td>20.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = Good</td>
<td>48.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 = Excellent</td>
<td>25.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min = 1 (poor)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Max = 4 (excellent)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.2 Baseline Characteristics for Older Adult Care Recipient

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>%</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adult Self-rated Health</td>
<td>1 = Poor</td>
<td>17.1</td>
<td>2.47</td>
<td>.932</td>
</tr>
<tr>
<td></td>
<td>2 = Fair</td>
<td>32.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = Good</td>
<td>36.1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4 = Excellent</td>
<td>13.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min = 1 (poor)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Max = 4 (excellent)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Older Adult</td>
<td>1 = 65-74</td>
<td>22.0</td>
<td>80</td>
<td>1.91</td>
</tr>
<tr>
<td></td>
<td>2 = 75-84</td>
<td>31.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 = 85 and older</td>
<td>46.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min =65</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Max = 107</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The majority of the family caregivers helped with one or more activities of daily living (ADLs) and between 4 to 5 instrumental activities of daily living (IADLs). The most commonly performed ADL was assisting the older adult with taking medication followed by assistance with getting dressed. The most commonly performed IADLs were helping with grocery shopping and doing small errands. Details for assistance with ADLs and IADLs are shown in Table 4.4.
Table 4.4 Assistance with ADLs and IADLs

<table>
<thead>
<tr>
<th>ADL</th>
<th>% Assisted with ADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with taking medications</td>
<td>36.2</td>
</tr>
<tr>
<td>Help with getting dressed</td>
<td>26.9</td>
</tr>
<tr>
<td>Help with walking</td>
<td>26.1</td>
</tr>
<tr>
<td>Help with bathing</td>
<td>25.6</td>
</tr>
<tr>
<td>Help with getting in or out of bed</td>
<td>20.2</td>
</tr>
<tr>
<td>Help with eating</td>
<td>11.9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IADL</th>
<th>% Assisted with IADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help with grocery shopping</td>
<td>71.7</td>
</tr>
<tr>
<td>Help with doing small errands</td>
<td>70.7</td>
</tr>
<tr>
<td>Helping around the house</td>
<td>62.0</td>
</tr>
<tr>
<td>Help with getting around the neighborhood</td>
<td>57.7</td>
</tr>
<tr>
<td>Help with doing laundry</td>
<td>56.7</td>
</tr>
<tr>
<td>Help with managing finances</td>
<td>46.4</td>
</tr>
<tr>
<td>Help with getting outside</td>
<td>41.9</td>
</tr>
<tr>
<td>Help with making telephone calls</td>
<td>33.1</td>
</tr>
<tr>
<td>Help with preparing special food</td>
<td>30.4</td>
</tr>
</tbody>
</table>

In this study, 10 formal resources were assessed for utilization with the most commonly used formal resource being assistive devices, such as wheelchairs and walkers (54.7%) and the least utilized resource being Adult Day Care or Senior Centers (4.2%). See Table 4.5 for details on the utilization of the study’s 10 formal resources.

Table 4.5 Resource Utilization of 10 Formal Resources

<table>
<thead>
<tr>
<th>Formal Resource</th>
<th>% Utilized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assistive devices such as wheelchairs or walkers</td>
<td>54.7</td>
</tr>
<tr>
<td>Personal Care or Nursing Care</td>
<td>28.7</td>
</tr>
<tr>
<td>Household modifications</td>
<td>27.3</td>
</tr>
<tr>
<td>Outside housework services</td>
<td>18.1</td>
</tr>
<tr>
<td>Meal delivery services</td>
<td>12.1</td>
</tr>
<tr>
<td>Transportation provided by an outside service</td>
<td>10.9</td>
</tr>
<tr>
<td>Information on financial assistance</td>
<td>10.8</td>
</tr>
<tr>
<td>Respite Care</td>
<td>8.9</td>
</tr>
<tr>
<td>Attended family caregiver support groups</td>
<td>4.7</td>
</tr>
<tr>
<td>Outside programs such as Adult Day Care or Senior Centers</td>
<td>4.2</td>
</tr>
</tbody>
</table>
Data Analysis

This study examined if resources, both utilization and the perception of their adequacy, moderated the relationship between caregiving demands and outcomes in the caregiving role. The first step in the analysis assessed if the data met the statistical assumption of normality. All the variables fell within ±1 for skewness and kurtosis with the following exceptions: number of ADLs performed, perception of resource adequacy, caregiver satisfaction and caregiver strain (global). These variables fell within ±2 which is acceptable in large sample sizes (George & Mallery, 2007). The family support variable exceeded the ±2 (2.39 for skewness and 5.55 for kurtosis). This variable was not transformed as due to the large sample size, the data can be assumed to be normally distributed as a consequence of the central limit theorem (Field, 2009).

For those variables that had less that 2% missing cases, listwise deletion was used (Graham, 2009; Kline, 2011). Listwise deletion is an acceptable procedure for handling missing data if the cases are small as biases and loss of power are thought to be inconsequential (Graham, 2009). Variables using listwise deletion included the predictor variables and the covariates. For missing data that had more than 2%, (Kline, 2011), or were developed scales (Graham, 2009) the patterns of missingness were assessed to determine if the data was missing at random or missing not at random. See Table 4.6 for a list of variables that used either listwise deletion or multiple imputation. When using listwise deletion and multiple imputation, the final sample size was 1,760.

In assessing the pattern of missingness for the imputed variables, resource utilization, caregiver satisfaction, caregiver strain (MCSI) and caregiver strain (global) were found to be missing completely at random (MCAR). Social Support, family support and formal resource adequacy were found to be missing not at random (MNAR). These three variables had a skip
pattern which resulted in missing data but it may not necessarily have been MNAR but rather missing at random (MAR) (Schafer & Graham, 2002).

There is debate regarding using multiple imputation for MNAR variables. In their work on the state of art on missing data, Schafer and Graham (2002) argue that multiple imputation may be used with MNAR and state that “nothing in the theory of MI requires us to keep the MAR assumptions” (p. 170). There are however, procedures for decreasing the estimation bias for the MNAR variables. Covariates were kept in each of the models to add variance to the imputation models (Graham et al., 2013). Scales for the imputed variables were used and this solution allowed for the estimation of the scale score based on the variables that were observed (Graham et al., 2013). In large sample sizes, MNAR imputed variables are also less susceptible to departures from the assumptions of MCAR (Graham, 2009, Graham et al., 2013) which was the case in this study.

<table>
<thead>
<tr>
<th>Table 4.6 Methods Used for Missing Data</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Listwise Deletion</strong></td>
<td><strong>Multiple Imputation</strong></td>
</tr>
<tr>
<td>Gender</td>
<td>Resource utilization</td>
</tr>
<tr>
<td>Relationship to the older adult</td>
<td>Social support</td>
</tr>
<tr>
<td>Race</td>
<td>Family support</td>
</tr>
<tr>
<td>Educational level</td>
<td>Adequacy of formal resources</td>
</tr>
<tr>
<td>Caregiver’s self-rated health</td>
<td>Caregiver satisfaction</td>
</tr>
<tr>
<td>Older adult’s self-rated health</td>
<td>Caregiver strain (MCSI)</td>
</tr>
<tr>
<td>Age of the older adult</td>
<td>Caregiver strain (Global)</td>
</tr>
<tr>
<td>Hours of caregiving</td>
<td></td>
</tr>
<tr>
<td>Length of time in caregiving role</td>
<td></td>
</tr>
<tr>
<td>Progression of caregiving responsibilities</td>
<td></td>
</tr>
<tr>
<td>Number of ADLs performed</td>
<td></td>
</tr>
<tr>
<td>Number of IADLs performed</td>
<td></td>
</tr>
</tbody>
</table>
The findings are presented according to each of the research questions.

*Question 1 A: Are caregiving demands associated with resource utilization by family caregivers?*

Response scales for caregiving demands variables are shown in Table 4.3. Bivariate correlation was used to assess the association between the caregiving demands (hours spent caregiving, length of time in the caregiving role, progression of responsibilities, ADLs performed and IADLs performed) and resource utilization of the 10 formal resources. Table 4.7 provides a summary of the associations. To avoid an inflated Type I error, a Bonferroni correction was calculated, and the alpha level for significance was set at \( p \leq .01 \) (Taylor, 2010). Resource utilization was positively correlated with each of the caregiving demand variables, indicating that high levels of resource utilization for the 10 formal resources were associated with high levels of caregiving demands. The strongest association for resource utilization was with the number of ADLs (\( r = .293, p \leq .001 \)) and IADLs (\( r = .259, p \leq .001 \)) performed. This indicates that as caregiving demands (particularly number of ADLs and IADLs performed) increase so does the amount of formal resources utilized.

**Table 4.7** Means, Standard Deviations and Zero-Order Correlations for Caregiving Demands and Formal Resource Utilization

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hours of Caregiving</td>
<td>1.50</td>
<td>.781</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2. Length of Caregiving</td>
<td>3.07</td>
<td>1.12</td>
<td>.048</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Progression of Caregiving</td>
<td>2.41</td>
<td>.673</td>
<td>.219**</td>
<td>.146**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. ADLs Performed</td>
<td>1.44</td>
<td>1.86</td>
<td>.557**</td>
<td>.032</td>
<td>.204**</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. IADLs Performed</td>
<td>4.70</td>
<td>2.67</td>
<td>.473**</td>
<td>.079**</td>
<td>.288**</td>
<td>.532**</td>
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</tr>
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<td>6. Resource Utilization</td>
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<td>.293**</td>
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** p \leq .001 \quad N=1864
Question 1 B: Are caregiving demands associated with family caregivers’ perceptions of resource adequacy (for social support, family support and formal resources)?

Bivariate correlation was also used to explore the association between caregiving demands and the perception of resource adequacy. To avoid an inflated Type I error, a Bonferroni correction was calculated, and the alpha level for significance was set at $p \leq .01$ (Taylor, 2010). Table 4.8 provides a summary of these associations. Caregiving demands did not have a significant association with social support. For the perception of family support, there were significant positive associations for each of the caregiving demand variables with the exception of length of caregiving which did not have a significant association.

The strongest associations between caregiving demands and family support were for progression of caregiving demands ($r=.122$, $p \leq .001$) and for the number of ADLs ($r=.122$, $p \leq .001$) and number of IADLs ($r=.120$, $p \leq .001$) performed. An important point here is the response scale for family support (1 = no disagreement between family members and 4 = quite a bit of disagreement). Therefore, a positive correlation between caregiving demands and family support indicates that higher levels of caregiving demands were associated with higher levels of family disagreement or conflict. Overall, this indicates that as caregiving demands increase so does family conflict. Caregiving demands did not have a significant association with perception of formal resource adequacy.
Table 4.8 Means, Standard Deviations and Zero-Order Correlations for Caregiving Demands and Perception of Resource Adequacy

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>1</th>
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<th>5</th>
<th>6</th>
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<th>8</th>
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<tbody>
<tr>
<td>1. Hours of Caregiving</td>
<td>1.50</td>
<td>.781</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>2. Length of Caregiving</td>
<td>3.07</td>
<td>1.12</td>
<td>.048</td>
<td>1.00</td>
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<td></td>
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</tr>
<tr>
<td>3. Progression of Caregiving</td>
<td>2.41</td>
<td>.673</td>
<td>.219**</td>
<td>.146**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. ADLs Performed</td>
<td>1.44</td>
<td>1.86</td>
<td>.557**</td>
<td>.032</td>
<td>.204**</td>
<td>1.00</td>
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<td></td>
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</tr>
<tr>
<td>5. IADLs Performed</td>
<td>4.70</td>
<td>2.67</td>
<td>.473**</td>
<td>.079**</td>
<td>.288**</td>
<td>.532**</td>
<td>1.00</td>
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<td>8. Perception of Formal Resources</td>
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<td>.059**</td>
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</table>

** p ≤ .001 N=1865

Question 2: Are caregiving demands associated with the outcomes of caregiver strain and satisfaction?

