

# Relation between severity of Alzheimer's disease and costs of caring



*Evidence*

*Études*

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## Abstract

**Background:** Data from the Canadian Study of Health and Aging (CSHA) were used to examine the relation between severity of Alzheimer's disease, as measured by the Mini-Mental State Examination (MMSE), and costs of caring.

**Methods:** The CSHA was a community-based survey of the prevalence of dementia, including subtypes such as Alzheimer's disease, among elderly Canadians. Survey subjects with a diagnosis of possible or probable Alzheimer's disease were grouped into disease severity levels of mild (MMSE score 21–26), mild to moderate (MMSE score 15–20), moderate (MMSE score 10–14) and severe (MMSE score below 10). Components of care available from the CSHA were use of nursing home care, use of medications, use of community support services by caregivers and unpaid caregiver time. Costs were calculated from a societal perspective and are expressed in 1996 Canadian dollars.

**Results:** The annual societal cost of care per patient increased significantly with severity of Alzheimer's disease. The cost per patient was estimated to be \$9451 for mild disease, \$16 054 for mild to moderate disease, \$25 724 for moderate disease and \$36 794 for severe disease. Institutionalization was the largest component of cost, accounting for as much as 84% of the cost for people with severe disease. For subjects living in the community, unpaid caregiver time and use of community services were the greatest components of cost and increased with disease severity.

**Interpretation:** The societal cost of care of Alzheimer's disease increases drastically with increasing disease severity. Institutionalization is responsible for the largest cost component.

## Résumé

**Contexte :** On a utilisé des données tirées de l'Étude sur la santé et le vieillissement (ESV) pour analyser le lien entre la gravité de la maladie d'Alzheimer, mesurée au moyen du mini-examen de l'état mental (MEEM), et les coûts des soins.

**Méthodes :** L'ESV était une étude communautaire sur la prévalence de la démence, y compris de sous-types comme la maladie d'Alzheimer, chez les personnes âgées au Canada. Les sujets chez lesquels on avait diagnostiqué une maladie d'Alzheimer possible ou probable ont été regroupés en fonction de la gravité de la maladie : légère (résultat MEEM de 21 à 26), légère à moyenne (résultat MEEM de 15 à 20), moyenne (résultat MEEM de 10 à 14) et avancée (résultat MEEM de moins de 10). Les éléments des soins disponibles à la suite de l'étude étaient l'utilisation des foyers de soins infirmiers, l'utilisation de médicaments, l'utilisation de services de soutien communautaires par les soignants et le temps non rémunéré des soignants. Les coûts ont été calculés dans une optique sociétale et sont exprimés en dollars canadiens de 1996.

**Résultats :** Le coût sociétal annuel des soins par patient augmente considérable-

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ment avec la gravité de la maladie d'Alzheimer. Le coût par patient a été estimé à 9451 \$ au stade léger, 16 054 \$ au stade léger à moyen, 25 724 \$ au stade moyen et 36 794 \$ au stade avancé. L'institutionnalisation a représenté l'élément le plus important du coût, atteignant jusqu'à 84 % du coût au stade avancé de la maladie. Dans le cas des sujets vivant dans la communauté, le temps non rémunéré des soignants et le recours aux services communautaires ont été les éléments du coût les plus importants, et ils augmentaient avec la gravité de la maladie.

**Interprétation :** Le coût sociétal des soins aux personnes atteintes de la maladie d'Alzheimer grimpe en flèche à proportion de la gravité du cas. L'institutionnalisation constitue le plus important élément des coûts.

According to the Canadian Study of Health and Aging (CSHA),<sup>1</sup> about 64% of the estimated 252 600 Canadians with dementia in 1991 had Alzheimer's disease. Given that the prevalence of Alzheimer's disease increases after age 65 and that the number of Canadians in this age group will more than double by the year 2031,<sup>2</sup> the number of Canadians with Alzheimer's disease will grow rapidly in the first few decades of the next century.

