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THE NATURE AND SCOPE OF STRESSFUL SPOUSAL CAREGIVING RELATIONSHIPS

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Abstract

The caregiving literature provides compelling evidence that caregiving burden and depressive symptoms are linked with stressful care relationships however relational difficulties around caregiving are seldom described in the literature. This paper presents findings from content analysis of baseline interviews with 40 Alzheimer's disease and Parkinson's disease spousal caregivers enrolled in a home care skill training trial who identified their care relationship as a source of care burden. *Disappointment and sadness about the loss of the relationship; tension within the relationship; and care decision conflicts within the relationship* were recurrent themes of relational stress in caregiving. These spousal caregivers had relationship quality scores *below* the mean and burden and depressive symptom scores *above* the means of the other caregivers in the study. These findings provide support for developing dyadic interventions that help spouses manage relational losses, care-related tensions and care decision making conflicts.

Keywords

Spousal caregivers; spousal relationships; relationship quality; relational stress; caregiving burden; Alzheimer's disease; Parkinson's disease

BACKGROUND

The quality of informal caregiving relationships (often defined as *relationship mutuality, closeness* or *satisfaction*) has been a recurrent topic in the family caregiving literature for the past two decades (Archbold, Stewart, Greenlick & Harvath, 1992; Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007; Norton et al, 2009; Williamson & Schulz, 1990). Caregivers who perceive their relationship with the care recipient as positive and supportive report less care burden and fewer depressive symptoms (Schumaker, Stewart & Archbold, 2007; Stedman, Tremont & Davis, 2007). Conversely, poor quality care relationships engender more depressive symptoms and a greater sense of care burden for informal caregivers (Braun et al. 2009) and spouses are more likely than non-spouses to experience these relational difficulties around caregiving (Beech et al, 2005; Robison, Fortinsky, Kleppinger, Shugrue & Porter, 2009).

Studies of informal caregiving historically have been grounded in role theory (Biddel, 1979) and emphasized role *changes, transitions, strains* and *conflicts* of caregiving or in stress and coping theory (Lazarus & Folkman, 1984) with an emphasis on caregiving stressors. Pearlin and colleagues (1990) integrated both theoretical views by conceptualizing the challenges associated with an illness as the primary stressor, and the social environment in which care occurs as a potential secondary stressor. The majority of published chronic illness caregiving studies have focused on the stresses associated with disease-related functional loss and care demands and comparatively little attention has been given to stressful caregiving relationships.

Although measurement of relationship characteristics is not new, existing studies have focused primarily on numerical ratings to quantify caregiving relationship quality. This paper presents findings from content analysis of interviews with Alzheimer's disease and Parkinson's disease spousal caregivers who described their relationship with the care recipient as a major source of caregiving distress. The intent of the analysis is to provide a contextual understanding of the link between care relationship quality and caregivers' depressive affect and burden.

Alzheimer's and Parkinson's disease

Alzheimer's and Parkinson's disease are age-related chronic diseases with downward trajectories that present unique challenges in maintaining the quality of caregiving relationship. Alzheimer's disease (AD) afflicts more than five million older adults in the United States and presents informal caregivers with a challenging combination of cognitive loss, problematic behaviors such as wandering, paranoia and physical aggression, as well as increasing dependence in physical self-care (Alzheimer's Association, 2009). Studies indicate AD caregiving relationships are stressful (Martire, Lustig, Schulz, Miller & Helgeson, 2004; McClendon, Smyth & Neundorfer, 2004; Schulz & Martire, 2004; Quinn, Clare & Woods, 2009; Vitaliano, Zhang, & Scanlan, 2003). Parkinson's disease (PD), exemplified by both progressive movement disorders as well as non-motor neuropsychiatric symptoms, afflicts more than 1.5 million older adults United States (Van Den Eeden, Tanner, Bernstein, Robin, & Fross, 2003) and places unique demands on informal caregivers to cope with complex medication regimens, increasing mobility limitations and, for 20% or more of PD care recipients, profound cognitive loss as well (Zakharov, Akhutina & Yakhno, 2001). An increasing number of PD study reports indicate that PD caregivers are particularly stressed by caregiving (Aarsland, Larsen, Karlsen, Lim & Tandberg, 1999; Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000; Roland, Jenkins & Johnson, 2009; Lyons, Stewart, Archbold, & Carter, 2009).

