

Economic impact of dementia in developing countries: an evaluation of costs of Alzheimer-type dementia in Argentina

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ABSTRACT

Background: There is no previous information about economic costs of Alzheimer’s disease (AD) in South America. The objective of this study was to evaluate the costs of AD in Argentina.

Methods: Eighty community-dwelling patients, 20 institutionalized AD patients and their respective primary caregivers, and 25 healthy elderly subjects participated in this study. The cognitive and neuropsychiatric impairments and severity of dementia were assessed with the Mini-mental State Examination, Neuropsychiatric Inventory and Clinical Dementia Rating, respectively. A structured interview about health and health-care resources used during the past 3 months was administered to family caregivers. The time devoted by carers to looking after the patients and the caregiver burden (Zarit’s Burden Interview) were recorded.

Results: The annual direct costs of the disease increased with cognitive deterioration from US\$3420.4 in mild to US\$9657.6 in severe AD, and with institutionalization (US\$3189.2 outpatient *vs.* US\$14 447.68 institutionalized). Most direct costs were paid for by the family.

Conclusions: With the projected increase in the number of persons at risk for developing AD in emerging countries, the economic familial cost of the disease will be significant. Dementia costs should be a matter of analysis when health policies are being designed in developing countries.

Key words: dementia, Alzheimer’s disease, economic costs, caregiver

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Introduction

The demographic structure of developing countries (with only a few exceptions) shows a population aging process that is more striking than in the developed world, which has undergone the acute phase of this graying phenomenon some decades earlier. Each month, there are, worldwide, 800 000 more persons over the age of 65, and 70% of them live in the developing world (Arizaga, 2005).

In demographic terms, Latin America is usually considered a young region. However, the ways people live and die have changed in the past decades for this area (Arizaga, 2002). As a result of progress in agricultural techniques, vaccines, antibiotics, ancillary diagnostic methods and surgery, mortality rate has fallen in the Southern Cone in the past two decades from 8.0 per thousand to 7.3 per thousand. During the same period, a clear decrease in fertility rate was observed (from 23.9 per thousand to 20.7 per thousand), fueled by the increase in women's access to education. This population graying process is particularly striking in the Southern Latin American region (Argentina, Chile and Uruguay) (Arizaga, 2002; 2005).

Alzheimer's disease (AD), the most frequent form of dementia, is characterized by a progressive impairment of cognitive, behavioral and functional abilities. AD is a clear example of an age-related disease. Various epidemiological studies have shown the exponential growth of prevalence rate with age, starting from around 2.5% in the 65–69-year band and reaching close to 40% in the 90–94-year age group. Dementia is considered the fourth cause of disability-adjusted life years in the developing world for both sexes (Arizaga, 2002; 2005; Wimo *et al.*, 2003).

The costs of dementia to society is the value of all goods and services that are given up to prevent, diagnose, treat and otherwise cope with dementia. Economic costs of AD are significant for health systems. Individuals, families and carers are affected both in the economic aspect and in the quality of life.

Costs are divided into direct (money used in an explicit way in hospital, medical services, drugs, social services) and indirect costs (money used in an implicit way as loss of income by the patient and loss or reduction for family members or carers).

Various studies have evaluated the costs of AD (Beeri *et al.*, 2002; Boada *et al.*, 1999; Cavallo and Fattore, 1997; Ernst and Hay, 1994; Hay and Ernst, 1987; Kronborg Andersen *et al.*, 1998; Menzin *et al.*, 1999; Ostbye and Crosse, 1994; Rice *et al.*, 1993; Wimo *et al.*, 1997) and some studies have focused on the relation between severity and costs (Beeri *et al.*, 2002; Boada *et al.*, 1999; Hux *et al.*, 1998; Rice *et al.*, 1993). Others have focused on the impact of drug therapies on the cost of dementia (Ernst *et al.*, 1997; Hauber *et al.*, 2000; Wimo, 2004).

