The Estimation and Validation of Pre-senile Dementia in Germany using Health Care Data of the AOK

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Introduction

In the course of demographic ageing the focus on dementia diseases in higher ages is more important than never before because their consequences are relevant for societies, politics and science. Within the shift of large proportions of the population into older ages the importance of another problem becomes apparent. It is the onset of pre-senile dementia (or early-onset dementia = EOD), generally defined as the occurrence before the age 65.

Background

Compared to the high numbers of demented people among the elderly, the share of people with EOD is probably low. Nonetheless, the importance of EOD is high. Analysing pre-senile dementia is reasonable because of its different consequences regarding to care or service needs in contrast to late onset dementia. There is need of studying the clinical effects on the patient as well as the effects on spouses and caregivers. A significant effect was found for spouses in terms of dependency, fear and increased depression. Similar results were shown for young children of affected patients. The early-onset of diseases like Alzheimer's disease is affecting people who are most often still actively engaged in the labour force and in raising children.

Although the differential diagnosis of EOD is wide and symptoms are diverse, behavioural, cognitive, neurological or psychiatric indications should be considered. In fact, there is no particular symptom or combination of symptoms. Some of them develop over time and severity, however, the process is not linear. In general, such symptoms can be the loss of short-term memory, anxiety, depression, isolation from relatives, and problems with carrying out everyday tasks to the same standard as previously, dealing with money or finding the right words.

A major problem in analysing pre-senile dementia is that accurate diagnoses like Alzheimer's disease in the younger population are rare because many health care providers don't look for

such diseases. The awareness of symptoms is not fully given or they may be incorrectly attributed to stress or other factors. There may be also conflicting diagnoses from different physicians. It is important to expand overall knowledge and understanding of EOD, particularly of the causes.

Objectives

For a better understanding and evaluation of EOD and its consequences a good and comprehensive data quality is needed. Due to recruitment aspects previous studies often provide only small sample sizes. The current study provides the opportunity of a large sample using German health care data. We want to analyse different aspects of EOD. The first objective of the study is to estimate the prevalence of pre-senile dementia in Germany and to compare the results with earlier international studies. In a second step we aim to evaluate and validate these results with regards to risk factors and the type of physician that has given the underlying diagnosis. As we are assuming that accurate diagnoses of EOD are rare and difficult we try to compare diagnoses by neuropsychiatrists and all other physicians, assuming that diagnoses by neurologists, psychiatrists or psychotherapists are more accurate and reliable. In contrast, diagnoses by non-specialists may include more likely misdiagnoses.

Data

For our analyses we use health claims data of the AOK. It is the largest German health insurance company including about one-third of the German population. The claims data include complete records of the stationary and ambulatory treatment received by each insured person with at least one day of insurance coverage by the AOK. The data are compiled on a quarterly basis, and include all plan members, regardless whether they sought medical treatment. We focus on all AOK insured persons in 2007.

Regarding to the early-onset of dementia we concentrate on people at age 45 to 64. We include all persons with dementia coded on the basis of ICD-10 classification (F00, F01, F02, F03, F05.1, G23.1, G30, G31.0 and G31.82). We further take into account only cases with a validated diagnosis.

Methods

Prevalence of dementia and its subtypes can be calculated now by the number of insured persons with a valid diagnosis at age x in time t divided by the total number of insured persons at age x in time t. The population at risk contains the number of AOK-insured-persons aggregated by sex and age and is provided by the WIdO.

$$\text{Prevalence}_x(t) = \frac{\text{persons with valid diagnosis}_x(t)}{\text{number of insured persons}_x(t)}$$

Prevalence rates will be calculated for the general dementia indicator and for the sub-diagnoses of pre-senile dementia.

We use negative binomial regression models to estimate the impact of risk factors and the presence of neuropsychiatrists during the process of diagnosing on the number of persons with pre-senile dementia. We assume that the number of persons with dementia follow a negative binomial distribution.

Results

Prevalence of dementia

The overall prevalence of dementia for the age group 45 to 64 is 475 cases per 100.000 persons. For the sake of brevity, the term “per 100.000 persons” is omitted in the following text. Male patients (524 cases) reveal a higher prevalence compared to women (424 cases). The prevalence is increasing with age for both male and female, and, thus, for the total population. For the latter it is 173 cases at age 45 and 1153 cases at age 64.

Among the individual dementia diagnoses, Alzheimer’s (80 cases for ages 45 to 64), vascular dementia (110 cases), circumscribed brain atrophy (18), dementia in diseases classified elsewhere (33 cases), and unspecified dementia (302 cases) show the highest prevalence rates.

Prevalence of EOD and presence of diagnoses by NPs

Taking into account the diagnoses by neuropsychiatrists reveals that only 29 per cent of the overall prevalence is related to the treatment of a specialist. Thus, the prevalence of pre-senile dementia related to NPs would be 138 cases and 336 cases related to non-NPs for the age group 45 to 64. A similar pattern emerges among the individual diagnoses. The share of diagnoses related to NPs for all ages together is 58 per cent (47 cases) for Alzheimer’s; 37 per cent (40 cases) for vascular dementia; 42 per cent (8 cases) for circumscribed brain atrophy; 48 per cent (16 cases) for dementia in diseases classified elsewhere; and 24 per cent (72 cases) for unspecified dementia.

Prevalence of EOD and presence of comorbidities

In our dataset, 25,878 of 30,276 persons with pre-senile dementia suffered at least from one of the comorbidities: cerebrovascular diseases, metabolic syndrome, endocrine diseases, ischemic heart diseases, depression, or mental and behavioral disorders due to psychoactive substance use. 18,110 of these persons suffered from at least two of the listed comorbidities

during the observation period. In terms of the prevalence estimation, it is shown that about 60 per cent of the total prevalence of pre-senile dementia is related to the presence of two or more comorbidities. Furthermore, about two thirds of the prevalence related to specialists is also related to the presence of two or more comorbidities. With 58 per cent, a somewhat smaller proportion of the prevalence related to non-NPs is also related to at least two comorbidities.

The results of the negative binomial regression models reveal that the count has increased more than fivefold for the presence of at least one of the comorbidities and that the presence of at least two comorbidities increases the expected count by about 33 per cent. Each model shows an increased expected count with age and a decreased count for women compared to men. Compared to the absence of a specialist involved in the diagnosis, the expected count of the presence of a specialist is only one third.

Comparison of prevalence to recent studies

While the overall prevalence measured in this study is higher than the prevalence estimations of other international studies, the prevalence related to neuropsychiatrists is on a comparable level.

Conclusion

The results reveal a considerable number of people suffering from pre-senile dementia. Only a small share of the diagnoses is related to neuropsychiatrists. This may indicate potential in both improving the accuracy of the diagnoses and the quality of treatment of patients with pre-senile dementia.

A further analysis of the risk factors and the diagnoses from neuropsychiatrists will define the prevalence more precisely. Another point that has to be done is the inclusion of alcohol-related diseases and its implications in a medical and social context.

Although there are some limitations the claims data used in our analyses offer clear benefits compared to other studies and their data sources: they are up-to-date and comprise a large number of cases in a large area. As far as we know, no comparable study for Germany exists yet.