Caregiver burden, health utilities and institutional service costs among community-dwelling paients with Alzheimer's disease

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Abstract

This study examined the moderating effect of caregiver burden on the relationship between patients' health status and institutional costs in Alzheimer's disease (AD). Data were obtained on whether 421 community-dwelling patients with AD in the CATIE-AD trial received institutional services in the month preceding baseline and at 3-, 6-, and 9-months follow-up. All participants had a caregiver who lived with or visited them regularly. Outcome variables include hospital, nursing home, residential, and combined institutional costs. Mixed models were employed to estimate the interaction of Health Utility Index (HUI)-III scores (a health status measure) and five measures of caregiver burden. Wherever significant, results indicate that greater caregiver burden weakens the inverse relationship between health utilities and institutional costs, leading to greater costs than would be expected at a given level of health. Altogether 45.0% of the models (9/20) showed this effect (positive coefficient on the burden-HUI interaction term). Interventions should be based on caregiver burden, regardless of care recipient health status, for even seemingly manageable patients may be at heightened risk for institutionalization if caregivers experience sufficiently high levels of burden.

Keywords

Alzheimer's disease; costs; caregiver burden; Health Utilities Index; correlates; institutions

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Introduction

Alzheimer's disease (AD) is the seventh leading cause of death among all Americans, affecting an estimated 5 million individuals, including one in eight persons age 65 years and older, at a cost of $148 billion per year.[1] Due, in part, to the aging of the population, the costs associated with AD will continue to rise well into the foreseeable future. Since the prevalence of AD doubles every five years after age 65, by 2030 the number of affected persons is projected to grow to 7.7 million; by 2050, when the bulk of the baby boom reaches 85, there will be over 13 million Americans with AD.[2] Medicare spending on AD is expected to increase to $394 billion in 2030 and $1 trillion by the middle of the century.[3]

There is an extensive literature investigating the correlates of cost and utilization associated with AD and other dementia, including inpatient medical,[4-8] nursing home,[7-18] and residential care.[7,8,14,15,19] However, few extant studies examine the relationship between service utilization or costs in AD and health utilities, which may be measured using standard, generic, multi-attribute preference-based utility instruments.[20,21] These instruments assign patients a quality of life state based on responses to a health status questionnaire weighted using previously determined weights from other populations. Because they are generic, these measures allow comparisons across different disease states. Since they incorporate values or preferences, and employ a scale with generally accepted anchors (from 0, death, to 1, perfect health), they may be used to compare the relative cost-effectiveness of different AD treatments, including pharmacological interventions.

Health utility instruments are multi-dimensional measures of health, accounting for cognitive, social, emotional, and physical well-being, whereas clinical measures such as the mini mental state examination (MMSE) and activities of daily living scale tend to be unidimensional, measuring only one aspect of functioning in patients with AD. Stronger health utilities suggest better adaptation and functioning, which, in turn, should reduce the likelihood of using particular health services. In AD, this expectation is reflected in the findings of two recent investigations where health utilities were the most consistently significant correlate examined, not only of total health services utilization but those for institutional care, specifically.[7,8]

Research to date while focusing on patient correlates of service utilization has not addressed caregiver burden as a potentially important independent determinant of service costs. Caring for chronically frail and disabled individuals can exert a considerable physical, mental, and emotional toll and result in financial hardships, retirement insecurity, lost jobs and other adverse consequences .[22] This is especially true of those caring for individuals afflicted with dementia.[23] In 2007, family members, friends, and other unpaid caregivers provided 8.4 billion hours of AD/dementia-related care valued at nearly $88 billion.[1] Caregivers face substantial stressors[24,25] and are at risk for depression.[26,27] They are also more likely to experience poor health,[28,29] use of psychotropic medications,[30,31] and increased use of health services.[32,33] Among community-dwelling patients with AD and other dementia, measures of caregiver burden are associated with increased risk of hospitalization,[4] residential care use,[19] and nursing home placement.[9,10,11,12,13,18]

It is established that more severe illness leads to increased caregiver burden.[34] Since the two phenomena may be mutually reinforcing, the primary aim of the present study was to assess whether the negative association between patient's general health status (i.e., as reflected in higher health utility scores) and service costs experiences in AD is moderated by caregiver burden. Data for this study derive from the Clinical Antipsychotic Trial of Intervention Effectiveness—AD (CATIE-AD), a 9-month randomized trial designed to evaluate the

performance of second generation antipsychotics (SGAs) and placebo vis-à-vis behavioral and psychological symptoms in dementia.[35,36]

Methods

Sample and source of data

CATIE AD has been described in detail elsewhere.[36] The trial was conducted at 42 sites in the US and included 421 ambulatory outpatients who, at baseline, fulfilled criteria dementia of the Alzheimer's type (DSM-IV) and probable AD on the basis of history, physical examination, structural brain imaging and MMSE scores ranging from 5 to 26.[37] Participants also had to be living at home at baseline in addition to having clinically severe delusions, hallucinations, aggression, or agitation, occurring after the onset of dementia. A caregiver who lived with or visited the participant for at least 3 days per week for an accumulative 8 hours was required to contribute to the assessments. The study was approved by the institutional review board for each site.

