

IMMEDIATE AND LAGGED EFFECTS OF DAILY
STRESS AND AFFECT ON CAREGIVERS'
DAILY PAIN EXPERIENCE

by

KEISHA D. CARDEN

REBECCA S. ALLEN, COMMITTEE CHAIR
NATALIE DAUTOVICH
PATRICIA A. PARMELEE
STEVEN H. ZARIT

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ABSTRACT

Using secondary data analysis of DaSH (R01AG031758, S. Zarit, PI), we examined the effect of daily stress, affect, and adult day service (ADS) use on the daily subjective pain experience among caregivers of individuals with dementia (IWD). Participants were interviewed for 8 consecutive days. Caregivers utilized an ADS program on some days and provided care at home on other days. We hypothesized a significant relation between daily stress and daily pain would be moderated by time-varying positive affect (PA) and negative affect (NA) within and beyond ADS use. Participants were 173 family caregivers of IWDs using ADS more than 2 days per week. Participants with IWDs diagnosed with “mild cognitive impairment” were excluded. Daily telephone interviews assessed stress, affect, and pain. Multilevel models were used to examine the relation between daily stress and daily pain and moderating effects of other daily experiences within the context of ADS use. Multilevel models revealed a significant relation between care-related and non-care related stress and daily bodily pain. ADS use and affect did not predict daily pain. Lagged effects revealed a significant moderation for the relation between ADS use and positive affect and pain such that positive affect was higher and pain was lower following an ADS day. Findings suggest that further studies are warranted for understanding and controlling pain among caregivers. Addressing the physical health needs of caregivers through pain management interventions may improve the overall wellbeing of caregiving dyads.

DEDICATION

To Dustin: for being my backbone and biggest source of support; for making me laugh until my ribs hurt; for pushing me to be the best version of myself; and for always believing in me even when I didn't believe in myself.

LIST OF ABBREVIATIONS AND SYMBOLS

a	Cronbach's index of internal consistency
B	Estimated value of unstandardized regression coefficient
β_{00}	Population mean intercept for individuals when predictor = 0
β_{x0}	Population mean difference in intercept for a 1-unit change in predictor value
df	Degrees of freedom: number of values free to vary after certain restrictions have been placed on the data
ε_{id}	Individual-level random measurement error
M	Mean: the sum of a set of measurements divided by the number of measurements in the set
N	Sample size
p	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
π_{i0}	Intercept of the true change trajectory for individual i in the population
π_{ix}	Slope of the true change trajectory for individual i in the population
r	Pearson product-moment correlation
SD	Standard deviation: amount of variation or dispersion of a set of data values
t	Computed value of t test
v_{i0}	Group-level random measurement error
$<$	Less than
$=$	Equal to

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CHAPTER 1

INTRODUCTION

“The cure for pain is in the pain”

-Rumi, 13th century Persian poet

The population of individuals suffering from age related disorders such as Alzheimer’s disease and dementia is increasing at a rapid rate (Alzheimer's Association, 2015; Haley, Bergman, Roth, McVie, Gaugler, & Mittelman 2008; Hebert, Weuve, Scherr, & Evans, 2013). As a result, the number of family caregivers is also increasing. Past research has identified many psychological factors associated with the caregiver role, including elevated stress levels, higher incidence of depression, and decreased quality of life (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Mahoney, Regan, Katona, & Livingston, 2005; Pinquart & Sörensen, 2003; Schulz & Martire, 2004). These psychological factors are also associated with pain (Affleck Tennen, Urrows, & Higgins, 1991). The caregiving role requires many significant care-related responsibilities across the course of the disease process that are often stressful, burdening, and overwhelming on a daily basis (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). The caregiving role might require assisting with both physical and instrumental activities of daily living, providing financial aid, navigating complex health care policies and facilities, and facing vast behavioral changes and outbursts (Alzheimer's Association, 2015; Alzheimer’s Association and National Alliance for Caregiving, 2004) that may exacerbate caregiver outcomes such as daily pain. Recently, caregiver pain has been identified as a significant predictor of the emotional and physical aspects of caregiver burden in informal caregivers (Jones, Hadjistavropoulos,

Janzen, & Hadjistavropoulos, 2011); however, the significance of daily pain trajectories and their determinants have yet to be investigated among dementia caregivers.

The caregiver experience has been conceptualized by stress process models (SPM; e.g., Folkman, 1997; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990) used to predict important caregiver outcomes including depression, quality of life, and overall health and wellbeing. **Figure 1** illustrates a condensed version of Pearlin's SPM (1990) adapted to include time-varying moderators and time-varying outcomes to account for daily associations and fluctuations of the caregiver experience. Pain has been incorporated here as an outcome of the stress process that has not been investigated among dementia caregiver populations within a daily context. To effectively target aspects of the caregiver experiences that are difficult and challenging, daily pain must be understood as it relates to all other aspects associated with the stress process (see **Figure 1**).

Daily Pain

While past research has explored both care recipient and caregiver variables related to the caregiver role (e.g., Cho, McCracken, Heiby, Moon, & Lee, 2013; Pinqart & Sørensen, 2006; Zakoscielna & Parmelee, 2013), few studies have emphasized the importance of daily pain as it relates to health and well-being in dementia caregivers. Nearly 20-25% of caregivers are over the age of 65 and experience pain often (Alexih, Zeruld, & Olearczyk, 2001; Shahly et al., 2013). Research has assessed caregiver pain in relation to proxy reports of individual with dementia (IWD) pain, concluding that caregivers with pain tend to overestimate their care recipient's pain (Hung, Pickard, Witt, Lambert, 2007; Orgeta, Orrell, Edwards, Hounscome, Woods, & REMCARE Team, 2014); however, few studies have investigated caregiver pain as it relates to the daily caregiver experience (Blyth et al., 2008; Jones et al., 2011). Only one known study has

examined the contribution of caregiver pain to level of caregiver burden (Jones et al., 2011). In their study, Jones and colleagues (2011) used hierarchical linear regression analyses to examine the extent to which caregiver pain was related to caregiver burden among 123 informal caregivers, age 60 and older, of physically frail and disabled individuals and IWD. They reported that overall pain significantly predicted levels of emotional and physical dimensions of caregiver burden. These studies, while emphasizing the importance of understanding pain in caregiver populations, did not consider daily pain fluctuations or time-varying predictors of pain within dementia caregiver populations. This study aims to add to this line of research by examining the daily pain experience within the context of ADS use among dementia caregivers.

Daily Stressors

Past studies of daily stressors have provided valuable insight into the relation between daily events and overall physical and emotional well-being in adults (Almeida, 2005; Almeida, McGonagle, & King, 2009). Daily events have immediate and cumulative effects that result in overload and subsequent adverse physical and emotional outcomes including clinical depression, high levels of stress, and negative affect (Yates, Tennstedt, & Chang, 1999). This cumulative risk threatens the caregiver's ability to be resilient and adapt to daily stressors and may decrease quality of life for both the caregiver and the care recipient (Everhart, Fiese, & Smyth, 2008). Pain is an important variable to consider in relation to stress as past research has yielded inconclusive results (see Lumley et al., 2011, for a review).

