# Dementia and Long-Term Care – An Analysis Based on German Health Insurance Data

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## Abstract

The aim of this study is to investigate patients' transitions to long-term care (LTC) following a diagnosis of incident dementia, and to determine whether these transitions differ depending on the type of physician who made the initial diagnosis: a general practitioner (GP) or a neurologist/psychiatrist (NP).

Longitudinal claims data of the AOK are analyzed using a Kaplan-Meier estimator, a piecewise constant model, and temporary life table computations for the risk of needing LTC after the diagnosis of dementia incidence based on the diagnosing physician and the antidementia drug treatment prescribed.

NP patients have a significantly reduced risk of needing LTC relative to GP patients. After a diagnosis of incident dementia, NP patients live two to 5.2 months longer without LTC than GP patients. Antidementia drug treatment has an adverse effect on LTC, while patients who are prescribed antidementia medication have an increased risk of needing LTC.

Patients diagnosed by an NP have certain advantages relative to patients diagnosed by a GP. Further research is needed to determine whether these advantages are attributable to earlier detection or to different treatment regimens.

## Introduction

Dementia is one of the most common diseases in the elderly, with a prevalence of 1% at age 60 to 64, up to almost 40% at the highest ages of 100 years and above (Schulz and Doblhammer 2012; Ziegler 2011) In 2010, 1.4 million people were affected by this syndrome in Germany alone (Schulz and Doblhammer 2012). There is some evidence of a decline in the incidence and prevalence of dementia (Rocca et al. 2011; Schrijvers et al. 2012). Nevertheless, the number of people with dementia is expected to multiply in the next 40 years. In the context of rising life expectancy and an increasing share of people reaching the highest ages, an estimated two to three million people in Germany will have dementia in the year 2050 (Doblhammer et al. 2012; Schulz and Doblhammer 2012; Ziegler and Doblhammer 2010).

Dementia is a very care-intensive illness. Rothgang et al. (2010) have shown that 90% of all demented persons will require long-term care (LTC). Dementia and cognitive impairments are leading factors in the development of functional limitations, and, subsequently, in the need for LTC (Agüero-Torres et al. 1998; Barberger-Gateau and Fabrigoule 1997; Campbell et al. 1983; Moritz et al. 1995; Sauvaget et al. 2002). Dementia patients not only require more intensive forms of care, they also tend to need care for longer periods than care-dependent persons without dementia (Rothgang et al. 2010).

Dementia is therefore one of the most expensive illnesses that is common among the elderly (Leicht and König 2012). Cost-of-illness statistics show that 9.229 billion euros were spent on the care of demented persons ages 65 and above in 2008 (Statistisches Bundesamt 2010). The costs of dementia largely depend on the stage of the illness (Leicht et al. 2011; Quentin et al. 2010). Leicht et al. (2011) estimated that the annual net costs of dementia care are 15,000 euros for mild cases, 32,000 euros for moderate cases, and 42,000 euros for severe cases. Unlike among non-demented control subjects, the majority of the costs associated with treating demented patients arise from nursing care, including informal care. The cost of medications is also significantly higher for dementia patients than for non-demented persons, but the average number of drugs taken does not differ (Leicht et al. 2011).

The ambulatory health care sector is an essential source of medical care for dementia patients. In Germany, the ambulatory and the hospital sectors are separate. Therefore, except in cases of dementia-related accidents or comorbidities, dementia patients are not treated in hospitals. The ambulatory sector provides patients with free access to all

specialists. Nevertheless, the majority of people, and especially the elderly, tend to consult their general practitioner (GP) first. Self-referrals to specialists such as neurologists or psychiatrists in suspected cases of dementia are possible, but patients are most often referred to these specialists by their GP (Eisele et al. 2010).

In Germany, cholinesterase inhibitors and memantine have been approved for treating dementia. Cholinesterase inhibitors are used for the treatment of mild to moderate Alzheimer's disease, and memantine is used to treat the severe forms (Förstl 2008). Because dementia currently cannot be cured, alleviating the symptoms of the disease and preserving the cognitive and functional status of the patient are the main goals of a pharmaceutical treatment with antidementia drugs (Atri et al. 2013). There are some contraindications for the use of cholinesterase inhibitors in the case of multimorbid and polypharmaceutical patients. The intake of memantine is less often connected with contraindications or side effects (Förstl 2008).

