

Predicting Desire for Institutional Placement Among Racially Diverse Dementia Family Caregivers: The Role of Quality of Care

Fei Sun, PhD,*¹ Daniel W. Durkin, PhD,² Michelle M. Hilgeman, PhD,³
Grant Harris, MA,⁴ Joseph E. Gaugler, PhD,⁵ Jana Wardian, MSW,¹
Rebecca S. Allen, PhD,⁴ and Louis D. Burgio, PhD⁶

¹School of Social Work, Arizona State University, Phoenix, Arizona.

²Center for Quality Aging, School of Medicine, Vanderbilt University, Nashville, Tennessee.

³Research & Development Service, Tuscaloosa VA Medical Center, Tuscaloosa, Alabama.

⁴Department of Psychology, Center for Mental Health and Aging, The University of Alabama, Tuscaloosa, Alabama.

⁵School of Nursing, Center on Aging, University of Minnesota, Minneapolis, Minnesota.

⁶School of Social Work, University of Michigan, Ann Arbor, Michigan.

*Address correspondence to Fei Sun, PO Box 37100, Phoenix, AZ 85069. E-mail: fei.sun.1@asu.edu

Received March 11, 2012; Accepted July 9, 2012

Decision Editor: Rachel Pruchno, PhD

Purpose: Literature on institutionalization of patients with dementia has not considered the role of caregivers' quality of care, which encompasses caregivers' exemplary care (EC) behaviors and caregivers' potentially harmful behaviors (PHBs) toward care recipients. This study sought to understand the role of quality of care in mediating between caregiving stressors and caregiver desire to institutionalize (DTI) a patient with dementia. **Design and Methods:** A sample of 612 family caregivers from diverse racial/ethnic backgrounds was drawn from the baseline data of the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) project. Multiple mediator models were run using Preacher and Hayes asymptotic and resampling strategies to assess direct and indirect effects of caregiver stressors (daily care bother, behavioral bother, and burden) on caregiver desire to institutionalize a patient with dementia. **Results:** Overall, PHB was positively related to caregiver desire to institutionalize their care recipients. Specifically, PHB was found to mediate the relationship between caregiving stressors and DTI in the Caucasian and Latino groups, whereas only the mediation effect of EC was significant in the African American group. **Implications:** Caregivers' perceptions of quality of care helped explain their desire

to institutionalize their care recipients with dementia. Including assessment of EC and PHB in clinical and social service settings is recommended for all ethnic groups. Interventions should facilitate EC behaviors among African American caregivers and address concerns of PHBs in Caucasian and Latino caregivers.

Key Words: Institutionalize, Exemplary care, Potentially harmful behaviors

Alzheimer's disease and related disorders (ADRD) are a major risk factor for nursing home institutionalization (Gallagher-Thompson et al., 2011). By 5 years after diagnosis, nearly 50% of ADRD patients are institutionalized (Luppa, Luck, Brahler, Konig, & Riedel-Heller, 2008). Moreover, patients with ADRD cost Medicaid nine times more on average when compared with patients without ADRD (Alzheimer's Association, 2011). Stress associated with the caregiving role including daily care burden (e.g., bathing and feeding; Habermann, Cooper, Katona, & Livingston, 2009), bother associated with behavioral problems (e.g., wandering, repetitive questions; Banaszak-Holl et al., 2004), and more global indicators of caregiver (CG) burden (e.g., reduced self-care, constantly feeling "on duty";

de Vugt et al., 2005) are all associated with nursing home placement. Research has found that AD/DR CGs tend to consider future institutionalization earlier than families providing care for other illnesses (Gallagher-Thompson et al., 2011). This endorsement of thinking and planning for institutional care has been termed “desire for institutionalization” (Morycz, 1985) and has emerged as a powerful, prognostic indicator of future nursing home admission (McCaskill, Burgio, DeCoster, & Roff, 2011).

Approximately 80% of the care for more than 5 million individuals with AD/DR in the United States is provided by families in the home (Alzheimer’s Association, 2011). However, little direct research attention has focused on the dynamic, dyadic impact of CG stress and emotional experience on the quality of care of the care recipient (CR) and concomitant CG desire to institutionalize the CR. To inform future research, the purpose of this article is to examine associations between CG and CR characteristics, quality of informal dementia care, and CG desire to institutionalize (DTI) the CR. Better understanding of the factors associated with informal care quality among diverse CGs may inform future interventions that directly target improving informal care or, potentially, identify families most in need of assistance preparing for institutional placement.

Quality of Informal Care

Quality of informal care (QOC) has been defined as the extent to which the informal care meets the CR’s needs both qualitatively and quantitatively (Morrow-Howell, Proctor, & Dore, 1998) and can range on a continuum from *least adequate* to *most desirable*. QOC, however, is a complex and multifaceted construct as CGs may do well in assisting with certain tasks (e.g., providing food) but poorly with others (e.g., handling CR inappropriate behaviors). Optimal care support is a dynamic process as the individual with dementia declines cognitively, often requiring a balance between supporting CR autonomy with considerations of safety and risk that may be different across care domains and time.

Christie and colleagues (2009) confirmed the multicomponent structure of QOC and identified three domains: (a) potential for harmful behavior (PHB), (b) adequacy of care, and (c) exemplary care (EC). EC refers to care delivery beyond adequate (e.g., promoting dignity, maintaining meaningful social interactions), whereas PHB refers to CG behaviors that could harm the CR (e.g.,

yelling, threatening to abandon) but may not be severe enough to warrant attention from legal or social service departments (Beach et al., 2005). This study focuses on EC and PHB because they were indicated as the most robust correlates of CG psychosocial characteristics (e.g., relationship with the CR, CG depression) (Christie et al., 2009).

Caregiving Stress and Quality of Informal Care

A large literature has identified the potential emotional, psychological, and physical health risks associated with informal care provision, including daily care burden, frustration by CR behavioral problems, and caregiver depression and stress. More recent research has begun to demonstrate how the dynamics of informal care provision may threaten the quality of informal care provided. For example, experiences with stressful life events place CGs at a greater likelihood of exerting potentially harmful behaviors toward the CRs (Christie et al., 2009). A recent longitudinal study (Smith, Williamson, Miller, & Schulz, 2011) found that declines in CG respectful interactions and their increased depressive symptoms predicted potentially harmful behavior (e.g., yelling at the CR) over time.

