Zeszyty Naukowe Ochrony Zdrowia

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DISEASE BURDEN COSTS

years of life lost and disability

cost of illness

rada programowa

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Wprowadzenie

Szanowne Czytelniczki, Szanowni Czytelnicy!

Przekazujemy Państwu kolejny numer „Zeszytów Naukowych Ochrony Zdrowia. Zdrowie Publiczne i Zarządzanie" poświęcony tym razem ocenie obciążenia społeczeństw chorobami. O kosztach chorób mówimy w sensie następstw, jakie odczuwa zarówno każdy człowiek z chorobą, jak i jego rodzina czy przyjaciele, a także pracodawcy, rządy, samorządy, całe społeczeństwo. Im bardziej choroba jest dotkliwa (wymagająca intensywnego, długiego leczenia lub powodująca więcej zgonów), im większej części populacji dotyka i im bardziej osłabia jej potencjał (ogólną aktywność i zdolność do pracy), tym bardziej rosną koszty choroby.

Analizy obciążenia chorobami wymagają odpowiedniego rozpoznania epidemiologicznego, ustalenia zarówno kosztów ponoszonych na ich zapobieganie i leczenie, jak i strat społecznych z ich powodu. Analizy te mają zastosowanie w kreowaniu polityki zdrowotnej opartej na dowodach (*Evidence-based Health Policy*), polegającej na podejmowaniu decyzji na podstawie potrzeb i wartości wyznawanych przez dane społeczeństwa. W tworzeniu polityki zdrowotnej proces zaczyna się od ustalenia głównych problemów zdrowotnych populacji, uporządkowania chorób według ciężkości skutków, jakie powodują, wyrażonych i zmierzonych miarami umożliwiającymi uchwycenie różnorodności tych skutków. Tak więc, analizy dostarczają danych o stanie zdrowia zarówno populacji świata, jak i w odniesieniu do różnych krajów, regionów, grup wiekowych oraz płci.

Wyniki analiz obciążenia chorobami są wykorzystywane w procesach rozwoju systemu ochrony zdrowia, do tworzenia priorytetów inwestycyjnych i alokowania ograniczonych zasobów. Aby zapewnić zbudowanie systemu ochrony zdrowia w kraju odpowiednio do prawdziwych wyzwań dla zdrowia populacji, decydenci muszą mieć możliwość porównania konsekwencji różnych chorób: tych, które zabijają ludzi przedwcześnie, z tymi, które powodują niepełnosprawność. Twórcy badania globalnego obciążenia schorzeniami społeczeństw świata (*Global Burden of Disease* – GBD) stworzyli syntetyczną miarę – wskaźnik DALY – Lata Życia Skorygowane Niesprawnością (*Disability-Adjusted Life Years*) w celu określenia liczby lat życia utraconych w wyniku zarówno przedwczesnych zgonów, jak i niepełnosprawności. Jedno DALY to utracony jeden rok w dobrym zdrowiu. Decydenci mogą korzystać ze wskaźnika DALY, aby szybko ocenić i porównać skutki spowodowane takimi schorzeniami, jak choroba nowotworowa czy depresja, stosując jedną miarę. Szacując liczbę DALY, uzyskuje się dokładniejszy obraz głównych przyczyn obniżenia poziomu zdrowia populacji. Dzięki wykorzystaniu metodologii badania GBD – narzędzia monitorowania zdrowia publicznego eksperci zaobserwowali, iż w ostatnich 25 latach w większości krajów świata wraz ze spadkiem umieralności znacznie zwiększyła się niepełnosprawność (lata życia z niepełnosprawnością).

Struktura prezentowanego numeru odzwierciedla główne podejścia i narzędzia pomiaru obciążenia chorobami, które można podzielić na trzy grupy: (i) jednostki niemonetarne, (ii) jednostki monetarne, (iii) inne (w tym bezpośrednie straty dobrobytu u poszczególnych osób na wszystkich etapach cyklu życia, skutki międzypokoleniowe i społeczne).

Do miar niemonetarnych zaliczamy:

a) wskaźniki epidemiologiczne (związane z umieralnością i zachorowaniami – liczba zgonów, nowych przypadków choroby lub liczba osób z chorobą w danym roku, współczynniki umieralności, zapadalności lub chorobowości);
b) liczbę utraconych lat życia:
   - bez uwzględnienia jakości życia, z założeniem, że zgony w różnym okresie życia nie są równe. Zgon w młodszym wieku stanowi większe obciążenie niż zgon w wieku późniejszym;
   - z uwzględnieniem redukcji jakości życia w czasie trwania choroby lub poprzedzającym zgon.

Pierwsze dwie pozycje w prezentowanym numerze przedstawiają wyniki obliczeń obciążenia społeczeństwa Polski w jednostkach utraconego czasu. Pierwszy artykuł stosuje dwa wskaźniki: utracone lata z potencjalnego limitu życia (*Potential Years of Life Lost* – PYLL) i utracone lata życia z oczekiwanego dalszego trwania życia (*Period Expected Years of Life Lost* – PEYLL), nie uwzględniając przy tym jakości życia. W drugim artykule analizy przeprowadzono za pomocą syntetycznego wskaźnika lata życia skorygowane niesprawnością (*Disability-Adjusted Life Years* – DALY) – miary obciążenia, zawierającej w swojej konstrukcji niepełnosprawność powodowaną przez chorobę.

Do głównych podejść wyrażających obciążenie chorobami społeczeństw świata w jednostkach monetarnych zaliczamy:

a) podejście kapitałowe związane z kapitałem ludzkim i rzeczowym (mierzy utracony wzrost gospodarczy – *Value of Lost Output*);
b) podejście oparte na koncepcji skłonności do płacenia (*Willingness-To-Pay* – WTP) (mierzy obciążenie poprzez wartości statystycznego życia ludzkiego (*Value of Statistical Life* – VSL);
c) podejście „koszt choroby" (*cost of illness*) (mierzy koszty bezpośrednie i pośrednie choroby).

Dwa z zaprezentowanych artykułów (trzeci i czwarty) przedstawiają wyniki analiz kosztów dwóch z pięciu głównych chorób przewlekłych niezakaźnych: cukrzycy na przykładzie Polski oraz demencji na przykładzie Rumunii. Badania te demonstrują również różne narzędzia gromadzenia danych o kosztach. Jedno – bazujące na dostępnej informacji o wykorzystaniu zasobów przez osoby z cukrzycą (dane z NFZ i ZUS), a drugie na wynikach prospektywnego badania kwestionariuszowego przeprowadzonego wśród opiekunów osób z demencją w Bukareszcie. Są to wyjątkowo ważne i ciekawe zagadnienia. We współczesnym świecie choroby przewlekłe niezakaźne (*chronic non-communicable diseases*) są największym obciążeniem dla społeczeństw. Są to: choroby układu krążenia, choroby nowotworowe, cukrzyca, przewlekłe choroby układu oddechowego, choroby psychiczne. Potwierdzają to również inne badania przedstawione w przekazywanym numerze naszych „Zeszytów Naukowych Ochrony Zdrowia".

Kompleksowa ocena i pomiar obciążenia chorobami wymagają również uwzględnienia wzajemnego oddziaływania schorzeń oraz ich wpływu na osiąganie celów polityki zdrowotnej. Jest to wielkie wyzwanie dla naukowców, praktyków i polityków zdrowia publicznego. Musimy jednak podjąć się tego wyzwania, dalej próbować wyjawić prawdziwe obciążenie każdej z chorób. Bo, tak jak autorzy raportu z najnowszego badania GBD z Instytutu Pomiaru Zdrowia i Ewaluacji (*Institute of Health Metrics and Evaluation* – IHME, The University of Washington) napisali w swoim wstępie do publikacji wyników badania z 2015 roku: „tego, czego nie mierzymy, nie znamy, a tego, czego nie znamy, nie możemy odpowiednio zmieniać".

Katarzyna Kissimova-Skarbek

Introduction

Dear Readers,

We are pleased to present you with the latest volume of "Public Health and Governance," which, this time, is devoted to the evaluation of the burden of disease. The costs generated by disease are understood as the consequences experienced by any person in connection with a given disease, as well as by their family and friends, but also employers, governments, local governments and entire societies. The more severe the disease (requiring an intensive, long-term treatment or causing more deaths) or the larger the affected share of the population, the more the population's potential (general activity and the ability to work) is weakened and the higher the costs of the disease are.

The analyses of the burden of disease require an appropriate epidemiological assessment and the evaluation of the costs incurred in connection with the prevention and treatment of given diseases and with the social losses incurred as a result of these diseases. The objective of these analyses is to create an evidence-based health policy, consisting in taking decisions on the basis of evidence and on the needs of a given society and the values shared within it. The process of creating healthcare policy begins with the identification of the health problems of a given population, prioritising diseases with regards to the severity of their outcomes, determined and measured in such a way that allows for grasping the diversity of these outcomes. Therefore, analyses provide data on the health condition of a population, with respect to various countries, regions, age groups and sexes.

The results of the analyses of the burden of disease are used for processes which help develop the healthcare system, determine investment priorities and allocate limited resources. In order to guarantee the creation of a national healthcare system which is adequate to the real challenges of the population's health, decision makers must have the possibility to compare various consequences of these diseases; comparing those diseases which cause premature death with those that lead to disability. The designers of the Global Burden of Disease (GBD) study created a synthetic indicator: the DALY measure (Disability-Adjusted Life Years) in order to determine the number of years lost both as a result of premature deaths and disability. One DALY reflects one year of good health that was lost. Decision makers may use the DALY indicator in order to evaluate and compare the consequences of such diseases as cancer or depression with the use of one system. The DALY measure provides a more accurate picture of the main causes of the deterioration of the population's health. Thanks to the use of the GBD methodology – a tool whose objective is to monitor public health status, experts have observed that in the last 25 years, in the majority of countries, a decrease of mortality was paralleled with a significant increase of disability (years lived with disability).

The structure of the presented volume reflects the main approaches and tools measuring the burden of disease, which can be divided into three groups: (i) non-monetary units, (ii) monetary units (iii), others (including the direct losses of wellbeing at all stages of the lifecycle, intergenerational and social outcomes).

The non-monetary measures comprise:

a) epidemiological indicators (connected with mortality and morbidity – the number of deaths, new cases of a diseases or the number of people with a given disease during a year, the mortality, prevalence or incidence rates);
b) the number of the life years lost:
   - without taking into consideration the quality of life, with the assumption that deaths are not equal in different periods of life. Death at a younger age is a greater burden that death at a later stage of life;
   - taking into consideration the reduction of the quality of life due to the disease in the years preceding death.

The first two items of the presented volume show the results of the calculations of the burden on Polish society expressed in the units of lost time. The first paper presents two indicators: Potential Years of Life Lost (PYLL) and Period Expected Years of Life Lost (PEYLL), without taking into account health-related quality of life; whilst in the case of the latter paper– analyses are based on the DALY indicator (Disability-Adjusted Life Years), which reflects the burden, and, in its construction, comprises also the disability caused by the disease.

The main approaches which express the burden of disease in monetary units in societies globally include the following:

a) the capital approach related to human capital and physical capital (measuring lost economic growth) – Value of Lost Output;
b) the approach based on the concept of the Willingness-to-Pay (WTP), which measures the burden by means of the value of statistical life (VSL);
c) the approach of the cost of illness, which measures the direct and indirect costs of an illness.

Two of the papers presented in this volume discuss the results of the analyses of the costs of two out of five chronic non-communicable diseases: diabetes mellitus (DM), illustrated with the example of Poland, and dementia as seen in the case of Romania. These studies also demonstrate various tools for collecting data concerning costs: one of them uses the available information on the use of resources by people with DM (data from the National Health Fund and the Social Insurance Institution – ZUS), whereas the latter applies the information from the prospective questionnaire carried out among people with dementia in Bucharest. These are exceptionally important and interesting issues. In the contemporary world, chronic non-communicable diseases such as cardiovascular disease, malignant neoplasms, diabetes mellitus, chronic respiratory diseases and mental illnesses pose the largest burden for societies. This is also confirmed by other studies presented in this volume of Scientific Issues.

The comprehensive evaluation and measurement of the burden of disease also require accommodating the mutual effect of diseases and their influence on meeting the objectives of the healthcare policy. This poses a great challenge for researchers, practitioners and politicians involved in public health. Yet, this challenge must be undertaken, attempting to assess the real burden of each disease. As the authors of the most recent GBD study, carried out by the Institute of Health Metrics and Evaluation (IHME) at the University of Washington, wrote in their introduction to the publication of the results of the 2015 study, we must do this “Because what you don’t measure you don’t know, and what you don’t know you can’t act on.”

Katarzyna Kissimova-Skarbek

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Years of Life Lost Due to Deaths in Poland Measured with Potential Years of Life Lost (PYLL) and Period Expected Years of Life Lost (PEYLL) Indicators in Years 2000–2014

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Abstract

Use of PYLL and PEYLL to present mortality figures allows for qualitative assessment of the burden on society caused by different causes of death. The figures from Poland, for a 15 year period (2000–2014), show that the number of PYLL (when the cut-off age is 75 years), decreased by 20%, while both the population and the overall number of deaths increased slightly (by 0.59% and 1.94% respectively). At the same time, the number of PEYLL rose marginally (by 0.24%), which resulted from the formulary nature of the measure. Mortality measured by PYLL reveals that the leading causes of premature death among males are diseases of the circulatory system, neoplasms and external causes (mainly accidents), while in females the leading cause of premature death is neoplasms and the second leading cause are diseases of the circulatory system. When calculating PEYLL, the leading causes of premature death in both sexes is due to circulatory diseases.

Key words: **Potential Years of Life Lost (PYLL), Period Expected Years of Life Lost (PEYLL), burden of disease, categories of causes of death, Poland**

Słowa kluczowe: **utracone lata życia z potencjalnego limitu życia (PYLL), utracone lata życia z oczekiwanego dalszego trwania życia (PEYLL), obciążenie chorobą, kategorie przyczyn zgonów, Polska**

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Introduction

One of the fundamental questions in health policy and public health concerns establishing health priorities: which of the existing health problems should become a policy priority? Scarcity of resources contributes to making such choices. Typically, the answer is sought in epidemiology. The priority is that which affects the largest part of the population. However, such an approach is intuitively flawed as the majority of health problems are commonplace and do not often require any further research. Ergo, the measurement of health problems has evolved over time, becoming focused on ranking health problems according to a system of common weights. Subsequently, the concept of burden of disease was established [1, 2]. The resulting conclusion is that health problems hamper individuals' lives by reducing different human functions and therefore quality of life. Consequently, the core indicators focus on the duration of time affected by a disease and may: (i) measure duration of life lost due to deaths without considering health related quality of life of persons with the disease such as Potential Years of Life Lost (PYLL), Period Expected Years of Life Lost (PEYLL), Cohort Expected Years of Life Lost (CEYLL), Standard Expected Years of Life Lost (SEYLL) [1–3]; or (ii) count the duration of life lost due to deaths caused by the disease and reduction of health related quality of life caused by the analyzed sequelae (such as the complex units of measure called Disability-Adjusted Life Years (DALY) and Health-Adjusted Life Expectancy (HALE).

The PYLL indicator was primarily introduced because crude mortality rates could not be relied upon to provide a comprehensive representation of the effects of premature deaths and their impacts on the population. The above mentioned limitations of mortality rates, such as not accounting for the different causes of premature death nor the considerable differences in the weighted value of death relative to age (the death of younger individuals has a larger impact on the indicator level than that of elderly individuals), have led to its decreasing usage [4]. This paper focuses on the recent measurements of PYLL and PEYLL in Poland.

Materials and methods

The number of deaths, due to causes of death by category, are used to estimate the time lost and are presented through two different units of measurement of disease burden: Potential Years of Life Lost (PYLL) and Period of Expected Years of Life Lost (PEYLL). No discounting of the lost stream of life was applied.

Potential Years of Life Lost (PYLL)

PYLL (also termed Years of Potential Life Lost (YPLL)) is an indicator of premature deaths and an estimate of the number of years that an individual would have lived if he or she had not died earlier [3, 5]. The PYLL measurement is based on the premise of a conventional cut-off age which people in a given population "should" ideally live to. Death at an age below the conventional cut-off is considered as premature and partly also preventable. The PYLL indicator therefore necessitates a definition of the potential limit of life. Researchers have suggested a range of different limits from 60 years through 65, 70, 75, an up to 80 years [2, 6, 7]. A suggested limit is typically determined by the intended application of the indicator and the value attributed to older ages [3]. The potential years of life lost is given the following formula:

$$PYLL = \sum_{x=0}^{L} \mathrm{d_x}\,(\mathrm{L} - \mathrm{x})$$

Where:

d_x is the number of deaths;

L is the potential limit to life (cut-off year of age);

x is the age of death.

The expression **(L–x)** can be thought of as a weight that is attributed to death at each given age. This means that the weight attributed to the death of an individual at the age of 40 is larger than that of an individual who died at 60. As a result, deaths occurring at older ages are given less value than those at younger ages to a degree that deaths occurring at ages above the cut-off year are assigned no value.

The limit chosen for the purposes of this paper is 75 years old. This limit correlates with the average life expectancy at birth for the population of Poland in 2015, which was approximately 77.4 years old (73.6 years for men and 81.6 years for women) [8], but not chosen to suit any further specific application. To avoid linking the concept of PYLL with productivity, which occurs when a limit is fixed at 60 or 65 years, a significant value has been applied to older years of life.

Period Expected Years of Life Lost (PYELL)

The PEYLL is a measure that reflects the mortality gap between the current period of life expectancy at a given age and the actual age at the time of death [2].

$$PEYLL = \sum_{x=0}^{L} \mathrm{d_x e_x}$$

Where:

e_x is the period life expectancy at each age;

L is the age of the oldest survivors;

d_x is the number of deaths at age x.

The starting point for calculating the PEYLL is a life table based on age-specific mortality patterns. The table estimates the duration of life expected at each age if the current age-specific mortality patters are to hold in the future. Deaths at each age can be weighted by the expected years of life lost at each age. This paper references the life tables published by the Central Statistical Office of Poland (GUS) for 2015 [8].

The values of the PYLL and PEYLL indicators have been evaluated based on the individual mortality data obtained from GUS for the period of 2000–2014, which specifically include: the cause of death, age at the time of death, the sex of the individual and the year of death. The overall number of deaths from the data base of individual records for the following years is presented below (**Table I**). The figures for some of the years differ slightly from the aggregated figures officially published by GUS, which however should not influence the results.

The sources of the demographic data are publications by the Central Statistical Office of Poland [9].

In accordance with the above outlined method of calculating PYLL, the number of years of life lost in each individual case is calculated by subtracting the person's age at the time of death from the cut-off age, which has been fixed at 75.

For each individual cause of death, the PEYLL was equal to the life expectancy, according to sex, at the given age and year.

The causes of deaths were organized into major categories according to the International Classification of Diseases (ICD10) (**Table II**) [10].

Table I. *Number of deaths by gender and year of death*

	M	F	Total
2000	194,318	171,581	365,899
2001	191,139	168,486	359,625
2002	190,777	166,713	357,490
2003	193,642	170,797	364,439
2004	194,540	168,350	362,890
2005	197,154	171,370	368,524
2006	198,788	171,251	370,039
2007	201,387	173,798	375,185
2008	201,910	176,319	378,229
2009	203,509	180,272	383,781
2010	199,751	177,952	377,703
2011	198,292	176,893	375,185
2012	201,748	181,501	383,249
2013	200,408	183,748	384,156
2014	193,928	178,565	372,493

Source: Individual deaths records provided by GUS.

Table II. *Death causes categories*

ICD10 codes	Category
A00-Z99	All causes
A00-B99	Certain infectious and parasitic diseases
C00-C97	Malignant neoplasms
D50-D89	Blood and blood-forming organ disorders
F00-F99	Mental and behavioural disorders
G00-H95	Diseases of the nervous system, eye and ear
I00-I99	Diseases of the circulatory system
J00-J99	Diseases of the respiratory system
K00-K93	Diseases of the digestive system
L00-L99	Diseases of the skin and subcutaneous tissue
N00-N99	Diseases of the genitourinary system
M00-M99	Diseases of the musculoskeletal system and connective tissue
Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities
P00-P99	Certain conditions originating in the perinatal period
R00-R99	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified
V01-Y99	External causes of morbidity and mortality

Source: ICD-10 Version: 2016.

Results

In 2014, 2,617,565 potential years of life were recorded as lost (PYLL) due to all combined causes of death, resulting in a rate of 6,803 PYLL per 100,000 population (**Table III**). In the period from 2000–2014, the cumulative number of PYLL observed after each year, decreased by 671,332, indicating a 20% drop from the total in 2000 (**Chart 1**). The decrease in the PYLL was noted each year, with the exception of a period of slight increase in the PYLL from 2004–2007. Over the years of evaluation, the decrease in the number of PYLL coincided with a slight increase in the population (0.59% total from 2000) and with an increase in the number of deaths (by 1.8% compared to 2000). However in certain years, there were changes in the rate and direction of the PYLL trajectory (**Chart 2**)

Table III. *PYLL and PEYLL per 100,000 population in years 2000–2014*

	PYLL			PEYLL		
	M	**F**	**Total**	**M**	**F**	**T**
2000	12,345.47	5,073.77	8,597.53	15,939.25	10,817.63	13,299.50
2001	11,982.76	4,882.35	8,321.91	15,829.57	10,656.16	13,162.25
2002	11,849.50	4,732.53	8,178.82	15,799.36	10,616.91	13,126.44
2003	11,646.66	4,650.39	8,036.98	15,626.56	10,654.88	13,061.46
2004	11,863.85	4,613.39	8,121.49	16,022.27	10,686.58	13,268.23
2005	11,961.05	4,629.74	8,175.37	16,291.25	10,884.34	13,499.28
2006	12,039.80	4,619.25	8,205.74	16,487.07	10,968.86	13,635.92
2007	12,094.80	4,620.45	8,230.88	16,650.24	11,078.69	13,769.99
2008	11,935.88	4,570.66	8,127.16	16,653.92	11,165.93	13,815.95
2009	11,634.82	4,557.19	7,974.56	16,459.63	11,244.48	13,762.57
2010	11,085.58	4,259.42	7,564.11	16,124.50	10,992.37	13,476.94
2011	10,906.53	4,214.38	7,453.72	16,127.20	11,058.07	13,511.79
2012	10,788.11	4,200.64	7,388.84	16,196.66	11,211.66	13,624.30
2013	10,363.87	4,111.07	7,137.04	15,933.98	11,217.41	13,499.94
2014	9,797.91	3,994.27	6,802.65	15,569.39	11,081.98	13,253.44

Source: Authors' own calculation based on GUS.