Studies have shown that the use of antidementia drugs (cholinesterase inhibitors and/or memantine) can significantly slow the decline in cognition and global function of patients with Alzheimer's disease (Atri et al. 2013; Förstl 2008; Koch et al. 2005; Lopez et al. 2002; Reisberg et al. 2003; Rogers et al. 1998; Sano et al. 2003). Caregiver hours and the overall burdens on caregivers are reduced when these drugs are administered. Furthermore, the entry into a nursing home can be delayed for patients treated with antidementia drugs (Feldman et al. 2009; Geldmacher et al. 2003; Lopez et al. 2009). A study by Kiencke et al. (2010) revealed that, on average, patients treated with memantine have lower care levels than untreated patients. Moreover, patients undergoing antidementia therapy are less likely to transition to a higher care level or to die over the course of one year.

However, the prescription rates for antidementia medication are rather low in Germany: only about one-quarter of all patients diagnosed with dementia are treated with dementia-specific drugs (Jeschke et al. 2011; van den Bussche et al. 2011a), and only 8% receive the appropriate medication based on the guidelines (van den Bussche et al. 2011). There are considerable differences in the prescribing behaviors of GPs and specialists. Neurologists/psychiatrists (NPs) prescribe antidementia drugs more frequently than GPs (Jeschke et al. 2011; Riepe and Gaudig 2010; van den Bussche et al. 2011a): only 7% of dementia patients receive dementia-specific drugs if their initial dementia diagnosis was made by a GP, whereas 26% of NP dementia patients are prescribed antidementia drugs.

This share is higher (45%) if the diagnosis was made by a GP and an NP simultaneously (van den Bussche et al. 2011a). The low prescription rate among GPs may arise from their perception that dementia-specific drugs are largely ineffective and offer few therapeutic benefits (Pentzek and Abholz 2004; van den Bussche and Kaduszkiewicz 2005). Budgetary restrictions may also lead to reduced prescription rates (Pentzek and Abholz 2004).

Many studies have examined the amount of time that elapses between a dementia diagnosis and long-term institutionalization, and the related factors, as a systematic review by Luppa et al. (2008) has shown. In a German population-based sample, the median time to institutionalization after the onset of dementia is 2.8 years (Luck et al. 2008). By contrast, an American study found that the median period of time between a dementia diagnosis and a nursing home placement is 5.3 years (Smith et al. 2001). Both studies used Cox modeling, which does not allow for an analysis of the distribution of the risk of institutionalization over time. But the study by Luck et al. (2008) showed that 33% of all nursing home placements within six years occurred in the first six months after diagnosis. The risk of institutionalization seems to be particularly high in the first few months.

In Germany, however, two-thirds of the care-dependent population are cared for in a private home setting (Statistisches Bundesamt 2013a). Therefore, the purpose of the present study is to analyze the transition to receiving benefits from statutory long-term care insurance among newly diagnosed dementia patients, and the potential determinants of this process. For the sake of brevity, this transition process is referred to in the following as the risk of LTC. We assume that the need for LTC arises prior to placement in a nursing home. In addition, we focus on the pathway of the risk of LTC based on the time elapsed since the incident dementia diagnosis.

In this study, we also look at the effect of the diagnosing physician. Given the differences in the antidementia drug and treatment prescription patterns of GPs and NPs, we assume that NP patients have a lower risk of LTC than GP patients.

Moreover, the treatment effect of antidementia drugs on the risk of LTC is analyzed. We hypothesize that patients receiving any antidementia drug will have a delayed transition to LTC compared to patients undergoing no antidementia drug treatments.

