Published in final edited form as:

Alzheimers Dement. 2016 August ; 12(8): 917–924. doi:10.1016/j.jalz.2016.03.008.

Closer Caregiver and Care-Recipient Relationships Predict Lower Informal Costs of Dementia Care. The Cache County Dementia Progression Study

Gail B. Rattinger^{a,b}, Elizabeth B. Fauth^c, Stephanie Behrens^d, Chelsea Sanders^d, Sarah Schwartz^{e,f}, Maria C. Norton^{c,f}, Chris Corcoran^{e,f}, C. Daniel Mullins^g, Constantine G. Lyketsos^h, and JoAnn T. Tschanz^{d,f}

^a School of Pharmacy and Pharmaceutical Sciences, Binghamton University State University of New York, New York, 13902

^b Pharmacy Practice Division, School of Pharmacy, Fairleigh Dickinson University, Florham Park, New Jersey 07932

^c Department of Family, Consumer and Human Development, Utah State University, Logan, UT 84322

^d Department of Psychology, Utah State University, Logan, UT 84322

^e Department of Mathematics and Statistics, Utah State University, Logan, UT 84322

^f Center for Epidemiologic Studies, Utah State University, Logan, UT, 84322

^g Pharmaceutical Health Services Research Department, University of Maryland Baltimore School of Pharmacy, Baltimore, Maryland 21201

^h Johns Hopkins Bayview Medical Center, Baltimore, Maryland 21224

Abstract

INTRODUCTION—Identifying factors associated with lower dementia care costs is essential. We examined whether two caregiver factors were associated with lower costs of informal care.

METHODS—271 care-dyads of the Cache County Dementia Study were included. Estimates of informal costs were based on caregiver reports of time spent in care-related activities and inflation-adjusted 2012 Utah median hourly wages. Caregiver coping and emotional closeness with the care-recipient were assessed using the Ways of Coping Checklist-Revised and Relationship Closeness Scale, respectively.

Corresponding author: JoAnn T. Tschanz, Ph.D., 2810 Old Main Hill, Utah State University, Logan UT 84322-2810, Phone: 435-797-1457; Fax: 435-797-1448; joann.tschanz@usu.edu.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Presented in preliminary form at the Annual Meeting of the Gerontological Society of America, November, 2013.

RESULTS—Higher closeness was associated with 24% lower costs [$\exp\beta=0.763$ (95% CI:0.583–0.999)] in linear mixed models controlling for demographics and baseline dementia severity and duration. Problem-focused coping was not associated with informal costs ($p=0.354$).

DISCUSSION—Caregiver closeness, a potentially modifiable factor, predicted lower dementia informal costs over time. Future studies examining the care environment in closer dyads may identify specific care-related behaviors or strategies that are associated with lower costs.

Keywords

informal costs of dementia; caregiver; relationship closeness

1. Introduction

Worldwide prevalence of dementia is increasing quickly and is projected to exceed 115 million by 2050 unless major advances in prevention and treatment are found [1]. Further, Alzheimer's disease (AD) prevalence, the dementia type most commonly affecting older adults, has now reached 5.1 million in the United States and is projected to nearly triple to 13.8 million by 2050 [2].

The psychosocial impact on individuals and families notwithstanding, dementia is one of the costliest conditions among older adults because most dementias are progressive with declines in cognition and function, and often with problematic neuropsychiatric symptoms (NPS). United States direct healthcare costs for AD and other dementias are estimated at \$226 billion in 2015, with Medicare and Medicaid covering \$153 billion (68%), out-of-pocket costs at \$44 billion (19%) and other sources comprising the rest (\$29 billion, 13%) [2]. While costs for healthcare, long-term care, and hospice were estimated at \$226 billion in 2015, they are expected to exceed \$1 trillion in 2050 [2]. Few longitudinal estimates of these costs were previously available and mostly based on administrative claims [3] or participant samples from academic medical centers [4] that are not necessarily representative of longitudinal costs of dementia care in community-dwelling individuals. Identifying dementia cases through administrative databases may contribute to biased estimates, based on more severe cases [5]. Of the studies estimating longitudinal costs, dementia characteristics such as severity or NPS are often lacking though previous studies have correlated costs with the presence of NPS [6] and with increased dementia severity [7-9]. Prior studies are limited in lower sensitivity of disease ascertainment, particularly for mild dementia [5] and few have examined factors that affect informal caregiver costs [4, 9].

Informal caregiver costs comprise a substantial component of the costs of dementia care, with 2010 estimates of replacement costs (the cost of purchasing these services from a home health agency) at \$215 billion, and costs of foregone wages estimated at \$159 billion [10]. Hurd and colleagues based these estimates on data from the national Health and Retirement Study (HRS). While the sample is representative of a community-dwelling population with dementia, factors that drive increased costs of care within this sample, such as dementia severity or NPS were not examined [10].