Measures

Service use and costs—It was determined whether or not study participants who were living at home with a caregiver at baseline had received each of three different types of institutional services—inpatient hospital, nursing home, and residential care—in the month preceding baseline and at 3-, 6-, and 9-months post-random assignment to treatment or placebo. Inpatient hospital care refers to hospitalization for medical, surgical, psychiatric, or substance abuse problems across six different types of facilities. Nursing home use refers to nights spent in nursing facilities at a skilled or intermediate level of care. Residential care use refers to placement in a halfway house or board & care home, or in respite care programs. Study participants could move back and forth between their homes and institutional care settings throughout the course of the study period.

Specific costs attributable to institutional service use were determined. These were estimated by multiplying the number of nights spent in each type of facility by the estimated local unit cost of services. Unit costs estimated for each type of service were specific to each of the 24 states in which CATIE sites were geographically located. When only national statistics were available, national figures were converted to state-specific figures by multiplying them by the ratio of the average annual wage in 2002 for all covered workers in a state to the average annual wage in 2002 nationally. Cost data derive from three primary sources: (1) secondary analyses from published articles and reports, (2) U.S. Department of Veteran's Affairs (VA) administration databases, and (3) the Marketscan Communical Claims and Encounters Database.[38] Medians were used when available; otherwise averages.

Three measures documented inpatient hospital, nursing home, and residential care costs; a fourth documented total institutional costs. Average daily hospital costs for medical and surgical patients in non-federal general and VA hospitals derived from the VA and Marketscan databases. Average daily nursing home and residential care costs derived from other sources.[39-43] Figures were converted to 2002 dollars using the Consumer Price Index for all Urban Consumers.

Health utilities—Patient health utilities were assessed using the HUI-III, which consists of a classification system describing 927,000 unique health states, and a preference or utility function.[44] Capacity is assessed in eight dimensions—vision, hearing, speech, ambulation, dexterity, emotion, pain or discomfort, and cognition. Preference measures collected from a population based in Hamilton, Ontario are used to score each state on a scale from −0.36 (worse than death) to 1 (perfect health), with 0 representing death. The original HUI-III

scores were multiplied by 10 to facilitate interpretation, so that a unit difference on the transformed HUI-III corresponds to a 0.10 difference on the original.[45] Assessments were completed by caregiver proxies rather than by AD patients themselves.

Caregiver burden—Because caregiver burden is a multidimensional construct, no one measure fully describes the caregiving experience.[24] Consequently, we elected to examine the relationship between caregiver burden, HUI-III score, and health outcomes using an index created by averaging the z-scores of the following four caregiver assessment instruments: the Caregiver Distress Scale, the Beck Depression Inventory, the Burden Interview Scale, and the Caregiver Assessment Survey. Each of these indicators is intended to measure a somewhat different underlying construct reflective of the caregiving experience, including subjective burden, caregiver depressive symptoms, distress with patient psychiatric symptoms, and time devoted to caregiver. Three of the four—Burden Interview, Beck Depression, and Caregiver Distress—are moderately correlated with one another (r=.43 to .58, all p<.001), suggesting that they measure distinct though somewhat overlapping aspects of the same phenomena. One measure—the CAS—is only weakly correlated with the other three (r<.12, all p<.05). To determine whether and how findings vary across particular measures we also estimated separate models using each of the four different caregiver burden indices identified.

The *Caregiver Distress Scale* is based on the distress items of the Neuropsychiatric Inventory (NPI).[46] These items ask caregivers to rate the levels of distress that they have experienced over the previous month stemming from 12 psychiatric symptoms, including delusions, hallucinations, agitation, dysphoria, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor behavior, nighttime behavior disturbances, and appetite and eating abnormalities. Each item is rated on a scale from 0 ("not distressing at all") to 5 ("extremely distressing"). The total Caregiver Distress score is calculated by totaling the individual subscale scores, with higher scores indicating greater caregiver distress. Total scores range from 0 to 60.

The *Beck Depression Inventory* asks respondents to respond to 21 items assessing their experience over the previous week with such behaviors and attitudes as mood, pessimism, self-hate, crying-spells, social withdrawal, body image, sleep disturbance, and libido.[47,48] Each item is rated on a scale from 0 (e.g., "I do not feel sad') to 3 (e.g., "I am so sad or unhappy that I can't stand it"). The total Beck Depression score is calculated by totaling the individual subscale scores, with higher scores indicating more severe depressive symptoms. Total scores range from 0 to 63; cuts points include minimum (0-13), mild (14-19), moderate (20-28), and severe (29-63) depression.

The *Caregiver Burden Interview* asks respondents to respond to 22 items assessing how they feel about taking care of another person.[49] These items cover perceived burden in a variety of areas, including physical health, psychological well-being, finances, and relationships with the care recipient, friends/family members, workplace and others. Each item is rated on a scale from 0 (e.g., "never") to 4 ("nearly always"). The total Caregiver Burden score is calculated by totaling the individual subscale scores, with higher scores indicating greater perceived caregiver burden. Total scores range from 0 to 88.