The components of care that contribute to the societal financial burden of Alzheimer's disease include nursing home care, physician services, other medical care, medications, and health and social services provided in the community, as well as resource costs for which no financial transfer occurs (primarily unpaid informal caregiver services provided by family, friends and volunteers).

A number of cost-of-illness studies for Alzheimer's disease have been performed in the US using epidemiological estimates of resource use<sup>3-7</sup> or results from small surveys of clinic populations.<sup>8,9</sup> Their annual costs of caring ranged from US\$17 000 to US\$48 000 per patient. In the United Kingdom Gray and Fenn<sup>10</sup> estimated the national economic burden of Alzheimer's disease and found that 66% of the cost to society was for care in residential facilities. In Canada Østbye and Crosse<sup>11</sup> found that the 1991 net annual societal cost of care for dementia was over \$3.9 billion and that the average annual cost per patient with dementia beyond the costs for normal elderly people was \$13 900. The most significant components were long-term institutional care and paid and unpaid care for assistance with activities of daily living in the community. The cost of diagnosis per patient has been calculated by Gauthier<sup>12</sup> to be US\$557, which includes the cost of laboratory tests and medical visits.

In addition, cost of care increases with disease progression. At the time of diagnosis, although there is some cognitive impairment and short-term memory loss, the care required is much less than that at later stages of Alzheimer's disease, when most patients require total support with basic self-care and may also exhibit difficult-to-manage behaviours. Hu and associates<sup>8</sup> found that pa-

tients with severe dementia required over twice as many hours of informal care as those with mild dementia. Ernst and colleagues<sup>13</sup> studied the relation between cognitive functioning, as assessed by the Mini-Mental State Examination (MMSE), and the cost of caring for Alzheimer patients attending a northern California geriatric clinic. They estimated the annual societal cost of care, including nursing home care, medical services, and paid and unpaid in-home care, to be US\$35 287 per patient, of which 57% was the cost of unpaid care. They found that the cost increased rapidly with deteriorating cognitive function, especially in patients with moderate to severe Alzheimer's disease living at home. They emphasized that their investigation used a small and highly selected patient population. A study of this kind ideally requires a large, geographically diverse sample of patients representative of the Alzheimer population.

In our study we use data from the CSHA to investigate the relation between the severity of Alzheimer's disease (as indicated by the MMSE score) and the cost of caring for a patient with this disease. This study will be useful to identify the possible impact on costs of new treatments that may relieve disease symptoms.

## Methods

### *Canadian Study of Health and Aging*

The CSHA was a joint initiative of a coordinating centre at the University of Ottawa and the Laboratory Centre for Disease Control, Health Canada, to estimate the prevalence of dementia and its subtypes, including Alzheimer's disease, in the elderly Canadian population. In addition, the study sought to determine risk factors for Alzheimer's disease and to describe the patterns of caring for people with dementia.<sup>1</sup> The survey was conducted between February 1991 and May 1992. A random selection of 9008 Canadians aged 65 years and over living in the community were interviewed and given a screening test for cognitive impairment using the Modified Mini-Mental State (3MS) Examination. Those screening positive for



impairment, and 1255 randomly selected people in long-term care institutions, were asked to undergo a clinical assessment to determine the presence of dementia and to provide a diagnosis. All people found to have dementia were included in a substudy of the patterns of caring for people with dementia. This included collection of data on the use of, and satisfaction with, community support programs used by caregivers over the previous year to help with the burden of care, and the amount of time caregivers spent providing direct care over the previous month for basic and instrumental activities of daily living and for supervision of the survey subject.

### **Present study sample**

The CSHA survey data were obtained from the CSHA Coordinating Centre at the University of Ottawa. A total of 750 survey subjects were identified with a diagnosis of probable or possible Alzheimer's disease.<sup>1,14,15</sup> Subjects with possible disease may have had atypical presentation or other coexisting dementia-related diagnoses. We excluded subjects with coexisting Parkinson's disease ( $n = 30$ ) because this disease is an independent source of impairment that can lead to substantial needs for supportive care. After controlling for dementia severity, subjects with both Alzheimer's disease and Parkinson's disease had a 30% higher rate of institutionalization than other subjects with Alzheimer's disease. Alzheimer subjects with coexisting vascular dementia were retained in our sample because vascular dementia is a dementing process and these subjects did not have significantly higher institutionalization rates after controlling for dementia severity.