Conversely, EC was more likely to be reported by family CGs who had a better preillness relationship with the CR (Christie et al., 2009; Dooley, Shaffer, Lance, & Williamson, 2007). In a recent study of dementia CGs, Harris, Durkin, Allen, DeCoster, and Burgio (2011) found that CGs who reported less daily care bother, behavioral bother, and burden were more likely to display EC and more positive feelings of caregiving.

Quality of Informal Care, Institutionalization, and Cultural Issues

Self-reflection or evaluation of the QOC one is providing might influence CG DTI. In a longitudinal national study of dementia CGs, Buhr, Kuchibhatla, and Clipp (2006) report that 65% of CGs ($N = 572$) who placed family members in nursing homes believed that they could not provide the care the patient deserved. Alternatively, if CGs believe that their care best meets the needs of their loved one, they may be less likely to place their CR in a nursing care facility. In that sense, QOC could allude to a mechanism through which subjective CG stressors may influence CG DTI.

Acknowledging that the perceptions of caregiving stress and positive aspects are appraised

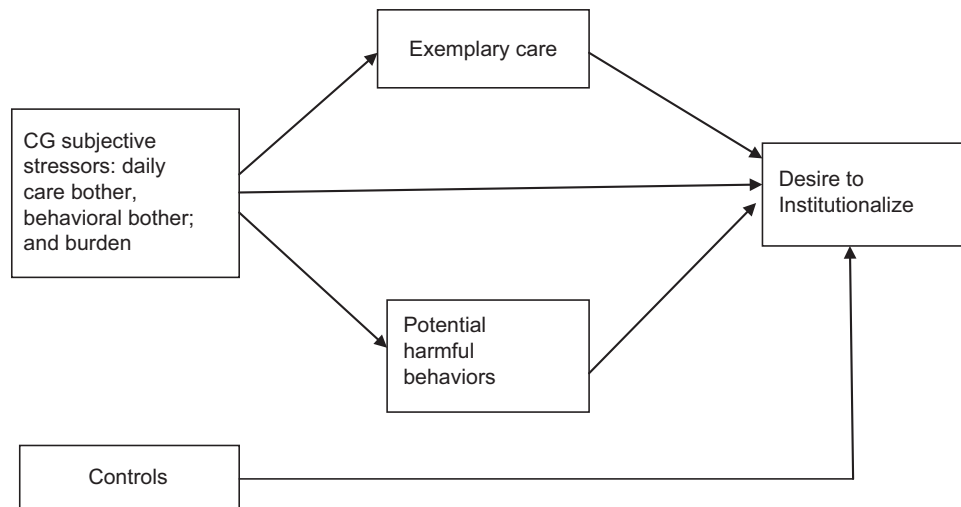


Figure 1. Conceptual model of this study.

Note. Control variables include CR demographics and CG demographic and resource variables (e.g., income adequacy)

through a cultural/ethnic lens (Calderón & Tennstedt, 1998), Caucasians generally engage in earlier placement of loved ones in care facilities (Gaugler, Duval, Anderson, & Kane, 2007), whereas African Americans and Latinos tend to delay institutional placement (Yaffe et al., 2002). African American and Latino cultural values related to the responsibility of caring for elders and a more positive view of the caregiving role may explain these discrepant trajectories (Mausbach et al., 2004). Given the ethnic/cultural differences in perceived caregiving stress and DTI, it is important to examine how QOC may mediate between stress and DTI differently across ethnic groups.

Conceptual Model and Research Hypotheses

Pearlin, Mullan, Semple, and Skaff's (1990) stress process model (SPM) provides a conceptual framework for analyzing the role of QOC as a mechanism influencing CG DTI. The basic components of this model include background characteristics of CRs and CGs, CG subjective stressors (e.g., CG bother by CR behavioral problems), resources (e.g., social support), and CG psychological and physical outcomes. Constructs such as caregiver stressors and social support mentioned in the Pearlin SPM have been identified as predictors for institutionalization (Gallagher-Thompson et al., 2011; Gaugler et al., 2000).

Consistent with the Pearlin SPM, caregiver subjective stressors are considered the primary cause of institutionalization (see Figure 1). This study extends the literature by examining the role of QOC (i.e., EC and PHB) in this process. People

undertake caregiving out of complex motives such as adherence to cultural norms or altruism. Simply put, caregiving is expected to benefit CR or CG, or both. Therefore, reflections on behaviors completed in the act of caregiving (e.g., EC or PHB) would strengthen or dampen egoistic or altruistic motivations for caregiving, contributing to consideration of continuing or giving up caregiving roles.

In light of this conceptual model, this study has two hypotheses. First, we hypothesize that QOC would directly influence DTI. Specifically, EC would be negatively related to DTI and PHB would be positively related to DTI. Second, we hypothesize that QOC would mediate the relationship between caregiving stress and DTI. EC and PHB would mediate the relationship between daily care bother and DTI, behavioral bother and DTI, and CG burden and DTI. Such relationship between QOC and DTI is explored across different racial/ethnic groups.

Methods

Procedure

Secondary data were drawn from the baseline assessment of the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) project (clinicalTrials.gov identifier: NCT00177489) supported through the National Institute on Aging and the National Institute of Nursing Research. REACH II was a 6-month multisite clinical trial that enrolled 642 CG/CR dyads to evaluate a multicomponent psychosocial intervention across five sites (i.e., Birmingham, AL; Memphis, TN; Miami,

FL; Palo Alto, CA; and Philadelphia, PA; Belle et al., 2006).

Caregivers were at least 21 years old, living with or sharing cooking facilities with the CR, providing four or more hours of care per day to a CR with at least two instrumental activity of daily living (IADL) or one activity of daily living (ADL) impairment, providing care for at least 6 months, and reporting at least two symptoms of distress (Belle et al., 2006). The CR had to have a diagnosis of ADRD or a Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) score of 23 or lower; however, bed-bound CRs with a score of 0 on the MMSE were excluded. Detailed information about the REACH II study, psychometric properties of all measures, recruitment procedures, and intervention outcomes are described elsewhere (Belle et al., 2006).

