People with Alzheimer’s disease living in a defined community in New York City were identified and assessed on two occasions to determine the number of hours of activities of daily living (ADL) care they received. Nearly half received all care hours from informal sources; however, a quarter received all ADL care hours from formal sources. The mean number of daily ADL hours in the sample was 9.7, of which 4.2 came from formal sources. This reflects the extensive use of Medicaid-based home care services in New York City. As dementia worsened, substitution of formal for informal care was rare, but formal care assumed a greater proportion of total care hours.

Key Words: Alzheimer’s disease, Caregiving, Indirect costs, Dementia, Community study

Hourly Care Received by People With Alzheimer’s Disease: Results From an Urban, Community Survey

Steven M. Albert, PhD, MSc, Mary Sano, PhD, Karen Bell, MD, Carol Merchant, MD, Scott Small, MD, and Yaakov Stern, PhD

Care for people with Alzheimer’s disease (AD) is particularly demanding because the severely affected patient requires help with virtually all basic functions as well as nearly constant supervision. Although estimates of hourly care received by people with AD are now available (Coughlin & Liu, 1989; Ernst & Hay, 1994; Ernst, Hay, Fenn, Tinklenberg, & Yesavage, 1997; Hu, Huang, & Cartwright, 1986; Huang, Cartwright, & Hu, 1985; Østbye & Crosse, 1994; Rice et al., 1993; Souêtre et al., 1995; Stommel, Collins, & Given, 1994; Weinberger et al., 1993), these have been based, for the most part, on clinic or tertiary care referral series and have mainly involved cross-sectional samples. Much less frequent are analyses using longitudinal panels (Tennstedt, Crawford, & McKinlay, 1993).

We had an opportunity to estimate hours of care received by people with AD as part of a New York City survey, in which respondents were also assessed on multiple occasions. This sample and longitudinal design offer several advantages over available clinic-based, cross-sectional samples. The most important advantage is representation of the full range of Alzheimer’s patients, including both the mildly affected elder who may not yet have come to medical attention for AD, as well as more severely affected elders still residing in the community.

The New York City sample is also valuable for presenting care patterns in AD for minority elders. Our sample is drawn from the Washington Heights-Inwood section of Manhattan, a well-defined neighborhood divided roughly evenly between non-Hispanic Whites, non-Hispanic Blacks, and Hispanics. Clinic and referral series typically underrepresent minority elders. Minority elders are less likely to be placed in nursing homes and may differ in other patterns of dementia care as well, including sources of care and perceived burden among informal caregivers (Aranda & Knight, 1997; Connell & Gibson, 1997).

Finally, the focus on a New York City community is valuable for offering information on the ways AD care (and costs) may vary with regional differences in the types and supplies of caregiving services (Ernst et al., 1997). To our knowledge, this study is the first to examine hours of care among people with AD in New York City, an area that is considered “service-rich” in comparison to most other areas of the country (Hokenstad, Ramirez, Haslager, & Finneran, 1997).

The goal of this research, then, was to derive estimates of hourly care, disaggregated by type of provider (informal family and friend care as opposed to formal, paid care provided by paraprofessionals), along with correlates of care hours received by people with Alzheimer’s disease. Because all respondents had complete neuropsychological and medical assessments, we were able to establish both the severity of dementia and the general medical status of people with AD. We were thus able to examine the extent to which dementia severity as well as the presence of other comorbidities predict caregiving hours received by people with AD.
The longitudinal data are particularly valuable for examining shifts in the source of care as dementia severity increases. Are families likely to make greater use of formal care as a patient's cognitive status declines? Do these formal hours "replace" or "substitute" for informal hours families might otherwise provide? Substitution of formal for informal care has been demonstrated in cross-sectional analyses (Greene, 1983), but studies using longitudinal designs have found that such service substitution occurs for only a minority of elders (Tennstedt et al., 1993). We have been unable to identify studies that have examined these issues specifically in an Alzheimer's cohort.

In short, we undertook this study to determine (1) reported hours of formal and informal care for AD patients ascertained in a community-based, largely minority sample; (2) the extent to which dementia severity predicts receipt of care hours in this sample; and (3) how care hours change, both in source and intensity, as patients show increasing dementia severity over time. These data also allow comparison of care hour estimates obtained in a community survey to those obtained for clinical samples, as well as a comparison of patterns of care for people with AD in a well-serviced area such as New York City relative to such patterns in less well-serviced areas.

