

# Cost of Dementia in Romania: A Cross-sectional Cost-of-Illness Study Undertaken in Bucharest

Vlad Onetiu<sup>1, 2</sup>, Sorina Maria Aurelian<sup>3</sup>, Ana Capisizu<sup>3</sup>, Florina Cristescu<sup>4</sup>, Ileana Codruta Zus<sup>4</sup>, Katarzyna Kissimova-Skarbek<sup>1</sup>

<sup>1</sup> Department of Health Economics and Social Security, Institute of Public Health, Faculty of Health Sciences, Jagiellonian University Medical College, Cracow, Poland

<sup>2</sup> Public Health Wales

<sup>3</sup> “Sf. Luca” Chronic Disease Hospital in Bucharest, Romania

<sup>4</sup> Promemoria Private Clinic in Bucharest, Romania

*Address for correspondence:* Vlad Onetiu, [v.onetiu@yahoo.co.uk](mailto:v.onetiu@yahoo.co.uk); Katarzyna Kissimova-Skarbek, Instytut Zdrowia Publicznego, Grzegorzewska 20, 31-531 Kraków, [kskarbek@uj.edu.pl](mailto:kskarbek@uj.edu.pl)

## Abstract

**Objective.** The main aim of the research was to investigate the costs of dementia in Romania based on the estimated average cost of each person with dementia in Bucharest.

**Method.** This was a cross-sectional, non-population based study, with a mix of “bottom-up” and “top-down” data collection methods, which adopted the *Cost-of-Illness* approach from a broad societal perspective. The study involved 31 carers of patients with dementia in two Bucharest clinics in 2013 and 2014: the PROMEMORIA Private Clinic and the “Sf. Luca” chronic disease hospital. Face-to-face individual interviews were conducted using a modified version of the Resource Utilisation in Dementia (RUD) questionnaire. The average direct and indirect costs of dementia per person in the study were estimated for the year 2013 and are presented for the three levels of disease severity – mild, moderate and severe.

**Results.** The mean carer age was 59.3 (SD = 13.3), with 77.4% of the participants being females. The average cost (direct and indirect) of dementia per person in the study ranged from 53,787 RON to 67,554 RON (depending on the hourly wage used for valuation of the caregivers’ time). Converted to the international dollar (I\$) currency, using the purchasing power parity (PPP) of the US dollar in Romania in 2013, the average annual cost of dementia in the study accounted for between I\$32,301 and I\$40,583. The estimated total annual cost of dementia in Romania in 2013 was between I\$9 bln and I\$11 bln.

**Key words:** dementia, Alzheimer’s disease, caregivers, Romania, cost of illness, direct costs, indirect costs

**Słowa kluczowe:** demencja, choroba Alzheimera, opiekunowie, Rumunia, koszt choroby, koszty bezpośrednie, koszty pośrednie



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## Introduction

### 1. Background to Dementia

#### 1.1. Dementia – definition and diagnosis

Dementia has been described as an “umbrella term” [1], which encompasses as many as 100 different diagnoses which, in certain key aspects, are more or less similar [2]. Usually, dementia presents itself as disturbance in specific and general brain functions may include memory, reasoning, orientation, comprehension, calculation, learning capacity, language and judgement [3], over a sustained period of time and is characterised by a progressive decline. Many researchers today agree that dementia is best described as a “syndrome” [1, 3–6]. Bayles and Tomoeda [7] explained that this term is used to denote a wide-ranging list of signs and symptoms that are associated with the progression of the disease. The most common forms of dementia are Alzheimer’s Disease (AD), which can be found in 50 to 60% of all dementia sufferers [8]. Other less common types of dementia include Vascular Dementia and Dementia with Lewy Bodies, fronto-temporal dementia, Huntington’s Disease and dementia due to other rare neurodegenerative disorders. A common distinction presented in literature is that between cortical and subcortical dementia [8], with AD belonging to the former group. Its neurological presentation features a development of plaques and tangles in the brain tissue, which are the main factors considered responsible for cell death and tissue loss [1].

However, there is still a debate around what constitute the valid categories of dementia and what are the true hallmark signs of AD [9]. This is one of the reasons that the diagnosis for AD is still carried out on a differential basis, as specialists need to account for “any other disease process that could be the cause of the observed cognitive decline” [8]. It should also be noted that, despite similarities in the above key aspects of brain function, the different types of dementia have separate neuropsychological profiles, depending on the area of the brain that is affected [8]. Furthermore, individuals with the same diagnosis may present different symptoms and manifestations, which is one of the reasons why the modern approaches to dementia care emphasise person-centred care and the individual tailoring of therapies [10].

#### 1.2. Current global context

The European Parliament’s initiative on Alzheimer’s Disease and other dementias [11] recognises that the accumulation of conditions should not be perceived as a normal outcome of the process of ageing. It also states that societies should ensure that the best medical treatment is available to patients, alongside other forms of care. However, during the last century there has been a significant change in the sociodemographic makeup of societies in general, marked by what is probably the most rapid and sustained period of population growth in recorded history. Coupled with increased life expectancy,

in some places to more than 80 years, it led to an unprecedented estimate of 7 billion number of people globally that has been reached in 2011. This state of affairs poses specific challenges to public health workers [12]. One such challenge is caused by the complex needs of an increasingly ageing population.

#### 1.3. Patterns in disease prevalence and burden

According to figures presented by the United Nations [13], the number of people aged 60 or over has increased approximately threefold between 1950 and 2000 and it is expected to continue growing by an even greater rate, to reach almost 2 billion by 2050. In 2005 24.3 million worldwide were living with dementia and it is expected that in 40 years’ time this number will have increased almost four fold. In the meantime, a WHO global report (completed in partnership with ADI) [3] has highlighted that 35.56 million people worldwide were then living with dementia and produced an even greater estimate for the number of people who will have dementia by 2050: 115.38 million people aged 60 or over. The most recent ADI report [14] estimates that worldwide there are over 9.9 million new cases of dementia each year, with updated estimates that every year surpass the projections made the previous year. The total number of people with dementia in 2015 was estimated at 46.6 million and, at this rate of growth, the prediction for 2050 was increased to 131.5 million.

When looking at mortality rates, one needs to bear in mind that dementia is usually accompanied by one or more somatic comorbidities. One multicentre study has found that most AD patients in a US population have at least three comorbid medical illnesses [15], which makes it difficult to attribute the outcomes to dementia alone. It is more likely that dementia and/or AD will count more towards “contributory” causes of death, rather than towards “underlying” causes [16]. A 14-year multicentre prospective cohort study has found that people with dementia could expect to live, on average, 4.5 years after receiving a formal diagnosis [17]. The authors also documented the impact of other factors, such as married life (in which case people with dementia lived for an average of 7 years), age, gender (with males dying faster than women) and the effect that functional impairment may have on the length of survival. This finding was confirmed by a French community-based cohort study, which found the same average survival time, for a population with a mean age at onset of 82.3 years [18]. Nevertheless, in a review of published studies on this topic, Todd et al. [19] concluded that there is substantial heterogeneity between studies, with regard to their design and concluded: “it is clear that dementia and AD are associated with significant mortality” (p. 1109). According to Murray et al. [20] the distribution of Disability-Adjusted Life Years (DALYs) indicate that the greatest burden on the global population is due to Non-Communicable Diseases (NCDs). AD and other dementias globally do not appear on top of the list for DALYs by cause, nor do they figure prominently on the list for Years of Life Lost. This

is because most people who die due to dementia have already passed, or are very near their threshold of life expectancy. Nevertheless, it is important to note, that, after broad consultations for the Global Burden of Disease report, the global community agreed to award a higher disability weighting for dementia: 0.67, one of the most severe ratings, with the exception of severe developmental disorders [14]. This means that every year lived with dementia entails the loss of two thirds of the year (causes 0.67 DALYs). According to the latest GBD study methodology in Romania [21] the burden of AD and other dementias on society of Romania has dramatically increased. Compared to the year 1990, the burden of AD and other dementias expressed in DALYs per 100,000 of the population in 2015 had increased by 82.82% (moving from 26<sup>th</sup> to 12<sup>th</sup> in the ranking of the top causes of disease burden in Romania) [21].

#### **1.4. Diagnosis and resource utilisation challenges**

In time, as more research has explored the progression of the syndrome, some organisations have seen increasing benefits in breaking down the three broad stages of disease progression into several, more specific stages (e.g., [22]). More recently, an entirely new diagnostic category has been added, namely Mild Cognitive Impairment (MCI), the purpose of which is to identify people with an increased risk of developing a form of dementia in the future [6]. It is defined as “Cognitive decline greater than expected for an individual’s age and education level, but which does not notably interfere with the activities of daily life” [23]. Such a diagnostic tool is believed to have real value in early identification and secondary prevention (p. 1262), although it should be mentioned that, according to [24], the early recognition of dementia poses certain “risks” to patients, those close to them, and even social and/or medical services. For this reason, an increased sensitivity in the detection of early signs of dementia in primary care needs to be accompanied by capacity building to manage the extra challenges caused by the increasing number of people with a formal diagnosis (A. Bayer, personal communication, the 26<sup>th</sup> of March, 2014).

While a project that would ensure most people with dementia receive a diagnosis might prove to be very costly in terms of resources, it is clear that the current situation is also rather costly for health and social services. Ultimately diagnosis is acknowledged to be a problem throughout Europe, including in the more developed health care systems of the Western countries [25, 26]. Some of the reasons invoked for this state of affairs are: social stigma, professionals’ disbelief regarding the capacity to offer help that makes a difference in the patients’ state [26] and the large demand on the human and financial resources needed to implement a Primary Care screening tool [27]. It may be that a high proportion of people with dementia are put in a position to receive a formal diagnosis only after they have been admitted

into emergency services [28]. Naturally, this combination usually has the effect of prolonging the patient’s stay in hospital, which can only bring unnecessary additional cost and distress to those who find it difficult to adapt to this environment. Thus, Lyketos et al. [29] have shown that the mean length of stay in a general hospital for people with dementia was, on average, more than double that of people without dementia. From a perspective of service use, additional resources will be needed to manage cases of people with dementia needing emergency treatment [30].

