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Economics of the Iceberg: Informal Care Provided to French Elderly with Dementia

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ABSTRACT

Objectives: Dementia has a substantial effect on patients and their relatives, who have to cope with medical, social, and economic changes. In France, most elderly people with dementia live in the community and receive informal care, which has not been well characterized. **Methods:** Using a sample of 4680 people aged 75 years and older collected in 2008 through a national comprehensive survey on health and disability, we compared the economic value of the care received by 513 elderly people with dementia to that received by a propensity score– matched set of older people without dementia. **Results:** More than 85% of elderly people with dementia receive informal care; the estimation of its economic value ranges from €4.9 billion (proxy good method) to €6.7 billion (opportunity cost method) per year. **Conclusions:** The informal care provided to people with dementia has substantial annual costs; further work should be done to examine the social and economic roles foregone as a result of this care.

Keywords: ADL, cost, count models, dementia, IADL, informal care, need for care, opportunity cost method, propensity score matching, proxy good method.

Introduction

Although aging is a worldwide concern [1], there are huge discrepancies across countries in both the speed of aging and the current age composition [2]. The 5.9 million people aged 75 years and older currently constitute more than 9% of the French population [3], a figure expected to grow to 15% by 2040 [4].

Thanks to advances in medical care and greater access to health care, people can expect to live longer in good health [5]. Functional limitations, chronic conditions, and disability, however, are frequently associated with old age; therefore, the elderly may live a number of years requiring human and/or technical assistance in their daily life to maintain functionality. Dementia, which is characterized by a loss of or a decline in memory and other cognitive functions, leads to an inability to perform everyday activities and is one of the major causes of need for care [6]. In France, the prevalence of dementia among people aged 75 years and older is about 17.8%, with most patients living in the community [7]; by 2040, an anticipated 1.3 million elderly French people will have dementia [8,9].

Cognitive impairments have a large negative effect on patients and their relatives. Although availability is increasing, the current supply of public services and support do not meet the care needs of older people, who still mainly rely on informal caregivers (family, friends, or neighbors) [10]. The provision of support and care by informal caregivers places substantial medical, social, psychological, and financial burdens on patients, families, and society [11].

The financing of long-term care is currently being debated in France [12]. Policymakers are challenged to find solutions that reconcile the provision of adequate care with public resource limitations [13]; dementia is of particular concern [14]. Although the contribution of informal caregivers is frequently not considered in such analyses [15], a recent comparative study has underscored the importance of informal care in the societal cost of dementia [16]. The total estimated worldwide costs of dementia were US $604 billion in 2010, about 70% of which was spent in Western Europe and North America. In such high-income regions, the costs of informal care (45%) and the direct costs of social care (40%) were found to be much more than direct medical costs (15%) [17]. In 2008, the total cost of dementia in the EU27 was estimated to be €160 billion (€22,000 per person with dementia per year), 56% of which was attributable to informal care [18]. A recent calculation found a total cost of about US $210 billion for Western Europe [6]. A recent review analyzed 17 studies examining the costs of Alzheimer's disease (AD). Depending on the study, annual total costs per patient vary from $2,935 to $52,954; in France, estimated annual costs were $31,153 (using data of 1996) [19]. But comparisons are problematic because of different approaches used to assess the costs of AD: for instance, informal costs range from $1,364 to $44,736 per year for patients with AD who live at home although the authors note that

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although "there is a lack of data about informal care time and costs among other dementias than AD… globally, AD is the most costly in terms of informal care costs than PD (Parkinson disease), $17,492 versus $3,284, respectively" [20]. A recent article stated that the average total monthly costs of informal care were €2450 [21], and a French longitudinal study found that "the mean cost of AD per month was €2918 at baseline, €3112 at year 1, and €4101 at year 2 [with informal care being] the largest cost component per month, and its importance in total costs increased over time: €2334 at baseline, €2510 at year 1, and €3373 at year 2" [15]. These results confirm that informal care constitutes a significant portion of the total cost of dementia [22,23].

