1 Epidemiologische Analyse und Bedarfsanalyse

1.1 Perspectives for Dementia Trends: Predictions Derived from Demographic Research

Gabriele Doblhammer and Uta Ziegler

The 20th century is marked by a systematic transition to low level mortality in almost all countries of the industrialized world. Life expectancy has been steadily increasing since the mid of the 19th century in most countries and best practice life expectancy – the highest recorded life expectancy in a year in a particular country – has been increasing linearly with a yearly gain of about three months (Christensen et al. 2009). Consequently, best-practice life expectancy at birth increased from about 45 years in 1840 to 86 among Japanese females in the year 2007. Even at the beginning of the 21st century, there is no sign of a deceleration in the increase (Oeppen and Vaupel 2002; Christensen et al. 2009).

While high life expectancy is one of the major achievements of our societies, and long lives are certainly the wish of many individuals, this development poses challenges for our public health and social security system. With the risk of dementia increasing exponentially with age, the future number of dementia patients depends on the current age structure of the population as well as on future gains in life expectancy, and on the medical and technological innovations which may postpone dementia. The latter two factors are characterized by a certain amount of insecurity concerning their future trends, however, in the past achievements they have always been underestimated (Oeppen and Vaupel 2002).
Despite the overall positive trend in old-age mortality there has recently been a divergence in European countries which can be interpreted as the beginning of a new stage of health transition (Meslé and Vallin 2006). In France, the expected years of life of the oldest-old (ages 85+) still increase and lead to an additional rise of the already high female life expectancy. This phenomenon seems to be a result of a general decrease of all major causes of death, especially because of the high reduction in cardiovascular mortality (Vallin and Meslé 2004; Meslé and Vallin 2006). In contrast, the increase in life expectancy in the Netherlands and Denmark has been decelerating at high age. The major causes of the deceleration among Dutch women are lower reductions in cardiovascular diseases and increases of other causes of death including mental diseases such as dementia (Nusselder and Mackenbach 2000).
Trends in Health

While life expectancy is an indicator that can be easily calculated for most developed countries by using official vital statistics, health is a more complex measure and several indicators are needed to capture trends in health (Verbrugge and Jette 1994). In addition, studies of health trends are complicated because indicators of health have been applied inconsistently, study designs, participation rates, and the wording of questions has changed over time and the institutional population is excluded from many studies. A review of recent trends (Christensen et al. 2009) finds that up to age 85 limitations and disabilities have been postponed to higher ages despite an increase in chronic diseases and conditions. The result is that people younger than 85 are living longer and, on the whole, are able to manage their daily activities for more years than previous cohorts.

Among the oldest-old the situation is less clear. Data are sparse and results are contradictory with improvements among Danish cohorts born at the beginning of the 20th century (Engberg et al. 2008) and deterioration among the Japanese oldest-old (Suzuki et al. 1995). Recent research shows that exceptional longevity does not necessarily lead to exceptional levels of oldest-old disability (Christensen et al. 2008). While on the individual level disability increases with age, on the aggregate level of a cohort the proportion of independent individuals declines only slightly between age 92 and 100. The reason is that high mortality of frail individuals leaves only the most robust to survive. Thus, on the societal level exceptional longevity does not lead to exceptional disability levels and the overall health characteristics of the cohort remains almost unchanged with age.

Trends in Dementia

With the ongoing population ageing more and more attention is paid to the diseases of the nervous and mental system. Mental and behavioural disorders represent four of the ten leading causes of disability worldwide and are estimated to account for 12% of the global burden of diseases (World Health Organization 2001). European and Northern American studies show that about one-quarter of the population at age 65 and older suffer from a mental health problem. About 6–10% of these illnesses involve severe dementia and severe functional psychoses (Bickel 2003; Hendrie 1998). In general, little is known about trends in cognitive function and dementia, as well as about country differences due to changes in coding practices over time. This is not only true for mortality from dementia but also for the incidence and the prevalence of the disease (Ziegler and Dobhammer 2009; Christensen et al. 2009). Freedman et al. (2002) report a reduction in cognitive impairment in the mid-1990s in the USA, which, however, was mainly the result of learning effects and methodological changes over time. Manton et al. (2005) report a fall in severe cognitive impairment of 55% for men and 45% for women between 1982 and 1999, which was caused by a decrease in the incidence of mixed dementia but not Alzheimer’s disease. Langa et al. (2008) show a compression of cognitive morbidity between 1993 and 2004 for Americans aged 70 years or older, with a decreasing number of people reaching a threshold of significant cognitive impair-
ment, and increasing mortality in those with cognitive impairment. A fall of prevalences of dementia is reported for Australia between 1998 and 2003, whereas data for Japan (1998–2004) and Sweden (1988–2004) suggest an increase (Lafor
tune and Balestat 2007; Meinow et al. 2006).