Though caregivers of IWDs experience a wide variety of stressors, behavioral and psychological symptoms (BPSD, or behavioral complications of dementia) of the IWD have typically been acknowledged as the most distressing (Algase et al., 1996; Huang, Lee, Liao, Wang, & Lai, 2012; Teri, 1997). These care-related stressors have been identified as a significant

predictor of caregiver depression and negative affective responses (Ornstein et al., 2013). As care-related stressors increase and caregivers allocate more time, energy, and emotional resources to the provision of care, the resulting strain can spill over into other aspects of the caregiver's life, thereby increasing stressors *not* related to care (Aneshensel, et al., 1995). This may result in other negative outcomes such as daily pain. This study aims to examine the relation between both care- and noncare-related stress and daily pain (**Figure 1**).

There are also important individual differences to consider regarding the degree to which caregivers experience stress-related negative outcomes. Consistent with a variety of SPMs (Folkman, 1997; Lazarus & Folkman, 1984; Pearlin et al., 1990), research has revealed that stress is not only an external force that automatically yields negative effects such as pain or depressive symptoms, but is a relationship between individuals and their environment within a fluid and time-varying context (Hilgeman, Allen, DeCoster, & Burgio, 2007; Tarlow, 2004). This underscores the need to further examine the daily pain experience.

Pain & Stressors

Although reported stress and pain have yet to been investigated among dementia caregivers, there is extensive evidence to provide a robust rationale for the importance of understanding how they are related. The transactional model of stress, put forth by Lazarus and Folkman (1984), posits that primary appraisals (stressor as irrelevant, benign-positive, or stressful) interact with secondary appraisals (regarding various coping mechanisms) and influence the resulting coping response. For example, prior to its emergence in the pain literature, catastrophizing, or the tendency to engage in and exaggerate negative mental beliefs brought about during real-time or anticipated pain experience, was typically discussed within a cognitive theoretical framework of emotional functioning. This framework classified

catastrophizing as a cognitive vulnerability factor for depression and anxiety (Beck, 1976; Sullivan, Bishop, & Pivik, 1995). There is evidence that catastrophizing, and its components, magnification, rumination, and helplessness, operate much like other coping mechanisms (Geisser, Robinson, & Riley, 2000; Parker et al., 1989; Sullivan et al., 2001) in their effects on the affective and sensory components of the pain experience. An individual's stress appraisal and subsequent coping response are well-established determinants of the pain experience; thus it is conceivable that reported care- and noncare-related stress may contribute to the daily caregiving pain experience.

Pain and Affect

Affect is an important contextual variable to consider when examining pain. The contemporary definition of pain is multidimensional and includes three domains: sensory-discriminative, affective-motivational, and cognitive-evaluative (Craig, 2002; Melzack, & Casey, 1968; Melzack & Wall, 1965; Sullivan et al., 2001; Vallath, Salins, & Kumar, 2013). Regarding the affective-motivational domain, pain research has historically focused on the relation between overall negative affective and depressive states of the pain experience (Casten, Parmelee, Kleban, Lawton, & Katz, 1995; Janssen, 2002; Parmelee, Katz, & Lawton, 1991; Shackman et al., 2011). More recently, there has been a paradigm shift, targeting positive affect as a mechanism through which to treat pain (Morely, Williams, & Eccleston, 2013; Zautra, Johnson, & Davis, 2005; Zautra, Smith, Affleck, & Tennen, 2001). Several psychosocial treatments now incorporate features of positive affect enhancement (e.g., acceptance and commitment therapy [ACT; Hayes, Luoma, Bond Masuda, & Lillis, 2006]). Finan & Garland (2015) put forth an upward spiral model of positive affect, resilience, and pain self-management, suggesting that positive affect buffers maladaptive responses to pain.

The notion that PA is negatively associated with pain outcomes varies as a function of diagnosis and level of stress. In a weekly diary study, Zautra et al. (2005) reported that individuals diagnosed with fibromyalgia reported greater daily pain and stress than age and sex-matched individuals diagnosed with osteoarthritis; PA accounted for the greatest amount of variance in the group differences. It is important to understand how PA and NA relate to the time-varying pain experience and if that potential relation varies as a function of context.

ADS Use

Previous studies suggest the utilization of Adult Day Services (ADS) and other programs providing respite care alleviates exposure to care-related stressors by as much as 40% (Zarit, Stephens, Townsend, & Greene, 1998; Zarit, Kim, Femia, Almeida, Savla, & Molenaar, 2011). ADS use is also associated with increased engagement in leisure activities (Gaugler et al., 2003), and lowered anger (Zarit, Kim, Femia, Almeida, & Klein, 2013). ADS use is also associated with *more* noncare-related stressors (Zarit et. al., 2013). It has been argued that ADS and other modes of respite only shift the time of stressor exposure and therefore do not reduce caregiver hardships (see Gottlieb & Johnson, 2000 for a review). However, emerging studies have suggested that stress is lower for those who utilize ADS as they do not provide all the care, and stress is lowest in the evening following ADS attendance with effects lasting through the night compared to caregivers who provided all the care (Zarit, et. al., 2011). This variability in the effects of ADS on stressor exposure and subjective stress underscores the need to understand day-to-day associations within a varying context to fully understand the caregiver experience. Furthermore, daily pain has not been explored in relation to ADS use or daily stress. Previous studies show ADS use decreases exposure to care-related stress but not noncare-related stress (Zarit et al.,

2013) and it is important to understand how ADS use and stressor exposure, together, affect the pain experience.

Current Study

The present study extends this prior work by further reviewing the effect of ADS use on daily pain and examining daily associations between stress (care- and noncare-related) and pain. It further assesses potential daily moderating effects of affect, and type of day (ADS/non-ADS) (**Figure 1**). Examining daily associations allows us to examine caregiver's responses on both high stress days when ADS services are not used and on low stress days when the IWD attends ADS. More specifically, we can examine whether daily pain outcomes are predicted by individual clustering of person-specific characteristics such as baseline pain and daily level of noncare- and care-related stress or to characteristics associated with ADS use. This study will examine the following hypotheses:

1. Daily reports of bodily pain will be lower on ADS days than non-ADS days.
2. Daily care-related and noncare-related stress will predict daily pain reports.
3. Positive affect, negative affect, and extent of ADS use will individually influence the association between care- and noncare-related stress and daily pain reports.

