Doctoral School of Business and Management

THESES

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THE ROLE OF THE COST OF DISEASES AND QUALITY OF LIFE IN THE ALLOCATION OF HEALTHCARE RESOURCES

Ph.D. thesis

Supervisors:

Prof. Péntek Márta, Prof. Gulácsi László Dsc

Budapest, 2020

Corvinus University of Budapest

Department of Health Economics

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I. BACKGROUND

I.1. Introduction

The economics of chronic diseases are issues of great importance from the point of view of health policy and financing, as the these diseases cause significant burden not only for the individual, the family, but on a societal level too.

Healthcare needs are similar to that of high-income countries. In Hungary, life expectancy was 76.2 years in 2018, healthy life expectancy was 61.1 years, while life expectancy in Germany was 81.0 years, and 81.8 years in Austria. Healthy life expectancy was 65.8 years 56,9 years in 2018 (Eurostat, 2018b, Eurostat, 2018a).

Knowledge of costs and outcomes (disease burden), and the analysis of the cost-effectiveness of new therapies is essential information for the financier and health policy-maker in order to achieve sustainable financing in health care sector and create the optimal allocation of resources.

The identification and measurement of different costs in chronic diseases, as well as the analysis of outcomes including the quality of life of patients (and family members, carers), contributes significantly to the disease burden assessment in financing decisions. In Hungary, such data are not available from the databases of the financier, the National Health Insurance Fund Management.

The importance of health economics analysis, similarly to other developed countries, is growing in Hungary. This is due to the fact that an increasing part of the health care budget is allocated, in accordance with legal requirements, taking into account the results of health economics analysis (EMMI, 2017, Gulácsi et al., 2014).

In the case of chronic diseases, not only the presence of direct health care costs, but also the direct non-health care and the indirect costs can cause significant burden on a societal level. Previous studies show that in many chronic diseases, informal care is a major factor in patient care. In addition to current demographic trends, the use of informal care is expected to become increasingly common (Zrubka, 2017).

I.2. Objectives

My thesis covers two major topics: costing and measuring health related quality of life

1. Health related quality of life

   1.1. A Comparison of European Polish, Slovenian and British EQ-5D-3L value sets using a Hungarian sample of 18 chronic diseases

   We aimed to compare the Slovenian, Polish, British and European EQ-5D-3L value sets, which are most commonly used or are potentially applicable for health economic evaluations in the CEE region. Our study was based on the comparative analysis of patient level data from cross-sectional surveys conducted in Hungary among patient populations in 18 different chronic conditions. We explored the differences of the EQ-5D-3L index scores calculated with the four value sets by diagnosis, age group and disease severity. Furthermore, we analysed the potential impact of the choice of value sets on health priority setting by comparing the disease burden evaluations across different conditions using different value sets.

   1.2. A detailed analysis of 'not relevant' responses on the DLQI in psoriasis: potential biases in treatment decisions

   Our objective was to explore the occurrence of NRRs on the DLQI on a large sample of psoriasis patients and to examine the effect of several socio-demographic and clinical factors on giving NRRs.

   1.3. The health state and productivity of the Huungarian general population

   We aimed to assess the health state, well-being and productivity loss experienced by the Hungarian general population with questionnaires like the ICECAP, WPAI and EQ-5D-5L, which are suitable for evaluating outcomes and contributing to the evaluation of strategy-making in a number of sectors (health-social sector, labour market).

1.4. Characteristics and determinants of informal care in chronic diseases in Hungary: A comparative analysis

The aim of our research was to analyse the characteristics and determinants of informal car in chronic conditions, with a special attention to observing the relationship between patients' health-related quality of life (measured by the EQ-5D questionnaire) and informal care. We performed a comparative analysis of previous studies.

2. Costing

2.1. Cost of informal care in chronic diseases in Hungary: A comparative analysis

Our aim was to analyse the cost of informal care in chronic disease. We performed a comparative analysis in 13 different chronic diseases. We analysis previous studies where patient level data was available.