Sample

People with AD were identified from the Washington Heights–Inwood Community Aging Project (WHICAP), a sample of Medicare enrollees aged 65 and older living in northern Manhattan (Gurland et al., 1995; Gurland et al., 1997). Sampling strata for this survey included age (65–74, 75–84, 85+), gender, and race-ethnicity (Hispanic, non-Hispanic Black, non-Hispanic White). Systematic replicate subsamples were drawn using random starts, such that each subsample contained age and racial-ethnic groups of equal size. Subjects all resided in the two northermost communities of Manhattan, the area north of Harlem bounded by the Hudson and Harlem rivers. Of 4,865 Medicare beneficiaries living in the area and identified for the survey, 2,128 were enrolled in 1992 (of the original 4,865, 470 had died, 896 lived outside the area, 47 were ineligible for other reasons, and 1,324 refused to participate). The response rate (62% of those alive, eligible, and living in the area) should be considered in light of the difficulty of conducting research in a multiethnic, low-income area of New York City. Participation in the survey did not differ by ethnicity.

Follow-up of the cohort yielded interviews with 1,416 elders in 1994 and 1,088 elders in 1996. Eliminating elders who moved (n = 66) or died (n = 209) by the time of the first follow-up yields a retention rate of 76%; eliminating those who moved (n = 22) or died (n = 78) by the time of the second follow-up yields a retention rate of 62%.

A caregiver interview for respondents with AD was added to the WHICAP protocol at the follow-up interviews. At the first follow-up, 209 of the 1,416 elders met criteria for dementia. Thus, the prevalence of dementia in the sample at the first follow-up was 14.8% (209/1416). Eleven of these elders were in nursing homes at this follow-up interview and were accordingly excluded from the care hour interview. At the second follow-up, an additional 42 elders met criteria for AD, none of whom were in nursing homes, yielding an incidence of 3.5% [42/(1416 – 209)] in the period between the first and second follow-up. The total sample available for cross-sectional analyses, then, was 240 (209 minus 11 in nursing homes, plus 42 incident cases). The source of these cases is shown in Figure 1.

As shown in Figure 1, nine of the 240 people with Alzheimer's disease sample.
AD died before their caregiver interview could be completed. Of the remaining 231 people with AD, caregiver interviews were completed for 166, a response rate of 72%. These 166 people and their caregivers constitute the cross-sectional sample for this research.

Between the first and second follow-up, 12 people died and one was admitted to a nursing home, leaving 153 elders eligible for the second follow-up caregiver interview. We successfully interviewed 113 of these people, a response rate of 74%. These 113 make up the longitudinal sample in the following analyses.

Because caregiver interviewers were not obtained for about a quarter of the elders with AD, we compared elders with caregiver interviews to those without in both the cross-sectional and longitudinal samples. Elders in the two groups did not differ in sociodemographic features, severity of dementia, or prevalence of comorbid conditions (results available upon request).

Caregivers to these elders were interviewed by telephone, or, for a small number of cases, in person. Caregivers were nominated by the respondent, identified during study medical assessments, or identified through telephone contact as the “primary helper,” that is, the person providing more than 50% of the care the elder received. Primary caregivers could be paid paraprofessionals or family-friend caregivers.

Measures

AD Status and Severity Indicators

All respondents were assessed by a neurologist and received a standardized battery of neuropsychological tests (Stern et al., 1992). This information was reviewed in a consensus conference of study neurologists and neuropsychologists to determine if respondents met NINCDS–ADRDA and DSM–III criteria for AD (McKhann, Drachman, Folstein, & NINCDS–ADRDA Work Group, 1984; American Psychiatric Association, 1987). Diagnosis according to these criteria requires that subjects show deficits in memory and other cognitive domains severe enough to interfere with daily occupational or social function, as well as exclusion of other potential sources of cognitive deficit. We adopted a fairly restrictive approach to AD diagnosis. Subjects were excluded from the AD sample if they met criteria at one assessment but did not meet criteria for AD or “questionable dementia” at subsequent assessments. We also excluded subjects who met criteria for AD but were later discovered to have non-AD etiologies for their condition.

To assess severity of AD, neurologists completed the Clinical Dementia Rating (CDR) scale, a composite measure of functional, cognitive, and social impairment (Hughes, Berg, Danziger, Cohen, & Martin, 1982). The scale yields severity estimates summarized as questionable, mild, moderate, severe, profound, or terminal. Because so few community respondents were considered to have profound or terminal disease (3%), these subjects were combined with the severe disease group.

