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Monetary costs of healthcare use associated with dementia in Europe

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MONETARY COSTS OF HEALTHCARE USE ASSOCIATED WITH DEMENTIA IN EUROPE

Master Thesis

Research Report

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Abstract

Background: With the increase of the elderly population in Europe, the dementia cases are also increasing every year. The impact of dementia in society is relatively significant. On the one hand, the healthcare costs for patients with dementia are high which makes them difficult to finance. On the other hand, dementia involves an important amount of informal care. The aim of this thesis is to estimate the total costs of the healthcare use associated with dementia.

Methods: The Survey of Health, Ageing and Retirement in Europe (SHARE) is used and the target population is adults aged 50 years or older. The Mini-Mental State Examination (MMSE) is used to estimate the number of people with dementia. Afterwards, panel data are used and a fixed effect model is performed to estimate the total costs and the costs per case.

Results: The results show that the total costs of dementia are estimated to be 10.1 billion euros and the projections for the following years are expected to increase. In particular, the annual costs of dementia per case are 1,866 euros. In addition, formal care and informal care are found to be the most relevant contributors of the dementia costs. The estimations of this study differ across regions and are also found to be lower than other research studies performed due to methodological issues, such as different cost approaches or dementia prevalence.

Conclusions: This thesis provides new information of the costs of dementia. The total costs of healthcare use associated with dementia are high and they are expected to increase in the near future. Additionally, formal and informal care are the key contributors to the costs of dementia. Public health care policies would be needed to decrease not only the burden of the disease to society but also the costs.

Contents

Chapter 1: Introduction

Nowadays, dementia is considered a global epidemic by the World Health Organization (WHO). Previous literature estimated that in 2015 approximately 47 million people were diagnosed of dementia worldwide [World Alzheimer Report, 2016]. In addition, it is known that only 40% to 50% of the people with the disease are diagnosed and therefore, this implies that the estimations would probably be higher.
According to Sheehan [2012], the incidence and prevalence of dementia is strongly correlated with age. Hence, as a result of the ageing of the population, it is projected that the number of dementia cases will increase to 135 million people by 2050 [Prince et al., 2016].

The main consequence of dementia is the vast economic impact that has, not only for the diseased people and their families but also for governments and in general, for society. Demented people have to deal with the direct costs of the disease, for instance, medical care or formal care costs, as well as indirect costs that are the costs of informal care. With reference to the last ones, there are an important number of studies that found that they account for more than half of the total costs of dementia. For example, in 2008 the economic impact of dementia was 160 billion euros in EU27 and 56% of these costs were associated to informal care [Wimo et al., 2011].

It is easy to imagine that dementia is an important issue in the European countries. Some countries, such as France, have developed specific programs that focus on the prevention, early diagnosis and economic subsidies with the purpose of decreasing the economic burden that dementia produces[1]. In spite of this, the difficulty in diagnosing dementia and estimating the costs of informal care associated, added to the few knowledge on this disease, makes policy design and implementation difficult.

In this study, the aim is to answer the following research question:

"What are the dementia costs in Europe and how do they differ between European regions?"

Additionally, several sub-questions are also stated: "Are there differences in out-of-pocket costs of these regions? Are there differences in nursing home care costs? Are there differences in formal care costs? Are there differences in informal care costs?" The objective is to decompose the total dementia costs and analyse whether there are similar levels in the regions analysed.

With a similar goal, different empirical research was performed. The majority of the studies used a cost-of-illness procedure to estimate the direct and indirect costs of dementia [Wimo et al., 2006; Wimo et al., 2007 and 2010; Wimo et al., 2011; Ostbye et al., 1994] However, there are only few studies that analysed the effect of dementia costs differentiating within direct costs and they were not performed at a global European level [Connolly et al., 2014; Ostbye et al., 1994; Hurd et al., 2013; Allegri et al., 2007].

1 www. alzheimer-europe.org

This research contributes and expands the health economics literature on dementia costs in the following way: first of all, the study differentiates between direct and indirect costs and also decomposes the direct costs into out-of-pocket, nursing home care and formal care costs. This allows to accurately identify the monetary costs attributable to dementia. Secondly, the SHARE dataset is used to estimate the dementia costs. Currently, there are no available studies that use the SHARE dataset for this purpose. The SHARE dataset was created with a similar design of the Health and Retirement Study (HRS) and the English Longitudinal Study of Ageing (ELSA). This is an important implication because it does not only allow to compare the results within the countries included in the dataset but also to compare the results across studies. Finally, the research is also relevant from a societal perspective. Recently, European governments focus on developing specific plans to address the growing effects of dementia. For this reason, a greater understanding of the costs of the disease would help governments to design more effective and efficient health public policies, such as Long Term Care (LTC) programs, with the purpose of decreasing the burden that dementia causes to the families and society.

This research paper is organized as follows: first, the theoretical framework with the relevant literature for this study is introduced. It is followed by an elaborate description of the methodology, variable measurement and data used. After this, the results are explained focusing on the most important and striking findings for the research question. Finally, the last chapter presents the discussion and the conclusion of this study.

Chapter 2: Theoretical Framework

The theoretical framework of this study is structured as follows: in the first section, the most important features related to the research question of the thesis are discussed. Relevant literature and their empirical results are explained in the second section. The reader is referred to section *5.2 Comparison with relevant literature* for a comparison of these findings to those obtained in this study.

2.1 Theoretical and empirical considerations

To answer the research question "What are the dementia costs in Europe and how do they differ between European regions?" two main problems have to be overcome. First of all, a proper measure that captures the amount of people that has dementia in the representative sample should be constructed. Some studies [Wimo et al., 2007 and 2010; Wimo, 2013], used the age-specific prevalence of dementia to estimate dementia in the sample. Other used an algorithm based on a sub-sample of individuals who performed a clinical assessment for dementia, to estimate the probability of dementia among the entire sample [Hurd et al., 2013]. Demographics, measures of Activity of Daily Living (ADLs), Instrumental Activity of Daily Living (IADLs), limitations and cognitive functioning are taken into consideration in the algorithm. Nowadays, assessment scales are also used to estimate dementia [Sheehan, 2012]. In this study, an assessment scale, the Mini-Mental State Examination [Folstein et al., 1975] is used to estimate dementia. The MMSE is based on short cognitive tests that are divided in five modules: orientation, registration, attention and calculation, recall and language. By summing up the total score that respondents obtain from each module, dementia is estimated (see section *3.2.1 Dementia* for a more detailed explanation).

The second main problem is how to estimate the costs of dementia. The difficulty falls in the fact that costs vary across countries and that sometimes it is difficult to gather the information required. Cost-of-illness analysis are used to estimate the total dementia costs in some studies, which rely on the assumption that there is a relationship between the direct costs and the resources for dementia care and the gross domestic product per capita [Wimo et al., 2007 and 2010; Wimo 2013]. In addition, econometric techniques are also used to estimate the costs of dementia [Hurd et al., 2013].

A regression model is used in this study to determine the costs of dementia, differentiating between direct and indirect costs. Moreover, direct costs are decomposed into out-of-pocket, nursing home care and formal care costs. The model includes a dementia variable as an explanatory variable and it also includes coexisting conditions[2] and demographic characteristics[3] variables to control for omitted variables. Not including these variables might bias the estimations because there would be variables in the error term which might be correlated not only with the dependent variables but also with the independent ones meaning that the zero conditional mean

2 Heart attack, hypertension, cholesterol, stroke, diabetes, lung, asthma, arthritis, osteoporosis, cancer, ulcer, Parkinson, cataracts, hip fracture, other and none coexisting conditions

3 Household income, educational level, marital status, age and gender.

assumption[4] is not satisfied. Some studies showed that, for instance, having lower education or diabetes are positively associated with having dementia [Mortimer and Graves, 1993; Ott et al., 1996]. The model equation is thus written as:

$$Costs_{it} = Dementia_{it} + X_{it}\beta + \varepsilon_{it}$$

where $Costs_{it}$ are the nursing home, out-of-pocket, formal care and informal care costs for each individual i and each time period t, $Dementia_{it}$ is the estimation of the number of people with no dementia, cognitive impairment but not dementia and dementia performed with the MMSE for each individual i and each time period t, X_{it} is a vector that includes the mentioned coexisting conditions and demographic characteristics for each individual i and each time period t, and ε_{it} is the error term (see section *3.4 The Model* for a further explanation).