This study will examine the following exploratory hypothesis:

4. ADS use and positive affect will exhibit lagged moderation effects on the subsequent day's bodily pain (exploratory).

CHAPTER 2

METHODS

Participants

In the primary study (DaSH; R01AG031758, S. Zarit, PI), the participants were 173 (86.5% of eligible participants) family caregivers of IWDs using ADS programs. To take part in the study, participants had to be related to the IWD, live in the same household, and indicate their primary responsibility operationally defined as spending the most time helping the IWD with daily tasks. The IWD had to have been diagnosed by a physician as having a type of dementia (e.g., Alzheimer’s disease, frontotemporal dementia) and must have been scheduled to attend ADS more than 2 days per week. Participants with relatives diagnosed with “mild cognitive impairment” or other pre-dementia syndromes (e.g., Age Related Cognitive Decline) were excluded.

Procedure: Secondary Data Analysis

In the primary study, ADS programs were identified through their regional state associations in five areas: Northern and Central New Jersey, the greater Philadelphia area, the greater Pittsburgh area, Northern Virginia, and Denver, Colorado. Meetings were conducted with ADS representatives to explain the study and provide informational fliers to display for potential participants with the research coordinator’s contact information. Announcements were also placed in ADS program newsletters, and reminder and study updates were given to ADS staff. A total of 57 programs provided referrals over a 3-year recruitment period.

Family caregivers who contacted the research coordinator were told about the study and screened for eligibility. Eligible caregivers were scheduled for an initial in-person interview. The interviewer obtained signed informed consent and gathered sociodemographic information and baseline data on a number of measures. The Penn State Survey Research Center conducted daily interviews. Participants received \$25.00 for completing the initial interview and \$50.00 for completing the eight daily interviews.

Measures (See Appendix A)

Daily Bodily Pain. Daily Pain was measured by a single item from Larsen and Kasimatis' Symptom checklist (1991). Respondents indicated how often they experienced headache, backache, or muscle soreness in the past day, using a 5-point scale that ranged between 1 (none of the day) and 5 (all day). This is an atypical measure of pain as single item measures of pain are generally used within the context of chronic pain conditions (e.g., rheumatoid arthritis, sickle cell disease; Affleck et al., 1999; Smith et al., 2008). This is, however, a novel outcome to consider among dementia caregivers; thus the findings will be useful and potentially inform future daily pain assessments outside of chronic pain conditions.

Type of Day. Type of day, that is, whether the IWD used ADS (ADS = 1) or did not use ADS (ADS = 0), was confirmed at the end of each day during the telephone interview.

Extent of ADS use. The total number of ADS days over the course of 8 consecutive days was summed.

Daily Affect. Daily positive and negative affect was assessed using an adapted inventory from the Non-Specific Psychological Distress Scale (Kessler et al., 2002; Mroczek & Kolarz, 1998). The 22-item scale assesses four affective domains relevant to caregivers: anxiety symptoms, anger, depressive symptoms, and positive affect. Positive affect was supplemented

with two items (interested, attentive) from the Positive and Negative Affect Schedule (Watson, Clark, & Tellegen, 1988) to create a broader assessment of positive emotions. Respondents reported the frequency of each emotion over the past day along a 5-point scale from 1 (*none of the day*) to 5 (*all day*).

A factor analysis was performed that replicated the four affective domains. Four items were dropped because they did not load on any scale or loaded approximately equally on two or more domains. The final scales in the primary study included the following: anxiety symptoms (three items, $\alpha = 0.84$), anger (four items, $\alpha = 0.83$), depressive symptoms, (four items, $\alpha = 0.84$), and positive affect (nine items, $\alpha = 0.92$). The four scales represent dimensions usually included in models of affect: negative affect scores were composed of high-activation negative emotion (anger symptoms), low-activation negative emotion (depressive symptoms) trait-related negative emotion (anxiety symptoms), and positive affect (Watson & Tellegen, 1985).

Care-related Subjective Stress Severity. Care-related subjective stress severity was measured using a 19-item version of the daily record of behavior (DRB; Fauth, Zarit, Femia, Hofer, & Stephens, 2006; Femia, Zarit Stephens, & Greene, 2007) drawn from six behavioral categories: resistance to help with activities of daily living (ADL), restless behaviors, reality problems, depressive behaviors, disruptive behaviors, and memory related behaviors. Up to three other behavioral events related to care could be added by caregivers. In daily diaries, days were divided into four periods: waking to 9:00 a.m., 9:00 a.m. to 4:00 p.m., 4:00 p.m. to bedtime, and overnight. For each period, each day, caregivers were asked if a behavior had occurred, and if yes, to rate the subjective stress severity of the behavior along a 5-point scale ranging from 1 (*not at all stressful*) to 5 (*very stressful*). A care-related stress severity score was computed by summing the stress ratings for all behaviors for each day that would include four time periods; 1)

the night before, 2) waking to 9:00 a.m., 3) 9:00 a.m. to 4:00 p.m., and 4) 4:00 p.m. to bedtime that same day. A zero was assigned if no behavior occurred.

Noncare-related Subjective Stress Severity. Noncare-related subjective stress severity was assessed through the Daily Inventory of Stressful Events (DISE, Almeida, 1998; Almeida, Wethington, & Kessler, 2002). Each day, caregivers reported whether each of the eight items had occurred. They were instructed to report stressful events not related to or encountered while assisting their IWD. Items included arguments with other people, avoiding an argument, stressors affecting friends or family, health-related issues, financial issues, work-related events, or any other incidents. Caregivers then rated the subjective stress severity of each event on a 5-point scale ranging from 1 (*not at all stressful*) to 5 (*very stressful*). A noncare-related stress severity score was computed by summing the stress ratings for each event for that day. A zero was assigned if no stressful event was reported.

Covariates. Variables likely to affect daily experiences were included as covariates. These included: age, gender, duration of care, IWD ADL impairment (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969), caregiver over the counter (OTC) medication use, and baseline reports of bodily pain (frequency and interference; Ware & Sherbourne, 1992). OTC medication use was measured by asking participants if they were taking OTC medication for each of the following; headaches, stomach/gastrointestinal problems, sleep problems, anxiety, tension, or depression, to improve memory, or for any other reason. A sum was then calculated for each individual. Race was not included as it was not significantly associated with daily bodily pain reports.

Analysis

A random intercepts, fixed effects, two-level multilevel model (SAS PROC MIXED) was employed to examine daily diary data nested within persons (Littell, Miliken, Stroup, & Wolfinger, 1996) to examine caregiver experiences as they varied across ADS and non-ADS days.

