

Original articles

The economic impact of dementia in Belgium : results of the National Dementia Economic Study (NADES)

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Abstract

Objectives : to estimate costs associated with dementia and its severity and to identify main cost determinants.

Design : one-year prospective cohort study.

Setting : 231 general practitioners (GPs) and 15 specialist clinics throughout Belgium.

Subjects : 605 patients aged ≥ 65 years (219 referent patients, 218 demented patients at home and 168 demented patients in institution).

Outcome measures : medical costs (visits to GPs/specialists, physiotherapy, hospitalisation, nursing, incontinence, medication) and non-medical costs (special equipment, services, professional help and caregiving).

Results : total monthly costs amounted to 368.50 € for referent patients, 445.56 € for demented patients at home and 2301.7 € for demented patients in institutions. Highest costs were measured in patients with severe dementia (556.88 € at home, 2465.28 € in institutions). In demented patients at home, 60% of costs were accounted for by the health system, with hospitalisation and medication being the main cost components (36% and 20%). In demented patients in institution, 46% of the costs were accounted for by the health system, with residential costs and nursing being the main cost components (42% and 32%). In multivariate covariance analysis, the main determinants of costs for demented patients at home were physical dependence and co-morbidity (neoplasm, cardiovascular disease). The adjusted difference between demented and referent patients was 25 € per month.

Conclusions : a large fraction of the costs observed in dementia is explained by the association of dementia with physical dependence, co-morbidity and need for caregiving. From an economic point of view, the results support the caring for patients at home.

Key words : Dementia ; cohort study ; costs ; cost of illness ; economy.

Introduction

Dementia covers a wide range of debilitating pathological conditions, the most common being Alzheimer's disease and vascular dementia. The prevalence of dementia rises steeply after the age

of 65. With the increase in life expectancy, dementia will thus represent an increasing medical and socio-economic burden. According to epidemiological studies, the prevalence of dementia in people aged 65 and more varies between 5 and 20%, the prevalence of Alzheimer's disease ranging from 5 to 10% (Hofman *et al.*, 1991 ; Fratiglioni *et al.*, 1999 ; Riedel-Heller *et al.*, 2000). In Belgium, the total number of cases of dementia among people over 60 years old was estimated at 173,000 in 1996 with about 81,000 patients suffering from Alzheimer's disease (Kurz and Dresse, 1996). More recently, a prevalence of dementia of 14.3% was found among elderly patients ≥ 65 years living at home and consulting in general practice. About 41% of these had been diagnosed at the time of the survey. A prevalence rate of 11.3% in patients ≥ 65 years was estimated after adjustment for the age and sex distribution of the elderly population in Belgium (Kurz *et al.*, 2001).

New treatments for dementia get considerable attention both for their therapeutic and economic value. Their economic assessment however requires data on the amounts and determinants of disease-related expenditure. In this respect, it is particularly important to separate costs associated with the disease and costs associated with ageing. In the last years, several studies aimed at evaluating the net economic cost of dementia have been carried out in various countries, leading to considerably different cost estimations (Wimo *et al.*, 1997 for review). No comparable study exists in Belgium and the results of studies performed in other countries cannot be extrapolated in view of large differences in unit costs, medical practice and resource use.

The objective of this work is to assess the economic impact of dementia in people aged ≥ 65 years followed for one year. This objective is achieved by measuring medical and nonmedical costs identified in patients with mild, moderate to mild, moderate and severe dementia, by comparing

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them to those estimated in two reference groups of patients (one without cognitive disorders, and one with cognitive disorders but without dementia), and by identifying their main determinants in a multivariate model. This paper uses data collected in the NADES study (NAtional Dementia Economic Study), a prospective cohort study designed to assess the socio-economic consequences of dementia in Belgium (Kurz *et al.*, 1999).