2.2. Cost-of-illness studies in nine Central and Eastern European countries

This review has been undertaken to provide a description of the COI studies in nine CEE countries, namely Austria, Bulgaria, the Czech Republic, Croatia, Hungary, Poland, Romania, Slovakia, Slovenia, in the past ten years. The main objectives were to describe study characteristics, methodology and the COI estimates reported.

2.3. Hungarian cost library

Our aim was to create a Hungarian cost library, containing country specific cost data. We aimed to analyse the possibilities of using the database for providing information in health policy decision making and financing in Hungary.

II. HIPOTHESES

Health related quality of life

Hypothesis 1.
We assume that the European, Polish, Slovenian and UK EQ-5D-3L value sets do not differ significantly
1.1. We assume that applying different value sets in the 18 chronic diseases that we examined, the health policy and funding decisions based on the results do not differ significantly in different countries.

Hypothesis 2.
We assume that the ’not relevant’ answers of the DLQI questionnaire differ in the different demographic groups.
2.1. We assume that the effect of the differences on decision-making and resource allocation can be observed.

Hypothesis 3.
We assume that the health status and work productivity of the Hungarian general population can be adequately measured by the standard questionnaires we used.

Hypothesis 4.
We assume that the characteristics and determinants of informal care in Hungary are similar to what can be observed in other countries.

Costing

Hypothesis 5.
We assume that the social burden and cost of informal care is very significant in Hungary as well, in accordance with international experience.

Hypothesis 6.
We assume that the costs of illness in Hungary are similar to those in other Central and Eastern European countries.
6.1. We assume that in Hungary the cost data published in other Central Eastern European country can be utilized and transferred better than the cost data originated in countries with high national income.

Hypothesis 7.
We assume that a Hungarian cost library can be created as sufficient local data is available.
7.1. We assume that the Hungarian cost library can contribute to the development of appropriate and sustainable health care financing decisions.
7.2. We assume that the Hungarian unit costs and cost are significantly different than what can be observed in high-income countries

III. METHODS

III.1. Health-related quality of life

III.1.1. A Comparison of European Polish, Slovenian and British EQ-5D-3L value sets using a Hungarian sample of 18 chronic diseases

This current study is a secondary analysis of 18 previous surveys conducted by the Department of Health Economics of the Corvinus University of Budapest. We only included those patients in our analysis, who had answers in all five EQ-5D-3L dimensions; hence EQ-5D-3L index scores could be calculated using the four different value sets.

III.1.2. A detailed analysis of 'not relevant' responses on the DLQI in psoriasis: potential biases in treatment decisions

We analysed data obtained from two cross-sectional surveys among psoriasis patients at two academic dermatology clinics in Hungary. Health-related quality of life was measured by employing DLQI and EQ-5D-3L, while disease severity was graded by Psoriasis Area and Severity Index (PASI).

III.1.3. The health state and productivity of the Hungarian general population

We conducted a cross-sectional questionnaire survey on a representative sample of the Hungarian general population. Work productivity loss was measured with the WPAI-GH questionnaire, and to assess the participant's health state we used the EQ-5D questionnaire, the MEHM (Minimum European Health Module) and the ICECAP-A (for participants under 65 years) and ICECAP-O (for participants over 65 years) questionnaires.

III.1.4. Characteristics and determinants of informal care in chronic diseases in Hungary: A comparative analysis

We conducted the secondary analysis of 18 previous surveys conducted by the Department of Health Economics of the Corvinus University of Budapest. We only included samples in our analysis, where health-related quality of life was measured by the EQ-5D-3L questionnaire and informal care use was recorded.

III.2. Costing

III.2.1. Cost of informal care in chronic diseases in Hungary: A comparative analysis

The detailed analysis of the sample was published previously (Beretzky and Péntek, 2017). We analysed the data obtained in previous cross-sectional surveys conducted by the Department of Health Economics of the Corvinus University of Budapest where informal care was observed and health related quality of life was measure with the EQ-5D-3L questionnaire. Altogether we conducted the secondary analysis of 13 previous studies.

III.2.2. Cost-of-illness studies in nine Central and Eastern European countries

We performed a systematic literature search between January 1, 2006 and June 1, 2017 to identify all relevant cost of illness studies from nine CEE countries. Cost of illness studies reporting costs without no restrictions on age, co-morbidities or treatment were included. Methodology, publication standards and cost results were analysed.