2.2 Empirical findings

There is an increasing literature with the aim of estimating the worldwide costs of dementia [Wimo et al., 2007 and 2010; Wimo, 2013]. On the other hand, others focused in a specific geographical area, for instance the United States [Hurd et al., 2013], Europe [Wimo et al., 2011], Canada [Ostbye et al., 1994], Denmark [Kronborg et al., 1999] and France [Rigaud et al., 2003], among others. Nevertheless, all these studies agreed to show that the costs of dementia are large and increasing over time. The empirical findings also showed that despite the direct costs are the highest, informal care costs also represent a substantial and significant part of the total costs. A description of the most relevant literature and their empirical findings is presented in the following paragraphs.

Wimo et al. [2011] performed a cost-of-illness (COI) study with the purpose of estimating the impact of dementia in Europe. In the same way as in this study, a societal perspective is followed to compute the costs. Consequently, direct medical and nonmedical costs were included as well as indirect costs referring only to informal care (the other indirect costs were not included because they were low and not significant). The age-specific prevalence of dementia, based on the Eurocode 2009c, was included in a cost model based on different COI papers. Costs were presented for three different areas: The Europe of the 27 countries, the Europe of the 27 countries and also candidate countries and finally, the entire Europe and its regions. They used the United Nations classification (UN, 2009) for defining the different regions (Northern, Western and Southern), as performed in this analysis. Additionally, the purchasing power parity was used to adjust for differences in GDP across countries. The total dementia costs in Europe were found to be 160 billion euros, from which 56% were attributable to informal care. Moreover, in northern Europe it was found to use more institutional care compared to southern and western Europe, while in southern Europe it was found to use more informal care compared to the other regions.

[4] The zero conditional mean assumption requires that the independent variables are exogenous and not correlated with the error term and it is a necessary condition to get unbiased estimators. It might happen that $E(\varepsilon_i|\text{Dementia}) \neq 0$ where ε_i can be, for instance, diabetes or education and Dementia is a variable indicating whether the individual has dementia or not. In this case, the estimations would be biased.

Another equally relevant paper for this study is Hurd et al. [2013]. The objective of this paper was to determine the monetary costs of dementia in the United States using data from the Health and Retirement Study (HRS). They used an algorithm based on the Aging, Demographics and Memory Study (ADAMS) to estimate the probability of having dementia in the HRS sample. Similar to this study, dementia was defined as a variable with three categories: no dementia, cognitive impairment but not dementia (CIND) and dementia. The algorithm was performed for both self-respondents and proxy-respondents. After this, a multivariate regression model was estimated to compute the dementia costs. As in this thesis, the model controlled for coexisting conditions and demographic characteristics and the output variables were divided into direct costs (out-of-pocket spending, spending by Medicare, net nursing home spending and formal home care costs) and indirect costs. The model was performed twice: firstly, including only formal care costs and secondly, including both formal and informal care costs. The authors concluded that the main costs of dementia were related to institutional and home based long-term care and that the cost of informal care for dementia was higher than for other diseases such as cancer.

Wimo et al. [2007 and 2010] estimated the total worldwide societal costs of dementia in 2005 and 2009, respectively. The authors used a cost model which was performed based on the estimated prevalence of dementia in different countries and regions of the world, COI studies from different countries and also studies of the amount of informal care. Direct costs were estimated assuming that there is a relationship between the costs per demented person and the GDP per person. Contrary to this study, informal care was valued using the opportunity cost of the caregiver's time. The human capital approach which uses the average wage by country, was used to value the working age caregiver's time. Two alternatives were given to set the maximum hours per day of informal care. The first one assumed that informal care was 1.6 hours per day, only taking into account ADLs and the second one considered that informal care was 3.7 hours per day, taking into account both ADLs and IADLs. Similarly, this study assumes that the maximum hours per day of informal care are 4 taking into consideration both ADLs and IADLs. Wimo et al. [2007] found that the total societal worldwide dementia costs were 315 billion dollars. From this amount, direct costs accounted for 210 billion dollars, while informal costs were 105 billion dollars. Wimo et al. [2010] found that in 2009 the total societal worldwide costs of dementia were 422 billion dollars, from which 279 billion dollars were costs of direct care and 142 billion dollars costs of informal care. Therefore, the societal worldwide costs of dementia increased by 107 billion dollars from 2005 to 2009.

Finally, Wimo [2013] analysed the societal costs of dementia in 2010. The country-specific annual per capita costs of societal prevalence-base COI were applied to the estimated number of people with dementia. Direct costs were divided into direct medical costs, referring to the costs of the medical care system for instance, hospital care and medication, among others, and direct societal costs, that were, the costs of the formal services provided outside the system. Informal care was valued using the opportunity cost approach and, as in this study, the replacement cost approach. The authors found that in 2010 the societal costs of dementia were 604 billion dollars and

that about 70% of these costs occurred in western Europe and north America (according to the WHO regions classification).

Chapter 3: Methodology, variable measurement and data

In this chapter, the dataset, the variables and the methodology used in the study are discussed. It is structured as follows: first, the dataset used in this study is introduced. Afterwards, a detailed description of the measurement of all the variables of interest for this study is presented: dementia, demographic characteristics, coexisting conditions and cost variables. Finally, the construction of the final model used for this study is explained.

3.1 SHARE dataset

The dataset used in this study is the SHARE (Survey of Health, Ageing and Retirement in Europe) which is a multidisciplinary, cross-national and panel dataset done in 27 European countries. The aim is to gather information on health, socio-economic status and social and family networks [Börsch-Supan et al., 2013]. In Börsch-Supan and Jürges [2005], an overview of the methodology used to collect the data can be seen. The data are organized in different modules that contain information about demographics, social network, children, physical health, behavioural risks, cognitive function, mental health and health care, among others. The information is collected through computed-assisted personal interviewing (CAPI) or through a self-completion paper. The dataset is formed by five waves in which similar information was collected during the years 2004, 2006, 2010, 2014 and 2015. Additionally, there is one special wave, collected in 2008, which is called SHARELIFE that focuses in people's life stories. This study uses the release 6.0.0 and waves 1 (2004), 2 (2006), 4 (2010) and 5 (2013) of the SHARE dataset. The final dataset is formed by a total amount of 123,144 observations, 51,765 in the no dementia sample, 63,848 in the CIND sample and 7,533 in the dementia sample.

3.2 Explanatory variables

In this section, the variables defined as independent variables in the model that might influence the annual costs of dementia are presented. First of all, how the dementia variable is designed is explained. Then, the variables used to control for omitted variables (demographic characteristics and coexisting conditions) are described.

3.2.1 Dementia

The main goal of this study is to estimate the costs of dementia in Europe. In the data used for this study, there is no direct measure for dementia status. Therefore, the first step needed is to estimate how many respondents of the dataset used might have dementia.

In this thesis, assessment scales are used to estimate dementia. With this purpose, different methods can be used. The method that has the highest validity and that is used as an international standard is the Clinical Dementia Rating (CDR), which focuses on gathering data on six domains: memory, orientation, judgment and problem solving, community affairs, home and hobbies and personal care. It classifies dementia in five

categories: absent, questionable, mild, moderate and severe, depending on the scores obtained by the respondents in the modules. The major problem of the CDR is that it needs a considerable amount of data to be performed. As a result, in this study the MMSE is used to estimate dementia because it is a test that requires less data to be performed and it was proved to be equivalent to the CDR [Perneczky et al., 2006]

The MMSE is based on short cognitive tests that are divided in five modules: orientation, registration, attention and calculation, recall and language. Dementia is computed by summing up the total score that the respondents obtain from each module. The maximum score that they can achieve is 30 points [Folstein et al., 1975]. The dataset used has a module of cognitive function that contains information about orientation, registration, attention and calculation and recall. Hence, it does not include information about the language module. Additionally, there is one module, concretely orientation, that does not incorporate all the questions from the MMSE. In consequence, in this study the MMSE maximum score that the respondents can obtain is 15 points: 4 points in the orientation module, 3 points in the registration module, 5 points in the numeracy module and 3 points in the recall module.