One reason for the divergent trends is that the quantification of dementia is generally difficult due to different definitions and measurement methodologies. First, the term dementia is used to describe different types 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 2003; 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-quarter of all cases (European Community 2005; Weyerer 2005). Most other forms such as Morbus Pick (fronto-temporal dementia), Morbus Binswanger, dementia in Parkinson’s disease, Chorea Huntington or the Lewy body disease are termed secondary dementias because they are caused by other diseases. Together they account for less than 10% of all cases (Priester 2004; Weyerer 2005). Second, it is difficult to differentiate the disease in its early stages from the normal cognitive changes that occur at older ages (Fratiglioni et al. 2001). Over time, a growing awareness might have influenced the number of affected cases because the disease is diagnosed earlier and more often. Cross-cultural differences and intra-cultural changes over time also make it more difficult to achieve a consistent understanding of the disease.

**Projection of Dementia Cases in Germany between 2002 and 2050**

More than one million people with moderate and severe dementia live in Germany today, numbers given for the year 2000 deviate between 0.8 and 1.3 million people (e.g.: 0.8–1.3 million (Bickel 2002), 0.95 million (Bickel 2003), 1.13 million (Hallauer et al. 2000), 1.0–1.3 million (Priester 2004)). Only few dementia projections exist for Germany. Ziegler and Dobhlammer (2009) give an overview and show that all projections are based on constant prevalences of dementia (Kern and Beske 2000; Bickel 2001; Bickel 2006, 2008; Hallauer et al. 2002; Priester 2004) based on two studies by Bickel (2000, 2002). The differences found for the year 2050, which are between 2.1 and 3.5 million demented people, can therefore all be ascribed to different assumptions regarding life expectancy.

The projections shown here are based on own population projections up to the year 2050 combined with prevalences of dementia published in Ziegler and Dobhlammer (2009). Three scenarios of future trends in life expectancy are joined with two scenarios of future trends in the prevalence of dementia. In addition, the status quo projection assumes constant mortality rates and constant dementia prevalences and reveals the pure effect of the age structure of the German population with ever more people reaching old age. Scenario 1 assumes a moderate increase in life expectancy to 82.61 years for males and 87.51 for females, while scenario 2 assumes larger gains in life expectancy with 84.30 years for men and 89.08 for women by the year 2050. Scenario 3 is the most optimistic
in terms of future gains in life expectancy with 87.90 for men and 92.52 for women. Scenarios 1 and 2 use about the same assumptions for the increases in life expectancy as the ‘basic’ and ‘high’ variants from the 11th coordinated population projection of the German Statistical Office (Statistisches Bundesamt 2006). The different scenarios are combined with age-specific prevalences of dementia where either future prevalences are kept constant at the 2002-level or a decrease of 1% per year is assumed. This gives six different scenarios (Figure 2) in addition to the status quo projection, which forecasts an increase in dementia cases from 0.96 million in 2002 to 1.52 million in 2050. An increase in life expectancy according to scenario 1.1 will lead to 2.2 million cases; the very optimistic increase in life expectancy as assumed in scenario 3.1 would lead to 2.7 million people with dementia. The reduction of the prevalence of dementia by 1% per year would lead to a much lower increase between 1.5 and 1.8 million people depending on the scenario.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Number of Cases in 2050</th>
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<tbody>
<tr>
<td>Status Quo</td>
<td>1.5 Mio.</td>
</tr>
<tr>
<td>Scenario 3.1</td>
<td>2.7 Mio.</td>
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<tr>
<td>Scenario 2.1</td>
<td>2.4 Mio.</td>
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<tr>
<td>Scenario 1.1</td>
<td>2.2 Mio.</td>
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<tr>
<td>Scenario 3.2</td>
<td>1.8 Mio.</td>
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<tr>
<td>Scenario 2.2</td>
<td>1.6 Mio.</td>
</tr>
<tr>
<td>Scenario 1.2</td>
<td>1.5 Mio.</td>
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Figure 2: Projection of the number of people with dementia according to different scenarios
Assumptions for 2050: Life Expectancy/Dementia Prevalence:
Status-Quo-Projection: Males 75.9, Females 81.5, constant prevalence
Scenario 1.1: Males 82.6, Females 87.5, constant prevalence
Scenario 1.2: Males 82.6, Females 87.5, decreasing prevalence by 1% per year
Scenario 2.1: Males 84.3, Females 89.1, constant prevalence
Scenario 2.2: Males 84.3, Females 89.1, decreasing prevalence by 1% per year
Scenario 3.1: Males 87.9, Females 92.5, constant prevalence
Scenario 3.2: Males 87.9, Females 92.5, decreasing prevalence by 1% per year
Conclusion