Argentina has a population of 36 million, with 10% aged 65 or over. In its capital city, Buenos Aires, people aged 65 or over make up 17.9% of the total population of 3.5 million (Arizaga, 2005). Despite the lack of an epidemiological dementia prevalence study, by considering the rates of international studies and especially the unpublished Montevideo study in Uruguay (Ketzoian *et al.*, 1997) and the Concepcion study in Chile (Quiroga *et al.*, 2000), it can be assumed that no less than 50 000 people are affected by AD in Buenos Aires. This implies that the burden of AD in Buenos Aires is similar to that in large cities in the developed world. However, with the differences in health-care resources, social networks and the economic situation, the disease burden is clearly heavier.

The aim of this paper was to analyze total, direct and indirect costs of AD in Buenos Aires and its variations in relation to disease severity and to whether patients are institutionalized or not.

Methods

Participants

Eighty community-dwelling patients with AD and their respective primary caregivers, 20 institutionalized AD patients and their respective primary caregivers, and 25 healthy elderly subjects participated in this study. The healthy elderly control sample was used to address the costs specifically attributable to the disease. Control subjects were drawn from the community (mainly patients' relatives) and were elderly individuals who had no central nervous system disease or any other disease that limits activities of daily living (ADL).

All included patients were diagnosed as probable AD according to NINCDS-ADRDA criteria (McKhann *et al.*, 1984). The sample was composed of patients from different socioeconomic levels. Patients were recruited in public (Memory Research Center, Zubizarreta Hospital) and private (Department of Neuropsychiatry, CEMIC University) centers in Buenos Aires. Private patients are considered, in Argentina, to be individuals that belong to health systems (union systems and prepaid systems) with a minority that are strictly private payers. The institutionalized sample was drawn only from the "Nuestra Sra de las Nieves" nursing home, an institute with private (health system and strictly private) facilities, because there were no public nursing homes in Buenos Aires. All recruited outpatients had primary caregivers, that is non-paid persons who had the responsibility of helping the patient with ADL and instrumental activities of daily living (IADL). These persons provided the patient with more unpaid hours of care than anyone else.

Procedure

A retrospective, observational and cross-sectional study was performed by interviewing patients and their caregivers. At the time, clinical information and

economic data for the previous 3-month period were considered. The interview was undertaken with outpatients and their primary caregivers of our clinics. The results are presented as average expenses over the previous 3 months multiplied by 4 to calculate annual expenses.

The research was performed in accordance with Good Clinical Practice ICH Rules, the last revision of the 1964 Helsinki Declaration and Tokyo 1975, Venice 1983 and Hong Kong 1989 amendments (World Health Organization, 2001) and the Buenos Aires Government Health Authorities.

Instruments

The interview included the following items and questionnaires:

- (1) An informed consent form: prior to the interview all patients and carers were informed orally about the study aims. A written text with this information was then given and an informed consent form signed.
- (2) Patient and caregiver sociodemographic data including age, gender, educational level, occupation, nationality, marital status, income (origin and amount), house (type and costs).
- (3) Patient comorbidities.
- (4) Cognitive assessment: the Mini-mental State Examination (MMSE; Folstein *et al.*, 1975).
- (5) Behavioral examination: The Neuropsychiatric Inventory (NPI-Q; Cummings *et al.*, 1994).
- (6) Evolutional state/severity of impairment: Clinical Dementia Rating (CDR; Hughes *et al.*, 1982).
- (7) Time spent caring for the patient (Gilleard, 1987).
- (8) Caregiver burden questionnaire (Zarit *et al.*, 1985), including 29 items assessing burden associated with caring for an elderly person with dementia: scores range from 1 (never) to 5 (always).
- (9) Direct and indirect costs evaluation structured questionnaire, an adaptation from the questionnaire used by the 10/66 group study (Prince *et al.*, 2003).

The total costs of the disease were broken down into direct and indirect costs. Direct costs include costs relating to the care of the patient, including services and materials for which money is explicitly exchanged. Costs for the health system were the direct medical costs (expenditures for hospital and nursing home care, physician services, medications, etc.). Direct non-medical costs were related to other items or services used for the person's caregiver as a result of AD. The deduction of the healthy subjects' costs from the patients' costs was operationalized as the direct cost measure specific for AD. Physicians' visits and payments to institutions were estimated with social security health system

values (the lowest in the Argentinean system), which are also the values that public hospitals use for administration. Payments to caregivers were based on relatives' reports. Payment for medication was estimated at 100% drugstore sale price.