III.2.3. Hungarian cost library

We conducted a literature search on PubMed to identify the relevant cost of illness, cost-effectiveness, budget-impact analysis publications, supported by a hand search of the Hungarian literature.

IV. RESULTS

IV.1. Health-related quality of life

IV.1.1. A Comparison of European Polish, Slovenian and British EQ-5D-3L value sets using a Hungarian sample of 18 chronic diseases

The 18 chronic conditions belonged to 9 different ICD-10 groups. The total sample included 2421 patients. The mean age of the patients was 55.87 years (SD=17.75). More than half of patients were older than 70 years in dementia, AMD, BPH and PAOD. More than half of the patients were female (n=1356, 58.6%) and it is worthy of note, that some studies involved exclusively female (endometriosis, osteoporosis, OAB) or male (BPH) patients. The mean disease duration in our sample was 8.75 (SD=8.95) years, with outstandingly high average disease duration in patients with psoriasis and epilepsy.

Slovenian and European value sets tended to have lower index values in milder health states, while the UK and Polish value sets provided the lowest values for the combination of severe problems (33333). Among all 243 EQ-5D-3L profiles, “worse than dead” health states with negative utility values were most prevalent in the British value set (35%), followed by the Polish (13%), the Slovenian (9%) and the European one (2%).

To conduct our analysis by diagnosis, we calculated the EQ-5D-3L index scores (mean, standard deviation) with all the four value sets for each diagnosis. The weighted mean EQ-5D-3L index scores in our total sample were respectively 0.598 (SD=0.279), 0.661 (SD=0.257), 0.770 (SD=0.261) and 0.644 (SD=0.334) with the Slovenian, European, Polish and British value sets. All pairwise value-set comparisons were significant ($p<0.001$).

Altogether, from the 153 pairwise comparisons of DB score that were evaluated between the 18 conditions (n=18*17/2), 22.9% provided diverse outcomes. Most of the diverse outcomes were combinations of non-significant differences and significant differences in one direction. We found remarkable differences across diagnoses, age groups or patients with different disease severity. For example, the mean EQ-5D-3L index difference was as high as 0.265 in PD, and 0.187 in the 55+ age group. The systematic pairwise comparison of DB evaluations between all disease conditions revealed inconsistent results between value sets determined via the VAS and TTO valuation methodology.

The choice of value set may cause significant differences, if the health status of a patient is improved from ‘22222’ (moderate problems in all dimensions) to ‘11111’ (perfect health) over a year with a new treatment, the QALY gain will be 0.685 with the Slovenian, but only 0.284 with the Polish value set. Improvement from the worst possible health state (‘33333’) to a moderate health state (‘22222’) would result in 1.239 QALY gain with the Polish, but only 0.555 with the European value set.

IV.1.2. A detailed analysis of ‘not relevant’ responses on the DLQI in psoriasis: potential biases in treatment decisions

Mean age of the 428 patients was 49 years, and 65% were males. Overall, more than one third (38.8%) of the patients had at least one NRR: 19.6% (one), 11.5% (two), 5.1% (three) and 2.6% (more than three). Most NRRs occurred in sport, sexual difficulties and working/studying items of the DLQI (28.4%, 16.4% and 14.0%, respectively). Female gender, older age and higher disease severity (PASI score) were associated with providing more NRRs, whereas highly educated patients and patients working in a full-time job less frequently tended to tick NRRs. The high rate of psoriasis patients with NRRs, especially among women, less educated and elderly patients, indicates a content validity problem of the measure. A reconsideration of the use of the DLQI for medical and financial decision-making in psoriasis patients is suggested.