Psychiatric status among AD patients was established with the Columbia University Scale for Psychopathology in AD (CUSPARD; Devanand et al., 1992). With the CUSPARD, informants report on the presence of psychopathologic symptoms typical of AD, including illusions, delusions, and hallucinations. Elders were scored as having any or no psychopathology.

Although all elders met research criteria for AD, we anticipated that many, especially those with mild dementia, would not be diagnosed with AD by primary care physicians. Undiagnosed or “silent” dementia is prevalent among community-dwelling elders (Ross et al., 1997). For this reason, the word “dementia” was never mentioned in the survey, and “Alzheimer’s disease” appeared in the interview only in a single instance, when informants were asked if a physician had ever diagnosed AD, along with other conditions, in the elder.

Information regarding medical comorbidities was also obtained by neurologists, who conducted a brief medical exam, inspected medications, and obtained medical histories. The presence of nine medical conditions was ascertained, including myocardial infarction, congestive heart failure, peripheral vascular disease, cerebrovascular disease, chronic obstructive pulmonary disease, liver disease, diabetes, renal disease, and neoplastic disease. A modified comorbidity index was constructed following Charlson’s recommendations (Charlson, Pompei, Ales, & MacKenzie, 1987).

Outcome: Daily Caregiving Hours

We approached elicitation of caregiving hours in a two-stage procedure. First, caregivers were asked how many hours in a day they spend with an elder, leaving caregiving tasks unspecified. They were next asked to estimate how many hours of this total time with an elder were spent providing help with activities of daily living (ADL), phrased as “help with basic tasks, such as eating, dressing, moving around the apartment, or personal care, including bathing, using the toilet, or brushing hair.” This two-step procedure, it was reasoned, would help caregivers distinguish hands-on, ADL hours from total time spent with an elder. Informants also reported “help hours” for any other regular caregivers. Each hour estimate was coded according to its source as either informal (unpaid family or friends) or formal (paid paraprofessional, such as home health attendant, housekeeper, or homemaker). These were summed to calculate total caregiving hours.

In 21.5% of the caregivers (virtually all of whom were family caregivers), respondents provided only total hours with the elder. These caregivers did not feel they could distinguish how many of their hours with the elder were actual ADL care hours. In such cases we imputed the informant’s care hours based on the mean proportion of total hours described as care hours for the sample as a whole. The mean proportion was .55, meaning that about half of the time spent with elders, on average, was considered time providing direct care. Also, 10% of the informal caregivers reported 24 hours per day of care. For these caregivers, we followed Ernst and recoded these values to 16 hours per day (Ernst et al., 1997). However, regression analyses
were conducted with both values and yielded similar results.

Information on formal, paid caregiving hours was also obtained in a separate interview during the medical assessment component of the survey, which took place, on average, 8 to 12 weeks earlier. These data were used to establish the reliability of informants' estimates of this component of total care hours.

Analyses

Reliability of hour estimates was established by correlating estimates obtained in the telephone informant interview with estimates obtained at the time of the elder's previous in-person medical assessment.

Cross-Sectional Analyses.—Mean weekly hour estimates of care, disaggregated by provider type, were calculated according to AD severity. Analysis of variance (ANOVA) was used to examine the relation between disease severity and sources of care hours. Multivariate OLS regression models were developed to assess the independent predictive significance of severity and comorbidity indicators for total hours of care, formal care hours, and informal care hours in models that adjusted for sociodemographic differences among elders (age, gender, years of education, Medicaid eligibility) and features of caregivers (relationship to elder, whether they shared homes with an elder, and whether they considered themselves primary caregivers).

Because informal and formal hours were simultaneously determined, we examined substitution in the cross-sectional analyses using a two-stage least-squares regression strategy (Boaz, 1996). For the first stage of the informal hours equation, informal care hours were regressed on the set of exogenous variables described previously. In the second stage, formal care hours were regressed on predicted informal care hours (derived from the first equation) and other covariates from the first stage, leaving out a variable without a direct effect on informal care hours to allow proper specification of the model (Rachel Boaz, personal communication). The procedure was repeated for formal care hours.