#### **1.5. Dementia on the public health agenda**

The historical trajectory of the public’s awareness of dementia (with particular reference to AD), resembles an exponential, rather than a linear function. Two decades ago, it is unlikely that most people knew about the clinical diagnosis of AD and its implications. However, relatively quickly, cases of dementia became more visible through the media reporting cases, such as: Iris Murdoch, Terry Pratchett, as well as people from the political sphere, such as the former prime-minister of Great Britain, Margaret Thatcher and the former president of the United States, Ronald Reagan. The latter’s diagnosis, received soon after stepping down from office, has raised issues about the capability of world leaders to retain their role in case of early symptomatology of the syndrome [31]. Academically, there has been a massive increase in research findings and, while it is agreed that not much can be done at present regarding genetic risk factors and effective treatment in the case of diagnosis, there are some positive insights gained from the study of environmental factors in the development of the disease [32]. The most promising line of research is focused on vascular dementia and, according to results from a major study, antihypertensive treatment (treating 1000 elderly people with systolic hypertension could prevent as many as 19 new cases of dementia in the next five years). Additionally, other strategies for prevention explored by scientists include: encouraging cognitive activity, physical exercise, social engagement, a healthy diet and recognition of depressive symptomatology [32].

Individual countries from the developed world also took national, political initiatives to “fight back” (in the words of prime-minister David Cameron – [33]) against the rising wave of dementia. This was followed by supranational joint agreements (e.g. [11]), the declaration of dementia as a public health priority on the agenda of WHO [3] and finally the G8 summit, hosted in London at the end of 2013, focused exclusively on dementia. Such recognition should also be taken to mean, apart from the fact that world leaders are genuinely interested in improving the lives of the elderly, that dementia has an economic cost. As stated previously, if inappropriate action (or none whatsoever) is taken, the cost of dementia is predicted to rise with devastating consequences for health systems in terms of service utilisation.

## **2. Cost of Illness study – a useful approach to assess burden of disease in monetary units**

### **2.1. Cost of Illness studies: their value and relevance**

Cost-of-Illness (CoI) studies are a form of economic analyses expressing in monetary units the burden of disease to a society. The aims of the authors of such studies are, according to Byford et al. [34], “to identify and measure all the costs of a particular disease, including the direct, indirect and intangible aspects” (p. 869). From an economic perspective, the method used to evaluate indirect costs (such as those valuing the time of informal carers) are not straightforward. As there is plenty of heterogeneity regarding the methods employed, CoI studies have become fairly controversial regarding the extent to which they should be used for decision-making purposes [35]. Some researchers recognise CoI studies as being useful for estimating the amount a society spends on a disease (and thereby calculate the how much could be saved if the particular disease could be eliminated) as well as breaking down the total costs into sectors based on the source of the contribution [36]. Others, such as Currie et al. [37] stress that, while CoI studies have “political” value in drawing general attention to a particular issue or disease, they are not fit for use in decision-making and academic research. Furthermore, Byford et al. [34] conclude that CoI research adds “little to the creation of an efficient healthcare system” (p. 1519) and that more focus should be placed on cost-effectiveness analyses and other economic evaluations. Other experts seem to be less trenchant on this matter, with McDaid [38] stating that, despite inherent issues in CoI studies with regards to valuing informal carer time, it is very important for academics to increase efforts to improve the accuracy of evaluating the time of informal carers. His paper lists a few reasons why this would be relevant in the present socio-economic context, including recognising that what is perceived today as a “free resource” by the state might need to be provided as a formal service in the future.

In the USA, CoI studies estimates are already being used by Congress as one measure of allocating research dollars among the National Institutes of Health specifically in: defining a problem economically, justifying intervention programs, offering a basis and a theoretical framework for future policy and planning interventions, as well as for further and better quality research [39]. The fact that some of the methods used for CoI do not provide satisfactory accurate results should not prompt one to generalise these misgivings onto the entire category. A careful analysis of key aspects, such as the perspective taken by the authors, the exact methods used to estimate and value specific resources used, as well as the aims of the research may help to establish the value of a particular study. In their review of CoI studies on dementia, Costa et al. [40] stressed that clear descriptions in the methodology section are the key to a better understanding of the variation in reported costs. The latter argue that CoI studies can serve as a basis for future projections of expenses linked to a particular dis-

ease and may be able to influence managerial decisions to control the costs of AD.

### **2.2. Cost of Illness studies – an empirical framework**

As mentioned earlier, the framework of CoI studies encompasses a wide variety of costs which are generally divided into two categories: direct and indirect. Direct medical costs include all forms of expenditure that derive from living with a particular illness, such as: prevention, detection, treatment, rehabilitation, research, training and annual costs of capital investment in medical facilities [41]. Additionally, this category includes non-medical costs, such as transport fees, social care costs – formal services provided outside of the medical care system, including community services such as home care, food supply and transport, and residential or nursing home care [42, 43]. The other large category included in the CoI studies, namely indirect costs (productivity costs), represents lost economic productivity due to death (mortality costs) or lost or impaired ability to work or to engage in leisure activities due to illness (morbidity costs) [44]. Morbidity costs are comprised of the economic consequences of reduced productivity during short-term and long-term absence from work (absenteeism) or productivity costs without absence (presenteeism) [45].

In practice, any cost that does not result in direct use of resources, but that leads to resource loss due to disease may be considered as indirect [39]. There are several methods currently employed in literature to value time lost due to the disease.

The human-capital approach is the most frequently used method [45–47]. It assumes that the productivity of a person may be valued according to his or her salary, and essentially measures the productivity lost by employers by the absence of people who take days off work for reasons of illness or caring responsibilities [48]. However, this method has not been without its critics who, interestingly, have argued that the human capital approach may both over-estimate [45] and under-estimate the indirect costs [39]. The former argue that the potential, rather than the real loss is measured, while the latter claim that the approach underestimates the value of children and the elderly. Another more recently developed approach to estimating the indirect costs is the “friction cost” method. It takes into consideration that short-term absence from work may be dealt with by the assignment of uncovered tasks to other employees while long-term absence might be overcome by hiring a new worker [45]. What it essentially does, is to limit the time frame for which the costs of absence are taken into account. Despite the theoretical indecisiveness, practical research can employ both methods, and then present the results with a sensitivity analysis.

Two main approaches may be used to collect data regarding the use of resources: (i) The bottom-up approach and (ii) The top-down method. The former implies that researchers collect data from individuals, usually using questionnaires, while the latter relies on studies that draw data from official publications and government releases



[40]. In practice, research that aims to make a comprehensive estimate of the use of resources will tend to use a mix of both approaches. Nowadays the questionnaires used in the bottom-up approach tend to be disease-specific and to tap into both direct and indirect costs. There are several instruments designed to evaluate the costs related to caring for dementia patients in particular, of which the most prominent are: the Caregiver Activity Survey (CAS) [49]), the Caregiver, Time Survey (CATS) [50] and the Resource Utilisation in Dementia (RUD) [51, 52]. For the purposes of the present study, the RUD instrument, whose authors claim it to be the most popular tool of its kind [52] was selected. The constant efforts invested by its creators to improve and adapt it have led to the development of versions fit for use in clinical settings (see [52] for further details), in community settings [53] or, more recently, in a global setting [51]. The questionnaire essentially asks carers to self-report their use of resources needed to care for their patient with dementia. This has been shown by Wimo and Nordberg [54] to present a close correlation with register data regarding hospital care, family physician and district nurse visits. In their conclusion, the authors recommended that interviews based on the RUD format may “serve as a valid and reliable substitute for observations”.

### **2.3. Global research on the costs of dementia**

Mirroring the unexpected growth and constant re-evaluation of the prevalence of dementia in the global population, the estimates for the economic costs of dementia have increased significantly with time [53, 55]. The latest estimate of the worldwide economic impact for dementia is for 2015 and it indicates a total cost of US\$ 818 billion [14]. This is an increase of 35.4% from the 2010 estimate of US\$ 604 billion. The dramatic change in the estimated cost in the last five years arises mainly from the fact that the 2010 prevalence values were not as accurate as those for 2015. In 2010 70% of the global costs occurred in Western Europe and North America [51]. Although both studies show that the most developed countries (e.g., G7, G20) incur a larger share of the total cost than all the other countries combined, the latest figures reveal that the greatest relative increases occurred in the African and East Asia regions, mirroring their higher rate of economic/social development. One of the reasons why high-income countries have a much higher cost of dementia than low-income or middle-income countries (apart from the obvious fact that living wages and, as a result, prices are generally higher) is that the costs of social care included in the direct non-medical costs category account for a greater percentage of the total costs. This is because care, especially in the West and North of Europe, is less frequently undertaken by the family or friends of patients, but more by professional services, whereas informal care, which gives a lower estimate of costs, remains the norm in other countries, including those from Eastern and Southern Europe [56].

In a European study of the costs of brain disorders, Olsen et al. (2011) found that dementia, in terms of di-

rect non-medical costs, was the most expensive disease presented in their study. This category of expenditures includes all costs directly related to the disease that may be required for social services, special accommodation and/or informal care, excluding health care costs (including pharmaceutical products) related to treatment of the disease (p. 722). The total cost of dementia in the EU27 was estimated by Wimo et al. [56] to be approximately €160 billion, with €22,000 per year required in average for each demented person, of which informal care accounted for 56% of the total cost. European estimates can be as high as £25,472 per year per person in the UK with dementia [25] converted to 2013 international dollars (\$) accounting for I\$42,956.5 (authors' own conversion).

