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The Burden of Informal Caregivers of Alzheimer's Patients: An Estimation to Portugal

Aida Isabel Tavares and Carolina Freitas

Abstract

The demographic phenomenon of ageing is speeding up in Europe. People live longer and so the prevalence of dementia increases, including Alzheimer's disease. This is a progressive disease in which people slowly lose their cognitive and physical capacities until death takes over. Alzheimer's disease not only imposes a very high burden in the affected person but also inflicts a high and overwhelming burden of the caregivers. The carers' burden includes health deterioration, labour damaging and losses and financial and social costs, while the care provided is not well valued. The aim of this chapter is to review the main trends and concepts related to ageing, caregivers and Alzheimer's disease. It also presents the economic burden associated with the disease and the monetary value of the care provided by caregivers in Portugal.

Keywords: informal care, Alzheimer's disease, burden of disease, Portugal

1. Introduction

Alzheimer's disease is the most common form of dementia, and it accounts for about 60–70% of the 50 million people suffering from dementia worldwide [1]. This means that between 30 and 35 million of people suffer from Alzheimer's disease across the world. However, the numbers of those with this disease may be underestimated as only about 40–50% of the cases of dementia are identified in developed countries [2].

Dementia and, in particular, Alzheimer's disease are a major reason for the disability and dependency across older people. The individual impact burden due to this disease is broad. It includes physical, psychological, social and economic aftermaths. But also the burden is shared with carers, families and society in general [1]. About 50% of carers say that their own health was affected by the responsibility of caring their Alzheimer's patients despite their positive sentiments about their role [3]. The economic repercussions of Alzheimer's disease are diverse, and they include the direct medical costs, the social care costs and the costs of informal care. The magnitude of these economic repercussions cannot be ignored neither by society nor by politicians.

The aim of this chapter is of twofold. Firstly, we review the phenomenon of ageing and describe the increasing prevalence of Alzheimer's disease; additionally, we highlight the relevance of informal care and the burden supported by informal caregivers. Secondly, this chapter aims to describe the social and financial burden of informal caregivers of Alzheimer's patients in Portugal and to estimate a monetary value for the care they provide and have to bear.

The chapter proceeds with a section describing the ageing phenomenon and Alzheimer’s disease, as well as the increasing prevalence of this disease. Next, it reviews the type of care available to deal with Alzheimer’s patients, and a particular emphasis is placed on informal care. In the following section, the socio-economic burden of informal caregivers is outlined. The chapter continues with a section presenting the estimation of the financial burden of carers of Alzheimer’s patients in Portugal followed by a conclusion section.

2. Ageing and the Alzheimer’s disease

The current major demographic phenomenon in Europe is ageing. The share of older people in the population is increasing, and the age distribution picture is changing to an oval shape, and it is tending to look like a block. The ageing trend may be explained by (i) the increased longevity of people, (ii) the declined fertility and (iii) the ageing of “baby boom” generations.

In Europe, as the cohort of baby boomers gets older, the wider stripes of the pyramid move up in direction of the top of the pyramid. Younger generations and their low fertility are reflected by their narrow stripes at the base of the age pyramid. As the time goes by, the top highest age group of the pyramid enlarges as an increasing large share of very old people who are living longer lives (Figure 1) [4].

So life expectancy has been increasing and people are living longer. These longer lives may be lived in a healthy status, but most likely the additional years of life are lived in unhealthy conditions, in particular, the last years of life. Among the health conditions, the most prevalent in older ages is dementia, which includes Alzheimer’s disease. This health condition is not a consequence of the ageing natural process, but it has a high prevalence among the older group of people [5]. It generates high economic and social costs, and for this reason it may be considered as one of the great challenges of society nowadays [5].