### **Severity of Alzheimer's disease**

Severity of cognitive impairment was assessed in the CSHA using the 3MS Examination, a test of mental function that measures selected aspects of cognition such as memory, orientation, praxis, attention and language.<sup>16</sup> Supplemental questions were also asked that allowed derivation of a score for the MMSE, a scale more commonly used in clinical practice. The 3MS Examination was administered to subjects in the community as part of the screening interview and as part of the clinical assessment.<sup>1</sup>

Screening interviewers were trained in the use of the 3MS Examination, and we considered their scores to be the most reliable. If a survey subject had an MMSE score available from the screening interview, that score was used. If the screening MMSE score was not available and a nurse-assessed MMSE score was, we used the latter. However, to adjust for systematically higher scores by nurse assessors, we used a regression model to adjust the score downward. Subjects with missing screening and

nurse-assessed MMSE scores (11 in the community and 107 in long-term care institutions) were excluded from further analysis.

The severity of Alzheimer's disease was classified as mild (MMSE score 21–26), mild to moderate (MMSE score 15–20), moderate (MMSE score 10–14) and severe (MMSE score below 10). One subject with a clinical diagnosis of Alzheimer's disease was excluded because the MMSE score was 27. This left a final study sample of 601 subjects.

### **Residential care**

The CSHA sampling frame was weighted to systematically oversample people in long-term care institutions.<sup>1</sup> This technique was used to provide stable prevalence estimates within small strata, and to allow for a sufficient number of people with dementia so that planned studies of risk factors and caregiving could be performed. We estimated the expected rate of institutionalization for each disease severity level and adjusted these rates for the oversampling of people in institutions. As an alternative estimate, we assumed that the 107 residents in long-term care institutions with missing MMSE scores had severe dementia, and the impact of this assumption was investigated on the total societal cost of care per patient.

### **Medications**

All current medications were recorded during the CSHA clinical interview.<sup>1</sup> Antidepressants, anxiolytics, antipsychotics and anti-Parkinsonian medications were identified as classes of drugs being used for symptomatic treatment of problems related to Alzheimer's disease. For each class, a typical medication that would be used for Alzheimer's disease was chosen on the basis of the most frequent specific medication reported in the CSHA data; the choice was validated by the use of claims data from the Ontario Drug Benefit Plan (ODB) and expert opinion. There was agreement on the choice of the specific medication for each class except antidepressants. Although the CSHA survey gave tricyclic antidepressants as the most commonly used drugs in this class, the survey was done before selective serotonin reuptake inhibitors were seen as safe and effective alternatives; expert opinion and ODB claims data confirmed fluvoxamine as the typical antidepressant.

### **Physician services**

A visit to a general practitioner every 8 weeks was assumed to be associated with the prescription and monitoring of medications and the referral of patients and their



families for supportive services throughout the course of the disease.

### **Community support services**

The CSHA asked caregivers about specific community support services that they may have used during the previous year. For each service used, they were asked who provided and paid for the service and whether they were satisfied with it.<sup>1</sup> The frequency of service use (e.g., the number of visits per week or month) was not assessed. For our analysis, we used CSHA data to estimate the proportion of people with Alzheimer's disease who use each community service and combined these estimates with published reports and expert opinion on frequency of use.

