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The economic burden of Alzheimer's disease care
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Dementia related to Alzheimer’s disease is placing substantial medical, social, psychological, and financial burdens on patients, their families, and their communities. Persons with Alzheimer’s disease require both “formal” medical and social services and “informal” services, usually provided by family members.

Over 10 percent of the total U.S. population age sixty-five or older had Alzheimer’s disease in 1990 (3.75 million cases); nine million Alzheimer’s disease cases are projected by the year 2040. The estimated prevalence of severe dementia, including Alzheimer’s disease, for persons age eighty-five or older (the oldest old) is much higher, ranging from 25 to 45 percent. Almost half of all nursing home patients have severe dementia.

State and federal governments shoulder some of the costs of caring for persons with Alzheimer’s disease, largely through Medicaid and Medicare. However, a large proportion of costs are borne by families who provide unpaid care. To assess the economic burden of caring for people with Alzheimer’s disease, this study examines the formal and informal care costs attributable to the disease for a sample of community-resident and institutionalized persons in northern California.
Methods

Sample selection. Data for the study were collected from ninety-three noninstitutionalized Alzheimer’s disease patients and their primary caregivers and from ninety-four institutionalized Alzheimer’s disease patients, their primary caregivers, and staff of the institutions in which the patients resided. A sample was drawn from five counties in northern California (Alameda, Contra Costa, San Francisco, Santa Clara, and Santa Cruz). Unfortunately, no sampling frame for this population exists from which to draw a random sample. Studies that have looked at whether the prevalence of Alzheimer’s disease differs by socioeconomic status or racial, ethnic, or gender group have yielded negative or conflicting results. Therefore, special efforts were made to obtain broad representations by age, gender, socioeconomic status, race, and ethnicity. The community sample was drawn from a variety of sources including Alzheimer’s Disease Diagnostic and Treatment Centers funded by the California Department of Health Services, adult day health care programs, retirement communities, senior centers, family support groups, and the Greater San Francisco Bay Area chapter of the Alzheimer’s Association. The institutionalized sample was drawn from sixteen skilled nursing facilities located in northern California, which range in size from thirty-one to 1,000 beds and represent a broad range of funding sources and ownership.

If a potential participant did not have a formal diagnosis of Alzheimer’s disease, patient medical records were abstracted using an instrument developed by the research team. Patients with comorbid conditions that might also result in dementia were excluded so that costs specific to Alzheimer’s disease could be isolated. Primary caregivers were identified as unpaid persons who had primary responsibility for helping the patient with activities of daily living (ADLs), instrumental activities of daily living (IADLs), or both. This person provided more unpaid hours of care to the patient than anyone else. In an effort to further isolate costs attributable to Alzheimer’s disease, caregivers were asked to describe only services used above and beyond what the patient would require if he or she were not demented.

It proved exceedingly difficult to locate eligible patients and caregivers for this study because of the stigma associated with the disease. Many initial contact letters were never returned or were returned by a caregiver who denied that the patient had Alzheimer’s disease. A total of 264 patient/caregiver pairs originally agreed to participate in the study. Elimination of participants who did not meet diagnostic and other criteria or who dropped out because the caregiver was subsequently institutionalized, moved out of the area, or was unable to find time to participate, or because the patient died, resulted in a final sample of 187 persons.
Adequate sociodemographic information was not available for patients and their caregivers who dropped out to enable us to estimate selection bias. Furthermore, the lack of a sampling frame would make this impossible. We recognize that the study population is not a random sample and may not be representative of the overall Alzheimer’s population. Nevertheless, a broad range of Alzheimer’s patients and their caregivers are included in this study, which represents the largest primary data collection effort to date using a sample of persons with Alzheimer’s disease studied for cost implications.

