



ELSEVIER

Available online at [www.sciencedirect.com](http://www.sciencedirect.com)

ScienceDirect

journal homepage: [www.elsevier.com/locate/jval](http://www.elsevier.com/locate/jval)

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

Alain Paraponaris, PhD<sup>1,2,3,4,\*</sup>, Bérengère Davin, PhD<sup>1,3</sup><sup>1</sup>INSERM, UMR912 (SESSTIM), Marseille, France; <sup>2</sup>Aix-Marseille University, UMR\_S912, IRD, Marseille, France; <sup>3</sup>ORS PACA, South-Eastern Health Observatory, Marseille, France; <sup>4</sup>Aix-Marseille School of Economics (AMSE), Marseille, France

### 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.

Copyright © 2015, International Society for Pharmacoeconomics and Outcomes Research (ISPOR). Published by Elsevier Inc.

### 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

\* Address correspondence to: Alain Paraponaris, INSERM U912, 23 rue Stanislas Torrents, F 13006 Marseille, France.

E-mail: [alain.paraponaris@inserm.fr](mailto:alain.paraponaris@inserm.fr).

1098-3015/\$36.00 – see front matter Copyright © 2015, International Society for Pharmacoeconomics and Outcomes Research (ISPOR).

Published by Elsevier Inc.

<http://dx.doi.org/10.1016/j.jval.2015.01.002>

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.

used for analysis consisted of 1026 individuals, half with dementia and half without.

### Count Models

To study characteristics associated with need for care with daily activities, we considered the presence of at least one need and the total number of activities for which people need assistance. When respondents reported being unable to perform an activity without help, they were considered to have a need for formal or informal care. To construct such variables that capture need, we calculated nonnegative integer-valued counts that ranged from zero to seven for activities of daily living (ADL [29]) and zero to eight for instrumental activities of daily living (IADL [30]). We used a count model to analyze these variables (see Table 2 for the detailed list of ADL and IADL). We present results using a negative binomial model for ADL and a Poisson model for IADL because basic conditions for the use of the Poisson model (the mean is equal to the variance) were not fulfilled for ADL. The appropriateness of such a model is confirmed by the support of a Vuong test ( $P < 0.001$ ) [31].

Because most respondents did not report any need, we used zero-inflated models, based either on a Poisson distribution (ZIP model) or on a negative binomial distribution (ZINB model) to generate unbiased results [31]. We chose which of these two models to use by using a likelihood ratio test. Using Stata 12, we estimated two equations; the first, based on a logit model, is the probability of reporting no need for care; the second estimates factors associated with the total number of needs.

Our count models included the following variables: sex, age (75–79 years, 80–84 years, 85+ years), household composition (alone, with spouse only, other), education (no degree, degree), individual income (quartiles), living area (rural, urban), self-assessed health (very good–good, pretty good, bad–very bad),

functional limitations (none, some, many), dementia (yes, no), and use of proxy respondent (yes, no).

Although we present results based on a restrictive definition of need, we used a less restrictive definition wherein we counted the report of difficulty completing the task as a “need.” Results from analysis of the less restrictive definition are largely similar to those using the more restrictive definition and are available on request.

### Assessment of Care

Informal care is the main source of human assistance, even among people with dementia [32]. Consequently, it must be considered in economic evaluations [33]. Given the lack of a market for informal care inherently and difficulties with the measurement of time spent caring [34,35], however, assessing the value of such an activity is challenging [36].

The literature is based on articles using different methods, each presenting both advantages and drawbacks [37,38]. The proxy good method (or replacement costs method) values time spent on caregiving at the labor market price of a close substitute. This requires the availability of a market substitute for the nonmarket commodity, which is assumed to be almost perfect, for example, same quality. Informal care time is generally valued at the wage rate or the market price of a professional caregiver. A second method relies on opportunity costs. The value of care is assessed through forgone benefits due to spending time on providing informal support. In general, they are approximated by individual’s market wage rate [39]. These two methods are rather simple to implement, but they also face some limits. With the proxy good method, it is often difficult to distinguish between normal tasks that caregivers use to do in the household and additional tasks due to disability. It also assumes that formal care and informal care are perfect substitutes. For instance, no differences in efficiency and quality are assumed to prevail [38]. The

**Table 2 – Prevalence of need for care among French elderly aged 75 y and older living in the community (Handicap Santé Ménages survey, N = 4680).**