IV.1.3. The health state and productivity of the Hungarian general population

Altogether 2023 respondents participated in our survey, 50.1%- (n=1013) of whom was female. The average age in our sample was 48,7 years (SD=17,9), 41.7%- had primary, 38.1% secondary and 20.2%- higher education. 19.7% of the respondents lived in Budapest, 52.5% in other cities and 27.8% in villages. The average number of household members was 2.5 (SD=1.3) with the average monthly income per capita of 128 000 HUF (SD=60 000 HUF). The mean EQ-5D-5L index was 0.92 (SD=0.15) in our sample. Most problems were reported in the Pain/discomfort dimension: 31.6% reported problems in this dimension. The EQ-VAS was 81.6 (SD=17.4). On average male respondents reported fewer problems than females, with the exception of the Self-care dimension in which 9.9% and 8.9% reported problems.

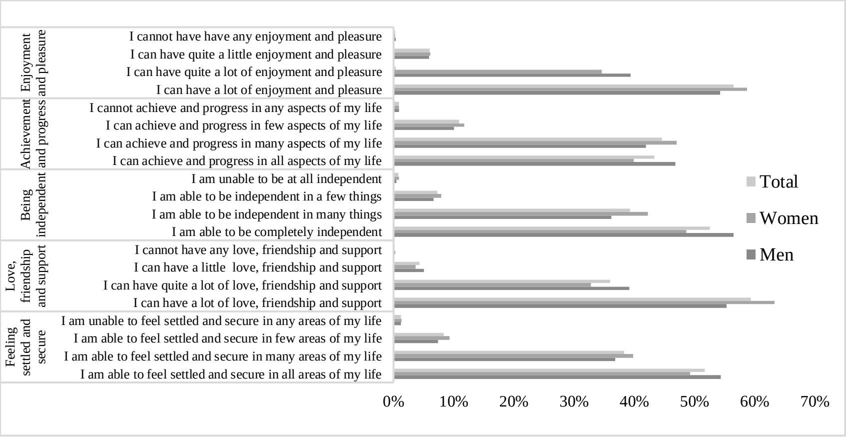
According to the WPAI results, the average productivity loss in other activities was 9.5% (SD = 21.0%), while the average total productivity loss at work was 7.7% (SD = 20.9%). For absenteeism and presenteeism, the mean values were 3.6% (16.4%) and 4.4% (14.2%), respectively. We did not find significant differences by gender, we found similar values for women and men in all four variables. By age groups, we found a significant difference between the mean productivity loss in other activities, the total productivity loss during work and in preseteeism (p = 0.000, in all cases).

Respondents under the age of 65 (n=1568) filled out the ICECAP-A questionnaire and reported the highest level of skills in the Love, friendship and support dimension. The Achievement and progress dimension was not problematic for 43.4% of respondents, and only about half (51.8%) of respondents felt secure in all areas of life. (Figure 1.)

The ICECAP-O questionnaire was filled out by respondents aged 65 and over (453 respondents in our sample). Nearly two-thirds (64.9%) of respondents reported some level of problem in the Attachment dimension. In the Enjoyment and pleasure dimension, this proportion was even higher: 78.4% indicated the existence of any problem. Independence was a problem for the majority (71.1%), and Role (the ability to do valuable things) dimension problems were generally present (72.8%) as well.

Differences by gender were small for both ICECAP questionnaires. The mean of the ICECAP-A index was 0.89 (SD = 0.13), while the mean of the ICECAP-O (over 65 years) index was 0.83 (SD = 0.15).

Figure 1. ICECAP-A answers by gender (%)

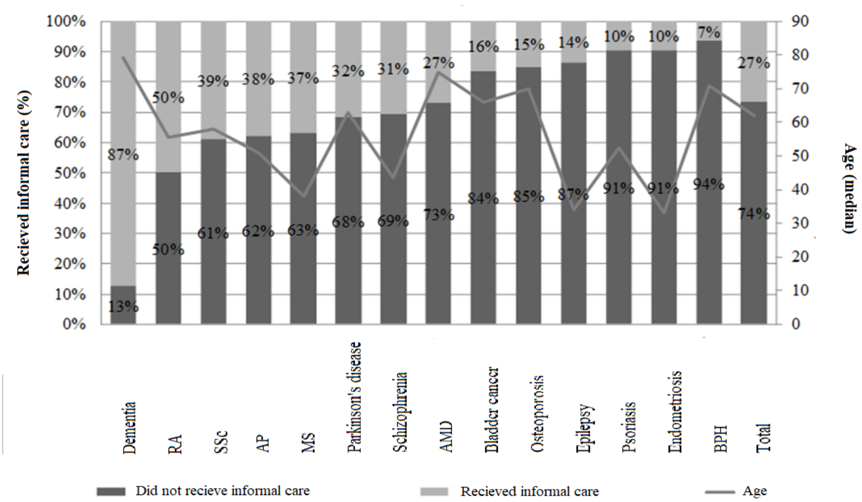


IV.1.4. Characteristics and determinants of informal care in chronic diseases in Hungary: A comparative analysis