Longitudinal changes in cognition, function and NPS with dementia progression have been studied in the Cache County Dementia Progression Study (DPS) a population-based study of persons with dementia and their caregivers [11]. The DPS is comprised of community dwelling participants, where all dementia cases were clinically diagnosed and followed for as many as 10 years after the diagnosis of dementia, with rich information including caregiving hours, dementia progression, and caregiver factors [11]. In a previous study of the informal costs of care in this population-based sample, we demonstrated that longitudinal costs increased with dementia severity [12], as assessed by the Mini-Mental State Exam (MMSE) [13] as a cognitive measure; the Clinical Dementia Rating (CDR) [14] scale as a functional measure; and the Neuropsychiatric Inventory (NPI) [15] as a behavioral measure.

Of particular interest to the current study, DPS has identified caregiver-environment factors that are also related to dementia progression. Specifically, Norton and colleagues (2009) found that among emotionally closer caregiver-care recipient dyads, that the care-recipient (person with dementia) demonstrated a slower rate of cognitive and functional decline [16]. This association was modified by the kin-relationship, with the slowest decline evidenced where caregivers were spouses [16]. Additionally, Tschanz and colleagues reported that dementia progression was slower among care-recipients whose caregivers more frequently used a problem-focused coping strategy [17].

The purpose of this paper is to extend previous findings related to the informal costs of dementia care [12, 16-17] by examining whether care-related factors associated with slower disease progression (closeness, kin-relationship and problem-focused coping), also predict lower costs over time. As care environment factors are modifiable, these analyses can provide important insights into potential cost-saving areas of dementia care.

2. Methods

Extant data from the prospective, population-based study of dementia, the DPS, were used for the current analyses. Cases of dementia were identified from the Cache County Study on Memory in Aging (CCSMA) in four triennial waves of dementia screening and ascertainment, described previously [18, 19]. Briefly, permanent residents of Cache County, Utah, aged 65 years or older in 1995 (Wave 1), were rescreened and assessed in 1998-1999, 2002-2004, and 2005-2007. Persons with dementia were diagnosed from a clinical examination that included a physical and neurological examination, neuropsychological testing, and clinical history provided by a knowledgeable informant. Participants with suspected dementia were asked to complete brain imaging and standard laboratory tests for dementia, and a physician exam to aid in the differential diagnosis of dementia. A panel of experts in neurology, geropsychiatry, neuropsychology or cognitive neuroscience assigned a consensus diagnosis for each case. Persons were classified with dementia if they met DSM-III-R criteria [20].

Dementia type was diagnosed following standard protocol, for example, AD was assigned following NINCDS-ADRDA criteria [21] and vascular dementia (VaD), NINDS-AIREN criteria [22]. Age of dementia onset was assigned as the age at which the individual unambiguously met DSM-III-R criteria for dementia. Incident cases of dementia were

followed approximately 12-to-18 months after diagnosis by the CCSMA and subsequently with their caregivers in the DPS. Included in the analyses were only those data from visits in which participants resided in a non-institutional setting. Persons with dementia and their caregivers were followed semiannually for up to 7.8 years from the start of DPS (for those with follow-up, mean = 2.8; sd = 1.6; median = 2.3).

2.1 Procedures of the DPS

The DPS invited CCSMA participants with dementia and their caregivers to join a longitudinal study to examine factors that influence the rate of progression of dementia [11]. Subjects completed a core battery of neuropsychological tests at semi-annual visits. A caregiver was interviewed about the participant's current functional abilities and NPS, demographic information about themselves, their relationship with the care-recipient, coping strategies and amount of informal and formal assistance in daily tasks provided to the care-recipient (see Measures). Based on the information gathered from the visits, ratings of dementia severity and overall health were assigned by the assessment team in consultation with a study neuropsychologist. A rating of dementia severity was assigned using the Clinical Dementia Rating (CDR) [14] as 0.5(questionable), 1(mild), 2(moderate), 3(severe), 4(profound) and 5(terminal) for each of the following domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. A global CDR was determined, following a standard algorithm [23]. Ratings of overall health were assigned using the General Medical Health Rating (GMHR) based on a standard physical exam, review of medical history and medications, and frailty [24]. The values for the GMHR are: 1(poor), 2(fair), 3(good), and 4(excellent). All procedures of the CCSMA and DPS were approved by institutional review boards at Utah State University, Duke University and the Johns Hopkins University.