Dementia is estimated as a categorical variable with 3 categories (no dementia, cognitive impairment but not dementia and dementia) which are computed proportionally to the MMSE ranges reported in Kenneth et al. [2001]. Accordingly, no dementia is categorized by scoring between the range 15 to 11 (both included) which corresponds to the proportional range of the categories “No dementia” and “Mild dementia”, CIND between the range 11 to 6 (included) which corresponds to the proportional range of “Moderate dementia” and dementia between the range 6 to 0 (included) which corresponds to the proportional range of the category “Severe dementia”.

3.2.2 Demographic Characteristics

The SHARE dataset also includes a module of demographic characteristics which is used with the aim of controlling for omitted variables. The variables used are described in the following paragraphs.

Age is a continuous variable that is computed by subtracting the survey year from the year of birth of the respondents. Additionally, all the individuals aged below 50 years old are excluded from the study because the SHARE dataset is only eligible for individuals aged 50 or older.

In the SHARE dataset, the 1997 International Standard Classification of Education (ISCED) is used to describe the educational level of the respondents. This system classifies education in 7 levels: 0 (pre-primary education), 1 (primary education or first stage of basic education), 2 (lower secondary or second stage of basic education), 3 (upper secondary education), 4 (post-secondary non-tertiary education), 5 (first stage of tertiary education) and 6 (second stage of tertiary education). In this study, the variable education is a categorical variable that takes the following values: 1 for “low education” which corresponds to the levels 0 and 1 of the ISCED 1997, 2 for “medium

education" which corresponds to the levels 2, 3 and 4 of the ISCED 1997, 3 for "high education" which corresponds to the levels 5 and 6 of the ISCED 1997 and 4 for "other types of education" which corresponds to those respondents who answered none of the ISCED 1997 levels of education.

Marital status is modelled as dummy variable that takes the value 1 for married respondents which corresponds to the categories "married and living together with spouse", "registered partnership" and "married, living separate"; and 0 for non-married respondents which belong to the categories "never married", "divorced" and "widowed".

The SHARE dataset also includes a direct measure of the individual income of the respondents. This variable is adjusted using the purchasing power parity (PPP) that takes the price of Germany in 2005 as the reference price. The purpose of this transformation is to make income comparable across the different European countries analysed. On the one hand, for those countries with the euro (Austria, Germany, the Netherlands, Spain, Italy, France, Greece and Belgium), the individual income is divided by the specific PPP of these countries for the years studied. On the other hand, for those countries that do not belong to the euro (Sweden, Denmark and Switzerland), the process is slightly different. First of all, the individual income, which is expressed in euros in the SHARE dataset, is transformed to the national currency by multiplying the individual income by the exchange rate. After this, the individual income expressed in the national currency is divided by the specific PPP of these countries for the years analysed.

3.2.3 Coexisting Conditions

Having other conditions besides from dementia might affect the total healthcare costs per year. Therefore, this study takes into account several coexisting conditions that might affect the total annual healthcare costs with the purpose of controlling for omitted variables. The following variables from the module of cognitive functioning of the SHARE dataset are used: heart attack, hypertension, cholesterol, stroke, diabetes, lung, asthma, arthritis, osteoporosis, cancer, ulcer, Parkinson, cataracts, hip fracture, other, and none coexisting conditions. These variables are categorized as dummy variables and are present in the four waves. All the other variables that are not present in all the waves used in this study, concretely Alzheimer, asthma, arthritis, osteoporosis, other fractures, tumour, other diseases, reumarthritis and osteoarthritis, are excluded.

3.3 Output variables

The ultimate goal of this study is to estimate the dementia costs in Europe. With this purpose, dementia costs are differentiated between direct costs and indirect costs. Additionally, direct costs are decomposed between nursing home, out-of-pocket and formal care costs. In the following paragraphs it is explained how these cost variables are estimated in this study.

3.3.1 Nursing home costs

Nursing home spending is estimated from the health care module of the SHARE dataset and costs are computed from the total weeks stayed in a nursing home and the weekly cost of staying in a nursing home reported in Hakkaart-van et al. [2015]. For respondents who during last year stayed permanently on a nursing home, 52 weeks of stay are assumed whereas for respondents who stayed temporarily, the reported weeks are used. Additionally, nursing home costs are reduced 8% because the cost per day of a nursing home reported by Hakkaart-van et al. [2015] include those costs for food and housing which are costs that respondents would have had to incur even though they were not in a nursing home [Hurd et al., 2013]. Otherwise, the total costs would be overestimated.

3.3.2 Out-of-pocket costs

This study estimates the total out-of-pocket (OOP) costs of the respondents with or without dementia (CIND and no dementia). Self-reported OOP spending from the health care module of the SHARE dataset for inpatient care, outpatient care, prescribed drugs and day care are used to compute the total amount of OOP.

The SHARE includes missing value imputation with brackets for those respondents who were unable or unwilling to give an exact amount of OOP spending. This method helps to mitigate the problem of missing values and it helps to achieve more consistent estimations. In this method, the respondents are asked for series of questions and based on the responses to these questions, an exact amount is imputed. In this study, the method has three different threshold levels (low, medium and high) that are assigned randomly to each respondent. Respondents are asked if their annual OOP spending is above, about or below the assigned threshold level. Only if the respondents answer that their annual OOP spending is about the threshold level, it is assumed that their total OOP spending corresponds to this amount. Otherwise, they are asked again the same question but with the following threshold level. This process is repeated until the respondent is asked for all the possible threshold levels.

The total amount of OOP costs is calculated by adding the OOP spending of inpatient care, outpatient care, prescribed drugs and nursing home, formal care and day care. It is important to highlight that for the year 2010 there is no information for OOP spending on the dataset. Consequently, OOP costs for 2010 cannot be estimated. Furthermore, in 2013 the SHARE dataset does not include neither a direct measure for outpatient OOP spending nor the amount of OOP spent in home and day care. In this case, two options are considered: first, leaving the year 2013 out of the analysis as it is done with the year 2010 and secondly, with the information that the dataset contains for the year 2013, estimating the total OOP spending by adding the OOP spending reported for inpatient care, outpatient care, prescribed drugs and nursing home care. The OOP for outpatient care can be computed because the dataset contains the OOP spending in doctor visits and dentists and therefore, by summing them the total amount of OOP spent in outpatient care is estimated. On the other hand, the total OOP spent in home and day care cannot be estimated and they would be missing in the analysis. The disadvantage

of the first option is that a lot of information would be missed and this would overestimate the results. Hence, the second option is chosen because it allows working with more data despite the fact that the results might be underestimated because home and day care costs are not taken into consideration.

3.3.3 Formal care costs

The health care module of the SHARE dataset also contains information regarding the formal care spending. Formal care costs are computed by multiplying the annual weekly hours of formal care by the hourly cost obtained from Hakkaart-van et al. [2015].

On the dataset, formal care costs are differenced between costs attributable to professional personal care, costs of professional domestic help and costs of meals-on-wheels. On the one hand, annual professional personal care weekly hours are valued at 50 euros per hour. On the other hand, annual professional domestic help weekly hours are valued at 20 euros per hour. With reference to meals-on-wheels, the annual weekly hours stated by respondents is not used in this study because the hourly cost of this activity is not reported in Hakkaart-van et al. [2015] and for this reason, the final outcome is underestimated. Additionally, formal care costs for the years 2010 and 2013 cannot be computed because there is no information in the SHARE dataset.

3.3.4 Informal care costs

Informal care costs are estimated through the social support module of the SHARE dataset. In this study, informal caregiving is defined as giving help or social support by a relative or non relative who live within or outside the household.

With the purpose of estimating the total annual informal care costs, there are different approaches that can be used. In this study, both the foregone wage approach and the replacement cost approach were considered. On the one hand, the opportunity cost approach values the forgone benefits, approximated by the individual's market wage rate of the informal caregiver [Koopmanschap et al., 2008]. The difficulty of this method resides in the fact that it is difficult to measure the cost for the informal caregivers who are not in the labour force. On the other hand, the replacement cost approach estimates the informal costs using a proxy method in which the hours of informal care are multiplied by the cost of performing these activities in the healthcare market [Koopmanschap et al., 2008]. The main advantage of this method is its simplicity. In this thesis, the replacement cost approach is chosen to value informal care.

With reference to the maximum hours of informal care that can be given, this study takes as reference Wimo et al. [2010] and it assumes that the maximum hours of informal care for those respondents who did not answer a specific amount, are 4 hours per day for both within and outside the household informal caregivers and taking into account ADLs and IADLs activities.

