EFFORT IN CAREGIVING AND ITS RELATIONSHIP TO
CAREGIVER DEPRESSIVE SYMPTOMS

by

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Submitted in partial fulfillment of the requirements
For the degree of Doctor of Philosophy

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May, 2009
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Acknowledgements

This dissertation study was possible because of the effort of many. I would like to acknowledge my dissertation committee chair, Dr. Diana L. Morris; as well as the rest of my committee: Dean May L. Wykle, Dr. Jaclene A. Zauszniewski, and Dr. Aloen L. Townsend. Their guidance and critique of the work, from conceptualization to conclusion, is very much appreciated.

I would also like to acknowledge funding that assisted me with two phases of this research. First, the pilot study that supported this dissertation study was designed and conducted as part of Summer Training in Aging Research Topics – Mental Health (START MH) fellowship. The National Institute of Mental Health funding, through the University of California San Diego, assisted me to conduct that study. Secondly, a research award from the Frances Payne Bolton School of Nursing Alumni Association research committee assisted me in recruiting the sample of caregivers for this study.

I appreciate the emotional and practical support of family and friends, who lived this experience with me. Finally, I would like to acknowledge the generosity of the family caregiver volunteers who participated in this study.
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Effort in Caregiving and its Relationship to Caregiver Depressive Symptoms

Abstract

By

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The purposes of this study were to describe effort as experienced by family caregivers in doing the work of caregiving to older adults and to investigate a possible relationship between effort and depressive symptoms in family caregivers. Effort is exerting energy to perform a workload; to balance the demands of work and prevent adverse health outcomes. Caregiving is work that is associated with disproportionately prevalent adverse health outcomes, including depression. With the theoretical influences of stress process and demand-control theory, a hybrid theoretical explanation was developed to conceptualize effort in caregiving and the effects of exerting energy to perform the caregiving workload on family caregivers.

A non-probability sample of caregivers was recruited in the community. Caregivers completed a mailed questionnaire that characterized the caregiving situation; and measured their workload; effort; and depressive symptoms. The final sample was 110 caregivers; mostly female; approximately 58 years old; Caucasian; employed full time; living with the care receiver, receiving some help from other family caregivers; and not
receiving help from formal caregivers older adult care receivers. Qualitative and quantitative data were obtained to describe four types of effort: physical; mental; emotional; and time-related. Many caregivers suggested that effort is multidimensional and several had difficulty placing their descriptions of effort into discrete types of effort. All four types of effort were significantly positively correlated with depressive symptoms, workload time, workload difficulty, and overload. Higher workload time, difficulty, and overload were related to more depressive symptoms. Poorer caregiver health and lower care receiver functional ability were related to more depressive symptoms, higher effort, and more overload. Higher levels of mental and emotional effort were reported, perceived physically, and highly intercorrelated. Self-assessed health, care receiver ADL, and overload predicted depressive symptoms. No direct effects were observed of effort on depressive symptoms. Model testing and methodological triangulation are recommended to investigate these relationships further. This information has the potential to guide health care providers and policy makers toward preventive physical and mental health care of family caregivers; the nation’s primary caregivers of older adults.
Chapter 1
Introduction

Purpose

The purposes of this study were to describe effort as it is experienced by family caregivers in the work of caregiving to older adults and to explore the relationship between effort in caregiving and depressive symptoms in family caregivers. An increased understanding of the role of effort in the work of family caregiving is needed to better understand the impact of caregiver workload on family caregivers’ physical and mental health. People may respond to more workload demands by working harder – that is, putting forth more effort – and this may be deleterious to their health. Family caregivers manage a challenging workload, and research suggests that the workload of caregiving adversely affects the caregiver’s health (Canfield, 2002; Schulz & Beach, 1999; Vitaliano, Zhang, & Scanlan, 2003). Effort, as a way in which individuals experience the demands of a workload such as caregiving, has not been examined in nursing research. Chapter one addresses the significance of the demands facing family caregivers; the significance of this research to nursing; and the theoretical framework, theoretical definitions, and research questions that guided this study of effort in family caregiving.

To understand the role of effort in the workload of caregiving, one must first understand the theoretical underpinnings about effort in relation to an individual’s resources and the demands of the work. Effort is a core concept in the work – health relationship (Hockey, 1993), where resources are emphasized. Effort, as a resource, is theorized to be allocated by an individual in response to demands and stressors in a workload (Kahnemann, 1973; Schonpflug, 1986; Hockey, 1997). In occupational
psychology, engineering, exercise, and work – stress research, effort is studied because of concerns about the impact of the workload on the worker’s performance and compensatory effects on the worker’s health (Hockey, 1993; DiDimenico, 2003). In caregiving, one of these resources may be an individual’s appraisal of the caregiving situation. Appraisal, or the evaluation of and attitudes toward the caregiving situation, has been considered in relation to the workload of caregiving and caregiver outcomes. In an investigation of caregiving stressors, appraisal of a heavy task workload in caregiving was linked to a lower affect (Braithwaite, 2000), but no clear relationship has been established between appraisal and the development of psychological health symptoms. There may be other resources which operate between appraisal and psychological health outcomes, because appraisal alone does not explain how the work of caregiving gets done or affects the worker. That is, appraisal does not necessarily lead to a particular response on the part of the caregiver. Effort is considered a core resource that the family caregiver uses to perform and regulate the workload of caregiving.

In the typical workplace, estimation is made of the demands of a workload; necessarily, the difficulty of tasks raises attention to the importance of evaluating the workload and the stress that can result from overloading the worker (Weithoff, 1997). A formal estimation of the intensity of the workload, or task analysis, attempts to characterize the extent of the work, in considering the individual’s performance and health (Weithoff, 1997; Shepherd, 1994). Effort is intricately linked to the demands and tasks inherent in that workload, as the individual attempts to assert either a regulating, low grade of effort, or direct control in the form of high effort.
Borg (1998) raised an important theoretical distinction about perception and workload: People cannot perceive a decrease in their productivity or capacity to work, but they can perceive an increase in their exertion. When the workload is physical in nature, perceived exertion is the way the individual experiences physical effort (Borg, 1970; 1998), where effort may be modulated to adjust to the stress of the work and the physiological response of the worker. When the workload is cognitive or involving information processing, the perceptual qualities of effort are perceived as physiological observances related to exerting energy, such as fatigue and heart rate variability (Weithoff, 1997; Schonpflug, 1986). Mental effort is exerting mental energy toward the performance of cognitive tasks (Mulder, 1986; Kahnemann, 1973), and is perceived physiologically.

Caregiving does not occur in a predictable workplace. Nevertheless, relationships between effort and workload may be discovered that clarify how caregivers manage the stressors, demands, and tasks that constitute the work of caregiving. Family caregivers are expected to perform the overwhelming majority of the work in caring for older adults without an apparent discussion of how to evaluate their effort and its impact on their performance or health. Conceptualizing caregiving as a workload has the potential to increase nurses’ understanding of the impact of caregiving on the caregiver’s health and functioning.

Statement of problem

The work of caring for older adults in America is performed mainly in the community, where at least 80% of care is provided by family caregivers (American Association of Retired Persons & National Alliance for Caregiving [AARP & NAC],
This care estimate that family caregivers provide has been stable for over 30 years (Kunkel, Applebaum, & Nelson, 2003/2004). Over 44 million family caregivers (NAC & AARP, 2004) provide care to a growing elderly population that will increase over the next 20 years from the current estimate of 11% to nearly 20% of the population (AARP & NAC, 1997; Bierman, Spector, & the AHRQ Task Force on Aging, 2001). Over 40% of these caregivers give 20 hours or more of care each week (Collins, 1999). Although in a recent, national, caregiving survey over 25% of respondents reported giving at least 20 hours of care per week; another half reported giving eight or fewer hours of care per week (NAC & AARP, 2004). Nearly a third of caregivers responded that they had been providing care for less than a year, while another third were veteran caregivers of at least five years’ duration in caregiving (NAC & AARP, 2004). The use of formal care services was reported by only about a fifth of these caregivers (NAC & AARP, 2004). These findings illuminate how characteristics of the caregiving situation representing the intensity and duration of care – hours of care per week and duration of care – vary broadly among family caregivers.

Family caregivers represent a prominent healthcare resource to the nation in that they provide the majority of care to older adults, and are essentially unpaid. If family caregivers were not able to provide this free care, it would be provided by the more costly formal caregiving providers. The value of family caregiving was recently estimated at over $300 billion (Arno, 2006). Just four years earlier, this figure was $250 billion, and that figure represented over twice the total cost of formal care in home care ($32 billion) and nursing home care ($92 billion) combined (Arno, 2002; Levit, Smith, Cowan Lazenby & Martin, 2002) for the same time period. The $250 billion figure represented
an escalation of $50 billion from the figure reported just three years earlier (Arno, Levine, & Memmott, 1999).

Family caregivers are a diverse and large workforce in the American health care of older adults. Certain demographic trends have been noted in describing family caregivers and this workforce of informal caregiving. Family caregivers tend to be largely spouses or adult children, predominantly female, and working in a job outside the home in addition to providing care.

Family caregiving has been female-dominated, with women comprising 61% (AARP & NAC, 2004) to 80% (Yin, Zhou, & Bashford, 2002) of all family caregivers. These caregiver demographics may be shifting, with recent evidence suggesting the direct involvement of more men in family caregiving. Over 40% of caregivers now are men (Arno, 2002; National Family Caregivers Association, 2005), though this is suggested to be because women urge them into, accompany them in, and substitute for them in family caregiving (Gerstel & Gallagher, 2001).

Findings from a national survey of caregiving suggest that over 60% of family caregivers are working, and that most of those caregivers work full time in addition to providing unpaid care to older adults (Metlife Mature Market Institute / NAC, 2004). The average age of a caregiver is 47 (NAC & AARP, 2004). While the majority of caregivers in the caregiving workforce are middle to older age (NAC & AARP, 2004), more than a third of older adults are estimated to provide care to family members (Johnson & Schaner, 2005), and many are under age 18 (NAC & United Hospital Fund, 2005). Differences in the caregiving experience due to ethnicity have been examined. For example, African American caregivers are more likely to be an adult child than a spouse,
as compared with Caucasian caregivers who are more likely to be a spouse (Connell & Gibson, 1997). Complex relationships among other resources of the caregiver, such as the types of coping, income, age, and social support have been thought to be associated with caregiver depressive symptoms (Sorensen & Pinquardt, 2005), though the resource of effort has not been investigated.

Demands on family caregivers

For well over twenty years, the findings of caregiver research suggest a strong theoretical connection between the workload of caring for older adults and diminishing caregiver psychological health, and some of this research is specific to the caregivers of persons with dementia (Haley, Levine, Brown, Berry & Hughes, 1987). Changes in psychological health are thought to be related to both the caregiving experience and degrading physical health of the caregiver (Haug, Ford, Stange, Noelker, & Gaines, 1999; Vitaliano, Zhang, & Scanlan, 2003). Burden was often conceptualized as a caregiving outcome (Zarit et al, 1980). Burden, according to early conceptualizations, refers to a load on the family member (Hoenig & Hamilton, 1966). This is more consistent with the conceptualization in this study of burden as a component of workload. Thus burden is a factor that may be associated with the outcomes of caregiving rather than an outcome per se.

Demands on family caregivers and the tasks they perform typically are described as the activities of daily living (ADL) and instrumental activities of daily living (IADL) with which they assist. For example, in a national survey, 80% of respondents provide assistance with three or more IADL, and all respondents were assisting with at least one ADL or IADL (NAC & AARP, 2004). The time and the difficulty associated with those
tasks is also considered (Bakas, Austin, Jessup, Williams, & Oberst, 2004). Caregiving may be conceptualized according to the amount or type of help that caregivers provide to older adults. Specifically, there is controversy in the literature about whether a differences exist among caregivers according to the condition of the older adult care receiver, with some findings suggesting dementia caregivers deal with significantly different needs for care (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999), while others found no significant difference in outcomes (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000) according to the condition of the care receiver. While it is important to examine the need for care in the caregiving situation in terms of the workload carried by the family caregivers, it is ultimately important to examine the ways the workload and the effort used in meeting those needs relates to the mental health outcomes of the caregiver.

In what can be described as a transition into caregiving, some of the demands on family caregivers are the realization that caregiving is required of the older adult. A transition into caregiving based on care receiver demands can be conceptualized longitudinally: The caregiver is a caregiving “entrant” within two months, or a “new” caregiver of two to twelve months duration, and these caregivers may be further distinguished in the caregiving trajectory from the “veteran” caregiver who has over twelve months experience (Lawton, Moss, Hoffman, & Perkinson, 2000, p. 439).

With shorter hospital stays, policy, and economic factors limiting the ability for older adults to receive skilled care in formal care settings, many technically-intensive tasks and behavioral care responsibilities shift to the home. This was formally acknowledged in an investigation of the demands facing caregivers to people with cancer
(Oberst, Thomas, Gass, & Ward, 1989), though it is thought to be similar for caregivers to people who have dementia (Montgomery et al, 1985) and older adults with chronic illnesses. In particular, there may be additional demands on caregivers immediately following the hospitalization of an older adult. These have been conceptualized as new demands (Given, Given, Stommel, & Azzouz, 1999), and may represent an increased workload in caregiving.

An interpersonal demand on family caregivers is the relationship between the caregiver and the care receiver. Family caregivers deal with the care needs of the older adult, including dealing with the behaviors of the older adult. Many caregiving studies examined the specific stressors related to behaviors of persons with dementia (Haley et al., 1987; Schulz et al., 1990; Schulz, 2000; Mittleman, Ferris, Shulman, Steinberg, Ambinder, Mackell, & Cohen, 1995).

The caregiving situation itself, besides putting the caregiver at risk for physical and mental health problems, may present an independent risk for harmful or abusive behavior toward the care receiver (Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2005). It is not clear if this association could be due to the demands of the caregiving situation exceeding the caregiver’s effort in meeting those demands. Despite this increased vulnerability, there appears to be a clear benefit to the care receiver’s function and survival through improved coping and psychological outcomes of the caregiver (McClendon, Smyth, & Neundorfer, 2004). This study examined the caregiving situation, the effort and coping used in caregiving, and the psychological health outcomes of the caregiver.
In this study, the family caregiver was considered an irreplaceable worker who is also a member of a vulnerable population. The family caregiver’s psychological health was the focus of this study. One of the demands on family caregivers is suggested in the impact of caregiving on the family caregiver’s health. Family caregivers have physical and psychological health difficulties that far exceed their non-caregiving counterparts (Amirkhanyan & Wolf, 2003; Gonzalez-Salvador, Arango, Lyketsos, & Barba, 1999; Haley, Levine, Brown, Berry, & Hughes, 1987; Pinquart & Sorensen, 2003; Schulz, O’Brien, Bookwala, & Fleissner, 1995). Even mortality rates are more pronounced among caregivers (Schulz & Beach, 1999). This study examined the health impact of the workload of caregiving on the caregiver.

**The health consequences of caregiving**

Family caregivers fulfill a necessary and valued role in society in addressing the caregiving needs of older adults, but not without a potential effect on their own health. The documented health risks of caregiving represent a significant health crisis in society. While many rewards are associated with caregiving, some of the stressors associated with caregiving may render the caregiver vulnerable to distress and disability. Family caregivers are more likely to suffer physiologically and psychologically when compared with non-caregivers (Vitaliano et al, 2003; Amirkhanyan & Wolf, 2003). To the extent that psychological symptoms interfere with the health and functioning of the family caregiver, they pose a vulnerability to the health and functioning of the older adult (Beach et al., 2005) as well as the caregiver’s own vulnerability to mortality (Schulz & Beach, 1999). These morbidity and mortality risks associated with caregiving suggest the vulnerability lies in the caregiver’s inattention to their own health and functioning.
Caregiver mortality represents puts in jeopardy the role that family caregivers fulfill in society, as they are the primary care providers for older adults.

Caregiver studies consistently yield concerns about workload and adverse health outcomes, yet intervention studies that have been aimed at reducing the harmful effects of caregiving, such as caregiver depressive symptoms, have not translated into reduced depressive symptoms among caregivers, as the findings of a recent meta-analysis (Vitaliano et al., 2003) suggest. Further investigation of the conceptual links associated with caregiver depressive symptoms is warranted. In this study, effort was conceptualized as a potential missing link in caregiving and nursing theoretical explanations for depressive symptoms among family caregivers.

Caregiver depressive symptoms

The negative health consequences of caregiving may come in the form of depressive symptoms. Depressive symptoms are the focus of inquiry in this study. The diagnosis of depression requires symptoms of a significant frequency and persistence according to standard diagnostic guidelines in the Diagnostic and Statistical Manual Fourth Edition, Revised (APA, 2000), which means that many caregivers who have sub-threshold symptoms will not be identified as having depression. It is these depressive symptoms that compromise the psychological and physical health and functioning of the caregiver. The degradation in health and functioning is likely to further compromise the caregivers’ ability to meet the demands of the workload of caregiving. Effort may be an additional explanatory factor for how the demands of caregiving may wear the caregiver down and manifest in depressive symptoms. To make a distinction, the prevalence of depressive symptoms and a diagnosis of major depression are among the concepts that
are often unfortunately used interchangeably in studies. Four of these concepts, depressive symptoms, depressive syndrome, depression, and psychiatric illness were identified by Ensel (1986), who emphasized that it is the prevalence of depressive symptoms in a population, and not the clinical diagnosis of psychiatric disorders with which researchers are interested. Furthermore, most depression scales are used to describe the presence of depressive symptoms in individuals, and not depression (Ensel, 1986). In considering this difference, Ensel suggests that it is an inappropriate conceptual leap to use a self-report scale to diagnose major mood disorders in community-based populations. In this study, the presence of depressive symptoms, and not depression, is the conceptual focus.

The prevalence of negative psychological and mental health symptoms for caregivers are disproportionately higher than non-caregivers (Vitaliano, Zhang, & Scanlan, 2003; Amirkhanyan & Wolf, 2003). For example, family caregivers of older adults have a disproportionately high prevalence of depressive symptoms and poor health outcomes, with suggestions of as many as 30 to 40% displaying significant depression (Cochrane, Goering, & Rogers, 1997; Covinsky, Newcomer, Fox, Wood, Sands, Dane, et al., 2003; Tennstedt, Cafferata & Sullivan, 1992; Wai Li, Seltzer, & Greenberg, 1999). Nearly half of caregivers have depressive symptoms and as many as one third have clinically significant depression (Tennstedt, Cafferta, & Sullivan, 1993; Schulz et al., 1995; Covinsky et al., 2003; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004). Some evidence suggests a relationship between caregiving and the development of depressive symptoms. When followed longitudinally, almost 40% of family caregivers converted from asymptomatic to significant depressive symptomatology (Schulz,
Williamson, Morysz, & Biegel, 1993). Additional evidence suggests that differences in the amount of depressive symptoms during caregiving may affect the amount and severity of depressive symptoms that are present following bereavement, or the end of caregiving (Aneshensel, Botticello, & Yamamoto-Mitani, 2004). After many years of research on the relationship between caregiving stressors and depressive symptoms, it is still unclear to what extent if any caregiving actually causes depressive symptomatology.

Caregiving researchers have described a prevalence of depression among family caregivers that exceeds the prevalence among non-caregivers (Amirkhanyan & Wolf, 2003; Haley et al., 1987; Collins, Stommel, Wang, & Given, 1994; Ranney, 2000; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). The relationship between effort and depression has been studied outside of caregiving and nursing research. In these studies, the findings suggest a directional relationship where problems with effort were predicted by the presence of depression (Roy-Byrne, Weingartner, Bierer, Thompson, & Post, 1986; Cohen, Weingartner, Smallberg, Picar, & Murphy, 1982); that is, depression led to problems with effort. In this study, a different direction in this relationship is suggested. It is not clear if problems with effort in caregiving lead to caregiver depression. For this descriptive correlational study, the relationship was examined. This relationship has not yet been documented in the caregiving literature and nursing literature.

Significance to Nursing

Effort in the work of family caregiving is an important area of inquiry for nurses. A novel explanation may be developed about the impact of the workload on the family caregiver, who is the performer of this work. Over the last thirty years, effort has been
Empirically linked to workload, task completion, exertion, performance, and recuperation in attempts to describe the interface of the work and the individual. An especially relevant relationship for nursing researchers to pursue is the link between unrestrained effort and the development of adverse health conditions due to overexertion. Nursing researchers have not yet considered the role of effort in investigating the workload demands on family caregivers and the health consequences of caregiving. Further, protective factors and risk factors associated with varying amounts of this effort in family caregiving have not yet been described.

Nursing as a discipline has fundamentally been concerned with people and their interactions with their environment to promote health and avoid adverse health outcomes. Represented as metaparadigm concepts, nursing as a discipline is concerned with the interactions of person, environment, and health (Fawcett, 2005). This study attempted to specify relationships among these abstract concepts, to conceptualize a basis for nursing inquiry into the health and functioning of the family caregiver. Family theorists would postulate that the family is an environment that is most immediately familiar to people (Minuchin, 1974). In conceptualizing family caregiving, the caregiving relationship and the caregiving situation is essentially a kind of environment. Nursing knowledge that is based on person environment health interactions has philosophically guided inquiry into the health and wellbeing of caregivers of older adults. The mid-range level theoretical framework for this study was built on these meta-paradigm concepts of person, environment, health, and nursing.

A hybrid theory was developed for this study. Elements were borrowed from other disciplines. The author is strongly influenced by the grand level theories and
conceptual frameworks developed by nursing theorists. An intended outcome of this study is a theoretical explanation for nursing knowledge development. An underpinning of the theoretical development in this proposed nursing study is the person-environment interaction that is historically characteristic of nursing as a discipline. The vital role that nursing plays in understanding the constant interaction of people with the demands of their environment is articulated in the seminal explanations by nurse theorists including Nightingale, Neumann, and Rogers (Fitzpatrick & Whall, 2004; Fawcett, 2005).

Nursing research such as this study, at a mid-level range of abstraction (Fawcett, 2005), has the potential to both guide the care of caregivers and offer theoretical support for these grand theory explanations. The abstract concepts of person, environment, and health are applied to a study of caregiving. It was posited in this study that family caregivers are in a constant interaction with the caregiving situation toward achieving desirable health outcomes for both the older adult care receiver and themselves. Unfortunately, the trend has been alarmingly headed in the direction of adverse caregiver health outcomes, according to the scholarly literature on family caregiving.

The conceptualization in this study was derived from related fields, toward a synthesized nursing theory of effort in caregiving. This is consistent with the recommendation by Walker and Avant (2005) that synthesis and derivation should be priorities for nursing knowledge development now and in the future. The potential for adverse health effects of family caregiving may be buffered by the knowledge nurses bring to the care of caregivers. Nursing inquiry has guided explanatory and intervention studies with family caregivers of older adults. As nursing is a practice discipline (Donaldson & Crowley, 1978), the vital contribution of nursing research is its translation
into practice. More work is needed in translating the research findings and prevention concepts into practice with caregivers and their older adult care receivers.

The essence of praxis in family caregiving is using knowledge to guide primary, secondary, and tertiary prevention with caregivers. The following are putative examples of praxis in nursing intervention with caregivers. Praxis in the form of primary prevention for family caregivers would be evidenced by educating future caregivers early in life to prepare for the role and responsibilities of caregiving. Praxis in the form of secondary prevention would involve early identification of any interference with the optimal health and functioning of the family caregiver, and early intervention that is based on the evidence for effective caregiver interventions. Praxis in the form of tertiary prevention would be evidenced by stabilizing a difficult caregiving situation: When nurses encounter caregivers in distress, tertiary prevention would guide care to reduce the excess disability of the caregiver and address the resultant vulnerabilities to the care receiver. More nursing knowledge is needed in identifying the factors affecting the workload of family caregiving, so nurses can use evidence-based methods to assist family caregivers to modulate their effort toward more desirable health outcomes.

America relies on family caregivers to provide the majority of care to older adults. Because of this reality, it is not sufficient to focus only on the needs of the caregiving situation if we as a nation are to support this workforce of family caregivers. Disability associated with performing the workload of caregiving represents a serious risk to both the caregiver and the older adult who receives that care. Recently, it was shown that caregiving activities operate separately from caregiving needs in the association between caregiving and caregiver health outcomes (Amirkhanyan & Wolf, 2006). This finding
suggests that distinguishing the needs, or demands, of caregiving situation from the
family caregiver’s effort in their caregiving activities would add explanatory power to
caregiving studies. The findings from this study have the potential to bring an enhanced
understanding to nurses about how effort is related to the workload of caregiving.

The effects of the workload on the worker have been studied outside of nursing
research for well over 30 years (Karasek, 1979; Hockey, 1993). Specifically, the
development of adverse health conditions has been suggested to be related to the amounts
and that workers use. (Mulder, 1996; Hockey, 1996). A certain amount of effort may
always be present, though it may be at a minimal or preferred level (Borg, 1998), or
operating in a regulating or sub-perceptual manner (Hockey, 1986; Mulder, 1986). In a
nursing investigation of effort, family caregivers nearly unanimously agreed that, at a
minimum, mental effort is always present if one is a caregiver, and that effort is nearly
always perceived physically (Juratovac, Wykle, & Morris, 2006).

Explaining the workload of family caregiving and its associated health effects are
appropriately in the domain of nursing research. The nursing metaparadigm concepts of
person, environment, and health are directly represented in this middle range theoretical
explanation of caregiving. Nursing, as a metaparadigm concept, may appear slightly more
obscure, though it is pervasive in this theory. Nursing assessment and preventive
intervention with caregivers to help them manage the workload of caregiving is inherent
in this theory development. If nurses understand how effort can be modulated in the work
that family caregivers perform, this has the potential to link currently understood
predictors of adverse caregiver outcomes with preventive education and interventions.