Although fewer in number, published reports indicate AD and PD care recipient outcomes also are influenced by care relationship quality. Based on findings from the *Cache County* dementia study of 167 care dyads in Utah, Norton and colleagues found symptom progression was slower for AD care recipients when their caregivers described the care relationship as close and satisfying (2009). Schrag, Hovris, Morley, Quinn, and Jahanshahi reported that PD care recipients whose caregivers were more distressed and depressed, experienced higher incidence of falls, more psychiatric symptoms and earlier disability (2006). Based on their interviews with family caregivers, Caron and Bowers (2003) observed that a decline in caregivers' sense of attachment to the care recipient increased the likelihood of caregiving termination. Findings from these and similar studies suggest effort should be directed to understanding the nature and scope of care relationships as contributory factors in caregiver and care recipient outcomes.

To explore caregiving relationships, we analyzed baseline interviews with spousal caregivers recruited into Project ASSIST.

METHOD

Project ASSIST

Project *ASSIST* (the parent study which provided the sample data for these analyses) was a 2-arm, randomized trial of home care skill training for informal caregivers of persons with either Alzheimer's (AD) or Parkinson's disease (PD). Inclusion criteria required AD and PD care recipients have early to mid-stage disease. At baseline, the functional status of AD care recipients was assessed with the Mini-Mental State Exam cognitive screening measure (Folstein, Folstein & McHugh, 1975), and PD care recipients with the Hoehn and Yahr mobility screening measure (Hoehn & Yahr, 1967). Caregivers of individuals who were bed-bound were ineligible for the ASSIST study.

Persons with AD or PD and their primary caregivers were recruited from memory clinics, general geriatric clinics, private medical practices, home care agencies and support groups across Alabama and North Carolina. Human subjects' protection procedures were reviewed and approved by university institutional review boards in Alabama and North Carolina. AD and PD caregivers interested in the ASSIST study contacted the project office and those who agreed were visited in their home where study objectives and the participation protocol were explained.

A total of 102 AD caregivers and 85 PD agreed to participate and signed the informed consent form. All completed a set of standardized quantitative measures of caregiving *burden* (Vitaliano, Russo, Young, Becker & Maiuro, 1991), depressive *symptoms* (Radloff, 1977), caregiving *preparedness* and *relationship quality* (Archbold, Stewart, Greenlick & Harvath, 1992). These quantitative measures have been used in prior caregiving studies and all had adequate internal consistency at baseline with the ASSIST caregiver sample. As part of study aim 2 to explore how ASSIST training influenced caregivers' management of caregiving burdens over time, all 187 caregivers also participated in baseline interviews about their caregiving burdens (*challenging and stressful caregiving situations*). After completion of the baseline measures and interview, AD and PD caregivers were randomly assigned to either a skill training group or a wait-list comparison group. Group comparisons on changes in quantitative measure scores over the 12-month study participation period have been reported elsewhere (in press). Our impetus for this qualitative analysis of caregiver relational burdens at baseline was the unexpected quantitative finding that 40 of the 130 spouses who participated in the study (31% of the sample) had baseline relationship quality scores below the sample mean.

Semi-structured Interviews

Project staff interviewers trained individually and collectively with simulated caregiver interviews and were accompanied on the first home interview visit by a research team member to verify consistency in conducting interviews. To engage caregivers in interviews about care stressors, ASSIST interviewers used the following introductory statement:

Caregivers often tell us that there are areas of caregiving for a family member that can be challenging or even difficult at times. We would like to spend some time discussing these areas with you. Describe a caregiving event or situation that stands out as being particularly difficult or stressful that has occurred in the last week/month.

Interviewers were trained to use circular and reflexive questions (Tomm, 1987) to explore stressful caregiving situations in more detail.

How did this come to be?

Is that a change from before the illness?

What do you think about it? How did you feel?

Tell me about your responses or what you did. First? Next?

How do you feel about your responses?

Does this remind you of other caregiving situations?

Were they handled in a similar or dissimilar fashion?

Have you made any changes as result of the situation you described?

Would you handle a similar situation the same way again?