Data collection procedures. A baseline interview of all primary caregivers in their homes included demographic, caregiving, and service use questions about themselves and the patients. Primary caregivers of non-institutionalized patients were also asked to assess the patient’s capacities in ADLs. During the baseline interview a Mini-Mental State Examination (MMSE) was administered to patients who resided in the community. Patients in institutional settings were administered the MMSE during a separate visit, and facility staff familiar with the abilities of the patient were asked to assess ADL functioning. Caregivers were provided a calendar to record time spent on tasks related to caring for the patient, formal services used, formal costs associated with caring for the patient, and reimbursement received from Medicare, Medicaid, or private insurance. These data were obtained from caregivers through twelve monthly telephone interviews conducted by trained interviewers from 1988 to 1990.

Estimating cost of care. The economic cost of Alzheimer’s disease represents the value of resources used or forgone as a result of the disease. Both formal and informal care services are estimated. Formal services refer to those rendered for a price in the traditional medical and social service marketplace, where dollars are explicitly exchanged for services. Informal services refer to services rendered outside those markets and for which providers are not reimbursed. Because the present study focuses on the cost of care rather than the total cost of the disease, indirect productivity losses are not estimated. The incremental costs associated with caring for a demented person and attributed to the disease were measured. To exclude costs associated with conditions other than Alzheimer’s disease, primary caregivers determined whether a formal service or an aspect of informal care was required because of the patient’s demented condition. Billing records were also requested from primary caregivers and formal service providers for all formal services.

Included in formal care costs are expenditures for hospital and nursing home care, physician services, social services, medications, and other items or services used for the care of the person as a direct result of Alzheimer’s disease. Social services are those that do not require the delivery of skilled medical care but that contribute to the health and welfare of the patient.
For most of these services, charges are used as a proxy for costs.

Informal care provided to the patient as a result of Alzheimer’s disease is valued using a replacement cost approach by imputing a market value for services performed. An alternative approach is to estimate the opportunity costs of caregivers’ services by estimating the dollar value of their time had they been employed or engaged in other activities. Data were collected on missed wages and job and lifestyle changes that resulted from caregiving responsibilities. However, most caregivers were unable to respond to these questions. Applying a common opportunity wage to all caregivers, as has been done elsewhere, would not consider the varying circumstances of the caregiver. Furthermore, market wages undervalue the time of women, the elderly, and minorities, who suffer from labor market discrimination. Thus we selected the replacement cost approach as the preferable methodology.

Monthly data on the hours spent per week on fourteen possible services that an informal caregiver might perform were collapsed into four broad categories: assistance with ADLs and IADLs, behavioral management, social/recreational activities, and other activities. If the patient had no system of informal support, similar services would have been performed by one of four types of paid employees: (1) a nursing assistant for help with grooming, bathing, eating, mobility, transportation, social activities, medications, behavioral management, and other activities; (2) a housekeeper for assistance with housekeeping, shopping, and cooking; (3) a bookkeeper for assistance with financial/legal work; and (4) a handyman for outdoor maintenance. An appropriate wage for each type of worker was used, reflecting 1990 California wages (including fringe benefits). Final wages used were $10.40 for a nurse’s aide, $8.41 for a housekeeper, $12.12 for a bookkeeper, and $11.37 for a handyman. Informal care provided in skilled nursing facilities by volunteers or others paid by sources other than the patient or family were valued with a similar approach. It was determined that the services were provided by clergy, teachers, recreational workers, and welfare aides, and the appropriate wages were used to value hours of care.

Characteristics Of Patients And Caregivers

More than one of every two (55 percent) Alzheimer’s disease patients residing in the community in northern California had severe cognitive impairments, compared with more than nine of every ten institutionalized patients (94 percent). One of five community-resident patients needed assistance with inside mobility, compared with seven of ten institutionalized patients, and almost all institutionalized patients required assistance with dressing, grooming, bathing, and using the toilet. These findings indicate that the nursing home is the caregiver of last resort for persons with...
Alzheimer’s disease, because very few patients were institutionalized unless they had significant cognitive and functional impairments.

Alzheimer’s disease patients residing in institutions compared with their community counterparts were older (38 percent versus 14 percent age eighty-five and over), female (77 percent versus 59 percent), widowed (59 percent versus 36 percent), with low incomes (38 percent versus 25 percent with incomes under $10,000), and enrolled in Medicaid (39 percent versus 12 percent). About 64 percent of the institutional sample resided in conventional nursing homes, 19 percent in “special care units” of skilled nursing facilities, 15 percent in distinct-part skilled nursing units attached to acute hospitals, and 2 percent in “life-care” skilled nursing facilities.