To assess **hypothesis 1 (Eq. 1)**, daily pain was modeled for the d th day in the i th person as a function of an intercept (β_{i0} , the average score on non-ADS days), ADS use (β_{i1}), and the person-specific deviations from the intercept (ε_{id}) at level 1 (within-person). At level 2, we included seven between-person covariates: caregiver's age, gender, duration of care, IWD's ADL impairment, OTC medication use, and baseline pain reports (frequency and interference)

Level 1: (Eq. 1)
Daily Bodily Pain _{id} = $\pi_{i0} + \pi_{i1}(\text{ADS day}_{id}) + \varepsilon_{id}$

Level 2:
 $\pi_{i0} = \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) + \beta_{30}(\text{Duration of care}_i)$
 $+ \beta_{40}(\text{IWD ADL impairment}_i) + \beta_{50}(\text{OTC medication use}_i)$
 $+ \beta_{60}(\text{Caregiver Pain Frequency}_i) + \beta_{70}(\text{Caregiver Pain Interference}_i)$
 $+ v_{i0}$

$\pi_{i1} = \beta_{01}$

Composite:

$$\begin{aligned} \text{Daily Bodily Pain}_{id} &= \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) \\ &+ \beta_{30}(\text{Duration of care}_i) + \beta_{40}(\text{IWD ADL impairment}_i) \\ &+ \beta_{50}(\text{OTC medication use}_i) + \beta_{60}(\text{Caregiver Pain Frequency}_i) \\ &+ \beta_{70}(\text{Caregiver Pain Interference}_i) + \beta_{01}(\text{ADS day}_{id}) + v_{i0} + \varepsilon_{id} \end{aligned}$$

To examine the effects of care-related and noncare-related stress on the daily experience of pain (**hypothesis 2; Eq. 2**) we first included ADS use to examine differences in the daily experience of pain. We then added daily sum scores for care-related stress (β_{01}) and noncare-related stress (β_{02}), centered at person-mean to represent the within-person effects (Hoffman & Stawski, 2009).

To test buffering effects of ADS use and positive affect (**hypothesis 3; Eq. 2**) on daily pain reports, we computed interactions between ADS use (within-person) by type of stress

(within-person). At level two, we entered the extent of ADS use (a summed score). In order to examine its potential buffering effects, we computed cross level interactions between the extent of ADS use and care-related and noncare-related stress. We further included seven between-person covariates: caregiver's age, duration of care, IWD's ADL impairment, OTC medication use, and baseline pain reports (frequency and interference).

Level 1: (Eq. 2)

$$\begin{aligned} \text{Daily Bodily Pain}_{id} &= \pi_{i0} + \pi_{i1}(\text{Care} - \text{related stress}_{id}) + \pi_{i2}(\text{Noncare} - \text{related stress}_{id}) \\ &+ \varepsilon_{id} \end{aligned}$$

Level 2:

$$\begin{aligned} \pi_{i0} = \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) + \beta_{30}(\text{Duration of care}_i) \\ + \beta_{40}(\text{IWD ADL impairment}_i) + \beta_{50}(\text{OTC medication use}_i) \\ + \beta_{60}(\text{Caregiver Pain Frequency}_i) + \beta_{70}(\text{Caregiver Pain Interference}_i) \\ + \beta_{80}(\text{Extent of ADS Use}_i) + v_{i0} \end{aligned}$$

$$\pi_{i1} = \beta_{01}$$

$$\pi_{i2} = \beta_{02}$$

Composite Equation

$$\begin{aligned} \text{Daily Bodily Pain}_{id} &= \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) \\ &+ \beta_{30}(\text{Duration of care}_i) + \beta_{40}(\text{IWD ADL impairment}_i) \\ &+ \beta_{50}(\text{OTC medication use}_i) + \beta_{60}(\text{Caregiver Pain Frequency}_i) \\ &+ \beta_{70}(\text{Caregiver Pain Interference}_i) + \beta_{80}(\text{Extent of ADS Use}_i) \\ &+ \beta_{01}(\text{Care} - \text{related stress}_{id}) + \beta_{02}(\text{noncare} - \text{related stress}_{id}) + v_{i0} + \varepsilon_{id} \end{aligned}$$

We further modeled lagged effects of ADS use and next day positive affect on next day daily pain (**exploratory hypothesis 4; Eq. 3**). ADS use, next day positive affect, and their interaction were entered on level-one. At level two, we included seven between-person covariates: caregiver's age, duration of care, IWD's ADL impairment, OTC medication use, and baseline pain reports (frequency and interference).

Level 1: (Eq. 3)

$$\begin{aligned} \text{Daily Bodily Pain}_{id} &= \pi_{i0} + \pi_{i1}(\text{ADS Use}) + \pi_{i2}(\text{Next Day Positive Affect}_{id}) \\ &+ \pi_{i3}(\text{ADS Use} * \text{Next Day Positive Affect}_{id}) + \varepsilon_{id} \end{aligned}$$

Level 2:

$$\begin{aligned}\pi_{i0} = & \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) + \beta_{30}(\text{Duration of care}_i) \\ & + \beta_{40}(\text{IWD ADL impairment}_i) + \beta_{50}(\text{OTC medication use}_i) \\ & + \beta_{60}(\text{Caregiver Pain Frequency}_i) + \beta_{70}(\text{Caregiver Pain Interference}_i) \\ & + \beta_{80}(\text{Extent of ADS Use}_i) + v_{i0}\end{aligned}$$

$$\pi_{i1} = \beta_{01}$$

$$\pi_{i2} = \beta_{02}$$

Composite Equation

$$\begin{aligned}\text{Daily Bodily Pain}_{id} & \\ & = \beta_{00} + \beta_{10}(\text{Caregiver age}_i) + \beta_{20}(\text{Caregiver gender}_i) \\ & + \beta_{30}(\text{Duration of care}_i) + \beta_{40}(\text{IWD ADL impairment}_i) \\ & + \beta_{50}(\text{OTC medication use}_i) + \beta_{60}(\text{Caregiver Pain Frequency}_i) \\ & + \beta_{70}(\text{Caregiver Pain Interference}_i) + \beta_{80}(\text{Extent of ADS Use}_i) \\ & + \beta_{01}(\text{ADS Use}_{id}) + \beta_{02}(\text{Next Day Positive Affect}_{id}) \\ & + \beta_{03}(\text{ADS Use} * \text{Next Day Positive Affect}_{id}) + v_{i0} + \varepsilon_{id}\end{aligned}$$

CHAPTER 3

RESULTS

Caregivers completed 98% of the daily interviews with approximately 4.09 occurring on ADS days ($SD = 1.46$) and 3.77 occurring on non-ADS days ($SD = 1.43$). Caregivers were 87% female and 73% Caucasian using ADS an average of 4.09 days per week (see **Table 1**).

We tested differences in daily pain, positive affect, and negative affect on ADS and non-ADS days. Negative affect was excluded in final models as it was insignificant and its inclusion or exclusion did not significantly effect the outcomes. **Table 2** shows within-person means and intraclass correlations (ICC). Results revealed daily pain reports did not differ across type of day, $\beta = 0.07, t(1071) = 1.46, p = .15$. Therefore, type of day was excluded from subsequent models.

