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Validation of the Transportation Burden Questionnaire Among Family Caregivers of Older Adults

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Validation of the Transportation Burden Questionnaire
Among Family Caregivers of
Older Adults

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A Dissertation Submitted to The Graduate School at the University of Missouri—St.
Louis in partial fulfillment of the requirements for the degree
Doctor of Philosophy in Nursing

May, 2014

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I love you both more than you will ever know. Now let's go play.

Abstract

Because family caregivers provide a substantial amount of informal care to dependent loved ones, the potential burden such care may place on family members is an important area for clinical research and intervention. Providing transportation is one aspect among many which family caregivers routinely provide which can add to the phenomenon of caregiver burden. Coughlin and D'Ambrosio ([2012](#)) note that over 25% of adults aged 75 or older will need alternative transportation services in the future due to disease-related inability to drive. While the provision of transportation is recognized in the literature as a caregiving task and a component of global burden, few studies, to date, have addressed this as a distinct concern for measurement and intervention.

The purpose of this study was to determine if an item set focused specifically on transportation burden would be additive to accepted global measures of burden in a volunteer sample of caregivers. This is the third phase of a combined qualitative and quantitative research effort. In Phase 1, a qualitative method was employed to examine the concept of transportation burden. In Phase 2, an iterative strategy was employed to formulate and refine a list of items concerning perceived burdens associated with the provision of transportation. A subset of these items became the proposed Transportation Burden Questionnaire (TBQ) item set. Since transportation burden is thought to contribute to caregiver burden, Phase 3 utilized exploratory factor analysis to finalize the TBQ structure. Criterion validity of this new measure was evaluated using two accepted caregiver scales, the Zarit Burden Interview (ZBI) and Caregiver Strain Index (CSI). The Center for Epidemiological Studies Depression Scale (CES-D) was also administered to assess for presence of depression among caregivers.

This sample included 150 self-selected, family caregivers. The mean age for this sample of caregivers was 58 and included a majority of Caucasian women that were caring for either a parent or husband who was suffering from both a cognitive and physical ailment. After exploratory factor analysis, five subthemes arose: definitive burden, extraneous factors, time and self-sacrifice, care recipient attributes, and acceptance. Three of these subthemes were consistent with preliminary qualitative studies. Criterion validity was acceptable for both the ZBI ($r = 0.645$) and the CSI ($r = 0.615$) which showed moderate correlations between the TBQ and extant scales. Overall, this sample of family caregivers had mild to moderate caregiver burden, caregiver stress, and was depressed based on total scores of the ZBI, CSI, and CES-D respectively. Based on total scores for the TBQ, the majority of this sample also showed evidence of transportation burden. This study offers a foundation for future family caregiver research because the TBQ allows for planning of tailored interventions by specifically measuring transportation burden as well as its' inherent subthemes.

Table of Contents

Acknowledgment	2
Abstract	5
Chapter One	
Introduction	10
Family Caregiver Burden	11
Family Caregivers and Caregiver Tasks	12
Transportation Burden	14
Significance	15
Purpose of this Study	15
Specific Aims	16
Chapter Two	
Review of the Literature	17
Conceptual Framework	17
Literature Review Methods	19
Dominant Family Caregiver Theory and Instrument	19
Caregiver Identity Theory	20
Caregiver Identity Model	22
Dominant Family Caregiver Instruments	24
Zarit Burden Interview	24
Caregiver Strain Index	24
Other Family Caregiver Burden Instruments	25
Family Caregiver Stress, Distress, Strain, or Burden	27
Family Caregiver Burden	28
Family Caregiver Burden and Care of Children	28
Family Caregiver Burden and Care of an Elder	29
Cultural Influences	31
Gender Influences	33
Family Caregiver Burden and Transportation	34
Gaps in the Literature	39
Chapter Three	
Method	41
Specific Aims	41
Hypotheses	41
Sample and Setting	42
Inclusion and Exclusion Criteria	43
Protection of Human Subjects	44
Measurement	44
Zarit Burden Interview	44
Caregiver Strain Index	45
Center for Epidemiologic Studies Depression Scale	46

Development of the Transportation Burden Questionnaire	47
Preliminary Qualitative Frameworks	47
Item Development	49
Content Validity	50
Demographics of the Sample	50
Procedure for Data Collection	51
Analysis Plan	52
Exploratory Factor Analysis	52
Strengths	55
Limitations	56
Chapter Four	
Results	57
Characteristics of the Sample	57
Table 1	58
Table 2	59
Missing Value Analysis	60
Replacement of Missing Values	61
Factor Analysis	62
Distribution of the Transportation Burden Questionnaire	64
Table 3	64
Hypothesis 1	65
Hypothesis 2	67
Hypothesis 3	67
Table 4	68
Hypothesis 4	68
Chapter Five	
Discussion	70
Sample Characteristics	70
Correlations with Extant Scales	71
Interpretation of the Transportation Burden Questionnaire	72
Revised Subthemes	73
Cross-Loading and Multiple Factoring Subthemes	78
Revised Transportation Burden Conceptual Framework	79
Implication for Nursing Research, Practice, and Policy	81
References	84
Appendices	
A: Proposed Transportation Burden Questionnaire Item Set	107
B: Zarit Burden Interview	115
C: Caregiver Strain Index	117
D: Center for Epidemiologic Studies Depression Scale	118

E: Transportation Burden Questionnaire	120
F: Factor Analysis of Transportation Burden Questionnaire	122

List of Tables

Table 1: Characteristics of Family Caregivers	58
Table 2: Caregiving Characteristics of Family Caregivers	59
Table 3: Summary of Scales Means, Standard Deviation, Range, Median...	64
Table 4: Correlation Between Scales, Age, and Education	68

List of Figures

Figure 1: Transportation Burden Conceptual Framework	18
Figure 2: Caregiver Identity Theory Model	22
Figure 3: Distribution of the Transportation Burden Questionnaire	65

Chapter One

Introduction

Overview

Family caregiver burden literature is extensive and much is known regarding the toll these caregivers sustain while caring for a family member. Historically, the measurement of caregiver burden has focused on global challenges of the family caregiver role including psychological, physical, financial, or time burden while caring for a family member. Generally, caregiver burden has been measured holistically making it difficult for health care providers to determine specific interventions needed to help caregivers. More recently, researchers of family caregivers have suggested moving from these global conceptualizations and measurement of family caregiver burden to more specific foci. For example, Montgomery and Kosloski (2009) recommended that researchers move from global perspectives to more specific conceptualizations of family caregiver burden in order to better understand, measure, and tailor interventions to assist family caregivers.

A specific measure of caregiver burden often overlooked and underestimated within these global measurements of caregiver burden, is the role of providing transportation by a family caregiver. Coordinating transportation for a family member to primary health care providers, physical therapists, nutritionists, grocery stores, pharmacies, entertainment, and family outings may all be part of a family caregiving responsibility and in turn, contribute to caregiver burden. Additionally, physical and mental impairments of a family member may further contribute to transportation difficulties for family caregivers. As such, these transportation challenges for family

caregivers may lead to a new concept: transportation burden. The literature review found no instruments that focus on defining or measuring the concept of transportation burden among family caregivers. This gap in the literature regarding the description and measurement of transportation burden led to the purpose of this dissertation. Defining and ultimately developing an instrument to measure transportation burden for caregivers may help health care providers understand transportation burden as well as the larger concept of caregiver burden and eventually lead to establishing specific transportation-based interventions which help family caregivers.

Family Caregiver Burden

The concept of caregiver burden is thought to be multifactorial, unique to each family caregiver, and heavily influenced by numerous individual and contextual variables (Daniewicz, 1995; Ducharme et al., 2005; Han, Choi, Kim, Lee, & Kim, 2008; Montoro-Rodríguez, Kosloski, Kercher, & Montgomery, 2009). Factors linked to family caregiver burden include the functional level and medical conditions of the care recipient, cultural influences, norms, and experiences of caregivers; overall time in the caregiver role; familial relationship between caregiver and care recipient (e.g. son vs. daughter, parent vs. spouse); role overload such as concurrently working or concurrently caring for young children; availability and presence of social and spiritual supports; and caregiver self-appraisal and expectations of the caregiver role (Ayalon & Huyck, 2002; Burke, 1996; Cassie & Sanders, 2008; Connell & Gibson, 1997; Dellasega, 1991; Hargrave, 2006; Knight & Losada, 2011; Mignor, 2000; Savundranayagam & Montgomery, 2010; Spira & Wall, 2009; Warren, Kerr, Smith, Godkin, & Schalm, 2003). For some family caregivers, burden appears to be cumulative and dynamic as fluctuations in the care

recipient's condition change, there may be a change in the caregiver's perception of the caregiver role (Hannum Rose et al., 2007; Pinguart & Sörensen, 2006).

Any additional role the caregiver incurs during the caregiving journey can add to the potential for increased caregiver burden. Increased time in the family caregiver role, increasing needs of the care recipient, competing demands on the caregiver, and lack of a social support network are all thought to contribute to caregiver burden (Bakas, Lewis, & Parsons, 2001; Fink, 1995; Marchi-Jones, Murphy, & Rousseau, 1996; McDaniel & Via, 1997; Robinson, 1997; Schur & Whitlatch, 2003). In turn, increasing family caregiver burden is thought to contribute to long-term care placement (Abraham & Berry, 1992; Barnes, Given, & Given, 1995; Cohen-Mansfield, Besansky, Watson, & Bernhard, 1994; Gates, 2000).

Family Caregivers and Caregiver Tasks

Family caregivers are usually adult women, either spouses or daughters, who provide wide-ranging assistance to loved ones who are unable to perform tasks on their own (Adler, Rottunda, Rasmussen, & Kuskowski, 2000; Daniewicz, 1995; Robinson, 1997). Often, family caregivers begin their caregiving career unknowingly with cleaning or providing transportation to the grocery store on an infrequent basis (Montgomery & Kosloski, 2009). These tasks cause little imposition for family caregivers, are accepted as normal, and usually not viewed as excessive or burdensome (Barnes, et al., 1995; Carey, Oberst, McCubbin, & Hughes, 1991; Oberst et al., 1989).

As family caregiver demands escalate because of the care recipient's changing health status or other factors, the family caregiver's responsibilities often increase (Abraham & Berry, 1992). The role of caregiving for a family caregiver may begin to

overshadow other aspects of the family caregiver's own life. Where the family caregiver once only provided basic household chore services, he or she may now be responsible for financial affairs, increasing transportation demands, or even more intimate assistance tasks (e.g., bathing, dressing). As these caregiving responsibilities mount, the risk for caregiver burden increases (Davis et al., 1997; Elmstahl, Malmberg, & Annerstedt, 1996; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; Mor, Allen, Siegel, & Houts, 1992; Patterson, Semple, Shaw, & Grant, 1996; Pinquart & Sörensen, 2006; Schur & Whitlatch, 2003).

Widely used scales to measure caregiver burden focus on global aspects such as time constraints, social life, work effects, physiological impacts, emotional aspects, and financial constraints or a combination of these (Novak & Guest, 1989; Robinson, 1983; Zarit, Todd, & Zarit, 1986). Such global instruments often measure the absence or presence of caregiver burden without focusing on specific areas of burden such as transportation. Although global instruments are an important starting point, understanding the various aspects of burden at an individual level is an important building process which is necessary before tailored interventions can be planned for the caregiver. Tailoring family caregiver interventions has been recently cited as optimal practice by many lead researchers in this area (Montgomery & Koslowski, 2009). A tailored intervention includes identifying specific needs of family caregivers and assisting with these on an individualized basis. Thus, developing an instrument to specifically measure potential transportation burden for caregivers may provide insights for healthcare providers to better tailor services for family caregivers.

Transportation Burden

When a family member can no longer drive safely because of physical or mental impairment, family caregivers are often confronted with the need to provide or arrange alternative transportation (Carr, 2006; King et al., 2011; Meuser, Carr, Berg-Weger, Neiwoehner, & Morris, 2006; Nichols, 2006; Ralston et al., 2001; Schumacher, Beck, & Marren, 2006). Some authors have attempted to globally describe the impact of driving cessation on family caregivers. Within the last ten years, this has been particularly evident in qualitative studies such as Ralston et al. whom noted the resultant global strains that family caregivers face when their relative stops driving. Other studies have looked at the incidence of driving among those with dementia, voluntary cessation, and strategies that both families and healthcare personnel can employ when older adults are no longer safe to drive (Carr, 2006; Meuser, et al., 2006; Meuser, Carr, & Ulfarsson, 2009; Perkinson et al., 2005) though these studies have failed to focus on the specific impact on family caregivers..

Other researchers such as Razani and colleagues (2007), found that providing transportation for a relative with dementia not only monopolized time, but was also a strong predictor of caregiver burden. In a study of over 300 caregiver respondents, Taylor and Tripodes (2001) found that caregivers tend to downplay the impact that transportation has on their lives, miss more work as a result of providing transportation, and underutilize public transportation options that are available to them. These studies provide further evidence of a need to develop an instrument to specifically measure transportation burden in order to gain a better understanding of how providing transportation affects family caregivers

Significance

Coughlin and D'Ambrosio (2012) estimate that over 25% of adults aged 75 or older will need alternative transportation services in the future given cognitive and functional limitations which effect driver safety. It is likely that family caregivers will have to provide transportation for many of these individuals. Healthy People 2020 has called for caregiver-specific goals to include improved definition of scope and services that family caregivers require. This includes improving access and availability of family caregiver services while tailoring these towards specific needs. As the population of those aged 65 and older grows, so too will family caregiving responsibilities. In turn, as caregiving responsibilities rise, the chance for developing transportation burden may increase if this is found to be part of caregiver burden. Many studies cite transportation as a global concern that caregivers relate as challenging (Bakas, et al., 2001; Casado, van Vulpen, & Davis, 2011; Krach & Brooks, 1995; Razani, et al., 2007; Taylor & Tripodes, 2001), however few if any have attempted to measure and quantify its role in overall caregiver burden. A reliable, valid measure of transportation burden allows researchers to parse out the relative impact of this part of family caregiver burden. If tangible, such an instrument could also assist health and social service professionals in identifying caregivers for transportation-related intervention.

Purpose of this Study

The purpose of this study was to determine if a specific measure of transportation-related burden is additive to current global understandings of caregiver burden. This was the third phase of a mixed-methods study. Phase 1, a qualitative method employed by Meuser and Marwit (2001), examined themes of the concept of transportation burden.

Phase 2 employed a strategy to develop items that resulted in a draft of a proposed Transportation Burden Questionnaire (TBQ). Since transportation burden is thought to be part of caregiver burden, in Phase 3 exploratory factor analysis was employed and criterion validity established using two accepted caregiver burden scales, the Zarit Burden Interview (ZBI) and Caregiver Strain Index (CSI).

In addition, researchers using global caregiver instruments have reported that family caregivers with higher burden scores may exhibit levels of depression or low mood (Chumbler, Pienta, & Dwyer, 2004; Gallagher-Thompson & Coon, 2007; Schur & Whitlatch, 2003; Siegler, Brummett, Williams, Haney, & Dilworth-Anderson, 2010). These findings suggest global measures of burden tend to be related to global measures of mood. Therefore, the Center for Epidemiological Studies Depression Scale (CES-D), a widely used depression scale was also administered in order to parse out those caregivers that may be concurrently affected by depression.

