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## Economic Analysis of the Intangible Impacts of Informal Care for People with Alzheimer's Disease and Other Mental Disorders

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### ABSTRACT

**Objectives:** Valuation of the intangible impacts of informal care remains a great challenge for economic evaluation, especially in the framework of care recipients with cognitive impairment. Our main objective was to explore the influence of intangible impacts of caring on both informal caregivers' ability to estimate their willingness to pay (WTP) to be replaced and their WTP value. **Methods:** We mapped characteristics that influence ability or inability to estimate WTP by using a multiple correspondence analysis. We ran a bivariate probit model with sample selection to further analyze the caregivers' WTP value conditional on their ability to estimate their WTP. **Results:** A distinction exists between the opportunity costs of the caring dimension and those of the intangible costs and benefits of caring. Informal caregivers' ability to estimate WTP is negatively influenced by both

intangible benefits from caring ( $P < 0.001$ ) and negative intangible impacts of caring ( $P < 0.05$ ). Caregivers' WTP value is negatively associated with positive intangible impacts of informal care ( $P < 0.01$ ). **Conclusions:** Informal caregivers' WTP and their ability to estimate WTP are both influenced by intangible burden and benefit of caring. These results call into question the relevance of a hypothetical generalized financial compensation system as the optimal way to motivate caregivers to continue providing care. **Keywords:** Alzheimer, cognitive impairment, contingent valuation, informal care, intangible impact of caring.

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### Introduction

It has been argued that Alzheimer's disease and other mental disorders can generate direct, indirect, and intangible costs [1–4]. Informal care, as part of the indirect and intangible impacts of caring, has been a subject of interest for both research and social policies. In the case of long-term care in particular, “family care management” is considered a substantial part of the total cost of care [5]. Analyzing the socioeconomic impacts of Alzheimer's-type disease in Europe (EU27), Kenisgsberg et al. [1] estimated that in 2008, on average 55% of the total cost of care was attributable to informal care.

Informal care was described by Van den Berg et al. [6] as a “quasi-market composite commodity [provided] by one or more members of the social environment of the care recipient, [and resulting] of the care demand of the care recipient.” Because ageism, combined with lack of public funding, could lead to informal care becoming the cornerstone of elderly care, a value must be placed upon it. The unpaid aspects of informal care have been the main focus of economic evaluation, and informal caregivers' time trade-off has been the subject of an abundant literature [7–11]. In addition, most economic studies to date have focused on the negative impacts of caregiving [12]; however, informal caregivers may also derive benefits from caring [13]. If research in psychology was a forerunner of the concept of the intangible impacts of caring [14], a growing economics literature

has also deemed these impacts to be worthy of inclusion in cost-benefit or cost-utility analysis [13,15–17].

Intangible impacts of caring are another facet of externalities. Applied to mental health care by Mulvaney-Day [18], intangible costs encompassed the “pain and the suffering associated with the illness” and related to the disease's subjective burden and lost quality of life. Such impacts have been progressively extended to informal care and the subjective burden of caring defined as the informal caregiver's perception of “the impact of the objective burden related to caregiving” [19–21]. Therefore, the subjective burden is influenced by the amount of time spent on caregiving, as well as by the social relations between the informal caregiver and his or her care recipient and the psychological and emotional consequences of caring [16,22]. Additional intangible effects may also be considered, such as grief, anxiety and social handicap, fatigue, giving up leisure activities, and fewer social contacts, ultimately [23,24].

There has been less literature about the intangible benefits of informal care. The latter, such as strengthened family ties, feeling of accomplishment, and alleviation of guilt or empathy, have to be part of the informal caregiver's utility function [25]. Caregiving satisfaction is inversely influenced by the same factors as burden of caring because it represents “the perceived subjective gains and rewards, and the experience of personal growth that occurs as a result of providing care [26].

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The main objective of our article was to examine the relationship between the positive and negative intangible impacts of caring and the monetary value informal caregivers are willing to pay to be replaced. By focusing on how intangible impacts of informal care may influence the willingness to pay (WTP), within the framework of the contingent valuation (CV) method, we developed an original approach. In our study, intangible impacts encompass both the intangible costs (i.e., lack of social relationships or negative effect on caregiver's morale) and benefits such as the change in caregiver-care recipient relationships or fulfilled motivations to provide care. In contrast to many studies' recommendations, we could not supervise the whole questionnaire drafting process. Because WTP does not increase at fixed intervals, the WTP question format was not standard. Furthermore, intangible impacts of caring were not approximated by any validated scale such as Caregiver Reaction Assessment or by any common measure such as quality-adjusted life-year (QALY). These impacts were therefore more broadly analyzed in a broader scope than is usual in research on informal care because we focused on more facets of intangible impacts of caring than do validated scales [27,28].