Primary caregivers of persons in the community varied from those who cared for persons in institutions. They were more likely to be women and spouses, were less likely to be sons or other relatives, and had been caring for the patients approximately half as long as caregivers of patients residing in institutions. Institutionalization is more likely when men are caregivers. Men were more likely to assume legal and financial responsibilities, while women tended to take on personal care responsibilities at home.\textsuperscript{13}

\begin{table}
\centering
\begin{tabular}{|c|c|c|}
\hline
\textbf{Costs Of Care} & \\
\hline
\textbf{Formal care.} Average annual formal care costs for our northern California sample amount to $12,572 per patient in the community (Exhibit 1). The distribution of formal care costs in the community by type of care shows that more than three-fourths (76 percent) are for social services such as day care, respite care, home-delivered meals, and homemaker/chore services, followed by hospital care (13 percent), medical items and physician visits (4 percent each), medications (2 percent), other goods and services (less than 1 percent), and skilled nursing facility services (less than 1 percent). Average annual formal care costs for institutionalized persons with Alzheimer’s disease amounted to $42,049 per patient, more than three times the cost for noninstitutionalized persons. About 93 percent of the cost for institutionalized patients is for nursing home care, followed by medical items (3 percent of formal costs). Physician visits, hospital care, and medications each account for approximately 1 percent of total formal care expenditures in institutions. The 25 percent and 75 percent quartiles are reported in Exhibit 1 to describe the distribution of costs.\textsuperscript{14} It is clear from the zero values for the first quartile that many patients did not use certain services and that a relatively small number of patients had large expenditures in certain cost categories. For example, only sixteen patients in the community and seven patients in institutions received hospital care. \\
\end{tabular}
\end{table}
### Exhibit 1
Annual Cost Per Person Of Formal Care For Alzheimer’s Disease Patients, By Type Of Care, Payer, And Setting, Northern California, 1990

<table>
<thead>
<tr>
<th>Type of care and payer</th>
<th>Community-based care</th>
<th>Institutional care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean amount</td>
<td>Quartile 25%</td>
</tr>
<tr>
<td>Total</td>
<td>$12,572</td>
<td>$2,455</td>
</tr>
<tr>
<td>Type of care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>1,648</td>
<td>0</td>
</tr>
<tr>
<td>Physician visits</td>
<td>62</td>
<td>0</td>
</tr>
<tr>
<td>Medications</td>
<td>232</td>
<td>0</td>
</tr>
<tr>
<td>Medical items</td>
<td>47.2</td>
<td>0</td>
</tr>
<tr>
<td>Social services</td>
<td>9,585</td>
<td>1,011</td>
</tr>
<tr>
<td>Other a</td>
<td>114</td>
<td>0</td>
</tr>
<tr>
<td>Type of payer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>1,527</td>
<td>0</td>
</tr>
<tr>
<td>Medicaid</td>
<td>47</td>
<td>0</td>
</tr>
<tr>
<td>Private insurance</td>
<td>250</td>
<td>0</td>
</tr>
<tr>
<td>HMO</td>
<td>8.3</td>
<td>0</td>
</tr>
<tr>
<td>Self-pay</td>
<td>7,864</td>
<td>640</td>
</tr>
<tr>
<td>Other b</td>
<td>2,802</td>
<td>40</td>
</tr>
</tbody>
</table>

Note: HMO is health maintenance organization.
a Includes items such as physical modifications to home and transportation to specialized diagnostic centers.
b Includes service funding provided by the Department of Veterans Affairs; private foundations; and state, city, and county governments.