Indirect costs included services without monetary reimbursement (hours informal caregiver spends with patients). We used the replacement cost approach to estimate indirect costs (number of hours consumed were multiplied by wage per hour considering a monthly salary of US\$350 and then multiplied by 12 to obtain annual costs).

Costs are expressed in US dollars (average exchange rate in 2001 was 1 Argentine peso = 1 US dollar).

AD patients were classified into three groups according to the MMSE score: mild (more than 20 points), moderate (11 to 20 points) and severe (less than 11 points) dementia (Fenn and Gray, 1999).

Descriptive statistics and frequency tables for all studied variables were performed to estimate sanitary resources, annual consumption and costs and economic and demographic characteristics of patients and caregivers. An analysis of variance (ANOVA) was performed to study the statistical significance between groups. For nominal and categorical variables, the χ^2 -test and Fisher's test were used. Data were analyzed using the Statistical Package for Social Sciences version 10.0 (SPSS, Chicago, IL, U.S.A.).

Results

Patients' profile

Demographic characteristics of the AD patients are summarized in Table 1. There were no significant differences between groups in terms of age, gender, marital status and education. There were no illiterate subjects. Only six patients had completed less than 4 school years, 33% had completed primary school, 29% high school and 20% had a university degree. The percentage of women was especially high among healthy subjects (80%). Healthy control subjects had lower incomes than the other groups, while AD patients probably received more money from their relatives than healthy subjects. Seventy-six percent of the patients were pensioners, 17.5% were receiving their income from rents, 18.5% received economical support from their families and 6.2% had no income. The monthly income rate ranged from US\$0 to US\$4000. During their active life 34% had been professionals or business people, 22% qualified workers and 41% non-qualified workers including housewives (26%). Twenty percent of moderate and 62.5% of severe AD patients were institutionalized. Neither healthy subjects nor mild dementia patients were included in the institutionalized group.

Table 1. Demographic characteristics

	AD PATIENTS				ANOVA <i>p</i>
	HEALTHY SUBJECTS	MMSE > 20	MMSE 20–11	MMSE < 11	
Patients					
Number	25	48	30	22	
Age (years)	74.5 ± 7.7	74.3 ± 8	74.5 ± 7.7	75.3 ± 7.6	0.73
Gender (% female)	80	64	46	50	N.S.
Marital status (% married)	56	67	66	58	N.S.*
Education (years)	8.0 ± 3.4	8.7 ± 3.5	8.7 ± 4.3	11.1 ± 5.6	0.21
MMSE (range 0–30)	26.1 ± 2.1	24.6 ± 2.4	15.2 ± 3.1	3.0 ± 3.5	< 0.001
CDR (range 0.5–3)	0.5 ± 0	0.8 ± 0.3	1.8 ± 0.7	3.0 ± 3.5	< 0.001
NPI (range 0–117)	–	19.5 ± 31.7	27.6 ± 24.8	26.2 ± 31.9	0.31
Disease evolution (months)	–	31.5 ± 22.8	47.5 ± 31.5	74.6 ± 38.8	< 0.001
Institutionalized (%)	0	0	20	62.5	
Income in US\$ (month)	558 ± 655	768 ± 895	786 ± 943	1405 ± 960	< 0.01
Primary caregiver					
Age (years)		55.2 ± 15.4	60.9 ± 14.2	59.1 ± 17.3	0.73
Gender (% female)		70	70	90	N.S.*
Education (years)		7.6 ± 2.4	10.2 ± 4.7	11.2 ± 3.3	< 0.05
Relationship to patient (%)					
Spouse		43.5	55	40	
Daughter or son		45	29	20	
Other		4	14	40	
Hours/week with patient**		24.4 ± 17.5	39.5 ± 15.9	43.8 ± 17.8	< 0.001
Burden (Zarit)**		21.2 ± 18.6	35.6 ± 18.6	40.5 ± 24.7	< 0.01

AD = Alzheimer's disease; MMSA = Mini-mental State Examination; ANOVA = analysis of variance; CDR = Clinical Dementia Rating; NPI = Neuropsychiatric Inventory; N.S. = not significant. ANOVA was performed for continuous variables to study statistical significance between healthy subjects and AD patients with different MMSE levels.