For caregivers who reported that the person with Alzheimer's disease attended a day centre, the frequency of attendance was determined from a survey of the use of 10 Ontario day centres conducted by the University of Guelph.<sup>17</sup> The number and duration of short-term admissions to a nursing home for respite care for caregivers was estimated from a survey of respite needs of caregivers of elderly people with dementia living in the Halton region.<sup>18</sup>

Health care may be provided in the community by visiting health professionals, and several community programs also provide home support to caregivers. The frequency of home visits by nurses and other health care professionals as well as the use of homemaking services for help with such areas as housekeeping was obtained from a survey of caregivers of elderly people with dementia living in the community and from baseline utilization data for caregivers involved in an intervention trial.<sup>18,19</sup> The estimated frequency of the use of a meal delivery service and of participation of the caregiver in self-help or support groups was based on expert opinion of the Hamilton Home Care Placement Program. The impact on total cost and the relation between the cost of care and severity of Alzheimer's disease were investigated using alternative values for resource utilization of the most frequently used, and the most costly services: home nursing, visits by other health care professionals, day centre attendance and respite nursing home admission. The alternative assumptions for these services involved an approximate doubling and halving of the frequency of resource use.

### **Unpaid caregiver time**

In the CSHA the primary caregiver was interviewed regarding the subject's ability to perform basic and instrumental activities of daily living. Areas of personal care assessed were walking, eating, dressing, personal care, getting in and out of the bath, using the washroom, getting in and out of bed, getting places, using a phone, shopping,

preparing meals, doing laundry, taking drugs and managing finances. The caregiver was also asked to report the time spent per month by up to 3 helpers.<sup>1</sup> Only the time reported for caregivers other than paid or institutional help was included in our analysis. If it was reported that the subject needed assistance with a task but no data were recorded, we used an estimate on the basis of time spent with other subjects in the same disease severity category and residence type (community or institution).

Primary caregivers were also asked about whether the subject could be left alone for a period with or without someone else in the house and about the amount of time that each caregiver spent in supervision.<sup>1</sup> Supervision time was summed from the CSHA data; "net supervision time," or time after subtracting direct care time, was used in our analysis because it was assumed that subjects would be supervised while direct care was provided.

We calculated the total amount of caregiver time per month separately for siblings and spouses of subjects with Alzheimer's disease because we assumed that these caregivers may not be in the workforce.

### **Costing of resource use**

Reimbursement to nursing homes in Ontario is based on a formula reflecting the case mix of residents in each facility. The Ontario Ministry of Health rates residents on a scale of A to G using an algorithm that combines weights for activities of daily living, behaviours of daily living and incontinence care. Expert opinion from a director of a local nursing home was used to determine the grading of residents with Alzheimer's disease at each level of disease severity; the cost per day of nursing home stay conditional on their level of care was obtained from the Ontario Ministry of Health. An alternative value of the average daily reimbursement for all nursing home residents was also used.

Medications were assigned a typical dosage, on the basis of clinical expert opinion, and a monthly cost was obtained from the ODB, including a 10% pharmacy markup and a \$6.11 ODB allowable dispensing fee. Physician fees were obtained from the Ontario Schedule of Benefits.

The per diem cost of admission to a nursing home for respite care for caregivers was taken to be the average per diem reimbursement by the Ontario Ministry of Health. The cost of 1 day's attendance at a day centre was provided by the Hamilton Home Care Placement Day Centre Program. Costs of homemaking, meal delivery service and counselling for caregivers were obtained from a study of community service costs conducted by McMaster University.<sup>20</sup> The cost of unpaid caregiver time was assigned a value equivalent to the Ontario minimum wage of \$6.85 per hour. We also used the average industrial aggregate



wage of \$15.91<sup>21</sup> as an alternative value for unpaid time. This value was used for all caregiving time and for time spent by caregivers assumed to be of an age eligible for the workforce (i.e., caregivers other than the spouse or sibling of the subject).

