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A New Approach for Assessing the Value of Informal Care in Alzheimer's Disease

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ABSTRACT

Objectives: Given that most informal caregivers providing help for patients with Alzheimer's disease are retired spouses or unemployed people, there is no market value for their time. Most articles that tried to estimate the cost of informal care for Alzheimer's disease rely on the so-called "replacement" methodology, which assumes that 1 hour of informal care has the same value as 1 hour of professional care. Little attention has been dedicated to exploring the validity of this assumption. In this article, we determine the relationship between the price of informal caregiving and professional care from the first-order condition of a theoretical model that maximizes informal caregivers' satisfaction with providing care.

Methods: This article formalizes the marginal substitution rate between informal and formal care. We assume that the caregiver's utility depends on the caregiver's burden and the patient's quality of life (QoL). After explaining the parameters of the marginal utility of caregivers, we estimate each of these parameters using PLASA data.

Results: Our results show how the value of informal care increases as the care contributes to improving patients' QoL but decreases as the burden on the caregiver increases and professionals contribute to patients' QoL.

Conclusions: The central assumption of the replacement cost method of perfect substitution between informal and formal care leads to a misestimation of the value of informal care. The effects of informal care must be considered (direct effect on the burden and indirect effects on the patient's QoL).

Keywords: Alzheimer's disease, informal care, replacement cost methods.

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Highlights

- The replacement cost method should consider a marginal rate of substitution between formal and informal care, which varies according to the care utility.
- The utility of care depends positively on the patient's quality of life and negatively on the burden associated with the care.
- By better considering caregivers' utility and disutility, informal care could be better valued, and support could be targeted at caregivers according to their needs.

Introduction

In Organisation for Economic Co-operation and Development countries, 1 in 5 people older than 85 years have dementia, costing more than 1 trillion US dollars annually.¹ Informal care accounts for more than 80% of total care provided to people living in the community with Alzheimer's disease (AD) and is, therefore, the main cost driver in dementia, accounting for approximately 50% to 80% of the total cost of caring (when patients with AD are not institutionalized).²⁻⁷ This proportion varies between countries (with a lower proportion in high-income countries), depending on the methodology used and the costs included in informal care (which may or may not include monitoring). Informal caregivers are "typically" family members or relatives, usually not professionally trained and unpaid, who provide care, such as with activities of daily living (ADLs) or instrumental ADLs, to disabled persons or older adults with health limitations. Informal care is a service that generates value, especially if it replaces formal care. Home care policies that encourage older people to remain in their own homes and age within their communities rely heavily on the presence of informal caregivers, which helps to contain the rise in public spending.

However, the value of informal care is frequently underestimated by the community or even considered to be "free" due to its nonmarket nature. Indeed, its costs and effects are often neglected in economic evaluations of healthcare interventions.⁸ Including the cost of informal caregiving for patients with AD can, in some cases, change the cost-effectiveness ratio and make the intervention cost-effective.⁸⁻¹¹ Thus, including the cost of informal care in these studies could lead to favoring interventions that would reduce the caregiver's burden and improve their experience of care (eg, those that would lead to less time spent on care or would include direct support for caregivers: discussion groups, psychological support, etc). Although there is growing recognition of the importance of including informal care costs in economic evaluations,¹²⁻¹³ they are not universally accepted or consistently included in health technology assessment (HTA) frameworks across different bodies and jurisdictions. For example, the Reference Case for Technology Appraisals produced by the National Institute for Health and Care Excellence in England and the methodological guidance of the French Health Authority (2020) typically do not include informal care costs in their standard reference cases for cost-effectiveness analyses, focusing on direct medical costs supported by the health system. The Swedish

Council for HTA or the Dutch HTA are more likely to include informal care costs, reflecting the broader societal perspective on HTA.

Given that there is no market for informal care, its evaluation represents a significant methodological challenge.¹⁴⁻¹⁵ Two types of methods are used to estimate the value of informal care, using revealed and stated preference methods.¹⁶ Revealed preference methods determine the value of informal care based on the market price of a substitute. This is the price of the closest market equivalent for the proxy goods method^{14,17} and the informal caregiver's wage for the opportunity cost method.¹⁸⁻¹⁹ Using the proxy goods method, we can estimate how much it would cost to obtain care (provided by relatives now) from professionals. This measure is particularly useful for guiding and organizing long-term care policies, which combine private (family) and public resources. Using the opportunity cost method, we can estimate how much caregivers would earn if all hours of care were now hours of paid work. This measure is particularly useful in policies more focused on work-life balance and gender inequalities (given that women are the main providers of unpaid domestic). Both approaches exclusively value the costs associated with the time invested in providing care, without considering other costs associated with providing care and without considering its full impact on caregivers' lives, including both utilities and disutilities associated with providing care.²⁰⁻²² Furthermore, they do not assess caregivers' and care recipients' preferences,¹⁷ and they value all hours of care in the same way, whereas the (dis)value and effectiveness may vary depending on the moment of care or the care task.¹⁶