The *Caregiver Activity Survey (CAS)* is a five-item questionnaire that measures the amount of time spent supervising and assisting AD patients during the previous 24 hours.[50] Items include: using transportation, eating, dressing, looking after one's appearance, and supervising the person. Total CAS scores equal the number of hours spent performing these four activities.

Control variables—*Sociodemographic factors* were represented by age, gender, race, marital status, and education. *Global cognitive functioning* was measured on a 0-30 scale using the MMSE.[37]*Psychiatric symptoms* were assessed using the neuropsychiatric inventory (NPI).[4]*Physical functioning* was measured using the AD Cooperative Study Activities of Daily Living Scale (ADCS-ADL).[51]*Quality of life* was assessed using the AD Related Quality of Life scale (ADRQoL).[52] We also considered controlling for caregiver demographics, including age, gender, education, and relationship to the care recipient but there were too many missing values. Consequently, only descriptive statistics are reported on these variables to provide the reader with a sense of what the caregivers of our sample of AD patients were like.

Analysis

To examine the moderating effect of caregiver burden on the relationship between health utilities and institutional service costs, we estimated a series of multivariate models interacting HUI-III score with one of the five caregiver burden measures described (i.e., HUI-III*Average Burden, HUI-III*Caregiver Distress, HUI-III*Beck Depression, HUI-III*Burden Interview, and HUI-III*CAS) net of the main effects of the HUI-III. Mixed models were used to examine the relationship between HUI-III score, caregiver burden, and HUI-III*caregiver burden interaction and institutional service cost, controlling for other sociodemographic and clinical/disease-specific indicators. Twenty models were estimated, four for each caregiver burden measure (i.e., predicting total institutional, hospital, nursing home, or residential care cost). All analyses were conducted using the pooled dataset of all observations across all four time periods and included fixed effects accounting for observation period (baseline and 3-, 6-, and 9-months).

Analyses involved estimation of random effects models with robust standard errors using PROC MIXED. Health care costs were log-transformed because each indicator is highly skewed to the right. Since there were high percentages of cases with zero institutional costs, we added $1.00 to each cost measure before log transformation; otherwise, missing values would have been generated on log costs, thereby excluding large numbers of cases from our analyses. The coefficient estimates produced from log transformed dependent variables are semi-elasticities. A semi-elasticity compares a level of change in one variable with a percentage change of a second variable; for example, the percent change in *y* associated with a one unit change in *x*. For continuous variables, each coefficient estimates the proportional change in costs for a unit change in the independent variable, holding all else constant. Thus, for a unit increase in the independent variable, costs increase/decrease by $100 \, \widehat{\beta}$ percent, where $\widehat{\beta}$ for each interaction term is the proportional change in costs for each unit change in the HUI-III*caregiver burden interaction.

Results

Patients averaged age 77.9 years. The majority were female (56.0%), married (59.0%), and white (79.0%). Relatively few (29.0%) were college educated (Table 1). Average HUI-III scores at baseline were 0.18, with individual scores ranging from -0.29 (worse than death) to 1.0 (perfect health). Average ADCS-ADL, NPI, MMSE, and ADRQoL scores were 39.4, 36.9, 15.0, and 67.3, respectively. Caregiver age averaged 63.0 years. Most were female (71.0%); the majority had at least some college education (55.0%). Approximately half were the spouse of a study participant (52.0%); one third a child (34.0%); 14.0% had another type of relationship (e.g., friend, sibling).

There was typical to high average levels of burden in CATIE-AD, depending on the caregiver burden score examined. For example, average Caregiver Distress Scale score in

CATIE was nearly twice that found in individuals caring for one community-dwelling sample of patients with possible or probable AD (16.5 v. 8.7),[46] while average Caregiver Burden Interview score was somewhat higher than that found in individuals caring for another community-dwelling sample of older adults with cognitive impairment (34.42 v. 20.59).[48] By contrast, average Beck Depression Inventory score approximated that found in a published randomized clinical trial of patients with mild to moderate AD (8.4 v. 8.6);[47] so too did the average score on the Caregiver Activity Survey, which approximated that found in a sample of individuals caring for community-dwelling AD patients (16.3 v. 16.4).[49]

On average, 13.0% of study participants were admitted to inpatient care monthly, including average monthly inpatient hospital, nursing home, and residential care rates of 4.5%, 5.6%, and 3.9%, respectively. Respondents spent an average of 2.4 days per month in institutions, including 0.31 days in hospitals, 1.28 days in nursing homes, and 0.81 days in residential care. Average monthly total institutional costs were $753.91; average monthly inpatient hospital, nursing home, and residential care costs were $494.39, $200.71, and $58.81, respectively. Of those using institutional services, an average of 18.4 days per month was spent in institutions, including 6.7, 23.0, and 22.5 days among those with hospital, nursing home, and residential care stays. Among service users, average monthly inpatient hospital, nursing home, residential care, and total institutional costs were $10,545, $3,541, $1,474, and $5,700.