## Material and Methods

*Study design and sample*

The analyses are based on the routine data of the German largest public sickness fund AOK. About one-third of the German population are insured by the AOK, and the proportion rises with increasing age (Schulz and Doblhammer 2012). We used a 5% stratified sample of 422,489 insured persons born prior to 1945 with at least one insured day in the first quarter of 2004. The data contain information on medical diagnoses coded by ICD-10 of the ambulatory and stationary sectors. The following ICD-10 codes were used to identify dementia diagnoses: G30, G31.0, G31.82, G23.1, F00, F01, F02, F03, and F05.1. Since a high proportion of the dementia diagnoses were coded as "unspecified dementia" (45%), no differentiation by dementia subtype was made. There are substantial advantages to using routine data. Our analysis is based on a large number of cases. The fact that a unique key is assigned to each insured person allows us to conduct longitudinal analyses over several periods. There is no bias due to sampling design or self-selection into the study. The whole population is covered, including the institutionalized population, which is particularly important for the analysis of dementia. The prevalence and incidence of dementia are many times higher in institutions than in the population living in the private home setting (Jakob et al. 2002). There are, however, also some disadvantages to our approach. Since medical diagnoses are not documented unless a physician or hospital files a claim, the underrepresentation or overrepresentation of diagnoses is possible. Moreover, the documentation may be subject to legal changes. Because an external validation of the diagnoses is not possible, an internal validation is needed (Doblhammer et al. 2012; Schubert et al. 2010; Swart and Ihle 2005). Nevertheless, routine claims data are a suitable data source for the analysis of dementia, as previous studies have shown (Doblhammer et al. 2012; Schubert et al. 2010; Schulz and Doblhammer 2012; Ziegler and Doblhammer 2009).

A diagnosis-free period of at least two years was chosen to distinguish prevalent cases from incident cases. All cases with at least one valid dementia diagnosis in 2004 or 2005 were excluded. This led to a reduction of the data set to 382,366 persons under risk. Each new case with a dementia diagnosis was defined as an incident dementia case. In the data set, 22,665 persons with an incident dementia diagnosis between the first quarter of 2006 and the last quarter of 2008 were identified. We followed those individuals up to the last quarter of 2010 in order to find out whether they underwent a transition to LTC. Incident cases after

2008 were not considered, as the observation period after the incident dementia diagnosis was not sufficiently long.

*Validation of diagnoses*

A two-stage validation procedure was applied in order to internally validate the diagnoses. First, diagnoses from the ambulatory sector were taken into account only if they were marked with the modifier "verified." Diagnoses from the stationary sector had to be either discharge or secondary diagnoses. Second, dementia diagnoses were confirmed by co-occurrence. Diagnoses were considered valid if they occurred simultaneously in the ambulatory and stationary sectors, or if at least two physicians made a diagnosis of dementia in the same quarter (a GP and an NP, a GP and another specialist, or an NP and another specialist). Furthermore, dementia diagnoses were confirmed by a co-occurrence over time, with all seven years being used as the validation period; e.g., a dementia diagnosis made in 2005 could be validated by a second diagnosis in 2009. If the patient died during the quarter in which the first dementia diagnosis was made, the case was considered valid even though the initial diagnosis could not be confirmed by a second diagnosis.

*Dependent variable: Long-term care*

In the current study, LTC is defined as receiving benefits or services from the German statutory long-term care insurance scheme. Statutory long-term care insurance was established in 1995, and is financed by a pay-as-you-go system. The entitlement to benefits is based on impairments in the activities of daily living (ADL). After a positive assessment by the Medical Review Board, applicants are assigned to one of three care levels based on their need for support. Care-dependent persons can then choose between benefits in cash or benefits in kind (Federal Ministry of Health Germany 2013). In the analyses, no differentiation was made between the care levels. Information on LTC was documented by quarter.

*Medical and demographic variables*

The medical data we used consisted of information on the physician who diagnosed the case, a history of the prescription antidementia drugs the patient was taking, and each

patient's history of cardiovascular comorbidities, including diabetes mellitus, cerebrovascular diseases, hypertension, ischemic heart diseases, atrial fibrillation, and hypercholesterolemia (Eisele et al. 2010; Kwok et al. 2011; Ziegler 2011).