Stated preference methods aim to capture caregivers' preferences and experiences of caregiving.²² In contingent valuation, informal caregivers are asked to hypothetically state the amount they would be willing to pay or receive for caregiving.^{17,23,24} In conjoint analysis, caregivers are asked to make hypothetical choices between several scenarios that vary according to the different components of care.²¹ These methods require the design, testing, and administration of surveys to gather data on individuals' preferences, which is particularly time consuming and costly to implement compared with revealed preference methods. These methods have 2 other drawbacks compared with revealed preference methods. First, there is a hypothetical bias because they are based on a hypothetical situation in which the amounts declared depend on the format and framing of the question asked and may be higher than they would be in a real situation and biased by strategic behavior responses.²³ Second, stated preference surveys can generate a cognitive burden on respondents, who may struggle to understand the hypothetical situations, leading to unreliable or inconsistent responses or a significant nonresponsive problem. Moreover, these methods face the issue of not controlling for the heterogeneity in preferences. Previous research underlined the importance of considering the heterogeneity in preferences when valuing informal care, given that monetary compensation is important for younger people but insignificant for older individuals.²¹

The limitations of these methods highlight the need to evaluate informal care in a way that considers both the costs and benefits of providing care, depending on the duration of care, the intensity of care, the tasks of care, and the characteristics of the caregiver and the care recipient.²³ This article introduces an improvement to the replacement cost method used in half of the publications valuing informal care for people with dementia.¹⁵ It provides a new conceptual framework that allows it to consider the utilities and disutilities of care. Using a simple microeconomic model, we show that the price of informal care depends on the marginal substitution rate between formal and informal care.

Using data from a sample of French patients with AD and their informal caregivers, we estimate the parameters that compose this marginal substitution rate and explain how the relationship between the price of formal and informal care varies depending on caregivers' and patients' characteristics.

Conceptual Background

In standard microeconomics theory, the marginal rate of substitution (MRS) between 2 goods (formal care f and informal care i) is a measure of the quantity of one good that a consumer is willing to exchange for an additional unit of another good while maintaining the same level of satisfaction or utility. At equilibrium, informal caregivers' MRS is equal to the ratio of the prices of these 2 goods. Therefore, the valuation of informal care using the replacement cost method assumes that the marginal substitution rate between informal care and formal care equals 1 (as in an equilibrium state), which means that informal and formal care are perfectly substitutable and provide the same utility for each additional consumption.

Consider p_i the price of informal care and p_f the price of formal care:

$$MRS = \frac{p_i}{p_f} \leftrightarrow p_i = p_f \times 1$$

Given that informal care does not have a market price, we cannot directly calculate the price ratio of the 2 types of care to validate or invalidate this hypothesis. To calculate the ratio of the marginal utilities of the care, we use a joint household production model in which each household member has his/her utility function. To simplify, we focus solely on informal caregivers' utility function. Informal caregivers decide on the levels of formal and informal care provided to the patient. They face a budget constraint, with R corresponding to their resources (including retirement pensions, salary, and assets), given by:

$$R = p_f \times f + p_i \times i$$

We then define informal caregivers' utility function, which negatively depends on the caregiver's burden B and positively depends on the patient's quality of life (QoL) Q . The caregivers' utility function is given by $U(B, Q)$. We assume that the burden is an increasing function of informal care time i and formal care time f : $B = B(i, f)$. Indeed, Byrne et al²⁵ and Van Den Berg et al²⁶ have shown that the amount of time spent on informal care has an impact on the caregivers' well-being (increased burden). In addition, previous work showed that the use of professional care can also create a burden in 2 ways: first, through the cost of coordination between professionals, where the informal caregiver becomes a care coordinator or manager,²⁷ and second, through the cost of "social stigma," where the use of professionals can lead to a sense of neglect and a feeling of guilt among relatives.²⁸⁻²⁹

Finally, we assume that patients' QoL is an increasing function of formal and informal care provided to the patient: $Q = Q(i, f)$. People receiving more care have a better utility for equivalent levels of need.

The following maximization program determines the level of informal and formal care chosen by the caregiver:

$$\begin{cases} \max_{i,f} U(B(i,f), Q(i,f)) \\ \text{st} : R = p_f \times f + p_i \times i \end{cases} \quad (1)$$

Consider the Lagrange function L , where l is the Lagrange multiplier:

$$L(i, f, \lambda) = U(B(i, f), Q(i, f)) + \lambda(R - p_f \times f - p_i \times i)$$