Longitudinal Analyses.—We examined change over time in the source and quantity of care hours in two ways. In one approach, we used a within-subjects, repeated measures ANOVA. The between-subjects factor in these analyses was a dichotomous variable indicating whether subjects' dementia severity had remained stable over the year or had increased. An increase in dementia severity was defined as a shift upward in Clinical Dementia Rating scale scores, i.e., from mild to moderate, moderate to severe, severe to profound. The within-subject factor was time. These analyses were repeated for informal hours, formal hours, and total hours. Covariates examined in this procedure included elder comorbidities as well as the caregiver and elder features previously described.

A second approach examined substitution directly and adapted the approach of Tennstedt and colleagues (Tennstedt et al., 1993). In their approach, substitution of formal for informal care requires (1) an increase of formal hours over two time points, with (2) a decline in informal hours over the same two points. We calculated the proportion of cases meeting this criterion but also examined other outcomes that indicate changes in the distribution of care. These include a decline in informal hours with no change in formal hours (a decline in care hours without true substitution), an increase in formal hours without change in informal hours (an increase in care hours without true substitution), and other combinations as well.

Results

The mean age of elders in the sample was 82.4, and 77% were women. Elders had completed a mean of 5.9 years of school. The majority of elders were Hispanic (57.7%) or African American (36.9%); only 5.1% were White, in keeping with White elders' lower likelihood of receiving a dementia diagnosis (Tang et al., 1998). The median yearly household income for the sample was $6,000, reflecting the low-income status of elders in this area of New York City. Nearly two thirds (62.7%) of the elders were receiving Medicaid coverage.

The majority of elders in the sample (70.5%) were mildly demented (CDR scale score of 1), 14.7% were moderately demented (CDR = 2), and 14.7% were severely demented (CDR = 3; as noted previously this score included a small number [3%] with profound or terminal disease). Fifty-seven percent of the elders demonstrated psychopathology by CUSPAD ratings. The average duration of AD was 2.4 years, as based upon our prior contact with subjects. Only 25% of the informants reported that elders had received a diagnosis of AD from a primary care physician.

Comorbid conditions were common in this sample; 55.5% had at least one of the comorbid conditions in addition to AD, and 26.9% had two or more comorbidities.

Reliability of Hour Estimates

The Pearson correlation between care hours reported during the informant telephone interview and hours reported earlier during the physician examination was 0.78 (p < .0001). Overall, estimates for this component of caregiving hours appear to have been reliably elicited.

Hours of Care and Care Arrangements: Cross-Sectional Findings

Source of care for the 166 people with AD fell into four types: (1) a small number (1.8%) had formal or informal caregivers who reported no hours of hands-on ADL care; (2) nearly half the sample (47.6%) had informal sources of care only; (3) nearly a quarter of the sample (23.5%) had formal care only; and (4) more than a third (36.3%) had a combination of formal and informal caregivers providing ADL care. Informal caregivers included spouses (24.8%), adult children (51.4%),
other family (17.1%), and friends and other nonrelatives (6.7%).

Table 1 summarizes a number of important features of these caregiving arrangements, excluding the small group whose caregivers reported no hands-on ADL care hours. Features of the caregiving arrangement and the elders receiving such care are presented according to type of care (informal only \(n = 79\), formal only \(n = 39\), or combined informal and formal care \(n = 45\)). Also, for the combined informal and formal care group, we subdivided the sample according to whether informal \(n = 35\) or formal \(n = 10\) caregivers served as the source of care information.

Turning first to features of the elders who receive care, it is clear that elders with AD receiving care from informal caregivers alone had milder dementia and fewer comorbidities. Only 3.8% of the elders in this group had severe dementia, compared with 23.1% among those receiving care from formal caregivers alone or 18.2% among those receiving care from both formal and informal sources \((p < .01)\). Similarly, primary care physician diagnoses of AD among elders was lowest in the group receiving care from informal caregivers alone (14.8%) and higher in the other two groups (37.5% and 32%, respectively, \(p < .01\)). Only 19.7% of elders in the informal care group had two or more comorbidities, compared to 35.7% and 45.7%, respectively, in the other two care arrangements \((p < .01)\). Elders in the three groups did not differ in the proportion who showed psychiatric symptoms.

Elders in the three groups were also quite similar in sociodemographic indicators, with no significant differences in age, proportion of women, or years of education. However, Medicaid eligibility did differ between the groups: 63.1% of elders in the informal care only group had Medicaid coverage, compared with 90% and 85%, respectively, in the groups receiving formal care \((p < .01)\).