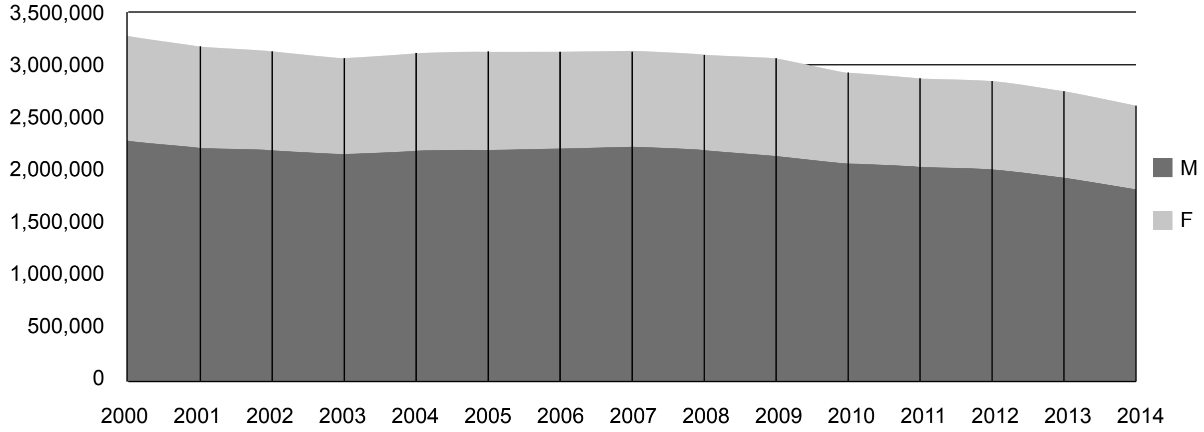
(**Table IV**). As a result number of PYLLs per 100,000 population was decreasing even faster.

When comparing the PYLL between sexes, the figures are decidedly less favourable among men. In the total years of life lost in 2014, close to 70% corresponded to the deaths of men. The decrease in PYLL occurred in both sexes and presented a similar pattern; in both cases the decrease during the period of 2000–2014 was about 20% (Chart 1).

The nature of the period of expected years of life lost indicator (PEYLL) differs from the PYLL and as such, so does its pattern during the period of study. In 2014, the number of PEYLL was 5,099,736 meaning a ratio of 13,253 PEYLL per 100,000 members of the population (Table III). From 2000 to 2014, the number of PEYLL grew by 12,152 which accounted for 0.24% of overall number of PEYLL in 2000. The years of life lost among the men according to the PEYLL accounted for 57% of the life lost of the overall population of Poland in 2014 (**Chart 3**). Over the years number of PYELLs per 100,000 population was generally stable.

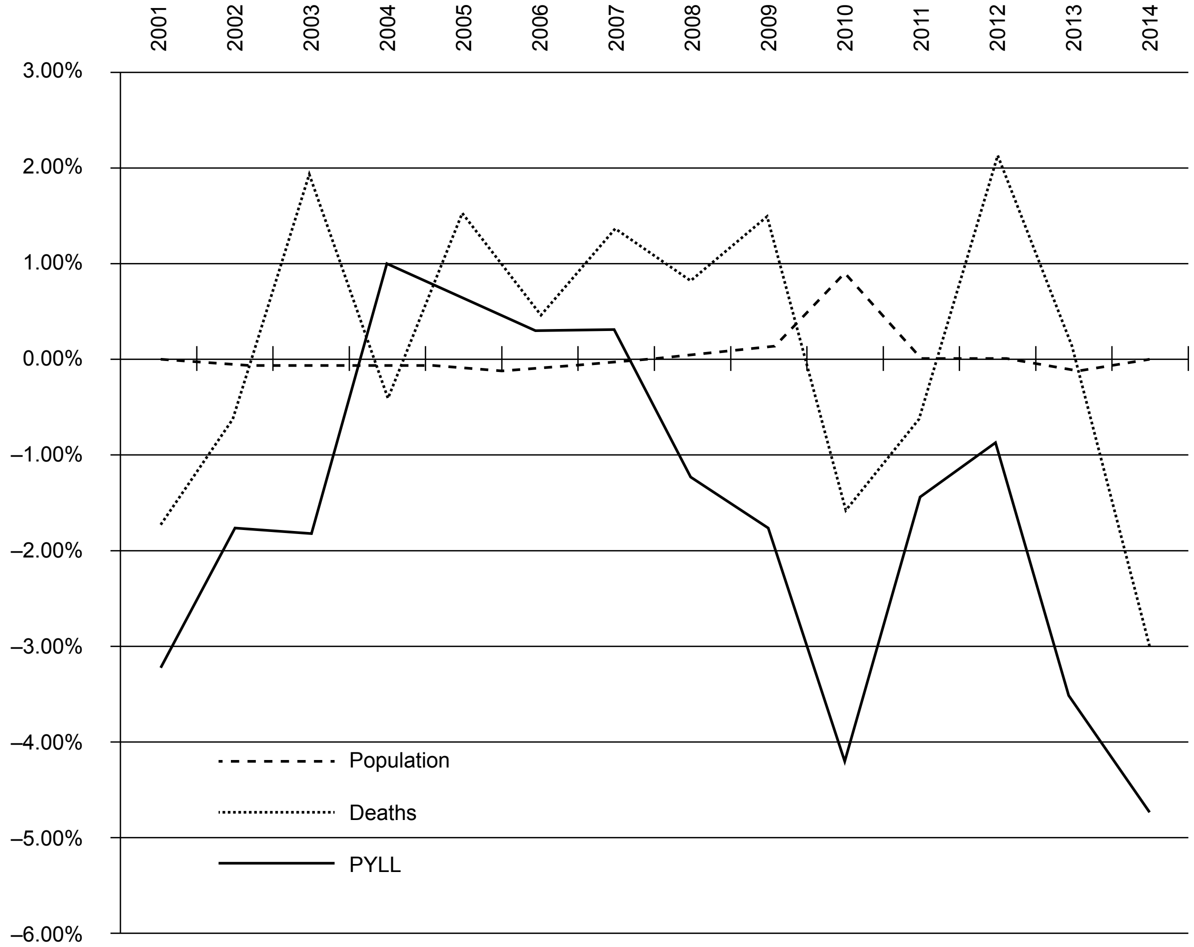
In addition to analyzing the rate of change in the numbers of PYLL and PEYLL, it is valuable to note the percentage rates of different individual health problems and their evolution over time. In 2014, 29% of the total years of life lost according to PYLL were due to neoplasms. Diseases of the circulatory system and external causes of morbidity and mortality also accounted for

Chart 1. *Evolution of PYLLs from all causes, from 2000 to 2014, population of Poland, by sex*



Source: Authors' own calculation based on GUS.

Chart 2. *Year to year changes in population, number of deaths and PYLL*



Source: Authors' own calculation based on GUS.

Table IV. *Change in count of population, deaths and PYLL in Poland between 2000–2014*

	Population	Deaths	PYLL
Change	Y/Y	Y/Y	Y/Y
2001	–0.03%	–1.71%	–3.24%
2002	–0.06%	–0.59%	–1.78%
2003	–0.07%	1.94%	–1.81%
2004	–0.04%	–0.43%	1.01%
2005	–0.04%	1.55%	0.62%
2006	–0.08%	0.41%	0.29%
2007	0.03%	1.39%	0.28%
2008	0.05%	0.81%	–1.21%
2009	0.08%	1.47%	–1.80%
2010	0.95%	–1.58%	–4.25%
2011	0.02%	–0.67%	–1.44%
2012	–0.01%	2.15%	–0.88%
2013	–0.10%	0.24%	–3.50%
2014	–0.04%	–3.04%	–4.73%

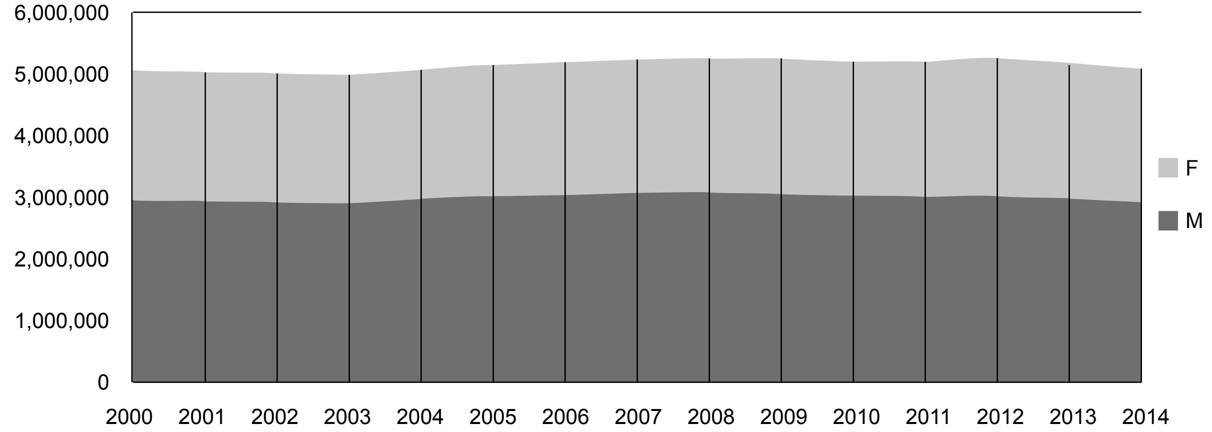
Source: Authors' own calculation based on GUS.

large percentages of the overall number of PYLL (25% and 18% respectively). Between 2000 and 2014, it was noted that across the general population, the proportion of loss of years of life due to neoplasms in total number of PYLL increased (by about 4 percentage points) whereas the share of losses due to diseases of the circulatory system and external causes of mortality groups of causes decreased slightly (**Chart 4**).

There is a considerable difference in the rate of impact of causes of death among men and women. In 2014, the leading cause of PYLL in women was neoplasms (41%) whereas in men the leading causes were diseases of the circulatory system (26%). External causes of morbidity and mortality in the overall number among men were as high as 21% but figured at only about 9% among women.

Since 2000, share of PYLL due to neoplasms in total number of PYLL in women increased significantly, from 34% to 41%, whereas PYLL due to diseases of the circulatory system and external causes dropped from 24% to 21% and from 12% to 9% of the total number, respectively. In men, decreases were observed in PYLL due to diseases of circulatory system from 27% to 26% as well as in external causes of morbidity and mortality from 24% to 21%. However, neoplasms as a cause of death among men in-

Chart 3. *Evolution of PEYLLs from all causes, from 2000 to 2014, population of Poland, by sex*

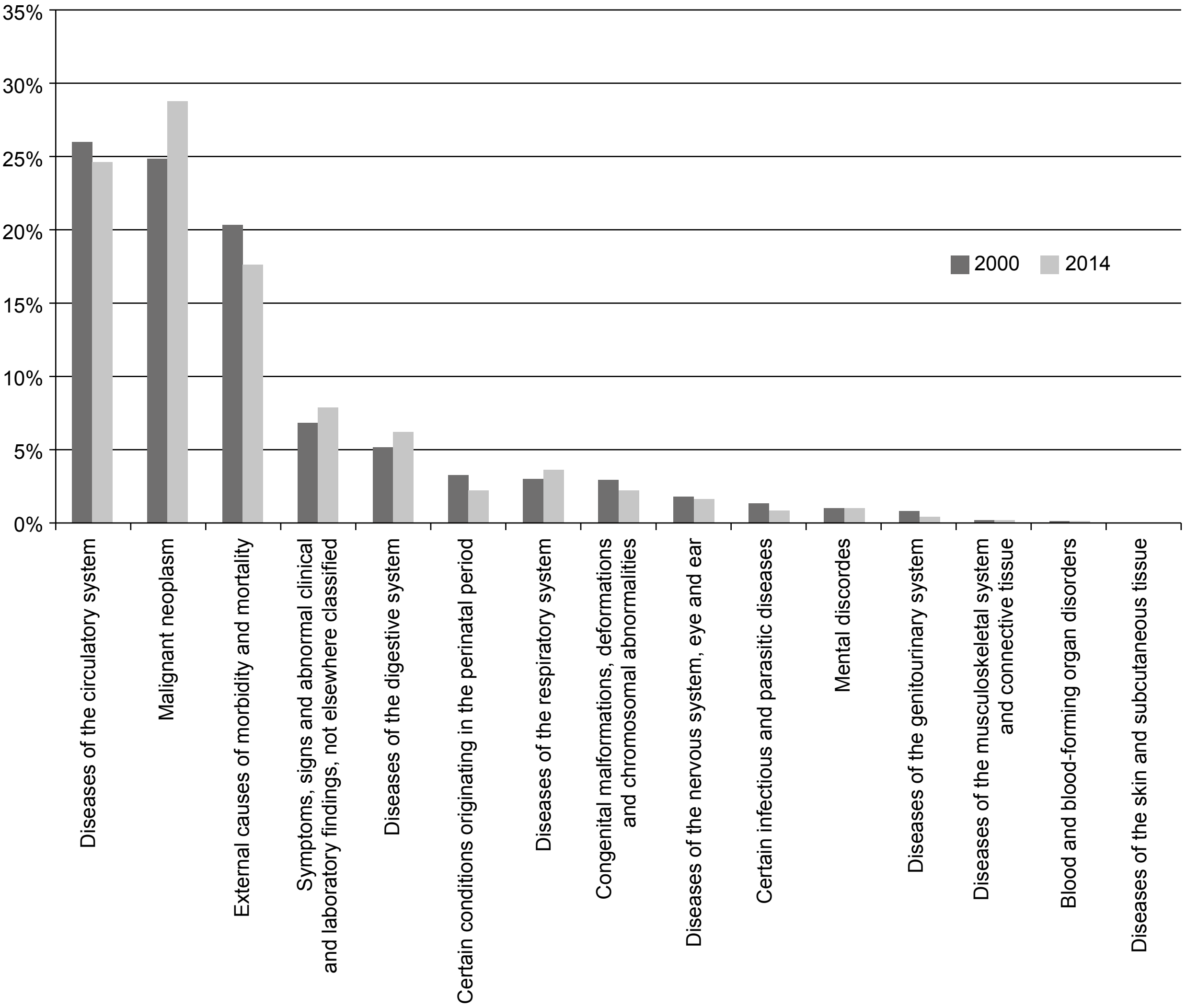


Source:Authors' own calculation based on GUS.

creased significantly, accounting for 23% of the potential years of life lost as compared to the 21% figure noted at the beginning of the millennium (**Chart 5**).

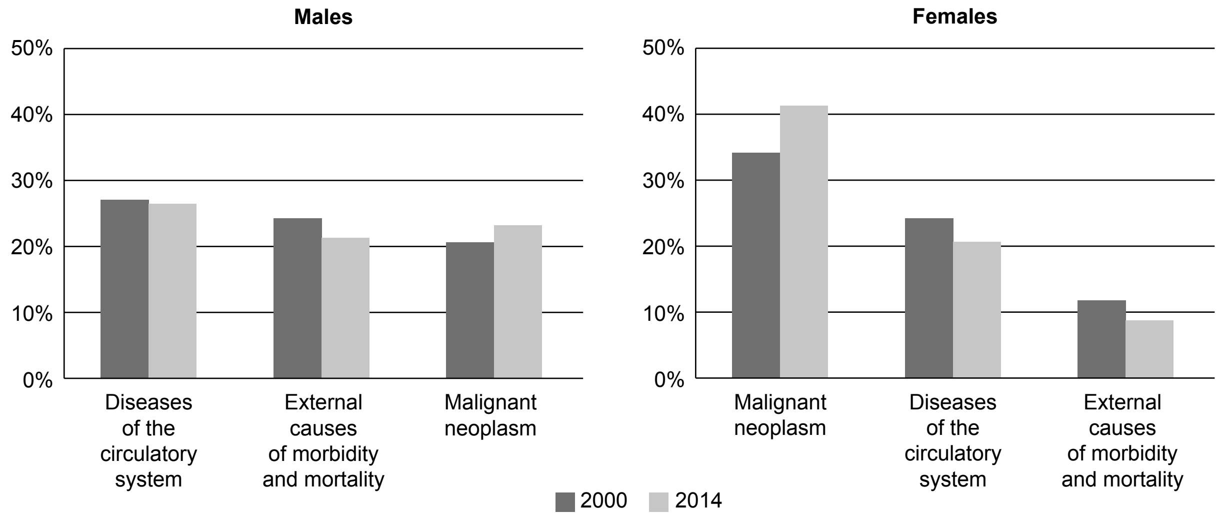
According to the PEYLL indicator, the leading cause of years of life lost in 2014 were diseases of the circulatory system, which fluctuated at around 35% both in 2000

Chart 4. *Main categories of causes of PYLL, general population, years 2000 and 2014*



Source: Authors' own calculation based on GUS.

Chart 5. *Main categories of causes of PYLL, males and females, years 2000 and 2014*



Source: Authors' own calculation based on GUS.

and 2014. In 2014, the impact of malignant neoplasms as a cause of years of life lost according to the PEYLL was at 29% which displayed an increase in the share of total PEYLL compared to the 25% figure at the beginning of the millennium (**Chart 6**). Years of life lost due to external causes dropped from 14% to 11%. Similarly to the PYLL results, the causes of losses of PEYLL in women and men differed. However conversely to PYLL, circulatory system diseases were the prominent cause of loss of expected years of life in both women and men (M – 32%, W – 37%), with neoplasms as the second largest cause (29%: M – 26%, W – 33%). External causes of morbidity and mortality figured at 15% PEYLL in men and 5% in women (**Chart 7**).

Discussion

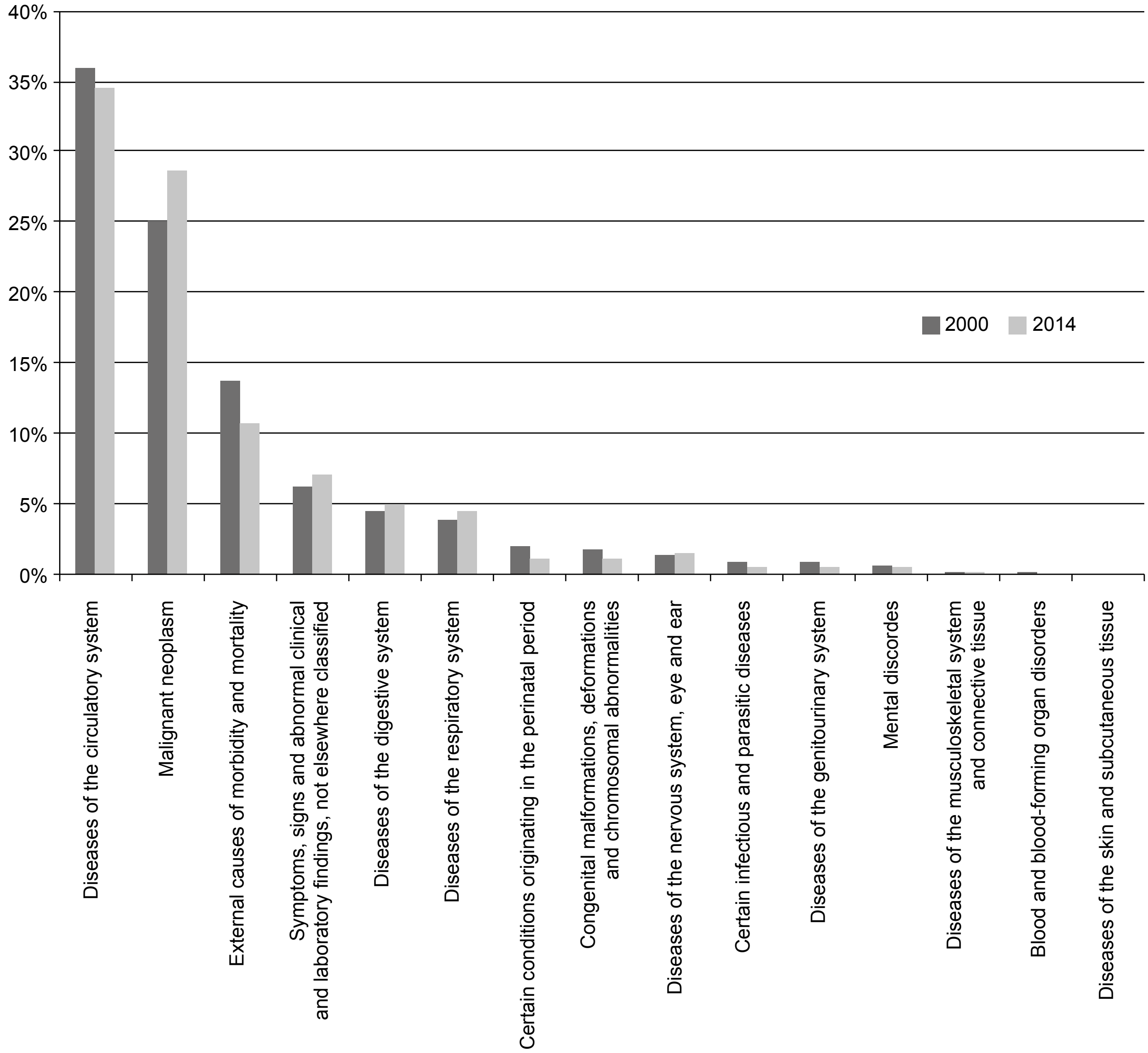
The method of calculating PYLL is based on an arbitrarily fixed cut-off age, from which the years of life lost are subtracted. For the purposes of this study, the cut-off age has been fixed at 75 years. This figure is the value between current life expectancy in men (about 73.6 years) and women (81.6 years). As a result of this cut-off age, the number of years of life lost according to the PYLL was significantly larger in men than in women. Therefore the overall number of PYLL presented an obvious and widespread excess mortality among men.

The results of this study present a positive phenomenon; a 20% decrease in the number of years of life lost recorded over the 15 years of analysis. If this trend were to continue over the next decade, the number of PYLL (75) would decrease by about half. The source of this rate of change in premature mortality is uncertain, however it is worth noting that the decrease in PYLL due to diseases of the circulatory system comprise 25%; 32% as a result of external causes; however only 8% as a result of neoplasms. Considerably larger decreases have been recorded in the cases of infectious diseases (51%), disorders of the genitourinary system (about 59%) and congenital disorders in the perinatal period (about 40–45%), thereby having a substantially smaller impact on the years of life lost.

