

The Cost of Alzheimer's Disease in Managed Care: A Cross-Sectional Study

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Abstract

Background: The number of people with Alzheimer's disease (AD) is expected to grow as the US population ages. Given the increasing enrollment in managed care organizations, growth in the number of managed care patients with AD is a certainty. To our knowledge, no study to date has focused on the cost of care of community-dwelling AD patients receiving care through a health maintenance organization (HMO) system.

Methods: One hundred and fifty patients were recruited from 4 managed care sites from July through December 1996. Staff at each site clinically confirmed patients' AD diagnosis, AD severity, and ascertained patients' comorbidities. Demographic, quality of life, and service utilization data were collected from proxy respondents. Costs of hospitalization, medications, doctor visits (formal costs), and caregiver assistance (informal costs) were analyzed separately.

Results: The average total (formal and informal) per-patient costs in the 4 settings in 1996 were \$18,804. Costs increased with cognitive impairment. For patients with mild, moderate, and severe AD, annual total costs were \$14,904, \$19,272, and

\$25,860, respectively. Annual direct costs were \$5520, \$7044 and \$10,992, respectively.

Conclusion: Across all severity levels, we calculated a total annual cost of \$8.8 billion for managed care enrollees older than 65 years in the United States. We did not estimate these costs for the population younger than 65 years because of the variability in AD prevalence estimates. Due to the increased costs for patients with more severe AD, interventions that would reverse or delay progression may result in significant cost savings.

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Alzheimer's disease (AD) afflicts 5.7% to 10% of the US population older than 65 years of age, and its prevalence increases dramatically with each succeeding decade of life.¹ Estimates indicate that 25% to 45% of the elderly who are 85 years old or older have AD.^{1,3} As the population of the United States ages, the number of people with AD is expected to grow.

AD is a brain disorder characterized by a progressive dementia that occurs in middle or late life.^{4,5} AD patients often require progressively more supportive services such as personal care assistance and homemaking as their ability to carry on basic and instrumental activities of daily living (ADLs and IADLs) becomes more impaired.⁶ Inevitably, neurodegeneration ultimately leads to the breakdown of most

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basic biological functions, resulting in the need for palliative care as well as aggressive medical treatment.⁷ The amount of informal care (ADL assistance) and formal care (medical treatment) AD patients require increases as the severity of the disease worsens.⁸ Care at all severity levels is typically provided by families and friends when available. For patients remaining in the community, informal care is generally supplemented through formal services—paid for through various public and private insurance programs and by out-of-pocket payments made by patients and their families.

Increasingly, people older than age 65 are electing to enroll in Medicare health maintenance organizations (HMOs) that may offer lower out-of-pocket expenses⁹ and additional benefits, such as prescription drug coverage not provided by Medicare.¹⁰ In 1994, 8.1% of Medicare-eligible persons were enrolled in an HMO plan; in 1996 this figure had increased to 12.7%, or 4.9 million people.¹⁰ Given the increasing number of elderly people entering managed care organizations (MCOs) under Medicare and Medicaid mandates, further growth in the number of MCO patients with AD is likely.¹¹ Therefore, knowledge of how MCOs care for AD patients and the cost of that care is critical.

Since the inception of Medicare in 1965, its mental health policies have changed. Formerly its reimbursement policies focused on inpatient care and provided limited outpatient services—especially for mental health.¹² Until 1988, outpatient mental health expenditures were covered up to \$500 annually, with a 50% copayment.¹³ Reimbursement reforms under the Omnibus Budget and Reconciliation Acts (OBRA) of 1987¹⁴ and 1989¹⁵ resulted in a 20% increase in the number of covered outpatient mental health services, removal of the annual cap for outpatient mental health services,^{16,17} and extension of provider status to social workers and psychologists.¹² Despite these improvements, the majority of elderly patients with mental disorders still lack adequate services and reimbursement.^{16,18} Federal and state reimbursement remains limited or nonexistent for adult day care, assisted living, residential care, and respite services that are essential dementia care services.¹⁹

To date, little has been published on the informal and formal costs of AD in managed care. This study has 2 principal objectives: (1) to estimate the impact of AD on managed care patient outcomes, including health-related quality of life (HRQOL), and service utilization, and (2) to provide cost estimates of formal and informal service consump-

tion for mildly, moderately, and severely impaired AD patients in MCOs.