Patients and methods

STUDY POPULATION

An overview of the study protocol was published in Kurz *et al.*, 1999. A total of 231 GPs, 15 specialists and 20 psychologists throughout Belgium participated in the study. In a first stage, 2784 patients aged ≥ 65 years consulting GPs (regardless of the reason for consultation) were registered and screened for the presence or absence of 10 warning signs of dementia defined by the American Association for Alzheimer's disease (website: http://alzheimers.com/health_library/diagnosis). In a second stage, a sample of these patients and a sample of patients diagnosed by specialists were selected to have a CAMDEX (Cambridge Mental Disorders of the Elderly Examination) (Roth *et al.*, 1986) administered at home by a trained psychologist. The validation of the diagnosis of dementia was performed with an algorithm designed by a panel of neurologists on the basis of the criteria of DSM-III-R ascertained from CAMDEX data (Kurz *et al.*, 1999). Data for dubious cases were independently reviewed by two neurologists. Demented patients were also stratified by level of severity of dementia. This classification was based on MMSE (Mini-mental State Examination) (Folstein *et al.*, 1975) scores extracted from the CAMDEX. Four mutually exclusive cohorts were created according to criteria used by Hux and collaborators (1998) and Stewart and collaborators (1998): a cohort of patients with mild (MMSE score ≥ 21 , $n = 83$), moderate to mild (MMSE score 15-20, $n = 108$), moderate (MMSE score 10-14, $n = 62$) or severe (MMSE score < 10 , $n = 133$) dementia, a cohort of referent subjects with cognitive impairment but no dementia ($n = 113$) and a cohort of referent subjects without any cognitive impairment ($n = 106$). Among demented patients, 218 lived at home and 168 lived in institutions. No referent patients were recruited in institutions.

DATA COLLECTION

Clinical, quality-of-life and socio-economic data were collected at baseline and twice during the follow-up period, about 6 and 12 months after the baseline visit and covering the period since the previous assessment. Data were collected from the

patient or his/her main caregiver, interviewed at home or by telephone (for caregivers of patients living in institutions) by a trained psychologist and from the clinical investigator (GP or specialist). A detailed assessment of all visits received on every day of one week, as well as the duration of these visits and the activities performed in each of them was also ascertained by telephone interview twice during the follow-up period.

The total survey period covered a period of 12 months preceding the inclusion into the study, plus an average follow-up duration of 14.3 months for referent patients and 12.8 months for demented patients. The percentages of patients with one and two follow-up visits made by psychologists at home were 83% and 72% respectively, for the referent patients, and 74% and 63% respectively, for the demented patients. A first and a second follow-up clinical assessments were performed by physicians for 88% and 80% of the referent patients and 87% and 71% of the demented patients.

COST ESTIMATION

Cost estimation was performed in two stages. In a first stage, all cost units (e.g. number of consultations, number of tablets of a drug, etc...) were assessed as accurately as possible by using all available sources of information. For each unit, a primary source of information was defined on the basis of its assumed validity. For example, the physician was the primary informant concerning the number of medical visits or the number of drug prescriptions while the patient or his/her caregiver were the primary informants for the assessment of costs incurred at home. The detailed data collection twice over one week of the follow-up period was used as the primary source for calculating the number of hours spent by visitors such as nurses and caregivers. In general, a good correlation was found between the number of cost units identified from various sources (Scuvée-Moreau *et al.*, 2001, unpublished report). The numbers of cost units measured at different time intervals were summed-up and averaged as mean numbers of units consumed per month. Data collected both retrospectively and prospectively were pooled given the small differences observed between these two periods.

In a second stage, each physical unit was valued according to the best available information, e.g. official tariffs, hospital costs, information obtained from institutions, actual costs declared by the patient, etc. Each cost was calculated globally and separately according to two perspectives: the health system on the one hand, the patient, his/her family and the caregiver(s) on the other hand (these three sources of payment are presented together due to the difficulty in clearly distinguishing between them).

A distinction was also made between medical and non-medical costs. Medical costs include costs which can be directly attributed to the diagnosis, treatment and support of medical conditions. Other costs are included among "non-medical costs", e.g. purchase or renting of equipment (home adaptations such as hand-rails on walls or raised toilet seat, specific equipment such as hospital beds or bed elevators, moving material such as wheelchairs or moving frames, alarm systems, etc.), special services (home delivery of hot meals, laundry), costs of professional help (housemaid, social worker) and costs associated with caregiving. The number of hours spent with the patients by other visitors were also counted, as it was difficult to differentiate between visits made for caregiving and visits for keeping the patient company. Costs considered for main caregivers and visitors included transportation costs and cost of the time spent with the patient, calculated as an opportunity cost on the basis of the hourly salary generally reported for housemaids. No transportation and opportunity costs were counted when the main caregiver was the patient's spouse or husband. For the main caregiver, all medication costs were also taken into account. For professional activities such as nursing, personal care or home help for which no payment was mentioned, a cost equal to 80% of the mean cost declared by people for which the information was known was taken into account. The monthly cost of purchased material was calculated based on a depreciation time of 24 months. The computation of nursing costs for the health system used the INAMI/RIZIV classes (A, B, C, C demented) based on the importance of the patient's dependency status and, for patients in institutions, the type of institution. Residential costs declared by the patients (mean: 959.12 €) were cross-checked with a survey performed in 53 institutions. As the result of this survey was comparable (mean: 955.78 €), the actual residential fees declared by the patients were used in the analysis.