The pattern of decrease in PYLL among women and men were similar (21% overall), however the PYLL was subject to fluctuate somewhat, relative to individual causes of death. In particular, years of life lost due to neoplasms among men dropped by 11% and by 4% among women. Other sources indicate that the most widespread malignant neoplasms, lung cancer, is becoming less frequent, affects predominantly men, and likely correlates with lower levels of exposure to tobacco. Conversely, the same neoplasms as well as breast cancer, are becoming increasingly common among women [11]. Between 2000 and 2014, a decline in the number of PYLL (75) among women due to circulatory system diseases of 32% was recorded. A similar pattern was observed among men, however the percentage was smaller with an observed decrease of 22% during the period of study. A significant decrease in years of life lost due to external causes of morbidity and mortality has been recorded in both sexes; 30% and 40% in men and women respectively. Further and more detailed research in the future may be beneficial in determining the causes of decreases in the number of PYLL in these two broad categories.

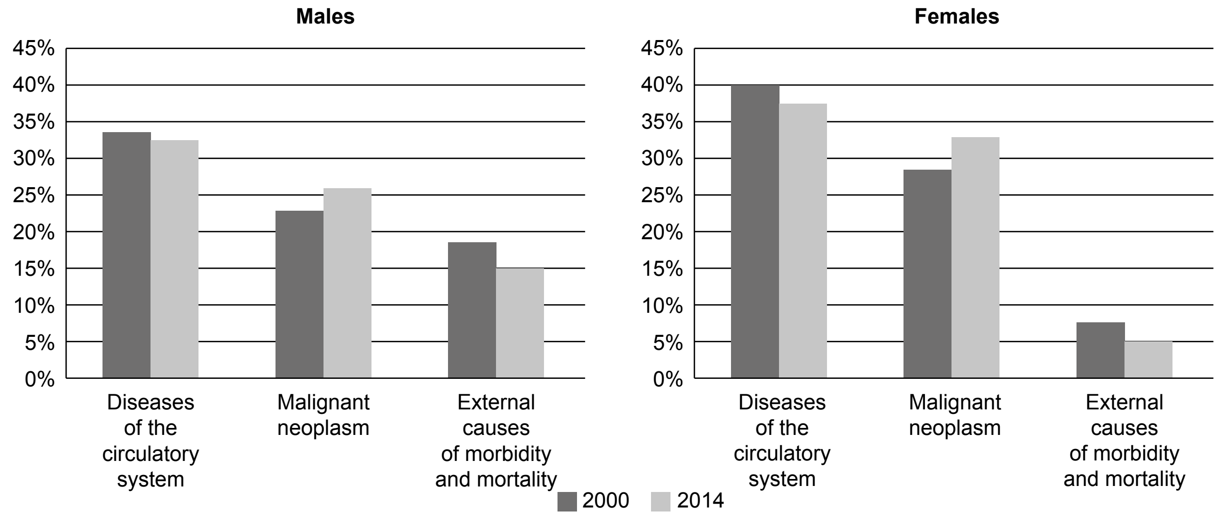
It may also be beneficial to compare the numbers of PYLL between different fixed cut-off ages such as 60, 65 or 70 years. With the lower ages in particular, such a study may provide insight into the country's potential productivity and gross domestic product. Where the cut-off age is 70 or 75 years the analysis treats equally the years of productive age as well as those of the post-productive age. Additionally, deaths occurring prior to the age of 70 are typically considered premature and avoidable. It is therefore highly beneficial to determine the number of years of life that are lost (measured with PYLL and especially with PEYLL) so as to establish and ensure measures for prevention of early death.

Chart 6. *Main categories of causes of PEYLL, general population, years 2000 and 2014*



Source: Authors' own calculation based on GUS.

Chart 7. *Main categories of causes of PEYLL, males and females, years 2000 and 2014*



Source: Authors' own calculation based on GUS.

The method of calculating the PEYLL rate takes into account the differences in life expectancy as related to age and sex, which results in smaller disproportion of value of the rates between women and men than observed in the PYLL. The PEYLL indirectly measures the frequency of mortality in younger ages than expected in the given sex and age category. As a result, the data presenting the number of years of life lost due to premature mortality in women and men is more stable (Chart 3). The dynamic of excess mortality among men disappears in the PEYLL because the life expectancy at the age of death is higher in females than males. The higher number of deaths in males compared to females is multiplied by the lower number of years lost which results in a lower conclusive number of years lost in males.

At the same time, PEYLL provides a better image of the scale of premature mortality by age and sex cohorts than PYLL. As a result PEYLL also more clearly indicates that the primary source of premature mortality are diseases of the circulatory system (about 35% in men as well as women). Malignant neoplasms are the second leading cause of death and pose a decidedly larger problem in women than in men (33% and 26% respectively). PYLL does not account for deaths occurring at ages above the fixed cut-off age (75 years). PEYLL counts deaths at all ages and thus presents the real burden of disease on society.

The pattern of the PEYLL rates differs considerably from the PYLL between 2000 and 2014. During these years, the life expectancy in both sexes and at particular age groups increased [12]. As a result of this increase, the number of overall PEYLL did not change (as is predictable based on the nature of the formula), wherein the percentage increased by 3% in women and decreased by 2% in men. In certain categories of causes of mortality, several interesting differences were noted. Resulting numbers of PEYLL due to diseases of the circulatory system showed slight improvement; in both women and men, the number of PEYLL decreased by about 3–4%. Considerably more favourable results can be observed in the figures representing external causes of morbidity and mortality, where their impact on premature mortality decreased among men by 20% and by 29% among women.

The impact of loss of PEYLL from malignant neoplasms shows adverse results through a 12% increase in men and as much as a 20% increase in women. In both cases it is necessary to interpret these figures (relative to the life expectancy in the given study group) as an increase in the number of premature deaths due to neoplasms. Another interpretation of this phenomenon is the gradual disappearance of circulatory system diseases as a cause of death in older individuals with an increasing appearance of neoplasms in their place. It is also worth noting the large increase in premature mortality due to disorders of the respiratory and gastrointestinal systems. A separate issue is the increase in the number of PEYLL due to symptoms and undetermined causes which indicates the flaws in postmortem diagnoses and reporting systems.

Conclusions

The PYLL and PEYLL indicators play an important role in complementing the widely applied mortality measures in public health; such as crude death rates and standardized death rates (CDR, SDR) [13, 14]. The information contained in the PYLL and PEYLL predominantly reflects observations made on the basis of the above mentioned measures [14–16]. However, the PYLL and particularly the PEYLL make it possible to identify the number of years of life lost due to premature deaths by categories of diseases more accurately than when using the CDR or SDR. Such information can and should be used to provide direction for establishing priorities in the scope of public health and healthcare. It is recommended that the analyses presented in this paper be developed further and in greater detail, and include a deeper analysis of the categories of causes of death (e.g. ischemic heart disease) as well as the categories of individuals affected (e.g. residence, marital status, etc.).

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Approaches to Disease Burden Measurement: Disability-Adjusted Life Years (DALYs) Globally and in Poland, and National Income Lost Due to Disease in Poland, 1990–2015

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Abstract

The purpose of this study was to identify the main health problems in Poland against global health problems using the latest Global Burden of Disease (GBD) study results. The burden of disease is assessed here in terms of: (i) time lost due to premature deaths and morbidity (expressed in Disability-Adjusted Life Years – DALYs measure) and (ii) national income lost due to disease in Poland. The study presents the estimates of total DALYs, Years of Life Lost (YLL) caused by deaths, Years Lived with Disabilities (YLD), both in total (due to all causes) and attributable to chronic non-communicable diseases (NCDs), in 2015 compared to year 1990. The economic value of time lost due to deaths and disability in Poland is measured using the method employed by the WHO Commission for Macroeconomics and Health, which makes the assumption that each DALY can be valued at between one and three annual GDPs per-capita for the country under study. In 2015 over 2.46 bln DALYs globally were lost due to all causes, of which 66.7% were due to NCDs and 18.2% were due to communicable diseases. Poland experienced over 11.3 mln DALYs in the year 2015, 81.9% of which were due to NCDs and 3.4% of which were due to communicable diseases. 68% of total DALYs globally and 41% in Poland were years of life lost due to deaths. 84% of the total years of life lost due to death in 2015 globally (69% in Poland) occurred under the age of 70 and are considered avoidable. Total income lost in Poland due to deaths in 2015 amounted to up to I$527 bln.

Key words: **burden of disease study, disability-adjusted life-years (DALY), years of life lost (YLL), avoidable YLL, years lived with disability (YLD), chronic non-communicable diseases, national income lost**

Słowa kluczowe: **badanie obciążenia chorobami, lata życia skorygowane niesprawnością (DALY), utracone lata życia (YLL), YLL do uniknięcia, lata życia z niesprawnością (YLD), przewlekłe choroby niezakaźne, utracony dochód narodowy**

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Introduction

In conditions of limited resources, establishing investment priorities in the health care sector is essential. These investment priorities should reflect the most pressing health needs of a country and be focused on those diseases that constitute the greatest burden on society. The most important health problems are determined by assessing the burden posed by different diseases, injuries and risk factors on society.

Burden of disease analyses are predominantly applied in creation of evidence-based health policy [1]. They provide data that enable the comparison of different diseases, ordering them with respect to the costs they impose on society as well as identifying areas where the health of the population can be potentially improved. In this way, they help develop preventative programmes geared towards solving the main problems which have been identified. Burden of disease studies provide a basis for allocating limited resources to those areas where the health and life of people is most at risk and where the greatest benefits for society can potentially be achieved. The results of disease burden analyses can also serve as a tool for benchmarking health care systems and help to understand the contribution of a health care system in preventing and treating particular diseases.

In the current study the existing methods of disease burden measurement were summarised and the main causes of health loss, both globally and in Poland, were identified using a complex measure of time lost and disability – DALY.

The research questions were: What causes the most deaths and years of life lost both globally and in Poland? What portion of the lost years (due to death) is avoidable? What causes the most disability and combined death and disability in Poland? What is the national income lost due to disease in Poland?

The secondary aim of this study was to illustrate the possible ways of using open access data sources available online, which can be easily applied to identify the main health problems in countries.

1. Methods and indicators for measuring a disease burden

A comprehensive analysis of disease burden requires making a correct epidemiological diagnosis (disease occurrence) and identifying the costs incurred in terms of both of treatment and social losses resulting from diseases as well as performing an analysis based on the method of calculating the direct and indirect costs of this treatment in addition to losses in economic growth. In order to identify the disease burden at national, regional or global levels, various approaches and units of measurement have been applied. The main indicators and approaches to measuring the disease burden can be divided into three groups which are presented in **Figure 1**. The first group – non-monetary units – includes: (i) natural units, consisting of mortality and morbidity indicators and (ii) time lost measures.

The simplest and most commonly used measures for assessing the health level of a population are mortality rate indicators. However, they do not take into account losses caused by factors that do not result in death. This is because they do not assess burdens in the form of impaired physical or mental capacity during the course of the disease or the time preceding death. Actually, these measures assume that a person who does not die remains "healthy" [3]. In such a way, losses resulting from the complications of disease, as well as any pain or disability caused by a particular disease, are overlooked. These also fail to take into account other consequences of diseases – the costs which they entail for people suffering from the disease as well as for the public payer and for society as a whole. Mortality rates do not usually show the social and economic dimension of death and disease in different periods of human life. In addition, it is believed that deaths at a younger age constitute a greater loss for society than deaths that occur over the age of 90.

Nevertheless, the indicator showing the number of deaths per 100,000 serves as a starting point for assessing the burden imposed on the health of a society by different diseases, risk factors and injuries in units of time lost.

1.1. Time lost measures without taking into account health-related quality of life – years of life lost caused by death

It was Dempsey [4] who first suggested that premature mortality should be measured in units of time lost [2, 5]. A number of variants of this method have been developed since 1947. These units measure the amount of time lost as a result of deaths caused by particular disease. The main idea is that death at an early age constitutes a greater burden than death at a later age. Depending on how we count a lost period of life, the following measures have been developed: Potential Years of Life Lost (PYLL), measuring the number of years between the age of death and an arbitrary chosen limit of life; Period Expected Years of Life Lost (PEYLL), counting the years lost equal to life expectancy at age of death (for males or females) in the country and Standard Expected Years of Life Lost (SEYLL), considering the period of life lost equal to the standard life expectancy at age of death (using a synthetic life table constructed from the lowest observed age-specific mortality rates for each age-group anywhere in the world). For more explanations and results on PEYLL and PYLL in Poland see [2] and Kozierkiewicz et al. in this issue [6].

1.2. Time lost measures taking into account health-related quality of life: DALY

In recent years, a number of studies have been targeted towards creating a synthetic (universal) unit for measuring the health of society that integrates measures of burdens associated with both mortality and disability and that makes it possible to compare the burden of different diseases as well as the effects achieved by various medical interventions.

DALY (*Disability-Adjusted Life Years)* is a measure developed by experts of the World Bank and World Health Organization within the Global Burden of Disease (GBD) study, the first results of which were reported in 1993 [7–9]. Since that time the burden of disease using DALY concept has been widely adopted by governments and international organizations in their attempts to identify the relative magnitude of different health problems. This information serves as crucial input in debates on the priorities of the health sector.

DALY is a combination of two measures: loss of life as a result of premature death (YLL – Years of Life Lost) and loss of years in health due to disability caused by disease or injury (YLD – Years Lived with Disabilities). DALYs = YLLs + YLDs.

As a unit for measuring the disease burden in a society as a whole, i.e. the sum of all burdens for particular groups of people, DALY provides a basis for assessing not only the losses to society due to deaths, but also the losses resulting from disabilities caused by different diseases. To any death from a particular cause is attributed YLLs number equal to the highest observed life expectancy (standard life expectancy at age at death). The YLL calculation, accordingly, places more weight on the causes of deaths that occur in younger age groups. YLD are estimated based on incidence or prevalence number of disease cases and imply disability weights [3].

GBD methodology is constantly being improved and so far four phases have been distinguished in this process[1, 2]. For this reason it is important to remain cautious when using GBD results published in previous years since they are not comparable.

2. Burden of disease measured in monetary units

Three approaches can be listed [2, 16]:

- The value of lost output: economic growth approach;
- The value of statistical life (VSL) approach;
- The cost-of-illness (CoI) approach.

2.1. Lost economic growth: assessing the cumulative value of lost output

This is a prognostic measure of the impact of disease on an economy's gross domestic product (GDP) and economic growth that takes into account the impact of disease on reducing factors of production (labour and capital) in a country. This method was used by a team of experts led by Professor D. Bloom of the University of Harvard [16], assembled by the World Economic Forum to assess the economic burden of chronic non-communicable diseases globally in the years 2011–2030[3]. The impact of these diseases on the economy (on the level of GDP) was estimated by assessing how these diseases reduce labour resources, physical capital and other factors in different countries. This approach used the WHO-EPIC (WHO tool for Projecting the Economic Costs of Ill-Health) model prepared in 2006 [17], which provides a simulation of the macroeconomic consequences of chronic diseases (in 169 countries around the world) by looking at the effects of chronic diseases on economic growth. The EPIC model takes into account the negative impact of chronic diseases on the amount of labour and capital resources available[4]. The results are unequivocal: NCDs pose a substantial economic burden and this burden will rise. The macroeconomic EPIC model simulations suggest that five main chronic NCDs: cardiovascular disease, cancer, chronic respiratory diseases, diabetes, and mental illness, will cause a cumulative output loss of US$ 47 trillion globally over the next two decades [16].

2.2. The value of statistical life approach

The value of statistical life (VSL) approach reflects society's willingness to pay (WTP) a certain sum with the aim of reducing the risk of disability or death caused by a particular disease. By placing a value on (establishing a monetary value) loss of health, the VSL approach goes beyond simply measuring the impact of disease on GDP and economic growth. It reflects the preferences of a society. Various factors affecting the level of VSL are considered. The factors most commonly shaping VSL are age, the level of national income (or the average wage in a country, or the average wage in a specific branch associated with some degree of risk), the kind of risk involved (for example, death from cancer), and the moment when a risk may appear in the future. When the age factor is taken into account, the value of life of an individual suffering from a disease is adjusted in accordance with a fixed indicator, or a reduced value of life is considered together with age. Such a correction is called the "senior discount" [18]. Bloom et al. found that the value of life lost due to NCDs in 2010 is US$ 22.8 trillion and will double by 2030 to US$ 43.4 trillion [16]. For more details on valuing statistical life and the disease burden results achieved, including those for Poland using this approach, see [2, 16].

2.3. The cost-of-illness approach

This is the third method for measuring the disease burden on society in monetary units: the value of resources used or lost as a result of the disease is measured. This approach makes it possible to determine the potential savings that can be achieved as a result of preventative interventions.

Today's costs of illness have their roots in studies published in the 1950s and 1960s [19–22] when, as in present times, there was a debate over the most suitable approach to measuring improvement of population health. The best approach appeared to be using the results of earlier conducted studies. In 1966 Dorothy Rice published a monograph [22] in which she proposed a methodology for estimating the costs of a disease using information from existing data bases. This work became the *de facto* standard for future cost analyses of different diseases. In the following years, this approach was developed and applied on a wide scale by different agencies and governments to identify the costs of different diseases [23–29].

The cost-of-illness approach measures different kinds of costs, depending on the criteria used, to divide resources into those used or lost caused by disease. *Direct costs* are the costs of medical care and non-medical costs incurred because of disease, such as the costs of transport to the health provider or caregiving costs – either paid or informal uncompensated care provided in the patient's home. In turn, *indirect costs* (or also called *productivity lost*) are the value of production lost as a result of death or an individual's inability to work during the time he or she is suffering from a disease.

The third category of costs, encompassing the "psychological" costs of disease and the costs caused by pain, i.e. the impact of a disease on an individual's quality of life, are called *intangible costs.* This category is usually mentioned when determining the different elements of the disease costs. However, owing to the difficulties involved in measuring such costs (primarily because their content differs greatly from the other two cost categories), it is usually not considered when estimating the costs of diseases [30, 31]. For a more in-depth explanation of the cost-of-illness approach and the techniques used to value resources used and lost please consult [2, 26, 28, 29, 32, 33]. To our best knowledge there is no example of a cost-of-illness study summarising the costs of all diseases globally. The abovementioned study by Bloom et al. [16] attempted to measure the disease burden of chronic NCDs in the world. Due to the incomparability of the methods applied for each of the five main analysed NCDs the results were presented separately. The direct and indirect costs of illness for five distinct disease categories were [16]:

- Cardiovascular diseases: US$ 863 billion in 2010, rising to US$ 1.04 trillion in 2030;
- Cancer: US$ 290 billion in 2010, rising to US$ 458 billion in 2030;
- Diabetes: nearly US$ 500 billion in 2010, rising to at least US$ 745 billion in 2030;
- COPD: US$ 2.1 trillion in 2010 rising to US$ 4.8 trillion in 2030;
- Mental illness: US$ 2.5 trillion in 2010 rising to US$ 6.0 trillion by 2030.

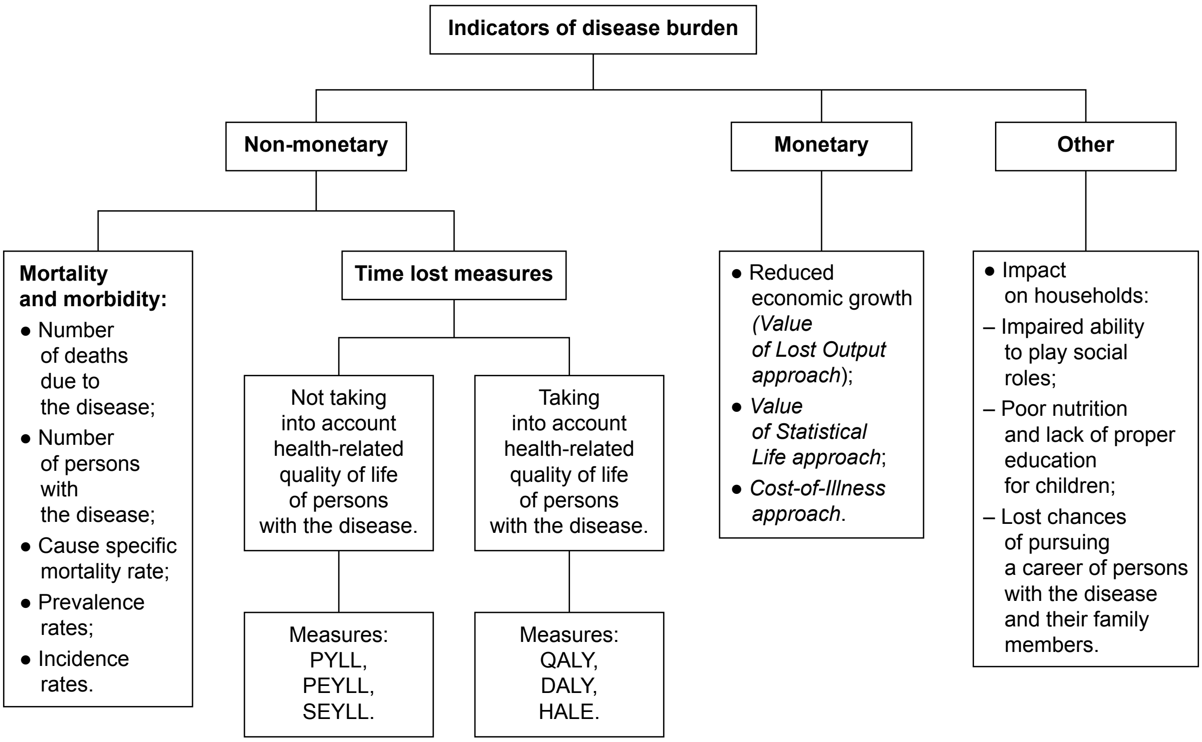
3. Considering individual and intergenerational spillovers of disease

Disease burden analyses may also focus on illnesses consequences other than those summarised in the first two groups described above (monetary and non-monetary units). These are called individual and intergenerational disease spillovers and may include: the impaired ability of ill persons to play social roles successfully, poor nutrition and lack of proper education for children, lost career opportunities both for persons with the disease and for their family members (**Figure 1**).

A disease causes direct loss of well-being to an individual. In their report, focusing on health investments in developing countries, the WHO Commission on Macroeconomics and Health [34] emphasised that there is a reduction in the "utility" of the individual as a result of poor health (even if there is no change in the level of goods and services consumed or in the life span of the individual) due to the likely significance of the long-term consequences of early disease episodes. Early disease may obstruct physical and cognitive development, which, in turn, may reduce an adult's economic productivity. Reduced cognitive capacity may lead to leaving school early, a lack of educational achievement, and reduced earnings in adulthood.

The intergenerational spillover of disease also occurs [34]. When one individual in a family is affected by disease, it may have important adverse effects on other family members, especially children. An adult's illness may result in the poor health, or even death, of a previously healthy child because of a drop off in care giving and family income. A parent's illness or death may, for example, force a child to leave school prematurely in order to help support the family. The adult's illness will also reduce the transfer of knowledge from parent to child.

