

Economic impact of Alzheimer's disease in the United Kingdom

Cost of care and disease severity for non-institutionalised patients with Alzheimer's disease

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Background While the costs associated with Alzheimer's disease have been shown to be significant, there are few data relating cost of care to severity of the disease.

Aims We aimed to compare the costs associated with different severities of Alzheimer's disease with those incurred by control subjects over a three-month period.

Method In this cross-sectional, multi-centre, naturalistic analysis, non-institutionalised patients with Alzheimer's disease (128), their care-givers (128), and 56 matched controls were interviewed once to establish resource use over the previous three months. Patients were stratified into three severity groups according to their Mini Mental State Examination score. Costs were calculated from the perspective of society as a whole.

Results Over the three-month period, total mean cost per control subject (£387) was minor compared with mean cost incurred by patients with mild (£6616), moderate (£10 250) and severe (£13 593) Alzheimer's disease. Indirect cost, mainly time spent by care-givers, was the main cost component in all groups (68.6%), followed by direct medical costs (24.7%).

Conclusions The cost of care for an Alzheimer's disease patient is directly related to the severity of the patient's illness.

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Alzheimer's disease has become a major public health issue, with approximately 10% of the population aged over 65 (Evans *et al*, 1989; Rocca *et al*, 1990), and as many as 47% of those aged 85 or older affected (Evans *et al*, 1989). The prevalence of the disease is similar in different countries (Breteler *et al*, 1992) and increased life expectancy and ageing populations will most likely result in an increased incidence of the disease. For the UK, projections estimate that the number of patients with Alzheimer's disease will be 521 000 in the year 2000 (Rocca *et al*, 1986), while in the United States similar projections estimate between 7.5 million and 14.3 million patients in the year 2050 (Evans *et al*, 1990). Although the financial burden associated with the disease has been shown to be significant (Huang *et al*, 1988; Gray & Fenn, 1993; Souëtre *et al*, 1995), there are few data relating the economic consequences of the progressive, debilitating nature of the illness. The objectives of the present study were to evaluate the cost of care for patients living in the community (i.e. non-institutionalised patients) suffering from probable Alzheimer's disease in the UK and specifically to quantify the costs associated with the disease at different levels of severity.

METHOD

Patients and control samples

The design of this cost-of-care study was cross-sectional with each patient, care-giver and control subject interviewed once. Non-institutionalised patients and their respective care-givers were recruited in a random (chronological) fashion by seven psychiatrists specialising in geriatric medicine, located throughout the UK, between May and December 1994. The specialists, who had been selected to give a mix of local and tertiary-based care, each designated a general practitioner in their vicinity to recruit controls.

Patients (≥ 50 years of age), already diagnosed as suffering from probable Alzheimer's disease, according to The National Institute of Neurological and Communicative Disorders and Stroke and the Alzheimer's Disease and Related Disorders Association criteria (McKhann *et al*, 1984), and for whom written informed consent had been given by a legal representative, were included in this study. Patients were excluded if they were resident in a long-term care institution, suffering from mental or neurological disorders other than Alzheimer's disease, or had acute major comorbidities. The care-giver was defined as a spouse, patient's relative or individual, other than salaried home help, who looked after the patient, was knowledgeable about the patient's medical history and who showed no symptoms of dementia.

Controls were individuals accompanying a person not suffering from Alzheimer's disease on a general practitioner visit, closely matched with the patients for age and gender and not suffering from any acute major comorbidity, but showing no evidence of dementia.

