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COSTS OF DEMENTIA IN HUNGARY

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Abstract: *Objective:* The main aim of this paper is to give an overview on the quality of life, health care utilisation and costs of dementia in Hungary. *Method:* A cross-sectional non-population based study of 88 consecutive dementia patients and their caregivers was conducted in three GP practices and one outpatient setting in 2008. Resource Utilization in Dementia (RUD), Mini Mental State Examination (MMSE) and quality of life (EQ-5D) were surveyed and cost calculations were performed. Costs of patients living at home were estimated by the current bottom-up cost-of-illness calculations, while costs of nursing home patients were considered by official reimbursement to determine the disease burden from a societal viewpoint. *Results:* The mean age of the patients was 77.4 years (SD=9.2), 59% of them were female. The mean MMSE score was 16.70 (SD=7.24), and the mean EQ-5D score was 0.40 (SD=0.34). The average annual cost of dementia was 6,432 Euros per patient living at home and 6,086 Euros per patient living in nursing homes. For the whole demented population (based on EuroCoDe data) we estimated total annual costs of 846.8 million Euros; of which 55% are direct costs, 9% indirect costs and 36% informal care cost. Compared to acute myocardial infarction the total disease burden of dementia is 26.3 times greater. *Conclusions:* This is the first study investigating resource utilisation, costs, and quality of life of dementia patients in the Central and Eastern European region. Compared to the general population of Hungary EQ-5D values of the demented patients are lower in all age groups. Dementia related costs are much lower in Hungary compared to Western European countries. There is no remarkable difference between the costs of demented patients living at home and in nursing homes, from the societal point of view.

Key words: Cost-of-illness, dementia, quality of life, Hungary.

Glossary: AD: Alzheimer's disease; EuroCoDe: European Collaboration on Dementia; EQ-5D: European Quality of life 5 Dimensions; IADL: Instrumental activity of daily living; MCI: Mild cognitive impairment; PADL: Physical activity of daily living; MMSE: Mini-Mental State Examination; RUD: Resource Utilization in Dementia; SD: Standard deviations; NHIFA: National Health Insurance Fund Administration.

Introduction

The disease burden of dementia is an important health policy issue in the developed world. In Hungary the importance of this topic is slowly gaining recognition, due to the lack of data on the epidemiology, quality of life and costs of dementia, and the acute care oriented health policy.

Although, a number of studies have been published regarding the cost-of-illness of dementia in Europe (Table 1), we were unable to identify any studies from Central and Eastern European countries in peer-reviewed journals covered by Medline. Assessments of disease burden at the European level usually apply estimations based on Western countries' results for these populations where locally conducted research is not available. However recently published studies for other chronic conditions (e.g. rheumatoid arthritis, psoriatic arthritis, scleroderma) have verified that cost-of-illness data in Hungary contrast strikingly with results of Western European countries (1-3). Therefore, it is reasonable to presume that the disease burden of dementia also differs significantly. Some specific aspects of the Hungarian health care system (organisation, financing, epidemiology data) might also have major impact on disease burden.

In Hungary, intensive data collection started at hospitals when the DRG reimbursement scheme was implemented between 1992 and 1995; before that time there were no available data about health care performance, not even the number of patients admitted to hospitals was known. However due to the financial incentives generated by the DRG scheme, "creative" coding became very common. As dementia falls within a low paying DRG category, hospitals often coded demented patients in higher payment DRG groups (6). Besides, chronic cases were pushed out from acute care hospitals more and more to chronic care and even to the social care sector where appropriate data collection is missing even to this day.

Local governments are responsible for providing health care services such as primary care, outpatient care and in-patient care. The health care system is financed by the National Health Insurance Fund Administration (NHIFA), the only health insurance fund in Hungary, covering the whole population. Capitation works as a basis for financing primary care, while an activity-based point system for outpatient specialist care, a prospective payment system (DRGs) for acute in-patient services and payment per diem for chronic care have been introduced. Dementia centres were established in 2003, on the basis of the former psychiatry and neurology outpatient care

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units, aiming to offer better care for this patient group. County hospitals serve as county dementia centres providing complex diagnostic and treatment services. Their catchment areas cover between 0.3 and 0.6 million citizens (3-6% of the population). Regional dementia centres with catchment areas of 2-3 million inhabitants (20-30% of the population) provide more specialised care. The social sector provides services to dementia patients in their own homes and in various institutions, such as nursing homes. Services are covered partly by the central state budget supplemented by multiple sub-budgets from the 3,187 local municipalities.