Table 4.19 at the end of this chapter provides an overall summary for all the relationships examined in research questions two and three. To answer research question two, hierarchical multiple regression was used to examine the relationships between caregiving demands (hours of caregiving, length of time in caregiving role, progression of caregiving responsibilities, number of ADLs and IADLs performed) and caregiver outcomes (satisfaction and strain). This type of regression was used as it allows for variables to be added into the model in a sequential order (Field, 2009) and allows for the examination of multiple predictors while controlling for covariates (Tabachnick & Fidell, 2007). Zero-order correlations, sample means, standard deviations, and internal consistency alphas (that were calculated for each scale used in the analysis) for caregiving demands and outcomes are presented in Table 4.9.
Table 4.9 Means, Standard Deviations, Alphas and Zero-Order Correlations for Caregiving Demands and Caregiver Outcomes

<table>
<thead>
<tr>
<th>Variable</th>
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<th>6</th>
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<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Hours of Caregiving</td>
<td>1.50</td>
<td>.781</td>
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<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Length of Caregiving</td>
<td>3.07</td>
<td>1.12</td>
<td>--</td>
<td>.048</td>
<td>1.00</td>
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<tr>
<td>3. Progression of Caregiving</td>
<td>2.41</td>
<td>.673</td>
<td>--</td>
<td>.219**</td>
<td>.146**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. ADLs Performed</td>
<td>1.44</td>
<td>1.86</td>
<td>--</td>
<td>.557**</td>
<td>.032</td>
<td>.204**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. IADLs Performed</td>
<td>4.70</td>
<td>2.67</td>
<td>--</td>
<td>.473**</td>
<td>.079**</td>
<td>.288**</td>
<td>.532**</td>
<td>1.00</td>
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<td></td>
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</tr>
<tr>
<td>6. Satisfaction</td>
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<td>.916</td>
<td>0.777</td>
<td>.003</td>
<td>-.005</td>
<td>.004</td>
<td>.020</td>
<td>.019</td>
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<td></td>
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<tr>
<td>7. Strain (Modified CSI)</td>
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<td>.092**</td>
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<td>.446**</td>
<td>.443**</td>
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<tr>
<td>8. Strain</td>
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<td>.128**</td>
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<td>.434**</td>
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<td>.718**</td>
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</table>

** p ≤ .001  N=1865

Three models were used to examine each of the outcomes variables. Model 1 used caregiver satisfaction as the outcome variable. Model 2 used caregiver strain (the modified caregiver strain index subscale or (MCSI)) as the outcome variable. Model 3 used caregiver strain (global) as the outcome variable. Each of the three models will be presented in turn, starting with Model 1.

Model 1: Caregiving Demands and Caregiver Satisfaction

Using Model 1, it was investigated how well caregiving demands account for caregiver satisfaction scores while controlling for the covariates. Block 1 in the hierarchal multiple regression model consisted of the covariates (gender, relationship to the older adult (spouse vs. non-spouse), race, educational level, caregiver’s self-rated health, older adult’s self-rated health and age of the older adult). Block 2 consisted of the caregiving demands (hours of caregiving, length of time in caregiving role, progression of caregiving responsibilities, number of ADLs and IADLs performed). Collinearity statistics show that no variables in Model 1 for caregiver satisfaction have a variance inflation factor (VIF) score greater than 2 or tolerance below .50,
therefore multicollinearity among the independent variables was not an issue (Field, 2009; Tabachnick & Fidell, 2007). The Durbin-Watson test for the final model was 2.03 indicating there was no serial correlation between the errors, the errors are independent of one another (Field, 2009). When the control variables were entered alone, they significantly accounted for caregiver satisfaction, \( F(7,1754) = 3.79, p = .001, \) adjusted \( R^2 = .011. \) However, as indicated by adjusted \( R^2 \) only 1.1% of the variance in caregiver satisfaction was accounted for by the covariates. When the caregiving demand variables were added, they did not significantly improve the prediction for caregiver satisfaction. In the final model, the entire set of variables significantly accounted for caregiver satisfaction, \( F(12,1749) = 2.30, p < .01, \) adjusted \( R^2 = .009. \) However, according to Cohen (1988) this is a small effect. The beta weights are presented in Table 4.10 and show, relationship to the older adult care recipient (\( \beta = -.095, p < .001 \)) and caregivers self-rated health (\( \beta = .061, p < .01 \)) significantly accounted for the variance in caregiver satisfaction while the caregiving demand variables did not significantly account for caregiver satisfaction in Model 1.

**Table 4.10** Model 1 - Hierarchical Multiple Regression Results of Caregiver Satisfaction Regressed on Caregiving Demands Controlling for Covariates (N=1762)

<table>
<thead>
<tr>
<th>Variable</th>
<th>b</th>
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<th>Beta</th>
<th>t</th>
<th>p</th>
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<td></td>
<td></td>
<td></td>
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<td>.034</td>
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<td>.061</td>
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<td>.012</td>
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Step 2

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<th>Race</th>
<th>Educational Level</th>
<th>Caregiver’s Self-Rated Health</th>
<th>Older Adult’s Self-Rated Health</th>
<th>Older Adult’s Age</th>
<th>Hours of Caregiving</th>
<th>Length of Caregiving</th>
<th>Progression of Caregiving</th>
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<td>-.004</td>
<td>-.010</td>
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<td>-.003</td>
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<td>-.004</td>
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Summary information for Model 1.

F= 2.30  
Multiple R=.125  
df=12, 1749  
R Square=.016  
p < .01  
Adj. R Square=.009

**Model 2: Caregiving Demands and Caregiver Strain (MCSI)**

Using Model 2, it was investigated how well caregiving demands account for caregiver strain (MCSI) scores while controlling for the covariates. Block 1 in the hierarchal multiple regression model consisted of the covariates (gender, relationship to the older adult (spouse vs. non-spouse), race, educational level, caregiver’s self-rated health, older adult’s self-rated health and age of the older adult). Block 2 consisted of the caregiving demands (hours of caregiving, length of time in caregiving role, progression of caregiving responsibilities, number of ADLs and IADLs performed). Collinearity statistics showed that no variables in Model 2 for caregiver strain (MCSI scale) have a variance inflation factor (VIF) score greater than 2 or tolerance below
.50, therefore multicollinearity among the independent variables was not an issue (Field, 2009; Tabachnick & Fidell, 2007).

The Durbin-Watson test for the final model was 1.98 indicating there was no serial correlation between the errors, that is the errors are independent of one another (Field, 2009). When the control variables were entered alone, they significantly accounted for caregiver strain (MCSI scale), \(F(7,1754) = 20.001, p < .001\), adjusted \(R^2 = .07\). However, as indicated by adjusted \(R^2\) only 7% of the variance in caregiver strain (MCSI) was accounted for by the covariates. When the caregiving demand variables were added, they significantly improved the prediction of caregiver strain (MCSI), \(R^2\) change = .26, \(F(5,1749) = 136.005, p < .001\). In the final model, the entire set of variables significantly accounted for caregiver strain (MCSI), \(F(12,1749) = 72.826, p < .001\), adjusted \(R^2 = .333\). According to Cohen (1988) this is a medium effect size. The beta weights are presented in Table 4.11 and show that when entered with the control variables, number of ADLs performed (\(\beta = .208, p < .001\)), number of IADLs performed (\(\beta = .196, p < .001\)) and hours of caregiving (\(\beta = .196, p < .001\)) contributed the most in accounting for caregiver strain. All the caregiving demands variables significantly contributed to the model indicating that as the demands of caregiving increase, so too does caregiver strain.

**Table 4.11** Model 2 - Hierarchical Multiple Regression Results of Caregiver Strain (MCSI Scale) Regressed on Caregiving Demands Controlling for Covariates (N=1762)

<table>
<thead>
<tr>
<th>Variable</th>
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<th>SE b</th>
<th>Beta</th>
<th>t</th>
<th>p</th>
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<td>.005</td>
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</table>
### Older Adult’s Self-Rated Health

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<th>Standard Error</th>
<th>t-value</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
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<td>.056</td>
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<td>-4.986</td>
</tr>
<tr>
<td>Older Adult’s Age</td>
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<td>.069</td>
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### Step 2

<table>
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<tr>
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<td>.056</td>
<td>.116</td>
<td>5.658</td>
</tr>
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<td>-5.466</td>
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<td>IADLs Performed</td>
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</table>

**Summary information for the Model 2:**

- **F** = 72.826
- Multiple **R** = .577
- df = 12, 1749
- **R Square** = .333
- p < .001
- Adj. **R Square** = .329

**Model 3: Caregiving Demands and Caregiver Strain (Global)**

Using Model 3, it was investigated how well caregiver demands account for caregiver strain (global) scores while controlling for the covariates. Block 1 in the hierarchal multiple regression model consisted of the covariates (gender, relationship to the older adult (spouse vs. non-spouse), race, educational level, caregiver’s self-rated health, older adult’s self-rated health and age of the older adult). Block 2 consisted of the caregiving demands (hours of caregiving,
length of time in caregiving role, progression of caregiving responsibilities, number of ADLs and IADLs performed). Collinearity statistics show that no variables in Model 3 for caregiver strain (global) have a variance inflation factor (VIF) score greater than 2 or tolerance below .50, therefore multicollinearity among the independent variables was not an issue (Field, 2009; Tabachnick & Fidell, 2007). The Durbin-Watson test for the final model was 2.02 indicating there was no serial correlation between the errors, that is the errors are independent of one another (Field, 2009). When the control variables were entered alone, they significantly accounted for caregiver strain (global), $F(7,1754) = 26.061$, $p < .001$, adjusted $R^2 = .091$. However, as indicated by adjusted $R^2$ only 9.1% of the variance in caregiver strain (global) was accounted for by the covariates. When the caregiving demand variables were added, they significantly improved the prediction, $R^2$ change = .188, $F(5,1749) = 91.645$, $p < .001$. In the final model, the entire set of variables significantly accounted for caregiver strain (global), $F(12,1749) = 57.315$, $p < .001$, adjusted $R^2 = .277$. According to Cohen (1988) this is a medium effect size. The beta weights are presented in Table 4.12 and suggest that when entered with the control variables, number of ADLs performed ($\beta = .251$, $p < .001$) and number of IADLs performed ($\beta = .134$, $p < .001$) along with hours spent caregiving ($\beta = .107$, $p < .001$) contributed the most to accounting for caregiver strain (global). In Model 3, all the caregiving demands variables significantly contributed to the model indicating that as the demands of caregiving increase, so does caregiver strain (global).

Table 4.12 Model 3 - Hierarchical Multiple Regression Results of Caregiver Strain (Global Scale) Regressed on Caregiving Demands Controlling for Covariates ($N=1762$)

<table>
<thead>
<tr>
<th>Variable</th>
<th>$b$</th>
<th>SE $b$</th>
<th>Beta</th>
<th>$t$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>.152</td>
<td>.049</td>
<td>.071</td>
<td>3.099</td>
<td>.002</td>
</tr>
<tr>
<td>Relationship to Older Adult</td>
<td>.081</td>
<td>.054</td>
<td>.038</td>
<td>1.515</td>
<td>.130</td>
</tr>
</tbody>
</table>
Race | .134  | .032  | .098  | 4.251 | .000  
Educational Level | .116  | .031  | .089  | 3.753 | .000  
Caregiver’s Self-Rated Health | -.268 | .028  | -.221 | -9.472 | .000  
Older Adult’s Self-Rated Health | -.167 | .026  | -.153 | -6.318 | .000  
Older Adult’s Age | .066  | .032  | .052  | 2.036 | .042  
Constant | 2.121 | .193  | 10.980 | .000  

Step 2

Gender | .063  | .044  | .030  | 1.433 | .152  
Relationship to Older Adult | -.033 | .048  | -.015 | -.674 | .501  
Race | .037  | .028  | .027  | 1.298 | .195  
Educational Level | .092  | .028  | .071  | 3.337 | .001  
Caregiver’s Self-Rated Health | -.207 | .025  | -.171 | -8.157 | .000  
Older Adult’s Self-Rated Health | -.087 | .024  | -.080 | -3.626 | .000  
Older Adult’s Age | .012  | .029  | .009  | .412  | .680  
Hours of Caregiving | .140  | .033  | .107  | 4.188 | .000  
Length of Caregiving | .074  | .019  | .082  | 4.000 | .000  
Progression of Caregiving | .104  | .032  | .070  | 3.248 | .001  
ADLs Performed | .136  | .015  | .251  | 9.366 | .000  
IADLs Performed | .051  | .010  | .134  | 5.282 | .000  
Constant | 1.213 | .194  | 6.259 | .000  

Summary information for Model 3:

F= 57.315  Multiple R=.531
df=12, 1749  R Square=.282
p < .001  Adj. R Square=.277

To address Question 2: “Are caregiving demands associated with the outcomes of caregiver strain and satisfaction?” caregiving satisfaction did not have a significant relationship with caregiving demands however, caregiver strain had a significant positive association. To summarize the three models, for Model 1 examining the relationship between caregiving...
demands and caregiver satisfaction, demands were not significantly related to caregiver satisfaction. In Model 2, caregiving demands significantly accounted for variance in the caregiver strain (MCSI) outcome variable, suggesting that as caregiving demands increase so do levels of caregiver strain. In Model 3, caregiving demands also significantly accounted for variance in the caregiver strain (global) outcomes variable, again showing that as caregiving demands increase so do levels of caregiver strain.

