An Integrated Model of Counseling, Support, and Ancillary Services for Caregivers of Dementia Patients

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The European Conference on Psychology and the Behavioral Sciences 2015
Official Conference Proceedings

Abstract

This study examined the confluence of several factors associated with caregiving that demonstrated alleviation of caregiver burden, lessening of a sense of isolation, and amelioration of related anxieties among spouses or partners caring for a person with mid-to late-stage dementia. Taken separately, the interventions did not alleviate stressors; however, together the integrated aspects constituting the model of care based upon the New York University Caregiver Intervention (NYUCI) were shown to enhance caregivers' quality of life in this three-year study.

Keywords: social support, caregivers, dementia, Alzheimer's, quality of life

This project was supported in part by grant number # XQ098*, from the U.S. Administration on Aging, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy.*

Introduction

A model of psychosocial treatment that works well is a powerful tool for caregivers under the stress of daily obligations, however motivated and loving the caregiver. Family members providing continual oversight of Alzheimer's patients are known to encounter stressors resulting in compromised health status for the caregiver, psycho-social distress, and even social and emotional burnout (Carretero, Garces, & Redenas, 2007; Gonzalez-Salvador, Arango, Lyketos, & Barba, 1999). Solutions have been proposed and tested through the years (Qualls & Anderson, 2009; Rose et al, 2007) and singly, many measures have been adopted by the caregiving public as well as professional health service workers in attempts to address the many stressors associated with caregiving (Bormann et al, 2009; Bradley, Whiting, Hendricks, & Wheat, 2010; Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). However, the factors that contribute to an integrated model of care for ill, disabled, and older family members have not been fully explored. A 36-month project funded by the U.S. Administration on Aging has demonstrated a model of interventions effective in ameliorating caregiver stress, and this study examined in some depth the stressors experienced by adult family caregivers as well as the factors that combined through an integrated model of caregiving appear to alleviate at least some of the burden and stress.

Caregivers of persons with dementia frequently believe that they "have things under control" and should not call upon other people for help, but eventually they can become overwhelmed and then unsure where to turn for help. The post-World War II generation has particular concerns about being a burden to other people and wanting to handle life events and life crises without having to call upon others (Bradley, Whiting, Hendricks, & Wheat, 2010; Nuttman-Schwartz, 2007). Within the project described here, the evaluators and clinical staff often heard such comments as "I'm too tired and worn out to get any help for myself" or "I have health issues of my own and I'm just hanging on with taking care of my husband." The knowledge gained from this study, however, appears to have implications for clinicians and health personnel working with stressed, anxious, and depressed caregivers and points to ways in which health services and social workers can be of greater help in alleviating at least some of the burden of caregiving, enhancing social support, and generally guiding families toward a greater quality of life.

Background and Rationale for the Study

This project constituted a three-year empirical study that served as a demonstration model of human services and family practice with caregivers of dementia patients in Sarasota Florida, one of the U.S. regions with the highest percentages of elder population (35%). The study produced measurable outcomes of counseling interventions, in-person therapy visits, ad hoc visits and telephone interviews, as well as familial social support. The outcomes, such as improved caregiver burden assessments and caregivers' improved understanding of memory loss and behavioral change in individuals with Alzheimer's Disease, were found to be positive for caregiving individuals. The most interesting finding, however, was that these interventions taken singly were not nearly as helpful to caregivers as they were in tandem with each other, or as an integrated and interdisciplinary approach to care. The findings present a cohesive argument that a systematic and evidence-based model of psycho-social interventions plays an important role in alleviating the stress commonly known as “caregiver burden”.