...METHODS ...

Subjects and Study Design

Leon et al⁸ conducted a cross-sectional study of 679 AD patient/family caregiver pairs that were consecutively recruited according to disease severity from 4 types of health service settings in 13 sites located in 9 states. Health service settings represented in the original study included community-based patients from MCOs and academic medical centers, and residential patients in assisted living facilities and nursing homes. The current analysis focuses on the subset of 150 patients from 4 managed care sites that were a convenient sample of large plans selected because of geographic diversity and their willingness to participate: Permanente Medical Center, Hayward, CA; Fallon Community Health Plan, Worcester, MA; Health Partners, Bloomington, MN; and Lovelace Scientific Resources, Albuquerque, NM. These 4 MCOs represent all managed care patients in the larger study.¹⁰

The study protocol was reviewed and approved by appropriate institutional review boards and conducted in accordance with the Declaration of Helsinki. Written informed consent was provided prior to enrollment by all caregivers and, when possible, all mildly and moderately impaired AD patients. At each site, patients' medical records were reviewed, and current patients that met both Alzheimer's Disease and Related Disorders Association (ADRDA) and National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) criteria for probable AD were prospectively recruited into the study. Clinical staff at each project site assessed patients' cognitive abilities via the Mini-Mental State Exam (MMSE).²⁰ MMSE scores were collapsed into 3 categories labeled mild (18–30), moderate (10–17), and severe (<10).²¹ Because the MMSE is a clinically accepted means of classifying severity, we used this measurement in our calculations of cost based on disease severity. Within 2 weeks of the MMSE screening, the clinical staff used the Clinical Dementia Rating Scale (CDR)²² to classify AD patients into 6 ordinal stages of disease severity, ranging from 0.5 (minimal impairment) to 5 (extreme impairment). CDR scores also were collapsed into 3 categories labeled mild (0.05–1.0), moderate (2), and severe (3–5).²²⁻²⁷ The 150 AD patients were recruited for the project during a 6-month period: July to December 1996.

Data Collection

In addition to staging patients for disease severity by means of the MMSE and the CDR, clinical personnel at each site ascertained patients' comorbidities by reviewing medical records and/or conducting physical examinations. Outcome information (eg, HRQOL status, service utilization, etc.) was obtained with demographic information by computer-assisted telephone interviews with proxy respondents. Proxy interviews were conducted with the primary family caregiver for each patient in the study. A family caregiver was defined as the primary family member or friend who provided the most day-to-day, hands-on care for the AD patient.

Measures and Variables

Demographic information consisted of age, gender, race, marital status, and relationship to the family caregiver (Table 1). The Cumulative Illness Rating Scale for Geriatrics (CIRS-g)²⁸⁻³¹ was used by clinical personnel at each site in reviewing medical records and conducting physical examinations. The CIRS-g covers 14 organ systems and rates each on a 5-point scale, where 0 indicates no problem and 4 indicates severe problems. In the present analysis, the number of CIRS-g problems (sum of indicated problems across the categories) was used as the measure of comorbid status.

Patient Outcomes

Three types of patient outcomes were examined in the analysis: (1) health status, as measured by the physical and mental health summary scores from the Medical Outcomes Study Short-Form (SF-36)³²; (2) health utilities as measured by the Health Utilities Index (HUI)³³; and (3) service utilization as measured by formal and informal care through ADL and IADL assessment.