### Relation of disease severity to cost of care

The mean cost for each component of care, the total cost for health and social services and the cost to society were compared between disease severity groups using an

**Table 1: Proportion of people with Alzheimer's disease in the Canadian Study of Health and Aging expected to be in long-term residential care and expected cost of care per subject, by level of disease severity**

Variable	Disease severity			
	Mild (MMSE score 21–26) <i>n</i> = 101	Mild to moderate (MMSE score 15–20) <i>n</i> = 129	Moderate (MMSE score 10–14) <i>n</i> = 128	Severe (MMSE score < 10) <i>n</i> = 243
No. (and %) in long-term care institution	0 (0)	37 (28.7)	85 (66.4)	225 (92.6)
Adjusted estimate of % in long-term care institution*	0.0	16.7	49.6	86.1
MOH reimbursement to nursing home per month	–	\$2425	\$2744	\$2996
Expected cost per month for residential care per subject	\$0	\$405	\$1361	\$2580

Note: MMSE = Mini-Mental State Examination, MOH = Ontario Ministry of Health.

\*Estimated proportion was adjusted for oversampling of institutionalized elderly people. One person sampled in institution represented 180 people in the Canadian population, and one person sampled in the community represented 362 people in the population. For example, for mild-to-moderate disease, the proportion institutionalized is  $(37 \times 180) / (37 \times 180) + (92 \times 362) = 16.7\%$ .

**Table 2: Monthly use of medications identified as relevant for the treatment of Alzheimer's disease and cost per subject, by disease severity**

Medication*	Disease severity; % of subjects (unless otherwise stated)			
	Mild	Mild to moderate	Moderate	Severe
<b>Subjects in long-term care institutions</b>	<i>n</i> = 0	<i>n</i> = 37	<i>n</i> = 85	<i>n</i> = 225
Antidepressant (fluvoxamine, 50 mg once daily)	–	13.5	8.2	14.2
Anxiolytic (lorazepam, 0.5 mg twice daily)	–	32.4	30.6	28.0
Antipsychotic (haloperidol, 0.5 mg twice daily)	–	13.5	17.6	36.0
Anti-Parkinsonian (benztropine, 2 mg twice daily)	–	0.0	7.1	6.7
Average cost per month per subject†	–	\$9	\$7	\$11
<b>Subjects in the community</b>	<i>n</i> = 101	<i>n</i> = 92	<i>n</i> = 43	<i>n</i> = 18
Antidepressant (fluvoxamine, 50 mg once daily)	6.9	3.3	9.3	11.1
Anxiolytic (lorazepam, 0.5 mg twice daily)	14.8	17.4	18.6	5.6
Antipsychotic (haloperidol, 0.5 mg twice daily)	2.0	4.4	9.3	16.7
Anti-Parkinsonian (benztropine, 2 mg twice daily)	1.0	3.3	0.0	0.0
Average cost per month per subject†	\$3	\$2	\$4	\$4
<b>All subjects</b>				
Average cost per month per subject (weighted by % in institutions)	\$3	\$3	\$6	\$10

\*The specific drug in parentheses for each class was selected as the typical medication in that class that would be prescribed for Alzheimer's disease (see Methods for details).

†Cost is based on reimbursable rate of the Ontario Drug Benefit Plan plus 10% markup and dispensing fee of \$6.11. One dispensing fee was assumed every month in institutions, and every 100 days in the community.



analysis of variance (ANOVA). The strength of the relation was investigated by Pearson correlation coefficient, and a regression model was used to predict change in total societal cost for each point decrease in the MMSE score for all subjects with Alzheimer’s disease, and separately for those living in institutions and the community.

## Results

The proportion of subjects with Alzheimer’s disease expected to be in long-term care institutions markedly increased as the severity of Alzheimer’s disease increased (Table 1). Multiplying these values by the amount per month reimbursed by the Ontario Ministry of Health gave us the expected (or average) cost of institutional care per subject. Hence, the “average” subject with mild-to-moderate disease incurs only \$405 per month in long-term care, but this amount increases to \$2580 per month for those with severe disease.

The proportion of subjects receiving at least one medication from each class identified as relevant for the treatment of Alzheimer’s disease is shown in Table 2. More subjects in institutions received medications than did those in the community, although there was not a large increase in medication use, or cost, with increased disease severity. Overall, the average medication cost per month ranged from \$3 per subject with mild disease to \$10 per subject with severe disease.