*The χ^2 -test was used for nominal and categorical variables.

**Institutionalized patients were excluded from these variables.

Primary caregivers' profile

Characteristics of primary caregivers are also summarized in Table 1. Seventy-six percent of primary caregivers were women, with an average age of 58 years and 9.9 completed school years. Eighty percent of primary caregivers were married. In 46% of the cases, the patient was the spouse and in 32% a parent of the caregiver. In the mild dementia group, 43.5% were spouses, 45% daughters or sons and 4% others. Of those with severe dementia, 20% were daughters

and sons and 40% others (brothers, sisters-in-law, and paid caregivers). Of all working primary caregivers, 41.3% had left their work or had decreased the number of working hours as a consequence of patient care. The average lost working hours were 7 a week. The average number of hours per week devoted to patient care was 35.9 with a range from 6 to 48 hours. Care-devoted hours increased with patient deterioration level (from 24.4 hours in mild dementia to 43.8 hours in severe dementia). Half of all non-institutionalized patients had more than one caregiver. Caregiver burden increased with severity of dementia.

Comorbidities

In relation to other associated pathologies, 88% of total AD patients had comorbidities (43% high blood pressure, 29% heart disease, 29% neurological disease, 25% high cholesterol level, 18% psychiatric disorders, 17% rheumatological processes, 10% diabetes and 24% urogynecological disorders). There were no statistically significant differences in comorbidity prevalence when the sample was segmented by deterioration level.

Costs analysis

Deduction of the costs for healthy subjects from those for patients was considered as the direct cost measure specific for AD. Table 2 shows a comparison of costs variations and resource utilization relative to the patient's place of residence. Costs of institutionalized patients are 54.6% higher than those for community-dwelling patients. Direct medical costs of institutionalized patients are three and a half times the equivalent community-dwelling patient costs. As the distribution of costs is not normal, both groups (institutionalized and community-dwelling) costs medians were compared using a non-parametric test (Mann-Whitney). We found statistically significant differences in total costs, direct and indirect costs.

Costs of prescription medications are 100% higher in institutionalized patients than in community-dwelling patients. Outpatients had four times more physician's visits. It must be consigned that in institutionalized patients are considered exclusively visits of physicians provided by the family. Periodical controls by institution's physicians are not considered because they are included in the institution fee.

Indirect costs are considerable in the case of community-dwelling patients and low in institutionalized patients (Table 2). Indirect costs reflect a heavy burden on caregivers with a mean consumed time of about 8 daily hours (a full working day). If this informal caregiver time were not available, use of paid caregivers or institutionalization would be the consequences, with corresponding costs.

Beeri *et al.* (2002) also found a predominant impact of direct costs in institutionalized patients and of indirect costs in community-dwelling patients.

Table 2. Costs and resource utilization according to patient's place of residence

		HEALTHY SUBJECTS	AD COMMUNITY DWELLING		AD INSTITUTIONALIZED		<i>p</i>
			US\$	%	US\$	%	
Direct costs (previous 3 months)	Hospitalization	–	139.8	17.5	109.5	3.0	0.62
	Physician's visits	–	101.0	12.6	22.0	0.6	< 0.01
	Ancillary studies	–	50.8	6.5	27.7	0.8	0.35
	Paid caregiver	–	55.7	7.0	25.0	0.7	0.81
	Drugs, medicines	–	450.0	56.4	979.4	27.1	< 0.05
	Institutionalization	–	0.0	0.0	2448.3	67.8	N.A.
	Total		797.3	100.0	3611.9	100.0	< 0.01
Annual direct costs		1684.1	3189.2		14 447.6		< 0.01
Annual indirect costs	Caregiver's time	–	4940.5		416.0		< 0.01
Annual total costs		1684.1	8129.7		14863.6		0.01

In direct costs, % is the percentage of resource utilization.
AD = Alzheimer's disease; N.A. = not applicable.