Regarding prevalence, the European Collaboration on Dementia (EuroCoDe) workgroup presented an estimated number of 131,995 demented individuals in Hungary in 2008 (prevalence of 1,316/100,000 inhabitants) (7). Furthermore, according to the 2009 Dementia Worldwide Cost Database (DWCD) estimations, there are 112,568 demented patients in Hungary, whose direct costs are 1,026.5 million USD (54% informal care costs). In this study the authors assumed a relationship between costs per demented person and GDP per person (based on PPP) for countries with missing or insufficient data (e.g. Hungary) (8).

According to the EuroCoDe project the estimated total costs of dementia in Europe were 160 billion Euros, (of which 56% were for informal care), or 22,000 Euros per demented patient per annum (9). Other cost estimates for the 27 member states of the EU showed lower annual average costs. The DWCD presented 12,000 Euros (adjusted for 2008) and The European Brain Council reported 11,700 Euros/patient/year based on the Cost of Disorders of the Brain in Europe study (10-12).

Table 1

Estimated monthly direct, informal care and total cost per demented patient (Euros), based on different prevalence sources

Estimated costs for EU 27	Direct costs	Informal care costs	Total costs
EuroCoDe 2009 (9), age-group 60+	828	1023	1,850
SBU 2008 (13) , age-group 60+	784	984	1,768
Ferri et al 2005 (14), age-group 60+	776	980	1,756
Lobo et al 2000 (15), age-group 65+	778	984	1,762
Eurodem 1991 (16), age-group 60+	777	979	1,757

In this paper we aim to provide some empirical findings on health care utilisation, quality of life and costs of dementia in Hungary.

Methods

Multiple data sources were used in our study: the dementia base case prevalence data is from the EuroCoDe estimation; clinical characteristics and health care utilisation were obtained from our cross-sectional survey of 88 consecutive patients in GP and outpatient settings; the number of patients living in nursing homes with dementia diagnosis is taken from the State Audit Office report, as well as from nursing home reimbursement figures.

Base case prevalence data

Having no prevalence data of dementia available from Hungarian data sources, the EuroCoDe estimation is used, that is 131,995 patients living with dementia (7).

Cross-sectional survey of patients living at home

In 2008 a cross-sectional questionnaire survey of 88 consecutive patients living at home with established diagnoses of dementia was conducted in 4 health care settings (3 GP offices and 1 neurology outpatient setting). To assess the societal burden of dementia we also collected data from these patients caregivers. They often served also as proxy informants regarding the patients´ situation. Questionnaires were completed during routine visits involving GPs and nurses. Our survey was a non-population based study since it involved a clinical sample.

An adapted Hungarian version of the Resource Utilization in Dementia (RUD) questionnaire was used. The RUD instrument was developed to capture the utilisation of both formal and informal resources by demented patients during the previous month (17, 18). The questionnaire consists of two sections, surveying the patients´ and caregivers’ health care utilisation, including the amount of caregivers’ time spent on physical and instrumental activities of daily living (PADL and IADL, respectively) and supervision time. Cognitive function was measured by the Mini-Mental State Examination (MMSE). (19) Health related quality of life was assessed by the EQ-5D. Negative values of EQ-5D were replaced by zero. Costs of dementia were calculated from the perspective of society as monthly costs, considering all disease-related direct medical and non-medical costs, as well as the indirect and informal care costs for carers. Hungarian official prices (drugs), tariffs (transportation) and NHIFA reimbursement lists (hospital and outpatient care) for 2007 were used (20-22) (Table 3). Real consumption data (drug, daily dose) provided by the specialist and GPs were considered by drug costs calculations for which official pricelist was used.

Valuing caregivers’ time, two subgroups were formed: employed people and pensioners. For the employees, indirect costs were calculated in terms of productivity losses (national average gross wage per month: 992.80 Euros). For retired caregivers, we evaluated the time they spent on caregiving (i.e. informal care) as indicated by patients. Daily hours of PADL and IADL was maximised as 8 hours/day each and multiplied by 2 Euros per hour as the base case (the hourly minimal salary in Hungary). Sensitivity analysis was performed to evaluate the impact of the different hourly informal care costs on the total costs with two more options: 0 and 4 Euros. The expenses of the non-reimbursed health and social care services were calculated as indicated by patients. All prices were calculated in Hungarian Forint (HUF) and converted to Euro (250

HUF/EUR).