The specific aims of this study were to:

1. Quantify the reliability and validity of an item set (tentatively entitled Transportation Burden Questionnaire) intended to measure transportation burden.
2. Estimate the concurrent validity with two extant scales and the new item set.
3. Evaluate the association of depression against the new item set

Chapter Two

Review of the Literature

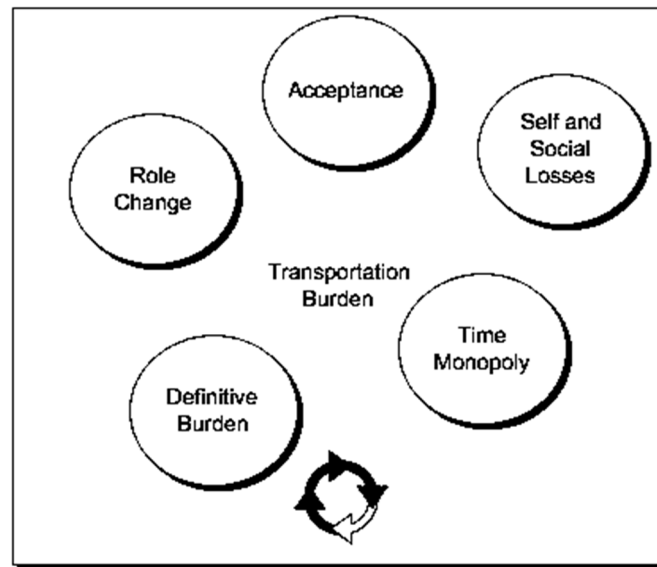
This chapter presents a review of the literature related to family caregiving and a new concept of transportation burden while defining a transportation burden conceptual framework linking the two areas of study. This review seeks to identify the state of the science related to caregiver burden and transportation burden, which will guide the development of an instrument to measure transportation burden among family caregivers.

Conceptual Framework and Transportation Burden

Family caregiving is unique to those providing the care. Family caregivers perform wide-ranging activities that include housekeeping tasks and transportation (Tennstedt & McKinlay, 1989) as well as personal care services such as eating, bathing, dressing, toileting, getting in and out of bed, or moving around inside the house (Select Committee on Aging, 1987). Though transporting a family member is often part of family caregiving activities, few studies have examined how providing transportation for family members influences the overall concept of caregiver burden.

This gap in the science led to the development of a transportation burden conceptual framework by this investigator using a qualitative approach (Meuser & Marwit, 2001) which guided interviews with a diverse sample of family caregivers (see Chapter 3 for an in-depth discussion). Themes from these qualitative interviews were reviewed and then reduced into five subthemes with agreement from a panel of graduate students as well as gerontology and nursing faculty. The proposed five subthemes (now concepts within transportation burden) are: definitive burden, self and social losses, time monopoly, role change, and acceptance (see Figure 1).

Figure 1. Transportation Burden Conceptual Framework



Based on the responses of family caregivers, definitions of the concepts within the transportation burden framework are presented:

Definitive burden. Providing transportation for the family caregiver's relative results in clear stress, strain, or burden.

Time monopoly. Providing transportation for the family caregiver's relative is challenging due to time demands including long travel and wait times.

Self and social losses. Providing transportation for the family caregiver's relative results in less time for: (a) social, leisure, and recreational activities; (b) balancing work and caregiver responsibilities; and (c) the ability to attend to the caregiver's own health care needs.

Role change. Providing transportation for the family caregiver's relative where the caregiver was not providing such care previously.

Acceptance. Providing transportation for the family caregiver's relative is not perceived as an additional burden or challenge.

How the subthemes of definitive burden, time monopoly, self and social losses, role change, and acceptance affect individual family caregivers is unknown. However, for some family caregivers, transportation burden is thought to be part of the larger concept of caregiver burden which will be presented in the following review of the literature.

Literature Review Methods

Databases searched included CINAHL, PsychINFO, and Medline for keywords including caregiver, stress, strain, and burden as well as the Boolean search for each, with a final search for these words combined with the keyword transportation. The majority of the literature was found within CINAHL and PsychINFO with less in Medline. Limited additional results were found in the databases of JSTOR, SCIEDIRECT, and Academic Search Complete. The following review of the literature presents caregiver identity theory; instrumentation specific to caregiver burden, distress, strain, and burden; and family caregiver stress, strain, distress, and burden. Family caregiver burden as well as family caregiver burden related to the care of children, the elder, and cultural and gender influences are also presented. Finally, the limited literature related to family caregivers and transportation challenges are presented with gaps in the literature completing the review section.

Dominant Caregiver Theory and Instrumentation

Important to this review of family caregiving is a historical perspective related to the dominant theory in family caregiving and the dominant instruments to measure family caregiver burden. The caregiver identity theory is presented because it is at the leading edge of growth that is moving family caregiving from a global perspective to a more

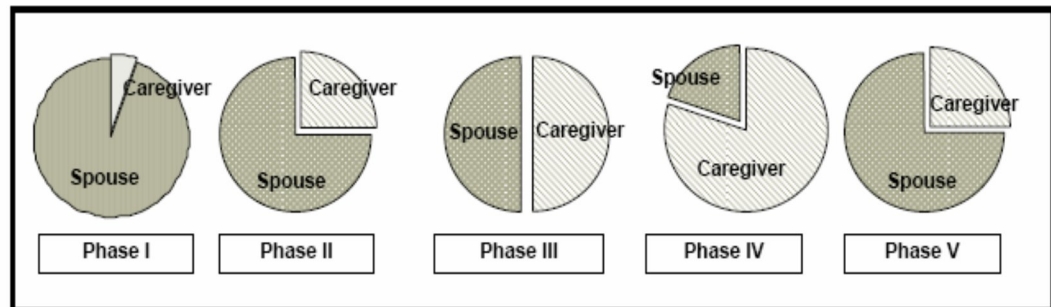
specific focus. The dominant caregiver instruments as well as other selected caregiver instruments are presented to give an overview of caregiver instruments that measure family caregiving globally. No caregiver instruments were found that measure the specific concept of transportation burden.

Caregiver identity theory. Montgomery and Hooyman (1985), dominant theorists in caregiving, began thinking of the family caregiving phenomenon on a global level, presenting family caregiving in a social context as objective and subjective forms of burden when the family caregiving experience became challenging. Family caregiving was thought to be a multifactorial experience that occurred between caregiver and care recipient, modified by objective descriptors such as demographics, physical measures, community, and social resources as well as subjective modifiers such as personality characteristics, attitudes, and values (Montgomery & Hooyman). This led to the Montgomery Burden Scale (MBS) which contains two distinct parts: (a) measurement of objective burden and (b) measurement of subjective burden. Objective aspects of burden include the extent of disruptions or changes in the lives and households of caregivers while subjective aspects relate to family caregiver responses, attitudes, or emotional reactions to the caregiving experience. The objective portion of the MBS contains 9 items which are scored on a Likert scale ranging from 1 to 5 with higher scores representing higher levels of objective burden. The subjective portion of the MBS contains 13 items scored on a 1 to 5 range with higher scores representing higher subjective burden. From this early work, Montgomery laid the foundations for her more recent theory regarding family caregiving: the caregiver identity theory.

The caregiver identity theory by Montgomery and Kosloski (2009) is presented because the theory is an important emerging theory for family caregivers that is moving the conceptualization of the caregiving experience from a global to specific level of understanding. Though Montgomery and colleagues continue to view family caregiving in terms of objective and subjective forms of burden, they have proposed moving away from a global interpretation of caregiver burden to a more specific interpretation which allows for tailored interventions for caregivers. The underlying premise of the caregiver identity theory is that caregiving is a dynamic change process that includes changes in care activities, relationships between caregiver and care recipient and in the caregiver's identity (Savundranayagam & Montgomery, 2010). Montgomery and Kosloski note that discord exists when familial roles clash with caregiver identity. Montgomery and Kosloski propose that among caregivers there are two definitive and unique identities: family member and caregiver, with these conflicting identities being those of spouse versus caregiver or son/daughter versus caregiver for example.

Their work is consistent with Burke and colleagues (1991, 1996) who proposed that identity maintenance is a continuous process in which identity standards are applied to the self in a social role. These standards are influenced by social, cultural, and familial norms which serve as reference points for self-appraisal in a social role (Burke). Consistency between identity standards and self-appraisal expectations maintain identity while inconsistency challenges identity, causes stress, and at times forces a transition to a different social role and new identity standard (Burke).

The caregiver identity model includes five phases caregivers may experience while caring for a spousal loved one (Montgomery & Kosloski, 2009) (see Figure 2).

Figure 2. Caregiver Identity Theory Model

Montgomery and Kosloski note that as care becomes more demanding over time and the care recipient's condition declines, increased demands on the caregiver create a higher awareness of caregiver identity in comparison to their own identity. During Phase I, the imposition of providing caregiving services for a loved one is relatively small and unperceived. During Phase II the role of caregiver becomes self-identified by the family caregiver. During Phase III, the role of caregiver increases in quantity and intensity and it becomes evident to the family caregiver that this assistance is beyond the normal boundaries of the initial family relationship. During Phase IV, the role of the family caregiver may extend for a long period of time to the extent that the caregiver can no longer tolerate the identity discrepancy and subsequent burden. During Phase V, a significant change has occurred for the family caregiver when the care recipient has transitioned to a new setting such as a nursing home, assisted living, or the home of another family member allowing the family member to resume the family member identity and assume less of a caregiving role (Montgomery & Kosloski).

Montgomery and Kosloski (2009) point out that the five phases of the Caregiver Identity Theory serve as a theoretical progression of family caregiving while emphasizing there is wide variability among family caregivers and their adaptation to the varied

identities within the caregiving role. The phases of the Caregiver Identity Theory may be influenced by factors such as the caregiver obtaining outside support, the care recipient's decline or improvement, a significant change in the caregiver's own physical health, or a combination of these factors. Additional influencing factors include family rank and role, social norms and rules, and cultural and ethnic expectations that are subjective to each caregiver (Montgomery & Kosloski). In addition, unique family ethos may determine which family members provide the caregiving, what type of care is provided, and the conditions that must exist in order to seek assistance outside of the family (Montgomery & Kosloski). Because of this wide variability, the chance of regression between phases is possible while transition through phases is unpredictable and unique for each family caregiver. Ultimately, burden results when family caregiving activities and responsibilities are incongruent with one's family identity and the family caregiver can no longer accept this discrepancy (Montgomery & Kosloski).

Caregiver identify theory fits well with the transportation burden framework because the framework seeks to measure specific components of caregiver burden related to providing transportation for a family member. This is consistent with Montgomery and Kosloski's (2009) proposition that family caregivers require a tailored and specific approach to their needs rather than a global and generic intervention strategy. As such, focusing on the specific aspect of transportation and whether it is considered an imposition to family caregivers is congruent with a tailored evaluation of caregiver burden.

Dominant Family Caregiver Burden Instruments

Three widely used seminal caregiver burden instruments which were developed based on clinical observations and experiences of the researchers are presented. Based on clinical experience rather than theoretical underpinnings, these instruments reflect the dominant view of family caregiver burden as a global phenomenon focusing primarily on psychological, physical, financial, or time burden when caring for a family member. Many researchers have utilized these instruments to measure family caregiver burden, guide their research, and develop their own instruments (Al-Janabi, Frew, Brouwer, Rappange, & Van Exel, 2010; Colantonio, Kositsky, Cohen, & Vernich, 2001; Elmstahl, et al., 1996; Hébert, Bravo, & Prévile, 2000; Martin-Cook, Trimmer, Svetlik, & Weiner, 2000; O'Rourke & Tuokko, 2003; Post, Festen, Ig, & Visser-Meily, 2007; Schreiner, Morimoto, Arai, & Zarit, 2006; Schwiebert, Giordano, Zhang, & Sealander, 1998).

Zarit burden interview (ZBI). The ZBI is a clinically based caregiver burden instrument that measures the global extent with which family caregivers perceive their physical health, emotional status, social life, and financial standing (Zarit, et al., 1986). The ZBI will be discussed further in Chapter 3.

Caregiver strain index (CSI). Like the ZBI, the CSI is clinically based on questions originally derived from family caregivers of hospitalized hip and heart surgery patients that measures multiple aspects of the family caregiving experience (Robinson, 1983). The CSI will be discussed further in Chapter 3.

Caregiver Burden Inventory (CBI). Similar to the ZBI and CSI, the CBI is also a widely known measurement of family caregiver burden that has no explicit theoretical foundation. Novak and Guest (1989) developed the 24 item CBI from the experiences of

family caregivers of loved ones diagnosed with dementia along with incorporating items from previously published scales.

Other Family Caregiver Burden Instruments

There are over 50 scales and tools measuring family caregiver burden, stress, and strain. Like the three major instruments above, the majority of these measure family caregiver burden on a global level.

Caregiving Appraisal Scale (CAS). The CAS, a frequently used scale is the designed to measure the positive, neutral, and negative appraisals that family caregivers assign to caregiving (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). This 21-item instrument measures three global dimensions of the family caregiving experience including subjective caregiver burden, perceived impact of caregiving, and caregiving satisfaction.

The Caregiver Reaction Survey (CRA). The CRA is another widely used instrument designed to globally measure the reactions of family caregivers caring for elderly loved ones with illness (Given et al., 1992). Given and colleagues designed this 24 item instrument to measure five dimensions including caregiver's esteem, impact of caregiving on finances, impact on the family caregiver's schedule, lack of family support, and impact on the family caregiver's health.

The Perceived Caregiver Burden Scale (PCBS). The PCBS is a 31 item scale measuring the global impact and reaction to the experience of caregiving (Stommel, Given, & Given, 1990). This scale contains five dimensions of caregiver burden including feelings of abandonment, impact on work schedule, sense of entrapment, impact on finances, and impact on the health of the caregiver.

The Caregiver Activity Survey (CAS). The CAS is a 13 item global instrument that is self-administered to family caregivers that asks caregivers to record the amount of time spent in 6 areas over the course of a 24 hour time period including communication, dressing, eating, looking after the care recipient's appearance, supervising their loved one, and providing transportation (Davis, et al., 1997). The CAS is important to mention since it asks caregivers to not only assign a time imposition to providing such tasks as transportation, but also report a burden level on a 1-10 scale. Even though the CAS is one of the few caregiver burden scales to incorporate transportation as it relates to caregiver burden, the authors noted in their discussion that caregivers were often reluctant to acknowledge that certain care was burdensome (Davis, et al.). This reluctance may lead to inaccuracies related specifically to providing transportation. The CAS also fails to consider the specific impact of transportation but rather groups transportation in with other issues that family caregivers may be dealing with.

The Caregiver Load Scale (CLS). The CLS is a 10 item self-report scale that measures global caregiver burden in terms of time and energy as it relates to 8 different domains of the caregiving experience which include: managing illness-related finances, managing behavior problems, emotional support, assistance with mobility, medical/nursing treatments, personal care, monitoring and reporting, and providing transportation (Oberst, et al., 1989). The CLS takes into account the length in the caregiver role, asks family caregivers whether they have alternative sources of help, and areas that they may need additional help with. This is an example of an instrument that attempts to measure transportation as part of caregiver burden, however the results may

be influenced by the other variables on the instruments and the specific measurement of the impact of transportation burden is lost.