Caregiver burden is a key typical measure in research about dementia caregivers, and it is often used as a baseline measure in intervention studies. Prior research has found many factors associated with caregiver burden, such as the relationship quality among family members of the caregiver, the patient’s cognitive ability, behavioral symptoms exhibited by the dementia patient, and demographics such as caregiver gender (Papastaurou & Kalokerinova, 2007). Interventions that focus on caregivers and provide pleasant activity would seem to alleviate some degree of caregiver burden, based upon prior knowledge (Thompson, Futterman, Gallager-Thompson, Rose, & Lovett, 1993). We believed, however, that providing pleasant or distracting activity would not be enough to create a significant decrease in the sense of burden, thus we added such factors as counseling, social support, ad hoc visits for supportive monitoring, and group and individual attention to depressed mood and other features of social and emotional distress.

It is well known that dementia caregivers have a high level of burden compared with caregivers of patients with other disabilities or diagnoses (Gonzalez-Salvador et al; Ory et al., 1999). Authors of a prominent book on caregiving described the caregiver role as a “36-Hour Day” (Mace & Rabins, 1999). If for patient well-being alone, caregiver burden has been cited as needing improvement (Brodaty et al., 1993; Mittelman et al., 2004). However, the author asserts that a caregiver in such circumstances warrants examination of (and alleviation of) the depth of burden in his or her own right (not only for patient well-being), in keeping with social work and other professional ethics to preserve individual dignity and choice, and to alleviate human suffering whenever possible.

The purpose of this quantitative study was the examination of any relationships among social support, quality of life, and caregiver burden in a population known to have difficult social and emotional adjustment: those caring for spouses or partners with dementia. We focused here primarily upon dementias of the Alzheimer’s type or “Alzheimer’s Disease and Related Dementias” (ADRD), as the diagnosis is known in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (2007). Caregiver burden is a key measure in research about dementia caregivers, and is often used as a baseline measure in intervention studies.

In one study specifically focused upon caregivers of dementia patients, the caregivers were found to endure “caregiver burden” due to several prominent factors: the degree of cognitive impairment of the person with dementia, the presence of behavior problems, a degree of personal care dependency, and the number of conditions needing attention (Bass et al, 2012). The most common problems that produced “burden” in these caregivers were social isolation and depression. Thus, the chronic and unremittent nature of dementia care seem to suggest that one solution would be respite care for the caregiver, to allow her (in the Bass study, all caregivers were also female) to get out occasionally and to alleviate the isolation and possibly improve the depressed mood. Even telephone support programs for family caregivers are known to lessen anxiety about isolation and to offer a greater perception of social support (Bormann et al, 2009), and thus we incorporated this intervention into our study. Behavioral interventions have been shown to reduce caregiver stress and the sense of having to go it alone (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). Such caregivers are also known to abdicate their own self-care in the process of making sure all needs are met for their loved ones (Thorpe et al, 2006), so it seems likely that any process that alleviates some of that burden of care will be useful and welcomed by caregivers. The high financial cost of caregiving is also known, although less costly in comparison with formalized nursing home care; an analysis of the National Longitudinal Caregiver Study estimated caregiving costs of $18,385 annually per patient in 1998, undoubtedly more at the present time, fifteen years later.

Prior research has found many social and relational factors associated with caregiver burden, such as the relationship quality among family members of the caregiver, the patient's cognitive ability, behavioral symptoms exhibited by the dementia patient, and demographics such as caregiver gender (Papastaurou & Kalokerinova, 2007). Research on family treatment considerations specifically found that the frailty of the dementia patient was especially problematic to witness by family members (Sherman, Fischer, Sorroco, & McFarlane, 2011), and that patient-centered care is worthwhile as a treatment methodology in that families' personal and professional experiences vary and each situation needs to be examined uniquely and treatment planned accordingly (Rose et al, 2007).

According to the Alzheimer's Association Facts & Figures for 2010, there are an estimated 5.3 million individuals living with Alzheimer's disease in the U.S. and more than 10.9 million unpaid family, friends and neighbors who provide care to those individuals. Florida State Profiles estimates that more than 500,000 Floridians suffer from Alzheimer's disease (2009 Florida State Profile). With more than 3.3 million Floridians 65 or older, the number of people who will develop Alzheimer's disease or related disorders (ADRD) and the number of families directly impacted with providing care within that state alone will reach an estimated 640,000 by 2025. Thus, Florida reflects the anticipated aging of the U.S. in many ways.