2.2 Measures

2.2.1 Outcome variable: Informal costs of care—As reported previously [12], at alternating visits, a caregiver completed a caregiver activity survey about how much time was spent over the past 24 hours by all caregivers providing supportive care for the participant in areas such as answering questions, leaving reminders, using transportation, dressing, assisting with meals and eating, assisting with grooming, and supervising the participant's activities. Values for each activity were summed to a maximum of 16 hours per day, following practices used in previous studies [25, 26]. Data from the visits in which the key caregiver (defined as the caregiver present at the majority of the visits) provided information were used in the current analyses.

To estimate the cost of informal care in 2012 dollars, we used the same approach as in the prior cost paper on this cohort [12]. We used the Utahan median hourly wage as reported in the U.S. Bureau of Labor's Occupational Employment Statistics for the year of the visit (spanning from 2002-2011), adjusting for inflation using a derived Medical Consumer Price Index (MCPI) multiplier based on the "medical care services" values from the annual average Urban Consumer Price Index [27].

2.2.2 Predictor variables—Two primary caregiver factors were examined as predictors of the informal costs of dementia care: closeness of the caregiving relationship and caregiver coping. Closeness of the caregiving relationship was assessed using the six-item instrument by Noelker and Whitlatch [28, 29]. Each item in the Relationship Closeness Scale (RCS) used a 4-point Likert scale that assessed the degree of caregiver agreement with six statements that characterized the current relationship with the care-recipient, for example, “My relationship with (NAME) is close” [28, 29]. Total scores (range: 6-24) were calculated by summing the scores on the six individual items, with higher values indicating closer relationships [16]. The RCS has a reported internal consistency (α) of 0.90 [29] calculated in a U.S. sample of 133 nursing home residents and their family-member caregivers. Similarly, past research with the DPS suggests high internal consistency ($\alpha = 0.86$) [30] and moderate correlations between current and prior relationship closeness ($r = 0.63$, $p < .001$) [31].

Caregiver coping strategies were assessed at each odd-numbered visit using the Ways of Coping Checklist-Revised (WCCL-R) [32]. This 57-item questionnaire assesses eight scales representing the following coping strategies: Problem-Focused, Seeks Social Support, Avoidance, Wishful Thinking, Blames Self, Blames Others, Counts Blessings and Religious Coping. Caregivers were asked to think of a problem and indicate the frequency with which they used the specific coping behavior (never, rarely, sometimes, or regularly). As reported previously [17], mean scores were calculated based on all items within the scale, preserving the original scale of measurement. Imputation of missing items was conducted using the mean of the scale for up to 10% of the items.

In the present analysis, we selected caregiver factors that were associated with clinical outcomes, specifically relationship closeness [16] and use of problem-focused coping [17], and examined their associations with the informal costs of dementia care. The other coping strategies listed above were not independent predictors of dementia progression.

2.2.3 Covariates—Caregiver sociodemographic factors tested as covariates in statistical models included caregiver kin-relationship (spouse, child or other), caregiver age, caregiver sex, caregiver education and whether or not the interviewed caregiver identified him/herself as the primary caregiver. Similarly, care-recipient factors tested as covariates included dementia severity at initial assessment as indicated by a global CDR score of mild (CDR of 0.5 or 1), moderate (CDR of 2) or severe (CDR of 3 or above); dementia duration as indicated by the time interval from estimated dementia onset to the initial visit; age of dementia onset; education; and dementia type (AD, VaD, or other).

2.3 Analytic approach

Baseline descriptive statistics are presented for caregiver and subject dyad demographics, caregiver relationship, health, dementia status and median costs of care. We examined longitudinal costs of care by modeling costs at each visit as the outcome and time as a predictor variable using linear mixed effects models with time and intercept as random effects. These models afford the flexibility of accommodating unequally spaced visits across participants and incomplete visits, where subjects contribute data as available. As in our

prior cost analysis [12], we used a log-link function to the gamma (probability) distribution to accommodate the positively skewed distribution of cost data. Similar to logistic regression, the exponentiated model coefficients ($\exp\beta$) are interpreted as having a multiplicative effect on the outcome rather than an additive effect as in linear regression, due to the use of the link function. To test whether each predictor significantly affected the average cost of care across time, each predictor was entered individually and retained if a -2 Log Likelihood chi-square test ($-2LL$) comparing a model with and without the term was significant at $p < 0.05$. Significance of each predictor on the rate of change in costs, was tested with $-2LL$ comparing a model with and without the predictor*time interaction, retaining the interaction if $p < 0.05$. All statistical analyses were run using SPSS version 21 software.