We differentiated between four possible combinations of diagnosing physicians: 1. the patient's dementia was diagnosed by the GP only; 2. the dementia was diagnosed by an NP only; 3. the patient's GP and an NP both diagnosed the dementia in the same quarter; and 4. "all other," a category which includes all other possible combinations of diagnosing physicians (another specialist only, the GP and another specialist, an NP and another specialist) and cases in which the dementia diagnoses were first coded in hospitals. The variables covering the prescription of antidementia drugs and the comorbidities were included in the model as time-dependent variables, taking the value of one from the first time the patient was on a medication or a comorbidity was noted in the data, and of zero otherwise.

The demographic data contain gender and age at the time of the initial dementia diagnosis in 10-year age groups beginning at age 60. The highest age group is 90+. All of the information is on a quarterly basis.

As a baseline hazard, the time since the first dementia diagnosis is included in the model as a time-dependent variable. The duration is defined as 10 indicator variables taking the value of one for each of the time periods (1-6 months, 7-12 months, 13-18 months, 19-24 months, 25-30 months, 31-36 months, 37-42 months, 43-48 months, 49-54 months, 55-57 months), and of zero otherwise.


*Statistical analyses*

Between the first quarter of 2006 and the last quarter of 2008, 13,699 persons out of 22,665 incident dementia cases lived in a private dwelling and did not receive any benefits or services from statutory long-term care insurance in the quarter before the incident dementia diagnosis. The dependent variable was the time to LTC. A Kaplan-Meier estimator was used to estimate the transition to LTC (Klein & Moeschberger 2003: 92). A piecewise exponential model was performed for the analysis of the determinants for the risk of LTC (Klein & Moeschberger 2003: 48, 296):

$$h_{LTC}\left[t \mid \mathbf{Z}(t)\right] = h_0(t)\exp\left[\sum_{k=1}^{p}\beta_k Z_k(t) + \sum_{j=1}^{q}\delta_j Z_j(t)\right] \quad,$$

where $h_{LTC}[t|\mathbf{Z}(t)]$ was the hazard rate at time t of needing LTC depending on the variables "diagnosing physician" and "antidementia drugs" $Z_k(t)$ and the covariates $Z_j(t)$. $h_0(t)$ was the baseline hazard rate following the exponential distribution, which represented the time since the first diagnosis of dementia. The baseline hazard was split into 10 time intervals in which different levels of the rate were allowed. Between two cut points the rate was assumed to be constant. The maximum observation time was 57 months. There was no left-truncation, as all individuals started at time zero, which was the middle of the incidence quarter. The analysis time was 0.75 for people who experienced the transition to LTC in the quarter in which the dementia was diagnosed. Later transitions took place in the middle of the quarter. People were followed until censoring or death, whichever occurred first. The censoring time was set in the middle of the last observed quarter, and the deaths were assumed to have been in the middle of the month of death.

Subsequently, the estimated hazard rates were entered into a life table computation in order to calculate the temporary life expectancy (Arriaga 1984) without LTC in the months after an incident dementia diagnosis based on the diagnosing physician, the antidementia drugs prescribed, and the age at diagnosis.

## Results

*Descriptive Results*

At the time of the first dementia diagnosis, the 13,446 insured persons were, on average, 79.2 years old. The highest age at dementia diagnosis was 100 years. Of the cases in the sample, 65% were female and 35% were male. The results also showed that 42% of the dementia cases were initially diagnosed by the patient's GP, and 12% were diagnosed by an NP. Only 2% of the cases received a dementia diagnosis from both a GP and an NP in the same quarter. The findings further indicated that 44% of cases were diagnosed by some other combination of physicians, while 66% of those diagnoses were made in the stationary

sector. NP patients were, on average, younger than patients diagnosed by GPs. The share of NP incident cases at ages 60-69 was twice as high as for GP patients. Half of the NP patients were 70 to 79 years old, whereas the majority of the GP patients were 80 to 89 years old (Table 1).