Adding an understanding of the protective and risky aspects of effort to the nursing
knowledge presents an opportunity to protect family caregivers from adverse health outcomes. This knowledge has the potential to guide nurses in providing physical and mental health care to family caregivers, America’s primary caregiving workforce.

**Theoretical Framework**

The theoretical framework for this study was inductively derived from the results of a pilot study of effort in family caregiving, and through a synthesis of two theoretical explanations for how people meet the demands of a situation or workload such as caregiving.

The theoretical framework for the present study was developed with two major theoretical influences. The resultant theoretical framework that guided the study represents the influence of the stress process theoretical framework (Pearlin, Mullan, Semple, & Skaff, 1990) and demand control theoretical framework (Hockey, 1997; Karasek, 1979). These theoretical foundations reflect the influence of systems theory and psychophysics theory.

The role of effort in performing tasks is in the occupational biology and psychology literature. This relationship is not typically identified in the caregiving literature and this represents a gap in knowledge. A unique contribution of this study was to describe the effort in the workload of caregiving. Effort may be useful in describing the work and workload of caregiving and its effects on the caregiver. If effort is to be explicated in a stress process explanation of caregiving, it would necessarily be postulated to be perceived as exertion of energy. This would be consistent with explanations of the role of effort offered by Borg (1970; 1998).
The stress process conceptualization of caregiving only partially explains the exertional aspects of caregiving. For example, in the stress process framework, overload and overexertion were identified (Pearlin et al., 1990), though this conceptualization may limit understanding to only that extreme of exertion. In this study, caregiver effort was conceptualized as self-reported exertion in the workload of caregiving. Nursing researchers have approached this understanding of workload by studying time involvement and task difficulty (Bakas et al., 2004) and caregiving overload (Pearlin et al., 1990; Yates et al., 1999). Unfortunately, these studies do not explain a relationship between effort and workload that suggests how demands that overexert the caregiver may lead to negative health outcomes. This study builds upon their work.

The stress process theoretical framework has guided research studies involving the stressors in caregiving and mental health outcomes. This framework has not, however, included a theoretical explanation for the effort that is involved in the workload of caregiving. Further, the relationship between overexertion and overload has not been examined. The workload or burden of caregiving, the management of caregiving stressors, and caregiver mental health outcomes have been investigated among family caregivers of older adults. More research is needed to understand the impact of effort on the caregiver who is performing the work of caregiving.

The primary theoretical influence for this study was the stress process theoretical framework described by Pearlin and colleagues (Pearlin et al., 1990). In this theoretical framework, three main types of factors are considered in caregiving. First, stressors and demands of the caregiving situation, both primary and secondary, are identified as predictors. Secondly, the caregiver’s resources and mediating influences are considered
as intervening factors. Finally, caregiver outcomes including caregiver health and functioning are identified as outcome factors. (Pearlin et al., 1990)

The stresses and strains of the caregiving process were originally proposed to be those that were directly related to the caregiving situation (primary stressors); those that were outside the immediate caregiving situation, and were related to the caregiver’s other relationships and responsibilities (secondary role strains); and those that operated internally as the caregiver’s internal stressors and issues (secondary intrapsychic strains) (Pearlin et al., 1990; Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995).

Assumptions implicit in the description of the model by the authors (Pearlin et al., 1990) are that stressors are a naturally-occurring part of family caregiving, and that family caregivers deal with stressors both within and external to their caregiving roles. Further, mediating factors are assumed to operate in family caregiving, and these include psychological, social, and practical supports. The detailed model of Pearlin and colleagues (1990) is depicted in figure 1.1.

*Figure 1.1*

**Stress Process Conceptual Model (Pearlin, Mullan, Semple, & Skaff, 1990)**
A refinement in the stress process model was achieved by the researchers condensing the stresses and strains within and outside of caregiving into one theoretical category of stressors. The resultant model, as represented in figure 1.2 (Aneshensel et al., 1995) is more parsimonious, but without losing the prominence of the main (stressors) and intervening factors in caregiver inquiry. This supports the inclusion of additional concepts such as stressors, tasks, and demands, into a larger concept of workload in the theoretical development for this study.

*Figure 1.2*

Stress Process Conceptual Model (Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995)

The stress process framework provided theoretical support for this study for two reasons. First, it is postulated that the work of family caregiving is represented by demands and stressors as the workload of caregiving, and as such they are influential in predicting caregiver outcomes. Secondly, it is suggested that effort may be one of the intervening processes that can be used by caregivers to achieve or avoid certain outcomes.
In this study, burden, which is often studied as an outcome of caregiving, was considered to be theoretically similar to the stressors or demands of the caregiving situation. As such, characteristics that are typically attributed to objective and subjective burden (Zarit et al., 1980) were conceptualized as predictors rather than caregiver outcomes. The stress process theoretical framework, in elucidating both the objective and subjective components of primary stressors (Pearlin et al., 1990), provided an approach to viewing what was conceptualized in this study as the workload of caregiving. Effort was conceptualized in the study as a way that caregivers manage the stressors, demands, and tasks of the caregiving situation, in order to achieve or avoid certain outcomes.

A limitation of the stress process theoretical framework is the conceptualization of intervening processes that it postulates are present in caregiving. If the modulating or intervening factors identified in the stress process theoretical framework are limited to coping, or to the use of goods and services by caregivers, then an explanatory factor in the caregiver stress process may be missing. In this study, a new conceptualization of the stress process in family caregiving was used. Thus, effort was explored as an explanatory factor in the development of adverse health outcomes, such as depressive symptoms in caregivers.

In this study, the conceptualization of effort as a factor in caregiving was additionally influenced by the demand control conceptual framework, as described by Hockey (1997). In the demand control theoretical framework, the workload, including tasks and demands, (including burden; provide more rationale here) is the predictor, and the worker (here, the family caregiver of an older adult) modulates energy and attention to achieve optimal performance or to avoid undesirable health outcomes. Hockey (1997)
explained two ways in which effort may operate in work: First, effort may have a regulating function and sub-perceptual quality in regular work. Secondly, active control may be exerted in situations of increasing workload. Hockey posited a two level system of a worker’s response to demands in tasks performance. This is depicted in figure 1.3.

Figure 1.3
Demand Control Conceptual Model (Hockey, 1997)

Schönpflug (1986) characterized effort as operating along with coping skills in meeting the demands of a situation and essentially supporting a conservation of energy explanatory view of effort. The Schönpflug theoretical model depicts a role that effort plays in the relationship between demands of a workload situation and skills. These skills may include coping. Effort is seen as regulatory, consistent with an energetics conceptualization (Schönpflug, 1986).

Recent support for this theoretical application has been documented. Researchers have very recently explored a demand control conceptualization in family caregiving
The authors used Karasek’s (1979) conceptualization of demand control. Though demand control was suggested to be a theoretical backdrop to the study, effort was neither explicated nor implied as a factor in the work of caregiving, as it has in workload research outside of caregiving research and nursing research.

By synthesis of existing theory, this research study sought conceptual clarification of the role of effort in the work of family caregiving. Effort may further explain the relationship between tasks and demands of the caregiving situation and caregiver health outcomes such as depressive symptoms.

Thus the proposed theoretical model represents the attributes of both a stress process conceptualization of family caregiving and a demand-control conceptualization of how family caregivers deal with the workload of caregiving (See Figure 1.5).

Figure 1.4
Research Model

Contextual and demographic factors may appear exogenous to the main model, but are potentially explanatory in the final characterization of effort in caregiving. In guiding the study, a condensed conceptualization is offered for the stressors of the
caregiving workload, much like the modified version of the stress process model in figure 1.2 (Aneshensel et al., 1995). In the model, stressors, demands, and workload of caregiving, and effort are considered the predictors of depressive symptoms. Background variables such as caregiver demographics and the caregiving situation itself are postulated as related to caregiver outcomes.

This theoretical framework is based on the strengths of the stress process and demand control theoretical frameworks. It was expected that this study would add an inductively-derived explanation of effort in family caregiving.

Assumptions

The following assumptions guided this study.

1. Caregiving is conceptualized as an environment.
2. The caregiver is in a constant state of interaction with this environment.
3. The workload of family caregiving is an ever-changing phenomenon, requiring an adaptive response by the family caregiver.
4. The stressors, tasks, demands, time, and difficulty of the caregiving situation constitute the workload of caregiving.
5. Effort is how caregivers exert energy to do the workload of caregiving.

Research questions

The research questions in this study were:

1. What are the characteristics of the caregivers, the care receivers, and the caregiving situation?
2. What are the types of effort used by family caregivers in the workload of caregiving to older adults?
3. What is the relationship between caregiver effort and caregiver depressive symptoms?

4. What are the relationships among characteristics of the caregiver and caregiving situation; the workload of caregiving; the effort that family caregivers use in caregiving; and caregiver depressive symptoms?

5. What are the relationships among characteristics of the caregiver and caregiving situation; the workload of caregiving; the effort that family caregivers use in caregiving; and caregiver depressive symptoms, when controlling for characteristics of the caregiver and caregiving situation?

Theoretical definitions

Caregiving was defined as providing care or supervision, in the form of activities of daily living (ADL) or instrumental activities of daily living (IADL), to an older adult who needs this care or supervision because of a behavioral or physical health difficulty.

Background characteristics of family caregiving included caregiver demographics and characteristics of the caregiving situation.

Workload of caregiving was defined as the stressors, tasks, demands, time, and difficulty spent in the caregiving situation.

Effort in family caregiving was theoretically defined as exerting energy to perform the workload of caregiving and to meet the demands of the caregiving situation; and to avoid adverse health outcomes. Effort was defined in this study as perceived exertion; where physical effort is exerting physical energy; mental effort is exerting mental energy; emotional effort is exerting emotional energy; and time-related effort is related to the interrelationship of time and energy in caregiving.
Caregiver depressive symptoms were defined as symptoms of depression, including somatic and affective observances.
Figure 1.5

Theoretical Substruction: Effort in Family Caregiving

Construct | Person | Environment | Health
---|---|---|---
Worker | Demand | Control | Psychological health

Concept | Characteristics of CG, CR, situation | Workload stressors, demands, tasks, time, difficulty | Effort | Caregiver depression

Variables | CG demographics | Workload time | Physical effort | Depressive symptoms
- CG situation | Overload | Workout difficulty | Mental effort | Emotional effort | Time-related effort |

Operational Definitions
- age, gender, education, ethnicity, income, employment, SAH;CG health; co-reside; # CR; relationship CG-CR help inf CG, help form CG CR health conditions; ADL
- OCBS time:15 items (1-5)
- OCBS difficulty:15 items (1-5)
- Overload: 4 items (1-4)
- VAS physical
- VAS mental
- VAS emotional
- VAS time
- CES-D:20 items (0-3)

Note: CG= Caregiver; CR= Care Receiver
Chapter Two

Review of Literature

The purposes of this study were to describe effort as it is experienced by family caregivers in the work of caregiving to older adults and to explore the relationship between effort in caregiving and depressive symptoms in family caregivers. This chapter provides a critical review of the theoretical and empirical literature that guided the selection of the theoretical framework and concepts used in this study. Effort is introduced in the conceptualization of how family caregivers manage the stressors, demands, tasks, and time, that constitute the workload of caregiving. The state of the knowledge in caregiving research is then presented, with a discussion of the theoretical and empirical literature about caregiver resources, including coping; and of caregiver psychological distress outcomes, including caregiver depressive symptoms. This chapter highlights gaps in the literature on caregiving; with suggestions for how the findings from this study may add to caregiving knowledge.

Effort

A central thesis in this study was that effort is a concept that transcends disciplines, and will be useful for the development of new nursing knowledge about caregiving. The following presents conceptualizations of effort, caregiver workload, caregiver coping, and the consequences of caregiver effort in relation to caregiver outcomes such as depressive symptoms.

 Definition and general attributes

The word effort derives from the French esforçier, which is exerting a force, and from the Latin words ex, meaning out, and fortis, meaning strong (Oxford English
dictionary, 2005). This suggests that effort is forcing outward or exerting power. Effort is the use of physical or mental energy – that is, exerting energy – in work; it is also considered something done through exertion or energy (Oxford English dictionary, 2005; Rooney et al., 2001) as in an effort. Simply put, physical effort is exerting physical energy; mental effort is exerting mental energy; and psychological effort is exerting psychological energy.

One general attribute of effort is its dual role: effort as regular control and effort as active control. Effort can be both strenuous and regular. Most overt definitions of effort identify only the strenuous quality of effort. Effort is likely more variable than this. Effort also suggests a regulating process. Effort is regulated or allocated by individuals to do work or achieve an outcome (Hockey, 1986; Mulder, 1986; Kahneman, 1973) Effort is defined by its placement between work and outcomes. Hockey (1986, 1997) placed effort between the tasks of a situation and the effects on the individual. In performing usual activity, the individual uses standard effort. If the activity is novel or intensified, the individual uses or allocates more resources – that is, a higher effort – to respond (Mulder, 1986).

Effort is allocated and actively-controlled. Allocating effort involves control and choice, and these choices are about the amount of effort used. These choices then affect work and performance, according to Kahneman (1973). Kahneman suggested that less than a regular amount of effort may not be enough for adequate performance, yet more than the regular amount of effort may overtax the individual. Two words may further clarify the definition of effort as actively-controlled: effectiveness and efficiency. Kahneman suggested that effectiveness of work was the quality of the performance and
that *efficiency* was the relation between the quality of that performance and the effort that was invested in the performance (Mulder, 1986). Effort is a mechanism that takes the individual from a general state of arousal to a more focused state of mental attention and physiological activation (Pribram & McGuinness, 1975).

**Domains of effort**

Effort is a perceptual concept. Conceptualizations of effort are typically placed conceptually in the domain of psychophysics, yet effort is also conceptually in the domain of energetics. In *psychophysics*, individuals perceive physics in subjective terms that are then measurable as physiological and psychological perceptions (Borg, 1990). Borg used the word effort interchangeably with the phrase *perceived exertion* (Borg, 1970; Borg, 1990; Russell, 1997) as an individual’s estimation of how “strenuous” a task is (Borg, 1998, p. 8). Effort is also placed in the domain of *energetics*, which encompasses cognitive and physical concepts such as motivation, attention, cognition, and activation: Hockey (1986) considered effort the core construct in the field of energetics.

**Physical effort**

Physical effort is operationalized as perceived exertion (Borg, 1970), and corresponds with performance / physiological measures. Borg (1970) devised a scale of perceived physical exertion that has been used in workload studies. Effort is explained by Russell (1997) as a process of active perception that correlates with emotion and distress. Effort has been suggested in models of coping and distress, though not studied directly.

Physical effort, as perceived exertion (Borg, 1970), is the individual’s response to a stimulus, situation, or stressor through three complementary domains: *perceptual,*
physiological and performance (Borg, 1970; 1998). Across these domains are four subjective levels of effort or exertion: minimum level, preferred or adaptation level, stress level, and maximal intensity. The individual’s experience starts with the perceptual domain, or the subjective meaning of the exertion or effort. The performance domain relates exertion to the workload and time. The physiological domain includes the physiological manifestations of exertion such as cardiopulmonary and musculoskeletal effects. These domains will then interact with the perceptual domain to influence the individual’s estimation of exertion. Accordingly, these three domains of effort represent how strenuous the work or a task is to the individual (Borg, 1998) and effort represents these dynamic, interrelated qualities.

**Mental effort**

Mental effort definitions are largely derived from theoretical and empirical literature in occupational biology and psychology, and more specifically in information processing. Effort is perceived exertion in the context of performance or work (Mulder, 1986). In studying workload and recuperation, the researcher considers both characteristics of the task, and characteristics of the individual (Weithoff, 1997). Mental effort has been described in the occupational literature, when measuring the impact of sustained attention to a task (Weithoff, 1997). In the medical literature, mental effort has been shown to be associated with poorer performance in persons with depression (Roy-Byrne et al., 1986; Cohen et al., 1982). Mental effort is conceptualized here to include concentration and cognitive energy.
**Psychological effort**

Definitions to support a conceptual sub-domain of psychological effort are even more obscure in the literature than those for mental effort. Psychological effort most closely resembles the psychological energy in studies of vigilance, where the work of caregiving is being on watch or on duty (Mahoney, 2003), and has a quality much like the sustained attention in the workload literature. Descriptions of mental effort and psychological effort are conceptually consistent with the exertional aspects of physical effort.

Effort is relatively active. Once, effort was thought to be a characteristic of motivation, specifically of an individual’s attempts to succeed or to avoid failure (Atkinson & Birch, 1974). More recent descriptions of effort expect that *active control* by the individual uses inner – usually cognitive – resources (Hockey, 1986; Kahneman, 1973). *Mobilizing* and *regulating* these resources, including skills, is required in order to meet demands (Schönpflug, 1986). There is not necessarily a fixed positive relationship between demands and activation. Initially, more control, or effort, is required to meet demands, and can result in more physiological manifestations of this activation (Hockey, 1986; Schönpflug, 1986; de Jonge, Mulder, & Nijhuis, 1999). The individual is thought to be actively allocating these resources (Ursin, 1986) and self-regulating the response through activation. However, if the amount of effort exerted is effective, then the outcome is a suggested effort “savings” (Schönpflug, 1986, p. 273).

Schönpflug’s conceptualization of *effort savings* evokes a few interpretations relevant to the proposed study. First, effort has levels, so it should be variable. Secondly, effort can be regulated or saved, so perhaps the goal of individuals can be to reduce,
decrease, or preserve effort. This regulating suggests a range in the individual’s perception of effort. While little literature explains the presence of low effort, the individual may have a level of effort that is considered regular (Mulder, 1986; Ursin, 1986) or preferred (Borg, 1998).

Physical effort has been conceptualized as both variable and constant. However, Borg (1970) usually conceptualized effort as dynamic while Stevens (1989) only conceptualized effort as static. Further, Borg described both constant (static) effort and perceived exertion, which is dynamic. These inconsistencies raise the question of whether effort is a dynamic or static phenomenon (Borg, 1970; Luximon & Goonetilleke, 2001). It is vital to explore the nature of effort and its characteristics over time.

Borg (1970; 1998) explained the characteristics of variations in effort. Effort at lower intensities represents activation and task completion. Effort at higher intensities represents a lower work capacity (Borg, 1998). Borg’s placement of effort between work demands and outcomes suggests that a higher intensity of effort might interfere with an individual’s ability to do work. Conversely, a lower intensity of effort might be associated with a positive form of activation that promotes an individual’s ability to complete work (Borg, 1998). Specifically, Borg (1998) suggested if an individual does not perceive strain or exertion, this may result in estimating the perceived exertion – that is, effort – as low or not present.

Effort has also been explored as a dimension of workload. Effort is one of six dimensions of workload that include mental demand, physical demand, temporal demand, performance, effort, and frustration level in the National Aeronautics and Space Administration’s Task Load Index model (NASA TLX, 2006; Hart & Staveland, 1988).
Effort has also been conceptualized as one of three subjective dimensions of time load, mental effort load, and psychological distress load in the Subjective Workload Assessment Test (SWAT) model (Boles & Adair, 2001; Luximon & Goonetilleke, 2001).

In contrast to both of these workload models, an alternate conceptualization is offered in this study. Effort is not a load, or a demand, but rather the mechanism through that the individual uses energy to deal with the load and demands. As such, in assessing workload, effort needs to be parsed out of workload. Effort should be a unique concept considered when evaluating workload, but not be assumed to be part of the workload.

_Effort, workload, and stress_

Effort has been described in relation to demands of a situation or a task (Kahneman, 1973) and to the relationship between work stressors and health outcomes of the worker (Hockey, 1997). Effort is necessarily present to meet these task requirements and the amount of effort varies according to how much effort a particular task requires (Fleishman, Gebhardt, & Hobart, 1984). That is, effort may be one of the factors that individuals can regulate in performing tasks or work under stress (Tafalla & Evans, 1997).

One of ways an individual can exert control in work is increasing effort, or trying harder, which is related to fatigue (Hockey, 1997). Hockey’s description of exerting direct control is explained as exerting energy (Hockey, 1997) and demonstrates a style of coping that resembles Lazarus and Folkman’s problem-focused coping. The description of indirect control (Hockey, 1997) resembles emotion-focused coping. Hockey also
discussed active coping in his explanation of how increasing workload and increasing effort may be associated with poorer individual outcomes.

One definition of effort is derived from a theoretical framework where effort is a process in active coping. In this process, effort produces outcomes of psychological and or physical strain on the individual who is performing a task or responding to a situation toward a particular outcome (Carver et al., 1989; James, 1994). Coping itself is suggested to involve effort (Lazarus & Folkman, 1984) in appraising and dealing with stressors. Thus, effort may result in physical activation and is implicated in the stress response.

Frankenhauser (1986) suggested that effort is the control that occurs in coping with stressful situations, and that effort can either co-occur with distress or act separately from distress. Further, she suggested a relationship between two biomarkers and two discrete kinds of effort. Frankenhauser proposed that short-term effort is associated with catecholamine excretion, and longer term or sustained effort, is associated with an increasing cortisol production. This means that the physical response differs with the duration of effort. The role of effort in coping is also consistent with control theory, where effort may be thought of as a component of control in work motivation (Carver & Scheier, 1982).

Trying harder to deal with work stressors is thought to put people at risk for adverse health outcomes (Hockey, 1997). Extended periods of high effort coping is implicated in the activation of the sympathetic nervous system (SNS), culminating in adverse cardiovascular events such as heart rate variability and blood pressure (Theorell & Karasek, 1996; James, 1994; Gerin, Litt, Deich, & Pickering, 1996) and is also suggested in hypothalamic activation (Iani, Gopher, & Lavie, 2004).
Overusing effort is suggested as being related to the physical and psychological demands of work, and the health outcomes or rewards associated with that work (de Jonge, Bosma, Peter, & Siegrist, 2000). This is termed “overcommitment” that involves “excessive” or “exaggerated” effort and impacts well-being negatively (de Jonge et al., 2000, p. 1318). This characterization of excessive effort has been used to describe the work stress experienced by nurses (Weyers, Peter, Boggild, Jeppesen, & Siegrist, 2006).

Gaillard (1993) suggested that effort is a normal response of trying harder to meet a harder or higher demand, and it is not a foregone conclusion that the workload itself leads to the stress. Thus, the manner in which an individual responds to the workload and recovers from the exertion may be implicated in the development of stress.

Effort is measured in studies involving workload and task completion in industry. Much of the industrial studies of effort involve tasks, productivity, and workload. Measuring effort is more conceptually feasible because individuals cannot perceive performance (Hockey, 1993), though they can perceive how much effort particular tasks require (Fleishman et al., 1984).

A review of theoretical literature suggests that demands are present in workload, and control is the intermediate outcome the worker desires to avoid adverse health outcomes, and to achieve satisfactory performance outcomes. In a study determining the factor structure of workload, two prominent factors were physical task requirements and mental task requirements (Yeung, Genaidy, Deddems, & Sauter, 2005). Effort was defined as “the amount of energy an individual expends to satisfy challenges presented via the characteristic of work tasks and work environment as well as the ability to cope with the external challenges”, including muscular, cognitive, and emotional effort (Yeung
et al., 2005, p. 88). Effort, as exerting energy, is characterized as control in response to the demands of a workload. The subjective and objective characteristics of effort need to be reconciled. Evaluating work, by estimating changes in effort as well as the tasks in the workload, has been reported (Weithoff, 1997) outside caregiving literature. Effort has the potential to add further explanation to demand-control in caregiving.

In caregiving research, an understanding of workload includes the consideration of time, difficulty, tasks, and ability. Some work has been reported in measuring the tasks and demands in the workload of caregiving (Oberst, Thomas, Gass, & Ward, 1989); the time and difficulty of those tasks in the workload of caregiving (Bakaset al., 2004); and caregivers’ perceived ability to do caregiving work (Phillips, Remphusheski, & Morrison, 1989).

Typically, effort is defined by its subjective, observational, perceptual quality, placing effort in the conceptual frameworks of psychophysics (Borg, 1990; Russell, 1997) and energetics (Hockey, 1986; 1997). For example, physical effort is present if the individual perceives it to be present (Hockey, 1993). Similarly, the presence of mental effort represents the individual’s perception of the use of mental energy, meaning that mental effort is present because the individual perceives it is present (Mulder, 1986).

Stress and physiology research supports an objective, quantifiable definition of effort (Frankenhauser, 1986), where effort is present if correlated with biochemical and physiological empirical referents representing the individual’s response to demands. Examples of these biomarkers in caregiving research have been reported. For example, studies exploring the presence and quantities of certain biomarkers among caregivers (Farran, Loukissa, Lindeman, McCann, & Bienias, 2004; Davis et al., 2004) are
reportedly measuring an individual’s physical response to stressors. These caregiving stress physiology studies may form a foundation for quantifying caregiving effort in future studies. In this study, the aims were to describe levels of effort through self-report and to examine them for a possible relationship to caregiver depressive symptoms.

The Workload of Caregiving

The assistance that is provided to older adults in America is largely provided by family members. Because these family members represent a care workforce, their health and performance is a concern to nurse researchers in promoting the health and well-being of older adults and their family caregivers. This section of the literature review provides an overview of the state of the knowledge in caregiving, the impact of interventions with caregivers, and the psychological distress caregivers experience.