Family Caregiver Stress, Distress, Strain, or Burden

This review examined the current knowledge of family caregiver experiences and found ambiguity among the concepts of stress, distress, strain, and burden. Determining the differences between stress, distress, strain, or burden is important in understanding the family caregiver's experience. Authors often use stress, distress, strain, and burden interchangeably, which leads to some confusion defining terms and measuring family caregiver experiences while in turn failing to truly capture the meaning of their experience (Glaser & Strauss, 1967). For example, a study by Honea and colleagues (2008) reviewed literature related to family caregivers of oncology patients. This literature review and synthesis found strain and burden were used interchangeably while making suggestions for oncology nurses regarding interventions to assist family caregivers in better coping with the strain of caring for a loved one with cancer (Honea et al.).

Vitaliano, Zhang, and Scanlan (2003) use burden interchangeably with stress in their meta-analysis examining physiological impacts of being a family caregiver while more recently, authors have suggested further paring down specific aspects of terms such as caregiver burden to more measurable constructs (Savundranayagam & Kosloski, 2011). Chatcheydang used strain and burden synonymously when studying family caregivers of stroke survivors in Thailand while Abraham and Berry used stress and burden interchangeably while investigating spousal caregivers of the frail elderly. In a sample of family caregivers and the challenges they face, Fink used the terms stress,

strain, and burden using instruments to measure each of the three concepts individually, similar to the approach used by Bush and Job (1999).

Kim and Schulz (2008) compared caregivers of loved ones suffering from either dementia, cancer, diabetes, or frailty and found caregivers of loved ones suffering from cancer and dementia generally experienced more physical burden and distress. Kim and Schulz noted no overt difference between the terms of burden and distress within the study and used these terms synonymously. In a Scandinavian study, researchers looked at the progression of dementia and its effects on family caregivers using the terms strain, burden, and distress interchangeably (Samuelsson, Annerstedt, Elmståhl, Samuelsson, & Grafström, 2001). Samuelsson and colleagues found that husbands generally experienced higher levels of burden and distress and suggested that the utilization of home health nursing may reduce strain, burden, and distress while failing to differentiate the terms.

Family Caregiver Burden

Family caregiver burden is the central focus of this review because caregiver burden is the most widely used term to describe the challenging experiences family caregivers sometimes face. This review focuses on caregiver burden and the care of children, caregiver burden and care of an elder, cultural and gender influences on caregiver burden, and interventions to reduce caregiver burden

Family caregiver burden and the care of children. There is diverse research related to family caregiver burden of children and how this burden relates to parents for children afflicted with various diseases such as renal failure, cancer, and bone disorders (Fedewa & Oberst, 1996; Koshti-Richman, 2009; Murphy, Flowers, McNamara, & Young-Saleme, 2008; Sparks, Ortman, & Aubuchon, 2004) teens with psychiatric disease

(Forchuk, 2003); cerebral palsy, autism, Huntington's chorea, cystic fibrosis, anorexia nervosa, AIDS, and traumatic brain injury (Hirakawa, Kuzuya, Masuda, Enoki, & Iguchi, 2008; Keitel, Parisi, Whitney, & Stack, 2010; Rizk, Pizur-Barnekow, & Darragh, 2011; Stewart, Ritchie, McGrath, Thompson, & Bruce, 1994; Whittingham, Wee, Sanders, & Boyd, 2011; Williams, Skirton, Barnette, & Paulsen, 2012; Winthrop, 2010). Common themes among caregiving parents in these studies include lost productivity days at work, concurrent demands, complaints of generalized fatigue, and feelings of being overwhelmed (Andr n & Elmst hl, 2007; Brehaut et al., 2009; Calder n et al., 2011; Koshti-Richman, 2009; Lin, Huang, & Hung, 2009; Murphy, et al., 2008). Despite the challenge of caring for their sick child, parents reported a sense of duty or responsibility and did not consider the care as a burden (Andr n & Elmst hl, 2007; Forchuk, 2003; Stewart, et al., 1994; Whittingham, et al., 2011; Winthrop, 2010).

Family caregiver burden and care of an elder. The majority of literature surrounding family caregiver burden and elderly care recipients is related to a variety of cognitive disorders, primarily dementia. Resoundingly, these researchers reported caregivers of loved ones with dementia experienced more burden than caregivers of those without dementia (Acton & Kang, 2001; Almberg, Grafstrom, & Winblad, 1997; Bertrand, Fredman, & Saczynski, 2006; Campbell, 2009; Ducharme, et al., 2005; Fopma-Loy, 1991; Laakkonen et al., 2008; Leong, Madjar, & Fiveash, 2001; Moore, Zhu, & Clipp, 2001; Morgan, Semchuk, Stewart, & D'Arcy, 2002; Razani, et al., 2007; Samuelsson, et al., 2001; Schoenmakers, Buntinx, Devroey, Van Casteren, & DeLepeleire, 2009; Siriopoulos, Brown, & Wright, 1999; Toseland, McCallion, Gerber, & Banks, 2002; Zarit, et al., 1986). Other studies of caregiver burden related to caring

for elderly relatives with: (a) psychosis; (Patterson, et al., 1996) noted caregivers were challenged when managing both positive and negative psychotic symptoms, and found the majority of caregivers were spouses; (b) chronic obstructive pulmonary disease; (Takata et al., 2008) reported a heavier burden among caregivers of relatives who were oxygen-dependent, were more likely to be in the caregiver role longer, and needed the most assistance from professional caregivers; (c) cancer; (Mor, et al., 1992) noted that older age and lower income elders generally needed more help and recommended healthcare personnel identify potential family caregivers to assist cancer survivors during transitions from hospital to home; (d) end-stage renal disease; (Belasco, Barbosa, Bettencourt, Diccini, & Sesso, 2006), reported family caregivers of relatives undergoing dialysis, particularly peritoneal dialysis, experienced very high levels of burden, and suggested increasing educational opportunities and psychological support for these caregivers; (e) orthopedic (including falls and fractures); (Bertrand, et al., 2006; Kuzuya et al., 2006; Lang et al., 2006), found that higher number of falls and fractures were often related to higher levels of burden; (f) congestive heart failure (Saunders, 2006) noted caregiver burden increased with more severe cardiopulmonary disease; (g) stroke; (Townsend, 1994), reported the level of disability related to the stroke, was directly related to the increased caregiver burden; (h) amyotrophic lateral sclerosis (ALS); (Chiò, Gauthier, Calvo, Ghiglione, & Mutani, 2005), found as the level of disability increased for loved ones with ALS, so too did family caregiver burden; and (i) end-of-life/hospice care; (Doorenbos et al., 2007) found that caregiver depressive symptoms correlated with length in the hospice program with spouses generally experiencing more caregiver burden and depression compared to non-spouses.

Often, disease states and conditions overlap as it is common to have multiple comorbidities with advancing age. Thus, caregivers are often dealing with the burden of multiple health care conditions which further compound caregiving challenges (Gaugler, Pearlin, Leitsch, & Davey, 2001; Ho, Chan, Woo, Chong, & Sham, 2009; Saunders, 2006). For example, a caregiver of an elder with dementia may also be struggling to manage and cope with the elder's declining pulmonary, renal, or heart function. Caregivers of a relative with dementia have been noted to have generally more burden than caregivers of elders without dementia when there are other concurrent health problems (Bertrand, Fredman et al. 2006).

Caregiver burden is also associated with a number of psychosocial and physiological variables. Lau and Au (2011) conducted a meta-analysis looking at predictors of distress in caregivers caring for loved ones with Parkinson's Disease, and found that as activities of daily living assistance, time in the caregiver role, and physical decline of the care recipient increased, so too did the incidence of caregiver burden. Vitaliano, Zhang, and Scanlan (2003) demonstrated that physiological indicators of stress are predominant in family caregivers of elders. Specifically, Vitaliano, Zhang, and Scanlan found that when compared to matched non-caregiver cohorts, caregivers of persons with dementia had 23% higher level of stress hormones and 15% lower levels of antibody responses. These findings provide a physiological underpinning to the impaired physical, mental, and interpersonal functioning often found among caregivers.

Cultural influences on caregiver burden. The literature offered a diversity of cultural influences on caregiver burden across several different countries. Family caregiver burden seems to be equally pervasive in Asian populations including Korean,

Taiwanese, and Chinese (Han, et al., 2008; Ho, et al., 2009; Lin, et al., 2009; Shyu, 2000; Yeung & Chiu, 2004) compared to western culture with common symptoms of resultant depression. Caregiver burdens were noted in the literature from Canada (Brehaut, et al., 2009; Colantonio, et al., 2001), France (Fink, 1995; Lang, et al., 2006), Italy (Rinaldi et al., 2005), Israel (Bachner & O'Rourke, 2007; Iecovich, 2008; Suleiman & Walter-Ginzburg, 2005), Australia (Björnsdóttir, 2002; Leong, et al., 2001), Japan (Hirakawa, et al., 2008; Kumamoto, Arai, & Zarit, 2006; Okamoto & Harasawa, 2009a; Yamada, Hagihara, & Nobutomo, 2008), and Sweden (Almberg, et al., 1997; Andrén & Elmståhl, 2007; Hanson, Tetley, & Clarke, 1999; Lundh, 1999). For each culture it was evident that nuances affecting the level of caregiver burden are often rooted in cultural norms. For example, a son or daughter caring for their parent in India may have a definitively different cultural norm compared to an adult child caring for a parent in Australia.

In a study conducted in Italy, Rinaldi and colleagues suggested the use of multiple scales to determine the extent of family caregiver burden as family members often downplay the effects of burden levels. By using multiple scales Rinaldi et al suggested that a more comprehensive picture of caregiver burden will emerge. This is echoed in French studies (Lang et al., 2006) that highlight overall functional status as being predictive of caregiver burden as well as Israeli studies (Iecovich, 2008) that point out that access to services and caregivers' characteristics, overall health, and economic status are all influencing factors to development of caregiver burden. Swedish studies (Lundh, 1999) suggest tailoring caregiver interventions which is consistent with Canadian (Colantonio et al., 2001) and American (Montgomery & Kosloski, 2009) studies suggesting the same.

Among several investigations of caregiver burden comparing cultural groups within the U.S., African-Americans have been noted to have increased resourcefulness as caregivers and overall less burden when compared to whites (Connell & Gibson, 1997; Hargrave, 2006; Richardson & Sistler, 1999). Hispanic-Americans were found to have similar family caregiver burden levels when compared to whites, but underutilization of services was common (Ayalon & Huyck, 2002; Chumbler, et al., 2004; Spira & Wall, 2009). Korean-Americans (Han, et al., 2008) had similar depressive symptomology when compared to whites, while Amish-Americans (Crist, Armer, & Radina, 2002) were found to often provide a supportive environment for elder loved ones until death and had seemingly low overall caregiver burden.

Clearly, of all cultural subgroups within the United States, whites express more caregiver burden comparably to other cultural subgroups (Bertrand, et al., 2006; Cassie & Sanders, 2008; Connell & Gibson, 1997; Gonzalez, 1997; Kim & Schulz, 2008; Sun, Roff, Klemmack, & Burgio, 2008). The reason for whites expressing more caregiver burden is unknown.

Gender influences on caregiver burden. The gender of the caregiver often impacts family caregiver burden. Gupta and colleagues (2009) compared male versus female family caregivers in India and found that for males only the size of the role overload was predictive of developing burden, while for females the size of the role coupled with social expectations of caregiver roles were important when considering the development of caregiver burden. Social roles and expectations were echoed elsewhere in Asian cultures where researchers in Japan (Okamoto & Harasawa), Korea (Han, et al.), Taiwan (Shyu), and China (Ho, et al.) all point out that discrepancies exist between male

and female family caregivers which often translates into increased caregiver burden among female caregivers with depression being a common resulting theme.

Gender and role expectations in American families are also seemingly related to caregiver burden. A meta-analysis of 168 caregiver studies comparing spousal versus adult children caregivers noted that spouses generally use less informal support, perceive their health to be worse, have higher levels of depression, and generally provide more care (Pinquart & Sørensen, 2011). Pinquart and Sorensen (2006) also found that women generally experienced more burden but these effects were small.

Family Caregiver Burden and Transportation

Family caregivers are faced with concerns for both their relative and the public at large when their loved one can no longer safely drive (Carr, 2006; King, et al., 2011; Meuser, et al., 2006; Nichols, 2006; Ralston, et al., 2001; Schumacher, et al., 2006). Most of these studies focus on how license revocation affects the individuals actually losing their license. Within the last ten years however, the impact on family caregivers transporting their loved ones has increasingly become the focus of more research. In early qualitative studies such as the one conducted by Ralston and colleagues, researchers found that burdens exist between elders who no longer drove and family caregivers who were suddenly responsible for transporting them. The authors noted that similar themes of feeling overwhelmed and burden existed between those who relinquished their driving and their family caregivers, with recommendations that further studies be conducted to guide practice to assist caregivers who assume transportation responsibilities (Ralston, et al.).

To date, there is a paucity of research related to the specific impact of providing transportation for dependent family members. In one of the earliest and largest studies, Krach and Brooks (1995) queried employees of a large Midwestern University and found 62% of family caregivers were providing transportation services to their relative. The authors noted that among these caregivers time limitations, healthcare problems, and missed work days were common themes (Krach & Brooks).

In a secondary analysis of cross-sectional and descriptive studies of 78 caregivers of family members with lung cancer, Bakas, Lewis, and Parsons (2001) found time management transporting their loved one with cancer was a major problem, particularly for adult children caregivers, which conflicted with competing demands such as employment or other family responsibilities. Bakas and colleagues used the Caregiver Burden Scale along with the Karnofsky Performance Status Scale and found on average family caregivers rated transportation as highly demanding (3.21 on a 1-5 scale when transporting a loved one with cancer). Time management concerns were echoed by Silva-Smith, Theune, & Spaid (2007) who noted that the provision of transportation required a greater amount of time than hands-on personal care, particularly for visually impaired care recipients. In this purposive sample, transportation to medical appointments or for leisure activities was listed as the most frequent activity with family caregivers indicating mild burden measured by the Caregiver Reaction Assessment tool that was used (Silva-Smith, et al.).

In a Canadian study of 122 caregivers using a mixed-methods design, Warren, Kerr, Smith, et al. (2003) looked at pre and post-admission to Adult Day Care (ADC) while evaluating caregiver burden and perceived health. Time conflicts related to

transportation problems to the ADC were the most frequently reported problem with suggestions that ADCs should offer assistance with transportation along with expansion of hours to overcome family caregiver transportation challenges (Warren, et al.).

Razani and colleagues (2007) found that providing transportation for a loved one with dementia not only monopolized time, but was also the single best predictor of burden in family caregivers. In this descriptive study of 34 patient-caregiver dyads, the authors used multiple scales to measure functional status, caregiver burden, and physiological symptoms with the brief symptom inventory, while noting that transportation needs were associated with the greatest burden in terms of time demands and restrictions for family caregivers (Razani, et al.). A limitation of this study (noted by the authors) was the majority of respondents were female and role change was an important influencing factor since the husband had historically provided the bulk of the transportation.