3. Results

There were 271 caregiver-subject dyads of the DPS cohort that met the study inclusion criteria over 571 assessments. Females comprised 51.7% (Table 1) of the participant sample and 78.2% (Table 2) of the caregiver sample. At dementia onset, mean (SD) DPS participant age was 82.4 (5.8) years. At first visit with cost data, mean (SD) caregiver age was 68.2 (13.9) years. A majority of the dyads were white (99%). 72.0% of DPS participants were diagnosed with AD. Table 1 provides information about DPS participant demographic data and dementia characteristics at the start of baseline observation. Median and mean (SD) costs of informal dementia care at baseline were \$8.96 /day and \$36.38 (\$71.12)/day in 2012 dollars, respectively. Table 2 provides information about caregivers' demographic data and relationship with the DPS participant. Of 271 caregivers, 211 (77.9%) identified themselves as primary; of primary caregivers 59.0% were spouses while 38.9% were adult children. Median and mean (SD) caregiver relationship closeness (CRC) [3.2 and 3.2 (0.6)] and problem-focused coping [2.1 and 2.0 (0.5)] scores at the start of the study were indicative of higher degrees of closeness ("agreement" to "strong agreement" on the measure) and caregivers "sometimes" using problem-focused coping respectively.

3.1 Costs of informal dementia care with time-varying caregiver relationship closeness

Multivariate linear mixed effects model results on the association between CRC over time and the daily costs of informal dementia care are given in Table 3 and Figure 1. In the adjusted CRC model, daily costs of informal dementia care increased approximately 14% per year [$\exp\beta = 1.139$; (95% CI 1.016 – 1.277)]. Higher CRC scores were associated with 23.7% lower daily costs of informal dementia care [$\exp\beta = 0.763$; (95% CI 0.583 – 0.999)] per each unit increase in closeness. Co-residence of caregiver with DPS participant was associated with approximately a 2.3-fold higher daily cost of informal dementia care [$\exp\beta = 2.349$; (95% CI 1.302 – 4.238)] compared with non-residing caregivers. The interaction between time and caregiver kin-relationship was significant such that daily costs of informal dementia care provided by other unpaid caregivers were significantly lower compared with spousal caregivers (see Table 3 and Figure 1). Moderate or severe dementia at baseline was associated with 1.8-fold [$\exp\beta = 1.839$; (95% CI 1.207 – 2.804)] and 4.2-fold [$\exp\beta = 4.249$; (95% CI 1.694 – 10.660)] higher daily costs of dementia care compared to mild dementia, respectively. Longer dementia duration at baseline was associated with higher

costs [$\exp\beta = 1.199$; (95% CI 1.088 – 1.320)] while lower DPS participant education [$\exp\beta = 0.552$; (95% CI 0.358 – 0.849)] was associated with lower daily costs of informal care, respectively.

3.2 Costs of informal dementia care with time-varying problem-focused coping

Problem-focused coping was not associated with informal costs of dementia care ($p = 0.354$). It should be noted, however, that the full sample did not have complete problem-focused coping measures and the number of observations with data for this measure was substantially lower than other analyses reported above ($n = 219$ caregivers; 412 observations).

4. Discussion

In this study we demonstrated that increased caregiver relationship closeness is associated with lower daily costs of informal dementia care, whereas co-residence of the caregiver with the care-recipient is associated with higher daily costs. We have extended the previous findings in the DPS cohort that: (1) caregiver relationship closeness is associated with slower dementia progression over time [16] and (2) dementia severity is associated with increasing costs of informal care over time [12]. We focused on these previous findings because caregiver factors, in particular behaviors, may be modifiable. Given the large financial burden that informal dementia costs represent as estimated in a national study [10] and in this cohort [12], identifying factors associated with lower informal costs of care offers intervention targets.

Relationship closeness is a construct that includes the quality of the emotional bond between the caregiver and care recipient [29]. As well, it is related to relationship quality, which includes “feelings of emotional closeness to the older person, having positive sentiment towards the older person, and similarities in values and beliefs” [33]. Relationship “closeness” contributes to the affective, cognitive and physical intimacy relationship components [34]. The construct of relationship closeness is used in our current study to represent these key relationship components.

While it could be argued that “closer” caregivers provide more effective care (slowing the rate of decline in the person with dementia), it is possible that this “better care” would involve increased financial costs. However, our current results do not support this, indeed suggesting that the slower decline of dementia participants in closer dyadic care relationships leads to overall lower costs of care. We acknowledge that summing time across caregivers is affected by the number of caregivers, which could overestimate total caregiver time (and thus costs). However, we capped caregiver time to 16 hours per day. Furthermore, our result of relationship closeness and informal costs was robust to the inclusion of a covariate for number of caregivers in the model (results not shown).

Contrary to expectations, caregiver use of a problem-focused coping strategy was not associated with informal costs of care. Previously in this same cohort, we found that caregiver problem-focused coping was associated with slower cognitive decline and lower functional impairment in dementia [17]. The lack of association with costs may reflect

inadequate power. Even so, we note that the direction of effect for the non-significant parameter estimate suggests *higher* costs with greater use of problem-focused coping. While this may suggest greater time and costs to promote a slower rate of progression of dementia, ultimately, there may be lower costs for formal or residential care later in the course of dementia. As our results were not statistically significant, further work in the area is warranted.