We then constructed models that examined type of day and the total care- and noncare-related stress reported for that day as time-varying covariates with the daily experience of pain. We tested interactions of type of day and the two types of stress. Nonsignificant interactions were excluded from the model. Both care-related stress, $\beta = .01, t(1035) = 4.02, p < .0001$, and noncare-related stress, $\beta = .04, t(1035) = 4.66, p < .0001$, were associated with higher reported bodily pain for that day. The extent of ADS use also predicted daily reports of bodily pain, $\beta = 0.12, t(142) = 2.17, p = 0.03$. Although the extent of ADS use predicted daily reports of pain, it did not buffer the effects of care-related or noncare-related stress. These interactions were nonsignificant. Positive affect and negative affect were also nonsignificant moderators of the

relation between daily care and noncare-related stress and daily reports of bodily pain
(hypothesis 3).

Based on prior work with this data (Zarit et al., 2014), we explored the potential buffering effects of daily ADS use and next day positive affect on the next days' reported bodily pain.

(hypothesis 4). Lagged effects modeling revealed a significant moderation for the relation between ADS use and positive affect and pain such that positive affect was higher and pain was lower following an ADS day $\beta = 0.32, t(895) = 2.69, p = .007$ (**Figure 2**).

CHAPTER 4

DISCUSSION

With the number of dementia caregivers on the rise, identifying effective interventions to mitigate the burden, stress, and negative health outcomes associated with the caregiver role has become a chief priority. It has become increasingly important to incorporate respite for caregivers in these interventions. However, these interventions rarely consider addressing bodily pain, as little is known about how the caregiver role influences the pain experience. To our knowledge, this is the first study to examine contributing factors to the daily reporting of bodily pain within the context of ADS use among dementia caregivers. The findings reveal stress, both care and noncare-related, influences the daily experience of bodily pain. Despite prior findings that ADS use reduces the occurrence of care-related stress and increases next day positive affect (Zarit et al., 2013), it does not yield significant decreases in same day bodily pain. These findings underscore the importance of providing both respite that could ameliorate the occurrence of reported stressors and stress management skills to assist caregivers in managing daily challenges such as pain.

Perhaps the most significant contribution of this study involves lagged effects. While ADS use did not influence same day daily reports of bodily pain, individuals who used ADS subsequently exhibited more positive affect and less pain on the following day. Additionally, the overall extent of ADS use provided a buffering effect against the experience of bodily pain. This may be due to the decrease in stressor exposure or an increase in next day positive affect, as

caregivers were not providing all of the care on the previous day. This is consistent with Finan and Garland's (2015) upward spiral model of positive affect, suggesting positive affect buffers maladaptive responses to pain. This is also consistent with prior findings that levels of a salivary biomarker of stress reactivity, dehydroepiandrosterone-sulfate (DHEA-S), were higher on days after ADS use (Zarit et al., 2014). This biomarker is a protective factor against physiological effects of stressor exposure and is associated with more positive mood.

Although the daily use of ADS did not change the experience of same day bodily pain, the extent of ADS use provided a buffering effect against the experience of daily bodily pain. Taken together, these findings are encouraging, as they identify future targets for intervention (e.g., stress management, positive affect maximization) beyond those addressed by respite alone. Policy makers are concerned with long-term benefits of ADS use and other respite programs, and these findings shed light on targets for improvement.

As with any research, the current study has several limitations. There may be a selection bias, as caregiver enrollment was voluntary and it is unclear how many caregivers decided not to contact the research team. Additionally, selection only of individuals utilizing ADS introduces an even larger selection bias. Moreover, this study did not include the objective occurrence of stressors within the models, and this might be important in terms of identifying further avenues of intervention (e.g., reducing number of stressors versus increasing stress management skills). This study also did not examine positive appraisals of stressors (PACs), and past findings have found these positive appraisals have lasting effects on burden and depression among dementia caregivers (Hilgeman et al., 2007). Lastly, this study used a single item as an index for pain. In the future, it is important to use a more comprehensive measure of pain, beyond the context of

chronic conditions, to garner a comprehensive understanding of differences in the daily and cumulative effects of stress and ADS use on caregivers' daily experience of pain.

Implications

In conclusion, this study adds to the literature by suggesting avenues for intervention to reduce daily pain among caregivers of IWD. The caregiving role can have distressing consequences for the dyad; these findings underscore the importance of considering daily pain in efforts to maximize coping responses. Research to date has underestimated the importance of pain in caregivers, but has revealed that pain is a robust correlate of caregiver burden and predicts coping behavior (Jones et al., 2011). This study examines daily pain outside of the chronic pain condition, suggesting daily pain, generally, is an important facet of the dementia caregiving experience to consider in the design and delivery of interventions to expand ADS benefits. For example, treatments for caregivers could incorporate a module regarding physical activity and active coping strategies such as mindfulness for pain management (Kabat-Zinn, 1982; Morone, Greco, & Weiner, 2008; Zeidan, Gordon, Merchant, & Goolkasian, 2010). Integration of treatments that address the physical health needs of caregivers has implications for the overall health, well-being, and quality of life of caregiving dyads.

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Table 1.
Caregiver Characteristics (N = 173)

Variable	<i>M</i>	<i>SD</i>	Range
Age	61.97	10.66	39-89
Education ^a	4.46	1.20	1-6
Income ^b	6.68	3.10	1-11
Duration of Care ^c	61.12	45.55	3-264
Female (yes = 1)	0.87	0.34	0-1
Relation to IWD			
<i>Spouse (yes = 1)</i>	0.38	0.49	0-1
<i>Child (yes = 1)</i>	0.58	0.49	0-1
<i>Other (yes = 1)</i>	0.04	0.20	0-1
White (yes = 1)	0.73	0.45	0-1
Married (yes = 1)	0.69	0.46	0-1
Employed (yes = 1)	0.42	0.49	0-1
Number of daily interview days	7.86	0.65	3-8
<i>Number of ADS days</i>	4.09	1.46	1-6
<i>Number of non-ADS days</i>	3.77	1.43	2-7

Note. ADS = adult day services; IWD = individual with dementia

^aRated on a 6-point scale ranging from 1 (less than high school) to 6 (post college degree).

^bRated on a 11-point scale ranging from 1 (less than \$10,000) to 11 (100,000 or over).

^cMeasured in months.

Table 2.
Daily Stress, Affect, and Pain of Family Caregivers (N = 173)

Variable	<i>Min</i>	<i>Max</i>	<i>M</i>	<i>SD</i>	<i>ICC</i>
Care-related stress ^a	76	266	88.31	21.37	0.73
Noncare-related stress ^a	8	31	10.75	3.49	0.43
Positive affect	1	5	3.02	0.95	0.74
Daily Pain	1	5	2.18	1.24	0.65

^aSummed scores for care and noncare-related stress; rated on a 5-point scale ranging from 1 (not stressful at all) to 5 (very stressful). Care-related stress ratings were given for each day for four time periods; 1) the night before, 2) waking to 9:00 a.m., 3) 9:00 a.m to 4:00 p.m., and 4) 4:00 p.m. to bedtime that same day.