**Table 1: Characteristics of the 13,446 incident dementia cases without LTC at the time of the dementia diagnosis.**

|  | Only GP | | Only NP | | GP & NP | | All other | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|
|  | n | % | n | % | n | % | n | % | n | % |
| **Gender** | | | | | | | | | | |
| Males | 1,753 | 31.3 | 622 | 38.8 | 120 | 36.8 | 2,169 | 36.6 | 4,664 | 34.7 |
| Females | 3,840 | 68.7 | 983 | 61.2 | 206 | 63.2 | 3,753 | 63.4 | 8,782 | 65.3 |
| **Age, years** | | | | | | | | | | |
| 60-69 | 499 | 8.9 | 281 | 17.5 | 30 | 9.2 | 546 | 9.2 | 1356 | 10.1 |
| 70-79 | 2,070 | 37.0 | 823 | 51.3 | 166 | 50.9 | 2,252 | 38.0 | 5,311 | 39.5 |
| 80-89 | 2,608 | 46.6 | 465 | 29.0 | 119 | 36.5 | 2,681 | 45.3 | 5,873 | 43.7 |
| 90+ | 416 | 7.4 | 36 | 2.2 | 11 | 3.4 | 443 | 7.5 | 906 | 6.7 |
| Mean age | 79.7 | | 76.0 | | 78.2 | | 79.7 | | 79.2 | |

Source: AOK Claims Data 2004-2010

When we look at the cases 57 months after the initial incident dementia diagnosis, we can see that 77% of those who did not require LTC prior to developing dementia experienced a transition to LTC (Figure 1). The rates of transition to LTC were particularly high in the months immediately following the diagnosis. One-quarter of all of the incident dementia cases needed LTC after three months. After 21 months, 50% of all of the people with dementia were in need of LTC. At time of the transition to LTC, the dementia patients were, on average, 81.6 years old.

The people with dementia who had been diagnosed by both a GP and an NP and by other physicians (including diagnoses from the hospital) experienced the transition to LTC earlier. Almost five years after receiving a dementia diagnosis, over 80% of patients (GP & NP: 85%; all other: 82%) needed LTC. Meanwhile, 71% of people diagnosed by a GP only and 65% of people diagnosed by an NP only were in need of care after 57 months. The Logrank and Wilcoxon test for the equality of the survivor function across groups showed that there were highly significant differences between the four groups.