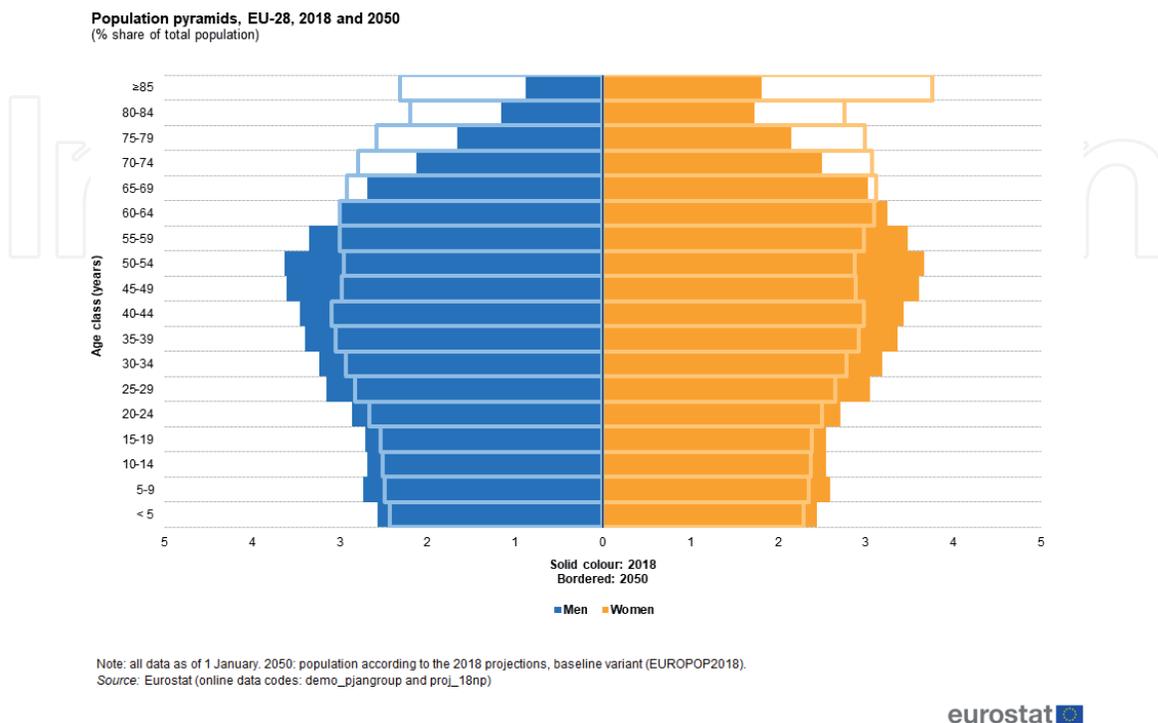


Figure 1.
Population age pyramid in Europe.

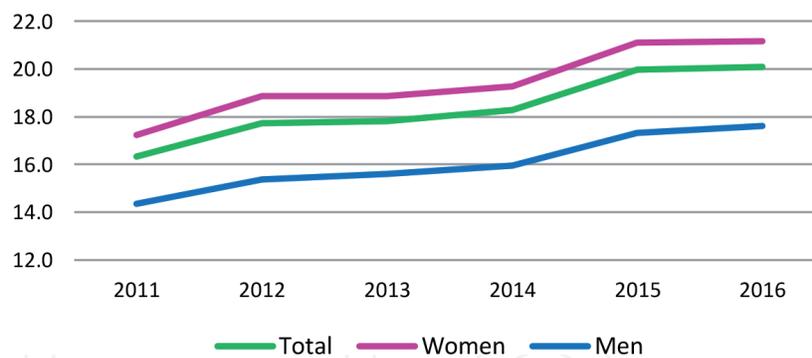


Figure 2. Standardised death rate due to Alzheimer's disease. Source: Based on Eurostat [hlth_cd_asdr2] [8].

Dementia (and Alzheimer's disease) is a syndrome, chronic or progressive, characterised by an abnormal and fast decline in the ability of people to reason and think (the decline of the cognitive function). Although consciousness is not affected, the remaining capacities are strongly diminished such as memory, thinking, orientation, comprehension, calculation, learning, language and judgement. Additionally, there is a decline in the emotional control and social behaviour [1].