Characteristics of both the caregiver and the caregiving situation are thought to be influential in whether caregivers experience distress. Theoretical explanations are derived largely from social, developmental, family, and psychological theories (Whitlach & Noelker, 1993). Dispositional traits of the caregiver, such as hardiness (Clark, 2002; DiBartolo, & Soeken, 2003; Nunley, 2002) have been investigated in descriptive studies of family caregivers. However, dispositional characteristics of the caregiver do not consistently explain how the caregiver responds to the workload of caregiving and to the development of distress.

In estimating how caregivers perform a workload of caregiving, the caregiver’s perception of being adequately prepared to provide care may be a factor. Caregiver preparedness refers to the caregiver’s perceived readiness to take on the caregiving role and to perform the necessary tasks of caregiving (Archbold, Stewart, Greenlick, &
Harvath, 1990). This differs from caregiving competence and mastery, which are estimations of how effective the caregiver is in performing the work of caregiving (Schumacher, Stewart, & Archbold, 1998).

Another theory that has been applied to how caregivers provide care is caregiver self-efficacy (Gilliam & Steffen, 2006), based on Bandura’s self efficacy theory. A high degree of self-efficacy would be represented by believing in one’s ability to perform the work of caregiving, and holding expectations about desirable outcomes of caregiving (van der Bijl, & Shortridge-Baggett, 2001). Further, one’s level of self-efficacy is thought to influence the caregiver’s well-being.

To summarize, the stressors in the caregiving situation are influenced by dynamics inside both the individual caregiver and their social networks. A consideration of how caregivers feel about and perform the workload of caregiving has been prominent in inquiry about caregiving. Caregiver distress symptoms, especially caregiver depressive symptoms, are often measured as an outcome representing caregiver well being in these descriptive studies.

Caregiving researchers have taken steps toward understanding the health impact of caregiving. This research has frequently focused on the adverse outcomes of caregiving. The core studies have examined the impact of caregiving as physical, psychological, and social consequences of caregiving. Caregiving is not only a risk for further morbidity (Vitaliano et al., 2003), but also a predictor of mortality (Schulz & Beach, 1999). It is therefore necessary to continue to explore concepts, such as effort, that can expand our understanding of factors affecting health vulnerabilities.
Physical consequences of caregiving

Potential physical hazards related to caregiving include changes in overall perceived health, specific changes in physiological markers of physical ill health, and vulnerability to subsequent health problems. Changes in physical health may be directly related to the workload of caregiving, and changes in psychological health may also be related to these changes in physical health (Haug et al., 1999). Among dementia caregivers, it has been suggested that increased self-reported physical and mental health difficulty is related to the particular demands of dementia caregiving (Ory et al., 1999; Schulz et al., 1995).

Specific changes in markers of immunity have been identified in caregiver research. Diminutions in the presence of certain biomarkers among caregivers might signal vulnerabilities to ill health (Vitaliano, Scanlan, & Zhang, 2003; Keikolt-Glaser, Preacher, MacCallum, Atkinson, Malarkey, & Glaser, 2003). Two kinds of immune responses are typically discussed. One is the hypothalamic-pituitary-adrenal axis response, abbreviated HPA, and the other is the sympathetic-adreno-medullary axis response, abbreviated SAM. (Davis, Weaver, Zamrini, Stevens, Kang, & Parker, 2004)

Cortisol has been investigated for its role in differentially identifying human responses to acute stress and chronic stress situations. In studying caregivers, examination of cortisol and self-report of stressors yielded some paradoxical results. The investigators found that some participants had a reduced physiological response to stressful situations and this was not expected. This finding has been attributed to
caregiver burnout (Davis et al, 2004). More research is needed in this area to understand factors that might explain such a finding of reduce physiological response.

Other biomarkers have received attention in the literature. While heat shock proteins, or HSP, were studied in the 1980’s and were found to increase in response to physical injury and psychological stressors (Fleshner & Laudenslager, 2004), these have not been examined in recent investigations regarding caregiver stressors. However, interleukins have been studied in caregivers. Interleukins such as IL – 6 have been found to increase in the presence of indicators of an unhealthy lifestyle such as smoking, sleep difficulty and physical inactivity. Interleukins were monitored in a longitudinal investigation of older adults who were dealing with a chronic stressor. Caregivers who had reported greater stress than non-caregivers had significantly greater changes in levels of IL – 6 as compared with the non-caregiving peers (Kiecolt-Glaser et al., 2003). This was highly suggestive of a physiological response and vulnerability to disease.

Among other stress response associations, IL – 6 seems to be involved with the release of C reactive protein, which is a marker that is often considered a predictor of myocardial infarction (Kiecolt-Glaser et al., 2003). This is a biomarker that may be important to explore for caregiver stressor investigations. Cytokines have been correlated with sleep difficulty (Opp, 2004) and have been suggested to be predictors of cardiovascular disease, diabetes, some cancers, arthritis, and even Alzheimer’s Disease (Davis et al., 2004; Kiecolt-Glaser et al., 2003).

As translated into practice, caregiver research is beginning to incorporate biomarkers into intervention studies where the purpose is reducing adverse health consequences of caregiving such as depression. Three intervention studies examined
coping and physiological measures of immunity in dementia caregivers. The treatment group received targeted coping strategies and management of care receiver behaviors. T cell response to two biomarkers were measured prior to, immediately following the main intervention, and six months later, following a telephone support intervention (Garand, Buckwalter, Lubaroff, Tripp-Reimer, Frantz, & Ansley, 2002). Similarly, a group of nursing investigators tested the effectiveness of a caregiver skill building intervention that targeted management of care receiver behaviors on a skin reactivity measure of immunity, called DTH. While caregiver depression decreased and the measure of immunity demonstrated relative constancy (Farran et al., 2004), no changes in biomarkers were found in either study. In another design, natural killer cell, NK, was monitored before and after five sessions of an intervention targeting caregiver stressors, and these investigators reported a significant improvement in this immunity marker (Hosaka & Sugiyama, 2003).

This research shows promise in illuminating the stress response of caregivers. The possibility is raised that increased presence of some of these biomarkers means immunity is being “enhanced”, rather than suppressed (Fleshner & Laudenslager, 2004, p. 119). The basis for the relationship between the workload of caregiving and caregiver biomarkers has not been established.

Psychological consequences of caregiving

Psychologically, several negative consequences of caregiving have been identified in the literature. Caregivers have been shown to have negative psychological health consequences that are disproportionately prevalent as compared with non-caregiving peers (Gallagher et al., 1989; Schulz et al., 1990). Increases in anxiety and
depression were prominent findings across studies (Schulz et al., 1995; Pinquart & Sörensen, 2003; Amirkhanyan & Wolf, 2003).

Depressive symptoms and caregiving are a particularly troubling relationship. The suggested causes of caregiver depressive symptoms are prominently documented in the caregiving literature, but the findings from these caregiver studies do not suggest absolute predictors of caregiver depression. Meanwhile, these research findings suggest several consequences of caregiver depressive symptoms. First, family caregivers compared to their non-caregiving counterparts are at an increased risk for morbidity and disability (Schulz, Visintainer, & Williamson, 1990; Vitaliano et al., 2003; Pinquart & Sörensen, 2003a; Amirkhanyan & Wolf, 2003). Secondly, if family caregivers neglect their health, or suffer from negative psychological sequelae, there may be consequences for the health and safety of the older adult for whom they provide care and sometimes a higher risk for abuse and neglect of the care receiver (Beach et al., 2005).

It is not at all clear that caregiving causes depression. Depressive symptoms may be just one of many adverse functional outcomes of caregiving. Caregiver depression has been explained in two ways. First, significant depressive symptoms have been identified as an adverse caregiver outcome or consequence of caregiving. Secondly, the presence of depression occasionally been suggested as predictor of adverse caregiver outcomes as an intervening or influential process in the development of difficulty (Tsai & Jirovec, 2005). For this study, depressive symptoms were not considered antecedent, though the complexity of caregiving does not rule out circularity of depressive symptoms adding another stressor to the caregiving situation.
The stress process theoretical framework (Pearlin, Mullan, Semple, & Skaff, 1990) has frequently been used to explain the relationship between the stressors of the caregiving situation and the development of adverse caregiver outcomes, including depressive symptoms. For example, caregiver burden, which encompasses both the tasks and demands of the caregiving situation and the caregiver’s perceptions about these demands, has been positively associated with the development of depressive symptoms in caregivers (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Findings from other studies of caregivers show the prominence of depressive symptoms (Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998; Powers, Gallagher-Thompson, & Kramer, 2002). Caregivers tended to report problems with sleep and energy as depressive symptoms. Whether such symptoms are related to depression or related to the caregiving situation is not entirely clear.

It is not clear as to whether the presence and level of depressive symptoms in caregivers is related to the care recipient’s health condition. Many studies limit their samples by the condition of the care receiver, for example older adults with dementia (Schulz et al., 1995; Gonzalez-Salvador et al., 1999; Ranney, 2000; Powers et al., 2002), or persons with cancer (Given, Wyatt, Given, Sherwood, Gift, DeVoss, et al., 2004). While some researchers identify experiences that are unique to dementia caregiving (Ory et al., 1999); others have found that the distress outcomes of caregiving may develop regardless of the condition of the older adult care receiver (Hooker et al., 2000).

Findings suggest that coping may intervene in the stress – depression relationship in caregiving (Pruchno & Resch, 1989). These findings provide a background for studies where caregivers are taught skills and strategies to deal with the stressors of caregiving.
The Resources for Enhancing Alzheimer's Caregiver Health (REACH) initiative is such a research program. One of these REACH studies used technology-assisted support and skills interventions with family caregivers. The researchers reported that depression symptoms were decreased at six months following the intervention, and reported that for some populations, this effect was sustained at 18 months (Eisdorfer, Czaja, Loewenstein, Rubert, Arguelles, et al., 2003). Other researchers reported that a group skills training in depression management and anger management intervention promoted a decrease in both depressive and anger symptoms among caregivers (Coon, Thompson, Steffen, Sorocco, & Gallagher-Thompson, 2003). Caregiver interventions may result in a decrease in depression symptoms and perhaps even a delay in placing the older adult in more costly formal care setting (Mittelman, Ferris, Shulman, Steinberg, Ambinder, Mackell, et al., 1995).

In summary, theoretical explanations for how caregivers manage the workload of caregiving often depict the physical, psychological, and social factors involved. The stress process theoretical framework examines the demands and stressors of caregiving, positing that intervening factors influence the relationship between the stressors of caregiving and caregiver psychological health outcomes. Pearlin and colleagues (1990) developed the stress process model to describe the relationships among stressors, appraisals, and psychological health outcomes within the caregiving context. Among these stressors, both intrapsychic and role-related strains are explored. The stress process model is most commonly applied to research that looks at the way stressors accumulate along a course of caregiving (Aneshensel et al., 1995). Further, the stress process framework has been used to describe how, as a chronic stressor, caregiving stress
overload (Yates, Tennstedt, & Chang, 1999) may intervene in producing caregiver depression.

Measuring the impact of the stressors in the workload of caregiving over time has contributed greatly to caregiving knowledge. The longitudinal investigation by Pearlin and colleagues (1990) has increased the understanding of how stressors within and outside of the caregiving role may impact the caregiver’s psychological health. These researchers measured the workload of caregiving with an emphasis on overexertion (Pearlin et al., 1990). Unfortunately, the questionnaire items that measured overexertion may have yielded information that limit the understanding to that extreme of exertion. In this study, the measurement of exertion as effort was along a range of self-reported exertion of energy in the workload of caregiving. Additionally, questionnaire items in this study were selected to measure a broader concept of workload than merely a quantity or intensity of tasks, demands, or appraisals.

To date, nursing researchers have approached the understanding of caregiving workload by studying time involvement and task difficulty (Bakas et al., 2004), and caregiving overload (Pearlin et al., 1990; Yates et al., 1999). These studies appear to offer theoretical support for the stress process conceptualization of caregiving. However, they do not explore how the level of energy exertion, or effort, may lead to negative caregiver health outcomes. It is these exertional aspects of caregiving that are unexplored areas of research.

**Burden and caregiving workload**

In caregiving research, particular attention has been given to the exploration of caregiver burden and caregiver strain. For this study, burden was subsumed within the
construct of workload, and not as a caregiver outcome. Burden has been conceptualized as having two dimensions: objective burden, suggesting the tasks or work related to the caregiving situation; and subjective burden, suggesting the caregiver’s appraisal of the caregiving situation (Zarit, Reever, & Bach-Petersen, 1980). Acton & Kang (2001) found inconsistent support for recommending burden as an outcome variable in descriptive and intervention studies.

Earlier studies of caregivers to older adults described burden in relation to the tasks of caregiving (Hooyman, Gonyea, & Montgomery, 1985). Higher levels of burden were correlated with poorer well-being of caregivers. Pratt, Schmall, Wight, and Cleland (1985) found that internal (problem-solving, reframing, passivity) and external (spiritual support and extended family) coping strategies were significantly positively correlated with burden. Importantly, those caregivers with more burden had poorer self ratings of health (Pratt et al., 1985). More recently, Braithwaite (2000) found that dealing with a heavy workload was significantly associated with a negative affect among caregivers. Time and difficulty of tasks among family caregivers of stroke patients are similar predictors of adverse caregiver outcomes (Bakas et al., 2004). Specifically, burden has been shown to significantly predict depression in caregivers (Clyburn, Stones, Hadjistravropolous, & Tuokko, 2000).

Positive consequences of caregiving

In the last decade, caregiver research has focused on examining rewards, uplifts, and generally positive consequences of caregiving (Picot, 1995; Pinquardt & Sörensen, 2004). Thus, a more balanced perspective on caregiving to older adults has been provided through the work of researchers who have examined the positive impact of caregiving.
Examples of the many gains associated with caregiving include satisfaction, personal growth, purpose, and self-acceptance (Kramer 1997a; 1997b). Caregiver satisfaction and caregiver esteem are common examples of the positive perceptions of caregiving (Hunt, 2003). These positive views may be associated with less caregiver distress.

Coping as a Caregiver Resource

To perform the workload of caregiving, caregivers may need to learn skills to manage tasks and demands precipitated by the older adult care receiver’s health condition or behaviors. Coping can be conceptualized as a caregiver resource. Coping research frequently cites Lazarus’ and Folkman’s stress appraisal and coping model (1984) which suggests an individual’s coping process and coping style involves “effort” (p. 132) to manage a situation or experience. According to Lazarus and Folkman (1984), coping involves primary appraisal, which means perceiving a threat. Secondary appraisal focuses on thinking about a response to the threat. This is followed by the process of coping, which is the actual response to the threat. This suggests that coping is one of the ways an individual responds to the demands of a situation.

Several conceptualizations of coping have been described in the literature. Additional theoretical clarity for the meaning of coping has been provided by Pearlin and Schooler (1978). They derived descriptions of coping that were related to four roles: being a marital partner; being a parent; managing household finances and responsibilities; and managing a workload in work outside the home (Pearlin & Schooler, 1978). A strength of this explication of coping is that the coping responses that individuals employ are described in relationship to the interpersonal and everyday nature of the individual’s social experiences and stresses. The strategies that were identified are conceptually
similar to dimensions that describe active and instrumental, as well as passive and reframing coping strategies, such as those identified by Kahana, Kahana, and Young (1987), and Carver, Schier, and Weintraub (1989).

Two dimensions of coping have been identified in the literature: problem-focused coping, when an individual is doing something to alter a situation or thought, and emotion-focused coping, when the individual is doing something to adjust to or endure a situation or thought (Carver et al., 1989; Lazarus & Folkman, 1984). These two types of coping provide a good conceptual fit for the stressors studied in caregiving research (Pruchno & Kleban, 1993; Powers et al., 2002; Haley et al., 1987). Coping tendencies have also been described as active and passive, as well as situational and dispositional (Carver et al., 1989).

Effort and coping

A relationship has been suggested between coping and effort. Active coping and effort are suggested to co-vary (Gerin et al., 1996). John Henryism Active Coping postulates the mechanism through which sustained effort, in difficult circumstances, specifically societal racism, leads to adverse cardiovascular health outcomes is high effort coping (James, 2002; James & Thomas, 2000). This conceptualization depends largely on sympathetic nervous system stimulation. It does not address levels of effort or modulation of effort in response to variant demands. However, Frankenhauser (1986) postulated that varying physiological responses were associated with short and long duration effort.

Hinrichsen (1991) described “deliberate effort” (Hinrichsen, 1991, p. 633), which was defined from items from the coping scale developed by Moos and colleagues (Moos,
Cronkite, Billings, & Finney, 1984). This deliberate effort was conceptualized as actions to change a situation, combined with thinking about the situation and one’s actions. This deliberate effort is similar to problem-focused coping, or perhaps to a combination of active coping and mental effort. Deliberate effort was associated with poor caregiver psychological adjustment. Hinrichsen’s (1991) description of deliberate effort resembles effort as it is conceptualized in this study.

Coping is a mediator between workload and depressive symptoms. One of the reasons the stress process theoretical framework was selected to inform this study is the description of mediators to explain how caregivers do the work of caregiving (Pearlin et al., 1978; Whitlach & Noelker, 1993). In fact, coping has been shown to be a mediator between stressors and caregiver mental health outcomes (Lane, 2003) and a mediator between the burden of caregiving and caregiver depression. However, coping, as a caregiver resource, has not been found to moderate the relationship between caregiving and psychological distress (Pot, Deeg, & van Dyck, 2000).

Emotion-focused coping and problem-focused coping are frequently described in studies of caregivers (Pruchno & Kleban, 1993; Powers et al, 2002; Haley et al, 1987). Evidence suggests certain kinds of coping mediate the stressors of caregiving to protect against caregiver depression. Haley and colleagues (1987) found that caregivers who used more problem-focused coping had less depression. More recently, Powers and colleagues (2002) demonstrated that both types of coping and coping style showed stability over time in predicting depression. Vedhara, Shanks, Anderson, & Lightman (2000) found that coping strategies were among the mediators that explained 27 to 41% of the variance in depression. Pruchno and Kleban (1993) found that with emotion-
focused coping, more stress meant more mental health symptoms. However, problem-focused coping did not mediate the effect of a stressor on mental health, in that more stress did not result in more mental health symptoms.

Viewing caregiving as a chronic stressor in daughters’ of older adults, problem-focused strategies were associated with less depression (Wai-Li, Seltzer, & Greenberg, 1999; Powers et al., 2002). Conversely, Pruchno and Resch (1989) found that more frequent use of an emotion-focused strategy was associated with more depressive symptoms. Coping had a mediating role that explained up to 40% of depression.

In general, researchers have seen a positive correlation between what has been called burden and the presence of caregiver depressive symptoms. Intervention studies, developed over the last decade, have explored the effects of coping and support on the relationship between burden and depression in caregivers. Research that explores the relationship between stressors in caregiving and caregiver psychological health outcomes has advanced caregiving knowledge. Generally, large intervention studies with caregivers have led to an understanding that learning coping skills helps caregivers, even if for a while. However, these studies have not included explicit measures of the effort that is involved in the workload of caregiving. More research is needed to understand specifically what happens in the caregiving workload for depressive symptoms to develop, progress, and ultimately interfere with the process of caregiving.

Effort and Depression

In this study, a relationship has been postulated between effort in family caregiving and the presence of caregiver depressive symptoms. Very limited literature documents the relationship between effort and depression.
Researchers who have examined the relationship between effort and depression found a directional relationship where problems with effort were predicted by the presence of depression (Roy-Byrne et al., 1986; Cohen et al., 1982). This relationship was studied among young, largely female, depressed inpatients. Thus, the findings may not be generalizable to a community-based population of family caregivers. No research related to the study of effort in caregivers, or effort and depression in caregivers was found.

In no other workplace could the person who performs the work be expected to perform and apply effort, without some estimation of the impact of that effort on the worker’s health outcomes. Yet in informal caregiving, family caregivers are expected to perform the work in caring for older adults without an apparent discussion of how to evaluate exertion and its impact on performance or on health. This study was a beginning exploration of the role of effort in understanding family caregiver health outcomes.

Summary

In chapter two, literature on the concept of effort was introduced. A review of workload, coping, and depressive symptoms literature was also presented. The relationship between effort in performing a workload, and the effects of the workload on the worker’s health was found in the occupational biology and psychology literature. Exploration of the relationship between effort in performing a caregiving workload, and the impact on the caregiver’s psychological health was not found in the caregiving literature.
Chapter 3

Methods

Introduction

The purposes of this study were to describe effort as it is experienced by family caregivers in the work of caregiving to older adults and to explore the relationship between effort in caregiving and depressive symptoms in family caregivers. Chapter three addresses the methods that were used in the study. This chapter includes a description of the study design and sampling. The results of a pilot study, which explicated the concept of effort and guided the selection of measures for this study, are presented. This chapter then specifies the measures used; recruitment; data collection; data management; data analysis; and protection of human subjects.

Study design

This study was conducted with a descriptive, correlational, cross-sectional design. A descriptive study design was appropriate (Burns & Grove, 2005) to explain the characteristics of the phenomenon of effort and its possible relationship to caregiver depressive symptoms.

Setting

This study was conducted in Northeast Ohio. It has been estimated that there are well over one million family caregivers in Ohio. According to 2000 census, almost 20% of the population in Cuyahoga County is 60 years of age or older. Of that population, approximately 40% of those who are 60 years of age or older are in an older age cohort, 75 years and older (Northern Ohio Data & Information Service [NODIS], 2003). These older adults potentially require the support of family members for daily care or
assistance. Access to these family members, through the many agencies in the region who serve older adults and their families was expected.

Sample design

In recruiting the sample for this study, correctly classifying caregiver status was considered important. To guard against misclassifying caregiver status, a screening question was asked in the recruitment phone call, “Do you have responsibility for any care and or supervision of an older adult?” and the same question was asked as a confirming question on the research questionnaire.

Sample eligibility

Inclusion criteria. To be included in the study, family caregivers needed to be at least 18 years of age; and, have primary responsibility for providing at least four hours per week of direct care or supervision for an older adult who requires assistance because of a physical or behavioral condition. This assistance was understood to mean help with activities of daily living (ADL) or instrumental activities of daily living (IADL) to promote the health of the older adult. Caregivers were unpaid, family members, kin, or friends. Caregivers were eligible whether or not they resided with the older adult care receiver. Only the first member of a family who self-identified as the caregiver for a care receiver, and called the researcher, was eligible to participate in the study.

Exclusion criteria. Brief cognitive screening was conducted in the telephone screening by the researcher. Potential participants who scored seven or more on the Short Portable Mental Status Questionnaire (SPMSQ) were eligible to participate. However, no caregivers were excluded from this study because of cognitive impairment. Individuals
were excluded if they had been in the caregiving role for less than two months. However, no caregivers were excluded from participation due to being too new to the role.

The major reasons that individuals were ineligible to participate were: the care receivers for whom they were caregivers were deceased (n=13) or in a 24 hour skilled nursing home level of care (n=5) rather than community-dwelling; the individuals were formal caregivers (n=7); or the individuals were soliciting the researcher for consultation regarding becoming a formal caregiver (n=2). The “lost” caregiver details are: one phone number – attempted five times over four weeks – went directly to a recorded greeting that indicated the individual did not accept incoming calls; and the second phone number was never answered in five attempts over four weeks. Finally, two individuals were out of state.

At the conclusion of data collection (sixteen months), 130 questionnaires had been mailed; 110 had been received. Of those 110; 21 were received after a reminder postcard was sent. Of the 20 questionnaires that were not returned to the researcher, 19 had been sent a reminder postcard; and one had called to decline to participate before a postcard was due to be sent. After receiving the reminder postcard, two caregivers phoned the researcher: one caregiver declined to participate; and the other caregiver suggested s/he misplaced the packet and asked for another packet to be mailed. The replacement packet was recoded so that if received, it would not be a duplicate questionnaire. Ultimately the original questionnaire was also received from this caregiver; but that questionnaire was not coded and entered as data.
Pilot Study

A pilot study was conducted with family caregivers of older adults. This was a mixed methods study that used focus groups and a self-administered, written, survey questionnaire. The purpose of this study was to elicit explanations of effort in family caregivers. Focus groups were used to obtain the qualitative data for the analysis. A purposive sample of family caregivers was recruited at a community setting that provides services to older adults and caregivers.