Informal care is computed in the following way: the annual hours of informal care are

multiplied by the reference hourly price from Hakkaart-van et al. [2015]. First of all, for within the household informal caregivers, it is assumed that they give help 4 hours per day during the entire year. Secondly, for the outside the household informal caregivers, the total hours of informal care reported are multiplied by the reference hourly price from Hakkaart-van et al. [2015].

For the years 2010 and 2013 a different method is used because the SHARE dataset does not include the daily hours of help given by outside the household informal caregivers. In this case, two alternatives are considered: firstly, ignoring the observations of these years when estimating the relationship between informal care and dementia and secondly, estimating the total costs for these years with the available information.

The second option is chosen because the first option would overestimate the final outcome. Therefore, the total costs of informal care are estimated as follows: for those respondents who answered that they received help almost daily, the hourly cost of informal care is multiplied by 4 hours per day per year. For those respondents who received help almost every week, the hourly cost of informal caregiving is multiplied by 4 hours per week per year. For those respondents who received care almost every month the hourly cost of informal care is multiplied by 4 hours per month per year. Finally, for those respondents who needed informal care less often, the total amount of informal caregiving is assumed to be zero. Few observations are lost when this method is used and thereby, the final sample size used is large enough to achieve consistent estimations. On the other hand, the main disadvantage is that the results might be underestimated because in the last step, it cannot be estimated the amount of informal care of those respondents who needed care less often and as a result, there are some observations which are set to zero.

3.4 The model

In this section, the model used to estimate the costs attributable to dementia is described. In section 2.1 it has been explained that, similar to this thesis, there are several studies that aim to estimate the costs attributable to dementia [Wimo et al., 2007 and 2010; Wimo, 2013; Ostbye et al., 1994; Kronborg et al., 1999; Rigaud et al., 2003; Hurd et al., 2013]. With this purpose, a vast amount of these studies have used COI analyses that rely on the assumption that there is a relationship between the direct costs and the resources for dementia care and the gross domestic product per capita [Wimo et al., 2007 and 2010; Wimo, 2013]. Opposite to these studies, this thesis follows econometric techniques to estimate the total costs of dementia. In the following paragraphs, the process followed to design the final model is explained.

First of all, a normal OLS regression model is designed. With the purpose of estimating the costs of dementia, demographic characteristics (gender, age, marital status, education and income) and coexisting conditions (heart attack, hypertension, cholesterol, stroke, diabetes, lung, asthma, arthritis, osteoporosis, cancer, ulcer, Parkinson, cataracts, hip fracture, other and none coexisting conditions) are included in the regression to control for omitted variables. There are several studies that show that both demographic characteristics for example, education, and coexisting conditions for

instance, heart attack, are strongly correlated with the probability of having dementia [Mortimer and Graves, 1993; Ott et al., 1996]. Therefore, not including these variables in the regression would bias the estimations because the zero conditional mean would not be satisfied. Additionally, it has to be taken into account that having dementia and at the same time, having another disease, for instance, hypertension, might affect the total costs attributable to dementia and therefore, overestimate the cost estimations. Hence, four interaction terms between the most important coexisting conditions (heart attack, hypertension, cholesterol and diabetes) and dementia are created and introduced in the regression. The coefficients of these interaction terms are tested and are found to be statistically not significant at 10%, significance level. Consequently, the interaction terms are excluded from the final regression model. The next step followed, is to test if all the OLS assumptions[5] required to have the best linear unbiased estimators (BLUE) are satisfied. Heteroskedasticity is corrected in the regression model and it is found that all the assumptions are satisfied with the exemption of the zero conditional mean assumption. There might be variables in the error term, for instance, distance to the hospital or neighbourhood where the respondents live, that might be correlated with both explanatory variables and outcome variables. As a result, the estimations obtained from this regression model might be biased.

The next model that is performed is the multivariate multiple regression. The multivariate multiple model is widely used in Health and Pharmaeconomics literature because it allows the dependent variables to have some degree of correlation and also to test whether the independent variables are significant across the equations specified. This model would help to correct for endogeneity because it allows correlation between the errors. One of the conditions required to perform this model is that the output variables need to have some degrees of correlation. Therefore, the correlation between the output variables of this model is tested and it is found that they are weakly correlated and consequently, this model is not used.

Finally, panel data are used with the purpose of improving the previous models performed. The preferred model and hence, the model that is used in this study is the fixed effects. The fixed effects model is similar to the normal OLS regression model but it allows controlling for individual unobserved heterogeneity. In addition, it requires that the time-varying error is not correlated with each explanatory variable across all time periods[6]. All the individual characteristics that do not change over time are excluded from the analysis. That is, all the factors that do not change over time included in the error term that might be correlated with both the explanatory and the output variables are excluded in the regression. However, this does not imply that the strict exogeneity assumption is satisfied because there might be still variables in the error term that might change over time, such as working status [Coe et al., 2009], that might be endogenous. Hence, a causal effect cannot be concluded in the estimations.

Firstly, the regression is performed for all the countries all together. Secondly, a region

5 OLS Assumptions: Linear in parameters (MLR1); random sampling (MLR2); no perfect collinearity (MLR3); zero conditional mean assumption (MLR4); homoscedasticity (MLR5) and the error term follows a normal distribution (MLR6).

6 The strict exogeneity assumption implies that $E(x_{it},u_{is})=0$ for all s and t where t and s are two different time periods.

variable was created as a categorical variable that takes the value 1 if the region is northern Europe (Sweden and Denmark), 2 if the region is western Europe (Austria, The Netherlands, Switzerland, Belgium, Germany and France) and 3 if the region is southern Europe (Spain, Italy and Greece). Then, the model is performed again separately for each of these 3 regions.

Chapter 4: Results

In this chapter, the results obtained from the regression model are shown. First, the descriptive statistics of the study population are explained. Then, the results for the nursing home, out-of-pocket, formal care and informal care costs are discussed. The results are presented first of all for the whole sample and after this, for each region (Northern Europe, Western Europe and Southern Europe).

4.1 Characteristics of the study population

Summary data on gender, age, education, marital status, income, coexisting chronic conditions, nursing home costs, out-of-pocket costs, formal care costs, informal care costs and region are presented below in Table 4.1. The table shows the weighted SHARE sample average of the variables used in this study, separately for the total, the no dementia, the CIND and the dementia samples.

The distribution of men and women in the total sample is more or less equally represented, being 46.2% men and 53.8% women. The same happens for the no dementia, CIND and dementia samples where women are slightly more represented than men, 51.8%, 54.7% and 59.5%, respectively.

In terms of age, the total sample weighted average is 65 years old. The weighted average age for the dementia sample is 74 years old while for CIND and no dementia samples is 66 and 63 years old, respectively. Dementia is an age-prevalent disease. For this reason, the average age noticeably increases with dementia, being the demented respondents the oldest.

With relation to education, 43.2% of the respondents in the total sample reported low education level, 33.8% reported medium education level and only 22.4% reported high education level. The difference between the educational level of the respondents across samples is significant. Higher levels of education attainment are observed for the no dementia sample while lower levels are seen for the dementia sample, where 83% of the respondents reported low educational level. Hence, it seems to be a negative correlation between the dementia prevalence and the educational level [Schoenhofen et al., 2011].

Concerning to marital status, 73.1% of the respondents of the total sample are married. This percentage remains almost the same for the dementia and CIND samples. In the first case, 76% of the respondents are married while in the second case, 72.7%. However, for the dementia sample, it can be observed that only 57% of the respondents are married and 43% are not married. The average age for the respondents in this sample is higher than for the other samples and therefore, an important amount of respondents reported to be widowed (2,442 respondents) which might contribute to explain this difference.

The average income in the total sample is 40 euros per year. For the no dementia sample, the respondents reported an average income of 47 euros per year while for

CIND and dementia samples the average income is 36 euros per year and 23 euros per year, respectively. Therefore, individuals with no dementia report higher income than individuals with dementia.

Regarding to chronic coexisting conditions, the most common in all the samples are heart (10.9%), hypertension (34.3%), cholesterol (21.9%), diabetes (10.3%), other (15.7%) and none (25.5%). However, it is important to highlight that the respondents of the dementia sample are more likely to report higher prevalence of chronic coexisting conditions. This might be due to the older age or to the dementia prevalence.

