

Relatives Near or Far: The Role of Geographically Distant or Close Social Support for Dementia Caregivers

Jane Roberts, Ph.D., LCSW, ACSW
Chair, Duvall Family Studies
University of South Florida
USA

Abstract

Research has demonstrated that all types of social support for caregivers of frail elders are not equally important or reflective of alleviating caregiver burden. Engaging in social interaction and including recreational activities appear to have a significant effect in diminishing the burden of caregiving. The present study pertains to social support and its relationship to quality of life overall among caregivers of community-dwelling dementia patients (M age=72.4 years). The author examined the relationships of caregiver burden, social support, and quality of life in caregivers with geographically local or distant relatives (N=144). Working from the assumption that having local support of relatives or others considered to constitute the support system would alleviate at least some caregiver burden, and that those with distant relatives would perceive less support, the authors found that those with formal interventions from a social service agency equally perceived adequate support despite the geographic location of relatives. The author concluded that the geographic distance of relatives who provide social support does not significantly impact the caregiver's perceived quality of life; thus, local support may sometimes take the place of relative or family support to caregivers.

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

Introduction

The purpose of this study was the examination of apparent effects of the quality of social support, quality of life, and caregiver burden in those caring for spouses or partners with dementia, primarily Alzheimer's Disease. Alzheimer's Disease and Related Dementias" (ADRD), as the diagnosis is known in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (2007), is widespread in American society, and anticipated to increase. Caregiver burden is a key measure in research about dementia caregivers, and 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).

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., 1996). 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, in keeping with social work and other professional ethics to preserve individual dignity and choice, and to alleviate human suffering whenever possible.

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.

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).

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 have steered away from using a quantitative numeric only 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.

Methods

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. Depression and caregiver physical health are not the subject of this particular article, as depression scores have not yet been evaluated over time and because physical health of the caregivers appears to have no great variability in the sample. Rather, we have focused upon social support, caregiver burden, and their relationship to quality of life.

The Alzheimer's Disease caregiver study 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 caregiving sample, 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.

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. Another lead agency 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 is served by one of 15 Florida designated memory disorder clinics which sees approximately 350 patients per year and 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 help or other relative assistance, they did not meet the study inclusion criteria, and thus, approximately 200 families eventually ended up in the study. Only spouse or adult caregivers were admitted to this study.

Procedures

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.

Sample

The sample 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, 201 eventually 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 125.

Participant Assessments and Instruments

The Social Support Scale, Geriatric Depression 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 Dillman standards and other estimations (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 ($\alpha=.77$). Thus, we were able to assess the influence of the quality of social support overall, rather than simply the number of contacts with friends or family.

Although caregivers in this study do consider themselves to be essentially self-sufficient and capable in their caregiving duties, 68% of respondents report they do not live close to family members. Anecdotally throughout the patient records kept for this study, they 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 ($\alpha=.77$).

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).

Results and Discussion

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 caregiver burden and quality of life measures. As mentioned earlier, depression scales were not yet complete enough to include within these analyses, but mentioned here for full disclosure of the methods.

For continuity of data analysis and to attend to all possible configurations of the relatives’ geographic status, initially the sample was divided into four groups: a) caregivers with no relatives to provide social support, b) caregivers with only local or close (in proximity) relatives, c) caregivers with only geographically distant relatives, and d) caregivers with both local and distant relatives. Because no respondent fell into the first category, and due to the small numbers in both of the first groups ($N=0$ and $N=11$), only the last two groups were used in the analyses (caregivers with only geographically distant relatives and caregivers with both local and distant relatives). 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 and types were entered in the model of individuals with distant relatives only, and self-rated health was entered for the group with both distant and local relative support. Finally, social network and social contact activity were added for both groups to assess the independent effects of social engagement on quality of life.

Associations among study variables. Descriptive characteristics of the sample and study variables include an examination of Groups 3 and 4 (recall that we excluded Groups 1 and 2); the two groups consisted of 144 older adults with comparable gender distributions (58% female). 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. In the group of caregivers with both local and distant relatives, women and those with more years of education had higher levels of perceived quality of life. Individuals with only distant relatives had a stronger association between social support (contacts) and quality of life ($r=.34$, $p<.001$) than did caregivers with both local and distant relatives ($r=.11$, $p=.02$). The author had hypothesized that those with more distant relatives would perceive less social support. However, it appears that caregivers who have only distant relatives may seek (or may somehow receive) more contact and more frequent activities even in the local area than those who have both distant and local relatives for social support.

Regression model of perceived quality of life. The results of the hierarchical regression model suggest that social support and social activity relate to life satisfaction in the presence of certain demographic variables. In the regression model for individuals with only distant relatives, demographic 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. Although caregiver burden had increased over time in both groups, the inclusion of marital status, self-rated health, and caregiver burden made no additional contribution to the model. In the regression model for individuals with both distant and local relatives, one demographic variable explained 8% of the variance of quality of life. A higher level of education was found to be an important predictor in this analysis. In the third model, social contacts and social support were found to explain 9% of the variance, resulting in a total explained variance of 22%.

Conclusion

Quality of life is an important variable in caregiving individuals, especially with dementia patient care. If a person has at least an adequate or better quality of life, one can surmise that the burden of caring for an impaired but loved family member may be less than if the quality of life is poor. For this study, the author questioned whether the geographic distance of those whom the caregiver had identified as giving social support would make a difference; i.e., was the quality of life different if the caregiver's source of family support was geographically distant? In the subset of caregivers with geographically distant relatives, the caregivers' gender and educational level were associated with a higher quality of life, with female caregivers expressing greater perceived quality of life. However, the same demographic (gender) was significant as a predictor of quality of life for those with both distant and local relatives; this suggests that the distance of relatives is not of as much import as one might anticipate. 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. In those with distant and close relatives, higher education was the factor seeming to enhance perceived quality of life, rather than distance from the family member.

Thus, if higher educational levels appear to influence one's perception of the quality of life or self-rated satisfaction with one's life overall regardless the proximity or distance of relatives who are considered to be supportive, we may surmise that better educated caregivers are better able to research diagnostic and treatment indicators, connect either virtually or in social circles with other caregivers, know how to access web-based or other evidence-based medical and social care information, or perhaps better interpret, understand, and be able to implement health instructions of health professionals encountered in the health caregiving milieu.

Those better educated may also partake of health support groups and have the means to access and have transport to those services. An interesting finding is the evidence of the importance of educational level in caregiving, despite the social support being received locally or from more geographically distant relatives.

A limitation of this study is the inability to assess the quality of social contacts and social activity in great depth, but it does go farther than prior research in examining qualitative factors rather than simply numbers of contacts as a measure of social support.

An additional limitation and subject of future study would be the apparent influence of local or distant relative support 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 make social support feasible and accessible: via transportation to social functions, education in web-based communications, and health professionals' encouragement toward social interactions with relatives and others.

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