BEHAVIORS IN PERSONS WITH DEMENTIA: A DYADIC EFFECT OF CAREGIVERS’ STRESS PROCESS?

By

JUDY LYNN MCGEE CAMPBELL

A DISSERTATION PRESENTED TO THE GRADUATE SCHOOL OF THE UNIVERSITY OF FLORIDA IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

UNIVERSITY OF FLORIDA

2008
To my husband David
ACKNOWLEDGMENTS

I would like to thank my dissertation committee for their continued support, patience, and assistance during this process. In particular, Dr. Meredeth Rowe, my dissertation chairperson, has been very instrumental in my growth as a researcher and writer. Without her sustained efforts in guiding and assisting me along the way, this would not have been possible. I also greatly appreciate the assistance of Dr. Michael Marsiske with the analyses and methodology. Lastly, Drs. Ann Horgas and Jennifer Elder were very influential early in my doctoral education and have continually read, made suggestions, and discussed ways to improve my dissertation. I am very appreciative of the phenomenal dedication of my dissertation committee.

I am extremely grateful for the support I have received from the University of Florida Alumni Fellowship and from the Hartford *Building Academic Geriatric Nursing Capacity* Scholarship. Without this support, I would not have been able to attend the University of Florida, and would not have been as successful in my studies. As a Hartford Scholar, my mentors, Dr. Meredeth Rowe and Dr. Ann Kolanowski (Pennsylvania State University), helped make it possible for me to meet the goals of the program, and make connections with persons who will be instrumental in my career as a gerontological nursing researcher. I am also appreciative of the opportunity to participate in the UF Gerontology Traineeship, and the mentoring in research associated with that program.

Many other persons have functioned as mentors, friends, and support system through this process; too numerous to mention. In particular, Drs. Claydell Horne and Annette Kelly provided excellent mentoring, support, and assistance, and served as co-investigators in Dr. Rowe’s research project that provided data for secondary analysis in my dissertation. Fellow students Dr. Brandy Lehman, Dr. Andrea Boyd, and many others have become friends, and are a large part of my success. Dr. Jason Beckstead from the University of South Florida provided
tutoring in advanced statistical techniques that contributed to my ability to do the dissertation analyses. Several others provided deeper understanding in statistical techniques, and experience in various aspects of the researcher role. The UF College of Nursing graduate faculty, administration, and staff have also contributed to my success. In particular, Cecile Kiley has been eager to assist in so many ways, and the staff members in Office of Research Support were all helpful. Staff and students associated with Dr. Rowe’s research project have been helpful in many ways.

It goes without saying that without the support and love of my family and my God this journey would not have been possible. I am very thankful to have a family that is willing to make sacrifices to further my potential for success. My husband, David, has been by my side during this entire process, and I will always be grateful for his listening, helping, and understanding as I dedicated myself to my studies.

Lastly, and of course not least, I would like thank the caregivers and persons with dementia that participated in the study that served as a parent study for my dissertation. Their willingness to participate despite their hectic, stressed lives is amazing, and I will dedicate my research to finding solutions for this vulnerable group.
<table>
<thead>
<tr>
<th>TABLE OF CONTENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>page</td>
</tr>
<tr>
<td>ACKNOWLEDGMENTS ............................................................................................................... 4</td>
</tr>
<tr>
<td>LIST OF TABLES ......................................................................................................................... 10</td>
</tr>
<tr>
<td>LIST OF FIGURES ....................................................................................................................... 11</td>
</tr>
<tr>
<td>ABSTRACT ................................................................................................................................... 13</td>
</tr>
<tr>
<td>CHAPTER</td>
</tr>
<tr>
<td>1  INTRODUCTION .................................................................................................................. 15</td>
</tr>
<tr>
<td>Statement of the Problem ........................................................................................................ 15</td>
</tr>
<tr>
<td>Study Concepts and Relationships .......................................................................................... 16</td>
</tr>
<tr>
<td>Behavioral Symptoms in Persons with Dementia ........................................................... 16</td>
</tr>
<tr>
<td>Caregivers’ Perceived Stress ........................................................................................... 17</td>
</tr>
<tr>
<td>Caregivers’ Emotional Responses ..................................................................................... 18</td>
</tr>
<tr>
<td>Correlates of Caregivers’ Perceived Stress and Emotional Responses ......................... 19</td>
</tr>
<tr>
<td>Dyadic Consequences of Caregivers’ Stress Process ...................................................... 21</td>
</tr>
<tr>
<td>Theoretical Foundations ......................................................................................................... 25</td>
</tr>
<tr>
<td>Caregivers’ Perceived Stress → Emotional Responses .................................................... 26</td>
</tr>
<tr>
<td>Caregivers’ Perceived Stress → Behavioral Symptoms ................................................... 26</td>
</tr>
<tr>
<td>Caregivers’ Emotional Responses → Behavioral Symptoms ........................................... 26</td>
</tr>
<tr>
<td>Secondary Analyses of BehSx as a Consequence of Caregivers’ Stress Process .......... 28</td>
</tr>
<tr>
<td>Specific Aim # 1: ............................................................................................................. 29</td>
</tr>
<tr>
<td>Specific Aim # 2: ............................................................................................................. 29</td>
</tr>
<tr>
<td>Summary ................................................................................................................................. 30</td>
</tr>
<tr>
<td>2  LITERATURE REVIEW ....................................................................................................... 33</td>
</tr>
<tr>
<td>Background and Significance ................................................................................................ 33</td>
</tr>
<tr>
<td>Dementia and Dementia Caregiving ...................................................................................... 33</td>
</tr>
<tr>
<td>Dementia-Related Care Dyads ............................................................................................ 37</td>
</tr>
<tr>
<td>Testing a Model including Dyadic Effects ......................................................................... 40</td>
</tr>
<tr>
<td>Theoretical Foundations ......................................................................................................... 41</td>
</tr>
<tr>
<td>Stress-Health Model .............................................................................................................. 42</td>
</tr>
<tr>
<td>Consequences of Dementia Caregivers’ Stress Process Model ........................................ 42</td>
</tr>
<tr>
<td>Expanded Consequences of Dementia Caregivers’ Stress Process .................................... 44</td>
</tr>
<tr>
<td>Caregiver Consequences ..................................................................................................... 44</td>
</tr>
<tr>
<td>Dyadic Consequences .......................................................................................................... 45</td>
</tr>
<tr>
<td>Consequences for persons with dementia ............................................................................. 45</td>
</tr>
<tr>
<td>Consequences for the dyad as a unit ..................................................................................... 47</td>
</tr>
</tbody>
</table>
### 3 MATERIALS AND METHODS .................................................................74

**Introduction**........................................................................................................74

**Original Study**....................................................................................................74
- **Design**............................................................................................................74
- **Subjects**..........................................................................................................75
  - Entry and exclusion criteria..............................................................................75
  - Sample and setting............................................................................................75
  - Recruitment and retention................................................................................76
- **Procedures**.......................................................................................................77
  - **Methods**.........................................................................................................77
  - **Vulnerable human subjects’ considerations**..................................................78
  - **Data considerations**.......................................................................................79
**Methodological Strengths of Original Study that Augment Dissertation Study** ..........80

**Dissertation Study**.............................................................................................82
- **Dissertation Design** .........................................................................................82
- **Dissertation Subjects** .......................................................................................82
- **Dissertation Procedures** ................................................................................83
- **Dissertation Measures** ....................................................................................84
  - **Neuropsychiatric Inventory**........................................................................84
  - **Neuropsychiatric Inventory-Questionnaire**....................................................86
- **Measurements from Original Study** ..............................................................86
  - **Mini-Mental Status Examination**.................................................................87
  - **Short version of the Zarit Burden Interview**....................................................87
  - **Center for Epidemiologic Studies-Depression scale**.......................................89
  - **Positive and Negative Affect Schedule**........................................................90
  - **Composite negative mood score**..................................................................91

**Statistical Analysis**...............................................................................................92
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1</td>
<td>Description of sample caregivers. 97</td>
</tr>
<tr>
<td>3-2</td>
<td>Description of sample persons with dementia. 98</td>
</tr>
<tr>
<td>4-1</td>
<td>Means, standard deviations, and t-tests by treatment status for observed scores across 9 data points for model variables. 115</td>
</tr>
<tr>
<td>4-2</td>
<td>Pearson correlations between model variables at Baseline (below the diagonal) and Month 12 (above the diagonal &amp; underlined with dashes). 116</td>
</tr>
<tr>
<td>4-3</td>
<td>Pearson correlations (and list-wise means) between model variables across all dyads and data points (list-wise N=308). 117</td>
</tr>
<tr>
<td>4-4</td>
<td>Model construction criteria for Perceived Stress 118</td>
</tr>
<tr>
<td>4-5</td>
<td>Model construction criteria for Emotional Responses 119</td>
</tr>
<tr>
<td>4-6</td>
<td>Model construction criteria for BehSx 120</td>
</tr>
<tr>
<td>4-7</td>
<td>Final Model Parameters for each Variable as modeled over Time and by Treatment. 121</td>
</tr>
<tr>
<td>4-8</td>
<td>Model construction criteria for effects of Caregivers’ Stress Process Variables on PWD BehSx. 122</td>
</tr>
<tr>
<td>4-9</td>
<td>Final Model Parameters estimated for BehSx as predicted by Perceived Stress and Emotional Responses. 123</td>
</tr>
</tbody>
</table>
### LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-1</td>
<td>Full “Consequences” model adapted from Schulz &amp; Martire’s Stress-Health model.</td>
</tr>
<tr>
<td>1-2</td>
<td>Reduced model for evaluation in current study.</td>
</tr>
<tr>
<td>3-1</td>
<td>Original Study subjects entry/exclusion from dissertation study analyses.</td>
</tr>
<tr>
<td>4-1</td>
<td>Caregivers’ Perceived Stress as observed over Time by Treatment Status (means and standard error bars).</td>
</tr>
<tr>
<td>4-2</td>
<td>Caregivers’ Emotional Responses as observed over Time by Treatment Status (means and standard error bars).</td>
</tr>
<tr>
<td>4-3</td>
<td>PWD Behavioral Symptoms as observed over Time by Treatment Status (means and standard error bars).</td>
</tr>
<tr>
<td>4-4</td>
<td>Caregivers’ Depressive Symptoms as observed over Time by Treatment Status (means and standard error bars).</td>
</tr>
<tr>
<td>4-5</td>
<td>Caregivers’ Negative Affect/Mood as observed over Time by Treatment Status (means and standard error bars).</td>
</tr>
<tr>
<td>4-6</td>
<td>Perceived Stress modeled over Time by Treatment Status; Demonstrates no effect of Treatment over Time.</td>
</tr>
<tr>
<td>4-7</td>
<td>Emotional Responses modeled over Time; Demonstrates no effect of Treatment over Time.</td>
</tr>
<tr>
<td>4-8</td>
<td>Behavioral Symptoms modeled over Time by Treatment Status; Treatment improved model and interaction of Treatment with Time approached significance.</td>
</tr>
<tr>
<td>4-9</td>
<td>Behavioral Symptoms modeled as predicted by Perceived Stress (C-top) and Emotional Responses (B-bottom); Combined model (center) inconclusive regarding “mediation” of Perceived Stress effects by Emotional Responses.</td>
</tr>
<tr>
<td>C-1</td>
<td>Outcome PWD BehSx plotted against Months paneled by Treatment Status with Regressions.</td>
</tr>
<tr>
<td>C-2</td>
<td>Observed variation in PWD Behavioral Symptoms over Time within subjects, paneled by Treatment Status.</td>
</tr>
<tr>
<td>C-3</td>
<td>Behavioral Symptoms over Months paneled by Dyad with Regressions—Control dyads only.</td>
</tr>
<tr>
<td>C-4</td>
<td>Behavioral Symptoms over Months paneled by Dyad with regressions—Experimental dyads only.</td>
</tr>
</tbody>
</table>
C-5  Predictor Caregiver Perceived Stress plotted against Months paneled by Treatment Status with Regressions. ..................................................................................................162

C-6  Predictor Caregiver Emotional Responses plotted against Months paneled by Treatment Status with Regressions. ..................................................................................................163

C-7  Observed variation in caregivers’ Perceived Stress over Time within subjects, paneled by Treatment Status. ......................................................................................................164

C-8  Observed variation in caregivers’ Emotional Responses over Time within subjects, paneled by Treatment Status. ......................................................................................................165

C-9  Perceived Stress over Months paneled by Dyad with Regressions—Control dyads only. .................................................................................................................................166

C-10 Perceived Stress plotted over Months paneled by Dyad with Regressions— Experimental dyads only.............................................................................................................167

C-11 Emotional Responses plotted over Months paneled by Dyad with regressions— Control dyads only. ..............................................................................................................................168

C-12 Emotional Responses plotted over Months paneled by Dyad with regressions— Experimental dyads only..............................................................................................................................169
I evaluated a newly developed model in which dementia caregivers’ stress process is viewed as a predictor of behavioral symptoms in persons with dementia. Multilevel modeling was used to assess both within- and between-persons change in caregivers’ perceived stress, caregivers’ emotional responses, and behavioral symptoms in persons with dementia. Additionally, caregivers’ perceived stress and emotional responses were modeled as predictors of behavioral symptoms over time, with emotional responses expected to reduce the influence of caregivers’ perceived stress on behavioral symptoms in a manner similar to formal mediation.

My study was a secondary analysis of a caregiver intervention, designed to reduce caregivers’ stress, worry, and subsequent emotional responses; the intervention was a technological innovation meant to assist caregivers in managing nighttime wandering of the care recipients. There was no expected influence on behavioral symptoms, such as agitation, aggression, and other symptoms. In my study, behavioral symptoms diverged over time according to treatment status, and the interaction between time and treatment approached statistical significance. However, caregivers’ perceived stress and emotional responses were not significantly influenced by treatment status as expected. The caregivers’ perceived stress and
emotional responses both predicted behavioral symptoms; however, the emotional responses did not fully reduce the effect of perceived stress on behavioral symptoms as expected.

Results support the underlying premise of my model; that caregivers’ stress process influences the behavioral symptoms in persons with dementia. However, further research is needed to develop relationships and the directionality of those relationships within the model. If my model is supported through further investigation, researchers and clinicians may be able to develop or utilize interventions that are more holistic and dyadic, directed at the caregiver, but with results for both caregivers and persons with dementia.
CHAPTER 1
INTRODUCTION

Statement of the Problem

As the population continues to live longer, the incidence of dementia increases, with over 13 million individuals expected to have dementia by the year 2050 (L. E. Hebert et al., 2003a). Since the large majority of those with dementia remain in the community (Czaja et al., 2000), informal caregivers provide much of the care of persons with dementia (Riggs, 2001). Community-based informal caregiving for persons with dementia is considered uniquely challenging when compared to other types of caregiving situations, with greater stress and more problems associated with care duties (Ory et al., 1999).

There are three salient aspects of dementia caregiving that were the focus of this study: care recipients’ behavioral symptoms, caregivers’ perceived stress, and caregivers’ emotional response to stress. These phenomena have most often been related in previous work through the informal caregivers’ stress process model, wherein behavioral symptoms may be perceived as a problem, and their behaviors are considered a primary stressor for the caregiver. Behavioral symptoms have generally been conceptualized in research in this manner, as a predictor of stress for caregivers (Goode et al., 1998; Pearlin et al., 1990; Pinquart & Sorensen, 2003b; Schulz & Martire, 2004). However, while the severity and/or frequency of behavioral symptoms may contribute to the caregivers’ perception of the behavior as a problem, caregivers’ own characteristics may also influence the perception of the behavior as a stressor. Additionally, researchers are beginning to recognize that the relationship between behavioral symptoms in persons with dementia (PWD) and caregivers’ stress process may be bi-directional; that is, caregivers’ stress may be as likely to cause behavioral symptoms as behavioral symptoms are to cause caregivers’ stress (Burgener & Twigg, 2002b; Schulz & Martire, 2004; Sink et al., 2006).
In this study, caregivers’ stress process will be investigated as one potential predictor of behavioral symptoms in persons with dementia in their care.

**Study Concepts and Relationships**

**Behavioral Symptoms in Persons with Dementia**

Behavioral symptoms (BehSx) almost universally occur in dementia syndromes (Lyketsos et al., 2002; Steinberg et al., 2006). BehSx are also referred to as ‘behavioral and psychological symptoms of dementia’ (BPSD) and ‘neuropsychiatric symptoms’ to reflect the neurological changes and psychopathology in dementia that underlie the symptoms (Cummings, 1997; Lyketsos, 2007). BehSx encompass domains such as delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, motor disturbance, nighttime behaviors, and appetite/eating disorders (Cummings, 1997; Cummings et al., 1994).

BehSx in dementia are a complex phenomenon with multiple underlying causes. While BehSx are associated with the neuro-degeneration that occurs in dementia (Cummings, 1997; Harwood et al., 2000; Mok et al., 2004), there are also social, environmental, and psychological contributing factors. For example, it has been proposed that BehSx reflect either the person’s stress related to the inability to effectively process and cope with environmental stimuli (Hall & Buckwalter, 1987; Smith et al., 2004), or the person’s needs related to physiological, psychosocial, or environmental conditions, that may be sought out and resolved (Algase et al., 1996). Lastly, BehSx in persons with dementia have been proposed to represent ‘expression’ or ‘communication’ of something, such as the stress they feel or a need that they can’t readily communicate (Kitwood, 1997; Touhy, 2004; Woods, 2001). This more contextual or relational view of BehSx is in contrast to that currently represented in the caregivers’ stress process, specifically, that of a problem to be managed. While caregivers certainly may perceive BehSx as
a problem or stressor, a more contextual view may allow an enhanced holistic understanding of
and response to BehSx (Kolanowski & Whall, 2000). Such a response may allow contextual
intervention to ameliorate the BehSx themselves, and in turn alleviate the caregivers’ perception
of BehSx as a stressor, providing valuable relief for community-based dementia care dyads.

**Caregivers’ Perceived Stress**

Common causes of caregivers’ stress include both primary stressors directly related to
caregiving, such as care recipient difficulties with activities of daily living, and secondary
stressors such as caregiving-related work and family issues; for example, loss of productivity at
work, or conflicting responsibilities for care recipient and for other family members. When
caregivers perceive that resources are too low, or demands too high or too threatening, overall
levels of perceived stress increase. Researchers have consistently demonstrated that informal
dementia caregivers (typically family members) on average report higher levels of perceived
stress than non-caregivers (Clyburn et al., 2000; Haley et al., 1987; Leinonen et al., 2001;
Pinquart & Sorensen, 2003b; Schulz & Martire, 2004), and higher levels than caregivers of
persons with other chronic illnesses (Bertrand et al., 2006; Garand et al., 2005; Martire & Hall,
2002; Pinquart & Sorensen, 2003b). When levels of perceived stress are high, dementia
caregivers have shown an associated increase in emotional responses, with subsequent
detrimental mental and physical health changes (Pinquart & Sorensen, 2003b, 2004, 2007;
Schulz & Martire, 2004).

In caregivers, perceived stress is often conceptualized as the more domain-specific
caregiver burden or caregiver strain, and these terms may be conceptually viewed as
interchangeable with perceived stress in this context (Donaldson et al., 1998; B. G. Knight et al.,
2000). The terms are defined similarly, with the capacity to adapt to stressors inadequate in
relation to the demands of the caregiving situation (O’Rourke & Tuokko, 2003; Pearlin et al.,
Additionally, measurement instruments for caregiver burden and perceived stress reflect overlapping latent concepts (Bedard et al., 2001; S. Cohen et al., 1983; Levenstein et al., 1993). In this study, caregiver burden was considered conceptually comparable to perceived stress.

**Caregivers’ Emotional Responses**

Caregivers’ emotional responses to stress vary, and dementia caregivers have higher levels of emotional responses such as depressive symptoms (Schulz et al., 2003), anxiety (Cooper et al., 2007), negative affect (Brummett et al., 2006; Haley et al., 1987), and others (Martire & Hall, 2002; Pinquart & Sorensen, 2003b). Depressive symptoms are frequently reported when caregivers’ emotional responses are included in research (Clyburn et al., 2000; Croog et al., 2001; Haley et al., 1987; Lee et al., 2006; Mausbach et al., 2007; Schulz et al., 1995; Thommessen et al., 2002; Zanetti et al., 1998), and may include changes such as a flat affect, sluggishness, lack of attention and flexibility, and other psycho-emotional or depressive symptoms. Additionally, negative affective responses reflecting distress, fear, irritability, nervousness, and jitteriness may occur (Radloff, 1977; Watson et al., 1988).

Dementia caregivers generally have increased depressive symptomatology (Martire & Hall, 2002; Pinquart & Sorensen, 2003b). In an early review, all studies reported increased levels of depressive symptoms (Schulz et al., 1995), and in the US Resources for Enhancing Alzheimer Caregivers’ Health (REACH) I trials, 41% of caregivers had risk for clinically significant levels of depressive symptoms (CES-D 16 or > out of 60). Participants had a mean score of 15.4 (SD=11.5; median 13; range 0-56; N=1222) across all REACH sites (Schulz et al., 2003). When a clinical diagnosis is required, rates are not as high, but remain noteworthy. In a recent systematic review of the literature, dementia caregivers were identified as having high rates of clinically diagnosed depressive disorders (22.3%), with increases in depression after
initiation of the caregiving role, and with women more at risk than men (Cuijpers, 2005). An earlier review also revealed high rates of both clinical depression and anxiety (Schulz et al., 1995).

Dementia caregivers have also reported significantly higher negative affect, in addition to higher levels of depressive symptoms and lower levels of life satisfaction, compared to controls (Haley et al., 1987). Negative affect has been associated with other measures of importance in caregiving. For example, in one study, negative affect, along with social support, explained 43% of the variance in the relationship between caregiving and sleep quality. Along with caregiver health and care recipient dependence in IADLs, negative affect was useful in predicting caregiver strain at 6 months after the care recipient’s stroke (Blake et al., 2003).

**Correlates of Caregivers’ Perceived Stress and Emotional Responses**

Perceived stress and emotional responses are often reported simultaneously in dementia caregiving research, and are recognized as important variables in dementia caregivers’ experiences. For example, in a study of 172 caregivers, 68% of subjects reported high levels of perceived stress, and 65% of subjects had depressive symptoms. Perceived stress was positively correlated with care recipient BehSx ($r = 0.54$, $p < 0.01$), as was depression ($r = 0.35$, $p < 0.01$). Additionally, perceived stress was related to coping style. In particular, caregivers who used emotion-focused coping had higher levels of perceived stress, as opposed to lower levels in caregivers who used problem-solving approaches (Papastavrou et al., 2007). Another study found that increased stress related to symptoms was, in turn, correlated to caregiver worsening mental health, including depressed mood (Hooker et al., 2002).

Several factors have been associated with perceived stress and emotional responses in dementia caregivers. BehSx were consistently the strongest correlate with these stress process variables in a review of 228 studies, with amount of care and physical disability less salient, and
with spouses having more difficulty with these symptoms than adult children (Pinquart &
Sorensen, 2003a). In an international, multi-continent review, the type and amount of care and
supervision required were predictors of perceived stress, while BehSx were more predictive than
physical needs. Additionally, living with the care recipient increased depression and anxiety.
Caregivers who were female and younger (the latter often confounded with adult child
relationship) were also more at risk for perceived stress, as were those who reported low self-
assessed competence (Torti et al., 2004). Problem behaviors, income, and caregivers’ health and
perceived stress were predictive of psychiatric morbidity in an earlier review (Schulz et al.,
1995). A feeling of closeness with the care recipient was among ‘uplifts’ caregivers could
receive from their duties, which were associated with lower levels of depression (Pinquart &
Sorensen, 2003a, 2003b), while negative spouse and social interactions, such as arguments, have
been found to predict depressive symptoms in dementia caregivers (Haley et al., 2003)

Caregivers’ background and care environment contributed to perceived stress in addition to
symptoms of the PWD (Onishi et al., 2005). In one study, behavioral symptoms contributed less
to caregivers’ depressive symptoms than caregivers’ perceptions of their own health and poor
performance (Zanetti et al., 1998). In a study that assessed care recipient and caregiver
characteristics for contribution to caregiver depression, BehSx, particularly angry or aggressive
behaviors, was only one of several contributing factors (Covinsky et al., 2003). In a Korean
study, the relationships of perceived stress with depressive symptoms and anxiety were mediated
by caregiver factors (Lee et al., 2006).

Caregivers’ high levels of perceived stress and emotional responses have been associated
with poor health outcomes, including morbidity and mortality, in several studies; these findings
were the basis for a model of stress-related health issues in dementia caregivers (Schulz &
Martire, 2004). The association between caregivers’ high levels of stress and morbidity continue to be supported through research (Son et al., 2007).

Many interventions designed to improve perceived stress and emotional responses in dementia caregivers have been studied. Several reviews have indicated that historically, interventions designed to improve perceived stress, depression, and psychological health have largely been unsuccessful. However, more recently developed and more comprehensive, multi-component interventions, particularly when carried out for longer periods of time, have proven helpful (Pinquart & Sorensen, 2006; Sorensen et al., 2002; Torti et al., 2004).

**Dyadic Consequences of Caregivers’ Stress Process**

The care relationship is by nature a dyadic process, which has the potential to overshadow previous interaction patterns (Lyons et al., 2002; Sebern, 2005). When the care recipient has dementia, changes occur that shake the core of the relationship and shape future interactions (Whitlatch, 2001; Woods, 2001). Primary informal caregivers and PWD develop a new dimension of their relationship, a connection or an interrelatedness, which provides the core of the care dyad and establishes rationale for the influence of one partner’s experiences on the other partner (Kenny et al., 2006; Kitwood, 1997; Quayhagen & Quayhagen, 1996). Persons with dementia and their caregivers have been shown to have significantly correlated quality of life (Thomas et al., 2006). This inter-connectedness can lead to negative dyadic influences. For example, caregivers’ ineffective coping with stress was related to shorter survival times in the PWD (McClendon et al., 2004; Schulz & Beach, 1999; Schulz & Martire, 2004). However, positive changes can also occur. In a qualitative examination of an intervention that involved dyadic cognitive remediation exercises, the authors concluded that the care dyad was a functional entity that had improvements in interactions and relationship quality that went beyond any individual benefits received by the intervention (Quayhagen & Quayhagen, 1996). Considering
caregivers and PWD dyadically may allow a more relevant understanding of the dynamic process and interaction that occurs (Lyons et al., 2002).

In research, dyads generally consist of paired individuals who are not independent, but linked into a relationship that is characterized by partner effects, mutual influence, or a common fate. Partner effects occur when one person’s characteristics affect the other’s outcomes, mutual influence occurs when each person’s outcomes influence the other’s, and common fate assumes that both members are exposed to the same causal factors. The two individuals are distinguishable as persons within a dyad by their roles, but have similarities or relatedness based on their mutual experience (Kenny et al., 2006). The caregivers and persons with dementia within the care dyad, like other dyads in research and practice, are not necessarily independent in their functioning, but each has an impact on the other through daily activities and routines (Kenny et al., 2006; Kitwood, 1997; Quayhagen & Quayhagen, 1996). Thus, the two exist within a functional entity that is dynamic, multi-dimensional, and influential for both its members (Quayhagen & Quayhagen, 1996).

Researchers interested in dementia are beginning to emphasize methodologies and interventions that address both members of the care dyad (Bourgeois, 1993; Cavanaugh et al., 1989; Gitlin et al., 2003b; Haight et al., 2003; Lyons & Sayer, 2005; Lyons et al., 2002; Quayhagen et al., 1995; Whitlatch et al., 2006a; Whitlatch et al., 2006b; Zarit et al., 2004). Dyadic research in dementia care may seek to include the opinions or outlook of the PWD within dyadic assessments. For example, in the early stages of dementia, researchers evaluated an intervention promoting the planning of future care. Findings indicated that caregivers, care recipients, and counselors found the intervention helpful and appropriate, assisting the dyad to gain knowledge and improve communication following diagnosis. In other instances, research
may be designed to develop and test interventions targeting one or both members, with hypothesized outcomes for one or both members of the dyad. Outcomes may measure changes in the member not targeted by the intervention, or may include both PWD and caregivers. For example, four interventions directed at both dyad members (cognitive stimulation, dyadic counseling, dual supportive seminar, and day care) were evaluated regarding their effects on both caregivers and persons with dementia. The cognitive stimulation group lead to improved measures of cognition in PWD and decreased depressive symptoms in caregivers. Two other interventions improved outcomes for caregivers only; use of daycare decreased caregiver hostility, and the seminar improved caregiver coping (Quayhagen et al., 2000).

As research begins to establish the inter-connected nature of the dementia care dyad, it is relevant to focus on the important relationship between caregivers’ stress and PWD BehSx. The next step in understanding this relationship is to establish whether caregivers’ stress can influence the presence or severity of BehSx in the PWD.