Table 2 reports mixed model results modeling institutional service costs. Wherever significant, coefficients reveal inverse associations between HUI-III score and institutional service costs when caregiver burden is zero. However, nine of the 20 models estimated indicate that this is less true when caregiver burden is higher, yielding a marginal increase in institutional service cost at a given HUI-III score for each unit change in burden score. Findings for each burden measure are addressed in turn.

Average Caregiver Burden (Z-Scores)

Although not significant, coefficients on HUI-III score in each of the four models estimated suggests that each 0.10 increment in HUI-score is associated with reductions in institutional costs, when Average Caregiver Burden (Z-Scores) is zero. Both the total institutional and nursing home cost models reveal inverse associations between Average Caregiver Burden (Z-Scores) and service costs as well (−29.120%, p<.10;−26.700%, p<01). Results for the HUI-III*Caregiver Burden (Z-Scores) interaction term further indicates that the inverse association between HUI-III score and total institutional and nursing home costs yields increased costs by 10.120% (p<.05) and 3.669% (p<.10) for each unit increase in Average Caregiver Burden (Z-Scores).

Caregiver Distress Scale

Each 0.10 increment in HUI-score is associated with reductions in total institutional, hospital, and nursing home costs of 18.8% (p<.001), 8.0% (p<.05), and 8.6% (p<.001), respectively, when Caregiver Distress score is zero. Both the total institutional and nursing home cost models reveal inverse associations between Caregiver Distress score and service costs as well (−4.3%, p<.001; −2.7%, p<001). Results for the HUI-III*Caregiver Distress interaction term further indicates that the inverse association between HUI-III score and total institutional and nursing home costs yields increased costs by 0.9% (p<.05) and 0.4% (p<.05) for each unit increase in Caregiver Distress.

Beck Depression Inventory

Each 0.10 increment in HUI-score is associated with reductions in total institutional and residential care costs of 12.7% (p<.01) and 4.0% (p<.10), respectively, when Beck

Depression Inventory score is zero. Results for the HUI-III*Beck Depression interaction term further indicates that the inverse association between HUI-III score and total institutional and residential care costs leads to increased costs by 0.9% (p<.05) and 0.5% (p<.05) for each unit increase in the Beck Depression Inventory score.

Caregiver Burden Interview

Each 0.10 increment in HUI-III score is associated with reductions in total institutional and nursing home costs of 19.7% (p<.01) and 12.5% (p<.01), respectively, when Caregiver Burden Interview score is zero. Both the total institutional and nursing home cost models reveal inverse associations between Caregiver Burden score and service costs as well (−2.1%, p<.001; −1.8%, p<001). Results for the HUI-III*Caregiver Buren interaction term further indicates that the inverse association between HUI-III score and nursing home costs is associated with increased costs by 0.2% (p<.05) for each unit increase in Caregiver Burden Interview score.

Caregiver Assessment Survey

Each 0.10 increment in HUI-III score is associated with reductions in total institutional, hospital, and nursing home costs of 12.6% (p<.01), 11.0% (p<.01), and 6.9% (p<.05), respectively, when CAS score is zero. Results for the HUI-III*CAS interaction term further indicates that the inverse association between HUI-III score and both hospital and nursing home costs change to yield increased costs by 0.4% (p<.05) and 0.3% (p<01) for each unit increase in CAS score.

Discussion

No previous study has examined the moderating effect of caregiver burden on the relationship between health utilities (or any other general health measure) and institutional service costs in AD. Wherever significant, the sign on the HUI-III*caregiver burden interaction term is positive. Since the sign on HUI-III score is generally negative in the baseline models without interactions,[7,8] a positive sign on the HUI-III*caregiver burden interaction term implies that caregiver burden has the effect of weakening the inverse relationship between health utilities and institutional service costs identified previously, i.e. leading to greater costs than would be expected at a given level of health. Or, in other words, higher utilities tend to be associated with lower costs. However, when caregiver burden is higher, this is less so. This relationship is reflected in nearly half of the models estimated (9/20; 45.0%), including at least two of the four models for each burden measure but the Burden Interview Score and three of the five models for total institutional costs and four of the five models for nursing home costs. It is interesting that the Burden Interview Score— the most general caregiver burden measure—should be a less consistent moderator than the other three instruments—the Beck, CAS, and Distress scales—which assess more targeted aspects of the caregiver experience—depression, time spent providing care, and distress with psychological symptoms, respectively. Thus it may be less caregivers' subjective burden about their relative's illness than objective time burdens and clinical psychopathology that is mainly at work in the observed phenomena.

Essentially, our results indicate that the inverse associations between HUI-III scores and service costs becomes less negative (i.e., more positive) as caregiver burden increases. To facilitate interpretation of our findings we report the percent change in cost for each .10 increment in HUI-III score at different levels of caregiver burden. This was calculated by multiplying the $\widehat{\beta}$ describing the HUI-III*caregiver burden moderator by the caregiver burden score and adding the $\widehat{\beta}$ describing the HUI-III main effect.[53] For each caregiver

burden measure we use baseline scores for the following: mean, mean plus/minus the standard deviation, minimum, and maximum.