Of the 642 CGs, 30 were excluded due to missing data. The remaining 612 participants included in this study were 34.5% (211) Caucasian, 32.7% (200) African American, and 32.8% (201) Hispanic/Latino; 82.4% were women; and the average age was 59.7 ($SD = 13.1$). Use of longitudinal data was considered; however, the low incidence rate of nursing home placement (7.5%) during the 6-month duration detracted from the ability to draw meaningful conclusions about causality.

Measures

Caregiving Context Variables.—Caregiver-focused measures included CG demographics (i.e., age, gender, relationship to the CR, year of caregiving, race/ethnicity, educational level, income adequacy to provide basic needs), self-reported health status, and social support. CG self-reported health status was measured by a single item ranging from 0 (*poor*) to 4 (*excellent*). Social support was measured by a modified social network scale (Lubben, 1988), using two items, with categories for the number of relatives or friends that the CG interacts with during the month on a 6-point scale (none, one, two, three or four, five to eight, nine or more). Scores range from 0 to 10, with higher scores indicating larger support networks. Cronbach's alpha for this sample is .69.

Care recipient functional status included three measures assessing CR cognitive, physical, and behavioral functioning. MMSE (Folstein et al., 1975) scores range from 0 to 30, with scores below 25 indicating cognitive impairment. Cronbach's alpha for this sample is .78. ADL (Katz, Ford, Moskowitz,

Jackson, & Jaffe, 1963) and IADL Scale—Frequency (Lawton & Brody, 1969) were combined to indicate CR physical dependence. Seven ADL items assessed the CR's ability to perform basic daily functioning tasks independently (e.g., bathing, dressing, toileting). Eight IADL items assessed whether or not assistance was needed to perform higher-level tasks such as shopping, cooking, or managing medications. A summed total level of assistance required for ADLs and IADLs was used with higher scores, indicating greater physical functional impairment. The range of possible scores was from 0 to 15. Cronbach's alpha for this sample is .82. Revised Memory and Behavior Problem Checklist—Frequency (RMBPC; Teri et al., 1992) assessed the presence of 24 CR problem behaviors exhibited in the past week (e.g., trouble remembering recent events, asking the same question repeatedly). Caregivers rated the frequency of behaviors on a 4-point scale from 0 = *not in the past week* to 3 = *daily or more often*. The potential range of scores was from 0 to 72. A summed total was used with higher scores indicating more behavioral problems present. Cronbach's alpha for this sample is .81.

Caregiver subjective stressors include daily care bother experienced by the CG as a result of providing assistance with ADLs or IADLs, behavioral bother experienced by the CG because of CR's memory-related, disruptive and emotion-related problems, and burden described as overall stress or worry.

Daily care bother (Gitlin et al., 2005). Bother associated with the tasks of providing daily care or assistance with ADLs (Katz et al., 1963) was computed. For each task of assistance provided, CGs reported their level of upset on a 5-point scale from 0 = *no upset* to 4 = *extremely upset*. An average CG bother score was calculated by dividing the amount of bother experienced across daily care tasks, with a range from 0 to 4; higher scores indicate more care-related upset. Cronbach's alpha for this sample is .93.

Behavioral bother (Teri et al., 1992). For each endorsed problem behavior (see RMBPC discussed previously), CGs reported how bothered or upset they were using a 5-point scale (0 = *not at all* to 4 = *extremely*). This conditional bother score is calculated by dividing the sum “bother” scores by the number of endorsed problem behaviors ranges from 0 to 4, with higher scores indicating greater level of bother. Cronbach's alpha for this sample is .85.

Zarit caregiver burden inventory (Bedard et al., 2001). Twelve items of the abbreviated Zarit Caregiver Burden Inventory were rated on a 5-point

scale from 0 = *never* to 4 = *nearly always* to assess burden associated with caregiving (e.g., not enough time for oneself, not as much privacy). Scores range from 0 to 48, with higher scores indicating higher reported burden. Cronbach's alpha for this sample is .86.

Mediators: Quality of Informal Care.—EC (Dooley et al., 2007). The Exemplary Care Scale contains 11 items that ask the CG to report the frequency (0 = *never* to 3 = *always*) that they engage in activities (e.g., “I take the time to sit and talk with [CR]”; “I make sure the food [CR] likes is available for meals and snacks”) or refrain from engaging in activities (e.g., being overcritical; interrupting the CR) during interactions with the CR. Total scores range from 0 to 33 with higher scores indicating higher EC. Cronbach's alpha for this sample is .74; additional validity data are published elsewhere (Dooley et al., 2007).

PHB (Beach et al., 2005). The eight-item PHB scale was adapted from the Conflict Tactics scale (Straus, 1979) with modified presentation of items by the REACH Investigators to increase likelihood of reporting high risk behaviors. REACH II modified items to ask CGs how often they “felt like” engaging in PHB rather than if they *committed that behavior* in the past 6 months on a 4-point scale from 0 = *never* to 3 = *always*. Psychological mistreatment was assessed using four items: yelling, using harsh tone of voice, blaming, and telling CR to stop doing things that worry the CG. Physical mistreatment was assessed across four items: hitting, shaking, confining, and using physical constraints. This original scale achieved adequate psychometric validity (Williamson, Shaffer, & Family Relationships in Late Life Project, 2001). Despite the social desirability concern, CGs are quite open to disclose their stress and consequent behavior responses (including those that could be considered abusive) to CRs (Cooper, Blanchard, Selwood, Walker, & Livingston, 2010). Total scores on the modified scale range from 0 to 24 with higher scores indicating more risk for PHB. Cronbach's alpha for this sample is .72.

Dependent variable—DTI (Morycz, 1985). Participants were asked six yes/no questions regarding their anticipated plans to institutionalize their CR (e.g., “In the past 6 months, have you considered a nursing home, boarding home, or assisted living for [CR]?”; “In the past 6 months, have you taken any steps toward placement?”). This scale has been validated elsewhere across three ethnic

groups using REACH II data (McCaskill et al., 2011). Total scores can range from 0 to 6, with higher scores indicating higher DTI. Cronbach's alpha for this sample is .72.

Statistical Analyses

One-way ANOVAs were performed for all variables in the model to determine differences between racial groups. Given the breadth of caregiving-related constructs addressed in the Pearlin SPM and available in the REACH II data, preliminary correlational analyses were conducted to select optimal control variables of DTI. Based on significant bivariate relations, CR ADL/IADL, behavioral problems, CG age, education, and income adequacy were included in subsequent analyses as controls. In addition, literature suggests that CR cognitive severity and nonspousal caregiver status (Gaugler, Yu, Krichbaum, & Wyman, 2009) are consistent predictors of institutionalization, and, thus, both variables were added as controls.