**Behavioral Symptoms in Persons with Dementia: A Consequence of Caregivers’ Stress Process?**

Since caregivers in community-based dyads play a predominant role in managing environmental stimuli and providing for care recipient needs, their stress may impede their ability to provide the optimal caregiving environment they strive for. For example, experts often recommend that caregivers adjust their own approaches, affect and demeanor to enhance the caregiving environment and reduce BehSx that are common in dementia (Cohen-Mansfield, 2000a; Colling, 2004; Haley, 1997; Hall, 1994; Kolanowski & Whall, 2000; Mittelman et al., 2004b; Quayhagen et al., 2000; Smith et al., 2006; Teri, 1999; Vitaliano et al., 1993). However, caregivers who are more stressed, with negatively affected emotional responses, may display altered interactions, attitudes, affect, or perceptions. The result may be that the dyadic care
relationship suffers, and that caregivers’ characteristics and stress process may influence BehSx (Dunkin & Anderson-Hanley, 1998; Sink et al., 2006).

In a systematic review of the literature from 1990-2001, Black and Almeida (2004) found associations between BehSx and caregivers’ psychological sequelae of care. While few articles met inclusion criteria, evidence did support correlations between BehSx and perceived stress (strong), psychological distress (moderate), and depression (poor-moderate). Furthermore, multivariate analyses added evidence that BehSx were predictive of these outcomes, often the most salient predictor. Nonetheless, longitudinal evidence was scarce, and the temporal nature of these relationships was not established with the limited evidence. Thus, it remains unknown whether BehSx are causative or simply correlated, with the potential for the opposite directional relationship (Black & Almeida, 2004).

Other reviewers have also noted a lack of rigor and ability to lead to conclusions concerning relationships between caregivers’ stress and symptoms in the PWD, specifically with regard to directionality of the relationships (Ballard et al., 2000; Donaldson et al., 1997; Teri, 1997). For example, one reviewer highlighted this phenomenon by noting that one study reported high rates of caregiver depression (75%) among those whose care recipients were depressed, while another study reported that 100% of care recipients with depression had caregivers who were depressed (Teri, 1997).

In summary, BehSx arise within the milieu of the dyadic care relationship. BehSx may be conceptualized, at least in part, as a function of the caregivers’ stress process, and may be an important gauge of the quality of the relationship or caregiving environment. The person with dementia may have a cognitively limited interpretation of caregivers’ non-verbal cues and verbal interactions, but may react based on that interpretation. BehSx in PWD reflect the inter-
connected nature of the relationship, with significance for both members of the dyad, not only ‘in
the moment,’ but also related to more distal outcomes, such as placement decisions and the
eventual characterization of behaviors as a problem or stressor. Understanding the temporal
nature of the relationship between caregiver stress process variables and PWD BehSx is central
to care provision and recommendations for dementia care dyads.

**Theoretical Foundations**

In preparation for this study, the Stress-Health model was adapted to explain behaviors in
relation to caregivers’ stress, and the newly revised model was adopted as the theoretical
foundation for this study. The resulting “Consequences of Dementia Caregivers’ Stress Process”
model is seen in Figure 1, with the concepts from the Stress-Health model shaded in gray. In the
revised model, consequences of caregivers’ stress are viewed broadly, with influence within the
dyad, not just for the caregivers. Please see Chapter 2 for a full discussion of this model.

In this study, a conceptual model of the “Dyadic Effect of Dementia Caregivers’ Stress
Process: PWD BehSx” was tested (see Figure 2). Key concepts from the revised theoretical
model, including caregivers’ perceived stress and emotional responses, and their relationships
with the BehSx in PWD, were considered. The premise of the model is that caregivers’
emotional responses, coupled with increased levels of perceived stress, may also have extensive
consequences within the dyad, beyond those effects related to caregivers’ health. In other
research, caregiver characteristics, as well as caregiver-directed interventions, have been linked
to several care recipient outcomes in dementia (de Vugt et al., 2004; McClendon et al., 2004;
Teri, 1999; Teri et al., 2005), indicating that caregivers have pervasive influence within the dyad.
A brief review follows regarding the model relationships, with more detail in chapter 2. In the
review that follows, caregiver perceived stress and burden are considered interchangeable.
Caregivers’ Perceived Stress ➔ Emotional Responses

The relationship between caregivers’ perceived stress and emotional response is part of the caregivers’ stress process. When caregivers appraise their adaptive capacities as lacking in the face of demands, perceived stress leads caregivers to respond emotionally. The depression, anxiety, and other emotional responses in caregivers are posited as predictors in more distal outcomes for the caregiver, such as personal health (Pearlin et al., 1990; Schulz & Martire, 2004) and may also influence outcomes within the dyad.

Caregivers’ Perceived Stress ➔ Behavioral Symptoms

Caregivers’ perceived stress was hypothesized to have an influence on PWD BehSx in this study. This relationship has not been well developed previously. In a few studies, caregivers’ stress has been identified as having influence on interactions within the dyad. For example, caregivers’ stress lead to an increase in the occurrence of care recipient behaviors in dementia (Burgener & Twigg, 2002b; Sink et al., 2006).

Wife caregivers of husbands with Alzheimer’s dementia were more depressed and more stressed, with less hope than non-caregivers, and also had less reciprocity and shared pleasures with their spouses (Gallagher-Thompson et al., 2001). Caregivers who were highly critical were also more strained/distressed, more likely to attribute care recipient actions as deliberate, and their care recipients had higher levels of BehSx (Tarrier et al., 2002).

Caregivers’ Emotional Responses ➔ Behavioral Symptoms

Caregivers’ emotional responses also may contribute to an increase in BehSx. Body language is an important communicator of emotional responses. Virtual imaging techniques were used to establish body posture and body angles representing reported affective states, including aversion, openness, irritation, happiness, and self-confidence, which were then accurately rated by volunteers (Grammer et al., 2004). In care dyads, researchers have noted that
caregivers who are depressed or have mood alterations may be irritable or visibly tense, appear sad or anxious, or perhaps even be overly critical of the person with dementia in verbal exchanges (Sink et al., 2006; Whitlatch, 2001; Woods, 2001). Caregivers who are depressed and resentful about their caregiving duties are more likely to treat the care recipient in a harmful manner, such as yelling or threatening the person with dementia (Shaffer et al., 2007), or handling them roughly (Williamson & Shaffer, 2001). Lastly, a correlation between depressed dementia caregivers and depressive BehSx in care recipients has been proposed (Teri, 1997).

In this study, emotional responses to stress, perhaps as demonstrated by body language and interactions, is considered to function in a manner similar to that of a mediator, contributing to BehSx severity, with the ability to at least partially explain the effect of caregivers’ perceived stress on BehSx. While this study will not include a formal test of mediation, modeling will reflect the anticipation of such a relationship.

Emotional responses have been indicated as a mediator in other relationships involving perceived stress. In dementia care dyads, emotional responses have been posited as a mediator between perceived stress and health (Schulz & Martire, 2004). Additionally, in a meta-analysis of dementia care interventions, reduction of psychological symptoms was identified as a mechanism by which interventions achieved delayed nursing home placement. For example, depressive symptoms, along with caregivers’ satisfaction with social support and response to BehSx, accounted for 61% of the effect a counseling intervention had on delaying institutional placement by 557 days (Mittelman et al., 2006). Changes in depression were also responsible for the counseling intervention’s indirect effect on caregivers’ self-reported health (Mittelman et al., 2007). In other settings, affective states, including positive affect and depressive symptoms have acted as a mediator between a variety of conditions/treatments and health, quality of life, and
mortality (Blane et al., 2008; Deichert et al., 2008; Grov et al., 2006; Hill et al., 2005; Pastor et al., 2003; Williams, 2005). While emotional responses to stress have not been specifically studied as a mediator between caregivers’ perceived stress and PWD BehSx, the relationships reported here confirm the important role of emotional responses in the more distal effects of the stress process.

**Secondary Analyses of BehSx as a Consequence of Caregivers’ Stress Process**

A monitoring system recently developed to assist caregivers in management of nighttime awakenings in persons with dementia was tested in a randomized clinical trial (pilot), providing an experimental design and longitudinal data intended to reflect caregivers’ stress process (Rowe, 2003a). Measures of stress process variables were expected to change over time in the intervention group in this study; however, no direct influences on PWD BehSx were hypothesized. Data were collected regarding BehSx, allowing the conceptual model to be tested using the parent study data in a secondary analysis.

Utilizing the monitoring system intervention groups from the parent study for comparison of variable trajectories may lend support to the direction of causality in relationships from caregivers’ stress process variables to BehSx. This is an important feature of this study because of the potential bi-directional nature of the relationships, wherein BehSx can eventually lead to caregivers’ interpretation of them as a problem or stressor. Ultimately, it will be imperative to distinguish whether the BehSx are an outcome or a predictor of the stress process variables, or both. In the parent study, there was no training geared toward managing BehSx; the intervention was a physical adaptation of the environment meant to decrease worry and stress for caregivers. Since BehSx were not directly targeted, any improvement or change in BehSx would be more likely due to changes in the caregivers’ stress process variables. If intervention group members improve and/or control group members worsen over time with regard to BehSx, this will provide
initial support for the direction of causality posited in the conceptual model proposed for this study.

The overall purpose of this study was to test a model (Figure 2) in which both CG Perceived Stress and CG Emotional Responses have a direct positive relationship with PWD BehSx, and the Perceived Stress—PWD BehSx relationship is mediated by CG Emotional Responses. A secondary purpose was to describe the temporal patterns of each of the model variables, and evaluate the influence of Treatment Status from the parent study on the concepts and relationships in the model. Treatment status was considered a factor in modeling of the change over time for Perceived Stress, Emotional Responses, and PWD BehSx. The specific aims and hypotheses are:

**Specific Aim # 1:**

To describe temporal patterns of change in each model variable (CG Perceived Stress, CG Emotional Responses, and PWD BehSx) with consideration of change a) within persons (level 1), and b) across persons (level 2) according to Treatment Status. It was hypothesized that experimental dyads would have improvement (or no deterioration) over time, on CG Short ZBI- Bedard, CG Emotion (comprised of Center for Epidemiological Studies-Depression & Negative PANAS), and PWD NPI-Q Behaviors, as compared to control dyads.

**Specific Aim # 2:**

To investigate the relationships between CG Perceived Stress, CG Emotional Responses, and PWD BehSx, with consideration of measures over 9 potential data points in a year, both within dyads and estimated across dyads within the population. It was hypothesized that, both within and across dyads, both CG Perceived Stress and CG Emotional Response would have a direct positive relationship with BehSx in PWD. Within a given dyad, this meant that when the caregivers’ Perceived Stress and Emotional Responses were above their own average, the PWD
in their care would have higher Behavioral Symptom severity. Across dyads, this meant that when caregivers’ Perceived Stress and CG Emotional Responses were, on average, higher, Behavioral Symptom severity in the PWD were also higher. It was also hypothesized that when both Perceived Stress and Emotional Responses in caregivers were modeled, the influence of Perceived Stress would diminish, in a manner similar to mediation.

**Summary**

If the model is supported through establishment of relationships, and directionality is supported through the modeling of change over time, future studies may further support this view of BehSx. Intervention to assist the caregiver by decreasing the impact of the stress process may have far-reaching implications, including amelioration of BehSx in dementia. This may potentially further relieve perceived stress and emotional responses for the caregiver, and may have a positive impact on more distal outcomes, such as institutionalization of the person with dementia. Therefore, it is important for research to establish whether or not the caregivers’ stress process does have consequences within the dyad, in particular as related to PWD BehSx. If this precept is supported through research, caregivers and clinicians will be better positioned to direct interventions appropriately.
Figure 1-1. Full “Consequences” model adapted from Schulz & Martire’s Stress-Health model.
Figure 1-2. Reduced model for evaluation in current study.
CHAPTER 2
LITERATURE REVIEW

Background and Significance

The focus of this study was the community-based dementia care dyad. In this section, dementia, and the care of persons with dementia is discussed. Furthermore, the dementia care dyad is developed as integral to the care of persons with dementia, and the problems associated with dementia caregiving are introduced.

Dementia and Dementia Caregiving

Dementia is a serious and costly health problem facing older adults and society at large, and will continue to increase its impact as the population ages (L. E. Hebert et al., 2003a; Hoyert et al., 2005; Snow et al., 2004). Dementia is a general term referring to global loss of cognitive function that also interferes with social and occupational performance; the most common form of dementia in older adults is Alzheimer’s Disease (AD) (Smith & Buckwalter, 2005). Medical treatment may improve the person’s functional life expectancy and reduce burden on informal caregivers and the health-care system, an important contribution for this impending public health crisis. However, the most common dementia syndromes have no cure. Decline is usually steady, with worsening disability as time passes, and medical treatments are limited in their effects (Doody et al., 2001; Geldmacher & Lin, 2006; Hart, 2004; Sink et al., 2005; Small et al., 1997).

Once diagnosed, a person with dementia will have a shortened life expectancy; however, the decline may last up to 20 years. It has been estimated that this long phase of care costs the U.S. approximately $100 billion each year, and expenditures will reach crisis proportions as the population ages ("Alzheimer's association: Statistics about Alzheimer's disease", 2006; Riggs, 2001). Persons with dementia get sicker and their care is complicated by dementia, with
hospitalization often related to mismanagement of medications, malnutrition, dehydration, or injuries. American taxpayers reportedly spend about $7000 per year for an average Medicare patient (in 2006), and a person with even a mild dementia may double that cost. Furthermore, costs significantly increase each year past diagnosis (Geldmacher & Lin, 2006; Taylor & Sloan, 2000). Medicare expenditures related to AD are expected to increase 75% between 2005 and 2010, and Medicaid spending related to nursing home stays will increase 14% ("Alzheimer's association: Statistics about Alzheimer's disease", 2006; Riggs, 2001).

Approximately 80% of persons who have dementia remain in the community; thus millions of Americans provide informal assistance to persons with dementia (Czaja et al., 2000). The unpaid informal caregivers of those with dementia are sometimes referred to as the ‘invisible’ part of the dementia care system (Riggs, 2001). The Alzheimer’s Association reports that families provide almost 75% of care for those with the disease, with the average lifetime cost of family care for AD at $174,000 ("Alzheimer's association: Statistics about Alzheimer's disease", 2006). When the cost of informal caregiving duties are considered, estimates are even higher, with a 1997 study reporting that informal caregivers personally provide services that would cost approximately $34,000 per year (in 1997) in the years prior to institutional care, spending almost $6000 on supplies and services each year (Haley, 1997). Additionally, businesses that are a part of the American economy lose approximately $61 billion per year related to lost productivity of informal caregivers ("Alzheimer's association: Statistics about Alzheimer's disease", 2006).

As cognition declines, the costs of care increase for families. A 1995 study found that caregivers of older Americans had out-of-pocket expenses from over the previous two years that included $1350 for those without dementia, $2150 for those with mild/moderate dementia, and
$3010 for those with severe dementia ($p < 0.01$) (Langa et al., 2004). In a study relating such costs to scores on the Mini-Mental State Exam (MMSE), researchers found that when the baseline score was 20, preventing cognitive decline of five points saved $2424, while the same level of prevention when the baseline was 12 could save as much as $7407 (Ernst et al., 1997).

Policy makers frequently seek to relieve some of the burden for caregivers, with the anticipation of delaying placement of the person with dementia into extended care. This is sensible from a policy perspective since extended care often increases the burden for taxpayers. However, others argue that decisions about care should consider what is realistic and appropriate for persons with dementia, without placing informal caregivers into a situation that they can not realistically shoulder alone. Placement should be considered when it is meeting the needs of both caregivers and persons with dementia (Riggs, 2001). An important consideration in this debate is that regardless of how difficult it becomes to care for an individual with dementia at home, many caregivers simply prefer to continue this arrangement. Additionally, while one recent study showed reduced burden after placement of the care recipient (Gaugler et al., 2007), other studies have indicated that caregivers may not be relieved of burden upon placement of the care recipient (Dellasega, 1991; Schulz et al., 2004). Even though placement may be the best solution, it is not a universal remedy to the difficulties of caregiving, and caregivers remain integral to the caring process in most instances. Caregivers who do initiate placement face further decline of the person with dementia, changing roles, travel to the facility, and even feelings of guilt and ambiguity (Schulz et al., 2004).

Understanding the consequences of dementia caregivers’ stress and finding ways to support them may be helpful to persons with dementia and caregivers alike, with the ‘side effect’ of delayed placement and overall decreased costs of care. One potential avenue of supporting
community-based dementia care dyads is through the alleviation of BehSx that often occur in dementia and contribute to the caregivers’ stress process (Schulz & Martire, 2004). Additionally, at least some of the increase in costs of dementia care may be attributable to these BehSx. For example, a recent study estimated that for each increase of 1 point on the NeuroPsychiatric Inventory, a researcher-administered tool that measures BehSx in dementia, total costs of care increase between $247 and $409 per year, depending on the value of unpaid caregiving (Murman et al., 2002). Addressing BehSx through evidence-based intervention may reduce financial costs and burden for informal caregivers.

The impact of dementia is far-reaching, involving much more than financial costs. Caregivers frequently sacrifice both psycho-emotional and physical health in order to care for persons with dementia. Caregivers of those with dementia have substantially more negative personal consequences than those who care for physically impaired older adults, losing more of their personal life, including hobbies, vacations, and family time that could help to ease their burden. Caregivers with these high demands are at risk for serious illness and even death (Haley, 1997; Ory et al., 1999; Schulz & Beach, 1999; Schulz & Martire, 2004). The importance of caregivers in any discussion of dementia care cannot be over-estimated. Howard Fillit, MD, Director of the Institute for the Study of Aging in New York may have said it best:

Caregiver burden is an exceedingly important component of what happens in this disease. If we lose the caregiver, we lose the patient (Geldmacher & Lin, 2006).

His assertion highlights not only the importance of the informal caregiver, but also the interconnectedness of the person with dementia and their primary caregiver. Perhaps in no other disease process in adulthood is the informal care dyad a more important consideration.
Dementia-Related Care Dyads

The relationship that develops between informal caregivers and care recipients with dementia is somewhat unique to caregiving situations involving adults. Even though all caregivers and recipients develop a dyadic relationship, the dementia care dyad has the declining cognition of the care recipient as a confounding factor. In any caregiving situation, protecting the basic relationship is important to enhance the caregiving experience and prevent the negative consequences of caregiving. Low levels of reciprocity and higher levels of negative exchanges from the care recipient have been linked to negative appraisals of caregiving (Carruth et al., 1997). After a diagnosis of a dementia, though, underlying relationships undergo an almost immediate change, with decreases in intimacy and companionship, emotional distancing, loss of control of the situation, and decreased predictability (Quayhagen & Quayhagen, 1996). In spouse caregivers, the degree of marital happiness, equality in relationships, and expressions of tenderness may decrease (Eloniemi-Sulkava et al., 2002). ‘Relational’ spouses may have greater positive well-being and lower caregiver distress than those who approach caregiving with reactive or other interactive patterns (Lewis et al., 2005).

Dementia care dyads face changes in personal identities, personality, reciprocity, and communication that affect the relationship. Caregiving may have rewards for some, particularly if the previous relationship was satisfying (Snyder, 2000). However, most caregivers find the experience very stressful (Haley & Pardo, 1989). Being a care recipient in such a relationship has challenges as well, as persons with dementia lose control of their own affairs (Davey & Eggebeen, 1998; Liang et al., 2001). Assisting either individual within a dementia care dyad requires recognition of the dyadic care relationship.

Researchers have begun to acknowledging the importance of maintaining and strengthening the relationship in dementia care dyads through interventions to build and/or
protect the relationship. These are particularly important early in the disease, while activities that require reciprocity or extensive communication skills are realistic (Haight et al., 2003; Sebern, 2005; Woods, 2001). Examples include: reminiscence and life review (Haight et al., 2003), communicating care preferences (Whitlatch et al., 2006a; Whitlatch et al., 2006b), memory clubs (Zarit et al., 2004), and using memory aids to facilitate conversations (Bourgeois, 1993). The findings from these studies show promise for disrupting the trajectory of decline in relationships that occur as a result of dementia.

Another intervention for helping dyads with psycho-emotional adjustment early in the disease process was developed by Quayhagen & Quayhagen (1996), with substantial positive impact. The intervention, designed to promote cognitive stimulation, communication skills, and practical problem-solving techniques to combat the effects of dementia, helped dyads return to ‘relationship quality.’ Although the intervention was launched into a context of depleted interaction skills, the dyads moved from a discordant phase, characterized by internal conflict, to equilibration, where the members of the dyad sought balance in their working relationship, then to regeneration, where skills were regained and/or affection was restored. Finally, there was an emergence of life quality in almost all of the care dyads. One caregiver remarked,

“It doesn’t matter whether she really improves or not….. It has brought us closer together as a family (Quayhagen & Quayhagen, 1996).”

Such closeness early in the caregiving journey may be one key to success as the person with dementia declines further.

As the condition of dementia progresses, the relationship may also influence caregivers’ perceptions of the experience of caregiving, with the quality of the relationship and interactions serving as the “lens through which appraisal of the caregiving situation is made” (Lyons et al., 2002). For example, resentment and perceptions of being unappreciated may surface as
relationships suffer. These may in turn affect interactions in a negative way. Even in non-dementia caregivers, quality of life indicators are thought to be dynamic and reciprocal within the care dyad, with the care recipient’s disease affecting burden, and burden in turn affecting the disease (Carruth et al., 1997; Glozman, 2004).

Established dementia care dyads face a wide range of phenomena related to their circumstances. A qualitative analysis based on direct observation of spouse dementia caregivers revealed 4 themes of caregiving, including activities of daily living, communication, supervision & surveillance (often a 24-hour endeavor), and activity/stimulation. All the caregivers had given up most of their own lives to take on the role of caregiving, which included responsibility for running the household which had previously been shared with the spouse, as well as providing support or help in care recipients’ activities. These caregivers were constantly on duty, rarely able to leave the care recipient alone, but demonstrated that they care about the person with dementia, as well as for them. The complexity and multi-dimensionality of the caregiving situation related to dementia was evident, and went far beyond overt care, with much of the stressful work of the situation ‘invisible’ (Jansson et al., 2001).

Caregivers face varied challenges as they struggle to provide care to a loved one with dementia, including lack of knowledge, feelings of guilt, isolation, uncertainty, loneliness (Gruffydd & Randle, 2006), and lack of personal time (Thomas et al., 2002). Perceived stress related to symptoms of depression and other behavioral changes in the care recipient contributed more to a perception of burden than physical needs (Donaldson et al., 1998; Pinquart & Sorensen, 2003a, 2003b; Thomas et al., 2002). Caregivers identified as ‘skilled’ were more flexible and accepting of challenges, while those less skilled were more rigid and had more intense emotional responses to caregiving (Farran et al., 2004).
Interventions that allow the caregiver a sense of control (Buckwalter et al., 1999; Parks & Pilisuk, 1991), or improve their belief in their ability to give adequate care (Fisher & Laschinger, 2001; Gilliam & Steffen, 2006; Gitlin et al., 2001), may improve the experience of caregiving in dementia, and thus have a major impact on the relationship and interactions within the dyad, with potential for lasting effects.

**Testing a Model including Dyadic Effects**

In research, dyads consist of paired individuals who are not independent, but linked into a relationship that is characterized by partner effects, mutual influence, or a common fate. Partner effects occur when one person’s characteristics affect the other’s outcomes (actor-partner); mutual influence occurs when each person’s outcomes influence the other’s (cross-partner); and common fate assumes that both members are exposed to the same causal factors. The two individuals are distinguishable as persons within the dyad by their roles, but have variables that may reflect their mutual experience (Kenny et al., 2006). ‘Dyadic analysis,’ in the statistical sense, often refers to measuring an identical outcome in both members of the dyad (for example, marital quality in both husbands and wives), and then assessing influences of one member on another.

Dementia care dyads do meet requirements of dyads usually considered in research; the interdependence, partner effects, mutual influence, and potential for common fate (Kenny et al., 2006). However, typically, the caregiver and care recipient in dementia care dyads have been considered independently in research studies, separate from the dyadic relationship, or dyadic effects have been assessed without specific conceptual recognition of the dyadic nature of the relationships. Recent methodological advances have prompted argument from some researchers that separating out members of a dyad for study does not adequately represent the actual situation (Lyons et al., 2002). Considering both dyad members simultaneously in research may
present methodological challenges when the care recipient has dementia, related to the difficulty in assessing relationship-based variables from the perspective of the person with cognitive decline.

Nonetheless, the influence of the dyad, with the caregiver in a prominent role regarding the tone of the relationship, must be recognized. Considering both caregiver and care recipient within the relationship allows a more relevant understanding of the dynamic process and interaction that occurs (Lyons et al., 2002).

Several studies have targeted both caregivers and persons with dementia within the dyad. For example, dyadic interventions using psycho-educational counseling and occupational therapy for practical approaches to cognitive losses have been used to impact outcomes for both members of the dyad (Gitlin et al., 2003a; Graff et al., 2006; Nobili et al., 2004). A dyadic exercise training program along with caregiver education about behavioral management strategies improved physical health and depression in persons with Alzheimer’s disease (Teri et al., 2003). In early stages of dementia, dyad-based interventions are particularly beneficial for planning future care. These results show that intervention geared toward one or both members of the dyad may have benefit for the other.

In this study, BehSx in persons with dementia are conceptually regarded as a dyadic effect of caregivers’ stress, with actor-partner effects from caregiver to PWD in relation to BehSx. While dyadic analyses in the traditional sense are not possible for testing these relationships, the dyad remains conceptually important.

**Theoretical Foundations**

The stress of caregiving in dementia-related dyads has been associated with serious and extensive effects in caregivers, including psychological, social, and physical health changes for caregivers (Bergman-Evans, 1994; Haley et al., 1987; Roth et al., 2001). The Stress-Health
model (Schulz & Martire, 2004) extended previously developed dementia caregivers’ Stress Process model, incorporating previous research and conceptual work, to emphasize dementia caregivers’ health outcomes related to the stress process (Goode et al., 1998; Haley et al., 1987; Haley et al., 1996; Pearlin et al., 1990; Schulz et al., 1995). The Stress-Health model was adopted and adapted to explain the consequences of caregivers’ stress process more broadly, and serves as the theoretical foundation for this study.

**Stress-Health Model**

Briefly, the Stress-Health model builds on previous work regarding the stress process in dementia caregivers, extending the effects of the stress process to include caregiver morbidity and mortality. Primary stressors related to care duties and secondary stressors related to family, work, and other aspects of the caregivers’ life as affected by the care duties are considered. The caregiver appraises the demands and their capacity to adapt, and when demands are overwhelming or resources inadequate, perceived stress occurs or increases. The caregivers’ subsequent emotional and behavioral responses to stress can lead to health problems in the caregiver, or may increase the stressor itself or worsen the caregivers’ perception of the stressor.

**Consequences of Dementia Caregivers’ Stress Process Model**

The Stress-Health model has been extended in preparation for this study to include consequences of caregivers stress beyond those related to health of the caregiver, in the ‘Consequences of Dementia Caregivers’ Stress Process’ model (Figure 1). Identifying BehSx as a potential consequence of caregivers’ stress, this model also considers the prominent role of caregivers in preventing or reducing BehSx in PWD: identifying and meeting needs, identifying and avoiding triggers for stress, and providing a positive and engaging social environment (Algase et al., 1996; Buckwalter et al., 1999; Cohen-Mansfield, 2000b; Hall, 1994; Kolanowski et al., 2005). Lastly, this model acknowledges that although the person with dementia may have
deficits related to cognitive losses, he or she remains a whole, relational being who reacts to the
caregiver and the care environment based on underlying personality and psycho-social
characteristics, as well as the context of the situation (Kitwood, 1997; Touhy, 2004; Woods,
2001).

The primary change from the core model is that a more comprehensive view of the
influence of caregivers’ stress is incorporated, with ‘caregiver consequences’ and ‘dyadic
consequences’ added as more global concepts, not necessarily measured directly, that serve to
classify the potential outcomes of caregivers’ stress. For example, caregiver morbidity and
mortality from the original model would be classified as ‘caregiver consequences.’

Additionally, the ‘feedback’ identified in the Stress-Health model could be considered
circular; however, with regard to BehSx, the change in frequency and/or severity of PWD BehSx
as a result of the caregivers’ stress process can also be viewed as separate from the perception of
BehSx as a problem when considered in light of all the stressful aspects of caregiving. Thus the
original ‘feedback’ connection between caregiver emotional and behavioral responses and
caregiver perception of BehSx as a problem and a stressor is removed. Rather, PWD BehSx and
CG reactions to BehSx (Figure 1 double border ovals) are outcome or dependent variables,
conceptualized as ‘dyadic consequences’ of the caregivers’ stress process.

While the distinction between BehSx as a dyadic outcome and perception of BehSx as a
problem may be slim, dissimilarities exist. The latter reflects the caregiver’s reflection on the
BehSx as one of several or many stressors that contribute to the overall appraisal of demands
versus their ability to adapt, while the former is specific to the severity of the behavior and how
they feel about or react to the BehSx. Even though the BehSx and reactions may contribute to
the eventual perception of BehSx as a problem and a stressor, it is the outcomes that stem from
the stress process that are the focus of this model. An introduction to the model concepts and relationships follows.

**Expanded Consequences of Dementia Caregivers’ Stress Process**

The basic precept of this newly revised model is that dementia caregivers’ stress process may have broad consequences. Caregivers’ stress process, with perceived stress and emotional and behavioral responses, may subsequently result in consequences for the caregivers themselves, or may have more global influence within the dyad.