**Resource Utilization**

*Question 3 A: Does resource utilization moderate the association between caregiver demands and the outcomes of caregiver strain and satisfaction?*

To answer research question 3 A, hierarchical multiple regression with moderation was used to examine if resource utilization moderates the relationship between caregiving demands and caregiver outcomes (satisfaction and strain). Steps outlined by Baron and Kenney (1986), Aiken and West (1991) and Jose (2013) were used in building the regression models. Block 1 in the hierarchal regression model consisted of the covariates (gender, relationship to the older adult (spouse vs. non-spouse), race, educational level, caregiver’s self-rated health, older adult’s self-rated health and age of the older adult). Block 2 consisted of the caregiving demands. Block 3 consisted of the resource utilization variable (this variable was the total of resources used and ranged from 0 to 10 resources used). Following the suggestion of Aiken and West (1991) the two main effect variables (caregiving demands and resource utilization) were mean centered before the interaction effect was computed. To examine the moderation effect of resource utilization, Block 4 consisted of the interaction term of caregiving demands X resource utilization. The same steps were used for each of the three models in this question.
Zero-order correlations, sample means, standard deviations, and internal consistency alphas for resource utilization and perception of resource adequacy (social support, family support and formal resource adequacy) and outcomes are presented in Table 4.13. For all the models in Questions 3 A, collinearity statistics showed that no variables in the hierarchical multiple regression models had a variance inflation factor (VIF) score greater than 2 or tolerance below .70, therefore multicollinearity among the independent variables was not an issue (Field, 2009; Tabachnick & Fidell, 2007). The Durbin-Watson test for the models ranged from 1.98 to 2.05 indicating the errors are independent of one another (Field, 2009).

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SD</th>
<th>α</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Social Support</td>
<td>3.16</td>
<td>.649</td>
<td>.919</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Family Support</td>
<td>1.32</td>
<td>.612</td>
<td>.931</td>
<td>-.045</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Formal Resource Utilization</td>
<td>1.8</td>
<td>1.66</td>
<td>--</td>
<td>.038</td>
<td>.196**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Perception of Resource Adequacy</td>
<td>2.6</td>
<td>.486</td>
<td>--</td>
<td>.059**</td>
<td>-.049*</td>
<td>.087**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Satisfaction</td>
<td>4.28</td>
<td>.916</td>
<td>.777</td>
<td>.147**</td>
<td>.028</td>
<td>.008</td>
<td>.005</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Strain (Modified CSI)</td>
<td>1.77</td>
<td>2.10</td>
<td>.825</td>
<td>-.049*</td>
<td>.322**</td>
<td>.366**</td>
<td>-.102**</td>
<td>-.073**</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>7. Strain</td>
<td>1.86</td>
<td>.100</td>
<td>.782</td>
<td>-.094*</td>
<td>.324**</td>
<td>.325**</td>
<td>-.005**</td>
<td>-.108**</td>
<td>.718**</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* p ≤ .05    ** p ≤ .01   N=1907

In examining the moderation effects of resource utilization on caregiving demands and caregiver outcomes, three models were used to examine each of the outcomes variables. Model 1 used caregiver satisfaction as the outcome variable. Model 2 used caregiver strain (MCSI) as the outcome variable. Model 3 used caregiver strain (global) as the outcome variable. Each of the three models will be presented in turn, starting with Model 1.
Model 1 – Resource Utilization as a Moderator Between Caregiving Demands and Caregiver Satisfaction

Model 1 examined if resource utilization moderates the relationship between caregiving demands and caregiver satisfaction. There were no main effects between caregiving demands and caregiver satisfaction or between resource utilization and caregiver satisfaction. As there were no main effects, resource utilization is not a significant moderator (Jose, 2013).

Model 2 – Resource Utilization as a Moderator Between Caregiving Demands and Caregiver Strain (MCSI)

Model 2 examined if resource utilization moderated the relationship between caregiving demands and caregiver strain (MCSI). The predictor variables accounted for 34.7% of the variance in caregiver strain ($R^2 = .347$, $F(10,1743) = 94.247$, $p<.001$). Caregiving demands revealed a significant, positive relationship with strain ($\beta = .430$, $t = 20.544$, $p<.001$) indicating that as caregiving demands increase so does caregiver strain. Resource utilization revealed a significant, positive relationship with caregiver strain (MCSI) ($\beta = .221$, $t=10.594$, $p<.001$) indicating that higher levels of resource utilization are related to higher levels of strain (MCSI). There were no significant interaction effects between caregiving demands and resource utilization ($\beta = .029$, $t=1.495$, $p=.135$) indicating resource utilization did not moderate the relationship between demands and strain (MCSI).

Model 3 – Resource Utilization as a Moderator Between Caregiving Demands and Caregiver Strain (Global)

Model 3 examined if resource utilization moderated the relationship between caregiving demands and caregiver strain (global). The predictor variables accounted for 29.6% of the variance in caregiver strain ($R^2 = .296$, $F(10,1743) = 74.610$, $p<.001$). Caregiving demands
revealed a significant, positive relationship with strain ($\beta = .357$, $t = 16.406$, $p < .001$) indicating that as caregiving demands increase so does caregiver strain (global). Resource utilization revealed a significant, positive relationship with caregiver strain ($\beta = .216$, $t = 9.951$, $p < .001$) indicating that higher levels of resource utilization are related to higher levels of caregiver strain (global). There were no significant interaction effects between caregiving demands and resource utilization ($\beta = .008$, $t = .386$, $p = .699$) indicating resource utilization did not moderate the relationship between demands and caregiver strain (global).

To address Question 3 A “Does resource utilization moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction?”, the answer in this study was no. Models 2 and 3 indicate that resource utilization had a direct positive relationship with caregiver strain but did not moderate the relationship between demands and caregiver outcomes. See Table 4.14 for an overall summary of the significant main effects and interaction effects when using resource utilization as a moderator.

**Table 4.14** Summary of Main Effect and Interaction Effects When Using Resource Utilization as a Moderator

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Demands</td>
<td>Caregiver Satisfaction</td>
</tr>
<tr>
<td>(Main Effect)</td>
<td>Caregiver Strain (MCSI)</td>
</tr>
<tr>
<td>Resource Utilization</td>
<td>Caregiver Strain (Global )</td>
</tr>
<tr>
<td>(Main Effect)</td>
<td>$\beta = .430^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Resource Utilization</td>
<td>$\beta = .357^*$</td>
</tr>
<tr>
<td>(Interaction Effect)</td>
<td></td>
</tr>
<tr>
<td>Resource Utilization</td>
<td>$\beta = .221^*$</td>
</tr>
<tr>
<td>(Main Effect)</td>
<td>$\beta = .216^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Resource Utilization</td>
<td>N/S</td>
</tr>
<tr>
<td>(Interaction Effect)</td>
<td></td>
</tr>
</tbody>
</table>

* $p < .001$

**Perception of Resource Adequacy**

**Question 3 B**: Do family caregivers’ perceptions of resource adequacy moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction?
To answer research question 3 B, hierarchical multiple regression with moderation was used to examine if perception of resource adequacy (including social support, family support and formal resource adequacy) moderated the relationship between caregiving demands and caregiver outcomes (satisfaction and strain). Steps outlined by Baron and Kenney (1986), Aiken and West (1991) and Jose (2013) were used in building the regression models. Block 1 in the hierarchal regression model consisted of the covariates (gender, relationship to the older adult (spouse vs. non-spouse), race, educational level, caregiver’s self-rated health, older adult’s self-rated health and age of the older adult). Block 2 consisted of the caregiving demands. Block 3 consisted of the perception of resource adequacy variable (this variable was one of the following: social support, family support or formal resource adequacy). Following the suggestion of Aiken and West (1991) the two main effect variables (caregiving demands and one of the perception of adequacy variables) were mean centered before the interaction effect was computed. To examine the moderation effect of resource perception, Block 4 consisted of the interaction term of caregiving demands X perception of resource adequacy (this was computed for each of the three resource adequacy variables). The same steps were used for each of the three perception of resource adequacy variables in this question.

Zero-order correlations, sample means, standard deviations, and internal consistency alphas for perception of resource adequacy and outcomes are presented in Table 4.13. For all the models in Questions 3 B, collinearity statistics showed that no variables in the hierarchical multiple regression models had a variance inflation factor (VIF) score greater than 2 or tolerance below .70, therefore multicollinearity among the independent variables was not an issue (Field, 2009; Tabachnick & Fidell, 2007). The Durbin-Watson test for the models ranged from 1.98 to 2.05 indicating the errors are independent of one another (Field, 2009).
Social Support.

In examining the moderation effects of social support on caregiving demands and caregiver outcomes, three models were used to examine each of the outcomes variables. Model 1 used caregiver satisfaction as the outcome variable. Model 2 used caregiver strain (MCSI) as the outcome variable. Model 3 used caregiver strain (global) as the outcome variable. Each of the three models will be presented in turn, starting with Model 1.

Model 1 – Social Support as a Moderator Between Caregiving Demands and Caregiver Satisfaction. Model 1 examined if social support moderated the relationship between caregiving demands and caregiver satisfaction. The predictor variables accounted for 3.3% of the variance in caregiver satisfaction ($R^2 = .033$, $F(10,1749) = 6.056$, $p<.001$). Caregiving demands had a non-significant relationship with caregiver satisfaction ($\beta = .019$, $t = .779$, $p = .436$). Social support had a significant positive relationship with caregiver satisfaction ($\beta = .137$, $t = 5.768$, $p<.001$) indicating that as the perceived adequacy of social support increases so does caregiver satisfaction. There were no significant interaction effects between caregiving demands and social support ($\beta = .021$, $t = .869$, $p = .385$) indicating social support did not moderate the relationship between demands and satisfaction (Jose, 2013).

Model 2 – Social Support as a Moderator Between Caregiving Demands and Caregiver Strain (MCSI). Model 2 examined the outcome of caregiver strain (MCSI). The predictor variables accounted for 30.8% of the variance in caregiver strain ($R^2 = .308$, $F(10,1749) = 77.718$, $p<.001$). Caregiving demands revealed a significant, positive relationship with strain ($\beta = .496$, $t = 24.049$, $p<.001$) indicating that as caregiving demands increase so does caregiver strain. Social support revealed a significant, negative relationship with caregiver strain (MCSI)
(β = -.051, t= -2.506, p<.05) indicating that as the perception of social support decreases, caregiver strain increases. There were no significant interaction effects between caregiving demands and social support (β = -.027, t= -1.330, p = .184) indicating social support did not moderate the relationship between demands and strain (MCSI) (Jose, 2013).

**Model 3 – Social Support as a Moderator Between Caregiving Demands and Caregiver Strain (Global).** Model 3 examined the outcome of caregiver strain (Global). The predictor variables accounted for 26.3% of the variance in caregiver strain ($R^2 = .263$, $F(10,1749) = 62.384$, $p<.001$). Caregiving demands revealed a significant, positive relationship with strain ($β = .418$, $t = 19.607$, $p<.001$) indicating that as caregiving demands increase so does caregiver strain. Social support showed a significant, negative relationship with caregiver strain (Global) ($β = -.069$, $t= -3.303$, $p<.001$) indicating that as the perception of social support decreases, caregiver strain increases. There were no significant interaction effects between caregiving demands and social support ($β = -.019$, $t = -.920$, $p = .358$) indicating social support did not moderate the relationship between demands and strain (Global) (Jose, 2013).

Overall, Model 1 indicated that social support had a direct negative relationship with caregiver satisfaction. Models 2 and 3 showed social support had a direct positive relationship with caregiver strain. Social support however, did not moderate the relationship between demands and caregiver outcomes. See Table 4.15 for an overall summary of the significant main effects and interaction effects when using social support as a moderator.
Table 4.15 Summary of Main Effect and Interaction Effects When Using Social Support as a Moderator

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Caregiver Satisfaction</td>
</tr>
<tr>
<td>Caregiving Demands (Main Effect)</td>
<td>N/S</td>
</tr>
<tr>
<td>Social Support (Main Effect)</td>
<td>β = .137*</td>
</tr>
<tr>
<td>Caregiving Demands X Social Support (Interaction Effect)</td>
<td>N/S</td>
</tr>
</tbody>
</table>

** p <.05  * p<.001

Family Support.

In examining the moderation effects of family support on caregiving demands and caregiver outcomes, three models were used to examine each of the outcomes variables. Model 1 used caregiver satisfaction as the outcome variable. Model 2 used caregiver strain (MCSI) as the outcome variable. Model 3 used caregiver strain (global) as the outcome variable. Each of the three models will be presented in turn, starting with Model 1.

Model 1 – Family Support as a Moderator Between Caregiving Demands and Caregiver Satisfaction. Model 1 examined if family support moderated the relationship between caregiving demands and caregiver satisfaction. There were no significant main effects or interaction effects indicating there is no a relationship between family support and caregiver satisfaction.

Model 2 – Family Support as a Moderator Between Caregiving Demands and Caregiver Strain (MCSI). Model 2 examined the outcome of caregiver strain (MCSI). The predictor variables accounted for 35.1% of the variance in caregiver strain ($R^2 = .351$, $F(10,1749) = 94.448$, p<.001). Caregiving demands revealed a significant, positive relationship with strain ($\beta = .462$, $t = 22.842$, p<.001) indicating that as caregiving demands increase so does caregiver strain. Family support revealed a significant, positive relationship with caregiver strain (MCSI)
(β = .229, t= 10.640, p<.001) indicating that as family support increases, caregiver strain also increases. There were no significant interaction effects between caregiving demands and family support (β = -.014, t= -.676, p = .499) indicating family support did not moderate the relationship between demands and strain (MCSI) (Jose, 2013).