This article compares the actual utilization and thereby incurred costs of formal and informal care reported by and assistance provided to people with dementia in order for them to conduct their daily activities to those for individuals without dementia and similar characteristics. Consequently, it seeks to assess the impact of dementia on the needs of the elderly, the human assistance supplied to meet those needs, and the economic value of informal and formal care provided.

Methods

Data

We used 2008 survey data on 29,931 respondents who lived in the community that was collected through the French national representative survey of health and disability (Handicap Santé Ménages [HSM] survey) [24,25]. The database documents physical and psychological health status, socioeconomic characteristics, social support, housing, and life conditions. The questionnaire was administered in face-to-face computer-assisted interviews. When necessary and if the intended subject agreed, the latter was helped or even replaced by a proxy respondent (spouse, child, or other relative).

We restricted the sample to 4680 individuals aged 75 years and older, 540 of whom suffered from dementia. A total of 27 individuals among the 540 individuals with dementia (5%) had missing values for some variables necessary to the analyses (for instance, need for assistance with some daily activities and hours of care received) and were excluded from the sample. The excluded individuals were not found to be basically different from the ones remaining in the sample.

We identified people as having dementia through a two-step process. First, if a respondent indicated that he or she had AD or another form of dementia provided on a list of common diseases, we categorized the individual as having dementia; 320 individuals were included through this criterion. Second, we probabilistically identified 193 individuals by conducting a hierarchical ascending classification on the factorial axes of a multiple correspondence analysis that reported medical problems or risk factors that were consistent with a diagnosis of dementia in the following way: first, a multiple correspondence analysis was carried out, in which 9 variables (mainly functional limitations and activity restrictions) were used and three factorial axes were retained; second, individuals were classified according to the axes with a hierarchical ascending classification and the resulting dendrogram led us to consider four classes; third, classes were refined with the nearest neighbor method (more details are available on request from the authors).

Propensity Score Matching

People with dementia differed from those without it on several characteristics such as age, household composition, and education (Table 1). To disentangle the impact of dementia from other individual characteristics, we used a propensity score matching (PSM) method to control for the observable heterogeneity between people with and without dementia [26,27]. Variables used for the matching process, performed with R software [28], were age, sex, diploma, household composition, individual income, living area, and respondent status. We used the nearest neighbor technique to match each person with dementia to one who did not suffer from dementia. The final matched sample

Table 1 – Sample characteristics of French elderly aged 75 y and older living in the community (Handicap Santé Ménages survey, N = 4680).

Variable	Characteristic	Before matching			After matching		
		Dementia (n = 513)	No dementia (n = 4167)	P value*	Dementia (n = 513)	No dementia (n = 513)	P value*
Sex	Male	33.6	37.5	0.215	33.5	37.2	0.215
	Female	66.4	62.5		66.5	62.8	
Age (y)	Mean	84.2	81.0	0.001	84.2	84.2	0.875
	75–79	19.7	43.5	0.001	22.8	22.8	0.906
	80–84	35.0	34.8		32.4	32.9	
	85+	45.3	21.7		44.8	44.3	
Household	Alone	28.6	43.6	0.001	26.9	30.6	0.361
	Spouse only	44.0	45.0		39.6	36.7	
	Other	27.4	11.4		33.5	32.7	
Education	No degree	37.7	32.1	0.067	50.5	55.0	0.151
	Degree	62.3	67.9		49.5	45.0	
Proxy respondent	Yes	87.7	13.0	0.001	88.9	88.9	1.000
	No	12.3	87.0		11.1	11.1	
Living area	Urban	65.3	68.7	0.269	73.1	74.8	0.522
	Rural	34.7	31.3		26.9	25.2	

Note. Values are percentages except otherwise indicated.

* *P* value for two-tailed percentages comparison test (H0: percentages are equal) for all variables but age (*P* value for two-tailed mean comparison test, H0: means are equal). After Bonferroni's correction for multiple comparisons, the conclusion of each test remains the same.