

Cost of Illness of Alzheimer's Disease: Case Study from Selected Region in the Czech Republic

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Abstract: Alzheimer's Disease (AD) is an incurable, degenerative, irreversible health condition affecting memory and thinking abilities due to neuron's reduction. These affect the ability to carry out the simplest tasks. AD is a severe health condition bringing burden not only to the patient but to health and social systems and, especially, to families who become informal and, often, the predominant caregivers. Research has shown that care for an AD patient is very costly. The cost increases with the progression of the disease throughout its more progressive phases. The aim of this research article is to calculate the costs of Alzheimer's disease using a framework based on cost-of-illness methodology. The data are based on four main pillars. The first is a caregiver's questionnaire, the second, the patients' case studies selected to represent each stage of the disease, the third is in-depth interviews with the patients and caregivers, while the fourth is data from the Institute of Health Information and Statistics of the Czech Republic (UZIS) which provides data of health care consumption. The results indicate that as the disease progresses, the overall cost of AD increases. The largest share of AD costs is indirect cost at each stage of the disease.

Keywords: Alzheimer's disease; cost-of-illness; case study; burden of disease

JEL Classification: I10; I11; I13

1. Introduction

Alzheimer's Disease is the most common form of dementia and affects up to 25 million people worldwide (Zgola, 2003). According to the 2009 European Collaboration of Dementia, there are around 7.3 million people living with dementia in Europe. In 2018, the Czech Republic's share of dementia patients exceeded 150,000 of which 60% are diagnosed with Alzheimer's Disease (Broulíková 2018). The beginnings of the disease are gradual, inconspicuous. Degradation may proceed smoothly or change randomly. The prognoses are purely individual. Duration of the disease can range from five to twenty years. Many factors influence progression such as combination with other diseases, lifestyle, or the patient's personality and genetics (Raboch et al. 2001). In most cases, combination with other diseases such as Parkinson's disease, vascular dementia, or neurodegenerative dementia with Lewy bodies (Borzová and Jiráček 2009) are more the norm.

Clinical symptoms in AD patients vary depending on the stage of the disease in which the person is. There are various stages of Alzheimer's disease. However, the vast majority of authors classify the disease as having three main stages - mild, moderate and severe (Callone 2008; Zvěřová 2017; Huang 2012; Gauthier 2007; Pidrman 2007).

Figure 1 shows the classic progression of the disease. The graph shows the development of primary symptoms through conclusion in death. Schematically, AD is divided into three levels - mild, moderate and severe. The vertical axis describes the value of cognitive functions evaluated using the Mini Mental State Exam (MMSE) which evaluates patient concentration, attention, temporal and spatial orientation, writing, counting, and speech in practice (Molloy et al. 1991). The horizontal axis depicts the time period of disease progression. There is also an overlapping of symptoms of varying intensity and duration. The graph well demonstrates the individuality of the disease and its possible diverse course. Jiráček (2008) mentions the link between quality of health care ensuring control over appropriate medication, rehabilitation exercises or preventive measures that struggle with collateral symptoms such as bedsores

and, at the same time, the interaction of social workers who care about hygiene, nutrition and hydration as effective supportive measures. A problem revealed, however, is the non-cooperation of the Czech Republic's health and social sector.