The SF-36 is a generic quality-of-life questionnaire consisting of 36 questions.³² Questions are categorized into 8 subscales that can be combined into summary physical and mental health measures. The summary physical health score is a combination of physical functioning, role-physical, bodily pain, and general health, while the mental health summary score is composed of vitality, social functioning, role-emotional, and mental health.³² Caregivers were used as proxy respondents for the SF-36 to overcome AD patients' difficulties in cognitive function and ability to communicate their HRQOL.³⁴

Measurements of Services Use and Costs

Informal Care. To measure informal care, family caregivers were asked about the amount of time they

spent on specific aspects of caring for AD patients, such as time in a typical day in the past month spent providing hands-on help with patients' specific ADLs such as eating, bathing, dressing, and toileting. Similar questions were asked about the hours per week spent helping the patient with specific IADLs such as shopping, housecleaning, transportation, and bill paying. In presenting the results, time measures were collapsed into 2 categories: (1) time spent assisting with ADLs and (2) time spent assisting with IADLs. Measures of informal care giving (ie, ADL and IADL assistance) were reported as hours per month.

A replacement cost approach³⁵ was used to estimate the costs of informal care giving. National average hourly wage rates for home health aides and homemakers according to 1995 figures from a national survey of home care nurses and paraprofessional home care workers³⁶ were used and inflated by 2.4%³⁷ to reflect 1996 dollars.³⁸ To measure ADL costs, the national average hourly wage rate for home health aides was multiplied by the number of hours devoted to ADL tasks. For IADL costs, the national average hourly wage rate for homemakers was multiplied by the number of hours devoted to IADL tasks.

Formal Care. The measures of formal health services included: number of days of overnight hospital stays; number of emergency room visits; average number of doctor visits; total number of prescribed medications including as needed orders and psychotropic medications; number of skilled nursing facility days; number of days the patient attended an adult day care program; and the average monthly use of homemaker and personal care services.

Measures of formal service use came from different sources. The number of days of inpatient and skilled nursing facility stays, the number of emergency room visits, and the number of prescribed medications were reported directly by proxy respondents for AD patients in the community. The proxy respondents were asked about the patient's use of adult day care, paid personal assistance, and homemaker services. All services covered the month prior to the interview. Mean monthly utilization responses were assumed to be constant over the previous year and were multiplied by a factor of 12 to estimate yearly utilization. National monthly estimates from various secondary sources were applied to these estimates. The cost of doctor visits was derived from average doctor visits for AD patients in the 1994 Medicare Current Beneficiary Survey (MCBS)³⁹ and its associated Medicare claim files. Data from the

MCBS are based on fee-for-service claims matched to sample AD patients using age and health status.

Formal Service Unit Costs. Unit cost estimates were also derived from secondary sources. The unit costs of hospital days, emergency room visits, doctor visits, prescribed medications, skilled nursing home days, and personal care and homemaker services were derived from 1994 MCBS data for beneficiaries identified from the survey as having AD. The daily cost of adult day care services came from nationwide surveys of adult day care programs for persons with dementia (Table 2).^{36,39,40} All service costs were standardized to represent costs for various subgroups of AD patients and were adjusted to reflect 1996 constant dollars.

...RESULTS ...

Using the MMSE as a criterion for measuring level of cognitive impairment, the clinical staff classified

the 150 patients in our sample as follows: 70 as mild 44 as moderate, and 36 as severe.

Patient Outcomes

The physical functioning SF-36 scores did not differ by severity levels, but the mental health summary scores did show a significant difference between the mild (43.3) and severe (38.2) patients ($P<.03$).⁴¹

The variation in health utilities by disease severity was significant ($P<.0001$) and showed that utility scores as measured by the HUI are related to disease severity. Scores were much higher for patients at the mild stage, indicating better HRQOL.⁴¹

Caregiver Outcomes

Caregivers reported that they spent about 30 hours per month providing ADL assistance and an additional 12 hours per month in IADL assistance (Table 2). None of the differences among the caregivers' SF-36 summary scores by disease stage were statistically significant.