Activity	Before matching			After matching		
	Dementia (n = 513)	No dementia (n = 4167)	P value*	Dementia (n = 513)	No dementia (n = 513)	P value*
Bathing	49.6	4.9	0.001	49.6	27.5	0.001
Dressing	39.5	2.5	0.001	39.5	22.2	0.001
Feeding	11.9	1.8	0.001	11.9	13.1	0.001
Going to toilets	25.5	0.9	0.001	25.5	4.1	0.001
Transferring	28.9	1.3	0.001	28.9	15.4	0.001
Moving inside	27.3	1.3	0.001	27.3	14.6	0.001
Going out	53.1	6.6	0.001	53.1	37.0	0.001
At least one ADL	66.9	9.4	0.001	66.9	45.2	0.001
Shopping	76.2	16.7	0.001	76.2	60.8	0.001
Cooking	62.5	5.7	0.001	62.5	34.5	0.001
Usual housework	64.6	10.9	0.001	64.6	46.6	0.001
Occasional housework	72.2	19.1	0.001	72.2	57.5	0.001
Managing money	79.0	9.9	0.001	79.0	48.5	0.001
Taking medications	61.5	2.2	0.001	61.5	17.9	0.001
Using transports	72.7	12.9	0.001	72.7	50.9	0.001
Using telephone	47.1	1.4	0.001	47.1	13.3	0.001
At least one IADL	90.0	26.4	0.001	90.0	71.7	0.001

Note. Values are percentages.

ADL, activities of daily living; IADL, instrumental activities of daily living.

\* P value for two-tailed percentages comparison tests ( $H_0$ : percentages are equal). After Bonferroni’s correction for multiple comparisons, the conclusion of each test remains the same.

opportunity cost method leads to different values of the same commodity due to different individual wages. It also underestimates the time of women and elderly, and does not allow the valuation of different informal caregiving activities [19]. Thus, as done by recent authors [40,41], we mainly focused on the proxy good method to provide an estimate of the costs that would be imposed on the health and social system and ultimately the taxpayers if informal care was not provided and had to be delivered by professionals. The opportunity cost method was used in that article as a sensitivity analysis.

In the HSM survey, each person had to list all of his or her formal and informal caregivers, and to state how much time they provided care each week, with no distinction between the types of activities such as ADL on the one hand and IADL on the other. Thus, we estimated the cost of informal care by including all daily activities and using only one unit cost, the French minimum gross hourly wage (€12.42 in 2008). Indeed, in France, care for ADL and IADL is often provided by the same professionals (except for medical tasks, such as toileting or giving medications, which have to be done by a trained nurse), paid at the minimum wage rate [42]. Hence, this article was aimed at assessing a minimum cost of care provision to the elderly living in the community from a society perspective, partly made of the cost of replacement of informal care by professional care. A similar approach has recently been used in an examination of French community dwellers [43] and in a German study about the costs of dementia by disease stage [44]. The value of formal care was also assessed by costing the total number of care hours provided by professionals at the French minimum gross hourly wage (€12.42), in order to compare the relative importance of informal care and the total cost of care with daily activities.

The opportunity cost of informal care was assessed by applying different mean wage rates according to the sex and age of caregivers. Wage rates ranged from €13.74 per hour for younger women to €21.41 for those next to retirement. For men, wage rates range from €14.92 to €28.70 per hour. The opportunity cost of retired caregivers was approximated by the French minimum gross hourly wage (€12.42), which is often that of professional caregivers.

## Results

### Prevalence of Need for Care with ADL and IADL

We found that two-thirds of the people with dementia needed human assistance for at least one ADL (Table 2); after controlling for age, women were more likely than men to have such care needs (70.9% vs. 61.6%;  $P = 0.009$ ). Fifty-three percent of those with dementia were unable to leave their home without assistance; 50% needed help with personal hygiene; 40% with dressing; and nearly 30% with moving from a chair or bed. The vast majority of those with dementia could not perform at least one IADL without any assistance. Inability to independently conduct a particular IADL ranged from 47% who were unable to use the telephone independently to 79% who could not manage their money independently. Three-quarters of the respondents reported that they needed help with shopping; 62% with cooking; and nearly two-thirds with doing usual housework.

In sharp contrast, fewer than 10% of those in the entire sample of respondents without dementia reported needing help with an ADL and fewer than a quarter needed help with an IADL. Results from the matched sample indicated that differences in need for assistance with ADL and IADL are primarily due to dementia: while the differences are somewhat mitigated, the need for help with conducting ADL and IADL is still substantially

higher among those with dementia than among those without dementia.

### Factors Associated with Need for Care

In the entire sample, we found that the probability of needing assistance with ADL increased with advancing age and was highest among women, those with many functional limitations, those in poor health, and those who used a proxy respondent (Table 3). A diagnosis of dementia, however, dramatically increases the probability that help with ADL was needed. Overall, people older than 85 years needed help with an additional 0.8 ADL (Table 3, column 4, marginal effect); those who used a proxy respondent with an additional 1.5 ADLs; and those who had dementia with an additional 1.2 ADLs.