**Model 3 – Family Support as a Moderator Between Caregiving Demands and Caregiver Strain (MCSI).** Model 3 examined the outcome of caregiver strain (global). The predictor variables accounted for 31.3% of the variance in caregiver strain (R² = .313, F(10,1749 = 79.712, p<.001). Caregiving demands revealed a significant, positive relationship with strain (β = .381, t = 18.311, p<.001) indicating that as caregiving demands increase so does caregiver strain. Family support revealed a significant, positive relationship with caregiver strain (Global) (β = .247, t= 11.151, p<.001) indicating that as family support increases, caregiver strain also increases. There were no significant interaction effects between caregiving demands and family support (β = -.005, t= -.240, p = .810) indicating family support did not moderate the relationship between demands and strain (global) (Jose, 2013).

Overall, Model 1 shows a non-significant relationship between family support and caregiver satisfaction. Models 2 and 3 indicate that family support has a direct positive relationship with caregiver strain. Family support however, did not moderate the relationship between demands and caregiver outcomes. See Table 4.16 for an overall summary of the significant main effects and interaction effects when using family support as a moderator.
Table 4.16 Summary of Main Effect and Interaction Effects When Using Family Support as a Moderator

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Demands</td>
<td>caregiver satisfaction</td>
<td>Caregiver Strain (MCSI)</td>
<td>β = .462*</td>
</tr>
<tr>
<td>(Main Effect)</td>
<td>N/S</td>
<td>β = .229*</td>
<td>β = .247*</td>
</tr>
<tr>
<td>Family Support</td>
<td>N/S</td>
<td>N/S</td>
<td>N/S</td>
</tr>
<tr>
<td>(Main Effect)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiving Demands X</td>
<td>N/S</td>
<td>N/S</td>
<td>N/S</td>
</tr>
<tr>
<td>Family Support</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| (Interaction Effect)|                 |                     |                   | *

* $p<.001$

**Formal Resources.**

In examining the moderation effects of perception of formal resource adequacy on caregiving demands and caregiver outcomes, three models were used to examine each of the outcomes variables. Model 1 used caregiver satisfaction as the outcome variable. Model 2 used caregiver strain (MCSI) as the outcome variable. Model 3 used caregiver strain (global) as the outcome variable. Each of the three models will be presented in turn, starting with Model 1.

**Model 1 – Formal Resource Adequacy as a Moderator Between Caregiving Demands and Caregiver Satisfaction.** Model 1 examined if formal resource adequacy moderated the relationship between caregiving demands and caregiver satisfaction. There were no significant main effects or interaction effects indicating there is no a relationship between resource adequacy and caregiver satisfaction.

**Model 2 – Formal Resource Adequacy as a Moderator Between Caregiving Demands and Caregiver Strain (MCSI).** Model 2 examined the outcome of caregiver strain (MCSI). The predictor variables accounted for 31.1% of the variance in caregiver strain ($R^2 = .311$, $F(10,1751) = 79.017, p<.001$). Caregiving demands revealed a significant, positive relationship with strain ($β = .495, t = 24.069, p<.001$) indicating that as caregiving demands increase so does
caregiver strain. Resource adequacy revealed a significant, negative relationship with caregiver strain (MCSI) ($\beta = -0.076$, $t = -3.803$, $p < 0.001$) indicating that as perception of resource adequacy increases, caregiver strain decreases. The interaction effect between caregiving demands and perception of resource adequacy was significant ($\beta = -0.040$, $t = -2.007$, $p < 0.05$) indicating that perception of resource adequacy moderated the relationship between demands and strain (MCSI). Figure 3 shows the relationship between caregiving demands and caregiver strain (MCSI) is strongest for those individuals who reported the lowest levels of resource adequacy and the weakest for those who reported the highest levels of resource adequacy.

**Figure 3**: Moderation of the Effect of Caregiving Demands on Caregiver Strain (MCSI) by Resource Adequacy

To determine if the three groups of resource adequacy (high, medium and low) are significantly different further analyses were completed (Jose, 2013). The additional analyses showed that there are significant differences between high, medium and low resource adequacy
groups confirming that those with the lowest resource adequacy are most at risk from higher levels of caregiver strain. The results showing the significant differences between the three groups of resource adequacy are presented in Table 4.17

<table>
<thead>
<tr>
<th>Resource Adequacy Group</th>
<th>Slope</th>
<th>t</th>
<th>S.e.</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>1.51</td>
<td>2.25</td>
<td>0.675</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>Medium</td>
<td>1.65</td>
<td>2.62</td>
<td>0.631</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>Low</td>
<td>1.79</td>
<td>2.89</td>
<td>0.619</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

**Model 3 – Formal Resource Adequacy as a Moderator Between Caregiving Demands and Caregiver Strain (Global).** Model 3 examined the outcome of caregiver strain (global). The predictor variables accounted for 26.6% of the variance in caregiver strain ($R^2 = .266$, $F(10,1751) = 63.536, p<.001$). Caregiving demands revealed a significant, positive relationship with strain ($\beta = .417, t = 19.653, p<.001$) indicating that as caregiving demands increase so does caregiver strain. Resource adequacy revealed a significant, negative relationship with caregiver strain (global)($\beta = -.080, t= -3.860, p<.001$) indicating that as resource adequacy decreases, caregiver strain increases. The interaction effect between caregiving demands and perception of resource adequacy was significant ($\beta = -.049, t= -2.367, p <.05$) indicating that perception of resource adequacy moderated the relationship between demands and strain (global). Figure 4 shows the relationship between caregiving demands and caregiver strain (global) is strongest for those individuals who reported the lowest levels of resource adequacy and the weakest for those who reported the highest levels of resource adequacy.
Figure 4: Moderation of the Effect of Caregiving Demands on Caregiver Strain (Global) by Resource Adequacy

To determine if the three groups of resource adequacy (high, medium and low) are significantly different further analyses were completed (Jose, 2013). The additional analyses showed no significant differences between the three groups of formal resource adequacy.

The type of moderation that was found for the effects of resource adequacy on the relationship between caregiving demands and caregiver strain is considered to have a “dampening” effect and is hence a buffer (Jose, 2013). That is, resource adequacy lessens the relationship between caregiving demands and caregiver strain. In general, the relationship between caregiving demands and caregiver strain is lowest for individuals who report the highest levels of resource adequacy. In contrast, individuals reporting the lowest levels of resource adequacy demonstrated the strongest relationship between caregiving demands and caregiver strain.
Overall, Model 1 showed a non-significant relationship between formal resource adequacy and caregiver satisfaction. Models 2 and 3 indicated that resource adequacy had a direct negative relationship with caregiver strain and moderated the relationship between demands and caregiver strain. See Table 4.18 for an overall summary of the significant main effects and interaction effects when using formal resource adequacy as a moderator.

**Table 4.18** Summary of Main Effect and Interactions Effects When Using Perception of Formal Resources as a Moderator

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Demands (Main Effect)</td>
<td>Caregiver Satisfaction N/S</td>
</tr>
<tr>
<td>Adequacy Formal Resources (Main Effect)</td>
<td>Caregiver Strain (MCSI) $\beta = .495^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Adequacy of Formal Resources (Interaction Effect)</td>
<td>Caregiver Strain (Global) $\beta = .417^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Adequacy of Formal Resources (Interaction Effect)</td>
<td>$\beta = -.076^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Adequacy of Formal Resources (Interaction Effect)</td>
<td>$\beta = -.080^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Adequacy of Formal Resources (Interaction Effect)</td>
<td>$\beta = -.060^*$</td>
</tr>
<tr>
<td>Caregiving Demands X Adequacy of Formal Resources (Interaction Effect)</td>
<td>$\beta = -.049^*$</td>
</tr>
</tbody>
</table>

* $p<.001$ **$p<.05$ ***$p<.01$

To address research question 3 B “Do family caregivers’ perceptions of resource adequacy moderate the association between caregiving demands and the outcomes of caregiver strain and satisfaction”, the answer in this study was no for caregiving satisfaction and yes for caregiver strain. Social support, family support and formal resource adequacy were not moderators in the relationship between caregiving demands and caregiver satisfaction. Social support and family support did not moderate the relationship between caregiving demands and caregiver strain. Significant moderation effects were found for formal resource adequacy on the relationship between caregiving demands and caregiver strain.

**Chapter Summary**

The data analysis in this study examined the association between caregiving demands and resource utilization and perception of resource adequacy. The analysis also investigated the
relationship between caregiving demands and caregiver outcomes. Finally, the resource utilization, social support, family support and formal resource adequacy were examined to determine if they had a moderating effect on the relationship between caregiving demands and caregiver outcomes. An overall summary of the results is presented in Table 4.19. Significant relationships are indicated with a check mark with either a negative sign signaling a negative relationship or a positive sign signaling a positive relationship.
### Table 4.19 Overall Summary of Relationships in Data Analysis

<table>
<thead>
<tr>
<th>Predictor Variables</th>
<th>Outcome Variables</th>
<th>Caregiver Satisfaction</th>
<th>Caregiver Strain (MCSI)</th>
<th>Caregiver Strain (Global)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving Demands</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>Resource Utilization</td>
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<td>+ ✓***</td>
<td></td>
</tr>
<tr>
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<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Utilization (main effect)</td>
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<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Moderation Effect</td>
<td>N/S</td>
<td>N/S</td>
<td>N/S</td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Demands (main effect)</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Social Support (main effect)</td>
<td>+ ✓***</td>
<td>- ✓*</td>
<td>- ✓***</td>
<td></td>
</tr>
<tr>
<td>- Moderation Effect</td>
<td>N/S</td>
<td>N/S</td>
<td>N/S</td>
<td></td>
</tr>
<tr>
<td>Family Support</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Demands (main effect)</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Family Support (main effect)</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Moderation Effect</td>
<td>N/S</td>
<td>N/S</td>
<td>N/S</td>
<td></td>
</tr>
<tr>
<td>Resource Adequacy</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Demands (main effect)</td>
<td>N/S</td>
<td>+ ✓***</td>
<td>+ ✓***</td>
<td></td>
</tr>
<tr>
<td>- Resource Adequacy (main effect)</td>
<td>N/S</td>
<td>- ✓***</td>
<td>- ✓***</td>
<td></td>
</tr>
<tr>
<td>- Moderation Effect</td>
<td>N/S</td>
<td>- ✓*</td>
<td>- ✓**</td>
<td></td>
</tr>
</tbody>
</table>

*p < .05   **p < .01   ***p < .001
Chapter V

Discussion

Summary of Findings

The purpose of this study was to determine if resource utilization and family caregivers’ perception of resource adequacy are associated with caregiver strain and satisfaction, specifically if the relationship between caregiving demands and outcomes are moderated by resources. To summarize the findings, a significant positive relationship was found between caregiving demands and caregiver strain, suggesting that as caregiving demands increase levels of caregiver strain do as well. The utilization of formal resources also had a positive relationship with caregiver strain indicating that as resource utilization increases so do levels of caregiver strain. Social support was found to have a positive relationship with caregiver satisfaction and a negative relationship with caregiver strain indicating that perceived levels of higher social support are associated with higher levels of caregiver satisfaction and lower levels of caregiver strain. Family support was found to have a positive relationship with caregiver strain, indicating that as levels of family support increase so do levels of caregiver strain. It is important to note that for the family support scale, higher numbers indicate more disagreement within the family regarding care provision to the older adult family member. Therefore, higher levels on the family support scale indicate higher levels of family conflict.

Finally, the perception of formal resource adequacy was found to have a negative relationship with caregiver strain meaning that higher levels of perceived adequacy are associated with lower levels of strain. Additionally, resource adequacy was found to moderate the relationship between caregiving demands and caregiver strain with individuals reporting the highest levels of resource adequacy experiencing the lowest levels of caregiver strain. The
following discussion will focus on the four major findings from the study, the limitations and strengths of the study, implications and will conclude with recommendations for future research. The first finding to be discussed is the relationship between demands in the caregiving role and caregiver outcomes.

**Effects of Caregiving Demands**

Demands in the caregiving role can vary individually from those that are perceived to be relatively easy to manage to those that cause caregiver strain (National Alliance for Caregiving, 2011) with previous research showing a significant relationship between caregiving demands and caregiver outcomes (Casado et al., 2011; Hong, 2010; Wakefield et al., 2012). On average, family caregivers provide 20 hours per week of care to an older adult with one or more limitations in ADLs (Johnson & Weiner, 2006) with more negative outcomes for caregivers being related to longer hours spent providing care (Kang, 2006; Lin et al., 2012). In addition to increases in functional dependency of the older adult care recipient and more hours spent providing care, the longer a family caregiver has been in the role has also been linked to caregiver strain (Seltzer & Wailing, 2000).