### WTP and Intangible Impacts of Caring

Informal care is part of health function production. Thus, informal caregiving time is not a free input [29]. Informal caregivers derive both direct and indirect (dis)utility from time spent on caregiving activities [13,30] and, according to the Hicksian theory, this affects their willingness to provide informal care [2,6]. What we call the intangible impacts of caring will be approximated by informal caregivers' WTP to be replaced for 1 hour of care, as WTP is supposed to be related to the caregivers' disutility (utility) associated with this intangible negative (positive) impact of caring. Although WTP has been used in many studies valuing informal care [6,13,15,28,31], few have explored how the intangible impacts of caring may affect the informal caregivers' ability to estimate their own WTP [13,32] and how these impacts are more likely to influence the value of their WTP.

To elicit an informal caregiver's WTP, we used the CV method, which has been proved to be relevant in the frame of nonmarket commodity. As stated by Glendinning et al. [33], this method is "capable of capturing all relevant aspects of informal care due to its sensitivity to the different circumstances informal caregivers are faced with, and it reflects their true preferences." In the literature about stated preference methods, several techniques are developed and allow informal caregivers to be asked for their WTP. The bidding game, the dichotomous choice, and the payment card can be considered benchmarks [34–36]. In addition, some validated scales are used to quantify the burden of caring when the intangible effects of informal care are valued [37–39].

As the "citizen worker" model has progressively replaced the traditional "male breadwinner" model in Western countries [40], informal care has tended to become more and more "commodified." Some authors, however, considered total "commodification" of care as being impossible because care also reflects emotional needs and remains socially embedded [41]. Lewis and Giullari, in line with Sen and Nussbaum's capability's approach [42–45], showed that valuing care was the only way to render "choice to care" equal to "choice to not care" among caregivers. These findings raise two fundamental questions for the present study: To what extent do the intangible impacts of caring limit caregivers' ability (capability) to estimate a price for their caregiving activities? What would this price be, given that limitation? Integrating the emotional and relational impacts of caring into the value of care could improve caregivers' capabilities in terms of making a decision to care and then improve their freedom to achieve care. From a societal perspective, giving

monetary value to these intangible impacts, given caregivers' potential inability to value WTP, should make the caring-noncaring trade-off fairer and might involve either a more efficient financial compensation policy or the development of more efficient alternative policies.

Our analysis was thereby developed on the basis of two main hypotheses related to the possible associations between the intangible impacts of caring and the caregivers' WTP. The first assumed that these impacts affect informal caregivers' ability to estimate their WTP to be replaced for 1 hour. Under the second hypothesis, the WTP value was assumed to be affected by the intangible impacts of caring. To our knowledge, such an analysis has not been carried out so far in economic evaluation.

The outline of this article is as follows. The main characteristics of our sample will be presented. Then, the empirical methods and model specifications used will be described. Results are presented and then discussed along with policy implications.

### Data Collection and Study Sample

Data collection was set by a French polling institute named BVA, associated with the Novartis Foundation, which is dedicated to informal caregivers in France. The data used stemmed from the fourth wave of the informal caregivers' panel data, collected in 2010, and comprises 533 nondependent caregivers, older than 15 years, and representative of French population. A close-ended questionnaire, specific to the French context, was used for the phone interviews and included 112 questions about the informal caregivers' feelings concerning both the objective and subjective impacts of informal caregiving. Representativeness of the sample was ensured by using the quota sampling method, based on sex, age, and occupation, after regional stratification.

We focused on informal caregivers providing care to elderly care recipients with cognitive impairments because the latter are known to mobilize more burdensome care than do elderly people without such impairment [46,47]. The inclusion criteria for our selected population of care recipients aged 65 years and older were suffering from Alzheimer's disease, "suffering from old age," and suffering from depression. There were two motivations behind this clustering of care recipients. First, we supposed that being considered a care recipient because of "old age" could hide dementia-stigmatization. Indeed, research in sociogerontology has already demonstrated that a loss of cognitive skills can be misinterpreted as a normal "old age" factor [48–50]. Second, depression is a mental disorder that can be hard to distinguish from dementia symptoms in the case of elderly patients [51]. Furthermore, preliminary chi-square tests were performed on informal assistance for activities of daily living activities (ADL) and instrumental ADL (IADL), which have been shown to be associated with patients' cognitive impairment [52–54], and on the negative impact of caring on caregivers' moral and social relationships (burden of caring proxies). Because the latter, as well as informal ADL and IADL assistance, were found to be significantly independent of the care recipients' disease at the 0.05 level, analyzing the intangible impacts of informal care of one cluster of care recipients with cognitive impairments was therefore possible. Consequently, 201 informal caregivers who met the care recipients' inclusion criteria were selected and represented our target population. Caregiver distribution among the main facets of the intangible impacts of caring studied is reported in Table 1.

In this article, the WTP question is designed as a derived payment card framework, although the latter used ranges of WTP that did not increase at fixed intervals. Basically, five answers to the WTP question were proposed and then converted into three categories for analysis, as presented in Table 2. "I don't know"

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