# FUTURE AMBULATORY AND IN-PATIENT COSTS OF DEMENTIA IN GERMANY

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## 1. Introduction

Mental and behavioral disorders represent 4 of the 10 leading causes of disability worldwide and are estimated to account for 12% of the global burden of disease (World Health Organization, 2001). European and Northern American studies show that about one fourth of the population above age 65 is suffering from a mental health problem. About 6% to 10% account for severe dementia and severe functional psychoses (Bickel 2003, Hendrie 1998). The number of sufferers from dementia in the beginning of the 21st century is estimated to about 25 million people worldwide. 46% of them live in Asia, 30% in Europe and 12% in North America (Wimo et al. 2003). A lower number is provided by Eurostat (2003), who estimate for the year 2000 that 4,624 million Europeans (EU25) between ages 30 and 99 suffered from different types of dementia (12.3 per 1000 inhabitants). Due to their higher mean age more women are affected, 2.9 million compared with 1.7 million men. In the year 2006 the number provided by the 'European Community Concerted Action on the Epidemiology and Prevention of Dementia group' (EURODEM) (Alzheimer Europe 2006) already rose to 5.37 million people.

It is very difficult to quantify dementia. Different definitions and measurement methodologies lead to diverging results. First of all it combines different kinds of diseases. The most frequent form today is Alzheimer's disease (AD), a neurodegenerative disorder which slowly and progressively destroys brain cells. The disease accounts for about 50-75% of all dementias (Bickel 2005, Breteler et al. 1992, European Community 2005, Eurostat 2003, Weyerer 2005). Vascular dementia (VaD) is the second most common form of dementia and accounts for about one forth of all cases (European Community 2005, Weyerer 2005, Skoog 2004). Secondly, it is difficult to differentiate the disease in its early state from the normal cognitive changes that occur in older ages (Fratiglioni et al. 2001, Schaie 2004). A rising awareness might have further influenced the number of affected cases, because the disease is earlier and more often diagnosed. Cross-cultural differences and within-culture changes over time additionally aggravate a consistent understanding of the disease. Recently, more attention is paid to the topic which reflects in a higher number of journals, programs and initiatives dealing with the topic, and a rising number of studies analyzing the epidemiology of dementia, the prevalence and incidence of dementing illnesses, and the risk factors of the disease (Fratiglioni et al. 1999, Larson et al. 1992). Definitions from the DSM-III, DSM-IV and the 'International Classification of Diseases and Related Health Problems' (ICD) are among the most widely accepted formal definitions of dementia today (American

Psychiatric Association 1987, 1994). All definitions have in common that a change in the brain occurs which leads to memory impairment and a change in personality. The disease hampers the daily living of the person. This is also an indicator for differentiation to normal aging: the age-related decline does not usually cause significant impairment of function, is slower, and people can compensate this decline (Larson et al. 1992). The condition usually worsens. The affected persons can suffer from changes in cognitive perception, emotional control, social behavior, motivation, in their personality, they can get depression, sleep disorders, angst, hallucinations, aggressions, constraints in daily living. The gradually deteriorating health state leads to complete dependence and the initial need for help turns into full-time care need. People with dementia have a higher institutionalization rate and a higher risk for other diseases such as hip fracture, urinary incontinence, blood pressure (Skoog 2004). Dementia causes a higher mortality rate (Bickel 2005, Dewey et al. 2001, Kliegel et al. 2004, Kokmen et al. 1996, Wilson et al. 2003). The average disease time from the beginning until death is estimated to last about 4.7 to 8.1 years for AD and about 1 year less for VaD (Weyerer 2005). In industrialized countries dementia is the fourth most common cause of death after heart diseases, malignant growth and cerebrovascular diseases (Bickel 2003).

Dementia is one of the most costly disease groups which is mainly due to the very high care need of demented people (World Health Organization 2006, Bickel 2001, Weyerer 2005). From the cognitively unimpaired people with chronic disabilities only 7% are in need of care, while this proportion increased to 80% for severely demented patients Schaeufele (1994).

With the aging of the population also the fear of more demented people and the economic impact increases. In this article we calculate prevalence and mortality rates of dementia, age- and sex-specific costs of demented people who survive and who die for Germany in the year 2002 and use the information to project the number of demented people and the costs until the year 2050.

## 2. Dementia in Germany Today

### Prevalence of Dementia

The prevalence rate of dementia shows the proportion of affected people within the total population. Many studies on dementia calculate age-specific prevalence rates. However, often the number of the study population is small and rates are erratic and have large confidence intervals. Meta-analyses overcome this problem by pooling data from several studies.
In the oldest review Jorm et al. (1987) pool data from 27 of the earliest prevalence studies and average the results with an exponential model. The single studies still vary greatly in method and sampling. Later meta-studies often specify a consistent scale as inclusion factor, e. g. Hofman et al. (1991) pool data from 12 European studies conducted between 1980 and 1990 which included the institutionalized population and used DSM-III or

equivalent criteria. Other meta-analyses are conducted by Ritchie et al. (1992) (pooled data on 13 studies since 1980), Ritchie et al. (1995) (9 papers where community and institutionalized population are included and only DSM-III diagnostic criteria are used are included), Fratiglioni et al. (1999) (35 prevalence studies) and Lopes et al. (2002) (38 studies between 1994 and 2000), Lobo et al. (2000) (pooled data from 11 European studies).

Age is the most important factor for the prevalence of dementia. Before age 65, dementia is negligible. There is one form of pre-senile dementia which occurs before age 65, however, there are only few cases. After age 60 or 65 most studies report a rapid increase of affected people. Many studies find, irrespective of the methodology, that the prevalence of dementia has been doubling every 5 to 6 years after age 60 (Jorm et al. 1987, Jorm et al. 1998). The results for all studies with pooled prevalence rates are quite similar. The rates are about 1% for people aged 60-64 and increase to about 35% to 55% for people above age 95. The rates rise steeply with age.