Co-residency resulted in increased daily costs of informal dementia care. This finding seems reasonable in that unpaid caregivers who co-reside with care-recipients are likely in the presence of or available to the care-recipient for greater amounts of time during any given day than caregivers residing elsewhere. This is also in line with our estimate of informal care costs being derived from estimates of time spent giving care.

Our cost estimates relied on the replacement cost method [10], except that we used the median wages of all Utah workers rather than those of professional caregivers. Alternative approaches to estimating costs include forgone wages [10], which are calculated from actual wages, and opportunity costs which are calculated based on leisure time for unemployed caregivers [35]. Forgone wages are highly variable and exclude unemployed caregivers. Opportunity costs may be a conservative approach if leisure costs fall below professional caregiver wages. Our use of the median wage for Utah workers applied to *all caregivers regardless of employment status* thus combines aspects of replacement and foregone wage cost approaches. Had we used the traditional method of estimating costs based on home health aide wages in a replacement cost approach, we would likely have underestimated actual costs (median hourly wage for a home health aide is approximately \$5 below the median wage of all Utah workers). Nonetheless, because our sample includes older, retired caregivers who are no longer in the workforce, and therefore arguably should not be incurring the same costs as employed caregivers, a limitation of our approach is that it may overestimate costs.

Our study has several limitations. The caregivers' categorization and estimation of caregiving time and closeness are subjective and those caregivers who are closer to their care-recipient may categorize time spent with their care-recipient as "time spent together" rather than as "time spent providing care." Conversely, less close caregivers may categorize a higher proportion of their time spent with their care-recipient as time spent providing care, thus resulting in higher estimates of costs for less close caregivers. We are unable to tease out the nature of reporting differences. However, when considered with our previous findings that closer caregiver relationships predict slower rates of cognitive and functional decline in AD [31], a reasonable extension of this finding is a reduction in caregiving time and lower informal costs of care. Small sample size and population homogeneity (the DPS lacked ethnic diversity and, possibly variability in participant socioeconomic status), are also limitations. Additionally, since informal cost data were derived from caregiver activity surveys based on key caregiver reports, our study is subject to recall bias that may differ among co-residing and non-co-residing dyads. We also acknowledge that the associations discussed here cannot be determined as causal in nature. That is, while closer dyadic relationships are associated with lower costs of care, we do not know if closeness causes fewer care needs and therefore lower costs, or if an unmeasured factor explains the

association. It is possible that persons with dementia that progress more slowly or require lower care costs elicit closer emotional relationships with their caregiver over time, perhaps because their higher functioning allows the caregiver/care-recipient dyad to maintain emotional bonds over a longer time period.

The uniqueness of the DPS as a longitudinal population-based cohort of community-dwelling persons with dementia and their caregivers with high participation rates, with frequent and long term follow-up are among this study's strengths [11]. Because of the available detailed data about both care-recipients and caregivers, we were able to construct longitudinal “real cost” estimates of informal caregiving in a community-dwelling dementia cohort and relate these to modifiable caregiver factors.

In conclusion, we demonstrated that caregiver relationship closeness is associated with lower daily costs of informal caregiving. Because caregiver behaviors and relationships represent potentially modifiable factors, interventions designed to help caregivers reinforce the closeness of their relationships may represent a viable strategy towards reducing informal costs of dementia care. Research examining care practices of closer caregivers may determine if they are, indeed, providing better care and more financially efficient care practices. For example, earlier DPS findings suggested that the use of cognitively stimulating activities is associated with slower decline in dementia [36], as are vascular treatments [37, 38], and the use of cognitive enhancing medications [39]. A natural follow-up would be to determine if caregivers with closer emotional relationships with their care-recipients are more likely to engage in the above practices.

Acknowledgements

This study was supported by NIH grants R01AG21136, R01AG11380, and P50AG005146 (Johns Hopkins ADRC). We are indebted to the Cache County Memory Study Investigators and staff and the participants and caregivers of the Cache County Studies.

References

1. Alzheimer's Disease International. World Alzheimer's Report 2012: Overcoming the stigma of dementia. Alzheimer's Disease International; London: 2012.
2. Alzheimer's Association. 2015 Alzheimer's facts and figures. Alzheimer's Association; Chicago, IL: 2015.
3. Hill J, Futterman R, Duttgupta S, Mastey V, Lloyd JR, Fillit H. Alzheimer's disease and related dementias increase costs of co-morbidities in managed Medicare. *Neurology*. 2002; 58:62–70. [PubMed: 11781407]
4. Zhu CW, Scarmeas N, Torgan R, Albert M, Brandt J, Blacker D, et al. Clinical characteristics and longitudinal changes of informal costs of Alzheimer's disease in the community. *Journal of American Geriatrics Society*. 2006; 54:1596–602.
5. Taylor DHJ, Ostbye T, Langa KM, Weir D, Plassman BL. The accuracy of Medicare claims as an epidemiological tool: the case of dementia revisited. *Journal of Alzheimer's Disease*. 2009; 17:807–15.
6. Lacey L, Niecko T, Leibman C, Liu E, Grundman M, Group E-A-I. Association between illness progression measures and total cost in Alzheimer's disease. *Journal of Nutritional Health and Aging*. 2013; 17:745–50.