Data collection occurred in the privacy of the caregiver's home. Because the interview might heighten the caregiver's awareness of the difficulty of their situation, interviewers spent time at the end of the interview debriefing the caregiver. While some caregivers were tearful as they talked about caregiving difficulties, most remarked that it was helpful to have the opportunity to discuss their care situation. Audio-taped interviews were transcribed and the accuracy of the transcription was verified by both the interviewer and a second staff member. Transcriptions were entered into *Atlas-ti*, a software program useful for analyzing large textual datasets (<http://www.atlasti.com/>) and the following sequential steps were used to develop caregiver burden theme codes.

To explore caregiving burden themes we read interviews for implicit rather than explicit meanings in caregivers' descriptions of difficult and stressful care situations within as well as across cases (Ayres, Kavanaugh & Knafl, 2003). First, research team member individually read transcripts line by line, made notes and developed preliminary burden theme codes. Next, four-six research team members met and collectively compared and refine burden theme codes. Those few cases where the team could not achieve consensus on burden theme codes were set aside. Third, to explore whether burden theme codes were applicable across interviews, an iterative process was used to select new interviews for review on the basis of *high*, and *low* quantitative burden scores. Transcripts were reviewed for code fit and congruence by three external reviewers with family caregiving expertise. Lastly, the team constructed matrices within and across cases of challenging and difficult burdens described by the caregiver respondents, and the strategies they used to manage those burdens.

FINDINGS

Table 1 shows the demographic characteristics of the 187 who participated in the study. One hundred and thirty (70%) of these caregiver participants were spouses; 21% were minority and more than 80% were women.

Forty-six percent of these 187 caregivers described **direct care** situations as difficult and stressful e.g., *managing his/hers memory loss, helping him/her with (intimate physical hygiene) care*. Caregivers who cited direct care problems frequently described a broad range of coping strategies, including transferring knowledge and skills from prior situations (*when my mother was sick, I learned to do this*), or seeking help from family and friends (*our son comes by and helps us ...I get a neighbor lady to come over and bathe my wife..*) or, they described self-directed learning activities (*I asked other women in my support group how they did it; I got some books on caregiving... I found this idea on the internet*).

Thirty-two percent of the caregiver sample described self care situations as stressful e.g., *feeling depressed and socially isolated*. Caregivers who cited self-care problems were also

often able to describe coping strategies: *I learned that if I get up earlier and had some time to myself, I felt less blue...I get one of my children to come by on Saturdays so I can have some personal time.*)

However, 40 of the 130 spousal caregivers who participated in the study described their relationship with the AD/PD care recipient as the major source of caregiving distress. Table 2 shows the scores of these 40 spouses on the caregiving burden, care preparedness, relationship quality and depressive symptoms compared to the other 147 caregivers in the study. These 40 spousal caregivers (18 AD spouses; 22 PD spouses) were more likely to have subjective care burden and depressive symptom scores *above* the mean and relationship quality scores *below* the mean for the total sample (see table 2). These 40 spousal caregivers often described their relational situations in emotional terms: *he no longer thinks of me as his wife...I am pretty much alone now*. Thematic analyses of those 40 baseline interviews revealed three care relationship themes: ***loss, disappointment and sadness about loss of the relationship; tension within the relationship; and, conflicts within the relationship***. Verbatim examples of these three are shown below.

Loss of the relationship

I think (sigh)...it's...being here and seeing him day to day, going, you know, slowly down...: And knowing that the things he does and say to me...that it's not the person that I knew before (voice breaks) (crying): If I say "Do you know who I am?" And he'll say "Yeah, you're my wife," you know. And used to be, he was... we were (voice breaks) close. We could talk to each other... but now we don't ... and it is impossible to have friends over...we don't...we don't do any of that anymore.

60 year-old woman caring 3 years for husband with AD

...it's like he doesn't...have anything to offer... it's...it's different. We had planned to travel some after he retired.. It's a lot different... And uh...so...just our life has changed dramatically. And it will continue to. ...we have more bad days than good days now.....you just try to make the best of it and go on. But it...it seems like that he...sometimes I think he really doesn't try...