Regardless of future trends in the prevalence of dementia there will be a strong increase in dementia cases. There are two reasons: First, the age structure of the population is already set and the large cohorts of the baby boomers will reach oldest-old age by 2050. Thus, the average age of the elderly is inevitably going to increase. Second, future numbers of dementia cases are strongly driven by developments in life expectancy. In our projections the difference between the low and the high assumptions about life expectancy results in a difference of about 500,000 dementia cases. Only a strong reduction of the prevalence could counterbalance this increase. Our example of a 1% decrease per year still results in an increase in dementia cases between 50% and 80% by 2050. Whether a 1% decrease per year can be achieved in the near future has to remain open. A recent review (Christensen et al. 2009) shows that mobility limitations have been improving at this speed over the past decades, however, trends are not as favourable in terms of disability in the activities of daily living or of mental health.

A reduction of risk factors, healthier lifestyles, as well as medical advances will help to postpone dementia into higher ages. But this is only one side of the coin. The increase in dementia patients needs new concepts for the provision of adequate care. At present, about two thirds of people in need of care are living at home. Among those, about 68% solely rely on the help from family members (Statistisches Bundesamt Deutschland 2007). Future health policies will have to take into account that family structures are changing and that women, the main providers of care, are increasingly active in the labor force.

References

1.1 Perspectives for Dementia Trends


Prospective studies: Aids to establish early and accurate dementia diagnoses

Wolfgang Maier and Frank Jessen

Introduction

An early diagnosis of dementia is decisive to detect reversible etiologies and is critical for a most efficient and timely treatment to slow down cognitive decline. Early diagnosis, if adequately communicated, also provides the time for the preparation of the needed future care and provides the opportunity of participation of the patient in planning and decision making. Subtyping according to an Alzheimer-related, vascular, Parkinson-related or frontal etiology is also important as pharmacological treatments differ between subtypes by indication, efficacy and effect of alternative treatments.

The public health relevance of early and accurate diagnoses of dementia is increasingly recognized given the steeply rising prevalences of dementia in industrialized countries due to the growing life expectancy (Brookmeyer et al. 2007).

General practitioners (GP) play the key role in health care for the elderly. In Germany more than 90% of the general elderly population have a personal general practitioner with usually several consultations during one year. Thus, the need for accurate and timely early recognition and diagnosis of dementia is a priority topic in the primary care setting.

Currently these needs are not met in the care system. The recognition of dementia in primary care is insufficient, e.g. in the US it is estimated that at least 66% of people with dementia in primary care are not diagnosed appropriately in
an early disease stage (Boustani et al. 2007). A recent review (Bradford et al. 2009) of the available literature concludes that a missed and delayed diagnosis of dementia in primary care is common due to a series of contributing factors. Unfortunately, the full problem cannot be appreciated as the precise prevalences for missed and delayed diagnoses cannot be derived from the literature.