CALCULATION OF ADJUSTED COST DIFFERENCES

Analysis of covariance was used to compare the mean monthly costs in patients with and without dementia, with the difference adjusted for potential confounding variables. Model selection was performed in two steps. In a first step, all variables were introduced individually as independent variables in an analysis of variance. In a second step, variables with a *p*-value lower than 0.10 in the analysis of variance were introduced into the adjusted covariance model. Presence of dementia, age and gender were forced into this model. No automated procedure for variable selection was used. The following variables were tested: gender (male/female), age (65-74, 75-84, ≥85 years old), educational level (none or primary school

only/higher than primary school), reimbursement category (ordinary or preferential VIPO/WIGW category), additional insurance (yes/no), physical dependence (yes/no) assessed by the Katz scale (Katz *et al.*, 1963) as dependency for either personal care, clothing, moving, going to the toilet, continence or eating (physical dependency rated as "yes" if dependency for at least one of these variables), presence of caregiver (yes/no) as assessed by the report of at least one visit of a caregiver in the weekly agenda, and the following physician-reported conditions assessed at baseline (yes/no): hypertension, other cardio-vascular disease, neoplasm, other disease. Income level was not considered due to the high number of missing values.

Results

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE STUDY POPULATION

The main socio-demographic characteristics of the study population are presented in Table 1. By protocol, all patients classified with dementia were included in the study, while similar proportions of male and female patients were recruited in the referent cohorts in order to achieve an adequate representation of male patients. For this reason, women represent 52.5% of referent patients and 71.0% of patients with dementia. Most subjects (59.4% of referents and 43.2% of demented patients) are in the age range 75-84 years, with a mean age of 78.1 years among all referents (median: 78.0, range: 65-93) and of 81.2 years among all demented subjects (median: 81.0, range: 65-100). The proportion of French and Dutch-speaking patients is comparable in the different cohorts (52% versus 48%). The difference between referent and demented patients regarding the proportion of patients with an education level higher than primary school (respectively 42.0% and 25.1%) is probably explained by the difference in the gender distribution. There were more patients with a VIPO/WIGW social security status in the dementia cohort (45.3%) than in the cohort of referent patients (37.9%). These figures are comparable to those reported for the general population (data from the Belgian National Insurance Institute, 1998).

COSTS FOR PATIENTS LIVING AT HOME

Mean monthly costs of 263.03 € and 226.46 € were paid by the health system for referent patients and patients with dementia, respectively (Table 2). The majority of these amounts are explained by hospital costs, as about 35% of referent subjects and 40% of demented patients were hospitalised during the two-year study period, with a mean

