



Evaluation of full costs of care for patients with Alzheimer's disease in France: The predominant role of informal care



Chloé Gervès^{a,b,*}, Pauline Chauvin^c, Martine Marie Bellanger^a

^a Département SHSC, Ecole des Hautes Etudes en Santé Publique, Avenue du Pr Leon Bernard, CS 72, Rennes, France

^b Laboratoire Santé Environnement Vieillesse, Hôpital Sainte Périne, 49 rue Mirabeau, 75016 Paris, France

^c Université Paris Descartes-LIRAES (EA4470), 45 rue des Saints-Pères, 75006 Paris, France

ARTICLE INFO

Article history:

Received 11 April 2013

Received in revised form

30 November 2013

Accepted 1 January 2014

Keywords:

Alzheimer's disease

Informal care

Formal care

Opportunity cost method

Proxy good method

France

ABSTRACT

Objective: It is crucial that the cost of Alzheimer's disease be evaluated, from a societal perspective, since the number of patients is expected to increase dramatically in the coming decades. This assessment of the full cost of care for community-dwelling patients with Alzheimer's disease in France also addresses the factors associated with informal care, its predominant component.

Data and methods: From 2009 to 2010, 57 patient/informal caregiver pairs were interviewed using the Resource Utilization in Dementia questionnaire, adapted to provide a micro-costing approach of the overall care process. Both the opportunity cost method and the proxy good method were used to value informal care. Ordinary least square regression was performed to determine factors associated with informal care.

Results: Average total monthly costs were €2450 with the proxy good method and €3102 with the opportunity cost method. Living with the patient, severity of dementia and hours spent on formal care were significantly associated with informal care time.

Policy implications: Since French allowance cannot cover all formal and informal non-medical costs, the choice for policy makers is either to spend more on formal care or to develop family care by investing in supportive programmes for informal caregivers.

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1. Introduction

Alzheimer's disease (AD) represents the lion's share of the dementia prevalence rate [1]. Along with an ageing population, the number of people with AD is expected to increase in the future since AD prevalence has been shown by Prince et al. (2013) to be positively associated with age [2]. In France in 2010, patients with AD were estimated to represent 2–4% of the population aged 65 and over [3],

and a similar distribution was observed in other developed countries [4].

Caring for patients with AD generates significant costs. Within the EUROCODE project, the cost of dementia was €160 billion in the EU27 in 2008 [5] corresponding to 1.3% of EU GDP. Since the number of AD patients is expected to be multiplied by 2.5 by 2040 in France [6], the related costs are likely to rise significantly. In addition to formal medical costs, assistance for community-dwelling patients with AD, who are 60% of total patients [7], constitutes the greatest part of costs [8] and is provided by both professional services (formal care) and relatives and friends (informal care). Previous studies have already measured costs generated by formal care for patients with AD, although only a few of these have focused on both informal and formal care [9–11]. However, all types of care have to be taken

* Corresponding author at: Département SHSC, Ecole des Hautes Etudes en Santé Publique, Avenue du Pr Leon Bernard, CS 72, Rennes, France. Tel.: +33 671 353 163.

E-mail addresses: chloe.gerves@ehesp.fr (C. Gervès), pauline.chauvin@parisdescartes.fr (P. Chauvin), martine.bellanger@ehesp.fr (M.M. Bellanger).

into account, and full costs of caring are very important in a comprehensive economic analysis when appropriate long term care policies have to be implemented – including choices made by government among cost-effective interventions or programmes designed to support caregivers [12].