Life expectancy for an Alzheimer's patient, after his diagnosis, is about 10 years. There are three stages of progressive gravity of the disease: early (2–4 years), mild (2–10 years) and late (1–3 years or more) stages. In the early stage, illness goes unnoticed, and its signs include forgetfulness, losing oneself in familiar surroundings and losing track of time. As the illness progresses, at the mild stage, the signs become clear, and patients begin to forget recent events and people's names, forget where they are, have difficulty communicating with others, need help with personal care and start to show behavioural changes as wandering and repeat questioning. When the last stage is reached, Alzheimer's patients are inactive and dependent. Their memories are seriously damaged and physical signs are obvious.

The clinical dementia rating (CDR) is the clinical instrument that measures the severity of dementia, including Alzheimer's disease. This instrument evaluates six domains of cognitive and functional performance of patients, including memory, orientation, judgement and community affairs. This instrument scores the patients impairment in five levels so that medical intervention is more adequate and effective.

CDR is not a clinical diagnosis; it rather is a measurement scale that helps the diagnosis of Alzheimer's disease. In fact, there is no single test that provides a consistent diagnosis of Alzheimer's disease. The diagnosis is a process of careful evaluation done by a multidisciplinary team which may include neurologists, geriatricians, nurses, psychologists and psychiatrists [6].

In Western Europe, in 2016, it has been estimated that 4,499,078 disability-adjusted life years (DALY) were attributed to Alzheimer's dementia disease [7]. Mortality associated to Alzheimer's disease has been increasing in Europe (Figure 2). Women die more than men, but the rate of increase has been identical for both genders. This trend is expected under the current conditions of longer lives and advance medical knowledge.

Currently, there are no medicines that prevent Alzheimer's disease or cure it, and so the numbers of patients and deaths will continue to grow, as well as the burden on the people suffering the disease, on the caregivers and on the health system as a whole.

3. Informal caregiver and the socio-economic burden

Caring of Alzheimer's patients may take place in two frameworks, which may be supplemental or complementary: the formal care and the informal care.

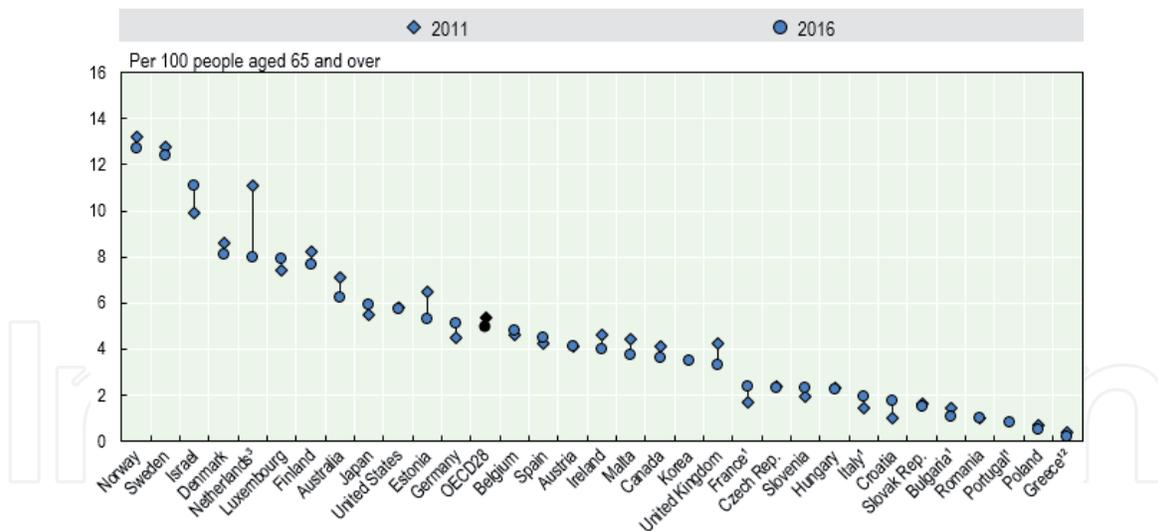


Figure 3. The number of LTC workers per 100 individuals aged +65, 2011 and 2016 (or nearest year). Note: LTC, long-term care. Source: OECD [9].