Figure 1. *Indicators and approaches to measuring disease burden*



Source: Author's own elaboration based on Kissimova-Skarbek K., Koszty obciążenia chorobami, in: Golinowska S. (ed.), Od ekonomii do ekonomiki zdrowia. Podręcznik ekonomiki zdrowia, PWN, Warszawa 2015: 354–391 [2].

Identification and recognition of individual and intergenerational spillover of disease should be, but rarely are, considered in *cost-of-illness* studies (particularly in estimating indirect costs of the disease). It is believed that *CoI* literature often understates, for example, the costs of nonfatal chronic conditions at all stages of the life cycle [34] by not considering the above mentioned spillovers. These may be substantial and should be taken in-to consideration when assessing indirect costs within the CoI studies.

4. The occurrence of diseases

Civilizational progress and medical advances have affected the balance (in terms of frequency) between the three main groups of diseases: (i) communicable, maternal, neonatal and nutritional, (ii) non-communicable diseases (NCDs) and (iii) injuries. At the present time, chronic non-communicable diseases, resulting both in death and permanent disability, impose the biggest burden on society.

Characteristics of chronic diseases

According to WHO experts [35], the main chronic diseases are: heart disease and cerebral strokes (cardiovascular diseases), neoplasms, asthma, obstructive pulmonary disease (chronic diseases of the respiratory system) as well as diabetes mellitus[5]. Neuropsychiatric diseases are also nowadays regarded as one of the most common non-communicable diseases.

Cardiovascular disease includes diseases affecting the heart and blood vessels as well as the conditions resulting from poor blood flow caused by vascular disease. More than 82% of global deaths as a result of cardiovascular disease are due to ischaemic heart disease, cerebral strokes (both haemorrhagic and ischaemic), hypertension and congestive heart failure. Over the course of the last decade cardiovascular disease has become the most important cause of death around the world (it accounts for almost 30% of all deaths as well as over 45% of deaths from chronic non-communicable diseases. In 2010, cardiovascular diseases caused 15.6 million deaths around the world.

Cancer consists in the rapid and excessive growth and division of abnormal cells in the body. These cells outlive normal cells and have the ability to make metastases and spread to other parts of the body as well as other organs. There are more than 100 different types of cancer as well as different risk factors contributing to the growth of cancers in different parts of the body. Cancers are the second biggest cause of death in the world, accounting for 16% of all deaths globally and 22% of global deaths due to NCDs. In 2015, 8.76 million people died of cancer globally. This translates into an increase of 54% compared to 1990.

Diabetes mellitus: Diabetes type 2 accounts for 90–95% of all cases of diabetes mellitus. In 2015, over 435 million people globally had diabetes [13], which represents a 30.6% increase compared to 2005. This number is expected to rise to over 642 million by 2040 if no major preventative measures are taken [36]. A considerable number (around 50%) of cases of diabetes type 2 remain undiagnosed. Delayed diagnosis of diabetes mellitus as well as ineffective treatment of this condition may cause late complications of the disease, in particular vascular complications, which result in premature invalidity and increased mortality in this group of people. They include microvascular complications, such as nephropathy and retinopathy as well as macrovascular complications, e.g., heart attacks, heart failure, strokes and peripheral artery disease, e.g., diabetic foot. International Diabetes Federation estimates that about 5 million deaths in 2015 were due to diabetes [36], and it accounts for 9% of all deaths and 13% of deaths caused by NCDs globally.

Chronic respiratory diseases together account for 3.8 million deaths worldwide, 7% of all deaths globally and 10% of deaths due to chronic non-communicable diseases [37]. They are the fourth main cause of deaths globally. The most common diseases in this group are asthma, chronic obstructive pulmonary disease (COPD), respiratory allergies, occupational lung diseases, and pulmonary hypertension. COPD refers to a group of progressive pulmonary diseases which cause breathing difficulties, including chronic bronchitis and emphysema.

COPD contributes to 3.8 million deaths each year [37] and accounts for 3–8% of all deaths in countries with a high national income and 4–9% of all deaths in countries with low and average national incomes [16]. Morbidity and mortality rates from COPD are expected to increase in the future. A causal relation exists between this disease and four main sources of exposure: tobacco smoking, smoke inside premises, environmental pollution and professional exposure to the effects of certain microparticles (e.g., asbestos). Despite the fact that the development of COPD can be checked be preventing exposure to the main risk factors, it cannot be cured fully according to the present state of medical knowledge.

Mental illness is a term referring to a group of medical conditions which affect the thinking, feeling and moods of an individual, his or her ability to relate to others and his or her ability to function in daily life. They are sometimes also referred to as mental disorders, mental health or neuro-psychiatric diseases. These disorders affect the lives of hundreds of people around the world. In 2015 over 311 million people in the world were suffering from major depressive disorders and almost 64 million were dependent on alcohol [13]. Close to 900,000 people suffering from mental illness commit suicide every year [16].

Methods

The techniques for measuring the disease burden and health of a population illustrated with examples have been described in detail elsewhere [2, 5].

The present study focuses on two approaches to assessing disease burden: (i) a GBD study that includes a DALY measure and (ii) the WHO Commission on Macroeconomics and Health, which values each unit of DALY at one or three times GDP per capita in the country in the year being evaluated. As mentioned earlier, the DALY is calculated by adding Years of Life Lost (YLL) due to deaths to Years Lived with Disability (YLD).

In accordance with the methodology adopted in the latest Global Burden of Disease (GBD) study [12], the global and Polish DALYs presented here are not age weighted, not discounted, and contain a higher (compared to GBD-2010 study version) equal standard life expectancy at age of death. The normative life table of 91.9 years at birth [12] has been used to calculate YLLs in order to avoid disparities both between countries and between males and females. Estimating YLDs involves three main steps [38]: (i) establishing the prevalence and incidence of causes and sequelae (health states caused by a disease, for example, the blindness that can be caused by diabetes) related to disability, (ii) classifying these disabilities according to their degree of severity, and (iii) combining these two results into one comprehensive measure of nonfatal health loss. Several data sources and techniques have been used in the present GBD 2015 study, such as collecting data from government reports, data from population-based disease registries, antenatal clinic data, hospital discharge data, and other sources as well as modelling[6] to generate estimates of the prevalence and incidence of disability-causing sequelae. To classify disability complications of diseases according to their degree of severity, surveys were conducted to establish disability weights, among other things. These weights are coefficients of severity on a scale of 0 to 1 attributed to each disability. These are used to estimate the period of life reduced due to disability [13].

The top ten health problems globally and in Poland in 2010 have been listed elsewhere [2, 39]. Presented in this paper, on the other hand, is the burden of diseases for 2015 compared with 1990 based on the results of the recently published GBD study [12, 13, 37]. This paper identifies the main causes of disease burden in different ways:

- the top ten causes in the world and in Poland based on deaths per 100,000 in 2015 and the percentage change compared to 1990;
- the ten main causes of DALYs, YLD and YLL in Poland in 2015 and the percentage change between 1990 and 2015;
- the number of YLLs due to all causes in Poland over a 25 year period (1990–2015), and the percentage of avoidable YLLs (occurring below the age of 70);
- DALYs by age group and sex due to NCDs in Poland;
- the value of income lost due to all causes of death and unnecessary income lost (and in consequence – a downturn in economic development) due to premature deaths;
- the value of income lost due to DALYs caused by NCDs in Poland.

The study also presents the distribution of DALYs in the working age population both globally and in Poland among three main groups of diseases – communicable diseases, maternal, neonatal and nutritional diseases, non-communicable diseases, and injuries (external causes of mortality and morbidity), which indirectly demonstrates the impact of diseases on the economy. By way of comparison, we adopted the 15–59 age group (the most commonly used in publications) as the working age for both Poland and the world[7]. Our analyses for Poland by gender also concerned different working age periods, according to the working age ranges for males and females advised by the Central Statistical Office of Poland.

To estimate the amount of income lost in Poland, we used the method utilised by the WHO Commission on Macroeconomics and Health so as to give a direct estimate of DALYs due to disease. It recommends valuing DALYs at between one and three times GDP per capita (referred to as CMH1 and CMH3, respectively) [34]. Constructing the CMH1 and CMH3 estimates required multiplying the annual number of DALYs by the relevant multiple (1 or 3) of income per capita in Poland for the year in question. GDP per capita was presented in current International Dollars (I$). Future time lost due to deaths (YLL) and in consequence – income lost due to all causes in Poland in 2015 was discounted at a 3% discount rate.

To determine the real change in income lost over time and to ensure international comparisons, levels of income lost in previous years have been converted to 2015 prices using GDP deflators for Poland in respective years [40]. Next, values in 2015 national currency units (NCU) were converted to 2015 I$ by applying purchasing power parity (PPP) conversion factors for GDP (NCU per I$) [41].

Results

1. Ranking of diseases by their burden, measured with death rate

The average ranks of diseases and injuries globally, measured by the deaths per 100,000 rate in 2015 and the percentage change compared to the year 1990 are shown in **Table I**. We can observe the direction of the change in the top ten causes. In 2015 five of the ten main global causes of deaths were chronic non-communicable diseases. Three of the NCD group causes have increased their position in the ranking. Neoplasms moved from the third rank in 1990 to the second rank in 2015. The global burden of diabetes mellitus also increased – shifted from the eighth place in 1990 to the fifth place in 2015. The burden of neurological disorders increased from rank eleven to rank seven (with an almost 47% increase within a 25 year period).

Chronic NCDs were responsible for 90% of all deaths in Poland in 2015. 46% were due to cardiovascular diseases, which still represent the main cause of death in Poland. The top ten causes of death in Poland in 2015 ranked by number of deaths per 100,000 are presented in **Table II**. Even though the death rate due to ischemic heart disease in 2015 has decreased compared to 1990 by 24.9%, it is still a main cause of death in Poland, causing 270.56 deaths per 100,000. Alzheimer disease and other dementias had the highest percentage increase in the last 25 years in Poland (73.4%).

Table I. *Top 10 global problems in 2015, ranked by number of deaths per 100,000 population and percent change, 1990–2015, both sexes, all age groups*

1990 ranking	
1	Cardiovascular diseases
2	Diarrhoea/LRI/other
3	Neoplasms
4	Chronic respiratory diseases
5	Neonatal disorders
6	Unintentional injuries
7	HIV/AIDS and tuberculosis
8	Diabetes, urogenital, blood, and endocrine diseases
9	Transport injuries
10	Neglected tropical disease and malaria
11	Neurological disorders

2015 ranking		Change
1	Cardiovascular diseases (243.13)	2.41%
2	Neoplasms (118.91)	11.91%
3	Diarrhoea/LRI/other (67.29)	–55.37%
4	Chronic respiratory diseases (51.49)	–22.4%
5	Diabetes, urogenital, blood, and endocrine diseases (46.25)	44.14%
6	HIV/AIDS and tuberculosis (31.27)	–7.47%
7	Neurological disorders (30.65)	46.84%
8	Neonatal disorders (29.35)	–55.73%
9	Unintentional injuries (24.95)	–35.14%
10	Transport injuries (19.9)	–12.71%
14	Neglected tropical disease and malaria (11.44)	–45.28%

🟥 I. Communicable, maternal, neonatal, and nutritional diseases
🟦 II. Non-communicable diseases
🟩 IIII. Injuries

The ratio of number of deaths per 100,000 by cause in 2015 is provided in parentheses. LRI = lower respiratory infections.

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

As in the global ranking, the top cause of mortality in Poland in 2015 was the cardiovascular disease group. Here (where a more detailed classification of diseases is used) ischemic heart disease together with cerebrovascular disease are the first two out of the top ten causes of mortality. This cause has not moved from the first rank since 1990 in either Poland or in the world. However, compared to the global burden, the ratio in Poland of 270.56 deaths due to ischemic heart disease per 100,000 members of the population in 2015 (vs. 120.97 deaths per 100,000 globally [37]) is over two times higher than average global rate. The global death rate due to cardiovascular diseases in 2015 was 243.13 deaths per 100,000 vs. 460.84 per 100,000 deaths in Poland in the same year [37].

On the other hand, unlike the global ranking where lower respiratory infections (from the communicable diseases group) have decreased their rank from third to fourth place, in Poland lower respiratory infections have increased their rank from 9th place in 1990 up to 7th place in 2015. However, the rate of number of deaths per 100,000 population in Poland in 2015 was lower compared to the global burden of LRI (30.48 vs. 37.13 [37]).

2. Burden of disease measured with DALY

2.1. The global and national burden of disease in the years 1990–2015

In 2015 over 2.46 bln DALYs globally were lost due to all causes, of which 67.9% were years of life lost due to deaths [37]. 84% of the total years of life lost due to deaths (and 57.2% of all DALYs in year 2015) appeared under the age of 70 and are considered avoidable.

The largest share of the global burden (60%) is attributable to NCDs. In 2015 over 1.47 bln DALYs globally were due to NCDs. (**Chart 1(a)**). During the entire period of 1990–2015, the share of YLL was much higher than YLDs. Deaths caused a higher number of YLLs in males compared to females (**Chart 1(b)**). In females a minor decline in YLLs was observed in 2010 compared to 2005. The highest increase in DALYs due to NCDs in the 1990–2015 period was observed in disability (YLDs) caused by disease. Both sex groups have presented an increase in YLDs.

Poland experienced over 11.3 mln DALYs in 2015, 86.7% of which were due to NCDs, followed by injuries (external causes of deaths and morbidity), responsible for 9.3% of DALYs, and communicable diseases,

Table II. *The top ten health problems in Poland, 2015, ranked by number of deaths per 100,000 population, both sexes, all age groups, and percent change, 1990–2015*

1990 ranking

1	Ischemic heart diseases
2	Cerebrovascular disease
3	Tracheal, bronchial, and lung cancer
4	Chronic obstructive pulmonary disease (COPD)
5	Alzheimer's disease and other dementias
6	Colon and rectal cancer
7	Cardiomyopathy and myocarditis
8	Road injuries
9	Lower respiratory infections
10	Stomach cancer
12	Diabetes mellitus
13	Self-harm

2015 ranking		Change
1	Ischemic heart diseases (270.56)	–24.86%
2	Cerebrovascular disease (113.78)	–5.38%
3	Tracheal, bronchial, and lung cancer (61.56)	34.17%
4	Alzheimer's disease and other dementias (46.27)	73.4%
5	Colon and rectal cancer (36.12)	45.14%
6	Cardiomyopathy and myocarditis (31.96)	36.99%
7	Lower respiratory infections (30.48)	39.52%
8	COPD (28.99)	0.96%
9	Self-harm (21.36)	41.77%
10	Diabetes mellitus (17.19)	11.36%
12	Stomach cancer (14.65)	–27.06%
18	Road injuries (12.06)	–48.11%

🟥 I. Communicable, maternal, neonatal, and nutritional diseases

🟦 II. Non-communicable diseases

🟩 III. Injuries

The ratio of number of deaths per 100,000 by cause in year 2015 is provided in parentheses.

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

maternal and nutritional disorders, accounting for 4.0% of all-cause DALYs [37]. The NCDs showed a 4.7% decrease in the number of DALYs compared to 1990. Injuries – with a decline of 30.2% and the group of communicable, maternal, neonatal, and nutritional diseases showed the highest decline of DALYs – 56.25%, compared to the 1990 number of DALYs. **Chart 1(c)** shows the number of YLL and YLD in Poland in the period of 1990–2015 and **Chart 1(d)** – divides these values among both sex groups. Similar to the global trend for both sex groups considered together, in Poland an increase in YLDs due to NCDs has been observed during the last 25 years (**Chart 1(a)** and **(c)**). In YLL due to deaths, Poland showed better achievement in averting YLLs compared to the entire world. This is further confirmed when analysing the number of YLLs by sex (**Chart 1(b)** and **(d)**). When observing DALYs over 25 years, the number of DALYs in Poland has slightly decreased (or stayed stable) as opposed to the global tendency where the number of DALYs has increased (**Chart 1(a), (b), (c), (d)**).

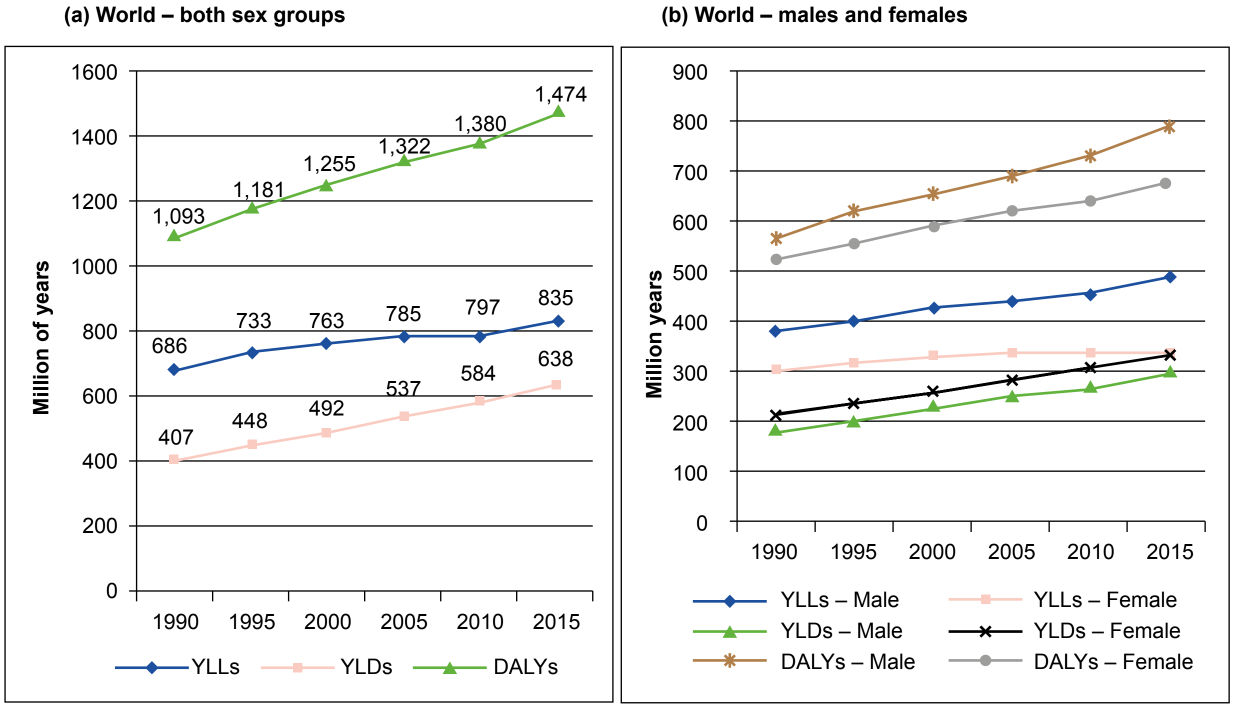
2.2. The global and national burden of NCDs by age group

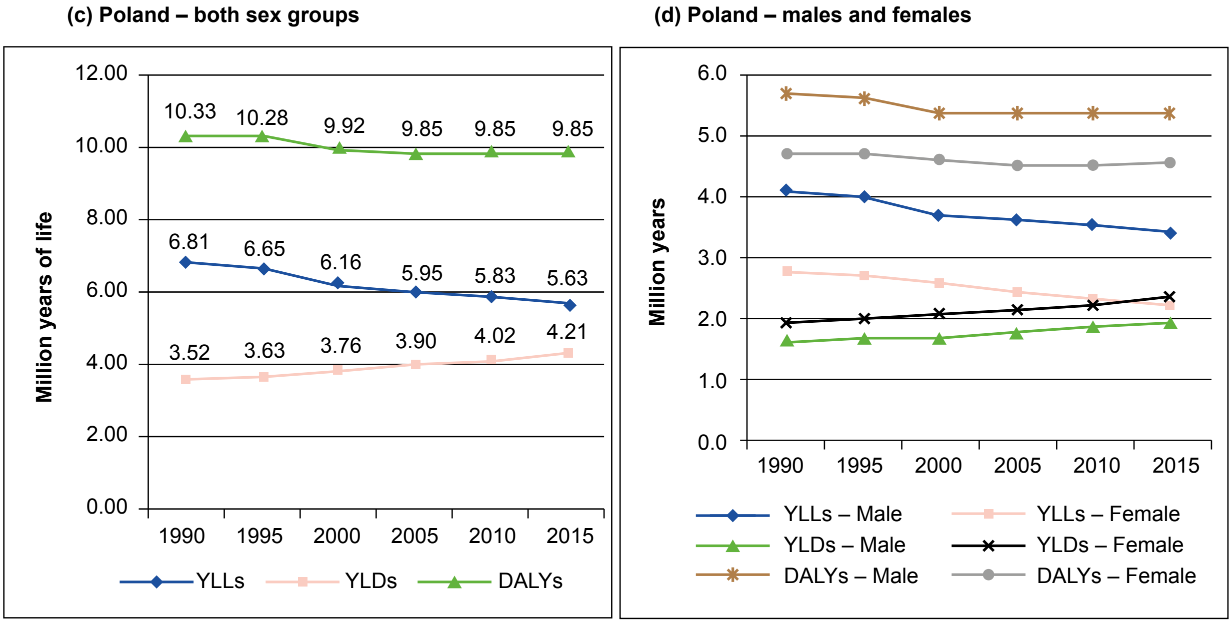
When the YLLs and YLDs due to NCDs in 2015 are presented by age groups the first observation is that in Poland the years of life lost due to both death and disability, appeared mainly over the age of 50 with few in the below 20 age group. In the entire world – the burden of NCDs (especially due to deaths) is substantial in the below age 20 age groups (**Chart 2**).

2.3. Ranking of diseases based on DALY in Poland in 2015

The leading causes of disability in Poland are presented in **Table III**. At the top of the list are lower back and neck pain, sense organ diseases, depressive disorders and diabetes.