Altogether 2047 patients (female: 58%) with mean age of 58.9 (SD = 16.3) years and EQ-5D-3L index score of 0.64 (SD = 0.33) were involved. 27% received informal care, the average time of care was 7.54 (SD = 26.36) hours/week. Both the rate of informal care use and its time differed significantly between the diagnoses ($p<0.05$), the highest were in dementia, Parkinson's' disease and in chronic inflammatory immunological diseases. Significant determinants were age, EQ-5D-3L scores, gender and certain diagnosis dummies ($R^2 = 0.111$).

One quarter (27.4%) of patients indicated that they had received informal care, with rates ranging from 6.5% (benign prostate enlargement) to 87.2% (dementia) in various diseases. More than one-third of patients received informal care for dementia (87.2%), rheumatoid arthritis (49.8%), systemic sclerosis (38.8%), psoriatic arthritis (37.7%) and multiple sclerosis (36.8%). (Figure 2.)

Figure 2. The rate of patients receiving informal care (%) by diagnosis and age



RA: rheumatoid arthritis, SSc: systemic sclerosis, AP: psoriatic arthritis, MS: multiple sclerosis, AMD: age-related macular degeneration, BPH: benign prostate hyperplasia

IV.2. Costing

IV.2.1. Cost of informal care in chronic diseases in Hungary: A comparative analysis

A total of 1,896 patients from 13 previous studies were included in our analysis, with a mean age of 58.29 (SD = 16.62) years, of whom 59.9% were female. Patients had a mean EQ-5D-3L index score of 0.629 (SD = 0.331) and a median score of 0.725, with a mean EQ VAS equal to 59.87 (SD = 20.21) (median: 60). Altogether 27.4% of patients received informal care, ranging from 6.5% (benign prostate enlargement) to 87.2% (dementia) in various diseases. More than one-third of patients received informal care in dementia (87.2%), rheumatoid arthritis (49.8%), systemic sclerosis (38.8%), psoriatic arthritis (37.7%) and multiple sclerosis (36.8%).

The weekly cost of informal care in our entire sample, using the 24-hour limit, was HUF 7,399 (SD = 25,648) on average, and using the 8-hour limit per day, it was HUF 4,696 (SD = 11828) per patient. (Table 1) Based on the results of the Kruslkal-Wallis test, the costs differ significantly in different diagnoses according to both our primary and secondary analysis (p <0.001 in both cases).

Table 1. Informal care cost of the informal care recipients (HUF/patient/week) by diagnosis

Diagnosis	Number of patients (n)	Received informal care (%)	Informal care cost of the informal care recipients (HUF/patient/week) mean (SD)	
			Maximized in 56 hours/week	Maximized in 168 hours/week
Psoriatic arthritis	183	37.7%	14130 (12527)	17288 (27474)
Psoriasis	200	9.5%	8204 (12756)	13939 (36718)
Age-related macular degeneration	122	27.9%	9752 (12520)	9752 (12520)
Rheumatoid arthritis	255	49.8%	11168 (11350)	12401 (17787)
Systemic sclerosis	80	38.8%	14203 (15489)	18157 (30904)
Dementia	86	87.2%	37218 (20899)	80530 (66503)
Endometriosis	84	9.5%	12223 (11470)	12223 (11470)
Osteoporosis	281	14.9%	8816 (11882)	14132 (34695)
Benign prostate hypoplasia	246	6.5%	22075 (15920)	22561 (16995)
Epilepsy	100	13.5%	18876 (21152)	39743 (61801)
Parkinson' disease	109	31.8%	10376 (16208)	14642 (33074)
Schizophrenia	78	30.8%	11554 (7181)	11554 (7181)
Multiple sclerosis	24	36.8%	14374 (16120)	19947 (35678)