Results for IADL are quite similar, but, here, socioeconomic factors also play a significant role, as those with no degree were more likely to need help with IADL. Overall, the oldest old, those with many functional limitations, and those using a proxy respondent needed more help conducting IADL. The presence of dementia increased the need for help with IADL by 80%.

### Type of Care Received by the Elderly

People with dementia are largely recipient of human assistance. Only 3% of them do not get any care, compared with 56% of their counterparts without dementia, who mainly have no need with daily activities (Fig. 1). Informal care constitutes the main part of support provided to people with dementia: nearly 85% receive care from relatives, either in a sole form (27.6%) or mixed with formal care (56.9%). Data unambiguously reveal that informal care is even more important for people with dementia.

### Cost of Care

On average, people with dementia received 44 hours of informal care each week and 23.2 hours of formal care. The mean number of care hours for people without dementia is lower: 17.2 and 7.4 for informal and formal care, respectively (Table 4).

Based on the proxy good method, the estimation of the total cost of formal and informal care for the elderly was close to €24 billion in France in 2008 (Table 4). Not surprisingly, the use of the opportunity cost method led to a higher estimate (€30 billion). A total of €15 billion out of the €24 billion of total costs (62.3%) consisted of the monetary equivalent of the time spent by all the informal caregivers (spouses, children, relatives, friends, neighbors) caring for the elderly (€21 billion out of €30 billion, 70%, with the opportunity cost method). The total cost of formal and informal care for elderly people with dementia was estimated at €7.6 billion with the proxy good method and €9.4 billion with the opportunity cost method, among which the costs of informal care represented from 64.5% (proxy good method) to 71.3% (opportunity cost method) of the total costs.

For elderly with dementia who receive care, the mean annual cost per capita based on the proxy good method was slightly more than €43,000 (€53,000 with the opportunity good method), about two times (two and a half times with the opportunity good method) more than the mean cost for supported elderly without dementia.

## Discussion

Our article was intended to assess the magnitude of informal care supplied to the elderly living in the community, as oceanographers are used to measure the hidden part of the icebergs. Paradoxically, informal care is known to be the main part of the human assistance given to the elderly but its recognition is not

**Table 3 – Factors associated with need for care with ADL and IADL among French elderly aged 75 y and older living in the community (Handicap Santé Ménages survey, matched sample: N = 1026).**

Variable	ADL			IADL		
	Logit model p(need = 1)	Count model (ZINB)		Logit model p(need = 1)	Count model (ZIP)	
	Coefficient (SE)	Coefficient (SE)	Marginal effect (at median) (SE)	Coefficient (SE)	Coefficient (SE)	Marginal effect (at median) (SE)
Age (y)						
75–79	–	–	–	–	–	–
80–84	.070 (.243)	.038 (.080)	.122 (.198)	.129 (.276)	.039 (.042)	.211 (.206)
85+	.810 (.255)*	.156 (.076)†	.791 (.208)	.645 (.292)†	.130 (.040)*	.760 (.202)
Sex						
Male	–.477 (.213)†	.041 (.065)	–.223 (.178)	–.852 (.247)†	–.024 (.035)	–.359 (.191)
Female	–	–	–	–	–	–
Household						
Alone	–	–	–	–	–	–
With spouse only	–.007 (.280)	.260 (.086)*	.614 (.244)	–.581 (.319)†	.076 (.043)†	.207 (.225)
Other	.279 (.266)	.343 (.076)*	1.063 (.237)	–.402 (.323)	.138 (.039)*	.582 (.209)
Education						
No degree	.010 (.205)	.027 (.059)	.061 (.148)	.429 (.239)†	.010 (.031)	.149 (.157)
Degree	–	–	–	–	–	–
Individual income						
First quartile	–	–	–	–	–	–
Second quartile	.303 (.267)	–.035 (.080)	.083 (.198)	.167 (.306)	.042 (.043)	.235 (.210)
Third quartile	.215 (.256)	–.002 (.078)	.111 (.198)	.515 (.316)†	.021 (.042)	.184 (.206)
Fourth quartile	.459 (.293)	.020 (.084)	.282 (.219)	.425 (.340)	.057 (.045)	.346 (.227)
Living area						
Urban	–	–	–	–	–	–
Rural	–.009 (.215)	.062 (.061)	.128 (.169)	.347 (.269)	.051 (.033)	.307 (.166)
Reported health						
Very good/good	–	–	–	–	–	–
Pretty good	.539 (.411)	.039 (.152)	.361 (.366)	.081 (.423)	.096 (.068)	.490 (.354)
Bad/very bad	.513 (.394)	.472 (.140)*	.987 (.220)	–.152 (.433)	.156 (.063)†	.649 (.263)
Functional limitations						
None	–	–	–	–	–	–
Some	.393 (.503)	–.366 (.267)	–.498 (.436)	1.659 (.438)*	–.058 (.150)	–.106 (.688)
Many	2.211 (.482)*	–.113 (.240)	1.361 (.327)	3.505 (.453)*	–.219 (.143)	3.089 (.559)
Proxy respondent						
Yes	1.397 (.330)*	.716 (.165)*	1.530 (.209)	1.646 (.306)*	.392 (.068)*	1.992 (.269)
No	–	–	–	–	–	–
Dementia						
Yes	1.314 (.201)*	.250 (.059)*	1.255 (.201)	1.549 (.255)*	.319 (.031)*	1.814 (.196)
No	–	–	–	–	–	–
Constant	–3.812 (.706)*	–.171 (.348)		–3.088 (.666)*	–.648 (.177)*	