Two organizations in Sarasota County have taken the lead in assisting caregivers of people with ADRD, currently intervening in more than 1,500 families of people with ADRD, and they participated in this federally-funded study. One of the agencies annually serves more than 70 people with ADRD and 80 caregivers of people with ADRD through individual counseling, family counseling, caregiver support groups, wraparound case management services, and respite care. Additionally, approximately 300 caregivers per year receive telephone counseling and support through these service agencies. Another 1,000 people attend educational workshops for caregivers each year, although only approximately 300 of those workshop participants are caring for people with ADRD.

Sarasota County, one of the "oldest" counties in the U.S., with areas of population consisting of 35% over the age of 65, is served by one of 15 Florida designated memory disorder clinics which sees approximately 350 patients per year. This clinic directly serves more than 400 caregivers by providing information and referral to community resources; this clinic was a major referral source for study participants. Professional staff currently are certified by the State of Florida to provide Alzheimer's training to professional and non-professional caregivers and in the last fiscal year provided training to more than 2,500 people on issues related to care and aging. These two entities therefore partnered to provide the NYUCI intervention model and to enroll caregivers into the study. Because many caregivers also receive formal agency help or other relative assistance, they did not meet the study inclusion criteria, and thus, over 200 families eventually enrolled in the study. Only spouses or adult caregivers were admitted to this study.

Research has suggested that interventions often offer only moderate relief to caregivers (Brodaty et al, 2003), and some have called for greater assessment of caregiver burden simply for the sake of caregiver relief (Schultz et al., 2002). Existing literature also lacks attention to variability among caregivers studied, and attention to variability among caregivers as a factor in caregiver burden (Mittelman et al, 2004; Carretero et al, 2007). Many studies have, in fact, focused upon the impact of the cognitive deficits in the care recipient, help with everyday functioning and level of care needs, and behavioral and psychological factors more generally (although without considering individual factors in the caregiver). However, relationships outside the marital or partner dyad have typically been neglected as objects of study (Pearlin et al, 1990). This study added knowledge about the role of social support from family members and others, as well as the influence of respite services that might alleviate some of the burden of caregiving.

The caregiver intervention study was funded by the U.S. Administration on Aging (now the Administration for Community Living) over a three-year period in which a demonstration project could take place in order to evaluate the effects of a specified intervention protocol that assessed social support as well as caregiver burden, caregiver depression, quality of life as perceived by the caregiver, and physical well-being of the caregiver during the study period.

Thus, this study endeavored to note relationships among several variables that include attention to the individual caregiver's aspects of support as well as the social and emotional variables of perceived social support and quality of life. A note: in homage to the idea that the number of social contacts does not equal a quality of social interaction, we acknowledge the difficulty of using only a quantitative numeric to describe social support in terms of contact with relatives. The author is more interested in the quality of the contact as perceived by the caregiver, as well as the relief of caregiver burden or stress resulting from contact and perceived social support from relatives, especially in relation to their geographic locations. Unfortunately, the numeric reporting of social support contacts is the longstanding measure of perceived social support (see greater discussion in the limitations section).

Methods

The Alzheimer's Disease caregiver study described here was designed to use the New York University Caregiver Intervention (NYUCI) counseling and support intervention to assess the well-being of caregivers. NYUCI elements consisted of an initial assessment of the family system and problems, a first individual session followed by four family sessions for counseling and problem-solving, as well as teaching dementia caregiving suggestions and answering family questions, ad hoc contacts to the agency for the following 18-month period if the caregiver wished for individual or group counseling, and follow-up assessments at quarterly intervals during the two-year enrollment period.

A pre- and post-survey design was used; the instruments were administered by licensed social work clinicians who assumed case management of the family's needs upon enrollment of each participant. As a demonstration project, the research method incorporates ongoing services targeting resolution of perceived needs followed by measurement of the behavioral and psychological outcomes of those services. The overall measures are designed to assess caregiver physical health, evaluate caregiver depressive symptoms, and to note caregiver social support and caregiver appraisal of patient memory and behavior.