In a recent study that examined caregiver stress and nursing home placement for the older adult care recipient, factors found to significantly increase stress included hours of caregiving, time in the caregiving role as well as caring for an older adult with a substantial disability (Spillman & Long, 2009). Family caregivers experiencing the greatest demands in caregiving also experienced the highest levels of stress. Older adults with highly stressed family caregivers were more likely than those with less stressed caregivers to be placed in a nursing home over a two year follow-up period (Spillman & Long, 2009). Consistent with these findings, another study examining the predictors of caregiving strain found that impairment in performing ADLs
and IADLs along with the number of hours spent providing care explained the most variance in caregiving strain (Kim, Chang, Rose, & Kim, 2012).

In this study the relationship between caregiving demands and caregiver satisfaction was non-significant. Higher levels of caregiving demands were associated with higher levels of caregiver strain. The relationship between caregiving demands and caregiver satisfaction was non-significant. These findings indicate that as the demands of caregiving increase, such as the time spent providing care or the functional dependency of the older adult, so does caregiver strain. Caregiving demands being positively associated with caregiver strain, in this study, adds to the existing evidence that more intense caregiving is related to higher levels of strain. That is, as family caregivers spend more hours providing care, have been in the role longer, have increased their caregiving responsibilities and assist with more ADLs and IADLs, they experience increased strain in the caregiving role.

**Effects of Resource Utilization**

The realities of the caregiving role and the demands that are associated with it result in caregivers reporting the wish for more support and assistance (Barbosa, Figueiredo, Sousa, & Demain, 2011). Assistance can be in the form of informal social or family support or formal home and community based support services (i.e. transportation, assistive devices, household modifications, respite care, in-home nursing care and senior centers). Despite caregivers’ wish for more support, utilization of these support services has remained historically low (Casado, 2008; Mast, 2013). Even with a variety of available formal resources, many caregivers do not utilize them or do so late in the care recipient’s illness trajectory (Hong, 2010).

Results from this study support previous evidence as the utilization of formal resources was found to be low, with the most commonly used formal resource being assistive devices
(54.7%) followed by in-home nursing care (28.7%) and the least used resources being respite care (8.9%) and adult day care or senior centers (4.2%). Explanations for the formal resources not being fully utilized could include caregivers not being aware of available resources or not knowing how to access the resources. Future studies could examine the extent of family caregivers’ knowledge of available resources. Are family caregivers aware of the types of resources that are available? If so, what is the extent of their knowledge and what is the source of their knowledge? Is lack of knowledge a barrier to resource utilization?

Family caregivers needing specific types of resources, such as respite care, does not imply they will be accessed indicating there may be various barriers to resource utilization (Friedemann, Newman, Buckwalter, & Montogomery, 2014). In a recent study on why family caregivers do not fully utilize available formal resources, the caregivers cited a lack of time and the ability to obtain their own information (Lim, Goh, Chionh, & Yap, 2012). Other reasons for under utilization include a perceived lack of need for the resource and reluctance to use the available services (Mast, 2013; Robison, Buckwalter, & Reed, 2005).

In addition to assessing the amount of resource utilization, the relationship between resource utilization and caregiver outcomes was also examined. The relationship between resource utilization and caregiver satisfaction was found to be non-significant, whereas a higher level of resource utilization was found to be associated with higher levels of caregiver strain. This positive relationship between resource utilization and caregiver strain was inconsistent with findings from a study examining caregiver stress which found caregivers with paid help had better health outcomes than their counterparts without paid help (Huang et al., 2006). Based on the study findings, the authors concluded that those with access to formal resources, such as paid in-home assistance, fare better in the caregiving role than those without this type of assistance
(Huang et al., 2006). The inconsistency could be the result of different formal resources being analyzed between the studies, that of paid help versus assistive formal resources such as assistive devices, transportation and senior centers.

The findings from this study suggest that as caregivers use more formal resources their strain from caregiving also increases. An explanation for this positive association could be that as older adults’ functional dependency increases, it is likely to involve an increased effort on behalf of the family caregiver. As previously noted, family caregivers generally use resources later in the older adults’ illness which could be happening in this study as the majority of the caregivers had been providing care for more than four years (51.3%) and were providing more care now that they had initially (51.3%). Older adult care recipients being further along in their illness trajectory may have higher levels of impairment resulting in the need for greater resource utilization and subsequent higher levels of strain. The findings in this study support existing evidence examining the relationship between resource utilization and caregiver strain. When examining family caregiver patterns of service utilization, it has been demonstrated that caregivers with the highest levels of strain use the most resources while caring for the most functionally dependent older adults (Hong, 2010; Stirling, Andrews, Croft, Vickers, Turner, & Robinson, 2010). A positive relationship between resource utilization and caregiver strain poses several significant questions including if the resources being used are adequately meeting the needs of the caregiver as well as which type of resources are best suited for individual family caregivers.

**Effects of Social Support**

Social support in this study was found to have a positive relationship with caregiver satisfaction and a negative relationship with caregiver strain. The finding that social support was
a significant predictor of caregiver outcomes is supported by previous research. Social support has been used as a predictor of caregiver outcomes and has been shown improve outcomes in the caregiving role (Glasdam et al., 2010; Onsworth et al., 2010). When examining the effect of social support on caregiver psychological well-being, satisfaction with social support was found to moderate the relationship between the functional dependency of the patient and caregiver psychological well-being. As older adult care recipients become more functionally dependent, social support becomes particularly important for enhancing caregiver well-being (Onsworth et al., 2010).

In a meta-analysis comparing spousal and non-spousal caregivers, social support was one of the two strongest predictors of caregiver strain indicating the importance of social support as an intervention for decreasing caregiver strain (Pinquart & Sorenson, 2011). Social support has been shown to predict caregiver strain with higher levels of perceived social support being related to lower levels of caregiver strain (Rodakowski, Skidmore, Rogers, & Schulz, 2012). Adding support to these findings, a recent cross-sectional study looking at the correlates of burden in primary caregivers of older adults found that perceived social support was negatively associated with subjective burden (Del-Pino-Casado, Millan-Cobo, Palomino-Moral, & Frias-Osuna, Casado, 2014).

The following two studies examined the effect of both social support on satisfaction and strain. The first study examining caregiver satisfaction and strain found that lower caregiver satisfaction was associated with lower levels of perceived social support which was also a predictor of caregiver strain (Wakefield et al., 2012). In the second study examining the negative and positive experiences of caregiving, social support was found to be an important factor for caregiver satisfaction, particularly for daughters providing care (Lin et al., 2012). Supporting the
findings from this study, previous research has demonstrated that higher levels of perceived social support enhance caregiver satisfaction and decrease caregiver strain. This study adds to the previous evidence by being one of the few studies to examine the effect of social support on caregiver satisfaction and strain in the same study.

**Effects of Family Support**

Family support in this study had a non-significant relationship with satisfaction and a positive association with caregiver strain indicating that increased family support is related to increased levels of caregiver strain. As the measurement of family support was limited to level of agreement or disagreement within the family, it may be that family conflict rather than family support was being captured in this study. To address this measurement issue, other elements to examine in future studies include assessing the functioning of the family unit while accounting for the level of disagreement. That is, do family members contribute to the care of the older adult even when there is a high level of disagreement within the family? Generally, one family member assumes the primary responsibility for providing care but this is frequently augmented by other family members who provide assistance as well as social and emotional support. In this study, the older adult care recipient identified those family members providing care with the person providing the most care completing the survey. Future studies could capture more than one family caregiver by including all family members providing care. Based on a quantifiable number, such as amount of care provided, primary and secondary family caregivers could be identified, if there are significant differences between the groups and how this impacts caregiver outcomes.

Previous research has shown that families can be a source of support as well as a source of additional strain for both the primary family caregiver and the older adults receiving care
Lin and colleagues (2012) in addition to examining the role of social support on caregiving experiences also examined the impact of family conflict on caregiver outcomes. Similar to the results found in this study, family conflict increased caregiver strain but was not significantly related to caregiver satisfaction.

In a study examining family conflict from the perspective of adult children caregivers, it was found that family conflict is related to caregiver strain with son and daughter caregivers experiencing the stress of caregiving in similar ways with family conflict contributing to that stress (Kwak, Ingersoll-Dayton, & Kim, 2012). Family conflict has been found to be a predictor of caregiver strain for both spouse and adult children caregivers, with higher levels of conflict predicting higher levels of caregiver strain for different types of family caregivers (Kang, 2006).

Family members can be a source of support for the primary family caregiver as well as sharing some of the care responsibilities for the older adult care recipient (Kwak et al., 2012). When caring for older adults with a chronic illness, however, family members may have different ideas of the type and amount of care that should be provided which may lead to disagreements and ultimately family conflict (Kwak et al., 2012). Due to this conflict, family members other than the primary family caregiver may be less inclined or able to provide additional support resulting in increased demands in the caregiving role (Scharlach et al., 2006).

Family support, similar to social support, may be used as a resource in caregiving when there is minimal family conflict within the family but it can also contribute to caregiver strain when there is significant family conflict. This may be a reason why family support had a significant relationship with strain but a non-significant relationship with satisfaction. To more accurately capture family support, future studies could use a different scale that measures the amount of assistance provided by various family members, the amount of emotional support provided and if
there is conflict within the family that affects the primary caregiver in their role. Similar to social support, this study adds to the previous evidence by being one of the few studies to examine the effect of family support on caregiver satisfaction and strain in the same study.

**Effects of Formal Resource Adequacy**

Formal resource adequacy while not associated with caregiver satisfaction, it had a negative association with caregiver strain. In this study, higher levels of resource adequacy were associated with lower levels of caregiver strain. Resource adequacy was also found to moderate the relationship between caregiving demands and caregiver strain. Resource adequacy significantly moderating the relationship between demands and strain indicates that caregiving demands have the least negative impact on strain for those individuals who report the highest levels of resource adequacy. Conversely, it also means those individuals reporting lower levels of resource adequacy are at the greatest risk of experiencing caregiver strain when the demands of caregiving are higher.

The work by Collins, Stommel, King and Given (1991) as well as Robinson (1988, 1990) provided the foundation for including the perceptions of caregivers into research on the use of formal resources. In their work on predictors of use of resources among caregivers, Robinson and colleagues (2005) found that evaluation of informal help from family and friends as well as formal resources varies by caregiver age with younger spousal caregivers being more likely to use home and community based resources than older spousal caregivers. In a study designed to assess the use of and needs for specific formal support programs, it was found that spousal caregivers reported different needs than adult children caregivers (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Spousal caregivers needed more emotional support while adult children caregivers required more formalized support in the form of information and
assistance with coordination of care. Other research has found the most salient factor in
determining formal resource use is the caregiver’s perceived need of the service (Casado, Lee, &
Davis, 2011; Chen & Thompson, 2010; Mast 2013).

Many family caregivers have unmet needs for formal services and support (Black,
Johnston, Rabins, Morrison, Lyketsos, & Samus, 2013). More specifically to unmet needs for
resources, Black and colleagues (2013) found that 97% of family caregivers (n=246) for persons
with dementia had one or more unmet needs with 85% of those having unmet needs for resource
referrals or caregiver education (such as available home and community based resources). As
discussed previously in the resource utilization section, unmet needs for resources have been
attributed to a perceived lack of need for the resource and reluctance to use the available services
(Mast, 2013; Robinson et al., 2005). In their study measuring caregivers’ unmet needs for
services, Stirling and colleagues (2010) found that more than half of the family caregivers’
reported wanting more help from the services they were currently receiving, which they defined
as “felt need”. Felt need of resources that were being utilized were correlated with the
caregivers’ level of strain with higher levels of felt need being correlated with higher levels of
strain. The concept of felt need is similar to perceived adequacy of resources in that both
measure family caregivers’ perceptions of resources that are being used rather than unmet needs
for resources not being utilized.

When family caregivers are strained they can still recognize they may require more
assistance from the resources they are using (Stirling et al., 2010). This study contributes to the
existing evidence by going beyond whether a resource is utilized or not and if the caregiver has
unmet needs for resources to evaluating the caregivers’ perception of resource adequacy.
Caregivers may be using specific resources but simply asking whether a resource is needed or
used does not fully capture the adequacy of a resource and conversely its impact on caregiver outcomes. Examining whether the use of a specific resource does or does not meet the needs of the family caregiver provides additional insight into the types of resources that are most beneficial to individual caregivers. To fully understand the family caregivers’ use and perception of resources, more studies are needed to fully elicit indicators of overall resource adequacy and if this signals an increased need for targeted resources or services. The full range of resources should also be considered and a determination made about the malleability of those resources. Which types of resources are most malleable, how are they malleable and in what way would the manipulation of resources benefit the family caregiver? Is the adequacy of a resource stable over time? If yes, which types remain stable? If not, how does adequacy change over the course of the caregiving trajectory and with changing caregiving demands?

**Study Limitations and Strengths**

There are several limitations within the study that must be considered when interpreting the results. Using moderation may have limited the significant effects found in the study as moderator effects can be extremely difficult to detect in observational studies (McClelland & Judd, 1993). Moderating effects were found for resource adequacy but not for the moderators of resource utilization, social or family support. This may be because there were no moderating effects or the ability to detect the effects was limited.