The weighted average of nursing home, out-of-pocket, formal care and informal care costs increases significantly with dementia prevalence, specially for nursing home care, formal care and informal care. First of all, the average nursing home costs for the total sample are 165 euros per year. For the no dementia sample, the average is 68 euros per year while for the CIND and dementia samples the average increases to 151 and 964 euros per year, respectively. Second, regarding to out-of-pocket costs, the total sample average is 367 euros per year. In this case, there are no significant differences across samples. For no dementia, the average costs are 416 euros per year, for CIND are 334 euros per year and for dementia, 374 euros per year. Third, the formal care costs have a weighted average of 476 euros per year for the total sample while 121 euros per year, 334 euros per year and 2,339 euros per year for no dementia, CIND and dementia samples, respectively. These latter costs present the largest increase with the dementia prevalence. Finally, the total sample average costs of informal care are 1,440 euros per year, being 1,264 euros per year the average for the no dementia sample, 1,497 euros per year for the CIND sample and 2,334 euros per year for the dementia sample.

Table 4.1. Descriptive statistics for the total sample and by dementia category.

Variable	Total sample	No Dementia	CIND	Dementia
Gender				
Male	0.462	0.482	0.453	0.405
Female	0.538	0.518	0.547	0.595
Age	**65.394**	**63.206**	**66.132**	**74.176**
Education				
Low	0.432	0.259	0.526	0.830
Medium	0.338	0.404	0.310	0.120
High	0.224	0.331	0.158	0.042
Other	0.006	0.006	0.006	0.008
Marital Status				
Married	0.731	0.760	0.727	0.570

Unmarried	0.269	0.240	0.273	0.430
Income	**39,713.26**	**47,347.12**	**35,508.91**	**22,893.88**
Coexisting Conditions				
Heart	0.109	0.081	0.121	0.198
Hypertension	0.343	0.319	0.356	0.397
Cholesterol	0.219	0.206	0.229	0.229
Stroke	0.033	0.022	0.035	0.084
Diabetes	0.103	0.084	0.110	0.176
Lung	0.057	0.049	0.060	0.094
Cancer	0.053	0.052	0.053	0.054
Ulcer	0.042	0.032	0.047	0.061
Parkinson	0.006	0.003	0.006	0.026
Cataracts	0.078	0.064	0.083	0.132
Hip fracture	0.019	0.012	0.021	0.042
Other	0.157	0.157	0.155	0.177
None	0.255	0.300	0.234	0.124
Nursing	**165.59**	**68.36**	**151.75**	**964.70**
OOP	**367.80**	**416.92**	**334.44**	**373.55**
Formal care	**476.59**	**121.80**	**334.06**	**2,339.84**
Informal care	**1,440.72**	**1,264.30**	**1,497.51**	**2,334.62**
Number of observations	**123143**	**51764**	**63848**	**7533**

4.2 Estimated total cost of dementia per case

Estimates of the annual total cost per case of dementia in Europe, adjusted for coexisting conditions and demographic characteristics, are shown in Table 4.2. In addition, the coefficients obtained from the regression can be seen in Appendix 2, Appendix 3, Appendix 4 and Appendix 5. The model is first regressed for all the European regions and it is found that dementia is associated with a cost of 1,289 euros per case for all direct care and with a total cost of 1,866 euros per case when informal care is taken into account. Analysing the decomposition of the direct costs, it is found that having severe dementia is statistically significant for the total out-of-pocket spending and also for formal care. In Table 4.2, it can be observed that having severe dementia compared to not having dementia, is associated with an increase in the total out-of-pocket spending of 77 euros per case, ceteris paribus. The effect is significant at 10%

significance level. At the same time, having severe dementia compared to not having dementia, is associated with an increase of 754 euros per case of the formal care spending, ceteris paribus. The effect is significant at 1% significance level. Additionally, having CIND compared to not having dementia, is associated with an increase of 157 euros per case of the formal care costs, ceteris paribus. The effect is significant at 10% significance level. With respect to informal care spending, it can be seen that for the total spending, both having CIND and having severe dementia are statistically significant at 5% and 1%, respectively. Hence, having CIND compared to not having dementia is associated with an increase of 121 euros per case of informal care spending, ceteris paribus, and having severe dementia compared to not having dementia is associated with an increase in informal care spending of 456 euros per case, ceteris paribus. According to the model, the most important attributable cost of dementia is for formal care, followed by informal care. Total nursing home spending and total out-of-pocket spending for people with CIND, are not interpreted because they are not statistically significant at 10% significance level in the model.

Afterwards, the model is regressed for each European region: North, West and South. It is found that for the direct costs, dementia is associated with a cost 3,847 euros per case in Northern Europe, 896 euros per case in Western Europe and 1,202 euros per case in Southern Europe. When informal care is included, dementia is associated with a cost of 4,784 euros per case for Northern Europe, 1,312 euros per case for Western Europe and 1,956 euros per case for Southern Europe. Therefore, there are significant differences in the dementia costs across regions. With regard to Northern Europe, having CIND compared to not having dementia, is associated with an increase of 68 euros per case of formal care spending, ceteris paribus. The effect is significant at 10% significance level. However, having severe dementia is not significant for formal care spending. In addition, the informal care costs for people having CIND and for people having severe dementia both compared to not having dementia are associated with an increase of 212 euros per case and 725 euros per case, respectively, ceteris paribus. The effects are significant at 5% and 10% significance level, respectively. The costs of nursing home care, out-of-pocket and formal care (only for CIND) are not interpreted because they are not significant at 10% significance level. Concerning Western Europe, nursing home costs, out-of-pocket costs, formal care costs and informal care costs are not interpreted due to they are not significant at 10% significance level. With respect to Southern Europe it can be observed that having severe dementia compared to not having dementia is associated with an increase of 956 euros per case of formal care spending, ceteris paribus. The effect is significant at 5% significance level. At the same time, having severe dementia compared to not having dementia, is associated with an increase in the informal care costs of 592 euros per case, ceteris paribus. The effect is significant at 5% significance level. The costs of nursing home care, out-of-pocket, formal care (for CIND) and informal care (for CIND) are not significant at 10% significance level and therefore, they are not interpreted. It can be concluded that for Northern Europe, informal care seems to be the most relevant cost for dementia and contrary, for Western and Southern Europe formal care appears to be the most significant cost (see *5.2 Comparison with relevant literature* for a comparison between the results obtained from this study and other research studies).

4.3 Estimated total cost of dementia

Estimations of the total costs of dementia in Europe are shown in Table 4.3. The costs of dementia per case shown in Table 4.2 are combined with the prevalence rates of dementia from Alzheimer Europe [2006] and the European population projections from the United Nations [World population projections: the 2015 revision] with the purpose of estimating the total costs of dementia in Europe.

The prevalence rate of dementia in people aged 80 years or older is 15.7% [Alzheimer Europe, 2006]. For 2015, this prevalence yields an estimation of 10.1 billion euros for the European population aged 80 years or older. The projections for 2030 and 2050, assuming that the prevalence rate remains the same, are even higher. For 2030, the total costs of dementia are estimated to be 13.5 billion euros while for 2050 the estimations increase to 20.7 billion euros. Therefore, the total dementia costs are expected to increase 33% from 2015 to 2030 and 54% from 2030 to 2050.

Table 4.2. Total costs of dementia specified by type of cost.

	All regions	Northern Europe	Western Europe	Southern Europe
Direct care				
Total nursing home spending				
CIND	-0.99	-45.15	6.40	-13.07
Severe dementia	261.01	3,019.22	-12.76	-66.91
Total out-of-pocket spending				
CIND	40.57	91.77	-9.27	126.57
Severe dementia	76.86*	95.49	84.67	109.41
Total formal care spending				
CIND	157.50*	68.30*	213.66	89.20
Severe Dementia	754.00***	617.48	613.69	956.43**
Total	1,288.96	3,847.11	896.38	1,201.63
Informal home care				
Caregiving time valued according to the replacement cost				
CIND	121.27**	212.29**	89.34	162.97
Severe Dementia	455.73***	724.81*	325.94	591.72**
Grand total	**1,865.96**	**4,784.21**	**1,311.66**	**1,956.32**

Note 1: * means 10% significance level; ** means 5% significance level; *** means 1% significance level.
Note 2: Reference group is no dementia.