In another study of 315 caregivers looking at caregiver burden and transportation, Taylor and Tripodes (2001) found that caregivers tend to downplay the impact that transportation has on their lives, miss more work as a result of providing transportation, and underutilize public transportation options that are available to them. Taylor and Tripodes studied 922 California residents who had their license revoked between 1995 and 1996 because of dementia. Family caregivers of these residents who had lost their license were queried on changes in the household travel patterns and responsibilities as well as the psychological effects on household members. Family caregivers reported that they experienced strain, missed or gave up work altogether, did not use public transportation despite availability, did not use paid transportation services regardless of

their income, and the authors noted that primarily women spouses assumed transportation responsibilities (Taylor & Tripodes).

More recently, through qualitative interviews, Mosavel and Sanders (2011) found that transportation services were cited among the top resource assistance needs identified by cancer survivors, caregivers of relatives with cancer, and professionals that serve these individuals. Mosavel and Sanders added that optimal transportation services improved quality of care, provider communication, and general outcomes. In another recent study looking at effects of transportation on family caregivers, authors found 11.6% of family caregivers reported they had definitive transportation needs while caring for their family member (Casado, et al., 2011). In this large (n=1021) retrospective and secondary analysis of the 1999 National Long Term Care study, Casado and colleagues noted that: 31.7% of family caregivers were unaware of transportation services available in their area, 23.6% had no transportation resources available, 14.6% of family caregivers or their relative were not eligible for services, and 10.6% of family caregivers did not want outsiders coming in their home. Additionally, these authors noted that significant predictors to unmet transportation needs included: being black, an increased number of care recipient health problems, family caregivers not living with the care recipient, and not having substitute help (Casado, et al.). Finally, another recent study noted that transportation was one of the most challenging tasks for spousal caregivers of coronary artery bypass surgery (Park et al., 2013). In their descriptive analysis study of 35 caregivers, Park and colleagues noted that transportation ranked 2nd out of 13 ranked items in terms of difficult tasks for family caregivers, but 1st in terms of time demand.

Findings from the literature related to care of children are comparable to those related to adults. Fedewa and Oberst (1996) studied twenty parents providing care for children who had received renal transplants and used several scales of caregiver burden reporting the findings in terms of demands and difficulty. Transportation was ranked 4 of 15 in terms of demands noted by these parents and 9 of 15 in terms of difficulty (Fedewa & Oberst). This suggests that though the demand of actually providing the transportation was considered moderate, the actual challenge of the transportation was considered less burdensome. Fedewa and Oberst note that challenges among parents who worked part-time versus full-time was different with the latter expressing transportation as more of a demand.

Baxter and Kahn (1996) found that transportation was a reported need of 109 inner-city parents caring for their infants and those with lower levels of burden generally had higher utilization of public transportation with lower reported transportation needs. These parents were evaluated using several instruments with 45.6% of parents reporting inadequate transportation resources for themselves and their infants, however having high access to alternative transportation services (including public transportation, cabs, or someone else's car) generally reduced the perception of burden (Baxter & Kahn). In a follow-up study, Baxter and Kahn (1999) interviewed 37 families of children enrolled in an early intervention program for inner-city children. In this study, the authors used a time series design interviewing parents at the initial enrollment and then 10-12 months later. In this study, 35% of caregivers were satisfied with the transportation assistance they received at program start which rose to 54% at Time 2 (Baxter & Kahn). Parental stress was noted to be lower at Time 2 and the authors conclude that this may be related

to decreased transportation concerns since parents became increasingly adept at accessing alternative transportation resources thus reducing transportation burden (Baxter & Kahn).

Other studies have looked at specific disease states and ailments that affect children and how these impose transportation challenges on their parents. Some parents reported having to make modifications to their vehicle in order to transport their child safely (eg., a child in a body cast) (Sparks, et al., 2004). Sparks, Ortman, and Aubuchon discuss proper methods for transporting a child in a body cast, but fail to elaborate on the specific effects or measure how these transportation challenges affect the parents of these children. Studies of parental caregivers of children with cancer (Murphy, et al., 2008), traumatic brain injury (Winthrop, 2010), and cerebral palsy (Whittingham, et al., 2011) suggest that transportation challenges exist for most family caregivers. In each of these studies, the authors gloss over the aspect of transportation and how it specifically affected family caregivers while failing to measure the effect transportation burden.

Gaps in the Literature

From the review of the literature, it is apparent that there are limited findings regarding the impact on the family caregiver who is providing transportation for their family member. Also, there is no clear definition of transportation burden. Little is known of the specific ways that transportation burden may affect family caregivers because current family caregiver research focuses on global aspects of caregiver burden. Although studies in the review of the literature provided a background and some understanding of the challenging role that transportation can play in caregiver lives, few focused on transportation as a specific contributor to caregiver burden or sought to measure transportation burden.

Recent research has suggested a more tailored approach to addressing family caregiver burden while moving the field from a comprehensive conceptualization of caregiver burden to a more specific one. This study attempted to fill this gap in the literature by using themes from a qualitative study to define the concepts of transportation burden, develop a questionnaire reflecting these concepts, and validate a proposed measure of transportation burden. This study also lays the foundation to further define the specific concept of transportation burden. By developing a validated transportation burden instrument, researchers may be able to measure the specific concepts of transportation burden among family caregivers needed to plan tailored interventions to assist family caregivers. In turn, the proposed TBQ has potential to contribute to the literature by measuring a very specific portion of the larger concept of caregiver burden.

Chapter Three

Method

This was the third phase of a mixed-methods study designed to validate a measure of transportation burden. Phase 1, a grounded qualitative method employed by Meuser and Marwit (2001), examined themes of the concept of transportation burden. Phase 2 employed a strategy to develop items that resulted in a draft of a Transportation Burden Questionnaire (TBQ). Since transportation burden is thought to contribute to caregiver burden, in Phase 3, exploratory factor analysis was employed and criterion validity established using two accepted caregiver scales, the Zarit Burden Interview (ZBI) and Caregiver Strain Index (CSI), designed to measure caregiver burden and caregiver strain, to determine concurrent validity of the TBQ.

Specific Aims

The specific aims for this study were:

1. Quantify the reliability and validity of an item set (tentatively entitled Transportation Burden Questionnaire) intended to measure transportation burden.
2. Estimate the concurrent validity with two extant scales and the new item set.
3. Evaluate the association of depression against the new item set.

Hypotheses

The hypotheses for this study were:

1. Factor analysis will reveal a factor structure consistent with at least three of the five qualitative themes represented in the draft TBQ items (described below).

2. A total TBQ score and at least two subscale scores will be found to have sufficient internal consistency reliability ($>.60$) for further analysis in Aims 2 to 4.
3. Moderate, significant correlations will be identified between general measures of burden and TBQ scores.
4. TBQ scores will vary as a function of other burden scores (i.e., higher general burden = higher transportation burden), the length of time in the caregiver role (i.e., more time = higher transportation burden), and TBQ scores and other burden scores will be positively correlated with scores on the depression scale (i.e. higher general burden and transportation burden = higher depression).

Sample and Setting

The sample for this study were caregivers of an older adult; either as a spouse, adult child, or extended family member. Self-defined family caregivers who may reside near to or many miles from the care recipient will be invited to participate in the study and complete an online survey supported by the Information Technology Services (ITS) of the University of Missouri - St. Louis (UMSL).

The sample size goal for this study was based on 6 to 10 participants for each of the 46 questions on the TBQ resulting in a total sample size goal ranging from 276 to 460 participants. Devellis (2012) recommends that 6 to 10 participants per question is a reasonable sampling target for a factor analytic study of this type.

Recruitment

Over a three month time frame, this researcher contacted gerontology experts and leaders via email and telephone, to identify and recruit a volunteer sample of family

caregivers. Existing contacts were also utilized as a result of this investigator's role as a nurse practitioner. Email solicitations in support of this study were also made to local and regional gerontological associations, including the Mid-East Area Agency on Aging (MEAAA), the Area Agency on Aging of Southwestern Illinois (AAASI), the St. Louis Alzheimer's Association, and several adult day care facilities within St. Louis City and County limits. A Study Information Sheet (in paper and/or electronic form) describing the study and the link for accessing the online survey was given to local gerontology leaders/experts and representatives of aging organizations to publicize the study.

Individual arrangements were made with each organization for disseminating information about the study and reaching potential participants. An electronic form describing the study was also posted on discussion boards at a national level through multiple national caregiver organizations. Subjects were recruited via a snowball or word-of-mouth methodology.

Inclusion and Exclusion Criteria

The inclusion criteria included participants who: (a) self-identify as a caregiver of a dependent adult aged 60 or older (either as a spouse, adult child, or extended family member), who provided transportation for that person; (b) were not paid caregivers; (c) were 18 years of age or older; and (d) had access to a computer and the internet.

The exclusion criteria for study participants were those who: (a) do not self-identify as a caregiver of an older adult, either as spouse, adult child, or extended family member; (b) were paid caregivers; (c) were under the age of 18 years; or (d) did not have access to a computer and the internet.

Protection of Human Subjects

Approval to conduct the study was obtained from the University of Missouri-St. Louis (UMSL) Institutional Review Board. Prior to accessing the survey, the participant received a study information sheet in paper or electronic form explaining the study, alternatives to participation, benefits and risks, the participant's role, and the link to the survey. Partial or full completion of the study instruments constituted evidence of consent for the study. Questions on these instruments did not entail any identifying, sensitive, or incriminating information.

Measurement

Two extant burden measures (the ZBI and CSI) were used to validate the TBQ and one extant depression measure (the CES-D) to determine concurrent depression in this sample which are described in the following. The development of the TBQ is also presented.

Zarit Burden Interview

Zarit and colleagues (1986) developed the Zarit Burden Interview (ZBI) from their clinical experience with caregivers (see Appendix B). The ZBI measures psychological well-being, caregiver health, finances, social life, and the relationship between the caregiver and care recipient (Zarit, et al., 1986). The ZBI is a 22 item, five-point Likert-based scale used to measure caregiver burden with scores ranging from 0 to 88, with higher scores indicating higher levels of burden (Zarit, et al., 1986). Higher scores on the ZBI represent respective higher levels of burden with overall scores ranging from 0-88 (Zarit, et al., 1986). Within the scale, scores on the ZBI are further delineated as: 0-20 = little to no burden, 21-40 = mild to moderate burden, 41-60 = moderate to

severe burden, and 61 or more = severe burden (Zarit et al.). It has been substantiated within the literature with Cronbach's alpha ranging from .83 to .94 (Bachner & O'Rourke, 2007; Chou, 2003; Hébert, et al., 2000; Schreiner, et al., 2006). Content validity is considered high as Zarit and colleagues based their question development on their clinical and research experience. Test-retest reliability at 4 to 12 weeks apart has been estimated at 0.71 along with excellent concurrent validity against subsequently created caregiver burden instruments (Chou, 2003).

The ZBI was chosen to assess concurrent validity with the proposed TBQ because of its wide acceptance and use within caregiver research and because of its focus on similar caregiver burden concepts found during the prior qualitative study. Specifically, there are elements of conceptual overlap between the ZBI and the proposed TBQ within the realms of personal time, work, health effects, and social life. Additionally, the ZBI taps caregiver feelings of embarrassment, relationships with others, and self-appraisal of both quality and amount of care provided to a loved one which differ from that of the TBQ. Because of these similarities and differences it is an acceptable gauge for which to conduct external validity assessment with the new instrument.

Caregiver Strain Index

Robinson (1983) created the Caregiver Strain Index (CSI) which is comprised of 13 yes/no items with positive responses added to give an overall caregiver strain score ranging from 0-13 with scores of 7 or higher considered positive for stress and strain (see Appendix C). The CSI measures the physical, emotional, social, and financial realms of caregiving and the subsequent strain these place on the caregiver. Advantages of the CSI include its relatively short and closed-ended format which can be administered and

completed within minutes. Cronbach's alpha for the CSI has been reported to be .81 to .86 (Al-Janabi, et al., 2010; Fopma-Loy, 1991; Marchi-Jones, et al., 1996; Robinson, 1983). The CSI has also shown very good test-retest reliability (Post, et al., 2007; van Exel, Wjm, Brouwer, Koopmanschap, & Gam, 2004).

The CSI was also chosen for concurrent validation as it taps similar concepts to the proposed TBQ including inconvenience, confinement, and need for life adjustments as reported by the caregiver. Differences between the CSI and the proposed TBQ include areas of physical and emotional strain, sleep, and overall strain appraisal which allow comparison and contrast to the concept of burden. This is important as the concept of strain is often used synonymously with burden by authors within the literature, making their distinction difficult. By comparing and contrasting the two concepts, a more comprehensive understanding of transportation burden will be achieved given its novelty as a concept.

Center for Epidemiologic Studies Depression Scale

The Center for Epidemiologic Studies Depression Scale (CES-D) is a widely used scale for measurement of depression (see Appendix D). The CES-D is a 20 item scale that measures multiple dimensions of depression including but not limited to overall happiness with life, self-worth, overall depressed mood, sleep, appetite, hopefulness, and motivation. Scores on the CES-D of 17 or higher represent presence of depression. Advantages of the CES-D over other depression scales is the wide capture of many depressive symptoms and subthemes as well as its proven reliability and validity across several cultures (Beekman, de Groot, & Geleijnse, 2010; Kim & Park, 2012; Zelaya et al., 2012). The CES-D has a Cronbach's alpha of 0.83-0.86 and good test-retest

reliability (Zelaya et al). Reference websites designed for family caregivers were provided at the end of the questionnaire for patients with high scores on the CES-D or for those who feel sad or upset after completing the survey.

Development of the proposed Transportation Burden Questionnaire

In their seminal article, Imle and Atwood (1988) stressed that the richness of qualitative data be preserved in quantitative instruments, with conceptualization and ultimately instrumentation being two purposes for qualitative research. Conceptualization refers to defining and portraying the boundaries of a concept such as transportation burden. Instrumentation refers to creating a test instrument that measures the concept, using the complexity of qualitative narrative data to compose items. Imle and Atwood recommend the following regarding validity of an acceptable psychometric scale derived from qualitative data: (a) saturation or exhaustive description of the conceptual category, (b) preservation of the context within which the concept was developed through interviewing experts or informants familiar with the concept, and (c) maintaining the emic or subjective perspective. Tilden, Nelson, and May (1990) have also implied that collecting qualitative data is imperative to enrich understanding of a concept prior to developing a tool to measure it. This has been echoed elsewhere, calling for researchers to combine both qualitative and quantitative approaches to optimize study outcomes and further nursing research (Knafl, Pettengill, Bevis, & Kirchhoff, 1988).

Preliminary qualitative frameworks. Phase 1, a qualitative study was done to define and portray the boundaries of transportation burden by interviewing family caregivers. It was theorized that providing transportation had the potential to add to the burden that family caregivers have and therefore be an additional factor within the larger

concept of caregiver burden. Qualitative research was necessary because little was known about the impact of transportation on family caregivers. After Institutional Review Board approval, subjects were recruited from local caregiver support groups, the St. Louis Alzheimer's Association, and local experts. After informed consent, 19 family caregivers were asked to describe their experiences providing transportation needs for dependent relatives. The interviews were recorded and the quality of their experience was assessed through their narration and in subsequent data analysis which revealed underlying themes regarding transportation burden.