To test the hypotheses (see Figure 1) about the indirect effects of subjective stressors on DTI through QOC, we conducted 12 separate mediation analyses for the whole sample and by racial/ethnic group. The indirect effect of each of the three stressors (daily care bother, behavioral bother, and burden) in predicting DTI through EC and PHB was tested. We conducted the mediation analyses using a SPSS multiple mediation macro developed by Preacher and Hayes (2008), which uses a *bootstrapping* procedure to obtain estimates and confidence intervals around the indirect effects. Baron and Kenny's (1986) four-step mediation approach using a series of regression analyses can only discover whether mediation effect exists or not but cannot identify the size of mediation effect. The Preacher and Hayes' (2008) approach draws on the methods of MacKinnon's (2008) multiple mediator models and provides statistical estimates of indirect effects along with confidence intervals using a bootstrapping method. Thus, the strength of the Preacher and Hayes' (2008) approach lies in that (a) it provides estimates of the indirect effect of multiple mediators and (b) it uses a bootstrapping procedure to generate more precise estimates. Our analysis used a bootstrap threshold of 5,000. If a zero was not included within the 95% confidence interval of the estimate, we concluded that the indirect effect was statistically significant (Preacher & Hayes, 2008).

Table 1. Descriptive Characteristics of Samples by Ethnicity

Measures (range)	Caucasians <i>n</i> = 200 <i>M</i> (<i>SD</i>)/%	African Americans <i>n</i> = 211 <i>M</i> (<i>SD</i>)/%	Latinos <i>n</i> = 201 <i>M</i> (<i>SD</i>)/%
Caregiver subjective stressors			
Daily care bother ^a (0–4)	0.87 (0.79)	0.79 (0.75)	0.52 (0.72)**
Behavior bother (RMBPC) ^b (0–72)	23.10 (9.09)	20.74 (10.44)**	24.52 (10.53)**
Burden ^b (0–48)	18.86 (8.65)**	15.06 (7.68)**	17.07 (9.65)
Quality of care			
Exemplary care (0–33)	26.63 (4.35)	26.04 (4.90)	27.14 (4.80)
Potential for harm ^a (0–24)	4.37 (2.73)	3.84 (2.69)	3.14 (2.75)*
Caregiving context variables			
Care recipient characteristics			
ADL/IADL (0–15)	9.88 (3.22)	9.89 (3.06)	10.06 (3.34)
Behavioral problems ^c (0–4)	1.71 (0.81)**	1.44 (0.82)**	1.78 (0.93)**
MMSE ^c (0–30)	14.31 (7.66)**	11.68 (7.19)**	11.33 (6.95)**
Caregiver demographics and resources			
Age ^a	62.88 (12.05)**	58.20 (13.13)	57.75 (13.70)
Gender (women)	82.4%	83%	81%
Education ^c (0–17)	13.80 (1.99)*	13.09 (2.20)*	10.82 (4.09)**
Spousal caregiver ^a	57.3%**	30.5%	38.3%
Years of caregiving ^a	4.07	4.26	6.04*
Income adequacy ^c (0–3)	1.42 (1.50)*	1.53 (0.98)*	1.26 (0.94)*
Health ^c (0–4)	1.77 (1.05)**	2.10 (0.89)**	2.51 (1.38)**
Supportive network ^c (0–10)	7.01 (2.29)*	6.44 (2.17)**	5.66 (2.29)**
Desire to institutionalize ^a (0–6)	1.42 (1.50)**	1.01 (1.37)	0.86 (1.38)

Note: Only ADL/IADL, behavioral problems, education, age, and income adequacy were selected as controls.

RMBPC = Revised Memory and Behavior Problem Checklist; ADL = activity of daily living; IADL = instrumental activity of daily living; MMSE = Mini-Mental State Exam.

^aOne group is significantly different from the other two groups.

^bTwo groups are significantly different from one group.

^cAll groups are significantly different from each other.

p* < .05, *p* < .01.

Results

Table 1 provides sample characteristics by racial/ethnic group for caregiving context variables, subjective stressors, QOC, and DTI. Although level of reported EC was not statistically different among racial groups, PHB was significantly lower for Latinos (*M* = 3.14, *SD* = 2.75) than for African Americans (*M* = 3.84, *SD* = 2.69) and Caucasians (*M* = 4.37, *SD* = 2.73). The three most frequently reported behaviors related to PHB were “felt like screaming or yelling” (24.8%), “told CR to stop doing things that caused worry” (17.8%), and “used a harsh tone of voice” (17%). The three most frequently reported EC behaviors were “providing food the CR likes” (95.4%), “ensuring CR feels refreshed and good about him/herself” (93.8%), and “making sure where CR lives is bright and cheery” (92.8%) (data not shown in the table). Racial differences also emerged for DTI, such that Caucasians (*M* = 1.42, *SD* = 1.50) endorsed significantly higher DTI than for African Americans (*M* = 1.01, *SD* = 1.37) and Latinos (*M* = 0.86, *SD* = 1.38).

Table 2 shows significant bivariate correlations (see table for values). Daily care bother, behavioral bother, and burden were negatively correlated with EC, as was DTI. Older age and lower income adequacy were related to higher EC. As expected, EC was negatively correlated with PHB. Daily care bother, behavioral bother, and burden were positively correlated with PHB, as was DTI. Higher education and CR behavior problems were also associated with higher PHB.