For community-based patients, private payments are considerably higher than public payments—65 percent (mainly self-pay) compared with 35 percent (mainly sources other than Medicare and Medicaid, such as Department of Veterans Affairs and services funded by the city, county, or state). The distribution of formal care costs by funding source for the institutionalized sample shows that private payments account for the largest share (64 percent), with the greatest proportion representing out-of-pocket payments. Medicaid paid 31 percent of the total formal cost, mainly for nursing home care. The preponderance of zeroes for both the 25 percent and 75 percent quartiles indicates that the distribution of data by payer source is highly skewed. That is, most payers reimbursed only a small number of patients for services used because of Alzheimer’s disease.

**Informal care.** Caregivers of community-resident patients provided eight times more care hours than caregivers of institutionalized patients—286 hours compared with thirty-six hours per month (Exhibit 2). Thus, caregivers in the community spent: on average almost ten hours per day (including weekends) in a variety of caregiving activities, compared with almost ten hours per week for caregivers of institutionalized patients. Primary caregivers of patients residing in the community spent an average of
249 hours per month providing care related to Alzheimer’s disease, compared with twenty-nine hours per month for patients residing in institutions. The average time spent by secondary caregivers was much less, with an average of thirty-seven hours per month caring for a patient residing in the community, and seven hours per month for an institutionalized patient. Caregiving services vary significantly by the patient’s residence. Almost one-third of the caregiving hours for community-resident patients were spent in behavioral management activities, while only 2 percent were spent thus by caregivers of institutionalized patients. On the other hand, 44 percent of the hours spent by caregivers of patients in institutions were for social/recreational services, compared with 13 percent of the caregiving hours for noninstitutionalized patients. More than half of the hours provided by both groups of caregivers was for assistance in ADLs and IADLs. Multiplying the average hours spent by caregivers in each task category by the hourly rates discussed earlier and including the estimate for volunteer services yields an average annual cost of informal care of $34,517 for patients residing in the community and $5,542 for patients in institutions (Exhibit 3).

Total costs per person in northern California. When formal and informal care costs are combined, annual costs of caring for a person with
### Exhibit 3
Annual Average Per Person Costs Of Care For Persons With Alzheimer’s Disease, By Type Of Cost, Location Of Residence, And Severity, Northern California, 1990

<table>
<thead>
<tr>
<th>Location of residence</th>
<th>Total</th>
<th>Formal costs</th>
<th>Informal costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community (N=93)</td>
<td>$47,083</td>
<td>$12,572</td>
<td>$34,517</td>
</tr>
<tr>
<td>Severely demented (n=51)</td>
<td>52,667</td>
<td>16,278</td>
<td>36,389</td>
</tr>
<tr>
<td>Mildly to moderately demented (n=42)</td>
<td>39,558</td>
<td>7,621</td>
<td>31,937</td>
</tr>
<tr>
<td>Institution (N=94)</td>
<td>47,591</td>
<td>42,049</td>
<td>5,542</td>
</tr>
<tr>
<td>Severely demented (n=89)</td>
<td>48,205</td>
<td>42,477</td>
<td>5,728</td>
</tr>
<tr>
<td>Mildly to moderately demented (n=5)</td>
<td>37,729</td>
<td>34,828</td>
<td>2,901</td>
</tr>
</tbody>
</table>


the disease in the two settings are not significantly different for the northern California sample—$47,083 for Alzheimer’s disease patients in the community and $47,591 for institutionalized patients. However, the distribution of costs for formal and informal care for the two groups is quite different. For institutionalized patients, informal services comprise 12 percent of the total costs of care; 88 percent is attributable to formal services. Conversely, for patients residing in the community, 73 percent of the total cost of care is for informal assistance, while 27 percent is for formal services.

To make a valid comparison of the cost of care in the two settings, one must control for severity of cognitive impairment. However, the small sample size for mild to moderately demented persons in institutions precludes rigorous statistical comparison. For the severely demented, the total cost of care for people in the community is $52,667—9 percent higher than for institutionalized patients. Formal care costs are two times higher for severely demented patients in nursing homes than in the community, but informal costs are over six times higher for those in the community. The distribution by severity of formal and informal costs differs for institutional and noninstitutional patients: 88 percent of the total cost of institutional care for the severely demented is for formal services, compared with only 31 percent for persons residing in the community.