Family caregivers were contacted by phone and the following questions were used to guide the interview:

1. What has it been like providing care to your relative and being a caregiver?
2. How has providing transportation to your relative impacted your life?
3. Do you currently utilize any additional services to aid with the care of your relative and if so could you elaborate on how these have or have not helped you?
4. Do you have any insight that you would like to offer to other caregivers who are in a similar caregiving role as yourself?

Phone interviews were audio recorded, transcribed verbatim, and each transcript was checked against the audio file for accuracy. Transcripts were then secondarily analyzed by a panel of nine experts for content and common themes. The experts included a faculty member from nursing, a gerontology faculty member, this investigator, and six graduate students in gerontology. Themes were reviewed and then pared down into the final five subcategories with agreement from the panel of experts. Subcategories

included: definitive burden, time monopoly, self and social losses, role change, and acceptance.

Definitive burden was described by respondents as clear stress or strain because of their transportation responsibilities for their relatives. Time monopoly was noted by participants who reported burdensome attributes from the time demands of having to transport their relative including long travel and wait times. Self and social losses were expressed by multiple respondents who indicated less time for leisure, recreational time, and their own preventative medical care. Role change was most evident among spousal caregivers, particularly women, who were providing transportation where they previously had not. Finally, acceptance was expressed by several respondents who felt providing transportation for their relative did not add additional burden or perceived significance to their lives.

Item development. Phase 2, a qualitative analysis of the transcripts and subthemes, was then performed by a secondary panel of experts (including 5 of the original 9 experts) to develop items for the proposed Transportation Burden Questionnaire (TBQ). These items were based on transcripts from caregivers from the original interview study using caregivers' own language. Tilden, et al. (1990) note that to ensure content validity for a new instrument, it is imperative to include native language, or the respondents own words, when composing items. Through expert dialogue and multiple reviews, the secondary panel worked to capture the five subthemes gleaned from the qualitative study and developed transportation burden items. Consensus by the secondary panel resulted in 46 transportation burden items for response on a four-point Likert-type scale (4 = strongly agree, 3 = agree, 2 = disagree, 1 = strongly disagree). A

four-point Likert scale was used because of the relatively low imposition to respondents and ease of understanding.

The proposed Transportation Burden Questionnaire (TBQ) item set was then assessed for face validity to identify items with double or overlapping meanings and overall clarity of the items. Ten family caregivers were asked to evaluate each of the 46 items to determine if they were both relevant to their caregiving experience and whether each item made sense to them as a caregiver. These family caregivers were also asked to offer any additional comments or suggestions for the items. After this review, all 46 items were retained (see Appendix A).

Of the original 46 items, 14 measured definitive burden, 8 self and social losses, 12 time monopoly, 6 role change, 4 acceptance, and 2 were unrelated to the five themes. The two questions unrelated to the five subthemes asked about: (a) concern the caregiver has about the vehicle used for transporting their loved one, and (b) whether the caregiver would utilize a publicly assisted transportation program for their loved one if available.

Content Validity

The content validity of the proposed Transportation Burden Questionnaire (TBQ) is considered high given the consultative approach used with a panel of experts. Following this, it is grounded in qualitative iterations directly from family caregivers, refined through professional input and multiple revisions, and ultimately validated on face value by a secondary group of family caregivers.

Demographic of the Sample

Common demographic information was collected to characterize the sample. These included: (a) age, (b) educational level, (c) race, (d) gender, (e) income level, (f)

employment status, (g) caregiver relationship to the care recipient, (h) presence of care recipient physical or cognitive impairment, (i) caregiver reported percentage of overall care for the care recipient, (j) years in the caregiver role, (k) setting (rural, suburban, or urban), and (l) concurrent utilization of assistance organizations such as the Alzheimer's Association or Call-A-Ride.

Procedure for Data Collection

All of the study materials were administered online via the UMSL contracted survey website Qualtrics (www.qualtrics.com). The Qualtrics platform was selected because Qualtrics: (a) has been recognized by UMSL Institutional Review Board as an acceptable and safe means of online data collection that meets privacy standards, (b) allows for direct exportation into the Statistical Package for Social Sciences (SPSS) database for analysis thus reducing statistical entry error of raw survey data, and (c) screens entries by the identifying number of the computer and thus only allows one entry per computer while allowing the ability to return to the survey at another time if the participant desires (<http://www.umsl.edu/technology/frc/qualtrics.html>).

Participants either logged into Qualtrics via the website provided in the study information sheet or directly into the survey via the ingrained hyperlink within an email. After reading a description of the study which incorporated informed consent, participants completed basic demographic questions and then proceeded to the proposed TBQ, ZBI, CSI, and the CES-D. Completion of the study instruments required approximately 20 minutes. The Qualtrics platform allowed participants to save their data and return at their convenience through recognition of their computer number. However, there was no way to link the computer number to the participants' responses. The

participant could choose to answer or not answer any question within the survey. Lastly, if participants felt sad or upset after completing the survey, optional self-help websites designed for family caregivers were included as direct links to assist them.

Upon completion of the survey, participants were given the option to navigate to an independent window to apply for a raffle for a chance to win a 50 dollar gift card at a national retail store for their participation. If the optional raffle prize was desired, participants provided identifying information including respondent name, email address, and optional phone number which was entered into an independent database. At no time were respondent answers on the caregiver instruments linked with identifying data.

Analysis Plan

Qualtrics on-line survey software was used to export responses into IBM SPSS (v21) SPSS database for analysis. Demographic data was characterized through frequency counts and measures of central tendency as appropriate. Distributions of key variables were examined to judge the diversity and potential representativeness of data from this volunteer sample.

Exploratory Factor Analysis

Exploratory factor analysis was utilized to examine the factor structure of the proposed Transportation Burden Questionnaire (TBQ) items in comparison to a priori, qualitative themes. As a first phase, item characteristics were examined and eliminated for the TBQ pool based on the following criteria:

Step 1. Missing values were replaced via expectation maximization. Expectation maximization uses a two-step process of expectation (E-step) and maximization (M-step) algorithms, calculates expected values based on all complete data points (E-step), and

then replaces the missing values while re-computing new expected values (M-step) (Musil, Warner, Yobas, & Jones, 2002). This process is then reiterated multiple times until changes in these iterations become negligible (Musil et al.).

Step 2. The 46 items on the proposed TBQ were examined for extreme skewness (significant non-normality of the response distribution) which can attenuate correlations and reduce reliability. Because relatively low skewness was found, no skewness metric was devised nor used to cull final items. Next, internal reliability using Cronbach's alpha was evaluated for the 46 item scale and two of the five subscales seeking a goal $\alpha \geq .60$.

Step 3. Principle component analysis (PCA) extraction was then employed to evaluate the items on the proposed TBQ (DeVellis, 2012). Sampling adequacy via PCA provides information regarding the groupings of survey items and as such better explains the constructs under investigation, evaluates how strongly an item is correlated with other items within the exploratory factor analysis matrix, and helps assess whether the items used in the survey have a relationship with one another (Burton & Mazerolle, 2011). As such, a Kaiser-Meyer-Olkin (KMO) correlation $> .60$ is considered adequate (DeVellis, 2012) and was sought as a goal for the TBQ. In addition to examining the sampling adequacy via the KMO, the correlation matrix was evaluated to ensure it was not an identity matrix (Burton & Mazerolle) and therefore Bartlett's test of sphericity was conducted before moving forward with factor analysis of the TBQ. Bartlett's test of sphericity should have a chi square value of $\leq .05$ in order to proceed with factor analysis (Devellis).

Oblimin with KMO rotation was utilized to evaluate which survey items to retain or delete. Using oblique rotation strategies has been cited as being optimal at identifying appropriate items for retention or deletion particularly when prior theory exists regarding a phenomenon as was the case here with transportation burden (Burton & Mazerolle, 2011; Given et al., 1992; Halcomb, Caldwell, Salamonson, & Davidson, 2011).

Once factors were rotated, selection of factors via the KMO, scree test, parallel analysis, and a priori theory occurred as this offers the most optimal factor retention (Burton & Mazerolle, 2011). Using the KMO Kaiser criterion, the most dominant factors with eigenvalues greater than 1.0 were retained, scree and parallel graphs analyzed, and a priori theory used to guide culling of the final items.

Considering this for the TBQ: (a) factor loadings with $< .30$ were discarded, (b) items loading $< .50$ on ≥ 3 factors, and (c) factors cross-loading $> .50$ on multiple factors were individually evaluated by this researcher for appropriateness since within the conceptual model of transportation burden, multi-factoring of items is possible for some variables. An example of this is the presence of time monopoly, self and social losses, role change, and definitive burden, occurring simultaneously in a family caregiver. As a result, each individual item with multiple factor loadings, were scrutinized based on wording of the item and whether it was consistent with cohorts within the factor.

Step 4. Concurrent validity was achieved through examination of Pearson correlations with two established measures of caregiver burden: the Zarit Burden Interview (ZBI) and Caregiver Strain Index (CSI). The ZBI and CSI were chosen because of similarities and differences to the new instrument as well as their established

validity and reliability within the literature (Al-Janabi, et al., 2010; Bachner & O'Rourke, 2007; Chou, 2003; Hébert, et al., 2000; Robinson, 1983; van Exel, et al., 2004).

Similar aspects among the ZBI, CSI, and the new instrument included elements of caregivers' personal time, work impositions, inconvenience, social impacts, and confining nature. Differences included embarrassment, self-appraisal, personal strain, and sleep impact. It is important to note that both similarities and differences between these established scales and the new instrument were imperative when evaluating a new tool, since some overlap is desired while not exactly measuring the same concept(s). This avoids duplication of tests that measure the identical concept, while ensuring the value of new instruments to add to gaps in the literature. Therefore, a moderate correlation between the new instrument and both the ZBI and CSI was sought (DeVellis, 2012; Nunnally & Bernstein, 1994).

The two extant caregiving instruments, the ZBI and CSI, were scored yielding overall scores. In order to achieve concurrent validity, the obtained correlations sought were moderate ($r = .30s$ to $.70s$), indicating a conceptual association with established caregiving burden scales but not so high ($r = .80s$ to $.90s$) that the two instruments would be conceptually identical.

Construct validity. Construct validity will be deferred for future research. This can be estimated through confirmatory factor analysis.

Strengths

This study and the TBQ measure itself have a number of strengths. Strengths include:

- An adequate sample of family caregivers.

- The concept, transportation burden, was defined using a grounded qualitative approach that portrays the boundaries of transportation burden and how this directly affects family caregivers caring for loved ones.
- TBQ items were grounded in the expressed views of family caregivers from the target population of this study.
- The final structure of the TBQ was analyzed through a vigorous and unbiased factor analysis process.
- The innovation in the present study was the addition of the TBQ to help guide assessment and intervention for family caregivers.

Limitations

Limitations of this study include:

- The sample was volunteer, self-identified, and nonrandom.
- This study excluded caregivers who do not possess computers or computer skills.
- The length of time (20 minutes to complete this survey) may have discouraged family caregivers from completing the online survey.
- Family caregivers may answer questions within caregiver burden questionnaires in a socially acceptable way (Novak & Guest, 1989), in that questions which have negative overtones may be answered with bias.

Chapter Four

Results

This chapter presents the sample demographics as well as more specific characteristics concerning the family caregivers within this sample. Additionally, missing value analysis will be described and how this was addressed, examination of the distribution of the variables within the proposed Transportation Burden Questionnaire (TBQ), discussion of the factor analysis process used for the proposed TBQ, as well as statistical analyses regarding internal reliability using Cronbach's alpha and concurrent validity against the other three extant scales using Pearson's r . Finally, a discussion of the results for each research hypothesis for this study will be addressed.

Characteristics of the Sample

Initially, 157 responses were collected over a three month period. Of these, seven were incomplete at the time of data analysis and were removed. After removal of these seven surveys, the final sample size was 150 family caregivers who completed the online survey.

Table 1 presents the demographic characteristics of the sample of the 150 family caregivers. The age range of family caregivers was 20 to 89 years, the mean age was 58 ($SD = 14$), and median age was 54. The majority of respondents were female (86%), Caucasian (86%), were employed full time (42%) or retired (27%), had a Bachelor's degree in College or higher (67%), and lived in a suburban residential setting (60%). Income range was varied for this sample though the majority of family caregivers reported an annual household income of \$50,000 or more (63%).

Table 1.

Characteristics of Family Caregivers (N = 150)

Characteristic	Frequency	Percent
Gender	(2 missing)	
Male	20	14
Female	128	86
Race		
Caucasian	129	86
African-American	13	9
Hispanic	5	3
Other	3	2
Work status	(8 missing)	
Employed full time	60	42
Employed part time	17	12
Unemployed	16	12
Retired	39	27
Other	10	7
Education		
High School/GED	13	8
Some college	37	25
Bachelor's degree	48	32
Master's degree	45	30
Doctorate	7	5
Household income	(5 missing)	
<\$30,000	19	13
\$30 to 39,999	25	17
\$40 to 49,999	12	7
\$50 to 59,999	23	16
\$60 to 69,999	8	6
\$70 to 79,999	6	4
\$80 to 89,999	10	7
\$90 to 99,999	8	6
>= \$100,000	34	24
Residential setting		
Urban	35	23
Suburban	90	60
Rural	25	17

Table 2 presents caregiving characteristics of the family caregiver and care recipient. The majority of caregivers were either a wife caring for a husband ($n = 45$, 30%) or daughter caring for a parent ($n = 55$, 37%). Time spent in the caregiver role

ranged from 3 months to 48 years. Mean time spent caring for a loved one was 5.76 years ($SD = 6.89$). The majority of family caregivers ($n = 98$, 65%) reported caring for their loved one for one to five years.

Table 2.

Caregiving Characteristics of Family Caregivers (N = 150)

Caregiving Characteristic	Frequency	Percent
Relation with care recipient		
Wife caring for husband	45	30
Daughter caring for parent	55	37
Son caring for parent	8	5
Husband caring for wife	6	4
Other	36	24
Years in the caregiving role (6 missing)		
<1 year	5	4
1 to 5 years	96	65
6 to 10 years	31	22
>=11 years	12	9
Percentage of care provided (4 missing)		
0 to 25%	36	25
26 to 50%	27	19
51 to 75%	32	21
76 to 100%	51	35
Use of assistance program for loved one (1 missing)		
Yes	52	35
No	97	65
Use of transportation service for loved one (1 missing)		
Yes	28	19
No	121	81
Care recipient impairment (1 missing)		
Cognitive	32	23
Physical	34	23
Combination	79	54
Neither	4	3

Most family caregivers reported they did not use an assistance program such as the Alzheimer's Association ($n = 97$, 65%) or any kind of formal transportation service

for their loved one ($n = 121$, 81%). The majority of family caregivers reported that their loved one had a combination of cognitive and physical limitations as the reasons for providing care ($n = 79$, 54%).

Missing Value Analysis

Missing data can pose a serious threat to data accuracy and research by limiting generalizability of the findings (Musil, et al., 2002). This threat is largely based on how much data is missing though there is no clear rule regarding how much missing data is too much (Musil, et al., 2002). Some authors have cited missing data is acceptable below 10% while others note that 40% or higher of missing data is too great (Musil, et al., 2002; Raymond & Roberts, 1987). Regardless of whether data is missing in small amounts or large, the potential for bias of findings are inherent unless the data is replaced (Costello & Osborne, 2005).