Costs of patients living in nursing homes

In 2007, 6,519 patients diagnosed with dementia were living in nursing homes according to State Audit Office's report in Hungary.(23) According to the same report the governmental reimbursement for general nursing homes (2,800 Euros/patient/year) covered 46% of total costs, with the remainder (54%) financed by the local governments and personal contributions of the patients and relatives. The total societal annual costs of patients living in nursing homes was 6,086 Euros/patient.

Estimating disease burden on the national level

Establishing the national disease burden we made cross-calculations with the base case prevalence of the EuroCoDe project for Hungary (131,995 demented people), and multiplied it by the yearly costs data of demented patients living at home and in nursing homes. The State Audit Office data (6,519 patients) represented 4.8% of the estimated prevalence data, thus patients living at home (125,659 patients) were 95.2% of the whole demented population (23).

Statistical analysis

We analysed the correlation between cognitive function (MMSE) and quality of life (EQ-5D), as well as RUD domains (daily hours of PADL and IADL). Spearman correlation coefficients were used because of the skewed nature of the data. Data were analysed using the Statistical Package of Social Sciences, version 14.0 (SPSS Inc., Chicago, IL, USA).

Results

Patients' characteristics

The mean age of patients' was 77.4 years (SD=9.2), 59% were female. The average disease duration was 4.8 years (SD=5.4). More than sixty percent (62.5%) were diagnosed with Alzheimer disease. The average MMSE score was 16.70 (SD=7.24) and for the EQ-5D this was 0.40 (SD=0.34). For a more detailed analysis patients were divided into four groups according to their MMSE scores (severe, moderate, mild dementia and mild cognitive impairment (MCI), with MMSE scores 0-9, 10-17, 18-23, 24-30, respectively) (24) (Table 2).

Caregivers' demographics

The caregivers' mean age was 60.0 years (SD=14.3) and 73% were female. Their mean EQ-5D was 0.78 (SD=0.22). 40% had part or full time jobs, the majority (60%) of the caregivers lived together with the patient.

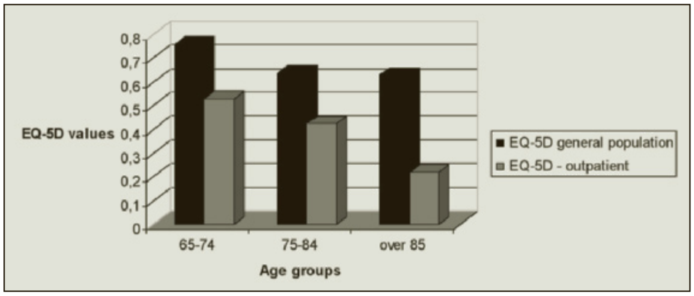
Quality of life

The mean EQ-5D values by age-groups 65-74, 75-84 and >85 years were 0.53 (SD=0.30), 0.42 (SD=0.34) and 0.22 (SD=0.26), respectively. (The sample size below age 65 was not large enough to analyse). EQ-5D score correlated significantly (at p=0.01) with MMSE score (rho= 0.361).

Compared to the general population of Hungary EQ-5D values of the demented patients were lower in all age groups (25) (Figure 1).

Figure 1

Comparison of the health related quality of life (EQ-5D score) of demented patients from outpatient settings (n=66) with the age-matched general Hungarian population



Caregivers' mean EQ-5D was 0.78 (SD=0.22), which is similar to the average score of the age-matched general population (age group 55-64: mean 0.77, SD=0.01).

Health care utilisation

A total of 75 patients (85%) were receiving drug therapy for dementia. The most commonly prescribed drugs were piracetam, vinpocetin and vitamin E; 64% of patients received donepezil, rivastigmine or memantine.

Table 2

GP and outpatient setting patients' data by disease severity

	MMSE groups				
Patients' characteristics	**severe (0-9) (n=14)**	**moderate (10-17) (n=22)**	**mild (18-23) (n=24)**	**MCI (24-30) (n=14)**	**Total (n=88)**
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Age (years)	75.3 (10.7)	77.7 (8.0)	79.1 (6.7)	75.7 (12.8)	77.4 (9.2)
Disease duration (years)	8.7 (6.4)	6.9 (5.9)	2.4 (2.7)	1.1 (1.6)	4.8 (5.4)
EQ-5D	0.19 (0.31)	0.29 (0.32)	0.56 (0.28)	0.53 (0.33)	0.40 (0.34)
VAS (mm)	30 (22)	42 (26)	59 (18)	54 (19)	48 (24)