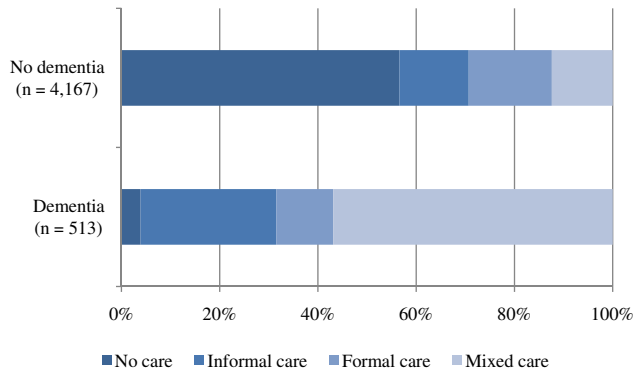
ADL, activities of daily living; IADL, instrumental activities of daily living; SE, standard error.

\* P &lt; 0.01.

† P &lt; 0.05.

‡ P &lt; 0.1.





**Fig. 1 – Type of care received by French elderly aged 75 years and older living in the community (Handicap Santé Ménages survey, N = 4680). (Color version of figure appears online.)**

straightforward because, by definition, the usual tools (the market price and the volume of transactions) used for the assessment of the value of an economic activity are missing.

To avoid the streetlight effect inherent to cohort studies [45], we used a national population health survey, which first makes available the same measurement tools for the two samples of elderly living with and without dementia and second allows not to restrict only to people who got in touch with the medical professionals and/or the community workers.

We also sought to disentangle the “pure” impact of dementia on the needs reported for both ADL and IADL. For this purpose, the use of the PSM technique allowed us to compare care supplied to the elderly with and without dementia. Admittedly, some authors may have considered that there is “little evidence that propensity score methods yield substantially different estimates compared with conventional multivariable methods” [46]. Yet, “the merits of using propensity score matching technique have become increasingly recognized over the years as its application has grown” [47]. We used reliable and thorough count models (ZINB and ZIP models) likely to identify the factors associated with the number of needs with ADL and IADL, considered separately, reported by French elderly with and without dementia and to take into account the fact that our data were partly made of null values. Because the results were expected to be biased because of heterogeneity between people with dementia and their counterparts without dementia, we controlled for observable heterogeneity thanks to the matching, which contributed to reducing some raw discrepancies between the two

categories. We first estimated ZINB and ZIP models on the whole sample (results available on request) and then on matched samples. We could observe that some variables (such as type of household or reported health) that were significant before PSM were not anymore after matching. Conversely, dementia still remains significant and appears to be a critical parameter associated with the increased need for care conducting ADL and IADL, as the literature regularly points it out [48].

As stressed in Millan-Calenti et al. [49], old age and bad health also increase the probability of reporting and adding needs. Sex is found to be discriminating as well: the probability of needing care with one activity at least is higher among women. Household composition has an impact on the total number of needs. Single households are less often subject to need for care. This result may hide a selection effect: elderly with or without dementia are able to live in the community if and only if they can rely on caregivers. Otherwise they have to be institutionalized to get adequate assistance to meet their needs. The role of socio-economic characteristics is here quite low. Only the absence of a degree seems to have a significant association with the probability of needing care with an IADL at least. It might be viewed as the consequence of a higher exposition to health events that induce impairments and functional limitations (occupational exposure, consuming habits, living conditions, etc). On the contrary, the use of a proxy respondent has a significant contribution to the equations. Proxy respondents are most often the main caregivers [50] and, as a result, may have emphasized their role of caregiver through the declaration of needs.