The following is a review of the procedures that were followed for data collection and data analysis. Caregivers (n=12) described effort as it related to their caregiving responsibilities and completed a questionnaire which included the CES-D-10 (Andresen, Malmgren, Carter, & Patrick, 1994) and visual analog scales (VAS) measuring physical, mental, and psychological effort. Audiotaped data from focus group sessions was transcribed and analyzed to identify themes. A second session was conducted with each of the groups to validate findings. The findings of the pilot study were used to inform design and measurement of the larger dissertation study.
Table 3.2

Variables and Measures

<table>
<thead>
<tr>
<th>Concept</th>
<th>Instrument</th>
<th>Items</th>
<th>Level of Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver depressive symptoms</td>
<td>Center for Epidemiological Studies Depression Scale (CES-D-20)</td>
<td>20</td>
<td>Continuous</td>
</tr>
<tr>
<td>Caregiving workload</td>
<td>Oberst Caregiving Load Scale; time difficulty</td>
<td>15</td>
<td>Continuous</td>
</tr>
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<td>VAS (modified Borg CR 10)</td>
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<td>Continuous</td>
</tr>
<tr>
<td>Effort, mental</td>
<td>VAS (modified Borg CR 10)</td>
<td>1</td>
<td>Continuous</td>
</tr>
<tr>
<td>Effort, emotional</td>
<td>VAS (modified Borg CR 10)</td>
<td>1</td>
<td>Continuous</td>
</tr>
<tr>
<td>Effort, time-related</td>
<td>VAS (modified Borg CR 10)</td>
<td>1</td>
<td>Continuous</td>
</tr>
<tr>
<td>Effort</td>
<td>Open-ended questionnaire item</td>
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<td>Qualitative</td>
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<td>Pruchno Coping Strategies Scale</td>
<td>16</td>
<td>Continuous</td>
</tr>
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<td>2</td>
<td>Categorical</td>
</tr>
<tr>
<td>caregiving situation</td>
<td>Care receiver (C.R.) age; ADL</td>
<td>2</td>
<td>Continuous</td>
</tr>
<tr>
<td>Caregiving background</td>
<td>Gender, Education, Ethnicity, Marital; Income; Employment</td>
<td>6</td>
<td>Categorical</td>
</tr>
<tr>
<td>caregiver demographics</td>
<td>Age, Self-assessed health</td>
<td>2</td>
<td>Continuous</td>
</tr>
</tbody>
</table>
Dependent variable

Caregiver depressive symptoms. The dependent variable in this study is caregiver depressive symptoms. Depressive symptoms were measured with the Center for Epidemiological Studies Depression (CES-D) scale (Radloff, 1977). The full 20 item scale was used in this study. The CES-D measures current depressive symptoms, where the respondent reports physical and behavioral observances based on a one-week recall (Radloff, 1977). This scale uses a four-point Likert scale. Each item is scored zero to three (0 means never, 3 means almost all of the time), where higher scores indicate more depressive symptoms. The summed scale score is reported as continuous data. The theoretical range of scores for this scale is 0 – 60. A cut point of 16 or greater is typically regarded as indicating clinically significant depression (Radloff, 1977; Ensel, 1986).

This scale was developed from items in established depression scales to represent the core depressive symptom domains (Radloff, 1977; Ensel, 1986). Factor analysis confirms four separate dimensions, representing depressed affect symptoms, positive affect symptoms, somatic/vegetative symptoms, and interpersonal distress symptoms. The CES-D had strong inter-item correlations and internal consistency with a Cronbach’s alpha of .80, and test-retest correlations of 0.51 to 0.57 (Radloff, 1977). Evidence for content validity and convergent validity was supported by correlations with other depression scales; for example, correlation coefficients of .49 to .60 were reported for interviewer-based and Bradburn self-report of depression, respectively (Radloff). Content validity, criterion validity, and construct validity have been reported in a variety
of populations, including older adults, and caregivers of older adults. In this study, the Cronbach’s alpha was .90.

**Independent variables**

*Caregiving workload.* Caregiving workload included the stressors; demands; tasks; time; and difficulty spent in caregiving. Oberst’s Caregiving Load Scale was developed to measure the time spent in meeting specific caregiving demands. The original scale included ten items, scored 1-5 where a higher score represents a higher perceived caregiving load. Oberst reported an interitem correlation of .40, and Cronbach’s alpha of .87 for the full scale (Oberst et al., 1989). The instrument was developed and used with caregivers of people who had cancer. An expanded version of the Oberst scale was used by Bakas and colleagues (2004) with caregivers of people who had survived a stroke. This instrument was selected in part because the items on the instrument were thought to be consistent with themes from focus group members in a pilot study, conducted by the author, about the responsibilities of caregiving they associated with effort in caregiving for older adults with a variety of health conditions.

The Oberst Caregiving Load Scale (OCLS) has ten items (Oberst et al., 1989). The Oberst Caregiving Burden Scale (OCBS) has 15 items (Bakas et al., 2004). Caregiving tasks items included on the 10-item OCLS are: treatments; personal care; assisting with mobility; emotional support; monitoring / reporting symptoms; transportation; managing illness-related finances / paperwork; extra housework; structuring activities; and managing behavior.

Caregiving tasks items included on the 15-item OCBS are treatments and medications; personal care; mobility; emotional support; monitoring symptoms;
transportation; finances; household tasks; planning activities; behavior problems; with the addition of errands; finding elder care while away; communicating with patient; finding resources; and communicating with health care professionals.

Bakas and colleagues (2004) used the 15-item version of Oberst’s scale to investigate two aspects of caregiving workload; time and difficulty associated with the tasks of caregiving. In the Bakas study, the population was caregivers of people who had survived a stroke. Psychometric analysis of two subscales was conducted. The items loaded on both factors. Bakas and colleagues (2004) reported a Cronbach’s alpha for the time subscale of .90; and a Cronbach’s alpha for the difficulty subscale of .94. In this study, the Cronbach’s alpha for the time subscale was .85 and the Cronbach’s alpha for the difficulty subscale was .88. The time subscale is scored 1 – 5 (“none” to “a great amount”) on a Likert scale. The difficulty subscale is scored 1 – 5 (“not difficult” to “extremely difficult”) on a Likert scale. The theoretical range of scores is therefore 15 to 75 for each of the subscales.

Caregiver overload. Additionally, stressors of the caregiving situation were measured with the four item subscale of Pearlin and colleagues’ (1990) stress process model questionnaire named “overload”. This subscale included items that related to the energy and time the caregiver perceived was used in caregiving, which appear to be conceptually consistent with perceived workload for this study. The themes addressed are: feeling exhausted, more to do than can handle; no time for self; and work hard without sign of progress. These items were qualitatively-derived through themes elicited in research regarding the cumulative effects of caregiving on the caregiver (Pearlin et al., 1990). The items are scored 1 to 4, where a higher score represents higher perceived
overload. The theoretical range of scores is 4 to 16. This subscale had a reported Cronbach’s alpha internal consistency reliability of .80. In this study, the Cronbach’s alpha was .76.

_Caregiver coping._ Coping was measured with the Coping Strategies Scale developed by Pruchno & Resch (1989), based on the work of Kiyak, Borson, Montgomery & Teri (1985) and the stress process model (Pearlin et al, 1990). The Coping Strategies Scale is a 16-item survey of the coping skills caregivers use in coping with their caregiving situation. The items represent four dimensions of coping: instrumental, intrapsychic, wishfulness, and acceptance. These groups of items have Cronbach’s alpha correlations of .77, .71, .73 and .69 respectively. The 16 coping items on the full scale were developed from items identified in previous work, including Kiyak, Montgomery, Borson, & Teri (1985); Pearlin & Schooler (1978); and Kahana, Kahana, and Young (1987).

For the Coping Strategies Scale, items are scored according to a Likert scale, 1 (never), 2 (rarely/seldom), 3 (sometimes), 4 (often), or 5 (most of the time). The total scores for the four subscales have been examined for bivariate comparisons with other variables in the Pruchno and Resch (1989) and Pruchno and Kleban (1993) studies. The theoretical range of scores for the subscales are: Wishfulness (3 items), 3 – 15; Acceptance (3 items), 3-15; Intrapsychic (4 items), 4-19; and Instrumental (5 items), 5 – 24. The theoretical range of scores for the total Coping Strategies Scale is therefore 16 to 80.

_Caregiver effort._ Effort is exerting energy in managing the stressors, tasks, and demands of the caregiving workload. Physical effort is exerting physical energy in
managing the caregiving workload. Mental effort is exerting mental energy in managing the caregiving workload. Effort was measured in two ways. First, qualitative analysis of the open-ended questionnaire item was conducted through content analysis, to describe types of effort. Caregivers who responded to this question (n=105) were given a box that encompassed most of the full page (8 ½ inches by 11 inches) to invite their detailed response. Respondents were also guided by a definition at the beginning of the research questionnaire: “Effort is exerting (or using) energy to do the work of caregiving.”

Secondly, visual analog scales (VAS) were used to measure effort based on VAS representations of effort proposed by Borg (1970) for physical effort and by Zijlstra (1997) for mental effort. Four VAS were used: physical effort; mental effort; emotional effort; and time-related effort. Each VAS was presented as a 10 centimeter (cm) long horizontal line. The line was anchored with zero (0) on the left and ten (10) on the right, without any vertical lines at the endpoints. The participant was instructed to draw a vertical line on the 10 cm line to rate, along the range from zero to ten, the corresponding estimate of the amount of effort they used in the past week in caring for an older adult.

A consideration in the design of the study was whether the VAS for psychological effort manifested enough discrete explanation and variance from mental effort in the pilot study work to warrant a third dimension of psychological effort for this study. A decision was made to include the VAS for psychological effort; but to rename it “emotional” effort; and to re-evaluate its usefulness with the larger sample of caregivers. Additionally, a fourth VAS to represent a proxy for the time and effort of caregiving was added.
Background Characteristics

Demographic items regarding the caregiver included age, gender, marital status, education, ethnicity, employment, and self-assessed health. Descriptive information about the caregiving situation and the care receiver included household income; whether the older adult care receiver resided with the caregiver; the relationship of the caregiver to the older adult care receiver; age and gender of the older adult care receiver; the number of care receivers; health conditions and ADL of the older adult care receiver; and whether help was received from other family caregiver and/or formal caregivers. See Appendix A for Background Characteristics questionnaire items.

Figure 3.1
Research Model
Procedures

Recruitment

Initial approval was received from the Case Western Reserve University Institutional Review Board (Case IRB) in September of 2007. The recruitment period began in September 2007 and concluded in January 2009. A request for a waiver of signed consent was requested from and granted by the Case IRB. Family caregivers were recruited through a variety of mechanisms and sites for this study. First, permission was obtained from a multi-agency community site that provides care to older adults and their caregivers in the region to post flyers at this site. The researcher made site visits at least weekly; with the exception of two holiday weeks within the study recruitment period. The purpose of the site visits was to verify that posted flyers were still in the locations.

The flyer invited potential participants to call the researcher to hear more about the study; and participants could voluntarily decide if they wanted to receive a study packet. Family caregivers who called were given a brief description of the purpose of the study by the researcher. If eligible and interested in the study, family caregivers provided contact information in order to receive the research study packet in the mail.

Recruitment strategies also included posting flyers in a variety of urban, suburban, and proximal rural communities. In addition, a program for family caregivers at the multi-agency site had a mailing list of over 200 “active” family caregivers. A letter with Case IRB – approved language was accompanied by the study flyer in a regular mailing from the caregiver program to the caregivers on the mailing list. The researcher provided the postage for the mailing. Finally, snowball and chain sampling was employed for recruitment.
Flyers were also posted in public institutions, such as the regional public library system branches; pharmacies and grocery stores; religious institutions; hair salons; and coffee shops in the Northeast Ohio region. As recruitment progressed, a second flyer and letter of explanation to the caregivers from the multi-agency site in their regular monthly mailing was sent. Lastly, electronic methods that included a one time posting on the university’s daily electronic newsletter; a one-time mailing sent through the campus development office to alumni of the school of nursing; a posting on the University Center on Aging and Health web page; and a posting on an electronic classifieds list were used to recruit potential participants.

Nearly half of the final sample (48%) reported that they learned about the study through posted fliers. The second largest source of participants in the final sample was through word of mouth or snowball (29.1%). Only about ten percent of the final sample responded to mailed fliers and less than 13% responded to electronic mailings.

One half of the final sample reported that they learned about the study through postings at public institutions and businesses (49.6%). Approximately a third of the final sample reported that they learned about the study through a multi-agency site that serves older adults and their caregivers (33.9 %). Markedly fewer participants in the final sample learned about the study through electronic postings in an online daily newsletter (7.8 %) and an alumni / development email (8.7%).

Data collection

The data collection method for this study was a mailed questionnaire. The research packet included the informed consent document, with information about the study, its potential risks and benefits, and contact information for the researchers; and the
study questionnaire. The packet also contained a list of mental health resources, for all potential participants; a certificate of appreciation; and a pre-addressed, stamped envelope in which to return the study questionnaire. Contact information was retained only for the purposes of sending a reminder postcard at one month if a coded questionnaire was not received.

The research questionnaire included an item to confirm that the caregiver was currently responsible for the care of an older adult; and demographic items about the caregiver. Next, the open-ended effort question was presented. This was followed by a page with the effort visual analog scales (VAS); then the demographic items about the caregiving situation and the older adult care receiver. The coping scale; depressive symptoms scale; workload scale; and activities of daily living scale followed. The demographic item for income was placed at the end of the questionnaire. The final item was “Is there anything else you would like to tell us about your experiences as a family caregiver of an older adult?”

During the screening telephone call, participants were instructed that they may respond to any and all of the questions, or leave questions blank. If participants were caring for more than one older adult; they were advised to select one of the older adults as the care receiver for the quantitative items on the questionnaire that referred to the tasks and responsibilities; functional status; and health conditions of an older adult. Two participants wrote additional information in the questionnaire about the ages and genders of their additional care receivers. For one participant, the entire demographic page was left blank, so only the care receiver gender, age, marital status, and relationship were
coded, based on the care receiver describing being a daughter of “my 93 year old mother” and being “married”, according to the caregiver’s responses.

Data Management and Analysis

Data management

The questionnaire was mailed back to the investigators in a pre-addressed, stamped envelope. Questionnaires were given a participant identification number. The questionnaire data was stored in a locked file in a separate location from information about the participants. Identifying information was shredded once a questionnaire was received; or alternatively, once a reminder postcard was sent one month after the date that the packet was sent. One caregiver put a return address on the outside envelope and the envelope was shredded. Identifying information about the study participants that was obtained at the screening phone call was retained only for the purposes of distributing a research packet to the potential participant.

Data entry and cleaning

Questionnaires were reviewed and inspected for unclear responses and missing data. Data cleaning was performed by the researcher, and data entry was cross-checked against the questionnaires. Frequencies were examined to screen for unusual values that would indicate incorrect data entry. Data were screened for univariate outliers; for normality and linearity of distribution; and to see if the assumptions for correlation and for multiple regression were met (Tabachnick & Fidell, 2001). VAS responses were measured by the researcher, with the same millimeter ruler, and reported as centimeters to one-tenth decimal point. Centimeters were chosen over millimeters for reporting
consistency and comparison with the findings of the pilot study. Consultation was sought about procedures for handling missing data.

Qualitative data were transcribed verbatim into a Word document and was analyzed by the researcher. Emergent themes were reviewed with the co-researcher during the data collection period.

*Missing data*

Workload total scores were calculated using SPSS. The calculated means for the two subscales were used to replace missing data in the respective subscale prior to calculating the total score. A mean was not calculated if there were missing data for more than half of the subscale items.

A total score for the CESD was calculated after reverse coding four items that are phrased positively. Missing data were replaced by imputing the group means for the missing items.

Two participants had not completed the questionnaire page with the VAS for effort, and one participant did not complete the physical effort VAS. No mean could be computed for the missing data. The three items for SAH were transformed to z scores and a summative score was calculated for data analysis.

*Analyses*

Question 1. What are the characteristics of the caregivers, the care receivers, and the caregiving situation?

Frequencies and measures of central tendency and dispersion were presented for characteristics of the caregivers; the caregiving situation; and the care receivers. Data
were collected for caregiver demographic characteristics; background characteristics of the caregiving situation; and characteristics of the older adult care receiver.

Question 2. What are the types of effort used by family caregivers in performing the workload of caregiving to older adults?

Question two was answered through two methods. First, frequencies and measures of central tendency and dispersion were presented for the four visual analog scale (VAS) ratings; representing four possible types of effort. Secondly, content analysis of the qualitative research question was used to identify the types of effort described by the participants.

Question 3. What is the relationship between caregiver effort and caregiver depressive symptoms?

Question three was answered using bivariate correlation analysis. Pearson’s product moment correlation was used to examine the relationships among physical, mental, emotional, and time-related effort; and depressive symptoms.

Question 4. What are the relationships among characteristics of the caregiver and caregiving situation; the workload of caregiving; the effort that family caregivers use in caregiving; and caregiver depressive symptoms?

Question four was answered using bivariate correlation analysis. Analyses included Spearman’s rho (ρ) for ordinal independent variables and Pearson’s r for continuous independent variables. Point biserial correlations were reported for relationships between dichotomous variables and continuous variables.
Question 5. What are the relationships among the workload in caregiving; effort in caregiving; and caregiver depressive symptoms; when controlling for characteristics of the caregiver and the caregiving situation?

Question five was answered through an exploratory regression analysis. The entry design for hierarchical multiple regression in this study was theoretically guided. To be consistent with the stress process theoretical framework (Pearlin et al, 1990), variables representing two background factors; workload factors (Pearlin and colleagues called these “stressors”); and effort were examined to explain the outcome variable (depressive symptoms). First, the two caregiving background characteristics (SAH and ADL) were entered. Next, workload variables were entered, followed by effort scores for each of the domains (physical, mental-emotional, and time-related). These were regressed on the dependent variable of the total CES-D score.

Regression diagnostics were performed to verify the critical assumptions of regression analysis are met. These included tests for standardized residuals and normality: these included standard deviations and histograms; and PP plots and Durbin-Watson (Tabachnick & Fidell, 2001; Verran & Ferketich, 1984). Residuals were plotted to diagnose for homoscedasticity, and tolerance and VIF were requested to diagnose for multicollinearity. Finally, to note if outliers are influential, the Cook’s D and leverage values were interpreted (Tabachnick & Fidell, 2001; Verran & Ferketich, 1984). Data were interpreted with a confidence level of .05 (Smithson, 2002).

A post-hoc power analysis was performed, using G-Power 2.0 (Faul & Erdfelder, 1992). Because of missing data that could not be imputed, the regression analysis was performed with a sample of 104 cases. The $f^2$ statistic was used for multiple regression,
and a medium effect size was selected (0.15). The alpha was set at .05. The sample size for the analysis was 104. Eight predictors were in the final analysis (2 characteristics, 3 workload, 3 effort). The post hoc power for this study was .78.

Human Subjects Protection

This study used survey data to answer the research questions and involved minimal risks to the participants. The researcher gave information to potential participants and answered questions about the study procedures and participant responsibilities. Information about the study, including risks and benefits of participation, was given by phone and included on the mailed informed consent document.

Benefits and alternatives. Potential participants were informed that there were no direct benefits to participating in the study, but that their participation may improve the understanding of stresses facing caregivers and contribute to appropriate nursing interventions with caregivers. The only alternative to participating in the study, through mailing back the survey, was not participating in the study.

Risks. Potential participants were informed that there were no direct risks associated with participating, though they may become aware of psychological discomfort in answering the questions. A mental health information form was included in the packet for all potential participants with community resources to address psychological discomfort. A recommendation that the individual consider seeking consultation with a health care provider if s/he experienced distress was included.

Procedures to lessen risks to privacy were also explained. Potential participants were informed that their responses would be kept confidential, and that their privacy
would be protected in that it would not be possible to identify a respondent by their answers to the survey items.

**Consent to participate**

A waiver for signed consent was approved by the CWRU IRB. Potential participants were instructed that by reading the consent form and sending back the questionnaire, that consent to participate was assumed. No personally identifying information was requested from potential participants in the survey packet.

Participation in this study was voluntary. Potential participants were informed that they were free to change their minds at any time and not participate in the study, by not mailing back the survey. Ultimately, two participants notified the researcher that they changed their minds and would not be completing the questionnaire. Participants were informed that refusal to participate would not result in any change in individuals’ relationships with the agencies through which they heard about the study, nor with the university with which this study was affiliated.

Access to the survey data was limited to the co-investigators (the researcher and faculty advisor); the dissertation committee members; and potentially the university institutional review board for the protection of human subjects. Participants were informed that they could have access to the findings of the study at the conclusion of the study. Participants were told that interested individuals could call the researchers in the Spring of 2009 regarding study findings.
Chapter Four
Results and Discussion

Introduction

The purposes of this study were to describe effort as it is experienced by family caregivers in the work of caregiving to older adults and to explore the relationship between effort in caregiving and depressive symptoms in family caregivers. This study was conducted with a cross-sectional, descriptive correlational design. In chapter four, the results of the data analysis for the five research questions are presented. This is followed by a discussion of the results of the study.

Results

Question 1. “What are the characteristics of the caregivers, the care receivers, and the caregiving situation?” Descriptive statistics, including frequencies; and measures of central tendency (mean) and dispersion (standard deviation) were used to answer this research question. Mean sample scores are also presented for the scales used in this study.

Description of the family caregivers.

Results are reported for the 110 family caregivers who returned research questionnaires. The response rate, based on 130 questionnaires mailed, was 84.6%. All of the caregivers indicated that they were currently responsible for the care of an older adult who was at least 60 years of age. The demographic information and characteristics of the family caregivers are presented in Table 4.1.

Gender and age. The majority of the caregivers in the study were women (n= 101, 91.8%). The caregivers’ mean age was 58.48 with a standard deviation of 11.73; and a median age of 56. Caregivers ranged in age from 27 to 92 years of age.
Marital status. The majority of the caregivers reporting marital status (n=109) were married (n=66, 61%) or partnered (n= 1, 1%). Other caregivers indicated that they were single (n=1, 1%); never married (n=22, 21%); separated (n=2, 2%); divorced (n=13, 12%); and three were widowed (3%).

Ethnicity. The majority of caregivers reporting ethnicity (n=107) were Caucasian (n= 80, 75%). The next largest group by ethnicity were African American (n=23, 22%). A very small proportion of the sample identified themselves as Asian (n=3, 3%); Hispanic (n=1, 1%); and “other” (n=3, 3%).

Education. All of the caregivers who responded (n=108) indicated they had at least completed high school. Fifteen caregivers (14%) completed high school. The remainder of the caregivers (n= 93, 86%) reported at least some college education. The majority of those with at least some college had completed a graduate school level of education (n= 43, 40%); 26 (24%) had finished college; and 24 (22%) had some college.

Employment. Most of the caregivers who responded (n=109) were employed full time (n=49, 45%). Thirty-four (31%) caregivers were retired. Five (5%) caregivers reported that they reduced hours; and 13 (12%) stopped working because of caregiving. Seven (6.4%) caregivers indicated that they worked part-time and one caregiver reported they were “self-employed”.

Income. Household income was reported by 104 caregivers. The largest group of caregivers reported income between $40,001 to $60,000 (n=22, 21%). Twenty (19%) had an income between $20,001 to $40,000; and 13 (10%) caregivers had incomes between $60,001 to $80,000. Three groups of 10 (10%) caregivers reported their income at “less than $20,000”; between $100,001 to $120,000; and in the “over $120,000”,
respectively. Six (6%) caregivers had incomes between $80,001 to $100,000 annually. Twelve caregivers did not want to respond and one caregiver indicated s/he did not know or was uncertain.

*Health.* Self-assessed health (SAH) was measured for the caregivers. The scores for individual items were transformed to z scores so a total score could be calculated. Measures of central tendency and dispersion were examined. When transformed to a standardized score, the mean score was .0159 with a standard deviation of 2.54 and a median score of .9175. The range of scores on the standardized total scale score for the caregivers was -6.07 to 3.69 with higher scores indicate higher (greater) self-assessed health.

Caregivers’ health was further characterized by describing their health conditions. Eighty caregivers responded about their health conditions. Thirteen (16.3%) reported arthritic conditions; 11 (13.8%) reported back problems; ten (12.5%) reported hypertension and blood pressure problems; seven (8.8%) reported fatigue, “tired”, or “exhausted”; six (7.5%) reported breathing problems, including asthma and “COPD”; six (7.5%) reported endocrine problems including “cholesterol” and “thyroid” problems; five (6.3%) reported that they were overweight; and four (5%) had psychological health problems, including anxiety and depression. Several caregivers identified more than one health condition.
Table 4.1.

Demographics and Personal Characteristics of Caregivers (n=110)

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>%</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>109</td>
<td>58.48</td>
<td>11.742</td>
<td>56</td>
<td>27-92</td>
<td></td>
</tr>
<tr>
<td>27-59 years</td>
<td>61</td>
<td>56%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>60-92 years</td>
<td>48</td>
<td>44%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>110</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>101</td>
<td>92%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>108</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>15</td>
<td>14%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>24</td>
<td>22%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Finished college</td>
<td>26</td>
<td>24%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate school</td>
<td>43</td>
<td>40%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>107</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>23</td>
<td>22%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>80</td>
<td>75%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>1%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Other”</td>
<td>3</td>
<td>3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital</td>
<td>108</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married, partnered</td>
<td>66+1</td>
<td>62%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>1+22</td>
<td>21%</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Caregiver workload. Measures of central tendency and dispersion were examined for workload time and difficulty items. The means, standard deviations, and numbers of respondents for each caregiver task / responsibility on the Oberst Caregiving Burden Scale (OCBS) are displayed in Appendix C. The highest mean scores for time-related workload tasks and responsibilities were emotional support and “being there” with a
mean of 3.86 (s.d.=1.056); household and yard-related chores with a mean of 3.39 (s.d.=1.161); providing transportation and accompanying to appointments with a mean of 3.29 (s.d.=1.138); and, watching for and reporting symptoms and progress with a mean of 3.27(s.d.=1.143). The mean score for the total time subscale was 43.74 with a standard deviation of 10.597; and a range of 1 to 73 (theoretical range of 15 to 75).

The highest mean scores for difficulty-related workload tasks and responsibilities were managing behavior problems with a mean of 2.9 (s.d.=1.193); communicating and explaining to the older adult with a mean of 2.68 (s.d.=1.173); and, emotional support and “being there” with a mean of 2.58 (s.d.=1.158). The mean score for the total difficulty subscale was 33.45 with a standard deviation of 9.744; and a range of 15 to 56, (theoretical range of 15 to 75).