Table 1
Socio-demographic profile of the NADES study population

N	Referent patients			Patients with dementia				
	without cognitive disorders	with cognitive disorders	all referent patients	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
	106 N %	113 N %	219 N %	83 N %	108 N %	62 N %	133 N %	386 N %
<i>Gender</i> ⁽¹⁾								
Male	51 (48.1)	53 (46.9)	104 (47.5)	29 (34.9)	27 (25.0)	16 (25.8)	40 (30.1)	112 (29.0)
Female	55 (51.9)	60 (53.1)	115 (52.5)	54 (65.1)	81 (75.0)	46 (74.2)	93 (69.9)	274 (71.0)
<i>Age category</i> ^(1,2)								
65-74 years	23 (21.7)	36 (31.9)	59 (26.9)	17 (20.5)	20 (18.5)	13 (21.0)	23 (17.3)	73 (18.9)
75-84 years	71 (67.0)	59 (52.2)	130 (59.4)	43 (51.8)	52 (48.1)	21 (33.9)	51 (38.3)	167 (43.2)
≥ 85 years	12 (11.3)	18 (15.9)	30 (13.7)	23 (27.7)	36 (33.4)	28 (45.1)	59 (44.4)	146 (37.9)
<i>Place of living</i>								
Home	106 (100)	113 (100)	219 (100)	73 (88.0)	80 (74.1)	33 (53.2)	32 (24.1)	218 (56.5)
Institution				10 (12.0)	28 (25.9)	29 (46.8)	101 (75.9)	168 (43.5)
<i>Language</i>								
French	57 (53.8)	57 (50.4)	114 (52.1)	45 (54.2)	52 (48.1)	37 (59.7)	65 (48.9)	199 (51.6)
Dutch	49 (46.2)	56 (49.6)	105 (47.9)	38 (45.8)	56 (51.9)	25 (40.3)	6 (51.1)	187 (48.4)
<i>Education level</i> ⁽¹⁾								
Primary school	53 (50.0)	63 (55.8)	116 (53.0)	50 (60.2)	76 (70.4)	44 (71.0)	91 (68.4)	261 (67.6)
> primary school	48 (45.3)	44 (38.9)	92 (42.0)	28 (33.8)	31 (28.7)	14 (22.5)	24 (18.1)	97 (25.1)
Missing	5 (4.7)	6 (5.3)	11 (5.0)	5 (6.0)	1 (0.9)	4 (6.5)	18 (13.5)	28 (7.3)
<i>Social security status</i> ⁽¹⁾								
ordinary	75 (70.7)	61 (54.0)	136 (62.1)	45 (54.2)	61 (56.5)	28 (45.2)	77 (57.9)	211 (54.7)
VIPO/WIGW	31 (29.3)	52 (46.0)	83 (37.9)	38 (45.8)	47 (43.5)	34 (54.8)	56 (42.1)	175 (45.3)

⁽¹⁾ p < 0.05 for the test of the difference between all demented and all referent patients.

⁽²⁾ p < 0.05 for the test of the difference between the mean ages for all demented (81.2 years) and all referent (78.1 years) patients.
N = number of patients.

Table 2
Patients living at home : mean monthly costs (€) for the health system

N	Referent patients			Patients with dementia				
	without cognitive disorders	with cognitive disorders	all referent patients	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
	106	113	219	73	80	33	32	218
MEDICAL COSTS								
Visits to/from GPs	15.47	26.52	21.17	20.33	19.01	18.69	20.85	19.68
Visits to specialists	3.74	4.16	4.00	2.97	2.55	2.28	3.00	2.70
Physiotherapy	10.91	6.87	8.83	10.31	11.82	9.35	29.65	13.56
Nursing	9.99	18.10	14.18	15.86	16.46	32.25	73.20	26.97
Hospitalisations	145.79	107.39	125.95	185.84	158.85	118.22	128.28	157.26
Medications	48.54	55.88	52.33	52.88	42.54	30.89	33.12	42.86
TOTAL	234.44	218.92	226.46	288.19	251.23	211.68	288.10	263.03

number of 0.2 to 1.3 hospital days per month. Medication is another source of important costs for the health system, as 99% of all patients took at least one drug during the study period. Cholinesterase inhibitors were taken by about 10% of patients with dementia (mild : 9.1%, moderate to mild : 10.2%, moderate : 15.7%, severe : 6.3%). It is noteworthy that hospitalisation and use of medication tend to decrease with the severity of dementia. In contrast to other cost items, physiotherapy and nursing are strongly associated with the presence and severity of dementia, the highest figures

being found for severe dementia. The percentages of patients with a need for nursing were 25% and 21% for patients with severe and moderate dementia respectively, versus 14.2% for referent patients. These figures can be compared to results found in a survey of the general population in Belgium, in 1997, by the Scientific Institute of Public Health – Louis Pasteur (Enquête de Santé, Belgique, 1997) ; according to this survey, 10% of people aged 65-74 years old and 17% of people aged ≥ 75 years reported the need for nursing at home at least once during the last year.

Table 3

Patients living at home : mean monthly costs (€) for the patient, his/her family and caregivers