Measures

The investigators collected socio-demographic, clinical and economic data using a specifically designed questionnaire, modified from one pilot-tested in an earlier study (Souëtre *et al*, 1995). Patients were stratified into three groups according to their cognitive function as assessed by the Mini Mental State Examination (Folstein *et al*, 1975) score and 48, 42 and 38 patients were enrolled in the severe (score < 10), moderate (score 10-18) and mild (score > 18) groups, respectively. The Alzheimer's Disease Assessment Scale, cognitive subscale (Rosen *et al*, 1984), was administered to confirm severity and the Global Deterioration Scale (Reisberg *et al*, 1988) was used as a general measure to assess cognitive decline. Data covering direct and indirect resource impacts for the three months prior to the interview were collected by interview with the care-giver (or control) and verified by the investigator with patient records.

Economic and statistical analysis

Costs of direct medical resource use for patients, care-givers and controls included costs of hospitalisation, short-term institutionalisation including for respite episodes, medical consultations, paramedical services, laboratory and diagnostic tests

and medication. Where appropriate, costs were based on Average Extra-Contractual Referral tariffs. *Per diem* cost of hospitalisation was calculated by dividing the cost for the average length of stay by the median duration of stay per speciality of 17 hospitals (Department of Health, 1993). In addition, direct cost of general practitioner consultations was based on capitation fees and the average remuneration linked to the number of patients. The cost of institutionalisation in nursing homes was calculated from the daily costs of four nursing homes. Drug costs were counted separately for part-time hospitalisations and outpatients, and were estimated using either the *Drug Tariff* for generic medication, or the *Chemist and Druggist* for trade names.

For direct non-medical costs, utilisation of community-based care centres, social services, equipment and home modification, personal expenses and transport costs related to the illness were included in the estimation. For costing of these resources, tariffs from several district health authorities, average hourly remuneration of social service personnel, market price of equipment, non-structural home modifications and ambulance and transportation costs were used for the evaluation. Costs were assigned using 1993 United Kingdom pound sterling values.

For indirect costs, time spent by the care-giver with the patient and working days and productivity lost were costed. Loss of productivity for employed care-givers was estimated from the loss of gross salary, using the global average daily salary in Great Britain, and the difference between loss of productivity and time spent was costed, thus avoiding double costing of care-giver time. For a retired care-giver, only the time spent with the patient was costed. The cost of time spent by the care-giver, in addition to loss of productivity, was assessed by using the average daily gross domestic product (GDP)/active person in 1993 of £92.74 (Organisation for Economic Co-Operation and Development, 1995). This method was used for all care-givers, whatever their working status.

A distinction was made in the questionnaire between direct medical and non-medical resource utilisation linked directly to the disease, and costs that would have occurred regardless of the disease. Based on this distinction, cost unrelated to Alzheimer's disease was determined to validate controls' reported costs.

All testing comparisons were performed for patients in the three severity groups and controls. For continuous variables, analysis of variance was used. The Kruskal-Wallis test was used for non parametric distributions and the χ^2 test for categorised data. Statistical tests were interpreted two-sided, with alpha being fixed at 5%.

RESULTS

Socio-demographic and clinical data

Socio-demographically, no significant differences were observed between controls and patients or across severity groups (Table 1). Patients were 79.1 years old on average, predominantly female (68.0%), married (64.9%) with an average of 1.8 children. A majority of patients (54.7%) had received secondary or high school education and lived in an urban environment (62.5%) of above 50 000 inhabitants. All patients and most controls were covered exclusively by the National Health Service. A significant difference between severity groups was recorded (Table 1) for the

dementia assessments used, confirming the progression of cognitive decline across groups. Socio-demographic details of the care-givers are shown in Table 2.