Depressive symptoms. Measures of central tendency and dispersion were examined for items on the Center for Epidemiological Studies Depression (CES-D). The means, standard deviations, and numbers of respondents for each depressive symptom item (CES-D) are displayed in Appendix D. The mean score for depressive symptoms was 17.47, with a standard deviation of 10.736; and a range of zero to 46 (theoretical range of 0 to 60). Forty-eight participants (44%) had CES-D scores above the established cut point on the CES-D; with scores of 17 or higher. Twenty-five (23%) of those 48 caregivers who were above the cut point had scores of 20 to 29 points, and 17 (15%) of those 48 caregivers had scores of 30 or higher.

Perceptions related to caregiving. Measures of central tendency and dispersion were examined for items on the Overload scale. For the caregivers who responded to the
Overload scale (n=109), the mean was 10.34 (s.d. = 2.95) and the range of scores was 4 to 16; (theoretical range of 4 to 16).

Caregiver coping strategies. Measures of central tendency and dispersion were examined for items and subscales of the Coping Strategies Scale. All of the caregivers (n=110) responded to the Coping Strategies Scale. Caregivers in this study had higher levels of acceptance coping, with a mean of 13.45, a standard deviation of 1.86, and a median of 13. The range of scores was 8 to 15 with a theoretical range of 3 to 15. For instrumental coping, the mean was 19.96 with a standard deviation of 4.65 and a median of 20. The range of scores was 7 to 30 with a theoretical range of 6 to 30. See Table 4.2.
Table 4.2.

*Caregiver Scores for Major Study Variables*

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Range</th>
<th>Cronbach’s α</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Effort</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical (n=106)</td>
<td>5.0406</td>
<td>2.815</td>
<td>(0-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental (n=108)</td>
<td>7.63</td>
<td>2.227</td>
<td>(.3-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional (n=108)</td>
<td>7.85</td>
<td>2.103</td>
<td>(.4-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time-related (n=108)</td>
<td>6.62</td>
<td>2.398</td>
<td>(1.7-10)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Workload</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time (n=110)</td>
<td>43.74</td>
<td>10.597</td>
<td>(1-73)</td>
<td>.865</td>
<td></td>
</tr>
<tr>
<td>Difficulty (n=110)</td>
<td>33.45</td>
<td>9.744</td>
<td>(15-56)</td>
<td>.878</td>
<td></td>
</tr>
<tr>
<td>Overload (n=109)</td>
<td>10.34</td>
<td>2.957</td>
<td>10.0</td>
<td>(4-16)</td>
<td>.757</td>
</tr>
<tr>
<td>Self-assessed health (n=107)</td>
<td>0.159</td>
<td>2.538</td>
<td>.9175</td>
<td>(-6.07-3.69)</td>
<td>.795</td>
</tr>
<tr>
<td>CES-D (n=110)</td>
<td>17.47</td>
<td>10.736</td>
<td>(0-46)</td>
<td>.90</td>
<td></td>
</tr>
<tr>
<td><strong>Coping</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instrumental (n=110)</td>
<td>19.96</td>
<td>4.651</td>
<td>20.0</td>
<td>(7-30)</td>
<td></td>
</tr>
<tr>
<td>Acceptance (n=110)</td>
<td>13.45</td>
<td>1.862</td>
<td>13.0</td>
<td>(8-15)</td>
<td></td>
</tr>
<tr>
<td>Wishfulness (n=110)</td>
<td>9.38</td>
<td>2.943</td>
<td>9.0</td>
<td>(3-15)</td>
<td></td>
</tr>
<tr>
<td>Intrapsychic (n=110)</td>
<td>11.59</td>
<td>3.630</td>
<td>11.0</td>
<td>(4-19)</td>
<td></td>
</tr>
</tbody>
</table>

Note.* actual / theoretical range (scores) ** internal consistency reliability: Cronbach’s α
Description of the caregiving situation. Characteristics of the caregiving situation are listed in Table 4.3.

Residence. Well over half of the caregivers who responded to the questionnaire item about residence (n=110) lived with the older adult care receiver (n =68, 62%).

Assistance. Sixty-six (62%) of 107 caregivers reported having help from other family and informal caregivers. The remaining 41 (38%) did not have help from other family or informal sources. Sixty-one (56%) of 109 caregivers reported that they had no help from formal caregivers, while 48 (44%) indicated that they had some help from formal caregivers.

Relationship of caregiver to care receiver. Most of the caregivers described themselves as adult children (n = 62, 57%); followed by spouses (n=24, 22%); and those who reported “other” relationships (n=22, 20%). The “other” category referred to a variety of relationships: daughter-in-law, niece, neighbor, and godmother; and one caregiver marked sibling.

Number of care receivers. All of the caregivers responded about the number of care receivers in their caregiving situation (n=110). Most of the caregivers (n=84, 76%) were currently caring for just one older adult. However, 20% (n=22) of the respondents reported caregiver responsibilities for two older adults. Only 4 (3%) caregivers identified caring for three or more care receivers.
Table 4.3.

*Characteristics of caregiving situation (n=110)*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG Relationship to CR</td>
<td>109</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>24</td>
<td>22%</td>
</tr>
<tr>
<td>Adult child</td>
<td>62</td>
<td>57%</td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>20%</td>
</tr>
<tr>
<td>CG Resides with CR</td>
<td>110</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>68</td>
<td>62%</td>
</tr>
<tr>
<td>No</td>
<td>42</td>
<td>38%</td>
</tr>
<tr>
<td>Help family CG</td>
<td>107</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>66</td>
<td>62%</td>
</tr>
<tr>
<td>No</td>
<td>41</td>
<td>38%</td>
</tr>
<tr>
<td>Help formal CG</td>
<td>109</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>44%</td>
</tr>
<tr>
<td>No</td>
<td>61</td>
<td>56%</td>
</tr>
</tbody>
</table>

*Description of the older adult care receivers*

*Age and gender.* The mean age of the older adult care receivers was 82.22 years, with a standard deviation of 8.22, and a median age of 82. The care receivers ranged in age from 60 to 98 years. Most of the care receivers were female. There were 70 women
(64%) and forty (36%) men. Characteristics of the older adult care receivers can be found in Table 4.4.

Table 4.4.

**Characteristics of Older Adult Care Receivers (n=110)**

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>(%)</th>
<th>Mean</th>
<th>(SD)</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>109</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>70</td>
<td>64%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>36%</td>
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<tr>
<td>Age</td>
<td>110</td>
<td>82.22</td>
<td>8.242</td>
<td>82</td>
<td>60-98</td>
<td></td>
</tr>
<tr>
<td># conditions CR</td>
<td>103</td>
<td>3.52</td>
<td>1.578</td>
<td>3</td>
<td>1-9</td>
<td></td>
</tr>
<tr>
<td>ADL</td>
<td>110</td>
<td>4.29</td>
<td>1.9</td>
<td>5</td>
<td>0-6</td>
<td></td>
</tr>
</tbody>
</table>

**Functional status.** Functional status of the older adult care receivers was measured with the Katz Activity of Daily Living (ADL) scale. For the sample of caregivers in this study, the mean score for ADL of the older adults was 4.29 with a standard deviation of 1.9, and a median score of 5. The theoretical range of scores is 0 to 6, where a higher score represents a higher functional ability of the older adult to perform the activity of daily living independently or with little assistance.

**Health conditions.** 103 caregivers described the conditions and diagnoses of the care receivers. The prominent conditions for which the older adults required care or supervision were cardiovascular and dementia conditions followed closely by arthritis and diabetes. The following are the five most prevalent conditions of the older adult care receivers in this study. Forty two (38%) care receivers had cardiovascular conditions,
including heart failure; 37 (34%) had dementia, Alzheimer’s disease, or a “memory problem”; 27 (25%) reported hypertension or high blood pressure; 26 (24%) reported arthritis; and, 24 (22%) had diabetes. The following acute and chronic health conditions were less frequent: cancer; stroke; sensory and mobility difficulties; and mental illness.

*Number of health conditions.* Some caregivers listed no health conditions for the older adult. Two (2%) listed eight conditions; one (1%) listed nine conditions while most listed three (n=31, 30%) to four (n=29, 28%) conditions. Fifteen (15%) caregivers listed two conditions, and nine (9%) caregivers listed one condition.

For the purposes of detailed description of the sample; statistical test analysis of variance (ANOVA) was used to test for differences in depressive symptoms in group means according to selected caregiver characteristics. No statistically significant differences were identified in depressive symptoms based on gender (F=.706, p=.403); education (F=2.191, p=.094); ethnicity (F=.406, p=.749); marital status (F= 1.820, p=.103); employment (F= 1.147, p=.340); income (F=.515, p=.842); or caregiver relationship to care receiver (F=.206, p=.892). See Table 4.5.
Table 4.5.

*Differences in Depressive Symptoms by Caregiving Characteristic*

<table>
<thead>
<tr>
<th>Variable</th>
<th>F</th>
<th>p</th>
<th>df (bg)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG Gender</td>
<td>.706</td>
<td>.403</td>
<td>1</td>
</tr>
<tr>
<td>Education</td>
<td>2.191</td>
<td>.094</td>
<td>3</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>.406</td>
<td>.749</td>
<td>3</td>
</tr>
<tr>
<td>Marital</td>
<td>1.820</td>
<td>.103</td>
<td>6</td>
</tr>
<tr>
<td>Employment</td>
<td>1.147</td>
<td>.340</td>
<td>5</td>
</tr>
<tr>
<td>Income</td>
<td>.515</td>
<td>.842</td>
<td>8</td>
</tr>
<tr>
<td>Relationship to CR</td>
<td>.206</td>
<td>.892</td>
<td>3</td>
</tr>
</tbody>
</table>

Chi-Square tests were used to test two relationships among two categorical variables. No statistical significance was found in the presence of help from other family or informal caregivers based on whether the care receiver lived with the caregiver ($X^2=1.229$, $p=.268$). There was no statistical significance found in the use of help from formal caregiving sources based on whether the care receiver lived with the caregiver ($X^2=.039$, $p=.844$).
Question 2. “What are the types of effort used by family caregivers in performing the workload of caregiving to older adults?”

This research question was answered by two methods. First, caregivers were asked to respond to a visual analog scale (VAS) for each of the four types of effort that were measured in this study: physical effort, mental effort, emotional effort, and time-related effort. The possible range of scores was 0-10 for all four of the VAS. The mean score for physical effort was 5.04; standard deviation of 2.815; median score of 4.95; and, a range of 0 to 10. The mean score for mental effort was 7.63; standard deviation of 2.227; median score of 8.25; and, a range of 0.3 to 10. The mean score for emotional effort was 7.85; standard deviation of 2.103; median score of 8.5; and, a range of 4 to 10. The mean score for time-related effort was 6.62; standard deviation of 2.398; median score of 6.85; and, a range of 1.7 to 10. The results are listed in Table 4.6.

Table 4.6.

<table>
<thead>
<tr>
<th>Type of effort</th>
<th>Mean</th>
<th>SD</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical (n=106)</td>
<td>5.04</td>
<td>2.815</td>
<td>4.95</td>
<td>0-10</td>
</tr>
<tr>
<td>Mental (n=108)</td>
<td>7.63</td>
<td>2.227</td>
<td>8.25</td>
<td>.3-10</td>
</tr>
<tr>
<td>Emotional (n=108)</td>
<td>7.85</td>
<td>2.103</td>
<td>8.50</td>
<td>4-10</td>
</tr>
<tr>
<td>Time-related (n=108)</td>
<td>6.62</td>
<td>2.398</td>
<td>6.85</td>
<td>1.7-10</td>
</tr>
</tbody>
</table>

Note. Score measured in centimeters (cm) from 0 – 10 cm on Visual Analog Scale (VAS)
A second method to obtain qualitative data to answer question two, was the 
questionnaire item: "What is caregiving like for you? We are interested in how 
caregivers of older adults describe the work of caregiving, and the effort needed to do the 
work of caregiving. Please explain in your own words what the effort is like for you in 
doing the work of caregiving." One hundred five caregivers provided written 
experiences exerting energy for caregiving; using resources; and outcomes of effort.

Content analysis was used to analyze the qualitative data. Excerpts from 
caregivers’ responses are presented as exemplars of physical, mental, emotional, and 
time-related effort in caregiving. Caregivers identified distinctions among types of effort 
and they place effort into the context of doing the workload of caregiving. For example:

"I see the "effort" and work of caregiving to be a combination of physical, 
mental, emotional, and spiritual energy that is needed and resources available 
inside of me! The degree of effort seems to vary, some days physical is needed 
more than mental, etc in different combinations. Some days the amount of energy 
varies as well so that the physical work may be easy and a breeze but there is 
little emotional energy / resources, so then the work of caregiving seems a lot 
more effortful. The biggest part of effort also involves the time involved, often not 
enough hours in a day, so time makes the work and effort needed more as well."

(45 year old female)

Physical effort is exerting physical energy to balance between the demands of the 
caregiving workload and caregiving outcomes.

“Caregiving effort, for me, feels like pushing an elephant up a mountain.” (53 
year old female)
“Effort requires mind body & soul to begin a caregiver task, follow thru & complete... However one must gather more energy to be ready for the next task. It is an ongoing depletion of energy, with little time to build, esp. if you are working a full time job. Sometimes you have to psych yourself for expending the effort...When one task is done it is time for another and it is repetitive with no end in sight.” (74 year old female)

“Although my father lives on his own he has stayed at my home many times... These stays included physical effort [examples of tasks and responsibilities]... Those stays are exhausting – a 24 / 7 role – never getting relief from the care giving role because my father lived with me...Accompanying my father to doctor appointments is constant. This takes stamina and persistence, patience and problem solving – but little physical effort (small physical effort to hoist his walker and keep him steady).” (55 year old female)

“It’s very hard. My husband isn’t much taller than I, but he weighs more so it is hard transferring him though he can help. My health isn’t great, either. I have COPD and asthma so I am limited, too.” (69 year old female)

“Strength – this is the actual upper and lower body stamina need to lift and move the person and/or heavy equipment, furniture, etc.” (60 year old female)

“The effort comes physically because it is extremely difficult for me to sit. And my mothers’ [sic] condition requires me to sit with her in order to communicate, which I feel is my primary responsibility. There is effort every minute as I am hypersensitive to her needs.” (47 year old female)
Mental effort is exerting mental energy to balance between the demands of the caregiving workload and caregiving outcomes.

“The mental & emotional demands outweigh the physical demands greatly in my particular case.” (37 year old female)

“Caregiving demands the most challenging balance of thinking, doing, supporting and gently guiding. It takes a lot of energy and creativity but it is highly rewarding.”

(53 year old female)

“I felt exhausted although I was not exerting any physical energy. Manipulating and managing the system to obtain appropriate care takes great mental effort.”

(55 year old female)

“It’s constant – I’m always managing things, arranging things, undoing things he shouldn’t have done, monitoring him.” (62 year old male)

“Constant alertness to the needs & potential needs & risks for my husband. If I get to relaxed I have to re-focus on what I should be anticipating.” (53 year old female)

“Planning and scheduling tasks … Problem-solving … Resource identification … Learning new skills … Decision-making …” (60 year old female)

“Caregiving is more difficult than I imagine [sic] I have been doing it for four years full time I [sic] hardest part is being patient with my mother’s dementia … Caregiving requires alertness and twice the energy that a person needs to take care of themselves…” (69 year old male)
“Some days it seems effortless and other days are burdensome primarily because I do not live with the older adults (my parents)... There are days when I know I am responsible... ... and then I don’t seem to care if I make any effort on their behalf however I feel I am cheating when I can live my life with ease... upon returning home there seems to be a greater effort on my part required in transition to complete my own tasks.” (47 year old female)

“...it takes so much effort to try and put things out of my mind at work” (53 year old female)

“Some days the juggling of work and caregiving seem under control and other days it is overwhelming – I am always thinking of ways to make life easier and better for my parents. It’s my choice to be there for my parents, and I wouldn’t have it any other way—but it’s still hard!” (32 year old female)

**Emotional effort** is exerting emotional energy to balance between the demands of the caregiving workload and caregiving outcomes.

“At this point in time most of my caregiving effort is considered emotional / mental effort. Even though the work requires minimal physical effort sometimes a “task” would be easier to deal with on a daily basis.” (53 year old female)

“The intensity of the emotional effort that I exert is influenced significantly by stressors in my life. For example, the routine daily call to check in with my mother requires so much more effort on days when I am stressed and/or tired. (51 year old female)

“It is a never ending job. The most energy consuming part is the constant anxiety. Where is he? What is he doing?” (82 year old female)
“For me the most effort used is what I call is the psychic effort needed to support, assist, coordinate, manage, advocate for my father through a healthcare crisis and recovery and even through routine health care as well as through the routine of living as an elderly person... worrying is an energy drain. Maintaining a realistic and supportive attitude and relationship takes psychological effort for me.” (55 year old female)

“There is the ‘worry work’ [examples of possible scenarios]” (53 year old female)

“My mother is not a happy person. She is very critical of both myself and my sister. This makes helping her more difficult and makes the effort of just being with her draining.” (50 year old female)

“Even ... when I’m gone, she wants to know when I am returning home...I am frequently awaken [sic] during the night to reassure her. I am an emotional support for her” (62 year old female)

“Being a caregiver is very stressful. Especially when the other sibling does not contribute time / emotion equitably.” (65 year old female)

“The most difficult issue is the feeling of being the ‘loan [sic] caregiver’ to my mom while in the midst of a large extended family.” (63 year old female)

“One thought to keep in mind is I am giving back to him and will be there for him. Yes, there are times I feel sorry for myself, but not very often. Most of the time I worry about him if he should need more care, will we have enough money to deal with whatever the future holds. It would be nice to take a vacation but there is no one to be there to do what needs to be done. And yes, there are times I
feel restricted, but, it could be worse. Also I am always tired.” (62 year old female)

“… I have a constant nagging fear and feel as if disaster will strike and I will not have the fortitude to deal with it. It is an irrational fear that verges on panic.”

(67 year old female)

“Worry about caring for her in my home in the future – my house isn’t equipped for a wheelchair, nor for bathing; also she would need 24 / 7 supervision; could I continue to work part time or would I have to quit my job – could I do it ???”

(55 year old female)

**Time-related effort** is related to the interrelatedness of time and exerting energy; to balance between the demands of the caregiving workload and caregiving outcomes.

“I spend more time and energy [lists responsibilities] …” (72 year old female)

“I consider caregiving my part time job. There is always something even though its [sic] something minor... Although my caregiving is more mental than physical it still is very demanding & time-consuming.” (58 year old female)

“Caregiving is a very time – consuming task, but one done out of love.” (43 year old female)

“Caregiving is a 24 hour around the clock job. Your time isn’t your own and you are on call at all times.” (76 year old female)

“It is my opinion that the single most important area of care of an older adult is in dealing with memory loss. This loss I believe is the nucleus of a major time-related ‘effort’ in giving care and impacts every other aspect of the older person’s life and the care givers [sic].” (52 year old female)
“I often feel conflicted between being a dutiful daughter and the amount of time and energy required for my mother, at 89, to live independently. She does not for the most part recognize how hard it is for me to take a chunk out of my day and attend to her needs...” (53 year old female)

“The biggest part of effort also involves the time involved, often not enough hours in a day, so time makes the work and effort needed more as well.” (45 year old female)

The multidimensionality of effort was identified by several caregivers. The following data illustrates how the perception of exertion was not limited to discrete types of effort.

“Caregiving effort is truly multidimensional...” (51 year old female)

“Caregiving for me is exaustive [sic] mentally and physically! It is demanding, continuous and ongoing effort...” (65 year old female)

“Caregiving, for me, was a multi-faceted experience. On the one hand, enriching, inspiring, a definite learning experience and a genuine privilege. On the other, it was physically, mentally, and emotionally exhausting for both my Mom, who was the patient, and me.” (67 year old female)

“Emotionally, physically, and psychologically I am drained 25-30% of the time from caring for her...The effort to care for my mom is strenuous... Being a constant overseer for my mom and family requires a great deal of effort and time.” (48 year old female)
Question 3. “What is the relationship between caregiver effort and caregiver depressive symptoms?”

The relationships among four types of effort (physical effort, mental effort, emotional effort, and time-related effort) and depressive symptoms were tested using a 2 tailed, Pearson’s product moment correlation. The results are presented in Table 4.7. All four types of effort were significantly, positively correlated with depressive symptoms.

Table 4.7.

*Pearson Correlation Results for Types of Caregiver Effort and Caregiver Depressive Symptoms*

<table>
<thead>
<tr>
<th>Type of effort</th>
<th>Correlation with CES-D</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical (n=106)</td>
<td></td>
<td>.222</td>
<td>.011</td>
</tr>
<tr>
<td>Mental (n=108)</td>
<td></td>
<td>.370</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Emotional (n=108)</td>
<td></td>
<td>.269</td>
<td>.003</td>
</tr>
<tr>
<td>Time – related (n=108)</td>
<td></td>
<td>.306</td>
<td>.001</td>
</tr>
</tbody>
</table>

There was a significant, positive relationship between physical effort and depressive symptoms with $r = .222$ and $p = .011$. There was a significant, positive relationship between mental effort and depressive symptoms with $r = .370$ and $p < .001$. There was a significant, positive relationship between emotional effort and depressive symptoms with $r = .269$ and $p = .003$. There was a significant, positive relationship between time-related effort and depressive symptoms with $r = .306$ and $p = .001$. 
Thus, for all four types of effort, higher effort is significantly correlated with more depressive symptoms.

Question 4. “What are the relationships among characteristics of the caregiver and caregiving situation; the workload of caregiving; the effort that family caregivers use in caregiving; and caregiver depressive symptoms?”

Data were analyzed using Pearson’s product moment correlation (r) to examine relationships between continuous variables. Point biserial statistics were used to examine relationships between continuous and dichotomous variables. Spearman’s Rho (ρ) was used to examine relationships between ordinal variables and continuous variables. Data were screened prior to analysis to verify the assumptions for correlation were met. These assumptions are normality, linearity, and homoscedasticity.

Good dispersion was noted in means and standard deviations for workload and effort. Data were slightly, positively skewed for depressive symptoms. In addition, data were slightly negatively skewed for mental effort; emotional effort; and ADL. Data approximated the normal curve for physical effort; time-related effort; workload time; workload difficulty; self-assessed health; and overload. The data for overload had a mild leptokurtosis, or positive kurtosis (Tabachnick & Fidell, 2001).

Approximate bivariate, linear relationships were noted between the independent variables measuring effort and workload, and the dependent variable measuring depressive symptoms. Examination of the scatterplots showed random scatter along a regression line. (Tabachnick & Fidell, 2001; Mertler & Vannatta, 2002). The relationships between characteristics; effort; workload; and depressive symptoms are described. Also, between group differences are described in effort, workload, and
depressive symptoms for the categorical caregiving characteristic variables. Results of the bivariate comparisons for the continuous data are also presented in Table 8.

Effort and caregiving characteristics

Physical effort. There was no significant relationship between caregiver age and physical effort with \( r = .089 \) and \( p = .336 \). There was no significant relationship between the age of the care receiver and physical effort with \( r = .017 \) and \( p = .859 \). There was no significant relationship between caregiver gender and physical effort with \( r = -.088 \) and \( p = .371 \). There was no relationship between the gender of the care receiver and physical effort with \( r = .125 \) and \( p = .203 \). There was no significant relationship between household income and physical effort with \( \rho = -.191 \) and \( p = .056 \). There was no significant relationship between whether the caregiver and care receiver co-reside and physical effort with \( r = .014 \) and \( p = .890 \). There was no significant relationship between receiving help from other family caregivers and physical effort with \( r = .045 \) and \( p = .654 \). There was no significant relationship between receiving help from formal caregivers and physical effort with \( r = .092 \) and \( p = .353 \). There was a significant, negative relationship between physical effort and ADL with \( r = -.419 \) and \( p < .001 \). There was no significant relationship between physical effort and self-assessed health with \( r = -.115 \) and \( p = .245 \).

Mental effort. There was no significant relationship between caregiver age and mental effort with \( r = -.081 \) and \( p = .406 \). There was no significant relationship between the age of the care receiver and mental effort with \( r = -.081 \) and \( p = .406 \). There was no significant relationship between caregiver gender and mental effort with \( r = -.022 \) and \( p = .820 \). There was no significant relationship between the gender of the care receiver and mental effort with \( r = -.022 \) and \( p = .820 \). There was no significant relationship between
household income and mental effort with $\rho = -.071$ and $p = .479$. There was no significant relationship between whether the caregiver and care receiver co-reside and mental effort with $r = -.010$ and $p = .916$. There was no significant relationship between receiving help from other family caregivers and mental effort with $r = -.120$ and $p = .222$. There was no significant relationship between receiving help from formal caregivers and mental effort with $r = .025$ and $p = .796$. There was a significant, negative relationship between mental effort and ADL with $r = -.189$ and $p = .050$. There was no significant relationship between mental effort and self-assessed health with $r = -.145$ and $p = .137$.