The monthly use and cost of community support services for subjects living in the community and their caregivers are summarized in Table 3. The most commonly

used services were those providing help and health care in the home; out-of-home services for respite care were used by a smaller proportion of caregivers, although these were costly services when used. Overall, there was a gradient in the average monthly cost per patient by disease severity category from \$164 for those with mild disease to \$340 for those with severe disease.

The time and societal cost for caregivers other than paid help or institutional help is summarized in Table 4. Because unpaid caregiver time may be largely a substitute for “formal” or paid care, the amount of caregiver time used by subjects in the community was greater than that in institutions. Although there was a clear gradient in the caregiver time by disease severity group within each residential setting, the overall cost of unpaid care was greatest for subjects with moderate and mild-to-moderate Alzheimer’s disease; this was because the rate of institutionalization increased with disease severity and less unpaid care was required for institutionalized subjects.

Combining data from the previous tables, we calculated the expected annual cost of health and social services and of unpaid caregiver time and the total annual societal cost of care for Alzheimer’s disease (Fig. 1). The total societal cost increased significantly with disease severity ( $p < 0.001$ ). Comparisons of costs between disease severity groups by ANOVA showed that differences were significant ( $p < 0.001$ ) for the total societal cost, the total cost of health and social services and for each cost component other than unpaid net supervision time. Unpaid time for care and supervision accounted for 77% of the total cost for subjects with mild disease; the propor-

**Table 3: Utilization and cost of community support services, by disease severity**

Community service	Disease severity; % of subjects in the community			
	Mild <i>n</i> = 101	Mild to moderate <i>n</i> = 92	Moderate <i>n</i> = 43	Severe <i>n</i> = 18
Day centre attendance (2.5 d/wk @ \$60/visit)	4.9	9.9	5.3	13.3
Respite care in nursing home (28 d/yr @ \$85/d)	3.7	1.2	5.3	6.7
Homemaking/home help (4.84 visits every 2 wk @ \$15/h)	34.6	45.7	44.7	66.7
Meal delivery (5 meals/wk @ \$3.92/meal)	11.1	9.9	10.5	20.0
In-home nursing (2.49 visits every 2 wk @ \$37.27/visit)	17.3	21.0	28.9	26.7
Visit by other health professionals (1.44 visits every 2 wk @ \$65/visit)	11.1	15.0	5.3	26.7
Caregiver counselling (6 sessions @ \$77/session)	3.7	6.2	7.9	13.3
Caregiver support group (2-h sessions with 5 people per group @ \$37.27/h)	1.2	7.4	5.3	0.0
Average monthly cost per subject	\$164	\$230	\$203	\$340



tion decreased to 14% of the total cost for subjects with severe disease.

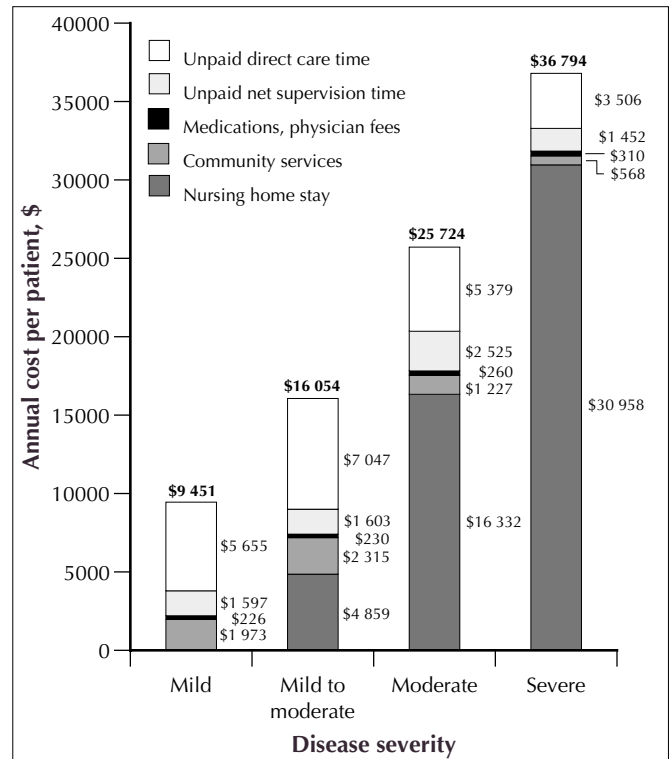
We found strong correlations (Pearson  $r = -0.72$  to  $-0.83$ ;  $p < 0.01$ ) between disease severity and components of cost such as nursing home stay, total health and social services, and total societal cost. A bivariate regression model indicated that each 1-point decrease in MMSE score was associated with a cost increase of \$1343 per subject per year; the annual cost increase was \$1108 per institutionalized subject and \$1395 per subject living in the community.