A second limitation is sampling weights were not used in the regression modeling. While there is general agreement in using weights for population based descriptive purposes, it is less clear whether weighting should be used when estimating regression equations (Faiella, 2010; Gelman, 2007; Winship & Radbill, 1994). Adding to the complexity of using weights in the regression, specific sampling weights were not provided for the Informal Caregiver Survey. As
such, sampling weights were not used in the analysis which limits the generalizability of the study and the results must be interpreted with caution.

This study is a secondary analysis of an existing dataset, and as such, it has the following limitations. One main limitation is the data was not specifically collected to address the research questions for the study. For example, the caregiver satisfaction outcome was only assessed using two questions. The satisfaction variable being assessed by only two questions could have resulted in data analysis issues, such as under-identification (Kline, 2011). Having only two questions addressing the caregiver satisfaction outcome variable may not have adequately measured the concept and could be the reason why only social support was found to have a significant relationship with satisfaction. To improve the measurement of caregiver satisfaction, further studies using the full Caregiver Satisfaction Scale are needed. Using the Conservation of Resources (COR) as a framework, it could also be that satisfaction (or resource gain) had a weaker relationship with caregiving demands and the moderator variables than did strain (or resource loss).

Another measurement limitation may be the caregiver strain outcome variable. No specific scale was used in the original study to measure caregiver strain. Several questions were asked to assess strain in the caregiving role so the Caregiver Strain Index scale was modified and included in this study ($\alpha = 0.825$) and remains similar to the original Caregiver Strain Index ($\alpha = 0.86$) (Onega, 2008; Wakefield et al., 2012). To address this limitation, several questions did assess caregiver strain in the original study. In this study two strain scales were used with similar results indicating that strain in the caregiving role was assessed even though no specific strain measure was used in the original study. The family support measure could also be addressed so that it more accurately captures the support provided by the family to the primary
caregiver rather than measuring the level of disagreement within the family. Additionally, awareness of available resources was not addressed. Future studies could include if a resource was utilized, and if not, why not including the family caregivers’ awareness of available resources.

The self-report nature of the original survey may have resulted in self-report bias. To address this issue, several questions were asked for the predictor and outcome variables. Self-reported health used only one question; however, previous research has used the self-reported health variable and it has demonstrated reliability and validity (Wakefield et al., 2012). Another potential limitation is not including the cognitive impairment of the older adult as one of the variables. Cognitive impairment of the care recipient has been shown to increase the strain of the caregiving role (Schulz & Sherwood, 2009) but this potential influencing factor was not controlled for in the analysis. An older adult’s cognitive impairment may also impede the communication between the family caregiver and older adult (Lin et al., 2012; Scharlach et al., 2006). Due to the extent of missing data, however, cognitive impairment was not included in this analysis. Another issue is age of the family caregiver was not directly measured in the original study. Demographic characteristics of the family caregiver have been shown to affect the caregiving experience, with age being consistently shown to be a factor (Casado, 2008; Pinquat & Sorensen, 2011; Schulz & Sherwood, 2009). Not including age as a variable may have impacted the results of this study. There may have been significant differences between younger and older family caregivers that affect their outcomes but this was another variable that was not controlled for in the study. To address these limitations, future studies could include the age of the family caregiver and whether the care recipient has any form of cognitive impairment.
Finally, this was a cross-sectional study so it did not fully capture the caregiving experience but rather provided a “snapshot” of a specific point on the caregiving trajectory. The caregiving trajectory is an important element to consider when assessing caregiver outcomes as transitions into, out of, and across the illness trajectory have been shown to impact caregiver outcomes (Martire et al., 2006; Penrod et al., 2011; Waldrop et al., 2005). In a study examining three time points of data measurement that captured different phases on the care recipients’ illness trajectory, significant increases in negative affect over the three times points and significant decreases in positive affect over the same time frame were found for family caregivers (Wilson-Genderson et al., 2009). Progression of caregiving was found to be positively associated with resource utilization indicating that the more care family caregivers provide, the more formal resources are used. In future studies, using a longitudinal design would help to address the transitory nature of caregiving and the potential changing needs for resources and the perception of their adequacy at different stages in the caregiving experience. The Informal Caregiver Survey would allow for longitudinal analysis of the individual level changes within the caregiving experience as it has several waves of data that extend over a 20 year period.

Although this study has limitations, it also has strengths. The large sample size allows for an in-depth examination of the effects of resources on caregiver outcomes while controlling for potential confounding variables. Additionally, the sample captures community-dwelling older adults with a myriad of chronic conditions rather than only one type of condition. There is also the benefit of being able to examine the family caregivers’ perceptions of resource adequacy for both informal and formal resources. Examining the perception of resource adequacy provides a more in-depth understanding of the relationship between resources and caregiver outcomes than just examining the amount of resource utilization.
Finally, the structure of the NLTC Survey and Informal Caregiver Survey can also be considered a strength. Procedures to capture the most rigorous data possible were employed. The field procedures, instruments, and organization of the original surveys were based upon the Demographic Surveys Division of the U.S. Census Bureau procedures minimizing bias and error. Trained interviewers familiar with the survey and interviewing techniques were also used for the telephone and in-person interviews to add to the consistency and quality of the data being captured.

Implications

This study was based on cross-sectional and self-report data and does not establish causality between the variables of interest (resources and caregiver outcomes). Despite limitations the study findings have implications for practice, research and policy. Examining resources in the caregiving role and their effect on caregiver outcomes, particularly resources as moderators between caregiving demands and caregiver outcomes is lacking in the caregiving literature. This study begins to address this gap by assessing the moderating effect of resource utilization and perception of resource adequacy. It is well established in the caregiving literature that family caregivers are at an increased risk for negative outcomes. In addition to negative outcomes, research is beginning to investigate the benefits of providing care to a family member and this study adds to the existing literature by examining both caregiver satisfaction and strain in the same study. Although more studies are required, this study indicates that assessment of family caregivers should include both caregiver satisfaction and strain as well as the awareness of and need for different types of resources as well as the perceived adequacy of resources to help address caregivers’ concerns regarding unmet needs. It is important to assess the needs of
the family caregivers early in the caregiving trajectory before caregiving demands become too overwhelming and caregiving strain escalates.

An area that shows promise for recognizing the complex needs of family caregivers is the increasing emphasis on patient and family centered care. The Joint Commission’s Roadmap has placed patient and family centered care at or near the top of hospitals and health systems’ priority lists (Kagan, 2011). The Joint Commission defines patient and family centered care as:

An innovative approach to plan, deliver, and evaluate health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Patient and family centered care applies to patients of all ages and it may be practiced in any health care setting (p. 92).

Patient and family centered care advocates for information sharing, participation and collaboration with patients and families and conceptualizes the patient and the family as the unit of care (Bell, 2013). Using patient and family centered care as a guide, caregivers can be considered as part of the patient care plan thus allowing for the assessment of their needs for resources and their own self-care (Boltz, 2012). Assessment of the family caregiver should include not only the strengths and challenges of the caregiving situation but also the larger family and community contexts (Mast, 2013). A beginning step for assessing the awareness of and need for resources would be discussing the accessibility and availability of relevant resources as well as evaluating the family caregiver’s level of knowledge and familiarity with resources (Mast, 2013). A next step would be to assess the perceptions of the family caregiver about any unmet needs and what is needed to address those needs.

To fully address the complexity of the caregiving role, components of a comprehensive caregiver assessment should include: 1) assessing the caregivers’ self-rated health; 2) the
perceived challenges of caregiving (i.e. difficulties in providing care to the older adult or with health care providers and if the caregiver has the necessary skills and or training for the role); 3) perceived benefits of caregiver (i.e. their satisfaction with providing care); and 4) caregiver resources (i.e. determining their needs for resources and/or referrals as well as their perceptions of resource adequacy) (Mast, 2013).

When developing family caregiver policy, components of caregiver assessment need to be considered and policy makers should not assume that caregivers have the knowledge, skills and resources to perform all caregiving tasks. Policy makers should consider individual family caregiver needs when developing models of care in that “development, funding and execution of innovative care and coordination models should have a strong, explicit focus in supporting family caregivers who are assuming ever more complex responsibilities” (Reinhard, Levine, & Samis, 2014, p.9). In 2010, more than half the states reported an increase in the demand for community based services that would support family caregivers and their older adult care recipients. During this same time however, 31 states cut non-Medicare aging and disability service programs (Feinburg et al., 2011).

The share of Medicaid spending for home and community based services doubled between 1995 and 2005 and is growing at a much fast rate than spending on institutional services (Shih, Concannon, Liu & Friedman, 2014) but it is unknown how this change in funding affects family caregivers in the community. Home and community based services that are publicly funded, such as paid help, remain inaccessible for many middle-income families because of Medicaid eligibility requirements that require them to pay out of pocket for services (Shih et al., 2014). Medicaid covers nursing home care and paid care provided in the community whereas Medicare only covers hospice costs and a portion of short-stay care. The Medicaid eligibility
rules in many states require assets no greater than $2,000 which puts many middle-income families at risk for financing long term care (Shih et al., 2014). Family caregivers provide as much as 80% of care for the older adult care recipient but this reliance on family caregiving is unsustainable as the average age in the United States continues to trend upwards. The aging of the population will create a growing imbalance between the older adults needing care and family members able to provide that care (Shih et al., 2014).

To address this growing imbalance, Shih and colleagues (2014) in their policy blueprint for improving dementia long term care outline several high-impact policy options. Although the recommendations are for persons with dementia and their family caregivers, several of the options are applicable to those with chronic illnesses other than dementia. One of the main challenges identified in the blueprint was “insufficient resource-finding infrastructure, employer programs, and financial resources to support family caregivers” (Shih et al., 2014, p. xix). Policy options to support family caregivers were suggested to meet this challenge including:

- Expand family caregiver compensation programs for lost wages and caregiving work. Increase availability of compensation (e.g., through Medicaid programs) and expand to all states.
- Disseminate educational materials on providing care, hands on training, and other information about respite care, community services, and other resources.
- Expand the Family and Medical Leave Act to cover paid time off and care provided to parents, grandparents, siblings, and others.
- Introduce government sponsored navigators to provide information to family caregivers on medical care access and available support and resources. (Shih et al., 2014, p. 18).
With the limited funds available to support family caregivers, it becomes critical to highlight the most efficacious resources that respect the caregiving context as this will allow for tailored resources that account for the heterogeneity of the caregiving role. Recently, Rhode Island passed the Family Caregivers Support Act of 2013. A large component of this act is the assessment of the family caregiver who, among others, is considered to be anyone who provides assistance to an older adult with a chronic illness. In this act, caregiver assessment is defined as a systematic process that gathers information on the needs, strengths and resources of the family caregiver as well as their ability to address the needs of the care recipient. This information is then used to develop an appropriate plan that includes applicable information and/or education, referrals and home and community based support services (Kelly, Wolfe, Gibson, & Feinberg, 2013). Using this type of model provides an opportunity for family caregivers to be supported and educated on the types of available resources by all members of the health care team that interact with the family caregiver. For example, family caregivers who lack social support could be informed about a formal social support group from which they may derive some benefit.

Improving the understanding of the types of resources that family caregivers perceive as needed and adequate allows for the development of caregiver toolkits and websites that educate family caregivers on what is available to them and how to access applicable resources.

Comprehensive assessment of the family caregiver allows for tailored resources and interventions that may assist and ultimately improve their outcomes in the caregiving role. As part of the National Caregiving Initiative, the Rosalynn Carter Institute for Caregiving (2010) calls for the development of three levels evidence-based interventions based on the unique needs and level of risk the family caregiver has for experiencing strain and/or stress in the role. The first level is universal interventions that should be made available to all caregivers (i.e.
information and education). The second level is selective interventions that would be targeted at families with an elevated risk due to the demands of their caregiving role (i.e. skills training). Finally, the third level is indicated interventions to address the heterogeneity of caregivers, particularly those with the highest demands and risks in the caregiving role (i.e. intensive counseling or assistance).

As highlighted in this study, not all caregiving demands or resources are created equal for individual family caregivers. Assessing caregivers for their needs and applicable resources to target those needs will allow for tailored resources that meet the requirements of the family caregiver. For example, family caregivers with strong social support may not benefit from a formal support group. However, if there is conflict within the family, resources and/or interventions addressing this conflict may be perceived as more adequately meeting the family caregiver’s needs. Or family caregivers may not have access to required resources or have access to formal resources that either do not meet their needs or are perceived as not being adequate for their individual situations. Assessment of the family caregiver allows for highlighting what caregivers need assistance with and the resources that would be most applicable and beneficial in individual caregiving situations.

Assessing family caregivers’ perceptions of resource adequacy and the impact this has on their outcomes will begin to address what the needs of individual family caregivers are and how different types of resources may meet those needs. In this study, perception of resource adequacy was found to be a significant moderator between caregiving demands and caregivers strain. Perception of resource adequacy buffering the relationship between demands and strain highlights the importance of listening to individual caregivers about their perceptions. Through assessment, family caregivers may become aware of and have access to resources that they
perceive as meeting their needs which will ultimately assist them with the demands of the caregiving role.