Table 1. Mean, Standard Deviation (SD), and Ranges for Variables

Variable	Managed Care (n=150)			Rest of Study* (n=529)			P value
	Mean	SD	Range	Mean	SD	Range	
Patient demographics							
Age	79.4	6.58	60-97	80.1	9.2	51-102	.01
Gender (% female)	50.0			72.0			.001
Education (years of schooling)	11.8	3.9	0-18	11.8	4.1	0-18	NS
Marital status (% married)	66.7			39.7			.001
Percent of patients living with family caregiver	83.3			30.1			.001
Family caregiver demographics							
Relationship to patient (% spouse)	62.7	—		32.5			.001
Age	66.7	13.4	34-90	61.6	13.3	31-95	.001
Gender (% female)	72.7	—		62.2			.05
Race/ethnicity (% white)	88.0	—		88.3			NS
Marital status (% married)	82.0	—		77.1			NS
Patient CDR	1.7	1.1	0.5-5.0	2.1	1.04	0.5-5.0	.001
Patient MMSE	15.3	8.3	0-29	10.8	8.6	0-30	.001
Patient comorbid conditions: CIRS-g total no. of categories	3.1	1.9	0-10	3.4	2.2	0-10	.001

*CDR=Clinical Dementia Rating; MMSE=Mini-Mental State Exam; CIRS-g=Cumulative Illness Scale for Geriatrics.

Cognitive Impairment and Comorbidities

Total monthly costs were \$1242, \$1606, and \$2155 for patients who were mildly, moderately, and severely impaired, respectively (Table 3). Total costs for the managed care patients increased by 29% from mild to moderate and 34% from the moderate to the severe levels. These increases were statistically significant.

Informal and Formal Costs

Table 3 presents estimates of monthly patient costs by MMSE scores categorized as mild, moderate, and severe. Average total monthly costs were \$1567: \$607 (39%) for formal care and \$960 (61%) for informal care.

The informal, formal, and total costs vary by cognitive level. For mildly impaired managed care patients, average monthly informal care costs were \$782 (63% of \$1242). At the moderate level, the costs of informal care increased by 30% to \$1019 (63% of \$1606). In the severe category, the costs of informal care increased by 22% to \$1239 (57% of \$2155).

Formal service costs for mildly impaired patients were \$460 and increased by 27% to \$587 for patients at the moderate level. From moderate to severe levels, the formal costs increased by 56% to \$916.

The data indicate a pattern of total costs increasing with cognitive decline. Both total costs and the costs for informal care significantly increased from the mild to moderate levels. From the moderate to the severe levels, most of the cost increases were for formal services. Total costs from mild to moderate severity increased from \$1242 to \$1606 ($P < .20$); informal costs increased from \$782 to \$1019 ($P < .8130$).

Impact of Comorbidities

Table 3 further breaks down the costs of the cognitive impairment levels by the number of comorbid conditions. For the managed care patients, the patients with 3 or more comorbidities required the most formal care (\$651), but had an 8.7% decrease in the cost of informal care (\$881) compared with patients without comorbidities. Informal care costs for the patients with 1 or 2 comorbidities con-

Table 2. Proxy Assessed Mean Service Use and Standardized Unit Cost Estimates

Type of Formal and Informal Service	Unit of Service	Mean ± SD*	Unit Cost in 1996 Dollars	Source of Unit Cost Estimates
Formal services				
Inpatient hospital stays	Inpatient day	.09 ± .77	1020	MCBS/Medicare claims ³⁹
Emergency room visits	ER visit	.11 ± .41	220	MCBS/Medicare claims ³⁹
Doctor visits	Physician visit	1.6 ± .51	51	MCBS/Medicare claims ³⁹
Prescriptions	Typical prescription	2.12 ± 1.8	29	MCBS/Medicare claims ³⁹
Skilled nursing home care	Day of care	.43 ± 3.46	260	MCBS/Medicare claims ³⁹
Adult day care	Day of care	2.97 ± 6.2	46	Partners in Care survey ⁴⁰
Homemaker services	Day of rate	.69 ± 2.0	80	MCBS/Medicare claims ³⁹
Personal care services	Day of rate	.65 ± 2.03	70	MCBS/Medicare claims ³⁹
Informal services				
ADL assistance	Hours/month for personal care	30.1 ± 52.6	6.95	Kaiser Home Care ³⁶
IADL assistance	Hours/month for homemaker services	123.6 ± 86.3	6.08	Kaiser Home Care ³⁶

*Mean monthly estimates as reported by proxy. ADL=activities of daily living; IADL=instrumental activities of daily living; ER = emergency room; MCBS = Medicare Current Beneficiary Survey.

tributed to the highest overall cost (\$1695) in the managed care population we studied.