Table 4.3. Total dementia costs in Europe for population aged 80 years or older

European costs	**2015**	**2030**	**2050**
Nursing home care	1,412.52	1,881.99	2,898.52
Out-of-pocket	637.90	849.91	1,308.98
Formal care	4,951.45	6,597.16	10,160.49
Direct costs	**7,001.87**	**9,329.08**	**14,367.99**
Informal care	3,134.39	4,176.17	6,431.84
Total costs	**10,136.26**	**13,505.243**	**20,799.83**

*The costs are expressed in millions euros.

Chapter 5: Discussion and conclusion

In this chapter, the research question analysed is answered in the first section using the results found in chapter 4. A comparison with other empirical results is presented in the second section. The most important methodological issues are explained in the third section. Finally, the relevance of this study and the implications for future research are discussed in the fourth and fifth section of this last chapter.

5.1 Discussion of the research question

In chapter 1, the research question analysed in this study is stated:

"What are the dementia costs in Europe and how do they differ between the European regions? "

Additionally, several sub-questions are also stated: "Are there differences in out-of-pocket costs of these regions? Are there differences in nursing home care costs? Are there differences in formal care costs? Are there differences in informal care costs?" The results presented in chapter 4 and concretely in tables 4.2 and 4.3, are now used to answer these questions.

The total dementia costs in Europe are found to be 10.1 billion euros for people aged 80 years or older. This cost is expected to increase in the following years to 13.5 billion euros in 2030 and 20.7 billion euros in 2050. Accounting only for the costs per case, it is found that the dementia costs per case are 1,289 euros per case per year when only the direct costs are included. Formal care costs appear to be the most important component of the direct costs, followed by nursing home costs and out-of-pocket costs. When informal care is taken into consideration, the total dementia costs are estimated to be 1,866 euros per case per year. Hence, it can be concluded that the most important component of the total dementia costs seems to be formal care. Having severe dementia compared to not having dementia is significant for both out-of-pocket costs and formal care costs. On the one hand, out-of-pocket costs seem to increase the total costs of dementia by 77 euros per case per year, being this effect significant at 1% significance level. On the other hand, formal care costs are estimated to be 754 euros per case per year, being the effect significant at 1% significance level. For informal care, having both CIND and severe dementia compared to not having dementia is associated with an increase in the total costs of dementia of 121 euros per case per year and 456 euros per case per year, respectively. Being both effects significant at 5% and 1% significance level, respectively.

Finally, with relation to the dementia costs by region, it is found that there are significant differences across regions. The results found that in northern Europe it is estimated that the annual cost is 3,847 euros per case when only direct costs are included and 4,784 euros per case per year when indirect costs are considered. On the other hand, western and southern Europe have lower annual cost per case. For western Europe, the annual costs per case are 896 euros when it is only considered the direct costs and 1,312 euros when indirect costs are included. For southern Europe, the direct annual costs per case

are 1,202 euros and they increase to 1,956 euros when considering the indirect costs. Hence, according to these results, it can be concluded that it seems to be regional differences across European regions. On the one hand, northern Europe is found to have higher costs compared to the other regions. In addition, the direct costs, concretely the formal care costs, are the most important component of the total dementia costs. On the other hand, informal care is found to be the main source of dementia costs in southern Europe. Prudence is required when interpreting these results because there are structural differences across regions in the dataset used.

5.2 Comparison with relevant literature

In section 2.2 the relevant framework for this thesis is presented. It is interesting to compare the results found in previous studies with the results found in this study. Wimo et al. [2011] tried to estimate the impact of dementia in Europe in 2008. The authors found that the total annual costs of dementia in Europe were 160 billion euros and 17,400 euros per case. They also found that for northern Europe, the direct costs of institutional care were the most relevant, specifically 36,356 euros per case while for southern Europe, the most significant costs were the informal care costs, specifically 22,679 euros per case. Opposite to these findings, the estimations are much lower in this study. The total annual costs of dementia are found to be 10.1 billion euros and 1,866 euros per case, being 4,784 euros the costs per case in Northern Europe, 1,312 euros per case in Western Europe and 1,956 euros per case in Southern Europe. In addition, the most relevant costs of dementia are found to be informal care in Northern Europe and formal care in Southern Europe. These findings contradict the results found in Wimo et al. [2011]. The reason might be the significant differences across regions and also differences in the methodology used such as the cost approaches. Other studies also found lower estimates for the total European costs of dementia compared to Wimo et al., [2011]. Wimo et al. [2007] estimated the total worldwide societal costs of dementia in 2005. They found that the annual costs per case were 12,000 euros. The authors also found that informal care was more important in southern Europe while direct care in northern Europe. In addition, Wimo et al. [2010] updated the estimates of 2005. They found that the annual costs of dementia were 14,000 euros per case in 2009, showing a slightly increase.

The main strengths of this study are presented as follows. First, the direct costs are decomposed into nursing home, out-of-pocket and formal care costs. In the relevant literature presented in this section, there is no sub-costing within the direct costs. The direct costs have been found to be the most relevant cost of dementia. Hence, decomposing within them, might help to identify which is the main component of these costs. Second, methodological issues might make comparisons across countries and studies problematic. In particular, in Wimo et al. [2011], the different cost approaches used to value informal care explain an important part of the differences found across regions. For example, the authors found that in southern Europe informal care is the most relevant cost of dementia. However, this finding might be mainly due to the higher imputation of informal care hours in southern Europe compared to other regions. With the purpose of avoiding this, the same cost approach, the replacement cost approach, is used in this study to estimate the informal care costs. In addition, using the Dutch

reference prices from Hakkaart-van et al. [2015] also contributes to make cross-country comparisons possible.

5.3 Methodological issues

The research methodology is critically discussed in this section because it might affect the accuracy of the results found by overestimating or underestimating them. First of all, informal care is one of the most important components of the total dementia costs. Informal care is very difficult to measure because most of the informal caregivers do not recognize themselves as informal caregivers and it is also difficult to measure the total amount of hours of informal caregiving.

In this study, the informal care is valued using the replacement cost approach (see section *3.3.4 Informal care costs* for a further explanation). This method has the advantage that it is very easy to perform. However, it does not specify the total impact of the informal care because it only values the time of informal caregiving. The opportunity cost of performing this activity and the physical and mental impact that has on informal caregivers are not valued with this method and therefore, the results might underestimate the real impact and the costs of informal care.

Secondly, the MMSE is not completely used because the language module is missing in the SHARE dataset. Additionally, there are also some questions of the orientation module that are missing (see section *3.2.1 Dementia* for a further explanation). Hence, the amount of demented people might be over or underestimated. As a consequence, the final cost estimations might also be over or underestimated.

Finally, some of the costs and the healthcare are self-reported. Others, are only reported by one member of the household. With reference to the first case, this might underestimate the total costs of dementia because self-reported answers of the demented individuals might be incomplete. Concerning to the second case, informal care given outside the household is asked at a household level. Hence, different options are considered. On the one hand, one option is to ignore the informal care given outside the household. This option might underestimate the results. On the other hand, the other option is to assign informal care given outside the household to all the household members. In this case, this option might overestimate the informal care costs. In this study, informal care given outside the household is relatively significant. For this reason, the second option is preferred and consequently, the results might be overestimated.

5.4 Relevance of the study

Dementia is an age-prevalent disease. For this reason, the ageing of the European population is yielding to an increase of the number of demented cases and the previsions are expected to continue increasing. According to the World Alzheimer Report [2015], dementia is "*one of the biggest global public health and social care challenges facing people today and in the future".* Nowadays, dementia is one of the diseases which has greater economic impact not only for the demented and their families but also for society in general. This challenging and critical situation needs

accurate estimates of the total costs of dementia specified by the type of cost to design the best national healthcare policies to address this problem. Additionally, a further development of European level policies would also be required.

The vast majority of the studies have estimated the dementia costs differentiating only between direct and indirect costs. In this study, the total costs of dementia are estimated differentiating between direct and indirect costs and also decomposing within direct costs. Hence, it adds new information to the current lack in the knowledge of the direct costs of dementia. This is an important contribution to the relevant literature because knowing the different costs of dementia might help not only to determine the performance of the healthcare system but also to design more effective public health care policies which might promote an efficient resource use. Furthermore, it might also help not only to reduce the burden of the disease but also to decrease the dementia costs in the future. For example, designing Long Term Care (LTC) policies might reduce the burden of the disease. In addition, designing preventive policies, such as promoting healthier lifestyles, might reduce the risk of developing Alzheimer disease and vascular dementia [UK, Health Forum, 2014] and hence, decrease the future dementia costs.