**Recommendations for Theory Development and Future Research**

Although the COR Model has not been used in the caregiving literature, it has been used to predict stress outcomes in organizational settings, health contexts, following traumatic stressful events, as well as with everyday stressors (Hobfoll, 2001). Caregiving has, however, often been investigated using the Stress Process Model (Pearlin et al., 1981, Pearlin et al., 1990). The basic premise of the Stress Process Model is that the process of social stress combines the conceptual domains of sources of stress, mediators of stress, and manifestations of stress (Pearlin et al., 1981). In the first domain, stress is conceptualized as stemming from two types of circumstances or sources, that of discrete events and from the presence of relatively continuous problems (Pearlin et al., 1981). As these two sources of stress converge over time and events, the process of stress evolves. Stressful life events and more chronic life strains contribute to overall stress which diminish a person’s self-concept (Pearlin et al., 1981).

To explain the lack of consistency between the intensity of stress exhibited and the intensity of the stress sources, Pearlin et al. (1981) proposed stress mediators, specifically social support and coping. Social support is viewed as how individuals or groups help deal with life’s issues. Coping is distinguished by functional behavior of which there are three functions: modifying stressful situations, modifying the meaning of the situation to reduce its threat, and managing stressful symptoms (Pearlin et al., 1981). These two mediators can intervene at any point in the stress process, for example before an event occurs, during an event or before the stress outcome occurs.
The last domain is the manifestations of stress or outcomes. In the Stress Process Model the focus is on the process of stress rather than the individual adaptation to stress. The process of stress focuses on the relationships among the conditions that lead to stress and the ways these relationships develop and change over time. That is, the model looks at how life events, chronic life strains, self-concepts, coping, and social support interconnect to form the process of stress. For example, events in people’s lives can create negative changes in their roles which diminish self-concept thus resulting in stress arousal. Social support and coping can intervene at different points in the process and impact the manifestations of stress. The Stress Process Model forces attention on the relationships among the many conditions leading to personal stress and the ways these relationships develop and change over time (Pearlin et al., 1991).

Rather than placing an emphasis on an individual’s cognitive process as in the Stress Process Model (Pearlin et al., 1981, 1990), the COR model (Hobfoll, 1989, 1998, 2001) is a stress theory which places equal emphasis on the environmental and internal aspects of the stress process. The COR model proposes that stress is a result of a threat to resources and that people will seek to gain and strive to avoid resources loss. As a result, COR places great responsibility with the individual because the model assumes that people will manage to the best of their abilities using the resources at hand (Hobfoll & Lily, 1993). In contrast to the Stress Process Model, COR is less focused on the factors that create stress and focused more on the resources that preserve well-being in the face of stressful situations. The underlying assumption in this model is that people seek to create and maintain their personal characteristics and social circumstances so as to avoid their loss while increasing the likelihood of reinforcement for their behavior (Hobfoll, 1989). Either the perceived or actual loss of resources or lack of gain results
in stress. As such, resources become central for understanding stress with environmental circumstances often threatening or causing a depletion of resources.

COR posits that a basic motivation for people is to obtain, retain, and protect resources and as a result they will strive to limit resource loss and maximize resource gain. As preventing resource loss is particularly salient, loss prevention strategies become important both in everyday challenges and major stressful events (Hobfoll & Lilly, 1993). Adaptation to stressful events requires an investment of resources which leaves individuals, for example family caregivers, vulnerable to further resource loss especially if they lacked resources to begin with. Those caregivers with greater initial resources will more likely meet the challenges of the caregiving role successfully. This cycle of resource loss and gain provides a basis to examine the role of the caregiving while accounting for the environmental context.

Both the Stress Process Model and COR model are appropriate theoretical frameworks to assess family caregiver outcomes. The theories allow for the examination of the physical and mental health effects of caregiving while accounting for the myriad of factors that contribute to the role. However, the two theories differ in fundamental ways. Based on the Stress Process Model (Pearlin et al., 1981, 1990), there are numerous relationships that could be explored when examining the effects of caregiving on family members. These relationships include those between the caregiving context and stressors, the relationship between stressors and manifestations of stress and whether this relationship is mediated by social support and coping. As the focus is on the cognitive process of stress, the theory may underestimate the influence environmental factors have on stress. In this theory, health outcomes are related to the stress process and the individual adaptation to stressful life events, both chronic and major life stressors. Social support and coping are viewed as mediators of stress in a reactive rather than
proactive mechanism. That is, the stressor must occur before the response can be mediated. Negative and positive outcomes are considered as either coping with the stress of caregiving or not.

Unlike the Stress Process Model, social support in COR is not conceptualized as a mediator of stress but rather as a resource to the extent that it helps to preserve valued resources but it can also detract from resources. Coping is also conceptualized differently from the Stress Process Model in that coping can be viewed as stressful. If the resources expended in coping are less than the resulting benefits, the outcome of coping is likely to be negative (Hobfoll, 1989).

COR (Hobfoll 1989, 1998, 2001) as the theoretical framework would examine caregiver outcomes through a different lens than the Stress Process Model. In COR, caregiver outcomes would be viewed as either resource gain or loss. COR is also proactive, in that people strive for resources before a stressful event occurs. Using COR allows for the examination of how environmental factors affect the resources available to family caregivers as well as how resources in the caregiving role can result in both positive and negative outcomes. As such, it provides a foundation in understanding why some caregivers have worse outcomes than others by considering their contextual and environmental situations.

A potential weakness of COR is the criticism that it does not clearly distinguish itself from other stress theories (Lazarus, 2001). Hobfoll (2001) does acknowledge this criticism and demonstrates the differences between the models based on the conceptualization of resources. Another limitation is there is less of a focus on the internal aspects of stress, such as appraisal of the situation as there is in the Stress Process Model. There is an overlap between appraisal and perception of adequacy but this is not explicit in the COR model. In this study the finding that perception of resource adequacy moderates the relationship between caregiving demands and
caregiver strain indicates that the caregiver’s perception is an important factor to consider. Also unlike the Stress Process Model, COR does not explicitly discuss coping as a way of modifying a stressful situation to decrease its threat (Pearlin et al., 1981, 1990). There is an emphasis on how resources can improve well-being and decrease stress. In this study, resource utilization was not found to decrease stress but rather had a significant positive relationship with caregiver strain. The concept of coping may be a more important factor to consider than is indicated by the COR model when examining how stressful situations, such as caregiving, are managed. An area that could be refined for the COR model would be to more explicitly define and include the internal aspects of stress. This would facilitate understanding how personal resources such as coping and resiliency influence and/or help to explain the continuum of the caregiving experience and the resulting outcomes.

Despite its limitations, the COR did offer an appropriate framework for this study as it provided a resource-oriented perspective for examining the relationship between caregiving demands and caregiver outcomes. In future studies COR could be used as a framework to examine the relationship between the caregiver’s resource pool and their physical and mental health outcomes. Each of the four types of resources could be investigated. For example, questions pertaining to housing, transportation and respite care would capture the condition resources. Questions pertaining to social support and level of family support would capture the object resources. To assess personal resources, variables of interest could include the family caregiver’s level of self-esteem and sense of mastery in the caregiving role. For the last type of resource, energies, family caregivers could be assessed on their level of knowledge about available community resources to assist them in their caregiving role.
In addition to investigating the four types of resources, COR could be used as a theoretical framework to examine research questions such as: Do resources in the caregiving role impact the relationship between the broader life conditions and outcomes for the family caregiver? If so, how? What type of resource (object, condition, personal, energies) has the strongest relationship with adaptation in terms of caregiver outcomes? How are the different types of resources interconnected and do they jointly affect the family caregiver outcomes? Is there a synergistic effect between the different types of resources and caregiver adaptation in terms of caregiver outcomes?

COR also allows for examining both the positive and negative aspects of caregiving within the same study. To date, there has been a lack of studies that have addressed not only the strains of caregiving but also the benefits to the family caregiver (Lin et al., 2012; Wakefield et al., 2012). In addition to examining the outcomes for family caregivers, an area that requires further investigation in the caregiving literature is the impact of the perception of resource adequacy. Examining caregivers’ perceptions of the resources they are using is an understudied area. For example, in a national survey on listening to family caregivers, the authors found that only three states asked about family caregiver’s use of support services and support (Kelly et al., 2013). Even the states that asked family caregivers about their needs, no assessment was included of whether currently utilized resources were adequately meeting their needs. An understanding of how these perceptions of adequacy change over the course of the caregiving trajectory is another area for future research. As caregivers provide care to an older adult with a chronic illness, their needs and/or the adequacy of the resources can change. Capturing the individual needs of family caregivers using a longitudinal design with multiple waves will help
to address the need for tailored resources and support the family caregiver as they face the changing complexities of the caregiving role.

Resource utilization of home and community based services has historically been low (Cassado, 2008; Hong, 2010). This is an important issue to address and understand as home and community based services, such as the formal resources investigated in this study (i.e. transportation, home modification, respite care and assistive devices) can help or prevent the admission to an institution for older adults with chronic conditions (Kelly et al., 2013). Understanding the barriers to resource utilization from the caregivers’ perspective, and how this may change over time, is also an area for future research. Using a Patient-Centered Outcomes Research approach would facilitate the communication for older adults and their family caregivers allowing for informed healthcare decisions as well as being educated about available and applicable resources. A patient and family centered approach that asks the family members what their preferences are and why particular resources are not used will help to highlight target areas for understanding how to efficiently tailor resources to meet the needs of individual caregivers.

Future studies could also assess the mental health of the family caregiver. For example, depression could be measured as it has been shown to be an adverse consequence for family caregivers. It is relatively common, associated with decreased quality of life and a risk factor for other negative caregiver outcomes such as functional decline (Covinsky et al., 2003; Pinquart & Sorensen, 2011). To assess how depression affects resource utilization and perception of adequacy studies comparing caregivers with and without depression and those without to see if there are significant differences between the groups would be informative. Understanding how
mental health issues, such as depression, impact resource utilization and their perceived adequacy may highlight additional barriers to accessing resources.

**Conclusion**

Understanding the caregiving experience and the impact it has on family caregivers is a critical consideration given the sheer numbers of caregivers and the invaluable service they provide. In fact, family caregivers are often considered the backbone of care in caring for the growing older adult population (IOM, 2008) and a “critical national health care resource” (Schulz & Sherwood, 2009, p. 23).

This study begins to address the question of how resources in the caregiving role can impact both the positive and negative outcomes for family caregivers. It also highlights that not all resources are equal; different resources are required to support the individual caregiving context. Findings from this study contribute to the importance of providing targeted resources to family caregivers which may be especially salient for those without a supportive family, lack social support or whose needs are unmet in the caregiving role. Providing adequate and tailored resources and supports for older adults and their family caregivers should be a “national priority so that tomorrow’s larger cohorts of older people can look forward to aging with dignity and independence” (Houser, Gibson, & Redfoot, 2010, p. 5).
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<table>
<thead>
<tr>
<th>Variable</th>
<th>Instrument</th>
<th>Type of Variable</th>
<th>Description</th>
</tr>
</thead>
</table>
| Hours spent caregiving per week                | Community Interview | Ordinal          | 1 = 0 to 20 hours  
2 = 21 to 40 hours  
3 = 41 or more hours |
| Length of time caregiving                     | Community Interview | Ordinal          | 1 = less than 3 months  
to 1 year  
2 = 1 to 2 years  
3 = 2 to 4 years  
4 = years or more |
| Progression of caregiving responsibilities    | Community Interview | Ordinal          | 1 = more care  
predicted  
2 = less care provided  
3 = same amount of care provided |
| Functional dependency of older adult care recipient | Community Interview | Ordinal          | Range = 0-6 for ADLs and  
Range = 0-9 for IADLs |
### Table 3.3 Variable Description – cont’d

#### Caregiver Outcome Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Instrument</th>
<th>Type of Variable</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Strain</td>
<td>3 item Global Strain Index scale including physical and emotional strain and financial hardship</td>
<td>Ordinal (will be treated as continuous for analysis)</td>
<td>Range 1 – 5 with 1 = no strain and 5 = very much strain</td>
</tr>
<tr>
<td></td>
<td>7 item Caregiver Strain Index Subscale</td>
<td>Ordinal (will be treated as continuous for analysis)</td>
<td>Range 0 – 7 with 0 = no strain and 7 = very much strain</td>
</tr>
<tr>
<td>Caregiver Satisfaction</td>
<td>2 item Caregiver Satisfaction Scale Subscale</td>
<td>Ordinal (will be treated as continuous for analysis)</td>
<td>Range 1 – 5 with 1 = disagree a lot and 5 = agree a lot</td>
</tr>
</tbody>
</table>