The first-order conditions are as follows:

$$\frac{\partial L}{\partial i} = Um_B \times B'(i) + Um_Q \times Q'(i) - \lambda p_i = 0$$

$$\frac{\partial L}{\partial f} = Um_B \times B'(f) + Um_Q \times Q'(f) - \lambda p_f = 0$$

$$\frac{\partial L}{\partial \lambda} = Y - p_i \times i - p_f \times f = 0$$

The resolution of (1) leads to the following relationship between the price of informal care and the price of formal care:

$$p_i = p_f \times \frac{Um_B \times B'(i) + Um_Q \times Q'(i)}{Um_B \times B'(f) + Um_Q \times Q'(f)}$$

Marginal rate of substitution
between the two types of care

This equilibrium can easily be interpreted and allows an understanding of the drivers of informal care prices. The price of informal care is proportional to the price of formal care p_f . In addition, it depends on the parameters composing informal caregivers' MRS: the marginal utility associated with an increase in the informal care provision (Um_B), the marginal utility of the perceived patient's QoL (Um_Q), the marginal burden associated with an increase in informal care time ($B'(i)$), the marginal burden associated with an increase in formal care time ($B'(f)$), and the incremental gain in patients' QoL observed when informal (respectively, formal) care use increases. Note that, according to our assumptions, $B'(i)$ and $B'(f)$ have negative values, whereas $Q'(f)$ and $Q'(i)$ have positive values.

The MRS is central to understanding the relationship between the value of informal and formal care (Figure 1). The higher the numerator, the more the value of informal care tends to be compared with the value of formal care. Conversely, the higher the denominator, the lower the value of informal care compared with formal care. In the numerator, we see that informal care becomes less valuable than formal care when the loss of utility associated with the burden of informal care increases. This effect is strengthened by the size of the impact of each additional hour of informal care provided on informal caregivers' burden. We also see in the numerator that the value of informal care compared

with formal care increases if each additional hour of informal care positively affects the patient's QoL. In other words, the numerator interpretation shows that, from the informal caregivers' perspective, the value of informal care increases compared with formal care when providing informal care creates more benefits than harms. In the denominator, we see that the value of formal care increases compared with informal care when formal care services contribute to reducing informal caregivers' burden. This is especially the case when providing informal care, which is particularly burdensome for the informal caregiver. Finally, the value of informal care compared with formal care decreases if each additional hour of formal care positively affects the patient's QoL. This last effect is strengthened by the importance of the patient's QoL on the informal caregivers' utility.

Using appropriate data, the parameters Um_Q , Um_B , $B'(i)$, $B'(f)$, $Q'(i)$, and $Q'(f)$ can be estimated.

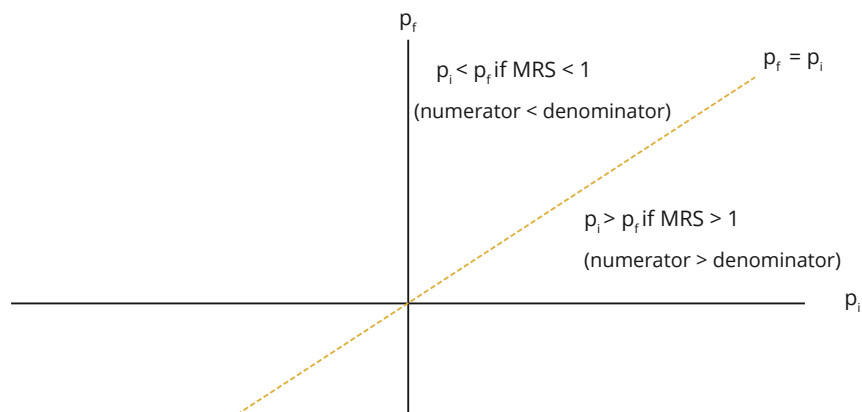
Methods

Data and Variables

Our sample came from the PLASA study, with patients diagnosed as having mild to moderate AD and their informal caregivers.³⁰ Patients were recruited between June 2003 and July 2005 from 50 French memory clinics. Patients were included in the study if they lived in the community, had a primary informal caregiver (self-reported), and had mild to moderate disease. Additional information on our data can be found in previous publications.²⁻³ We used a sample of 432 patient-informal caregiver couples with the variables needed to estimate the MRS parameters.

Informal caregivers' utility level was measured by asking whether the informal caregiver is very satisfied, satisfied, rarely satisfied, or never satisfied when providing informal caregiving. We created a dichotomous variable, which was 1 when the caregiver was either very satisfied or satisfied and 0 otherwise. This variable represents the utility of care. Informal caregivers answered the Zarit burden interview (ZBI) questionnaire to assess their level of burden associated with the caregiving activities they provide.³¹ The ZBI consists of 22 items with 5-point Likert-scale response categories that scored 0 (never) to 4 (nearly always). All 22 items calculate a total score ranging from 0 to 88, with higher scores indicating higher burden. The ZBI focuses on the caregiver's health, psychological well-being, finances, social

Figure 1. Graphical representation of the MRS between formal and informal caregivers.