**Caregiver Consequences**

Several outcomes specific to the caregiver may be classified as consequences of stress. The case for the caregiver outcomes of morbidity and mortality is clearly made by Schulz and colleagues (Schulz & Beach, 1999; Schulz & Martire, 2004; Schulz et al., 1997; Schulz et al., 1995), and there is extensive evidence to support this model, including several meta-analytic reviews (Pinquart & Sorensen, 2003a, 2003b, 2007; Vitaliano et al., 2003). Examples of specific health effects of dementia caregiving include changes in immunity, blood pressure, hormones, and lipid levels (Haley, 1997; Vitaliano et al., 2003; Wilkins et al., 1999). Ineffective self-care routines and preventive practices, such as regular exercise, complicate this picture of compromised health in caregivers of those with dementia (Haley, 1997; Schulz et al., 1995). Additional caregiver outcomes may include social isolation (Nagatomo et al., 1999; Upton & Reed, 2006) and fatigue (Nagatomo et al., 1999; Teel & Press, 1999), among others. In addition to physiological and psycho-social sequelae, cognitive performance of older adult caregivers may be influenced (Caswell et al., 2003).
Dyadic Consequences

In the newly revised model, actor-partner effects may mean that consequences of caregivers’ stress extend to the person with dementia, or may include outcomes rooted in the dyadic relationship. Such outcomes are classified as ‘Dyadic Consequences.’

Consequences for persons with dementia

McClendon and colleagues (McClendon et al., 2004) have previously suggested that the stress process model (Goode et al., 1998; Pearlin et al., 1990) be extended to examine the effect of caregiver characteristics on survival in the person with dementia. In addition to survival, serious consequences for the PWD may include abuse, mistreatment, potential for injury or becoming lost related to unsupervised activity, or premature institutionalization related to the caregivers’ stress rather than the needs of the person with dementia. Each of these consequences is discussed briefly in this section.

Care recipient abuse or mistreatment. Abuse is generally considered a risk factor for persons with dementia (Wolf, 1998), although there is some controversy in this regard (Gainey & Payne, 2006; Wijeratne, 1997). There was a statistically significant higher prevalence of dementia in a sample referred for abuse than in a sample referred for other reasons (Dyer et al., 2000). In another study, 11.9% of those completing questionnaires reported abuse toward the person with dementia, while 33% reported receiving abuse. The latter group was more likely to direct abusive BehSx back at the care recipient (Coyne et al., 1993). Lower functioning in the person with dementia, more years of caregiving, and higher levels of burden and depression, contributed to the possibility of abuse (Coyne et al., 1993; Williamson & Shaffer, 2001), and persons with dementia who have communication problems or disinhibition that may contribute to a cycle of violence are more at risk (Hansberry et al., 2005). Even when abuse is not overt, the care recipient may not be treated well. For example, in a qualitative study about relinquishing
the caregiving role, one participant captured her responses to the stress by saying that she found that she was “not nice anymore…impatient” with her mother (Caron & Bowers, 2003).

**Injury or Becoming Lost.** It is well documented that circadian rhythm and sleep disturbances are common in dementia (Motohashi et al., 2000). Ineffective sleep patterns because of nighttime caregiving duties or concern for the PWD can add to the caregiver’s susceptibility to the deleterious effects of caregiving. The resulting sleep disruption, fatigue, and continual worry can lead to excessive caregiver burden, which can in turn lead to increased depressive symptomatology (Donaldson et al., 1998; Rowe et al., 2004; Teel & Press, 1999). The combination of caregivers who are fatigued, sleepy, over-burdened and depressed with care recipients’ potentially unsafe activity (Klein et al., 1999; Rowe & Bennett, 2003; Rowe & Glover, 2001) may lead to the person with dementia becoming lost or injured. This serious consequence is certainly not limited to community-based care dyads, and is also fundamentally related to characteristics of the person with dementia, such as functional problems, memory, judgment, anger or agitation. Nonetheless, injury or death of the care recipient may result if a person with dementia does become lost (Logsdon et al., 1998; Rowe, 2003b; Rowe et al., 2004), and falls or serious injury can occur even if the person doesn’t get lost during unsupervised or unsafe activity (Kallin et al., 2005; Kolanowski et al., 2006; Oliver et al., 2007; Rowe & Fehrenbach, 2004; van Doorn et al., 2003). Awareness of care recipients’ dangerous activity and the resulting concern about the person becoming injured or lost, in the face of other stressors, may trigger institutional placement.

**Premature Institutionalization.** Perhaps the most obvious and most often discussed distal outcome of caregivers’ stress process is that of institutional placement of the person with dementia. When mounting caregiving stressors become severe, or reach a “breaking point,”
institutionalization is seen as a method of surrendering, at least in part, the caregiving role, often after several crises have occurred (Annerstedt et al., 2000; Butcher et al., 2001). A majority of those placing a loved one cited the need for more skilled care than they could provide (Annerstedt et al., 2000; Buhr et al., 2006). However, in a prospective study, dementia was found to be predictive of nursing home admission even when controlling for functional decline (Banaszak-Holl et al., 2004). Caregivers who exhibited a desire to institutionalize their care recipient had higher burden, more family dysfunction, and decreased social support (Spitznagel et al., 2006). Caregiver perceived stress and associated depressive symptoms, along with problem BehSx, may result in placement as the only option for care (R. Hebert et al., 2001). While placement may indeed reflect the best option for both caregivers and persons with dementia as the condition progresses and caregiver health is compromised, placement earlier than is necessary may decrease survival rates (McClendon et al., 2006).

**Consequences for the dyad as a unit**

The caregiving relationship is by nature a dyadic process, and has the potential to overshadow previous interaction patterns (Lyons et al., 2002; Sebern, 2005). When the recipient has dementia, changes occur that shake the core of the relationship (Whitlatch, 2001; Woods, 2001). Consequences of caregivers’ stress that affect both members of the dyad are primarily embedded within the care relationship, and may include changes in the relationship or in interpersonal interactions.

**Conversational interactions.** While interpersonal interactions may be affected by caregivers’ stress process, there is very little in the literature specifically regarding conversational interactions within dementia care dyads. One case study reported on a woman with severe dementia in a nursing home, her caregiving daughter, and a researcher. Supportive conversations and initiation of the topic by the woman herself increased the amount of lucidity.
displayed during the conversation; however, the daughter was not as supportive and placed more
demands on the woman than the researcher. Supportive conversation included using therapeutic
communication techniques, as well as ignoring errors and helping to find words and complete
sentences when needed. Demanding conversation included questioning and correcting. The
author suggests that ‘communion,’ defined as a shared sense of reality and affective state, may
be the most appropriate person-centered approach during interaction, with emphasis on staying
within the person with dementia’s frame of reference, listening and asking only open-ended
questions, and leaving the initiative to the person with dementia (Normann et al., 2005). Formal
caregivers of nursing home residents with dementia reported episodes of lucidity related to such
non-demanding interactions, where trustworthiness and respect were maintained (Normann et al.,
1998).

**Negative changes in the relationship and/or interactions.** Caregivers’ stress process
may influence their interpersonal interactions in specific ways. For example, caregivers’ level of
anxiety was among predictors of abusive interactions in rural dementia care dyads (Compton et
al., 1997). Caregiver ‘role stress,’ comprised of personal distress, domestic upset, and negative
feelings about the care recipient with dementia, predicted psychological well-being and
productive BehSx in persons with dementia, including problem-solving, task performance, and
social BehSx (Burgener & Twigg, 2002b). Dyadic outcomes such as ‘mutuality,’ the positive
aspects of the care relationship (Archbold et al., 1990; Lyons et al., 2007), and ‘communality,’
the level of mutual responsiveness to the partner in the relationship (Williamson et al., 1998),
may reflect aspects of caregivers’ stress process.

**Caregiver ‘coherence’ and care recipient ‘attachment.’** Caregivers’ psycho-emotional
state related to past losses may influence their caregiving relationships. In dementia care dyads
comprised of adult daughters who cared for mothers with mild to severe dementia, non-verbal interactions in the mother upon reunion after a brief hiatus were correlated to the caregiving daughters’ ‘coherence.’ Coherence, established during a previous interview, was defined as resolution of any losses they had experienced in a way that they could establish close attachments. In daughters who displayed more coherence, mothers displayed more signs of joy and responsiveness upon reunion, including joyful facial expressions, proximity seeking, contact-maintaining behavior, and responsiveness of the mothers, as well as reciprocal emotional attachment between mothers and daughters. The authors suggest that this relationship is based on daughters’ emotional availability to their mothers, without hindrance of emotional conflicts related to their attachment histories. Furthermore, the mothers’ almost universal ability to display attachment to a preferred other reflects the core social and emotional ‘self,’ with earliest socio-emotional connections surviving the longest, namely, a working model of their capability of attachment. The authors conclude that mothers with dementia who live with a daughter who struggles with past history and related attachment issues, the result may be a fearful, intimidated existence (Steele et al., 2004).

**Positive vs. negative affect exposure.** Caregivers’ affective manifestations may reflect their stress process. It has been previously proposed that exposure to genuine positive affect states improve how well any individual or social unit flourishes. Furthermore, experiences of negative affect are more detrimental than experiences of positive affect are protective. The benefits of a high positive to negative affect ratio cover a wide spectrum of valuable outcomes, including improved longevity. Positive thinking and actions can be triggered by pleasant feelings, and vice versa (Fredrickson & Losada, 2005). This supports the importance of affective
responses in any relationship, but the care recipient with dementia may be particularly vulnerable to an imbalance toward negative affect exposure related to their cognitive limitations.

**Are BehSx in PWD a dyadic consequence of caregivers’ stress process?**

BehSx have most commonly been studied as a stressor in relation to the caregivers’ stress process, and have frequently been identified as the most important predictor for caregivers’ stress (Torti et al., 2004). However, while persons with dementia contribute to caregivers’ stress, that same stress process may influence caregivers’ general affect and ability to provide an optimal care environment, specifically, to be responsive, accommodating and pleasant in interactions. Because of their cognitive losses, persons with dementia may be vulnerable to the tone of interactions within the relationship. Persons with dementia may perceive the caregivers’ stress/burden, depression, anxiety, or negativity, and react accordingly. Such a convergence of interactions provides the foundation for the influence of the caregivers’ stress within the dyad, particularly as related to PWD BehSx.

While health professionals and researchers should not ignore contributions from the historical relationship or from other contextual factors, the caregivers’ stress process merits attention as a potentially influential predictor of BehSx and caregiver behavior-related reactions. For example, in one study, high ‘expressed emotion,’ characterized as critical remarks or hostility toward the care recipient, increased the presence of disturbing BehSx in persons with dementia up to a year later. Authors concluded that environmental stimuli rather than organic causes resulted in BehSx (Vitaliano et al., 1993). It may be unrealistic to expect informal caregivers to provide an optimal care environment without first addressing their increased risk for perceived stress and psycho-emotional sequelae (Schulz & Martire, 2004).

In this person-centered conceptualization, dementia-related BehSx are recognized as an ‘expression’ or ‘communication’ of something rather than simply a ‘problem to be managed’
(Kitwood, 1997; Touhy, 2004; Woods, 2001). This conceptualization is also consistent with other works that seek to explain dementia-related BehSx. Two models emerge as the most prevalent theoretical explanations of BehSx. A ‘lowered stress threshold’ model (Hall & Buckwalter, 1987) posits an ever-increasing stress response related to environmental stimuli, which includes interactions with the caregiver. A ‘need-based’ model (Algase et al., 1996) views BehSx as representing physiological and psycho-social needs that cannot otherwise be communicated by the PWD, and the caregiver as responsible for deciphering and responding to these needs. Both these models acknowledge the importance of the caregiver in the management of BehSx.

This conceptualization also acknowledges that informal caregivers provide services that put them at substantial risk. This model was not proposed to claim that informal caregivers should be ‘held accountable’ for managing the very BehSx that increase their stress, or for moderating their own reactions to BehSx. Rather, this model advances the notion that caregivers and persons with dementia are a dyadic unit that should not be separated in care practices or research. The model supports the development of caregiver- or dyad-directed interventions that will have positive outcomes for both dyad members. Discovering or promulgating effective methods to reduce caregivers’ perceived stress and emotional responses may also have more pervasive effects within the dyad. Additionally, if BehSx and caregivers’ behavior-related reactions are reduced, the eventual perception of BehSx as a problem and stressor may also be reduced. Consistent attention to both members of the dyad in research questions and intervention designs and delivery may allow professionals to more rapidly move past the “hidden victim” and “lack of personhood” conceptualizations to acknowledge that both caregivers and persons with dementia may best be assisted when they are considered a dyadic entity.
Relevance of the Proposed Theoretical Model

Walker & Avant (2005) propose that a theory is most useful when it presents new insight, a better understanding, or a different view of the phenomenon. When the theory reflects an already-developed body of knowledge, there should be clarification, with new predictions or control possible where none previously existed (Walker & Avant, 2005). Currently missing from the literature is a model recognizing BehSx as a product of the dyadic relationship including the caregiver, whose stress process has pervasive influence within the dyad. This conceptualization will allow the science to move forward, with interventions geared at helping both caregivers and persons with dementia, rather than expecting caregivers to provide an optimum environment to alleviate BehSx without the personal support to first decrease their own stress related to this intense care environment. Although some researchers have recognized this tenet within their studies, the work is most often presented from one dyad member’s perspective or the other. This model is a realistic natural advance in theory and science at this juncture.

The newly developed theoretical model is an attempt to extend current views of the influence of caregivers’ stress within the care dyad, while also providing a new way of looking at dementia-related BehSx within a holistic, dyadic care context. This model is most relevant in community-based care dyads, reflecting the caregiving milieu as a function of the caregivers’ stress. The model recognizes that outcomes for both members are inextricably imbedded within the context of the informal care relationship. This model is not an attempt to fully explain BehSx in persons with dementia. However, if supported through research, this theoretical model supports adopting a view of BehSx as at least partially a product of the dyad rather than solely related to the disease. This viewpoint may provide a more relevant framework for intervention, emphasizing the salience of caregiver-directed or dyad-directed intervention with emphasis on stress reduction, and recognizing the care dyad by addressing the issues they face as a unit.
**Dyadic Effect of Caregivers’ Stress Process: PWD BehSx**

A conceptual model with selected key relationships for beginning the process of testing the newly revised theoretical model was developed for this dissertation study. This reduced model, the “Dyadic Effect of Caregivers’ Stress Process: PWD BehSx” model, posits that PWD BehSx are a dyadic effect of caregivers’ perceived stress, that may also be influenced by caregivers’ emotional responses to stress, with the latter acting in a manner similar to that of a mediator (Figure 2). The review that follows will focus on the concepts and relationships in the reduced model to be tested in this study.

**Caregivers’ Perceived Stress**

‘Perceived stress’ is defined as an appraisal that one’s adaptive capacities are lacking in relation to the demands of the situation; i.e., that resources are inadequate or demands are too high (Pearlin et al., 1990; Schulz & Martire, 2004). In comparison, Zarit operationally defined caregiver burden as the extent to which caring for a relative has caused a perception that caregiver emotional or physical health, social life, or finances are suffering in relation to the caregiving role (Zarit et al., 1980; Zarit et al., 1986). Burden related to caregiving is generally seen as subjective belief that resources are not or will not be sufficient to meet the demands of the role, and burden is viewed as a precursor to negative outcomes such as caregiver depression (O'Rourke & Tuokko, 2003). The similarity of the ‘perceived stress’ and the ‘caregiver burden’ definitions is striking.

These similarities extend to the most widely used instruments designed to measure these concepts. For example, in one version of the Zarit Burden Interview, participants are asked to rank items reflecting their levels of stress, anger, negative affect, privacy, uncertainty, loss of control, inadequacy, strain, time pressure, and degree to which their health and social life have suffered (Bedard et al., 2001). In contrast, the Perceived Stress Scale (S. Cohen et al., 1983) asks
for rankings regarding stress, adequacy, coping with change and unexpected events, lack of control, time pressure, anger, confidence, and feelings of being overwhelmed. The Perceived Stress Questionnaire (Levenstein et al., 1993) is somewhat more subjective and comprehensive but includes some of the same responses, for example, worries, pressures, frustrations, time pressures, too many demands, inadequacy (or judgment from others), fears, and overloaded with responsibility.

Given these evident similarities, including studies that use dementia-caregiving-specific terminology and approach will add to the discussion of the stress process in this population, and will be included in this review. Burden is a much more common measurement in dementia caregiving literature, and is more specific to caregiving demands and stressors. While caregiver burden may not be a pure reflection of perceived stress, burden and perceived stress do encompass many of the same latent concepts. In this review, the two terms are used interchangeably.

The perceived stress associated with dementia caregiving is pervasive among informal caregivers. Authors of a multi-national, multi-continent review state that the remarkable findings of substantial perceived stress in caregivers of those with dementia, coupled with an aging population, are “staggering” in their impact. While the perceived stress of dementia caregiving could be described as universal across studies and geographic regions, cultural considerations such as obligations of women in caregiving also had considerable influence (Torti et al., 2004).

**Predictors of Perceived Stress/Burden**

In a study of 1,874 community-dwelling care recipients, perceived stress has been correlated to basic ADLs, IADLs, depression, severity of dementia, and co-morbidities in care recipients, as well as depression in caregivers. Caregiver perceived stress ratings were significantly higher when care recipients were male, had fallen in the last 6 months, had
behavioral disturbance, or a diagnosis of dementia or chronic obstructive pulmonary disease. Furthermore, caregiver perceived stress was significantly worse when caregivers themselves were spouses rather than children, had poorer health, or fell in the age range just after retirement, 65-74. Multiple regressions identified independent predictors of caregiver perceived stress: care recipient fall history, depression, basic ADLs, and severity of dementia, and also caregiver depression. These, together, explained 33% of the variance in caregiver perceived stress in this study (Kuzuya et al., 2006). Perceived stress was also significantly correlated to BehSx in persons with dementia, with aggressive BehSx most disturbing and memory-related BehSx least burdensome (Papastavrou et al., 2007).

**Caregiving duties.** Types of care tasks required, number of hours spent in caregiving duties, amount of supervision required by the person with dementia, and living with the care recipient all influence dementia caregivers’ perceived stress (Torti et al., 2004). Based on a critical review of caregiving literature, Chou and colleagues (1999) developed and tested a model of caregiver perceived stress in Taiwanese dementia caregivers, where caregiving involvement and emotion-focused coping had a positive effect on caregiver perceived stress (more perceived stress as these factors increased). Filial obligation, caregiving self-efficacy, and problem-focused coping had direct negative effects (less perceived stress as factors increased). While the demands caregivers face increase their perceived stress, it was the person involvement in that care which lead to caregiver burden/stress (Chou et al., 1999).

**Caregiver characteristics.** Once the informal caregiver is involved, a confident approach to the associated problems is more beneficial to the caregiver than an emotional response to the situation (Chou et al., 1999). Personality traits of caregivers may influence perceived stress and the associated psychological symptoms more than the stressors. In one study, neuroticism, or the
trait tendency to negative affect and sensitivity to stress, accounted for 28% of the variance of caregiver perceived stress, while care recipient behavior problems accounted for 4%. Neuroticism was also negatively associated with positive affect, and social support was positively associated with positive affect. Positive affect was in turn related to reduced perceived stress (Shurgot & Knight, 2005). This supports previous research that indicated neuroticism (high) and mastery (low) increased reports of perceived stress related to caregiving (Bookwala & Schulz, 1998).

**Care receiver characteristics.** BehSx of dementia are consistently reported as one of the main contributors to caregiver perceived stress. In a systematic review regarding this relationship, cross-sectional studies supported this connection, with pooled data suggesting a moderately strong association of BehSx to perceived stress, distress, and depression. However, the temporal relationship between the variables was not successfully established, reportedly due to lack of longitudinal studies meeting inclusion criteria (Black & Almeida, 2004). BehSx are also consistently found more burdensome than physical tasks of caregiving, and emerge as the primary source of caregiver stress in North American studies (Torti et al., 2004). Care recipient anger and aggressiveness were associated with caregiver psychological burden, but not social burden or guilt (Ankri et al., 2005). In another study, perceived stress was significantly related to BehSx in persons with dementia and reactions in caregivers, with aggressive BehSx most disturbing and memory-related BehSx least burdensome (Papastavrou et al., 2007).

**Communication.** Using structural equation modeling, communication difficulties related to dementia were found to affect caregiver perceived stress. Communication problems were linked to demand burden, stress burden, and objective burden in the caregiver, but the relationship was mediated by BehSx. Communication problems mediated the relationship
between cognitive and functional status and BehSx in the persons with dementia, indicating that perhaps the inability to communicate could lead to frustration and then BehSx, which in turn contributes to perceived stress in caregivers. Communication problems and BehSx also fully mediated the relationship between cognitive/functional status and time burden; however, there remained a direct link from cognitive/functional status to ‘demand’ burden (Savundranayagam et al., 2005). These findings highlight the importance of communication within the care dyad, and its relationship to the negative effects of caregiving.

Progression of Perceived Stress/Burden in Dementia Caregiving

There is substantial perceived stress early in the dementia caregiving process, while there seems to be some adaptation to the role over time, with lessening perceived stress (Torti et al., 2004). In an Australian study, longer duration of caregiving and practical coping were related to less perceived stress (McConaghy & Caltabiano, 2005). A Canadian study revealed that perceived stress increased over 6 months time when the care recipient had Alzheimer’s dementia, while perceived stress decreased over the same period when the presenting dementia was not Alzheimer’s (Bedard et al., 2001).

Caregivers of persons with dementia who have poor health, limited social life, and lack of positive outlook on the situation were vulnerable to burnout related to caregiving burdens in one study. Women, particularly wives, are more at risk for burnout, and may be more emotionally involved, closer to the situation, than men. Furthermore, those who cared for the person with dementia at home had virtually no differences in risk of burnout than those whose loved one was institutionalized; guilt and grief related to caregiving do not go away when the care recipient is institutionalized. Even siblings and distant relatives are at risk for burnout if they are closely involved (Almberg et al., 1997). When the relationship between perceived stress and ‘collapse of caregiving at home,’ or institutionalization, was explored, those caregivers who were not
living in the same home had greater ‘collapse,’ as did those caring for someone with behavior problems (Gort et al., 2007).

**Treatment of Perceived Stress/Burden**

Caregiver perceived stress has proven resistant to treatment. In a meta-analysis meant to clarify the state of science, Acton & Kang (2001) found that, overall, the interventions evaluated had no positive effect on perceived stress; in some cases perceived stress worsened in the intervention group or improved more in the control group. The interventions were grouped by type: support group, education, psycho-education, counseling, respite care, and multi-component, with only the latter type showing significant effects on perceived stress. Citing the tenet of ‘more is better’ with regard to treating perceived stress, the authors state that although blanketing caregivers with help in many areas seems logical, several interventions considered multi-component did not successfully demonstrate a difference. The authors propose that perceived stress as a construct is perhaps too multi-dimensional for use in evaluating interventions (Acton & Kang, 2001).

**Association between Perceived Stress and Emotional Responses**

Caregiver perceived stress has been shown to play a large role in mental and psychological outcomes for dementia caregivers. For example, perceived stress has been associated with psychiatric symptoms across studies in a review of the literature (Schulz et al., 1995). In a study that associated mental health and sleep, older wife caregivers of persons with Alzheimer’s Dementia had significantly poorer mental health outcomes than controls. However, the caregiver perceived stress score was a better predictor of mental health than the set of caregiving stressors, which included BehSx, years of caregiving, and hours spent in caregiving each day (Willette-Murphy et al., 2006). In a small sample of dementia caregivers in Australia, caregiving burden was found to influence satisfaction with life (47% of variance in the measure) and psychological
stress, with perceived stress diminishing over time when practical coping was utilized (McConaghy & Caltabiano, 2005). In a recent study of 172 dementia caregivers, 68% had high levels of perceived stress, and 65% had depressive symptoms, with almost half at risk for clinical depression, and these symptoms were further correlated with BehSx (Papastavrou et al., 2007).

Berger and colleagues (2005) found differing relationships over time in their longitudinal study (2-yr.) of dementia symptoms, caregiver perceived stress, and caregiver psychological variables. In the face of declining cognitive and functional status, worsening severity of dementia, and increased behavioral disturbances, perceived stress was essentially stable, increasing only slightly. Depression, on the other hand, did become more prevalent over time. However, there was a decrease in the amount of severe depression even as slight and moderate depression increased. The authors conclude that some caregivers have an intense emotional adjustment in the beginning of the caregiving process that subsides over time, while the perceived stress and depression that is related to symptoms generally increase (Berger et al., 2005).

Caregiver Emotional Responses to Stress

Emotional responses stem from the perceived stress or burden of caregiving, and may include such responses as depression, anxiety, negative affect, anger, irritability, and others. In a comprehensive review of the literature, it was found that virtually all studies of dementia caregivers reported high rates of depressive symptoms and anxiety (Schulz et al., 1995). For example, in a study of 44 dementia caregivers with matched controls, caregivers had significantly worse depression, affect, and satisfaction (Haley et al., 1987). More recent research has suggested that those caregivers with less stress and more meaning and benefit from duties, and more support, had lower depression and improved life satisfaction (Haley et al., 2003). Mahoney and colleagues (2005) reported dissimilar results, with 10.5% of older adult caregivers
at risk for clinical depression, similar to that of the general older adult population. Anxiety was more common in this sample, with 23.5% displaying ‘case’ levels. Their sample reflected caregivers from various settings, including living alone, with caregiver, or in an institution (Mahoney et al., 2005). In the national, multi-site REACH trials, prevalence of risk for depression (CES-D > 16) was 30% (Burns et al., 2003).

Predictors of Emotional Responses

**Caregiving duties.** While the duties related to caregiving would intuitively qualify as a predictor of caregivers’ emotional responses, the research findings mixed in this regard. Care recipient disability has been associated with emotional symptoms in caregivers (Berger et al., 2005). Caregivers of those with more severe dementia, with increased ADL and functional dependence, and increased hours spent caregiving per week were more likely to have depressive symptoms (Covinsky et al., 2003). In contrast, another study found that those non-caregivers with dependent relatives who had more severe disability, including physical or cognitive decline, had higher levels of depressive symptoms, while caregivers and those without severe care needs did not have increased levels of depression (Amirkhanyan & Wolf, 2003), suggesting that it is not the provision of care that causes depression but the needs of the person for which care is provided, and that providing such care may even be protective. In female caregivers in the natural environment, situational stressors increased negative mood, while perceived support reduced the impact of the stressor on mood (Atienza et al., 2001).

**Caregiver characteristics.** Caregivers with positive feelings about caregiving have been shown to have significantly lower depression scores (C. A. Cohen et al., 2002). Subjects that appraised caregiving tasks as ‘less stressful’ and associated meaning and benefits with caregiving also had less depression (Haley et al., 2003). Optimism consistently impacted mental health and affect in a positive way, more than effective coping mechanisms. However, effective coping did
improve caregivers’ affect, and also reduced stress when dealing with difficult caregiving situations (Gottlieb & Rooney, 2004).

**Care recipient characteristics.** BehSx in persons with dementia were predictors of caregiver depression, with angry and aggressive BehSx particularly influential (Covinsky et al., 2003). Irritability in the care recipient and more impairment in ADLs in the care recipient have also been found associated with depression and anxiety (Mahoney et al., 2005). In Alzheimer’s dementia, Neundorfer and colleagues (2001) used multi-level modeling to examine change in depression in caregivers over time. Higher dependency in IADLs and more depressive symptoms in the patient were related to caregiver depression at the beginning of the study. Over 5 years time, increase in patient depression and IADLs was associated with increase in caregivers’ depression, while the rate of acceleration in caregivers’ depression was associated only with patients’ acceleration of functional decline. The authors compare caregivers in this study to spouses whose depressed partners may be critical, negative, and unappreciative (Neundorfer et al., 2001).

**Progression of Emotional Responses**

Several researchers have found an increase in depression over time in dementia caregivers, often related to BehSx in care recipients (Berger et al., 2005; Gaugler et al., 2005; Neundorfer et al., 2001). However, this finding is not consistently reported. Powers and colleagues (2002) examined stability of depressive symptoms using the Beck Depression inventory in caregivers over a two-year period in the face of cognitive decline in persons with dementia. Depressive symptoms were ‘substantially’ similar over time using intra-class correlations, and avoidance coping strategies were positively correlated to depressive symptoms. The authors conclude that depressive symptoms are likely trait-based rather than dependent on a state; and thus may not adequately assess response to an intervention (Powers et al., 2002). In another study, caregivers
were examined in relation to depressive symptoms prior to becoming caregivers, and existing depressive symptoms upon care recipient diagnosis actually decreased as dependency in IADLs increased, while those without previous depressive symptoms had increased symptoms as care recipient dependency increased (Neundorfer et al., 2006).

Progression of emotional responses may be independent of decisions regarding placement. Schulz and colleagues demonstrated that placement of a relative in long-term care did not ease the symptoms of depression and anxiety, and may even make these symptoms worse, particularly in spouse caregivers (Schulz & Martire, 2004). Furthermore, among those caregivers whose relatives resided in nursing homes, those who cared for someone with dementia were exposed to more psychological distress. This was despite no difference in coping strategies or number of visits to the facility (Levesque et al., 1999).