DTI Across Racial Groups

Table 3 provides the direct and indirect effects of daily care bother, behavioral bother, and burden on DTI for all CGs. Three stressors remained significant in these multiple mediation models. Yet, partial mediation effects were identified for daily care bother through PHB (*B* = .12) with an explained variance of 14.1%, for behavioral bother through both EC (*B* = .03) and PHB (*B* = .14) with an explained

Table 2. Significant Correlations of Desire to Institutionalize

	2	3	4	5	6	7	8	9	10	Desire to institutionalize
1. Daily bother	.56**	.52**	-.23**	.39**	.20**	-.05	-.13**	.05	.20**	.24**
2. Behavior bother	—	.54**	-.17**	.48**	.25**	-.01	.02	-.05	.38**	.24**
3. Burden		—	-.27**	.42**	.19**	-.17**	-.06	.07	.37**	.34**
4. EC			—	-.36**	-.08	.11**	-.08*	.03	-.05	-.20**
5. PHB				—	.15**	.01	.05	.04	.27**	.30**
6. Education					—	-.12**	.28**	-.06	.03	.17**
7. Age						—	.11**	-.08*	-.14**	-.08*
8. Income inadequacy							—	-.07	-.07	.09*
9. ADL/IADL								—	.13**	.09*
10. Behavior problem									—	.18**

Note: EC = exemplary care; PHB = potentially harmful behavior; ADL = activity of daily living; IADL = instrumental activity of daily living.
 p* < .05; *p* < .01.

Table 3. Bootstrapped Estimates, Confidence Intervals, and Explained Variance for the Entire Sample

IV	MV	Effect of IV on MV (a)	Effect of MV on DTI (b)	Direct effect of IV on DTI (c')	Indirect effect (a x b), confidence intervals	R ²
Daily care bother	EC	-1.67**	-.02	.26**	.03 [-.004, .09]	14.1
	PHB	1.32**	.09**	.26**	.12* [.06, .21]	
Behavior Bother	EC	-1.11**	-.03*	.14*	.03* [.005, .07]	13.3
	PHB	1.37**	.10**	.14*	.14* [.06, .23]	
Burden	EC	-.16**	-.02	.03**	.003 [-.001, .01]	16.0
	PHB	.12**	.08**	.03**	.01* [.004, .02]	

Note: Controlled variables include caregiver age, education, relation to the care recipient, income adequacy, CR ADL/IADL, CR MMSE, and CR RMBPC. DTI = desire to institutionalize; EC = exemplary care; PHB = potentially harmful behaviour; RMBPC = Revised Memory and Behavior Problem Checklist; ADL = activity of daily living; IADL = instrumental activity of daily living; MMSE = Mini-Mental State Exam; CR = care recipient; MV = Mediating Variables; IV = Independent Variables.
 ***p* < .01; **p* < .05.

Table 4. Bootstrapped Estimates, Confidence Intervals, and Explained Variances for Tests of the Indirect Effects for Caucasians (n = 211)

IV	MV	Effect of IV on MV (a)	Effect of MV on DTI (b)	Direct effect of IV on DTI (c')	Indirect effect (a x b), confidence intervals	R ²
Daily care bother	EC	-1.52**	.02	.67**	-.02 [-.13, .05]	.17
	PHB	1.20**	.10*	.67**	.12* [.03, .29]	
Behavior bother	EC	-.1.23**	.001	.19	-.001 [-.07, .06]	.11
	PHB	1.38**	.13**	.19	.17* [.05, .37]	
Burden	EC	-.18**	.01	.04*	-.002 [-.01, .01]	.13
	PHB	.15**	.11*	.04*	.01* [.003, .03]	

Note: Controlled variables include caregiver age, education, relation to care recipient, income adequacy, CR ADL/IADL, CR MMSE, and CR RMBPC. DTI = desire to institutionalize; EC = exemplary care; PHB = potentially harmful behavior; RMBPC = Revised Memory and Behavior Problem Checklist; ADL = activity of daily living; IADL = instrumental activity of daily living; MMSE = Mini-Mental State Exam; CR = care recipient; MV = Mediating Variables; IV = Independent Variables.
 p* < .05, *p* < .01.

variance of 13.3%, and for burden through PHB (*B* = .01) with 16.0% variance explained.

Caucasian Caregivers and DTI

Table 4 provides the direct and indirect effects of three subjective stressors on DTI for Caucasian

CGs. For daily care bother and burden, both direct and indirect effects on DTI were significant. Daily care bother was associated with higher DTI (*B* = .67) and indirectly influenced DTI through PHB (*B* = .12). Similarly, higher levels of burden were directly associated with greater DTI

Table 5. Bootstrapped Estimates, Confidence Intervals, and Explained Variances for Tests of the Indirect Effects for African Americans ($n = 200$)

IV	MV	Effect of IV on MV (a)	Effect of MV on DTI (b)	Direct effect of IV on DTI (c')	Indirect effect (a × b), confidence intervals	R ²
Daily care bother	EC	-2.09**	-.07**	-.09	.14* [.05, .31]	.07
	PHB	1.14**	.05	-.09	.06 [-.04, .18]	
Behavior bother	EC	-1.25*	-.07**	-.02	.08* [.02, .22]	.06
	PHB	1.42**	.04	-.02	.05 [-.08, .21]	
Burden	EC	-.24**	-.06*	.03	.01* [.005, .03]	.10
	PHB	.13**	.01	.03	.002 [-.01, .01]	

Note: Controlled variables include caregiver age, education, relation to care recipient, income adequacy, CR ADL/IADL, CR MMSE, and CR RMBPC. DTI = Desire to institutionalize; EC = exemplary care; PHB = potentially harmful behavior; RMBPC = Revised Memory and Behavior Problem Checklist; ADL = activity of daily living; IADL = instrumental activity of daily living; MMSE = Mini-Mental State Exam; CR = care recipient; MV = Mediating Variables; IV = Independent Variables. ** $p < .01$; * $p < .05$.

Table 6. Bootstrapped Estimates, Confidence Intervals, and Explained Variances for Tests of the Indirect Effects for Latinos ($n = 201$)

IV	MV	Effect of IV on MV (a)	Effect of MV on DTI (b)	Direct effect of IV on DTI (c')	Indirect effect (a × b), confidence intervals	R ²
Daily care bother	EC	-1.19*	-.01	.22	.01 [-.03, .08]	.17
	PHB	1.40**	.11**	.22	.16* [.06, .31]	
Behavior bother	EC	-.79	-.01	.12	.01 [-.02, .06]	.17
	PHB	1.16**	.12**	.12	.14* [.05, .26]	
Burden	EC	-.10*	-.01	.03	.001 [-.003, .007]	.19

Note: Controlled variables include caregiver age, education, relation to care recipient, income adequacy, CR ADL/IADL, CR MMSE, and CR RMBPC. DTI = desire to institutionalize; EC = exemplary care; PHB = potentially harmful behavior; RMBPC = Revised Memory and Behavior Problem Checklist; ADL = activity of daily living; IADL = instrumental activity of daily living; MMSE = Mini-Mental State Exam; CR = care recipient; MV = Mediating Variables; IV = Independent Variables. ** $p < .01$; * $p < .05$.