*Emotional effort*. There was no significant relationship between caregiver age and emotional effort with $r = -.158$ and $p = .103$. There was no significant relationship between the age of the care receiver and emotional effort with $r = -.153$ and $p = .114$. There was no significant relationship between caregiver gender and emotional effort with $r = .009$ and $p = .927$. There was no significant relationship between the gender of the care receiver and emotional effort with $r = .035$ and $p = .720$. There was no significant relationship between household income and emotional effort with $\rho = -.126$ and $p = .207$. There was no significant relationship between whether the caregiver and care receiver co-reside and emotional effort with $r = -.061$ and $p = .530$. There was no significant relationship between receiving help from other family caregivers and emotional effort with $r = -.121$ and $p = .219$. There was no significant relationship between receiving help from formal caregivers and emotional effort with $r = -.025$ and $p = .796$. There was no significant relationship between emotional effort and ADL with $r = -.031$ and $p = .748$. There was no significant relationship between emotional effort and self-assessed health with $r = -.139$ and $p = .156$. 
**Time-related effort.** There was no significant relationship between caregiver age and time-related effort with $r = .163$ and $p = .094$. There was no significant relationship between the age of the care receiver and time-related effort with $r = .075$ and $p = .440$. There was no significant relationship between caregiver gender and time-related effort with $r = .018$ and $p = .855$. There was no significant relationship between the gender of the care receiver and time-related effort with $r = -.045$ and $p = .642$. There was no significant relationship between household income and time-related effort with rho $= -.192$ and $p = .053$. There was no significant relationship between whether the caregiver and care receiver co-reside and time-related effort with $r = .132$ and $p = .173$. There was no significant relationship between receiving help from other family caregivers and time-related effort with $r = -.032$ and $p = .747$. There was no significant relationship between receiving help from formal caregivers and time-related effort with $r = .101$ and $p = .300$. There was a significant, negative relationship between time-related effort and ADL with $r = -.381$ and $p < .001$. There was no relationship between time-related effort and self-assessed health with $r = -.018$ and $p = .857$.

**Differences in effort by caregiving characteristics.** There were no differences according to caregiver gender for physical effort ($t = -.899$, $p = .371$); mental effort ($t = -.229$, $p = .820$); emotional effort ($t = .092$, $p = .927$); and time-related effort ($t = .184$, $p = .855$). There were no differences according to care receiver gender for physical effort ($t = 1.280$, $p = .203$); mental effort ($t = -.148$, $p = .883$); emotional effort ($t = .360$, $p = .720$); and time-related effort ($t = -.467$, $p = .642$). There were no between group differences found by caregiver education for physical effort ($F= 1.069$, $p = .366$); mental effort ($F= 1.294$, $p = .280$); emotional effort ($F = .483$, $p = .695$); and time-related
effort (F= .282, p= .838). There were no between group differences found by caregiver ethnicity for physical effort (F= 2.449, p= .068); mental effort (F= .387, p= .763); emotional effort (F= .166, p= .919); and time-related effort (F= .707, p= .550). There was a significant, between-group difference found in physical effort by caregiver marital status (F=4.080, p=.001). There were no between group differences found by caregiver marital status for mental effort (F= 1.817, p= .366); emotional effort (F= 1.010, p= .423); and time-related effort (F= 1.566, p= .165). There were no between group differences found by caregiver employment for physical effort (F= 1.687, p= .145); mental effort (F= .765, p= .577); emotional effort (F= .504, p= .772); and time-related effort (F= 1.770, p= .126). There were no between group differences found according to whether the caregiver and care receiver resided together for physical effort (F= .019, p= .890); mental effort (F= .011, p= .916); emotional effort (F= .397, p= .530); and time-related effort (F= 1.885, p= .173). There were no between group differences found by the relationship of the caregiver to the care receiver for physical effort (F= .287, p= .835); mental effort (F= .195, p= .900); emotional effort (F= .374, p= .772); and time-related effort (F= .348, p= .790). There were no between group differences found according to whether the caregiver received help from other family members for physical effort (F= .202, p= .654); mental effort (F= 1.507, p= .222); emotional effort (F= 1.528, p= .219); and time-related effort (F= .105, p= .747). There were no between group differences found according to whether the caregiver received help from formal caregivers for physical effort (F= .872, p= .353); mental effort (F= .067, p= .796); emotional effort (F= .067 p= .796); and time-related effort (F= 1.083, p= .300).
Effort and workload

There was a significant, positive relationship between physical effort and workload time with \( r = .417 \) and \( p < .001 \). There was a significant, positive relationship between physical effort and workload difficulty with \( r = .359 \) and \( p < .001 \). There was a significant, positive relationship between physical effort and overload with \( r = .281 \) and \( p = .004 \).

There was a significant, positive relationship between mental effort and workload time with \( r = .487 \) and \( p < .001 \). There was a significant, positive relationship between mental effort and workload difficulty with \( r = .498 \) and \( p < .001 \). There was a significant, positive relationship between mental effort and overload with \( r = .384 \) and \( p < .001 \).

There was a significant, positive relationship between emotional effort and workload time with \( r = .379 \) and \( p < .001 \). There was a significant, positive relationship between emotional effort and workload difficulty with \( r = .426 \) and \( p < .001 \). There was a significant, positive relationship between emotional effort and overload with \( r = .302 \) and \( p = .001 \).

There was a significant, positive relationship between time-related effort and workload time with \( r = .538 \) and \( p < .001 \). There was a significant, positive relationship between time-related effort and workload difficulty with \( r = .288 \) and \( p = .002 \). There was a significant, positive relationship between time-related effort and overload with \( r = .308 \) and \( p = .001 \).

Effort and depressive symptoms

There was a significant, positive relationship between physical effort and depressive symptoms with \( r = .222 \) and \( p = .022 \). There was a significant, positive relationship between mental effort and depressive symptoms with \( r = .336 \) and \( p = .001 \). There was a significant, positive relationship between emotional effort and depressive symptoms with \( r = .312 \) and \( p = .001 \). There was a significant, positive relationship between time-related effort and depressive symptoms with \( r = .308 \) and \( p = .001 \).
relationship between mental effort and depressive symptoms with $r = .366$ and $p < .001$. There was a significant, positive relationship between emotional effort and depressive symptoms with $r = .259$ and $p = .007$. There was a significant, positive relationship between time-related effort and depressive symptoms with $r = .285$ and $p = .003$.

*Workload and caregiving characteristics*

*Time related to workload.* There was no significant relationship between caregiver age and workload time with $r = -.020$ and $p = .833$. There was no significant relationship between the age of the care receiver and workload time with $r = -.030$ and $p = .758$. There was no significant relationship between caregiver gender and workload time with $r = -.005$ and $p = .958$. There was no significant relationship between the gender of the care receiver and workload time with $r = .058$ and $p = .546$. There was no significant relationship between household income and workload time with $\rho = .013$ and $p = .896$. There was no significant relationship between whether the caregiver and care receiver co-reside and workload time with $r = .136$ and $p = .155$. There was no significant relationship between receiving help from other family caregivers and workload time with $r = .095$ and $p = .329$. There was a significant, positive relationship between receiving help from formal caregivers and workload time with $r = .192$ and $p = .045$. There was a significant, negative relationship between workload time and ADL with $r = -.434$ and $p < .001$. There was no relationship between workload time and self-assessed health with $r = -.019$ and $p = .844$.

*Difficulty related to workload.* There was no significant relationship between caregiver age and workload difficulty with $r = -.069$ and $p = .478$. There was no significant relationship between the age of the care receiver and workload difficulty with
There was no significant relationship between caregiver gender and workload difficulty with \( r = 0.002 \) and \( p = 0.986 \). There was no significant relationship between the gender of the care receiver and workload difficulty with \( r = 0.021 \) and \( p = 0.827 \). There was no significant relationship between household income and workload difficulty with \( \rho = -0.040 \) and \( p = 0.690 \). There was no significant relationship between whether the caregiver and care receiver co-reside and workload difficulty with \( r = 0.007 \) and \( p = 0.941 \). There was no significant relationship between receiving help from other family caregivers and workload difficulty with \( r = 0.033 \) and \( p = 0.733 \). There was no significant relationship between receiving help from formal caregivers and workload difficulty with \( r = 0.144 \) and \( p = 0.136 \). There was a significant, negative relationship between workload difficulty and ADL with \( r = -0.234 \) and \( p < 0.001 \). There was a significant, negative relationship between workload difficulty and self-assessed health with \( r = -0.244 \) and \( p = 0.011 \).

**Overload.** There was a significant, negative relationship for caregiver age and overload with \( r = -0.190 \) and \( p = 0.049 \). There was no significant relationship between caregiver gender and overload with \( r = 0.019 \) and \( p = 0.845 \). There was no significant relationship between household income and overload with \( \rho = -0.078 \) and \( p = 0.431 \). There was no significant relationship between whether the caregiver and care receiver co-reside and overload with \( r = -0.030 \) and \( p = 0.754 \). There was no significant relationship between the gender of the care receiver and overload with \( r = -0.022 \) and \( p = 0.819 \). There was no significant relationship between the age of the care receiver and overload with \( r = -0.109 \) and \( p = 0.258 \). There was no significant relationship between receiving help from other family caregivers and overload with \( r = -0.066 \) and \( p = 0.504 \). There was no
significant relationship between receiving help from formal caregivers and overload with \( r = -0.029 \) and \( p = .767 \). There was a significant, negative relationship between ADL and overload with \( r = -0.236 \) and \( p = .013 \). There was a significant, negative relationship between self-assessed health and overload with \( r = -0.263 \) and \( p = .006 \).

*Differences in workload by caregiving characteristics.* There were no differences according to caregiver gender for workload time (\( t = -0.053, p = .958 \)); workload difficulty (\( t = .018, p = .986 \)); or overload (\( t = .059, p = .953 \)). There were no differences according to care receiver gender for workload time (\( t = .605, p = .546 \)); workload difficulty (\( t = .219, p = .827 \)); or overload (\( t = .524, p = .602 \)). There were no between group differences found by caregiver education for workload time (\( F = 1.514, p = .215 \)); workload difficulty (\( F = 1.888, p = .136 \)); and overload (\( F = 2.013, p = .117 \)). There were no between group differences found by caregiver ethnicity for workload time (\( F = .121, p = .948 \)); workload difficulty (\( F = .726, p = .539 \)); and overload (\( F = .435, p = .729 \)). There were no between group differences found by caregiver marital status for workload time (\( F = 1.732, p = .121 \)) and workload difficulty (\( F = 1.516, p = .180 \)). There was a significant, between group difference found by marital status for overload (\( F = 2.533, p = .025 \)). There were no between group differences found by caregiver employment for workload time (\( F = .443, p = .817 \)); workload difficulty (\( F = 1.683, p = .145 \)); and overload (\( F = 1.555, p = .180 \)). There were no between group differences found by whether the caregiver and care receiver reside together for workload time (\( F = 2.769, p = .099 \)); workload difficulty (\( F = .026, p = .872 \)); and overload (\( F = .714, p = .400 \)). There were no between group differences found by the relationship of the caregiver to the care receiver for workload time (\( F = .559, p = .643 \)); workload difficulty (\( F = .533, p = .025 \)).
and overload (F = 0.074, p = 0.974). There were no between group differences found according to whether the caregiver received help from other family members for workload time (F = 1.332, p = 0.251); workload difficulty (F = 0.370, p = 0.544); and overload (F = 1.610, p = 0.207). There was a significant, between group difference according to whether the caregiver received help from formal caregivers for workload time (F = 4.796, p = 0.031). There were no between group differences found according to whether the caregiver received help from formal caregivers for workload difficulty (F = 2.818, p = 0.096) and overload (F = 0.038, p = 0.847).

Caregiving characteristics and depressive symptoms

There was no significant relationship between caregiver age and depressive symptoms with r = -0.105 and p = 0.277. There was no significant relationship between the age of the care receiver and depressive symptoms with r = -0.128 and p = 0.182. There was no significant relationship between caregiver gender and depressive symptoms with r = 0.081 and p = 0.403. There was no significant relationship between the gender of the care receiver and depressive symptoms with r = -0.064 and p = 0.508. There was no significant relationship between household income and depressive symptoms with rho = -0.141 and p = 0.153. There was no significant relationship between whether the caregiver and care receiver co-reside and depressive symptoms with r = -0.003 and p = 0.974. There was no significant relationship between receiving help from other family caregivers and depressive symptoms with r = -0.139 and p = 0.154. There was no significant relationship between receiving help from formal caregivers and depressive symptoms with r = 0.044 and p = 0.652. There was a significant, negative relationship between ADL and depressive
symptoms with $r = -.262$ and $p = .006$. There was a **significant, negative** relationship between self-assessed health and depressive symptoms with $r = -.372$ and $p < .001$.

*Differences in depressive symptoms by caregiving characteristics.* There was no difference in depressive symptoms found by caregiver gender ($t = .840$, $p = .403$) or care receiver gender ($t = -.664$, $p = .508$). There were no between group differences in depressive symptoms found by caregiver education ($F = 2.191$, $p = .094$); ethnicity ($F = .406$, $p = .749$); marital status ($F = 1.820$, $p = .103$); employment ($F = 1.147$, $p = .340$); whether the caregiver and care receiver reside together ($F = .001$, $p = .974$); the relationship of the caregiver to the care receiver ($F = .206$, $p = .892$); whether the caregiver received help from other family members ($F = 2.065$, $p = .154$); or whether the caregiver received help from formal caregivers ($F = .204$, $p = .652$).

*Workload and depressive symptoms*

There was a **significant, positive** relationship between workload time and workload difficulty with $r = .589$ and $p < .001$. There was a **significant, positive** relationship between workload time and overload with $r = .297$ and $p = .002$. There was a **significant, positive** relationship between workload difficulty and overload with $r = .451$ and $p < .001$. There was a **significant, positive** relationship between workload time and depressive symptoms with $r = .247$ and $p = .009$. There was a **significant, positive** relationship between workload difficulty and depressive symptoms with $r = .341$ and $p < .001$. There was a **significant, positive** relationship between overload and depressive symptoms with $r = .586$ and $p < .001$. 
Table 4.8.

_Bivariate Comparisons among Characteristics, Workload, Effort, and Depressive Symptoms (listwise deletion: n=104)_

<table>
<thead>
<tr>
<th>Variable</th>
<th>CESD</th>
<th>Physical Effort</th>
<th>Ment Emot Effort</th>
<th>Time-related Effort</th>
<th>Workload</th>
<th>Workload Time</th>
<th>Workload Difficulty</th>
<th>Overload</th>
<th>SAH</th>
<th>ADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>CESD</td>
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<tr>
<td>Physical Effort</td>
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<td></td>
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<tr>
<td>Ment Emot Effort</td>
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<td>.343***</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Time-related Effort</td>
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<td>.301**</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workload</td>
<td></td>
<td>.234**</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<tr>
<td>Workload Difficulty</td>
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<tr>
<td>Overload</td>
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<td>-.364***</td>
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<td></td>
</tr>
<tr>
<td>SAH</td>
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<tr>
<td>ADL</td>
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</tbody>
</table>

**Note.***  *** $p \leq .001$; ** $p \leq .01$;  * $p \leq .05$  (two-tailed)
Question 5.

“What are the relationships among the workload in caregiving; effort in caregiving; and caregiver depressive symptoms; when controlling for characteristics of the caregiver and the caregiving situation?”

An exploratory multiple regression analysis was conducted to answer this question. Data screening and regression diagnostics were conducted. First, data were screened for outliers and influential data points. Results and tests included frequencies, histograms and plots, standardized residuals, Durbin Watson, scatterplots, tolerances and VIF, Cook’s D and Leverage values. (Fox, 1991; Tabachnick & Fidell, 2001). Next, variables were entered into a regression analysis in three steps, using the “enter” method, based on a theoretical placement: characteristics of the caregiver and caregiving situation; caregiving workload; and effort.

*Regression diagnostics*

Regression diagnostics were performed to verify the critical assumptions of regression analysis were met. The critical assumptions for multiple regression are normality, independence, and homoscedasticity. Procedures for evaluating standardized residuals and normality included examining standard deviations and histograms; and PP plots and Durbin-Watson (Tabachnick & Fidell, 2001; Verran & Ferketich, 1984). Residuals were plotted and examined to diagnose for homoscedasticity, and tolerance and VIF were examined to diagnose for multicollinearity. The Cook’s D and leverage values were interpreted to check for outliers and influential data (Tabachnick & Fidell, 2001; Verran & Ferketich, 1984). A confidence level of .05 was used (Smithson, 2002).
One issue in examining the data analysis was pursued further. The Mahalanobis distance was 1.979 to 37.690 with a mean of 7.923. When the data were explored for outliers it was determined that one case was suggested to be an outlier. Standardized residuals that are greater than three as an absolute value may represent outliers; and the recalculated standardized residual for this case was 3.072. The Cook’s D was less than one. The leverage values ranged from .019 to .366 with a mean of .077. This was not considered an influential outlier. Upon further examination, this participant did not have the most extreme score on the variable (depressive symptoms) to be entered into further analysis; so the case was not deleted from analysis.

Multiple regression is considered robust to mild violations of the assumptions of normality, independence, and homoscedasticity (Mertler & Vannatta, 2005; Tabachnick & Fidell, 2001). The untransformed dependent variable (CES-D) was used. Examination of the histogram reveals a slightly positively skew; yet it approximates the normal curve. Inspection of the PP plot revealed an approximately linear relationship. Residuals were also checked. The constant is represented in the equation. Standardized residual for the mean in the dependent variable was zero and the standard deviation was one; so the assumption of zero mean was met. Independence means that the residuals for the independent variables are independent of each other. The Durbin Watson equaled 1.566, which is close enough to 2 that autocorrelation of error was not a problem in this model. Values were widely dispersed around a regression line. Inspection of the scatterplot revealed no extreme nonrandom scatter. The assumption of homoscedasticity was met.

Data were examined to check for multicollinearity, which exists when independent variables are so highly correlated that they decrease the coefficient of
determination (R) and it is difficult to see their independent prediction in the model. (Mertler & Vannatta, 2005). Two variables that were highly correlated with each other (Pearson’s $r > .70$) were determined to be problematic in a preliminary analysis: mental effort and emotional effort. The decision was made to create a composite variable, “Mental Emotional Effort” for use in the regression analysis.

**Results of regression analysis**

A regression analysis was conducted by entering the variables in three steps. Variables were selected based on examining the correlation matrix and on literature. Listwise deletion was selected; which resulted in 104 cases included in the regression analysis. In the first step, the following variables were entered: self-assessed health and ADL. In the second step, the following variables were entered: self-assessed health; ADL; workload time; workload difficulty; and overload. In the third step, the following variables were entered: self-assessed health; ADL; workload time; workload difficulty; overload; physical effort; mental emotional effort (composite); and time-related effort.

Explained variance and influence of the independent variables were reviewed and interpreted. The results can be found in Tables 4.9 and 4.10. Results were reported for adjusted $R^2$ and beta ($\beta$). The adjusted $R^2$ takes into account the number of independent variables in the model; so it is a more accurate description of the regression model. The beta ($\beta$) is based on a standardized score and is a more accurate representation of how strong a predictor is, relative to the other potential predictors in the regression model. The model summary is graphically displayed in Table 4.9.

**Model 1.** The first model contained the variables for characteristics of the caregiver and caregiving situation. The results of the ANOVA indicated that the first
model was significant with $F = 11.551$ and $p < .001$. The adjusted $R^2$ indicated that the first model accounted for 17% of the variance in depressive symptoms. Self-assessed health (SAH), a caregiver characteristic, was a statistically significant predictor of caregiver depressive symptoms in the first model with $\beta = -.352$ and $p < .001$. Activities of Daily Living (ADL), to describe care receiver need in the caregiving situation, was a statistically significant predictor of caregiver depressive symptoms in the first model with $\beta = -.232$ and $p = .011$.

Model 2. In the second model, the workload variables were added. The results of the ANOVA indicated that the second model was significant with $F = 15.700$ and $p < .001$. The adjusted $R^2$ indicated that the second model accounted for 41.6% of the variance in depressive symptoms. Self-assessed health (SAH) was a statistically significantly predictor of caregiver depressive symptoms in the second model with $\beta = -.237$ and $p = .004$. Overload, a workload variable, was a statistically significant predictor of caregiver depressive symptoms in the second model with $\beta = .587$ and $p < .001$.

Model 3. In the third model, the effort variables were added. The results of the ANOVA indicated that the third model was significant with $F = 9.755$ and $p < .001$. The adjusted $R^2$ indicated that the third model accounted for 40.5% of the variance in depressive symptoms. Self-assessed health (SAH) was a statistically significant predictor of caregiver depressive symptoms in the third model with $\beta = -.238$ and $p = .004$. Overload was a statistically significant predictor of caregiver depressive symptoms in the third model with $\beta = .563$ and $p < .001$. 
Regression summary

Self-assessed health and ADL were the only variables that predicted caregiver depressive symptoms in the first model of the exploratory regression analysis. Self-assessed health and overload were the only variables that predicted caregiver depressive symptoms in the second model. Self-assessed health and overload were the only variables that predicted caregiver depressive symptoms in the third model. None of the types of effort – physical, mental/emotional, and time-related – predicted caregiver depressive symptoms.

Table 4.9.

*Caregiving Characteristics, Workload, and Effort Regressed on Depressive Symptoms (listwise deletion, n=104)*

<table>
<thead>
<tr>
<th>Variables</th>
<th>ANOVA</th>
<th>Model</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>p</td>
</tr>
<tr>
<td>Step 1</td>
<td>SAH</td>
<td>11.551</td>
</tr>
<tr>
<td></td>
<td>ADL</td>
<td></td>
</tr>
<tr>
<td>Step 2</td>
<td>SAH</td>
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</tr>
<tr>
<td></td>
<td>ADL</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time workload</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Difficulty workload</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Overload</td>
<td></td>
</tr>
<tr>
<td>Step 3</td>
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<td>ADL</td>
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<td></td>
<td>Time subscale workload</td>
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<tr>
<td></td>
<td>Difficulty subscale workload</td>
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</tr>
<tr>
<td></td>
<td>Overload</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physical effort</td>
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</tr>
<tr>
<td></td>
<td>Mental/Emotional effort</td>
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</tr>
<tr>
<td></td>
<td>Time-related effort</td>
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</tr>
</tbody>
</table>
Table 4.10.

**Coefficients for Variables in Exploratory Multiple Regression Analysis (n=104, listwise del)**

<table>
<thead>
<tr>
<th>Model</th>
<th>Variables</th>
<th>b</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>p</th>
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<tbody>
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<td>1</td>
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<td>.009</td>
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<td>-.087</td>
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<tr>
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<td>Overload</td>
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<td>.563</td>
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<td>.513</td>
<td>.079</td>
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<td>.484</td>
</tr>
</tbody>
</table>
Discussion

Effort, by definition, is a dynamic and often sub-perceptual phenomenon, so distinctions based on the study data are tentative. The findings in this study do, however, suggest some relationships among workload and effort, and workload and depressive symptoms. In family caregiving, effort is exerting energy to respond to needs, do tasks, monitor the status of the older adult; simultaneously balancing among responsibilities and relationships; in caring for the self and others. Effort is present even in the context of shared care; where resources are mobilized, yet regular and active control are still mobilized.

Question 1. “What are the characteristics of the caregivers, the care receivers, and the caregiving situation?”

According to national statistics, the average caregiver in the United States provides some care or assistance to a family member is a female; 47 years old; married; Caucasian; and employed outside the home (NAC/AARP, 2004). The final sample for this study was 91% female; 75% Caucasian; 57% adult children. The mean age of the family caregivers was nearly 60; over 11 years older than a national average (NAC/AARP, 2004); and nearly 44% of the caregivers were 60 or older. This is consistent with some estimates; where almost half of family caregivers are late middle age or elderly themselves (Johnson & Schaner, 2005). Women between the ages of 50 and 64 have been considered the most likely (18% of those surveyed) to be providing care for family members with health problems or disabilities; according to the Commonwealth Fund study (Ho, Collins, Davis, & Doty, 2005). Hence, many caregivers were balancing their own aging, as well as balancing multiple social roles. Most of the
caregivers reported annual income of $40,000 to $60,000. This is slightly higher than a national report of caregiver average income that was just under $40,000 annually (NAC/AARP, 2004). In addition, this was a highly educated sample of caregivers. Anecdotally, no pattern was identified for why many caregivers who identified completing college education or higher (64%) ultimately comprised the sample of caregivers.

In this study, 62% of those responding reported having help from other family caregivers; and 44% of those responding reported having help from formal caregivers. This latter finding is higher than some national findings about help with the workload. Nationally, the use of formal care services has been reported by only about a fifth of family caregivers (NAC & AARP, 2004). Having help from other family members might constitute both emotional support and practical support; but this is not a forgone conclusion.

This sample was mainly comprised of adult children (57%) and spouses (22%). Although there was only one caregiver eligible to participate in this study; shared care among family members was identified by several of the caregivers. Most of these caregivers were employed; though some had altered their hours of work or stopped working due to caregiving. It has been estimated that United States businesses may lose as much as $34 billion due to employees needing to take time off work to care for ill relatives (Metlife / NAC, 2006). This dollar amount does not portray the loss of wages for caregivers who have to take unpaid leave or leave paid employment due to caregiving work.
Health of caregivers. For the caregivers who responded about their own health conditions, conditions commonly related to pain (such as joint and arthritic conditions) and fatigue symptoms were identified most often. Fatigue was commonly reported by caregivers in a large national survey of caregivers (NAC / Evercare, 2006). Other researchers have examined fatigue among older caregivers and concluded that the caregivers reported more fatigue, lower energy, and poorer health as compared with non-caregiving counterparts. These symptoms seemed less likely to be related to the time and tasks of the caregiving (Teel & Press, 1999).