Resource utilisation

The frequency of both hospitalisation and short-term institutionalisation, and the duration of stay for each, all increased with disease severity, and in all cases were greater for patients than for controls (Table 3). In contrast, the number of medical consultations decreased with increasing disease severity while paramedical service use was highest for the moderate group (24.2 per person) and lowest for controls (0.8 per person). Resource utilisation linked directly to the disease showed that hospitalisations for mild and severe groups were almost all Alzheimer's-related, compared with only 40.0% in the moderate group, and that on average, 43.8% of general practitioner consultations were disease related. For all the items considered, resource utilisation by controls and resource utilisation unrelated to the disease by patients were very close, except for paramedical services,

Table 1 Socio-demographic and clinical parameters of subjects

	Severity of disease				P
	Controls n=56	Mild n=38	Moderate n=42	Severe n=48	
Demographics					
Age (mean (s.d.))	76.8 (8.1)	78.4 (6.2)	80.9 (7.9)	78.1 (7.9)	0.07 ¹
Gender (% female)	67.9	63.2	66.7	72.9	0.81 ²
Married/cohabiting (%)	66.1	63.2	64.3	66.7	0.89 ²
Number of children (mean (s.d.))	2.0 (1.5)	1.9 (1.6)	1.5 (1.6)	2.1 (1.7)	0.17 ³
Secondary/high school (%)	51.8	60.5	54.8	50.0	0.78 ²
City > 50 000 inhabitants (%)	78.6	47.4	71.4	66.7	<0.05 ¹
Professional status					
Retired (%)	93.0	100.0	100.0	100.0	0.02 ¹
Income <£9000 (%)	76.8	73.0	69.0	66.7	0.69 ²
From retirement pension only (%)	33.9	45.9	28.6	31.3	⁴
From retirement pension and other (%)	60.8	54.0	71.4	66.7	⁴
National health insurance only (%)	91.1	89.5	92.9	95.8	0.68 ²
Clinical data					
Mini Mental State Examination (mean (s.d.))	27.1 (2.6)	22.2 (2.1)	15.0 (2.2)	5.9 (3.6)	<0.001 ³
Alzheimer's Disease Assessment Scale (mean (s.d.))	⁴	19.9 (7.2) ⁵	33.0 (8.8) ⁶	54 (10.7)	<0.001 ³
Global Deterioration Scale (mean (s.d.))	⁴	3.0 (0.8)	4.3 (0.6)	5.7 (0.8)	<0.001 ³

1. F-test from ANOVA.

2. χ^2 test.

3. Kruskal-Wallis test.

4. Not determined.

5. n=35.

6. n=41.

Table 2 Socio-demographic parameters of care-givers classified by disease severity of patients

	Mild (n=38)	Moderate (n=42)	Severe (n=48)	P
Age (years) (mean (s.d.))	68.2 (13.3)	69.0 (14.0)	67.7 (9.7) ¹	0.38 ²
Gender (% female)	55.3	59.5	45.8	0.41 ²
Relationship to patient (%)				
Spouse	57.9	64.3	66.7	0.48 ²
Daughter/son	31.6	16.7	20.8	3
Other	10.5	19.2	12.6	3

1. Birth date of one care-giver missing.

2. Kruskal-Wallis test.

3. Not determined.

which were high for the moderate disease group.

Direct and indirect costs

Total costs increased with disease severity, with averages of £6616, £10 250 and £13 593 for the mild, moderate and severe groups respectively, compared with £387 for the control group (Table 4). Indirect cost was the main component in all disease groups and represented 74.4%, 62.9% and 68.4% of the total cost in the mild, moderate and severe groups, respectively. This cost was made up mainly of care-giver time spent with the patient (6.8 hours/day on average) and increased with severity of disease. The second major cost driver was patients' direct medical costs (Table 4), contributing 18.4%, 30.9% and 24.9% to the total costs in the mild, moderate and severe groups, respectively. Hospitalisation or institutionalisation accounted for most

of this cost (80.8% on average) and increased across severity groups. Paramedical services were highest in the moderate group, whereas consultations and laboratory and diagnostic tests decreased with increasing disease severity. Direct non-medical costs were only a minor component of the total costs for the three patient groups (6.7% on average) and also increased with severity of disease. Care-givers' direct costs were comparable to the direct cost borne by the control group during the study period. In general, the costs unrelated to Alzheimer's disease were similar across groups, including the control group (Table 4). Overall, total mean cost per person for controls (£387) was similar to the mean patient costs (cost unrelated to Alzheimer's disease) for the mild (£382) and severe (£369) groups. However, mean costs unrelated to the disease were higher for the moderate group (£1508).