($B = .04$) and indirectly increased DTI through PHB ($B = .01$). The effect of behavioral bother on DTI for Caucasian CGs was not significant in the multivariate model. But there was a significant full mediation effect through PHB ($B = .17$), suggesting that PHB explained the influence of behavioral bother on DTI. The explained variance for caregiver subjective stressors in DTI in three models ranged from 11% to 17%.

African American Caregivers and DTI

Table 5 provides the direct and indirect effects of three subjective stressors on DTI in African American CGs. In these multivariate models, none of the three subjective stressors had a direct effect on DTI. PHB was not related to DTI in the three models. Yet, EC was related to lower scores on DTI and further mediated the effect of all three subjective stressors (i.e., daily care bother, behavioral bother, and burden) on DTI. The explained variance in DTI for African Americans in three models ranged from 6% to 10%, somewhat lower than for other racial/ethnic groups.

Latino Caregivers and DTI

Table 6 provides the direct and indirect effects of the three subjective stressors on DTI for Latino CGs. None of the three subjective stressors showed a significant effect in the multivariate models. EC was not related to DTI in any model. Yet, PHB was predictive of DTI such that higher levels of PHB were associated with greater DTI. In addition, PHB mediated the effects of all three subjective stressors (i.e., daily care bother, behavioral bother, and burden) on DTI. The explained variance in DTI in the three models with respective stressor ranged from 17% to 19%.

Discussion

Using the Pearlin SPM as a conceptual foundation, this study represents an initial effort to examine the role of QOC in explaining the relation between caregiving subjective stressors and CG desire to institutionalize an ADRD patient in different racial/ethnic contexts. Previous studies on QOC have largely relied on reports from cognitively intact older adults or their CGs; and dementia patients typically

accounted for less than 30% of their sample size (Beach et al., 2005; Dooley et al., 2007). When data were directly collected from CRs, patients with severe cognitive impairment were often excluded (Dooley et al., 2007). This study extended the current body of knowledge by focusing on the QOC perceived by a culturally diverse group of dementia CGs—a group who often report heightened stress compared with their nondementia counterparts (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Descriptively, we found that CGs reported both EC and the PHBs. About 90% of CGs reported that they felt like engaging in at least one PHB in the past 6 months, and all CGs reported one or more EC behaviors. Notably, EC and PHB are not mutually exclusive but were only moderately (and inversely) correlated; caregiving can be a bittersweet journey affected by situational factors, and a typical exemplary CG may have a bad day feeling like acting out on their negative emotions at the CR.

Our findings largely confirmed the first hypotheses about associations between QOC and DTI. For the overall sample, EC was negatively related to DTI at a bivariate level, whereas PHB was positively related to DTI at bivariate and multivariate levels. It is possible that engaging in PHB more directly reflects CG capacity to handle CR needs and CG stress level, evidenced by the stronger correlations between PHB and CG subjective stressors in this study. Moreover, harmful behaviors directed at CR can cause safety concerns triggering the institutionalization of CR.

Our second hypotheses that EC and PHB would mediate the relationship between subjective stressors and DTI were partially supported, depending on racial/ethnic context. PHB was a mediator among Caucasian and Latino CGs, whereas only EC explained the relation between subjective stressors and DTI among African American CGs.

In the African American group, EC—and not PHB—explained the relation between the subjective stressors and DTI. This suggests African American CGs believe that they are “communicating to care recipients that they are loved, respected, and worthy of special consideration” (Dooley et al., 2007, p. 360) and that this perception partially explains the link between their subjective appraisal of the caregiving situation and their relative lack of desire to institutionalize their loved one. It may be that engaging in EC behaviors is what encourages African Americans’ continuation of care.

It is quite noteworthy that among African Americans, EC is the salient explanatory pathway. The experience of meaning or the positive aspects

of caregiving that are often experienced among CGs might be more salient in African Americans’ caregiving activities and might explain the racial/ethnic differences found in this study (Harris et al., 2011). As mentioned in prior research among palliative CGs (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008) and dementia CGs (Hilgeman et al., 2009), African American culture may particularly embrace positively valenced interventions when caring for aging CRs with advanced chronic illness. Our current findings suggest that, among African Americans, increasing EC behaviors will be of more benefit in creating positive changes within the dementia CG–CR dyad.

However, among Caucasians and Latino CGs, PHB—and not EC—mediated the relation between subjective stressors and DTI. Thus, interventions focused on decreasing the potential for negative care behaviors may best assist Caucasian and Latino dementia CGs, particularly when targeted at improving preparations and considerations regarding future institutionalization of their CRs. Caucasian and Latino CGs express their subjective distress through PHBs that may then increase their desire to institutionalize CR. One possible explanation is that Caucasians and Latinos may be concerned about the possibility of harming their CRs when making the decision to institutionalize. Given little prior evidence in this regard, we recommend future studies explore whether concerns about safety emerge for these two cultures and whether initiating interventions to prepare for future long-term care placement eases concerns in the context of increased risk for PHBs.

Another contributing factor could be related to the higher rates of depression reported in Caucasian and Latino CGs (Gallagher-Thompson et al., 2000). As suggested by Shaffer, Dooley, and Williamson (2007), depression is associated with resentful feelings and aggressive coping strategies, which are risk factors for PHB. Greater and specific research and clinical attention to the practical and culturally competent delivery of treatment for depression within Caucasian and Latino dementia CG groups may assist in alleviating distress associated with care and delay institutionalization, if appropriate.

Limitations of this study include those based upon secondary data analysis; we were limited to the variables included in REACH II baseline data. Additional possible confounding factors for DTI such as family relationship history (Spitznagel, Tremont, Davis, & Foster, 2006) and previous coping experience were not included. Second, the interpretation of mediation models tested in this

study is limited due to the cross-sectional nature of the study. Due to the short 6-month outcome assessment examined in the REACH II clinical trial, actual institutionalization of CRs was minimal ($n = 46$) and precluded examination of racial/ethnic differences in placement. DTI and institutionalization are highly correlated (Gallagher-Thompson et al., 2011). DTI may serve as a “canary in a coal mine” such that higher DTI scores should lead to further assessment (including QOC), especially given the brevity and ease of administering this six-item measure. Still, longitudinal research with a longer time span is needed to test the effect of QOC on DTI across ethnic groups. Finally, our findings regarding Latino CGs are limited due to the heterogeneity within the collapsed Latino groups (e.g., Mexican-Americans, Cuban-Americans, etc.).