Treatment of Emotional Responses

Despite findings that suggest depressive symptoms may be trait-like characteristics (Powers et al., 2002), depressive symptoms seem more amenable to treatment than caregiver perceived stress. For example, Buckwalter and colleagues (1999) were successful in alleviating depression in caregivers by teaching them techniques to manage behavioral issues in care recipients with dementia using the ‘progressively lowered stress threshold’ theory. The authors argue that the intervention helps caregivers regain a sense of control over their lives that is lost when faced with dementia caregiving; this loss of control may exacerbate depressive symptoms. They also measured subjective affect, and found significant improvements in caregiver tension-anxiety, anger-hostility, fatigue-inertia, and confusion-bewilderment (Buckwalter et al., 1999). Another intervention, teaching caregivers to match assistance to level of disability in dementia, was successful in reducing depressive symptoms over time, as compared to those who received a
periodic phone call only (Chang, 1999). In the REACH trials, risk of clinical depression was reduced in the enhanced care group (Burns et al., 2003).

**PWD Behavioral Symptoms**

It has become evident in recent years that challenging BehSx are quite common in all stages of dementia (Tractenberg et al., 2002), with a total prevalence rate as high as 90% (Steinberg et al., 2003), and with the potential for up to 98% developing symptoms over a five-year period (Lyketsos, 2007; Steinberg et al., 2006). Regardless of this high rate of occurrence, it is important to consider that troubling BehSx may not be related to cognitive decline alone. Although cognitive symptoms such as short-term memory loss and declines in judgment and other cognitive functions are hallmark symptoms of dementia, ‘non-cognitive’ symptoms are pervasive in this population as well (Shah & Allen, 1999). Thus, BehSx are multi-dimensional and may reflect cognitive disability as well as psycho-social features. This study focuses on psychosocial aspects of BehSx. For example, poor previous interpersonal relationships and co-morbid clinical depression may contribute to BehSx (Compton et al., 1997; Hamel et al., 1990; Schulz & Martire, 2004; Wolf, 1998).

BehSx have been conceptualized as dyadic in nature, reflecting the influence of actor-partner effects within the dyad. BehSx can thus, when considered distressful, be interpreted as a problem or stressor and contribute to the caregivers’ stress. For example, care recipient BehSx, particularly apathy, led to deterioration of the marital relationship in those dyads where spouses cared for a husband or wife with dementia, regardless of cognitive or functional abilities of the patient (de Vugt et al., 2003). These findings highlight the strong clinical significance of BehSx within the care dyad, especially since apathy has been shown one of the most commonly appearing initial symptoms (Lyketsos et al., 2002; Steinberg et al., 2003). Stress within the dyadic relationship related to apathy in the beginning of the disease process may set the stage for
negative interactions that will have long-term effects within the dyad. More importantly to this study, caregivers’ stress and emotional responses may contribute to the severity of BehSx. The review that follows will highlight the evidence that supports this relationship.

**Influence of Caregiver Stress Process on PWD BehSx**

Experts emphasize that it is the caregiver’s responses and approaches that must be altered to effectively deal with BehSx in persons with dementia, and that the person with dementia can not willingly change. Good communication, creativity, flexibility, accommodation, affection, reassurance, patience, consideration, and compassion are emphasized (Cohen-Mansfield, 2001a; Logan, 2004) to contend with BehSx in persons with dementia.

Coping with difficult BehSx in dementia caregiving was the primary theme that emerged in a descriptive study that selected subjects from a major caregiver clinical trial. The authors reported that skilled caregivers were more aware of behavioral sequences and responded with creativity and persistence, aware that their responses could escalate or alleviate the BehSx. Skilled caregivers were more able to attribute BehSx to the condition rather than a personal affront. Creativity, flexibility, attentiveness, persistence, emotionally responsive interactions, and monitoring their own responses to care recipient BehSx were seen as key to effective care of the person with dementia with difficult BehSx (Farran et al., 2003).

In a large population-based (US) study, researchers sought to delineate caregiver characteristics which may contribute to BehSx in dementia. Citing a clear association between caregiver perceived stress, depression, and care recipient BehSx, the authors propose that the relationship is likely bidirectional. Their findings indicated that younger and less educated caregivers reported more BehSx, as did those who were more burdened, more depressed, or spent more hours in caregiving. This relationship persisted after controlling for dementia.
severity, and the authors propose that this relationship is likely valid despite the cross-sectional nature of the study (Sink et al., 2006).

In addition to links between caregiver perceived stress, depression, and ways of interacting with care recipients, the potential influence of the caregiver stress process is evident in literature regarding a) caregiver coping and management strategies, b) caregivers’ presenting affect, and c) interventions meant to assist caregivers, but with direct outcomes related to BehSx.

**Influence Related to Caregiver Coping and Stress Management**

Caregiver coping strategies have been associated with survival in persons with dementia, which may in turn be linked to behavioral and functional decline. In particular, wishfulness— intra-psychic coping was related to shorter survival time in the person with dementia, while instrumental—acceptance coping was not. The authors propose that caregivers who use intra-psychic coping may be less responsive and psychologically available to the person with dementia, which may in turn lead to inadvertent contributions to decline in the person with dementia (McClendon et al., 2004).

In another study, those caregivers labeled as non-adaptive were more neurotic, more burdened and depressed, felt less competent, and reported more BehSx in general, and more hyperactivity symptoms specifically in the care recipient with dementia. Furthermore, changes in behavior patterns over time reflected caregivers’ non-adaptive approaches, suggesting that the BehSx were in direct response to the caregiver interactions, such as impatience or irritation. The authors suggest that effective strategies may decrease caregiver perceived stress and also improve BehSx in the persons with dementia (Aalten et al., 2003; de Vugt et al., 2004).

A separate study indicated that trait-based optimism had more influence on coping effectiveness than situation-based factors such as ways of coping. Optimism improved coping, increased positive affect, and decreased negative affect, over and above the contribution of
coping effectiveness, which also decreased negative affect and improved mental health. BehSx such as stubbornness, repetitiveness, and frequent complaints in persons with dementia were correlated to significantly poorer mental health scores and less positive affect in caregivers (Gottlieb & Rooney, 2004).

**Influence Related to Caregiver Presenting Affect**

Even in cognitively intact older adults, negative social exchanges have been associated with distress and sense of well-being, while positive social exchanges were linked only to well-being. Emotional exchanges, such as anger or criticism, signifying deterioration of the relationship, were the strongest negative predictors. When these occurred in relationships with spouses or family members they were especially hurtful. Alternatively, companionship was strongly associated positively with well-being and negatively with distress. These findings support the need for positive social interaction to promote psychological health in older adults, who may be especially sensitive to negative exchanges such as criticism (Newsom et al., 2005).

In dementia care dyads, ‘enmeshment’ or cohesion seemed to play a protective role for caregivers. Depressed and anxious caregivers had less ‘expressed positive affect’ and less ‘conflict resolution.’ Burdened caregivers expressed more anger. Depressed and burdened caregivers were more likely to have care recipients who showed signs of disengagement (Mitrani et al., 2005). More depressed spouse caregivers were also found more likely to treat their partner in potentially harmful ways, such as threatening or handling roughly (Williamson & Shaffer, 2001).

In burdened caregivers of persons with Alzheimer’s disease, emotional lability and destructive BehSx in the patient led to anger-resentment and restrictions in caregiver’s personal time and social life. When social and personal time were limited, depression and anxiety were outcomes. The authors conclude that perceived stress in caregivers may create a situation where
both caregivers and persons with dementia may experience negative changes in day-to-day interactions and morale in the home. (Croog et al., 2006).

In Australia, in rather optimal cultural conditions with regard to support and living conditions, caregivers approached BehSx by ignoring the problem or providing tolerance and understanding. Rebukes and threats had been abandoned as not effective or making matters worse. Researchers concluded that these caregivers naturally practiced methods recommended for optimal, dementia-friendly care (Ward et al., 2003).

In a study of families where affective responsiveness (closeness vs. anger, sadness, & criticism), problem solving, communication were impaired, caregivers reported both poor family functioning and higher ratings of strain and burden. However, it was not clear whether perceived stress/strain resulted in poor family functioning, or vice versa (Heru et al., 2004).

Caregiver affective approaches can also influence BehSx in a positive way. Caregivers singing during morning care routines, which can be stressful to persons with dementia, were compared to background music and usual care without music. Music, and even more so, singing, resulted in dramatic improvements in balance and sensory awareness, physical strength, and use of space. For example, persons with dementia had improved posture, were able to participate more fully in activities, and seemed more happy (Gotell et al., 2003).

‘Expressed emotion,’ considered the level of criticism and conflict displayed in the relationship, was higher in adult children caregivers than in spouses, and in dyads where BehSx in the care recipient were a problem. Caregivers’ attribution of behavior problems to the control of the care recipient was predictive of patient-to-caregiver, caregiver-to-patient, and general criticism/overall conflict in the relationship. The authors caution that correlational analyses limit these interpretations (Spruytte et al., 2002). However, increased expressed emotion (criticism) in
Caregivers did predict an increase in BehSx in the care recipient over five years (Vitaliano et al., 1993) in another study.

Caregivers taught to maximize communication with the person with dementia, based on abilities, contributed to significantly decreased BehSx, while symptoms increased in the control group. Suggestions ranged from simplifying language and concepts to using primarily non-verbal communication in later stages (Silvestri et al., 2004).

In comparison with the degree of cognitive losses, persons with Alzheimer’s dementia do retain some ability to recognize non-verbal cues and use them to identify emotions in facial expressions, although this skill is lessened in comparison to normal older adults. Furthermore, persons with decline were able to recognize several diverse emotions such as anger, happiness, and sadness. The authors emphasize that it is important that caregivers pay attention to their own non-verbal communication, keeping it congruent with what they are saying. They also propose that non-verbal responses from the person with dementia may be a response to accurate perceptions of emotions in others (Bucks & Radford, 2004).

In videotaped observations of couples that did or did not have Alzheimer’s disease, non-caregiving couples had more interaction in general and were more supportive of each other; caregivers were more depressed and more stressed, and also had less reciprocity and shared pleasures with their spouses. Non-caregivers had higher scores on the measure of hope, but there were no differences between caregivers and non-caregivers in shared values and emotional closeness. Caregiving wives were more facilitative during a complex planning task than during a meal, while husbands with AD tended to use interactions meant to build rapport. Husbands without AD became more facilitative during the planning task, but those with AD were not able to manage such facilitation (Gallagher-Thompson et al., 2001).
Interventional Evidence for Caregiver Influence on BehSx

A meta-analysis review of caregiving interventions supports the influence of caregivers on persons with dementia. In addition to caregiver outcomes, a meta-analysis assessed the effectiveness of caregiver interventions on ‘care receiver symptoms.’ Multi-component and interactive, participatory psycho-educational programs for caregivers were found most helpful. Longer interventions and those delivered in group settings were most effective in improving care receiver symptoms (Pinquart & Sorensen, 2006).

In a review to establish which psychological interventions provided adequate evidence for practice, interventions based on the PLST model and a standard antecedent-behavior-consequence model emerged as most helpful. In all studies that contributed to the evidence, a problem-solving approach, with identification of trigger/antecedents, and modifications of the environment, the schedule, or interactions were recommended for treatment (Logsdon et al., 2007).

Within the National Institutes of Health Resources for Enhancing Alzheimer’s Caregivers Health (REACH) initiative, one study demonstrated that an in-home skill-building program designed to teach caregivers management techniques and to enhance the environment for safety and ease in caregiving, could help both caregivers and persons with dementia. At 6 months caregivers had improved skills and persons with dementia had fewer behavioral issues. At 12 months caregiver affect was improved and BehSx remained in a decreasing trend. The authors suggest that caregivers’ sense of personal control through enhancement of skills may result in less feelings of being overwhelmed, thus changing their affect, and their more skilled approaches could help to reduce BehSx (Gitlin et al., 2005).

A dyadic exercise intervention along with education of caregivers about managing BehSx was found to improve behavioral and functional outcomes in the persons with dementia (Teri et
This study extends a previous body of evidence that education of the caregiver(s) can make a difference in reducing behavioral ‘problems,’ and may even reduce institutionalization (Teri, 1999).

In an intervention based on a stress and coping framework, treatment consisted of a psycho-educational program designed to decrease the impact of BehSx within the dyad. After 16 weeks, treatment subjects had significantly reduced their reaction to BehSx compared to controls, 14% and 5% decrease, respectively. The frequency of BehSx was also reduced, as was the composite frequency/reaction scores. The authors suggest that the reason frequency of BehSx was reduced was that they had likely improved their coping abilities, with a resulting effect on BehSx in the person with dementia. However, there was no impact on secondary measures such as burden, stress, or anxiety (R. Hebert et al., 2003b).

Significant findings for both members of the dyad were described after a randomized control trial testing the effectiveness of inter-disciplinary collaborative care emphasizing non-pharmacologic management of BehSx in dementia. BehSx and caregiver distress related to BehSx, and caregiver depression were significantly improved (Callahan et al., 2006).

BehSx have emerged as important outcomes when both members of the dyad are targeted in intervention studies. However, research has not consistently found that caregiver-directed interventions had an influence on BehSx. For example, BehSx, functional decline, and caregiver responses to these were assessed for longitudinal change after a psycho-educational intervention geared toward caregivers, yielding positive outcomes, but outcomes which varied according to relationship of caregiver to care recipient (Gerdner et al., 2002). Negative caregiver appraisal of BehSx, but not BehSx, were found reduced in a 4-year longitudinal study using a counseling and support intervention (Mittelman et al., 2004a) and in a 3-year longitudinal psycho-educational
support intervention (Ostwald et al., 1999). An intervention designed to improve caregivers’ sense of personal competence and control led to fewer declines in instrumental activities of daily living in care recipients, but not in BehSx. Nonetheless, women in the study reported enhanced self-efficacy with regard to handling BehSx, and spouses reported less upset about BehSx (Gitlin et al., 2001).

In the REACH initiative, one study targeted behavior management through a primary care intervention. While BehSx were expected to improve, the measurement consisted of how bothered the caregiver was by the BehSx rather than behavior severity. Over 2 years, caregivers’ bother significantly decreased in a basic behavioral management intervention, but did not improve significantly more in a comparison group who received an enhanced intervention with additional treatment geared toward relieving caregiver depression and improving well-being. Depressive symptoms did improve more in the enhanced intervention group (Burns et al., 2003). While the improvement of bother related to BehSx seems independent of improvements in depressive symptoms in this sample, BehSx in the enhanced care group were initially significantly lower than those in the basic group, and may not have had room for extra improvement. For instance, in the basic group bother was reduced from 19.6 to 14.8, while in the enhanced group, bother was reduced from 11.8 to 9.2 (Burns et al., 2003). Even though baselines were controlled for in analyses, the range for bother was 0-96, and a score of 9-11 could reflect the minimal amount of bother on less than half the possible 24 behavior items.

**Summary**

Dementia and its sequelae can be considered an impending public health crisis. As persons with dementia lose cognition, a dyadic relationship develops between informal caregivers and care recipients that can have extensive influence. The stress that dementia caregivers’ experience related their role can have substantial, sometimes severe consequences. The resulting
‘perceived stress’ and associated ‘emotional responses’ may influence outcomes not only for the caregivers, but within care recipients, or the dyad as a unit. While severity of BehSx in persons with dementia may result in eventual interpretation of them as stressors for caregivers, and contribute to the caregivers’ stress process, caregivers may have, as a result of the intense process, altered interpersonal interactions with the person they care for. Persons with dementia are fully relational beings who can respond to interactions with the caregiver, and even when caregivers are vigilant about verbal responses in interactions, negative messages may be received from non-verbal mannerisms. It may not be realistic to expect caregivers to alter their interactions and reduce BehSx without first assisting them with their own stress, so assisting caregivers with stress/burden related to caregiving may also improve the situation for the care recipient. Therefore, developing our knowledge and understanding regarding caregiver influence within the dyad, particularly with regard to PWD BehSx, may provide a basis for more appropriate caregiver- or dyad-directed interventions to alleviate BehSx. If BehSx are alleviated, the entire caregiving milieu may be enhanced, and both dyad members may have substantial benefits.

BehSx may have influence on serious, more distal outcomes such as institutionalization, and may also eventually translate into increased stress for the caregiver, resulting in an endless cycle that continually worsens the quality of the caregiving milieu. For example, while caregiver factors such as perceived stress and depression are also factors, the severity of BehSx have been cited in decisions regarding institutionalization placement (Buhr et al., 2006; Coelho et al., 2007; de Vugt et al., 2005; Gaugler et al., 2005; Yaffe et al., 2002). Research to better understand antecedents to these BehSx may have influence for persons with dementia, caregivers, and society at large. Regarding BehSx as a dyadic consequence of the caregiver’s stress may provide
a unique insight into how BehSx might best be treated, with caregiver- or dyad-directed interventions to alleviate caregiver stress, adding to the non-pharmacologic measures available to address BehSx. Such interventions might help to break the cycle, and ultimately improve quality of life for both caregivers and care recipients.
This study was a secondary analysis of data previously collected from the parent study, described herein as the ‘original’ study. The dissertation study was conceptualized early in the data collection phase of the original study, and changes were made to accommodate the dissertation study. Key components of the original study’s materials and methods will first be summarized, and then the dissertation study plans will be outlined.

Original Study

Design

The original study was designed as a randomized clinical trial to create and test a new monitoring system for nighttime activity in persons with dementia (Rowe, PI, STTR, NINR, NIH 2R42NR004952-02A2). Data were collected over 12 months in a longitudinal design, at baseline (month 0), and at months 2, 3, 4, 5, 6, 8, 10, & 12. The system is a newly developed technology that uses components similar to those of home security systems, with alarms on outer doors, motion sensors as needed within the home, a bed sensor, and bedside alerts so that the caregiver is aware when the person with dementia is out of bed and moving around the home at night. The overall aim of the original study was to test the efficacy of the monitoring system on proximal clinical outcomes such as improved caregiver sleep and reduced worry; and in the PWD, reduction of injuries and unattended exits from the home. Secondary outcomes in the caregivers were also assessed, such as sleepiness/fatigue, perceived stress, depressive symptomatology, mood/affect, and desire to institutionalize (Rowe et al., 2007).
Subjects

Entry and exclusion criteria

To be eligible, care recipients were required to have a medical diagnosis of dementia, and needed to be cared for in the home without provisions for professional care at night. The primary caregiver was required to speak English, and needed to have some concern about the person with dementia regarding their nighttime activity. Additionally, the caregiver could not have sleep conditions, medications, or cognitive/functional limitations that would limit their ability to respond to system alerts (Rowe, 2003a).

Sample and setting

A convenience purposive sample of community-dwelling care dyads was recruited from three areas in central/north Florida, and the primary setting of the research was in the homes of the participants. Geographic areas were chosen to reflect a more diverse population, and every attempt was made to seek minority participants, with over-sampling accomplished for African-Americans, while Hispanics were more difficult to over-sample related to the inability of potential participants to speak English (Rowe, 2003a).

The first 4 dyads recruited were used in the preliminary study phase to establish reliability of the newly designed system. These subjects were automatically recruited into the experimental group. Subsequent group assignment was random after verbal consent to participate, managed by a staff member not on the research team, for 45 of the dyads recruited. Two dyads were allowed to self-select into the control group because of difficulties recruiting in this population and their desire not to receive the system, and two voluntarily accepted assignment to the control group because their sleeping arrangements were incompatible with configuration of the system (Rowe et al., 2008).
Recruitment and retention

Subjects for the original study were recruited through advertisements in newspapers and flyers distributed at support groups and conferences. Researchers contacted a variety of dementia-appropriate local clinics and organizations to explain the study, and those willing to recruit individuals for the study were provided with material packets and a means for potential subjects to call the researcher. It was up to the interested caregivers to contact the researcher, and no record was kept of those given informational packets. Advertisements also utilized e-mail/web-based newsletters, the Alzheimer’s Association newsletter, and the IRB-01 web advertising, as allowed (Rowe, 2003a). On several occasions, researchers presented the study to interested groups, and then information packets were left with a contact person within the group.

In this difficult-to-recruit population, retention of subjects was very important. Several measures were instituted in the original study to improve retention. For the experimental group, the caregiver was allowed the opportunity to keep the system at the end of the study, with limited access to technical assistance after the research team completed their visits. For the control group, $15 gift certificates for local stores were given out at each data collection point (total potential $135), and information pamphlets regarding dementia caregiving were supplied at each visit. Alzheimer’s Association ‘Safe Return’ program fees were paid if registration was desired by the subject. Throughout the study, retention was encouraged through letters, communications, prompt availability for problem-solving or to answer questions, and birthday and holiday cards for subjects. Letters of appreciation were sent upon subjects’ leaving the study, and after completion of the entire study, certificates of appreciation were presented (Rowe, 2003a).
Procedures

Methods

In the original study, there were three investigators involved in the collection of data, each assigned to a geographic area intended to maximize diversity of the sample. At the outset of the study, intensive training was provided regarding installation and trouble-shooting of the system. Each investigator had a research assistant assigned to assist with scheduling and other tasks associated with the study. Regular monthly meetings were held to discuss any issues and progress of the study. The primary investigator was available to assist co-investigators as needed with trouble-shooting.

Computers were assigned to each investigator for the purpose of collecting data in an efficient manner. Assessment tools were entered into a user-friendly interface by a technical consultant, which allowed caregivers to quickly complete tools using an attached mouse. In the event that there were computer failures, investigators carried paper copies that were then transported by hand and entered into the data storage program by the research assistant or investigator. In the field, data sets were saved to portable drives as well as to the laptop computer, and were e-mailed through secure servers to assistants for uploading into data storage sets at the earliest possible time. The data sets never included personal or identifying information. Data were stored in a Microsoft Access database until ready for analyses. Outliers in the data were checked for coding errors and validity prior to entry into SPSS for statistical analyses (Rowe, 2003a).

Month 2 for those in the experimental group followed a minimum 2-week reliability phase that varied in length from participant to participant; thus ‘baseline’ and ‘month two’ time points were not equidistant among participants. This rigorous ‘reliability testing’ phase was necessary to manipulate sensors to suit the dyad, verify that the person with dementia did not exit the
critical exterior doors without an alarm sounding, verify proper system functioning, and confirm appropriate caregiver knowledge regarding operation of the system (Rowe, 2003a). Likewise, due to scheduling issues, subsequent months were not always exactly one month apart.

**Vulnerable human subjects’ considerations**

Persons with dementia are considered a vulnerable population in ethical reviews. However, the primary impact of this study was on the caregivers. Interested caregivers, who contacted the research team for information, were given an explanation of the study and pre-screened by phone for inclusion criteria (except cognitive status assessment). Those qualifying were visited in the home, where the caregiver’s Mini-Mental State Exam (MMSE) (Folstein et al., 1975) was conducted. One caregiver scored too low on the MMSE and was not recruited. Consents differed according to group due to the complexity of the experimental consent; thus recruited subjects were asked to sign informed consents after group assignment was determined. An adult caregiver, including spouse, adult child, or other relative, gave consent for him or herself, and gave proxy consent for the person with dementia. Persons with dementia were asked to give assent for participation in the study (Rowe, 2003a).

Approval was obtained from the University of Florida Health Science Center Institutional Review Board. Data collected regarding persons with dementia were primarily collected from the caregiver; thus the main impact for the more vulnerable persons with dementia was the completion of an MMSE. There were times when collecting the MMSE for the person with dementia was not possible, for example, when persons with dementia were either non-verbal or seemed stressed by the researcher’s presence in the home. When it was determined that obtaining this measure of cognition was inappropriate given the specific situation, it was not collected (Rowe, 2003a).
Participants were allowed to withdraw from the study at any time; however, no subjects withdrew for reasons other than medical illness, death, or change in caregiving circumstances such as institutional placement. One subject consented but did not have any data collected after family concerns arose regarding her participation. One subject moved without notice, and another was lost to follow-up for unknown reasons (Rowe et al., 2008).

**Data considerations**

Data for this study were stored and maintained in a secure fashion. There were no personal identifiers such as name, address, etc. placed on questionnaires, forms, or data files from the field. Files for the study data are locked in a file cabinet in the office of the PI, and the key for ID numbers with personal information and informed consents remain in a separate locked file. Electronic data is stored in networked storage drives at the University of Florida Health Science Center, with only subject numbers as identifiers, accessible only with a password. Data from the original study will be maintained in this manner for a minimum of three years after completion of the study (Rowe, 2003a).

The study was monitored by the Data Safety Monitor Board (DSMB), to observe for adverse events related to the system, and for preliminary review of data. Reviews scheduled after the reliability phase of the first four subjects, after 10 homes reached the 3-month point, and after all treatment homes were in the trial for at least 3 months did not result in changes in the study. The PI of the original study generated a report at each point, and alerted the DSMB that a review was needed. Although there were provisions for early closure (Rowe, 2003a), these were not necessary as interim analysis did not demonstrate a worsening pattern in experimental group variables (caregiver sleep and injuries/exits in PWD).
Methodological Strengths of Original Study that Augment Dissertation Study

According to experts, researchers designing studies for community-based dementia care dyads should consider the inextricably ‘intertwined’ nature of the caregiver/PWD dyad, and in intervention studies, should include positive effects with clinical significance for both members of the dyad (Opie et al., 1999; Schulz, 2001; Zarit & Leitsch, 2001). The intervention in the original study had hypothesized clinical significance for both members of the dyad. More importantly to the dissertation study, the original study provides the dyadic caregiving setting necessary for the dissertation purpose and aims. The model proposed for the dissertation will be most suitable for use in studying non-pharmacologic, dyadic interventions for those in the community, provided it is supported in the dissertation and in future research, and delineates relationships between caregiver and care receiver variables. The original study provides the milieu necessary for initial testing of this model.

Another concern of experts is that dementia-related intervention studies should have more stringent designs to move the science forward (Ayalon et al., 2006; C. Beck, 1998; Burgener & Twigg, 2002a; Cohen-Mansfield, 2001b; Opie et al., 1999). Several design issues strengthen the original study, and thus the data that will be used in the dissertation study. First, the experimental design and mostly random assignment to treatment status group strengthens the study considerably, reducing possible threats to validity. In dementia care dyads, however, the control condition, meant to have little or no impact on outcomes, is often problematic. Many caregivers respond positively to a program simply because they receive affirmation for their efforts, attention, and a ‘sympathetic ear.’ Control and experimental groups should be developed with these considerations in mind (Schulz, 2001; Zarit & Leitsch, 2001). In the original study, caregivers were not in contact with other through the study intervention, and caregivers in both groups were visited at each collection point, and thus provided equivalent doses of this natural
part of the intervention. Additionally, the longitudinal design allows time for such a ‘placebo effect’ to wane.

The longitudinal design also lends strength to the data’s ability to describe change over time, and facilitates the use of more powerful statistical analysis techniques such as multi-level modeling to describe both within- and between-person change (Lyons & Sayer, 2005; Zarit & Leitsch, 2001). This was particularly important for the dissertation study, since data points in which there were no data available were easily accommodated using these techniques. Also, the capability of modeling both within-person and between-person changes over multiple waves in the study period will facilitate the ability to test the model (Fauth et al., 2006), since the relationships in the model were reflective of person-level trends, and dyad-level relationships. Acknowledging relationships within dyads provided more relevant results to test the model than combining the data from all caregivers and PWD would have yielded.

Lastly, in studies related to dementia subjects, the degenerative nature of diseases that cause dementia may be problematic, since changes in outcomes related to cognition may obscure any changes in related measures over time. Dementia-related BehSx may be more stable, may be more resistant to intervention, and may require a sufficient period of assessment to adequately understand their change trajectory (Gitlin et al., 2003a; Mittelman et al., 2004a). Even modest improvements or lack of decline over time can have a lasting impact within the dyad (Burns et al., 2003; Herrmann & Black, 2000; Zarit & Leitsch, 2001). The multiple measurement points in the original study will allow for within-person trends to be predicted, establishing change slopes over a year, and will also allow comparison by treatment group. While the intervention effectiveness for these outcomes is not the primary focus, demonstrating such change is
important for indirect support of the directionality of model relationships, as discussed in
Chapter 1.

In summary, the original study provides an excellent dataset for the dissertation study.
Change over time in the dissertation outcomes can be tested in relation to time-varying measures
from the original study that will adequately reflect stress process concepts included in the model.
The longitudinal design will allow more precise delineation of model pathways, with
consideration of within-person (or dyad) change, and between-person (or dyad) changes
according to group. The original study provides an appropriate community-based dyadic setting
for the testing of the proposed model.

**Dissertation Study**

**Dissertation Design**

The dissertation study is designed as a secondary analysis of data collected in the
previously described original study. The dissertation study aims primarily to test a conceptual
model of caregivers’ stress process and its influence within the dyad, particularly as related to
BehSx. Longitudinal data regarding variables that reflect the caregivers’ stress process, collected
in the original study, will be used in dissertation analyses. In addition, explicit design changes
were made early in the original study to include a tool for measuring outcomes for the
dissertation study, specifically, the Neuropsychiatric Inventory-Questionnaire (NPI-Q) (Kaufer et
al., 2000) for the measurement of PWD behavioral symptoms. NPI-Q data were collected at
each data point in the original study specifically for use in the dissertation, and these data were
used along with original study data to assess model relationships over time.