## Projections of People with Dementia in Germany

Projections of the possible development of people with dementia are rare in Germany. Table 1 shows the existing studies conducted from 2000 onwards. All studies are based on prevalence rates. Bickel (2001) estimates that the number of demented people is going to increase from about 0.93 million in 1996 to 2.05 million people in 2050. He uses population projections from the 9$^{th}$ coordinated population projection from the Statistical Office and assumes constant prevalence rates. The rates are a mean of age-specific prevalence rates of several studies (Bickel 2000). Hallauer et al. (2002) uses mean prevalence rates of several studies from Bickel (2002) (for the 2002 mean rate Bickel uses two more studies than for the 2000 mean rate which leads only to very slight differences) and two different population projections, the 9$^{th}$ projection from the German Statistical Office and projections from Birg et al. (2000). Although Hallauer et al. (2002) and Bickel (2001) both use nearly the same prevalence rates and the 9$^{th}$ population projection, Hallauer et al. (2002) projects much higher numbers of demented people. He uses variant 2a, where higher life expectancy and migration is assumed compared with the medium variant Bickel (2001) uses. In a second projection Hallauer et al. (2002) uses population projections from Birg et al. (2000) who assume an even higher life expectancy than the high variant from the Statistical Office and therefore the number of expected demented people in 2050 increases accordingly when constant dementia rates are applied. Priester (2004) uses constant mean prevalence rates from several studies from Bickel (1999) and the 10$^{th}$ population projection from the Statistical Office. Numbers according to this assumption are going to rise from 0.99 million in 2002 to about 2.36 million demented people in 2050. However, since the prevalence rates from Bickel (1999) only measure moderate and severe dementia, Priester (2004) estimates total numbers including early dementia of up to 5 million people in 2050. An older projection is from Kern et al. (2000) who project constant prevalence rates from the 4$^{th}$ family report from the 'Ministry of family, senior citizens, women and youth' with the 8$^{th}$ population projection from the Statistical Office. Despite this fact, the projected numbers are quite high – they

increase from 1.3 million in 1997 to 2.2 million in 2030. On the one hand the population projection underestimates the aging effect, but on the other hand the rates from the 4th family report from 1986 which where taken as dementia prevalence rates actually comprise 'psychiatric illnesses' in general and thus overestimate dementia prevalence.

Table 1: Dementia Projections for Germany

| | 2000 | 2020 | 2030 | 2040 | 2050 |
|---|---|---|---|---|---|
| Kern & Beske 2000 | 1.3** | 1.98 | 2.21 | | |
| Bickel 2001 | 0.93* | 1.39 | 1.56 | 1.81 | 2.05 |
| Bickel 2002 | 0.94 | 1.41 | 1.69 | 1.92 | 2.29 |
| Hallauer et al. 2002 [1] | 1.13 | | 1.95 | | 2.8 |
| Hallauer et al. 2002 [2] | 1.13 | | | 3.0 | 3.5 |
| Priester 2004 | 0.99*** | 1.5 | 1.74 | 2.03 | 2.36 |

*1996, **1997, ***2002
[1] Prevalence Rates from Bickel 2002, Population from 9th projection Statistical Office
[2] Prevalence Rates from Bickel 2002, Population from Birg et al. 2000

**Costs of Dementia**

In Germany the total cost of illness in 2004 added up to € 224.9 billion (10.6% of the GDP) (Statistisches Bundesamt & Robert Koch Institut 2007). 10,1% of these total costs (€ 22.8 billion) were spent for mental and behavioural disorders, the fourth largest cost group after diseases of the circulatory system, diseases of the digestive system (including diseases of oral cavity, salivary glands and jaws) and diseases of the musculoskeletal system and connective tissue. Within the group of mental and behavioural disorders dementia accounts for € 6.1 billion of the costs. (Weyerer 2005). However, these are only direct costs. Costs of dementia and AD are usually classified into direct, indirect and intangible costs (Moise et al. 2004). The main driving factor which makes dementia one of the most costly disease groups are the indirect costs such as unpaid care by family members and the lost added value of the national economy. Direct costs are driven by institutional care. Medical diagnosis and treatment play only a minor part for the costs. In the last month of dementia the care within the family is barely feasible and many patients have to move into institutions (e. g. in Germany about 80% (Bickel 2001)). Not only the very high indirect costs make it difficult to estimate the total costs of dementia, also other hidden costs have to be included, such as health problems of caregivers (stress and depression), higher average hospital costs of dementia patients, co-morbidities and underdiagnosis (Schwam et al. 2007, Weyerer 2005).

Total cost estimations for the about 1 Million demented people in Germany range from € 10 to 44 billion per year (Bischoff et al. 2004, Hallauer et al. 2000, Hessel et al. 2004). E. g. Hessel et al. (2004) take yearly costs of € 30,700 per patient with brain disorders into account which add up to total costs of € 27.8 to 37.7 billion in 1994. Hallauer et al.

(2000) calculate more than € 43,700 total costs per year per AD patient. The costs comprise of 67.9% indirect costs from family care, followed by 29.6% from the long-term care insurance (GPV) and 2.5% from the public sickness funds (GKV). They furthermore differentiate the costs for AD for several severity grades measured with the MMSE scores of 21-26, 15-20, 10-14, and 0-9. While costs for the GKV stayed nearly constant, the burden for the GPV and the family increased steeply with less MMSE scores. Yearly contribution of the GPV in the early state was about € 3,000 and increased to about € 23,000. While the family had no care effort in the early state it increased to 2.75, 9.85 and 13.94 hours per day, respectively, which equals expenses (mainly lost income) of about € 12,500, 46,000, and 68,000 per year. The total amount in the early stage of cognitive decline adds up to less than € 5,000 per year and increases to more than € 90,000 per year.

Costs estimations per person often have a wide range. Bickel (2001) analyses international studies and finds yearly costs of dementia per patient ranging from about € 25,000 to 50,000 (2). Moise et al. (2004) analyse total costs for AD for 5 studies conducted in OECD countries. Costs range from US $ 19,529 in Spain to US $ 44,301 in the US. The direct costs in all countries increase with the severity grade, however, this is not for all studies the case for indirect costs. With the severity of the disease also the institutionalization of patients increases and therefore the informal caregiver may increase paid working hours. The costs are shifted from the family to the society (Sadik et al. 2003).

Wimo et al. (2007) estimate the total worldwide societal costs of dementia on the basis of 29.3 million people in the year 2005 to about US $ 315.4 billion. The costs can be split into direct costs: US $ 210 billion and indirect costs for informal care: US $ 105 billion (33%). For the direct costs a relationship between costs per demented person and GDP per person is assumed. Informal care costs are difficult to estimate, because there often is no market value for caregiver time. The authors use the UN classification of working activities group 07900 'providing unpaid caregiving services to household members' (International Monetary Fund 2007). An institutionalization rate of 27% was taken into account which, however, increased to 50% in a sensitivity analysis.

**Cost Projections of Dementia for Germany**

Only few cost estimations exist for Germany. Hessel (2004) estimates average costs of € 34.6 billion for the year 1994 (average costs per patient with brain disorders of € 30,700). Under constant conditions costs would add up to € 60 billion in 2020 and more than € 100 billion in 2050. For the US Schneider et al. (1990) also project a steep increase of the costs for dementia until 2040 by about 150% to 300% according to different mortality assumptions.