MRS indicates marginal rate of substitution.

life, time constraints, and the relationship between the caregiver and the care recipient. The 22 ZBI items are presented in Appendix 1 (see Appendix 1 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856>). Care recipients answered a specific questionnaire to assess their perception of their QoL, including living conditions, family and friendship relationships, self-esteem, and appreciation of life.³² Finally, caregivers received the Resource Utilization in Dementia questionnaire to determine the levels (in hours per month) of formal and informal care provided to the patients.³³

Models

We ran 3 models. Model 1 was a probit model to explore the relationship between informal caregivers' satisfaction with help and the ZBI and QoL variables. We computed marginal effects to measure to what extent marginal variations in ZBI and QoL were associated with a change in caregiving satisfaction (utility) (model 1). Model 2 explored the relationship between informal and formal care provision (in hours per month) and ZBI. Model 3 explored the relationship among formal care use (in hours per month), informal care use (in hours per month), and QoL. Models 2 and 3 were estimated using ordinary least squares regressions. Linear probability models (ie, models using ordinary least squares regressions with discrete dependent variables) are frequently used in health economic analyses, particularly when there are interaction terms in the models that cannot be directly interpreted in probit or logit models. Although these models face accuracy issues when computing predictions, the marginal effects and standard errors are often consistent with probit/logit estimations. In sensitivity analyses presented in Appendix 4 (see Appendix 4 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856>), we show that the results are similar with a logit for model 1 and with probit or ordered probit for models 2 and 3.

We controlled the models for patients' health status, the severity of limitations, and cognitive impairment because they are strongly correlated with the probability of receiving informal and formal care³⁴⁻³⁵ as well as patient's QoL and caregiver burden.³⁶ The control variables are as follows: patients' Mini Mental Score Examination, Neuropsychiatric Inventory, number of difficulties with ADL and instrumental ADL, and the severity of deficit (clinical evaluation). We also control the models for the duration since diagnosis, because this affects the use of long-term care.³⁷ The patient's age, gender, highest education degree obtained, and income were also added as control variables. Women and high-income people are more likely to receive informal and formal care, whereas more highly educated people have less access to informal care.^{34,38} Studies also show that the caregiver burden is higher for people who care for a young male patient with a low level of education.³⁹⁻⁴⁰ Models 1 and 3 (caregiver satisfaction and burden) also controlled for informal carer's gender and age. A recent systematic review shows that the caregiving burden remains more prevalent among female caregivers, even when men and women share similar care responsibilities.⁴¹ Older caregivers are also the ones who are affected most by the impact of caring on their health.⁴² The 3 models were tested without these control variables and the results remained identical (except for model 3 where the effect of formal care became insignificant on the patient's QoL) (see Appendix 4 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856>).

All models were run using robust standard errors to avoid potential heteroscedasticity issues. Low values obtained for the variance inflation factor score (less than 2) ruled out potential

multicollinearity issues. In the second stage, we integrated interaction terms into these 3 models. Only significant interaction terms have been reported in the article. In model 1 (caregiver's satisfaction), we include 4 interaction terms between the caregiver's burden and their gender and age (older than 60 years)—women typically report greater burdens associated with caregiving than men, especially due to age differences in male and female caregivers⁴³—and between the patient's QoL and the patient's age and household income. In model 2 (patient's QoL), we include an interaction term between formal care time and the patient's age (older than 80 years). The age of the person with dementia was found to be a predictor of the use of formal care time (home nursing and home help services).⁴⁴ In model 3 (caregiver's burden), we include an interaction term between informal care time and household income. Cheneau and Simonnet (2022) show that informal care and formal care are more likely to be given to patients with higher incomes, and informal care also compensates for the lack of formal care for the most economically vulnerable.³⁴

Results

Our sample is described in Table 1. More than half of informal caregivers (76.4%) declared they were either very satisfied or satisfied when providing informal care. The average ZBI score was 24.06 (SD = 15.08), indicating a moderate psychological burden associated with informal care provision. Patients' QoL score was 14. Patients' Mini Mental Score Examination and Neuropsychiatric Inventory scores were 19.41 and 17.65, respectively, which match mild AD severity.

The regression results are presented in Table 2 (see Appendix 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856> for the full model with all control variables). The estimations confirm the model's assumptions. We find that a 1-point increase in ZBI (informal care burden) was associated with a 3.1 percentage points (pp) decrease in the probability of seeing the informal caregivers satisfied with informal care provision ($P <$

Table 1. Descriptive statistics.

Variable	Mean	SD	Min	Max
Satisfaction to help	0.764	0.42	0	1
Zarit burden index	24.069	14.98	0	76
Patient's QoL	13.893	2.463	4	20
MMSE	19.414	3.859	12	26
NPI	17.650	15.79	0	97
Duration since diagnosis	1.294	1.513	0	7
Sum of the difficulties on ADL and IADL	23.622	8.241	9	48
Patient is male	0.324	0.468	0	1
Patient's age	79.74	5.88	56	97
Caregiver is male	0.347	0.476	0	1
Caregiver's age	64.42	13.74	28	92
Care recipient's household income > €2300/month	0.219	0.414	0	1

ADL indicates activity of daily living; IADL, instrumental activity of daily living; MMSE, Mini Mental Score Examination; NPI, Neuropsychiatric Inventory; QoL, quality of life.