### Study Strengths And Limitations

The strength of this study is that it represents the largest sample of people with Alzheimer’s disease studied for cost implications and extends previous research on the cost of Alzheimer’s disease. Lien-fu Huang, William Carewright, and Teh-wei Hu estimated both the direct social and medical care costs and the indirect informal care costs of senile dementia in general, not Alzheimer’s disease alone. Their estimates were based on secondary data and included costs associated with lost productivity and premature death that are not included in our study. Their study did not closely track
over an extended period the activities of informal caregivers to measure those actually performed for people with the disease. Nor did it track the provision of informal care and associated costs for demented persons admitted to institutions. This is important because caregivers continue to provide informal care up to and including the period after placement.\textsuperscript{16}

Joel Hay and Richard Ernst examined the costs of caring for persons specifically with Alzheimer’s disease using secondary data sources and including costs associated with medical care, lost productivity, and informal care.\textsuperscript{17} Their one-year per person cost estimate (including only costs equivalent to our formal care cost) was $8,196. Inflated to 1990 dollars, this equals $16,264. Our comparable California per person cost for a patient in any setting is $9,194. Hay and Ernst included only patients who were demented severely enough to have gone through a formal diagnostic workup, whereas our study includes participants in the community identified earlier in the course of the disease, resulting in lower costs. In northern California patients are likely to be diagnosed earlier because of the availability of state-funded Alzheimer’s Disease Diagnostic and Treatment Centers. Our sample thus includes patients with lower annual costs, given that severity of dementia is an important determinant of cost. The Hay and Ernst total costs are lifetime costs and are not directly comparable with ours.

The limitations of our research are that the study population is not a random sample of Alzheimer’s disease patients and their caregivers and that it covers only one geographic area. Prevalence and costs of Alzheimer’s disease undoubtedly vary across the country. Thus, our cost findings are not easily generalized. Nevertheless, our study design and data collection efforts are meticulously careful and comprehensive. The study presents the best estimates to date of the formal and informal costs of caring for Alzheimer’s disease patients. There remains a need for more research in this area. It is hoped that this study will stimulate other researchers to undertake similar studies in other regions. This will help us to understand whether significant regional differences in the cost of caring for Alzheimer’s patients exist and will enable the estimation of nationwide costs. Further research should also focus on determinants of service use by Alzheimer’s patients in the community and in institutions, particularly as influenced by severity of the disease.

\underline{Conclusions And Policy Implications}

Informal care costs are almost three times the cost of formal care for persons with Alzheimer’s disease in the community. Although these costs represent an imputed value rather than a dollar expenditure, if unpaid caregivers were not available, caregiving services would probably be purchased from paid providers, or else demented persons now cared for in the
community would be placed in institutions. The changing nature of family composition and the increasing labor-force participation of women will result in fewer available caregivers for elderly persons in the future. Therefore, more of these imputed costs may become actual expenditures.

More than three-fourths of formal costs of care for people with Alzheimer’s disease in the community are for social services, including home care. A current policy issue is whether publicly paid home care and social support services for the chronically ill, including Alzheimer’s disease patients, should be expanded to enable elderly ill and disabled persons to remain in the community and to be less burdensome to relatives. Although employed families may use the dependent care tax credit to subtract a portion of elder care expenses from their federal taxes, most low-income families are not reimbursed for these expenses, and few families can use the credit because of eligibility restrictions. Paid help is more prevalent among elderly people with adequate resources and with access to entitlements.

Another policy question is whether relatives and friends would reduce the amount of informal care they provide if a disabled dependent person received paid in-home care. Various studies have shown that the amount of informal home care received is not significantly affected by the level of formal care and that an increase in paid home care does not erode informal support.