The formal care is supplied by the public or private sector and by its health-care professionals, who provide a service and are paid for that service. Across Europe, the number of formal carers is low. In some countries, such as Portugal, the number of formal carers is extremely low, less than an average of 2 long-term care (LTC) professionals per 100 older persons aged above 65 (Figure 3). While in some countries the number of LTC workers per old person has increased between 2011 and 2016 (as in France and Croatia), in other countries there has been a decrease (as in the Netherlands, Estonia and the UK) (Figure 3).

Informal care is offered by someone who is close to the older patient, either family, friends or neighbours. Informal carers provide help in a voluntary and non-paid manner. Usually caregivers provide assistance to patients in their own home, and this assistance is mainly directed for patients' daily tasks [9].

Despite international data on informal carers is hard to compare and it is based in several sources of information, the OECD has gathered the information for several countries concerning the share of informal carers among the population aged more than 50 (Figure 4) [10].

In spite of being difficult to find numbers for informal carers along the time and across countries, it is expected that this number will not be sufficient to attend to the increased number of dependent older people [11].

The total cost of dementia in EU27 in 2008 was estimated in round number of \$160 billion, and 56% of these are costs of informal care. While in Northern Europe the larger proportion goes for formal care, in Southern Europe the larger share is on the informal care [12].

The importance of informal care has become a more prominent issue recently, as the share of elderly in the population began to increase and as the LTC system funding began to be a social concern. Not only informal care is a cost-effective alternative, but also it is a well-being alternative for patients who may remain at their homes. So in several countries across Europe, different public supports have been offered to informal care as a form of incentive and as a support to families and friends of patients. That being so the distinction between formal and informal and paid and unpaid care is becoming unclear in European countries [13].

Informal care is provided at home, and it basically aims to help Alzheimer's patients in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) but also to give emotional support. ADLs are activities that include