Implications and Conclusions

Based on the findings of this research, we recommend including assessment of QOC in clinical and social service settings. Buhr and colleagues (2006) suggest that during office visits physicians screen CGs for low life satisfaction, effects of CRs problem behaviors, and daily care burden as a way of determining timing of institutionalization. We suggest that assessment for the CG’s ability to provide EC and to prevent PHB should be included in this discussion as they are significant mediators in the decision to place a loved one in a care facility. If needs are identified, those CGs should be linked to in-home and/or community-based services, which can be helpful if used earlier in dementia caregiving careers, to delay institutionalization (Gaugler, Kane, Kane, & Newcomer, 2005).

Both EC and PHB suggest intervention implications, particularly regarding preparations for future care. As EC provides examples of care behaviors identified as ideal, CGs can use EC as guidelines in modeling their care behaviors. Attention should also be paid to foster a positive orientation to caregiving by increasing CG motivation, encouraging times of warmth and connection, and identifying activities that both CG and CR enjoy. Given that EC is particularly important in influencing DTI for the African American CGs, we recommend specific cultural considerations (e.g., relying on religion/spirituality, extended family) in interventions with this group (Gallagher-Thompson et al., 2003).

As reported earlier, the three most frequently reported PHB in this study were related to verbal abuse such as screaming or yelling, telling CR to

stop doing things, and using a harsh tone of voice. These verbal demonstrations of frustration are perhaps more socially accepted ways of venting anger, which may be amenable to interventions designed to keep PHB at a minimum through teaching CGs alternative ways to manage their negative emotions. This may be particularly important given changes in the ability to understand language as dementia progresses; caregiver education regarding the importance of tone, approach, and other nonverbal means of communicating could also be emphasized. Finally, it is likely that CGs can benefit from anger management interventions, which have demonstrated effectiveness in increasing positive cognitive coping and reducing levels of anger (e.g., Steffen, 2000), particularly considering that anger may increase the chance that feelings of depression or resentment might lead to PHB (MacNeil et al., 2010)

QOC is a fairly new concept in caregiving that could drive the field forward by potentially serving as the basis for new clinical content across a range of caregiving intervention protocols. The addition of this construct in the Pearlin PSM model—and our improved understanding of its relations in the model—adds another area for focus/change for clinicians. QOC plays a potentially important role in the stress process and thus can serve as a point of emphasis in individual or family consultation, support groups, or skill-training protocols as an outcome of interest. Still, additional research on the role of QOC in the Pearlin PSM model is needed as it is unclear whether self-reported care quality reflects actual care received and therefore belongs in the model with more objective or background characteristics (e.g., CR MMSE scores, education, etc.) or whether self-reported QOC is most closely related to other subjective appraisals (e.g., role mastery) of the caregiving relationship and context. Having such information could guide interventionists to either do more skill building and education on caregiving techniques or, perhaps, focus more on caregivers’ perceptions and expectations regarding optimal care provision.

As the number of ADRD patients grows, more family members will join the caregiver fight against the struggles and stress associated with caregiving. The formal service system needs to applaud the contributions of these family members and, simultaneously, should increase attention on optimal care quality for ADRD patients. Understanding of the role of QOC offers a promising direction toward this goal.