Total and formal costs for patients within cognitive impairment levels were significantly higher for patients with greater levels of comorbidity. For example, formal services costs for moderately impaired patients with 3 or more conditions totaled \$826 compared with \$298 for patients with 1 or 2 conditions and \$47 for patients with no comorbidities ($P<.006$). Patterns were similar for AD patients with severe impairment.

Total costs for patients at different comorbidity levels were relatively constant within levels of cognitive impairment. For example, for patients at the severe level, the \$218 difference in total monthly costs between patients with 1 or 2 comorbid conditions (\$2258) and for patients with 3 or more conditions (\$2040) was not statistically different.

...DISCUSSION ...

In this managed care sample, the caregivers on average provided 3 times the ADL and IADL assistance compared with the rest of the study popula-

tion ($P=.001$).⁸ The caregiver was also more likely to be the patient's spouse (Table 1). The study also showed that costs were less for married patients whose caregivers were spouses than for unmarried patients and married patients whose caregiver is someone other than their spouse.⁸ Compared with the entire sample population, the managed care patients were slightly younger and more likely to be married, male, and living with a family caregiver.⁸

Caregiver outcomes, physical functioning, mental health status and caregiver HRQOL varied little between AD severity levels. The majority of variation was related to caregiver demographics and whether the caregiver was the spouse of the patient. Since the caregivers were proxies for patients' SF-36 assessments, the statistically significant differences in the patients' mental health summary score could reflect caregiver distress.

First-time estimates of the costs of care for managed care patients by level of cognition and by comorbid status indicate that costs increased by both level of cognitive impairment and elevated comorbid status. Lower monthly costs observed in the small sample of patients classified as severe with more than 3 comorbidities, suggest that the results

Table 3. Monthly Patient Costs (in \$) of Formal and Informal Care by AD Severity and Number of Comorbid Conditions*

Settings	Cognitive Impairment Level by MMSE											
	Mild Monthly Costs			Moderate Monthly Costs			Severe Monthly Costs			All Severity Levels Monthly Costs		
	Informal	Formal	TOTAL	Informal	Formal	TOTAL	Informal	Formal	TOTAL	Informal	Formal	TOTAL
MCO (n=150)	782	460	1242	1019	587	1606	1239	91	2155	960	607	1567
Comorbidities												
None	NA	NA	NA	1116 [†]	47 [†]	1163	844	364 [†]	1208[†]	965	223	1188[†]
1 or 2 conditions	795	305	1100	1275 [†]	298 [†]	1574[†]	1322	1206	2258	1097	598	1695
3 or more conditions	776	526	1302	865	826	1692	1278 [†]	762 [†]	2040[†]	881	651	1532

*Tests for significant differences are provided in the text.

[†]Represents fewer than 15 cases.

MCO=managed care organization, NA=not applicable.

might not be representative of the general population, and further research with a larger sample would be informative.

In general, care increases as severity increases,⁴² with costs driven by increases in both formal and informal care. As new products that slow AD progression are approved, they may decrease costs. A study of patients taking donepezil for 6 months found a significantly lower rate of institutionalization as compared with age- and sex-matched controls that were not on medication and found that mean direct medical expenses were slightly lower (1%).⁴³ These estimates may provide a rationale for MCOs to begin treatment earlier for AD. Patients that begin treatment in the early stages of AD may have a better chance for self-care and may delay the need for institutionalized forms of care.⁴² These estimates may also support more accurate calculations of the costs of care by insurance programs designed to cover AD patients across the duration of the disease.

Estimates from the present analysis show that average total per-patient costs in 1996 were \$18,804 for managed care patients. For patients with mild, moderate, and severe levels of cognitive impairment, annual total costs amounted to \$14,904, \$19,272, and \$25,860, respectively. Because the 4 sites were not representative of the entire United States, however, national cost data were used to minimize the bias. While treatment patterns may differ among the sites, the combined data provide the means for a rough national estimate.