**Table 4: Unpaid caregiver time and societal cost, by disease severity**

Variable	Disease severity; time and cost per month per subject			
	Mild	Mild to moderate	Moderate	Severe
<b>Subjects in long-term care institutions</b>				
<i>No. of hours</i>				
Direct care	–	11.9	16.7	30.2
Net supervision	–	\$82	\$114	\$207
<i>Cost</i>				
Direct care	–	2.6	1.4	9.7
Net supervision	–	\$18	\$10	\$66
<b>Subjects in the community</b>				
<i>No. of hours</i>				
Direct care	68.8	100.5	113.4	120.0
Net supervision	19.4	22.9	59.5	67.0
<i>Cost</i>				
Direct care	\$471	\$688	\$777	\$822
Net supervision	\$133	\$157	\$408	\$459
<b>All subjects</b>				
<i>Cost*</i>				
Direct care	\$471	\$587	\$448	\$292
Net supervision	\$133	\$134	\$210	\$121

\*Weighted by % in institutions.

The effect of several alternative assumptions on the total estimated cost by disease severity group is shown in Table 5. The assumption that the cost of nursing home stay would be equal to the average per diem estimate for



**Fig. 1: Mean annual cost of Alzheimer's disease per patient, by disease severity. Mild = Mini-Mental State Examination (MMSE) score 21–26, mild to moderate = MMSE score 15–20, moderate = MMSE score 10–14, severe = MMSE score < 10. Differences between severity groups for each component of care were significant at  $p < 0.001$ , except for unpaid net supervision time (time after subtracting direct care time [see Methods] ( $p = 0.64$ )).**

**Table 5: Effect of alternative assumptions about resource utilization on mean annual societal cost of Alzheimer's disease per patient, by disease severity**

Variable	Disease severity; mean annual societal cost per patient, \$				<i>p value</i>
	Mild	Mild to moderate	Moderate	Severe	
Actual estimate of total societal cost	9 451	16 054	25 724	36 794	< 0.001
<b>Assumptions</b>					
Institutionalized subjects with missing MMSE score have severe disease	9 451	16 054	25 724	38 257	< 0.001
Community service utilization higher than estimated	10 793	17 776	26 664	37 216	< 0.001
Community service utilization lower than estimated	8 343	14 759	25 067	36 481	< 0.001
All unpaid caregiver time valued at industrial wage	19 043	27 495	36 179	43 352	< 0.001
Unpaid caregiver time by spouse/sibling valued at minimum wage, and by others at industrial wage	16 651	22 171	32 030	40 053	< 0.001



nursing home stay regardless of the care level, and the assumption that all institutionalized subjects with no MMSE score had severe Alzheimer's disease did not change the general comparison of the relation between the cost of care and the disease severity level.

Because there were no data directly available from the CSHA on the amount of community services used and we thus had to derive these amounts from other sources, one-way and multi-way sensitivity analyses were performed of the effect of other levels of care on the total cost per patient. Table 5 shows the impact of increased and decreased utilization of community services. These alternative assumptions did not have a large effect on the overall comparison of the cost per patient for each level of care. Alternative values for unpaid caregiver time had a large effect on the total cost of care, particularly in the mild and moderate disease groups, with the total annual cost of care ranging from \$19 043 per person with mild Alzheimer's disease to \$43 352 per person with severe disease.