Table 3 illustrates the moderating effect of caregiver burden on the health utilities-health care cost relationship. It shows that an increase in Average Burden, Caregiver Distress, Beck Depression, Burden Interview, and Caregiver Assessment score from the minimum to the mean minus one standard deviation reduces the percentage decrease in costs associated with each 0.10 increment on the HUI-III scale from 0.6 to 8.0 percentage points. Further increasing each score, however, results in considerably more spending on institutional services for each 0.10 increment. Thus, whereas each 0.10 increment in HUI-III score is associated with an 10.3% decrease in total institutional costs when Average Burden score is at its minimum (−1.3); it is associated with an 10.3% decrease when Average Burden core is one standard deviation below the mean (−.5); a 3.2% percent decrease when Average Burden score is at its mean (.2); and a 3.9% and 19.6% increase when average burden is one standard deviation above the mean (0.9) and at its maximum score (2.4), respectively. Though not as dramatic, similar changes are reflected in the HUI-III-nursing home cost relationship as well, with each 0.10 increment in the HUI-III being associated with a 7.4% reduction in nursing home costs when Average Burden is at its minimum (−1.3) and a 6.3% percent increase when Average Burden is at its maximum.

Similarly, each 0.10 increment in HUI-III score is associated with decreases in total institutional costs of 18.8% and 11.9%, respectively, when Caregiver Distress score is zero and one standard deviation below its mean (8.0), and increases in total institutional costs of 2.6% and 19.6% when Caregiver Distress is one standard deviation above its mean (25) and at its maximum (45). Likewise, each 0.10 increment in the HUI-III is associated with an 8.6% reduction in nursing home costs when Caregiver Distress is zero and a 9.2% percent increase when Caregiver Distress is at its maximum. Compared to percent decreases in total institutional and residential care costs of 12.7% and 11.8%, respectively, with each .10 increment in HUI-III score, when Beck Depression Inventory score is zero, total institutional and residential care costs are 1.7% and 4.8% higher for each .10 increment when Beck score is one standard deviation above the mean (16) and 25.1% and 19.1% higher when at the dataset maximum (42). The percent change in nursing home costs for each 0.10 increment in HUI-III score increases steadily from −12.5% to −4.4% to 5.5% when Burden Interview score increases from zero to its mean (34) to its dataset maximum (76). With an increase in CAS score from zero to its mean (16) the percent change in hospital (−11.0% to −4.1%) and nursing home (−6.9% to −2.8%) care costs for each .10 increment in HUI-III score rises substantially. By one standard deviation above the mean CAS score (28) the percent change in institutional service costs is no longer negative for each .10 HUI-III increment but positive; by the maximum score (54), each .10 increment is associated with a 12.3% and 6.9% increases in hospital and nursing home costs.

In short, results indicate that the well-established inverse relationship between generic health status and service costs in AD is moderated by caregiver burden such that even in patients in comparatively good health high levels of caregiver burden could result in increased service use. This suggests that factors such as caregiver depression, distress, and time commitments to caregiving overrides the protective effects of health on decreasing the likelihood of institutional service use and costs when high caregiver burden prevails. Say an AD patient has a health utility score of 0.7. This score, while seemingly not very low, will have different effects depending on the level of burden experienced by the people caring for them. Whereas a spouse, for example, with low caregiver burden may be well equipped to care for a demented loved one at that health level, a spouse with high caregiver burden may not be as well equipped; thereby increasing the chances that institutional services will be needed.

Meeting the health and social needs of AD patients is one of the major tasks assumed by primary caregivers.[1] Doing so is often made difficult by the confusion, disorientation, disruptive behaviors, and poor health associated with AD. Not only is caregiver burden associated with increased risk of institutional placement,[4,9-13,18,19] but it is associated with decreased use of preventative measures that may slow down the trajectory toward institutionalizations,[22] including, for example, whether or not persons with dementia receive influenza vaccination.[54] Because less burdened caregivers should be in a better position for arranging and sustaining care in the community than more burdened caregivers, AD patients at similar levels of health may experience very different risks for institutional placement depending on perceived or realized caregiver burden. This, perhaps, is the most important implication of the present study which implies that even comparatively healthy AD patients may be at high risk for institutionalization if their health level is too much for their primary caregivers to handle because they are so overwhelmed.

This circumstance—comparatively healthy patients and high caregiver burden—is not as unusual as it may seem. In the present dataset, the HUI-III is weakly but inversely correlated with each caregiver burden measure, including the Caregiver Distress Scale (r=-.29, p<.001), Beck Depression Inventory (r=−.15, p<.01), Caregiver Burden Interview (r=−.24, p<.001), and CAS (r=−.26, p<.001). This suggests, as one would expect, that comparatively healthier AD patients with higher HUI-III scores tend to have caregivers with lower burden. However, 18.3% of those in the top HUI-III quartile ("best" health) had Beck Depression Inventory scores in the top quartile (highest burden) (4.0% of the entire sample); 19.2% of those in the top HUI-III quartile ("best" health) had CAS scores in the highest quartile (highest burden) (4.5% of the entire sample); 13.7% of those in the top HUI-III quartile ("best" health) had Burden Interview scores in the top quartile (highest burden) (3.3% of the entire sample); and 8.7% of those in the top HUI-III quartile ("best" health) had Caregiver Distress Scale scores in the highest quartile (highest burden) (1.9% of the entire sample). Together these findings suggest that a nonnegligible percentage of better functioning AD patients in our sample had among the most burdened caregivers.