Chart 1. *Global and national in Poland burden of non-communicable diseases expressed in YLLs, YLDs and DALYs, years 1990–2015*





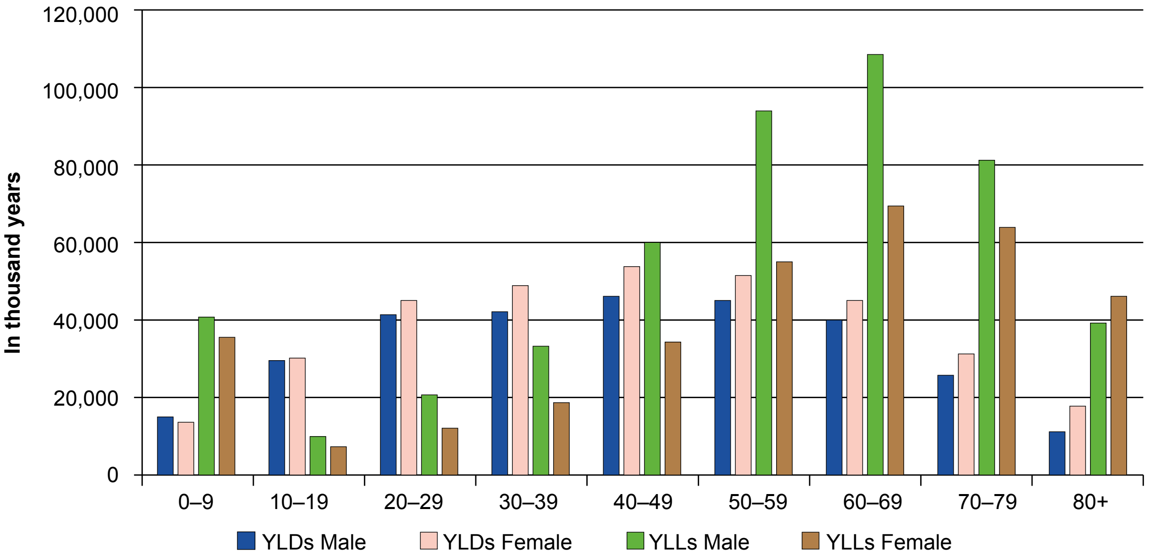
Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

As can be seen in **Table III,** all the top ten causes of disability in Poland in 2015 were due to NCDs. Lower back and neck pain in the first rank (the same as 25 years ago) caused the most disability in Poland (803,456 years lived with disability) representing a 17.2% increase compared to 1990. The second rank was held by sense organ diseases, which showed an over 30% increase since 1990 and led to 513,612 YLD in the Polish population in 2015. Depressive disorders in the third rank caused 330,423 YLDs and demonstrated an increase by 15.5% since 1990. The largest increase of burden in the last 25 year period has been observed in diabetes (77%) which caused 223,139 YLDs and moved from 6th to 4th place. Osteoarthritis showed a 48.5% increase, causing 118,030 YLDs. Falls demonstrated an over 22% decrease and iron deficiency anaemia from the first group (communicable diseases) – almost a 26% decline in the last 25 year period.

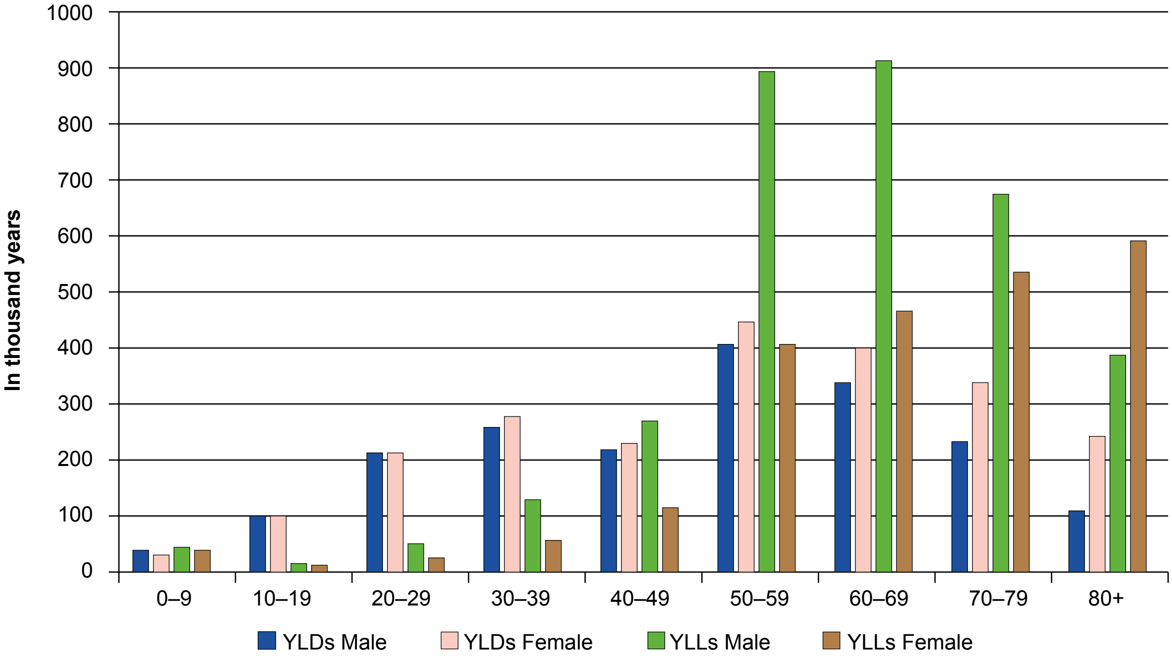
Table IV shows the leading causes of years of life lost due to deaths in Poland in 2015. Seven of the ten causes were non-communicable diseases with ischemic

Chart 2. *Burden of NCDs globally and in Poland, by sex and age groups in 2015*

(a) World NCDs – 2015



(b) Poland NCDs – 2015



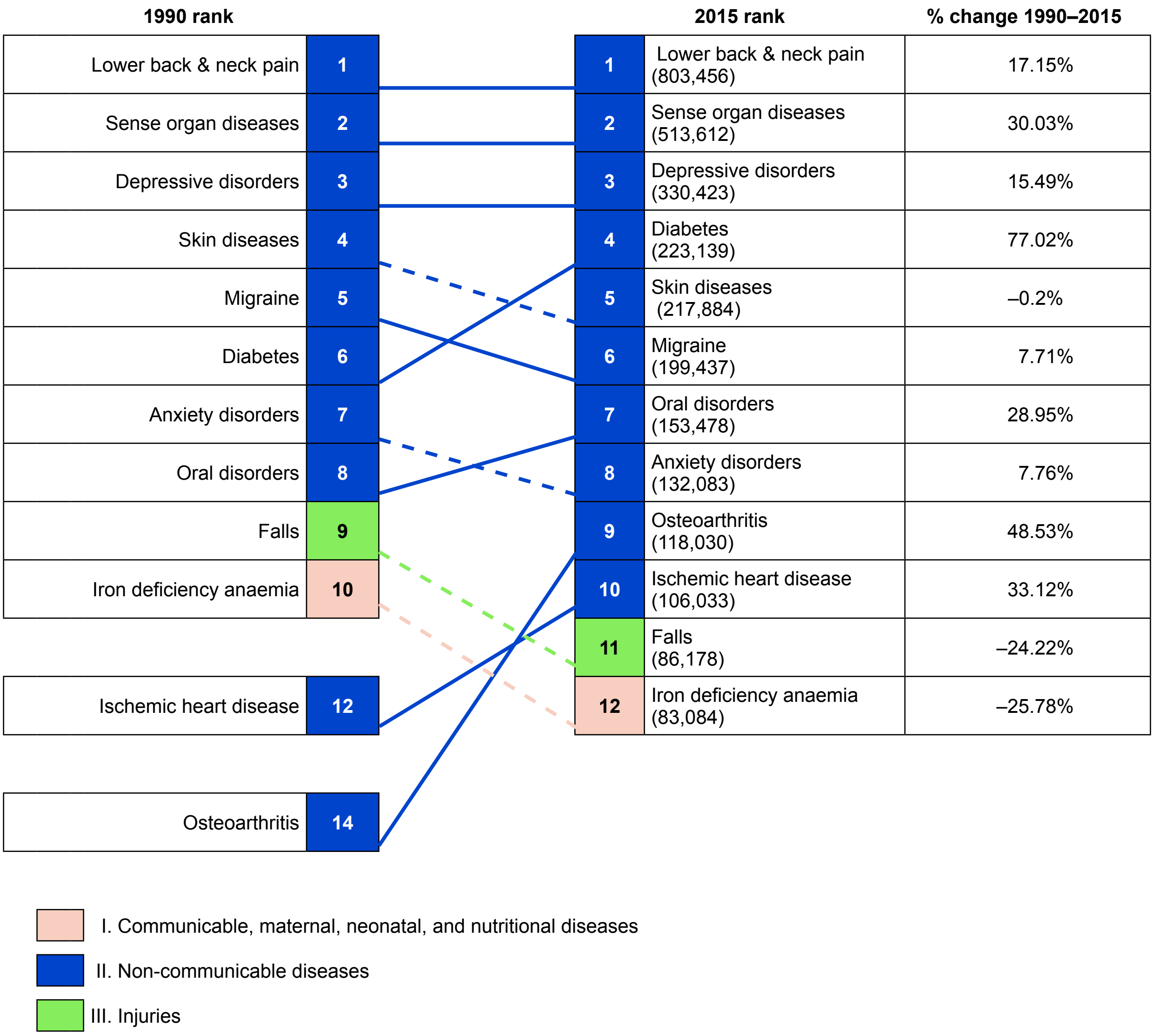
Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

heart disease in the top position. Even with five of these seven NCD causes having shown a decline in YLL numbers, these are still the leading causes of premature death in Poland. Three of the causes showed a substantial increase in time lost during the last 25 years: lung cancer (by 19.2%), self-harm (by almost 29%), colorectal cancer (by 26.4%) and the highest, almost a 50% increase demonstrated by Alzheimer's disease.

Applying the DALY measure, the main diseases causing the most death and disability combined in Poland are presented in **Chart 3**.

Eight out of the ten leading causes of death and disability combined in Poland 2015 were NCDs (**Chart 3**). The top cause of disability adjusted life years in Poland in 2015 was ischemic heart disease, which showed a 38% decrease compared to 1990. However, it still remains the number one cause of years of life lost due to death and disability in Poland (accounting for over 1.45 bln DALYs in 2015). The second leading cause of burden to the Polish population was lower back and neck pain, accounting for 803,456 DALYs and presenting a 17% increase in the 25 year period. The biggest improvement Poland

Table III. *Leading causes of disability (YLDs) in Poland in 2015 and percent change, 1990–2015*



1990 rank	
Lower back & neck pain	1
Sense organ diseases	2
Depressive disorders	3
Skin diseases	4
Migraine	5
Diabetes	6
Anxiety disorders	7
Oral disorders	8
Falls	9
Iron deficiency anaemia	10
Ischemic heart disease	12
Osteoarthritis	14

2015 rank		% change 1990–2015
1	Lower back & neck pain (803,456)	17.15%
2	Sense organ diseases (513,612)	30.03%
3	Depressive disorders (330,423)	15.49%
4	Diabetes (223,139)	77.02%
5	Skin diseases (217,884)	–0.2%
6	Migraine (199,437)	7.71%
7	Oral disorders (153,478)	28.95%
8	Anxiety disorders (132,083)	7.76%
9	Osteoarthritis (118,030)	48.53%
10	Ischemic heart disease (106,033)	33.12%
11	Falls (86,178)	–24.22%
12	Iron deficiency anaemia (83,084)	–25.78%

🟧 I. Communicable, maternal, neonatal, and nutritional diseases
🟦 II. Non-communicable diseases
🟩 III. Injuries

The number of YLDs by cause in 2015 is provided in parentheses.

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 22.10.2016 [37].

achieved was in preventing consequences of road injuries (–46% compared to1990). Unfortunately, road injuries still remain among the ten leading causes of death and disability (ranking 9th). The DALYs due to colorectal cancer in Poland in 2015 were 252,875 and presented an almost 30% increase in the last 25 years.

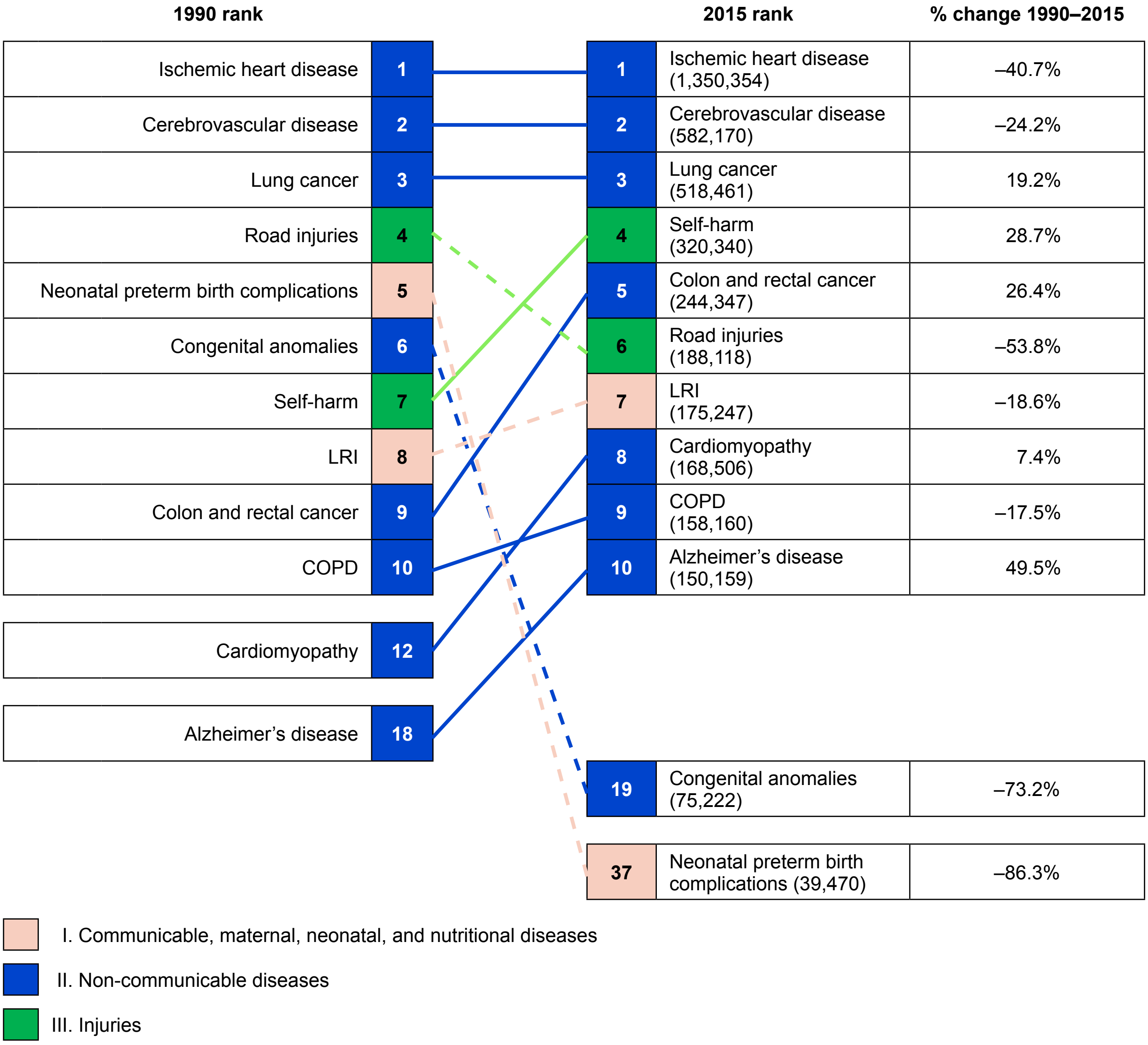
2.4. Burden of diseases on the working age population

In 2015 45.7% of all disability adjusted life years globally were from the working-age (in 15–59 years of life) population (an aggregate distribution of working-age DALYs can be seen at **Chart 4(a)**). In Poland – almost 47% of DALYs due to all causes were in the working age population. Over 66.7% of global DALYs in the working age population were due to NCDs, 18.2% due to communicable diseases and 15.1% due to injuries (**Chart 4(a)**).

Although the share of non-communicable diseases in the overall burden of disease varied in countries with different income levels, it was prevailing everywhere. In *High-Income Countries* as in Poland about 82% of DALYs in the working age population are due to chronic non-communicable diseases.

Chart 4(b) presents the share of working age DALYs attributable to the three main groups of diseases in Poland. To assure the comparability of results, the identical age group of 15–59 years was considered as the working age group for analyses performed for both Poland and the world. This is the age interval most commonly used in publications.

Table IV. *Leading causes of premature deaths (YLL) in Poland, 2015 and percent change, 1990–2015*



1990 rank	
Ischemic heart disease	1
Cerebrovascular disease	2
Lung cancer	3
Road injuries	4
Neonatal preterm birth complications	5
Congenital anomalies	6
Self-harm	7
LRI	8
Colon and rectal cancer	9
COPD	10
Cardiomyopathy	12
Alzheimer's disease	18

2015 rank		% change 1990–2015
1	Ischemic heart disease (1,350,354)	–40.7%
2	Cerebrovascular disease (582,170)	–24.2%
3	Lung cancer (518,461)	19.2%
4	Self-harm (320,340)	28.7%
5	Colon and rectal cancer (244,347)	26.4%
6	Road injuries (188,118)	–53.8%
7	LRI (175,247)	–18.6%
8	Cardiomyopathy (168,506)	7.4%
9	COPD (158,160)	–17.5%
10	Alzheimer's disease (150,159)	49.5%
19	Congenital anomalies (75,222)	–73.2%
37	Neonatal preterm birth complications (39,470)	–86.3%

🟥 I. Communicable, maternal, neonatal, and nutritional diseases

🟦 II. Non-communicable diseases

🟩 III. Injuries

LRI = lower respiratory infections; COPD = Chronic Obstructive Respiratory Disease; The number of YLLs by cause in 2015 is presented in parentheses.

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 22.10.2016 [37].

Chart 5 presents the distribution of working-age DALYs results for Poland for men and women adopting the working age range for women of 18–59 and for men of 18–64. In the group of women 26.4% of all cause DALYs were in the working age (18–59) group, in males it was 64.6% (in the 18–64 age group), which leads to substantial productivity losses for the economy. In women the share of working-age DALYs due to NCDs is much higher than in men. This is mainly due to the larger share of injuries for men (specifically road traffic accidents), which in males was 17.37% compared to 6.5% in the female group.

The impact of NCDs on the working age population in Poland in 2015 is substantial. 89.6% of working age DALYs in females were due to NCDs, in males – 80.33%. Females had a higher number of working age DALYs due to communicable, maternal, neonatal and nutritional discceases than males (3.9% vs. 2.3%).

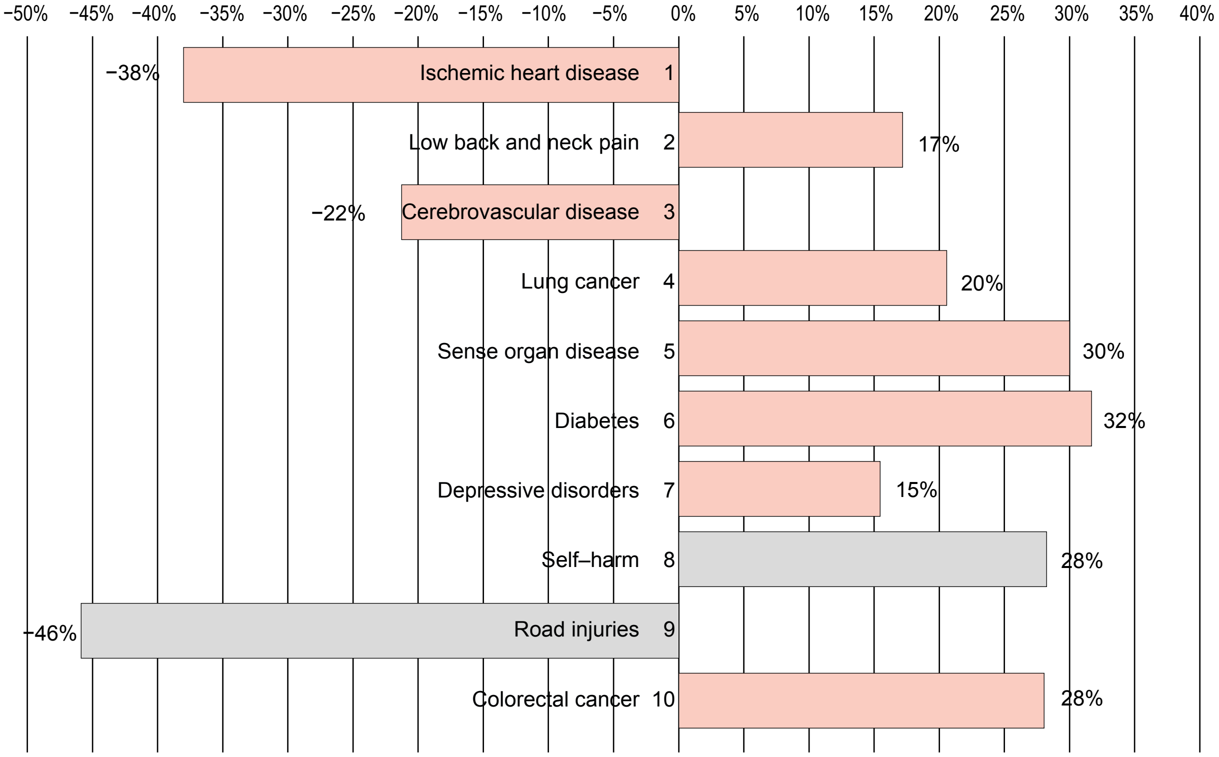
3. Income lost due to ill health in Poland

The income lost due to diseases is calculated based on number of DALYs presented earlier.

3.1. Income lost due to all causes deaths in Poland

The results of applying the WHO Commission on Macroeconomics and Health (CMH1 and CMH3) approach in measuring the income lost due to diseases are presented in **Chart 6**.

Chart 3. *Leading causes of DALYs in Poland, 2015 and percent change, 1990–2015*



Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 22.10.2016 [37].

The total income lost due to all causes in Poland in 2015 was I$176 bln according to CMH1 and I$527 estimated with the CMH3 approach (Chart 6). After discounting with a 3% discount rate the income lost due to all causes YLL in Poland 2015 accounted for I$108 bln when CMH1 was used and I$324 bln estimated with the CMH3 method. Almost 69% of lost income occurred due to deaths below the age of 70 and is assumed to have been avoidable.

3.2. Income lost due to NCDs in Poland 2015

Estimated income lost due to non-communicable diseases in Poland 2015 due to NCDs is presented in **Table V**.

The total economic burden of NCDs in Poland 2015 estimated with the CMH1 and CMH3 approaches accounted for between I$259 bln and over I$776.7 bln (Table V). 57% of the lost income was due to deaths. Among them, 61% were below the age of 70, which are considered avoidable and the economic loss could have been avoided.

Conclusion

The disease burden globally and in Poland was assessed here with non-monetary units: the death rate and a synthetic indicator considering both duration of time lost due to deaths and reduced quality of life during disease – the DALY measure with YLLs and YLDs in its construct. The DALY also formed the basis for estimating the income lost due to disease in Poland.

Below are the key findings in the study.