## Interpretation

We have estimated that the annual cost to society ranges from \$9451 per person with mild Alzheimer's disease to \$36 794 per person with severe disease and that a single point decline in the MMSE score is associated with an estimated cost increase of \$1343 per person per year. These estimates are consistent with those of Ernst and colleagues.<sup>13</sup>

The largest cost factor for people with mild Alzheimer's disease was the cost of unpaid caregiver time, and for those with severe disease it was the cost of institutional care.

Our choosing the minimum wage was a conservative estimate of the value for unpaid caregiver time. The use of the industrial aggregate wage for unpaid care time resulted in a significant increase in the total cost of caring per person with Alzheimer's disease, particularly mild and moderate disease, and the relation between the cost of care and the severity of disease remained strong and statistically significant.

Long-term care in a nursing home was the largest component of the cost of care for patients with more severe disease. This cost factor was mostly driven by the large increase in the proportion of patients with moderate and severe disease who were in institutions. The use of the average per diem reimbursement for nursing homes regardless of the disease severity and level of care required did not have a large effect on the total cost of care per subject between the disease severity groups. Our alternative assumption that all institutionalized subjects in the CSHA who did not have an MMSE score had severe dementia increased the average cost per subject with severe

Alzheimer's disease somewhat, to \$38 257 per year. Although in the CSHA none of the subjects with mild Alzheimer's disease was in an institution, patients who wander and are living alone may be admitted to a nursing home for this reason, and so this may be another potential source of underestimation of the cost of caring for people with Alzheimer's disease.

In our analysis, we used survey information to estimate the proportion of patients who use community services. This was supplemented by data from other sources to estimate the average amount of services provided in order to determine resource utilization. The resulting estimates of resource utilization, and thus the total cost of care, although unbiased, contain less variability than would exist if we had been able to measure the actual amount of resources used for each subject in the CSHA.

The primary strength of our study is that it is based on a representative sample of elderly Canadians with Alzheimer's disease identified using a comprehensive and consistent protocol for the diagnosis, assessment of severity of cognitive deficit, and measure of caregiver burden. A weakness is that data on hospitalization, physician services, resource utilization of community services, and dosage and duration of medications were not collected in the CSHA. Several authors have found that the incidence of acute medical care and hospitalization among people with dementia is not higher than that normally expected among elderly people.<sup>11,22</sup>

Using the CSHA data as well, Østbye and Crosse<sup>11</sup> estimated the economic burden of dementia in Canada to be \$13 900 per patient in 1991 dollars. Our analysis of the CSHA data focused on Alzheimer's disease specifically, and we also estimated the cost at different levels of disease severity. Our estimate of the cost of care for Alzheimer's disease is somewhat higher than that obtained by Østbye and Crosse for several reasons. We did not subtract the cost of care for normal elderly people to give the incremental cost of care for those with Alzheimer's disease. The cost of community services was quantified more completely in our study. The cost of unpaid time for supervision and direct care by caregivers was included. If resource information was reported as missing or not known, we estimated the cost from other cases at the same level of disease severity and residence type.

In some survey subjects anti-Parkinsonian medications were used, presumably to counter extrapyramidal side effects of antipsychotic medications, since all subjects with coexisting Parkinson's disease had been removed from the study sample. Although not recommended as appropriate prescribing in elderly patients,<sup>23</sup> we included the cost of these medications because their use was reported.

The costs to caregivers and to health and social service sectors for the care of patients with Alzheimer's disease





are known to be great. We have demonstrated in this study how these costs increase substantially with severity of disease. A quantification of this disease burden and cost is important in light of emerging treatments. We will need to factor in the costs of drugs used specifically for Alzheimer's disease, primarily in mild to moderate stages of the illness. Delaying progression to the more disabling and costly severe stage by 6 to 12 months may be an important target for long-term effectiveness of these medications, to be demonstrated in phase IV studies. Given the strong relation between the costs of care and the severity of cognitive deficit, modest clinical improvements may be associated with substantial cost savings.

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