## 3. Data and Method

### Data

In 2007 data from the public sick funds about more than 2 million people (Stichprobendaten von Versicherten der gesetzlichen Krankenversicherung nach § 268 SGB V) (Lugert 2007) were made available for open research by the research centers from the German Statistical Office. It is possible to analyse the complete medical ambulatory and stationary treatment during the year 2002, diagnosis, costs, pharmaceutical prescriptions by age, sex and region.
This unique data set was drawn on the basis of more than 350 sick funds. 23 regional associations of statutory health insurance physicians (Kassenärztlichen Vereinigungen (KV)), the German Federal (Social) Insurance Authority (Bundesversicherungsamt (BVA)), the National Provider of Social Security Services (Bundesversicherungsanstalt für Angestellte (BfA)), and the German Institute of Medical Documentation and Information (Deutsches Institut für medizinische Dokumentation und Information (DIMDI)) participated in the data collection process (translations used from (Kassenärztliche Bundesvereinigung 2007)). The 3% random sample is based on a birthday sample. Every person born on the 11$^{th}$ day of any of the 12 month is included in the data.

In general our data resembles that of the total German population very well. There are 2,301,015 people in the sample, 1,226,736 females (53.3%) and 1,074,279 males (46.7%). 51.1% of the total German population are women and 48.9% men on January 1$^{st}$, 2003. 18.2% of the German population live in the Eastern part, 81.8% in the Western part (Human Mortality Database (1)), represented in our sample by 413,233 people from East Germany (18.0%) and 1,887,782 (82.0%) from West Germany. The death probability is slightly higher with 1.14% in the data compared with 1.02% in the total population. The differences between the data and the total population can be ascribed to the different age profiles of people insured in public and in private sick funds. People in private sick funds are on average younger (Niehaus 2006). The age structure in our sample is slightly older than in the total population, e.g. 24.0% of the total population are older than 60 years in 2002, which applies to 25.0% of the people in our data. 320 people in the data are aged 100 or above - 0.014%, in the total population the proportion is 0.008% (Human Mortality Database (1)). Therefore our data comprises more women and more death occurrences.

Of the total German population 70.7 million people, about 86%, are insured in public sick funds in 2002. 8.0 million people, nearly 10%, are privately insured. Of the remaining 4% most are eligible for benefit because they are on welfare (‘anspruchsberechtigt als Sozialhilfeempfänger’) and some are covered in the public welfare of police, German Federal Armed Forces or alternative civilian service (Freie Heilfürsorge der Polizei, Bundeswehr und Zivildienstleistenden). Only about 188.000 people (0.23%) are not insured in 2003 (Statistisches Bundesamt & Robert Koch Institut 2007), primarily because their income is well above the assessable income limit (Beitragsbemessungsgrenze) beyond which people can choose their insurance mode (Wahner et al. 1997).

## Method

Diagnoses in the data are encoded according to the 'International Classification of Diseases and Related Health Problems' (ICD), 10th Revision (World Health Organization 2006).
Dementia here was measured when either of the diagnoses are asserted:

- F00 Dementia in Alzheimer's disease
- F01 Vascular dementia
- F02 Dementia in other diseases classified elsewhere
- F03 Unspecified dementia
- G30 Alzheimer's disease

The prevalence is measured as any ambulatory or in-patient dementia diagnosis during the year 2002 (3). Furthermore, mortality rates for not demented and demented people are calculated. Data for the starting population in 2004 is taken from the Human Mortality Database (age- and sex-specific population size and death rates) (1).

A methodological problem appears when calculating the costs of dementia. Costs in this data are given per doctor visit. Since co-morbidity is increasing with age and high for people with dementia it is thus not possible to calculate the single costs of the disease but the total costs per dementia case with accompanying diseases.

For the population projection the program ‘Population - Development – Environment’ (PDE) was used which was developed at the International Institute for Applied Systems Analysis IIASA in Laxenburg, Austria (Dippolt et al. 1998). The population was projected with single-year age-groups until age 104, the last age group is 105+. For further calculation 5-year age-groups were combined with the highest age-group 100+.

The cost development of dementia depends on three main aspects: first of all the general population development, secondly the development of the dementia prevalence and thirdly the costs of the disease. Three different population developments were projected. In a first model constant mortality rates (P1) are taken to show the effect of a status quo development. Two further models show the more likely variants with an increase in life expectancy to 86 for males and 90 years for females (P2) and 88 for males and 92 years for females (P3). The dementia prevalence rates of the year 2002 are then applied in order to see the increase in the number of demented people. Again, three different assumptions are made: a constant model (D1), and two models with a yearly decrease of dementia of 0.1% (D2) and 1.0% (D3), respectively. The obtained age- and sex-specific numbers of demented people are multiplied with the age- and sex-specific mortality rates and in a last step these numbers are multiplied with the mean costs of the respective surviving or not surviving age- and sex-specific group. Because the future costs of dementia depend on many medical and economic factors which are hard to predict, constant costs were projected.

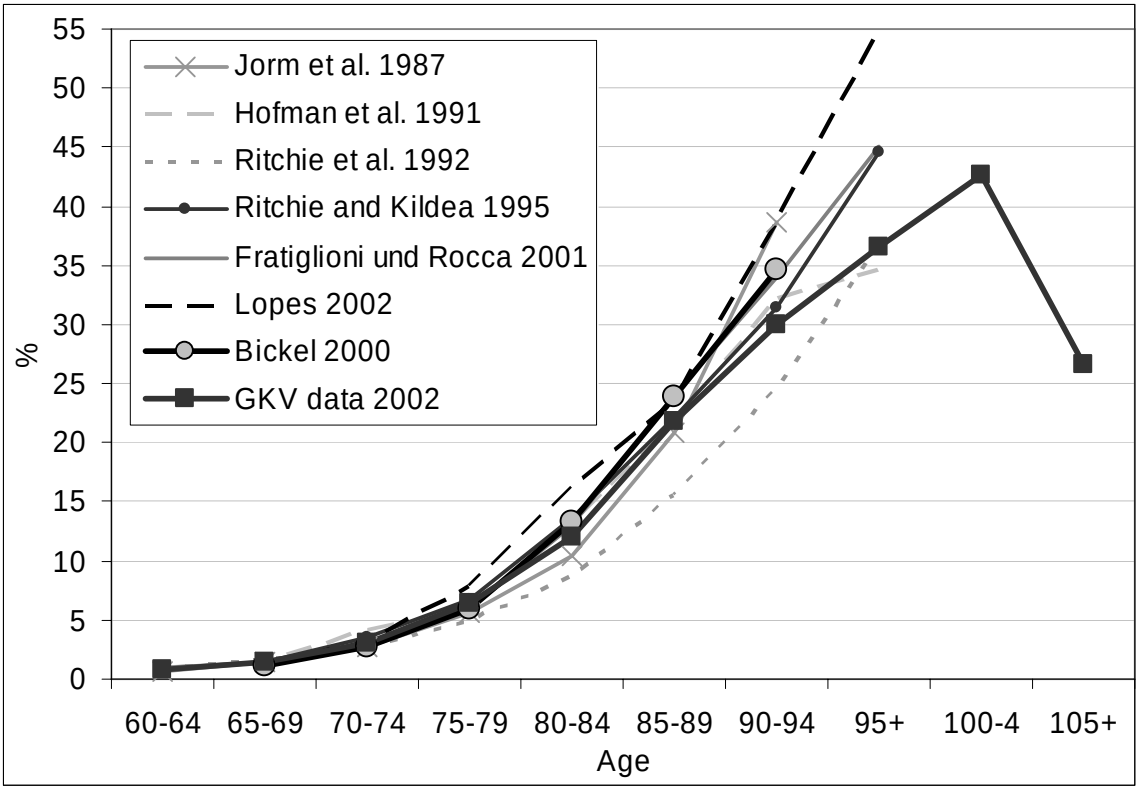
A final projection of the total dementia costs combines own population projections with average cost calculations from Hallauer et al. (2000) of € 43,700 per patient.