Table 4 reports the direct costs for other conditions studied in managed care.^{44,45} Treatment costs for degenerative conditions such as human immunodeficiency virus, diabetes, heart disease,⁴⁵ and cancer⁴⁴ were all higher than those we found for AD in the managed care environment. Comparing the direct costs of AD with the direct costs of these other conditions, AD care is within the range of payments currently being made. Due to comorbidities, however, the AD patients may also be receiving care for other conditions and as a result, may have a higher overall cost.

Using information from the US Bureau of the Census, we calculated that there were 30.1 million persons 65 to 84 years of age, and 3.8 million persons aged 85 or older. Using the average

prevalence rates of 7.85% and 35% for the groups aged 65 to 84 and 85 years and older,¹⁻³ respectively, and then applying the Medicare HMO rate of 12.7%,¹⁰ we calculated that there are approximately 467,000 persons with AD in Medicare HMOs (300,072 aged 65 to 84; 167,221 85 or older). Assuming our MMSE severity distribution (47% mild, 29% moderate, and 24% severe) to categorize patients, we calculated the US managed care population to have 218,070 patients as mildly impaired, 137,073 as moderately impaired, and 112,150 as severely impaired. Using our estimates of \$14,904, \$19,272, and \$25,860 per year for mild, moderate, and severe cases, we estimated the managed care costs for AD to be \$3.2 billion per year for mild, \$2.6 billion per year for moderate, and \$2.9 billion per year for severe patients. Across all severity levels, we calculated a total annual cost of \$8.8 billion for community-based Medicare managed care enrollees older than 65 years. We did not estimate these costs for the population younger than 65 years because of the variability in prevalence estimates. Patients requiring residential care in nursing homes and assisted-living facilities are primarily funded by Medicaid.¹⁷

Table 4. 1996 Annual Managed Care Spending for Other Diseases

Author	Disease	Direct Costs (\$)
Leon & Neumann	Alzheimer's disease	7284
Fishman et al, 1997 ^{45*}	Hypertension	6391
	Anxiety	6463
	Depression	6777
	Diabetes	7540
	Heart disease	8628
	Dementia†	11,114
	HIV infection	11,592
Fireman, 1997 ⁴⁴	Breast cancer (female)	8141
	Prostate cancer	10,433
	Colon cancer	11,815
	Rectal cancer	13,685
	Non-Hodgkin's lymphoma	13,819
	Lung cancer	17,114
	Ovarian cancer	17,411

*Inflated by the prescription drugs and medical supplies component of the consumer price index.

†Nonspecific dementias that include, but are not limited to, those related to Alzheimer's disease.

This study provides insight into how MCOs provide care for AD patients. For moderately impaired patients, informal care costs constituted more than 70% of the total MCO costs, compared with 52% for patients in academic medical centers. The difference translates into approximately 43 hours of additional informal care per month for MCO patients.⁸ This difference may result from MCOs indirectly placing the burden of care on families that might not know how to access the system.⁴⁶ Such findings hold implications for MCO administrators and policymakers who expect to increasingly use managed care as an alternative to traditional fee-for-service. If it can be assumed that informal care is being substituted for formal services, these differentials also imply that MCOs are reducing the costs of formal care by placing more burdens on the informal care network. MCOs and fee-for-service organizations have different approaches to providing healthcare. In addition to some MCOs limiting access to formal in-home care, additional biases such as MCOs attracting healthier patients⁴⁷ may account for some of these differences. Recent legislation might impact how MCOs treat and are reimbursed for care provided.