Note: Negative affect was excluded as it was omitted from the analyses.

Figure 1. Time-Varying Stress Process Model (Adapted from Pearlin's [1990] SPM)

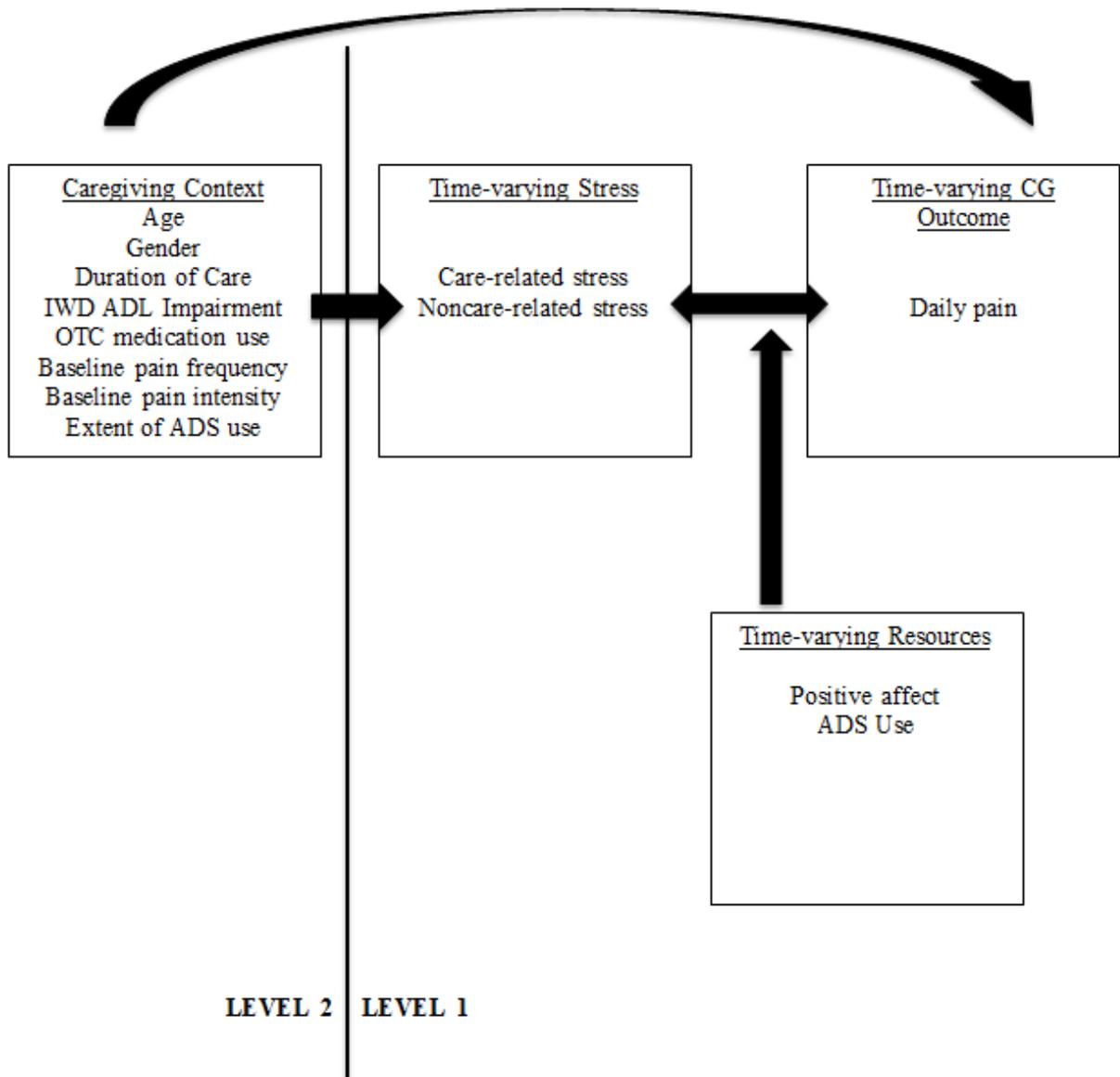
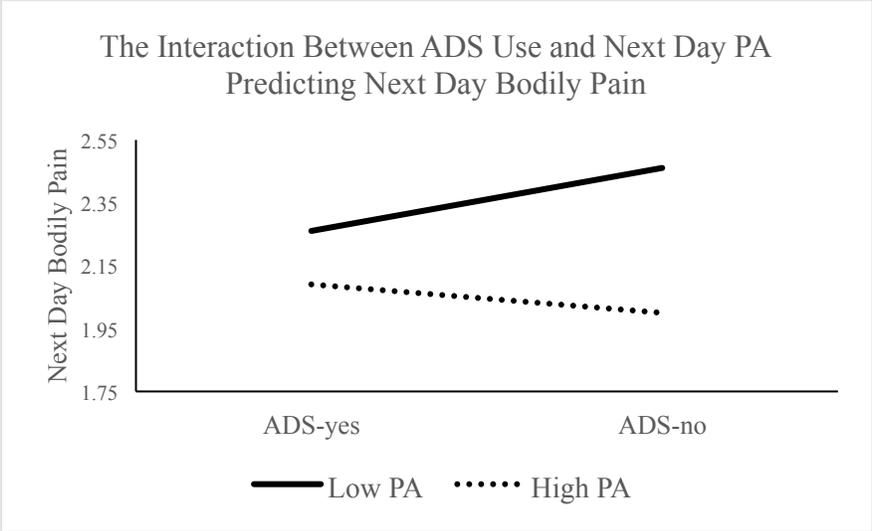


Figure 2. The Interaction between ADS Use and Next Day PA Predicting Bodily Pain



APPENDIX A

Caregiver Background and Demographics

Items:

1. GENDER
 - (1) Male
 - (2) Female

2. How old are you? (ROUND TO CLOSEST YEAR)
____ __ YEARS

3. How would you classify your race? (ASK IF UNCERTAIN; SPECIFY IF 'OTHER')
 - (1) WHITE
 - (2) BLACK/AA
 - (3) ASIAN
 - (4) NATIVE AM/ALASKAN
 - (5) NAT HI/PACIFIC ISLANDER
 - (6) OTHER:

4. Are you of Hispanic origin?
 - (1) YES
 - (5) NO

5. What is your marital status?
 - (1) Married/Partner
 - (2) Widowed
 - (3) Divorced
 - (4) Separated
 - (5) Never Married

6. Do you have children?
 - (1) YES
 - (5) NO

Number of sons _____
Number of daughters _____

7. What is the highest level of education you have completed?

- (1) Less than High School
- (2) Some High School
- (3) High School Graduate
- (4) Some College/Trade/Vocational
- (5) College Graduate
- (6) Post College Degree

8. Are you currently employed?

- (1) YES
- (5) NO

If you are employed, how many hours per week do you work? _____

16. If we include the income from all sources, what would your total household income before taxes be for the last 12 months?