Our study illustrates and confirms the preponderance of informal care in the support provided to the elderly, particularly to persons with dementia. More than 80% of them receive care from their relatives. Thanks to the information available in the survey, we estimated the value of informal care on the basis of the proxy good method, as already done in previous studies [40,51–53]. By applying the French minimum wage rate to the care hours counted up in the data set, the amount of informal care provided to people aged 75 years and older living in the community was assessed to have been about €15 billion in 2008. For people with dementia, it represents nearly €5 billion or more than €2300 per month and per capita (compared with €925 for a person without dementia). Thus, adopting an excess cost approach—that considers the additional costs of an individual with the disease beyond the costs of an individual without the disease [54]—people with dementia and their relatives face an additional cost of €1400 per month. The gap could even reach €1900 with the opportunity cost method.

**Table 4 – Costs of care provided to French elderly aged 75 y and older living in the community (Handicap Santé Ménages survey, N = 4680).**

Number of care hours and cost of care	Dementia (n = 513)	No dementia (n = 4167)	Overall (n = 4680)
Number of care hours (average, per week)			
Formal care	23.2	7.4	9.3
Informal care	44.0	17.2	21.5
Cost per person receiving care (average, per year, €2008)			
Formal care	14,959	4,807	6,031
Informal care			
Proxy good method	28,417	11,107	13,910
Opportunity cost method	38,481	15,902	19,556
Cost of care (total, per year, billion €2008)			
Formal care	2.7 (2.1-3.2)	6.3 (5.5-7.0)	9.0 (7.6-10.2)
Informal care			
Proxy good method	4.9 (4.3-5.6)	10.0 (9.0-11.0)	14.9 (13.3-16.6)
Opportunity cost method	6.7 (6.1-7.4)	14.3 (13.3-15.5)	21.0 (19.4-22.9)

The choice of the proxy good method used to assess the contribution of informal carers to the assistance provided to people with dementia living in the community can be discussed because it may have drawbacks [39]. But it enables us to approach a measure of informal care cost easily and gives an idea of the economic impact of dementia on families, which is mostly unknown [11]. In this respect, our results reveal that French official accounts of welfare expenses for elderly with disabilities are, like icebergs, only the emerged part of a much more important cost of care. In addition, public expenditures for elderly with disabilities (including both medical care and the provision of human assistance for daily activities) were estimated at €24 billion in a recent national report [55]. The report dealt with people aged 60 years and older and included those living in nursing homes. Despite differences in methodology, population, and criteria, we might then consider that public coverage does not meet the whole needs of the elderly. In the same time, amounts found in the literature vary greatly from a study to another [20] and differences also exist in methodology, population, and criteria. But informal care still appears as the main source of support provided to the elderly, even when the latter suffer from dementia [32,56]. In this case, informal care is more often associated with formal care. Consequently, care to people with dementia required obviously extended time that informal caregivers have to devote [57]. For working caregivers, it often includes working time arrangements and rescheduling, which can be deleterious for professional earnings [58] and the professional career and more generally health and quality of life [59–61]. It also implies psychological consequences [62–64]. Higher weekly time commitment to informal care is associated with increased risk of depressive symptoms [65]. The importance and the strong consequences of informal care provision, however, are mainly disregarded. It is generally free of charge, but this does not mean it is not valuable [66,67], with no intangible effects [68] and no opportunity costs.

Some of our results should be viewed with caution because of several limitations. First, we used data from a health population survey; these, as all such collected data, have the potential for declarative bias [69]. Most of the respondents with dementia, however, used a proxy respondent to answer the questionnaire; this might reduce the expected bias [70,71].

Second, we used a restrictive definition of “need” in completing an ADL or IADL; restrictive definitions might affect results [72]. However, we found that when using a less restrictive approach (for instance, including “difficulty” in performing an activity as indicating a need), results were similar, and not surprisingly, the prevalence of need is stronger as well as costs incurred by the provision of care are higher. Our results are therefore conservative estimates; true costs might be higher.

Finally, the survey did not include the institutionalized elderly. Especially for individuals with disabilities, living in the community is possible only if they can rely on a family and/or social network [73]. Because people with highest severity of dementia usually live in institutions [8], our costs of care are, again, a conservative estimate.