The mean number of caregiving hours per day was 7.2 in the informal care only group, 9.8 in the formal care only group, and 14.6 in the formal-informal combined group (7.4 from informal sources, 7.2 from formal sources). On the whole, formal caregivers did not consider themselves the “primary caregiver,” even when they were the only source of such care. Only 8.3% considered themselves primary caregivers, suggesting family involvement and a directive role for informal caregivers even when they do not provide ADL care (as in the case of an elder with 24-hour paraprofessional care). Few formal caregivers reported that they shared homes with elders, but the meaning of the question may be unclear in the case of a home health care attendant who provides 24-hour care for 3 or 4 days each week. Finally, the table reveals some specialization of services, or division of labor, between informal and formal caregivers in the combined group. Formal caregivers were less likely to perform night and early morning care but more likely to take elders to their doctors. This likely reflects use of formal caregivers during work hours, allowing family caregivers to work.

Figure 2 displays hours of care by dementia severity for the cross-sectional sample. Total hours per day were 8.2 among elders with questionable AD (who, it

<table>
<thead>
<tr>
<th>Caregiver</th>
<th>Informal (n = 79)</th>
<th>Formal (n = 39)</th>
<th>Informal (n = 35)</th>
<th>Formal (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coreside (%)</td>
<td>68.0</td>
<td>8.3</td>
<td>63.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Primary Caregiver (%)</td>
<td>69.0</td>
<td>8.3</td>
<td>60.6</td>
<td>0.0</td>
</tr>
<tr>
<td>Take Elder to MD (%)</td>
<td>80.0</td>
<td>85.7</td>
<td>57.6</td>
<td>70.0</td>
</tr>
<tr>
<td>Morning Care (%)</td>
<td>70.8</td>
<td>54.3</td>
<td>66.7</td>
<td>30.0</td>
</tr>
<tr>
<td>Check at Night (%)</td>
<td>65.7</td>
<td>22.2</td>
<td>65.6</td>
<td>10.0</td>
</tr>
<tr>
<td>ADL Hours Per Day (μ)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informal</td>
<td>7.2 (±5.3)</td>
<td>—</td>
<td>7.4 (±5.0)</td>
<td></td>
</tr>
<tr>
<td>Formal</td>
<td>9.8 (±8.1)</td>
<td>7.2 (±5.3)</td>
<td>14.6 (±6.3)</td>
<td></td>
</tr>
<tr>
<td>Total**</td>
<td>7.2 (±5.3)</td>
<td>9.8 (±8.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elder</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (μ)</td>
<td>80.0 (±6.8)</td>
<td>81.1 (±6.9)</td>
<td>8.13 (±7.0)</td>
<td></td>
</tr>
<tr>
<td>Female (%)</td>
<td>89.7</td>
<td>74.7</td>
<td>76.0</td>
<td></td>
</tr>
<tr>
<td>Education (μ, year)</td>
<td>5.2 (±4.1)</td>
<td>6.8 (±4.3)</td>
<td>5.9 (±4.1)</td>
<td></td>
</tr>
<tr>
<td>Medicaid (%)**</td>
<td>63.1</td>
<td>90.0</td>
<td>85.0</td>
<td></td>
</tr>
<tr>
<td>Severe Dementia (%)**</td>
<td>3.8</td>
<td>23.1</td>
<td>18.2</td>
<td></td>
</tr>
<tr>
<td>AD Dx (%)**</td>
<td>14.8</td>
<td>37.5</td>
<td>32.0</td>
<td></td>
</tr>
<tr>
<td>Psych Sx (%)</td>
<td>51.4</td>
<td>58.3</td>
<td>60.0</td>
<td></td>
</tr>
<tr>
<td>2+ Comorbidities (%)**</td>
<td>19.7</td>
<td>35.7</td>
<td>45.7</td>
<td></td>
</tr>
</tbody>
</table>

Note: Excludes three elders with AD who had caregivers who reported no hands-on care hours. Significance tests conducted for comparison of elder features and total ADL hours per day \(χ^2\) and one-way ANOVA. **\(p < .01\).
should be noted, had an AD diagnosis at a prior visit), 8.3 among elders with mild dementia, 11.3 among elders with moderate dementia, and 15.9 among elders with severe or greater dementia severity (p < .001 by one-way ANOVA). The figure also shows the distribution of formal and informal care hours by dementia severity. In cross-sectional analyses, informal care hours did not increase linearly with disease severity; the correlation is nonsignificant (r = .08), a finding reported by others as well (Ernst et al., 1997). Formal hours, by contrast, were significantly correlated with disease severity (r = .30, p < .001).