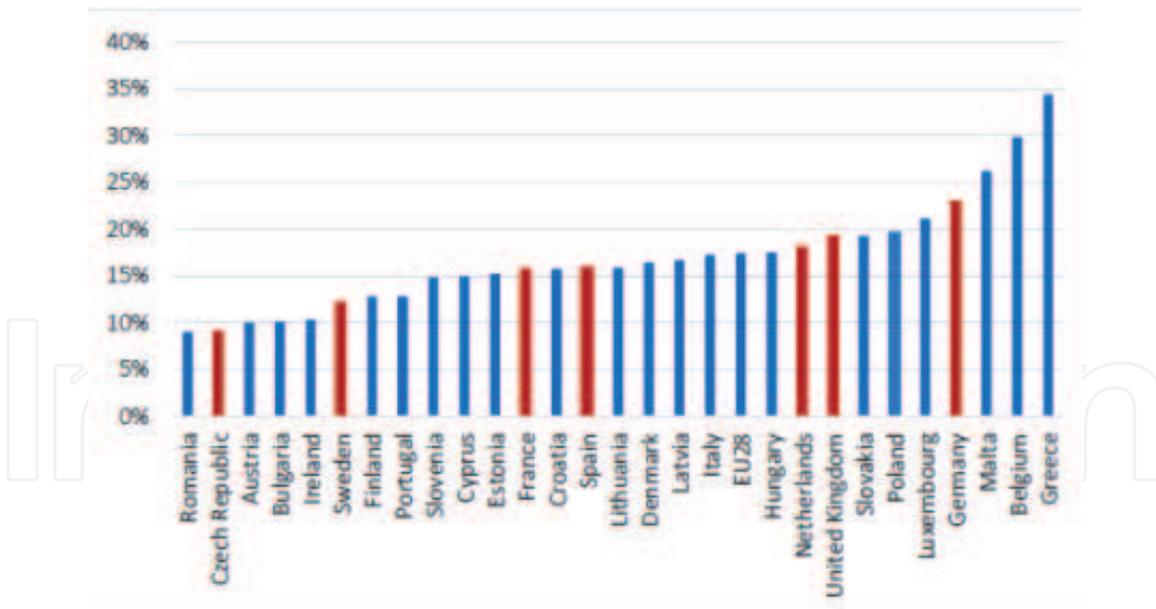


Figure 4. Informal carers as a % of total population, EQLS 2016. Source: EQLS 2016, figure adapted from EQLS overview report [10].

basic self-care tasks such as walking, toileting, bathing, feeding and dressing. IADLs are self-care activities, which require some complex thinking, skills and organisation. These include managing finance, transportation, shopping, meal preparation, communication and managing medications.

Helping with these activities systematically along time is uncomfortable, unpleasant and overwhelming. Informal caregiving is emotionally rewarding, bringing up self-esteem and sense of worthiness and life mission. But it is a very demanding role, and informal carers very often suffer burnout and health problems [14]. On top of this, several carers have difficulties combining the care with their labour responsibilities, and some quit their jobs to be able to respond the patient needs. In fact, this decision may be harmful in their future as it compromises future employability and leads to permanent drop-out from the labour market [15].

Several studies have been devoted to estimate the cost of taking care of Alzheimer's patients. In general, these costs depend on the number of hours of care, the severity degree of the disease, the use of formal care and the weather the carer is cohabiting with the patient [16].

The most used methods to estimate the monetary value of informal care to Alzheimer's patients are those based on "stated preferences" and those based on revealed preferences, which include the "proxy-good method" (also called market cost method) and the "opportunity cost method" [17].

"Stated preferences" is a method to provide a monetary value to something that has no market value. It is based on questions collected by a survey. The answers are given in the form of monetary amounts, choices, ratings or other scales which allow the monetary value.

The "proxy-good method" values time spent on informal care at the market prices of a close market substitute. So an almost perfect substitute in the market needs to be found and used as a reference. The "opportunity cost method" values the informal caregiver's benefit forgone due to spending time on providing informal care. Usually this is done using the individual's wage rate. Both these methods do not cover all costs and effects of informal care, and so they are usually used as complements [17]. However, in our work due to the data availability, only "proxy-good method" is used.

Concerning the care provided, data is collected using the instrument called Resource Utilization in Dementia (RUD), which provides information relative to the formal and informal care given to the patient according to his level of dementia [18].

4. Estimation of the burden of carers in Portugal

It has been estimated that the number of people with dementia in Portugal, in 2012, was 182,526 in a population of less than 10 million people. This number represents about 1.7% of Portuguese population, and it is higher than the EU averages of 1.55% [19] (Alzheimer Europe 2019). Considering that 60–70% of those patients with dementia suffer from Alzheimer’s disease, it means that currently there are more than 110,000–128,000 Alzheimer’s patients in Portugal. It is estimated that in the next 20 years, the number of Alzheimer’s patients in this country will be around 322,000 [9].

The current health expenditure (CHE) in Portugal directed for long-term care (LTC) has two functions, both social and health. Despite the inexistence of the EU average reference and comparing with Sweden which has some well-functioning long-term care system, Portugal presents a low share of expenditure (CHE) in long-term care expenditure for health but a reasonable level for long-term care expenditure for social support (Figure 5).

Public aid to informal caregivers in Portugal is in its infant stages, and the formal care is insufficient for the current demand. This national institutional framework pushes nearly all the care of Alzheimer’s patients to their families, who have stood for the overwhelming task of taking care of them, even if they do it with affection and love or even if they have no conditions to do so.