## Conclusions

Our results suggest a need for a better and more formal recognition of informal care. Informal caregivers, who try to meet the needs of elderly with disabilities, and especially those with dementia, are likely to also need care for themselves. To maximize their efficacy and to prevent “burnout,” these caregivers likely need to be supported, replaced, or helped. Without suitable support, informal care could compound social and health inequalities [74]. Therefore, actions and public policies targeting

informal caregivers are essential to avoid their exhaustion and ensure their quality of life as well as their ability to continue to care for the needs of elderly with disabilities.

## Acknowledgments

Research grants from the Scientific Cooperation Funds on Alzheimer Disease (Fonds de Coopération Scientifique Alzheimer), Human and Social Sciences Program (AAP-SHS 2009 and AAP 2012), and France Alzheimer Association are greatly acknowledged.

Source of financial support: The authors have no other financial relationships to disclose.

## REFERENCES

- [1] United Nations. World Population Ageing 2009. New York: United Nations, Department of Economic and Social Affairs, Population Division, 2009.
- [2] Kapteyn A. What can we learn from (and about) global aging? *Demography* 2010;47(Suppl):S191–209.
- [3] Bellamy V, Beaumel C. Bilan démographique 2012. La population croît, mais plus modérément (Report No. 1429). Paris: INSEE, 2013.
- [4] Blanpain N, Chardon O. Projections de population à l'horizon 2060. Un tiers de la population âgée de plus de 60 ans (Report No. 1320). Paris: INSEE, 2010.
- [5] Cambois E, Clavel A, Romieu I, et al. Trends in disability-free life expectancy at age 65 in France: consistent and diverging patterns according to the underlying disability measure. *Eur J Ageing* 2008;5:287–98.
- [6] World Health Organization. Dementia: A Public Health Priority. Geneva: World Health Organization, 2012.
- [7] Helmer C, Pérès K, Letenneur L, et al. Dementia in subjects aged 75 years or over within the PAQUID cohort: prevalence and burden by severity. *Dement Geriatr Cogn Disord* 2006;22:87–94.
- [8] Jacqmin-Gadda H, Alperovitch A, Montlahuc C, et al. 20-Year prevalence projections for dementia and impact of preventive policy about risk factors. *Eur J Epidemiol* 2013;28:493–502.
- [9] Mura T, Dartigues JF, Berr C. How many dementia cases in France and Europe? Alternative projections and scenarios 2010–2050. *Eur J Neurol* 2010;17:252–9.
- [10] Rapp T, Grand A, Cantet C, et al. Public financial support receipt and non-medical resource utilization in Alzheimer's disease results from the PLASA study. *Soc Sci Med* 2011;72:1310–6.
- [11] Alzheimer's Disease International. World Alzheimer Report 2010: The Global Economic Impact of Dementia. London, UK: Alzheimer's Disease International, 2010.
- [12] Chevreul K, Berg Brigham K. Financing long-term care for frail elderly in France: the ghost reform. *Health Pol* 2013;111:213–20.
- [13] Da Roit B, Le Bihan B. Similar and yet so different: cash-for-care in six European countries' long-term care policies. *Milbank Q* 2010;88:286–309.
- [14] Rosow K, Holzapfel A, Karlawish JH, et al. Countrywide strategic plans on Alzheimer's disease: developing the framework for the international battle against Alzheimer's disease. *Alzheimers Dement* 2011;7:615–21.
- [15] Rapp T, Andrieu S, Molinier L, et al. Exploring the relationship between Alzheimer's disease severity and longitudinal costs. *Value Health* 2012;15:412–9.
- [16] Wimo A, Winblad B, Jonsson L. The worldwide societal costs of dementia: estimates for 2009. *Alzheimers Dement* 2010;6:98–103.
- [17] Wimo A, Jönsson L, Bond J, et al. The worldwide economic impact of dementia 2010. *Alzheimers Dement* 2013;9:1–11.
- [18] Wimo A, Jönsson L, Gustavsson A, et al. The economic impact of dementia in Europe in 2008—cost estimates from the Eurocode project. *Int J Geriatr Psychiatry* 2011;26:825–32.
- [19] Costa N, Derumeaux H, Rapp T, et al. Methodological considerations in cost of illness studies on Alzheimer disease. *Health Econ Rev* 2012;2:1–12.
- [20] Costa N, Ferlicq L, Derumeaux-Burel H, et al. Comparison of informal care time and costs in different age-related dementias: a review. *Value Health* 2013;16:A18.
- [21] Gervès C, Chauvin P, Bellanger M. Evaluation of full costs of care for patients with Alzheimer's disease in France: the predominant role of informal care. *Health Policy* 2014;116:114–22.
- [22] Gustavsson A, Jönsson L, Rapp T, et al. Differences in resource use and costs of dementia care between European countries: baseline data from the ICTUS study. *J Nutr Health Aging* 2010;14:648–54.