In multiple regression models using the cross-sectional sample, total care hours were significantly associated with dementia severity (p < .01; an additional 2.4 hours per day for each grade of dementia severity) and number of comorbidities (p < .05, an additional 1.5 hours per day for each point on the modified Charlson index), independently of elder sociodemographic indicators. Addition of other dementia indicators, including presence of psychiatric symptoms and reports of a primary care physician diagnosis of AD, did not improve the fit of the model and showed that neither was independently associated with total care hours in models that included dementia severity and comorbidity status. These findings are summarized in Table 2. We repeated the analyses using a square root transformation for the total care hour measure to reduce skewness in the distribution. Results were unchanged.

Examining the two sources of care hours separately showed that each had different correlates. The number of formal hours was significantly related to dementia severity (p < .01), comorbidity status (p < .001), and Medicaid eligibility (p < .05). The number of informal hours was related to whether caregivers shared a home (p < .001) and elder gender (p < .01). Men received more hours of informal care, reflecting the greater likelihood of men receiving ADL care hours from spouses.

To examine formal and informal hours jointly, we used the two-stage least-squares model described previously. Despite a significant inverse zero-order correlation between formal and informal hours (r = -.30, p < .001), the two-stage analysis showed that
Table 3. Change in Caregiving Arrangements for People with AD, New York City, Over One Year

<table>
<thead>
<tr>
<th>Change in Informal Hours</th>
<th>Change in Formal Hours</th>
<th>% (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase</td>
<td>Increase</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Stable</td>
<td>5.3 (6)</td>
</tr>
<tr>
<td></td>
<td>Decrease</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Stable</td>
<td>Increase</td>
<td>7.1 (8)</td>
</tr>
<tr>
<td></td>
<td>Stable</td>
<td>77.0 (87)</td>
</tr>
<tr>
<td></td>
<td>Decrease</td>
<td>&lt;1 (1)</td>
</tr>
<tr>
<td>Decrease</td>
<td>Increase</td>
<td>1.8 (2)</td>
</tr>
<tr>
<td></td>
<td>Stable</td>
<td>8.0 (9)</td>
</tr>
<tr>
<td></td>
<td>Decrease</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Note: Percentages may not total 100 because of rounding.

Stability in caregiver arrangement was the most common outcome, with an identical number of formal and informal hours in 77% of the cases. Substitution of formal for informal hours, following Tennstedt’s definition (Tennstedt et al., 1993), occurred in just two of the 113 cases (<2%). More common were cases of an absolute increase in hours (increase in informal hours/stable formal hours, 5.3%; stable informal hours/increase in formal hours, 7.1%) or absolute decrease in hours (decline in informal hours/stable formal hours, 8%; stable informal hours/decline in formal hours, <1%).

Figures 3 and 4 show changes in daily hands-on care hours over the one-year period, by initial severity of dementia. Figure 3 shows that the number of total care hours increased with follow-up for all dementia severity groups. In a repeated measures ANOVA, both time (p < .01) and dementia severity (p < .02) were significant; the interaction between the two, however, was not, indicating that increases in care hours were not significantly different across severity groups. Care hours increased, on average, about 1 hour per day in the group of initially mildly demented elders, 3 hours per day in the moderately demented, and 1.5 hours per day in the severely demented. Controlling for differences in initial elder comorbidity status did not alter these results.

Figure 4 examines changes in informal and formal hours over the follow-up period, dividing the sample into a group whose dementia status was unchanged over the year and a group that declined, as indicated by worsening scores on the Clinical Dementia Rating scale. Worsening CDR scores were evident in 28% of the elders. Among elders whose dementia status did not change over the year, informal and formal care hours were relatively constant. However, among elders whose dementia status worsened, Figure 4 shows

![Figure 3: Longitudinal follow-up of AD cohort: Daily care hours by dementia severity. Note: n = 113 with two assessments, p < .01 for time trend and p < .02 for severity in repeated measures ANOVA.](https://academic.oup.com/gerontologist/article-abstract/38/6/704/654301/10760465d001/18042019)
that the number of informal hours remained constant one year later, whereas formal hours increased markedly, from about 6 to 9 hours per day. Repeated measures ANOVA models showed that formal hours significantly increased over time ($p < .001$) and that the increase differed between stable and declining groups ($p < .01$ for group contrast, $p < .001$ for group by time interaction). Informal care hours, by contrast, did not change significantly with time or according to change in dementia severity.