Table 3
Unit costs used in calculating outpatient disease burden

Resource utilisation	Unit cost (Euro)
Direct medical costs	
GP visit	3.7 per visit
Outpatient specialist visit (Psychiatry, Neurology, Geriatrics)	7.81 per visit
Outpatient emergency care	60.3 per visit
Inpatient care	by DRGs
Other health care services (Remedial gymnast, Psychology, Social worker)	5.84 per hour
Diagnostic procedures (in outpatient settings- based on activity-based points)	0.58per 100 points
Direct non-medical costs	
Transportation	
- ambulance transportation	2.4 per travel
- public transportation	1.1 per visit
- private car	0.14 per km
- patient transportation (as social service)	5.84 per visit
Social services	
- Domestic care, domestic help	12.20 per day
- Social catering	0.89 per day
Other social care	5.84 per hour
Indirect costs (Productivity losses of working age care-givers)	5.84 per hour

Laboratory tests were conducted on 26% of patients during the previous 30 days. Psycho-diagnostics (22%) and cranial CT scans (12%) were the most common examinations alongside with cranial MR (9%) and carotid ultrasonography (7%). Dementia-related GP visits occurred in 57% of cases, while outpatient specialists' care was received by 50% of patients. Eleven percent of patients were hospitalised and 10% received emergency care. Half (52%) received other health care services not related to dementia, 62% of these services were GP visits. Social services were used as well: transportation, domestic help, social catering and home nursing were the most common (13, 11, 10 and 3% of cases). Informal care was received by 70.5% of patients, 13% of them reported that they paid for this service. The average amount of caregiver time for the PADL was 3.5 hours (SD=6.1) and 4.5 hours (SD=6.8) for the IADL.

Cost assessment

In this study we calculated the cost-of-illness on the basis of health and social care utilisation of patients and caregivers. Total societal costs were defined as the sum of direct costs, productivity loss related costs of the working-age caregivers (indirect costs) and informal care costs of retired caregivers. The monthly total cost per patient is presented in Table 4. The average monthly total costs per patient were 535.7 Euros (SD=735.7) (direct costs 282.8 Euros, indirect costs 50.0 Euros and informal care costs 203.0 Euros). There was a fair negative relationship between the MMSE score and the total costs (p=0.019, rho= -0.275).

Sensitivity analysis of informal care for unwaged caregivers which analysed the impact on the total costs using 0 Euro per hour fee for informal care, resulted in a total cost of 332.7 Euros (SD=722.8) for MMSE 0-30, while it was 370.9 Euros (SD=789.7) for MMSE 0-24. Using 4 Euros/hour unit cost for informal care, resulted in 738.7 Euros total cost (SD=850.7) and 783.5 Euros (SD=900.0) for MMSE 0-30 and MMSE 0-24,

Table 4
Distribution of monthly total costs by disease severity per patients (Euros) *