- [23] Jönsson L, Wimo A. The cost of dementia in Europe: a review of the evidence, and methodological considerations. *Pharmacoeconomics* 2009;27:391–403.
- [24] Bouvier G. L'enquête Handicap-Santé. Présentation générale. Paris: INSEE, 2011.
- [25] Renaut S. Les apports de l'enquête Handicap-Santé. *Gérontologie et Société* 2012;5(HS1):55–74.
- [26] Caliendo M, Kopeinig S. Some practical guidance for the implementation of propensity score matching. *J Econ Surveys* 2008;22:31–72.
- [27] Heckman JJ, Todd PE. A note on adapting propensity score matching and selection models to choice based samples. *Econom J* 2009;12 (Suppl):S230–4.
- [28] Sekhon J. Multivariate and propensity score matching software with automated balance optimization: the matching package for R. *J Stat Software* 2011;42:1–52.
- [29] Katz S, Ford AB, Moskowitz RW, et al. Studies of illness in the aged: the index of ADL, a standardized measure of biological and psychosocial function. *JAMA* 1963;185:914–9.
- [30] Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969;9:179–86.
- [31] Sousa RM, Ferri CP, Acosta D, et al. Contribution of chronic diseases to disability in elderly people in countries with low and middle incomes: a 10/66 Dementia Research Group population-based survey. *Lancet* 2009;374:1821–30.
- [32] Bakker C, de Vugt M, van Vliet D, et al. The use of formal and informal care in early onset dementia: results from the NeedYD study. *Am J Geriatr Psychiatry* 2012;21:37–45.
- [33] Hoefman RJ, van Exel J, Brouwer W. How to include informal care in economic evaluations. *Pharmacoeconomics* 2013;31:1105–19.
- [34] Brouwer WB, van Exel NJ, Koopmanschap MA, et al. The valuation of informal care in economic appraisal: a consideration of individual choice and societal costs of time. *Int J Technol Assess Health Care* 1999;15:147–60.
- [35] Hirst M. Costing Adult Care: Comments on the ONS Valuation of Unpaid Adult Care. York: University of York, Social Policy Research Unit, 2002.
- [36] Mentzakis E, Ryan M, McNamee P. Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. *Health Econ* 2011;20:930–44.
- [37] Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. *Value Health* 2012;15:975–81.
- [38] van den Berg B, Brouwer WB, Koopmanschap MA. Economic valuation of informal care: an overview of methods and applications. *Eur J Health Econ* 2004;5:36–45.
- [39] van den Berg B, Brouwer W, van Exel J, et al. Economic valuation of informal care: lessons from the application of the opportunity costs and proxy good methods. *Soc Sci Med* 2006;62:835–45.
- [40] Jakobsen M, Poulsen PB, Reiche T, et al. Costs of informal care for people suffering from dementia: evidence from a Danish survey. *Dement Geriatr Cogn Disord Extra* 2011;1:418–28.
- [41] Schwarzkopf L, Menn P, Kunz S, et al. Costs of care for dementia patients in community setting: an analysis for mild and moderate disease stage. *Value Health* 2011;14:827–35.
- [42] Bressé S. L'enjeu de la professionnalisation du secteur de l'aide à domicile en faveur des personnes âgées. *Retraite et Société* 2003;39:119–43.
- [43] Paraponaris A, Davin B, Verger P. Formal and informal care for disabled elderly living in the community: an appraisal of French care composition and costs. *Eur J Health Econ* 2012;13:327–36.
- [44] Leicht H, Heinrich S, Heider D, et al. Net costs of dementia by disease stage. *Acta Psychiatr Scand* 2011;124:384–95.
- [45] Hernan MA, Hernandez-Diaz S, Robins JM. A structural approach to selection bias. *Epidemiology* 2004;15:615–25.
- [46] Stürmer T, Joshi M, Glynn RJ, et al. A review of the application of propensity score methods yielded increasing use, advantages in specific settings, but not substantially different estimates compared with conventional multivariable methods. *J Clin Epidemiol* 2006;59:437–47.
- [47] Baser O. Too much ado about propensity score models? Comparing methods of propensity score matching. *Value Health* 2006;9:377–85.
- [48] Millan-Calenti JC, Tubio J, Pita-Fernandez S, et al. Cognitive impairment as predictor of functional dependence in an elderly sample. *Arch Gerontol Geriatr* 2010;54:197–201.