Distribution of costs for community-dwelling patients in our sample is similar to that found by Beeri *et al.* (2002) (40% direct and 60% indirect costs).

The sample was divided into three groups according to the severity of dementia (mild, moderate and severe) in order to compare illness costs. No significant age differences were found on comparing the three groups (see Table 1).

Table 3 shows the mean costs and resource utilization by patients relative to severity of dementia. The total annual costs by patients with moderate and severe dementia are higher than those with mild dementia. An increasing direct costs trend with severity of dementia is observed.

As the costs distribution is not normal, costs medians were evaluated by different non-parametric tests. The median equality hypothesis could not be accepted for total costs for the three groups. Pairs of medians comparisons by severity level (Mann–Whitney test) were performed. The median difference hypothesis could not be rejected for total costs on comparing mild and severe and mild and moderate dementia patients. When direct costs were considered, the median difference hypothesis could not be rejected on confronting mild and severe and moderate and severe affected individuals. Indirect costs are similar between mild and moderate patients but are lower in severe patients. This decrease in indirect costs in severe patients is produced by the relative composition of this group (where the proportion of institutionalized patients is clearly higher than in the other two groups). For institutionalized patients, informal caregivers' time registry is lower than for community-dwelling patients. The median difference hypothesis could not be rejected for indirect costs when comparing severe and moderate patients.

Table 3 show resources utilization and subcomponent costs in patients with probable AD divided into the three groups based on severity of dementia.

Conclusions

AD is a neurological degenerative illness with an average evolution of 10 years and a high population prevalence in those over 60. AD has been decisive as a considerable social, family and economic burden and requires new health-care policies in emergent countries such as Argentina, where resources are scarce and not well distributed and effective social networks are non-existent. Even in developed countries economic studies on AD have been published, describing the economic burden of AD (Hu *et al.*, 1986).

Two Memory Clinics were selected for the present work, one belonging to the free public system (Memory Research Center, Zubizarreta Hospital, Government of Buenos Aires City) and one from the unions', prepaid and private systems (Department of Neuropsychiatry at CEMIC University). The selection

Table 3. Costs and resource utilization by severity of dementia

		MILD		MODERATE		SEVERE		<i>p</i>
		US\$	%	US\$	%	US\$	%	
Direct costs (previous 3 months)	Hospitalization	152.9	17.9	150.0	13.1	91.2	3.8	0.68
	Physicians visits	98.5	11.5	74.2	6.5	37.2	1.6	< 0.05
	Ancillary studies	68.2	8.0	60.0	5.2	24.2	1.0	< 0.05
	Paid caregiver	64.5	7.5	26.2	2.3	50.8	2.1	0.92
	Institutionalization	0.0	0.0	343.9	30.0	1382.1	57.2	< 0.01*
	Drugs, medicines	471.0	55.1	491.5	42.9	828.9	34.3	0.68
	Total	855.1	100.0	1145.8	100.0	2414.4	100.0	< 0.05
Annual direct costs		3420.4		4583.2		9657.6		< 0.05
Annual indirect costs	Caregiver's time	1860.2		2050.1		1584.2		0.18
Annual total costs		5281.6		6633.3		11241.8		< 0.05

Patients with Alzheimer disease were classified in three groups according to the Mini-mental State Examination (MMSE) score: mild (more than 20 points), moderate (11 to 20 points) and severe (less than 11 points) dementia.

In direct costs, % is the percentage of resource utilization.

*Comparison between moderate and severe patients.

approach of these centers was high medical quality and international standards in use for diagnosing and handling patients. To avoid variation in costs among the different health-care systems, a conservative objective was homogenized, calculating them at social system costs as they represent the minimum in the Argentinean health-care system.