	Referent patients			Patients with dementia				
	without cognitive disorders	with cognitive disorders	all referent patients	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
N	106	113	219	73	80	33	32	218
MEDICAL COSTS								
Visits to/from GPs	5.63	7.04	6.37	5.88	5.23	3.40	6.40	5.33
Visits to specialists	1.14	1.12	1.14	0.94	0.87	0.47	0.72	0.82
Physiotherapy	5.97	2.38	4.12	4.26	5.26	2.43	15.57	6.00
Nursing	2.97	1.07	1.98	2.48	1.24	0.64	6.17	2.28
Hospitalisations	4.98	3.17	4.04	6.27	5.45	2.60	4.54	5.16
Incontinence	5.30	5.06	5.18	9.25	10.96	13.58	24.27	12.74
Medications	30.94	36.27	33.69	44.99	45.12	48.96	57.16	47.42
NON-MEDICAL COSTS								
Equipment	2.73	4.64	3.72	3.42	5.50	4.78	4.02	4.49
Services	10.76	8.28	9.49	15.96	9.25	14.20	15.96	13.24
Professional help	33.76	34.46	34.13	31.63	23.57	38.42	54.12	32.99
Main caregiver	31.93	36.64	34.36	39.51	41.37	36.54	50.47	41.35
Other visitors	5.40	2.33	3.82	11.53	5.48	3.54	29.38	10.71
TOTAL	141.51	142.46	142.04	176.12	159.30	169.56	268.78	182.53

Table 4

Patients living in an institution : mean monthly costs (€) for the health system

	Patients with dementia				
	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
N	10	28	29	101	168
MEDICAL COSTS					
Visits to/from GPs	22.09	31.04	24.79	25.73	26.23
Visits to specialists	2.83	0.94	2.03	3.47	2.75
Physiotherapy	13.26	20.97	19.31	24.27	22.21
Nursing	187.51	391.62	595.27	924.62	735.05
Hospitalisations	63.19	363.09	186.19	239.81	240.58
Medications	40.26	46.28	43.01	40.18	41.70
TOTAL	329.13	853.94	870.60	1258.06	1068.55

Mean monthly costs for patients living at home, their family or their caregivers amounted to an average of 182.53 € for patients with dementia and 142.04 € for referent patients (Table 3). The majority of these expenses are explained by the cost of medication and by the non medical costs of assistance needed at home for household tasks and caregiving. A main caregiver was identified for 95% of patients with dementia and 71% of referent patients. The main caregiver cohabited with the patient in 79.2% and 81.9% of the cases, respectively, and the cohabitant was most often the wife or husband (67.7% and 79.5%), while the non cohabitant caregiver was most often a child (55.8% and 71.4%). In case of a non-cohabitant, the average number of visits per month during the study period was 3.8 (range : 0-60) for demented patients and 3.9 (range : 0-30) for referent patients. An equal mean number of visits per month (16.4) from other visitors were reported for all referent and all

demented patients. The total number of hours spent by these visitors was on average 66 and 72 hours per month. For medical costs and costs for caregivers and visitors, a large difference was observed between patients with severe dementia and patients with less severe forms of the disease.

COSTS FOR PATIENTS LIVING IN INSTITUTIONS

An important shift in resource use was observed for demented patients living in institutions, as expenses increase by about five-times in comparison to patients living at home, both for the health system (Table 4) and the patients, families and caregivers (Table 5). Contractual prices for nursing were the main cost component for the health system. The percentages of all patients with dementia in INAMI/RIZIV classes A, B and C or C demented (reflecting increasing dependency status) were 6.5%, 22.0% and 44.6% respectively, with 26.8%

Table 5

Patients living in an institution : mean monthly costs (€) for the patient, his/her family and caregivers

	Patients with dementia				
	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
N	10	28	29	101	168
MEDICAL COSTS					
Visits to/from GPs	4.39	7.34	4.86	7.19	6.64
Visits to specialists	0.45	0.22	0.35	0.62	0.50
Physiotherapy	8.08	9.35	9.74	11.38	10.56
Hospitalisations	2.28	14.08	4.69	7.19	7.61
Incontinence	38.87	23.20	24.39	43.06	36.27
Medications	48.98	37.06	43.03	35.65	37.95
NON-MEDICAL COSTS					
Residential costs	1001.02	1015.10	910.61	951.81	959.12
Main caregiver	43.98	47.10	52.46	49.38	49.18
Other visitors	78.23	178.23	180.59	100.94	125.34
TOTAL	1226.28	1331.68	1230.72	1207.22	1233.17