The cost of informal care for those who received informal care was HUF 24,509 (SD = 42,281) per week, on average using the 24-hour limit, and HUF 1,5,646 (SD = 17,100) using the 8-hour limit per day. We found the highest cost in dementia (using a 24-hour limit of 80530 HUF / patient / week and with an 8-hour limit of 37218 HUF / patient / week), and the lowest cost in age-related macular degeneration (9752 HUF / patient / week) and endometriosis (12223 HUF / patient / week). patient / week).

To identify patients with the worst health condition, we examined patients who had an EQ-5D-3L index value of 0 or lower, and 162 (9.1%) such patients were identified. Of them, 26.1% had rheumatoid arthritis, 17.6% psoriatic arthritis, 13.9% dementia, and 13.3% had osteoporosis. The mean age of those with the worst health status was 62.1 years (SD = 14.6 years) and almost one third (31%) lived alone.

IV.2.2. Cost-of-illness studies in nine Central and Eastern European countries

We identified 58 studies providing 83 country-specific COI results. The 58 studies reported results on 48 different diseases. The highest total cost per patient could be observed in multiple sclerosis in three countries (Austria: EUR 50599, Czech Republic: EUR14777 and Poland: EUR 12343). (Blahova Dusankova et al., 2012, Kobelt et al., 2006, Szmurlo et al., 2014).

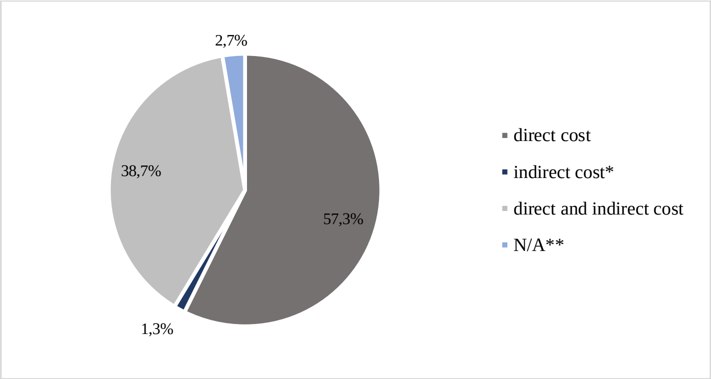
Cot of illness studies varied considerably in terms of methodology, publication practice and clinical areas. Due to these heterogeneities, transferability of the COI results is limited across Central and Eastern European countries. To assess the quality of the publications, we examined the description of the methodology used. It is important to note, that resource use data and the year of costing was reported in almost all publications (98% and 95%), however several important indicators are reported lot less frequently.

IV.2.3. Hungarian cost library

We conducted our literature search in four steps. As a result, altogether 75 studies met our criteria and were included. The studies were heterogeneous regarding methodology, data source, costing methods. Cross sectional studies and retrospective database review were the most common resource use data source with a total of 57 publications (76%).

More than half of the publications (57.3%, n=43) only reported direct costs. However out of those publications which also reported indirect costs, three estimated the indirect costs based on the length of hospital stay, which may lead to underestimation. (Figure 3.)

Figure 3. Distribution of the publications according to type of cost reported



*The study only reported indirect costs (Mandel et al., 2014)**N/A: two publications, which reported informal payments (Baji et al., 2012a, Baji et al., 2012b)

V. NEW RESULTS

V.1. Health related quality of life

V.1.1. A Comparison of European Polish, Slovenian and British EQ-5D-3L value sets using a Hungarian sample of 18 chronic diseases

We found methodology based differences between the value sets. The choice of value set may affect utility of health states significantly and could affect health policy decision making.

V.1.2. A detailed analysis of ’not relevant’ responses on the DLQI in psoriasis: potential biases in treatment decisions

We were the first to report the detailed analysis of the ’not relevant’ responses on the DLQI questionnaire. We found that the incidence of ’not relevant’ responses is common. They are more likely to occur among older, less educated, and female patients, so these patients may be at a disadvantage due to the specifics of DLQI scoring.