Table 3 Direct medical resource utilisation over three months. Figures in parentheses represent items related to Alzheimer's disease

	Controls (n=56)	Mild (n=38)	Moderate (n=42)	Severe (n=48)
Hospitalisation				
Mean length of stay/patient (days)	0.1	2.7 (2.7)	5.0 (2.0)	5.4 (5.1)
Total number of admissions	2	6 (6)	10 (4)	12 (11)
Institutionalisation				
Mean length of stay/patient (days)	1	2.0	2.7	6.3
Total number of admissions	1	6	5	19
Mean number of consultations/patient				
Psychiatrist	0	1.0 (1.0)	0.8 (0.8)	0.6 (0.6)
General practitioner	1.4	1.9 (0.9)	1.2 (0.4)	0.8 (0.4)
Mean number of paramedical services/patient				
Mean number of nurse visits	0.5	1.2 (0.1)	16.8 (16.4)	2.5 (2.3)

1. Not applicable.

DISCUSSION

Importance of indirect costs

The findings of this study show a direct relationship between the severity of Alzheimer's disease and costs attributable to the illness. From the society perspective, indirect costs, predominately time spent by the care-giver with the patient, was the main cost driver. Previous studies have shown that indirect costs are a major factor in Alzheimer's disease (Huang *et al*, 1988; Souètre *et al*, 1995). In France, these costs, calculated as they were in the present study by estimating the cost of time spent by a care-giver, represent 36–40% of the total cost of care of Alzheimer's disease patients treated on an out-patient basis (Souètre *et al*, 1995). In the United States, indirect costs, amounting to \$74.6 billion, were identified as contributing 85% of the total overall cost of senile dementia in 1985 (Huang *et al*, 1988). Of this total amount, \$31.46 billion was the estimated value of time lost by family members for the care of the demented elderly patient at home. The remaining indirect cost component was due to the morbidity, disability and increased mortality associated with the disease (Huang *et al*, 1988), components that were not evaluated in the present study.

Direct medical costs

Within direct medical costs, hospitalisation and institutionalisation of the patient were the major cost drivers, increasing up to four times from mild to severe patients. There was a shift in type of resources used with disease progression, as hospitalisation and institutionalisation increased while consultations decreased. This shift probably reflects the need for more intensive, professional care in severe patients (Erkinjuntti *et al*, 1986; Hodgkinson *et al*, 1988; Pfeiffer, 1995). The higher cost of paramedical services, namely nurses, in the moderate group, suggests a transitional phase between family care and greater dependency upon secondary care. Although an increased rate of depression and stress-related illness has been reported for care-givers (Morrissey *et al*, 1990), the present study showed similar direct medical costs for care-givers, at all levels of disease severity, and controls, suggesting that no specific financial cost was associated with the psychological cost of caring for patients participating in this study.

Table 4 Direct and indirect costs of controls and of patients with Alzheimer's disease. Figures in parentheses represent items related to Alzheimer's disease

	Mean costs (£)/3 months/patient ¹			
	Control (n=56)	Mild (n=38)	Moderate (n=42)	Severe (n=48)
Direct costs				
Hospitalisations	18	654 (654)	1431 (494)	2156 (2121)
Institutionalisations	0	159 (159)	1223 (1223)	955 (955)
Consultations	78	199 (132)	148 (101)	92 (74)
Paramedical services	34	27 (8)	209 (132)	84 (74)
Laboratory/diagnostic tests	12	153 (71)	131 (60)	73 (32)
Medication	57	28 (6)	23 (6)	27 (6)
Total direct medical costs	199	1220 (1030)	3165 (2016)	3387 (3263)
Community care centres	147	255 (115)	196 (4)	377 (206)
Social services	26	59 (7)	193 (26)	202 (128)
Home modifications/equipment	12	51 (51)	121 (121)	175 (175)
Other (personal expenses, transport)	3	109 (109)	126 (126)	148 (148)
Total direct non-medical costs	188	474 (282)	636 (277)	902 (657)
Indirect costs				
Working days lost by care-giver	²	15	27	61
Time spent on the patient ³	²	4907	6422	9243
Total indirect costs	²	4922	6449	9304
Total cost	387	6616 (6234)	10 250 (8742)	13 593 (13 224)
Care-givers' direct costs	²	615	244	390