## 4.1 Results

### Prevalence of Dementia in Germany in 2002

The prevalence rate we obtain is in the middle of international results, as is shown in figure 1 (GKV data 2002). The rate increases from 0.7% for people aged 60 to 64 to 42% in 100 to 104 year olds. The results are very close to the rates Bickel (2000) gets when he calculates the mean of meta-analyses. The large sample size allows an extension of the rate up to ages 105+ where the rate does not increase anymore. A higher rate for women and in higher ages for East Germans is found (not shown). Expressed in numbers we find that about 1.05 million Germans suffer from any dementia in 2002.

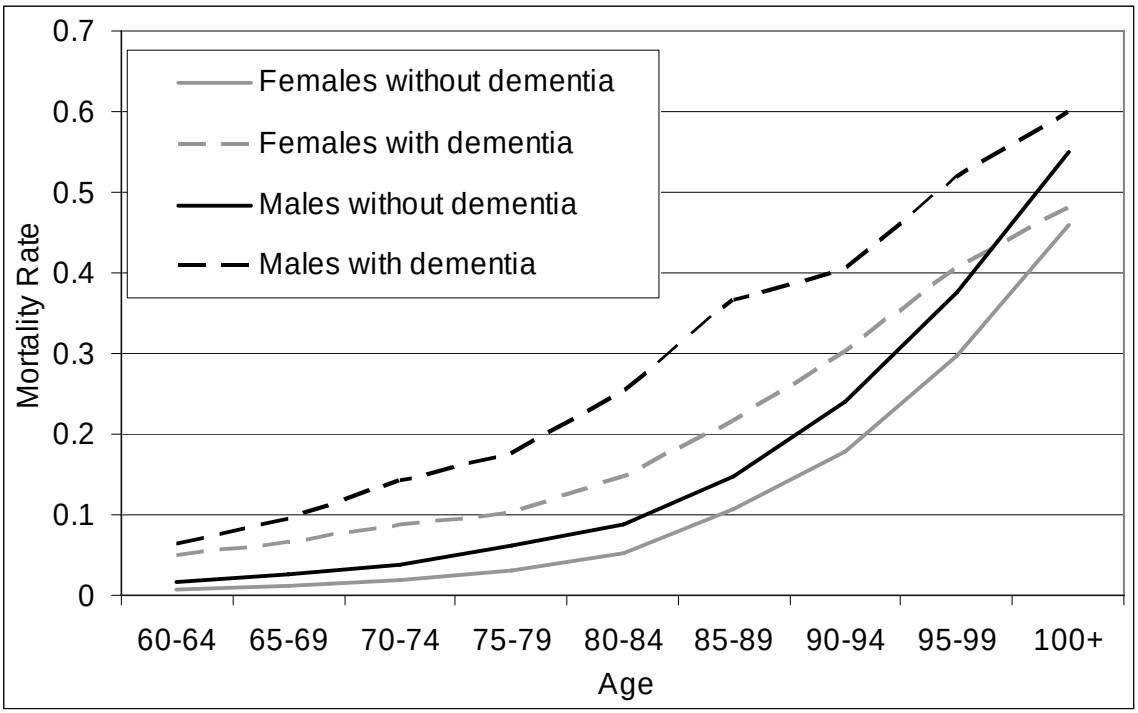
Figure 1: Prevalence of Dementia in Germany in Comparison with Meta-Analyses



**Mortality Rates of Demented and Not Demented People**

The gender difference that is usually found between males and females persists for demented people and is even more pronounced. The excess mortality within the genders, however, is higher for females. The rate at ages 60-64 is about 7 times higher for demented than for not demented women, for men 4 times higher. At age 95-99 the rate is for both genders still about 1.4 times higher, only in the highest age group the difference nearly vanishes.