Several of the caregivers in this study identified health problems of their own. The average score for self-assessed health, for the majority of the caregivers, was just above the halfway point in a range of possible scores. This finding suggests only fair to good health among caregivers who are simultaneously attending to the health concerns of a family member. This “double burden”, as it has been called, is the experience of many caregivers who are providing care to a family member while dealing with their own health problems (Ho et al., 2005). Perhaps it is the energetical features of fatigue and effort that explain these “double burdens”. It is possible then, that the resultant health risks from exerting energy represent a double jeopardy in caregiving. Fatigue and effort are perceptual (Hockey, 1993), and are symptoms that can be monitored and then modulated by the caregiver.

Health of care receivers. The prevalence and magnitude of the health conditions affecting the health and functioning of the older adults cared for by the caregivers closely matches descriptions of the top chronic health conditions of older adults (e.g., arthritis, heart disease, and diabetes [CDC, 2004]). The functional status of the older adult care
receivers was measured based on the dichotomous Katz ADL scale. A mean score of over 4 for the aggregate of care receivers in this study suggests higher independent ADL ability. It is uncertain as to whether the health demands of the care receiver are a reliable predictor of the caregiver’s mental health, as some have suggested (Given et al., 1999; Clipp & George, 1993).

It was outside the scope of this study to examine group differences for effort according to the specific health conditions of the older adult. Two areas warrant further examination based on themes from the caregivers. Higher mental and emotional effort was reported by some caregivers of persons with dementia and other cognitive difficulties. Conversely, higher physical effort was not necessarily observed among caregivers whose older adult care receivers had reported neurological and musculoskeletal disability. The strains associated with caregiving workload and burden were recently examined among caregivers of people with chronic diseases, including cancer, dementia, diabetes, and heart disease (Kim & Schulz, 2008; Saunders, 2008). No relationship was found that offers support for differential experiences of effort according to the conditions of the care receivers.

*Time and difficulty associated with caregiving workload.* Item and scale means were presented to understand the types of responsibilities facing caregivers and the associated time and difficulty of those responsibilities. A review of the highest mean scores per time subscale item on the fifteen–item Oberst Caregiving Burden Scale (OCBS) suggests that the three most time-consuming responsibilities for caregivers were emotional support, transportation, and household/yard tasks. Oberst and colleagues, using the ten-item Caregiving Load Scale (OLS) identified these same three
responsibilities as the highest time-consuming responsibilities (1989). Bakas and colleagues had similar findings as they identified emotional support, transportation, managing finances and bills, and household/yard tasks as the four most time-consuming responsibilities for caregivers (2004).

A review of the highest mean scores per difficulty subscale item on the OCBS suggests that the three most difficult responsibilities for caregivers were managing behavior problems, communicating with and explaining to the care receiver, and emotional support. Bakas and colleagues identified managing behavior problems, emotional support, and household/yard tasks as the responsibilities perceived as most difficult (Bakas et al., 2004).

One observation about caregiver workload to consider is that the time and difficulty workload scores may not reflect all participants’ experience because of a lack of data. Some caregivers left items blank, resulting in lower mean scores. When caregivers left items blank, as missing or not applicable data, the item means were lower. (See Appendix C). Thus the appearance of less time or less difficulty may not reflect the actual time and difficulty involved.

Caregiver depressive symptoms. The mean CES-D score (17) for this sample of caregivers is above the cut point at which further investigation of clinically significant depressive symptoms has been recommended (Radloff, 1977; Schulz, O’Brien, Bookwala, & Fleissner, 1995). Thus, several of the caregivers rated their depressive symptoms as moderately high to high and a sizable proportion of this sample of caregivers may be considered highly distressed. In a national study, 60% of caregivers experienced moderate to severe depression (NAC / Evercare, 2006).
Question 2. What are the types of effort used by family caregivers in performing the workload of caregiving to older adults?

While most caregivers described effort; a few of the caregivers described their workload in their responses to open-ended questions. These descriptions of workload initially appeared to be a departure from the descriptions of effort. Upon further examination, the caregivers who wrote about workload described tasks and responsibilities associated with their caregiving situation within the context of resource allocation and meeting demands. A description of task difficulty is linked to a description of the effort required to complete that task (Fleishman et al., 1984). Also, allocating resources to meet demands represents a conceptual link to both physical and mental effort (Schönpflug, 1986; Ursin, 1986).

Three of the four types of effort measured in this study emerged from the themes in the caregiver effort pilot study conducted by the researcher and they were labeled physical, mental, and emotional. Emotional effort was selected as the label to replace “psychological”, as it was more consistent with the themes. Another type of effort, time-related effort, was added as a proxy for the caregiver to measure time and effort in caregiving and used in the present study. A repeated theme in the caregivers’ responses is that caregiving effort is difficult, physically, mentally, and emotionally. One caregiver even acknowledged that this was a shared experience of both the caregiver and the care receiver.

Physical effort. The physics of physical effort mean that perceived exertion can result both from static and dynamic situations. The physics of being still were described by only one caregiver. Largely, the caregivers’ descriptions were supported the dynamic,
constant quality of effort (Borg, 1989; Hockey, 1997); contrary to the static nature of
effort suggested by Stevens (1989). The psychophysics conceptualization of effort was
supported when caregivers perceived the strenuous aspects of caring for an older adult.
Caregivers identified variability in effort and influences on the magnitude or intensity of
perceived exertion. Caregivers described effort in physics terms such as drag; drain;
deplete; recharge; strength; strenuous; exhausting; leverage; and, pushing.

Perceiving a difficult and strenuous nature of task completion may be related to
perceiving higher effort (Weithoff, 1996; Hockey, 1986). The caregivers in this study
described effort when it was perceived as strenuous, physically. However, descriptors of
exhaustion are identified both physically and mentally/emotionally. Descriptions of
“doing” suggest physical effort. Though the magnitude of effort may differ among these
caregivers’ depictions; there is a constant state of readiness, and a regulating quality to
effort (Mulder, 1986; Hockey, 1997).

Mental effort. Mental effort has been described by caregivers as conceptually
distinct from physical effort. Mental effort exemplars described learning and skill
acquisition. Thinking and creativity may be examples of mental effort. Creativity in
caregiving was identified by caregivers as they discussed diversional strategies used with
care receivers who have impulsive and resistive behavior; and mobility difficulty.

Emotional effort. Emotional effort was identified within relationships and within
the context of formal and informal supports. Themes from participants suggested that
being the sole caregiver had higher effort than when sharing the workload. Stated
differently, shared caregiving possibly distributes the effort. No literature was located to
support this theme. Some caregivers suggested that effort may have differed according to
the condition or the behavior of the older adult care receiver; or according to their own health. Some caregivers described the nature of their emotional effort to effort in caring for more than one care receiver; to more than one task or behavior; or whether the caregiver and care receiver resided together. According to Hockey’s (1997) description of effort, effort has both regular (i.e., regulating) and active control qualities. It is possible that effort, as perceived exertion, varies by the perception of difficulty or strain (Borg, 1998) but may also be affected by the immediacy of an acute caregiving demand.

Emotional effort was described when effort was characterized as more inner, psychological, or emotional than physical. It could be inferred from the themes and the effort ratings that certain caregivers have resigned emotionally. The caregiver is putting in the time, exerting physical and mental energy, but reports low emotional effort.

Time-related. Effort is related to time, energy, and demands of the workload. Caregiving effort can require “24/7” time and effort in responding to demands and needs of the caregiving situation. A potential distinction is that effort is energy-consuming and caregiving is time-consuming.

Many caregivers enumerated responsibilities that suggested surveillance or being on alert, being there, being “on”, 24 hours a day, seven days a week. For some caregivers, effort may be perceived greater when “off” duty and that their time was not their own. Some caregivers referred to a period of more intense caregiving with greater time demands when the care receiver was in a protracted, complicated acute health crisis.

Multidimensionality of effort. Often, caregivers referred to the work and effort of caregiving as multidimensional. Planning and worrying about future needs and supporting and guiding may be a combination of mental and emotional effort. There is a
tension among the simultaneous responsibilities that could represent time-related and physical effort. Additionally, some of the effort in caregiving is direct assistance in the workload, where caregivers described “spending more time and energy” (72 year old female). Most importantly, many of the caregivers’ depictions of effort transcended the reduction of effort into several distinct dimensions.

To examine the results of research question two; one must consider if effort is a multidimensional construct with several domains. If framed in the context of multidimensionality the four types of effort may be formative indicators that are reflective of a higher construct (Netemeyer et al., 2003). Additionally, many descriptions of effort from the family caregivers reflected additional qualities of effort that were unable to be categorized as one of the four types of effort. There is a totality in that effort was described as “all-consuming”.

Conceptually, support was found regarding the interrelatedness among types of effort. Mental effort and emotional effort appear to be conceptually distinct from physical effort though the examples suggest the exertion of both mental and emotional energy is perceived physically. Second, many caregivers had difficulty or were actually unable to identify separate distinct types of effort.

Question 3. What is the relationship between caregiver effort and caregiver depressive symptoms?

Statistically significant positive associations were found between all four types of effort – physical, mental, emotional, and time-related – and depressive symptoms. Only one study was located that directly examined effort and depression. The findings of the study suggested greater difficulty with mental effort among young, hospitalized, female
patients who were depressed (Roy-Byrne et al., 1986). These findings cannot be
generalizable to the population represented by the study’s sample.

Question 4. What are the relationships among characteristics of the caregiver and
caregiving situation; the workload of caregiving; the effort that family caregivers use in
caregiving; and caregiver depressive symptoms?

*Caregiver health.* A statistically significant relationship between self-assessed
health and workload time was not supported in this study. However, self-assessed health
was inversely related to workload difficulty. The inverse relationship between self-
assessed health and workload difficulty found in this study is not surprising. It is
congruent to discussions of work-health relationships put forth by prior work in
occupational psychology and occupational biology literature. This literature suggests a
relationship between difficult workload conditions and adverse worker health effects.

The time associated with workload was significantly correlated with receiving
help from formal caregivers. A possible interpretation of this finding is caregivers who
estimated a higher time associated with caregiving tasks and responsibilities were more
likely to obtain help from formal caregiving services.

A significant negative relationship was found between ADL and workload time.
Thus, as one would expect, caregivers who reported lower functional ability of the care
receiver also reported more time associated with caregiving tasks and responsibilities. In
a national study, half of the caregivers assisted family members with ADL difficulty
(NAC & AARP, 2004).

A significant positive relationship was found between receiving help from formal
caregivers and workload time. Therefore, caregivers who reported receiving help also
reported more time associated with caregiving tasks and responsibilities. Further exploration of this relationship and what caregiving factors and contexts can explain the lack of decreased responsibilities in the face of formal help.

Overload was significantly, negatively correlated with caregiver age and self-assessed health. This finding suggested that younger and less healthy caregivers perceived more overload. Perhaps younger caregivers are balancing the demands of being in both the paid workforce and the family caregiving workforce as working age caregivers (NAC/AARP, 2004). These caregivers may be balancing multiple caregiving roles for parents and their child.

The practical significance of these findings may be explained by the attributes of overload captured by the scale items. The items address the feelings associated with the entirety of caregiving, and not just the workload demands. It is not clear why overload and (younger) caregiver age were inversely related. Perhaps the relationship is explained by the high numbers of caregivers who reported that they were employed full time.

The relationship between caregiver health and workload in this study was a key finding. In occupational and work-health literature, the closest analogy can be found in Hockey’s (1993) description of the degradation of work performance under high effort. Degradation then is thought to lead to declining health and fatigue leading to degrading health and fatigue.

There is the possibility that there are two ways of looking at the caregiver work–caregiver health relationship. Researchers should consider examining both the impact of caregivers’ health on managing a caregiving workload, as well as the impact of managing a caregiving workload on caregiver health. To the author’s knowledge, this recursive
relationship has not been explicated in literature about the health effects of caregiving. Within the limits of the current study design, a statement can be made that caregiver health and caregiver workload were interrelated.

*Relationships among characteristics of caregiving and effort*

A statistically significant relationship between self-assessed health and any type of effort was not supported in this study. Lower care receiver functional ability was associated with higher physical, mental, and time-related effort. A higher magnitude of the correlation coefficient was noted for physical effort than for mental and time-related effort. Because workload time and workload difficulty were also negatively correlated with ADL, a broader interpretation may be suggested. Lower care receiver functional ability means more caregiving load. One would expect that more effort would be required to meet the demands of that increased workload.

Receiving help from family was not found to be related to effort. This is somewhat of a surprising finding if receiving family help is understood as a means to distribute or lessen the workload. However, an alternative explanation is that help from family members may also heighten conflict about caregiving roles, responsibilities, and work.

*Relationships among characteristics of caregiving and depressive symptoms*

*Caregiver health.* Self-assessed health was inversely related to depressive symptoms. The significant negative relationship between caregiver health (SAH) and depressive symptoms found in this study is not surprising. Much of the caregiver research has focused on the interrelatedness of physical health and psychological health in caregivers. In this study, caregivers who rated their health lower also reported more
depressive symptoms. Researchers have reported that physical health problems have been strongly associated with the development of psychological health problems in caregivers (Haug et al., 1999; Vitaliano et al., 2003).

Older adult care receiver functional ability. An inverse relationship between ADL and caregiver depressive symptoms was found in this study. Thus, lower ADL ability of the care receiver was related to higher depressive symptoms in the caregiver. Few studies have found an association between care receiver ADL and caregiver depressive symptoms. Covinsky and colleagues (2003) found a significant relationship between care receiver ADL and caregiver depressive symptoms. These researchers proposed that caregiver ADL – which could be interpreted as a measure of the caregiver’s ability to meet the demands of caregiving – should also be examined (Covinsky et al., 2003).

With the exception of caregiver self-assessed health and care receiver functional ability; no caregiver characteristics were significantly correlated with depressive symptoms. This is contrary to the stress process framework in which caregiver characteristics are posited to have a direct effect on caregiver outcomes including depressive symptoms (Pearlin et al., 1990; Aneshensel et al., 1995; Meshefedjian et al., 1998).

Relationships among caregiving workload and caregiving effort

Time and difficulty of workload were significantly, positively correlated with each other. Conventionally, when studying a workload, the time and the difficulty of tasks are interconnected aspects of the workload estimation (Boles & Adair, 2001; Luximon, & Goonettleke, 2001). Both time and difficulty of workload were significantly
positively correlated with effort in the present study. No research among family
caregivers has addressed the time, difficulty, and effort.

Time and difficulty of workload were positively correlated with overload in this
study. Current research has focused on primary stressors (Pearlin et al., 1990) or
objective burden (Zarit et al., 1981) but has not directly addressed the time and difficulty
as examined in this study. The relationship between overload and types of effort were
identified in the present study but have not been explored elsewhere.

Question 5. What are the relationships among the workload in caregiving; effort in
caregiving; and caregiver depressive symptoms; when controlling for characteristics of
the caregiver and the caregiving situation?

The only independent variables that predicted caregiver depressive symptoms in
the exploratory multiple regression analysis were overload, self-assessed health, and
ADL. Self-assessed health (SAH) and ADL were entered in step one (characteristics).
Both SAH and ADL were significant predictors of caregiver depressive symptoms. When
workload variables were added in step two, overload and SAH were significant predictors
of caregiver depressive symptoms. ADL did not predict caregiver depressive symptoms
in step two. When effort variables were added in step three, overload and SAH were
significant predictors of caregiver depressive symptoms. ADL did not predict caregiver
depressive symptoms in step three. No direct support was found in literature to explain
how self-assessed health and overload continued to be significant predictors of caregiver
depressive symptoms – in step one, two, and three for SAH; and in step two and three for
overload – while ADL did not. While the relationship between overload and ADL has
been studied (e.g., Pot, Zarit, Twisk, & Townsend, 2005), in the present study, overload was not an outcome variable of interest, and was measured at only one point in time.

The items in the overload scale were meant to measure both the demand and the never-ending aspect of the workload of caregiving, as originally conceptualized by Pearlin and colleagues (Pearlin et al., 1991). The beta (β) coefficient for self-assessed health was negative and lower in absolute value than overload. Two considerations are offered, based on these results. First, the negative sign means that lower self-assessed health predicts higher depressive symptoms. This finding suggests that caregivers with poorer health would tend to be more “depressed”, in the non-clinical use of the word. Secondly, overload may be a succinct, all-inclusive empirical indicator of what the workload is to the caregiver. The four item scale had sufficiently high internal consistency reliability (the Cronbach’s α was .757); and the scale may tap an aspect of the workload of caregiving that would not otherwise be represented by measures of the time and difficulty associated with caregiving responsibilities on the OCBS.

The Caregiving Burden Scale, used by Carey and colleagues (Carey, Oberst, McCubbin, & Hughes, 1991); was the first to use a modified Oberst (1989) Caregiving Load Scale (OCLS) with a calculated composite score. Fourteen items for time and difficulty of caregiving tasks were presented to the caregiver. The “time” items were meant to conceptualize demand. Carey explained the procedure to create a “burden” score: “A burden score is calculated for each item by multiplying demand [time] by difficulty; a square root transformation is used to return the score to the original metric” (Carey et al., 1991, p. 1343). The calculation of a variable to represent burden, as described by Carey and colleagues appears to be more than just a semantic distinction
between the words, burden and workload: that is, a composite of time and difficulty was not conceptualized in this study to equate with “burden”, as was noted in the study by Carey and colleagues (Carey et al., 1991). Tennstedt and colleagues (1992) created a composite variable that represented “caregiving tasks” and the composite variable was entered into the regression equation to examine predictors of caregiver depression. Their decision was based largely on multicollinearity and did not appear to be theoretically driven. If a next step is to be recommended in the investigation of effort in caregiving; it is to test the theoretical model for intervening effects of effort. At that time; perhaps calculating a composite variable for workload (time and difficulty) would be theoretically meaningful.

An unexpected finding in this study was that effort did not predict depressive symptoms. While effort was significantly correlated with several variables in the study, no direct effects on depressive symptoms were observed. No literature was found to support the relationship. A surprising finding in this study was that workload difficulty did not directly predict depressive symptoms; considering that it has been so well documented that people who perform a caregiving workload have more depressive symptoms than those who do not. A few possible explanations are offered. First, the study was underpowered for the final number of cases that were examined, because of missing data on some scales that could not be imputed. However, the more parsimonious model with higher statistical power did not reveal any additional significant predictors, such as workload time and difficulty. Also, it is not clear if some other variable moderates the relationship between workload difficulty and depressive symptoms, as testing this possibility would have been beyond the scope of this study.
Figure 4.1

*Regression Analysis Caregiving and Effort Model*

Characteristics Of Caregiver, Care Receiver, and Caregiving Situation

Effort

Caregiver Depressive Symptoms

Workload: Stressors Demands Time and Difficulty of Tasks
Chapter Five

Summary

The purposes of this study were to describe effort as it is experienced by family caregivers in doing the work of caregiving to older adults and to investigate a possible relationship between effort in caregiving and depressive symptoms in family caregivers. First, chapter five briefly summarizes the findings of the study. Next, limitations of this study are identified. Then, implications are identified for nursing science; for nursing practice; for education of nurses and other health care providers; and for caregiver-related policy. Finally, recommendations are made for future caregiving research.

This was a cross-sectional, descriptive, correlational study of effort in caregiving. Effort is exerting energy to perform a workload. Caregiving was conceptualized in this study as a workload and caregivers were conceptualized as the workers. The hybrid theoretical framework for this study was based on the stress process theoretical model (Pearlin et al., 1990) and the demand control theoretical model (Hockey, 1997).

Five research questions were answered in this study. The first question described characteristics of the caregivers and caregiving situation. The second question addressed types of effort in caregiving, through visual analog scale self-ratings and an open-ended qualitative question about effort in caregiving. The third question examined relationship between effort and depressive symptoms through bivariate correlation analysis. The fourth question examined the relationships among characteristics, workload, effort, and depressive symptoms through bivariate correlation analysis. The fifth question examined relationships among characteristics, workload, effort, and depressive symptoms through an exploratory regression analysis.
A non-probability sample of family caregivers, who were responsible for the care or supervision of older adults, was recruited in the community. Recruitment methods included posted flyers, mailed flyers, electronic postings, and snowball sampling. Recruitment sites included a multi-agency site that serves older adults and families, and public institutions and businesses.

The data collection method was a mailed research questionnaire. Demographic information on the questionnaire elicited information about the caregiver, the older adult care receiver, and the caregiving situation. The questionnaire included visual analog scales to measure physical effort, mental effort, emotional effort, and time-related effort that was developed by the researcher and tested in a pilot study with caregivers. The research questionnaire also included an open-ended qualitative question about effort in caregiving; the Activities of Daily Living scale (Katz, Down, Cash & Grotz, 1970) to measure care receiver functional status; Self-assessed Health (Haug et al., 1989) to measure caregiver health; the Pruchno Coping Strategies Scale (Pruchno & Resch, 1989) to measure caregiver coping; the Oberst Caregiving Burden Scale (Bakas et al., 2004) to measure the time and difficulty of the workload of caregiving; the Overload scale (Pearlin et al., 1990) to measure overload in the workload of caregiving; and the Center for Epidemiological Studies Depression scale (Radloff, 1977) to measure depressive symptoms. Caregivers called for information about the study. If interested and eligible, a research packet was mailed to the caregiver. Because a waiver of signed consent was granted by the university institutional review board, only a coded questionnaire was returned to the researcher. No contact information was retained.
Over half of the final sample of 110 caregivers was recruited through public businesses and approximately one third of the final sample came from a multi-agency site. The response rate was nearly 85%. The majority of participants were married or partnered (over 60%); female (over 90%); adult children (57%); employed full time (45%); Caucasian (75%); close to sixty years of age, and highly educated (64% completed college or higher); with annual household income of $40,001 to $60,000; caring for older adults who were mostly female (64%) and whose average age was 82 years. Most caregivers reported they were residing with the older adult care receiver (62%); receiving help from other family caregivers (62%); and most reported they were not receiving help from formal caregivers (56%).

**Pertinent findings**

Forty-four percent of the caregivers reported moderately high to severe levels of depressive symptoms. The caregivers had higher levels of acceptance coping and instrumental coping than intrapsychic coping and wishfulness coping. Support was offered for four types of effort: physical effort; mental effort; emotional effort; and time-related effort. All four types of effort were significantly, positively correlated with each other. Participants had the greatest difficulty distinguishing between mental effort and emotional effort. Mental effort and emotional effort were perceived physically by several caregivers. In response to an open-ended question about the type of effort experienced by caregivers, effort was described as constant physical exertion; using energy to meet the demands in the relationships and responsibilities associated with caregiving; and, effort was needed balancing among doing for others and caring for self. Importantly, a
multidimensional quality of effort was noted in terms of physical, mental, emotional, and
time-related exertion.

All four types of effort were significantly, positively correlated with caregiver
depressive symptoms. Effort was also positively correlated with the time, difficulty, and
overload associated with doing the workload of caregiving. In an exploratory regression
analysis, caregiver perceptions of overload; caregiver self-assessed health; and care
receiver ADL were predictors of caregiver depressive symptoms. In the exploratory
regression analysis, effort did not have a direct effect on depressive symptoms.

Limitations

The results of this study are not generalizable to all family caregivers, due to non-
probability sampling. One cannot generalize to diverse caregiver populations because
there is no documented benchmarking for effort in any aspect of caregiving.

Instruments designed for evaluating task difficulty and job analysis in industry do
not capture the phenomenon that is family caregiving and could be a limitation. Thus, the
instrument selected for this study may not reflect the theoretical influence of demand-
control. Also, the OCBS that measures both time and difficulty associated with
caregiving responsibilities could have been cumbersome for caregivers to complete, due
to two response categories for each of the 15 items. The findings of this study suggest
that limitations in the instrument are the absence of a “not applicable response” and
possibly floor effects.

Implications for science

The model tested in this exploratory research proposed directional relationships
for the caregiving characteristics and depressive symptoms; for workload and depressive
symptoms; and for effort and depressive symptoms. The results of data analysis suggest that effort is statistically correlated with workload but not with depressive symptoms. The model tested is a first step in developing a theoretical model that incorporates stress process and energetics as a way to explain the relationship between caregiving demands and caregiver psychological health outcomes.

The findings of this study are a first step in the development of a middle range theoretical explanation for how families manage the responsibilities within caregiving relationships. Effort may be a way to translate the conceptualization of work – health relationships into conversations with family caregivers about their health and their caregiving workload. These findings regarding effort suggest a potential buffer to be explored in the stress process theoretical framework of Pearlin and colleagues (Pearlin et al., 1991; Aneshensel et al., 1995). Similarly, effort has the potential to contribute to demand – control theoretical models, as de Jonge and colleagues (de Jonge et al., 1999) suggested that more explanatory concepts are needed.

Implications for nursing practice

A greater understanding of the health care needs of family caregivers is a potential offshoot of this investigation of effort in caregiving. Fundamentally, this study was an exploration of the impact of the workload on the worker. A potential role exists for nurses to note impending caregiving responsibilities and the requisite effort required among family members of older adults; and to invite a proactive, collaborative entry into a beginning or advanced caregiving role.

Thus, caregiver workload assessment is recommended for clinical assessments. Caregivers were asked to describe and rate their own health in this study. The work of a
national consensus group resulted in broad-based principles for family caregiver
assessment (Family Caregiving Alliance, 2006); though there appear to be few
instruments that have emerged for service providers to use with families; and few states
require family caregiver assessment as part of the overall service provision to older adults
(Feinberg, Newman, Gray, Kolb, & Fox-Grage, 2004).

Further, clinicians need to be sensitized to recognizing the signs of overexertion
(that is, overusing energy) in family caregivers. In addition, practice standards can
incorporate guidelines for early referral when it seems apparent that sharing the workload
is appropriate.