**Dissertation Subjects**

Entry and exclusion criteria in the dissertation study were the same as those utilized in the
original study. However; of the 53 dyads, four subjects from the original study had only baseline
data and were excluded from the dissertation analyses, which focused on change trajectories over time. Please see Figure 3-1 for the subject flow chart, and Tables 3-1 and 3-2 for complete demographic data on the sample caregivers and persons with dementia, respectively. These tables represent the entire sample except where indicated. Caregivers had a mean age of 62.81 and persons with dementia averaged 80.85 years. Over eighty percent of caregivers were female, and there were more male persons with dementia (54% male). Caregivers were more often wives (40%) or adult daughters (38%), with fewer husbands and sons in this role. There were proportionately more daughter caregivers in the control status, but this difference did not reach significance. Caregivers were predominantly white (78%), with 18% African-American, and 4% Hispanic. With the exception of 2 dyads, caregivers and PWD within dyads had the same race. The caregivers most often had at least some college education. There were no significant differences in the demographic findings according to treatment status. MMSE (Folstein et al., 1975) scores for persons with dementia were obtained in about half the original sample, with no significant difference in mean scores according to treatment status. The average score on the MMSE was 13.83 (range 2-26), reflecting moderate levels of dementia in the sample.

**Dissertation Procedures**

The dissertation study relies on the methods and rigor employed in the original study, and all procedures remained in compliance with IRB approval. Data for this study were stored and maintained under the auspices of the original study. IRB approval for changes to allow the addition of the NPI-Q for outcomes was obtained early in the data collection phase of the original study, and this dissertation study investigator was added to the original study team. Subjects already enrolled were consented again after the IRB approval of the NPI-Q for the dissertation study, and were aware that the data would be used to assess additional outcomes separately from the original aims of the study. Subsequently enrolled subjects were consented to
include outcome measures for the dissertation study (Rowe, 2003a). Although the NPI-Q was collected for re-consented subjects during subsequent data collection points, only 37 subjects had baseline data on the NPI-Q. Institutional Review Board approval was obtained to utilize the original study data in a secondary analysis.

The NPI-Q takes approximately 5 minutes to complete; thus it is anticipated that this did not deter persons from entering and completing the original study, despite the somewhat intense battery of tools that were completed at each data point. Every effort was made to make this additional time commitment convenient for participants, incorporating it into the user-friendly computer interface and providing any assistance needed in completing the tool.

**Dissertation Measures**

The NeuroPsychiatric Inventory-Questionnaire (NPI-Q) (Kaufer et al., 2000) was chosen to measure the dual outcomes of PWD behavioral symptoms and CG behavior-related reactions, reflecting the theoretical concept of dyadic consequences of the CG’s stress process. The NPI-Q was recently developed as a more efficient, self-administered version of the original Neuropsychiatric Inventory (NPI). The tool’s use of the caregiver as informant, as well as its brevity (and thus less time burden for stressed caregivers), were the primary features that made the NPI-Q appealing for this study. However, the NPI-Q is a more recent adaptation of the well-established, interview-based NPI; thus both will be discussed below.

**Neuropsychiatric Inventory**

The original NeuroPsychiatric Inventory (NPI) (Cummings, 1997; Cummings et al., 1994) was originally designed to help differentiate between types of dementia, and has been used extensively in medical research. The NPI is an informant-based, directed interview intended to assess a comprehensive set of neuropsychiatric symptom domains that may have occurred in persons with dementia over the previous month, including: delusions, hallucinations, dysphoria,
anxiety, agitation/aggression, euphoria, disinhibition, irritability/lability, apathy, aberrant motor behavior, and more recently, nighttime behaviors and appetite/eating disturbances (Cummings, 1997; Cummings et al., 1994; Lange et al., 2004).

Participant caregivers rate any present behaviors with regards to severity on a 3-point scale (1-3), and frequency on 4-point scale (1-4). Caregivers may then rate the distress they feel related to each positive symptom, from 0 (not distressing at all) to 5 (extremely distressing). Behavioral severity and frequency scores are multiplied to obtain a maximum score for each type of behavior, and domains are totaled for a sum score. Distress scores are totaled for a separate score reflecting caregiver reaction to behaviors (Cummings et al., 1994).

Reliability and validity have been established for the NPI (Cummings, 1997; Cummings et al., 1994; Forester & Oxman, 2003; Lange et al., 2004). Test-retest reliability for frequency/severity ranges from 0.51 to 1.0, and inter-rater reliability has been demonstrated as high (93.6-99%). Internal consistency has been established for severity (alpha 0.87), frequency (alpha 0.88), and frequency/severity product (0.88). The NPI has shown content validity, and convergent validity with the Reisberg BEHAVE-AD (Behavioral Pathology in Alzheimer’s Disease Rating Scale) (Reisberg et al., 1987) and the Hamilton Rating Scale for Depression (Hamilton, 1967). Various researchers have established differing factor structures among the behavior domains. The NPI is very well-accepted, and has been cited over 250 times in the research literature (Cummings, 1997; Cummings et al., 1994; Forester & Oxman, 2003; Lange et al., 2004). The tool has demonstrated change in relationship to treatment, and is one of the most commonly used measures in clinical trials. Clinical significance has been established as a score equal to or greater than 4 on the behavior scale (Lyketsos, 2007).
Neuropsychiatric Inventory-Questionnaire.

The NeuroPsychiatric Inventory-Questionnaire (NPI-Q) (Kaufer et al., 2000) was subsequently designed to allow for self-administration by informal caregivers, with proxy assessment of behaviors in PWD, to improve the applicability of the NPI, using written instructions to direct the caregiver in rating items. Caregivers first answer yes/no regarding presence absence of behaviors in the domain, using guiding questions to improve understanding. If behavioral domains are endorsed, severity is ranked (from 1-3, total 36) and related caregiver distress may be ranked (from 1-5, total 60). Only severity of BehSx is ranked in this tool to improve its brevity, one of its primary design criterions. The frequency is removed, with the rationale that severity more closely correlates with caregiver distress, and having both is somewhat redundant since they are highly correlated (Forester & Oxman, 2003).

The NPI-Q demonstrated convergent validity with the NPI using 60 dementia caregivers, as well as internal consistency and test-retest reliability. Correlations between the NPI total score and the NPI-Q total score was 0.91 for behaviors. Correlations were higher in the group of subjects with lower cognition. Prevalence of behaviors was slightly higher (5%) on the NPI-Q. For the NPI-Q domains, correlations ranged from 0.71 and 0.93 for behaviors and between 0.71 and 0.97 for caregiver distress. Test-retest correlations for behaviors and distress were 0.80 and 0.94, respectively (Kaufer et al., 2000). In this study, only the behavior scale was utilized in the testing the model, and the Cronbach’s alpha for the behavior scale in this study was 0.817.

Measurements from Original Study

The dyads’ treatment status group assignment in the original study will be used as a predictor in analyses in the dissertation study. Additional measures from the original study are described below.
Mini-Mental Status Examination.

The Mini-Mental Status Examination (MMSE) (Folstein et al., 1975) was used as an inclusion criteria for caregivers, and was measured in care recipients to establish cognitive disability among PWD. The MMSE assesses orientation, recall, attention, calculation, reading, language, and ability to follow commands, name objects, write a sentence, and copy an object. The maximum score is 30, and higher scores reflect higher cognition. Reliability and validity were originally established in 206 patients with mental disorders and 63 normal patients. Normal subjects averaged scores of 27.6, while those with dementia averaged 9.7; age did not contribute significantly to scores. Test-retest reliability at 24 hours and 28 days were adequate, at .89 and .98, respectively. Two examiners achieved 24-hour retest reliability of .83. Concurrent validity was established with the Wechsler Adult Intelligence Scale (WAIS), with Pearson $r$ of .78 on verbal portions of the WAIS, and .66 on the performance portions. It was concluded that the exam distinguished those with cognitive impairment from normal subjects (Folstein et al., 1975).

Some concerns have arisen regarding the MMSE’s potential education bias, flooring effects and sensitivity for diagnosing and staging dementia. However, these concerns are not consistently supported, and the MMSE has been widely used and considered a reliable and valid instrument, quick to administer, for screening of cognitive status (Ashford et al., 1989; Harrell et al., 2000; Jones & Gallo, 2001; Mitrushina & Satz, 1991; O'Connor et al., 1989; Perneczky et al., 2006; Rapp et al., 2002; Schmand et al., 1995; Tombaugh & McIntyre, 1992). In this study, among the persons with dementia who completed the MMSE, the alpha was 0.821.

Short version of the Zarit Burden Interview

An abridged version of the Zarit Burden Interview (ZBI) (Zarit et al., 1985; Zarit et al., 1980) was selected to measure caregiving burden in the original study, and will be used to reflect
caregivers’ perceived stress in the dissertation study. The original form of the Zarit (Zarit et al., 1980) tool included 29 items, but the 22-item revised version (Zarit et al., 1985) gained recognition and is the instrument most often used to measure perceived stress in dementia caregiving research. Considered valid and reliable, it has been used to demonstrate differences between groups of participants and to measure change over time (Bedard et al., 2001). Several versions of shortened interview scales have been proposed (Bedard et al., 2001; R. Hebert et al., 2000; Whitlatch et al., 1991), but the Bedard version was designed to be more appropriate for longitudinal research (Bedard et al., 2001). The Short Zarit Burden Inventory-Bedard (ZBI-Bedard) was utilized in the original study.

To validate the Short ZBI-Bedard, the data were analyzed from 413 caregivers at baseline, with follow-up at about 6 months. All care recipients had cognitive impairment, and caregivers were primarily spouses (62.5%) and women (58.8%). The authors used factor analysis, change scores, and dementia diagnosis, along with item-total correlations, to reduce the 22-items down to twelve; the alpha coefficient was 0.89 in the final version. Correlations between the short and full versions ranged between 0.92 and 0.97. The authors suggested that a score of 17 or higher may reflect high perceived stress, but cautioned that this can not be considered normative. The short version was confirmed as an adequate substitute for the longer version, appropriate for cross-sectional, longitudinal, and intervention studies. Questions regarding burden perceptions are answered on a scale from 0 (never) to 4 (nearly always), with a potential range of 0-48 (Bedard et al., 2001). The tool was further validated and found reliable in a population-based (Canadian) randomly selected sample, where a cut-off score of 10 improved sensitivity (to 75%) but lowered specificity (to 68%), leading authors to conclude that it was premature to assign a
cut-off score for ‘too much burden’ (O’Rourke & Tuokko, 2003). In this study, the Cronbach’s alpha was 0.889.

**Center for Epidemiologic Studies-Depression scale.**

The CES-D (Radloff, 1977) is a self-administered instrument that assesses subjects regarding the frequency of 20 depressive symptoms during the past week, using a 4-point scale from ‘rarely or none of the time’ to ‘most of the time.’ Composite scores range from 0 to 60, with higher scores indicating more depressive symptoms. In the original tool, four items were worded to assess positive affect with the intent of breaking tendencies toward responding negatively, and were reverse-scored for contributing to the composite score (Radloff, 1977). This practice was later questioned, considered a violation of assessing the construct of ‘negative affect’ using ‘positive affect’ symptoms, with only the 16 negative item factor confirmed valid (Schroevers et al., 2000). In the original study, where data were collected for use in this dissertation study, these four positive items were changed to reflect the opposite negative affect, to present a less confusing assessment to the stressed caregivers in this sample (Rowe et al., 2008). For example, feeling *not as good* replaced *just as good* as others, *hopeless* replaced *hopeful*, *unhappy* replaced *happy* and *not enjoying* replaced *enjoyed* life.

The validity and reliability of the CES-D is widely supported. The original tool was validated with large samples of normal adults from two communities in the US (average 9.25, n=2,514), and a patient sample (average 24.42, n=70) (Radloff, 1977). Validity was supported in a community sample of older adults (average 9.1, n=3,932) compared to those with schizophrenia (average 13.0, n=50), persons recovered from depression (average 14.9, n=87 and those with acute depression (average 38.1, n=148) (Weissman et al., 1977). The CES-D has demonstrated criterion and construct validity; it has excellent internal consistency with alpha coefficients usually ranging from .85 to .91, moderate test-retest correlations, and has
demonstrated response to intervention (Beekman et al., 1997; R. G. Knight et al., 1997; Musil et al., 1998; Radloff, 1977; Rose-Reggo et al., 1998; Weissman et al., 1977).

A score of 16 or greater on the CES-D has been established to reflect significant symptomatology (Myers & Weissman, 1980; Radloff, 1977). This cut-off score resulted in 100% sensitivity and 88% specificity in one study (Beekman et al., 1997), and in 1711 older adults, scores greater than 16 during a 9-months period was correlated with greater use of health services and poorer perceived health (Callahan et al., 1994). The CES-D has been utilized in caregivers extensively to assess depressive symptoms (C. A. Cohen et al., 2002; Gallicchio et al., 2002; Hooker et al., 2000; Loewenstein et al., 2001; Rose-Reggo et al., 1998; Schulz et al., 2004). For example, in dementia caregivers from a national caregiver research initiative, 1229 caregivers were used to demonstrate associations between greater frequency and importance of religious practices and lower CES-D scores (R. S. Hebert et al., 2007). In this study, the Cronbach’s alpha was 0.923.

**Positive and Negative Affect Schedule.**

The Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988) was developed as a simple, brief self-report assessment of positive and negative affect, using items that were relatively pure markers of the mood factor, with near zero loadings on the opposite factor. The 10 positive and 10 negative items on the tool are scored with a 5-point Likert scale ranging from ‘very slightly or not at all’ to ‘extreme.’ Various temporal designations can be used, from ‘now, this moment,’ to ‘year,’ or ‘in general’ (Watson et al., 1988). In the original study reported herein, the number of items was reduced to 10, five each positive and negative, to decrease the burden of completing the tool in the sample of time-stressed dementia caregivers (Rowe, 2003a). The items chosen were those that had the greatest variability in a large sample of community-dwelling older adults (Diehl, 2005). In this dissertation study, only the items reflecting response
to the stress process in a negative way were scored, including the items ‘distressed,’ ‘scared,’ ‘irritable,’ ‘nervous,’ and ‘jittery.’ The daily mean of these items was calculated and ranged from 0-5. These were measured each morning upon awakening over a one-week time period, and daily mean scores were averaged to give a mean negative affect score for the week at the measurement point if at least 3 days were recorded.

The PANAS was originally tested in a sample of primarily college students, and found to have high internal consistency (alpha coefficients ranging from .86-.90 for various temporal designations), excellent convergent and discriminant validity with lengthier measures and with items compared to their own and opposite factor, concurrent validity, and re-test stability over a 2-month time period. When rated for ‘the moment,’ the items verified fluctuations in mood, while measures for ‘year’ or ‘in general’ demonstrated trait-like stability; even moment-based measurements were found to be somewhat reflective of one’s general dispositional affect. The negative affect scale, but not the positive, was significantly related to perceived stress, and was stable across the 24-hour time period. The tool was comparatively valid and reliable in a smaller clinical sample (Watson et al., 1988) and in a large non-clinical sample (n= 1,003) in the UK (Crawford & Henry, 2004). The negative and positive factor structure has been supported, (Crawford & Henry, 2004; Denollet & De Vries, 2006), and the negative affect portion of the scale has also been shown to split further into two factors, such as ‘anxiety & anger,’ vs. ‘guilt & shame’ (J. G. Beck et al., 2003), and ‘upset’ vs. ‘afraid’ (Killgore, 2000). In this study, the Cronbach’s alpha for the reduced instrument using only the negative 0.960.

**Composite negative mood score.**

In the dissertation study, a composite Negative Mood score was established using scores from the CES-D and the Negative Affect scale from the PANAS. Z-scores were created from both measures based on the sample means, and these two Z-scores were averaged. The resulting
negative mood score was used in analyses regarding model relationships to reflect caregivers’ emotional responses to stress.

**Statistical Analysis**

In this dissertation study, stress process variables and treatment status from the original study were examined in relation to BehSx. Systematically missing data for these outcomes is addressed, and preliminary analyses are described. Lastly, multilevel modeling was used to test the model presented herein. All data analyses used SPSS version 14, and SPSS syntax was used for multilevel analyses. This study used a significance level of < 0.05 in all statistical tests, with corrections as noted.

**Missing data**

Due to a computer glitch in the laptop-based data collection interface, there was data missing in approximately 1-2% of the potential NPIQ behavior items (9 data points; 53 dyads, 12 NPI-Q items (5724 total possible items); 81 values missing). This error occurred as selections were made by subjects on the electronic data collection interface. When the caregiver answered yes to questions on the presence of 3 of the 12 items, ‘irritability,’ ‘motor disturbance,’ and ‘nighttime behaviors,’ they were mistakenly directed to the screen that assessed their distress, skipping the option to rate the severity of behavior. This issue was addressed early in the study, but there remained some missingness even in later months from some study computers.

These data were not missing at random, since an equipment failure caused errors in which data that were missing were related to observed data in the same assessment tool; this data could be considered to be ‘systematically’ missing. Furthermore, although multi-level modeling using maximum likelihood can accommodate missingness across data points such as is related to drop-outs or skipped appointments (Fitzmaurice et al., 2004; Schafer, 2007), the missingness
described in this instance occurred within items that were used for sum scores collected at each
data point, and thus could not be accommodated by such sophisticated modeling methods.

Conventional wisdom says that one could use one or several methods to calculate a score
for these missing values: other subjects’ answers for those items, that subject’s answers at other
months, and other answers on the scale for that subject at that month; in this particular case
caregiver ratings of distress related to the behavior could also be used to assist with imputation of
the missing items. However, since the rate of missingness was low and range of possibilities was
so narrow, such complicated techniques were considered inappropriate given the returns on the
investment of effort. Simple averaging methods have been shown to perform adequately
compared to more complex, state-of-the-art techniques in similar situations (Schafer, 2007;
Schafer & Graham, 2002), and were also considered (see Appendix A).

This missingness was ultimately remedied by calculating behavioral symptoms as a mean
of the items available for that person at that data point. In other words, if 9 items were
answered, the total score was divided by 9, and then the mean was multiplied by twelve (# of
items that should have been scored) to return the value to the more familiar scale. This adjusted
value was identical to sum scores for those subjects who answered all 12 items, but reflected
what was known about the behaviors in persons where less than 12 items were answered. This
method was used if at least 9 items on the scale were answered. This method was also utilized in
instruments from the original study when an item was missing.

**Preliminary analyses**

Univariate and bivariate statistics were used to describe the sample across all data points
for each model variable. Means and standard deviations were calculated for the sample, and
according to treatment status group. Histograms were examined for evidence of normality. T-
tests were used to establish the outcome of group random assignment for model variables at
baseline. Pearson correlations were used to establish relationships between variables at baseline. T-tests were also used to compare treatment status group means across data points, with Bonferroni corrections for multiple comparisons. Individual subjects’ outcomes were graphed over time and examined for evidence of non-linear patterns.

**Model testing**

The repeated measures, the presence of missing data, and the unequal time distances for data collection made multilevel modeling a natural fit for these analyses. A brief description of the analyses follows, and a more detailed account of the estimation methods and analysis techniques may be found in Appendix B.

Multilevel modeling techniques are very versatile, and models can be estimated in a number of ways. Of interest in this study was their ability to estimate variable trajectories both within persons over time, and averaged across persons over time. In the data, the measurements over time (level one) were nested within persons and the persons were level two, with treatment status a person level factor that influenced measures within persons. Such longitudinal designs are considered a special case of hierarchical or multilevel modeling that addresses such clustering of data within persons rather than ignoring it by aggregating the person’s data together (Cho, 2003). ‘Days,’ indicating days from baseline, was a considered the covariate that reflected time. While measurement occasion or month of the study might also have been used to indicate time, these did not adequately reflect the study design, wherein measurements were not equidistant, particularly from baseline to month 2 in the experimental group compared to controls, and in the last six months compared to the first six. Month of study was, however, used as the repeated term to provide structure for the covariances, and in graphical comparisons of modeled values.
Maximum likelihood was used to estimate models for each variable, in several stages: a) an unconditional means model without predictors, to establish variance for further modeling; b) an unconditional growth model with only time as a predictor, to establish whether there was enough variance within persons to model level 2 factors; c) an unstructured conditional model, with treatment status as a level 2 or person-level factor, to assess for reduction in within-person variance; and lastly d) several conditional models with treatment status at level 2 and with the covariance structured. The covariance was structured by adding a random statement with \textit{month} as the repeated variable and testing several covariance structures, including \textit{unstructured}, \textit{ante-dependence}, \textit{first order}, \textit{compound symmetry}, \textit{compound symmetry, heterogeneous}, \textit{auto-regressive}, \textit{first order}, \textit{auto-regressive, heterogeneous}, \textit{toeplitz}, and \textit{toeplitz, heterogeneous}. These structures were chosen based on their expected longitudinal variances and correlations across elements. The Akaike information criterion (AIC) was used to compare the models with the default covariance model (\textit{variance components or diagonal}); this criterion balances complexity with parsimony in indicating the best model fit. The covariance model with the lowest AIC was considered the final model for each of the variables.

In order to evaluate the hypotheses related to relationships in the model, variables were created to reflect the caregivers’ average and centered predictors. These variables were designated as fixed effects, and in the case of the centered predictors, as random effects, to allow assessment of predictor influence on PWD BehSX \textit{within} dyads and averaged \textit{across} dyads (fixed effects) to reflect the population’s effects. These analyses were also conducted using maximum likelihood estimation, and the covariance was structured using the repeated statement and AIC as the criterion for evaluating various structures.
Figure 3-1. Original Study subjects entry/exclusion from dissertation study analyses.
Table 3-1. Description of sample caregivers.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control</th>
<th>Experimental</th>
<th>Sample</th>
<th>Group Assignment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>t (p)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>62.81 (10.50)</td>
<td>61.83 (13.83)</td>
<td>62.35 (12.05)</td>
<td>0.28 (0.78)</td>
</tr>
<tr>
<td>Count (Expected)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>23 (21.2)</td>
<td>17 (18.8)</td>
<td>81.6%</td>
<td>1.72 (0.19)</td>
</tr>
<tr>
<td>Male</td>
<td>3 (4.8)</td>
<td>6 (4.2)</td>
<td>18.4%</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>22 (20.2)</td>
<td>16 (17.8)</td>
<td>77.6%</td>
<td>2.89 (0.24)</td>
</tr>
<tr>
<td>African-American</td>
<td>4 (4.8)</td>
<td>5 (4.2)</td>
<td>18.4%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 (1.1)</td>
<td>2 (.9)</td>
<td>4.1%</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS graduate</td>
<td>3 (4.2)</td>
<td>5 (3.8)</td>
<td>16.3%</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>12 (13.3)</td>
<td>13 (11.7)</td>
<td>51.0%</td>
<td>3.29 (0.35)</td>
</tr>
<tr>
<td>College graduate</td>
<td>7 (4.8)</td>
<td>2 (4.2)</td>
<td>18.4%</td>
<td></td>
</tr>
<tr>
<td>Graduate school</td>
<td>4 (3.7)</td>
<td>3 (3.3)</td>
<td>14.3%</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>17 (17.5)</td>
<td>16 (15.5)</td>
<td>67.3%</td>
<td>0.10 (0.76)</td>
</tr>
<tr>
<td>Employed</td>
<td>9 (8.5)</td>
<td>7 (7.5)</td>
<td>32.7%</td>
<td></td>
</tr>
<tr>
<td>Relationship to PWD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>9 (11.1)</td>
<td>12 (9.9)</td>
<td>42.9%</td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>2 (2.1)</td>
<td>2 (1.9)</td>
<td>8.2%</td>
<td></td>
</tr>
<tr>
<td>Daughter</td>
<td>14 (9.6)</td>
<td>4 (8.4)</td>
<td>36.7%</td>
<td>8.63 (0.07)</td>
</tr>
<tr>
<td>Son</td>
<td>1 (2.7)</td>
<td>4 (2.3)</td>
<td>10.2%</td>
<td></td>
</tr>
<tr>
<td>Granddaughter</td>
<td>0 (0.5)</td>
<td>1 (0.5)</td>
<td>2.0%</td>
<td></td>
</tr>
</tbody>
</table>
Table 3-2. Description of sample persons with dementia.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Control</th>
<th>Experimental</th>
<th>Sample</th>
<th>Group Assignment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>t (p)</td>
</tr>
<tr>
<td>Age (in years)</td>
<td>80.85 (9.29)</td>
<td>78.65 (6.64)</td>
<td>79.82 (8.15)</td>
<td>0.94 (0.35)</td>
</tr>
<tr>
<td>PWD cognition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N</td>
<td>14</td>
<td>13</td>
<td>27</td>
<td>0.51 (0.61)</td>
</tr>
<tr>
<td>MMSE score</td>
<td>14.00 (7.84)</td>
<td>15.38 (6.08)</td>
<td>14.67 (6.95)</td>
<td></td>
</tr>
<tr>
<td>PWD Gender*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13 (11.5)</td>
<td>9 (10.5)</td>
<td>45.8%</td>
<td>.80 (0.37)</td>
</tr>
<tr>
<td>Male</td>
<td>12 (13.5)</td>
<td>14 (12.5)</td>
<td>54.2%</td>
<td></td>
</tr>
<tr>
<td>Race*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>20 (19.3)</td>
<td>17 (17.7)</td>
<td>77.1%</td>
<td>1.16 (0.56)</td>
</tr>
<tr>
<td>African-American</td>
<td>5 (5.2)</td>
<td>5 (4.8)</td>
<td>20.8%</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 (0.5)</td>
<td>1 (0.5)</td>
<td>2.1%</td>
<td></td>
</tr>
<tr>
<td>Diagnosis*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer's</td>
<td>18 (19.7)</td>
<td>19 (17.3)</td>
<td>78.7%</td>
<td></td>
</tr>
<tr>
<td>Lewy body</td>
<td>2 (1.1)</td>
<td>0 (0.9)</td>
<td>4.3%</td>
<td></td>
</tr>
<tr>
<td>Vascular</td>
<td>3 (2.1)</td>
<td>1 (1.9)</td>
<td>8.5%</td>
<td></td>
</tr>
<tr>
<td>Unspecified</td>
<td>1 (1.6)</td>
<td>2 (1.4)</td>
<td>6.4%</td>
<td>4.19 (0.38)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (0.5)</td>
<td>0 (0.5)</td>
<td>2.1%</td>
<td></td>
</tr>
</tbody>
</table>

*Note: One control caregiver did not specify gender & race for the PWD, and one PWD in each treatment status group did not have a diagnosis indicated.*
CHAPTER 4
FINDINGS

The purpose of this study was to test a model in which both CG Perceived Stress and CG Emotional Responses were hypothesized to have a direct positive relationship with PWD BehSx, and it was expected that when both variables were modeled as predictors, the effects of Perceived Stress would be reduced, in a manner similar to mediation. A secondary purpose was to describe the temporal patterns of the model variables, and evaluate the influence of Treatment Status from the parent study on the concepts’ trajectories over time. In this chapter, preliminary descriptive findings are presented, and study variables and relationships are modeled over time, within and across dyads. The sample was previously described in chapter 3, along with management of systematically missing data on the NPI-Q instrument (also discussed in detail in Appendix A). Appendix B contains detailed information about the multilevel analyses conducted in this study.

Univariate and Bivariate Descriptives

Sample means and standard deviations for model variables are displayed in Table 4-1. These are presented across each data point (months) in the study, and then considering all data points available for all caregivers.

The Short Zarit Burden Inventory (ZBI)-Bedard was utilized as a measure of Perceived Stress. Caregivers’ scores, on average, ranged from 19.09 to 21.86 on a scale of 0-48 across the data points. When all available data points for all caregivers were considered, the mean was 20.74 (SD= 8.62) with a range of 0-47.

The caregivers’ CES-D and Negative PANAS scales had a significant moderate correlation (0.57; p=.000; N=49) at baseline and are conceptually similar. In order to reduce the total number of model variables, Z-scores were created using the grand mean across all subject and
data points, and subjects Z-scores were averaged to form a composite Emotional Response measure. Caregivers’ emotional responses averaged between -0.086 to +0.069 across the study. When all data points for all caregivers were considered, the mean was -0.002 (SD= 0.90), and caregivers Emotional Responses ranged from -1.25 to +2.86.

The NPI-Q behavior scale was used to measure BehSx, and since it was added after the original study began, only thirty-four dyads out of the total sample of 49 had baseline values. PWD BehSx scores, on average, ranged from 9.04 to 11.58 across the study. When all available data points from all PWD were considered, the average was 10.55 (SD= 7.28), with a range from 0 to31.

Bivariate relationships were described using t-tests. Baseline means for the treatment status groups were compared for significant differences, for each of the model variables. The significance level was corrected due to the large number of comparisons (Bonferroni: there are 3 t-tests, 0.05 /3 = 0.017). After adjustments, there were no significant differences at baseline for any of the model variables.

T-tests comparing treatment status groups for each of the variables are also reported across all data points in Table 4-1. In general, differences between treatment status groups decreased from baseline to month 5, and then increased from month 6 to month 12. Finally, all available data points for all dyads were considered, and there was a significant difference in each of the model variables over the study period. These differences are simply aggregate comparisons, however, and do not reflect change over time.