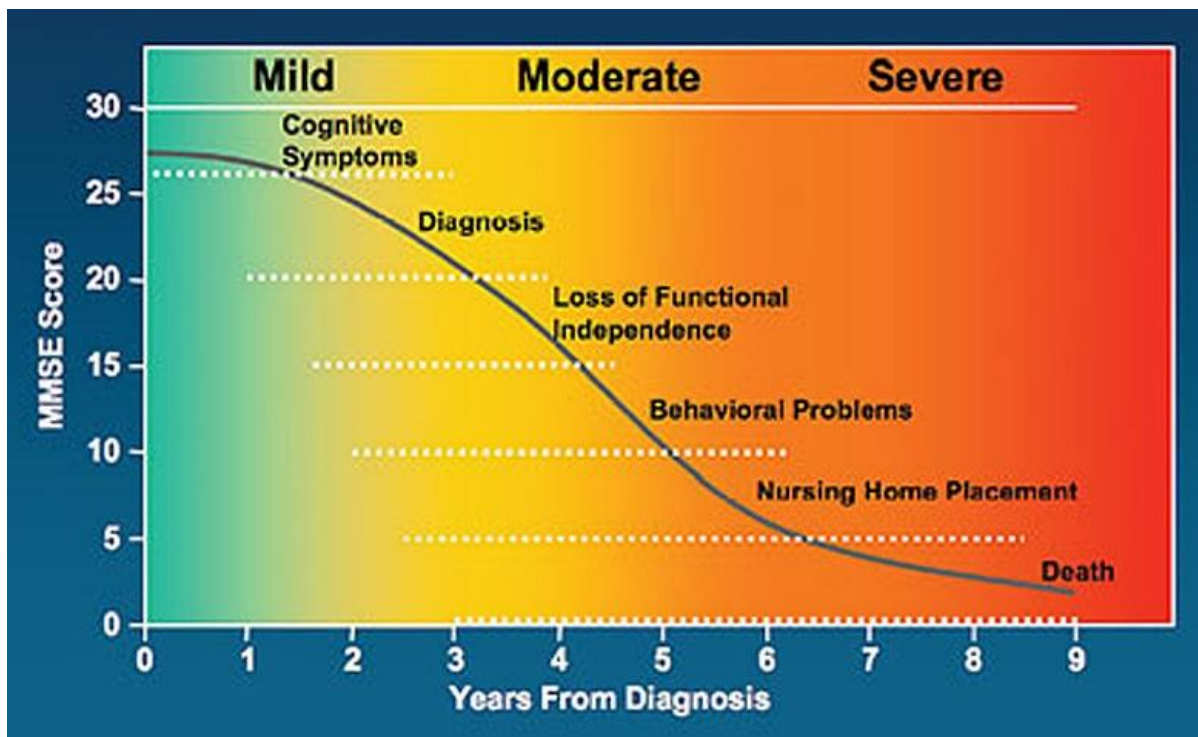


Figure 1. Alzheimer's disease progression. (Dementia and Alzheimer's 2014)

The care provided to AD patients varies in scope and type. Act No. 108/2016 Coll. defines available social services and divides them into three basic types as shown in Figure 2. The sources of funding vary by region. However, funding is on the edge between the health and social sector, and the patient/caregivers themselves.

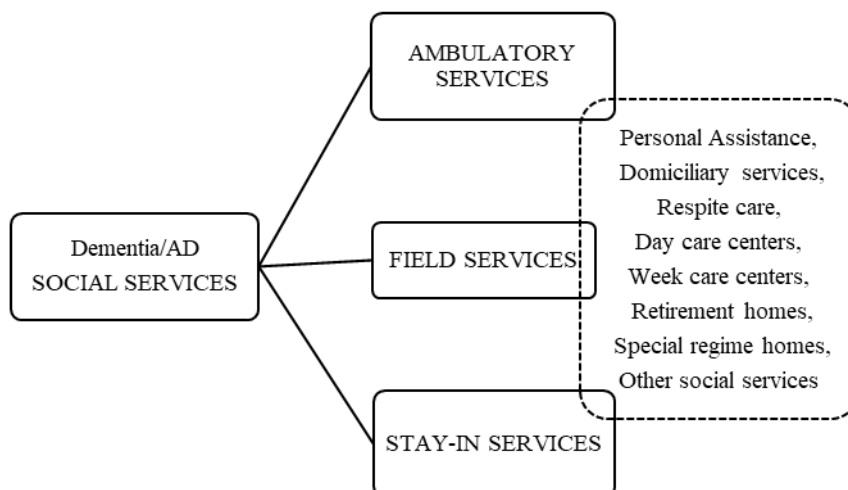


Figure 2. Own processing based on Kandilaki et al. (2019).