The patients studied represented the population of the city of Buenos Aires, with 91.7% completing primary school (7 years of education) and only 6.2% without revenue. However, the sample's income spectrum was wide (revenues from US\$0 to US\$4.000 per month), 34% had been autonomous professionals or merchants, 22% qualified workers, and 41% non-qualified workers including housewives (26%). Twenty percent were institutionalized, and of those who lived in community, most remained in their own home (88%). However, this sample is not representative of the whole country.

Eighty-eight percent of the patients presented comorbidities, the most frequent being high blood pressure, urogynecological problems, heart disease, high cholesterol level, arthrosis and diabetes. However, there were no differences in relation to comorbidity prevalence among the dementia groups (mild or severe). Those comorbidities in patients with probable AD are independent of the evolution of the disease.

Patients with an informal primary caregiver were recruited for the present study. Of these, 81% were women. In our Latin culture, this function of care is assumed by the wife or the daughter. This situation is similar in Italy (Cavallo and Fattore, 1997) and Spain (Boada *et al.*, 1999).

From the current study sample, the annual social cost of an AD patient in Buenos Aires, regardless of type of residence, reaches US\$7736. The economic costs of the illness were divided into direct and indirect costs. When indirect costs were evaluated, we found that 41.3% of the caregivers stopped working for an average 6 hours per week. The time devoted to care increased with the progression of the disease, from 19.7 hours a week in mild dementia to 43.8 in severe dementia. In the study by Hu *et al.* (1986) in the U.S.A., an average of 6.28 daily hours was estimated for the care of patients with dementia. The Italian study of Cavallo and Fattore (1997) reported 45 hours per week of primary caregivers' time. Indirect costs are the most important component of total costs in community-dwelling patients. They do not represent a direct monetary expenditure but are a heavy burden on caregivers, with an accumulation of lost time of about 8 hours per day (a full labor day). If this informal caregiver time is not available, caregiving must be provided by paid carers or supplied through patient institutionalization (two ways of converting indirect into direct costs).

In the future, fewer informal caregivers will be available for elderly people, as a result of the changing family composition and increasing participation of women in the labor force (Beeri *et al.*, 2002; Boada *et al.*, 1999).

Direct economic costs, as well as total costs, also increase with the disease's progression, where 50% of the total costs in patients with severe AD derive from nursing home expenses.

The largest annual costs, US\$47 000, were reported in the U.S.A. (Rice *et al.*, 1993). Annual costs of patients in Buenos Aires were US\$8129.2 for community-dwelling and US\$14 863.6 for institutionalized patients. Our total annual costs were close to Israel's US\$17 000/year (Beeri *et al.*, 2002).

Costs have a wide variation for the different considered components that are related to each country's characteristics. For example, distribution of patients among community-dwelling and institutionalized patients differs in the U.S.A. from Italy, Spain or Israel, where patients are kept in their homes most of the time, the family thus absorbing a large part of the direct costs (Trabucchi, 1999). Argentina, with a Latin culture, clearly has the largest proportion of costs for the family.

Our total costs for patients with moderate (US\$6633.3) and severe (US\$11 241.8) dementia are greater than for those with mild dementia (US\$5281.6). In the Canadian work by Hux *et al.* (1998), the costs were US\$9500 and US\$36 000 for patients with mild and severe dementia, respectively.

Direct costs increase according to dementia severity. Indirect costs are greater in moderate AD patients, in general not institutionalized, burdening the family with the impact of these indirect costs. Decrease of indirect costs in severe AD patients is due mainly to the fact that in the institutionalized patients' group, the time spent by informal caregivers is less than in the community patients' group.

This is the first paper on direct and indirect costs of AD in South America. With the increase of the aging population in developing countries, dementia costs should be a matter of analysis when health policies are being designed.

Conflict of interest

None.

Description of authors' roles

R.F.A. conceived the project, designed the study, supervised the data collection, statistically analyzed the data and wrote the paper. J.B. was involved in carrying out the study, collecting the data and writing the paper. G.M. collaborated in designing the study and analyzing the data. C.S., D.S. and L.L. were involved in carrying out the study. R.L.A. and F.E.T. helped to design the study and write the paper.

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