Figure 2: Mortality Rate by Health Status and Gender



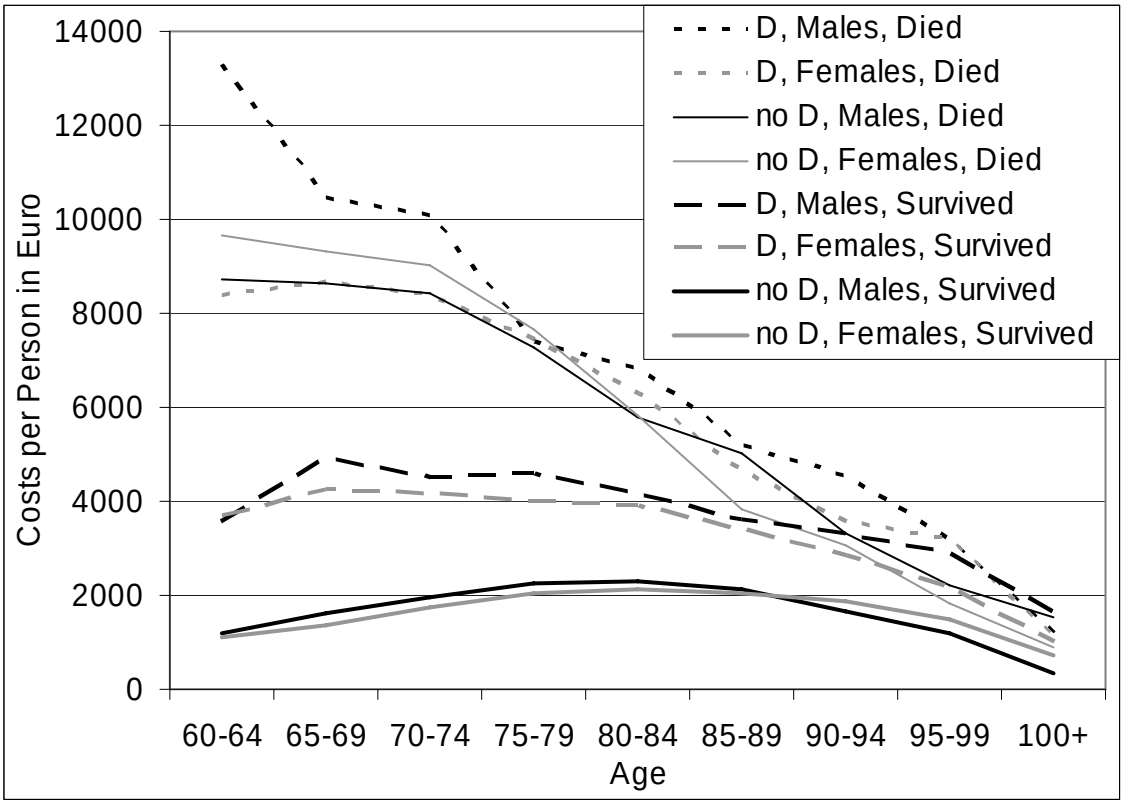

**Costs**

Figure 3 shows the differences in the costs between demented and non-demented males and females, additionally taking into account if people survived this year or not. Death is the main cost factor. Especially in younger ages costs for people who die in that year are higher and range between € 8,385 (9,652) on average for women aged 60-64 with (without) dementia up to € 13,280 (8,739) for males aged 60-64 with (without) dementia. Costs are decreasing with every age group to less than one third above age 95. The difference between costs for demented and non-demented people who died is small. It is slightly higher for males, for females only above age 80. For surviving people a stronger cost effect appears - people with dementia cause costs which are on average about twice as high as for people without dementia and which is higher at younger ages. 60-64 year

old males and females with dementia cause average costs of € 1,212 and € 1,093. With dementia in the same age group more than three times the money is spent: € 3,582 for males and € 3,696 for females. Cost differences for demented and not demented people do not converge as strongly with age as cost differences between surviving and dying people. The decreasing difference between the groups with the lowest and highest spending (surviving males without dementia (€ 324) and surviving males with dementia (€ 1,678)) above age 100 is mainly due to decreasing dying costs.

Also noticeable is that the costs are always higher for males, except for surviving males above age 90. Within the regions the costs are higher in West than in East Germany (not shown). Costs are highest between ages 60 to 84, and decrease thereafter. Before age 60 costs of death are higher, general treatment costs are lower, also for demented people (not shown).

Figure 3: Age- and Sex-Specific Costs of Demented and Not Demented People according to Survival Status




D=Dementia

## 4.2 Projection Results

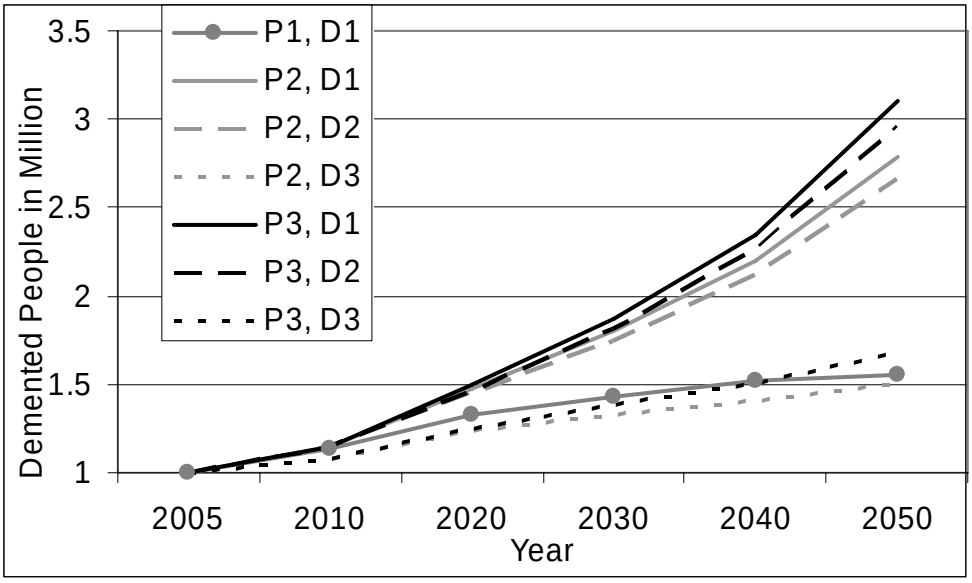
### Population Projections

The German population above age 60 is projected from 2004 until the year 2050. If mortality rates would stay constant the change in population size would only result from earlier fertility changes. In 2004 20.44 million people were aged 60 and above, which increases to 25.96 million in 2030 and decreases again to 21.89 million in 2050. When life expectancy is increasing to 86 (88) and 90 (92) years for males and females, respectively, the number of people above age 60 would increase to 28.84 (30.31) million in 2050.

### Projection of Demented People

When constant dementia prevalence rates are assumed, only the expected number of elderly people influences the change in the number of demented people. Even with the constant mortality the number of demented people above age 60 would increase from 1.00 million people in 2004 to 1.55 million simply because of the changing age structure. With higher life expectancy the increase is much higher: constant dementia rates and an increase in life expectancy to 86 (88) and 90 (92) years for males and females,