**Figure 1: Kaplan-Meier estimator, time until LTC after incident dementia diagnosis by diagnosing physician, men and women, Germany, 2006-2010.**
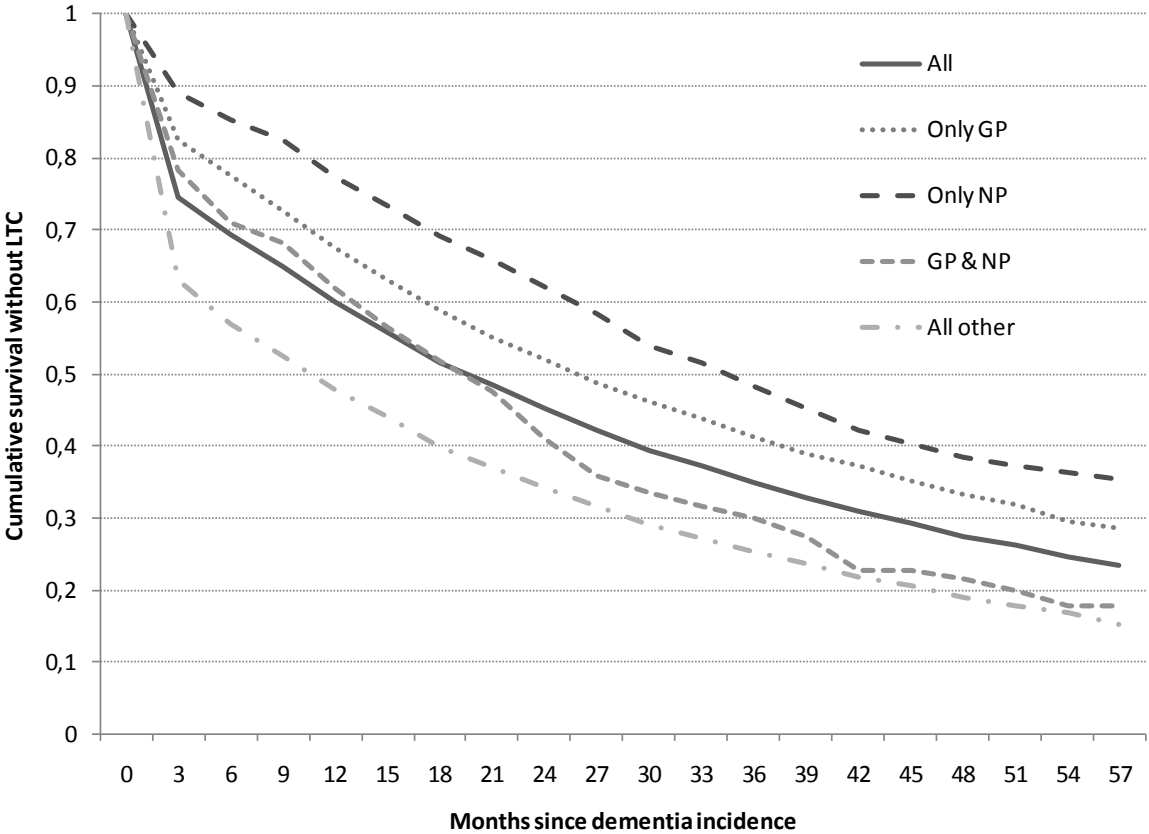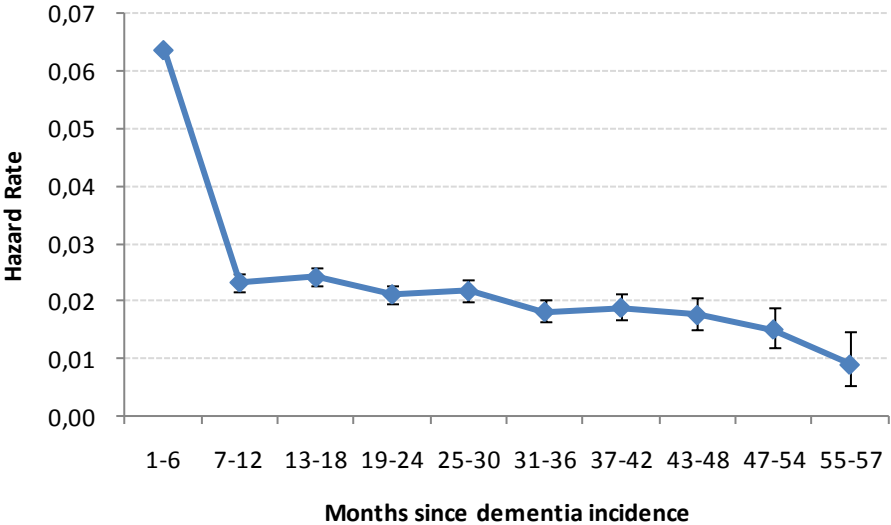


Source: AOK Claims Data 2004-2010

*Model results*

Figure 2 shows the baseline hazard rate for the risk of LTC after an incident dementia diagnosis. In the first six months after diagnosis, there was a hazard rate of 0.064 for LTC, which means that each month 64 people out of 1,000 dementia incident cases required LTC for the first time. The risk of LTC decreased significantly in the following months to reach a relatively stable rate of about 0.02. All of the confidence intervals overlapped with each other. After 47 months, the risk decreased slightly to a rate of 0.01. However, the risk of needing LTC was highest in the first half year after receiving the dementia diagnosis.

**Figure 2: Baseline hazard rate for the risk of LTC after incident dementia with 95% confidence interval, reference: one to six months after the initial diagnosis, Germany, 2006-2010.**



Source: AOK Claims Data 2004-2010

Table 2 presents the results of the regression analysis. Patients diagnosed by an NP had a significantly reduced risk of LTC relative to the reference group who received their diagnosis from a GP. If the diagnosis was made by the GP in conjunction with an NP, the risk of LTC was slightly higher than in the reference group. The risk was significantly higher when the dementia diagnosis was made by any other type of physician, including doctors in the stationary sector.

Patients who underwent an antidementia treatment showed an increased risk of LTC relative to those who received no antidementia medication. This was true for all patients, regardless of whether the diagnosis was made by a GP or an NP (see Figure 3).