A 2014 dementia CoI study in France was undertaken by following a methodology similar to that used in our own study [57]. 57 patients and their carers were interviewed using a modified version of the RUD questionnaire, with the explicit aim of taking both formal and informal care into consideration for the final estimate of cost – a feature less frequently seen in CoI literature. The monthly average total cost per person varied between €2,450 (converted to the 2013 international dollars accounted for I\$2,952; annually I\$35,424) when using the proxy good method, and €3,102 (I\$3,737.6; annually I\$44,851) when using the opportunity cost method. The authors argued that the figures indicate that the current French allocation will be unable to meet all costs involved in caring for patients with dementia. As a result there are clear policy implications, with decision-makers having to balance spending more on formal care, or on programmes dedicated to developing a patient's relatives as informal carers.

While it is beyond doubt that there are clear cost differences between the West and East of Europe, the use of different methodology and currencies make international comparisons and extrapolations difficult and untenable. Furthermore, beyond methodological difficulties, the validity of European estimates of the cost of illness is clearly biased towards a Western European database, with most studies concentrated in countries such as the UK, France, Belgium, Ireland, the Nordic Countries, Germany, Italy and Spain [56], with few studies in Eastern Europe. To our knowledge there have been only two cost-of-illness studies carried out in the East of Europe: one in Hungary [58], and one in Turkey [59], but the latter may not be particularly representative of Eastern Europe. Indeed, the literature on the burden of dementia generally outlines the key priorities for the future, including the need for more research to be undertaken in Eastern Europe ([14], p. 13; [56], p. 830).

## **3. Background to the Romanian context**

### **3.1. Romania – socio-political and economic context**

Romanians can be categorised as a nation formerly operating with a socialist economy. Its public system still pays tribute to its previous communist government, branded, following the Second World War, as one of the

**Table I.** Total health expenditures % of GDP in EU countries, year 2014

Country name	Total expenditure as % of GDP
Sweden	11.9
France	11.5
Germany	11.3
Austria	11.2
Netherlands	10.9
Denmark	10.8
Belgium	10.6
<b>European Union</b>	<b>10.0</b>
Malta	9.7
Finland	9.7
Portugal	9.5
Italy	9.2
Slovenia	9.2
United Kingdom	9.1
Spain	9.0
Bulgaria	8.4
Greece	8.1
Slovak Republic	8.1
Croatia	7.8
Ireland	7.8
Czech Republic	7.4
Hungary	7.4
Cyprus	7.4
Luxembourg	6.9
Lithuania	6.6
Estonia	6.4
Poland	6.4
Latvia	5.9
Romania	5.6

Source: World Bank, *Health expenditure, total (% of GDP)*, <http://data.worldbank.org/indicator/SH.XPD.TOTL.ZS>, 2014; accessed: 15.10.2016 [73].

harshest totalitarian regimes in Eastern Europe [60]. Understanding the historical transition of the Romanian state, from exclusively state-owned public services before the December 1989 revolution, to the transition to a market-based economy post-1990 is essential in framing the context for healthcare or the system of social care. These have not only inherited a heavily centralised structure, with most funds directed towards tertiary/hospital care but additionally, they have a low priority on the policy agenda [61]. Furthermore, in an evaluation of the Romanian social care system at the time of the country's integration into the EU, Zaman [62] described it as institutionally "fragmented", without "clear delineation of responsibilities" and inadequately decentralised (p. 1). In terms of the proportion of the older population

that live in poverty, Romania has an average position, with an estimate of approximately 20% at the time of the accession to the EU [63]. Nevertheless, it should be taken into account that an unexplored, but considerable, social issue in Romania is the degree to which the elderly can afford to buy the required medication and/or to lead a healthy lifestyle. Indeed, Vintila et al. [64] (p. 84) reported that many old people from Romania invoke lack of funds as the main reason for not implementing the rules for a healthy lifestyle, rather than ignorance. Knowing more about the needs and resources available to this population is critical for designing better and more effective services, especially for those facing chronic diseases.

The Romanian population has been decreasing steadily and steeply since the 1990s, with a reduction of approximately 1,100,000 people between 1992 and 2002 [65, 66] and by a further 1,800,000 between 2002 and 2012 (Eurostat estimates [67]), resulting in an estimated total population of approximately 20,000,000 in 2013, due mainly to increased rates of migration (after accession to the EU) and to low birth rates [67]. This has translated into a total decrease in population of almost 3 million in just 20 years. The estimates grouped by categories of age, show that the only group that increased rather than decreased is that of people older than 60 [68] (p. 10). Indeed, some projections [69] predict that by 2060 Romania will have become the country worst affected by an ageing population, with an effective economic old-age dependency ratio that is expected to exceed 100%<sup>1</sup>. This makes Romania a good example of a middle-income, developing country, since this group is expected to face the greatest increase in dementia cases in its population in the next 50 years [70, 71].

With a Gross Domestic Product (GDP) per capita estimated at \$21,403 in 2015 [72], Romania remains one of the EU countries that allocates the smallest share of its (GDP) to healthcare and health-related services (5.6% according to the World Bank [73] (**Table I**)). It has moved towards a social insurance system based on the Bismarck model, especially since the National Health Insurance House was established by the *Social Health Insurance law* no.145/1997. In 2012, approximately 75% of the total health budget was met by social health insurance [74]. Nevertheless, according to a few academic articles discussing this topic, the healthcare system in Romania remains fraught with issues such as resource mismanagement, corruption, the migration of large numbers of people, or unequal distribution of funds [75].

### 3.2. Dementia in Romania: analysing available resources

The state of Romanian awareness and action regarding Alzheimer's and other dementias today is still at a basic level. At the moment there are no epidemiological studies to investigate dementia in Romania and the awareness of the disease and its implications are at a low level nationally. This has been suggested as a reason for the late management of cases with dementia and, as a result, for the larger number of comorbidities found in

the Romanian population [76]. Nationally, research dedicated to the syndrome has increased in recent years, but it focuses more on the biological and clinical approaches to dementia, with very few studies documenting the social, psychological and/or economic dimensions.

There are two main memory clinics in Bucharest: the Memory Centre at the Dr. Obregia Hospital and the Centre for Diagnosis and Treatment of Memory-related Diseases. The former, the first such clinic opened in Romania, was established in 2000, as a partnership between the Romanian Alzheimer's Society (RAS) and the leading psychiatry hospital in Bucharest: Prof. Dr. Alexandru Obregia [77]. The clinics are meant to act primarily as ambulatory centres, with accurate diagnostic, patient monitoring and individualised treatment schemes being among their core service aims [77, 78]. In 2009 the PROMEMORIA private clinic was established for similar purposes [79]. The development and provision of services for dementia in Romania is still underdeveloped and lacks the multidisciplinary approach present in many Western countries. Additionally, the training of medical staff, support and protection of patients, as well as carers, are all insufficient or even non-existent. The effects of the financial crisis have been visible, especially on the provision of resources for public services: the Memory Clinic at the Dr. Obregia hospital (the first of its kind to be established in Romania) has had to face several setbacks, including the lack of financial support to manage and sustain its office. The lack of political commitment to the issue of dementia was outlined at the 2014 National Dementia Conference by the President of the RAS, Prof. Dr. Catalina Tudose [80].

At this event the RAS released the first National Strategy and a Plan of Action for dementia [81], which aimed to address the lack of coherence in the political objectives. Unfortunately, this document has not been assimilated politically, unlike the case in other countries where, sometimes with the explicit backing of the leading politicians (e.g. The UK National Dementia Challenge was backed by the former Prime-Minister, David Cameron) and the French strategy for dementia 2008–2012 promoted by the former president, Nikolas Sarkozy [82, 83]. Nevertheless, the article by the RAS describes the Romanian institutional framework for care and medical services for dementia as “incipient” (p. 2), with an insufficiently-developed care system for patients and their carers. At the same time, financial constraints, as well as a dearth of clinical and epidemiological data and the absence of a National Registry are seen as key barriers to future developments in this field. Estimating that 270,000 people suffer from dementia in Romania, of whom only 35,000 have received a formal diagnosis, the strategy calls for a multidisciplinary approach, involving partnerships between key public and private institutions in order to improve an early access to diagnosis and treatment. The main aims included in the document, involve raising public awareness of the syndrome, creating a national patient database, increasing the amount of research on dementia and de-stigmatising patients.

### 3.3. Aims and objectives of the study

The aim of the research was to investigate the cost of dementia for individual budgets (both for health and social care), the Romanian social health insurance system and the broader, societal costs related to the income lost because of the care provided by caregivers to patients. We believe that this project can be a political tool and that it should be part of a broader increase in the research and planning, needed to push dementia onto the public agenda. It is hoped that the results and methodology used will provide a resource for the relevant authorities that would increase their awareness of the socio-economic impact of dementia in Romania, using a national sample, rather than estimates based on the findings from Western populations. Obviously, the results of this research project cannot offer a definitive estimate of the cost of dementia in Romania, principally because of the small sample and the patients not being used to participating in research. There have been several instances during this research, when participants have avoided giving particular kinds of information. This is why we encourage the project to be viewed as a pilot intended to refine the national approach to costing dementia. As stated earlier, to improve global estimates another CoI study in a Eastern European country is very necessary and is a resource requested by international researchers.