Figure 4: Projected Number of People With Dementia According to Different Models



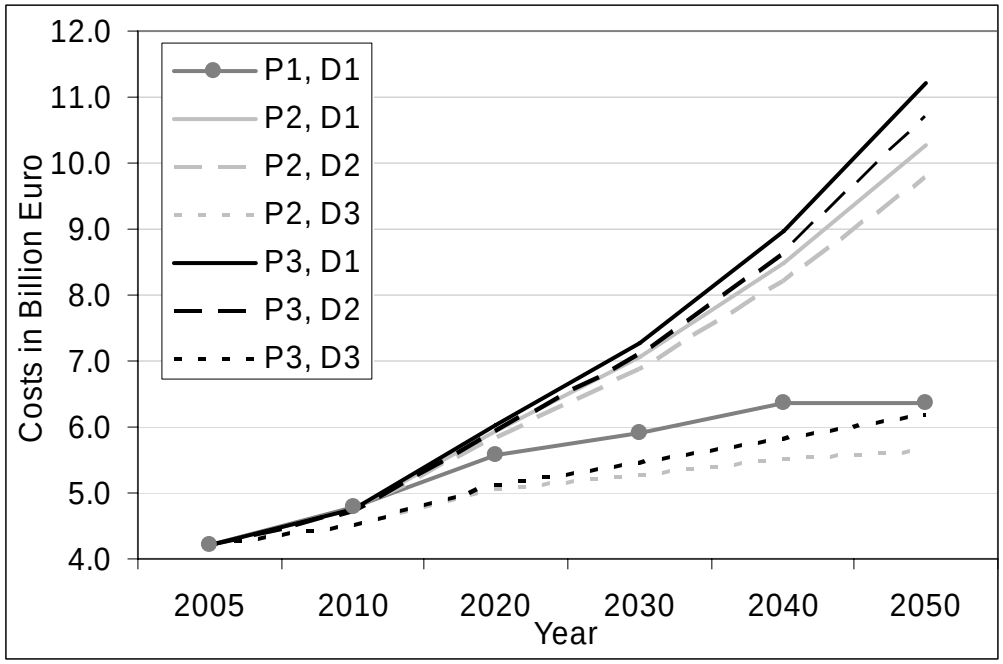

P1 constant mortality
P2 life expectancy increases to 86 (m) and 90 (f) years in 2050
P3 life expectancy increases to 86 (m) and 90 (f) years in 2050
D1 constant dementia prevalence rate
D2 decrease in dementia prevalence of 0.1% per year
D3 decrease in dementia prevalence of 1.0% per year

respectively, would lead to 2.79 (3.10) million demented people in 2050. Only a yearly decrease of dementia prevalence rate of 1% would keep the expected numbers on about the same level as if no increase in life expectancy would occur. The results are displayed in figure 4.

**Cost Projections: Ambulatory and In-Patient Costs of Dementia**

Figure 5 shows the sum over all groups: age- and sex-specific dementia rates were differentiated into those people who survived and those who died and multiplied with the average costs of each group. As shown above huge differences exist between those who survive and those who die, furthermore gender and age play an important role. When all factors are taken into account, total ambulatory and in-patient costs add up to € 4.2 billion in 2002. (The total population above age 60 is taken into account, not only those insured in public sick funds in 2002. For the other 14% privately or otherwise insured equal costs and rates were assumed. Otherwise about € 3.6 billion are allotted to the GKV.) The costs are going to increase steeply. The constant mortality model shows the age-structure effect were an increase to about € 6.4 billion would occur. When the life expectancy increases without any prevalence changes costs would increase steeply to € 10.3 billion (P2, D1) and € 11.2 billion (P3, D1). Only a decrease in the prevalence of dementia of about 1% (D3) per year could keep the cost increase below 50%.

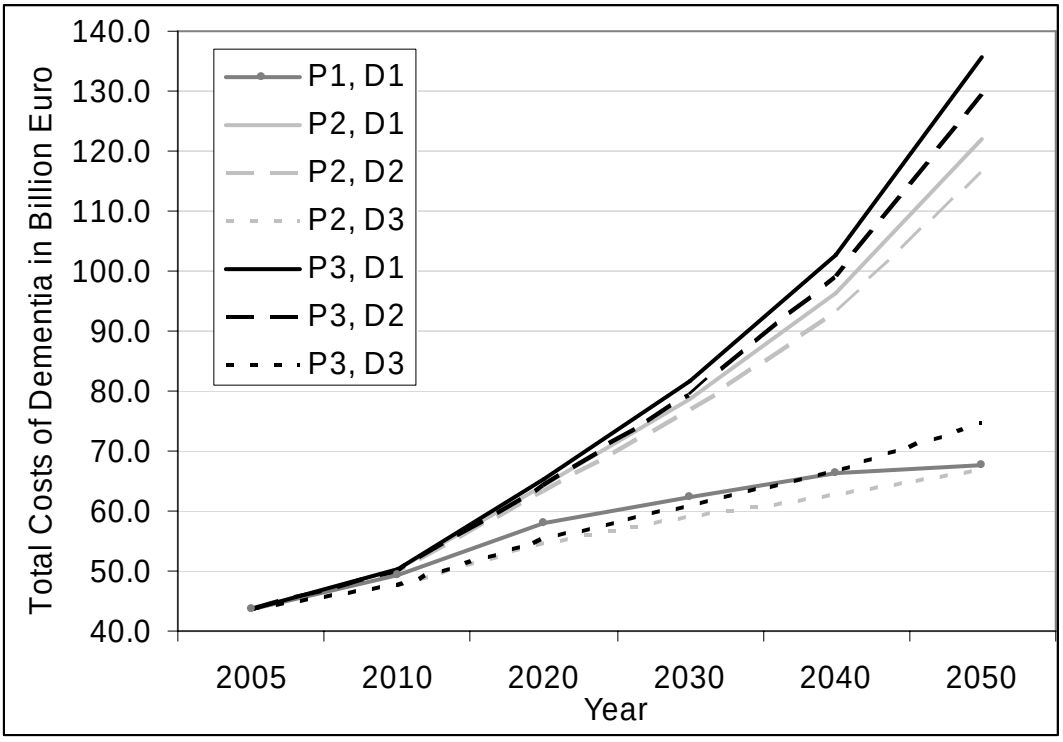
Figure 5: Projection of Ambulatory and In-Patient Costs of Dementia According to Different Models



**Cost Projections: Total Costs of Dementia**

The result of the total costs projections of dementia, calculated from own population projections of people with dementia and the average cost estimations per patient from Hallauer et al. (2000) is displayed in figure 6. The about 1 million demented people today cause total costs of € 43.8 billion. According to the different models these costs are going to increase to at least about € 70 billion when the prevalence can be compressed. When it stays constant and life expectancy increases, constant total costs would triple to about € 122 billion (P2, D1) or € 136 billion (P3, D1), respectively.

Figure 6: Projection of Total Costs of Dementia According to Different Models*




*The projections are based on average cost estimations per person of € 43,700 from Hallauer et al. (2000) and own population projections

## 5. Discussion

The unique data-set with its very large sample size offers the opportunity of detailed analysis of dementia in the German population. Here the prevalence of dementia, the mortality rate for not demented and demented people and the costs of ambulatory and in-patient dementia are calculated. The results are combined with a population projection in order to project people with and without dementia and ambulatory and in-patient and total costs of dementia.