7. Leicht H, Heinrich S, Heider D, Bachmann C, Bickel H, van den Bussche H, et al. Net costs of dementia by disease stage. *Acta Psychiatrica Scandinavica*. 2011; 124:384–95. [PubMed: 21838738]
8. Andersen CK, Lauridsen J, Andersen K, Kragh-Sorensen P. Cost of dementia: impact of disease progression estimated in longitudinal data. *Scandinavian Journal of Public Health*. 2003; 31:119–25. [PubMed: 12745762]
9. Zhu CW, Leibman C, McLaughlin T, Zbrozek AS, Scarmeas N, Albert M. Patient dependence and longitudinal changes in costs of care in Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*. 2008; 26:416–23. [PubMed: 18946219]
10. Hurd M, Martorell P, Delavande A, Mullen K, Langa KM. Monetary costs of dementia in the United States. *The New England Journal of Medicine*. 2013; 368:1326–34. [PubMed: 23550670]
11. Tschanz JT, Corcoran CD, Schwartz S, Treiber K, Green RC, Norton MC, et al. Progression of cognitive, functional, and neuropsychiatric symptoms in a population cohort with Alzheimer dementia: The Cache County Dementia Progression Study. *The American Journal of Geriatric Psychiatry*. 2011; 19:532–42. [PubMed: 21606896]
12. Rattinger GB, Schwartz S, Mullins CD, Corcoran CD, Zuckerman IH, Sanders C, et al. Dementia severity and the longitudinal costs of informal care in the Cache County population. *Alzheimer's & Dementia*. 2015; 11:946–54.
13. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12:189–98. [PubMed: 1202204]
14. Morris JC. The Clinical Dementia Rating (CDR): Current version and scoring rules. *Neurology*. 1993; 43:2412–4.
15. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The neuropsychiatric inventory: comprehensive assessment of psychopathology in dementia. *Neurology*. 1994; 44:2308–14. [PubMed: 7991117]
16. Norton MC, Piercy KW, Rabins PV, Green RC, Breitner JC, Østbye T, et al. Caregiver–recipient closeness and symptom progression in Alzheimer disease. The Cache County Dementia Progression Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2009; 64:560–8.
17. Tschanz JT, Piercy K, Corcoran CD, Fauth E, Norton MC, Rabins PV, et al. Caregiver coping strategies predict cognitive and functional decline in dementia: The Cache County Dementia Progression Study. *American Journal of Geriatric Psychiatry*. 2013; 21:57–66. [PubMed: 23290203]
18. Breitner JCS, Wyse BW, Anthony JC, Welsh-Bohmer KA, Steffens DC, Norton MC, et al. APOE-E4 count predicts age when prevalence of AD increases, then declines. *Neurology*. 1999; 53:321–31. [PubMed: 10430421]
19. Miech RA, Breitner JCS, Zandi PP, Khachaturian AS, Anthony JC, Mayer L. Incidence of AD may decline in the early 90s for men, later for women: The Cache County study. *Neurology*. 2002; 58:209–18. [PubMed: 11805246]
20. *Diagnostic and Statistical Manual of Mental Disorders*. 3rd Revised ed.. American Psychiatric Association; Washington, DC: 1987.
21. McKhann G, Drachman D, Folstein MF, Katzman R, Price D, Stadlan E. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group under the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology*. 1984; 34:939–44. [PubMed: 6610841]
22. Roman GC, Tatemichi T, Erkinjuntti T, Cummings JL, Masdeu JC, Garcia JH. Vascular dementia: diagnostic criteria for research studies. Report of the NINDS-AIREN International Workshop. *Neurology*. 1993; 43:250–60. [PubMed: 8094895]
23. CDR Overview & Abstracts. Washington University School of Medicine; 2011.
24. Lyketsos CG, Galik E, Steele C, Steinberg M, Rosenblatt A, Warren A, et al. The General Medical Health Rating: a bedside global rating of medical comorbidity in patients with dementia. *J Am Geriatr Soc*. 1999; 47:487–91. [PubMed: 10203127]