It should be noted that, with progression stages of AD, the overall cost of patient care increases. According to Trávníčková (2012), costs range from € 572/month for in mild stages and rises to € 942/month. In terminal stages, there are slight decreases. The most expensive phases are those in the middle with direct costs of € 303 per month and indirect costs of up to € 638. It is, therefore, clear that

indirect costs account for a major proportion of the total cost. These data were based on the 2012 Alzheimer's Disease Cost Analysis in the Czech Republic using the RUD (The Resource Utilization in Dementia) questionnaire.

2. Methodology and Data

The framework of this study covers many sources and methodologies. The most important component is the (1) COI methodology. In this particular case, we used the COI methodology to calculate the annual cost arising from AD for three patients. Besides the calculation itself, the main aim is to compare the share of each type of cost on overall costs. The input data are obtained through a (2) questionnaire survey of the informal caregivers represented by, primarily, family members. To get a clear idea of the different stages of the disease, (3) a case study representing each stage was conducted. In order to identify usage of social services (4), in-depth interviews were conducted. Data on the utilization of health services and their financial statements were requested from the (5) Health Information and Statistics Office (UZIS).

2.1. COI

COI is a descriptive analysis focusing on the calculation of economic costs of the examined disease focusing on the patient characterized by gender, age and stage. The basic approach is to include direct medical and social costs, direct non-medical costs and indirect costs (Segel 2006). The direct costs include the costs of health care (diagnostic and imaging methods, costs of medicines, rehabilitation, outpatient treatment, hospital stays, transport to a health care facility, treatment of the patient, food for the patient, etc.). Indirect costs arise from lost benefits/profits. Intangible costs are recognized as losses in terms of reduced length and quality of subsequent years of life (Larg 2011).

All costs are, as far as possible, calculated in monetary terms. Data are obtained from UZIS and from questionnaire survey of informal caregivers and in-depth interviews.

Table 1. Examples of Costs entering the COI. (Jo 2014)

Direct health care	Direct non-health care	Indirect costs
Home health care	Social services	Loss of productivity
Physicians	Counseling	Morbidity
Physical therapist	Data analysis	Mortality
Capital costs (incl. depreciation)	Repair of property destruction	Impairment
Construction of facilities	Legal costs	Job absenteeism
Relocation expenses	Transportation costs	Foregone leisure time
Device or equipment cost	Time (searching, traveling, waiting)	Time spent by family
Variable costs of utilities	Housekeeping	Visitors attending patient
Medications	etc.	etc.
Drug costs		
Consumable supplies, personnel time, etc.		

2.2. Questionnaire

One method used for data collection was a survey questionnaire. The questionnaire used was anonymous and semi-structured designed for caregivers who are, generally, a related family member. The questionnaire consisted of 24 semi-structured questions divided into four areas. The first area was focused on the characteristics of the patient-relative and family. The second, identified direct health and social costs that a relative, caregiver or family incurs in connection with AD. The third area focused on the quantification of direct non-medical expenditures, while the final was devoted to indirect expenditures. This questionnaire was developed for TAČR TL1000300 research project purposes and provided preliminary results only at this stage.

2.3. Case studies

Case study is a detailed examination of a given individual or group of subjects (Bredesen 2017). Patients with the similar difficulties were the target, seeking to present a new perspective on identifying the issues or, conversely, confirming issues already established. These studies sought to establish the essence of the cases and subsequently describe the links that individual cases have with one another or how they differ. The assumption was that by carefully examining the phenomenon of AD care, insight might be provided to understand other cases. (Hendl 2005)

2.4. In-depth interview

An in-depth interview (IDI) is one of the qualitative methods of data collection employed. Such methods seek a closer and more thorough understanding of the issues and their complexities. Interviews examined one or a small sample of respondents and proved to be an excellent tool for gaining deeper knowledge of the respondent, their feelings, and a clearer understanding of the impact on the subject in question. The results were valuable and rich in information that helped clarify the topic and related hypotheses. The essence of IDI was the use of open questions, their systematic recording and documenting by means of audio recordings supplemented by written notes to include verbal and non-verbal expressions of the respondent, his / her actual feelings, and impressions (Guion et al. 2011).