Cost categories	severe (MMSE 0-9) (n= 14) Mean (SD)	moderate (MMSE 10-17) (n=22) Mean	mild (MMSE 18-23) (n=24) Mean	Total demented (MMSE 0-23) (n=60) Mean	MCI (MMSE 24-30) (n=14) Mean	Total (MMSE 0-30) (n=74) Mean
Drug costs	28.29 (48.64)	53.59 (78.32)	72.33 (66.99)	55.18 (68.89)	42.64 (50.41)	52.81 (65.67)
GP visit costs	3.57 (3.03)	4.00 (2.83)	2.75 (3.21)	3.40 (3.03)	3.79 (6.10)	3.47 (3.75)
Outpatient visit costs	5.71 (6.60)	3.64 (4.77)	5.96 (7.40)	5.05 (6.34)	6.21 (7.63)	5.27 (6.57)
In-patient care costs	188.45 (402.88)	31.14 (100.79)	0.00 (0.00)	55.39 (212.25)	56.00 (209.55)	55.51 (210.31)
Emergency care costs	8.61 (21.90)	13.71 (41.33)	12.56 (50.23)	12.06 (41.24)	4.31 (16.12)	10.59 (37.82)
Transportation costs	0.83 (1.36)	0.26 (0.66)	1.36 (1.47)	0.83 (1.28)	0.87 (1.56)	0.84 (1.33)
Diagnostic costs	27.30 (67.69)	12.67 (41.47)	37.61 (64.97)	26.06 (58.21)	39.90 (86.69)	28.68 (64.09)
Non dementia-related health costs	46.05 (109.73)	20.26 (51.93)	11.45 (35.38)	22.75 (65.45)	7.52 (11.63)	19.87 (59.35)
Direct medical costs	308.83 (524.32)	139.26 (134.09)	144.02 (117.83)	180.73 (278.33)	161.24 (261.80)	177.04 (273.63)
Social care costs	10.57 (10.84)	245.68 (890.38)	12.13 (24.68)	97.40 (543.49)	0.00 (0.00)	78.97 (490.11)
Other people's (paid) help	17.14 (64.14)	6.36 (18.34)	0.00 (0.00)	6.33 (32.71)	0.00 (0.00)	5.14 (29.52)
Health care cost of the caregiver	31.18 (93.21)	28.94 (97.74)	20.54 (62.20)	26.10 (82.73)	2.46 (4.73)	21.63 (74.99)
Direct non-medical costs	58.90 (103.68)	280.98 (888.67)	32.66 (69.53)	129.84 (546.72)	2.46 (4.73)	105.74 (494.07)
Direct cost	367.72 (518.60)	420.25 (919.66)	176.68 (136.28)	310.57 (616.51)	163.70 (260.85)	282.78 (568.04)
Productivity loss related costs of the working-age caregivers	182.71 (653.66)	46.99 (128.16)	1.22 (3.44)	60.35 (324.09)	5.42 (15.45)	49.96 (292.24)
Indirect costs	182.71 (653.66)	46.99 (128.16)	1.22 (3.44)	60.35 (324.09)	5.42 (15.45)	49.96 (292.24)
Informal care costs of retired caregivers (2 Euros/hour)	334.29 (355.13)	156.36 (280.86)	177.33 (228.80)	206.27 (285.36)	188.86 (3 00.14)	202.97 (286.19)
Total costs	884.72 (957.71)	623.60 (997.66)	355.23 (302.94)	577.18 (797.14)	357.98 (336.30)	535.71 (735.65)

* The MMSE test section of the questionnaire was not completed in 14 cases.

respectively. In further calculations we used the middle value, 2 Euros/hour as the base option in valuing retired-age caregivers' time.

We analysed the correlation among disease severity, quality of life and costs. Informal care costs were calculated in three different ways, by 0, 2, up to 4 Euros per hour. Calculating with 0 Euro per hour no correlation was seen between total costs and QoL (EQ-5D) and disease severity (MMSE scores). However, calculating with 2 and 4 Euros per hour correlations were significant. The option of 2 Euros showed significant correlation between total costs and QoL and disease severity (p=0.01). In case of 4 Euros costs were in significant correlation with EQ-5D values (p=0.01) and MMSE scores (p=0.05) as well.

Disease burden of dementia in Hungary

As 95% of demented patients live at home, the disease burden of the home-living dementia population is 808,240,232 Euros per annum from the societal viewpoint (53% direct costs). The total annual cost per patient residing in a nursing home is 6,086 Euros, resulting in 38,559,435 Euros per year at national level. Thus, for the whole demented population in Hungary, we estimate that the total annual societal costs are 846,799,667 Euros (6,417 Euros/patient/year).

As there is only a minor difference that can be seen between costs of the patients living at home or in nursing home, the change of distribution of patients living at home or nursing homes has no impact on the disease burden of dementia at the national level: 1% change in the share of people living at home or in nursing homes would result in 0.05% decrease in the total disease burden of dementia.

Discussion

In this bottom-up, cost-of-illness study, we investigated the disease burden of dementia from a societal viewpoint. The average monthly total cost per patient living in their own home was 535.7 Euros (SD=735.7), while for patients living in nursing homes it was 507 Euros. The total annual disease burden is 847 million Euros (6,417 Euros / patient / year). Our result is lower compared to the figure from EuroCoDe estimate (929 million Euros) for Hungary, but the difference does not seem to be important (26).

Comparing the costs of dementia to the official financial data of NHIFA this equates to 65% of total drug expenditure in Hungary or about 29% of expenditure for treatment and prevention budget of the NHIFA. If we restrict our analysis to the direct costs of dementia, these proportions are 36% and 16%, respectively. Compared to the costs of acute myocardial infarctions the annual total disease burden from a societal viewpoint is 26.3 times higher (27).