68 year-old woman caring 5 years for husband with PD

...we were looking at cards and one had an interesting stamp with this baseball player, must have been a Hall of Fame baseball player and I said, "Did you ever know Jackie Robinson?" and he said, "Oh sure, he played for the Brooklyn Dodgers.." Then he started telling me statistics and everything...and I thought, I do like baseball but there's our life tucked away behind somebody I never heard of...

75 year-old woman caring 12 years for husband with AD

Tension within the relationship

Going out by myself, to go out to church or to the store or anyplace really.. when he sees me begin to get my things together to go to the store or to get my hair done, he starts pacing and talking to himself...but he is really talking to me...he says **no, no, no, no**...I am faced with sneaking out or not going.....,but I can't just stay home all the time....

61-year old woman caring 5 years for her husband with AD

She won't let me help; she just won't; when I step in and help her anyway...she gets perturbed with me...I try to ignore it but believe me, it causes some tough moments..

63 year-old man caring 6 years for his wife with PD

When he first got sick, he said you need to learn to do these things.. so he taught me how to keep the books and manage the money.. so I learned, but when I called and got a man out to fix the back door he said **"why did you do that? I could have done that!"**...I said but you told me to start doing things...he went upstairs and he would not talk to me for the rest of the day...

61 year-old woman caring 4 years for husband with PD

Care decision conflicts within the relationship

And he demands to know "Well what was this check written for? Well, what did you write that check for?" And I try to explain to him, you know, "Look. We've been married fifty-one years. **If you can't trust me with your money now, something's wrong!**" You know. "Well I just like to know what you **do** with it," he said. Well, it's right there in the checkbook, you know, what everything's for.

70 year-old woman caring 2 years for husband with AD

I feel ... in a bind ... feeling that I make stress in our relationship if I push her to exercise formally. She was standing up on both feet and she fell, she was very angry at me. She said she'd been screaming for me. It's always like **"Why aren't you hearing me?" "Why aren't you doing something?"**

78-year-old man caring 2 years for wife with PD

I asked her to clean up; to take her bath and there's no rhyme or reason to how it sets her off. If I knew, then I'd get...get over it, so... All you can do is **hope** to change the subject...look in another direction, and she cussed me out...punched me... **"Get outta here." Get outta here.**

74 year-old man caring 7 years for wife with AD

He doesn't want to let anybody really help and so we get into sort of a big to-do about that..so I am very tearful today and it...s just, it...s just not good. I mean, **you get to the point that you feel like you just want to give up and just say, okay, you think you can handle it all on your own, you just go ahead and do it...**I'm getting to that point....

67 year-old woman caring 5 years for husband with PD

Both AD with its initial loss of cognitive function and subsequent loss of physical ability, and PD with its initial loss of physical function and subsequent loss of cognitive ability, presented relationship challenges for spousal caregivers. While both AD and PD caregivers described sadness and grief about the loss of the relationship, PD caregivers were more likely to describe tension and care decision conflicts within the relationship.

DISCUSSION

Given the empirical links between stressful care relationships, increased caregiving burden and caregivers' depressive symptoms from this analysis, we proposed these findings suggest the scope of home care skill training should be broadened focus to include care relationship interventions. These might include interventions that help caregivers deal with loss and chronic grief, and when the care recipient is cognitively able, dyadic interventions that help

both care partners cope with the tensions associated with role changes and manage conflictual issues that arise around care decision making. Caregiver grieving has been noted in AD and PD literature (Mayer, 2001; Dyck, 2009) and there are a few reports of interventions to help grieving AD caregivers manage bereavement issues after the death of a afflicted spouse (see for example, Haley, Bergman, Roth, McVie, Gaugler and Mittelman, 2008). We propose more attention should be given to developing strategies that help caregivers manage the sense of loss and grief as a chronic illness progresses over time.

The finding that PD caregivers were more likely than AD caregivers to describe tensions and conflicts within the care relationship suggests that PD care recipients sought to participate in managing their care but caregiver and care recipient lacked the skills to function as partners in PD management. Several recent papers have noted the limitations of unidirectional skill training that focuses exclusively on increasing caregivers' skills and knowledge (Lingler et al, 2008; Norton et al, 2009) and we propose our finding demonstrates the limitations of skill training that focuses on one member of a care dyad. While Whitlatch, Judge, Zarit and Femia describe training of AD care dyads to collaborate in anticipatory planning for future disease progression (2008), caregiving literature of the past decade offers few examples of care collaboration for persons managing other progressive chronic diseases, and none that concentrate specifically on helping spousal dyads manage the tensions and conflicts that arise around role transitions and care collaboration decisions. Caregivers who described relational burdens often described avoidance coping strategies: *I try not to talk with him about this....I just walk away when she starts getting upset with me....* We propose these findings support inclusion of care collaboration content in dyadic skill training for chronic illness management.