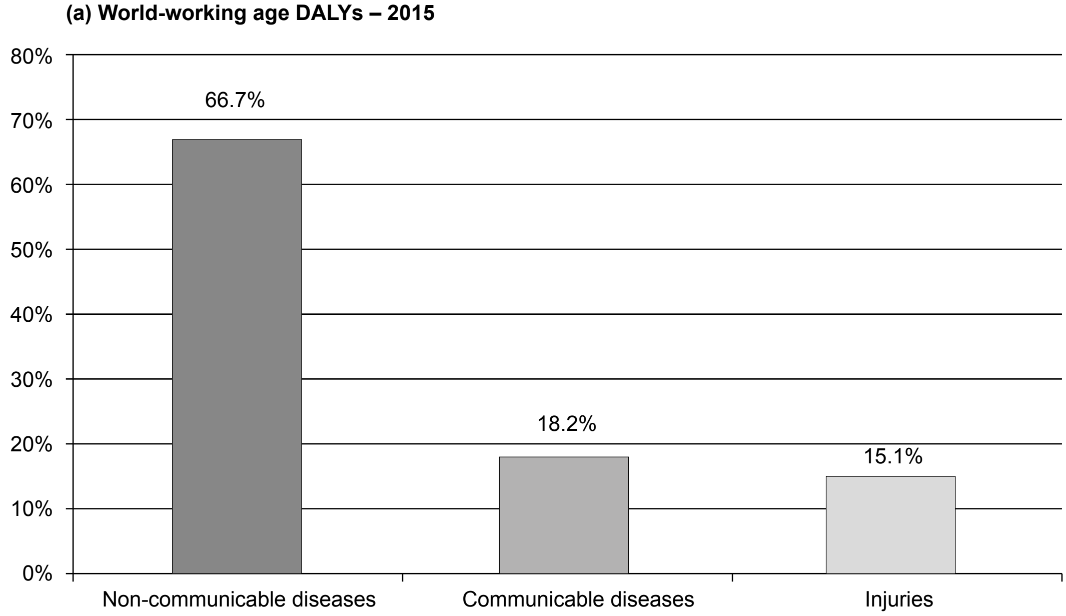
Main causes of deaths both globally and in Poland

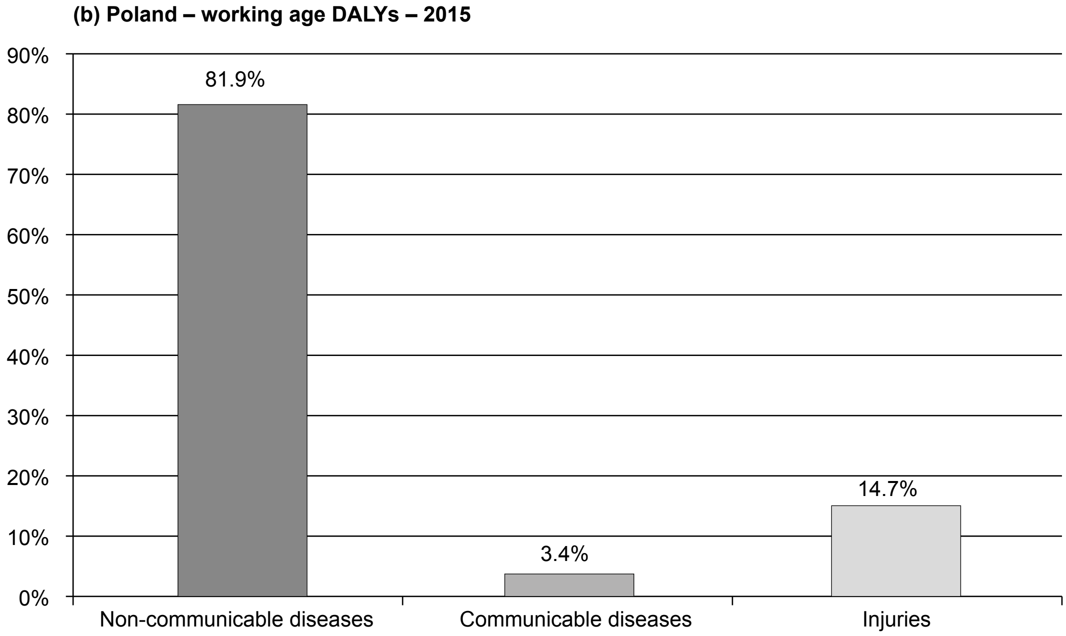
In 2015 the leading causes of deaths globally were non-communicable diseases: cardiovascular diseases, neoplasms, chronic respiratory disorders, diabetes and neurological disorders. Most of them increased or held the same high rank during the last 25 years.

In Poland eight out of the ten top causes were also from the NCD group. Most of them moved upward in the ranking during the last 25 years like: diabetes, Alzheimer's disease and other dementias, cardiomyopathy and colorectal cancer. Others have held their position in the first three ranks: ischemic heart disease, cerebrovascular disease and lung cancer. Even having achieved a decrease in the mortality rate of almost 25% compared to 1990, ischemic heart disease is still at the top of the list. Some of substantial changes in disease burden due to deaths elicited in the study (the percent increase of death rates in diseases like Alzheimer's disease and other dementia, or diabetes mellitus) may be due to an improved diagnosis of the cases or as a result of improved recognition by researchers[8].

In 2015, 54% of all deaths globally and about 43% of deaths due to NCDs were premature and avoidable (oc-

Chart 4. *Distribution of working age DALYs due to three main groups of diseases globally and in Poland, 2015*





Source: Author's own elaboration based on Oxford Health Alliance working group, Economic consequences of chronic diseases and the economic rationale for public and private intervention, Draft for circulation to participants of OHA 2005 conference, 21 October 2005 [35] and data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

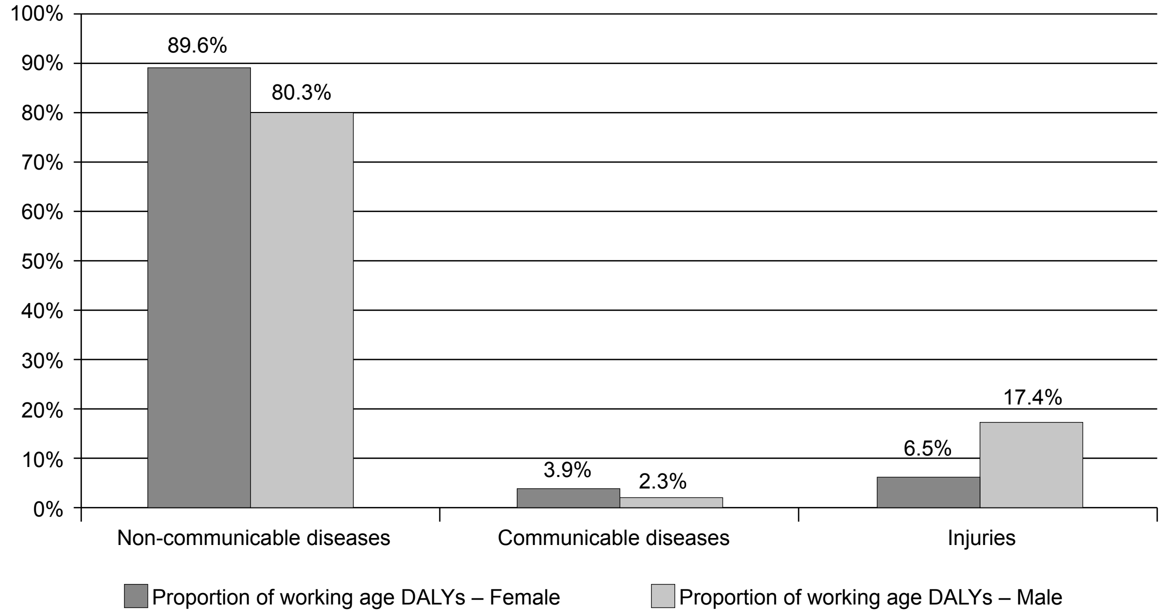
curring before the age of 70). Compared to the previous analyses done by the author [2] there has been a clear shift in the age of death in the direction of the older ages.

The world has achieved an improvement in combating deaths in the last 25 years. The all cause death rate in 2015 was 756.92 deaths per 100,000 which, compared to 1990, has decreased by 16.24%. In Poland the all cause death rate in 2015 was 994.13 deaths per 100,000 which, compared to 1990, has decreased by 3.02%.

The burden of non-communicable diseases is growing due to the aging population and unhealthy life styles. Due to its mass character, this has become a huge burden to societies. At present, over 71% of all deaths (accounting for over 39.8 mln) globally are due to NCDs [37]. In Poland 90% of all deaths in 2015 (accounting for over 348.7 thousands) are due to NCDs. 32% of these deaths occur below the age of 70 and are considered to be avoidable.

The burden of communicable diseases, maternal, neonatal and nutritional diseases declined from 1990 to 2015 – both globally and in Poland, with the bulk of that achievement being driven by reductions in the burden of child and maternal mortality. In Poland the community

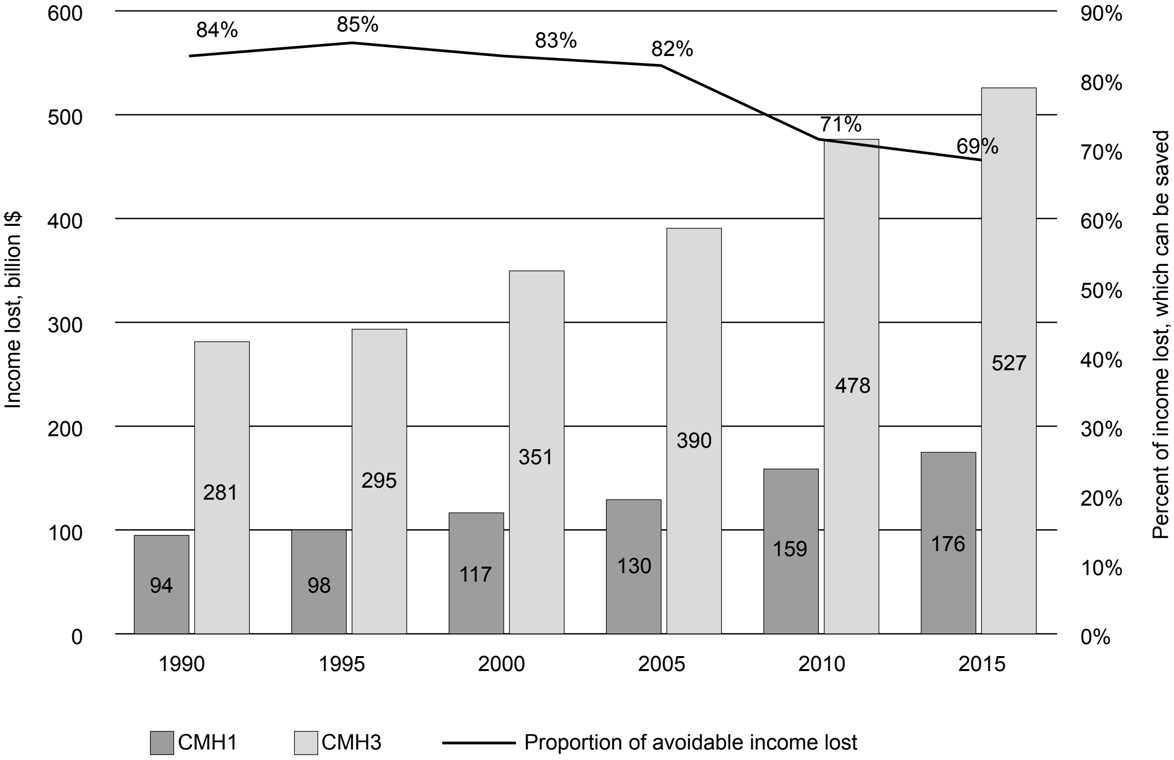
Chart 5. *Distribution of working age* DALYs among the main groups of diseases in Poland in 2015, by sex*



* Working age according to GUS Poland

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37].

Chart 6. *Income lost due to years of life lost caused by deaths in Poland, all causes, both sex groups (in bln I$, 2015 prices) – CMH1 and CMH3 methods*



Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37], World Bank, World Development Indicators, GDP per capita PPP (current international $) [43], World Bank, World Development Indicators, GDP deflators [40] and World Bank, World Development Indicators, PPP conversion factor, GDP (Local Currency Unit per international $), International Comparison Program database [41].

Table V. *Income lost due to NCDs in Poland in 2015 estimated with the CMH1 and CMH3 (bln current I$)*

Measure	Income lost due to NCDs Males 2015 (CMH1)[1]	Income lost due to NCDs Females 2015 (CMH1)	Income lost due to NCDs Both sex groups 2015 (CMH1)	(%)	Income lost due to NCDs Males 2015 CMH3[2]	Income lost due to NCDs Females 2015 CMH3	Income lost due to NCDs Both sex groups 2015 CMH3
YLD	50.2	59.9	110.1	43%	150.6	179.7	330.3
YLL	89.5	59.3	148.8	57%	268.5	177.9	446.4
DALY	139.7	119.2	258.9	100%	419.1	357.6	776.7

[1] CMH1 when 1 × GDP per capita is applied.
[2] CMH3 when 3 × GDP per capita is used.

Source: Author's own elaboration based on data from Global Burden of Disease Study 2015. (GBD 2015) Results. Seattle United States: Institute for Health Metrics and Evaluation (IHME); accessed: 08.10.2016 [37], World Bank, World Development Indicators, GDP per capita PPP (current international $) [43], World Bank, World Development Indicators, GDP deflators [40] and World Bank, World Development Indicators, PPP conversion factor, GDP (Local Currency Unit per international $), International Comparison Program database [41].

focus on child survival appears to be reaping rewards as the neonatal preterm birth complications cause in 2015 dropped to the 37th from the 5th rank in 1990 in the top leading causes of premature deaths (accounting for an over 86% decline in YLLs).

Main causes of premature deaths – years of life lost in Poland

Over 6.7 mln years of life were lost in Poland in 2015 due to all causes. 57.4% of these were due to the top ten causes (seven of which were NCDs). Compared to 1990, Poland has achieved a decrease in the number of YLL by 24%. Ischemic heart disease caused 1.35 mln YLLs and held, as in 1990, the first rank of the diseases causing the most premature deaths.

Main causes of disability and combined death and disability in Poland

All of the top ten causes of disability in Poland 2015 were non-communicable diseases. These are: lower back and neck pain, sense organ diseases, depressive disorders, diabetes, skin diseases, migraines, oral disorders, anxiety disorders, osteoarthritis and ischemic heart disease. All above listed causes, except skin diseases, demonstrated a substantial increase of YLDs compared to 1990. The highest increase was observed in diabetes mellitus (over 77%), followed by osteoarthritis (almost 49%), ischemic heart disease (over 33%), sense organ disorders (30%) and oral disorders (29%).

The leading causes of DALYs in Poland in 2015 were ischemic heart disease, lower back and neck pain, cerebrovascular disease, lung cancer, sense organ disease, diabetes, depressive disorders, self-harm, road injuries and colorectal cancer. Eight of these are from the NCD group. Seven of these causes showed an increase in the last 25 years. In three of them a decrease of DALYs was observed: in ischemic heart disease (–38%), in cerebrovascular disease (–22%) and in road injuries (–46%).

National income lost due to disease in Poland

The total income lost in Poland in 2015 due to years of life lost as a consequence of all cause deaths was between I$176 bln, estimated with the VSL-CMH1 method, and I$527 bln, estimated with VSL-CMH3 method. 69% of this dramatic effect could have been saved.

Chronic non-communicable diseases have been established as a clear threat not only to human health but also to global development. NCDs reduce the national income, the supply of labour and productivity, cause early retirement, high turnover in the work place and large production losses due to a reduction in productivity[9]. Chronic non-communicable diseases affect the economy by virtue of the fact that a significant portion of the lost life years fall on the working-age.

National income lost due to NCDs in Poland

The distribution of working age DALYs establishes the prevailing burden of NCDs in Poland as well as in the world. 82% of working age (15–59 years of life) DALYs in Poland in 2015, and 67% globally, were due to NCDs. NCDs in Polish women cause a larger share of working age (18–59 years) DALYs than in men (aged 18–64): almost 90% vs. 80%.

The total income lost due to NCDs in Poland (due to death and disability, both sex groups) was between I$259 bln and I$777 bln. The national income that could have been saved if the premature deaths had been avoided accounts for between I$91 bln to I$273bln.

The approximations of income lost in Poland presented here are probably underestimations because GDP growth has not been considered.

A course of action

The world is in the middle of an epidemiological transition [38]. As countries increase their levels of development, their communicable disease burden is declining and non-communicable disease burden is raising. The disease burden change is mainly through an increase in burden due to disability.

Poland has achieved an impressive decline in the number of DALYs due to causes like ischemic heart disease, cerebrovascular diseases, road injuries and neonatal preterm birth complications. However there is still a lot of work to do in combating NCDs.

Overall, the extent of the burden of non-communicable diseases is rising. The burden of some non-communicable diseases has declined, but generally not quickly enough to overtake the rate of population growth. As populations grow and increase in average age, however, the total burden of disability is rising quickly [38]. While development drives many positive changes in health outcomes, certain diseases (such as ischemic heart disease and diabetes) tend to worsen with development and need preventive actions.

The DALY measure, the principal metric of the GBD study, helps decision-makers compare the impact of different diseases and injuries not just in terms of early death but also in terms of disability and suffering. Now researchers are focusing on transferring the analyses of burden of diseases to local, regional and county levels. The aim is to increase the impact of burden of disease analyses on improving decentralized health policy making.

Notes

[1] 1) GDB results released in 1993–1995: six classes of disability were used to estimate the average disability weights for both treated and un-treated forms of a disease [3, 10]; 2) results published in 1996–2009, in which disability weights based on 7 classes of disability were used. Both of the stages described above took into consideration social preferences – age weighting (differentiated values depending on the age of a person – reflecting changes in the way the value of an individual's life during the life cycle is assessed); 3) Work in years 2010–2013, during which the new GBD-2010 methodology was introduced and results released in 2012 [11]. This was the first significant revision in the approach to calculating DALY in that it: (i) eliminates age weights in the YLD and YLL calculation models; (ii) uses a morbidity approach to calculate YLD; (iii) introduces a new standard life expectancy at each age that is equal for women and men in order to avoid gender inequalities when assessing disease burden and health programmes (in previous studies males had a lower life expectancy at birth than females); 4) The recently published GBD-2015 assessment of disease burden [12, 13], as the authors have declared, provides new and more robust evidence on the health of populations worldwide through the inclusion of an expanded group of countries and data sources. The new data set – the entire time series from 1990 to 2015 – has been updated on the basis of newly identified data sources released or collected since GBD 2013 [12, 13]. As a consequence, the 2015 results may differ from the previous findings for particular years.

[2] Examples of assessing the disease burden in Poland (using the old methodology – the first three stages of the GBD study described above) have been given elsewhere [2, 14, 15].

[3] The results were presented in September 2011 at a United Nations High Level Summit devoted to problems associated with chronic non-communicable diseases.

[4] The EPIC model is the standard model of economic growth. It reflects gross domestic product depending on capital and labour inputs, a relationship that is also mediated by technology and productivity. The basic assumption is that if it were not for chronic non-communicable diseases there would be more resources of labour and physical capital available, and thus GDP would be higher. Chronic non-communicable diseases are introduced into the model with the assumption that they have a destructive impact on both physical capital and labour capital. Physical capital is reduced as a result of diminished savings (and, in turn, lower investment) due to the increased consumption of medical services for individuals with chronic diseases. Labour resources are depleted as a result of mortality caused by chronic diseases. This model does not take into account domestic growth in human capital or technological progress due to expenditure on research and development. It likewise does not reflect any changes in the savings rate in society as a result of mortality caused by chronic diseases (a fixed savings rate is assumed). The model only considers mortality caused by chronic diseases, while overlooking any losses in capital and labour caused by morbidity [16].

[5] Non-communicable diseases are identified by WHO as "Group II Diseases", a category that aggregates (based on ICD-10 code) the following of conditions/causes of death and disability: malignant neoplasms, other neoplasms, diabetes mellitus, endocrine disorders, neuropsychiatric conditions, sense organ diseases, cardiovascular diseases, respiratory diseases (e.g. chronic obstructive pulmonary disease – COPD, asthma, other), digestive diseases, genitourinary diseases, skin diseases, musculoskeletal diseases (e.g., rheumatoid arthritis), congenital anomalies (e.g., cleft palate, down syndrome), and oral conditions (e.g., dental caries). These are separate from "Group I Diseases" (communicable, maternal, perinatal and nutritional conditions) and "Group III Diseases" (unintentional and intentional injuries).

[6] With a tool called DisMod-MR 2.1 (Disease Modeling--Metaregression).

[7] Working age refers to that age range within which people are usually employed in some form of work. Depending on the classification used, working age covers the following groups: women aged between 15 or 18 and 59 and men aged between 15 or 18 and 59 or 64. According to the methodology employed by the Central Statistical Office of Poland, the following groups are of working age: men between 18 and 64 and women between 18 and 59.

[8] This issue was raised during the Meeting: "Development is Not Destiny", the launch of the annual Global Burden of Diseases, Injuries, and Risk Factors Study on Friday, Oct. 7 in Washington D.C; the event was co-sponsored by the World Bank Group, The Lancet, and the Institute for Health Metrics and Evaluation (IHME) at the University of Washington.

[9] Considering these facts, the UN held on 19–20 September 2011 in New York City the First High Level UN Summit on chronic NCDs. World leaders have agreed to meet to focus on global action that will reverse the NCD epidemic.

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Analysis of Costs of Diabetes in Poland in 2012 and 2013

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Abstract

Diabetes mellitus is now recognized as a societal disease_that significantly burden health care systems in highly developed as well as developing countries and constitutes a serious problem of public health world-wide. The aim of this study was to estimate the value of reimbursement of diabetes-related drugs in 2012 and 2013 and to analyze indirect costs generated by diabetes in Poland in 2012. It was revealed that reimbursement of glucose test strips, antidiabetic drugs and insulins covered by the National Health Fund was as high as 1.3 billion PLN in 2012 and 1.5 billion PLN in 2013 and the dominant cost drivers were glucose test strips (49% of costs in 2012 and 52% of costs in 2013) and insulins (40% and 38% of total reimbursement costs due to diabetes, respectively). Total indirect costs of diabetes type 1 and type 2 in 2012 were as high as 59 million PLN and 66.5 million PLN and absenteeism due to sick leave was a main cost driver (61% in diabetes type 1 and 95% in diabetes type 2, respectively). In summary, costs associated with diabetes constitute a serious burden for the National Health Fund as well as for the Social Insurance Institution in Poland.