There was a strong age effect. The older the person was at time of the incident dementia diagnosis, the higher the risk that he or she would need LTC in the following five years. The hazard ratio for the age group 90+ was four times higher than for the youngest age group. The risk of LTC among demented women was significantly higher than among demented men. The presence of diabetes mellitus, cerebrovascular diseases, and atrial fibrillation were shown to have increased the risk of LTC, but no effect was found for hypertension and ischemic heart diseases. By contrast, demented persons with hypercholesterolemia had a significantly reduced risk of LTC.

*LTC-free time after an incident dementia diagnosis*

The translation from hazard rates to life table computations leads to the indicator months without LTC after having received the first dementia diagnosis. Patients who were diagnosed by a GP alone, an NP and a GP together, and an NP alone were compared.

Table 3 shows that NP patients who were diagnosed at between 60 and 69 years of age lived, on average, 42.7 months without LTC if they did not receive antidementia medication. By contrast, patients who were diagnosed by a GP needed LTC after only 40.7 months on average. This means that GP patients aged 60 to 69 had a disadvantage of two months. This disadvantage increased with age. At ages 90+, GP patients needed LTC 3.2 months earlier than NP patients. This effect was even stronger for demented persons who were treated with antidementia drugs. In this case, the disadvantage of patients diagnosed by a GP ranged from 3.7 months for people aged 90+ to 5.2 months for patients aged 70 to 89. The chances of spending longer periods of time without the need for LTC were particularly low for patients who had received a dementia diagnosis from both a GP and an NP in the same quarter. These patients required LTC 8.4 to 11.7 months earlier than NP patients if they received no antidementia drug treatments. The difference declined to 2.4 to 3.3 months for patients who underwent antidementia drug therapies. In this group, the use of antidementia medications did not seem to influence the length of the LTC-free time period.

**Table 2: Hazard Ratios, risk of LTC after incident dementia diagnosis, Germany, 2006-2010.**

| Variable | | Hazard Ratios (95 % Conf. Interval) | p-value |
|---|---|---|---|
| Diagnosing Physician (Ref.: Only GP) | Only NP | 0.801 (0.740-0.867) | 0.000 |
| | GP & NP | 1.194 (1.040-1.370) | 0.012 |
| | All other | 1.657 (1.583-1.735) | 0.000 |
| Antidementia Drugs (Ref.: No) | Yes | 1.615 (1.532-1.701) | 0.000 |
| Age (Ref.: 60-69) | 70-79 | 1.432 (1.309-1.565) | 0.000 |
| | 80-89 | 2.448 (2.241-2.675) | 0.000 |
| | 90+ | 4.386 (3.922-4.905) | 0.000 |
| Gender (Ref.: Male) | Female | 1.073 (1.025-1.124) | 0.003 |
| Comorbidities Diabetes mellitus (Ref.: No) | Yes | 1.126 (1.077-1.78) | 0.000 |
| Cerebrovascular Diseases (Ref.: No) | Yes | 1.364 (1.206-1.425) | 0.000 |
| Hypertension (Ref.: No) | Yes | 1.048 (0.990-1.110) | 0.108 |
| Ischemic Heart Diseases (Ref.: No) | Yes | 1.010 (0.966-1.056) | 0.668 |
| Atrial Fibrillation (Ref.: No) | Yes | 1.334 (1.269-1.203) | 0.000 |
| Hypercholesterolemia (Ref.: No) | Yes | 0.846 (0.803-0.892) | 0.000 |
| Constant | | 0.027 (0.024-0.031) | 0.000 |