Limitations and Implications for future research

We readily acknowledge several limitations in this study. First, in that informal caregiving occurs within the context of existing relationships, pre-illness relationship quality must influence the quality of a caregiving relationship to some degree. These analyses provided little insight into the pre-morbid quality of the caregiver-care recipient relationship of these spouses. Although only two of the 40 spouses who identified the care relationship as a source of care stress noted pre-illness relationship difficulties as well, this may have been influenced in part by the focus of our interview questions on current care situations. We strongly recommend that in future studies investigators explore caregivers' beliefs about their relationships prior to the onset of the illness, and the contribution of that pre-illness relationship to the current care relationship quality.

Second, because spouses report more distress than adult child caregivers, we focused this analysis on interviews with the 130 spouses (who entered the ASSIST study). It may well be that the nature and scope of poor quality caregiving relationships are different for adult children and other, non-spousal caregivers, and we encourage other investigators to explore adult children and other kin descriptions of their care relationship.

Third, while care relationships are dyadic, these analyses focused on care relationship quality exclusively through the eyes of spousal caregivers. Whether these perceptions/interpretations were shared by the care recipients is unknown. Although the cognitive losses experienced by all AD care recipients and some PD care recipients in the study limited their ability to participate in interviews about stressful caregiving situations, inclusion of care recipients with chronic illness that are not characterized by severe cognitive losses is crucial to gain a complete picture of chronic illness caregiving relationships. Finally, care dyads in the ASSIST study were followed for only 12 months. Future studies should explore the interaction of relational stress over time as a progressive chronic illness like AD and PD continues to evolve.

Increased life expectancies mean more individuals will have the experience of caring for a spouse or partner with a progressive chronic disease such as AD and PD. The personal, social, and health impact of long-term caregiving have been well documented in the literature and the caregiving literature suggests that *direct care* and caregiver *self care* issues are the most challenging aspects of care situations such as Alzheimer's and Parkinson's disease. However, previous studies indicate positive quality caregiver-care recipient relationships can moderate chronic illness burden and mediate the negative effects of a progressive illness for caregivers, and consequently for care recipients. When viewed through the prism of symbolic interaction, the three relational challenges reported by these 40 spousal caregivers in are all themes of loss: the loss of a shared identity, the loss of a shared view and the loss of an ability to collaborate as partners in managing difficult life situations. Spouses who experienced these relational losses were also more burdened, more depressed, and perceived themselves as less prepared to give care. We suspect it may be the coexistence of these (seldom-noted) relational losses with direct care and caregiver self-care difficulties that make long-term care challenging for families and often predict adverse outcomes for caregivers and care recipients. We propose the care relationship stressors around loss and sadness, tensions and conflicts described by the 40 spousal caregivers in the ASSIST study provide strong impetus for further exploration of care relationship quality.