- (1) Less than \$10,000
- (2) \$10,000-19,999
- (3) \$20,000-29,999
- (4) \$30,000-39,999
- (5) \$40,000-49,999
- (6) \$50,000-59,999
- (7) \$60,000-69,999
- (8) \$70,000-79,999
- (9) \$80,000-89,999
- (10) \$90,000-99,999
- (11) \$100,000 or over
- (88) SKIPPED
- (99) DON'T KNOW/REFUSED

Relative Background and Demographics

9. IF UNCERTAIN ASK, is your [REL] male or female?

- (1) Male
- (2) Female

10. How old is your [REL]? (ROUND TO CLOSEST YEAR)

___ __ YEARS

11. How would you classify your [REL's] race?

- (1) WHITE
- (2) BLACK/AA
- (3) ASIAN
- (4) NATIVE AM/ALASKAN
- (5) NAT HI/PACIFIC ISLANDER
- (6) OTHER:

12. Is your [REL] of Hispanic origin?
(1) YES
(5) NO

13. What is your [REL'S] marital status?
(1) Married/Partner
(2) Widowed
(3) Divorced
(4) Separated
(5) Never Married
(8) Skipped (married to CG)

14. Does your [REL] have children?
(1) YES
(5) NO
(8) Skipped

Number of sons _____
Number of daughters _____

15. What is the highest level of education your [REL] completed?
(1) Less than High School
(2) Some High School
(3) High School Graduate
(4) Some College/Trade/Vocational
(5) College Graduate
(6) Post College Degree

17. If we include the income from all sources, what would your [REL'S] total household income before taxes be for the last 12 months?
(1) Less than \$10,000
(2) \$10,000-19,999
(3) \$20,000-29,999
(4) \$30,000-39,999
(5) \$40,000-49,999
(6) \$50,000-59,999
(7) \$60,000-69,999
(8) \$70,000-79,999
(9) \$80,000-89,999
(10) \$90,000-99,999
(11) \$100,000 or over
(88) SKIPPED
(99) DON'T KNOW/REFUSED

Daily Positive & Negative Affect

Non-Specific Psychological Distress Scale (Adapted; Kessler, Andrews, Colpe, Hiripi, Mroczek, Normand, Walters, & Zaslavsky, 2002; Mroczek & Kolarz, 1998)

Scale:

- (1) None of the day
- (2) A little of the day
- (3) Some of the day
- (4) Most of the day
- (5) All day

Items:

Subscale 1: Anxiety (e.g., nervous, worried)

- F1. Restless or Fidgety
- F2. Nervous
- F3. Worried about the future
- F18. Afraid
- F19. Jittery

Subscale 2: Depression (e.g., helpless, worthless)

- F4. Worthless
- F6. Everything was an effort
- F7. Hopeless
- F17. Lonely
- F21. Ashamed
- F22. Upset
- F24. So sad that nothing could cheer you up

Subscale 3: Hostility (e.g., anger)

- F10. Angry
- F11. Frustrated
- F20. Irritable

Subscale 4: Positive Emotions

- F5. Close to others
- F8. In good spirits
- F9. Cheerful
- F12. Interested in things that happened today
- F13. Extremely happy
- F14. Calm and peaceful
- F15. Satisfied
- F16. Full of life
- F23. Attentive

Care-related Subjective Stress Severity
(DRB; Fauth Zarit, Femia, Hofer & Stephens, 2006; Femia Zarit Stephens, & Green, 2007)

Scale:

Did behavior occur during the previous 24 hour period?	In-Home Interview Response Format During this time period, did your REL. . .	Daily Interview Response Format During this time period, did your REL. . .	Appraisal rating How stressful was this for you?
(1) Yes (5) No (8) SKIPPED	A. Early morning (waking - 9:00am) B. Daytime (9:00am - 4:00pm) C. Evening (4:00pm - bedtime) D. Overnight (bedtime - this morning)	A. Last evening to waking this morning B. Early morning (waking - 9:00am) C. Daytime (9:00am - 4:00pm) D. Evening (4:00pm – to time of call)	(1) Not at all stressful (2) (if the participant indicates that the stress level was between 1 and 3) (3) Somewhat stressful (4) (if the participant indicates that the stress level was between 3 and 5) (5) Very stressful

Items:

ADL-RESISTANCE

B1. Struggle, resist or refuse to wash, bathe or shower?

B2. Have problems around dressing?

B3. Resist or refuse to take his/her medication?

B4. Have any problems related to toileting?

B5. Have problems at mealtime?

RESTLESS BEHAVIOR

B6. Pace up and down?

B7. Follow you around?

B8. Want or try to leave the house or another situation?

B9. Exhibit another agitated or restless behavior?

REALITY-BASED BEHAVIORS

B10. Ask to go home (even though he/she is already at home)?

B11. See or hear things that are not there?

DEPRESSIVE BEHAVIORS

B12. Talk about feeling sad or lonely or become tearful?

B13. Comment about feeling worthless or being a burden?

B14. Argue, complain, or was irritable?

DISRUPTIVE BEHAVIORS

B15. Show physical or verbal aggression: hit, kick,

push, shout, or yell?

B16. Act suspicious, jealous, or make accusations?

MEMORY-RELATED BEHAVIORS

B17. Ask the same question repeatedly?

B18. Lose, hide, misplace things?

B19. Try to cover up memory problems or argue
about forgetting something?

OTHER BEHAVIOR

B20. Other #1

B21. Other #2

B22. Other #3

Noncare-related Subjective Stress Severity
(DISE; Almeida 1998; Almeida, Wethington, & Kessler, 2002)

Scale:

Did this happen in the last 24 hours?	How stressful was that for you?
(1) Yes (5) No (8) SKIPPED	(1) Not at all stressful (2) (if participant indicates the stress level as between 1 and 3) (3) Somewhat stressful (4) (if participant indicates the stress level as between 3 and 5) (5) Very stressful

Items:

- C1. Did you have an argument or disagreement with someone over your [REL]?
- C2. Did you have an argument or disagreement with someone about something else? (This does not include an argument with your (REL).
- C3. Did you avoid an argument with someone?
- C4. Other than what you've already reported today, did anything happen to a close friend or relative?
- C5. Did you experience a health-related issue (either your health or someone else's health)?
- C6. Did you experience a money or finance-related issue?
- C7. **IF EMPLOYED**, did you experience a work-related issue?
- C8. Did you experience anything else that was stressful last night or today?