## Methods

The present CoI study assessed the national burden of dementia from a societal perspective. It analysed costs at both individual and public level (represented in Romania by the single, National Health Insurance House – NHIH) and it additionally investigated the cost of the hours dedicated by informal carers to patients with the disease. Several data sources were used to achieve this: official government statistics, official reports on dementia (including those released by third sector organisations), individual data and clinical records. As a result, our approach can be described as both top-down and bottom-up, with regard to its approach to costing. Additionally, we used a prevalence-based design [84] so that we were focusing only on an estimate of the annual cost of dementia for 2013, with prospective sampling of the caregiving population (patients were not included in the individual interviews, because of logistic difficulties and the expense involved).

### 1. Participants

We recruited 31 participants from two partner institutions in Bucharest: 12 participants from the “Sf. Luca” Hospital of Chronic Diseases and from the PROMEMORIA centre for diagnosis and treatment. The former is a public hospital, while the latter is a private clinic which specialises in screening, diagnosis, disease monitoring and long-term personalised treatment for cerebral ageing. All participants were carers of patients with vari-



ous forms of dementia. Most questionnaires [24] were completed by female respondents. In the current sample the population of people living in a care home is grossly underrepresented (only 1 respondent stated that the cared for patient resided in a care institution). This means that the present analysis will not establish and investigate the differences between the costs for patients living at home or in an alternative form of accommodation. It should be stressed that the present study focuses mainly on *carers* and the resources needed to care for dementia patients. However, data on the medical care of patients with dementia were also collected.

## 2. Questionnaire

The RUD questionnaire was translated and adapted to better evaluate the costs within the Romanian health-care system (See **Appendix**). The Romanian version was obtained by a process of back translation, with the help of two Psychology Masters students (see **Acknowledgements** for more details), with an input from one of our collaborating doctors. As stated earlier, we have inserted some additional questions: 1. The diagnosis received by the patient, which has been completed together with the doctor managing the patient's illness (number A1.1.5); 2. The distance between the current residence of the carer and that of the patient (question A1.1.7); 3. The means of transportation used to reach the patient's residence (question A1.1.8); 4. The number of other carers looking after the patient (number A1.1.9); 5. The number of people living with the carer (question A1.1.11); 6. The carer's household income (question A1.1.12); 7. Recent changes in the patient's accommodation (altering section A2.1); 8. The services needed, but not received by the patient: For this purpose, we added, at the beginning of section A2.2 a question about the number of times the patient had been referred to a hospital in the past year, followed by question 2, which asks whether the patient was actually hospitalised after each referral, and then question 3, which asks for the reason that prevented the patient from going to the hospital; 9. Whether the patient has visited public or private practices (questions A2.2.5 and A2.2.7); 10. Emergency care (question A2.2.8); and 11. Use of medication (question A2.2.10).

We excluded from our version the sections on health care and medication use by the caregiver, included by the original RUD [52] and we modified some of the time frames proposed by the original authors: (e.g. when asking carers about the number of patient hospitalisations, a 12-month period was considered, instead of 30 days; the question about outpatient health specialist visits was applied for a period of 30 days, as used in the original version and the emergency services use was monitored for the last 90 days, instead of 30 days. The table describing the number of nights spent in a specific hospital ward (question A2.2.4) has been expanded to include transport costs, medical and non-medical out-of-pocket payments and, similarly the table for outpatient visits, has two columns added for out-of-pocket expenditure and transport costs (question A2.2.6. of the questionnaire).

## 3. Procedure

Between December, 2013 and March, 2014 a cross-sectional questionnaire survey of 31 carers of patients with dementia in Bucharest was conducted in the two health care centres referred to earlier. The questionnaires were completed by carers during visits to the clinic (either for regular monitoring of the patient, or for the receipt of the monthly drug prescription) with the assistance of either, a member of staff, or the leading researcher. The carers were used as proxy informants regarding the patients' situation. Because of the characteristics presented, the survey conducted is a non-population, cross-sectional study, employing the modified RUD questionnaire described above. The benefit of this questionnaire is that it enables us to divide the time allocated by carers into three categories: Personal Activities of Daily Living (PADL), Instrumental Activities of Daily Living (IADL) [85] and the time dedicated to supervision [54]. The first two are easier to conceptualise, with the former referring to basic activities, such as washing, eating and getting dressed, while the latter (IADL) captures more complex tasks, not needed for fundamental functioning, such as shopping, cooking, managing finances, using a telephone to communicate, doing the laundry and travelling independently in public. The category "Supervision" describes any caring activity that does not support a clear daily function, but which rather monitors a patient's behaviour and prevents accidents. For the purposes of the research, we have taken into consideration the carer's reported hours spent undertaking PADL and IADL together (See Appendix, Section A1.2, Questions 2.a) to 3.b)) when calculating the indirect costs associated with the syndrome. Prior to undertaking the research project, an ethical approval was obtained from the Ethics Committee of the "Sf. Luca" Hospital.

## 4. Calculating costs

Costs were divided into two categories: direct and indirect, with the former being split into medical and non-medical costs. Services related to inpatient and outpatient hospital care, emergency services, medication and diagnostic services were included in the medical category, while the latter included non-medical services costs, transportation costs, additional products and services needed during hospitalisation and the caregiving cost. When analysing direct medical costs in particular, we looked at costs covered by the public payer (in our case, the NHIH) and the amount paid out-of-pocket (OOP) by patients. All costs were for 2013. For outpatient visits, the official tariff per visit by specialisation, as set in the most recent government order concerning methodological standards for implementing the National Framework Contract, was used. The NFC regulates the prices and criteria of medical practices contracted for by the NHIH [86]. These prices were multiplied by the average number of outpatient visits from all participants to estimate monthly and yearly average costs by specialisation. When calculating OOP payments, we gener-



ally used values reported by carers, but where they were unavailable, the number of times services were utilised by dementia patients was multiplied by the value of the newly introduced co-payment rate. It should be noted that these rates vary, as each hospital is entitled to set its own co-payment rate, estimated at 10 RON per visit, with the exception of GP visits, estimated at 5 RON per visit, and physiotherapy sessions (which were calculated by dividing the cost of a therapeutic intervention (50 RON) by 10, the average number of sessions included in an intervention). Theoretically, these are the only payments a patient should make when accessing these forms of medical services. Inpatient costs were calculated in a similar fashion, using the cost of one day of hospitalisation for different medical specialisations and multiplying this by the average number of days spent in each ward by the participants. The OOP was calculated by adding the fixed co-payment amount (multiplied by the number of hospitalisations, since the co-payment rate set for hospitalisation is a fixed sum to be paid at the end of the inpatient stay) to the additional medical costs reported by carers in the questionnaire.

Additionally, under the same category (direct medical costs), we also included the cost of medicines. The monthly use of medication has been, with few exceptions, thoroughly documented by the collaborating doctors and information regarding the costs and the amount covered by the NHIH were taken from the official “nomenclature” issued by the National Medicine Agency (NMA) in [87]. Since information was not always provided for the particular coverage scheme that was applied to each individual patient, we assumed the regular patient coverage by the NHIH applied when the percentage of medication cost covered was not indicated by the doctor. There was no cap on the total amount of medicines one could report, but generally, with only one exception, participants mentioned 10 or less prescribed medicines that were currently being used by patients. Each patient had their individual medical costs calculated for OOP, NHIH reimbursement and overall costs and these sums were multiplied by 12, assuming that the medication was used throughout the year. We excluded medication that was likely to be prescribed on a temporary basis (such as vitamins, or sleeping pills), although aspirin was included, because to its prolonged use to prevent cardiovascular complications. Finally, the individual yearly totals were added and divided by the number of participants, to obtain the annual average per patient. To obtain national costs, this value, as with other costs was multiplied by the estimated number of people in Romania living with dementia. If medicines could not be found within the main NHIH database, the price was derived from at least 2 different online pharmacies and the average value used. Apart from the cost of medication, the medical expenses included diagnostic services, taken from the nationally approved Official Guide for Diagnosis and Treatment of Dementia, issued by the Romanian Neurology Society (RNS) and the RAS, 2007 and costed on a fixed, individual level using the aforementioned Government document [86]. The diagnostic services are fully funded by the NHIH. Ad-

ditionally, we evaluated the use of Emergency Services separately, using the number of cases reported by carers and multiplying that by the cost of an 8-hour stay in one of the Emergency Departments in Bucharest [88].

As stated above, the other category calculated as a direct cost included non-medical services. The section covering non-medical expenses which were incurred during a hospital stay (usually products such as disposable diapers, tissues or bed sheets) per year was estimated using the carer’s reported costs. The transport costs were calculated using carers’ estimates of the cost involved in a one-way trip to the hospital/clinic, either for outpatient, or for inpatient care (assuming equal transport costs for both directions). When cost data was missing, the number of visits to the hospital was multiplied by twice the cost of bus ticket in Bucharest (1.3 RON) (a two-way trip being assumed). We also calculated the cost of other services shown in the table for question 9 from section A2.2 of the RUD questionnaire, multiplying the costs per visit indicated by carers, by the number of visits per 30 days, and then by 12 to obtain annual estimates. Finally, the annual direct cost of caring was calculated using the carer’s response to question 4 from section A1.3 of the questionnaire and multiplying the number of hours spent formally caring for the patient by a carer’s hourly wage in Bucharest. Where carers did not earn a formal salary we considered the time spent tending to the patient, which meant adding the values in questions 2a) and 3a) from section A1.2 of the questionnaire, i.e. IADL+PADL), and multiplying it by the number of days during the last 30 days that this had been done. No cap, except for the obvious 24 hours cap, was placed on the total number of hours of patient care per day. Additionally, we considered at the personal contribution of the particular carer (i.e. the percentage of care time covered by him or her – see question A1.1.10) and used that to compute the total caring time required by the patient. The final estimate was obtained by multiplying the hours spent caring per month by the minimum hourly salary, and then by 12, in order to obtain an annual amount.