The university researcher, a specialist in gerontological social work, maintained close contact with all study partners to implement each facet of the research. The researcher achieved approval by the institutional review board and conducted a comprehensive evaluation of all phases of the program. At the conclusion of the 36-month project, the researchers now have an easily replicated program of interventions for people/families affected by ADRD.

Participants and the Sample Frame

Participants are 58% female in the overall project's caregiving sample of 213 families providing care to a patient with dementia, and the female preponderance is concomitant with the general population of U.S. caregivers. Caregiver ages ranged from 58 years to 101 years, with more than one care recipient over the age of 100. All but three of the caregivers are partners or spouses of the care recipient (98%); three (2%) are adult relative (daughter) caregivers. The initial study's inclusion criteria called for only spouse or partner caregivers, and two years into the study the lead funding agency allowed adult child caregivers to participate; an amendment was requested and granted by the Institutional Review Board. None of the caregivers are formal or paid help; this was also specified in the original study protocol and this requirement has been adhered to throughout the study.

The sample (N=213) was drawn from the Sarasota County, FL, elder population, which approaches 35% of the total population in some areas of the county, (in contrast to approximately 18% of the total U.S. population presently). The majority of program participants were White (94%), 2% were African-American, and 4% were Hispanic or Latino. Although socio-demographic characteristics were obviously skewed toward White participants, other demographic characteristics such as urban/rural residence, number of family members, social support resources, and quality of life perceptions were essentially similar.

As a community-based, cross-sectional study of older adults in caregiving situations, eligible individuals were drawn from two large referral sources: the Jewish Family and Children's Services program and a Sarasota hospital system and memory disorder clinic. Eligible individuals between 50 and 101 became the sample frame. Among the 250+ individuals contacted to offer the no-cost demonstration project's services, 213 ultimately accepted the offer to participate in the interviews, assessment, counseling sessions, groups, and instruments of measure. The present analysis used cognitively intact caregiving participants. The size of the resulting sample completing the social support, caregiver burden, and quality of life scales in their entirety was 98 (the results reported here pertain to the 98 female caregivers).

Quantitative inquiry was chosen to determine the effects of this project's interventions due to the availability of good established measurements for the outcomes of interest: social support, caregiver burden, and quality of life. Similar studies of caregiver burden and quality of life have also used quantitative measures (Pearlin, Mullan, Semple, & Skaff, 1995; Sherman, Sorocco, Fischer, & McFarlane, 2011; & Thorpe et al, 2006).

Once an interview was arranged and the participant enrolled in the program, a licensed clinical social worker (LCSW) made an assessment visit and began the protocol of visits, both in-person and by telephone or electronic message if more feasible for the participant. Especially with distant relatives, the alternative methods were often utilized. At the first in-person visit, regardless, the participant signed an informed consent form outlining the nature of the research and the duration and content of the study. The scales and other instruments of measure were described, explained if needed, and made available to the participant for leisurely review. The caregivers (deemed the "participants" in this study) completed a psychosocial assessment and demographic information pertaining to age, gender, relationship status, and the like was gathered within that instrument as well. Detailed information about social support and social relationships was a major part of the data collection.

Participant Assessments and Instruments

The Social Support Scale, Caregiver Burden Inventory, and a quality of life measure were administered at baseline (initial visit) and for subsequent months thereafter at a six-month interval for a pre-and post-measure design. If participants preferred, instruments were mailed to them at the home address rather than brought physically to the home. Response rate was 62%, considered a high rate of return by typical and historically accepted research standards (Dillman, 1978).

Social Support. This measure tallies the number and type of social relationships perceived by the caregiver to be offering support, defined as being available for consult or companionship, making the caregiver feel less isolated, and helping the caregiver realize that he or she is not alone in caregiving. The measures included six items assessing the number of relatives or friends considered to be a part of the support system, frequency of contact, and the degree of emotional closeness experienced, as well as geographic distance or nearness. Reliability was satisfactory (α=.77).