25. Zhu CW, Scarmeas N, Torgan R, Albert M, Brandt J, Blacker D, et al. Longitudinal study of effects of patient characteristics on direct costs in Alzheimer disease. *Neurology*. 2006; 67:998–1005. [PubMed: 16914696]
26. Penrod JD, Kane RL, Finch MD, Kane RA. Effects of post hospital Medicare home health and informal care on patient functional status. *Health Service Research*. 1998; 33:513–29.
27. Occupational Employment and Wage Estimates. Bureau of Labor Statistics; 2013.
28. Noelker, LS. Final report to the Cleveland Foundation. A Benajamin Rose Institute; Cleveland, OH: 1996. Promoting positive relationships between nursing assistants and the families of cognitively impaired nursing home residents..
29. Whitlatch CJ, Schur D, Noelker LS, Ejaz FK, Looman WJ. The stress process of family caregiving in institutional settings. *The Gerontologist*. 2001; 41:462–73. [PubMed: 11490044]
30. Fauth E, Hess K, Piercy K, Norton M, Corcoran C, Rabins P, et al. Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging Ment Health*. 2012; 16:699–711. [PubMed: 22548375]
31. Norton MC, Piercy KW, Rabins PV, Green RC, Breitner JC, Ostbye T, et al. Caregiver-recipient closeness and symptom progression in Alzheimer disease. The Cache County Dementia Progression Study. *J Gerontol B Psychol Sci Soc Sci*. 2009; 64:560–8. [PubMed: 19564210]
32. Vitaliano PP, Russo J, Carr JE, Maiuro RD, Becker J. The ways of coping checklist: Revision and psychometric properties. *Multivariate Behavioral Research*. 1985; 20:3–26. [PubMed: 26776273]
33. Lawrence RH, Tennstedt SL, Assmann SF. Quality of the caregiver--care recipient relationship: does it offset negative consequences of caregiving for family caregivers? *Psychology and aging*. 1998; 13:150–8. [PubMed: 9533197]
34. Blieszner R, de Vries B. Perspectives on intimacy. *Generations*. 2001; 25:7–8.
35. McDaid D. Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. *Int J Geriatr Psychiatry*. 2001; 16:400–5. [PubMed: 11333428]
36. Treiber KA, Carlson MC, Corcoran C, Norton MC, Breitner JC, Piercy KW, et al. Cognitive stimulation and cognitive and functional decline in Alzheimer's disease: The Cache County Dementia Progression Study. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*. 2011; 66:416–25.
37. Mielke MM, Rosenberg PB, Tschanz J, Cook L, Corcoran C, Hayden KM, et al. Vascular factors predict rate of progression in Alzheimer's disease. *Neurology*. 2007; 69:1850–8. [PubMed: 17984453]
38. Rosenberg PB, Mielke MM, Tschanz J, Cook L, Corcoran C, Hayden KM, et al. Effects of cardiovascular medications on rate of functional decline in Alzheimer's disease. *The American Journal of Geriatric Psychiatry*. 2008; 16:883–92. [PubMed: 18978249]
39. Mielke MM, Leoutsakos JM, Corcoran CD, Green RC, Norton MC, Welsh-Bohmer KA, et al. Effects of Food and Drug Administration-approved medications for Alzheimer's disease on clinical progression. *Alzheimer's & Dementia*. 2012; 8:180–7.

Research in Context

1. Systematic review: In our literature review, we sought studies of longitudinal costs of dementia care and their association with disease progression as well as the association of caregiver factors on longitudinal costs of informal dementia care conducted among community dwellers with dementia. The few longitudinal studies identified involved caregiver factors and association with disease progression however, lacked information on informal caregiving costs.

2. Interpretation: In our population-based community dwelling cohort with dementia, we demonstrated that caregiver – care-recipient dyads with higher levels of relationship closeness predicted lower daily informal costs of dementia care over time. Targeting interventions to promote relationship closeness, a potentially modifiable factor, is important to decreasing annual costs of dementia care.

3. Future directions: Identifying specific care-related behaviors within closer dyads associated with lower costs and extending our findings to larger, racially diverse, urban community-dwelling dementia cohorts will provide important results concerning generalizability and help prioritize appropriate disease management strategies.

Figure 1. Informal dementia care costs per day by relationship closeness, caregiver co-residency, and kin relationship

The plots show lower mean daily costs of informal dementia care for closer caregiver relationship. Note the higher costs for co-residing dyads.