4.1 Method for collecting data

To collect data for Portugal, a questionnaire based on RUD, which includes questions about the informal caregiver concerning their socio-demographic characteristics, health status, received external support, professional status, activities performed and time management, was used [20].

This questionnaire was applied over 5 months, in 2018, in the Neurology Services of the Hospital Centre of the University of Coimbra, Portugal, to informal caregivers of Alzheimer’s patients. This study has been approved by the ethical commission of the hospital centre, and participants have signed an informed consent form. Confidentiality and anonymity are guaranteed to participants in this study.

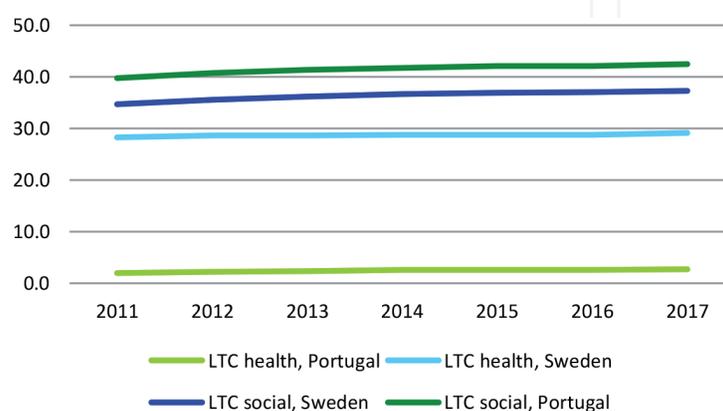


Figure 5. Share of LTC expenditure in total current health expenditure. Note: LTC, long-term care expenditure. Source: Based on Eurostat [hlth_sha11_hc] [8].

The study includes 86 Alzheimer's patients and 97 informal caregivers. The difference in these numbers is due to the fact that some patients have more than one carer.

4.2 Descriptive results

Alzheimer's patients were on average 75 years old, and about 60% were women; around 28% were in the very early stage of the disease, 28% were in the mild stage, 20% were in the moderate stage and, finally, about 24% were in the severe stage.

Informal caregivers were on average 60 years old, and the majority of them (about 67%) were women, 53.6% of carers live in the same home as the patient, 50.5% are spouses, and more than 60% of carers reported suffering some health problem; and nearly 50% reported being professionally inactive, the remaining share of carers reported being absent from work for about 4 days a year to comply with the patient needs, and 70% of them report penalties in terms of salary and day off reduction and hour replacement from these work absences.

Lastly, it must be highlighted that 90% of the carers have no public financial support, and so all expenses are supported privately, by the patient, by the carer or by the family budget.

4.3 Estimated monetary costs

The results concerning the costs and monetary values relatively to the informal caregivers are expressive and informative for policymakers. From the point of view of the cost with health care supported by caregivers, data shows that the total amount spent annually is almost 590€ or almost 50€ a month. These costs are reported by caregivers (**Table 1**).

From the different activities performed by caregivers for their patients, data obtained from the questionnaire unveil that the activities that absorb the highest share of daily hours are the activities of daily living (ADL), such as toilet visits, eating, dressing, grooming, walking and bathing, and the instrumental activities of daily living (IADL), such as shopping, food preparation, housekeeping, laundry, transportation, taking medication and managing financial matters and supervision (**Figure 6**).

Finally, according to hours of care provided for the Alzheimer's patient, the total average annual monetary value of those hours may be estimated. Taking into account the average number of daily hours of care and the monetary value of each hour (the value is estimated using the proxy-good method), the total average annual value of care sums up to 14,152.32 euros (**Table 2**). The values may vary according to the level of severity of the disease. At the most severe level of severity, these values decrease because there is an increasing share of burden with formal care.