Although caregivers in this study did consider themselves to be essentially self-sufficient and capable in their caregiving duties, 68% of respondents report that they do not live close to family members. Anecdotally throughout the patient records kept for this study, caregivers all noted that mobility and transportation are problematic issues as they age. In fact, 85% have considered their options in regard to continuing to maintain independence and their ability to be effective caregivers if unable to drive.

Caregiver Burden

The Caregiver Burden Scale is a 21-item measure of perceived stress within the caregiving role, with such items as "I don't have enough time for myself" and "I fear what will happen to my relative in the future". The scale is essentially a rating of the degree of stress or burden encountered by the caregiver in his or her role with the person with dementia. Participants all scored in lesser ranges at the completion of the post-test. The caregiver burden scale showed significant difference from pre-to post-test, with a mean overall decrease in caregiver burden score of 14.9 points, with both men and women reporting significantly fewer indicators of caregiver burden (12.1 in men and 13.9 in women of a possible total score of 45).

Quality of Life

A five-item measure of participants' perception of change in the quality of their overall life experience reveals low to high satisfaction with life events and life processes. Respondents were asked to report whether they agreed with such statements as "Things seem better than they were a few months ago" or "These are the best years of my life". All items were positively worded; i.e., no reverse-scoring was necessary on the 3-point Likert-type scale ranging from 0 (strong disagreement) to 2 (strong agreement). Reliability was shown to be high in the present sample (α=.77).

Other Variables

Demographic information included age (in years), gender (0=male, 1=female), marital status (0=not married, 1-married or partnered), educational attainment (actual years of education), and financial income status (numerical range). Although not a measurable instrument, the presence of respite services was also noted and entered into the stepwise regression analysis. Respite services were offered to all participants in the study, although all of the participants did not accept the service.

Results

Data were analyzed with SPSS Version 12 (SPSS 2008). Descriptive analyses, including frequencies, mean values, chi-square and analysis of variance (ANOVA), were conducted on the demographic and pre-test items. ANOVA was used to test for statistically significant differences by gender. Paired-sample t-tests were used to compare pre- and post-test results on social support measures, caregiver burden, and caregiver's perception of the quality of life.

For continuity of data analysis and to attend to all possible configurations of the relatives' geographic status, initially the sample was divided into three potential groups: a) caregivers with no provision of social support; b) caregivers with a "high" level of social support defined as acceptance of counseling interventions, family visits, ad hoc visits and phone calls, and ancillary services offered by the NYUCI model; and c) caregivers with "low" social support as defined by the same indicators above. To further operationalize "high" and "low" levels of support or utilization of the model, the cut points of greater or lesser than 40 visits of any combined type (family, counselor, ad hoc interventionist, etc.) denoted "high" support levels as those receiving 40 or more visits or treatments, and "low" support considered when fewer than 40 visits were indicated. Because no respondent fell into the first category (N=0), only the last two groups were used in the analyses (caregivers with high or low support indicators: HSS or LSS to abbreviate high social support or low social support). The higher or lower support groups did not vary significantly in other aspects of family, social, or demographic conditions.

Independent samples t-tests and chi-squares analyses were conducted to assess differences between these groups. Correlation coefficients among study variables in the last two groups were compared using Fisher's *r-to-z* transformation, which allows a statistical determination of the difference between independent correlation coefficients (Steiger, 1980). In multivariate analyses, a hierarchical regression model of quality of life scores was estimated in each group. After controlling for demographic variables, the relative contact frequencies, social support, and quality of life measures were entered in the model of individuals receiving respite.

Associations among study variables. Descriptive characteristics of the sample and study variables include an examination of Groups 2 and 3, those receiving high or lower social support (recall that we excluded Group 1). On average, participants were 74.2 years of age (SD=6.14) and more than 94% were married. The average years of education were 14.2, and the large majority was White (98.5%). The author notes that this sample was biased with regard to a slightly higher educational level than the general national population and it included few non-White participants; however, that is reflective of the region's ethnic disposition, which is 92% White.