A variety of interventions have been developed to support informal caregivers caring for chronically ill and disabled individuals.[22] These typically involve directing additional resources and supports to caregivers through more simplified access to a broader array of services and the provision of more timely and accurate information. Examples include the expansion of respite and adult day care, in-home support, care coordination and counseling, public reporting, integrated service delivery programs, and consumer direction. Findings deriving from the present study provide further evidence supporting investments in caregiver support strategies such as these, potentially yielding dividends in reduced institutional service costs. However, they also highlight the importance of broadening eligibility to include individuals caring for people with less advanced dementia for even seemingly manageable patients may be at heightened risk for institutional placement depending on the level of burden experienced by their caregivers. Caregiver interventions are typically allocated based on the characteristics of care recipients and not the actual or perceived burden of caregivers themselves. On the one hand, our findings suggest basing such decisions on a combination of both caregiver and care recipient characteristics. On the other hand, if the goal is to reduce institutional service costs through the maintenance of informal care in the community, policymakers would do well to consider basing eligibility for caregiver interventions on caregiver burden regardless of health status.

This is the first study to examine the moderating effect of caregiver burden on the relationship between HUI-III score and institutional service use and costs. Several limitations, however, are worth noting. First, although we used a longitudinal dataset, the findings are associational in nature and, as such, may not be indicative of causality.

Second, the results may not be generalizeable to other populations of AD patients. Although most AD patients develop psychiatric or behavioral symptoms, CATIE-AD relied on a cohort of AD cases with substantial symptoms thought to potentially benefit from antipsychotic therapy. Furthermore, all CATIE participants had active caregivers who were provided basic information and education, two counseling sessions, and could speak with staff members as needed.

Third, our study accounted for the direct costs associated with meeting the medical and social service needs of people with AD but not the indirect costs associated with forgone wages, missed worked, disability payments, and lost productivity, nor the substantial economic value of unpaid caregiving.

Fourth, there are alternative methods for measuring health utilities, with unknown implications for our results, though we believe the HUI-III most appropriate because it places greater emphasis on cognitive impairment than prevailing alternatives.[20]

Fifth, since 20 models were estimated, there may be some concern that results derive, in part, from the presence of multiple comparisons. While recognizing this possibility, we do not believe the multiple comparison issue should be a major concern. Although we use data deriving from a randomized clinical trial, we do not use it for the purpose for which it was originally collected, to assess the relationship between a particular treatment—atypical antipsychotic medication—and various outcomes. Instead, our study is expressly exploratory —it is the first, as far as we know, to examine the relationship between health utilities, caregiver burden, and health care costs. It is not meant to test hypotheses or generate definitive conclusions regarding that relationship; only to determine if one might exist and, if so, in what direction. Further, far more HUI-III*caregiver burden interaction terms were significant—in 9 out of the 20 analyses that were run, all positive—than would be expected based on chance alone (1 at the .05 level, 2 at the .10 level). If the results were due to chance we would not expect to see all significant findings fall in the same direction. Moreover, the analyses employed four different dependent variables, each of which appears only four times, and five different measures of caregiver burden. Thus, while we explored the same relationship we did so using different independent and dependent variables in each analysis, thereby, on the one hand, reducing concern associated with multiple comparisons, and, on the other, increasing confidence in the informativeness of the observed relationships. For the sake of completeness, however, we note that none of the interaction terms examined would have reached statistical significance had a Bonferonni corrected alpha level of .0025 (.05/20) or .005 (.10/20) been applied.

Last, the data used in this study derived from proxy raters rather than from the patients themselves. Though this is also true of most other AD studies, it remains uncertain whether caregiver proxy or patient provided information is most appropriate, especially since: (a) greater caregiver burden has been shown to be correlated with overstated functional impairments in individuals with cognitive impairment;[55] and (b) proxies routinely rate impairments higher than patients do, including when measured using health utilities. This potentially upward bias of caregiver impairment rating is reflected in studies which reveal lack of agreement between utilities derived directly from people with AD/dementia and caregiver proxies. Naglie, et al.[21], for example, found that mean HUI-III-, EuroQoL-5D-, and Quality of Well Being Scale-derived utilities among AD patients were significantly higher than mean proxy scores, though disproportionately so for the HUI-III, perhaps because proxy raters rated patients much lower on the HUI-III's cognitive item than patients themselves. Although no study has examined the relationship between caregiver burden, proxy- and patient-rated utilities, it seems reasonable to suppose that more burdened caregivers would be more likely to underestimate patients' utilities than less burdened ones,

with unknown ramifications for our results. Though the jury is still out on the reliability of utility assessment in patients with mild dementia, especially, say, when administered using a facilitated interview,[21] it is unlikely that self-assessment would have been possible or appropriate among the more advanced AD cases recruited for CATIE. Clearly, further research is needed to determine the validity of proxy-rated utilities among patients with AD and how those ratings may vary with caregiver burden.