While the Mental Health Parity Act of 1996 required elimination of coverage limits for mental healthcare,⁴⁸ this change has not occurred at all MCOs. Some MCOs have attempted to carve out the

mental health component, with various degrees of success.^{50,51} One MCO analysis found that, despite a 30% annual increase in expenditures before a carve out, the plan reduced costs by more than 40% in the first year.⁵¹ Over the 6-year follow-up, costs continued to decline.⁵¹ The RAND institute also found almost 90% of the 1996 benefit designs of 4000 behavioral health plans were inconsistent with federal legislation and in need of being rewritten.⁴⁸ In addition, Iowa's Medicaid managed mental health-care carve-out plan included only authorization for services considered medically necessary, community supports, and limited community-based services in rural areas, and it lacked coverage for provider, consumer, and family education.⁴⁶

The Health Care Financing Administration (HCFA) is proposing additional changes by adjusting payments to capitated plans based on the reason for hospitalization (as indicated by the principal inpatient diagnosis).⁵² HCFA's request for public comment states that physician, outpatient hospital, skilled nursing facility, and home health data will be collected no earlier than October 1999, and that all other data (eg, psychologist, social workers) is deemed necessary no earlier than October 1, 2000.

As in our original study, the total per-patient costs estimated from this study were lower than estimates provided by other investigators.^{53,54} A comparison of those other estimates is provided in Table 5,^{53,54} with all dollars inflated by the prescription drugs and medical supplies component of the consumer price index to 1996 dollars. These differences are in large part the result of our using more conservative hourly wage rates for calculating the costs of informal care and by restricting the range of informal time to realistic ranges. Because caregivers are constantly monitoring their patients for behav-

Table 5. Comparison of Other Estimates of the Cost of Care in 1996 Dollars

Study Subjects (n)	Cost				
	Total (\$)	Formal (\$)	%	Informal (\$)	%
Community managed care patients with dementia (150)	18,804	7284	39	11,520	61
Mildly demented community patients (70)	13,068	4836	37	8232	63
Moderately demented community patients (44)	21,768	6444	30	15,324	70
Severely demented community patients (36)	30,480	16,020	53	14,460	47
Community patients with dementia (93) ⁵³	62,941*	16,806	27	46,143	73
Mild or moderately demented community patients (42)	52,882*	10,188	19	42,694	81
Severely demented community patients (51)	70,406*	21,761	31	48,646	69
Community patients with dementia (64) ⁵⁴	36,698*	15,886	43	20,812	57

*Inflated by the prescription drugs and medical supplies component of the consumer price index.

ioral problems, we conservatively elected to record only the time specifically related to ADL and IADL assistance. Ernst and Hay used \$10.41 per hour in calculating the cost of informal care; we used a replacement cost approach as used in other caregiver studies^{35,55,56} and used hourly costs of \$6.05 for homemaker and \$6.95 for personal care services. These conservative hourly wage estimates were based on a survey of agency-based and independent home care workers.³⁶ If we had used \$10.41 as the hourly wage rate, our informal cost estimates for the managed care patients would have increased by almost 40%.

Since many MCOs do not routinely capture the outcome information we desired, we obtained this information directly from the proxies. Several researchers with cognitively impaired patients have advocated the use of proxy data.⁵⁷ A study of proxy respondents for AD concluded that SF-36 scores obtained from proxies were reliable measures of HRQOL.⁸ A study of proxy validity of community-dwelling women aged 65 and older where the proxy was self-designated observed almost perfect agreement (Kappa values > 0.6): 6 of 7 ADLs and 7 of 7 IADLs.⁵⁸ While proxies might not provide ideal responses, they may provide the only insight into patients with AD that are cognitively impaired. Since the proxies tend to have omission (not commission) errors, we elected to use a 1-month time frame as part of our strategy to increase the accuracy of the data.^{34,59}

Additionally, there are reasons to believe that, in general, the current Medicare HMOs have benefited from favorable selection, attracting healthier people.^{47,60} Since the patients in the MCBS database (Table 2) were fee-for-service instead of managed care, it is likely that these patients were sicker and required more extensive treatment. Despite some attempts at innovative geriatric programs,⁶¹ most MCOs have made few adaptations to address the care giving needs of geriatric clientele,⁶² perhaps because active, visible geriatric programs could attract too many frail older people.⁶³ A study of Medicare home healthcare indicated that managed care was associated with fewer visits and poorer outcomes.⁶⁴ Even though our study did find lower costs, it did not find outcomes to be poorer for this cohort.

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