### 5. Valuing carers’ time

The indirect costs are comprised of the cost of the carer’s time lost while caring for the patient (which varied due to the range of carers’ salaries), the cost of the patient’s time lost accessing care (valued at the minimum wage) and the carer’s time of work (permanent reduction of working hours or unemployment) undertaking caring responsibilities (valued at the average wage). In valuing informal caregiver time, Wimo et al. [51, 55] recommend the use of the *proxy good method* (also called the replacement/market cost method). This is considered by some to be a “non-marketed use of time” [89] (p. 38), as it usually values time spent caregiving using the market price of a close substitute (e.g. a paid caregiver). According to Van den Berg et al. [90], at a conceptual level, it focuses on the output of production and attempts to find a market equivalent to an

**Box 1.** Steps of recalculation of published data in order to ensure comparability

Conversion is done in two steps:

Step 1: Presenting costs from publication in terms of 2013 value. To convert from costs in year A of original costs (for example 2006) in national currency units (NCU) to costs in year B (for year 2013) in NCU the following formula was used, incorporating national deflators for the corresponding years [91]:

$$\text{Costs in 2013 in NCU} = \text{Costs in 2006 in NCU} \times \frac{\text{National Deflator in 2013}}{\text{National Deflator in 2006}}$$

Step 2: In converting costs in 2013 NCU to international dollars (\$) in 2013, the national currency per US dollar PPP conversion factors for GDP were used [92].

Source: Authors' own elaboration.

informal service (such as caregiving) and use the market price in the final analysis. However, there are other approaches that could be considered, for instance, when performing a sensitivity analysis, most notably the *opportunity cost*. This values the opportunity foregone by a carers as a result of fulfilling their duties towards the dementia patients, which could include working and earning a salary [40]. In our research we have tried to vary the value placed on caregivers' time, using a sensitivity analysis. Thus, we have used three different approaches: 1. The hourly salary of a carer in Bucharest (as this figure is not officially available, our estimate is based on the information given by the relatives of dementia patients who employ a carer for the patient); 2. The average hourly salary in Romania (available from the National Statistics Institute – NSI website); 3. The minimum hourly salary in Romania (also known as the salary for unqualified work), based on estimates delivered by the NSI. The amount of time dedicated to the care of dementia patients was estimated on the basis of the sum of the two types of daily caregiving activities PADL and IADL. It should be reiterated, that, while the study done in Hungary [58] placed a cap of 8 on the total number of daily hours that could be reported, we have decided to simply leave the cap at 24 hours. This was because we have spoken to many carers who claim that they and, if it is the case, the additional carers do more than just a nine-to-five job when it comes to their responsibilities towards the patient.

**6. Comparability of results**

In order to ensure the comparability of costs estimated in our study with the international estimates published in different national currency units and for different years, we have converted the results to 2013 international dollars (\$).

To convert published data on costs of dementia to 2013 values (the year of costs data in our study) the GDP deflators approach was applied. GDP deflator series provide indicators of growth in price level for entire economies.

The GDP deflator accounts for inflation by converting output measured at current prices into constant-dollar GDP. The GDP deflator shows how much a change in the base year's GDP relies upon changes in the price

level. The GDP deflator has an advantage over the Consumer Price Index (CPI) because it is not based on a fixed basket of goods and services. The method is summarised in **Box 1**.

**Results**

**1. Participants' characteristics**

As mentioned above, there were, in total, 31 participants, all carers of a patients with dementia. For further participant characteristics please consult **Table II**. We have noticed a slight predominance of moderate cases of dementia, but, as has been suggested by our partner doctors, most patients in Romania only obtain a diagnosis in the moderate to severe stages of dementia, with most cases currently remaining undetected.

**Table II.** Participant characteristics

Caregiver age (mean, 95% confidence interval)	
• All participants	59.29 (54.42, 64.16)
Caregiver gender	
• Male	7 (22.6)
• Female	24 (77.4)
Relationship to patient	
• Spouse	7 (22.6)
• Brother/Sister	1 (3.2)
• Daughter/Son	15 (48.4)
• Friend	1 (3.2)
• Other (grandchildren and carers)	8 (22.6)
Patient dementia severity	
• Mild	9 (29.0)
• Moderate	14 (45.2)
• Severe	8 (25.8)
Caregiver economic status	
• Earn an income	14 (45.2)
• Do not earn an income	16 (51.6)
Live with patient	
• Yes	23 (74.2)
• No	8 (25.8)
Caregiver household monthly income (Median, IQR)	
• All participants	3,000 (1,650–4,000)
<i>Data are n (%) unless otherwise stated.</i>	

Source: Authors' own elaboration.

**Table III.** Annual number of medical services used per person with dementia by disease severity.

	Study subjects who reported using the service		p value	All study subjects		p value
	n (%)	mean (SD)		N	mean (SD)	
<b>Hospital admissions</b>						
All patients	12 (38.7%)	1.08 (0.29)	0.145	31	0.42 (0.56)	0.422
Mild	1 (11.1%)	2.00		9	0.22 (0.66)	
Moderate	6 (42.9%)	1.00 (0)		14	0.43 (0.51)	
Severe	5 (62.5%)	1.00 (0)		8	0.63 (0.52)	
<b>Days of hospitalisation per person</b>						
All patients	12 (38.7%)	17.08 (13.84)	0.276	31	6.61 (11.91)	0.217
Mild	1 (11.1%)	55		9	6.11 (18.33)	
Moderate	6 (42.9%)	15.83 (7.99)		14	6.79 (9.52)	
Severe	5 (62.5%)	11.00 (6.24)		8	6.88 (7.40)	
<b>Outpatient visits</b>						
All	15 (48.4%)	71.2 (149.16)	0.171	31	34.45 (108.12)	0.017
Mild	8 (88.9%)	66.00 (143.14)		9	58.67 (135.69)	
Moderate	3 (21.4%)	164.00 (252.95)		14	35.14 (121.33)	
Severe	4 (50.0%)	12.00 (0)		8	6.00 (6.41)	

n = number of respondents reporting use of service; N = number of respondents in the study group  
p values reported for differences in service use between the disease severity of patients groups

Source: Authors' own calculations.

## 2. Service utilisation

Of the participants 27 (87%) reported that the patient in their care received medication therapy for dementia. Of these, two thirds were taking memantine (Ebixa), while the remainder had been prescribed donepezil. With regards to inpatient care, 4 carers (12.9%) reported patient hospitalisation in the Internal Medicine ward, while only one carer reported that their patient had been hospitalised in an undisclosed type of ward, in the past year. Furthermore, 4 patients (12.9%) were reported to have visited a GP outpatient practice in the past 30 days, 11 (35.5%) had visited a Geriatrician, 1 (3.2%) had visited a Neurologist, 1 (3.2%) had visited a Psychiatrist, 1 (3.2%) had visited a Physiotherapist and 3 (9.7%) had visited other services not specified in the questionnaire: a Urologist, a Bioenergy Therapist and a Medical Nurse (see **Table III** for more information on outpatient and inpatient visits). As can be seen in **Table III**, the difference between the service utilisation of dementia patients by severity of disease groups was statistically significant only in outpatient services and when all study subjects were considered ( $p = 0.017$ ). Of the total participant population, 4 (12.9%) reported the patient's use of emergency medical services in the past 90 days. Social services were rarely used: 4 (12.9%) had reported regular visits from a home aid. Only 1 (3.2%) reported patient attendance at a day care centre, while 2 (6.7%) reported regular visits from a medical nurse. Services such as visits by social assistants and food delivery were not used by anyone in our sample.

## 3. Costs

The present study evaluated the Cost-of-Illness of dementia in Romania from a societal perspective, although we did not include in our final analysis losses due to mortality or the carer's health-related expenses. The mean total (direct and indirect) costs of dementia using different units for valuing time lost due to caring were: a) 67,554.3 RON (I\$40,583.3 in 2013 international dollars) per patient when an average hourly wage of 10 RON per hour was used for estimating the indirect costs; b) 55,712 RON (I\$33,469) when an hourly carer wages of 5.75 RON was employed and c) 53,787 RON (I\$32,312.6) when the minimum wage of 5.06 RON was used. The total annual cost of dementia in Romania using these assumptions was: a) 18.24 bln RON (I\$10.96 bln), b) 15,04 bln RON (I\$9.04 bln), and c) 14,52 bln RON (I\$8.72 bln) based on the unofficial estimate of about 270,000 people suffering from dementia, the [81] and based on figures produced by Alzheimer Europe [93]. The unit costs used to estimate direct and indirect costs are presented in **Table IV**.

The annual total direct costs extrapolated to the entire population suffering from dementia in Romania amounted to 9.3 bln RON (I\$5.6 bln) (with on average, an annual direct cost per patient of approximately 34,362 RON, I\$20,643). **Table V** presents the breakdown of direct costs by the severity of the disease. The mean direct medical costs accounted for 11,132.3 RON (I\$6,687.74) (Table V). Over 51% of these are incurred by patients and their families (**Figure 1**). **Figure 2** pre-

**Table IV.** Unit costs

Service	Cost (RON)
Dementia diagnostic tests	247.9
Cost of one visit to the emergency service	125
Cost of one GP consultation	9.9
Cost of one Geriatric consultation	25.9
Cost of one Neurologist consultation	58.3
Cost of one Physiotherapist consultation <sup>1</sup>	19.4
Cost of one Occupational Therapist consultation	19.4
Cost of one Social Worker consultation	19.4
Cost of one Psychologist consultation	19.4
Cost of consultations by other specialists	19.4
Cost of inpatient stay in the Internal Medicine ward	915
Cost of inpatient stay in the Geriatric ward	171.1
Cost of inpatient stay in the Psychiatric ward <sup>2</sup>	198.3
Cost of inpatient stay in the Surgery ward	198.3
Cost of inpatient stay in the General Medicine Ward	198.3
Cost of inpatient stay in other wards	198.3
Transportation	As indicated by the patient. If costs were not provided, we assumed a return trip using public transportation services, with a one-way ticket cost of 1.3 RON
Social services	As indicated by patients
Indirect costs of caregiving	
• Using average national wage	10 per hour
• Using caregiver hourly wage	5.8 per hour
• Using minimal (unqualified hourly wage)	5.1 per hour

<sup>1</sup> Due to lack of data for these services, a default value was used for the costs of consultations by Physiotherapist, Occupational Therapist, Social Worker, Psychologist and other specialisms.