Confounding this missing data problem is a second issue that must be determined: whether the missing data is missing at random (Costello & Osborne, 2005). Most authors agree that random missingness is more important than the actual amount of missing data that may be present since distinct patterns of missingness represent the highest levels of bias (Costello & Osborne, 2005; DiStefano, Zhu, & Mindrila, 2009; Musil, et al., 2002). Data missing completely at random (MCAR) are considered to reflect the highest degree of randomness while demonstrating that the missing data is unrelated to other variables in the data and is randomly distributed across all cases (Musil, et al., 2002).

In this study, missing data ranged from 1.3% to 8.7% for all 46 items in the Transportation Burden Questionnaire (TBQ). For comparison instruments, the range of

the missing data was: a) Zarit Burden Interview ranged from 0.7% to 4.0%; b) Caregiver Strain Index which ranged from 0.7% to 4.7%; and c) the Center for Epidemiologic Studies-Depression ranged from 0.7% to 2.7%. All of the study instruments' missing data were found to be below the acceptable range of 10% as cited in the literature (Costello & Osborne, 2005; Musil, et al., 2002).

Little's test for variables missing completely at random (MCAR) was used and found not statistically significant ($chi\ square = 5021$, $df = 5013$, $p = 0.438$) suggesting that data were missing completely at random. Data that are MCAR are less likely to introduce serious bias regardless of the method chosen to deal with their replacement (Musil et al.). Since data were found to be MCAR, expectation maximization (EM) imputation was the method used to replace missing values.

Replacement of Missing Values

Expectation maximization (EM) imputation was the method used to replace missing values. Expectation maximization uses a two-step process of expectation (E-step) and maximization (M-step) algorithms, calculates expected values based on all complete data points (E-step), and then replaces the missing values while re-computing new expected values (M-step) (Musil, et al., 2002). This process is then reiterated multiple times until changes in these iterations become negligible (Musil et al.).

Expectation maximization is considered superior to mean substitution, listwise, and pairwise deletion methods because EM is assumed to produce unbiased estimates for a data set missing completely at random (MCAR) as well as less biased estimates for nonignorable missing data (Musil et al.). As a result, EM was used to replace values within the Transportation Burden Questionnaire (TBQ), Zarit Burden Interview (ZBI),

Caregiver Strain Index (CSI), and the Center for Epidemiologic Studies Depression scale (CES-D).

Factor Analysis

Initial analysis was performed using principal component extraction method and Kaiser-Meyer-Olkin (KMO) correlation which noted an overall sampling correlation for the TBQ of 0.861. KMO values range between 0-1 with those above 0.5 acceptable and higher values representing higher levels of sampling adequacy (Musil, et al., 2002).

Bartlett's test of sphericity was conducted noting a chi-square of 4834.06 (df=1035, sig<0.001) showing statistical significance and therefore these findings were not suggestive of an identity matrix. This was an encouraging finding since an identity matrix would indicate that all of the items within the TBQ were measuring the same variable.

Next, Oblimin rotation was conducted to further evaluate survey items to retain or delete as well as overall correlations between the survey items. After evaluating each item within the Transportation Burden Questionnaire (TBQ) and their respective factor cross-loadings, scree plots, and using *a priori* theory based on this researcher's understanding of transportation burden from previous qualitative work, 12 items were removed from the original 46 items on the TBQ for a new total of 34 items. Items with loading values of < .30 were discarded. Each item with a factor loading of .30-.50 on multiple factors were individually evaluated for their strength within the factors based on the wording of the each item and how these corresponded with other items loading strongly within each factor. Those items loading on > .50 on dominant factors were retained as long as they clustered with other items. Less dominant factors that loaded <.50 without any sort of rationale across multiple factors were discarded. Appendix F

depicts all of the items within the original item set as well as the items that were labeled for deletion. Factor loadings and ultimate final factors were considered based on clustering of the analysis after both orthogonal and oblique rotations as well as using a priori theory from this researcher's review of the literature and early phase qualitative findings (Musil, et al., 2002). After reviewing findings of this analysis, 12 items were removed from the original 46 preliminary items to result with the final 34 items of the Transportation Burden Questionnaire (TBQ) based on this researcher's understanding of the literature, evaluation of the factor analysis, and a priori theory. The following 12 items were removed from the original 46 item preliminary item set to comprise the final TBQ:

- Providing transportation for my loved one is not a big deal.
- I currently arrange or provide most of the transportation for my loved one.
- I make significant changes to my own schedule to provide transportation for my loved one.
- I have others I can call on to assist me with transporting my loved one.
- Providing transportation for my loved one has required adjustments in my life.
- I am proud of my ability to provide transportation for my loved one.
- My loved one's mental challenges make transporting him/her difficult.
- I am less able to care for other family members because of the time required to transport my loved one.
- I have no time for myself because of the time it takes to transport my loved one.
- Transporting my loved one conflicts with my own appointments.
- I feel more secure driving my loved one than allowing him/her to drive.

- Because I transport my loved one, I have long waits at their appointments.

After these items were removed, 34 items remained and were carefully analyzed as to how these 34 items factored within the five groups and at times, across multiple loadings. These final five subthemes will be discussed further in the discussion section. The TBQ may be seen in Appendix D.

Distribution of the TBQ and Data Results

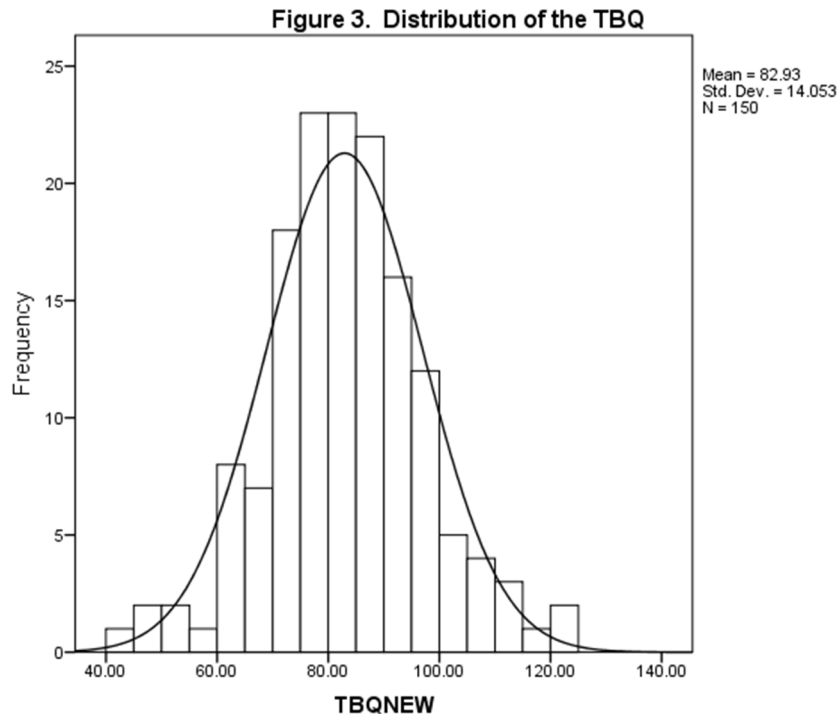
The Transportation Burden Questionnaire (TBQ) has a possible score range of 34 to 136. Respondents had scores ranging from 44 to 123 with a mean score of 82.93 (SD = 14.05), median of 83.61, and mode of 87.00. Table 3 presents a summary of the statistics for each scale in the study. Higher scores on the TBQ are hypothesized to

Table 3.

Summary of Scales Mean, Standard Deviation, Range, Median, and Cronbach's Alpha
(*N* = 150)

Scales	Sample size	Mean (Standard Deviation)	Range	Median	Cronbach's Alpha
Transportation Burden Questionnaire (TBQ)	150	82.93 (14.05)	44.00-123.00	83.61	.93
Zarit Burden Interview (ZBI)	150	39.66 (16.97)	3.00-79.00	39.46	.75
Caregiver Strain Index (CSI)	150	7.02 (3.32)	.00-12.00	7.00	.78 (KR20)
Center for Epidemiologic Studies-Depression (CES-D)	150	19.77 (7.27)	3.00-39.00	19.00	.74

to correspond with higher levels of transportation burden. The distribution of the TBQ has a skewness of 0.07 and kurtosis of 0.62. Figure 3 depicts the revised TBQ distribution and its total scores.



Hypothesis 1. To test hypothesis one, factor analysis was hypothesized to reveal a factor structure consistent with at least three of the five qualitative themes represented in the draft Transportation Burden Questionnaire (TBQ) items. Initial analysis was performed using principal component extraction method and Kaiser-Meyer-Olkin (KMO) correlation which noted an overall sampling adequacy for the TBQ of 0.86 well above acceptable values of 0.5 which is considered higher level sampling adequacy (Musil, et al., 2002). Bartlett's test of sphericity revealed a chi-square 4834.06 ($df = 1035$, $p < 0.001$) indicating normality of the sample for the TBQ. Initial analysis displayed 10 components with eigenvalues over Kaiser's criterion of 1 which explained 70.26% of the

variance in the sample. However, a priori theory, factor loading, and scree plot results indicated a curvature which would justify retaining components 1-5 from the factor analysis.

After evaluating each item within the Transportation Burden Questionnaire (TBQ) and their respective factor cross-loadings, scree plot, and using a priori theory based on this researcher's understanding of the novel concept of transportation burden from previous qualitative work, 12 items were removed from the original 46 items on the TBQ for a new total of 34 items. Decision to remove items were based on the following criteria: a) items with factor loading values of $< .30$ were discarded; b) each item with a factor loading of $.30$ to $.50$ on multiple factors were individually evaluated for their strength within the factors based on the wording of the item and how these corresponded with other items loading strongly within each factor; c) items loading $> .50$ on dominant factors were retained; and d) less dominant factors that loaded $< .50$ without any sort of rationale across multiple factors were discarded.

After careful deliberation and considering the above analysis, 5 factors were retained. This was based on attributes of each item within the TBQ and how these maintained congruence based on wording of the items and understanding of a priori theory regarding transportation burden. The reduced final 5 factors, subthemes, and the respective number of items they factored/co-factored on include: a) definitive burden, 10 items; b) extraneous factors, 8 items; c) time and self-sacrifice, 7 items; c) extraneous factors, 8 items; d) acceptance, 5 items; and e) care recipient attributes, 4 items. These will be discussed further in Chapter 5 as well as how each subtheme arose from the data.

Hypothesis 2. To test hypothesis two, a total transportation burden questionnaire (TBQ) score and at least two subscale scores were sought to have sufficient internal consistency reliability ($>.60$). Reliability assessment was performed using Cronbach's alpha. The overall Cronbach's alpha for internal reliability was found to be 0.93 for the final 34 items studied. For each of the five subthemes within the TBQ the following were noted: a) the 10 of the 34 items within the subscale of definitive burden had Cronbach's alpha of 0.91; b) the 8 items within the subscale of extraneous factors had Cronbach's alpha of 0.81; c) the 7 items within the subscale of time and self-sacrifice had Cronbach's alpha of 0.92; d) the 5 items within the subscale of acceptance had Cronbach's alpha of 0.81; and e) the 4 items within the subscale of care recipient attributes had Cronbach's alpha of 0.82.

Hypothesis 3. To address hypothesis three, a moderate, significant correlation was sought between general, extant measures of burden and transportation burden questionnaire (TBQ) scores. Bivariate correlation was used to analyze the relationship between the TBQ and both the Zarit Burden Interview (ZBI) and the Caregiver Strain Index (CSI). The overall ZBI score for this sample had a mean score of 39.66 ($SD=16.97$) indicating moderate caregiver burden. Pearson's r correlation between the ZBI and the overall TBQ score was 0.65 ($p < 0.001$) revealing a moderate correlation. The overall CSI score within this sample had a mean score of 7.02 ($SD=3.32$) which suggests a high level strain or stress in this caregiver population. Pearson's r correlation with the CSI and the overall TBQ score was 0.63 ($p < 0.001$) indicating a moderate correlation. Table 4 presents the bivariate correlations.

Table 4.

Correlations between Scales, Age, and Education

Scale	Transportation Burden Questionnaire	Zarit Burden Interview	Caregiver Strain Index	Center for Epidemiologic Studies-Depression	Age	Education
Transportation Burden Questionnaire	1	.65 ($p < .001$)	.63 ($p < .001$)	.32 ($p < .001$)	-.002 ($p = .977$)	-.006 ($p = .946$)
Zarit Burden Interview		1	.707 ($p < .001$)	.491 ($p < .001$)	-.164 ($p = .047$)	-.047 ($p = .564$)
Caregiver Strain Index			1	.507 ($p < .001$)	.042 ($p = .609$)	.041 ($p = .620$)
Center for Epidemiologic Studies-Depression				1	.044 ($p = .598$)	.020 ($p = .812$)
Age					1	.111 ($p = .180$)
Educational Level						1

Hypothesis 4. To investigate hypothesis four: a) the transportation burden questionnaire (TBQ) scores were hypothesized to vary with the function of other burden scores (i.e., higher general burden = higher transportation burden); b) the length of time in the caregiver role (i.e., more time = higher transportation burden); and c) TBQ scores and other burden scores will be positively correlated with scores on the depression scale (i.e. higher general burden and transportation burden = higher depression). Total scores on the TBQ were compared to the total scores on the Zarit Burden Interview (ZBI) through bivariate correlation were .65 ($p < .001$) while correlation between total scores on the caregiver strain index (CSI) and the TBQ were .62 ($p < .001$) both suggesting

moderate correlations. Total scores on the ZBI had a mean score of 39.66 ($SD = 16.97$) revealing moderate levels of burden while mean score for the CSI was 7.02 ($SD = 3.32$) representing higher levels of strain and stress. The TBQ had a possible score range of 34 to 136. Respondents in this study had TBQ scores ranging from 44 to 123 with a mean score of 82.93 ($SD = 14.05$), median of 83.61, and mode of 87.00. The true median for this scale is 68 and it is hypothesized that scores above this value represent positive findings for transportation burden. Therefore, for respondents in this study, it appears that higher levels of burden on extant scales correlate with higher scores on the TBQ.

Length in time in the caregiver role varied and ranged from less than one year to more than 40 years with the mean time in the caregiver role being 5.76 years ($SD = 6.89$). Bivariate correlations between years in the caregiving role and total TBQ scores yielded Pearson's r of .19 ($p < .001$) showing little to no correlation.

Despite total scores on centers for epidemiologic studies—depression (CES-D) scale of 19.77 ($SD = 7.27$) suggesting positive findings for depression, bivariate correlation between the CES-D and the transportation burden questionnaire (TBQ) revealed Pearson's r value of .32 ($p < .001$). This suggests a low correlation between the scales. Similar, yet slightly stronger correlations were noted between the CES-D and the ZBI of .49 ($p < .001$) as well as the CES-D and the CSI of .51 ($p < .001$) for this sample of respondents.

Chapter Five

Discussion

Results will be presented along with their implications for nursing research and practice. The findings will also be related to the review of the literature including similarities and differences.