Pain (Baseline)
(three items from MOS, SF-36; Ware & Sherbourne, 1992)

Domain 4: Bodily pain

44. How much bodily pain have you generally had during the past month?
- (1) None
 - (2) Very mild
 - (3) Mild
 - (4) Moderate
 - (5) Severe
 - (6) Very severe
 - (9) DON'T KNOW/REFUSED
45. During the past month, how often have you had pain or discomfort?
- (1) 1-2 times in the past month
 - (2) At least one per week
 - (3) 2-3 times per week
 - (4) Every day or almost every day
 - (8) SKIPPED
 - (9) DON'T KNOW/REFUSED
46. During the past month, how much did pain interfere with your normal work, including both work inside and outside the home?
- (1) Not at all
 - (2) A little bit
 - (3) Moderately
 - (4) Quite a bit
 - (5) Extremely
 - (8) SKIPPED
 - (9) DON'T KNOW/REFUSED

Daily Pain
(Single item; from Larsen and Kasimatis, 1991)

Scale:

- (1) None of the day
- (2) A little of the day
- (3) Some of the day
- (4) Most of the day
- (5) All day
- (88) Skipped/NA

Item:

- 1. Headache, backache, or muscle soreness?

ADLs
(Kats, Ford, Moskowitz, Jackson, & Jaffe, 1963)

IADLs
(Lawton & Brody, 1969)

Scale:

- (1) Does not need help
- (2) Needs a little help/reminders
- (3) Needs a lot of help
- (4) Cannot do without help

Items:

30. I'd like to know a little more about some of the activities that your [REL] might need help with and who is helping him/her with them. How much help does your (REL) need with:

- 30A. Taking medications?
- 30B. Housework/housecleaning?
- 30C. Shopping for food?
- 30D. Cooking/preparing food?
- 30E. Laundry?
- 30F. Driving or using public transportation?
- 30G. Money issues?

31. Now I'd like to find out how much help your (REL) needs with some other activities. We'll do these activities the same way as we did before. How much help does your (REL) need with:

- 31A. Eating?
- 31B. Dressing/undressing?
- 31C. Grooming/hygiene?
- 31D. Bathing/showering?
- 31E. Going to the bathroom?
- 31F. Getting in/out of bed?

Caregiver Medication Usage

Short description: CG prescription medicine usage

Caregivers were asked for the names of all the medications that have been prescribed for the caregiver, regardless of whether they actually took them. Both the name of the medicine and the reason for taking it were recorded.

Items:

Next we want to know all of the medicines which have been prescribed by a doctor for you to take (regardless of whether or not you actually took the medicine). Include all the medicines that the doctor wants you to take now, or that have in the past month. You can get the bottles if you want, in order to get the name of the medicine as it appears on the label of the medicine bottle. *[UP TO 13 MEDICINES WERE RECORDED. MEDICINE NAME AND INDICATION ARE RECORDED IN THE EXCEL FILE 'BASELINE INPERSON OPEN ENDS']*

Short description: CG over-the-counter medicine usage

Caregivers were asked whether they have taken or used each of five over-the-counter medicines in the past month. Responses were recorded as yes or no. The categories of over-the-counter medicines include medicines for headaches, stomach or gastro-intestinal problems, sleep difficulties, anxiety or tension or depression, and to improve their memory.

Scale:

- (1) Yes
- (5) No
- (9) DON'T KNOW/REFUSED

Items:

- 64. For the next set of questions, we would like to know about the over-the-counter medications, homeopathic or herbal substances you have used on a regular basis over the last month.
- 64A. Headaches? ...Have you taken anything regularly over the last month for...
- 64B. Stomach/Gastro-intestinal problems? ...Have you taken anything regularly over the last month for...
- 64C. Sleep problems? ...Have you taken anything regularly over the last month for...
- 64D. Anxiety, tension, or depression? ...Have you taken anything regularly over the last month for...
- 64E. To improve your memory? ...Have you taken anything regularly over the last months for...
- 64F. For any other reason? ...Have you taken anything regularly over the last month for...

APPENDIX B

IRB Approval

Office for Research
Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

May 21, 2015

Keisha Carden
Dept. of Psychology
College of Arts and Sciences
Box 870348

Re: IRB: EX-15-CM-072, "Daily Stress Health and Well-Being of
Caregivers"

Dear Ms. Carden:

The University of Alabama Institutional Review Board has granted approval for
your proposed research.

Your application has been given exempt approval according to 45 CFR part
46.101(b)(4) as outlined below:

(4) Research involving the collection or study of existing data, documents,
records, pathological specimens, or diagnostic specimens, if these sources are
publicly available or if the information is recorded by the investigator in such a
manner that subjects cannot be identified, directly or through identifiers linked to
the subjects.

This approval expires on May 20, 2016. If the study continues beyond that date,
you must complete the appropriate portion of the IRB Renewal Application. If
you modify the application, please complete the Modification of an Approved
Protocol Form. Changes in this study cannot be initiated without IRB approval,
except when necessary to eliminate apparent immediate hazards to participants.
When the study closes, please complete the IRB Study Closure Form.

Should you need to submit any further correspondence regarding this application,
please include the assigned IRB application number.

Good luck with your research.

Sincerely,


Carpantano T. Myles, MSM, CIM, CIP
Director & Research Compliance Officer



358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
(205) 348-8461
FAX (205) 348-7189
TOLL FREE (877) 820-3066

IRB Project #: EX-15-CM-072

UNIVERSITY OF ALABAMA
INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS
REQUEST FOR APPROVAL OF RESEARCH INVOLVING HUMAN SUBJECTS

I. Identifying information

	Principal Investigator	Second Investigator	Third Investigator
Names:	Keisha Carden	Rebecca S. Allen	Steven H. Zarit
Department:	ARIA/Psychology	ARIA/Psychology	Human Development and Family Studies
College:	Arts & Sciences	Arts & Sciences	Health & Human Development
University:	University of Alabama	University of Alabama	Pennsylvania State University
Address:	309 Osband Hall, Tuscaloosa, AL	204 Osband Hall Tuscaloosa, AL	305 Health & Human Development East
Telephone:	803-526-4039	205-348-9891	814-865-5260
FAX:	N/A	205-348-7520	814-865-5260
E-mail:	kcarden1@crimson.ua.edu	rsallen@ua.edu	z67@psu.edu

Title of Research Project: Daily Stress Health and Well-being of Caregivers

Date Submitted: 5/13/2015

Funding Source: N/A - This is a secondary data analysis; original grant: DaSH; R01AG031758, S. Zarit, PI)

Type of Proposal New Revision Renewal Completed Exempt

Please attach a renewal application

Please attach a continuing review of studies form

top of the page

UA faculty or staff member signature: _____

II. NOTIFICATION OF IRB ACTION (to be completed by IRB):

Type of Review: _____ Full board _____ Expedited

IRB Action:

___ Rejected Date: _____
___ Tabled Pending Revisions Date: _____
___ Approved Pending Revisions Date: _____

Approved-this proposal complies with University and federal regulations for the protection of human subjects.

Approval is effective until the following date: 5/20/2016

Items approved: Research protocol (dated _____)
___ Informed consent (dated _____)
___ Recruitment materials (dated _____)
___ Other (dated _____)

Approval signature _____

Date 5/21/2015