Table 1

Dementia Progression Study Dementia Subject Cohort Characteristics at Start of Study

Characteristic	Total	
	N	%
Sample Size	271	100.0
Female	140	51.7
Co-reside with caregiver	150	55.0
Age at dementia onset, years		
<i>Median (range)</i>	<i>83 (68-104)</i>	
<i>Mean (sd)</i>	<i>82.4 (5.8)</i>	
Education (less than high school)	40	14.8
Dementia Type		
Alzheimer's disease	195	72.0
Vascular dementia w/o AD	36	13.3
Other dementia	40	14.8
General Medical Health Rating		
<i>Median (range)</i>	<i>3 (2-4)</i>	
<i>Mean (sd)</i>	<i>2.94 (.56)</i>	
2=fair/poor	50	18.5
3=good	186	68.6
4= excellent	35	12.9
Died during study (2002 –2011)	211	77.9
Dementia duration in years at Baseline		
<i>Median</i>	<i>2.99</i>	
<i>Mean (sd)</i>	<i>3.44 (1.90)</i>	
Follow up time, years post baseline[†]		
<i>Median, among those with follow-up</i>	<i>2.34</i>	
<i>Mean (sd), among those with follow-up</i>	<i>2.77 (1.64)</i>	
No follow up (baseline only)	117	43.2
Number of assessments per person		
<i>Median</i>	<i>2</i>	
<i>Mean (sd)</i>	<i>2.18 (1.41)</i>	
Mini Mental State Examination (range 0 –30)		
<i>Median</i>	<i>22.76</i>	
<i>Mean (sd)</i>	<i>20.99 (6.16)</i>	
Clinical Dementia Rating Scale (range 0-5)		
<i>Median</i>	<i>1</i>	
<i>Mean (sd)</i>	<i>1.27 (.54)</i>	
Neuropsychiatry Inventory (range 0-144)		
<i>Median</i>	<i>8</i>	
<i>Mean (sd)</i>	<i>11.36 (10.95)</i>	
Baseline costs of giving care (\$/day)		

Characteristic	Total	
	N	%
Median	\$8.96	
Mean (sd)	\$36.38 (71.12)	

[†] Follow-up from first assessment to last assessment

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2**DPS Caregiver Characteristics**

Characteristic	Total	
	N	%
Sample Size	271	100.0
Female	212	78.2
Relationship with DPS Subject		
Spouse	120	44.3
<i>Primary (%)</i>	<i>116 (96.7)</i>	
<i>Not primary (%)</i>	<i>4 (3.3)</i>	
Adult Child	130	48.0
<i>Primary (%)</i>	<i>82 (63.1)</i>	
<i>Not primary (%)</i>	<i>48 (36.9)</i>	
Other	21	7.7
<i>Primary (%)</i>	<i>13 (61.9)</i>	
<i>Not primary (%)</i>	<i>8 (38.1)</i>	
Age at first CAS with cost, years		
<i>Median (range)</i>	<i>69.26 (35.64-96.38)</i>	
<i>Mean (sd)</i>	<i>68.16 (13.94)</i>	
Education (less than high school)	12	4.5
General Medical Health Rating		
<i>Median (range)</i>	<i>3 (2-4)</i>	
<i>Mean (sd)</i>	<i>3.41 (.59)</i>	
2=fair/poor	13	4.8
3=good	133	49.1
4= excellent	124	45.8
missing	1	0.4
Died during study (2002 -2011)	31	11.4
Caregiver Relationship Closeness (range 6-24)		
<i>Median</i>	<i>3.2</i>	
<i>Mean (sd)</i>	<i>3.2 (0.6)</i>	
Problem-Focused Coping (range 0-3)		
<i>Median</i>	<i>2.1</i>	
<i>Mean (sd)</i>	<i>2.0 (0.5)</i>	

Table 3

Association of caregiver relationship closeness with informal costs of dementia care since dementia onset (N = 271)

Variable	Unadjusted [†]				Adjusted [†]			
	expβ	95% CI	p - value		expβ	95% CI	p - value	
Time (years)	1.039	0.952 1.134	0.392		1.139	1.016 1.277	0.026	
Relationship Closeness ^{††}	0.683	0.513 0.910	0.009		0.763	0.583 0.999	0.049	
CG relationship (vs. spouse)					1 (ref.)			
Adult child					1.167	0.715 1.904	0.536	
Other unpaid								
CG					0.879	0.430 1.799	0.725	
Time*CG relationship (vs. spouse)					1 (ref.)			
Adult child					1.022	0.841 1.243	0.823	
Other unpaid								
CG					0.792	0.668 0.940	0.008	
Co-reside (vs. not co-reside)					2.349	1.302 4.238	0.005	
Baseline CDR (vs. Mild)					1 (ref.)			
Moderate					1.839	1.207 2.804	0.005	
Severe					4.249	1.694 10.660	0.002	
Less than HS/GED					0.552	0.358 0.849	0.007	
Baseline Dementia Duration					1.199	1.088 1.320	< 0.001	
Primary Caregiver (vs. other)					0.938	0.606 1.450	0.772	

[†] Multivariable mixed models using GEE with gamma distribution and log link.

^{††} Time varying average relationship closeness value