Sample Characteristics

This study consisted of a convenience sample of 150 family caregivers. The mean age of family care givers was 58. The majority of family caregivers were Caucasian women that were caring for a parent or husband who were suffering from both a cognitive and physical ailment. This finding is consistent with findings in the literature where family caregivers in most studies were daughters caring for parents, or wives caring for their husbands (Carey, et al., 1991; Dautzenberg, Diederiks, Philipsen, & Tan, 1999; Knight & Losada, 2011; Krach & Brooks, 1995; Motenko, 1989; Robinson, 1997; Sims-Gould, Martin-Matthews, & Gignac, 2008). Racial demographics in this sample were consistent with other caregiver studies where the majority of respondents were Caucasian (Cassie & Sanders, 2008; Kim & Schulz, 2008; Siegler, et al., 2010; Son et al., 2007). This study captured a large proportion of well-educated and higher income participants who held a Bachelor's degree or higher and an annual household income of \$50,000 or more. This finding was not surprising because survey participants were required to have access to both computers and internet access to link them to the surveys since this research was conducted entirely online.

Caregivers in this study reported their loved ones had combinations of both physical and cognitive limitations. This is consistent with other caregiver research that

noted care recipients generally have overlapping cognitive and physical ailments particularly in older age (Acton & Kang, 2001; Bertrand, et al., 2006; Given, et al., 1992; Mosavel & Sanders, 2011; Sherwood, Given, Given, & Von Eye, 2005; Takata, et al., 2008). The majorities of caregivers within this sample reported providing 26% or more of the overall care for their loved and were in the caregiver role for one or more years. Interestingly, this sample had many caregivers who reported having been in a family caregiver role for six or more years. This may account for the higher rates of burden and depressive symptoms found in this study and is consistent with findings elsewhere in the literature that noted higher levels of burden in caregivers over time (Kim & Schulz, 2008; Lau & Au, 2011; Rinaldi, et al., 2005).

Correlations with Extant Scales

Overall, respondents reported mild to moderate burden on the Zarit Burden Interview (ZBI); were considered generally stressed as evidenced by the Caregiver Strain Index (CSI); and were depressed as evidenced by scores on the Centers for Epidemiologic Studies Depression (CES-D). These are interesting findings because interpretation of the TBQ findings validity and reliability should be made in the context of these findings of depression in this sample. This finding is consistent with several authors who found that depressive symptomology tends to increase with higher levels of stress, strain, and burden (Cassie & Sanders, 2008; Clark & Standard, 1997; Ho, et al., 2009; Lai, 2009; Marcell, 2006; Matsumoto et al., 2007; Sherwood, et al., 2005; Siegler, et al., 2010; Taylor, Kuchibhatla, Ostbye, Plassman, & Clipp, 2008; Thompson, Fan, Unützer, & Katon, 2008).

Pearson's r correlations between the ZBI and TBQ as well as the CSI and TBQ were moderate. These findings also support a good correlation without being excessively similar with the extant scale while falling within the desired correlation range (DeVellis, 2012). For the correlation between the CES-D and the TBQ, aims were not necessarily to have these two scales correlate. Rather, simply comparing findings on the two scales was enough while measuring respondents for possible depression which could influence the findings given the noted confounding effect of depression on caregiver burden and vice-versa (Sherwood, et al., 2005; Stommel, et al., 1990; Taylor, et al., 2008). Findings in this study are therefore consistent with the literature where it is reported that depression is common among family caregivers and may influence reporting on caregiver burden scales (Clark & Standard, 1997; Doorenbos, et al., 2007; Hébert, et al., 2000; Ho, et al., 2009).

Interpretation of the TBQ

Mean score for the Transportation Burden Questionnaire was 82.93 which lies above the possible median score for the revised TBQ of 68. Formal delineation of what overall scores mean will be left for further research, however for purposes of this study, scores above the possible median score of 68 implies that transportation burden may exist as it is hypothesized that higher scores represent burden. Given the mean score, this seems consistent with findings elsewhere for this cohort of respondents who also reported mild-moderate caregiver burden both on the ZBI and CSI as well as the apparent depressive symptomology that was present based on scores of the CES-D (Acton & Kang, 2001; Bachner & O'Rourke, 2007; Pinquart & Sörensen, 2011; Vitaliano, et al., 2003; Yin, Zhou, & Bashford, 2002).

Revised Subthemes

Within the 34 items of the Transportation Burden Questionnaire (TBQ), lie the final five subthemes that are apparent within this scale. These differed from the original five postulated subscales from earlier phases of this research and will be further delineated.

Definitive burden. Definitive burden was the strongest loading factor of the five subthemes having factored on 10 different items. The specific items which were unique to definitive burden included:

- Providing transportation for my loved one tries my patience.
- It frustrates me to provide transportation for my loved one.
- Providing transportation for my loved one is stressful.
- I would prefer not to be providing transportation for my loved one.
- Providing transportation for my loved one is burdensome.
- Providing transportation for my loved one feels confining to me.
- I would utilize an outside transportation service for my loved one if it was available in my community.
- Transportation demands are becoming too much for me.
- My loved one needs more with respect to transportation assistance than I can provide.
- Providing transportation for my loved one is time consuming for me.

These items exemplify transportation burden in the strongest sense of their wording. For the most part, the items are self-explanatory and positive responses to these questions would indicate higher levels of burden. Key words used in these

items were gleaned from some the original interviews from the qualitative study in the earlier phase of this research and were incorporated into these items. Seven other items within the definitive burden subtheme cross-factor on other components and will be discussed in the next sections.

Extraneous factors. Extraneous factors factored on eight different items. The specific items which were unique to the subtheme of extraneous factors included:

- I worry that my vehicle will not work well for providing transportation in the future.
- I cannot afford to pay for transportation assistance for my loved one.
- I have often missed or been late to work because of transporting my loved one.
- Transporting my loved one conflicts with my work schedule.
- My loved one has frequent transportation needs.
- Others in my family do not understand how much it takes to provide transportation for my loved one.
- Transporting my loved one has cost me a lot of money.
- Transporting my loved one is a challenge because of the long wait times.

Extraneous factors are those thought to complicate transportation burden. Issues such as vehicle concerns, cost of maintaining the vehicle, fuel expenses, and the influence of concurrent work demands may all be considered extraneous factors. It is thought that for each caregiver, there are moderating factors that influence the overall concept of transportation burden and may be present for some, but likely absent for others (Hannum Rose, et al., 2007; Montgomery, 1985; Savundranayagam, 2010). For example, a family caregiver who has no overt cost constraints such as gas or who has a newer car with

relatively low maintenance concerns, may not be influenced by these extraneous factors. Likewise, family caregivers whose employers allow time off, provide paid leave, or are able to take time away from work may have fewer burdens than family caregivers whose employers may not offer such allowances.

Time and self-sacrifice. The subtheme of time and self-sacrifice was the third most common factor, having factored on seven different items. The items unique to the subtheme of time and self-sacrifice were:

- My leisure time has decreased because of providing transportation for my loved one.
- My recreational time has decreased because I provide transportation for my loved one.
- Providing transportation for my loved one takes time away from my own social life.
- I have less time to take care of my myself because I provide transportation for my loved one.
- I have less time to do things I enjoy because of transporting my loved one.
- I am less able to care for my own health since I am providing transportation for my loved one.
- The long travel times that are involved with transporting my loved one are a challenge.

It was originally thought that the subtheme time and self-sacrifice would be a more commonly occurring subtheme. It is clear that the time limitations and subsequent impact of transportation burden on family caregivers' social life are evident in this this

sample. This is consistent with studies in the literature that noted time demands were a particular challenge for caregivers when providing transportation for their dependent loved ones (Baxter & Kahn, 1999; Park, et al., 2013; Razani, et al., 2007; Rizk, et al., 2011). On a global level, most caregiver burden literature references the aspect of time limitation which is similar to the findings in this study (Bakas, et al., 2001; Baxter & Kahn, 1996; Carey, et al., 1991).

Acceptance. The subtheme of acceptance factored on five different items. The items unique to the subtheme of acceptance were:

- I find providing transportation for my loved one to be personally beneficial.
- I have always been the one to provide transportation for my loved one.
- I have always provided transportation for my loved one.
- Transporting my loved one is rewarding.
- I enjoy providing transportation for my loved one.

Though two of these questions are very similar they were left in place because of their strong factoring within this subtheme. Some family caregivers have always provided transportation for their loved one and for some respondents in this study, the responsibility of providing transportation was not seen as an imposition. Having two items that address acceptance within the TBQ clarifies the concept of transportation burden and the subtheme of acceptance. Overall, the subtheme of acceptance for this study is hypothesized to be analogous to the concepts of obligation or duty (Reed & Weicherding, 1999). It is thought that many family caregivers may not consider the provision of transportation challenging and instead think of providing transportation as a necessary responsibility. Part of this acceptance of responsibility is consistent with the

concepts of duty and obligation which are echoed elsewhere in the literature, particularly among parents caring for ill children (Baxter & Kahn, 1996; Fedewa & Oberst, 1996; Murphy, et al., 2008; Nelson, 2002; Stewart, et al., 1994). Interestingly, some of the items that factored on the subtheme of acceptance also factored on definitive burden which will be discussed in a subsequent section.

Care recipient attributes. The subtheme of care recipient attributes factored on four different items. The items unique to the subtheme of care recipient attributes were:

- Getting my loved one in and out of a vehicle is a challenge.
- My loved one's physical challenges make transporting him/her difficult.
- I have had to make modifications to my vehicle in order to transport my loved one.
- Getting my loved one ready for transportation is a challenge.

Care recipient attributes, like the subtheme of extraneous factors described above, is considered a moderating subtheme that affects the overall concept of transportation burden (Leong, et al., 2001; Li, Seltzer, & Greenberg, 1997). The concept of transportation burden is affected by caregiver challenges related specifically to care recipient's limitations such as the inability to walk or confusion which make transporting their loved one a challenge. Thus, transportation burden may increase. This is consistent with findings in the literature where it is widely noted that as the care recipient's condition declines, family caregiver burden tends to increase (Belasco, et al., 2006; Cassie & Sanders, 2008; Elmstahl, et al., 1996; Ho, et al., 2009; Iecovich, 2008; Knight & Losada, 2011; Leong, et al., 2001; Patterson, et al., 1996; Pinquart & Sörensen, 2006; Schur & Whitlatch, 2003; Vitaliano, et al., 2003).

Cross-loading and Multiple Factoring Subthemes

All five subthemes had items that cross-loaded on multiple subthemes. There were no items that cross-loaded on all five subthemes but several that loaded on three. For example:

- Transportation demands are becoming too much for me.

This item cross-factored on definitive burden, time and self-sacrifice, and care recipient attributes. This suggests an interplay of these three subthemes but remains unclear why this question cross-factored on these three factors. One possible explanation is the subjective interpretation of each family caregiver who participated in this study. In other words, for some family caregivers, the wording of this item represented purely transportation burden (or definitive burden) while for others the demands were related to care recipient issues that were contributing to transportation burden, while still others felt these demands were related to time limitations.

Other examples include:

- My loved one needs more with respect to transportation assistance than I can provide.

This item cross-loaded on definitive burden, care recipient attributes, and extraneous factors.

- Providing transportation for my loved one is time-consuming for me.

With this item, factor loadings were noted for definitive burden, time and self-sacrifice, and acceptance. This is interesting because the item incorporates the subtheme of acceptance while cross-loading on two burdensome factors suggesting that burden may

exist with an overarching level of acceptance. This was echoed elsewhere in this study with the following item:

- Transporting my loved one is rewarding.

Not surprisingly, this item loaded strongly on acceptance, but also loaded on definitive burden. This reinforces the thought that acceptance may double as an unwanted responsibility, obligation, or perceived duty and sometimes may not be truly representative of what family caregivers are experiencing.

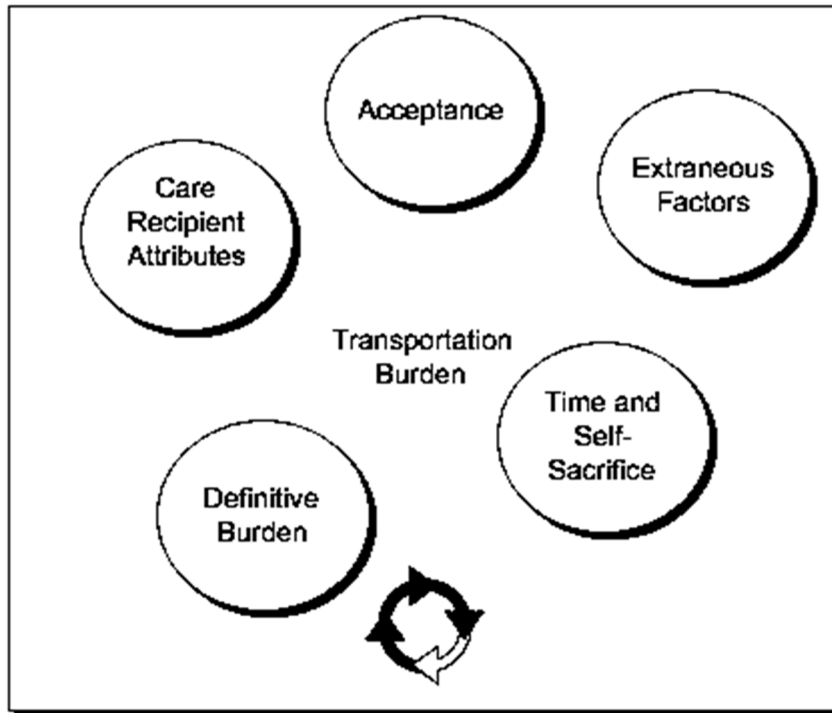
- Others in my family do not understand how much it takes to provide transportation to my loved one.

This item loaded on definitive burden, extraneous factors, and acceptance.

All of the above examples suggest that there seems to be interplay between the subthemes and that subthemes within transportation burden are not mutually exclusive. It is unclear from this investigation the true extent of how these subthemes overlap. Additional research is needed to further extrapolate findings on larger and different samples of family caregivers.

Revised Transportation Burden Conceptual Framework

Based on the results of this study, revision of the original transportation burden conceptual framework is necessary. Figure 4 presents the Revised Transportation Burden Conceptual Framework:

Figure 4. Revised Transportation Burden Conceptual Framework

As depicted in Figure 1 (page 17) and Figure 4, the original subthemes of definitive burden and acceptance remain. However the previous subthemes of role change, time monopoly, and self and social losses (see Figure 1) have been transformed into the revised categories of extraneous factors, time and self-sacrifice, and extraneous factors (see figure 4). These changes were made because of the findings from the study, clustering of the items in factor analysis, and a priori theory. In addition, the removal of the 12 items from the original TBQ altered the final results of this study both in factor analysis and moreover, interpretation of the findings which further guided the revised categories and their titles.

Implications for Nursing Research, Practice, and Policy

Results of this research add a new concept, transportation burden, to caregiver burden. This is because this study suggests transportation plays an important role in family caregiver burden. Many authors (Adler, Rottunda, Bauer, & Kuskowski, 2005; Baxter & Kahn, 1996, 1999; Casado, et al., 2011; Krach & Brooks, 1995; Mosavel & Sanders, 2011; Razani, et al., 2007; Taylor & Tripodes, 2001) have suggested that transportation offers a global influence in the lives of caregivers, but none of these researchers have sought to specifically measure transportation burden. This study offers a foundation on which to understand the impact of transportation burden on family caregivers. Furthermore, it provides the underpinning for better understanding and measuring transportation burden while suggesting further research through future confirmatory factor analysis and construct validity of a larger sample size of family caregivers.