1. £ of 1993 were applied.

2. Not applicable.

3. For retired care-givers, only time spent was costed. For an employed care-giver loss of productivity was subtracted from time spent to avoid double counting.

Methodological considerations

Certain limitations of this study should be considered. Time spent by the care-giver may have been overestimated, since a number in the severe group reported spending 12–24 hours a day with patients. However, this may be a reflection of continuous direct responsibility on the part of the care-giver rather than continuous direct care. Indeed, insofar as other activities can be done at the same time as care-giving, the economic cost of care-giver time is overestimated (the 'joint production' problem).

The method of valuation of care-giver time is still an unresolved issue among health economists, with the two most frequently used approaches being the care-giver opportunity cost approach (i.e. what is the value of the time the care-giver would otherwise have had?) and the shadow-price method (i.e. what would be the cost if the care were provided by professional care-givers?). In this analysis, a single opportunity cost figure has been used to give the cost estimates, £92.74 per day, although in any given situation this cost will vary according

to the valuation method selected and the time involved.

The cost of the disease may also have been influenced by the patient recruitment period, which included the summer months for some patients. Some care-givers may have left their patients in institutionalised care to go on holiday, thereby increasing the cost of care for these patients.

The present study was accomplished using a cross-sectional design with retrospective data collection over three months, a technique used in previous studies (Hellinger, 1993). Since it is widely acknowledged that health care costs increase with age (Schneider & Guralnik, 1990), this study differentiated between costs attributable to the disease and those unrelated to the patient's mental state by the inclusion of a non-Alzheimer's control group, and by specific questions directed toward this distinction. The fact that total mean cost for control subjects and mean cost unrelated to the disease for Alzheimer's disease patients were comparable support the internal validity of this approach. In addition, the socio-demographic characteristics of

patients, with respect to their mean age and the prevalence of married females, reflect epidemiological studies of Alzheimer's disease prevalence in various countries (Heyman *et al*, 1984; Erkinjuntti *et al*, 1986; Evans *et al*, 1990) providing external validity for the present study.

Implications

The present study demonstrates that the cost of care of non-institutionalised patients with Alzheimer's disease is substantial, and increases with the severity of the disease. With an ageing population and increasing longevity, the economic and social impact of Alzheimer's disease in the UK is likely to increase. Future health care policies will have to incorporate adequate resources for management of the disease in the community and identify the most cost-effective way to apply these resources. The present study establishes baseline estimates of the size and impact of the costs of Alzheimer's disease treated in the community, for future planning and assessments of management of the disease.

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CLINICAL IMPLICATIONS

- The burden of caring for Alzheimer's disease patients living in the community falls largely upon informal care-givers.
- With the expected growth in the numbers of people suffering from Alzheimer's disease, together with the changes in family structures, there is likely to be greater pressure for support from care-givers in the future.
- For patients to continue to be cared for in the community, there will need to be greater attention to the functions currently provided by care-givers and greater consideration of the needs of care-givers.

LIMITATIONS

- The study was conducted in patients living in the community: the results cannot be generalised to institutionalised patients or to the Alzheimer's disease population as a whole.
- Inaccuracies may have been introduced with the retrospective nature of the study design.
- Individual costs can be sensitive to costing methods applied.

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