Observed scores for each of the model variables were compared over the study period according to Treatment Status, and the means are graphed in Figures 4-1 through 4-3. For Emotional Responses, the component measures, depressive symptoms (CES-D) and mood
(Negative PANAS) are also graphed over the study period for comparison, in Figures 4-4 and 4-5. Standard errors are also presented in the graphs. Control caregivers and persons with dementia had visually evident higher variability among scores than experimental subjects over measurement points in the study, particularly during the last half of the study. At month 5, in an unexplained inconsistent occurrence, the two groups had essentially the same mean for PWD Behavioral Symptoms, with the control group symbol obscuring that of the experimental group. It is noteworthy that regardless of treatment status, average BehSx remained above the score that reflects clinical significance (>4).

Pearson correlations were calculated between the three model variables at baseline and at 12 months (see Table 4-2). Perceived Stress and Emotional Responses had the highest correlation at baseline, and at the final data point, BehSx and Perceived Stress were most correlated. BehSx correlated more strongly to both predictors at Month 12 than at baseline. Correlations among model variables across all potential data points were moderate and significant (see table 4-3), with the outcome BehSx more strongly correlated to Perceived Stress than to Emotional Responses.

Lastly, distribution of the measurements was assessed over time. Distribution of Perceived Stress is adequately normal; however, both Emotional Responses and BehSx are slightly skewed to the right, with values bunched more densely at the lower end of the range (median= -.2004 and 9.0, respectively). Histograms were examined and also reflected this skewness. However, the skewness statistics remained between 1 and -1 (Perceived Stress 0.23, SE= 0.13; Emotional Responses 0.75, SE=0.13; Behavioral Symptoms 0.59, SE=0.14), reflecting adequately normal distributions; kurtosis values were below 0.5 for each variable.
Change over Time in Model Variables

Multilevel modeling was used to estimate separate models of change over time for each of the model variables, as outlined in Aim #1. A brief description of the analyses follows. Please see Appendix B for more detailed information. Multilevel modeling was chosen to allow individual trajectories to be predicted at Level 1 (within persons), and to allow estimation by Treatment Status at Level 2 (across persons). Each variable was first assessed with an empty model, with no random effects. For each variable, several models with both fixed and random effects were estimated. First, an unconditional means model determined whether there was enough variation at Level 1 to conduct further analyses (Model A). Next, an unconditional growth (i.e., change) model assessed the effect of time (Model B). Random effects were assessed for significant variance to model a Level 2 predictor. Within-person variance (random effects) and between-person population effects (fixed effects) were estimated with Treatment Status as the Level 2 predictor (Model C), and the covariance was structured by adding a repeated statement and testing alternative structures, which were chosen for their suitability to longitudinal data (Model D).

All models estimated using the maximum likelihood procedures. Maximum likelihood estimation uses an iterative procedure to determine the estimates that represent the highest probability that the data came from the population, through examination of within- and between-person variability, and assigning sample means more weight when persons had high within-persons variability compared to the sample, or were missing data points (Fitzmaurice et al., 2004; Singer & Willett, 2003). Variance components structure was used for random structure in initial modeling of each variable. Models were compared to the baseline unconditional models using change in the -2LL criterion. Additionally, the model’s ability to explain variance identified at both Level 2 (fixed effects; between-persons variance) and Level 1 (random effects;
within-persons variance) were considered in assessing models’ improvement. This reduction in variance through modeling is somewhat comparable to the use of $R^2$ in traditional models. However, this so-called pseudo- $R^2$ is a bit different. This figure represents the reduction of explainable variance in the models, so a fairly small change can result in a large percentage of change (Singer, 1998). Lastly, covariance structures were evaluated using fit statistics that adjust for degrees of freedom automatically, the AIC and BIC. The AIC was determined to be the most appropriate criterion in this study (Fitzmaurice et al., 2004); however, the two criteria often agreed, and most often did not improve upon the default (variance components).

Multilevel models assume a linear trend, and deviations from this need to be addressed in modeling. Trends over time within individuals were investigated, and these preliminary assessments are addressed in Appendix C. The findings from these assessments supported the use of linear modeling. However, there was substantial intra-individual variability in all three model variables, and the variation in direction and magnitude of change was such that within-person modeling was warranted, and that it was prudent to establish the form of the trend over time within the modeling process. Therefore, change models were estimated with linear, quadratic, and cubic change (cubic not presented herein). Orthogonal quadratic change functions were computed to avoid multi-collinearity between the linear and quadratic terms, using the residuals from a regression of the quadratic term on the linear term. The residuals from this regression reflected the unique contribution of quadratic change, independent of linear change.

**Perceived Stress in Caregivers**

The model construction procedure for caregivers’ Perceived Stress is outlined in Table 4-4. The unconditional means model (A) revealed that approximately 71% of the variance in Perceived Stress was unexplained. Intra-class correlations were calculated, and approximately 18% of the explainable variance was within subjects ($12.99 + 58.33=71.32; 12.99/71.32= 0.18$),
with the large majority between subjects. In the unconditional change models (B), while the linear change model had improved criteria, the linear trend itself was non-significant. The form of the overall change trend most representative of the data was quadratic. The fixed quadratic trend was significant, and the random, within-person trend approached significance (shown separately in Table 4-7), indicating that the general overall trend (across dyads) was quadratic. The quadratic change model resulted in an improvement over the unconditional means model, with a significant reduction in the -2LL, and with approximately 17% of the explainable within-persons variance explained (between-person variance essentially unchanged). Using this model as a baseline for further comparisons, adding treatment status approached significance ($p=0.08$) in its improvement in the model (C), and the addition of month as a repeated variable and various covariance structures (D) did not converge or improve the model. Since the model with treatment added (C) approached significance in criteria reduction, and explained an additional 11% of the variance between persons, this model was accepted as the final model for Perceived Stress, indicating a better representation of the data than change alone.

Parameters for the final model are described in Table 4-7. In the final model, the overall intercept at mid-study for Perceived Stress was 18.56 ($p=0.00$), and the effect of treatment status was significant ($p=0.018$), with control subjects averaging 5.03 points higher than experimental subjects (at mid-study). The effect of linear time was not significant, but quadratic time was significant in the population ($p=0.01$); the quadratic estimate, however, was negligible, although it did approach significance within persons. These findings indicate that, on average, subjects displayed a quadratic trend. The Treatment*Time interactions with both linear and quadratic time were not significant, indicating that both treatment status groups followed the same pattern of change over time. The random residuals, reflecting variation within persons, remained
significant (estimate 10.83, \( p=0.00 \)). The intercept variance also reflected significant variability remaining between subjects (estimate 52.70, \( p= 0.00 \)).

**Emotional Responses in Caregivers**

The model construction procedure for Emotional Responses is outlined in Table 4-5. The unconditional means model (A) revealed that the unexplained variance was low (.82). Intra-class correlations revealed that 27% of the unexplained variance was within subjects (.22 +.60=.82; \( .22/ .82=.27 \)) and 73% was between persons (.60/.82=.73). In the unconditional change models (B), the form of the overall change trend was quadratic across subjects (seen separately in Table 4-7). The primarily quadratic change model resulted in an improvement over the unconditional means model and the linear change model, with a significantly improved \( \chi^2 \) LL, and with approximately 22% of the within-persons variance explained compared to 14% in the linear change model (between-person variance increased 3%). Using the quadratic change model as a baseline, adding treatment to the model (C) did not result in significant improvement in the \( \chi^2 \) LL (decreased 1.932 with 2 degrees of freedom). Furthermore, there was only a 4% gain in between-persons variance explained, and the within-persons variance changed negligibly.

Structuring the random effects (D) by adding both month as a repeated variable and AR1 as the covariate structure improved the amount of between-persons variance explained to 8%, but the previously described within-persons variance explained (in the accepted change model) dissipated almost completely (decreased 21%). Furthermore, this covariance-structured model also lacked significance in the \( \chi^2 \) LL change. Based on these analyses, it was concluded that the unconditional change model represented the data best.

The parameters for the final change model (unconditional change) are presented in Table 4-7. The overall intercept for Emotional Responses was 0.0002 and non-significant at mid-study \( (p=0.999) \). Linear and quadratic change over time were negligible; however, the fixed quadratic
trend was significant ($p= 0.045$), indicating that the general trend within the population was quadratic. Treatment and Treatment*Time interactions were not included in the final Emotional Responses model because they failed to improve the model. The random residuals reflected significant within-person variance remaining (estimate $0.17$, $p= 0.00$), and intercepts across persons were significantly variable ($0.62$, $p= 0.00$). Additionally, random linear and quadratic changes within persons were estimated. While the change over time within persons was very small, linear change was significant ($p= 0.018$), and quadratic change was non-significant. Stated otherwise, the quadratic trend did not hold for all persons; some displayed linear trends more prominently that distinguished them from the sample as a whole.

**Behavioral Symptoms in Persons with Dementia**

The model construction procedure for BehSx is outlined in Table 4-6. The unconditional means model (A) revealed that approximately half the variance in BehSx was unexplained. Intra-class correlations were calculated, and approximately 35% of the unexplained variance was within subjects ($17.29 + 32.27= 49.56$; $17.29/49.56 = .35$), with the remaining variance due to between-subjects effects. The form of the overall change trend was indiscernible in the sample when unconditional change models were run (B); thus the simplest form, linear, was utilized. The linear change model resulted in an improvement over the unconditional means model: a significant reduction in the `2LL, with approximately 2% of the within-persons variance explained, and approximately 3% reduction in between-person variance. However, the fixed (averaged) linear trend itself was non-significant, and the random (within-person) effect over time needed to be removed to allow convergence of the model to occur. Random intercepts remained, allowing subjects to vary in intercepts, but they had similar slopes over time. Adding treatment status to the model (C) provided further improvement in the model: the reduction in the `2LL was significant compared to the accepted change model, and an additional 7% of
between-persons as well as 1% of within-persons variance was explained. Providing structure for the random effects through adding a repeated measures statement and various covariance structures did not improve the model. These models either did not converge or increased the criteria, indicating poor fit compared to the default variance components structure.

Parameters from the final model are described in Table 4-7. The overall intercept (population mean) for BehSx was 9.084 at mid-study \( (p= 0.00) \), and the effect of time was not significant. The effect of treatment status approached significance \( (p= 0.056) \), with control subjects averaging 3.19 points higher than experimental subjects at mid-study. The linear time*treatment interaction also approached significance \( (p= 0.075) \), with control subjects increasing approximately 0.06 per day from baseline \( (p= 0.082) \), and experimental subjects decreasing 0.003 (NS). The random residuals reflected significant variance remaining within subjects’ measurements (estimate 16.61, \( p= 0.00 \)), and the intercepts across persons were significantly variable (estimated variance 29.29, \( p= 0.00 \)) at mid-study. The high variability remaining within and across persons supports the addition of either fixed or random predictors to explain the variance.

**Model Assumptions**

In this study, careful consideration of missingness due to dropout was important, since the outcome measure, BehSx, is known to contribute to institutional placement decisions, and thus dropout may have been related to current and future unobserved data. This generally means that data were *missing not at random*. However, according to Singer & Willett (2003), missing data may be considered *missing at random*, even though it is related to the measures that are missing, if those missing measures are expected to be strongly correlated with values that have been previously obtained (p. 159). In this study, unobserved BehSx scores that may have been associated with dropout through institutional placement were expected to be correlated with
previously observed measures for the subject, supporting the plausibility of the *missing at random* assumption.

Nonetheless, careful examinations of violations of the assumption of missingness were conducted in two ways. First, final models were run with dyads that completed the study and results were compared to those of the total sample. Second, completion of the study (vs. not completing) was used in comparative analyses to determine whether dropout was related to covariates or factors that should be considered in future modeling.

Completion of the study was defined for these analyses as those dyads that remained in the study at month 12. Missed data points earlier in the study did not disqualify the dyad from designation as a completer. The final models for each variable were run using only those who completed the trial (67% of dyads), and there were only minor differences. For example, in the BehSx model, the Time*Treatment interaction moved to significant (despite fewer subjects/observations and supposed less power), and the treatment difference (intercept at mid-study) was not yet significant. Slightly more of the within-subject variance was explained, while less of the between-subject variance was accounted for. Similar findings resulted when Perceived Stress and Emotional Response final models were run.

Completion of the study vs. not completing was used as a factor in exploring time-invariant sample descriptives from baseline for potential contributions to missingness, including:

- Treatment status
- Caregiver gender, race, relationship, working/not, education, and age
- PWD gender, race, diagnosis, age, and MMSE

For example, this allowed determination regarding whether variables (such as gender) influenced dropout later in the study. All chi-square and ANOVA tests were non-significant, indicating that these descriptive variables did not influence whether dyads completed the study or not.
Additionally, within-person-averaged perceived stress, emotional responses, and BehSx were not significantly different between those who completed the study and those who did not.

Although it remains possible that drop-out related missingness is missing not at random, these analyses lend support to the tenability of the missing at random assumption. Furthermore, selection models or missingness pattern models were considered unrealistic (no determinable patterns of covariate-related missingness). In this study, therefore, the drop-out related missingness was considered missing at random, or ‘ignorable.’

In addition to addressing the missing data assumption, residuals from each of the model were assessed for meeting the assumptions of multilevel models as recommended by Singer & Willett (2003, pages 131-132). The probability plots of the residuals from the estimated final models against the observed estimates were inspected, and displayed adequate normality. The model residuals were also assessed for equal variance at each data point (month), to support the homoscedasticity assumption. Visual inspections of the plots reveal similar range and variability at each data point.

**Hypothesized Relationships**

The relationships hypothesized in aim #2 were also assessed using multilevel modeling. First, variables were created from each subject’s data to reflect the caregivers’ within-person variation and within-person mean for both Perceived Stress and Emotional Responses.

Specifically, within-person change was represented with centered variables, using each caregiver’s own mean to establish subjects’ deviation or variation from their mean at a given data point, and these were modeled as both a random (within dyad) and a fixed effect (averaged across dyads for the population or fixed effect). The effect of centered variables within dyads was interpreted as the effect of the caregiver’s current perceived stress level (compared to average) on BehSx in their care recipient with dementia. Across dyads, the effect of centered
caregiver variables was that, on average, when the populations’ caregiver stress variables were higher than usual, the BehSx in PWD were higher as well, with the opposite also occurring. This effect reflected how caregivers’ changing stress process might influence BehSx over time within the population.

Additionally, within-person means were modeled as a fixed effect (means were averaged across dyads for the average population or fixed effect); each subject’s contribution to the average was the same regardless of data point. The effect of mean caregiver variables was interpreted such that caregivers whose stress was, for example, higher than the population average, had care recipients with dementia who also had more severe BehSx, across the study regardless of data point.

Caregivers’ Perceived Stress and Emotional Responses were modeled as predictors in this manner separately first, and then in a combined model wherein Emotional Responses was expected to reduce the effects of Perceived Stress, similar to way a mediator reduces the effect of a predictor. This reduction was expected both within and across dyads.

Separate Effects of Perceived Stress and Emotional Responses

The initial step of assessing these relationships was to establish patterns in BehSx for PWD within the dyads, which was also the first step in aim #1. Therefore, the model building represented in Table 4-8 begins with the accepted change model for BehSx from aim #1. Adding the caregivers’ Perceived Stress (model C) and Emotional Responses (model D) as both fixed effects (centered and mean) and random effects (centered) improved the model criteria significantly, indicating that both variables are associated with BehSx (more on the interpretation in the next section).

In the significantly improved Perceived Stress → BehSx model, 33% of the between-persons variance and 13% of the within-persons variance was explained, that had previously
been unexplained in the BehSx change model. The significantly improved Emotional Responses$\rightarrow$BehSx model comparatively explained 27% of the between-persons and 6% of the within-persons variance previously unexplained. While not shown in the table both mean Perceived Stress and mean Emotional Responses were also modeled as moderators of the change over time in these relationships; in both cases, the interactions were non-significant and the model criteria did not improve.

‘Mediation’

Next, both variables were entered in a combined model with the Perceived Stress$\rightarrow$BehSx model as a comparison, in effect assessing whether Emotional Response variables mediated the relationship between Perceived Stress and BehSx. The change in the $-2\text{LL}$ from the Perceived Stress$\rightarrow$BehSx model was not significant, and the model did not converge successfully. Thus, the combined model did not improve upon the Perceived Stress$\rightarrow$BehSx model. However, once the random effects of the centered variables were removed, model convergence was successful and the combined model was significantly improved in comparison to the Perceived Stress$\rightarrow$BehSx model. Thus, in this combined model, mean and centered Perceived Stress and Emotional Responses were fixed effects, and only the random intercept was modeled. Attempts to further improve the model (by providing structure to the random parameters) were not successful; model criteria did not improve. This model did explain an additional 4% of between-persons variance, but also explained 4% less of the within-persons variance compared to the Perceived Stress$\rightarrow$BehSx model, probably because the random effects included the intercept only. To assess for reduction of the effects of Perceived Stress in the combined model, the model parameters will be assessed.
Model Parameters

The estimated parameters for each of the models are shown in Table 4-9. Recall that time is centered at mid-study. Therefore, intercepts reflect the average number of days from baseline.

Perceived stress

When controlling for the effects of caregivers’ Perceived Stress (mean and centered), the mid-study intercept of BehSx severity and the effects of time on BehSx were not significant in the population. When a caregiver’s mean Perceived Stress is one point higher than the population average, BehSx in the PWD increases by 0.42 ($p = 0.00$). In addition, on months when caregivers’ current level of perceived stress, on average, are one point higher than usual, PWD levels of BehSx severity increase by 0.33 ($p = 0.00$). Within dyads, the residual random effects of BehSx are highly variable (estimate 14.69, $p = 0.00$) when the caregivers’ Perceived Stress average and deviation from average are considered. Across dyads, there is also significant variability remaining among intercepts (estimate 21.14, $p = 0.00$), and the random within-dyad effect of the caregiver’s Perceived Stress compared to their average on BehSx was not significant at mid-study. In other words, at this particular point in the study, the individual caregiver’s level of Perceived Stress had not influenced the BehSx of the PWD in their care.

Emotional responses

The BehSx intercept at mid-study was 10.67 (SE = 0.73; $p = 0.00$) while controlling for caregivers’ Emotional Responses (mean and centered). The effect of time was non-significant. When mean Emotional Responses differ by 1 point, BehSx also differ by 3.57, and when caregivers’ emotional responses vary, on average, from their usual by one point, BehSx vary by 2.14. Though these effects may seem high compared to those of Perceived Stress, recall that the Emotional Responses variable was based on z-scores with a range constrained between 1 and −1; thus these values reflect an approximate maximum change in BehSx based on caregivers’
Emotional Responses. The residual random effects, or variability of BehSx within dyads, remains high (estimate 15.78, \( p = 0.00 \)). Variability of BehSx intercepts across dyads is also significant (estimate 23.10, \( p = 0.00 \)), and there is no significant within-dyad effect of current deviation of caregiver’s emotion on BehSx of the PWD they care for at mid-study.

**‘Mediation’ model**

In the combined ‘mediation’ model, mid-study intercepts and the effects of time are again not significant, and Mean Emotional Responses no longer have significant effects on BehSx. When caregivers’ Mean Perceived Stress differs by one point, the BehSx vary by 0.32. Although this is slightly reduced from the Perceived Stress \( \rightarrow \) BehSx model, the non-significant effect in Mean Emotional Response negates the possibility of reduction of the effect by the presence of Mean Emotional Response. However, caregivers’ current level of Emotional Responses, on average, did have a significant effect, and may have contributed to these changes. When caregivers’ measures were, on average, increased by one point, BehSx in PWD, on average, increased by 0.29 and 1.29 for Perceived Stress (\( p = 0.00 \)) and Emotional Responses (\( p = 0.02 \)), respectively. Thus current levels of Emotional Responses may have reduced effects of current levels of Perceived Stress on BehSx. However, the effect was only slightly reduced. The BehSx intercepts resulting from this model remain highly variable across dyads (estimate 20.42, \( p = 0.00 \)), and within-person variability is also significant (estimate 15.13, \( p = 0.00 \)).

**Summary of Findings in relation to Proposed Model**

The model was supported to some extent, as seen in the effects presented in Figures 4-6 through 4-9. BehSx and Perceived Stress models were improved by adding treatment, but Emotional Responses model was not. Only BehSx revealed a Treatment*Time interaction that was supportive of the model. Perceived Stress did not change over time in interaction with treatment status. To summarize, BehSx did appear to diverge over time according to treatment
status. Yet BehSx may not have changed as a result of changes in caregivers’ stress process, since Perceived Stress and Emotional Responses did not diverge significantly according to Treatment status.

Regarding the model relationships, Path C (adding Perceived Stress as a predictor of BehSx) was significant with 33% between- and 14% within-dyad variance explained. Path B (adding Emotional Responses as a predictor of BehSx) was significant with 27% between- and 6% within-dyad variance explained. While it was expected that when both predictors were modeled (combined model), the effects of Perceived Stress would be reduced in the presence Emotional Responses, this model was only partially supportive of the hypotheses. Effects of Perceived Stress, on average, were slightly reduced, and caregivers’ current levels of Emotional Responses may have been responsible for the reduction of the reduction. However, the mean levels of Emotional Responses overall were not significant in the combined model. Furthermore, the current levels of Emotional Responses were also reduced from their previous model. These results are, therefore, inconclusive regarding whether a “mediation” effect occurred. Nonetheless, there is strong evidence for the effect of caregivers’ stress process variables on BehSx separately, and this provides support for the underlying model premise, that caregivers’ stress process may affect BehSx in PWD.
Table 4-1. Means, standard deviations, and \( t \)-tests by treatment status for observed scores across 9 data points for model variables.

<table>
<thead>
<tr>
<th>Month of study (M)</th>
<th>Base-Line</th>
<th>M2</th>
<th>M3</th>
<th>M4</th>
<th>M5</th>
<th>M6</th>
<th>M8</th>
<th>M10</th>
<th>M12</th>
<th>All Months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>(SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Short Zarit Burden</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interview-Bedard)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diff. t-test</td>
<td>5.14</td>
<td></td>
<td>5.44</td>
<td>5.16</td>
<td>3.94</td>
<td>4.32</td>
<td>3.76</td>
<td>5.60</td>
<td>6.87</td>
<td>7.40</td>
</tr>
<tr>
<td>df</td>
<td>47</td>
<td></td>
<td>44</td>
<td>46</td>
<td>38</td>
<td>37</td>
<td>36</td>
<td>30</td>
<td>28</td>
<td>25</td>
</tr>
<tr>
<td>(p)</td>
<td>.04</td>
<td></td>
<td>.02</td>
<td>.05</td>
<td>.13</td>
<td>.11</td>
<td>.14</td>
<td>.07</td>
<td>.05</td>
<td>.07</td>
</tr>
<tr>
<td>Emotional Responses</td>
<td>.102</td>
<td>(.906)</td>
<td>.011</td>
<td>.086</td>
<td>.058</td>
<td>.054</td>
<td>.048</td>
<td>.147</td>
<td>.069</td>
<td>.021</td>
</tr>
<tr>
<td>(CES-D &amp; NegPANAS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.002</td>
</tr>
<tr>
<td>combined*)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diff. t-test</td>
<td>0.34</td>
<td></td>
<td>0.48</td>
<td>0.37</td>
<td>0.56</td>
<td>0.36</td>
<td>0.23</td>
<td>0.54</td>
<td>0.52</td>
<td>0.55</td>
</tr>
<tr>
<td>df</td>
<td>47</td>
<td></td>
<td>41.99</td>
<td>47</td>
<td>38</td>
<td>37</td>
<td>23.05</td>
<td>29</td>
<td>31</td>
<td>354.47</td>
</tr>
<tr>
<td>(p)</td>
<td>.19</td>
<td></td>
<td>.07</td>
<td>.33</td>
<td>.06</td>
<td>.20</td>
<td>.42</td>
<td>.04</td>
<td>.08</td>
<td>.17</td>
</tr>
<tr>
<td>Behavioral Symptoms</td>
<td>11.58</td>
<td>(7.12)</td>
<td>9.49</td>
<td>11.00</td>
<td>11.22</td>
<td>9.04</td>
<td>9.70</td>
<td>10.61</td>
<td>11.07</td>
<td>11.44</td>
</tr>
<tr>
<td>(Neuro-Psychiatric</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10.55</td>
</tr>
<tr>
<td>Inventory-Questionnaire-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Behaviors)</td>
<td>2.92</td>
<td></td>
<td>3.34</td>
<td>4.60</td>
<td>2.35</td>
<td>0.63</td>
<td>1.89</td>
<td>2.56</td>
<td>2.89</td>
<td>3.14</td>
</tr>
<tr>
<td>Diff. t-test</td>
<td>1.18</td>
<td></td>
<td>1.36</td>
<td>2.12</td>
<td>.98</td>
<td>.03</td>
<td>.82</td>
<td>1.04</td>
<td>1.53</td>
<td>1.65</td>
</tr>
<tr>
<td>df</td>
<td>32</td>
<td></td>
<td>31</td>
<td>43</td>
<td>34</td>
<td>34</td>
<td>35</td>
<td>30</td>
<td>27</td>
<td>20.5</td>
</tr>
<tr>
<td>(p)</td>
<td>.25</td>
<td></td>
<td>.19</td>
<td>.04</td>
<td>.33</td>
<td>.98</td>
<td>.42</td>
<td>.31</td>
<td>.14</td>
<td>.11</td>
</tr>
</tbody>
</table>

*combined z-scores from Center for Epidemiologic Study-Depression and negative portion of the Positive & Negative Affect Schedule.

Note: SD= standard deviation; Diff.= difference in means between control and experimental subjects.
Table 4-2. Pearson correlations between model variables at Baseline (below the diagonal) and Month 12 (above the diagonal & underlined with dashes).

<table>
<thead>
<tr>
<th></th>
<th>Perceived Stress</th>
<th>Emotional Response</th>
<th>Behavioral Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>Perceived Stress</td>
<td>Emotional Response</td>
<td>Behavioral Symptoms</td>
</tr>
<tr>
<td>N</td>
<td>1</td>
<td>.725**(n=30)</td>
<td>.786**(n=27)</td>
</tr>
<tr>
<td></td>
<td>.688**(n=49)</td>
<td>1</td>
<td>726**(n=27)</td>
</tr>
<tr>
<td></td>
<td>.442** (n=34)</td>
<td>.490**</td>
<td>1</td>
</tr>
</tbody>
</table>

**Significant at the 0.01 level (2-tailed).
Table 4-3. Pearson correlations (and list-wise means) between model variables across all dyads and data points (list-wise N=308).

<table>
<thead>
<tr>
<th></th>
<th>Perceived Stress</th>
<th>Emotional Response</th>
<th>Behavioral Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Stress</td>
<td>1</td>
<td>.680**</td>
<td>.527**</td>
</tr>
<tr>
<td>Emotional Response</td>
<td>--</td>
<td>1</td>
<td>.475**</td>
</tr>
<tr>
<td>Behavioral Symptoms</td>
<td>--</td>
<td>--</td>
<td>1</td>
</tr>
</tbody>
</table>

Mean and (SD)

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Stress</td>
<td>20.61</td>
<td>(8.91)</td>
</tr>
<tr>
<td>Emotional Response</td>
<td>-0.005</td>
<td>(.93)</td>
</tr>
<tr>
<td>Behavioral Symptoms</td>
<td>10.49</td>
<td>(7.21)</td>
</tr>
</tbody>
</table>

**Significant at the 0.01 level (2-tailed).
### Table 4-4. Model construction criteria for Perceived Stress

<table>
<thead>
<tr>
<th>Model Description</th>
<th>2LL'</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual (within) variance</th>
<th>Intercept (between) variance</th>
<th>Δ2LL' From Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>r² btw</th>
<th>r² wth</th>
</tr>
</thead>
<tbody>
<tr>
<td>A) Unconditional means model</td>
<td>2053.47</td>
<td>2059.47</td>
<td>2071.04</td>
<td>12.99</td>
<td>58.33</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>B1) Unconditional linear change Random intercept + slopes</td>
<td>2042.96</td>
<td>2052.96</td>
<td>2072.20</td>
<td>12.65</td>
<td>58.45</td>
<td>10.51</td>
<td>5</td>
<td>(&lt;.0005)</td>
<td>0.002</td>
<td>0.0261</td>
</tr>
<tr>
<td>B2) Unconditional quadratic orthotic chg. Random intercept + slopes</td>
<td>2022.58</td>
<td>2036.58</td>
<td>2063.52</td>
<td>10.79</td>
<td>58.85</td>
<td>30.89 (+20.38)</td>
<td>7</td>
<td>(&lt;.0004)</td>
<td>-0.009</td>
<td>0.1695</td>
</tr>
<tr>
<td>Based on above modeling, accepted quadratic orthotic change model with random intercept + slopes (model B2) as &quot;baseline&quot; for treatment models. All unconditional models used &quot;variance components&quot; (VC) random structure.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C) Conditional quadratic orth. chg. With Treatment (VC)</td>
<td>2015.80</td>
<td>2035.80</td>
<td>2074.30</td>
<td>10.83</td>
<td>52.70</td>
<td>6.78</td>
<td>10</td>
<td>(0.08)</td>
<td>0.1046</td>
<td>-0.004</td>
</tr>
<tr>
<td>D1) Conditional quadratic orth. chg. With Treatment, Month repeated</td>
<td>2009.41</td>
<td>2045.41</td>
<td>2114.70</td>
<td>By Month</td>
<td>53.63</td>
<td>13.17</td>
<td>18</td>
<td>(0.28)</td>
<td>0.0984</td>
<td>n/a</td>
</tr>
<tr>
<td>D2) Conditional quadratic orth. chg. With treatment, month, AR1</td>
<td>2013.32</td>
<td>2035.32</td>
<td>2077.67</td>
<td>11.62</td>
<td>52.57</td>
<td>9.249</td>
<td>11</td>
<td>(0.06)</td>
<td>0.1103</td>
<td>-0.217</td>
</tr>
</tbody>
</table>

Based on above modeling, accepted the conditional quadratic orthotic change model with treatment status as the final model for change (C); approached significance and explained 11% of previously unexplained variance between persons (D1-3 did not converge or improve).