Table 2. Estimation of the parameters included in the marginal substitution rate.

Variable	Model 1: probit regression on caregiver's satisfaction	Model 2: linear regression on caregiver's burden	Model 3: linear regression on patient's QoL
	Average marginal effect (robust SE)	Coefficient (robust SE)	Coefficient (robust SE)
Zarit burden index	-0.031*** (0.006)		
Patient's QoL	0.083* (0.030)		
Informal care time		0.013* (0.005)	0.000 (0.001)
Formal care time		-0.009 (0.034)	0.016* (0.007)
Observations	432	432	432
R ² /pseudo R ²	0.1286	0.3152	0.0738
Mean VIF		1.43	1.33

Note. The 3 models are controlled by variables relating to the patient's state of health: duration since diagnosis, the severity of deficit (clinical evaluation), difficulties with ADL and IADL, memory and cognitive problems (MMSE), and behavioral problems (NPI). The 3 models are also controlled by sociodemographic variables: patient's sex and age, care recipient's household income, and diploma. Models 1 and 2 are additionally controlled for the age and gender of the caregiver. Model 3 is additionally controlled for public disability allowance (allocation personnalisée d'autonomie) and caregiver burden. The full model is presented in Appendix 2 (see Appendix 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856>). Formal and informal care times are calculated in hours/month. Empty cells mean that variables have not been estimated for these models. The *P*-value significance thresholds are as follows: **P* < .05; ***P* < .01; ****P* < .001 respectively.

ADL indicates activity of daily living; IADL, instrumental activity of daily living; MMSE, Mini Mental Score Examination; NPI, Neuropsychiatric Inventory; QoL, quality of life; VIF, variance inflation factor.

.01). In contrast, a 1-point increase in informal caregivers' estimations of patients' QoL was associated with an 8.3 pp increase in informal caregivers' chances of being satisfied when providing help (*P* < .01). Moreover, a 1-hour/month increase in informal care provision was associated with a 0.01 pp increase in the ZBI score (*P* < .01). Finally, a 1-hour/month increase in informal care provision was associated with a 0.016 pp increase in patients' evaluation of QoL (*P* < .01).

The regression results with interaction terms are presented in Table 3 (see Appendix 3 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856> for the full model with all control variables). We find that informal caregivers caring for people older than 80 years report 50.3 pp greater satisfaction with caregiving (*P* < .01). The burden effect on caregiver satisfaction is stronger for caregivers older than 60 years (*P* < .01). We observe that the effect of a 1-hour/month increase in formal care hours on patients' QoL is 3.1 pp higher for patients older than 80 years (*P* < .01). Male caregivers report lower ZBI scores than females (*P* < .01). Moreover, the wealthier informal caregivers are less sensitive to the effect of informal care on ZBI score (*P* < .01).

Table 3. Estimation of the interaction terms.

Variable	Model 1: linear regression on caregiver's satisfaction	Model 2: linear regression on patient's QoL	Model 3: linear regression on caregiver's burden
	Coefficient (robust SE)	Coefficient (robust SE)	Coefficient (robust SE)
Informal care time		0.000 (0.001)	0.018*** (0.005)
Formal care time		-0.004 (0.009)	-0.007 (0.034)
Zarit burden index	-0.011*** (0.002)		
Patient's QoL	0.051*** (0.012)		
Formal care time × patient 80+		0.031** (0.011)	
Zarit × Aidant 60+	0.006* (0.003)		
Zarit × Aidant male	-0.003 (0.003)		
Patient QoL × patient 80+	-0.036* (0.016)		
Patient QoL × income > 2300	-0.029 (0.018)		
Informal care time × income > 2300			-0.015* (0.007)
Patient is male	-0.056 (0.057)	0.158 (0.262)	2.177 (1.676)
Patient 80+	0.503* (0.228)	-0.452 (0.269)	-1.829 (1.277)
Caregiver 60+	-0.125 (0.069)		-0.348 (1.415)
Caregiver is male	0.042 (0.076)		-4.410** (1.556)
Diploma ≥ high school diploma (care recipient)	-0.112 (0.066)	-0.521 (0.417)	-1.141 (1.916)
Care recipient's household income > €2300/month	0.449	0.476	3.457

continued on next page

Table 3. Continued

Variable	Model 1: linear regression on caregiver's satisfaction	Model 2: linear regression on patient's QoL	Model 3: linear regression on caregiver's burden
	Coefficient (robust SE)	Coefficient (robust SE)	Coefficient (robust SE)
	(0.260)	(0.312)	(1.815)
Observations	432	432	432
R ² /pseudo R ²	0.1658	0.085	0.3269
Mean VIF		1.67	1.49