In this case, IDI were conducted through pre-arranged appointments with the caregivers at home. Steps were taken to maintain anonymity. Interviews lasted about an hour. The structure of interviews was open but guided by a pre-established AD protocol. Interviews were often very emotionally demanding for all respondents. The data provided showcased the seriousness of the issues revealed. The output was, among other things, not only informative about the total monetary costs but also about the indirect costs for which no monetary value can be ascribed.

2.5. UZIS

UZIS is a state statistical service under the Ministry of Health of the Czech Republic. The purpose of UZIS is to collect and process data of health care consumption. All data is used in accordance with the relevant regulations, directives and laws, and interest in personal data protection. For this work, UZIS provided data on the consumption of health care of patients diagnosed with AD for the whole Czech Republic. The data are broken down by region, by disease stage, age and gender. Upon request, UZIS provided data on the structure as defined for the year of 2017.

3. Results

Case studies are based on the methodological framework (Table 2) in which individual data from the sources are used in conjunction with UZIS (healthcare costs), costs of social care, family cost (ID questionnaire) and IDI (additional information and utilization of social services).

Table 2. Methodological framework.

		Source of data	
		Health care	Social care
		UZIS	Region
Direct health and social care	Total health care received per year expressed in monetary terms		Social care provided in the territory of the Region, which falls within the Region's social network, is subsidized by the Region
			In-depth interview
			Family costs
			Questionnaire
			Pharmacy
			Medical equipment
			Outpatient procedures paid by the patient
			Alternative medicine etc.
			Paid household services
			Professional personal assistance

	Clarification of information and usage of social care	Day Care Center Respite residential care Inpatient care Private care
Direct non-health care		Questionnaire Housing adjustment Remote care aids Financial losses (money transfer, unpaid bills...) Scams on the patient Damages and claims Transports to the doctor, day care center, inpatient care, caregiver to the patient home
Indirect costs		Questionnaire Workload reduction Missed hours at work Nursing care allowance Time spent on housework for the patient Personal care and hygiene of the patient Practical patient support Emotional support

3.1. Case study I

The first respondent was a daughter caring for her fifty-eight-year-old mother. The caregiver's profession was as a shop assistant in local food store where the average wage was € 880. The respondent's monthly productivity loss was about 4 hours. The patient in her care suffered from the first stage of Alzheimer's disease and still lived alone. The caregiving daughter regularly commuted and took complete care of everything. The first symptoms of the disease began to manifest two years ago in the form of a slight forgetfulness and, rarely, time and space disorientation. The ability of self-care was still possible. The patient responded promptly and could participate in meaningful conversations.

Patient 1 Gender: Female
 Age: 58
 Stage: Mild
 Region: Vysočina

Table 3. Case study I.

	Health care cost	Social care cost	Family costs
Direct health and social care	UZIS EUR 336*		EUR 16/ month
Direct non-health care	EUR 534 **		EUR 140 *** + EUR 24/month

Indirect costs	Care allowance – EUR 35/ month **** Informal care - 40h/ month Informal care - 4h/ month
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* Average for given patient characteristics for the Vysočina Region.

**Average for given characteristics of patients for the whole Czech Republic.

***Cost from the beginning of the disease.

****Care allowance from the Ministry of Labor and Social Affairs, which according to the caregiver corresponds to 5 hours of care.

3.2. Case study II

The second respondent was a daughter caring for her mother whom she took into her home. The respondent worked in agriculture where the average wage was around € 720. The caregiver had to quit her work duties completely in order to provide needed care. The patient was eighty-eight years old and suffered from second stage Alzheimer's disease. The onset of the disease was dated as four to five years ago. Due to the combination with other diseases, the patient's condition was considered bad and was confined to bed. The manifestations of the disease gradually worsened. The ability to speak and put together meaningful sentences had deteriorated. But she could still provide answers. For most of the time, the patient was confused and disoriented by place and time. There were moments, however, when noticeable short-term improvements were evident. Occasionally, there were so-called "return in time," singing songs from childhood and recalling pictures of youth. More and more confusion became evident with loses of knowing who was near. Self-care ability was considerably impaired although the patient could drink by herself and eat with the assistance of another person. Movement in a walker was assessed as very difficult deteriorating to immobility.