Conclusion

The ease with which the HUI-III is administered together with the inverse association found between it and health services use and costs[7,8] suggest that health utility scores may be combined with other known correlates to help predict service costs among persons afflicted with AD or other dementia. The present study, however, suggests that the relationship between general health measures such as the HUI-III and costs vary with caregiver burden, thereby implying that more complex dynamics such as this be taken into account when using patient-level information to inform population planning and resource allocation decisions associated with AD. Indeed, what may be needed is a burden screener to identify those caregivers with significant depression or psychological distress, or who spend relatively large amounts of time in caregiver activities, to identify not only those patients in comparatively poor health but their caregivers who could benefit from assistance, regardless of AD patient health. Future research should determine whether caregiver burden, depression, or caregiving time moderates the effects of other known correlates of institutional service costs such cognitive impairment, functional impairment, and prior service use. It should also determine whether caregiver burden moderates the relationship between the HUI-III, other known correlates, and non-institutional service costs as well.

Acknowledgments

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TABLE 1

Characteristics of Study Sample at Baseline (n=308–421)

	n	Mean	St. Dev.	Minimum	Maximum
Patient Characteristics					
Age	421	77.9	7.5	51.0	103.0
Female	421	0.56	0.50	0.00	1.00
Non-Hispanic White	419	0.79	0.41	0.00	1.00
Married	421	0.59	0.49	0.00	1.00
Some College or More	421	0.29	0.45	0.00	1.00
ADCS-ADL Scale	413	39.44	17.11	2.00	76.00
Neuropsychiatric Inventory	414	36.88	18.29	3.00	104.00
Mini-Mental State Exam	416	15.00	5.80	4.00	29.00
AD-Related Quality of Life	416	67.31	14.66	18.71	100.00
Health Utilities Index	414	0.18	0.25	−0.29	1.00
Caregiver Characteristics					
Age	271	63.0	15.5	22.0	89.00
Female	320	0.71	0.45	0.00	1.00
Some College or More	308	0.55	0.50	0.00	1.00
Spouse of Patient	318	0.52	0.50	0.00	1.00
Child of Patient	318	0.34	0.47	0.00	1.00
Other Relationship	318	0.14	0.34	0.00	1.00
Caregiver Distress Scale	414	16.47	8.56	0.00	45.00
Beck Depression Inventory	410	8.40	7.33	0.00	42.00
Burden Interview Score	409	34.42	15.99	0.00	76.00
Caregiver Activity Survey	409	16.34	11.91	0.00	54.00
Avg. Caregiver Burden (Z-Scores)	400	0.16	0.70	−1.33	2.42

n varies depending on the number of missing values

TABLE 2

Results of Mixed Models of Institutional Service Costs (logged) Using Pooled Dataset (Baseline, 3, 6 and 9 months)*

Average Caregiver Burden (Z-Scores) (n=1,288 for each model)

Variable	Total Institutional		Hospital		Nursing Home		Residential	
	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect
Health Utilities Index (transf.)	−.049 (.042)	−4.859	−.008 (.032)	−.777	−.026 (.021)	−2.550	−.004 (.019)	−.439
Average Burden Z-Score	−.291# (.154)	−29.120	.0876 (.098)	8.763	−.267** (.093)	−26.700	−.099 (.104)	−9.861
Health Utilities Index*Avg. Z	.101* (.043)	10.120	.048 (.031)	4.792	.037# (.022)	3.669	.015 (.021)	1.464
(Constant)	−.773 (1.564)	−77.340	.220 (.818)	21.990	−.151 (1.115)	−15.120	−.959 (.713)	−95.930
	−2 Log Likelihood: 5888.7***		−2 Log Likelihood: 5094.8***		−2 Log Likelihood: 4449.4***		−2 Log Likelihood: 4173.7***	

Caregiver Distress Scale (n=1,355 for each model)

Variable	Total Institutional		Hospital		Nursing Home		Residential	
	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect
Health Utilities Index (transf.)	−.188*** (.049)	−18.750	−.080* (.035)	−8.017	−.086** (.030)	−8.604	−.021 (.024)	−2.108
Caregiver Distress Scale	−.043*** (.011)	−4.298	−.007 (.008)	−.724	−.027*** (.007)	−2.704	−.008 (.005)	−.814
Health Utilities Index*Distress	.009* (.003)	.852	.004 (.002)	−.373	.004* (.002)	.396	.001 (.002)	.076
(Constant)	.691 (1.384)	69.110	.724 (.769)	72.440	.841 (.943)	84.120	−.884 (.769)	−88.430
	−2 Log Likelihood: 6298.5***		−2 Log Likelihood: 5469.7***		−2 Log Likelihood: 5030.3***		−2 Log Likelihood: 4396.6***	

Beck Depression Inventory (n=1,307 for each model)