The increase in the total elderly population (28.8 and 30.3 million people above age 60 in 2050 according to P2 and P3, respectively) is only slightly lower than predicted from the Statistical Office (2006). They calculate an increase for the basic variant to 27.8 million and for the high life expectancy variant to 29.7 million people. This might be mainly due to migration assumptions, the Statistical Office assumes in these variants a net migration of +100,000 (variants W1, also variants with 200,000 immigrants (W2) are calculated), we do not take migration into account. Our assumptions for the increase in life expectancy are slightly higher than the ones used from the German Statistical Office for the 11$^{th}$ coordinated population projection. For the basic variant there is a rise to 83.5 and 88.0 years for males and females, respectively, for the high increase variant to 85.4 and 89.8 years (Statistisches Bundesamt 2006). However, these assumptions could be seen as conservative (compare e. g. Schnabel et al. (2005)) and therefore we use higher life expectancies.

The prevalence rate we obtain seems to resemble that of other studies very well, especially that of Bickel (2000) where the mean of meta-analyses is determined. All studies agree on the fact that age is the biggest risk factor for developing a dementia (Bickel 2003, 2005, Fichter et al. 1995, Fratiglioni et al. 1999, Hatada et al. 1999, Kokmen et al. 1996, Mortimer 1983, Nitrini et al. 2004, Ravaglia et al. 2005, Ritchie et al. 1992, Rocca et al. 1999, Weyerer 2005) which is confirmed in this study. Before age 60 or 65 it is negligible, very few people suffer from presenile dementia. Bickel (2005) estimates that about 20,000 people are affected, our results show a higher number of about 130,000 people which might be due to a higher uncertainty of diagnosis especially at younger ages when the disease can be confused with depression or other mental problems. However, uncertainty about the number of presenile dementia is high. After age 65 the increase of prevalence is steep. The prevalence in meta-analyses seems to double every five years from about 2% for ages 65 to 69 to 8% to 13% for ages 80 to 84 and 25% to 42% for ages 90+. Our data allows extension of the highest age group to ages 105+. In the age group 100-104 we find a prevalence of 42%, in the highest age-group 105+ it is decreasing to 27%, however, the sample is small (15 people, 4 diagnosed with dementia) and uncertainty might be high: on the one hand normal cognitive aging is difficult to define at that age and furthermore difficult to distinguish from cognitive impairments. On the other hand mortality is high and people might die before a diagnosis is made. High institutionalization at that age might play a role: when people have a high multi-morbidity and are bed-ridden the care need is already very high and a further diagnosis of dementia would not change the handling of the patients. However, another explanation could be that the rate is truly stabilizing or even decreasing due to a ‘survival of the fittest’. There is a discussion going on about an age- or aging-relatedness of the disease, ignited by Ritchie (1995) which, however, due to space constraints, cannot be entered here. We find a higher rate for females than for males which increases with higher ages (not shown here, in the highest age group 100 to 104 the difference is 14% with a prevalence for males of 30% and for females of 44%) which is not always confirmed in the literature. For an overview of gender as a risk factor for dementia see e. g. Muth et al. (2007). Besides age only some genetic factors are approved risk factors for AD and dementia (Jorm 1995, Bickel 2005). Many other risk factors have been looked at which show some consistency, others have initiated lively controversial discussions.

They are too numerous to list them here and not purpose of this study. A short overview can be found e. g. in Muth et al. (2007).

Multiplication of the prevalence rate with the total population results in a number of about 1.05 million demented people for Germany in 2004 which resembles that of other estimations very well (e.g. Bickel 2005). However, it is difficult to estimate the true number of demented people. The result might still be an underestimation: on the one hand there has been a rising awareness of the disease which might have led to earlier diagnoses. On the other hand the meta-studies Bickel (1999, 2000) uses for his estimation of a mean prevalence rate usually comprise moderate and severe cases. Priester (2004) estimates the actual number of demented people including mild cases to about 1.2 to 2.0 million in 2002. When the first symptoms appear it is often difficult to differentiate between normal cognitive aging and a beginning dementia. Many general practitioners might be overstrained to diagnose the illness in its early state correctly and do not refer patients to neurologists which would lead to an underestimation of true cases.

Besides the prevalence rate of dementia we need mortality rates of the not demented and the demented population for the costs projections. Demented people have a much higher mortality as can be seen in figure 3 and is consistent with literature findings (Dewey et al. 2001, Kokmen et al. 1996, Bickel 2005, Kliegel et al. 2004, Wilson et al. 2003, Werner 1995, Jagger et al. 2000). It might be higher in VaD than AD (Dewey et al. 2001) and also being male, older and having more severe dementia especially affects survival negatively (Heyman et al. 1997, Bickel 2005). The excess mortality is highest in younger ages and decreased with increasing age. In a literature review Dewey et al. (2001) do not find significant results, probably also due to study designs and small samples, but they conclude that the data suggests a slower increase of the mortality risk for people with dementia compared to those without. Starting from a much higher level our results find strong evidence for a slower rise in mortality for demented people, which might most probably be due to the competing risk of other diseases in higher ages. A clear gender difference can be seen as well – the rate ratio difference is higher for females than for males. The higher mortality risk of males compared with females might lower the excess risk to die from dementia because they already have a higher risk to die from another disease.

In figure 3 one can see that it is important for the cost estimation to differentiate between people with and without dementia and furthermore if people survive the year or not. When looking at the costs of illnesses it is often crucial to differentiate between surviving and dying people. Death is an important factor for the costs, the period before death is often marked by acute treatment and/or hospitalization which is more expensive than general doctor visits. Many studies find that proximity to death is the main driving cost factor (Lubitz et al. 1993, Brockmann 2002). The small cost difference between people who die with and without dementia confirm this. The acute treatment causes the highest costs, especially in younger ages. The large age gradient might on the one hand be causes because older people are weaker, have a different disease pattern and higher co-morbidity and therefore might die quicker (and less costly). On the other hand, however, also a cost rationing is found: elderly patients often receive less costly treatment than younger

patients with the same disease; the effect is stronger for those who die (Brockmann 2002). The surviving people show that dementia causes higher ambulatory and in-patient costs which is caused by a high number of regular doctor visits, high drug costs and high in-patient costs (Hallauer et al. 2000). Hallauer et al. (2000) calculate detailed dementia costs for different severity states of dementia and show that in more moderate states especially doctor visits and drug costs are high and in more severe states in-patient care increases. On average he finds ambulatory and in-patient costs per patient of € 1,311 (2) which is lower than the € 3,890 we obtain. However, our costs also comprise the accompanying diseases. Costs are usually higher for males than for females except for surviving males without dementia above age 90 and males without dementia who died before age 80. Selection effects might leave the fittest males which need less health care. Presenile dementia is not very common and therefore left out of the cost projections. It seems to be less costly than dementia between ages 60 and 95 (which could also be a comorbidity-effect in higher ages), however, numbers are low and strong fluctuations appear.