Regression model of perceived quality of life and caregiver burden. The results of the hierarchical regression model suggest that a higher degree of social support as indicated by the greater level of intervention was associated with lessened caregiver burden although family visits alone and counseling visits alone did not relate to lowered caregiver burden. Only the array of interventions embedded in the entire model when taken together appeared to alleviate caregiver burden.

In the regression model for individuals with family support only, support variables explained 9% of the variance in perceived quality of life, with female gender and higher levels of education being the most important predictors of high satisfaction with quality of life. The inclusion of marital status, having respite services, and caregiver burden made no additional contribution to the model. In the regression model for individuals receiving all aspects of the NYUCI model and thus, high social support, demographic variables explained 8% of the variance of quality of life. A higher level of education was also found to be an important predictor in this analysis. In the third model, social contacts, counseling interventions, ad hoc visits, and gender when combined were found to explain 19% of the variance, resulting in a total explained variance of 36%.

Discussion: Why an Integrated Model is Important

Quality of life and the alleviation of caregiver burden are important considerations for caregiving individuals, especially with dementia patient care. If a person has a basis of an adequate or better quality of life, one can imagine that the burden of caring for an impaired but loved family member may be ameliorated by social support during difficult times. For this study, the author questioned whether the addition of counseling services and ad hoc availability of professional caregiving services would make a difference to caregivers who already received some family support; i.e., was the quality of life different if the caregiver's source of social support was "added to" by the model of integrated services? In the subset of caregivers with the entire range of services, the caregivers' gender and educational level were associated with a higher quality of life, but the addition of integrated caregiving services also explained a variance in overall life satisfaction and a lessened sense of burden. Of note, marital status and self-rated health seemed to have no particular association with quality of life; whether or not one is married, a committed relationship may engender a similar degree of caregiver burden and impaired quality of life as one observes a family member's decline and distress.

Caregivers find their tasks physically and emotionally demanding, often stating something indicating that "I'm on the go for 24 hours per day." It appears that the emotional demands have the greatest impact. Because caregivers are known to have difficulty setting boundaries and setting aside time for themselves, it may alleviate some degree of burden to know whether social support is available and to understand that taking advantage of that support can be beneficial for the patient as well as for themselves. In our study, those with the highest scoring on the scale of caregiver burden also related the greatest relief when utilizing social support systems. Further, anecdotally we heard that delaying the acceptance of support delayed the alleviation of the sense of burden, and this will be further explored in future study. If the acceptance of social support and especially formalized social interventions does alleviate caregiver burden to any extent as apparent here, the greater normalization of this practice would seem also to lessen the extent of shame or guilt that caregivers often experience in using such services. Thus, the belief in needing to "go it alone" might be modified.

Ultimately, if a better integrated model of caregiving relief appears to influence one's perception of the quality of life or self-rated satisfaction with one's life overall, we may surmise that the entire model of care is worth considering when implementing services for burdened caregivers of dementia patients.

These findings emphasize the importance of screening the caregiver's social support status when medical and other clinical assessments are made. It would follow that an alleviation of isolation and caregiver burden could potentially decrease visits to doctors, hospitals, or emergency rooms, or could have an impact upon decisions about nursing home or assisted living placements. Thus, the costs of health care could indirectly be affected by greater social support and/or lessened caregiver burden. At least anxieties about the caregiver's ability to provide adequate supervision and services for the dementia patient might be eased.

A limitation of this study is the inability to assess the quality of social contacts and social activity, as the scales measured numbers of social contacts and social support persons in the caregiver's life. An additional limitation and subject of future study would be the relative influence of respite or non-respite service provision in the presence of varying degrees of quality of that support; i.e., is a high number of supporting relatives (or friends) as important as the support of a few high quality interactions with fewer friends and relatives? Additional study could focus upon ways that families and communities or veterans' organizations and governmental agencies make social support feasible and accessible. Many communities offer fine examples of social support to caregivers in their homes as well as programs that can help when they have inadequate support or attention from their own family systems. Community social service practitioners should be aware of the utility of an integrated model of care.