Type of annual average costs	Monetary value €
Emergency care	9.00
Consultations	51.58
Diagnostic tests	65.78
Medication	469.08
Total annual average costs	586.44
Total monthly average costs	48.87

Source: Freitas [20].

Table 1.
Annual average costs supported by informal carers.

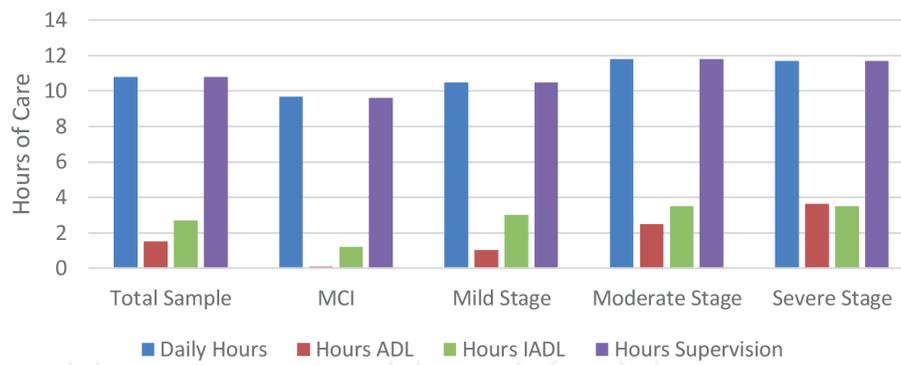


Figure 6. Distribution of daily hours across activities. Source: Freitas [20].

Average Numbers	Total	Early stage	Mild stage	Moderate stage	Severe stage
No. of daily hours	10.8	9.7	10.5	11.8	11.7
Daily cost €	45.36	40.74	44.10	49.56	49.14
Days of week	6	5.7	6	6.3	6.3
Week cost (7 days) €	272.16	232.22	264.60	312.23	309.58
Annual cost (52 weeks) €	14,152.32	12,075.34	13,759.20	16,235,86	16,098.26

Source: Freitas [20].

Table 2. Monetary value for care given by the informal carer.

Summing up, the burden taken by an Alzheimer’s patient caregiver includes the costs related to labour absence, to the lack of social activities and to health deterioration which may be reflected in health-care costs or untreated health conditions. These health-care costs were valued by 586.44€ average a year, even though caregivers seldom find time to look after themselves.

On the other hand, the caregivers provide care which was estimated to value over an average of 14,100€ per year, mainly resulting from daily activities and supervision activities. However, these values may be underestimated. On the one hand, caregivers tend to under-report the time spent providing care; on the other hand, the proxy-good method does not account for all cost, and it undervalues some activities, because they are associated with low labour market qualifications.

5. Conclusion

Undoubtedly one of the great challenges of society nowadays is to deal and to manage the increasing trend of Alzheimer’s patients in families as well as its associated increasing burden in the suffering individuals, in their caregivers and in society in general.

The care provided to Alzheimer’s patients may be formal or informal. In the latter case, it is provided by family, neighbours and friends in the patient home. The burden imposed on carers is heavy. It includes health deterioration, labour negative impacts, inexistent social life and a cost of the time spent helping the patient with their daily activities and supervising their actions.

In this chapter, the burden and value of caregivers of Alzheimer’s patients in Portugal were estimated and presented. The values may be underestimated, but they serve as a floor cost reference for policymakers. Several measures may be

undertaken in order to alleviate the burden supported by these carers. For instance, substitute carers, supplied by the health or social system, could coordinate tasks and daily help so that the caregiver himself could have more time to do other things such as go medical consultations, sleep and perform other social activities. Another measure that would be welcome is to provide a complementary subsidy for the patient expenditures in medical treatment and formal care. In this way, the caregiver budget would be protected, and it could be used on the carer's own needs. Informal care is an increasing substitute and complement of formal care, and it should be valued from a societal perspective. Caregivers must be looked after and protected for their valuable contribution to society.

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