<sup>2</sup> Due to lack of data we similarly used a default rate for the following services: Psychiatric, Surgery, General Medicine and other wards.

Source: Authors' own elaboration.

**Table V.** Direct costs (medical and non-medical) per patient in the study by illness severity

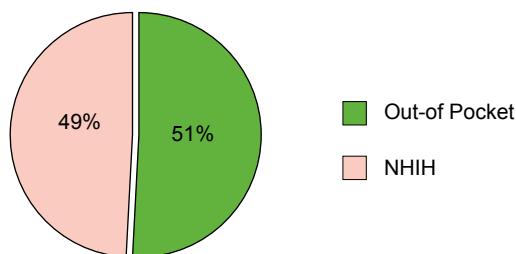
	Cost categories	Mild (n = 9) Mean RON (SD)	Moderate (n = 14) Mean RON (SD)	Severe (n = 8) Mean RON (SD)	Total (n = 31) Mean RON (SD)
Direct medical costs	Medication	9,138.6 (10,452)	4,006.2 (4,032.9)	14,563 (20,224)	8,220 (12,283.6)
	Outpatient visits costs	1,115 (2,646)	530.7 (1,852.8)	175 (241.5)	608.6 (1,870.4)
	Inpatient costs	1,541.7 (4,625)	1,859.3 (3,176.1)	2665.2 (4,264.1)	1,975.1 (3,809)
	Ambulance services	111.1 (333.3)	35.7 (133.6)	125 (231.5)	80.7 (227.2)
	Diagnostic costs	247.9*	247.9*	247.9*	247.9*
Direct non-medical costs	Direct non-medical services costs	66.7 (200)	1,817.1 (3,575.9)	18,000 (50,911.7)	5,485.2 (25,830.3)
	Direct cost of caregiving	14,282.9 (11,298.5)	18,074 (15,398.3)	19,930.2 (12,852.3)	17,452.79 (13,422.4)
	Non-medical costs during hospitalisation	101.4 (304.2)	75.4 (185.4)	80.7 (206.5)	84.3 (222.8)
	Annual transportation costs	467 (815.9)	98.9 (313.6)	103.3 (249.7)	206.9 (513.1)
<b>Average total direct costs</b>		<b>27,072.3 (13,658.1)</b>	<b>26,746 (18,103.3)</b>	<b>55,890.5 (57,261.0)</b>	<b>34,362 (33,517.5)</b>

\* fixed rate

Source: Authors' own elaboration.



**Figure 1.** Proportion of average direct medical costs paid by patient and health insurance



Source: Authors' own elaboration.

sents the proportion of direct medical costs incurred by different payers.

The total extrapolated to the entire population indirect costs varied, according to the different hourly wages used for valuing caregiving time between: a) 8,96 bln RON (I\$5.38 bln); b) 5.76 bln RON (I\$3.46 bln) and c) 5.24 bln RON (I\$3.15 bln), equating to individual average annual costs of: a) 33,192.8 RON (I\$19,940.6); b) 21,350.6 RON (I\$12,826.39) and c) 19,425.9 RON (I\$11,670.13) respectively. See **Tables VI to VIII** for further information on the indirect costs by type of disease severity.

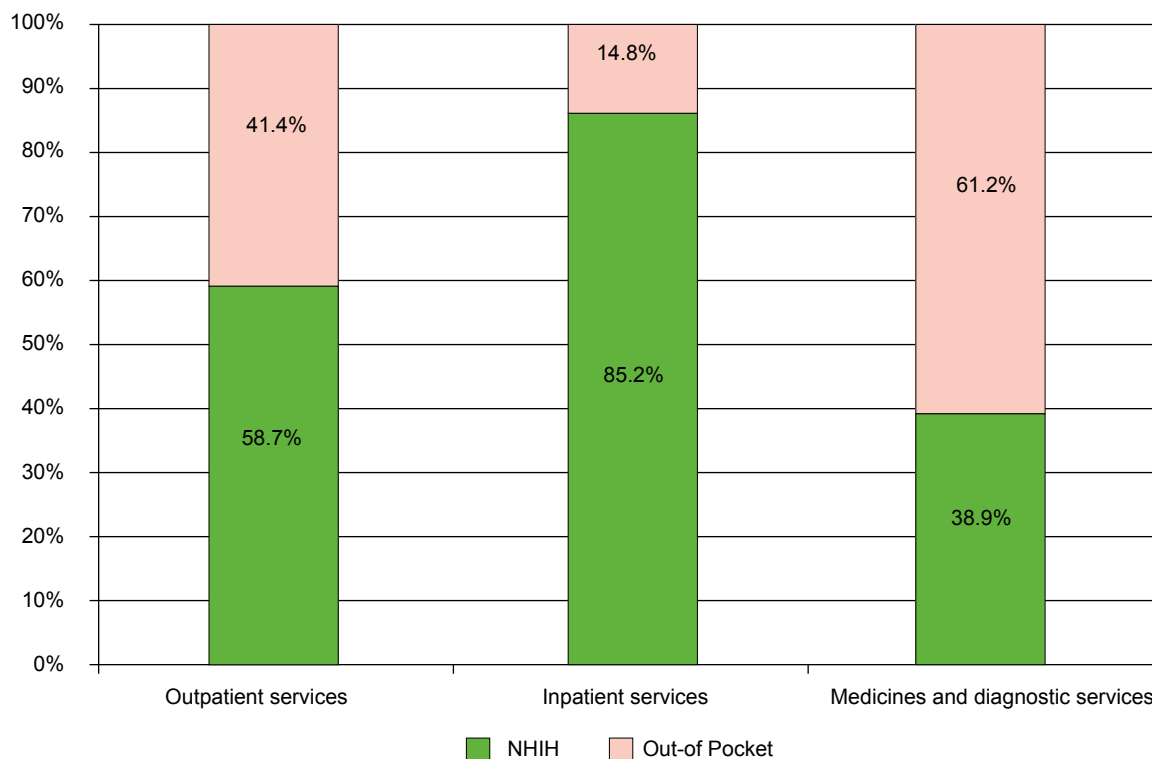
The first category of the estimated indirect cost per person with dementia from the study contains value of

time spent caregiving by carers of both productive and retirement age. The time that retired caregivers dedicated to caring after people with dementia was valued at the minimum hourly wage in Romania in 2013. This, on average, accounted for 7,972 RON (25%, 40% and 44% of the totals presented for this category in **Tables VI, VII and VIII** respectively).

### Discussion

In this cost-of-illness study, with a mix of top-down and bottom-up approaches for collecting data, the societal cost of dementia was investigated. Based on the World Bank, World Development Indicators PPP conversion factor for GDP (LCU per international \$) in the year 2013 [92], our calculations place the total cost of dementia in Romania between I\$10.96 and I\$8.72 bln 2013 international dollars. The latest statistical report we could find shows that total healthcare expenses reached 31.2 bln RON in 2011 [94] which, after converting it to its 2013 value in RON (following step one of the method presented in Box 1), amounts to 33.8 bln RON. This means that the total direct medical cost of dementia (of 3.0 bln RON for all 270,000 people with dementia in Romania) calculated in the study represents approximately 8.9% of the total annual health spending. Our estimate differs considerably (representing a value which is five to seven times higher) from the previous estimate of the

**Figure 2.** Proportion of direct medical costs by type of service and source of payment



Source: Authors' own elaboration.

**Table VI.** Indirect costs per patient, by illness severity (using average national wage)

Cost categories	Mild (n = 9) Mean RON (SD)	Moderate (n = 14) Mean RON (SD)	Severe (n = 8) Mean RON (SD)	Total (n = 31) Mean RON (SD)
Yearly indirect cost of caregiving for patient (using the average national hourly wage)	23,482.3 (24,508.8)	31,646.4 (31,087.9)	41,614.8 (23,258.8)	31,848.7 (27,416.4)
Cost of patient time lost accessing medical care	1,153.5 (2,110.4)	923.6 (1,994.1)	384.5 (304.8)	851.2 (1,737.9)
Cost of unemployment or permanent reduction of work time due to caring responsibilities	0	774.3 (1744)	555 (1,472.2)	492.9 (1,391.6)
<b>Total indirect costs</b>	<b>24,635.8 (24,494.4)</b>	<b>33,355.3 (31,335)</b>	<b>42,554.2 (23,250.6)</b>	<b>33,192.8 (27,512.9)</b>

Source: Authors' own elaboration.

**Table VII.** Indirect costs per patient, by illness severity (using caregiver wage)

Cost categories	Mild (n = 9) Mean RON (SD)	Moderate (n = 14) Mean RON (SD)	Severe (n = 8) Mean RON (SD)	Total (n = 31) Mean RON (SD)
Annual indirect cost of caring for patient (using the carer's hourly wage)	16,096.4 (12,806.5)	19,972.3 (17,477.8)	24,465.1 (12,605.7)	20,006.4 (14,935.6)
Cost of patient time lost accessing medical care	1,153.5 (2,110.4)	923.6 (1,994.1)	384.5 (304.8)	851.2 (1,737.9)
Cost of unemployment or permanent reduction of work time due to caring responsibilities	0	774.3 (1,744)	555 (1,472.2)	492.9 (1,391.6)
<b>Total indirect costs</b>	<b>17,249.8 (12,716.5)</b>	<b>21,670.2 (17,709.1)</b>	<b>25,404.6 (12,595.1)</b>	<b>21,350.6 (15,017)</b>

Source: Authors' own elaboration.