Finally, the longitudinal sample excludes caregivers whose elders died in the follow-up period. These elders were receiving more care hours initially than elders who did not die in the follow-up period (12.7 hours vs 9.7 hours per day, $p < .05$).

**Discussion**

This research offers estimates of hourly care received by a sample of elders with AD in New York City (NYC). We stress that these elders were not ascertained in a medical setting. Rather, elders in the sample were screened and examined as part of a more general community survey. A clear advantage of the sample is the greater likelihood that elders with the full range of cognitive impairment are represented. Indeed, only a quarter of the sample had ever received a diagnosis of AD from their primary care physician. On the other hand, the response rate for the first wave of the survey was 62%, indicating that the sample may not be fully representative of the community.

We were sensitive to caregivers' tendencies to report all hours spent with an elder as hours of help, or simply to report 24 hours of care. In AD, supervisory or social hours might well be considered caregiving time (Kane, Saslow, & Bundage, 1991); however, it is also clear that much of the total time spent with an elder is not caregiving per se, but rather time spent on more general housekeeping tasks. Also, the number of hours of actual hands-on care is likely to be more useful as an outcome for assessing disease severity or the efficacy of interventions. For this reason, we asked caregivers to distinguish total time with an elder from time spent providing ADL care. More than three quarters of the caregivers were able to make this distinction. Given the high correlation between number of formal care hours reported in two separate assessments, reports of hourly care appear to have been reliably elicited.

We did not elicit hours of help with instrumental tasks (IADL). In pretesting, we determined that these tasks were even harder for caregivers to distinguish from supervisory care or general housekeeping tasks. Also, we were concerned that this elicitation would be confounded by variation in what caregivers actually do for elders. Unlike personal care, for which demented elders require more or less hours of help each day, IADL activities (such as using the telephone, handling money, or light housekeeping) may no longer be part of an elder's daily activities. Although we restricted this inquiry to ADL care hours, we recognize that a finer elicitation of IADL care hours is required if we are to fully understand the caregiving demands of AD.

We report hours of care received. This is an imperfect measure of the care hours someone with AD may require. The number of care hours someone receives depends not simply on disease severity, but on a variety of other factors, including access to informal
caregivers and the availability of formal services. It is impressive, then, to note that total and formal care hours were significantly related to dementia severity and number of comorbid conditions in this sample, clear indicators of elder need for care, whereas informal hours were not. Ernst and colleagues reported the same relationship in their clinic-based sample (Ernst et al., 1997). On the other hand, IADL help hours, if measured, might show such a relation to informal hours.

The NYC data show that the lack of association between informal care hours and dementia severity is largely due to increases in formal care as elders reach states of severe dementia, without a corresponding increase in informal care hours. Elders whose dementia status worsened were likely to receive, on average, three additional ADL hours over the follow-up period, without a change in the number of informal care hours they received. In only a very few cases (<2%) did formal care hours increase in the presence of a decline in informal hours. Thus, results for this AD cohort support the findings of Tennstedt and colleagues, who also report that such service substitution occurs in a only a minority of cases (Tennstedt et al., 1993). The cross-sectional results shown in Figure 2, then, are deceptive, insofar as they suggest substitution of services in the more severe stages of AD. In fact, the two-stage least squares model, which takes into account the simultaneity of the two outcomes, also did not support a substitution effect.

One may still ask why informal hours did not increase when elder dementia worsened and elders began to receive additional formal care hours. It may be that these families are already providing the maximum number of hours they can provide. Because formal hours increased significantly over the follow-up period only among elders with worsening dementia (Figure 4), these additional formal hours appear to have been properly targeted. It is also possible that caregiver IADL hours did increase when elder dementia worsened; this increase may not have been detected with our measure of informal care hours.

Noninstitutionalized elders with Alzheimer’s disease in northern Manhattan received a mean of 9.7 hours per day of hands-on care. We defined hands-on care as help with the activities of daily living (ADL), but it is likely that caregivers reported more generally on hours spent helping elders, which almost certainly include supervision of activities and management of problem behaviors. These activities are hard to separate from ADL care because even mildly impaired AD patients require supervision in ADL activity and because problem behaviors typically occur during ADL care (Kane, Saslow, & Brundage, 1991). Our estimate of total daily care hours should be compared with those reported for other samples, which are summarized in Table 4.