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References

- Aarsland D, Larsen J, Karlsen K, Lim M, Tandberg E. Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatric Psychiatry*. 1999; 44(10):866–874. [PubMed: 10521886]
- Alzheimer' Association. Alzheimer's Disease Facts and Figures. 2009. (accessed from http://www.alz.org/national/documents/report_alzfactsfigures2009.pdf)
- Archbold, P.; Stewart, B.; GreenlickMHavath, T. Clinical assessment of mutuality and preparedness in family caregivers to frail older people. In: Funk, S.; Tornquist, E.; Champagne, M.; Wiese, R., editors. *Key aspects of elder care: managing falls, incontinence, and cognitive impairment*. New York: Springer Pubs; 1992. p. 328-339.
- Ayres L, Kavanaugh K, Knafl K. Within-case and cross-case approaches to qualitative data analysis. *Qualitative Health Review*. 2003; 13:871–883.
- Beech S, Schulz R, Williamson G, Miller S, Weiner M, Lance C. Risk factors for potentially harmful informal caregiver behavior. *Journal of the American Geriatrics Society*. 2005; 53(2):255–261. [PubMed: 15673349]
- Biddel, B. *Role Theory: Expectations, Identities and Behaviors*. New York: Academic Press; 1979.
- Braun M, Scholz U, Bailey B, Perren S, Hornung R, Martin M. Dementia caregiving in spousal relationships: A dyadic perspective. *Aging & Mental Health*. 2009; 13(3):426–436. [PubMed: 19484607]
- Caron C, Bowers B. Deciding Whether to Continue, Share, or Relinquish Caregiving: Caregiver Views. *Qualitative Health Research*. 2003; 13(9):1252–1271.
- Dyck C. Who cares for the caregiver? *Parkinsonism & Related Disorders*. 2009; 15:S118–S121. [PubMed: 20082970]
- Folstein M, Folstein S, McHugh P. Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12(3):189–198. [PubMed: 1202204]
- Haley W, Bergman E, Roth D, McVie T, Gaugler J, Mittelman M. Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptom. *The Gerontologist*. 2008; 48(6):p732–740.

- Hoehn M, Yahr M. Parkinsonism: onset, progression and mortality. *Neurology*. 1987; 17(5):427–442. [PubMed: 6067254]
- Hooker K, Manoogian-O'Dell M, Monahan D, Frazier L, Shifren K. Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers. *The Gerontologist*. 2000; 40(5):568–573. [PubMed: 11037935]
- Lazarus, R.; Folkman, S. *Stress, Appraisal, and Coping*. New York: Springer Pubs; 1984.
- Lingler J, Sherwood P, Crighton M, Song M, Happ M. Conceptual challenges in the study of caregiver-care recipient relationships. *Nursing Research*. 2008; 57(5):367–372. [PubMed: 18794721]
- Lyons KS, Sayer AG, Archbold PG, Hornbrook MC, Stewart BJ. The enduring and contextual effects of physical health and depression on care-dyad mutuality. *Research in Nursing and Health*. 2007; 30:84–98. [PubMed: 17243110]
- Lyons KS, Stewart BJ, Archbold PG, Carter JH. Optimism, pessimism, mutuality, and gender: Predicting 10 year role strain in Parkinson's disease spouses. *The Gerontologist*. 2009; 49(3):378–387. [PubMed: 19386827]
- Martire L, Lustig A, Schulz R, Miller G, Helgeson V. Is it beneficial to involve a family member? A meta-analysis of family-focused interventions for chronic illness. *Health Psychology*. 2004; 23(6):599–611. [PubMed: 15546228]
- McClendoin M, Smyth K, Neundorfer M. Survival of persons with Alzheimer's disease: caregiver coping matters. *The Gerontologist*. 2004; 44(4):508–19. [PubMed: 15331808]
- Mayer M. Chronic sorrow in caregiving spouses of patients with Alzheimer's Disease. *Journal of Aging and Identity*. 2001; 6(1):49–60.
- Norton M, Piercy K, Rabins P, Green R, Breitner J, Ostbye T, et al. Caregiver-Recipient closeness and symptom progression in Alzheimer's disease. The Cache County dementia progression study. *Journal of Gerontology: Psychological Sciences*. 2009; 64B (5):560–568.
- Pearlin L, Mullan J, Semple S, Skaff M. Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*. 1990; 30(5):583–594. [PubMed: 2276631]
- Quinn C, Clare B, Woods L. The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. *Aging & Mental Health*. 2009; 13(2):143–154. [PubMed: 19347681]
- Radloff L. The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*. 1977; 1(3):385–401.
- Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M. A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *Journal of Gerontology: Psychological and Social Sciences*. 2009; 64(6):788–98.
- Roland K, Jenkins M, Johnson A. An exploration of the burden experienced by caregivers of individuals with Parkinson's disease. *Movement Disorders*. 2009; 25(2):189–193. [PubMed: 20063397]
- Schrag A, Hovris A, Morley D, Quinn N, Jahanshahi M. Caregiver-burden in Parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism Related Disorders*. 2006; 12(1):35–41. [PubMed: 16271496]
- Schulz R, Martire L. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *American Journal of Geriatric Psychiatry*. 2004; 12 (3):240–249. [PubMed: 15126224]
- Schumacher K, Stewart B, Archbold P. Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research*. 2007; 56(6):425–433. [PubMed: 18004189]
- Shim B, Landerman LR, Davis LL. Correlates of care relationship mutuality among carers of people with Alzheimer's and Parkinson's disease. *Journal of Advanced Nursing*. in press.
- Steadman P, Tremont G, Davis J. Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry & Neurology*. 2007; 20(2):115–9. [PubMed: 17548782]
- Tomm K. Interventive interviewing: Part III. Intending to ask, linear, strategic, circular and reflexive questions. *Family Process*. 1987; 21:1–15.