Table 6

Summary table : total monthly costs (€), by cohort and place of living

Place of living	Referent patients			Patients with dementia				
	without cognitive disorders	with cognitive disorders	all referent patients	mild dementia	moderate to mild dementia	moderate dementia	severe dementia	all demented patients
	Home	375.95	361.38	368.50	464.31	410.53	381.23	556.88
Institution				1555.41	2185.62	2101.32	2465.28	2301.72

of patients without dependence. The percentages of patients in categories C (in non specialised institutions) or C demented (in specialised institutions) increased with the severity of dementia, being 10.0%, 17.9%, 34.5% and 58.4% respectively, in patients with mild, moderate to mild, moderate and severe dementia. Hospitalisation was another important source of costs as 30.0% (mild dementia) to 50.5% (severe dementia) of patients in institutions had at least one hospital admission during the study period. Expenses for caregivers and visitors amounted to an average of about 170 € per month. A main caregiver was identified for about 73% of demented patients in institutions, with a mean of 8.7 visits per month (range : 0-30) and a mean of 4.7 hours per patient (range : 0-16.6) spent per month in the institution. For about 45% of patients, one or more additional visitors were identified (mean : 1.9 ; range : 1-3), with a mean of 3.3 visits and 16.1 hours per patient per month.

TOTAL COSTS

A summary table of total costs by cohort and place of living is shown in Table 6. Total costs for patients living at home, irrespective of the source of payment, amounted to 368.50 € for referents and 445.56 € for demented patients with about 60% of the costs being paid by the health system. For refe-

rents, there was no influence of the presence of cognitive disorders. For demented patients, the highest costs were observed for patients with mild dementia and patients with severe dementia. The costs for demented patients living in institutions were about five times higher than the costs for patients living at home, amounting to an average of 2301.72 € per month for all patients with dementia, 46% of this cost being taken in charge by the health system. Total costs were markedly influenced by the severity status of dementia, ranging from 1555.41 € in patients with mild dementia, to 2465.28 € for patients with severe dementia. The lowest amount observed for moderately demented patients can be explained by less medical conditions in our sample of patients with moderate dementia than in the sample of patients with other levels of dementia severity (data not shown) ; in fact, the difference is mainly accounted for by lower medical costs and, among these, by lower costs incurred for visits by/to GPs or specialists, for hospitalisation and for medication.

ADJUSTED COST DIFFERENCE ASSOCIATED WITH DEMENTIA

Individual variables with the largest effect on total costs (Table 7) were physical dependence (+ 306.05 €) and co-morbidity, especially history

Table 7

Variables associated with total costs (medical and non-medical) in NADES patients living at home (n = 437)

	N (%) subjects	Crude cost estimate (€)	Unadjusted cost difference (€)	Adjusted cost difference (€)
<i>Cognitive status</i>				
– no dementia	219 (50.1)	368.44	0	0
– dementia	218 (49.9)	445.61	77.17 (¹)	25.21
<i>Age (years)</i>				
– 65-74	117 (26.8)	466.51	0	0
– 75-84	234 (53.5)	386.24	(-) 80.24	(-) 70.03
– ≥ 85	86 (19.7)	382.15	(-) 84.36	(-) 136.91 (²)
<i>Gender</i>				
– males	179 (41.0)	416.29	0	0
– females	258 (59.0)	402.93	(-) 15.84	(-) 19.06
<i>Hypertension</i>				
– no	239 (54.7)	372.86	0	0
– yes	198 (45.3)	448.09	75.24 (¹)	66.01
<i>Other cardio-vascular disease</i>				
– no	215 (49.2)	337.63	0	0
– yes	222 (50.8)	474.07	136.47 (¹)	105.53 (²)
<i>Osteo-muscular disorder</i>				
– no	144 (33.0)	373.90	0	0
– yes	293 (67.0)	423.18	49.28	
<i>Neoplasm</i>				
– no	398 (91.1)	389.12	0	0
– yes	39 (8.9)	588.80	199.65 (¹)	158.48 (¹)
<i>Other disease</i>				
– no	164 (37.5)	286.59	0	0
– yes	273 (62.5)	479.23	192.64 (¹)	130.42 (²)
<i>Physical dependence</i>				
– no	338 (79.2)	345.64	0	0
– yes	89 (20.8)	651.69	306.05 (¹)	303.07 (²)
– missing	10			
<i>Caregiver</i>				
– no	84 (19.2)	350.52	0	0
– yes	353 (80.8)	420.35	69.86	
<i>Educational level</i>				
– none or primary school only	237 (54.7)	385.65	0	0
– higher than primary school	196 (45.3)	435.53	48.88	
– missing	4			
<i>Social security status</i>				
– ordinary	263 (60.2)	399.43	0	0
– VIPO/WIGW	174 (39.8)	418.30	18.86	
<i>Additional insurance</i>				
– no	212 (48.5)	396.08	0	0
– yes	225 (51.5)	417.18	(-) 21.10	

(¹) p < 0.1 for the test of a statistically significant difference.