Key words: **type 1 diabetes, type 2 diabetes, the disease costs, indirect costs, direct costs**

Słowa kluczowe: **cukrzyca typu 1, cukrzyca typu 2, koszty choroby, koszty pośrednie, koszty bezpośrednie**

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Introduction

Diabetes mellitus belongs to a group of metabolic diseases characterized by hyperglycemia caused by disorders in insulin secretion or by its effects. Currently, diabetes mellitus is regarded as a societal disease which puts a significant strain on the health care system in the developed as well as the developing countries and constitutes a serious problem for public health worldwide [1]. According to data for 2014 provided by the International Diabetes Federation – IDF, the number of persons with diabetes worldwide amounted to around 387 million [2]. In Poland, it is estimated that the number of person with diabetes in 2013 was about two million, with the diabetes type 1 morbidity rate for Poland of 0.3% (incidence of 10.2/100 thousand of cases per year), while the prevalence of diabetes type 2 oscillates between 1.6–4.7% (incidence of about 200/100 thousand cases per year) [1]. As a result of its considerable incidence, the morbidity and economic consequences, diabetes mellitus has become the subject of many epidemiologic studies and cost analyses of the disease and it also creates a significant problem for public health in its broad context.

Within the framework of cost analysis connected with different diseases, we can identify the following cost groups: direct costs, indirect costs and intangible costs. Direct costs can be split into medical costs (expenses relating to the purchase of medical equipment, medication, salaries of medical staff, diagnostics and hospital stay) and non-medical costs (e.g. connected with third-party care provided to patients, the cost of transportation of patients, adjusting patients' accommodation to their needs or special diets) [3]. By indirect costs we understand the value of lost production resulting from absenteeism, disability (disability benefits) and premature deaths of people of working age, which generates specific productivity losses [3].

One particularly significant aspect associated with the measurement of indirect costs is the implementation of an appropriate method of assessment of the costs of lost production (valuation of lost time). The main methods assessing the cost of the lost production comprise the following: friction cost method – FCM, human capital approach – HCA and health state valuation; the least frequently used approach in practice [3].

Human capital approach is the most popular and the most frequently used method assessing indirect costs. As a result of the disease prevalence, the capital at the disposal of a unit cannot be used to the full. The consequence of such an approach is that indirect costs occur as long as the human capital potential is limited [4]. Indirect costs are estimated by the HCA method as the product of the length of a disease (i.e. the time when human capital is not utilized) and productivity of an employee per unit of time (productivity of human capital) to the effect that the estimated value corresponds with theoretical, potential loss of productivity. A pure, classical HCA method assumes the lack of system unemployment and full maximum work efficiency when no health problems take place. In friction cost method, on the other hand, costs associated with a disease are analyzed from the point of view of a company (the assessment concerns the real loss of productivity), and in the FCM approach it is requested that the assessment of the long-term effect of an employee's sickness should take into account the circumstances which could diminish the real loss of productivity (an employee could be substituted by e.g. a new staff member) [3, 4].

In case an employee is forced to discontinue work, then indirect cost is equal to the volume of production which is lost because of an employees' sick absence (the so-called absenteeism). The loss of productivity connected with the presenteeism takes place when an employee decides to undertake professional activities despite his/her bad health condition and then their efficiency falls down due to illness [4].

One very important element in the analysis of costs of disease is the choice of an appropriate point of view from which the assessment of the cost of disease is made (i.e. the perspective). The perspective of a patient takes into account solely costs incurred directly by the patient himself omitting the costs incurred by the public payer (e.g. the National Health Fund). In turn, the perspective of a public payer takes into account the costs of reimbursement from public funds omitting the costs incurred by the patient; there is also the perspective of a payer taking into account both the costs of the public payer and a patient. The social perspective reflects the broadest presentation of costs of the disease, which comprises all kinds of costs associated with an illness and its treatment, regardless of their source; hence it requires the consideration of not only economic consequences connected with the process of treatment and complications, but also it requires the consideration of indirect costs connected with the loss of productivity of a sick employee in the analysis [5].

Cost of illness studies make it possible to measure and identify costs of a particular disease entity. The studies also allow to assess the burden imposed on a given society by an illness occurring in a given population [6]. This type of analysis comprises all sorts of costs which are connected, among others, with prevention, diagnostics and the course of treatment but they omit in their calculations health effects obtained from medical technologies data. At present, we can distinguish two main types of cost of disease analyses, which are dependent on the accepted analytical method: incidence-based cost of disease and prevalence-based cost of disease analysis [6–8].

The prevalence-based method assesses costs connected with a given disease entity within a year. This method is characterized by a simpler, analytical approach; therefore it is used much more often .

It is based on adding direct and indirect costs associated with a given disease entity which were incurred in a given year in a group of patients with the analyzed disease. In turn, the prevalence-based method assesses costs associated with a given disease entity within the whole life-span of people who were diagnosed with the analyzed disease entity in a given period of time. In this method, patients are divided into groups on the basis of prevalence which will be under observation from the beginning of an illness till the patient's death in order to make an assessment of the total costs of the disease for each of these patients [6].

Diabetes mellitus treatment costs

1. Diabetes mellitus treatment costs world-wide

Diabetes mellitus is a disease which constitutes a huge epidemiological problem which translates into more and more serious economic consequences for individual societies [9], [10]. According to International Diabetes Federation (IDF) report of 2013, it is estimated that the cost of diabetes treatment amounted to 548 billion UDS and constituted around 11% of the total costs incurred by healthcare world-wide (healthcare provided by healthcare institutions as well as individual care organized by patients themselves) [10]. The available research results also indicate that costs generated by diabetes are not evenly distributed in particular age groups and that the majority of costs (76%) are connected with diabetes treatment in adult population (50–79 years of age) [10]. Additional costs connected with undiagnosed diabetes complications are assessed from the perspective of a payer and amount to 18 billion USD per year (2864 USD per capita in the USA) [11].

The analysis of expenses covering diabetes treatment per person with diabetes, depending on the economic situation of a country, implies that in countries of low and medium income only 20% of financial means is connected with diabetes treatment (on average 356 USD per person with diabetes, 545 USD PPP[1] – Purchasing Power Parity per person with diabetes). In turn, in countries of high income, the cost of diabetes per capita is estimated at 5621 USD [10]. In 2013, the total cost of diabetes treatment in Europe remained at the level of around 147 billion USD [10]. It is assumed that one fourth of the expenses is allocated to monitoring the level of glucose in patients' blood, the next 25% is allocated to the treatment of diabetes complications, and the remaining 50% make up the sum of the remaining direct costs connected with doctors' and nurses' consultations, costs of hospitalization, medical equipment, medication as well

Table I. *The total cost of diabetes treatment in the chosen countries in 2013.*

Country	Prevalence coefficient of diabetes for a country (%)	Number of the population (aged 20–79) [thous.]	Number of person with diabetes [thous.]	Average cost covering diabetes treatment (USD)	Total cost of diabetes treatment (USD)	(USD)
Croatia	6.97	3,220.08	224.49	1,378	309,347,220	96.06
Denmark	8.58	4,041.69	346.73	7,272	2,521,420,560	623.85
Russia	10.03	108,928.97	10,924.11	899	9,820,774,890	90.15
Finland	8.85	3,946.2	349.14	4,547	1,587,539,580	402.29
France	7.50	45,009.94	3,374.7	5,406	18,243,628,200	405.32
Greece	7.01	8,336.17	584.6	2,453	1,434,023,800	172.02
Ireland	6.47	3,209.3	207.49	5,598	1,161,529,020	361.92
Germany	11.95	63,281.33	7,559.78	4,718	35,667,042,040	563.62
Poland	**6.50**	**28,907.31**	**1,879.69**	**1,037**	**1,949,238,530**	**67.43**
Czech Republic	9.23	8,190.15	755.7	1,610	1,216,677,000	148.55
Slovak Republic	10.16	4,159.07	422.64	1,621	685,099,440	164.72
Sweden	6.36	6,892.52	438.63	5,806	2,546,685,780	369.48
United Kingdom	6.57	45,307.03	2,974.95	3,994	11,881,950,300	262.25
Italy	7.95	45,637.2	3,626.04	3,501	12,694,766,040	278.16
Mexico	11.77	74,137.43	8,723.42	834	7,275,332,280	98.13
USA	10.90	223,937.51	24,401.77	9,800	239,137,346,000	1067.87
China	9.62	1,023,050.42	98,407.38	333	32,769,657,540	32.03
Indonesia	5.55	154,061.95	8,554.17	143	1,223 246 310	7.93
Japan	7.56	95,304.38	7,203.78	4,054	29,204,124,120	306.43
Brazil	9.04	131,959.75	11,933.58	1,477	17,625,897,660	133.57
Egypt	15.56	48,276.39	7,510.6	176	1,321,865,600	27.38
India	8.56	760,429.73	65,076.36	84	5,466,414,240	7.18
Total	–	–	–	–	–	151

Source: Own elaboration based on International Diabetes Federation, Diabetes Atlas Update 2013 6th Edition, Brussels, Belgium, 2013, http://www.idf.org/diabetesatlas/download-book; accessed: 2.07.2014 [10].

as indirect costs (the loss of productivity or efficiency at work and absenteeism) [9].

It was possible to make an assessment of costs incurred by diabetes per capita per year thanks to the compilations of data on the number of patients with diabetes in 2013 (on the basis of a prevalence coefficient for a country), the average costs covering diabetes treatment for 2013 and through relating this data to the number of people aged between 20–79 (**Table I**). As data analysis carried out in the developed countries indicates (the USA, Denmark, Sweden and France), on average, a sum between 5406 USD (France) and 9800 USD (the USA) is allocated for the treatment of one person with diabetes, while in China these expenses reach merely 333 USD (Table I). Relating this data to the total number of the population in a given country, it can be observed that the highest social burden is noted in the USA (1 068 USD per capita), France (405 USD per capita) and Finland (402 USD per capita). It should be stressed that in Poland, on average 1037 USD is allocated for the treatment of one person with diabetes, with the estimated cost burden of 67 USD per inhabitant. The average burden per capita for all the analyzed countries amounts to 151 USD (per capita) (Table I).

2. Diabetes costs in Poland

Few studies conducted in recent years assess the real costs of diabetes treatment in Poland.

In the study on the burden on the Polish society caused by diabetes mellitus type 1 and diabetes mellitus type 2, the results are shown in the form of public expenses on health care among patients with diabetes and also in the form of a shortened life span caused by premature death and disability resulting from diabetes [12]. It is one of very few studies on the global scale which conducted an evaluation of the diabetes burden expressed in disability adjusted life years – DALY, based on the prospective epidemiological research. It has been calculated that in 1998 the direct costs of diabetes in Poland borne by the state budget reached 1937 million PLN, which made up 9.3% of all the public expenditure incurred on the health care at that time (and considering the purchasing power of the dollar, it was 1076 million USD PPP). It has also been determined that the total number of lost DALYs in the analyzed period amounted to 112 584 DALY, representing over 3% of all DALYs lost in 1998 due to all the diseases and afflictions in Poland [12]. In 1998, the average costs of treating a patient with diabetes mellitus type 1 were 6.4 times higher than in case of patients with diabetes mellitus type 2–3 times higher than the average cost per capita in Poland [13]. Projections relating to diabetes costs would amount to 2.46 billion PLN in 2003, whereas the estimated cost of care for a patient with diabetes ranges between 4.9 and 6.8 billion PLN in 2002 [13]. In turn, projections for 2005 incline towards the 22% growth in costs of diabetes treatment, mainly because of the expected rise in the number of patients [13].

One of the studies dealing with the issue of diabetes costs in Poland is CODIP (Cost of Diabetes Type 2 in Poland) [14]. The aim of the study was to make an overall assessment of the total costs of diabetes type 2 treatment in Poland in 2002. The assumption and methodology of the study were similar to the assumptions of CODE-2 study, which makes it possible to compare international results obtained within the CODIP study. A retrospective, multi-centre study (20 centres) of the bottom-up type was conducted on a group of 303 patients with diabetes type 2 (average age 61). As Polish epidemiological data was limited, the authors of the study applied randomization without stratification in order to choose a test group. The aim of the CODIP study was to determine the structure of the total costs of diabetes type 2, the overview of current strategies of treatment and the evaluation of the impact of diabetes complications on costs. The estimated value of the resources used by health care and its costs were converted into a period of one year. In direct costs analysis three categories were presented: outpatients' costs, hospital and medication costs, Total direct costs connected with diabetes were assessed for around 2.6 billion PLN, which made up 8% of all the expenses on health care in 2002 in Poland. The greatest share in total diabetes costs are the costs of hospitalization and pharmacotherapy. According to the authors of the study, the purchase of insulin formulations made up about 2/3 of the costs of hypoglycemic agents and the average time of hospitalization resulting from complications amounted to 6.2 days. The average total direct cost per patient with diabetes type 2 in Poland in 2012 amounted to 2430 PLN (1185 EUR). The dominant cost drivers per patient are anti-diabetic drugs (46%) and hospitalization costs (30%) [14].

The evaluation of indirect costs of diabetes (using the human capital method) carried out additionally within the framework of CODIP study indicates that they amount to 6797 PLN (3316 EUR). The main component of indirect costs were costs associated with taking early retirement or disability pension (4382 PLN = 2137 EUR), which made up about 64% of the total indirect costs. Costs associated with the third party care were in the second position in the structure of indirect costs (34%) [14].

The comparison of the results of pharmacotherapeutic costs has shown that the patients taking part in the CODIP study were over twice more often treated with insulin than the patients participating in the CODE-2 study. In comparison with CODE-2, the cost of drugs in the CODIP study made up a substantial part of the total costs, which is probably connected with the relatively high prices of drugs in Poland. On the other hand, significantly lower expenses connected with hospitalization were observed in the CODIP study when compared with CODE-2, which is probably due to the underestimation of costs. This situation may result from a huge debt of Polish hospitals; alternatively, it may be the outcome of too low values of unit costs. (i.e. day of hospitalization) [14].

Insulin pharmacotherapy makes up 30% of the total expenditure on diabetes type 2 treatment in Poland, and the cost of oral anti-diabetic drugs constitute 17% of medical costs and around 4.5% of the total costs. On the other hand, in case of diabetes type 1 treatment, the dominant role is played by the costs of insulin therapy (63%) where hospitalization is responsible for 22% of the cost. Insulin therapy has a significant share in the cost of diabetes type 2 treatment (46%), similarly as hospital treatment (26%). Globally, the cost of insulin therapy and the cost of hospitalization have the greatest share in the direct costs of diabetes treatment (50% and 25%, respectively). In the group of indirect costs, a significant role is played by the costs of lowered productivity due to early retirement or disability retirement (74%). It should be also noted, that the cost of sick leave in the overall indirect costs connected with diabetes makes up 11% [15].

It is worth mentioning the significance of very high costs generated by diabetes complications, which were not taken into account within the framework of the CODIP study. It is estimated that the cost of treatment of diabetes complications in Poland amounts to around 0.5 billion PLN which makes up about 25% of the total costs (2–2.6 billion PLN). Other sources [15] indicate that the cost of treatment of diabetes and its complications amount to around 6 billion PLN per year in Poland. Diabetes complications, type 2 in particular, are the drivers of additional costs of in-patients' and hospital care [15, 16]. It is worth mentioning, that in 2002 the dominant role in overall costs of complications treatment was played by the costs of in-patients' consultations (42%) and costs of hospitalization resulting from microangiopathic complications (38% and 21%, respectively). When it comes to the cost structure of microangiopathic complications, the highest costs are observed in connection with the treatment of kidney complications (54%) and ocular complications (37%), whereas in case of macroangiopathic complications, over 50% of the costs were related with the coronary heart disease [17]. Direct costs connected with diabetes complications amounted to 1.3 billion PLN in 2012, whereas indirect costs amounted to almost 1.7 billion PLN [18].

The findings of the research [18] on the costs of diabetes generated between 2004–2009 indicate that the costs of health benefits (encompassing basic health care and medication) in 2009 went up by 25% in case of diabetes type 1 and by 29% in case of diabetes type 2 in comparison with 2004. Additionally, it was shown that the costs of health benefits (encompassing hospitalization and specialist care) doubled in the researched period. In case of diabetes type 1, a considerable increase in costs was caused by an over 80% rise in the average benefit cost, which was mostly connected with the introduction of the reimbursement of insulin pumps and the pump equipment for children at that time. It can be assumed that the rise in diabetes type 2 costs was connected with the rise in the prevalence of the disease, as the average cost of the benefit for 2009 was only 30% higher in comparison with 2004. Both in case of diabetes type 1 and type 2 the main source of additional costs were hospital services. In 2009 the average cost of health benefits provided to a patient with diabetes type 2 in Poland was 414 PLN, and those with diagnosed diabetes type 1 – 926 PLN [19].

Within the scope of the conducted research, a calculation of direct as well as indirect costs connected with diabetes in Poland was carried out. As no reliable studies of this kind referring to the most recent data are available, it was considered as appropriate to carry out this type of analysis (the exact data were presented in chapters 2.1 and 2.2).

2.1. The evaluation of direct costs in diabetes treatment in Poland from the perspective of the public payer (the National Health Fund)

On the basis of the data published by NFZ (the National Health Fund) concerning the amount of reimbursement and also information concerning the reimbursed formulations placed in announcements by the Health Minister, a detailed analysis of the reimbursement expenses was conducted in 2012 and 2013 [20, 21].

It is estimated that from January to December 2012 the value of the reimbursed drugs applied in the treatment of diabetes (including anti-diabetic drugs, insulin and glucose test strips) amounted to over 1.3 billion PLN, which made up 19% of the total reimbursement sum of around 6.9 billion PLN. In 2013, the amount of reimbursement of drugs for diabetes was even higher and it amounted to 1.5 billion PLN, similarly as its share in the total amount of reimbursement, which was 21% for 2013 [20, 21].

The highest costs are generated by glucose test strips – about 49% (645 million PLN) in 2012 and 52% (793 million PLN) in 2013. A slightly lower share in total direct cost of diabetes belongs to insulin; 40% (518 million PLN) and 38% (583 million PLN), respectively. The lowest share in total direct costs of 11% (144 million PLN) and 10% (155 million PLN) respectively, belongs to anti-diabetic drugs (**Table II, Figure 1**).

While conducting a detailed analysis of the individual cost categories, it should be emphasized that in 2012 and 2013 the National Health Fund allocated over 518 million PLN and 583 million PLN respectively for the reimbursement of insulin, where about 60–62% was the cost of human insulin (323 million PLN and 353 million PLN respectively), while the remaining 38–40% consisted of insulin analogues (195 million PLN and 231 million PLN, respectively). The highest reimbursement costs among human insulins are incurred by the public payer with reference to a mixture of human insulins (65–66% of the reimbursement costs of human insulin), whereas in case of insulin analogues the highest costs are generated by mixtures of insulin analogues (47–52% of the reimbursement cost of insulin analogues) (**Figure 2**). In a group of oral anti-diabetic drugs, substantial costs are generated by biguanides (49–54% of the amount of reimbursement of oral anti-diabetic drugs), and then sulfonylurea derivatives (40–44% of the reimbursement amount) (**Figure 3**) [20, 21].

According to the National Health Fund (pol. NFZ) data, in the compilation of the top 25 substances whose

Table II. *The value of the reimbursed drugs applied in diabetes treatment in 2012 and 2013*

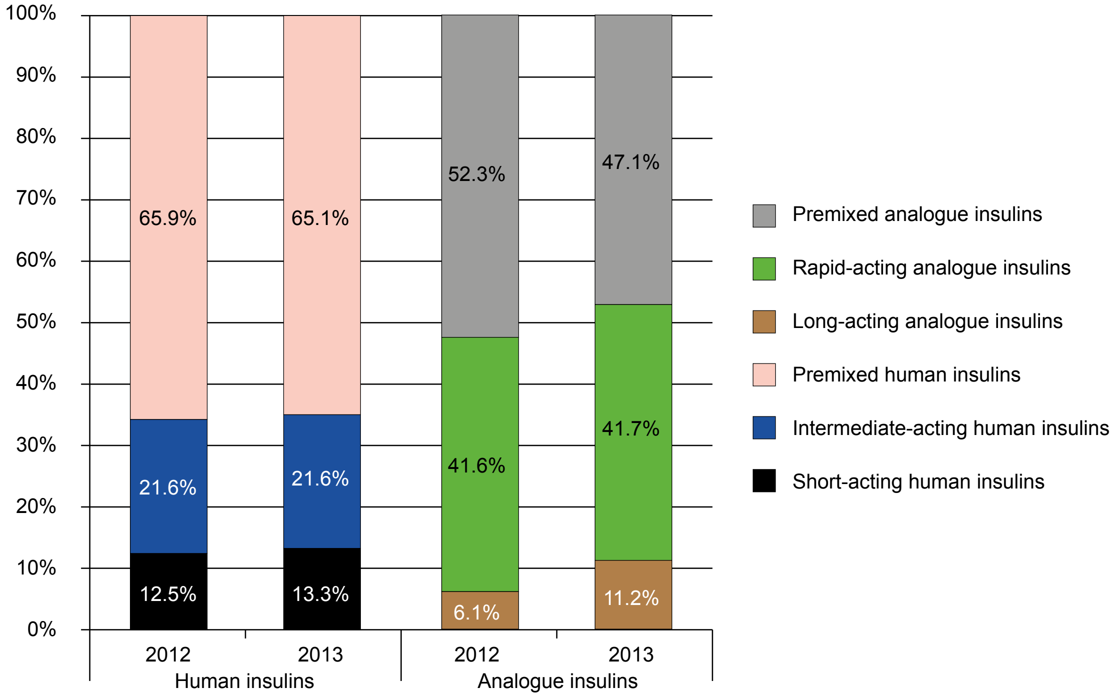
No.	Category	The reimbursement costs (PLN) in 2012	The reimbursement costs (PLN) in 2013
1.	**Anti-diabetic drugs**	**143,749,543**	**155,312,792**
1.2	Sulfonylureas	62,609,577	61,912,963
1.2	Biguanides	69,729,083	83,145,399
1.3	Alpha-glucosidase inhibitors	11,410,883	10,254,430
2.	**Insulins**	**518,472,407**	**583,709,379**
2.1	Human insulins	323,214,782	352,999,147
2.1.1	Short-acting human insulins	40,475,551	46,822,755
2.1.2	Intermediate-acting human insulins	69,843,724	76,410,157
2.1.3	Premixed human insulins	212,895,508	229,766,235
2.2	Analogue insulins	195,257,625	230,710,231
2.2.1	Long-acting analogue insulins	11,895,070	25,753,189
2.2.2	Rapid-acting analogue insulins	81,189,738	96,166,952
2.2.3	Premixed analogue insulins	102,172,817	108,790,091
3.	**Glucose test strips**	**645,254,221**	**792,809,381**
–	**Total**	**1,307,476,171**	**1,531,831,551**

Source: Own elaboration based on Komunikaty Departamentu Gospodarki Lekami (DGL). Wartość refundacji cen leków według kodów EAN narastająco od początku roku do grudnia 2012 roku [20]; Obwieszczenie Ministra Zdrowia w sprawie wykazu refundowanych leków, środków spożywczych specjalnego przeznaczenia żywieniowego oraz wyrobów medycznych z okresu 2012 roku [21].