V.1.3. The health state and productivity of the Hungarian general population

We assessed the Hungarian general populations ICECAP-A and ICECAP-O scores alongside the use of the EQ-5D-5L and WPAI questionnaires.

V.1.4. Characteristics and determinants of informal care in chronic diseases in Hungary: A comparative analysis

For the first time in Hungary and in the region, we assessed and published results on the use of informal care and its relation to health-related quality of life in 14 chronic diseases, and provided data for further health economics analysis.

V.2. Costing

V.2.1. Cost of informal care in chronic diseases in Hungary: A comparative analysis

We analysed the informal care cost in Hungary and in the region on a large sample and found that these are significant and comparable to that of other countries.

V.2.2. Cost-of-illness studies in nine Central and Eastern European countries

We analysed the relevant publications and compared the cost of illness results across several countries in the Central and Eastern European region. The results of our analysis show that the generally accepted opinion that the disease burden results of the countries of the region are transferrable between countries is not realistic. This is due to a high degree of methodological heterogeneity and a lack of standards.

V.2.3. Hungarian cost library

Due to the need for utilizing local data, we created the fourth country specific cost library in Europe, by identifying the relevant publication.

VI. ANSWERS TO THE HIPOTHESES

Health related quality of life

Hypothesis 1.
We assume that the European, Polish, Slovenian and UK EQ-5D-3L value sets do not differ significantly
Our results suggest that the value sets show significant differences, we reject Hypothesis 1.

1.1. We assume that applying different value sets in the 18 chronic diseases that we examined, the health policy and funding decisions based on the results do not differ significantly in different countries.
Our results suggest that the use of different value sets would cause differences in health policy decision making, hence we reject Hypothesis 1.1.

Hypothesis 2.
We assume that the ’not relevant’ answers of the DLQI questionnaire differ in the different demographic groups.
Our research results show that there may be significant differences in not relevant responses between groups with different demographic and socioeconomic characteristics, accordingly, we accept Hypothesis 2.

2.1. We assume that the effect of the differences on decision-making and resource allocation can be observed.
Our results suggest that the effect of the differences on medical decision-making and resource allocation can be observed and significant, hence we accept Hypothesis 2.1.

Hypothesis 3.
We assume that the health status and work productivity of the Hungarian general population can be adequately measured by the standard questionnaires we used.
The health status and work productivity of the Hungarian general population can be adequately measured by the standard questionnaires we used, hence we accept Hypothesis 3.

Hypothesis 4.
We assume that the characteristics and determinants of informal care in Hungary are similar to what can be observed in other countries.
Our results suggest that the characteristics and determinants of informal care in Hungary are similar to the results in other countries, hence we accept Hypothesis 4.

Costing

Hypothesis 5.
We assume that the social burden and cost of informal care is very significant in Hungary as well, in accordance with international experience.
Our research results show that the social burden and cost of informal care is significant in Hungary and is in line with international experience. In Hungary, this burden is lower in absolute terms than in the higher GDP/capita countries, but in similar proportions, accordingly we accept Hypothesis 5.

Hypothesis 6.
We assume that the costs of illness in Hungary are similar to those in other Central and Eastern European countries.
Our research results show that the costs of illness in Hungary are similar to other Central and Eastern European countries, so we accept Hypothesis 6.

6.1. We assume that in Hungary the cost data published in other Central Eastern European country can be utilized and transferred better than the cost data originated in countries with high national income.
The results of our research show that the usability and transferability of cost data published in Central Eastern European countries is strongly limited, we assume that the results of other countries (eg. UK) can be better transferred, accordingly we reject Hypothesis 6.1.

Hypothesis 7.
We assume that a Hungarian cost library can be created as sufficient local data is available.
Our results suggest that sufficient local data is available in Hungary to create a local cost library, hence, we accept hypothesis 7.

7.1. We assume that the Hungarian cost library can contribute to the development of appropriate and sustainable health care financing decisions.

The data needs of the current health care reforms show that such data are needed more than ever before, therefor we accept the hypothesis 7.1.