**Table VIII.** Indirect costs per patient, by illness severity (using minimum wage)

Cost categories	Mild (n = 9) Mean RON (SD)	Moderate (n = 14) Mean RON (SD)	Severe (n = 8) Mean RON (SD)	Total (n = 31) Mean RON (SD)
Annual indirect cost of caring for patient (using the national minimal wage)	14,895.9 (10,976)	18,075 (15,398.3)	21,677.8 (10,900.3)	18,081.8 (13,003.5)
Cost of patient time lost accessing medical care	1,153.5 (2,110.4)	923.6 (1,994.1)	384.5 (304.8)	851.2 (1,737.9)
Cost of unemployment or permanent reduction of work time due to caring responsibilities	0	774.3 (1744)	555 (1,472.2)	492.9 (1391.6)
<b>Total indirect cost</b>	<b>16,049.4 (10,859)</b>	<b>19,772.9 (15,622.5)</b>	<b>22,617.3 (10,888.8)</b>	<b>19,425.9 (13,079.1)</b>

Source: Authors' own elaboration.

cost of dementia in Romania which was compiled by Alzheimer Europe [95]. The authors of this research, Wimo and colleagues, estimated the total costs of dementia in Romania at 605.4 mln Euros, with a breakdown of 270.5 mln for direct and 334.9 mln for indirect costs [95]. We have converted these estimates to 2013 international dollars using the official exchange rate of RON to EUR in 2008 and the GDP deflators for 2008 and 2013 to present these costs in terms of NCU (RON) in the year 2013. After applying the procedure presented in **Box 1** the estimates by Wimo and colleagues [95] for the total cost of dementia in Romania in 2013 accounted for over I\$1.67 bln (I\$0.75 bln direct costs and I\$0.93 bln indirect costs). It is likely that the estimated number of dementia sufferers was lower in 2008 than in 2013. The difference

is probably also because of our choice to take into account more than 8 hours per day of work when it comes to calculating the costs of care.

Our results showed that direct costs outweigh indirect costs, which is contrary to theoretical expectations about the regional cost structure [95]. It should be recognised that this may be due to certain cost dimensions being excluded from our analysis, such as mortality costs, or morbidity costs associated with a carer's illness, which would have normally been added to the total indirect cost figure. The situation in Romania regarding caregiving is different from most Western countries and is more similar to the way patients are treated in Mediterranean Europe. Thus, the use of care homes is relatively rare, with most patients being cared for by a relative (usually their

spouse or child). It has been suggested that this attitude reflects deeply held values and social norms, which are to a great extent, shaped by religious beliefs as well. Indeed, religion is an important aspect of social life in Romania, where the predominant religion is Christian Orthodoxy, with approximately 86% of the total population declaring their adherence to this denomination [96]. Like other Christian denominations, it considers caring (including care for elderly dependents) a key duty for its followers. The Church dedicated 2012 to the promotion of care for the sick [97]. Additionally, there is also a growing number of home care programmes delivered nationally by Catholic organisations.

The higher costs generally recorded for Eastern European countries, as compared to Western countries, can be explained by the better medical and social infrastructure present in the West. Nevertheless, we can also speculate that inter-generational relations differ between these cultures, as influenced by the economic behaviour of the “baby-boomers” and the increasing general burden felt by the younger generations. This is something that was outlined by de Hennezel and Hennezel [98] in a socio-psychological study of French people aged 35 to 45, who often stated that they did not feel responsible for the care of their parents as they aged, giving as reasons, the economic excesses indulged in by the latter and the lack of support received by the former. It may be that the different political and economic realities which were present in communist Romania have encouraged relationships based on solidarity and mutual help.

In the Results section, we have distinguished the direct costs covered out-of-pocket by patients and those reimbursed by the public payer (i.e. the NHIH). It should be noted that, in some instances, the individual costs were much higher than expected, which is probably due to incomplete questionnaires being returned. For instance, the medication and diagnosis costs were covered, according to our calculations, only to a level of 38.85% by the NHIH, leaving the yearly out-of-pocket payment of individuals as 5,027 RON (I\$3,020) for this expense alone. It is likely that this is an overestimate of out-of-pocket costs, since many participants did not indicate to what extent the medication cost of the patient in their care was covered by the public payer and, in such cases, we used the default rates present in the official NHIH database. However, it is likely that many of the participants were beneficiaries of special reimbursement schemes (e.g. the full reimbursement of dementia drugs). Most of the other medical costs (inpatient and outpatient) are generally covered by the public purse, although it should be noted that usually hospitals do not provide discounted essential services and products, such as food, disposable diapers or products for skin treatment, especially those used in the treatment of bed sores.

It is likely that our figures for transportation costs are an underestimate, since participants very rarely provided the necessary information about the costs involved. As a result, a return journey using public transport services was assumed, using the cost of a bus ticket in Bucharest (1.3 RON) for a one-way journey. Additionally, we used

the online pharmacy price for medicines not included in the official database provided by the NHIH and we assumed this indicated that the cost of the particular drugs were not covered by the public payer. In this way, the final figure for medication use is also probably slightly underestimated. It should also be mentioned that our “yearly” estimates contain a year made up of 360 days, due to the use of 30 days as a proxy for 1 month when calculating total costs.

Our results seem to confirm that costs for dementia peak towards the severe and final stage, when medical costs rise and, especially, the time spent caring for patient approaches a maximum. Carers also seem more likely to give up on their working hours in order to care for patients in the later stages of dementia (moderate and severe), while no such incident was recorded in the case of patients with mild dementia. The use of non-medical social services is not common for the studied population sample, which may reflect a more typical tendency in the Romanian population and the poor development of social services, when compared to Western countries. Even when provided, social services in Romania (such as daily caring, or food delivery) are more likely to be provided by an informal caregiver, for an unofficial wage, which also explains why we were unable to obtain an official estimate of a carer’s wage. Even official websites, intended to connect patients to potential carers do not indicate the cost, stating that they are to be negotiated on an individual basis with the particular carer.

Finally, our results underestimate the average direct medical costs. In order to reduce the length of interviews we did not ask about the impact of caregiving on the carer’s health (and in consequence did not include the costs of health care services used by carers). This is a crucial issue and needs to be a subject of further research to elicit what the impact of care for dementia patients on Health Related Quality of Life is and what the costs of health care services used by caregivers are, attributable to the care for dementia patients.

The trend in developed countries has shifted massively towards issues such as early detection of the signs and prevention of dementia (see [99] for an example of a more recent national strategy regarding dementia). The aim is to identify future patients early, using intermediary, non-clinical stages such as the MCI, which was referred to in the section on early diagnosis, and to focus on educating the public as well as professionals. Furthermore, mixed teams are proposed in order to deal with the various challenges of dementia in a wide range of settings, and not only the medical. In Romania, however, there still is a struggle to diagnose more patients in the mild stage, since most are usually diagnosed only in the moderate to severe stage. The level of public awareness is still low, albeit improving, with most patients being taken to a specialist by their families when they start getting lost more frequently, or when they display serious behavioural disturbances. Relatives are not worried as much about the fact that patients become confused and/or more forgetful, which reveals an important deficit in knowledge about the signs and symptoms of dementia.

However, as mentioned in the introduction, it is clear that most Romanians would not downplay the significance of the diagnosis of dementia.

The investments made by Western European countries; such as the UK, France and Switzerland, in funding awareness campaigns, supporting primary care, detection of early cases and in building new medical facilities, dedicated to patients with dementia, have reached a considerable level in recent years. A good instance of this latter point is the special ward recently constructed at the Cefn Coed Hospital in Swansea, which features architecture specially designed for patients' needs, including sensory stimulating chambers, a quiet garden, easy to navigate and colour-based marks that help the patient to move easily within the hospital bounds. The amount of investments made by the Romanian government, however, has been minimal, and the physical space dedicated to ambulatory care of dementia patients is also scarce and, many a time, self-sustained (as is the case with the centre run by the RAS or the Ana Aslan centre). It is fair to say that, Romanians probably use social and medical services much more infrequently than their Western counterparts. In itself, this may in fact be a positive aspect, since many care improvement programmes developed recently stress that it is important that hospitalization and/or institutionalisation are avoided and focus instead on improving home care [100]. Governments may also use this as a cost-controlling strategy. However, there is a real need for political commitment to the cause of dementia in Romania, which has been largely ignored to date.

We have given some of the limitations of the present study: the small sample size, the exclusion of certain cost categories, due to logistic difficulties (such as the indirect costs due to deaths and carer's medical care services costs), or the gaps in carer's response to different questions or sections in the questionnaire. This led us to use alternative, default values, where this was possible. Furthermore, we should indicate that we have probably overestimated the figures when calculating the indirect costs of caring for patients. A better estimate would need to take into account the national unemployment rate, which was not considered in the present analysis.

The final point is that the study was mainly a pilot project aiming to test the feasibility of the study tool (the modified RUD questionnaire); an attempt to show the significance of dementia costs in Romania and to find some key areas for further investigation and action. From what we have determined so far, there is a real need for better and targeted carer support, since the indirect costs of caring (the value of production lost by carers looking after the patients) constitute between a third and a half of the total costs of dementia in Romania. The state should also value the role of carers in offering costly services that would otherwise need to be covered by a mix of social and medical insurance, as well as by individuals themselves. Finally, the state should take more into account that "the family and friends of the person with dementia, are in all regions of the world, the cornerstone of the system of care and support" [14, p. 46].