*Implications for policy*

The economic worth of family caregiving is now estimated to be more than $375
billion (AARP, 2007). The estimate *worth* of family caregiving dwarfs a much more
invisible estimate of the true *work* of family caregiving. It is hoped that the findings from
this investigation about effort in family caregiving helps to emphasize the functions and
health of a workforce. The policy implications are wide ranging, but two
recommendations will be highlighted. Early training and “apprenticeship” in caregiving
is an area to explore in public discussion about preparing future family caregivers. The
psychophysics conceptualization of effort suggests a balance between push and pull
forces. Family caregivers are pushed by society toward family-centered care because it is
preferable and cheaper. Family members are also pulled by their circumstances to earn
income. Policy that recognizes and supports this vital workforce is needed. Certainly, an
exploration of adaptation or revisioning of labor workforce policy may be helpful to
businesses, governments, and families who are dependent on informal family caregiver manpower for the provision of health care.

Recommendations for future research

- A strategic nursing research goal, outlined in the National Institute for Nursing Research’s (NINR) strategic plan, is to “evaluate factors that impact the health and quality of life of informal caregivers and recipients” (NINR, 2006, p.19). This study introduces effort as one of those factors that impacts the health and functioning of family caregivers; which, in turn, impacts the health and functioning of the older adults for whom they care.

- Further evaluation of methods for measurement of effort experienced by family caregivers in a larger, more diverse representative sample of caregivers is recommended.

- Future research could also investigate how effort varies according to the condition or behavior of the care receiver.

- Additional exploration is warranted to examine statistically the possibility that there is a recursive relationship between depressive symptoms and effort.

- Future studies could examine ways that caregivers self-manage to exert and replenish their energy.

- Model testing is recommended to examine the potential moderating effect of effort in the relationship between caregiving workload and the health outcomes of caregiving.

- Prospective, longitudinal research is required to further examine the role of effort in explanatory models of caregiver health.
Appendix A

Questionnaire for Study about Caregiving
Questionnaire for Study about Caregiving
**General Instructions:**

On this questionnaire, you are asked to think about your caregiving situation. This is a study about how caregivers manage the work of caregiving.

You will be asked to respond to questions about your caregiving workload, your health and the health of the older adult who receives care from you. You will be asked about effort. Family caregivers helped to develop the definition of effort that is used in this study: Effort is exerting (or using) energy to do the work of caregiving.

In each section, specific directions will guide you in how to answer the questions.

When you have completed as much of the questionnaire as you are interested or able, please return the questionnaire to us in the pre-addressed, stamped envelope.

**General questions:**

First, please answer some questions to help the researcher describe the overall group of family caregiver participants completing this questionnaire. Please answer as accurately as you can. Your answers will not be identified with you personally.

<table>
<thead>
<tr>
<th>Description</th>
<th>(☐) check box to the left of your answer; or fill in the blank</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is your age in years?</td>
<td>Age:</td>
</tr>
<tr>
<td>2. What is your gender?</td>
<td>1 female 0 male</td>
</tr>
<tr>
<td>3. What is your highest grade of school completed?</td>
<td>1 grade school 2 junior high 3 some high school 4 high school 5 some college 6 finished college 7 graduate school</td>
</tr>
<tr>
<td>4. What is your ethnicity?</td>
<td>1 African American 2 Hispanic / Latino 3 Caucasian 4 Asian 5 Other</td>
</tr>
<tr>
<td>5. What is your marital status?</td>
<td>1 married 2 never married 3 significant partner 4 widowed 5 separated 6 divorced</td>
</tr>
<tr>
<td>6. What is your employment situation outside of the home?</td>
<td>1 employed full time 2 employed part-time 3 retired 4 stopped working because of caregiving responsibilities 5 reduced hours because of caregiving responsibilities 6 never worked outside of the home</td>
</tr>
</tbody>
</table>
What is caregiving like for you?

We are interested in how caregivers of older adults describe the work of caregiving, and the effort needed to do the work of caregiving. Please explain in your own words what the effort is like for you in doing the work of caregiving: (please write your ideas in the box below)

Thank you. Please go on to the next page
Effort is exerting energy to do the work of caregiving. For example, physical effort is exerting physical energy. Now please answer the following questions about how much effort you experience in doing the work of caregiving, or managing your caregiving situation. Consider the amount of effort you used on a typical day in the past week. For each question, draw a vertical line at the point on the horizontal line where you believe it measures the amount of effort you used in a typical day over the last week. Here is an example:

|_________________________|________________________|

1. **This is about the physical effort you use in caregiving:**

   How much **physical effort** do you spend in caregiving on a scale from 0 to 10, where 0 is the lowest amount and 10 is the highest amount? (draw a vertical line on the line below where you would rate your physical effort)

   0 _________________________________ 10

2. **This is about the mental effort you use in caregiving:**

   How much **mental effort** do you spend in caregiving on a scale from 0 to 10, where 0 is the lowest amount and 10 is the highest amount? (draw a vertical line on the line below where you would rate your mental effort)

   0 _________________________________ 10

3. **This is about the emotional effort you use in caregiving:**

   How much **emotional effort** do you spend in caregiving on a scale from 0 to 10, where 0 is the lowest amount and 10 is the highest amount? (draw a vertical line on the line below where you would rate your emotional effort)

   0 _________________________________ 10

4. **This is about the time-related effort you spend in caregiving:**

   How much **time-related effort** do you spend in caregiving on a scale from 0 to 10, where 0 is the lowest amount and 10 is the highest amount? (draw a vertical line on the line below where you would rate your time-related effort)

   0 _________________________________ 10
Please answer the following questions about your caregiving situation. This includes information about your own health and the care needs of the older adult. (Please ☑ check the box to the left of the response you select)

<table>
<thead>
<tr>
<th>Description:</th>
<th>1. Do you have responsibility for care and / or supervision of an older adult for at least four hours a week?</th>
<th>1 yes 0 no</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Do you live in the same residence as the person for whom you provide care?</td>
<td>1 yes 0 no</td>
<td></td>
</tr>
<tr>
<td>3. What is your relationship to the older adult who receives care from you?</td>
<td>1 spouse 2 adult child 3 sibling 4 other</td>
<td></td>
</tr>
<tr>
<td>4. What is the gender of the older adult who receives care from you?</td>
<td>1 female 0 male</td>
<td></td>
</tr>
<tr>
<td>5. What is the age of the older adult who receives care from you?</td>
<td>Age:</td>
<td></td>
</tr>
<tr>
<td>6. If you are a caregiver for more than one person in your family, how many people in your family receive care or supervision from you?</td>
<td>How many:</td>
<td></td>
</tr>
<tr>
<td>7. Do you have help from other family members or kin in providing care to a family member?</td>
<td>1 yes 0 no</td>
<td></td>
</tr>
<tr>
<td>8. Do you have help in providing care from paid, agency people or services?</td>
<td>1 yes 0 no</td>
<td></td>
</tr>
<tr>
<td>9. What health conditions does the older adult have? Please list as many as you can recall.</td>
<td>Health problems:</td>
<td></td>
</tr>
<tr>
<td>10. How good would you say your health has been in the past month?</td>
<td>4 excellent 3 good 2 fair 1 poor</td>
<td></td>
</tr>
<tr>
<td>11. Would you say your health is better than, about the same as, or worse than most people your age?</td>
<td>3 better 2 about the same as 1 worse</td>
<td></td>
</tr>
<tr>
<td>12. How much does your health stand in the way of your doing the things you want to do?</td>
<td>3 not at all 2 a little 1 a great deal</td>
<td></td>
</tr>
</tbody>
</table>

Please answer the following questions about the energy and time it takes to do caregiving work. Please answer according to how accurately each statement describes you over the past week. (please ☑ check the box to the left of the response you select)

<table>
<thead>
<tr>
<th>Description:</th>
<th>Select one (☑ check box to the left)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You are exhausted when you go to bed at night.</td>
<td>How well does this describe you? 4 completely 3 quite a bit 2 somewhat 1 not at all</td>
</tr>
<tr>
<td>2. You have more things to do than you can handle.</td>
<td>How well does this describe you? 4 completely 3 quite a bit 2 somewhat 1 not at all</td>
</tr>
<tr>
<td>3. You don’t have time just for yourself.</td>
<td>How well does this describe you? 4 completely 3 quite a bit 2 somewhat 1 not at all</td>
</tr>
<tr>
<td>4. You work hard as a caregiver but never seem to make any progress.</td>
<td>How well does this describe you? 4 completely 3 quite a bit 2 somewhat 1 not at all</td>
</tr>
</tbody>
</table>
Now please answer the following questions about how you cope with your caregiving situation. Please answer according to how you felt over the past month:
(please ☐ check the box to the left of the response you select)

<table>
<thead>
<tr>
<th>Strategy:</th>
<th>Select one (☐ check box to the left)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Made the best of it</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>2. Accepted the situation</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>3. Refused to let it get to you</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>4. Wished you could change the way you felt</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>5. Daydreamed or imagined a better time or place than the one you were in</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>6. Wished you could change what had happened</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>7. Hoped a miracle would happen</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>8. Wished you were a stronger person to deal with it better</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>9. Told yourself things to help you feel better</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>10. Had fantasies about how things might turn out</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>11. Did something totally new to solve the problem</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>12. Felt inspired to be creative in solving the problem</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>13. Came up with a couple of different solutions to the problem</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>14. Made a plan of action and followed it</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>15. Changed something about yourself so you could deal with the situation better</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
<tr>
<td>16. Knew what had to be done so you tried harder to make things work</td>
<td>5 most of the time 4 often 3 sometimes 2 rarely/seldom 1 never</td>
</tr>
</tbody>
</table>
ID #________

The following questions are about physical and emotional health symptoms you might be experiencing. Please answer according to the way you have felt in the past week, and if so, how much. (For example, 1 to 2 days) (please check the box of the response you select).

<table>
<thead>
<tr>
<th>Did you feel or behave this way in the last week or so?</th>
<th>Not at all or less than 1 day</th>
<th>Seldom, 1 to 2 days</th>
<th>Often, 3 to 4 days</th>
<th>Much of the time, 5 to 7 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was bothered by things that don’t usually bother me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. I did not feel like eating; my appetite was poor.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. I felt that I could not shake off the blues, even with the help of my family or friends.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. I felt that I was just as good as other people.</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>5. I had trouble keeping my mind on what I was doing.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. I felt depressed.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. I felt that everything I did was an effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. I felt hopeful about the future.</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>9. I thought my life had been a failure.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10. I felt fearful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11. My sleep was restless.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12. I was happy.</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>13. I talked less than usual.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. I felt lonely.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. People were unfriendly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16. I enjoyed life.</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>17. I had crying spells.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. I felt sad.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19. I felt that people dislike me.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20. I could not get going.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
The following questions are about caregiving work. For each of the tasks or activities, please answer according to the amount of time you spent doing these tasks, and the difficulty of these tasks. Consider the caregiving work you did on a typical day in the past week. (please ☑ check the box to the left of the response you select)

<table>
<thead>
<tr>
<th>Caregiving task or activity</th>
<th>Select one (☑ check box to the left)</th>
<th>Select one (☑ check box to the left)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Medical or nursing treatments, giving medications</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>2. Personal care (bathing, toileting, dressing, feeding)</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>3. Assistance with walking, getting in and out of bed, exercise</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>4. Emotional support, “being there” for the person</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>5. Watching for and reporting symptoms, watching how the person is doing, monitoring the person’s progress</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>6. Providing transportation or “company” (driving, riding along with person, going to appointments, driving person around for errands)</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>7. Managing finances, bills, and forms related to the person’s illness</td>
<td>Time&lt;br&gt;5 a great amount&lt;br&gt;4 a large amount&lt;br&gt;3 a moderate amount&lt;br&gt;2 a small amount&lt;br&gt;1 none</td>
<td>Difficulty&lt;br&gt;5 extremely difficult&lt;br&gt;4 very difficult&lt;br&gt;3 moderately difficult&lt;br&gt;2 slightly difficult&lt;br&gt;1 not difficult</td>
</tr>
<tr>
<td>ID# 154</td>
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<td></td>
</tr>
<tr>
<td>--------</td>
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<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. <strong>Additional household tasks for the person</strong> (laundry, cooking, cleaning, yard work, home repairs)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
<td>4 very difficult</td>
<td></td>
</tr>
<tr>
<td>a moderate amount</td>
<td>3 moderately difficult</td>
<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. <strong>Additional tasks outside the home for the person</strong> (shopping for food and clothes, going to the bank, running errands)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<td></td>
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<tr>
<td>a moderate amount</td>
<td>3 moderately difficult</td>
<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>10. <strong>Structuring / planning activities for the person</strong> (recreation, rest, meals, things for the person to do)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<tr>
<td>a moderate amount</td>
<td>3 moderately difficult</td>
<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>11. <strong>Managing behavior problems</strong> (moodiness, irritability, confusion, memory loss)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<td></td>
</tr>
<tr>
<td>a moderate amount</td>
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<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>12. <strong>Finding and arranging someone to care for the person while you are away</strong></th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>13. <strong>Communication with the person</strong> (using phone, reading, writing, explaining things, trying to understand the person)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>14. <strong>Coordinating, arranging, managing services and resources for the person</strong> (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help)</th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
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<tr>
<td>a moderate amount</td>
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<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>15. <strong>Seeking information and talking to doctors, nurses, and other professional health care workers about the person's condition and treatment plans</strong></th>
<th><strong>Time</strong></th>
<th><strong>Difficulty</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>a great amount</td>
<td>5 extremely difficult</td>
<td></td>
</tr>
<tr>
<td>a large amount</td>
<td>4 very difficult</td>
<td></td>
</tr>
<tr>
<td>a moderate amount</td>
<td>3 moderately difficult</td>
<td></td>
</tr>
<tr>
<td>a small amount</td>
<td>2 slightly difficult</td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>1 not difficult</td>
<td></td>
</tr>
</tbody>
</table>
Now please answer some questions about the specific abilities of the older adult. We want to know for the following activities of daily living if the older adult is able to do these activities by herself or himself; or if the older adult needs assistance. (please check the box to the left of the response you select)

<table>
<thead>
<tr>
<th>Activity of Daily Living</th>
<th>(☐) Check box to the left of your answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Bathing (sponge bath, tub bath, or shower): Receives either no assistance or assistance in bathing only one part of the body</td>
<td>1 yes 0 no</td>
</tr>
<tr>
<td>2. Dressing: Gets clothes; and dresses self without any assistance except for tying shoes</td>
<td>1 yes 0 no</td>
</tr>
<tr>
<td>3. Toileting: Goes to toilet room, uses toilet, arranges clothes, and returns without any assistance (may use cane or walker for support and may use bedpan / urinal at night)</td>
<td>1 yes 0 no</td>
</tr>
<tr>
<td>4. Transferring: Moves in and out of bed and chair without assistance (may use cane or walker)</td>
<td>1 yes 0 no</td>
</tr>
<tr>
<td>5. Continence: Controls bowel and bladder completely by self (without occasional &quot;accidents&quot;)</td>
<td>1 yes 0 no</td>
</tr>
<tr>
<td>6. Feeding: Feeds self without assistance (except for help with cutting meat or buttering bread)</td>
<td>1 yes 0 no</td>
</tr>
</tbody>
</table>

Now please answer a question to help us describe the overall group of family caregiver participants completing this questionnaire. Please answer as accurately as you can. Your answer will not be identified with you personally. This question is about your household income. (please check the box to the left of the response you select)

| What is your annual household income? | 1 less than $20,000 2 $20,001 - $40,000 3 $40,001 - $60,000 4 $60,001 - $80,000 5 $80,001 - $100,000 6 $100,001 - $120,000 7 over $120,000 8 do not want to answer |

Is there anything else you would like to tell us about your experiences as a family caregiver of an older adult?

Thank you very much for your time.
Appendix B

Informed Consent Document
Effort in Caregiving Study

You are being asked to participate in a research study about the effort that family caregivers experience in doing the work of caregiving. You are invited to participate because you are a family caregiver of an older adult who is at least sixty years of age and lives in the community. Please read this form, and then call us to ask any questions that you may have before agreeing to participate in the study. Two nurse researchers at Case Western Reserve University are conducting this study. Evanne Jurovacz, RN, MSN is conducting this study for her PhD degree in nursing. Diana Morris, RN, PhD is her faculty advisor and co-researcher.

Background Information
Effort is the way people use energy to do work or meet the needs of a situation. The purpose of this study is to understand the effort, or use of energy, involved in the day-to-day care and/or supervision of older adults. This study is based on the results of a study in which family caregivers explained the ways they used energy to perform the tasks and meet the demands of giving care to an older adult.

Procedures
If you agree to participate in this study, we ask you to do the following:
1. First, the questions that you answered in the screening phone call were meant to make sure you are eligible to participate in this study; that phone call was not an official part of the study. Only one family caregiver per family is eligible to participate in the study.
2. Now, we ask you to read this consent form, mailed to you along with the questionnaire in the study packet. Keep this form for your information. Although you heard information about the study during the phone call, the study is described in detail on this form. You are welcome to call us back with any additional questions after reading this form. You will not need to sign and mail back this form. Mailing back the questionnaire will mean that you agree to participate in the study.
3. Next, we ask you to answer the questions on the questionnaire. You may choose to leave some questions blank, or you can respond to as many of the questions on the questionnaire as you are able. The estimated time it will take to complete the questionnaire is thirty minutes.
4. Finally, return the completed questionnaire to the researchers in the envelope that was enclosed with the questionnaire. The postage has already been applied to the return envelope for you.
5. Your questionnaire will have a code number on it. This questionnaire with the code number will be separated from your address information that was used to mail the study packet to you.
6. We will send a reminder postcard a month after the questionnaire was sent to you. Your participation is voluntary, and if you have decided not to participate in the study, the postcard is only intended to remind you that we have not received the questionnaire yet. Your address information will be shredded, once this postcard has been sent.
7. Mailing in the questionnaire will mean that you are done participating.

Risks and Benefits to Being in the Study
There is minimal risk to participating in this study. There is a chance that you may become aware of emotionally upsetting feelings in answering the questions. If you believe upsetting feelings are a problem for you, you can stop at any time. Also, you should discuss these upsetting feelings with your health care provider (a doctor or nurse); and information about how to get help is included in the study packet that goes out to all possible participants.

There are no direct benefits to you by participating in this study. The information that is gathered from the questionnaires will potentially help other family caregivers and the older adults that receive care from them. The only alternative to participating in this study is not volunteering to participate in this study.
Compensation
You will receive no cash payment for participating in the study. A certificate of completion will be included with the research packet that we mail to you, thanking you for your participation.

Confidentiality
The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify any individuals who participated in the study. Study records will be kept in a locked file, and access will be limited to the researchers, the University review board responsible for protecting human participants, and regulatory agencies.

Voluntary Nature of the Study
Your participation is voluntary. If you decide not to participate in this study, it will not affect your current or future relations with the University; nor with any of the agencies at Fairhill Center. There is no penalty or loss of benefits for not mailing back the questionnaire. You may decide to not answer particular questions, or you may stop participating entirely. You are eligible to be provided with the findings that come out of this study.

Contacts and Questions
The researchers conducting this study are Diana Morris, RN, PhD and Evanne Juratovac, RN, MSN. If you have any additional questions, concerns, or complaints about the study, you may contact them at any time:
Phone (216) 368-6472 or e-mail diana.morris@case.edu (Dr. Morris) and
Phone (216) 368-6688 or e-mail evanne.juratovac@case.edu (Ms. Juratovac).

If the researchers cannot be reached, or if you would like to talk to someone other than the researcher(s) about: (1) questions, concerns or complaints regarding this study, (2) research participant rights, (3) research-related injuries, or (4) other human subjects issues, please contact Case Western Reserve University's Institutional Review Board at (216) 368-6925 or write: Case Western Reserve University; Institutional Review Board; 10900 Euclid Ave.; Cleveland, OH 44106-7230.

Please keep this form for your records.

Statement of Consent
I have read the above information. I have received answers to the questions I have asked. I agree to participate in this study. I am at least 18 years of age. I will keep this form. Mailing in the questionnaire means that I volunteered to participate in the study. Once I mail in the questionnaire; that will mean that I am done participating in the study.
## Items for Time and Difficulty of Workload (n=110)

<table>
<thead>
<tr>
<th>Workload Item</th>
<th>Time</th>
<th>mean / SD / n</th>
<th>Difficulty mean / SD / n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatments, medications</td>
<td>2.29</td>
<td>1.023 / 106</td>
<td>1.54 / 0.817 / 102</td>
</tr>
<tr>
<td>Personal care</td>
<td>2.54</td>
<td>1.131 / 106</td>
<td>1.92 / 0.987 / 101</td>
</tr>
<tr>
<td>Walk, in/out bed, exercise</td>
<td>2.33</td>
<td>1.131 / 106</td>
<td>1.89 / 1.095 / 101</td>
</tr>
<tr>
<td>Emotional support, being there</td>
<td>3.86</td>
<td>1.056 / 104</td>
<td>2.58 / 1.158 / 105</td>
</tr>
<tr>
<td>Report symptoms, progress</td>
<td>3.27</td>
<td>1.143 / 104</td>
<td>2.17 / 1.03 / 103</td>
</tr>
<tr>
<td>Transport, accompany appts</td>
<td>3.29</td>
<td>1.138 / 106</td>
<td>2.33 / 1.014 / 103</td>
</tr>
<tr>
<td>Finances, bills, forms</td>
<td>3.1</td>
<td>1.263 / 105</td>
<td>2.19 / 1.124 / 104</td>
</tr>
<tr>
<td>Household tasks, chores, yard</td>
<td>3.39</td>
<td>1.161 / 104</td>
<td>2.37 / .025 / 104</td>
</tr>
<tr>
<td>shop, bank, errands</td>
<td>3.18</td>
<td>1.003 / 106</td>
<td>2.19 / .943 / 107</td>
</tr>
<tr>
<td>structure, plan activities</td>
<td>2.85</td>
<td>1.191 / 105</td>
<td>2.2 / 1.081 / 102</td>
</tr>
<tr>
<td>Manage behavior problems</td>
<td>3.00</td>
<td>1.201 / 105</td>
<td>2.9 / 1.193 / 100</td>
</tr>
<tr>
<td>Find, arrange care when away</td>
<td>2.22</td>
<td>1.204 / 103</td>
<td>2.48 / 1.322 / 96</td>
</tr>
<tr>
<td>Communicate, explain</td>
<td>3.28</td>
<td>1.07 / 105</td>
<td>2.68 / 1.173 / 105</td>
</tr>
<tr>
<td>Coordinate services, resources</td>
<td>2.72</td>
<td>1.07 / 105</td>
<td>2.2 / 1.028 / 104</td>
</tr>
<tr>
<td>Talk w healthcare workers</td>
<td>2.74</td>
<td>0.079 / 106</td>
<td>2.19 / 1.066 / 105</td>
</tr>
</tbody>
</table>
Appendix D

*Items Related to Depressive Symptoms (n=110)*

<table>
<thead>
<tr>
<th>CES-D Item</th>
<th>Mean</th>
<th>SD</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. bothered by things</td>
<td>1.03</td>
<td>.855</td>
<td>109</td>
</tr>
<tr>
<td>2. appetite was poor</td>
<td>.61</td>
<td>.912</td>
<td>109</td>
</tr>
<tr>
<td>3. could not shake blues</td>
<td>.84</td>
<td>.914</td>
<td>110</td>
</tr>
<tr>
<td>4. just as good as others</td>
<td>.90</td>
<td>.045</td>
<td>109</td>
</tr>
<tr>
<td>5. trouble keep mind on things</td>
<td>1.07</td>
<td>.875</td>
<td>110</td>
</tr>
<tr>
<td>6. felt depressed</td>
<td>.89</td>
<td>.932</td>
<td>110</td>
</tr>
<tr>
<td>7. everything was effort</td>
<td>1.36</td>
<td>.906</td>
<td>110</td>
</tr>
<tr>
<td>8. hopeful about future</td>
<td>1.20</td>
<td>1.039</td>
<td>110</td>
</tr>
<tr>
<td>9. life was a failure</td>
<td>.39</td>
<td>.743</td>
<td>110</td>
</tr>
<tr>
<td>10. felt fearful</td>
<td>.73</td>
<td>.913</td>
<td>108</td>
</tr>
<tr>
<td>11. sleep restless</td>
<td>1.37</td>
<td>1.012</td>
<td>110</td>
</tr>
<tr>
<td>12. was happy</td>
<td>1.17</td>
<td>1.246</td>
<td>109</td>
</tr>
<tr>
<td>13. talked less than usual</td>
<td>.78</td>
<td>.817</td>
<td>110</td>
</tr>
<tr>
<td>14. felt lonely</td>
<td>.99</td>
<td>1.009</td>
<td>110</td>
</tr>
<tr>
<td>15. people unfriendly</td>
<td>.42</td>
<td>.669</td>
<td>110</td>
</tr>
<tr>
<td>16. enjoyed life</td>
<td>.95</td>
<td>.913</td>
<td>110</td>
</tr>
<tr>
<td>17. crying spells</td>
<td>.44</td>
<td>.748</td>
<td>110</td>
</tr>
<tr>
<td>18. felt sad</td>
<td>.90</td>
<td>.881</td>
<td>109</td>
</tr>
<tr>
<td>19. people dislike me</td>
<td>.44</td>
<td>.789</td>
<td>108</td>
</tr>
<tr>
<td>20. could not get going</td>
<td>.97</td>
<td>.933</td>
<td>110</td>
</tr>
</tbody>
</table>
Bibliography


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