5.5 Indications for future research

It has been explained before that dementia cases are estimated to increase in the following years. This is one of the major challenges of the actual and future healthcare public sector. Cross-country comparisons of healthcare costs associated with dementia are increasingly becoming more important for a number of different applications. For example, they might help to determine the performance of the health care system. Hence, it is not only important to determine and completely understand all the relevant costs of dementia but also to compare these costs across countries. Nowadays, there are an important number of studies that have estimated the direct and indirect costs of dementia [Wimo et al., 2006; Wimo et al., 2007 and 2010; Wimo et al., 2011; Ostbye et al., 1994]. However, there are only few studies that have decomposed within direct costs [Connolly et al., 2014; Ostbye et al., 1994; Hurd et al., 2013; Allegri et al., 2007]. Consequently, there is a notable need for more extensive research to estimate and analyse the sub-costs of the direct dementia costs. Moreover, different ways of organizing and financing the health care systems and the dementia care, the availability resources and the informal care importance, among other factors, make it difficult to compare the costs across countries. The traditional methods used for international comparisons of costs, such as the GDP purchasing power parities (PPPs), the medical care PPPs, the exchange rates and the GDP per capita, among others, do not often reflect the price differences in an appropriate manner. Future research is needed to explore new methods, such as the episode-specific PPPs (ESPPPs), that reflect prices and resource use in a more accurate way than traditional approaches [Schreyögg et al., 2008].

In addition, an important component of the total dementia costs is found to be informal care. There are different methods that can be used to value informal care. The most widely used are the opportunity cost approach and the replacement cost approach. The

former uses the average wage to estimate the opportunity cost of informal caregivers and hence, overestimate the costs because people who are not in the labour market are valued in the same way than people who are in the labour market. The second one only values the time of informal caregiving and it does not value the indirect costs, such as the production losses or the premature mortality. These costs are important because it is known that informal caregiving affects the health of caregivers [Do et al., 2015]. Therefore, affecting in an indirect way society. Further research in health economics is needed to estimate accurately these costs. Using discrete choice experiments might be one possible solution to value informal care because it helps to account for preference heterogeneity between informal caregivers [Mentzakis et al., 2010].

5.6 Conclusion

While previous literature only discussed the direct and indirect costs of dementia in Europe, this thesis highlights the importance of additionally, decomposing within the direct costs. In particular, formal and informal care are found to be the key contributors to the dementia costs. The results of the analysis would recommend applying health public policies to prevent and address the costs of healthcare use associated with dementia at a national and European level. In the future, these programs will not only decrease the burden of the disease to society but also decrease its costs.

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Appendixes

Appendix 1. Explanatory variables definition.

Socioeconomic	
Gender	Gender of the respondent. Dummy variable: 1 = male , and 0 = female
Age	Age of the respondent at the year of the interview. Continuous variable.
Education	Level of education reported by the respondent. Categorical variable: 1 = Low level of education, 2 = Medium level of education, 3 = High level of education and 4 = other
Marital Status:	Current marital status of the respondent. Dummy variable: 1 = married, and 0 = non-married
Income	Annual income of the respondents. Continuous variable
Chronic conditions	
Heart attack	Whether the respondent reports heart attack. Dummy variable: 1 = respondent reports heart attack, and 0 = otherwise
Hypertension	Whether the respondent reports high blood pressure or hypertension. Dummy variable: 1 = respondent reports high blood pressure or hypertension, and 0 = otherwise
Cholesterol	Whether the respondent reports high blood cholesterol. Dummy variable: 1 = respondent reports high blood cholesterol, and 0 = otherwise
Stroke	Whether the respondent reports stroke. Dummy variable: 1 = respondent reports stroke, and 0 = otherwise
Diabetes	Whether the respondent reports diabetes or high blood sugar.

	Dummy variable: 1 = respondent reports diabetes or high blood sugar, and 0 = otherwise
Lung disease	Whether the respondent reports chronic lung disease. Dummy variable: 1 = respondent reports chronic lung disease, and 0 = otherwise
Cancer	Whether the respondent reports cancer. Dummy variable: 1 = respondent reports cancer, and 0 = otherwise
Ulcer	Whether the respondent reports stomach or duodenal ulcer or peptic ulcer. Dummy variable: 1 = respondent reports stomach or duodenal ulcer or peptic ulcer, and 0 = otherwise
Parkinson disease	Whether the respondent reports Parkinson disease. Dummy variable: 1 = respondent reports Parkinson disease, and 0 = otherwise
Cataracts	Whether the respondent reports cataracts. Dummy variable: 1 = respondent reports cataracts, and 0 = otherwise
Hip fracture	Whether the respondent reports hip fracture or femoral fracture. Dummy variable: 1 = respondent reports hip fracture or femoral fracture, and 0 = otherwise
Other conditions	Whether the respondent reports other chronic conditions. Dummy variable: 1 = respondent reports other chronic conditions, and 0 = otherwise
None	Whether the respondent reports none chronic conditions. Dummy variable: 1 = respondent reports none chronic conditions, and 0 = otherwise

Appendix 2. Results obtained from the fixed effects model for nursing home costs.

	Nursing home costs			
	All regions	**Northern Europe**	**Western Europe**	**Southern Europe**
Dementia				
CIND	-0.987	-45.146	6.398	-13.067
	[23.428]	[37.744]	[27.938]	[89.403]
Severe dementia	261.014	3,019.219	-12.763	-66.912
	[339.724]	[3,409.376]	[117.506]	[182.764]
Heart attack	8.564	130.118	-34.187	62.285
	[49.499]	[94.837]	[60.526]	[142.300]
Hypertension	-53.524	-14.166	-44.061	-97.304
	[34.247]	[80.273]	[34.807]	[101.142]
Cholesterol	14.566	42.163	10.583	1.306
	[35.176]	[59.594]	[41.953]	[97.524]
Stroke	241.758**	368.817	97.722	610.423
	[111.442]	[249.197]	[107.649]	[454.422]
Diabetes	-91.984	-64.524	-109.078	-37.911
	[71.241]	[45.166]	[87.633]	[187.863]
Lung	-105.637	29.143	-198.765**	103.337
	[72.496]	[46.229]	[89.800]	[208.286]
Cancer	-67.957	-122.852	-144.092*	309.984
	[64.025]	[86.087]	[84.084]	[198.282]
Ulcer	-110.817	242.085	-64.426	-483.479**
	[87.899]	[184.457]	[107.174]	[218.757]
Parkinson	256.986	1.338.965	85.543	9.455
	[295.353]	[1406.49]	[273.394]	[57.945]
Cataracts	-12.108	-48.1	4.844	-21.898
	[43.466]	[55.798]	[54.571]	[133.127]
Hip Fracture	70.803	-17.528	264.511	-435.318*
	[127.191]	[255.679]	[178.448]	[233.084]
Other	-18.318	26.974	-8.762	-67.175
	[30.908]	[41.178]	[43.358]	[78.384]
Married	-100.635	-177.88	-38.703	-214.858
	[85.827]	[166.494]	[109.135]	[237.521]
Age	0.365	8.462*	-4.67	-1.299
	[3.047]	[4.653]	[3.426]	[8.473]
Education				

Medium Education	16.155	37.541	16.07	62.756
	[33.403]	[83.048]	[26.478]	[89.187]
High education	-156.07	26.792	-225.572	36.121
	[145.591]	[84.096]	[212.913]	[83.663]
Income	0.000	-0.001	0.000	-0.001
	[0.000]	[0.001]	[0.000]	[0.000]
Intercept	275.279	-339.441	560.468	559.765
	[211.348]	[371.738]	[222.928]	[641.303]
Number of observations	**122555**	**21168**	**73203**	**28184**

Note 1: * means 10% significance level; ** means 5% significance level; *** means 1% significance level.
Note 2: Reference groups are no dementia, none chronic coexisting conditions, unmarried and low level of education.

Appendix 3. Results obtained from the fixed effects model for out-of-pocket costs.