Good quality epidemiologic data are essential for disease burden estimations at the national level. However no study on prevalence, incidence or disease burden of dementia has been published so far in Hungary. Some research has focused on the proportion of different dementia types by neuropathological examinations or on the distribution of dementia types among nursing home patients (28-33). There are some studies on the reliability of different screening tests and on the relationship between cognitive decline and risk factors (34, 35). Two surveys from GP practices were published on the epidemiology of dementia and MMSE scores distribution (36, 37). These publications present very different figures of dementia prevalence due to methodological weaknesses (38).

The Hungarian Central Statistical Office reports 7,267 patients diagnosed in dementia in year 2007, based on GP practices data (20). According to the NHIFA reports the number of patients hospitalised annually with the diagnosis of dementia varies between twenty and fifty thousand (4-6). These differences might be the consequences of "coding optimalisation" under the DGR scheme (6). Nevertheless, both GP and NHIFA data represent much lower number of patients that is expected based on the European average prevalence. Improving our knowledge on the epidemiology of dementia in Hungary should be one of the first strategic steps.

Lack of basic information for health policy decisions is not restricted only to the area of epidemiology. Data on costs, health status or quality of life is not required by the regulators, professional organisations or by policy-makers. The same can be said about the monitoring of need, costs and quality of services provided. No health or social policy reforms have focused on these issues during the last two decades. The activity-based monitoring, financing and quality criteria are still missing, as well as the appropriate national regulation and follow-up of the effects and costs of new medical technologies. Considering the estimated changes in the age-structure and prevalence of mental disorders, especially in all types of dementia, the Hungarian health and social systems do not seem to be sustainable. There is a strong need for a long-term strategy, emphasising volume, availability and quality of all types of service. For instance, access to drugs might be limited for most demented patients within Hungarian population because of high co-payment prices. With a 50% reimbursement of drugs for dementia treatment, co-payments for patients or their families are significant. In the case of expensive drugs, this can exceed 40 Euros per month, which amounts to 10-15% of the average old-age pension. For further consideration it is essential for policy makers and funders in Hungary to develop and maintain information on the capacity of nursing homes and future demands for long term care. In Scandinavian countries, for instance, a high proportion of elderly patients are receiving formal care in nursing homes (38% in Sweden, 47% in Denmark), as opposed to the Southern European countries, where this percentage is much lower (18% in Italy, 7% in Greece), and the reliance on informal care is much greater (39). It is not clear at the moment whether Hungary is following the Northern or Southern European route, but we assume that the absolute number of demented people in nursing homes will grow (40). Moreover, regardless of the development of services, it will be important to estimate both the costs to formal services and to family carers resulting from dementia. If family caregivers are not available many informal care costs may in future fall on the state. Currently societal costs of patients living at home or in nursing homes are the same, mainly due to low reimbursement level but if this were to change there could be a huge increase in disease burden and difference in the two types of living arrangement. When making allocation decisions, the information concerning the burden of the disease, and the especially the burden of informal care to families is important. Informal care in the families is not a 'free good' and the society might want to take a part of this burden from the families

There are some important potential limitations of our study. Prevalence data of dementia is from the EuroCoDe estimates, based on data from other countries. Our cross sectional study included a selected group of patients such as patients living at home with dementia, partly because the study was performed in a GP and outpatient settings, with mild and medium severity of dementia. Cost per day of the patients living in nursing homes is available from official Hungarian sources. Using these data, the disease burden of dementia was calculated at national level. We assume our results underestimate the real social burden of dementia. Probably more dementia patients are admitted to different institutions except nursing homes, or remain at home and receive more home help and home care, but the burden of disease of these patients are not counted in this study. Our main aim is to show the magnitude of the disease burden of dementia on society and inform health policy makers both in Hungary and in the new Central and Eastern European member states and to initiate further research. This aim is not affected negatively by these limitations.

Conclusions

According to our knowledge, this is the first study investigating resource utilisation, costs, and quality of life of dementia patients in the Central and Eastern European region. Our findings also have health policy relevance, because collection, analysis and use of such data as indicators of quality of care are not required either by the health/social ministries and funders or by professional bodies. The lack of research funding is also an important barrier against getting more information on dementia care. Furthermore, current Hungarian legislation does not allow cross-links to be made between different data sources (e.g. GP reports with inpatient care financing data), thus existing valuable information resources are practically wasted.

Although our data has limited validity about the prevalence and the burden of dementia, we established that the average cost per patient in Hungary is lower than that in other parts of Europe, according to available data. This is probably conservative. Our estimate of 846.8 million Euros per annum is probably low due to the uncertainty on epidemiology and costing. Our survey nonetheless help inform the policy making process can inform policy-makers, but there remains a strong need for an extensive research to establish effective and sustainable ageing policy, management and financing in Hungary.