**Note:** 2LL' = 2 Log Likelihood; AIC = Akaike's Information Criteria; BIC = Schwarz's Bayesian Criterion; Δ2LL = change in 2LL from previous baseline model; # PAR = number of parameters in model, used to establish df and p to determine whether model is a significant improvement over baseline model or last accepted model (using chi-square); $r^2_{btw}$ = between-subjects pseudo R-squared, estimate of the portion of variance explained; $r^2_{wth}$ = within-subjects pseudo R-squared, estimate of the portion of variance explained; VC = Variance Components (default); UN = unstructured; AR1 = Auto-Regressive, First Order; ARH1 = Auto-Regressive, Heterogeneous; AD1 = Ante-Dependence, First Order; CS = Compound Symmetry; CSH = Compound Symmetry, Heterogeneous; TP = Toeplitz; TPH = Toeplitz, Heterogeneous.
Table 4-5. Model construction criteria for Emotional Responses.

<table>
<thead>
<tr>
<th>Model</th>
<th>'2LL'</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual (within) variance</th>
<th>Intercept (between) variance</th>
<th>Δ '2LL From Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>r²_btw</th>
<th>r²_wth</th>
</tr>
</thead>
</table>
| A) Unconditional means model  
“Baseline” for change models | 626.19 | 632.19 | 643.87 | 0.22 | 0.60 | - | 3 | - | - |
| B1) Unconditional linear change  
Random intercept + slopes | 604.98 | 614.98 | 634.37 | 0.19 | 0.62 | 21.21 | 5 | 2 (.<0001) | -0.021 | 0.1458 |
| B2) Unconditional quadratic orth. chg.  
Random intercept + slopes | 595.57 | 609.57 | 636.71 | 0.17 | 0.62 | 30.63 (+9.41) | 7 | 2 (.009) | -0.034 | 0.2224 |

Based on above modeling, accepted quadratic orthotic change model with random intercept & slopes (model B2) as "baseline" for treatment models. All unconditional models used ‘variance components’ (VC) random structure.

<table>
<thead>
<tr>
<th>Model</th>
<th>'2LL'</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual (within) variance</th>
<th>Intercept (between) variance</th>
<th>Δ '2LL From Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>r²_btw</th>
<th>r²_wth</th>
</tr>
</thead>
</table>
| B2) Unconditional quadratic orth. chg.  
Random intercept + slopes | 595.57 | 609.57 | 636.71 | 0.17 | 0.62 | - | 7 | - | - |
| C) Conditional quadratic orth. chg.  
With Treatment (VC) | 593.63 | 613.63 | 652.41 | 0.17 | 0.60 | 1.93 | 9 | 2 (0.381) | 0.0379 | 0.0002 |
| D1) Conditional quadratic orth. chg.  
With Treatment, Month repeated  
By Month | 584.99 | 620.99 | 690.79 | 0.21 | 0.58 | 7.07 | 11 | 4 (0.132) | 0.0772 | 0.214 |
| D2) Conditional quadratic orth. chg.  
With treatment, month, AR1 | 588.50 | 610.50 | 653.15 | 0.21 | 0.58 | 7.07 | 11 | 4 (0.132) | 0.0772 | 0.214 |

Based on above modeling, accepted the unconditional quadratic orthotic change model (B2) as the final model for change (treatment did not improve model).

Note: '2LL' = 2 Log Likelihood; AIC= Akaike’s Information Criteria; BIC= Schwarz’s Bayesian Criterion; Δ '2LL = change in '2LL from previous baseline model; # PAR= number of parameters in model, used to establish df and p to determine whether model is a significant improvement over baseline model or last accepted model (using chi-square); r²_btw = between-subjects pseudo R-squared, estimate of the portion of variance explained ; r²_wth = within-subjects pseudo R-squared, estimate of the portion of variance explained; VC= Variance Components (default); UN= unstructured; AR1= Auto-Regressive, First Order; ARH1= Auto-Regressive, Heterogeneous; AD1= Ante-Dependence, First Order; CS= Compound Symmetry; CSH= Compound Symmetry, Heterogeneous; TP= Toeplitz; TPH= Toeplitz, Heterogeneous.
Table 4-6. Model construction criteria for BehSx.

<table>
<thead>
<tr>
<th>Model</th>
<th>‘2LL’</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual variance (within)</th>
<th>Intercept variance (between)</th>
<th>Δ2LL From Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>r² btw</th>
<th>r² wth</th>
</tr>
</thead>
<tbody>
<tr>
<td>A)  Unconditional means</td>
<td>1879.41</td>
<td>1885.41</td>
<td>1896.61</td>
<td>17.29</td>
<td>32.27</td>
<td>-</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>B1) Unconditional linear change</td>
<td>1853.73</td>
<td>1863.73</td>
<td>1882.35</td>
<td>16.83</td>
<td>31.55</td>
<td>25.67</td>
<td>5</td>
<td>(&lt;.0001)</td>
<td>0.0223</td>
<td>0.0264</td>
</tr>
<tr>
<td>Random intercept + slopes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B2) Unconditional linear change</td>
<td>1853.73</td>
<td>1861.73</td>
<td>1876.63</td>
<td>16.83</td>
<td>31.55</td>
<td>25.67</td>
<td>4</td>
<td>(&lt;.0001)</td>
<td>0.0223</td>
<td>0.0264</td>
</tr>
<tr>
<td>Random intercept only</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B3) Unconditional quadratic change</td>
<td>1850.90</td>
<td>1862.90</td>
<td>1885.24</td>
<td>16.45</td>
<td>31.18</td>
<td>28.50 (+2.83)</td>
<td>6</td>
<td>0.243</td>
<td>0.0339</td>
<td>0.0487</td>
</tr>
<tr>
<td>Random intercept + slopes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B4) Unconditional quadratic orthotic chg.</td>
<td>1850.80</td>
<td>1862.80</td>
<td>1885.14</td>
<td>16.38</td>
<td>31.35</td>
<td>28.60 (+2.93)</td>
<td>6</td>
<td>0.231</td>
<td>0.0284</td>
<td>0.0527</td>
</tr>
<tr>
<td>Random intercept + slopes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on above modeling, accepted linear change model with random intercept only (model B2) as "baseline" for treatment models (B1 did not converge).

All unconditional models used 'variance components' (VC) random structure.

| B2) Unconditional linear change            | 1853.73 | 1861.73 | 1876.63 | 16.84                      | 31.55                        | -             | 4     | -          | 0.0223 | 0.0264 |
| Random intercept only (VC)                 |         |         |         |                            |                              |                |       |            |        |        |
| C)  Conditional linear change with         | 1846.91 | 1858.91 | 1181.26 | 16.61                      | 29.29                        | 6.82           | 6     | 0.033      | 0.0715 | 0.0134 |
| Treatment (VC)                             |         |         |         |                            |                              |                |       |            |        |        |
| D)  Providing Structure for covariance     |         |         |         |                            |                              |                |       |            |        |        |
| did not improve model fit (Month as repeated; UN, AR1, ARH1, AD1, CS, CSH, TP, & TPH structures) |         |         |         |                            |                              |                |       |            |        |        |

Based on above modeling, accepted the conditional linear change model with treatment status (C) as the final model for change.

Note: ‘2LL’ = -2 Log Likelihood; AIC= Akaike’s Information Criteria; BIC= Schwarz’s Bayesian Criterion; Δ2LL = change in ‘2LL from previous baseline model; # PAR= number of parameters in model, used to establish df and p to determine whether model is a significant improvement over baseline model or last accepted model (using chi-square); r² btw = between-subjects pseudo R-squared, estimate of the portion of variance explained; r² wth = within-subjects pseudo R-squared, estimate of the portion of variance explained; VC= Variance Components (default); UN= unstructured; AR1= Auto-Regressive, First Order; ARH1= Auto-Regressive, Heterogeneous; AD1= Ante-Dependence, First Order; CS= Compound Symmetry; CSH= Compound Symmetry, Heterogeneous; TP= Toeplitz; TPH= Toeplitz, Heterogeneous.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Fixed Effects (Population) Estimates</th>
<th>Type III sig. tests</th>
<th>Estimates of Covariance Parameters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate</td>
<td>SE</td>
<td>df</td>
</tr>
<tr>
<td>PERCEIVED STRESS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>18.56</td>
<td>1.54</td>
<td>48.63</td>
</tr>
<tr>
<td>Linear time</td>
<td>0</td>
<td>0</td>
<td>Redundant</td>
</tr>
<tr>
<td>Quadratic time</td>
<td>0.00004</td>
<td>0.00</td>
<td>26.96</td>
</tr>
<tr>
<td>Treatment (con)</td>
<td>5.03</td>
<td>2.12</td>
<td>49.32</td>
</tr>
<tr>
<td>Linear*Treatment (con)</td>
<td>0.005</td>
<td>0.00</td>
<td>48.30</td>
</tr>
<tr>
<td>Quadratic*Treatment (con)</td>
<td>0.00003</td>
<td>0.00</td>
<td>43.38</td>
</tr>
<tr>
<td>quadractic*Treatment (exp)</td>
<td>0.00002</td>
<td>0.00</td>
<td>28.88</td>
</tr>
<tr>
<td>BEHAVIORAL SYMPTOMS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>0.0002</td>
<td>0.12</td>
<td>48.97</td>
</tr>
<tr>
<td>Linear time</td>
<td>0.00004</td>
<td>0.00</td>
<td>36.96</td>
</tr>
<tr>
<td>Quadratic time</td>
<td>0.00005</td>
<td>2.21</td>
<td>22.44</td>
</tr>
<tr>
<td>quadractic*Treatment (exp)</td>
<td>0.00002</td>
<td>0.00</td>
<td>271.36</td>
</tr>
<tr>
<td>quadractic*Treatment (exp)</td>
<td>0.00002</td>
<td>0.00</td>
<td>271.49</td>
</tr>
</tbody>
</table>

Note: Bold= Significant; Bold Italics= approached significance; Intercepts reflect mean number of days from baseline.
Table 4-8. Model construction criteria for effects of Caregivers’ Stress Process Variables on PWD BehSx.

<table>
<thead>
<tr>
<th>Model</th>
<th>'2LL'</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual (within) variance</th>
<th>Intercept (between) variance</th>
<th>( \Delta 2LL' ) from Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>( r^2_{bw} )</th>
<th>( r^2_{wth} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>B4)</td>
<td>1853.73</td>
<td>1861.73</td>
<td>1876.63</td>
<td>16.83</td>
<td>31.55</td>
<td>-</td>
<td>4</td>
<td>-</td>
<td>0.0223</td>
<td>0.0264</td>
</tr>
<tr>
<td>C)</td>
<td>1810.87</td>
<td>1824.87</td>
<td>1850.94</td>
<td>14.69</td>
<td>21.14</td>
<td>42.86</td>
<td>7</td>
<td>3</td>
<td>(0.0001)</td>
<td>0.3298</td>
</tr>
<tr>
<td>D)</td>
<td>1826.85</td>
<td>1840.85</td>
<td>1866.91</td>
<td>15.78</td>
<td>23.10</td>
<td>26.89</td>
<td>7</td>
<td>3</td>
<td>(0.0001)</td>
<td>0.2678</td>
</tr>
</tbody>
</table>

Based on modeling from Table 4-4, BehSx model with random intercept only (model B4) as "baseline" for further modeling of caregiver variables’ effects.

Based on above modeling, both Perceived Stress and Emotional Responses have influence on BehSx. Model C (Perceived Stress \( \rightarrow \) BehSx) will serve as baseline for combined models to examine the relationships in the theoretical model.

<table>
<thead>
<tr>
<th>Model</th>
<th>'2LL'</th>
<th>AIC</th>
<th>BIC</th>
<th>Residual (within) variance</th>
<th>Intercept (between) variance</th>
<th>( \Delta 2LL' ) from Bas</th>
<th># PAR</th>
<th>df (p)</th>
<th>( r^2_{bw} )</th>
<th>( r^2_{wth} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1)</td>
<td>1806.67</td>
<td>1826.67</td>
<td>1863.90</td>
<td>15.13</td>
<td>20.91</td>
<td>4.205</td>
<td>10</td>
<td>3</td>
<td>(0.24)</td>
<td>0.0344</td>
</tr>
<tr>
<td>E2)</td>
<td>1804.35</td>
<td>1836.35</td>
<td>1895.93</td>
<td>15.13</td>
<td>20.42</td>
<td>4.205</td>
<td>8</td>
<td>1</td>
<td>(0.04)</td>
<td>0.0344</td>
</tr>
<tr>
<td>E3)</td>
<td>1804.35</td>
<td>1836.35</td>
<td>1895.93</td>
<td>15.13</td>
<td>20.42</td>
<td>4.205</td>
<td>8</td>
<td>1</td>
<td>(0.04)</td>
<td>0.0344</td>
</tr>
<tr>
<td>E4)</td>
<td>1806.49</td>
<td>1824.49</td>
<td>1858.00</td>
<td>15.30</td>
<td>20.27</td>
<td>4.381</td>
<td>9</td>
<td>1</td>
<td>(0.6748)</td>
<td>0.0414</td>
</tr>
<tr>
<td>E5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on above modeling, both Perceived Stress and Emotional Responses have influence on BehSx. Model C (Perceived Stress \( \rightarrow \) BehSx) will serve as baseline for combined models to examine the relationships in the theoretical model.

Note: '2LL' = 2 Log Likelihood; AIC= Akaike’s Information Criteria; BIC= Schwarz’s Bayesian Criterion; \( \Delta 2LL \) = change in 2LL from previous baseline model; \# PAR= number of parameters in model, used to establish df and p to determine whether model is a significant improvement over baseline model or last accepted model (using chi-square); \( r^2_{bw} \) = between-subjects pseudo R-squared, estimate of the portion of variance explained; \( r^2_{wth} \) = within-subjects pseudo R-squared, estimate of the portion of variance explained; VC= Variance Components (default); UN= unstructured; AR1= Auto-Regressive, First Order; ARH1= Auto-Regressive, Heterogeneous; AD1= Ante-Dependence, First Order; CS= Compound Symmetry; CSH= Compound Symmetry, Heterogeneous; TP= Toeplitz; TPH= Toeplitz, Heterogeneous.
Table 4-9. Final Model Parameters estimated for BehSx as predicted by Perceived Stress and Emotional Responses.

<table>
<thead>
<tr>
<th></th>
<th>Fixed Effects (Population) Estimates</th>
<th>Type III sig. tests</th>
<th>Estimates of Covariance Parameters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Estimate</td>
<td>SE</td>
<td>df</td>
</tr>
<tr>
<td>PERCEIVED STRESS ALONE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>1.86</td>
<td>2.01</td>
<td>48.48</td>
</tr>
<tr>
<td>Linear time</td>
<td>0.00</td>
<td>0.00</td>
<td>277.03</td>
</tr>
<tr>
<td>Mean Perceived Stress</td>
<td>0.42</td>
<td>0.09</td>
<td>48.67</td>
</tr>
<tr>
<td>Centered Perceived Stress</td>
<td>0.33</td>
<td>0.08</td>
<td>31.83</td>
</tr>
<tr>
<td>EMOTIONAL REPSONSES ALONE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>10.67</td>
<td>0.73</td>
<td>49.29</td>
</tr>
<tr>
<td>Linear time</td>
<td>0.00</td>
<td>0.00</td>
<td>276.94</td>
</tr>
<tr>
<td>Mean Emotional Responses</td>
<td>3.57</td>
<td>0.91</td>
<td>48.80</td>
</tr>
<tr>
<td>Centered Emotional Resp.</td>
<td>2.14</td>
<td>0.61</td>
<td>18.19</td>
</tr>
<tr>
<td>COMBINED MODEL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with random intercept only</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>4.01</td>
<td>2.90</td>
<td>48.13</td>
</tr>
<tr>
<td>Linear time</td>
<td>0.00</td>
<td>0.00</td>
<td>277.74</td>
</tr>
<tr>
<td>Mean Perceived Stress</td>
<td>0.32</td>
<td>0.13</td>
<td>48.71</td>
</tr>
<tr>
<td>Mean Emotional Responses</td>
<td>1.29</td>
<td>1.30</td>
<td>49.50</td>
</tr>
<tr>
<td>Centered Perceived Stress</td>
<td>0.29</td>
<td>0.07</td>
<td>259.66</td>
</tr>
<tr>
<td>Centered Emotional Resp.</td>
<td>1.29</td>
<td>0.56</td>
<td>261.18</td>
</tr>
</tbody>
</table>

Note: Intercepts reflect mean number days from baseline.
Zarit Burden Interview-Bedard

Figure 4-1. Caregivers’ Perceived Stress as observed over Time by Treatment Status (means and standard error bars).
<table>
<thead>
<tr>
<th>Month of Study</th>
<th>CON</th>
<th>EXP</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0.21</td>
<td>-0.08</td>
</tr>
<tr>
<td>2</td>
<td>0.19</td>
<td>-0.26</td>
</tr>
<tr>
<td>3</td>
<td>0.09</td>
<td>-0.23</td>
</tr>
<tr>
<td>4</td>
<td>0.29</td>
<td>-0.19</td>
</tr>
<tr>
<td>5</td>
<td>0.22</td>
<td>-0.13</td>
</tr>
<tr>
<td>6</td>
<td>0.07</td>
<td>-0.15</td>
</tr>
<tr>
<td>8</td>
<td>0.18</td>
<td>-0.39</td>
</tr>
<tr>
<td>10</td>
<td>0.47</td>
<td>-0.22</td>
</tr>
<tr>
<td>12</td>
<td>0.12</td>
<td>-0.26</td>
</tr>
</tbody>
</table>

Figure 4-2. Caregivers’ Emotional Responses as observed over Time by Treatment Status (means and standard error bars).
Figure 4-3. PWD Behavioral Symptoms as observed over Time by Treatment Status (means and standard error bars).
Figure 4-4. Caregivers’ Depressive Symptoms as observed over Time by Treatment Status (means and standard error bars).
Figure 4-5. Caregivers’ Negative Affect/Mood as observed over Time by Treatment Status (means and standard error bars).
Model ($p=0.08$) explained 10% between-dyad variance & 17% within-dyad variance.

**Perceived Stress over Time across dyads (by Treatment Status)**

Fixed Estimates:
- Intercept 18.56 ($p=0.00$);
- Control status +5.03 ($p=0.02$);
- Quadratic Time 0.0004 ($p=0.11$; type III $p=0.01$);
- Linear Time & Treatment*Time Interactions NS

Random Covariance Parameters:
- Variance Within 10.83 ($p=0.00$)
- Intercept variance 52.70 ($p=0.00$)

Linear Time NS
- Quadratic Time 0.000 ($p=0.07$)

Figure 4-6. Perceived Stress modeled over Time by Treatment Status; Demonstrates no effect of Treatment over Time.
Model ($p = 0.009$) explained 3% between-dyad variance & 22% within-dyad variance.

**Emotional Responses over Time across dyads (no Treatment Status)**

**Fixed Estimates:**
Intercept & Linear Time NS;
Quadratic Time 0.000005 ($p = 0.05$)

**Random Covariance Parameters:**
Variance Within 0.17 ($p = 0.00$)
Intercept variance 0.62 ($p = 0.00$)
Linear Time 0.000003 ($p = 0.02$)
Quadratic Time NS

Figure 4-7. Emotional Responses modeled over Time; Demonstrates no effect of Treatment over Time.
Figure 4-8. Behavioral Symptoms modeled over Time by Treatment Status; Treatment improved model and interaction of Treatment with Time approached significance.
Figure 4-9. Behavioral Symptoms modeled as predicted by Perceived Stress (C -top) and Emotional Responses (B-bottom); Combined model (center) inconclusive regarding “mediation” of Perceived Stress effects by Emotional Responses.
CHAPTER 5
DISCUSSION AND IMPLICATIONS

In this study, relationships between BehSx in PWD and caregivers’ Perceived Stress and Emotional Responses were investigated to evaluate the tenability of newly developed model. These variables have been considered in previous studies with BehSx as the predictor; however, in this study BehSx were posited as the outcome. Caregivers’ Perceived Stress and Emotional Responses were modeled as predictors for PWD BehSx. Additionally, these variables were modeled over time. While there were expected improvements in Perceived Stress and Emotional Responses from the parent study intervention, no impact on BehSx was expected. Therefore, any improvements in BehSx were more likely an outcome of changes that occurred in caregiver variables (Perceived Stress and Emotional Responses), lending support to the premise that PWD BehSx may be a response to caregivers’ stress process.

Support of Proposed Theoretical Model

When PWD BehSx were estimated over Time, the trajectories modeled with Treatment status added were a significant improvement over Time alone, and both Treatment (at mid-study) and Treatment*Time interactions (linear time) approached significance. Particularly after the mid-point of the study, PWD in the control group had increasingly worse BehSx, while those in the experimental group improved. Furthermore, the Caregivers’ Perceived Stress and Emotional Responses each diverged in their measurement according to Treatment status after the mid-point in the study, although the Treatment*Time interaction was non-significant for Perceived Stress and the Emotional Responses model with Treatment status did not have improved criteria (did not better represent the populations’ trajectories).

The parent study intervention was expected to change the caregivers’ stress process variables (Perceived Stress and Emotional Responses), but did not have components to address
BehSx. Therefore, these findings of divergence based on Treatment status partially support the underlying premise of the model, that caregivers’ stress process may negatively affect BehSx. Nonetheless, the lack of significant differences over time according to treatment status in caregiver variables is counter-intuitive when attempting to reconcile the models with such a premise. It is unclear how BehSx could change significantly without corresponding significant changes in caregivers’ stress process variables.

The models reflecting the relationships between caregivers’ stress process variables and BehSx also provide some limited evidence to support the model. When caregiver stress process variables were modeled separately, and were, on average, higher than usual either as a group (centered variables averaged across dyads) or in comparison to the group (means considered across dyads), BehSx in the PWD also increased.

Additionally, in the combined model with both Perceived Stress and Emotional Responses, there is some limited reduction in effects of average Perceived Stress on BehSx, with current levels of Emotional Responses, on average, possibly responsible. It was hypothesized that Emotional Responses would ameliorate the influence of Perceived Stress on BehSx both within and across persons. The random, within-dyad effects of current levels could not be determined because they needed to be removed to allow the model to converge. However, the effect of caregivers’ current levels Perceived Stress, on average, on BehSx was significant in the combined model, and slightly reduced. The mean Emotional Responses was no longer significant, indicating that average Emotional Response did not influence BehSx. Support of the proposed model would have been improved by the opposite finding, with Emotional Responses remaining significant and Perceived Stress losing both magnitude of effect and significance.
Findings in Relation to Past Research

The findings from this study are primarily in agreement with the published literature. In the discussion that follows, previous research will be compared to findings in three areas. First, the general descriptive findings regarding model variables will be discussed. Second, the relationships investigated will be covered. Lastly, the directionality of the relationships will be discussed, along with potential reasons for this directionality.

Model Variables

As in previous studies, BehSx were a substantial issue in the care dyads in this study. In both experimental and control status participants, BehSx, on average, remained over 4 throughout the study; this is considered the cut-off level for clinical significance (Lyketsos, 2007). In previous research, multilevel modeling was used to establish that over a 3-month period caregivers’ stress and PWD BehSx were, on average, stable, but that there was significant intra-individual variability, indicating that not everyone displayed this short-term stability (Fauth et al., 2006). This study’s subjects also displayed substantial intra-individual variability, and time alone did not influence severity of BehSx in this study.

Caregivers in this study, on average, also had consistently high scores on variables reflecting the stress process. The abridged version of the Zarit Burden Interview utilized to measure Perceived Stress had a scale 0-48, and previous studies have suggested either 10 (based on sensitivity vs. specificity) or 17 (based on upper quartile of sample) as potential cut-offs for excessive burden (Bedard et al., 2001; O'Rourke & Tuokko, 2003); neither of these are considered normative for the population without further research. Nonetheless, caregivers in this study consistently averaged approximately 20, above these initial estimates of high Perceived Stress. Although there are no cut-off scores available for the composite measure reflecting Emotional Responses, average depressive symptom scores were high, and in some months,
approached 16, the cut-off for clinical depression risk (Radloff, 1977). In contrast, the mean scores on negative affect were, on average, under 1 on a scale of 0-5. These items were rated upon arising during a one-week period for each measurement occasion, in contrast to the burden and depressive symptoms that were scored at the beginning of the measurement period during the day, often when caregiving duties for the day were well under way. Despite these inconsistencies, the over-all picture in this sample is one of highly stressed caregivers.

**Relationships between Model Variables**

The relationship between the two caregiver variables, Perceived Stress and Emotional Responses to stress, has been very well-developed in the literature, and was not a concern in this study. This relationship is embedded within the Stress-Health model that was adapted for this study. The Stress-Health model emerged from previous well-accepted theory and a body of research, and has extensive support from reviews of the research literature (Goode et al., 1998; Pearlin et al., 1990; Pinquart & Sorensen, 2003a, 2003b, 2007; Schulz & Beach, 1999; Schulz & Martire, 2004; Schulz et al., 1997; Schulz et al., 1995; Vitaliano et al., 2003). Furthermore, each of the caregivers’ stress process variables explained approximately one third of the variance in BehSx that was unexplained with change over time alone. Therefore, this study confirmed a well-developed body of research that establishes relationships between variables representing the caregivers’ stress process and BehSx. While most of the reports and reviews discuss these relationships in the opposite direction as hypothesized in this study, experts acknowledge that previous work has not established directionality of the relationships (Black & Almeida, 2004).

The combined model did not fully support the hypothesis that Emotional Responses would act in a manner similar to a mediator. It is counter-intuitive that this study did not fully substantiate the part of the adapted model that is most entrenched in previous theory and research findings. Possible explanations include the measures from the parent study that were utilized for
Perceived Stress and Emotional Responses. Different measures may have allowed this model to more closely support the model. Perhaps simply using depressive symptoms alone rather than in combination with negative affect would have provided more evidence of reduction in the influence of Perceived Stress.

However, the movement of the mean Emotional Responses to non-significant in the combined model points to a different possibility. It may be that the directionality between these two caregiver stress process variables from this sample does not reflect a clear directional path as supported by the Stress-Health model. For example, the Emotional Responses to stress and Perceived Stress may be more enmeshed together in the stress process, rather than the latter directly leading to the former. In this sample, the caregivers’ high levels of Perceived Stress and Emotional Responses reflect long-term stress related to caregiving. It is plausible that the Emotional Responses have themselves become a stressor or have decreased the caregivers’ perception of their ability to manage or cope with the stressors, thus leading to higher Perceived Stress.

**Directionality of Relationships between Caregiver Stress Process Variables and BehSx**

The findings in this study are in agreement with previous works that proposed caregiver influence on PWD outcomes. One review of the literature examined and highlighted caregivers’ influence on PWD outcomes, in particular, BehSx (Dunkin & Anderson-Hanley, 1998). In a study of over 5000 dementia care dyads in a population-based study, caregiver depression and burden, indicative of the stress process, were among predictors of increased BehSx (Sink et al., 2006). In a prospective study of 96 dementia care dyads, caregiver role stress (negative attitude toward the care recipient) predicted worse social behaviors in PWD. Overall, 32% of variance in care recipient quality of life (psychological well-being, productive behaviors, & functional ability) was explained by caregiver factors (Burgener & Twigg, 2002b).
While not a direct reflection of the relationships in this study, there is a small body of previous research that proposes that caregiver coping and management strategies may influence BehSx and other outcomes in PWD. This includes studies regarding 1) caregiver management strategies and relationship with BehSx (de Vugt et al., 2004), 2) caregivers’ cognitive decline and related increased BehSx, possibly linked to the inability to provide an optimum care environment (de Vugt et al., 2006), 3) caregivers’ training in management of BehSx and subsequent improvements in caregivers’ stress process variables and BehSx (Teri et al., 2005), and lastly, 4) caregiver coping strategies and the relationship between ineffective coping and low survival rates in PWD (McClendon et al., 2004). It is reasonable that coping and management strategies would indirectly result in changes in BehSx associated with a more intense stress process.