Patient 2 Gender: Female
Age: 88
Stage: Moderate
Region: Vysočina

Table 4. Case study II.

	Health care cost	Social care cost	Family costs
Direct health and social care	UZIS EUR 319*		EUR 56 / month
Direct non-health care			EUR 100*** + EUR 40/ month
Indirect costs			Care allowance + EUR 512 / month**** Informal care - 140h/ month Loss of working time - 160h/ month

* Average for given patient characteristics for the Vysočina Region.

**Average for given characteristics of patients for the whole Czech Republic.

***Cost from the beginning of the disease.

****Care allowance from the Ministry of Labor and Social Affairs, which according to the caregiver corresponds to 60 hours of care.

3.3. Case study III

The third respondent was a daughter-in-law who took care of her sixty-six-year-old mother-in-law. The patient was completely dependent on the help of another person. The respondent worked as a hospital orderly in a nearby hospital where the average salary was € 736. The caregiver had to resign from her job in order to provide the level of care required. The patient had almost no reaction to verbal stimuli. Response to physical stimuli, such as, taking blood samples, remained. Occasionally, the patient made meaningless noises. There were involuntary twitches and muscle spasms. The capacity to mix food, feed oneself, self-sufficiency and self-care disappeared. Supervision and care were required throughout the day.

Patient 3 Gender: Female
 Age: 66
 Stage: Severe
 Region: Vysočina

Table 5. Case study III.

	Health care cost	Social care cost	Family costs
Direct health and social care	UZIS EUR 256* EUR 395**		EUR 112/ month
Direct non-health care			EUR 272*** + EUR 32/ month
Indirect costs			Care allowance – EUR 768 /month**** Informal care- 170h/ month Loss of working time - 120h/month

* Average for given patient characteristics for the Vysočina Region.

**Average for given characteristics of patients for the whole Czech Republic.

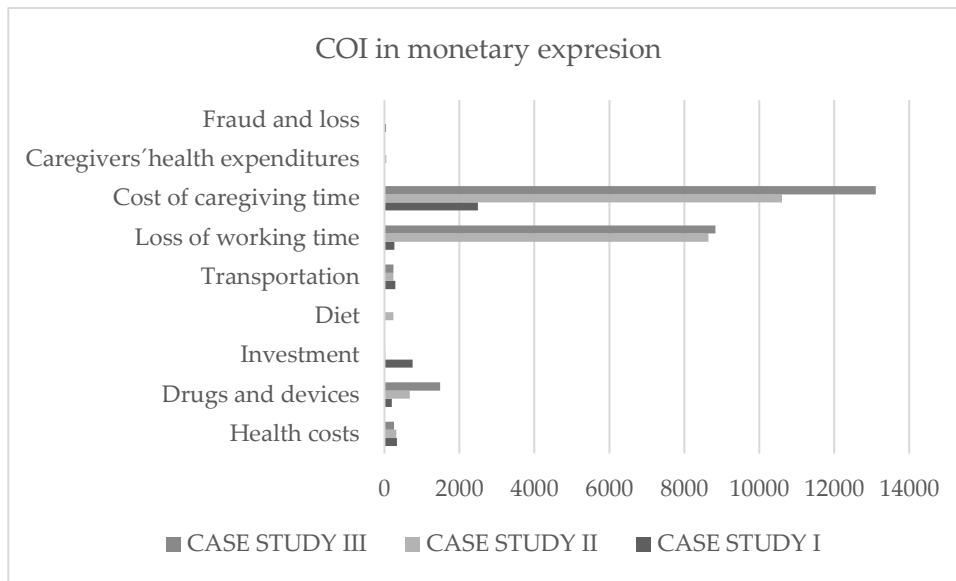
***Cost from the beginning of the disease.

****Care allowance from the Ministry of Labor and Social Affairs, which according to the caregiver corresponds to 150 hours of care.