References

Bass, D.M., Judge, K. S., Snow, A. L., Wilson, N. L., Looman, W. J., McCarthy, C., et al. (2012). Negative caregiving effects among caregivers of veterans with dementia. *The American Journal of Geriatric Psychiatry, 20,* 239-247.

Bormann, J., Warren, K.A., Regalbuto, L., Glaser, D., Kelly, A., Schnack, J., & Hinton, L. (2009). A spiritually based caregiver intervention with telephone delivery for family caregivers of Veterans with dementia. *Alzheimer's Care Today, 10*, 212-220.

Bradley, L., Whiting, P., Hendricks, B., & Wheat, L. (2010). Ethical imperatives for intervention with elder families. *The Family Journal, 18*(2), 215-221.

Brodaty H., Green, A., & Koschera K. (2003). Meta-analysis of psychosocial interventions for caregivers of people with dementia. *Journal of the American Geriatrics Society, 51*(5), 657-664.

Carretero, S., Garces, J., & Redenas, F. (2007). Evaluation of the home help service and the impact on the informal caregiver's burden of dependent elders. *International Journal of Geriatric Psychiatry, 22,* 738-749.

Diagnostic and Statistical Manual of Mental Disorders-IV-TR (2007).

Dillman, D.A. (1978). *Mail and telephone surveys: The total design method*. New York: John Wiley & Sons.

Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C.L., Coon, D.W., & Futterman, A., (2012). Impact of psychoeducational interventions on distressed family caregivers. *Journal of Geropsychology, 6,* 91-110.

Gonzalez-Salvador, MT, Arango, C., Lyketos, CG, & Barba, A.C. (1999). The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry, 14,* 701-710.

Mittelman, M. S., Roth, D. L., Haley, W. E., & Zarit, S. H. (2004). Effects of caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's Disease: Results of a randomized trial. *Journal of Gerontological Psychology, 59,* 27-34.

Nichols, L.O., Martindale-Adams, J., Burns, R., Graney, M.J., & Zuber, J. (2011). Translation of a dementia caregiver support program in a health care system--REACH VA. *Archives of Internal Medicine, 171,* 353-359.

Nuttman-Shwartz, O. (2007). Men's perceptions of family during the retirement transition. *Families in Society: The Journal of Contemporary Social Services, 88*(2), 192-202.

Ory, M.G., Hoffman, R. R., Yee, J. L. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and non-dementia caregivers. *The Gerontologist, 39,* 177-185.

Papastaurou, E., & Kalokerinova, A. (2007). Behavior, burden, and depression in caregivers. *Journal of Advanced Nursing, 58,* 446-457.

Pearlin, L., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1995). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-591.

Qualls, S., & Anderson, L. (2009). Family therapy in late life. *Psychiatric Annals*, 39(9), 844-850.

Rose, J., Bowman, K., O'Toole, E., Abbott, K., Love, T., Thomas, C., & Dawson, N. (2007). Caregiver objective burden and assessments of patient-centered, family-focused care for frail elderly Veterans. *The Gerontologist, 47*(1), 21-33.

Sherman, M. D., Fischer, E. P., Sorocco, K., & McFarlane, W. R. (2011). Adapting the multifamily group model to the Veterans Affairs system: The REACH program. *Couple and Family Psychology: Research and Practice*, *1*(S), 74-84.

Thorpe, J.M., Sleath, B.L., Thorpe, C.T., Kalinowski, M., Van Houtven, C.H., Blalock, S. J., Landerman, L.R., Campbell, W.H., & Clipp, E.C. (2006). Caregiver psychological distress as a barrier to influenza vaccination among community-dwelling elderly with dementia. *Medical Care, 44,* 713-721.

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