Particular emphasis should be put on informal care assessment since most resources used for patients suffering from the less severe forms of AD are informal [9] as is the largest care component for all patients with AD in high-income countries such as the US, Italy, and France [13,14]. In the latter, 60% of total AD care costs were attributable to informal care, whereas these only represented 55% across all EU27 countries [14]. From a societal perspective, valuing informal care along with formal care allows accurate estimation of overall AD related costs and better anticipation of future demand and supply for care. A monetary value needs to be given to informal care given that it has no market price, being referred to by Van den Berg et al. as a ‘quasi-market composite commodity’ arising out of care recipients’ demand [15]. Valuing this last is thus a complicated task when estimating costs related to AD. However, two benchmark methods are available for valuing informal care time: stated preference methods, which rely upon hypothetical scenarios, and revealed preference methods, based on observable behaviours [16]. Among the latter, our study used two competing – and theoretically different – approaches to time unit estimation: we valued caregiving inputs using the opportunity cost method and caregiving outputs using the proxy good method [17]. In comparison with stated preference methods – such as the contingent valuation and conjoint measurement methods – these are more straightforward to implement, and both estimate informal care on the basis of the amount of time spent on it.

Because of demographic changes (i.e. lower fertility rates, ageing population), the increasing participation of women in the labour market and geographical distance between family members, caregiving for elders has gradually become a public policy concern rather than a family one [18]. As a result, the commodification of care (which often implies marketization of care [19,20] or welfare mix policies) combines private and public care [21]. In such a context, public financial subsidies have been introduced in most OECD countries in order to offer some measure of support to patients’ AD-related economic burden [22]. Since 2002, a means-tested allowance in France, named APA (Allocation Personnalisée d’Autonomie) has been provided to patients aged over 60 and needing formal and informal assistance for activities of daily living (ADL). APA was estimated at around €500 per month for community-dwelling patients in 2009 [23].

Current concerns about the APA’s ability to compensate the full cost of AD (including informal costs) have directly underpinned our research. The study first aimed to assess all costs for community-dwelling patients with AD in France using both the opportunity cost method and the proxy good method. Second, factors associated with informal care time were analyzed. The paper is set out as follows. Material and methods are described in Section 2. In Section 3, we summarize and interpret the results for

the estimated costs and factors influencing informal care time. Finally, the results are discussed before concluding by some policy implications.

2. Materials and methods

2.1. Study design

The study was developed as part of a research project targeting the trajectories of patients with AD and other mental disorders, and financed by the French National Fund for Solidarity & Autonomy. Three regional public multi-disciplinary memory clinics located in mid-sized towns participated in the recruitment of patients, referred by GPs, other health professionals or families, since they are used to caring for more socially diverse range of patients than are specialists in private practice [24].

To be included in the study, patients had to have been diagnosed at least one year before the interview, be community-dwelling and over 60 years old. Fifty-seven AD patients meeting these criteria were selected. Being cared for by informal caregiver(s) was only a secondary inclusion criterion. Patients and/or informal caregivers were interviewed from September 2009 to June 2010.

The Resource Utilization in Dementia – (RUD) – Lite questionnaire [25] was slightly adapted to better fit the micro-costing approach we adopted. First the ADL and IADL subcategories of RUD lite codebook were also used as questions to collect related data, conversely to the overall ADL & IADL caring activities of RUD lite questions. Second, drug and non-drug therapy related questions were added to the original RUD questionnaire to estimate their costs precisely. Socioeconomic characteristics of patients and their primary caregivers were also collected, along with qualitative information related to patient care pathways [26].

2.2. Cost assessment

Of the three main types of costs – direct, indirect and intangible – defined in Cost Of Illness (COI) studies, we have focused exclusively on the two first categories, since these allow a societal perspective for evaluation. Basically, “*Direct costs measure the resources used to treat an illness [whereas] indirect costs measure the loss of productivity, the effect of the illness on the patient or caregiver abilities to work*” [27]. Although there is a growing literature in favour of including intangible costs in cost-benefit or cost-utility analysis [28,29], we were unable to take these into consideration due to data availability. These costs are seldom included in economic evaluations, mainly because of the difficulty of monetizing the subjective burden of caring [30,31].

Costs incurred by patients and their caregivers, and by health insurance or social funds, were estimated in the study. Based on the micro-costing method (a bottom-up approach including all resources used in a production process of care) [32–35], direct and indirect resources were listed and valued as shown in Table 1. Direct resources were estimated for medical care, encompassing AD-related drug consumption, hospital stays, physicians and nursing services. Where costs were estimated for formal non-medical care, these included home assistance and respite care,

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