Note. The 3 models control for variables relating to the patient's state of health: duration since diagnosis, the severity of deficit, difficulties with ADL and IADL, memory and cognitive problems (MMSE), and behavioral problems (NPI). Model 3 is additionally controlled for public disability allowance (allocation personnalisée d'autonomie) recipients and caregiver burden. The full model is presented in Appendix 2 (see Appendix 2 in Supplemental Materials found at <https://doi.org/10.1016/j.jval.2024.10.3856>). Formal and informal care times are calculated in hours/month. Empty cells mean that variables have not been estimated for these models. The significance thresholds are 0.05 (5%)*, 0.01 (1%)** and 0.001 (10%*** respectively). ADL indicates activity of daily living; IADL, instrumental activity of daily living; MMSE, Mini Mental Score Examination; NPI, Neuropsychiatric Inventory; QoL, quality of life; VIF, variance inflation factor.

Conclusion

Our results show that the assumption that formal and informal care prices are equal, used in half of the academic literature valuing informal care for people with dementia,¹⁵ is theoretically and empirically wrong. A high burden associated with informal care provision (such as a reduction in the caregiver's social life or a deterioration in his/her health because of the care) reduces the value of informal care compared with formal care, especially for caregivers older than 60 years, who face more health problems with age. Conversely, the contribution of informal care to the patient's QoL increases the value of informal care, especially for caregivers of patients younger than 80 years. Moreover, the patient's QoL increases with the number of formal care hours, especially for patients older than 80 years, which reduces the value of informal care relative to formal care. Finally, our results show that the value of informal care will be lower for older informal caregivers (who are affected more by the burden of care), for low-income households (whose informal care has a higher impact on the burden), and for caregivers of people older than 80 years (for whom professional caregivers improve patients' QoL more). These results show that calculating a single value for informal care in a country using the replacement cost method is inaccurate and does not reflect the true value of informal care because of the heterogeneity of the population of caregivers. Contingent evaluations or discrete choice experiments, although costly in terms of time and setup, would provide a better estimate of the value of informal care (depending on the burden of care or the patient's QoL). If the replacement cost method is used anyway, it should be restricted to subpopulations of informal caregivers and patients with similar characteristics. In any case, it will not be possible to compare the monetary value of informal care among several categories of caregivers. For instance, the literature has shown that caregivers of people with dementia report a higher burden,⁴⁵ so the value of informal care for these caregivers would be overestimated with the replacement cost method compared with caregivers of people without cognitive impairment. Using the

replacement method could also lead to underestimating the value of informal care in a subpopulation of patients whose QoL is greatly improved by the number of informal care hours provided. Note that the MRS reflects the exchange rate between the 2 types of care and not a compensation price. Indeed, the price of informal care will tend to fall as the burden of care increases relative to the price of formal care. As in any standard market, a low price reflects an abundant resource or a smaller preference for the good. This argument contradicts the usual estimates of the price of informal care, particularly with stated preference methods, where high prices for informal care reflect a lower preference for informal care, and the price then reflects a compensation price for the negative effects of care.

Limitations

Our analyses face 3 main limitations. First, our model assumes that informal and formal care are substitutes. Otherwise, it would not be possible to analyze the MRS. However, using SHARE data, Bonsang⁴⁵ showed that informal care is an effective substitute for long-term care if the needs of patients are low and unskilled care is required.^{46,19} Given that our data cover patients with mild to moderate impairments, we assume we can analyze the rate of subjective exchange between the 2 types of care. This possible substitution between the 2 types of care still raises the question of corner solutions in our model, that is, if dependent persons receive no informal or formal care. This can occur in 2 situations: either in the case of a strong preference or aversion for 1 of the 2 types of care over the other or because of an external constraint (no access to professional care or absence of family or close friends). Note, however, that these situations are less frequent in the case of patients with AD. Previous work showed that, in France, more than 57% of people with dementia use both formal and informal care.⁶ Moreover, AD requires much supervision and, therefore, more often involves mixed care or may lead to more frequent institutionalization of patients.¹⁰

The second limitation of our study is the assumption of pure altruism when caregivers could also be motivated by financial incentives (donations from parents: gifts or bequests) and see care as an investment for the future.⁴⁷ This impure altruism would affect the caregiver's utility function. Although we did not formalize the utility function with this possibility, the estimates considered the household income of the person being cared for as a control variable, which had no effect on the utility of the caregiver. This financial incentive to provide care may be weaker in France, given that a child cannot be legally disinherited and that each child must receive his or her share of the inheritance reserve (whatever the relationship with the parent).