#### Moderator Variables

<table>
<thead>
<tr>
<th>Object (formal) Resources:</th>
<th>10 item scale with the different categories of formal resources</th>
<th>Ordinal</th>
<th>Range 0 – 10 with 0 = no service utilized and 10 = all services utilized</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formal resource utilization</td>
<td>10 item scale with 3 possible responses</td>
<td>Ordinal</td>
<td>Range 1 - 3 with 1 = resource did not meet needs, 2 = partly met needs and 3 = fully met needs</td>
</tr>
<tr>
<td>Formal resource perception of adequacy</td>
<td>8 item Medical Outcomes Study Social Support Survey subscale</td>
<td>Ordinal (will be treated as continuous for analysis)</td>
<td>Range 1 – 4 with 1 = strongly disagree and 4 = strongly agree</td>
</tr>
<tr>
<td>Condition (informal) Resources: Social Support</td>
<td>8 item Family Support Scale</td>
<td>Ordinal (will be treated as continuous for analysis)</td>
<td>Range 1 – 4 with 1 = no disagreement and 4 = quite a bit of disagreement</td>
</tr>
</tbody>
</table>
Table 3.3 Variable Description – cont’d

<table>
<thead>
<tr>
<th>Variable</th>
<th>Instrument</th>
<th>Type of Variable</th>
<th>Description</th>
</tr>
</thead>
</table>
| Gender                                  | Community Interview         | Dichotomous      | 1 = male  
                                          |                             | 2 = female                    |
| Marital Status                          | Community Interview         | Dichotomous      | 0 = non-spouse  
                                          |                             | 1 = spouse                    |
| Race/Ethnicity                          | Community Interview         | Nominal          | 1 = Caucasian  
                                          |                             | 2 = African American  
                                          | 3 = Hispanic                 | 4 = Other                     |
| Education                               | Community Interview         | Ordinal          | 1 = Less than high school  
                                          |                             | 2 = High School               | 3 = More than High School     |
| Self-reported health for family caregiver| Single-item question       | Ordinal          | Range 1 - 4 with 1 = poor health and 4 = excellent health |
| Self-reported health for the older adult care recipient | Single-item question | Ordinal          | Range 1 - 4 with 1 = poor health and 4 = excellent health |
| Age of older adult care recipient       | Community Interview         | Ordinal          | 1 = 65 – 74  
                                          |                             | 2 = 75 – 84                   | 3 = 85 and older              |
Table 3.4 Comparison of Original Caregiver Strain Index Questions and Caregiver Strain Index Subscale Questions

<table>
<thead>
<tr>
<th>Caregiver Strain Index Question</th>
<th>Modified Caregiver Strain Index Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cargiving is inconvenient (e.g., because helping takes so much time)</td>
<td>As a caregiver you have had less time for other family members than before.</td>
</tr>
<tr>
<td>There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)</td>
<td>As a caregiver you have had to give up vacations, hobbies, or your own activities.</td>
</tr>
<tr>
<td>There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)</td>
<td>I don’t have as much privacy when I take care of (SAMPNAME).</td>
</tr>
<tr>
<td>Caregiving is confining (e.g., helping restricts free time or cannot go visiting)</td>
<td>Taking care of (SAMPNAME) limits my social life or free time.</td>
</tr>
<tr>
<td>Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)</td>
<td>I have to give (SAMPNAME) almost constant attention.</td>
</tr>
<tr>
<td>Caregiving is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)</td>
<td>Taking care of (SAMPNAME) has caused my health to get worse.</td>
</tr>
<tr>
<td>Caregiving is a financial strain</td>
<td>Taking care of (SAMPNAME) costs more than I can really afford.</td>
</tr>
</tbody>
</table>
**Table 3.5** Instrument Properties Reported for the Informal Caregiver Survey Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Scale Properties</th>
<th>Scale Sample Size</th>
<th>Score Range</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Strain</td>
<td>3 item Global Strain Index Scale, 5 point Likert Scale</td>
<td>N = 1894</td>
<td>3 - 15</td>
<td>$\alpha = 0.782$</td>
</tr>
<tr>
<td></td>
<td>7 item Caregiver Strain Index subscale, yes /no responses</td>
<td>N = 1867</td>
<td>0 - 7</td>
<td>$\alpha = 0.825$</td>
</tr>
<tr>
<td>Caregiver Satisfaction</td>
<td>2 item Caregiver Satisfaction subscale, 5 point Likert scale</td>
<td>N = 1898</td>
<td>2 - 10</td>
<td>$\alpha = 0.777$</td>
</tr>
<tr>
<td>Resources:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Support</td>
<td>8 item Medical Outcomes Study Social Support Survey subscale, 4 point Likert Scale</td>
<td>N = 1753</td>
<td>8 – 32</td>
<td>$\alpha = 0.919$</td>
</tr>
<tr>
<td>Family Support</td>
<td>8 item Family Support Scale, 4 point Likert Scale</td>
<td>N = 1782</td>
<td>8 - 32</td>
<td>$\alpha = 0.931$</td>
</tr>
</tbody>
</table>
Appendix A
Hi Stephanie,

Thank you for this information. I appreciate knowing that a new PRAMS submission is not required for my dissertation research.

Regards,
Gwen

Gwen McGhan RN, MN
Doctoral Student
Penn State University, School of Nursing
127 HHD East
University Park, PA 16802

gem18@psu.edu

On Tue, Oct 23, 2012 12:17 PM, "Krout, Stephanie" <sqk2@psu.edu> wrote:
Hi Gwen,

Joyel forwarded me your message for response because I review the Exemption Determinations and Non-Human/Non-Research submissions.

If you are using the same data set as was submitted for IRB #38964 ("The Older Adult Caregiving Experience: An In Depth Exploration Using the National Long-Term-Care Survey"), then a new submission is not warranted since this data set was determined to be Non-Human/Non-Research and does not meet our definition of “human participant research.”

Thank you,

Stephanie L. Krout

Research Compliance Coordinator

The Pennsylvania State University | Office for Research Protections | The 330 Building, Suite 205 | University Park, PA 16802

Direct Line: (814) 865-2935 | Main Line: (814) 865-1775 | Fax: (814) 863-8699 | www.research.psu.edu/orp

---He is your friend, your partner, your defender, your dog. You are his life, his love, his leader. He will be yours, faithful and true, to the last beat of his heart. You owe it to him to be worthy of such devotion.

---Rescuing one dog may not change the world but for that one dog, his world will be changed forever.

---Within the heart of every stray lies the singular desire to be loved.
Appendix B
SECTION A: Amounts and Kinds of Help

AKH BEGIN
Time & Date

1. Paid to Help
   AKH_1

2a. Help Around Inside
    AKH_AD_A

2b. Help Eat?
    AKH_AD_B

2c. Help In/Out Bed?
    AKH_AD_C

2d. Help Dressing?
    AKH_AD_D

2e. Help Injections
    AKH_AD_E

2f. Help Medicine
    AKH_AD_F

For all "Yes" answers (1-2f),
ask only the relevant corresponding questions 3a - 3f.

If = "No" to All
  Skip to 4a.
  AKH_BTH1

If = Any "Yes"

    CAPI CHECK
    AKH_CHKAD

    If = "No" to All
      Skip to 4a.
      AKH_BTH1

3a. Times Help Around Inside
    AKH_AT_A

3b. Times Help Eating
    AKH_AT_B

3c. Times Help with Bed
    AKH_AT_C

3d. Times Help Dressing
    AKH_AT_D
12b. Hours Alone in Room
AKH_60_H_R

13a. Care Interrupt Sleep?
AKH_7A

If = No, D_R
Skip to 14a.
AKH_8_A

If = Yes
13b. Times Sleep Interrupted
AKH_7B

14a. Helped When Ill
AKH_8_A

14b. Special Needs
AKH_8_B

14c. Emotionally Difficult
AKH_8_C

14d. Difficult to Move
AKH_8_D

AKH END
Time & Date

SECTION B: Help from Others

HFO BEGIN
Time & Date

1. Replacement Caregiver
HFO_1

2. Any Government Help
HFO_2

3a. Requested Financial Information
HFO_3A

If = No
Skip to 3d.
HFO_3D_1

If = D_R

If = Yes

3b. Who Helped?
HFO_3B_1

Skip to 4a.
HFO_4A
SECTION C: Caregiver’s Experience

CGE BEGIN
Time & Date

1a. No Privacy
CGE_1_A

1b. Limited Social Life
CGE_1_B

1c. Constant Attention
CGE_1_C

HFO END
Time & Date
1d. Worse Health
   CGE_I_D

1e. Can't Afford Care
   CGE_I_E

2. Magnitude of
   Physical Strain
   CGE_2

3. Magnitude of
   Emotional Strain
   CGE_3

4. Magnitude of
   Financial Hardship
   CGE_4

5a. Exhaustion Level
    CGE_5_A

5b. Too Much to Handle
    CGE_5_B

5c. No Time For Self
    CGE_5_C

5d. No Progress
    CGE_5_D

6. Stress Level
    CGE_6

7a. Feel Good About Self
    CGE_7_A

7b. Appreciate Life More
    CGE_7_B

8a. Keep Up At Night
    CGE_8_A
SECTION D: Caregiver’s Living Situation

CLS BEGIN
Time & Date

CHECK RELATIONSHIP
CLS_OK1
If = Yes
Skip to 7a.
CLS_T_1
If = No
CHECK HH MEM
CLS_OK2
If = No
Skip to 3.
CLS_3_MIN
If = Yes

CLE END  
Time & Date
SECTION E: Caregiver's Work Situation

CWS BEGIN
Time & Date

1a. Length Caregiving
CWS_1A

1b. Amount of Care
If = Same, D, R
CWS_2B
If = More, Less
CWS_2C

1c. When Amount Care Changed
CWS_2C

Note: Question 2 not used in 2004.
5b. How Long Ago?
CWS_5B

If = Yes

6a. Arranged Work Schedule
CWS_6A

If = Yes

6b. How Long Ago?
CWS_6B

7a. Taken Time Off
CWS_7A

If = Yes

7b. How Long Ago?
CWS_7B

7c. Length of Time Without Pay
CWS_7C_N, CWS_7C_U

8a. Quit Job
CWS_8A

If = Yes

8b. How Long Ago?
CWS_8B

9a. Employer
CWS_9A

9b. Business Type
CWS_9B

9c. Kind of Work
CWS_9C

9d. Key Duties
CWS_9D
SECTION F: General Information on Caregiver

GIC BEGIN
Time & Date

1a. Health Status
GIC_tA

1b. Heavy Housework
GIC_HW
14c. Monthly SSI Estimate
GIC_14C

Note: Questions 15 & 16 not used in 2004.

17a. HH Receive Food Stamps
GIC_17A
If = Yes

17b. Food Stamp Value
GIC_17B
If = D, R

17c. Monthly Food Stamp Estimate
GIC_17C

18a. HH Receive TANF?
GIC_18A
If = No, D, R
Skip to 19a
GIC_16A

18b. Monthly TANF Estimate?
GIC_18B
If = D, R

18c. Monthly TANF Estimate
GIC_18C

19a. HH Receive Other Welfare?
GIC_19A
If = No, D, R
Skip to 21a
GIC_21A

Open Family Roster
19b. Name(s) on Check
CGFEKE01-20

Close Family Roster
19c. Check Amount
GIC_19C1
If = $1 - $5000
Skip to 16d
FAML_XF1-20
1. CG Available
   CG.STAY
   If = No, D, R, Set CG_OUTCOME = 782
   If = Yes
   2. When Available
      CG.COMDATE
         CAREGIVER OUTCOME
         CG_OUTCOME
      CAREGIVER END
VITA

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EDUCATION

PhD  August 2014  The Pennsylvania State University, University Park, Pennsylvania
       Nursing, Minor in Gerontology

BA  2009  University of Alberta, Edmonton, Alberta

MN  2007  University of Manitoba, Winnipeg, Manitoba

BN  2003  University of Manitoba, Winnipeg, Manitoba

EXPERIENCE

2013 – 2014  Project Administrator, Hartford Center of Geriatric Nursing Excellence, The
             Pennsylvania State University, University Park, Pennsylvania

2012 – 2014  Teaching Assistant, College of Nursing, The Pennsylvania State University,
             University Park, Pennsylvania.

2010 – 2013  Research Assistant, College of Nursing, The Pennsylvania State University,
             University Park, Pennsylvania

SELECTED PUBLICATIONS

Who Wants to Die in Here? Perspectives of Prisoners with Chronic Conditions. Journal
of Hospice and Palliative Nursing, 16(3), 173-181.

Challenges Faced by Older Adult Women. Journal of Gerontological Nursing, 39(6), 45-
54.

Influence of the Culture of Care on Informal Caregivers’ Experiences. Advances in
Nursing Science, 35(1), 64-76.

SCHOLARSHIPS AND AWARDS

Janet A. Williamson Excellence in Graduate Studies Award (2013-2014)
Sigma Theta Tau International, Rising Star of Scholarship and Research (2011)
Jonas/Hartford Predoctoral Scholar (2010 – 2012)
Penn State Hartford Center Predoctoral Scholar (2010-2014)