(²) p < 0.05 for the test of a statistically significant difference.

of neoplasm (+ 199.65 €), cardiovascular disease (+ 136.47 €), hypertension (+ 75.24 €) and other diseases (+ 192.64 €). These variables were introduced into the covariance model with adjustment of effects, as well as presence of dementia, age category and gender. The difference of crude cost estimates between demented and non-demented patients (77.17 €) represents the difference between the two groups irrespective of their associated characteristics. In the adjusted model, the difference between the two groups was reduced to 25.24 €, which was not statistically significant at

the 95% confidence level. This value is the difference explained by the presence of dementia assuming equal distribution of other characteristics (e.g. level of physical dependence and co-morbidity) in the two groups. Therefore, it excludes the effect of dementia on costs explained by the fact that, on average, demented patients are more dependent than non-demented ones.

The adjusted analysis shows that cardiovascular or severe chronic disease (such as neoplasm), physical dependence and age have the highest impact on medical costs with a trend towards a decrease of

costs with higher age. Gender is not associated with significant differences in costs, in unadjusted or adjusted analyses. Most of the differences between demented and referent patients disappear after controlling for other determinants such as physical dependency and presence of caregiver, suggesting that these variables explain most of the unadjusted difference observed between demented and non-demented patients. On the other hand, socio-economic variables such as educational level, VIPO/WIGW status and additional insurance have a weak effect on costs.

It is noteworthy that the adjusted model fitted in this analysis is additive, which means that the values of parameters can be summed up. For example, the difference of the cost in patients who have dementia and physical dependence in comparison to non-demented non-dependent patients can be estimated by summing up the difference obtained for each of the two variables in the adjusted model, all other variables of the model being equal. Therefore, Table 7 allows computing a large range of cost estimates based on different patient characteristics.

Discussion

One of the primary objectives of the NADES study was to estimate the cost of dementia and identify determinants of high costs. This objective was achieved, thanks to the active participation of a large number of GPs, specialists and psychologists across Belgium. This dedication exemplifies the interest raised by the disease in general and, more specifically, by its socio-economic consequences.

METHODOLOGICAL ASPECTS

From a methodological point of view, we are confident that this study provides robust and valid estimates of costs measured in patients with dementia and in referent patients. Costs were estimated from data collected both retrospectively and prospectively. Each period had advantages and disadvantages. Whereas a retrospective evaluation may be less accurate than a prospective one due to longer recall periods, prospective data collection may induce an observation bias which may lead to under- or overestimated resource use. As comparable values were observed for estimates pertaining to both periods, data from both periods were averaged to monthly estimates covering a two-year period. Data were also collected repeatedly from different sources of information: the patient himself, the investigator and, if available, a caregiver. In general, these various sources of information provided estimates of the same order of magnitude. Results are thus likely to be a true representation of the costs incurred by the study subjects.

An original contribution of the NADES study was the inclusion, in the same study, of two referent groups of patients without dementia and of one group of patients in institutions. These groups allowed to perform several comparisons discussed below. The choice of cost units assessed in the study was based on the best scientific knowledge in order to measure the economic consequences of dementia. For example, the cost of medication of the main caregiver was included in the analysis in order to detect the possible impact of dementia on caregivers well-being and need for medication. Therefore, absolute values of the cost estimates should be interpreted having in mind the physical units surveyed, the completeness and accuracy of the data collection and the assumptions made for the valuation of the physical units.

COSTS IN DEMENTED PATIENTS : ASSOCIATION WITH PLACE OF LIVING

An average monthly cost of 445 € per patient was found in a cohort of 218 demented patients living at home. About 23% of this amount (103 €) was accounted for by nonmedical costs (including opportunity costs), the rest (342 €) being associated with medical costs. Among these, the costs of hospitalisation (162 €) and medication (90 €) are the largest ones and are mostly supported by the health system. Professional help and caregiving represent the largest part of non-medical costs. These data suggest that providing services and caring for the demented patients at home do not represent expensive activities in absolute terms (about 100 € per patient and per month for all non medical costs). These activities actually amount to only a small fraction of the medical costs spent by the health system, even if unpaid assistance is valued.