The third limitation of our study relates to the data used for the analyses. The PLASA data are old (2003–2005), which could raise some issues given the changes (on political, demographic, and health levels) experienced by the French healthcare system over the past 20 years. However, this issue is limited because this research focuses on the role of factors such as QoL, burden, and formal/informal care provision on the value of informal care. We do not think these factors have changed significantly over the past 20 years. Moreover, the empirical analysis illustrates the implications of the theoretical framework provided in this article, which does not depend on changes that may have occurred since 2003. Indeed, the interest lies more in analyzing heterogeneities in the values of informal care. Finally, one could argue that the sample is small (N = 432) and restricted to people with moderate dementia, which raises generalizability concerns. Further work needs will need to confirm our results using samples of patients

with more severe dementia. In addition, a larger sample size would make it possible to perform subgroup analyses, particularly according to the age of the patients and caregivers, to more precisely analyze the effect of age on burden, utility of care, patient QoL, and use of formal and informal care.

Author Disclosures

Author disclosure forms can be accessed below in the [Supplemental Material](#) section.

Supplemental Material

Supplementary data associated with this article can be found in the online version at <https://doi.org/10.1016/j.jval.2024.10.3856>.

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REFERENCES

- OECD. *Care needed: improving the lives of people with dementia*. OECD Health Policy Studies. Paris: OECD Publishing; 2018. https://www.oecd.org/en/publications/care-needed_9789264085107-en.html. Accessed January 16, 2025.
- 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;72:1310–1316.
- Rapp T, Andrieu S, Molinier L, et al. Exploring the relationship between Alzheimer's disease severity and longitudinal costs. *Value Health*. 2012;15(3):412–419.
- 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(6):827–835.
- Wimo A, Jönsson L, Bond J, Prince M, Winblad B. Alzheimer Disease International. The worldwide economic impact of dementia 2010. *Alzheimers Dement*. 2013;9(1):1–11.
- Paraponaris A, Davin B. Economics of the Iceberg: Informal Care Provided to French Elderly with Dementia. *Value Health*. 2015;18(4):368–375.
- Engel L, Ajdukovic M, Bucholc J, Mccaffrey N. Valuation of informal care provided to people living with dementia: a systematic literature review. *Value Health*. 2021;12:1863–1870.
- Goodrich K, Kaambwa B, Al-Janabi H. The inclusion of informal care in applied economic evaluation: a review. *Value Health*. 2012;15:975–981.
- Krol M, Papenburg J, Van Exel J. Does including informal care in economic evaluations matter? A systematic review of inclusion and impact of informal care in cost-effectiveness studies. *Pharmacoeconomics*. 2015;33:123–135.
- Wübker A, Zwakhalen S, Challis D, et al. Costs of care for people with dementia just before and after nursing home placement: primary data from eight European countries. *Eur J Health Econ*. 2015;16(7):689–707.
- Peña-Longobardo LM, Rodríguez-Sánchez B, Oliva-Moreno J, Aranda-Reneo I, López-Bastida J. How relevant are social costs in economic evaluations? The case of Alzheimer's disease. *Eur J Health Econ*. 2019;20(8):1207–1236.
- Drummond M, Sculpher M, Torrance G, O'Brien B, Stoddart G. *Methods for The Economic Evaluation of Health Care Programmes*. Oxford, England: Oxford University Press; 2002.
- Sanders GD, Neumann PJ, Basu A, et al. Recommendations for Conduct, Methodological Practices, and Reporting of Cost-effectiveness Analyses: Second Panel on Cost-Effectiveness in Health and Medicine. *JAMA*. 2016;316(10):1093–1103.
- Van Den Berg B, Brouwer WBF, Koopmanschap MA. Economic valuation of informal care: an overview of methods and applications. *Eur J Health Econ*. 2004;5(1):36–45.
- Engel L, Ajdukovic M, Bucholc J, Mccaffrey N. Valuation of informal care provided to people living with dementia: a systematic literature review. *Value Health*. 2021;12:1863–1870.
- Koopmanschap MA, Van Exel JN, Van Den Berg B, Brouwer WB. An overview of methods and applications to value informal care in economic evaluations of healthcare. *Pharmacoeconomics*. 2008;26:269–280.
- Van Den Berg B, Bleichrodt H, Eeckhoudt L. The economic value of informal care: a study of informal caregivers' and patients' willingness to pay and willingness to accept for informal care. *Health Econ*. 2005;14:363–376.
- Carmichael F, Charles S. The opportunity costs of informal care: does gender matter? *J Health Econ*. 2003;22(5):781–803.
- Hassinck WH, Van Den Berg B. Time-bound opportunity costs of informal care: consequences for access to professional care, caregiver support, and labour supply estimates. *Soc Sci Med*. 2011;73(10):1508–1516.
- Al-Janabi H, Coast J, Flynn T. What do people value when they provide unpaid care for an older person? A meta-ethnography with interview follow-up. *Soc Sci Med*. 2008;67(1):111–121.
- Mentzakis E, Ryan M, McNamee P. Using discrete choice experiments to value informal care tasks: exploring preference heterogeneity. *Health Econ*. 2011;20:930–944.
- Oudijk D, Woittiez I, Boer A. More family responsibility, more informal care? The effect of motivation on the giving of informal care by people aged over 50 in the Netherlands compared to other European countries. *Health Policy*. 2011;101:228–235.
- Gerves C, Bellanger MM, Ankri J. Economic analysis of the intangible impacts of informal care for people with Alzheimer's disease and other mental disorders. *Value Health*. 2013;16:745–754.
- Liu W, Lyu T, Zhang X, Yuan S, Zhang H. Willingness-to-pay and willingness-to-accept of informal caregivers of dependent elderly people in Shanghai, China. *BMC Health Serv Res*. 2020;20:1–11.
- Byrne D, Goeree M, Hiedemann B, Stern S. Formal Home Health Care, Informal Care and Family Decision-Making. *Int Econ Rev*. 2009;50(4):1205–1242.
- Van Den Berg B, Fiebig DG, Hall J. Well-being losses due to care-giving. *J Health Econ*. 2014;35(10):123–131.
- Da Roit B, Le Bihan B. La prise en charge des personnes âgées dépendantes en France et en Italie. Familialisation et défamilialisation du care? *Lien social et politiques*. 2009;62:41–55.
- Carpentier N, Ducharme F, Kergoat MJ, Bergman H. Social representations of barriers to care early in the careers of caregivers of persons with Alzheimer's disease. *Research on Aging*. 2008;30(3):334–357.
- Berard A, Gzil F, Kenigsberg PA, Ngatcha-Ribert L, Villez M. *Le répit : des réponses pour les personnes atteintes de la maladie d'Alzheimer ou de maladies apparentées, et leurs aidants (Rapport d'étude n°1)*. Fondation Médéric Alzheimer; 2011.
- Nourhashemi F, Gillette-Guyonnet S, Andrieu S, Rolland Y, Ousset PJ, Vellas B, PLASA group. A randomized trial of the impact of a specific care plan in 1120 Alzheimer's patients (PLASA Study) over a two-year period: design and baseline data. *J Nutr Health Aging*. 2008;12(4):263–271.
- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20:649–655.
- Logsdon RG, Gibbons LE, Mccurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*. 2002;64:510–519.
- Wimo A, Nordberg G, Jansson W, Grafstrom M. Assessment of informal services to demented people with the RUD instrument. *Int J Geriatr Psychiatry*. 2000;15:969–971.
- Cheneau A, Simonnet V. Care use by the disabled: are professional and informal care substitutes. *Annals of Economics and Statistics*. 2022;168:109–140.