7.2. We assume that the Hungarian unit costs and cost are significantly different than what can be observed in high-income countries
Our research results show that Hungarian unit costs and costs differ significantly from those of high-income countries, we accept the hypothesis 7.2.

VII. PRACTICAL USE

In this dissertation, we aimed to examine the role of disease burden and quality of life in decision making and resource allocation in health care, which is a particularly important issue, as the disease burden and costs of chronic diseases are significant and growing not only at the individual but also on societal level.

The research areas discussed in the dissertation and the data included in the research are therefore necessary in order to provide information for decision making and to optimally organize the allocation of resources.

In many cases, we do not have sufficient information about certain costs of an illness, such as the cost of informal care provided by relatives or the cost of labour productivity loss. It is important to point out that these data are not routinely collected and available in public databases, so the total social burden of the diseases is not known.

Another important factor in relation to chronic illness is quality of life. Data on quality of life and the social dimension of quality of life are also not collected routinely, which raises the problem of not being able to fully measure the outcome of therapies, as therapies often are not only targeting the elimination of clinical symptoms, but improving quality of life and helping patients in regaining skills. These data on all this can only be obtained from health economics research.

In the present dissertation we discussed both quality of life measurement and cost calculation: During the examination of the quality of life issue we examined the general EQ-5D questionnaire and a disease-specific questionnaire, as well as the quality of life, social skills and productivity loss of the Hungarian general population.

The results of a detailed analysis of ’not relevant’ responses to the disease-specific DLQI questionnaire show that ’not relevant’ responses are more among older, less educated, and female patients.

In this dissertation, we paid special attention to the analysis of informal care, and we found that the use of informal care is extremely significant in Hungary as well. For the first time in Hungary, we analysed and published the costs of informal care in 13 chronic diseases on a large sample and we found that the costs are significant in Hungary, similarly to other countries.

In order to examine the cost of diseases, the dissertation presents an overview of cost of illness studies in the region, in nine Central and Eastern European countries. The results of our analysis show that the generally accepted opinion that the disease burden results are transferrable between countries is not realistic. Based on our results, we conclude that the domestic usability and transferability of the cost data published in the region is strongly limited, as great methodological heterogeneity is present in the publications.

The Hungarian cost library also plays a significant role in learning about the costs of illness and the financing of health care. In Hungary, the almost exclusive source of cost data is currently the databases of the National Health Insurance Fund, which do not contain a lot of data that are essential for health economic analysis (for example: direct non-health costs, indirect costs, outcomes). Hence there is a great need for library of health care costs in Hungary. In the dissertation, the process of developing the Hungarian coat library was published: we conducted a literature search in order to identify the relevant publications. As a result of our search, we developed the structure of the Hungarian cost library, using 75 selected publications and assessed the characteristics of the publications. We found that the methodology used in the publications is extremely heterogeneous, and is not fully described in all cases, the source of the data is not clearly identifiable in many cases and the real costs do not necessarily coincide with the funding.

VIII. REFERENCES

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IX. OWN PUBLICATIONS RELATED TO THE THESIS

Zrubka Zs, **Beretzky Zs**, Hermann Z, Brodszky V, Gulácsi, L, Rencz, F, Baji P, Golicki D, Prevolnik-Rupel V, Péntek M (2019): A comparison of European, Polish, Slovenian and British EQ-5D-3L value sets using a Hungarian sample of 18 chronic diseases. European Journal of Health Economics 20, Suppl. 1, pp. 119-132. doi: 10.1007/s10198-019-01069-8.

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Beretzky Zs: Az informális ellátás költsége krónikus betegségekben: magyarországi kutatások összehasonlító elemzése. Köz-Gazdaság, accepted for publication

Péntek M, **Beretzky Zs**, Brodszky V, Szabó, A. Kovács, L. Kincses, Á. Baji P, Zrubka Zs, Rencz F, Gulácsi L: A magyarországi lakosság egészséggel összefüggő munkaképessége: keresztmetszeti reprezentatív felmérés a Munkaképességre és Tevékenységcsökkenésre vonatkozó kérdőívvel. Orvosi Hetilap, accepted for publication