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References

1. Brodszky V, Balint P, Geher P, Hodinka L, Horvath G, Koo E et al. Disease Burden of Psoriatic Arthritis Compared to Rheumatoid Arthritis, Hungarian Experiment. Rheum Int 2009;30(2):199-205
2. Minier T, Péntek M, Brodszky V, Ecseki A, Kárpáti K, Polgár A. Cost-of-illness of patients with systemic sclerosis in a tertiary care centre. Rheumatology. Doi: 10.1093/rheumatology/keq165
3. Péntek M, Kobelt G, Czirják L, Szekanecz Z, Poór G, Rojkovich B et al. Costs of rheumatoid arthritis in Hungary. J Rheumatol. 2007 Jun;34(6):1437
4. Gabányi J, Mónok G, Demencia diagnózisú kórházi esetek költségelemzése, OEP, 2003.
5. Falusi Zs, Gabányi J, Gulácsi L, A demencia epidemiológiája és költsége Magyarországon; jelenlegi helyzet és a várható trendek, Egészségügyi Gazdasági Szemle, 2004;43:1:50-58.
6. Kovács T., Bereczki D., Dementia: The Hungarian perspective, Corvinus Health Policy and Health Economics Miniconference November 12, 2009. http:// http://hecon.uni-corvinus.hu/download/conferences/nov.12/K.Tibor_Corvinus AD_ea_KT.pdf Downloaded: 12.01.2010
7. Estimated number of people (2006) with dementia. Alzheimer Europe 2009 http://ec.europa.eu/health/ph_information/dissemination/echi/docs/dementia2_en.pdf Downloaded: 29.12.2009
8. Wimo A, Winblad B, Jönsson L. The worldwide societal costs of dementia: Estimates for 2009. Alzheimers Dement. 2010 Mar;6(2):98-103.
9. Wimo A, Jönsson L, Gustavsson A. Cost of illness and burden of dementia - The base option. Alzheimer Europe. http://www.alzheimer-europe.org/EN/Our-Research/European-Collaboration-on-Dementia/Cost-of-dementia/Cost-of-illness-and-burden-of-dementia Downloaded: 29.12.2009
10. Wimo A, Nordberg G. Validity and reliability of assessments of time. Comparisons of direct observations and estimates of time by the use of the resource utilization in dementia (RUD)-instrument. Arch Gerontol Geriatr. 2007; 44(1): 71-81.
11. Jonsson L, Berr C. Cost of dementia in Europe. Eur J Neurol. 2005 Jun;12 Suppl 1:50-3.
12. Andlin-Sobocki P, Jonsson B, Wittchen HU, Olesen J. Cost of disorders of the brain in Europe. Eur J Neurol. 2005;12 Suppl 1: 1-27.
13. SBU. Dementia. A systematic review. Stockholm: Staten beredning för medicinsk utvärdering (SBU) (The Swedish Council on Technology Assessment in Health Care) 2008. Report No.: 172E/1-3
14. Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, et al. Global prevalence of dementia: a Delphi consensus study. Lancet. 2005 Dec 17;366(9503):2112-7.
15. Lobo A, Launer LJ, Fratiglioni L, Andersen K, Di Carlo A, Breteler MM, et al. Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts. Neurologic Diseases in the Elderly Research Group. Neurology. 2000;54(11 Suppl 5):S4-9.
16. Hofman A, Rocca WA, Brayne C, Breteler MM, Clarke M, Cooper B, et al. The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings. Eurodem Prevalence Research Group. Int J Epidemiol. 1991 Sep;20(3):736-48.
17. Wimo A, Nordberg G, Jansson W, Grafström M. Assessment of informal services to demented people with the RUD instrument. Int J Geriatr Psychiatry. 2000; 15(10): 969-71.
18. Wimo A, Nordberg G. Validity and reliability of assessments of time. Comparisons of direct observations and estimates of time by the use of the resource utilization in dementia (RUD)-instrument. Arch Gerontol Geriatr. 2007; 44(1): 71-81.
19. Guerrero-Berroa E, Luo X, Schmeidler J, Rapp MA, Dahlman K, Grossman HT, Haroutunian V, Beeri MS. The MMSE orientation for time domain is a strong

predictor of subsequent cognitive decline in the elderly. Int J Geriatr Psychiatry. 2009; 24(12): 1429-37.