Several researchers have presented evidence that might help to explain why caregivers who have a more intense stress process care for PWD who have more severe BehSx. For example, previous quality of relationship (i.e., how ‘communal’ or reciprocal the relationship was), predicted both depressive symptoms in caregivers and frequency of harmful treatment of the care recipient (Williamson & Shaffer, 2001). Additionally, caregivers with higher strain and distress were also higher in ‘expressed emotion,’ or criticism toward the care recipient, and those more critical were more likely to attribute BehSx to willfulness in the PWD, or as controllable by the PWD (Tarrier et al., 2002). Another study showed that longitudinally, caregivers’ high expressed emotion was predictive of increased negative behaviors over time (Vitaliano et al., 1993). Caregivers that are burdened, strained, distressed, or depressed may treat the care recipient in ways that increase stress or leave emotional needs unmet in PWD, which may in turn lead to increased BehSx (Algase et al., 1996; Hall & Buckwalter, 1987; Smith et al., 2004).
In summary, the findings in this study were in general alignment with findings in previous studies. Despite the different approach in the model tested herein, there is support from the literature for this approach. The finding in this study that is in contrast to the current science is the lack of a clear ‘mediation’ or reduction in the influence of Perceived Stress on BehSx when Emotional Responses is modeled simultaneously. While current levels of Emotional Responses may have had some effect as expected, mean Emotional Responses become non-significant, calling the reason for the slight reduction of Perceived Stress→BehSx effects into question. It is not clear why this finding occurred in the current sample, and these relationships bear investigation in further analyses.

**Strengths, Limitations, and Directions for Future Research**

The use of multilevel modeling allowed change within dyads to be considered in the study analyses. These analyses provided more precise estimates than would be seen in traditional analyses. For example, population estimates allow for individual trajectories to “borrow strength” from the population averages when there is higher occasion-to-occasion variability within the person’s measurements than exists in the sample. Furthermore, missing data points are accounted for efficiently. This reduces measurement error and adds precision to estimates. This emphasis on precision over unbiasedness is the primary motivation to utilize multilevel modeling to estimate change trajectories (Schafer, 2007; Singer & Willett, 2003).

While modeling likely strengthened estimates in this study, it is important to recall that estimates may be biased toward the sample, particularly if there is substantial missing data. Of concern is the missingness due to attrition (70% completed study) or missed data collection points in this study; power and precision, particularly in later measurement points, may have been compromised (Schafer, 2007). Since results in this study pointed to more divergence in groups at the end of the study, future research might prudently use a piecewise approach to
modeling, allowing the trajectories to change after month 6. As previously discussed, the systematically missing data may also have influenced analyses regarding the primary outcome in this study, BehSx; however, attempts were made to reduce that possibility.

One limitation of this study is its secondary nature, and the lack of control over data collection. However, this study was conceptualized shortly after the beginning of data collection in the original study, and specific data were collected with the intent of this study in mind. Measures collected in the original study can arguably be considered appropriate measures for stress process variables considered in the dissertation study. However, it is not known whether these are the best measures for these concepts. This issue may need to be clarified in future research. Additionally, a convenience purposive sample was used rather than random selection. Descriptive statistics will allow for readers to make conclusions about the degree to which findings are generalizable, since it is not realistic to collect a population-based sample for a study such as the one designed here.

A concern regarding the data available from the parent study was that MMSE measures were the only measure of cognition in persons with dementia, and that this measure was not repeated at collection points; only one score was obtained, within the first 2 months of the study. Furthermore, there is a high rate of missingness of MMSE data for persons with dementia, with approximately half of dementia subjects completing an MMSE. In the subjects who did have this data collected, there were no significant differences according to treatment status. Nonetheless, it would be valuable to have repeated measures of this variable, at least three times during the study period, for better control of dementia severity in within-individual analyses over time.
Some note concern in the literature about using caregiver report of behaviors in the person with dementia, rather than direct observation. Others acknowledge that there is ‘intuitive logic’ in using caregivers as raters, noting that caregivers know better than anyone else what behaviors are exhibited, and can capture a wider time frame than direct observation would allow (Davis et al., 1997). The Cohen-Mansfield Agitation Inventory, a common caregiver-report measure of BehSx, was significantly correlated to direct observation of BehSx, using informants who were formal caregivers who likely had heavy patient loads (Cohen-Mansfield & Libin, 2004). These findings support the appropriateness of using caregiver report when direct observation is not a realistic option, perhaps particularly appropriate in community-based dyads where the caregiver and person with dementia are in close proximity much of the time and caregivers are intimately aware of BehSx patterns. Additionally, in researching dementia care dyads in the community, the use of direct observation could be perceived as intrusive and disruptive to PWD, and the study of BehSx in the natural setting is key to the model being tested. It would be difficult to maintain such a natural environmental setting using direct observation or videotaping, with researcher presence. As technology improves, careful consideration of the most appropriate methods of measurement are in order, with consideration of subjects’ privacy in decisions regarding implanted videotaping vs. using caregiver report instruments.

Regarding the analyses, weaknesses included the lack of covariates in these basic initial assessments of the model. For example, based on previous research, gender, relationship, and race could have possibly served as factors in the changes and relationships. In this study, these were equal in the two groups, and were controlled for in that manner. Furthermore, sample descriptives were assessed for correlation with completion of the study. Nonetheless, further analyses are in order to assess their impact more directly. An example of a potential covariate
that was not available in the original study data is that of the quality of the relationship prior to onset of the care dyad relationship. Covariates such as these are easily included in modeling and should be considered in future research.

Lastly, the causal pathways were assessed with data that was collected simultaneously, and the proposed relationships are imbedded within a dyadic environment that is influential for both members of the dyad. For example, BehSx might have caused changes in Perceived Stress and Emotional Responses as well as vice versa. While the modeling of mean and centered predictors and change over time in variables theoretically supported direction of causality, analyses which more specifically assess the directionality of the relationships, such as multivariate mediation (simultaneous assessment of model pathways within dyads) and lagged comparisons to determine which variables change first, are in order in future studies.

**Summary**

This study has provided initial confirmation of the proposed model, and enough findings that meet expectations in order to move forward with further testing. It is reasonable that BehSx act as a stressor among many in caregivers’ stress process, particularly when the upset, bother, or distress they cause leads to their perception as a problem. However, it is also plausible that they may emerge as an outcome of that process, when caregivers’ Perceived Stress and Emotional Responses impact their interactions and ability to provide an optimal care environment. Further research to evaluate this model may lead to improved intervention strategies that target caregivers’ stress process but also improve BehSx, interrupting this cycle and positively impacting more distal outcomes for both members of these vulnerable dyads. Such research has the potential to improve the quality of life of millions of community-based dementia care dyads, reducing the social, emotional, and financial costs of this condition.
APPENDIX A
MISSING DATA

Systematically Missing Items in the NPI-Q

This study had systematically missing data in the NPI-Q behavior scale items related to a computer glitch. Several methods were considered to address this missingness. First, the following were investigated as corrective options.

- **Mean Substitution.** Simple averaging methods were considered, often referred to as mean substitution. All other subjects’ answers for that item during that data collection point were averaged together and the resulting mean was imputed where systematically missing items occurred. This resulted in values that were representative of the sample.

- **Substitution of the Mean of Potential Item Scores.** Another simple method involved consideration of the potential scores had the item been answered. In this case, the possible severity scores ranged from 1-3, since 0 was not an option (in the first question, caregivers were asked whether the behavior domain occurred, with 0=no and 1=yes, but in this item, severity was rated only if the behavior occurred). The mean of this range is 2, indicating moderate severity. This resulted in values that were indicative of the potential range in the population.

The sensitivity of the mean substitution method was evaluated by comparing it to the method of using the mean of Potential Item Scores. The average of the imputed values for mean substitution was 1.84, calculated by summing all imputed values and dividing by the total number of imputations. This would provide similar results to simply using the average potential score. Using either of these methods could have inflated (or deflated) the sum score by as much as 3 points, however.

In this study, the interest was in change within subjects, as well as across subjects to yield population estimates. Sums using these imputed values could have distorted or muted those effects over time. Therefore, these methods of imputation of data from sources other than the subject ultimately seemed unrealistic. To address this issue, methods of substitution were considered that utilized the person’s own data, such as:
• Last value carried forward. This method of using the value from the previous occasion for that person was unrealistic for 2 reasons. First, the behavior domain may not have occurred previously and the attempt was to replace the item, not the sum score. Secondly, since this was a study of change, the lack of variability from one occasion to the next would be problematic.

• Complex computations from related information. In this study, there was information available at that time point for that individual in the form of the distress caused by the behavior. Complex computation of that caregiver’s usual ranking of the severity of the behavior in relation to the distress it caused could have been undertaken.

• Multiple imputation. Use of multiple item response sets in an iterative comparative manner could have resulted in converging on the best possible estimation of the missing response using both the subject’s and the sample’s data. This method is superior to those previously considered in precision of the imputed value, but is effort-intense and technically complex.

According to an expert on missing data, such intensive methods may not be necessary when the range of the missing item is narrow, and the volume of missingness is low. The effort and time needed to accomplish such methods is counter-productive in such simple cases (Schafer, 2007).

**Solution for Systematically Missing Data in this Study**

Based on these considerations, a simple method that capitalized on the subjects’ own data was utilized. When items were missing, the items that were answered for the subject, for that data point, were averaged together, and then multiplied by 12 to return the summary score to the familiar scale. This method utilized what was known about the subjects’ BehSx severity, without imputing based on data from other sources.

Similar techniques to the one chosen for the NPI-Q missing data were used in the original study for other variables representing the model. The CES-D was averaged if at least 15 of the 20 items were scored, and then returned to scale. The Short ZBI-Bedard was scored as a mean if 9 items of the 12 were scored, and was multiplied by 12 for use in this study to reflect the
familiar scale. The Negative PANAS was scored each morning during a 1-week data collection period, and means were reported if at least 3 values were present.

This simple method provided the most realistic option for the systematically missing data in this sample. In addition to the systematically missing data within the NPI-Q instrument, there were missing data points for approximately one third of the subjects due to missed appointments or drop-out. These have been considered \textit{missing at random} (see Chapter 4) and were addressed through the use of multilevel modeling to accommodate such missingness.
APPENDIX B
STATISTICAL ANALYSES

Multilevel Analyses

Preparation of the Data

Prior to estimation, the longitudinal data were prepared by restructuring the data to a univariate format. This meant that each subject had one entry (case) for each data point from which any data were available, sometimes referred to a ‘long’ or ‘stacked’ rather than ‘wide’ data structure. This allowed the computer program to establish parameters over time based on the data point connected to each case.

In multilevel models for change, a sensible time metric is chosen based on the study design and hypotheses. This allows for data that is not precisely time-structured to be included in analyses, with variable timing and spacing of waves easily accommodated. Additionally, while balanced data with equal numbers of measurements may be appealing, this occurrence is usually not realistic in dementia caregiving research. Failure to obtain precisely balanced data does not limit the multilevel analyses, which can accommodate missingness within individual’s waves of data.

In this study, several considerations were made to accommodate the data collection scheme in the parent study. While there were 9 data collection occasions over 12 months, the spacing was not time-structured. The experimental and control group differed in length between Baseline and Month 2 due to a reliability phase in subjects who received the system. Additionally, while data was collected each month during the first half of the study, spacing was every two months in the last half. In order to better reflect data collection patterns in individual dyads, ‘days from baseline’ was utilized as the time metric in analyses. Four subjects from the parent study were eliminated; 1 had no outcome data, and three had only one data point.
Subjects who had between 2 and 9 data points collected were included in analyses. Lastly, in restructuring the data, on those occasions when time-varying variables that represented model concepts were not collected, the occasion was eliminated. This allowed estimation of population parameters based on all available data, without prediction of those occasions that were missing. Since only 67% of subjects completed the study, this allowed 33% of subjects to be included in analyses of change with partial data. In this study, covariates were not modeled for simplicity’s sake; the random assignment with equal groups at baseline for potential covariates was appealed to for reducing the potential for spurious findings.

**Estimation Techniques**

Maximum likelihood estimation was used in analyses to add precision to estimation of trajectories, determining the maximum likelihood that the sample’s data came from the population. Random or within-person trajectories were estimated, as well as fixed, or population-based trajectories. Such model estimates are created by balancing the individual’s variability over time against the group’s variability. If within-subject variability is greater than that of the group, more weight is given to the average, and if between-subject variability is greater than the individual’s, the person’s values are more heavily weighted. The number of data points present for each individual is also considered in weighting the influence of the subjects’ data, with fewer observations resulting in more shrinkage toward the mean for that individual’s trajectory and lessened contribution to the population trajectory (Fitzmaurice et al., 2004; Singer & Willett, 2003).

According to Singer & Willett (2003), these techniques make model-based estimates considerably more precise than observed data because measurement error is reduced, and thus estimates more closely mirror the true population characteristics as compared to sample averages. However, the estimates may be biased toward the sample if there is a large amount of
missing data or a small sample. Restricted maximum likelihood is an alternative method for estimating multi-level models that offers less bias and handles high correlation more effectively, but is only useful for evaluating random effects (Fitzmaurice et al., 2004; Garson, 2007; Singer & Willett, 2003). In this study, the fixed effects were also of interest, so the maximum likelihood method was the best option. The modeled fixed effects are considered ‘estimated,’ and random effects are said to be ‘predicted;’ the latter can be used to graph individuals’ and also ‘average’ trajectories. In this study, 67% of the subjects completed the study. The dropout of 33% of subjects as the study progressed means that model-based estimates toward the end of the study may be less precise than those during the first part of the study.

**Modeling Nested Data**

The central feature of multilevel models is that the lower level units are ‘clustered’ or ‘nested’ within upper level units, and the covariance structure among level one units is modeled to fit the data, rather than requiring that data meet assumptions about the structure. Longitudinal or repeated measures data represent a clustering of measurements within subjects. When data is collected in this manner, use of statistical techniques that do not accommodate the design may lead to erroneous inferences. For example, in traditional analyses, intra-individual variability is considered measurement error or ‘noise,’ and incomplete data may exclude the subject from analyses; individual change trajectories are not assessed. In contrast, multilevel models allow intra-individual change, as well as deviation from one’s own change trajectory to be included in analyses. Additionally, the ability of multilevel modeling to accommodate unbalanced (time-unstructured or incomplete) data improves precision of estimates at both levels of data collection (Fitzmaurice et al., 2004; Singer & Willett, 2003).

Assumptions underlying multi-level modeling include a) random groupings (assumed to be a random sample of all such groups—in this study, dyads were the grouping units); b) non-
independence of lower level units (measures within persons are correlated); c) independent blocks (subjects-or persons in this study) that are assumed to have similar covariance, but are independent of each other; d) properly specified covariance structure; e) similar group sizes (estimation handles unbalanced designs, but grossly unbalanced data due to missingness may inflate Type I errors); f) estimates that are produced with asymptotic (approximate) normal distribution in larger samples; and g) adequate sample size. The number of subjects that constitutes an adequate sample size is controversial, with estimates ranging from 20-150. An important issue is that the number of observations per unit of the sample increases the overall power, and power is also determined at each level according to the number of units at that level. Severely unbalanced data at either level may compromise power and require a larger sample size (Garson, 2007).

Modeling Change over Time

Variables representing each concept in the theoretical model were estimated in a multilevel model, including CG Perceived Stress, CG Emotional Responses, and PWD Behavioral Symptoms. The Short ZBI-Bedard represented Perceived Stress, the composite of Depressive Symptoms and Negative Mood scores represented Emotional Responses, and the NPI-Q was used to measure PWD Behavioral Symptoms.

Random coefficient models were used to assess within-person and between person change over time. In a multilevel model for change, level 1 analyses evaluate the time-varying parameters over the course of the study within individuals. Level 2 analyses utilize predictors posited at the dyad/individual level that are not time-varying; to estimate differences in averaged change trajectories. Level one units are considered non-independent or correlated within level grouping units (grouping units follow the command ‘subject =’ in SPSS). Level two categorical predictors are called factors (factors follow the command ‘by’ in SPSS), and interval or higher
predictors are considered covariates (covariates follow the command ‘with’ in SPSS). Level two factors can be used to estimate average trajectories across levels of the factor (Singer, 1998). In this study, each variable was modeled ‘with Days’ and ‘by Treatment Status.’ ‘Treatment Status by Days’ interaction was also included to determine if trajectories differed over time by treatment status.

Preliminary models were used to prepare for model fit analyses. The outcome was first modeled without any predictors. This so-called ‘unconditional means’ model established the sample’s estimated mean, across all persons and data points, and allowed intra-class correlation to be calculated, to determine how much of the total variance was at each level, within persons vs. across persons, to substantiate further analyses. An unconditional growth model, with persons as the subject (or blocking variable for covariance matrix), and with the default covariance structure, was estimated to determine the effect of time within the sample. Across persons (fixed effects), the intercept reflected the average outcome value at time 0, and the time coefficient (Days) reflected the average change in the outcome for each unit of time. Within persons (random effects), intercepts and slopes were assessed for significant variance to model with a person-level covariate (Singer, 1998).

**Comparisons over Time by Treatment Status**

In this study, Treatment Status was considered a person-level (level 2) factor with influence on slopes over time within persons, and was thus modeled as a fixed effect. Results included the following fixed effects (or effects across persons for population estimates):

- Averaged intercepts and slopes (time) while controlling for Treatment Status
- Treatment Status (impact on averaged initial status, at time 0, or intercept)
- Treatment Status in interaction with time (for each unit of time, averaged slope changed X amount)
In this study, linear time was centered at mid-study (average # of days from baseline) in order to separate out the quadratic effects. Quadratic change (centered linear change*centered linear change) was regressed on linear change (centered), and the residuals from the regression represented orthogonal quadratic change, or the quadratic effect that was independent of linear change. Therefore, references to time 0 or intercept in this study represent the mid-point of the study. In addition to fixed effects, random (within-person) estimates for intercepts and slopes were assessed for reduction in variance and if this occurred, the percentage of reduction was calculated (Singer, 1998). Predicted trajectories were displayed over time in a graphical format according to treatment status.

**Modeling the Covariance**

Once the final was selected, the random errors were structures to allow appropriate conclusions from the results. Unless the covariances are modeled, erroneous inferences may be made. In longitudinal data, the structure must consider within-person correlation over time (all of subject A’s measures are correlated), and between-person correlation (all subjects’ measurements at a particular time may display correlation). Adding a repeated statement with occasion or, in this case, month, reflects the time structure of the data (days from baseline remained a covariate). ‘Unstructured’ is a complex structure that allows variances and correlations among elements to be unpredictable, often results in numerous parameters in the modeling, and in this study, had difficulty converging. *Variance components* is the default structure in SPSS and was used for initial models in this study—other structures were modeled to assess for improvement of the criteria from the *variance components* model. In SPSS, *variance components* uses a diagonal structure for repeated statements. *Diagonal* has heterogeneous variances, with no correlation between elements. *Ante-Dependence, First Order* has heterogeneous variances and heterogeneous correlations across elements, with the correlation
between two non-adjacent elements determined by those between the two elements. *Compound Symmetry-Heterogeneous* has heterogeneous variances and equal correlation between elements. *Auto-regressive, First Order* has homogenous variances, with correlation between elements lagged such that data from points further away in time are less correlated. *Auto-regressive Heterogeneous* is similar, but with heterogeneous variances. *Toeplitz* is also similar, except that lagged correlations may vary according to unique features of the time point (rather than just distance) (Fitzmaurice et al., 2004; Garson, 2007; Singer & Willett, 2003). These co-variance structures were modeled, and the one with the most improvement in information criteria was chosen for reporting.

**Building Models using Information Criteria and Psuedo- $R^2$**

Models were built using the change in the $-2 \log$ Likelihood ($2LL$) information criteria. The current model was compared to the previous one by subtracting the current $2LL$ from that of the previous one. The resulting chi square units were assessed for significant change in the model by comparing the value to standard chi square tables. Only those models that converged appropriately and also had significant change in the $2 LL$ were accepted as improved.

In building the models, each model’s ability to explain variance identified at both Level 2 (fixed effects; between-persons variance) and Level 1 (random effects; within-persons variance) were considered. This reduction in variance through modeling is somewhat comparable to the use of $R^2$ in traditional models. However, this so-called pseudo- $R^2$ is a bit different. This figure represents the reduction of *explainable* variance in the models, so a fairly small change can result in a large percentage of change (Singer, 1998).

In comparing models to structure the covariance, the information criteria that automatically adjust for degrees of freedom were considered. These included the AIC, or Akaike Information Criteria, and BIC, or Schwarz Bayesian Criteria. These criteria are flexible and more amenable
to use with non-nested models, where decisions do not necessarily center on removing or retaining a covariate. The BIC more strongly penalizes the addition of covariance parameters, and thus may result in choosing a model that is too parsimonious. The AIC strikes a balance between complexity and parsimony (Fitzmaurice et al., 2004). The latter was therefore considered more relevant in this study. However, they often agreed, and most often did not improved upon the criteria in baseline models.

**Additional Considerations**

There are three considerations regarding the manner in which these analyses were conducted that bear mentioning. First, a ‘repeated statement’ was not used in the initial models. While adding a repeated statement may add to the specification of the covariance structure of the measurements within persons, this is often not necessary in longitudinal modeling, since choosing the covariant structure effectively describes how the errors act over time (Singer, 1998; Singer & Willett, 2003). Nonetheless, once the final model was chosen and attention turned to structuring covariances, this was accomplished using ‘month’ as a repeated statement. Secondly, the choice of using Treatment Status as an influential person-level factor rather than specifying a three-level model with persons nested within groups was made for ease in interpretation. Lastly, the centering of time for the beginning, middle, and end of the study, as recommended by Singer & Willett, to assess the influence of Treatment Status on the intercept and slopes was not included. Time was centered at mid-study to address collinearity with quadratic time, and model intercepts reflect mid-study. The univariate test of differences in the estimated marginal means was also not used, since the change over time by treatment status was the interest rather than differences at a particular point in the study. In future analyses, additional models or analyses may lend more insight to differences at various points in the study, questions that were not posed in this study.
Modeling Mediation

To test the hypotheses related to the relationships in the model, a specialized technique was used to evaluate the effects of caregiver variables on care recipient variables within dyads and across dyads (Marsiske, 2008; McCrae et al., 2008). Variables were created to reflect both between-persons’ effects and within-persons’ effects of both predictors:

- Within-person averaged Perceived Stress and Emotional Responses were assessed for effects between persons at Level 2, with each caregiver contributing the same value at each data point collected to the fixed effects estimates (across dyads in the population) of BehSx. The interpretation of this effect was that, on average, caregivers’ general level of Perceived Stress and Emotional Responses influenced BehSx in general. For illustration, when caregivers in the population had, say, higher Perceived Stress, PWD might have more severe BehSx across all data points.

- Within-person centered Perceived Stress and Emotional Responses reflected effects both at Level 1 and at Level 2, with each subject contributing to the fixed effects estimates based on the data points collected for that dyad. Individual caregivers’ contribution at a given data point reflected their value’s deviation from their own mean. These variables were interpreted at both levels:
  - At Level 1, the current level of centered Perceived Stress and Emotional Responses were assessed for impact on BehSx within the dyad. For illustration, when a caregiver’s level of Perceived Stress and Emotional Responses were higher than average, BehSx in the PWD in their care might be more severe.
  - At Level 2, the current levels of centered Perceived Stress and Emotional Responses, on average in the population, were assessed for influence on current BehSx across dyads in the population. This effect reflected how the caregivers’ changing stress process might influence changes in the BehSx over time, within the population as a whole.

In this study, these variables allowed assessments regarding mean and centered influence of both variables on BehSx, but there were not formal tests of mediation. Nonetheless, the effect of caregivers’ Perceived stress on PWD BehSx was assessed with an expectation that this relationship would at least partially dissipate when Emotional Responses were also considered.

In general, formal tests of mediation models require that a) the variables co-vary with each other, b) causes occur before the presumed outcomes, and c) sources of spurious co-variation are eliminated. The temporal feature of predictors, mediators, and outcomes in any mediation model
is difficult to ensure, particularly when the measures are collected contemporaneously, as they occurred in this study, at the same data points. Experimental manipulation of X and M, as was done in this study using within-person centered values, lends strength to a mediation model’s specification. However, as some experts suggest, this may require separate analyses or subsequent studies to establish definitive evidence of mediation, particularly related to direction of causality (Bauer et al., 2006; Kenny et al., 2003).

In this study, in addition to manipulating the variables to reflect centered values, the change over time may lend support to direction of causality. In the parent study, X (Perceived Stress) and M (Emotional Responses) were hypothesized to change according to treatment status, but the outcome (BehSx) was not expected to be influenced by the experimental system. All variables were modeled over time according to randomly assigned treatment status in separate analyses. Therefore, the diverging change over time in the BehSx according to treatment status may lend some support to directionality in the causal hypotheses.
APPENDIX C
PRELIMINARY TREND ANALYSES

Multilevel models for change assume intra-individual individual linear trends in change, and deviations from this assumption must be considered in modeling. Singer & Willett (2003) recommend examining intra-individual Level 1 empirical change data and also evaluation of trends according to Level 2 predictors, for assessing tenability of this assumption (page 128) and to become familiar with subjects’ trends.

Initially, the general form or shape of the trend over time was assessed (e.g., linear, quadratic, cubic). Subjects’ BehSx were first plotted against time in months and are displayed in Figure C-1, according to treatment status. This plot was assessed for initial appearance of general trends over time. A regression for each treatment group is plotted among the measurements, and demonstrates a flat or somewhat linear trend.

Next, preliminary assessment of individual subjects’ BehSx was accomplished by graphing them over data points and examining them for evidence of non-linear patterns. Figure C-2 displays PWD BehSx for all dyads paneled by treatment status. Individuals’ BehSx patterns from occasion to occasion display a great deal of variability. Due to this variability, it is difficult to identify linear or non-linear trends as a usual occurrence for individuals in either treatment group. The variability of this data within persons emphasizes one of the strengths of multilevel modeling; that is to model intra-individual trajectories while also considering a subject’s own variation around that trajectory.

To further assess the within-individual trends, scatter plots for each individual were developed. Figure C-3 and C-4 reflect these plots with regular regressions of BehSx on months for control and experimental subjects, respectively. Examination of these descriptive plots lends some support to the use of linear modeling for BehSx. However, while many of the subjects had
fairly stable trends, there was variation in both direction and magnitude of change over time within both treatment status groups, again underscoring the need to allow individuals’ trajectories to differ within person to adequately represent the data.

Analyses for caregivers’ stress process variables revealed similar variability when within-person change was assessed. The variation both between subjects (including direction and magnitude), and within subjects over time (months in the study), remains the most notable feature of the trends (see figures C-5 through C-12). These assessments of prominent variability lend support to using analyses that will identify the form of the change trend over time. This became the first step in modeling each these variables’ change over time.
Figure C-1. Outcome PWD BehSx plotted against Months paneled by Treatment Status with Regressions.
Figure C-2. Observed variation in PWD Behavioral Symptoms over Time within subjects, paneled by Treatment Status.
Figure C-3. Behavioral Symptoms over Months paneled by Dyad with Regressions—Control dyads only.
Figure C-4. Behavioral Symptoms over Months paneled by Dyad with regressions—Experimental dyads only.
Figure C-5. Predictor Caregiver Perceived Stress plotted against Months paneled by Treatment Status with Regressions.
Figure C-6. Predictor Caregiver Emotional Responses plotted against Months paneled by Treatment Status with Regressions.
Figure C-7. Observed variation in caregivers’ Perceived Stress over Time within subjects, paneled by Treatment Status.
Figure C-8. Observed variation in caregivers’ Emotional Responses over Time within subjects, paneled by Treatment Status.
Figure C-9. Perceived Stress over Months paneled by Dyad with Regressions—Control dyads only.
Figure C-10. Perceived Stress plotted over Months paneled by Dyad with Regressions—Experimental dyads only.
Figure C-11. Emotional Responses plotted over Months paneled by Dyad with regressions—Control dyads only.
Figure C-12. Emotional Responses plotted over Months paneled by Dyad with regressions—Experimental dyads only.
LIST OF REFERENCES


---

182


Williamson, G. M., & Shaffer, D. R. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. The family relationships in late life project. *Psychology and Aging, 16*(2), 217-226.


BIOGRAPHICAL SKETCH

Judy Campbell was born in Mississippi in 1957, the second child of Mr. and Mrs. Wilbur A. McGee. She graduated from Weir High School in 1975, and attended Holmes Junior College in Goodman before completing her Bachelor of Science in Nursing at the University of Southern Mississippi in 1979. Judy has practiced as a Registered Nurse in medical-surgical, gerontological, and gynecological units in Nebraska (1979-83) and Florida (1983-1994).

Judy took the role of Nurse Educator at Brevard Community College in 1990. She received tuition assistance and support to complete her Master’s degree, awarded in 1995 at the University of Florida. Judy received the Advanced Registered Nurse Practitioner Certificate on graduation, as a Gerontological NP. Judy returned to education and taught for 14 years at before pursuing her doctoral education.

Judy attended the University of Florida from 2004-2008, and was awarded the UF Alumni Fellowship, the Hartford Building Academic Geriatric Nursing Capacity Scholarship, a position as a UF Gerontology Research Trainee (non-funded), and the UF College of Nursing “Outstanding Research” Award. She has been awarded membership in the National Scholars Honor Society, Sigma Phi Omega (gerontology honor society), and Sigma Theta Tau (nursing honor society).

Judy has a long history of professional activity and community service within nursing, primarily through the Florida Nurses’ Association and as a mentor at the local and state level for the Florida Nursing Students’ Association. She is a member of the Southern Nursing Research Society, the Gerontological Society of America, and the American Nurses Association.

Judy has been married to David Campbell since 1979. She also has two adult children, one granddaughter, and two “nephews” who have blessed her life. Judy has lived in Brevard County, Florida’s “Space Coast,” in Cocoa (Port St. John), since 1983.