- Van Den Eeden S, Tanner C, Bernstein A, Robin R, Fross D. Incidence of Parkinson's Disease: Variation by Age, Gender, and Race/Ethnicity. *American Journal of Epidemiology*. 2003; 157(11): 1015–1022. [PubMed: 12777365]
- Vitaliano P, Russo J, Young H, Becker J, Maiuro R. The screen for caregiver burden. *The Gerontologist*. 1991; 31(1):76–83. [PubMed: 2007478]
- Vitaliano P, Zhang J, Scanlan J. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*. 2003; 129(6):946–972. [PubMed: 14599289]
- Whitlatch C, Judge K, Zarit S, Femia E. Dyadic intervention for family caregivers and care receivers in early stage dementia. *The Gerontologist*. 2008; 46 (5):688–694. [PubMed: 17050761]
- Williamson G, Schulz R. Relationship orientation, quality of prior relationship and distress among caregivers of Alzheimer's disease patients. *Psychology and Aging*. 1990; 5(4):502–509. [PubMed: 2278672]
- Zakharov T, Akhutina V, Yakhno NN. Memory impairment in Parkinson's Disease. *Neuroscience and Behavioral Physiology*. 2001; 31(2):157–163. [PubMed: 11388367]

Table 1

ASSIST Participant Profile at Baseline (N=187)

Characteristic	AD Caregivers (n=102) M (SD)	PD Caregivers (n=85) M (SD/%)
Age	64.1 (12.7)	66.7 (10.4)
Caregiving experience in years	4.5 (2.94)	8.8(5.64)
Gender		
Male	17 (17%)	17 (20%)
Female	85 (83%)	68 (80%)
Race		
Caucasian	77 (75%)	76 (90%)
Minority (AA)	25 (25%)	9 (10%)
Kin relationship		
Spouse	58 (57%)	72 (85%)
Adult child	29 (28%)	13 (15%)
Other	15 (12%)	0

AD= Alzheimer's disease; PD= Parkinson's disease

M = Mean; (SD) = Standard Deviation, % = percentage

AA = African American

Table 2

Baseline Burden, Care Preparedness, Relationship Quality and Depressive Symptoms Scores for Spouses with Relational Burden (n=40) and Other Caregiver Participants (147)

	AD caregivers (n=102)	PD Caregivers (n=85)
Measure	M (SD)	M (SD)
Subjective care burden (USCB)		
Spouses reporting relational burden (n=40)	20.1 (12.7)	15.8 (9.5)
Other caregiver participants (147)	16.1 (10.4)	9.74 (7.4)
Care preparedness (PREP)		
Spouses reporting relational burden (n=40)	2.4 (0.8)	1.98 (0.6)
Other caregiver participants (147)	2.6 (10.4)	2.7 (0.6)
Relationship quality (RQ)		
Spouses reporting relational burden (n=40)	2.2 (0.8)	2.32 (0.7)
Other caregiver participants (147)	2.4 (0.7)	3.1 (0.6)
Depressive symptoms (CES-D)		
Spouses reporting relational burden (n=40)	12.9 (12.2)	17.00 (12.5)
Other caregiver participants (147)	10.9 (8.9)	11.0 (8.6)

AD= Alzheimer's disease; PD= Parkinson's disease

SCB = subjective caregiving burden; higher scores indicate greater caregiver distress about care demands

PREP = caregiving preparedness; higher scores indicate more preparation to give care

RQ = relationship quality; higher scores indicate more positive relationship with care recipient

CES-D = depressive symptoms; higher scores indicate more symptoms

M = Mean; (SD) = Standard