Variable	Total Institutional		Hospital		Nursing Home		Residential	
	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect
Health Utilities Index (transf.)	−.127** (.048)	−12.710	−.044 (.033)	−4.352	−.018 (.027)	−1.798	−.040^I (.024)	−3.971
Beck Depression Inventory	−.010 (.013)	−1.021	.004 (.009)	.439	−.003 (.008)	−.322	.003 (.007)	−.321
Health Utilities Index*Beck	.009# (.005)	.901	.002 (.003)	.178	−.001 (.003)	−.069	.005* (.002)	.549
(Constant)	−.921 (1.306)	−92.100	.296 (.739)	29.560	−.237 (.796)	−23.670	−1.077 (.765)	−107.690
	−2 Log Likelihood: 6000.7***		−2 Log Likelihood: 5242.8***		−2 Log Likelihood: 4558.2***		−2 Log Likelihood: 4231.8***	

Burden Interview Score (n=1,331 for each model)

Variable	Total Institutional		Hospital		Nursing Home		Residential	
	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect
Health Utilities Index (transf.)	−.197** (.066)	−19.650	−.062 (.046)	−6.216	−.125** (.038)	−12.470	−.019 (.034)	−1.919
Burden Interview Score	−.021*** (.006)	−2.106	0.000 (.004)	.022	−.018*** (.004)	−1.824	−.007* (.003)	−.672
Health Utilities Index*Burden	.003 (.002)	.284	.000 (.001)	.010	.002* (.237)	.237	.000 (.001)	.008
(Constant)	.026 (1.335)	2.599	.303 (.787)	30.280	.475 (47.47)	47.470	−.592 (.771)	−59.180
	−2 Log Likelihood: 6112.9***		−2 Log Likelihood: 5350.9***		−2 Log Likelihood: 4648.8***		−2 Log Likelihood: 4343.7***	

Caregiver Activity Survey (n=1,313)

Variable	Total Institutional		Hospital		Nursing Home		Residential	
	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect	Coef. (S.E.)	Marg. Effect
Health Utilities Index (transf.)	−.126** (.049)	−12.640	−.110** (.034)	−11.000	−.069* (.028)	−6.939	.011 (.025)	1.126
Caregiver Assessment Survey	.006 (.008)	.554	.004 (.006)	.376	−.003 (.517)	−.293	.005 (.004)	.455
Health Utilities Index*Assess.	.003 (.002)	.343	.004* (.002)	.432	.003# (.001)	.256	−.001 (.001)	−.125
(Constant)	−.814 (1.331)	−81.440	.189 (.772)	18.910	−.093 (.814)	−9.331	−1.029 (.782)	−102.920
	−2 Log Likelihood: 6028.3***		−2 Log Likelihood: 52.65.9***		−2 Log Likelihood: 4608.3***		−2 Log Likelihood: 4281.6***	

*
There were 1,429 potential cases available for each of the five groups of analyses based on the cost information available in the dataset. As such, the total number of cases for each group depended on the number of cases missing on the sociodemographic variables collected at baseline and the various patient and caregiver scales reported during each observation period (baseline, 3, 6, and 9 months).

*
Control variables include: age, female, non-Hispanic White, Married, Some College or More, ADCS-ADL Scale, Mini-Mental State Exam, Neuropsychiatric Inventory, AD-Related Quality of Life, and Time Fixed Effects (Three Months, Six Months, Nine Months)

#
p<.10

*
p<.05

**
p<.01

***
p<.001

TABLE 3

Moderating Effect of Caregiver Burden on the Health Utilities-Institutional Cost Relationship[*]

Baseline Burden Score	Min.	−1 St.Dev.	Mean	+1 St.Dev	Max.
Average Burden Score (Z-Scores)	(−1.3)[1]	(−.5)	(.2)	(0.9)	(2.4)
Total Institutional	−18.3%[2]	−10.3%	−3.2%	3.9%	19.6%
Nursing Home	−7.4%	−4.5%	−2.0%	.6%	6.3%
Caregiver Distress	(0)	(8)	(16)	(25)	(45)
Total Institutional	−18.8%	−11.9%	−5.1%	2.6%	19.6%
Nursing Home	−8.6%	−5.4%	−2.3%	1.3%	9.2%
Beck Depression	(0)	(1)	(8)	(16)	(42)
Total Institutional	−12.7%	−11.8%	−5.5%	1.7%	25.1%
Residential	−4.0%	−3.4%	0.4%	4.8%	19.1%
Burden Interview	(0)	(18)	(34)	(50)	(76)
Nursing Home	−12.5%	−8.2%	−4.4%	−0.6%	5.5%
Caregiver Assessment	(0)	(4)	(16)	(28)	(54)
Hospital	−11.0	−9.3	−4.1	1.1	12.3
Nursing Home	−6.9	−5.9	−2.8	0.2	6.9

[1] Numbers in parentheses represent corresponding scores on each caregiver burden measure.

[2] Percent change in costs for each .10 increment in HUI-III score.

[*] The table shows the moderating effect of burden measure score on the percent change in residential, hospital, nursing home, and total institutional costs for each 0.10 increment on the HUI-III scale. For example, whereas each 0.10 increment in HUI-III score is associated with an 18.8% reduction in total institutional costs when Caregiver Distress score is 0 and a 11.9% reduction when Caregiver Distress score is 1 SD below the mean (8.0), it is associated with a 2.6% increase in total institutional costs when Caregiver Distress is 1 SD above the mean.