- [49] Millan-Calenti JC, Tubio J, Pita-Fernandez S, et al. Prevalence of cognitive impairment: effects of level of education, age, sex and associated factors. *Dement Geriatr Cogn Disord* 2009;28:455–60.
- [50] Wolinsky FD, Bentler SE, Hockenberry J, et al. Long-term declines in ADLs, IADLs, and mobility among older Medicare beneficiaries. *BMC Geriatr* 2011;11:43.
- [51] Harrow BS, Mahoney DF, Mendelsohn AB, et al. Variation in cost of informal caregiving and formal-service use for people with Alzheimer's disease. *Am J Alzheimers Dis Other Dement* 2004;19:299–308.
- [52] Hurd MD, Martorell P, Delavande A, et al. Monetary costs of dementia in the United States. *N Engl J Med* 2013;368:1326–34.
- [53] Trépel D. Informal cost of dementia care – a proxy-good valuation in Ireland. *Econ Soc Rev* 2011;42:479–503.
- [54] Waldeyer R, Brinks R, Rathmann W, et al. Projection of the burden of type 2 diabetes mellitus in Germany: a demographic modelling approach to estimate the direct medical excess costs from 2010 to 2040. *Diabet Med* 2013;30:999–1008.
- [55] Fragonard B. Stratégie pour la couverture de la dépendance des personnes âgées. Paris: Ministère des solidarités et de la cohésion sociale, 2011.
- [56] Nordberg G, von Strauss E, Kareholt I, et al. The amount of informal and formal care among non-demented and demented elderly persons—results from a Swedish population-based study. *Int J Geriatr Psychiatry* 2005;20:862–71.
- [57] Ory MG, Hoffmann RR, Yee JL, et al. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist* 1999;39:177–85.
- [58] Moore MJ, Zhu CW, Clipp EC. Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. *J Gerontol B Psychol Sci Soc Sci* 2001;56(Suppl):S219–28.
- [59] Gordon J, Rouse E. The relationship of job and elder caregiving involvement to work-caregiving conflict and work costs. *Res Aging* 2013;35:96–117.
- [60] Lilly MB, Laporte A, Coyte PC. Do they care too much to work? The influence of caregiving intensity on the labour force participation of unpaid caregivers in Canada. *J Health Econ* 2010;29:895–903.
- [61] Schneider U, Truckeschtz B, Mühlmann R, et al. “Do I stay or do I go?”—job change and labor market exit intentions of employees providing informal care to older adults. *Health Econ* 2013;22:1230–49.
- [62] Coe NB, Van Houtven CH. Caring for mom and neglecting yourself? The health effects of caring for an elderly parent. *Health Econ* 2009;18:991–1010.
- [63] Schifczyk C, Romero B, Jonas C, et al. Appraising the need for care in Alzheimer's disease. *BMC Psychiatry* 2013;13:73.
- [64] Sherwood PR, Given CW, Given BA, et al. Caregiver burden and depressive symptoms: analysis of common outcomes in caregivers of elderly patients. *J Aging Health* 2005;17:125–47.
- [65] Cannuscio CC, Colditz GA, Rimm EB, et al. Employment status, social ties, and caregivers' mental health. *Soc Sci Med* 2004;58:1247–56.
- [66] Connolly S, Gillespie P, O'Shea E, et al. Estimating the economic and social costs of dementia in Ireland. *Dementia* 2014;13:5–22.
- [67] Faria R, Weatherly H, van den Berg B. Something for nothing? The value of informal care. *Value Health* 2012;15:A463.
- [68] Gervès C, Bellanger MM, Ankré J. Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders. *Value Health* 2013;16:745–54.
- [69] Lynn Snow A, Cook KF, Lin PS, et al. Proxies and other external raters: methodological considerations. *Health Serv Res* 2005;40:1676–93.
- [70] Ostbye T, Tyas S, McDowell I, et al. Reported activities of daily living: agreement between elderly subjects with and without dementia and their caregivers. *Age Ageing* 1997;26:99–106.
- [71] Davin B, Joutard X, Paraponaris A, et al. Endogénéité du statut du répondant à l'état de santé: quelles implications pour la mesure des besoins d'aide dans les enquêtes en population générale? *Revue Economique* 2009;60:275–91.
- [72] Laditka SB, Jenkins CL. Difficulty or dependency? Effects of measurement scales on disability prevalence among older Americans. *J Health Soc Policy* 2001;13:1–15.
- [73] McCann M, Donnelly M, O'Reilly D. Living arrangements, relationship to people in the household and admission to care homes for older people. *Age Ageing* 2011;40:358–63.
- [74] Trannoy A, Tubeuf S, Jusot F, et al. Inequality of opportunities in health in France: a first pass. *Health Econ* 2010;19:921–38.