The ambulatory and in-patient costs for the population above age 60 with dementia in 2004 sum up to € 4.2 billion. They are going to rise in future, even when a compression of dementia prevalence rates occurs. The aging of the population has the largest impact on the cost development (when constant costs are assumed).

According to Hallauer et al. (2000) these ambulatory and in-patient costs account only for 2.5% of the total costs. It is the very high indirect costs that make dementia one of the most expensive diseases and let the average total costs of an AD patient amount to € 43,700. When this value is taken into account the total costs for dementia in 2004 would sum up to € 43.8 billion. This is in accordance with other cost estimations, e. g. Hessel et al. (2004) (€ 34.6 billion for the year 1994) and a little higher than Bischoff et al. (2004) (€ 10-25 billion).

With constant costs the amount would triple to about € 122 billion when life expectancy is increasing to 86 years for males and 90 years for females and no changes in the dementia prevalence would occur (P2, D1). A tripling of the costs was also projected by Hessel et al. (2004) for the same time span of 46 years between 1994 and 2040. Still a compression of the prevalence by 1% per year would lead to a nearly twofold increase in costs to about € 70 billion (P2, D3; P3, D3). It is very arguable to take the same average cost per patient while it was just shown that the costs of the disease are dependent on the disease stage, the age of the patient and the proximity to death. However, it is an average estimation over all patients and a calculation example how the costs would develop under these conditions. The indexed increase for the two different cost calculations is shown in table 2. The increase in ambulatory and in-patient costs until 2050 is 51% for the constant scenario P1, D1 and 166% for the scenario with the highest gains in life expectancy but a constant dementia rate P3, D3. The increase is higher for the total costs: 55% for the constant scenario and 210% for scenario P3, D3. The shift of the age structure could be taken into account for the ambulatory and in-patient cost calculations. Higher ages have been shown to cause lower ambulatory and in-patient costs. However, it would not be correct to apply the age-, sex- and mortality-specific increase proportion of the

ambulatory and in-patient costs, because the indirect costs might have a completely different pattern. Hallauer et al. (2000) do not give age-specific costs, but costs according to the severity of dementia, which we, however, cannot measure with our data.

Table 2: Cost Increase (Index) in Ambulatory and In-Patient and Total Costs of Dementia According to Different Models until 2020 and 2050

| | 2020 | | 2050 | |
|---|---|---|---|---|
| | Amb. Costs* | Total Costs | Amb. Costs* | Total Costs |
| P1, D1 | 132.3 | 132.8 | 151.3 | 154.9 |
| P2, D1 | 141.0 | 146.8 | 243.5 | 278.5 |
| P2, D2 | 138.9 | 144.6 | 232.6 | 266.0 |
| P2, D3 | 119.8 | 124.8 | 133.9 | 153.2 |
| P3, D1 | 142.8 | 149.0 | 266.2 | 309.7 |
| P3, D2 | 140.7 | 146.7 | 254.2 | 295.8 |
| P3, D3 | 121.4 | 126.6 | 146.4 | 170.3 |

* Ambulatory and In-Patient Costs

Costs projections of dementia are very difficult for several more reasons. Costs do not only depend on the development of the number of people with the disease, but also on the care arrangement, the change of mortality, the economic development and medical progress (Comas et al. 2003, 2006). The care arrangement is dependent on the familial situation of the patient. Do spouses and children exist who are able and willing to care? Institutional care is very expensive, but also caring of a spouse or parent causes a loss of gross national product. If mortality decreases a longer period with dementia could mean higher costs. A shift of the onset of the disease has a large impact because disease costs are also shifted into higher ages. The financial situation of the GPV is dependent among other things on the economic development. Medical research is very expensive on the one hand and could have more impact than the population aging. On the other hand earlier treatment of the patients could help to delay the onset of the disease and save high indirect care costs. Thus medical progress is not necessarily going to increase health care expenditure (Brockmann et al. 2005). Already these few examples show that future cost estimations are highly arguable, unit-care costs and inflation not yet included.

## 6. Conclusion

Projections of the number of people with dementia in Germany are very important. The change in the population structure with a rise of the elderly population leads on the one hand to an increase in affected people. Results of a European study on the number of people in need of care shows that even if all years gained in life expectancy are years in good health, the number is going to increase simply because of the changing age structure (Doblhammer et al. 2006). A decreasing mortality for both groups – which is the most likely scenario - results in a larger number of not demented, but also of demented elderly people. On the other hand the number of potential caregivers is going to diminish, not

only because of the changing age structure, but also because of the increasing labor-force participation of women aged 40 to 65, which today are the main caregivers. Thus less potential caregivers are faced with more patients. In the severe state demented people are fully dependent on support. This imposes not only a high burden on the caregivers but causes furthermore financial constraints for family and society due to high opportunity costs. In the severe state often institutional care is inevitable.

With the number of patients also the costs of dementia, one of the most costly diseases, are going to rise, even under optimistic scenarios. The cost development depends on many highly variably factors. The best way to decrease costs would be to cure the disease. Today no effective treatment to cure dementia has been developed, yet, only some drugs exist that can palliate the aetiopathology about 8 to 12 month (Förstl 2008). However, promising research is going on. There is not only one mechanism researchers try to stop or even reverse, different kinds of drugs have been developed which mostly concentrate on fighting the β-amyloid plaques and the neurofibrillary tangles which destroy the brain cells. Most hope is put on vaccines which have already successfully been tested on mice (Brendza et al. 2005, Maier et al. 2006). After problems in the first human trial (Gilman et al. 2005) an improved vaccine has been developed and the results are currently awaited (Masters et al. 2006). Earlier diagnoses are important in fighting the disease. New methods improve early and reliable diagnoses e. g. of AD (Klunk et al. 2004, Ikonomovic et al. 2008) which just a few years ago have thought to be with certainty diagnosed only after death (Bischoff et al. 2004).

Further research will include improved trend assumptions about the development of dementia. Population projections will be done with incidence rates to better take changes in mortality into account. Cost development assumptions have to be adapted to these changes.

The number of demented people is going to increase due to population aging, however medical advances will most probably lower the age-specific prevalence and incidence rates which would result in a less than parallel increase in the number of demented people and a less than parallel cost increase under constant cost assumptions.

(1) Human Mortality Database, www.mortality.org

(2) The used currency in the studies was Deutsche Mark, it was converted into Euro with a factor of 2:1.

(3) In a second measure ‘unstable’ cases which were coded as dementia cases in the first and second quarter but not thereafter (and did not die) where taken out of the enumerator. The influence on the prevalence rate is small. If only persistent prevalence cases are counted the number of affected people decreases by about 50,000 to 0.99 million people. This problem is probably smaller than the underestimation of the mild dementia cases.

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