35. Gramain A, Roquebert Q, Tenand M. Aide informelle à domicile et en EHPAD : déterminants, valeur monétaire et implication pour la répartition des coûts de la dépendance. *Revue D'économie Financière*. 2023;152(4):125–139.
36. Dauphinot V, Delphin-Combe F, Mouchoux C, et al. Risk factors of caregiver burden among patients with Alzheimer's disease or related disorders: a cross-sectional study. *J Alzheimers Dis*. 2015;44(3):907–916.
37. sm-Rahman A, Meinow B, Hydén LC, et al. Long-term care use among people living with dementia: a retrospective register-based study from Sweden. *BMC Geriatr*. 2022;22:998.
38. Gramain A, Hegé R, Roquebert Q, Tenand M. *La tarification des services d'aide à domicile : un outil au service des politiques départementales*. HAL Open Science; 2014. <https://hal.science/hal-01092496v5/document>. Accessed January 16, 2025.
39. Germain S, Adam S, Olivier C, et al. ICTUS-EADC Network. Does cognitive impairment influence burden in caregivers of patients with Alzheimer's disease? *J Alzheimers Dis*. 2009;17:105–114.
40. Agüera-Ortiz L, Frank-García A, Gil P, et al. Clinical progression of moderate-to-severe Alzheimer's disease and caregiver burden: a 12-month multicenter prospective observational study. *Int Psychogeriatr*. 2010;22:1265–1279.
41. Xiong C, Biscardi M, Astell A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: a systematic review. *PLoS One*. 2020;15(4):e0231848.
42. Cheneau A. La diversité des formes d'aide et des répercussions de l'aide sur les aidants. *Revue Française des Affaires sociales*. 2019;1:91–113.
43. Barusch AS, Spaid WM. Gender differences in caregiving: why do wives report greater burden? *Gerontologist*. 1989;29(5):667–676.
44. Bieber A, Nguyen N, Meyer G, et al. Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review. *BMC Health Serv Res*. 2019;19:88.
45. Bertrand RM, Fredman L, Saczynski J. Are all caregivers created equal? Stress in caregivers to adults with and without dementia. *J Aging Health*. 2006;18(4):534–551.
46. Bonsang E. Does informal care from children to their elderly parents substitute for formal care in Europe? *J Health Econ*. 2009;28(1):143–154.
47. Canta C, Cremer H. Long-term care policy with non-linear strategic bequests. *Eur Econ Rev*. 2019;119:548–566.