An important issue related to the care of persons with Alzheimer’s disease is general underuse of available formal services. This phenomenon points to two concerns surrounding the care of demented persons. The first is whether low service usage rates are due to the lack of appropriate reimbursement mechanisms to assist in paying for formal services. The second is whether service delivery mechanisms are adequate to meet the needs of caregivers of persons with Alzheimer’s disease. Both of these questions are currently being addressed by the Health Care Financing Administration’s Medicare Alzheimer’s Disease Demonstration. The demonstration provides both a reimbursement mechanism (that is, a monthly dollar cap per enrollee for the purchase of community-based services) and a service delivery mechanism (case management) to address these issues, which are thought to be barriers to formal service use. The findings of the demonstration will provide valuable insight into the effects of service delivery and reimbursement models that attempt to reduce barriers to the appropriate use of formal services to augment informal care.

The availability of services to assist families in their caregiving role is vitally important. Family assistance programs should include home, personal, and respite care as well as nursing home care. Long-term care coverage has emerged as a key issue facing the growing number of elderly persons. The Pepper Commission recommended social insurance coverage for home
and community-based care, public long-term care benefits at home or in a
nursing home for assistance with ADLs, and personal care, homemaker/chore services, shopping and other support services, day care, respite
services, and training for family caregivers.  

With projected increases in the number of persons at risk of developing
Alzheimer’s disease, its economic impact on future long-term care costs will
be substantial. Since a higher proportion of the costs for institutional care
is borne by the federal and state governments than for community care, the
costs to the public sector will be high. Medicaid, currently the largest public
payer for institutional long-term care, will be especially affected. Informal
and formal care costs paid out of pocket will also rise, eclipsing by a
substantial margin the costs borne by the public sector. The public sector
currently is financing only a small proportion of the care of Alzheimer’s
disease patients—12.5 percent of the care provided to community-based
patients and 34 percent to institutionalized patients. The roles and respon-
sibilities of the public and private sectors in caring for Alzheimer’s disease
patients need to be carefully reassessed and must account for changes in the
availability of potential informal caregivers.  

Decisions about the appropriate roles and responsibilities of the public
and private sectors in the provision of care for persons afflicted with
Alzheimer’s disease can only be made considering moral, ethical, value, and
political concerns that help to frame the debate about the allocation of
health care resources. It is clear, however, that the preponderance of care
for persons with Alzheimer’s disease is currently provided and paid by
private sources, usually the patient’s family. In addition, as the baby-boom
generation ages, the cost of caring for people with the disease will increase
dramatically for no other reason than the growth in the number of people
at risk of developing the disease.

The high costs of providing care for persons with Alzheimer’s disease
highlight the importance of assessing the effectiveness and appropriateness
of services targeted for persons with dementia. As specialized dementia
services proliferate, the distribution of formal and informal costs may shift
over time. The substantial cost to families providing informal care also have
direct impact on the financial viability of caregivers and may reduce the
ability of the families to care for their family members at home. Placement
of patients in nursing homes will increase demands on the public sector.

If medical interventions are discovered that slow the progression of
Alzheimer’s disease or cure it altogether, future public and private costs of
caring for people with the disease may be reduced. Current knowledge does
not indicate that therapeutic pharmacological, genetic, or other interven-
tions to substantially reduce or eliminate illness and death caused by the
disease are likely to be developed in the immediate future. In the meantime,
the public, private, personal, and social costs of Alzheimer’s disease will continue to escalate.

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NOTES

9. The monthly data collection instrument was tested for interrater reliability at baseline. We validated the formal cost data by obtaining bills from service providers and comparing these with caregiver-reported cost data.

11. For a detailed methodological description of both formal and informal cost-of-care estimation, write to the authors at the Institute for Health and Aging, School of Nursing, University of California, San Francisco, San Francisco, California 94143-0612.

12. The level of cognitive impairment was determined through clinical judgments of neuropsychology consultants from Alzheimer’s Disease Diagnostic and Treatment Centers in the State of California utilizing a cutoff score of 12 or lower on the MMSE as an indicator of severe cognitive impairment. Functional status was measured using the Katz nine-item ADL scale. The patient was considered dependent in an ADL if he or she received a score greater than 1 (1 is defined as “independent”).


14. Standard deviations are not reported because the large number of zero values makes them meaningless and because correlated data complicate their estimation.