20. Hungarian Central Statistical Office online database, www.ksh.hu
21. NHIFA online database, www.oep.hu
22. Hungarian Tax and Financial Control Administration database, http://en.apeh.hu/
23. National Audit Office Report Nr. 0820. Summary of the Audit of the Utilization of Funds Appropriated for Nursing by Hospitals and Residential Social Institutions of Local Governments (http://www.asz.hu/ASZ/www.nsf/reports.html)
24. Jonsson L, Lindgren P, Wimo A, Jonsson B, Winblad B. Costs of MMSE-related Cognitive Impairment. Pharmacoeconomics. 1999; 16: 409-16.
25. Szende A, Németh R. Health-related quality of life of the Hungarian population. Orv Hetil. 2003; 144: 1667-74.
26. Wimo A, Jönsson L, Gustavsson A. Regional/National cost of illness estimates. Alzheimer Europe: http://www.alzheimer-europe.org/Our-Research/European-Collaboration-on-Dementia/Cost-of-dementia/Regional-National-cost-of-illness-estimates Downloaded: 29.12.2009
27. Gulácsi L, Májer I, Boncz I, Brodszky V, Merkely B, Maurovich Horváth P, Kárpáti K. Hospital costs of acute myocardial infarction in Hungary; 2003–2005. Orv Hetil. 2007; 148(27): 1259-66.
28. Leél- ssy L, Sz cs I, Kindler M, Schwarz T. Incidence of Alzheimer pathology in the autopsy material of two hospitals (1996-1997) Clin. Neurosci./Ideggyogy Sz. 1998; 51/suppl.1: 34-5
29. Leél- ssy L, Kindler M, Sz cs I, Schwarcz T. Neuropathologic investigation in autopsies with special emphasis on findings in Alzheimer's disease. Clin. Neurosci./Ideggyogy Sz. 2006,. 59(5-6): 164-77.
30. Kovács GG, Kovári V, Nagy Z. Frequency of different forms of dementia at the Department of Neuropathology of the Hungarian National Institute of Psychiatry and Neurology during a 3-year period. Clin Neurosci/ Ideggyogy. Sz. 2008;61(1–2) p. 24–32.
31. Leel- ssy, L. Incidence of Alzheimer's dementia in homes for the elderly. Arch Gerontol Geriatr. 1995; 21(1): 21-6.
32. Tariska P, Knolmayer J, Kiss É, Urbanics K, Mészáros Á, Angyalosné Takó E, Mihocsa I, Baranyai Zs. The first Memory Clinic in Hungary: Experiences based on the data of the first five-year period. Clin Neurosci/ Ideggyogy Sz. 1998; 51/suppl 1.: 40-2.
33. Kálmán J, Boda K, Bende Z, Janka Z. Screening for dementia syndromes: the Hungarian experience with the 7-Minute-Test. Orv Hetil. 2003; 144(39): 1929-38.
34. Tariska P, Paksy A. Mini-Cog: a simple method for very brief screening of mental decline. Orv Hetil. 2003; 144(17): 803-9.
35. Vincze G, Almos P, Boda K, Döme P, Bódi N, Szlávik G, Maglóczki E, Pákáski M, Janka Z, Kálmán J. Risk factors of cognitive decline in residential care in Hungary. Int J Geriatr Psychiatry. 2007; 22(12): 1208-16.
36. Linka E, Kispál Gy, Szabó T, Bartkó Gy. A dementia sz rése és a betegek egyéves követése egy háziorvosi praxisban. Clin Neurosci/ Ideggyogy Sz. 2001. 54 (5-6)
37. Leel- ssy L, Józsa I, Sz s I, Kindler M. Sz r vizsgálatok a dementia korai felderítésére (Családorvosi körzetekben és id sek otthonában). Medicus Universalis 2005. (3)
38. Érsek K, Kárpáti K, Kovács T, Csillik G, Gulácsi LÁ, Gulácsi L: Epidemiology of Dementia in Hungary. Clin. Neurosci./Ideggyogy. Sz. – 2010; 63(5-6): 175-182.
39. Pommer E, Woittiez I, Stevens J. Comparing Care. The care of the elderly in ten EU-countries. The Netherlands Institute for Social Research (SCP). Publication number: 2007/32.
40. Health, Ageing and Retirement in Europe. First Results from the Survey of Health, Ageing and Retirement in Europe (SHARE) Mannheim Research Institute for the Economics of Aging (MEA), 2005.