This investigation is also consistent with modern caregiver theorists who postulate that tailored rather than global interventions for family caregivers are more advantageous and beneficial (Montgomery & Kosloski, 2009). This is because in this investigation transportation burden emerges as a valid concept present in this sample of family caregivers. By identifying family caregivers with transportation burden, targeted interventions and strategies towards assisting these individuals with providing transportation for their loved ones may be planned.

This study provides more information about transportation burden and an understanding of concepts that can help identify when caregiver burden is occurring. This finding is consistent with other authors who agree that caregiver burden is

multifaceted (Acton & Kang, 2001; Almberg, et al., 1997; Mosavel & Sanders, 2011; Wenzel, Shaha, Klimmek, & Krumm, 2011). Narrowing to specific subthemes within transportation burden may further guide assessment and interventional strategies. For example if the subtheme of definitive burden is evident, linking family caregivers with alternative transportation (if this is available) is clearly indicated. Conversely, if the subtheme of extraneous factors such as concurrent employment complicates transportation provision, assisting the family caregiver to better convey this issue to their employer to foster accommodations accordingly would be indicated.

Further research is needed at the clinical level to determine if the revised TBQ can provide an improved measure of transportation burden that may guide clinicians to tailor nursing interventions. Scoring of the subthemes to identify a specific sub score may further allow clinicians to focus on specific aspects of transportation burden. The TBQ allows for planning of tailored interventions by measuring transportation burden as well as its' inherent subthemes. Tailored and specific, rather than a global approach to caregiver interventions has been cited by leading authors within the caregiver burden literature as an optimal management strategy to address family caregiver concerns (Hannum Rose, et al., 2007; Kosloski, Montgomery, & Youngbauer, 2001; Montgomery & Kosloski, 2009; Montoro-Rodríguez, et al., 2009; Savundranayagam, 2010). By using a tailored approach, clinicians will have more success because specific needs can be identified and unnecessary costly interventions that waste caregiver time, can be avoided (Montgomery & Kosloski, 2009).

The concept of transportation burden has important state and national policy implications as well. In their text entitled "Aging America and Transportation: Personal

Choices and Public Policy,” Coughlin and D’Ambrosio (2012) point out that over 25% of adults aged 75 or older will need alternative transportation services in the future given their inability to safely drive. For many older adults who can no longer safely drive, family members and loved ones will assume this responsibility. In many cases, this will be occurring concurrently with other responsibilities such as financial management, household upkeep, and even more intimate tasks such as ADL assistance which can be challenging.

In summary, this research adds a new understanding of how transportation intersects with caregiver burden. This study quantifies transportation burden and its subthemes, which are considered an important aspect of the broader concept of caregiver burden. Furthermore this research clarifies a very real element for many caregivers who are struggling with transporting their loved one along with the other challenges of being a family caregiver. Lastly, this study provides a foundation for future research while offering an instrument to measure the novel phenomenon of transportation burden.

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Appendix A
Transportation Burden Questionnaire (original)

Please consider the following questions and answer them accordingly

1. Providing transportation for my loved one has required adjustments in my life.

Strongly disagree Disagree Agree Strongly agree

2. I am proud of my ability to provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly agree

3. I currently arrange or provide most of the transportation for my loved one.

Strongly disagree Disagree Agree Strongly agree

4. I make significant changes to my own schedule to provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly agree

5. Providing transportation for my loved feels confining to me.

Strongly disagree Disagree Agree Strongly agree

6. It frustrates me to provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly agree

7. I feel more secure driving my loved one than allowing him/her to drive.

Strongly disagree Disagree Agree Strongly agree

8. Providing transportation for my loved one is time-consuming for me.

Strongly disagree Disagree Agree Strongly agree

9. I have others I can call on to assist me with transporting my loved one.

Strongly disagree Disagree Agree Strongly agree

10. Providing transportation for my loved one tries my patience.

Strongly disagree Disagree Agree Strongly agree

11. I cannot afford to pay for transportation assistance for my loved one.

Strongly disagree Disagree Agree Strongly agree

12. Providing transportation for my loved one is stressful.

Strongly disagree Disagree Agree Strongly agree

13. Providing transportation for my loved one is burdensome.

Strongly disagree Disagree Agree Strongly agree

14. I have less time to do things I enjoy because of transporting my loved one.

Strongly disagree Disagree Agree Strongly agree

15. I have less time to take care of myself because I provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly agree

16. Transporting my loved one conflicts with my work schedule.

Strongly disagree Disagree Agree Strongly agree

17. Providing transportation for my loved one is not a big deal.

Strongly disagree Disagree Agree Strongly agree

18. I am less able to care for other family members because of the time required to transport my loved one.

Strongly disagree Disagree Agree Strongly agree

19. I have no time for myself because of the time it takes to transport my loved one.

Strongly disagree Disagree Agree Strongly agree

20. Because I transport my loved one, I have long waits at their appointments.

Strongly disagree Disagree Agree Strongly agree

21. Transporting my loved one conflicts with my own appointments.

Strongly disagree Disagree Agree Strongly agree

22. Getting my loved one ready for transportation is a challenge.

Strongly disagree Disagree Agree Strongly agree

23. Getting my loved one in and out of a vehicle is a challenge.

Strongly disagree Disagree Agree Strongly agree

24. My loved one's physical challenges make transporting him/her difficult.

Strongly disagree Disagree Agree Strongly agree

25. I have had to make modifications to my vehicle in order to transport my loved one.

Strongly disagree Disagree Agree Strongly agree

26. My loved one has frequent transportation needs.

Strongly disagree Disagree Agree Strongly agree

27. Transporting my loved one is rewarding.

Strongly disagree Disagree Agree Strongly agree

28. I have often missed or been late to work because of transporting my loved one.

Strongly disagree Disagree Agree Strongly agree

29. Transporting my loved one has cost me a lot of money.

Strongly disagree Disagree Agree Strongly agree

30. The long travel times that are involved with transporting my loved one are a challenge.

Strongly disagree Disagree Agree Strongly agree

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31. I worry that my vehicle will not work well for providing transportation in the future.

Strongly disagree Disagree Agree Strongly agree

32. Others in my family do not understand how much it takes to provide transportation to my loved one.

Strongly disagree Disagree Agree Strongly agree

33. My loved one's mental challenges make transporting him/her difficult.

Strongly disagree Disagree Agree Strongly agree

34. I would utilize an outside transportation service for my loved one if it was available in my community.

Strongly disagree Disagree Agree Strongly agree

35. Providing transportation for my loved one takes time away from my own social life.

Strongly disagree Disagree Agree Strongly agree

36. I have always been the one to provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

37. I am less able to care for my own health since I am providing transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

38. My recreational time has decreased because I provide transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

39. I have always provided transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

40. I find providing transportation for my loved one to be personally beneficial.

Strongly disagree Disagree Agree Strongly Agree

41. My leisure time has decreased because of providing transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

42. I would prefer not to be providing transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

43. Transporting my loved one is a challenge because of the long wait times that are involved.

Strongly disagree Disagree Agree Strongly Agree

44. I enjoy providing transportation for my loved one.

Strongly disagree Disagree Agree Strongly Agree

45. Transportation demands are becoming too much for me.

Strongly disagree Disagree Agree Strongly Agree

46. My loved one needs more with respect to transportation assistance than I can provide.

Strongly disagree Disagree Agree Strongly Agree

Appendix B

BURDEN INTERVIEW

INSTRUCTIONS:

The following is a list of statements which reflect how people sometimes feel when taking care of another person.

After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he or she needs?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

2. Do you feel that, because of the time you spend with your relative, you don't have enough time for yourself?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

4. Do you feel embarrassed about your relative's behavior?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

5. Do you feel angry when you are around your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

6. Do you feel that your relative currently affects your relationship with other family members?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

7. Are you afraid about what the future holds for your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

8. Do you feel that your relative is dependent upon you?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

9. Do you feel strained when you are around your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

10. Do you feel that your health has suffered because of your involvement with your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

12. Do you feel that your social life has suffered because you are caring for your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

13. Do you feel uncomfortable having your friends over because of your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

16. Do you feel that you will be unable to take care of your relative much longer?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

17. Do you feel that you have lost control of your life since your relative's death?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

18. Do you wish that you could just leave the care of your relative to someone else?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

19. Do you feel uncertain about what to do about your relative?

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

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

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

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

0 NEVER 1 RARELY 2 SOMETIMES 3 QUITE FREQUENTLY 4 NEARLY ALWAYS

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

0 NOT AT ALL 1 A LITTLE 2 MODERATELY 3 QUITE A BIT 4 EXTREMELY

Appendix C

Caregiver Strain Index

Yes = 1

No = 0

1. Sleep is disturbed (e.g., because . . . is in and out of bed or wanders around at night)
2. It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)
3. It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)
4. It is confining (e.g., helping restricts free time or cannot go visiting)
5. There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)
6. There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)
7. There have been emotional adjustments (e.g., because of severe arguments)
8. Some behavior is upsetting (e.g., because of incontinence; . . . has trouble remembering things; or . . . accuses people of taking things)
9. It is upsetting to find . . . has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)
10. There have been work adjustments (e.g., because of having to take time off)
11. It is a financial strain
12. Feeling completely overwhelmed (e.g., because of worry about . . . ; concerns about how you will manage)

Total Score (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)

Appendix D

Center for Epidemiologic Studies Depression Scale (CES-D), NIMH

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

During the Past Week

Rarely or none of the time (less than 1 day)

Some or a little of the time (1-2 days)

Occasionally or a moderate amount of time (3-4 days)

Most or all of the time (5-7 days)

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with help from my family or friends.
4. I felt I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people dislike me.

20. I could not get “going.”

SCORING: zero for answers in the first column, 1 for answers in the second column, 2 for answers in the third column, 3 for answers in the fourth column. The scoring of positive items is reversed. Possible range of scores is zero to 60, with the higher scores indicating the presence of more symptomatology.

Appendix E

Transportation Burden Questionnaire

Please consider each question individually and respond as one of the following:

Strongly Disagree Disagree Agree Strongly Agree

1. Providing transportation for my loved one tries my patience.
2. It frustrates me to provide transportation for my loved one.
3. I would prefer not to be providing transportation for my loved one.
4. I would utilize an outside transportation service for my loved one if it was available in my community.
5. I have always provided transportation for my loved one.
6. I have often missed or been late to work because of transporting my loved one.
7. Providing transportation for my loved one is stressful.
8. I have always been the one to provide transportation for my loved one.
9. I find providing transportation for my loved one to be personally beneficial.
10. Transporting my loved one is rewarding.
11. I enjoy providing transportation for my loved one.
12. Transporting my loved one conflicts with my work schedule.
13. I worry that my vehicle will not work well for providing transportation in the future.
14. My loved one has frequent transportation needs.
15. Others in my family do not understand how much it takes to provide transportation to my loved one.
16. I cannot afford to pay for transportation assistance for my loved one.

17. Transporting my loved one has cost me a lot of money.
18. Transporting my loved one is a challenge because of the long wait times that are involved.
19. Providing transportation for my loved one feels confining to me.
20. Providing transportation for my loved one is burdensome.
21. Transportation demands are becoming too much for me.
22. My loved one needs more with respect to transportation assistance than I can provide.
23. Providing transportation for my loved one is time-consuming for me.
24. My leisure time has decreased because of providing transportation for my loved one.
25. My recreational time has decreased because I provide transportation for my loved one.
26. Providing transportation for my loved one takes time away from my own social life.
27. I have less time to take care of myself because I provide transportation for my loved one.
28. I have less time to do things I enjoy because of transporting my loved one.
29. I am less able to care for my own health since I am providing transportation for my loved one.
30. The long travel times that are involved with transporting my loved one are a challenge.
31. Getting my loved one in and out of a vehicle is a challenge.
32. My loved one's physical challenges make transporting him/her difficult.
33. I have had to make modifications to my vehicle in order to transport my loved one.
34. Getting my loved one ready for transportation is a challenge.

Appendix F
Factor Analysis of Transportation Burden Questionnaire

Factored Item	Definitive Burden	Time and Self Sacrifice	Extraneous Factors	Acceptance	Care Recipient Attributes
Providing transportation for my loved one tries my patience.	.770				
It frustrates me to provide transportation for my loved one.	.756				
I would prefer not to be providing transportation for my loved one.	.714				
Providing transportation for my loved one is stressful.	.713				
Providing transportation for my loved one feels confining to me.	.711	.318			
Providing transportation for my loved one is burdensome.	.700				
I would utilize an outside transportation service for my loved one if it was available in my community.	.576		.439		
Transportation demands are becoming too much for me.	.523	.373			.408
My loved one needs more with respect to transportation assistance than I can provide.	.480		.364		.457
Providing transportation for my loved one is time-consuming for me.	.394	.393		.385	
My leisure time has decreased because of providing transportation for my loved one.		.825			
My recreational time has decreased because I provide transportation for my loved one.		.802			
Providing transportation for my loved one takes time away from my own social life.		.774			
I have less time to take care of myself because I provide transportation for my loved one.	.330	.757			
I have less time to do things I enjoy because of transporting my loved one.	.433	.649			
I am less able to care for my own health since I am providing transportation for my loved one.		.615	.330		
The long travel times that are involved with transporting my loved one are a challenge.		.457	.367		
Transporting my loved one conflicts with my work schedule.			.839		
I have often missed or been late to work because of transporting my loved one.			.814		
I worry that my vehicle will not work well for providing transportation in the future.			.682		

Factored Item	Definitive Burden	Time and Self Sacrifice	Extraneous Factors	Acceptance	Care Recipient Attributes
My loved one has frequent transportation needs.			.571	.329	
Others in my family do not understand how much it takes to provide transportation for my loved one.	.377		.547	.344	
I cannot afford to pay for transportation assistance for my loved one.			.535		
Transporting my loved one has cost me a lot of money.		.476	.487		
I have always been the one to provide transportation for my loved one.				.838	
I have always provided transportation for my loved one.				.825	
I find providing transportation for my loved one to be personally beneficial.				.796	
Transporting my loved one is rewarding.	.312			.783	
I enjoy providing transportation for my loved one.	.431			.752	
Getting my loved one in and out of a vehicle is a challenge.					.886
My loved one's physical challenges make transporting him/her difficult.					.881
I have had to make modifications to my vehicle in order to transport my loved one.					.634
Getting my loved one ready for transportation is a challenge.					.628

Deleted Items

1. Providing transportation for my loved one is not a big deal.
2. I currently arrange or provide most of the transportation for my loved one.
3. I make significant changes to my own schedule to provide transportation for my loved one.
4. I have others I can call on to assist me with transporting my loved one.
5. Providing transportation for my loved one has required adjustments in my life.
6. I am proud of my ability to provide transportation for my loved one.
7. My loved one's mental challenges make transporting him/her difficult.
8. I am less able to care for other family members because of the time required to transport my loved one.
9. I have no time for myself because of the time it takes to transport my loved one.
10. Transporting my loved one conflicts with my own appointments.
11. I feel more secure driving my loved one than allowing him/her to drive.
12. Because I transport my loved one, I have long waits at their appointments.