	Out-of-pocket costs			
	All regions	**Northern Europe**	**Western Europe**	**Southern Europe**
Dementia				
CIND	40.567	91.772	-9.267	1.265.699
	[26.955]	[68.298]	[22.957]	[83.413]
Severe dementia	76.862*	95.487	84.665	109.41
	[42.785]	[92.144]	[67.924]	[90.751]
Heart attack	49.074	-54.838	105.903***	40.211
	[32.311]	[110.440]	[31.256]	[37.772]
Hypertension	13.097	-27.409	-3.91	76.955
	[31.563]	[88.461]	[19.716]	[80.050]
Cholesterol	4.594	-56.754	13.031	38.246
	[36.805]	[104.673]	[48.188]	[56.574]
Stroke	146.599***	176.135**	96.672**	256.183**
	[36.805]	[85.599]	[37.930]	[128.857]
Diabetes	106.471***	80.461	123.602**	89.926
	[39.674]	[63.443]	[55.910]	[82.941]
Lung	144.982	57.078	67.251	363.764
	[73.746]	[51.290]	[46.714]	[257.775]
Cancer	115.503**	207.775	76.577	50.258

	[52.089]	[143.790]	[43.854]	[90.187]
Ulcer	63.718**	66.096	70.687	33.433
	[31.622]	[49.902]	[39.900]	[75.938]
Parkinson	152.071	-37.365	234.701	112.801
	[125.767]	[274.776]	[182.628]	[196.184]
Cataracts	31.674	40.048	12.289	52.341
	[44.500]	[34.706]	[35.693]	[153.639]
Hip Fracture	74.738	73.631	1.817	195.371**
	[53.566]	[104.014]	[84.524]	[88.727]
Other	95.818***	43.828	58.163**	231.837**
	[30.487]	[31.444]	[22.833]	[115.288]
Married	103.878***	140.407***	68.946	158.589**
	[30.757]	[44.556]	[44.693]	[76.343]
Age	24.205***	23.611***	22.435***	29.587***
	[2.341]	[4.165]	[2.439]	[7.151]
Education				
Medium Education	-225.613	-55.34	-327.355	-14.579
	[149.204]	[101.993]	[205.021]	[111.523]
High education	-150.868	5.192	-316.105	249.989
	[168.008]	[102.769]	[274.487]	[216.600]
Income	0.000	-0.001	0.000	0.000
	[0.000]	[0.001]	[0.000]	[0.000]
Intercept	-1,264,088.00	-1,264,304.00	-1,007,151.00	-1,900,235
	[194.271]	[371.854]	[212.539]	[560.384]
Number of observations	**84421**	**16536**	**45949**	**21936**

Note 1: * means 10% significance level; ** means 5% significance level; *** means 1% significance level.

Note 2: Reference groups are no dementia, none chronic coexisting conditions, unmarried and low level of education.

Appendix 4. Results obtained from the fixed effects model for formal care costs.

	Formal care costs			
	All regions	**Northern Europe**	**Western Europe**	**Southern Europe**
Dementia				
CIND	157.496*	68.297*	213.658	89.197
	[93.891]	[40.948]	[143.470]	[93.681]
Severe dementia	754.004*	617.483	613.688	956.431**
	[395.894]	[489.072]	[670.678]	[464.085]
Heart attack	-177.491	-129.512	46.009	-938.880
	[224.365]	[156.788]	[267.248]	[696.604]
Hypertension	-298.596	27.865	-615.574	213.535
	[242.565]	[181.094]	[393.631]	[265.318]
Cholesterol	190.260	201.861	214.333*	212.797
	[126.212]	[160.947]	[128.799]	[431.775]
Stroke	910.904**	504.579	613.134	2,285.275
	[440.970]	[825.440]	[410.927]	[1,669.195]
Diabetes	-219.437	-97.549	37.951	-620.237
	[388.775]	[107.439]	[550.461]	[786.225]
Lung	548.503	-93.397	1,345.848**	-921.456
	[414.022]	[324.520]	[635.062]	[773.622]
Cancer	-66.903	-94.437	43.341	-344.816
	[211.615]	[215.854]	[323.932]	[382.884]
Ulcer	364.147**	172.437	319.550	531.636*
	[174.707]	[286.176]	[271.747]	[280.755]
Parkinson	2,982.415	-70.227	9,243.933*	-11,464.600
	[4,095.562]	[100.237]	[4,984.121]	[10,323.54]
Cataracts	20.966	68.771	-324.871	858.813
	[387.969]	[120.506]	[447.657]	[1,144.567]
Hip Fracture	1.752.729*	87.180	2,152.929	3,193.620
	[992.999]	[276.394]	[1,600.543]	[2,432.327]
Other	-126.844	123.245*	-232.130	-382.798
	[188.124]	[72.134]	[347.298]	[257.646]
Married	-641.885	298.431	-1,090.706	-733.335
	[528.086]	[453.965]	[855.892]	[714.473]
Age	151.633***	122.221**	153.233***	174.478**
	[34.025]	[58.516]	[45.668]	[73.853]
Education				

Medium Education	-57.388	118.583	-158.975	268.508
	[163.675]	[199.954]	[208.640]	[906.593]
High education	-103.961	162.631	-296.903	186.121
	[163.582]	[206.921]	[246.153]	[506.569]
Income	0.000	0.003*	-0.001	0.000
	[0.002]	[0.002]	[0.002]	[0.001]
Intercept	-9,000.650	-8,133.274	-8,560.184	-10,674.430
	[2,250.426]	[3,907.561]	[3,001.679]	[4,968.885]
Number of observations	**47790**	**9507**	**25748**	**12535**

Note 1: * means 10% significance level; ** means 5% significance level; *** means 1% significance level.
Note 2: Reference groups are no dementia, none chronic coexisting conditions, unmarried and low level of education.

Appendix 5. Results obtained from the fixed effects model for informal care costs.

	Informal care costs			
	All regions	**Northern Europe**	**Western Europe**	**Southern Europe**
Dementia				
CIND	121.272**	212.288**	89.338	162.971
	[56.352]	[105.827]	[71.323]	[158.036]
Severe dementia	455.730***	724.814*	325.942	591.723**
	[163.542]	[406.182]	[222.954]	[298.859]
Heart attack	53.525	173.688	135.111	-341.151
	[110.517]	[190.600]	[134.540]	[325.520]
Hypertension	16.966	72.464	1.684	41.405
	[77.864]	[152.719]	[97.629]	[186.703]
Cholesterol	103.277	-293.019*	193.554**	122.669
	[76.874]	[155.226]	[96.608]	[184.854]
Stroke	362.546*	-305.731	508.791**	643.660
	[194.188]	[300.747]	[245.876]	[587.734]
Diabetes	336.425	-284.674	30.768	244.053
	[144.534]	[274.781]	[178.309]	[348.181]
Lung	244.476*	210.315	302.189	85.946
	[144.659]	[250.315]	[185.579]	[346.941]

Cancer	390.028***	485.278*	319.652*	575.316
	[139.557]	[262.869]	[172.068]	[437.056]
Ulcer	207.755	76.942	57.894	680.984*
	[154.021]	[301.312]	[197.891]	[350.444]
Parkinson	-191.501	217.198	-182.521	-597.069
	[451.256]	[640.555]	[563.598]	[1,189.299]
Cataracts	99.320	-72.557	107.711	257.980
	[112.676]	[203.274]	[141.906]	[309.644]
Hip Fracture	606.792**	-105.553	791.984**	776.351
	[248.069]	[392.578]	[323.354]	[661.611]
Other	108.428	38.805	148.341*	56.969
	[70.033]	[117.519]	[8.941]	[190.903]
Married	348.421	449.316	272.466	463.591
	[245.896]	[428.343]	[319.839]	[677.327]
Age	110.981***	89.311***	113.971***	128.166***
	[7.116]	[12.305]	[8.993]	[20.064]
Education				
Medium Education	686.121	-160.937	-187.155	5,153.973**
	[856.979]	[220.217]	[956.472]	[2,430.71]
High education	1,203.394	-475.122	806.473	2,133.636
	[911.478]	[295.048]	[1,142.892]	[1,756.49]
Income	0.001	0.000	0.000	0.005
	[0.001]	[0.002]	[0.001]	[0.002]
Intercept	-6,802.683	-5,203.288	-6,513.068	-8,499.447
	[706.151]	[881.475]	[903.651]	[1,618.354]
Number of observations	**109129**	**18511**	**65609**	**25009**

Note 1: * means 10% significance level; ** means 5% significance level; *** means 1% significance level.

Note 2: Reference groups are no dementia, none chronic coexisting conditions, unmarried and low level of education.