## Note

<sup>1</sup> We define effective economic old-age dependency ratio as the percentage of the employed population aged between 15 to 64 represent out of the inactive population aged 65 and above.

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**Appendix: The modified RUD questionnaire that was used in our research with variables' coding displayed**

**The resource utilization in dementia (RUD) questionnaire**

**A1. Caregiver**

**A1.1. Description of Primary Caregiver**

1. Age: Age \_\_\_\_\_ years
2. Sex:
  1. Male
  2. Female
3. RP: Relationship to patient:
  1. Spouse
  2. Sibling
  3. Child
  4. Friend
  5. Other \_\_\_\_\_   
(Staff not allowed)
4. NoCh: Number of children currently living with you: \_\_\_\_\_ child(ren)
5. SEV: Please state the disease severity:
  - a) Mild
  - b) Moderate
  - c) Severe
6. LWP: Do you live together with the patient? If your answer is **Yes**, then please skip to question number 9.
  1. Yes
  2. No
7. DIST: How far do you live from the place where the patient currently resides?  
\_\_\_\_\_ (preferably in kilometres)
8. TTP: How do you access the patient's residence from your home?
  - a. By walking
  - b. By bicycle
  - c. By scooter/motorcycle
  - d. By private car
  - e. By public transportation
  - f. By taxi
  - g. Other \_\_\_\_\_
9. NoCa: How many other caregivers are involved in caring for the patient?
  - 0
  - 1
  - 2
  - 3
  - 4 or more

10. CON: Among all caregivers what is your level of contribution? Please note that 100% = the total caregiving time for the patient;
  1. 1–20%
  2. 21–40%
  3. 41–60%
  4. 61–80%
  5. 81–100%
11. NoFl: How many people live together with you?
  - None
  - 1
  - 2
  - 3
  - 4
  - 5
  - 6 or more

12. MI: Please state your household income per month:  
\_\_\_\_\_ RON

**A1.2. Caregiver Time**

1. LEEP: On a typical care day during the last 30 days, how much time per day and night did you spend asleep?  
\_\_\_\_\_ hours and \_\_\_\_\_ minutes per day
2. a) PADL1: On a typical care day during the last 30 days, how much time per day did you assist the patient with tasks such as toilet visits, eating, dressing, grooming, walking and bathing?  
\_\_\_\_\_ hours and \_\_\_\_\_ minutes per day
2. b) PADL2: During the last 30 days, how many days did you spend providing these services to the patient  
\_\_\_\_\_ hours and \_\_\_\_\_ minutes per day
3. a) IADL1: On a typical care day during the last 30 days, how much time per day did you assist the patient with tasks such as shopping, food preparation, house-keeping, laundry, transportation (including hospital and visits), taking medication and managing financial matters?  
\_\_\_\_\_ hours and \_\_\_\_\_ minutes per day
3. b) IADL2: During the last 30 days, how many days did you spend providing these services to the patient?  
\_\_\_\_\_ days
4. a) SUP1: On a typical care day during the last 30 days, how much time per day did you spend supervising (that is, prevent dangerous events) the patient?  
\_\_\_\_\_ hours and \_\_\_\_\_ minutes per day



4. b) SUP2: During the last 30 days, how many days did you spend providing these services to the patient?  
\_\_\_\_\_ days

**A1.3. Caregiver Work Status**

1. INC: Do you currently work for pay from any sources (including caregiving)?

- 1. Yes  If **yes**, please answer questions 3 to 5
- 2. No  If **no**, please answer question 2

2. WSW: Why did you stop/reduce working?

- 1. Never worked
- 2. Reached retirement age
- 3. Early retirement (not disease-related)
- 4. Laid off
- 5. Own health problems
- 6. To care for patient
- 7. Other \_\_\_\_\_

3. NoHPW: How many hours per week do you work for pay in total?

\_\_\_\_\_ hours per week  None

4. NoDPC: Of this number of hours, how many hours per week are you paid to care for the patient?

\_\_\_\_\_ hours per week  None

5. WHR: During the last 30 days, by how many hours have you cut down on the number of hours that you usually work each week because of your caregiving responsibilities?

\_\_\_\_\_ hours per week  None

6. During the last 30 days, please specify the number of times that your caregiver responsibilities have affected your work in the following ways:

A. Missed a whole day of work

ICRA1: \_\_\_\_\_ number of times  None

B. Missed a part of a day of work

ICRA2: \_\_\_\_\_ number of times  None

**A2. PATIENT**

**A2.1. Patient Living Accommodation**

1. CPA: Please specify the patient's current living accommodation

- 1. Own home (owner occupied or rented)
- 2. Intermediate forms of accommodation (not dementia-specific)
- 3. Dementia-specific residential accommodation
- 4. Long-term institutional care
- 5. Other \_\_\_\_\_

2. LW: Who does the patient live together with?

- 1. Alone
- 2. Spouse
- 3. Sibling
- 4. Child
- 5. Other
- 6. Not applicable \_\_\_\_\_

3. AAac: During the last 30 days, if the patient temporarily changed living accommodations (i.e. moved to a new location for more than 24 hours and then back to the original location), please specify the number of nights spent in this temporary living accommodation.

- 1. Own home (owner occupied or rented)
- 2. Intermediate forms of accommodation (not dementia-specific)
- 3. Dementia-specific residential accommodation
- 4. Long-term institutional care
- 5. Other \_\_\_\_\_

**A2.2. Patient Health Care Resource Utilization**

1. NoR: During the last year, how many times was the patient referred to a hospital (for more than 24 hours)? If your answer is **None**, please go to question 6.

\_\_\_\_\_ number of times  None

2. HAR: Was the patient admitted to a hospital each time he/she was referred by a specialist? If your answer is **Yes**, please go to question 4.

- Yes
- No

3. RNH: Can you specify for what reason the patient was not admitted to a hospital?

- 1. Financial reasons
- 2. Long waiting time
- 3. Would have taken too long to go there/too far away
- 4. Lack of means of transport
- 5. Other (please specify)  \_\_\_\_\_

4. If the patient was admitted to a hospital during the last year, please specify the total number of nights spent in each type of ward

	Number of nights during the last 12 months	Transportation costs (one-way)	Out-of-pocket payment for entire stay in the ward. This may include costs of medical services and medicine not covered by the insurance during the stay in the hospital	Please estimate additional expenses not related to medical costs (e.g. food, disposable diapers, waterproof sheds etc.)
Geriatric	G_NoN	G_TrC	G_OOPP	G_AdE
Psychiatric	P_NoN	P_TrC	P_OOPP	P_AdE
Internal medicine	IM_NoN	IM_TrC	IM_OOPP	IM_AdE
Surgery	Sg_NoN	Sg_TrC	Sg_OOPP	Sg_AdE
Neurology	N_NoN	N_TrC	N_OOPP	N_AdE
General ward	GW_NoN	GW_TrC	GW_OOPP	GW_AdE
Other (please specify)	O_NoN	O_TrC	O_OOPP	O_AdE

5. Hosp\_Pu\_Pr: Was the patient admitted into a private or a public ward?

- Public
- Private

6. During the last 30 days, consider how many times the patient has visited a doctor, physiotherapist, psychologist or other health care professional. Please specify the number of visits for each type of care received.

The patient did not visit any of these health care professionals during the last 30 days

	Number of visits during last 30 days	Out-of-pocket payments for all visits (by type of care)	Transportation costs in average per visit (one way)
General practitioner	V_GPN	V_GPC	V_GPTC
Geriatrician	V_GN	V_GC	V_GTC
Neurologist	V_NN	V_NC	V_NTC
Psychiatrist	V_PtN	V_PtC	V_PtTC
Physiotherapist	V_PhN	V_PhC	V_PhTC
Occupational therapist	V_OTN	V_OTC	V_OTTC
Social worker	V_SWN	V_SWC	V_SWTC
Psychologist	V_PsN	V_PsC	V_PsTC
Other (e.g. specialist; please specify)	V_ON	V_OC	V_OTC

7. V\_PuPr: Was the patient seen in public or private practice?

- Public
- Private

8. CER\_90days: During the last 90 days, how many times did the patient receive care in a hospital emergency room (for less than 24 hours)?

\_\_\_\_\_ number of times  None

9. For each service listed below, please specify the number of times the service was received during the last 30 days and the average number of hours per visit.

The patient did not receive any of these services during the last 30 days

	Number of visits during the last 30 days	Number of hours per visit	How much did the patient pay for these services, on average per visit, during the last 30 days?
Social assistant	S_SAV	S_SAH	S_SAVC
Home aid/orderly	S_HAV	S_HAH	S_HAVC
Food delivery	S_FDV	N/A	S_FDVC
Day care	S_DCV	N/A	S_DCVC
Transportation (care related)	S_CTV	S_CTH	S_CTVC
Other (please specify)	S_OV	S_OH	S_OVC

10. Please specify what medication the patient is currently taking (please include both prescription-based as well as over-the-counter medicines).

The patient is not taking any medications currently

Name of medication	Strength (mg)	Number of times per day taken	Number of days taken in the last 30 days	Was the payment for the medicine compensated by the insurance?	How much did you pay the last time you bought this medicine out-of-pocket?	How many pills or other units of medicine did you get?
1_N	1_S	1_TPD	1_DT	1_C	1_LAP	1_UNITS
2_N	2_S	2_TPD	2_DT	2_C	2_LAP	2_UNITS
3_N	3_S	3_TPD	3_DT	3_C	3_LAP	3_UNITS
4_N	4_S	4_TPD	4_DT	4_C	4_LAP	4_UNITS
5_N	5_S	5_TPD	5_DT	5_C	5_LAP	5_UNITS
6_N	6_S	6_TPD	6_DT	6_C	6_LAP	6_UNITS