3.4. Results

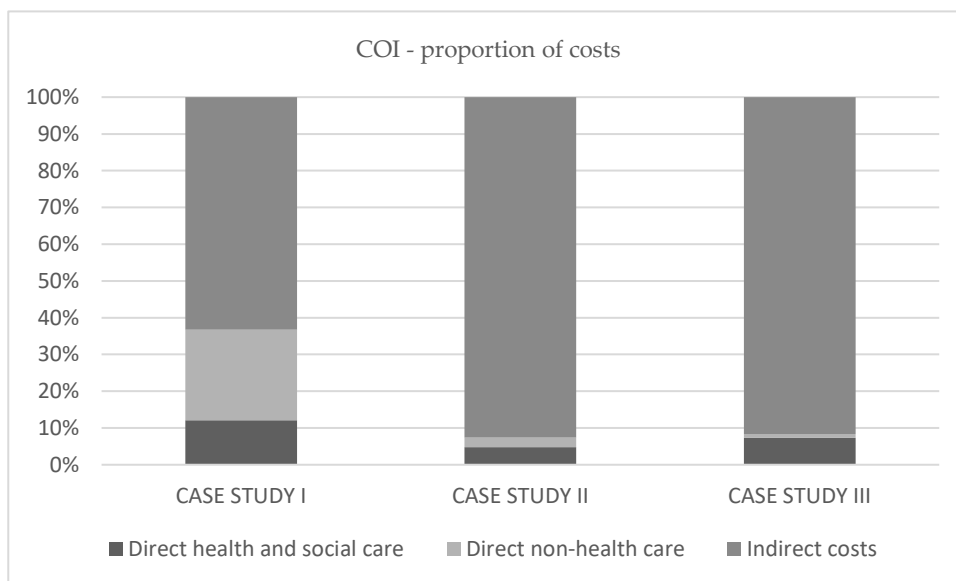
All input data were converted to yearly values. Direct non-medical costs were adjusted for depreciation and, in the case of long-term investment in the amount was reduced to one fifth. In the case of investments in the form of communication technology, the amount was cut in half. The financial expression of the loss of working time was calculated as the average wage in the industry multiplied by the percentage loss of full-time employment. The resulting calculations show that the COI for Case study I was based on EUR 3,646 per year, equivalent to EUR 304 per month. For Case study II, the annual cost was EUR 20,793, equivalent to EUR 1,733 per month. Case study III reported an annual cost of EUR 23,936, which corresponds to a monthly cost of EUR 1,995.

Figure 3. Comparison of COI according to the type of costs of each Case study.



The largest share of the cost of the disease was spent on cost of caregiving by the informal caregiver. The value of working time lost by the caregiver as the disease progressed was added in the case study II and III.

Figure 4. Comparison of COI according to the type of costs of each Case study.



4. Discussion

The results of our study indicate that as the disease progresses, the overall cost of AD increases. The largest share of AD costs is indirect cost at each stage of the disease. The loss of ability to work and time spent on patient care are the two most important components. These costs arise also due to the fact that the needed care in all selected case studies is not solved with the help of social services.

Further research direction should ensure more researched data. The research should also focus on the whole Czech Republic. Our preliminary results show that the average medical costs for Case studies I and III are significantly lower than the national average. It is also necessary to extend the research area to patients who intensively use social care. An interesting point for further research is

the utilization of care allowance on purchasing social services and the financial burden of patients/caregivers.

4.1. Limitations

The presented study and its conclusions cannot be generalized for the population of the Czech Republic. The small n-size is the primary concern. Additionally, the monitored patients were female from the Vysočina Region and the survey was carried out only in the Vysočina region, which is non-representative of the entire population of the Czech Republic. The results may also have been influenced by the non-random selection of patients used for the case study. This is also evident in the case of social services used, as none of the patients received social services. The final limitation of the article is the fact that data from in-depth interviews and caregiver questionnaires were collected in 2019 while data available on healthcare usage date to 2017.

The exchange rate used was set at CZK 25 for 1 EUR.

4.2. Recommendations

The methodology employed for this study shows promise in an expanded inquiry. The combination of available quantitative data with hard-to-obtain qualitative data provided by interviews, has the potential to develop and increase accuracy for more insightful understanding of Alzheimer's Disease, its true impact on the population of the Czech Republic, and the possible tailoring of services in support of those affected by it.

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