Figure 1. *The structure of the reimbursement costs dedicated to diabetes treatment in 2012 and 2013*

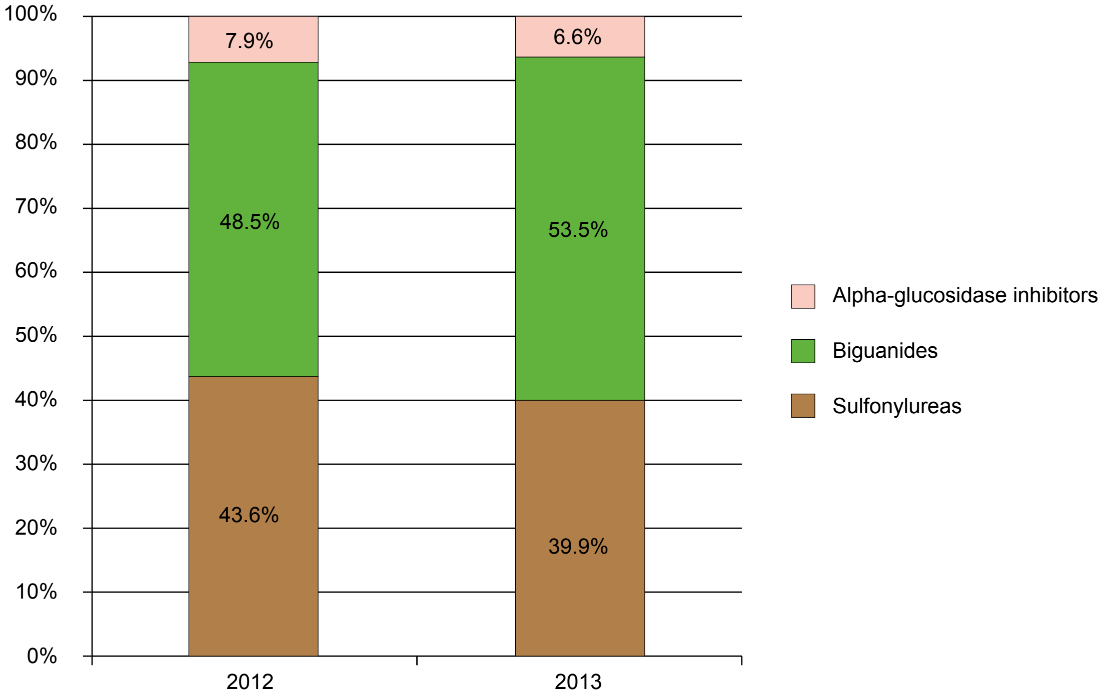
Source: Own elaboration on the basis of the National Health Fund data: Komunikaty Departamentu Gospodarki Lekami (DGL). Wartość refundacji cen leków według kodów EAN narastająco od początku roku do grudnia 2012 roku [20]; Obwieszczenie Ministra Zdrowia w sprawie wykazu refundowanych leków, środków spożywczych specjalnego przeznaczenia żywieniowego oraz wyrobów medycznych z okresu 2012 roku [21].

Figure 2. *The structure of reimbursement costs for human insulin and insulin analogues in 2012 and 2013*



Source: Own elaboration on the basis of the National Health Fund data: Komunikaty Departamentu Gospodarki Lekami (DGL). Wartość refundacji cen leków według kodów EAN narastająco od początku roku do grudnia 2012 roku [20]; Obwieszczenie Ministra Zdrowia w sprawie wykazu refundowanych leków, środków spożywczych specjalnego przeznaczenia żywieniowego oraz wyrobów medycznych z okresu 2012 roku [21].

Figure 3. *The structure of reimbursement costs for anti-diabetic drugs in 2012 and 2013*



Source: Own elaboration on the basis of the National Health Fund data: Komunikaty Departamentu Gospodarki Lekami (DGL). Wartość refundacji cen leków według kodów EAN narastająco od początku roku do grudnia 2012 roku [20]; Obwieszczenie Ministra Zdrowia w sprawie wykazu refundowanych leków, środków spożywczych specjalnego przeznaczenia żywieniowego oraz wyrobów medycznych z okresu 2012 roku [21].

reimbursement is the most costly (about 40% of the overall reimbursement amount), insulin is in the third position (5.26% of the overall reimbursement amount).

When analyzing the direct cost of diabetes treatment, attention should be paid to the issue of undiagnosed diabetes, which is undoubtedly a serious social and health problem. It is estimated that 609.02 thousand of people aged 20–79 in Poland do not realize that they are affected by diabetes [10].The analysis of type MZ-11 reports, which are directly passed to the head office of the National Health Fund from regional branches has shown that the detection rate of diabetes is steadily increasing and so is the number of patients diagnosed with diabetes. Diabetes detection rate growth will be translated into increasing expenditure for its treatment in the following years as well as the decrease in the expenditure for complications treatment (because of its early detection).

2.2. The evaluation of indirect costs of diabetes in Poland

So far research on indirect costs connected with diabetes in the Polish conditions has been conducted on the basis of the National Health Fund and Social Insurance (pol. ZUS) data so far. It should be stressed, that because of the implementation of the system solutions, the number of granted disability pensions is falling down every year. The number of decisions on incapacity for work due to diabetes has also fallen down in case of diabetes [18]. On the basis of the report by Leon Koźminski Academy, (ALK) in Warsaw [19] it has been observed that between 2004–2009 the decrease rate for decisions on incapacity for work among people with diabetes is lower than for the whole population. In the analyzed years, on the other hand, the rise in the number of the granted rehabilitation services and sickness benefits has been observed. The ALK report indicates that indirect costs make up almost 50% of the cost of diabetes.

On the basis of the data provided by the Social Insurance, the Department of Statistics and Actuarial Projections, in numbers of [22]:

- sick absences in 2012 due to illness of people insured in ZUS in the order of disease entity;
- first-time medical decisions by Social Insurance certifying physicians issued in 2012 qualifying for rehabilitation services by gender and disease entity (the value used to define short-term disability);
- first-time medical decisions by ZUS certifying physicians issued in 2012 qualifying for rehabilitation services with the simultaneous need for remedial rehabilitation by gender, the projected period of disability for work and disease entity (the value used to determine short-term disability);
- first-time and renewed medical decisions establishing complete inability to work issued by ZUS certifying physicians to people applying for a social assistance pension, by gender and disease entity (the value used to determine long-term disability, i.e. pensions),

indirect costs of insulin-dependent diabetes (type 1) and insulin-independent diabetes (type 2) were assessed in Poland in 2012.

Table III. *The cost of sickness absence and short and long-term disability to work for patients with diabetes type 1 and 2*

Parameter	Category	Costs in 2012	
		Diabetes type 1	Diabetes type 2
Sickness absence	Number of sick leaves	20,368	39,753
	Number of years	871	1,522
	GDP value[a]	36,065,620	62,992,625
	Cost per 1 sick leave[b]	1,771 PLN	1,585 PLN
Short-term disability to work	Number of permissions for rehabilitation benefits	380[c]	173[c]
	Average length of rehabilitation benefit [months]	5	5
	Number of years[d]	158	72
	GDP value[a]	6,554,683	2,980,656
	Cost per 1 short-term benefit[e]	17,249 PLN	17,249 PLN
Long-term disability to work (disability pension)	Number of decisions of total disability to work	396	15
	GDP value[a]	16,393 608	620,970
	Cost per one decision[f]	41,398 PLN	41,398 PLN

[a] calculated as number of years multiplied by GDB per capita (41 398 PLN); [b] calculated as quotient of GDP value and number of sick leaves; [c] including 5 and 2 permissions for rehabilitation benefit with simultaneous need of therapeutic rehabilitation in case of diabetes type 1 and 2, respectively; [d] calculated as number of permissions for rehabilitation benefits multiplied by an average length of benefit in years; [e] calculated as quotient of GDP value and number of permissions; [f] calculated as quotient of GDP value and number of citizens (GDP per capita).

Source: Own elaboration based on Zakład Ubezpieczeń Społecznych (ZUS) – Portal Statystyczny ZUS, http://www.psz.zus.pl/; accessed: 20.07.2014 [22].

In the calculations of indirect costs, additional information was used – gross value added (GVA) per employee in 2012, remuneration per employee in 2012 and gross domestic product (GDP) per capita in 2012. The information above was obtained from the Central Statistical Office (www.stat.gov.pl). The **Table III** presents a breakdown of figures described above for diabetes type 1 and type 2 in 2012.

In 2012 one sickness absence of an employee with diabetes type 1 or 2 generated the average cost of productivity loss of 1771 PLN or 1585 PLN, respectively.

A short-term cost in the form of one entitlement to a rehabilitation service in 2012 amounted to 17 249 PLN, both in case of diabetes type 1 and 2. The cost is generated by patients who need rehabilitation and is the same, regardless the type of diabetes, because in both cases the average length of rehabilitation is the same (5 months) and thus the cost of productivity loss also remains the same [22]. In 2012 the highest unit costs were generated by decisions about permanent disability to work (disability pensions). The cost of one medical decision (one disability pension) in case of patients with diabetes type 1 and 2 amounted to 41 398 PLN [22].

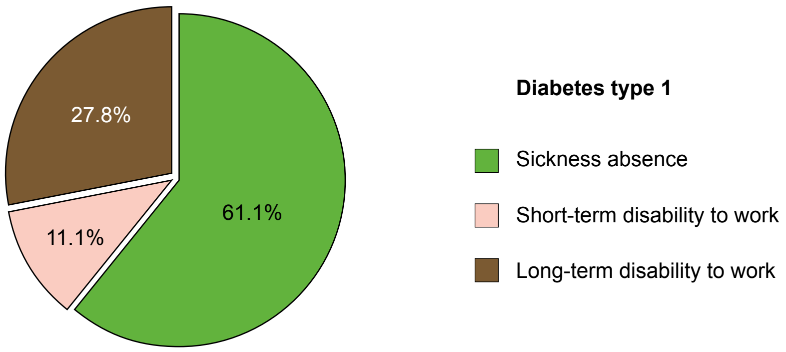
The total indirect costs of diabetes type 1 and 2 in Poland in 2012 amounted to 59 013912 PLN and 66 597 701 PLN, respectively. The greatest share in indirect costs in case of diabetes type 1 in Poland in 2012 belongs to sickness absence. A considerable share in indirect costs was also observed in case of medical decisions about long-term disability to work (disability pension). The entitlements to rehabilitation services issued to patients with diabetes type 1 in Poland in 2012 were responsible for over 11% of the total indirect costs (**Figure 4**). The case of diabetes type 2 presents itself in a slightly different way. In 2012, very few decisions about long-term disability to work were issued to patients with diabetes type 2; thus the cost of these decisions amounted to just a little below 1% of the total indirect costs. A slightly higher number of people with diabetes type 2 received short-term services in the form of entitlement to rehabilitation services; however, their costs did not exceed a 5% share in total indirect costs. 95% of indirect costs of diabetes type 2 in Poland in 2012 were made up of the cost of sickness absence (**Figure 5**) [22].

Summary

The conducted study overview concerned the evaluation of the total direct and indirect costs of diabetes treatment – in Poland and world-wide. Research findings indicate that the prevalence of this disease is associated with high costs burdening the societies in individual countries. It is estimated that the treatment of diabetes in 2013 absorbed 548 billion USD, which makes up about 11% of the total expenditure on health care all around the world [10].

Studies concentrating on costs of a disease, indirect cost in particular, currently constitute a serious challenge for decision-makers, e.g. in the health service or for specialists in public health. Studies concentrating on direct costs are simpler to conduct as gathering data is easy and popular; therefore a number of publications of this type about diabetes are available. On the other hand, indirect cost analysis is more difficult to carry out, mainly because of the lack of clear-cut, comprehensive data sources and because of difficulties with their measurement.

Figure 4. *Individual categories of indirect costs of diabetes type 1 in Poland in 2012*



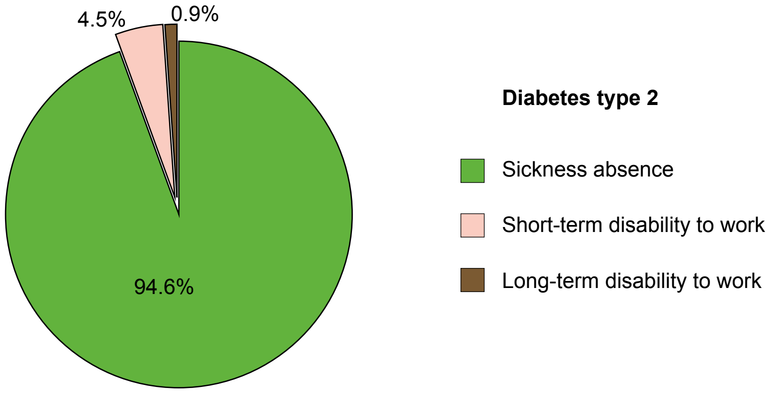
Source: Own elaboration based on Zakład Ubezpieczeń Społecznych (ZUS) – Portal Statystyczny ZUS, http://www.psz.zus.pl/; accessed: 20.07.2014 [22].

Therefore, there are no reliable publications dealing with indirect costs; indirect costs of diabetes in Poland in particular. The chosen HCA method estimates maximum costs but it does not take into account the unemployment rate or marginal efficiency.

As presented in the SMG/KRC report, "Diabetes treatment and costs in Poland" [23], the expenses allocated to diabetes treatment in Poland are definitely lower (almost 3 times) than in countries of the so-called "old European Union". Analyzing carefully the expenses connected with diabetes in Poland, we can see that the highest share belongs to costs of hospitalization, in-patients' treatment and pharmacotherapy [14]. The structure of funds allocated for diabetes treatment in Poland is similar to the structure of expenses typical to the developing countries and it differs from the one which can be observed in modern European countries. Additionally, taking into account indirect costs connected with diabetes in the developed countries, the direct investment in controlling diabetes does not exceed 25% of the total costs connected with diabetes. On the basis of the identified studies' findings it can be assumed that economic growth in Poland will contribute to the changes in the health care system, bringing the rise in financial investment dedicated to hospital and in-patients' are (i.e. the rise in doctors', nurses' and medical staff salaries to reduce immigration). It should be also stressed that in the subsequent years and decades, the number of patients with diabetes in Poland will grow (it is estimated that in 2035 the number of patients with diabetes world-wide will rise from 382 million to almost 592 million [10], which in consequence will additionally burden the budget with costs of medical care, in particular within the scope of complications treatment, and will bring the rise of indirect costs generated by complications, the so-called costs connected with sickness absence at work, reduced productivity, lowered standard of life, reduced productivity of patients' carers or disability pensions which at present absorb a significant part of the Polish GDP [23].

The analysis of the reimbursement expenses of the National Health Fund has proved that the reimbursement of drugs in diabetes therapy amounted to 1.3 billion PLN in 2012 and 1.5 billion PLN in 2013. These figures made up 19% and 21%, respectively of the total

Figure 5. *Individual categories of indirect costs of diabetes type 2 in Poland in 2012*



Source: Own elaboration based on Zakład Ubezpieczeń Społecznych (ZUS) – Portal Statystyczny ZUS, http://www.psz.zus.pl/; accessed: 20.07.2014 [22].

NHF expenses allocated for the reimbursement of drugs and medical products in Poland. It should be also highlighted that the highest costs (almost half of them) are generated by the reimbursement of glucose test strips and insulin (mostly human insulin) [20, 21]. In turn, the analysis of indirect costs of diabetes has indicated that in 2012 these costs amounted to almost 60 million PLN in case of diabetes type 1 and over 66 million PLN in case of diabetes type 2. What is more, sickness absence had the highest share in indirect costs in case of diabetes type 1. A significant share in indirect costs was also observed in case of medical decisions about long-term disability to work (disability pension). In 2012, 95% of indirect costs of diabetes type 2 in Poland consisted of the cost of sickness absence [22].

The conclusions presented within the above research review, especially those referring to Poland, should to a greater extent draw the attention of decision-makers in health care as well as the public opinion. A number of steps should be taken to try and reduce diabetes type 2 prevalence, to carry out earlier and better diagnosis as well as to reduce and delay the onset of diabetes complications. To achieve this aim, effective health and education programmes should be implemented, while patients should be provided with professional care and access to modern therapeutic methods.

Note

[1] Purchasing Power Parity – a way of expressing the currency of one country in the currency of another country. It defines a relation between the level of prices in one country to the level of prices in another country.

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

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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 neuroprogressive 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 commorbidities. One multicentre study has found that most AD patients in a US population have at least three commorbid 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 26th to 12th 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 26th 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. Ultimely 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, Lyketsos 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 disease 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 reevaluation 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 direct 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 nternational dollars (I$) 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
European Union	**10.0**
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%[1]. 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 I$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 various 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 healthcare 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 generally 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. Additionally, 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 (I$) 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 (I$).

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 Indexes (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)
Data are n (%) unless otherwise stated.	

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)	
Hospital admissions						
All patients	12 (38.7%)	1.08 (0.29)		31	0.42 (0.56)	
Mild	1 (11.1%)	2.00	0.145	9	0.22 (0.66)	0.422
Moderate	6 (42.9%)	1.00 (0)		14	0.43 (0.51)	
Severe	5 (62.5%)	1.00 (0)		8	0.63 (0.52)	
Days of hospitalisation per person						
All patients	12 (38.7%)	17.08 (13.84)		31	6.61 (11.91)	
Mild	1 (11.1%)	55	0.276	9	6.11 (18.33)	0.217
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)	
Outpatient visits						
All	15 (48.4%)	71.2 (149.16)		31	34.45 (108.12)	
Mild	8 (88.9%)	66.00 (143.14)	0.171	9	58.67 (135.69)	0.017
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[1]	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[2]	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 • Using caregiver hourly wage • Using minimal (unqualified hourly wage)	 10 per hour 5.8 per hour 5.1 per hour

[1] 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.

[2] 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.

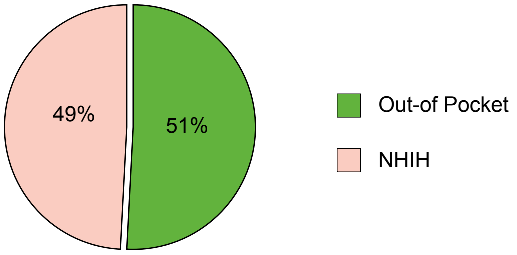
Table V. *Direct costs (medical and non-medical) per patient in the study by illness severity*

	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)
Average total direct costs		27,072.3 (13,658.1)	26,746 (18,103.3)	55,890.5 (57,261.0)	34,362 (33,517.5)

* 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.

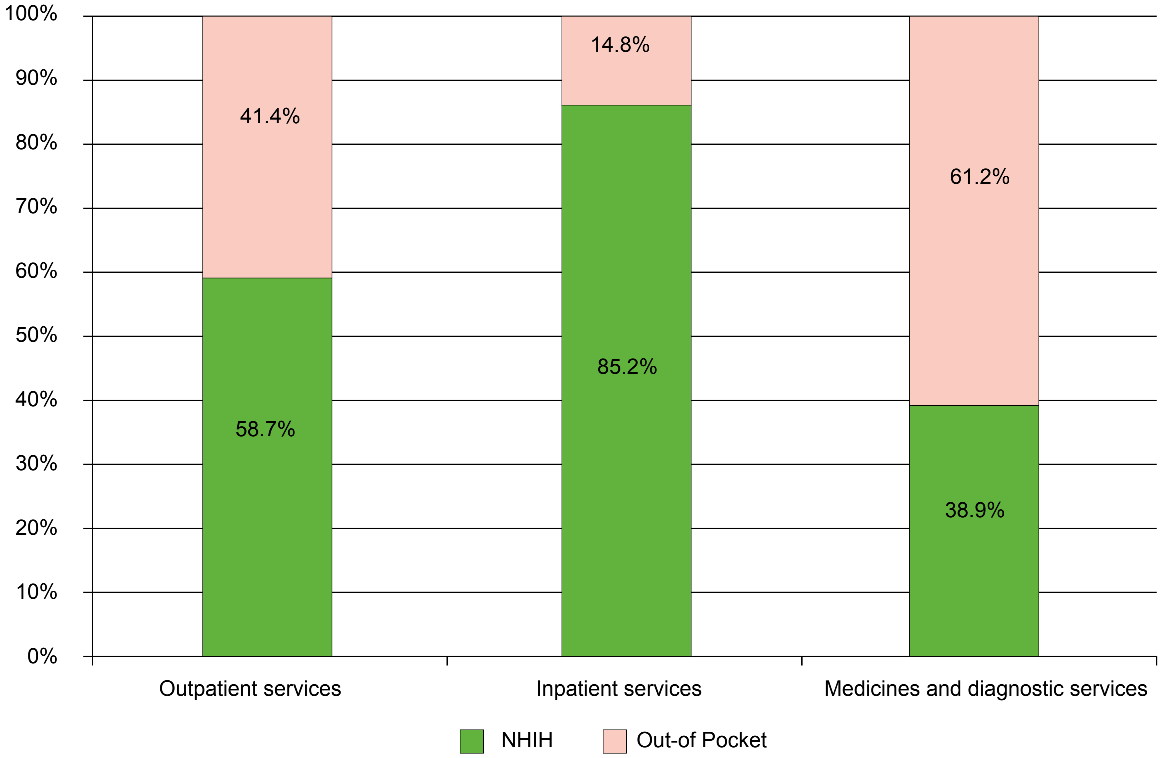
The total extrapolated to the entire population indirect costs varied, according to the different hourly wages used for valuing caregiving time between: a) 8,96 bln RON (I$5.38 bln); b) 5.76 bln RON (I$3.46 bln) and c) 5.24 bln RON (I$3.15 bln), equating to individual average annual costs of: a) 33,192.8 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)
Total indirect costs	24,635.8 (24,494.4)	33,355.3 (31,335)	42,554.2 (23,250.6)	33,192.8 (27,512.9)

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)
Total indirect costs	17,249.8 (12,716.5)	21,670.2 (17,709.1)	25,404.6 (12,595.1)	21,350.6 (15,017)

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)
Total indirect cost	16,049.4 (10,859)	19,772.9 (15,622.5)	22,617.3 (10,888.8)	19,425.9 (13,079.1)

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

[1] 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 reserch 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?
   ___________________ (preferrably 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, housekeeping, 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. AAc: 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, disposale 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 anny 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