On the other hand, total costs for 168 demented patients living in institutions amount to very high figures, with a mean monthly cost of 2302 € per patient, more than five times the cost for a patient living at home. It is noteworthy that the largest costs for patients living in institutions are explained by residential costs (959 €) and nursing costs (735 €). Residential and nursing costs are, among all cost items, those which could be reduced if patients lived at home rather than in institutions.

It is remarkable that only 5% of demented patients were living at home without a caregiver. This proportion was about 20% for patients with mild dementia and less than 5% for patients with moderate/mild dementia or a more severe disease. In contrast, about 29% of referent patients were in a similar situation.

From an economic point of view, there is no doubt that our figures support the caring for the patient at home rather than in institutions, even if the cost of unpaid care (provided to the majority of patients in this study) is valued.

COSTS IN DEMENTED PATIENTS : ASSOCIATION WITH SEVERITY OF DEMENTIA

The distribution of the total monthly costs per severity of dementia do not support a linear trend towards an increase of costs with the severity of dementia. The costs are clearly higher in patients with severe dementia (557 € for patients living at home, 2465 € for those living in institutions) than in the other categories. The lowest costs were unexpectedly observed for patients with moderate dementia, but this observation is probably explained by sampling variability as these patients had less medical conditions and, therefore, less visits to GPs or specialists, less hospitalisation and less medication. Among medical costs, those associated with nursing and physiotherapy explain most of the differences between patients with severe dementia and patients with lower severity of the disease.

The pattern for nonmedical costs shows less consistent differences. However, the impact of severe dementia on the need for caregiving and assistance was shown.

COSTS IN DEMENTED PATIENTS : COMPARISON WITH REFERENT PATIENTS

The increase of total costs between patients living at home with and without dementia amounted to 77.06 € (445.56 versus 368.50 €), or 20.9%. This relatively small difference demonstrates why it was justified to include a referent group in the study. Nearly 85% of the costs observed in patients living at home are not associated with dementia but with the age-related need for medical treatments and non-medical services. As the group of demented patients was on average three years older than the group of referent patients, it may be assumed that part of the difference might be explained by this age difference. The difference observed between males and females however does not support this hypothesis as the difference between demented and referent patients was larger in males (183.07 €) than in females (9.91 €), although the age difference was 0.3 year for men and 4.6 years for women. The difference between demented and referent patients is equally distributed among medical and nonmedical costs, with figures of about 59.8 and 17.26 €, respectively. With regards to medical costs, the difference is mainly explained by differences on all items except consultations to/from GPs and specialists. As regards non-medical costs, the main difference is observed for the item "professional help", especially when severe dementia is considered.

Two categories of interest are those of referents with cognitive disorders but without dementia and of patients with mild dementia, because they are close to each others in terms of cognitive status.

The data show that the differences in total costs are accounted for by differences in medical rather than non-medical costs. This observation is best explained by the fact that, in our sample, dementia is associated with cardiovascular disease in many patients who require more intensive use of health services.

COSTS IN NON DEMENTED PATIENTS

Small differences were observed in total costs, medical costs and non-medical costs between patients without cognitive disorders and patients with cognitive disorders but without dementia. Total costs (including opportunity costs) amounted to 375.95 and 361.38 € per month, respectively, with a mean value of 368.50 € for all referent patients. This mean total cost was lower in males (339.59 €) than in females (394.55 €). Only small differences between the two referent groups were found for almost all cost estimates and parameters, irrespective of the source of information and the source of payment. This observation may be interpreted as showing that our measure of cognitive problems (≥ 3 warning signs) was not sensitive enough to impact on the economic evaluation. On the other hand, it could also indicate that cognitive problems have a real economic impact only when they develop to a certain limit, for example when the patient has advanced dementia. Another explanation may also reside in the adjustment capability of the familial environment which can cope with the burden associated with cognitive disorders, even if this coping causes other problems to one or several family member(s).

ASSOCIATION BETWEEN COSTS AND DEMENTIA

A multivariate covariance analysis was performed in order to assess the impact of dementia on total costs, taking into account the effect of other cost predictors. Results clearly show that most of the costs are associated with physical dependence, the need for caregiving and the presence of chronic diseases such as neoplasm or cardiovascular diseases. Once it is adjusted for important cost predictors, the difference in costs between demented and non-demented patients is reduced from 77 € to 25 € per patient and per month. This reduction suggests that about two third of the excess costs observed in demented patients may be explained by the association of dementia with concomitant diseases, physical dependence and the need for caregiving.

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