Barriers to a correct diagnosis in primary care have different sources (care provider, patient and caregiver system) and were extensively discussed by Bradford et al. (2009). One obstacle referring to the patients' characteristics is the severity of dementia, low levels of severity explain a substantial proportion of missed diagnoses. Another contributor derives from the common attitude among physicians that a dementia diagnosis in early stages is more harmful than helpful (because of the wrong assumption that no efficient treatments are available). Taken together diagnoses of dementia will particularly be missed among incident cases early in the disease phase with low severity of impairments and diagnostic uncertainty among doctors. Although specialists have refined tools for dementia diagnoses, they are usually contacted at a later stage – after the clinical suspicion of the GP motivated the referral to a specialist.

New insights from prospective cohort studies

The potential of prospective cohort studies with a focus on early stages for uncovering reasons for diagnostic failures are lacking; most of the available investigations cover the whole range of dementia states without specific focus on early stages. Prospective cohort studies in unselected elderly patients in primary care are particularly useful tools to fill this gap.

The German AgeCoDe study among 2177 initially undemented patients identified across a follow-up period of three years 111 patients with incident dementia. The study demonstrated that physicians apparently changed their reluctance to diagnose dementia: Surprisingly, in this study general practitioners detected more incidental dementia cases (n = 120) compared to the independent expert assessments based on well accepted gold standards (n = 111). The consistency of both diagnostic approaches turned out to be very poor: About half of the «gold standard» cases were missed by the GP (n = 56) in spite of the large number of GP diagnosed cases with dementia; on the other hand most of the GP «dementia-cases» are not allocated to the diagnosis of dementia under the «gold standard» (Pentzek et al. 2010). The specifying and sensitivity of the GP-diagnoses were 91% resp. 51%, the positive predictive value was limited to 24% (negative predictive value 99%); the interpretation of the high specificity has to take into account the high prevalence of subjects without dementia. Particularly the sensitivity of 51% is a disappointing figure given the requirement of 80% and more; the positive predictive value of GP-diagnosis for the gold standard-diagnosis also is extremely bad; thus, a lot of cases wrongly received the diagnosis of dementia. This constellation requires a comprehensive public health approach to improve diagnostic skills in dementia among general practitioners (Brayne et al. 2007).
What are the reasons for the lack of accuracy? How to improve?

Several cases were identified for under- resp. misdiagnosis: GPs missed dementia more frequently in patients living alone. In contrast, they overrated the presence of dementia more frequently in patients with problems in mobility or hearing, with memory complaints, and in patients with a GP-documented depression.

Is there a general reluctance of GPs to diagnose dementia in an early stage?

Apparently not – given the relatively large number of diagnosed cases. In more general terms: 70% of the GPs and 77% of specialists agree »that patients with dementia should be informed early because of the possibility to plan their lives« (Kaduszkiewicz et al. 2008).

Thus, physicians seem to be open to a proactive approach in early diagnosis. Yet, the same physicians were also concerned about putative adverse consequences of disclosure of the diagnoses and felt uncertain in how to handle the task. This attitude might introduce a diagnostic bias.

How to improve the diagnosis of dementia in primary care?

Diagnoses are usually based on clinical suspicion, which is highly subjective. Standardized tests fitting in the primary care setting might help to come closer to the »gold standard« diagnosis. Indeed, recently a self-administrated, time economic cognitive screening test for the detection of Alzheimer’s disease was successfully developed; specificity and sensitivity turned out to be highly satisfactory (> 90%, > 80%; Brown et al. 2009). This test can easily be applied to primary care patients for early diagnoses of dementia without consuming doctors’ time.

Detection of high risk groups

Major progress in epidemiological and biomedical research has uncovered a series of modifiable risk and protection factors (physical and mental activity, diet, social life factors); physical health and appropriate treatment of dementia associated somatic diseases also creates protection against dementia. In order to make use of these advantages, particularly for those elderly people who are not at an elevated risk, a practical definition of high risk states for dementia is needed. These high-risk states are likely to convert to dementia/Alzheimer’s disease with substantially increased probability. Is it feasible to identify those target groups for dementia prevention by the means of a general practitioner?

In the prospective cohort study AgeCoDe tools for prediction of conversion to dementia are derived which are easily accessible to dementia. Besides considering the age, these tools are mainly referring to the domains of cognition and function. It is well known that norm deviations in memory tests (objective) predict subsequent subjective dementia (Mild Cognitive Impairment; Gauthier et al. 2006). However, memory impairments preceding the first objective cognitive impair-