References

- Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster, J. L., Jr, & Burgio, L. D. (2008). Legacy activities as interventions approaching the end of life. *Journal of Palliative Medicine, 11*, 1029–1038.
- Alzheimer's Association. (2011). 2011 Alzheimer's disease facts and figures. Retrieved from http://www.alz.org/downloads/Facts_Figures_2011.pdf
- Banaszak-Holl, J., Fendrick, A. M., Foster, N. L., Herzog, A., Kabeto, M. U., Kent, D. M., et al. (2004). Predicting nursing home admission: Estimates from a 7-year follow-up of a nationally representative sample of older Americans. *Alzheimer Disease & Associated Disorders, 18*, 83–89.
- Baron, R. M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 61*, 1173–1182.
- Beach, S., Schulz, R., Williamson, G., Miller, L., Weiner, M., & Lance, C. (2005). Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society, 53*, 255–261.
- Bedard, M., Molloy, D. W., Squire, L., Dubois, L., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden interview: A new short version and screening version. *The Gerontologist, 41*, 652–657.
- Belle, S. H., Burgio, L., Burns, R., Coon, D., Czaja, S. C., Gallagher-Thompson, D., et al. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine, 145*, 727–738.
- Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist, 46*, 52–61.
- Calderón, V., & Tennstedt, S. (1998). Ethnic differences in the expression of caregiver burden: Results of a qualitative study. *Journal of Gerontological Social Work, 30*, 159–178.
- Christie, J., Smith, G. R., Williamson, G. M., Lance, C. E., Shovali, T. E., & Silva, L. (2009). Quality of informal care is multidimensional. *Rehabilitation Psychology, 54*, 173–181.
- Cooper, C., Blanchard, M., Selwood, A., Walker, Z., & Livingston, G. (2010). Family carers' distress and abusive behavior: Longitudinal study. *The British Journal of Psychiatry, 196*, 480–485.
- de Vugt, M. E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., & Verhey, F. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics, 17*, 577–589.
- Dooley, K. W., Shaffer, D. R., Lance, C. E., & Williamson, G. M. (2007). Informal care can be better than adequate: Development and evaluation of the Exemplary Care Scale. *Rehabilitation Psychology, 52*(4), 359–369.
- Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189–198.
- Gallagher-Thompson, D., Arean, P., Coon, D., Menendez, A., Takagi, K., Haley, W. E., et al. (2000). Development and implementation of invention strategies for culturally diverse caregiving populations. In Richard Schulz (Ed.), *Handbook on dementia caregiving: Evidence-based interventions for family caregivers* (pp.151–186). New York: Springer Publishing Company.
- Gallagher-Thompson, D., Haley, W., Guy, D., Rupert, M., Arguelles, T., Zeiss, L. M., et al. (2003). Tailoring psychological interventions for ethnically diverse dementia caregivers. *Clinical Psychology, 10*, 423–438.
- Gallagher-Thompson, D., Mhaolain, A. N., Crosby, L., Ryan, D., Lacey, L., Coen, R. F., et al. (2011). Determinants of the desire to institutionalize in Alzheimer's caregivers. *American Journal of Alzheimer's Disease & Other Dementias, 26*, 205–211.
- Gaugler, J. E., Duval, S., Anderson, K., & Kane, R. (2007). Predicting nursing home admission in the US: A meta-analysis. *BMC Geriatrics, 7*(1), 13–27.
- Gaugler, J. E., Edwards, A. E., Femia, E. E., Zarit, S. H., Stephens, M., Townsend, A., & Greene, R. (2000). Predictors of institutionalization of cognitively impaired elders: Family help and the timing of placement. *Journal of Gerontology: Psychological Sciences, 55B*, 247–256.
- Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R. (2005). Early community-based service utilization and its effects on institutionalization in dementia caregiving. *The Gerontologist, 45*, 177–185.
- Gaugler, J. E., Yu, F., Krichbaum, K., & Wyman, J. F. (2009). Predictors of nursing home admission for persons with dementia. *Medical Care, 47*, 191–198.
- Gitlin, L. N., Roth, D. L., Burgio, L. D., Loewenstein, D. A., Winter, L., Arguelles, S., et al. (2005). Caregiver appraisal of functional dependence individuals with dementia and associated caregiver upset: Psychometric properties of a new scale and response patterns by caregiver and care recipient characteristics. *Journal of Aging and Health, 17*, 148–171.
- Habermann, S., Cooper, C., Katona, C., and Livingston, G. (2009). Predictors of entering 24-h care for people with Alzheimer's disease: Results from the LASER-AD study. *International Journal of Geriatric Psychiatry, 24*, 1291–1298.
- Harris, G. M., Durkin, D. W., Allen, R. S., DeCoster, J., & Burgio, L. D. (2011). Exemplary care as a mediator of the effects of caregiver subjective appraisal and emotional outcomes. *The Gerontologist, 51*, 332–342.
- Hilgeman, M. M., Durkin, D. W., Sun, F., DeCoster, J., Allen, R. S., Gallagher-Thompson, D., & Burgio, L. D. (2009). Testing a theoretical model of the stress process in Alzheimer's caregivers with race as a moderator. *The Gerontologist, 49*, 248–261.
- Katz, S., Ford, A., Moskowitz, R., Jackson, B., & Jaffe, M. (1963). Studies of illness and the aged: The index of ADL, a standardized measure of biological and psychological function. *Journal of the American Medical Association, 185*, 914–919.
- Lawton, M., & Brody, E. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist, 9*, 179–186.
- Lubben, J. E. (1988). Assessing social networks among elderly populations. *Family Community Health, 11*, 42–52.
- Luppa, M., Luck, T., Brahler, E., König, H. H., & Riedel-Heller, S. G. (2008). A systematic review. *Dementia and Geriatric Cognitive Disorders, 26*, 65–78.
- McCaskill, G. M., Burgio, L. D., DeCoster, J., & Roff, L. L. (2011). The use of Morycz's desire-to-institutionalize scale across three racial/ethnic groups. *Journal of Aging and Health, 23*, 195–202.
- MacKinnon, D. P. (2008). *Introduction to statistical mediation analysis*. New York: Lawrence Erlbaum Associates.
- MacNeil, G., Kosberg, J. I., Durkin, D. W., Dooley, K., DeCoster, J., Nelson-Gardell, D. M., et al. (2010). Anger as a mediating and moderating influence on mental health and potentially harmful behavior in caregivers. *The Gerontologist, 50*, 76–86.
- Mausbach, B. T., Coon, D. W., Depp, C., Rabinowitz, Y. G., Wilson-Arias, E., Kraemer, H. C., et al. (2004). Ethnicity and time to institutionalization of dementia patients: A comparison of Latina and Caucasian female family caregivers. *Journal of the American Geriatrics Society, 52*, 1077–1084.
- Morrow-Howell, N., Proctor, E., & Dore, P. (1998). Adequacy of care: The concept and its measurement. *Research on Social Work Practice, 8*, 86–102.
- Morycz, R. K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease: Possible predictors and model development. *Research on Aging, 7*, 329–361.
- Ory, M., Hoffman, R., Yee, J., Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist, 39*, 177–185.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583–594.
- Preacher, K. J., & Hayes, A. F. (2008). Asymptotic and resampling strategies for assessing and comparing indirect effects in multiple mediator models. *Behavioral Research Methods, 40*, 879–891.
- Shaffer, D. R., Dooley, W. K., & Williamson, G. M. (2007). Endorsement of proactively aggressive caregiving strategies moderates the relation between caregiver mental health and potentially harmful caregiving behavior. *Psychology and Aging, 22*, 494–504.
- Smith, G. R., Williamson, G. M., Miller, L. S., & Schulz, R. (2011). Depression and quality of informal care: A longitudinal investigation of caregiving stressors. *Psychology and Aging, 26*, 584–591.
- Spitznagel, M. B., Tremont, G., Davis, J. D., & Foster, S. M. (2006). Psychosocial predictors of dementia caregiver desire to institutionalize: Caregiver, care recipient, and family relationship factors. *Journal of Geriatric Psychiatry and Neurology, 19*, 16–20.
- Steffen, A. M. (2000). Anger management for dementia caregivers: A preliminary study using video and telephone interventions. *Behavior Therapy, 31*, 281–299.
- Straus, M. (1979). Measuring intrafamily conflict and violence: The Conflict Tactics (CT) scales. *Journal of Marriage and Family, 41*, 75–88.

Teri, L., Traux, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1992). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist (RMBPC). *Psychology and Aging, 18*, 375–438.

Williamson, G. M., Shaffer, D. R., & Family Relationships in Late Life Project. (2001). Relationship quality and potentially harmful behaviors

by spousal caregivers: How we were then, how we are now. *Psychology and Aging, 16*, 217–226.

Yaffe, K., Fox, P., Newcomer, R., Sands, L., Lindquist, K., Dane, K., et al. (2002). Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA: The Journal of the American Medical Association, 287*, 2090–2097.