Variations in these estimates are due to a variety of factors, including differences in the severity of dementia in the AD samples, variation in definitions of care, exclusion in some samples of elders with non-AD comorbidities, and use of different sources of information. The NYC AD sample is, on the whole, older, more impoverished, and less healthy than the other

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<thead>
<tr>
<th>Table 4. Daily Care Hour Estimates in Alzheimer’s Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sample</td>
</tr>
<tr>
<td>--------</td>
</tr>
<tr>
<td>Tertiary Care</td>
</tr>
<tr>
<td>Channeling</td>
</tr>
<tr>
<td>Tertiary Care</td>
</tr>
<tr>
<td>Tertiary Care (ADL)</td>
</tr>
<tr>
<td>Tertiary Care</td>
</tr>
<tr>
<td>National Estimates:</td>
</tr>
<tr>
<td>USA</td>
</tr>
<tr>
<td>Canada</td>
</tr>
<tr>
<td>Tertiary Care</td>
</tr>
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<tr>
<td>Estimates: NYC</td>
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Note: NA = not available.

*Sample chosen evidently to exclude subjects with formal care.

*From Coughlin & Liu (1989), Table 3, excludes mild/no cognitive impairment group.

*From Weinberger et al. (1993), sum from Table 3 (Adult day care category interpreted as hrs/week).

*Estimate from Rice et al. (1993), Exhibit 1, “Social Services,” valued at $9 = 1 formal hour. Hour totals for ADL, ADL + IADL, and ADL + IADL + behavioral management provided.

*Estimate from incomplete information.

712 The Gerontologist
samples listed in Table 4. The NYC care hour estimate is closest to that of Ernst and Hay (1994), who estimate an average of 6.6 hours per day for the national population of Alzheimer's patients. Note, however, the different contributions of formal and informal care in NYC as compared to Ernst and Hay's national estimates. The NYC sample of AD patients received, on average, 5.5 hours per day from informal caregivers and 4.2 hours per day from formal providers. Ernst and Hay estimated an average daily contribution of 7.5 and 1.1 hours, respectively, for the two sources of care hours.

In fact, the proportion of formal care hours in AD care is higher for the NYC sample than for any of the other samples. Although nearly half (47.6%) of AD patients in the NYC sample were not receiving any hands-on care hours from formal providers, about a quarter (23.5%) received all ADL care hours from such providers. Moreover, the contribution of formal care to total care hours increased with increasing dementia severity, both in cross-sectional and longitudinal analyses. By the time these NYC elders reached a stage of severe dementia, a majority of their care hours, on average, came from formal providers.

This finding is consistent with the largely Medicaid status of the sample and its eligibility for New York City's Medicaid Home Care Services Program. Three quarters of the sample were receiving Medicaid services. As detailed in a recent evaluation, the Medicaid Home Care Services Program provides ADL support to 65,000 elders in NYC, of whom nearly a third have moderate to severe dementia and half have some degree of cognitive impairment (Hokenstad, Ramirez, Haslanger, & Finneran, 1997). More generally, statewide Health Care Financing Administration data show that New York has the highest percentage of Medicaid recipients (both total and in older age groups) and the highest expenditures for home care services (HCFA, 1997).

In summary, this research suggests a number of conclusions. First, cost estimates of AD must recognize the large regional variation in the availability of paraprofessional home care. The contribution of formal care to total AD care hours is likely to vary dramatically by region. Second, dementia severity and comorbid conditions remain the strongest predictors of hands-on care in AD; other features of AD, such as the presence of psychiatric symptoms, did not predict hourly care. Also, total care hours were not associated with features of the elder (age, gender, education, Medicaid status) in models that controlled for dementia severity and comorbid conditions. Finally, this research suggests that "substitution" of formal for informal care at late stages of AD is perhaps better understood as supplementation. By the time elders reach more severe stages of dementia, families may already be providing the maximum number of hours they can muster. Longitudinal results from this survey suggest that formal hour increases are, for the most part, properly targeted to elders with increasingly severe dementia and greater need. This last finding is reassuring from a policy perspective, for it suggests that the increased availability of formal services, provided through Medicaid-waiver programs, does not encourage inappropriate use or substitution of formal services for informal care.

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