Coefficients for baseline hazard are not shown here

Source: AOK Claims Data 2004-2010

**Figure 3: Effect of physician and medication on the risk of LTC, men and women, Germany, 2006-2010.**
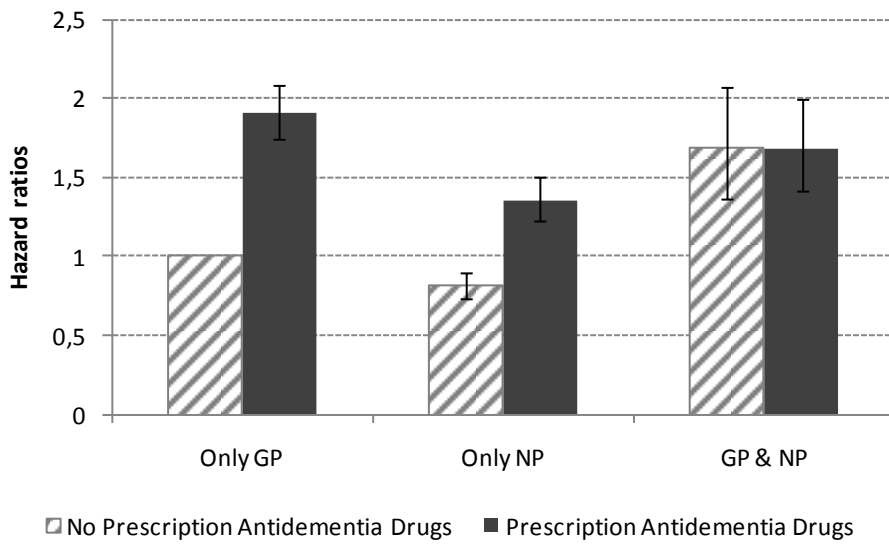


Source: AOK Claims Data 2004-2010

**Table 3: Months without LTC after incident dementia diagnosis, men and women, Germany, 2006-2010.**

*No Prescription Antidementia Drugs*

| Age | Only NP | Only GP | GP & NP | Disadvantage "Only GP vs. Only NP" in months | Disadvantage "GP & NP vs. Only NP" in months |
|---|---|---|---|---|---|
| 60-69 | 42.7 | 40.7 | 34.2 | -2.0 | -8.4 |
| 70-79 | 38.1 | 35.6 | 27.8 | -2.5 | -10.3 |
| 80-89 | 30.0 | 26.8 | 18.3 | -3.2 | -11.7 |
| 90+ | 20.4 | 17.2 | 10.1 | -3.2 | -10.3 |

*Prescription Antidementia Drugs*

| Age | Only NP | Only GP | GP & NP | Disadvantage "Only GP vs. Only NP" in months | Disadvantage "GP & NP vs. Only NP" in months |
|---|---|---|---|---|---|
| 60-69 | 36.6 | 32.1 | 33.9 | -4.5 | -2.8 |
| 70-79 | 30.6 | 25.4 | 27.4 | -5.2 | -3.2 |
| 80-89 | 21.2 | 16.0 | 17.9 | -5.2 | -3.3 |
| 90+ | 12.3 | 8.6 | 9.8 | -3.7 | -2.4 |

Source: AOK Claims Data 2004-2010

**Discussion**

The findings of the present study demonstrate that dementia is a very care-intensive illness. Before the first dementia diagnosis, almost 40% of all patients already needed LTC and/or lived in an institution. Of those who were not in need of LTC before the quarter in which they were diagnosed, 77% experienced a transition to LTC in the following 57 months. As expected, we found that median time until LTC became necessary was shorter than the median time until institutionalization. Luck et al. (2008) reported a median time of 2.8 years until a nursing home placement was made. In our analysis, the median amount of time that elapsed between the diagnosis and the need for LTC arose was 21 months, or 1.75 years. The risk of transitioning to LTC was highest in the first three to six months after the incident dementia diagnosis. In the following months, the risk decreased and remained significantly lower than it was in the first six months. This result is independent of the age at which the incident diagnosis occurred.

In line with our hypothesis, the analysis revealed that patients who were first diagnosed by an NP had a significantly reduced risk of LTC compared to patients who received their first diagnosis from a GP. Among GP patients, the disadvantage in terms of time spent without LTC after a dementia diagnosis ranged from two to 5.2 months. Despite our initial assumption, this result was not attributable to differing antidementia drug prescription patterns. There are two possible explanations for this finding. First, several studies have shown that GPs have difficulties in diagnosing dementia, especially the mild cases (Mitchell et al. 2011; Pentzek and Abholz 2004; Pentzek et al. 2009). This lack of expertise would result in a delayed diagnosis of dementia patients. Although NP patients and GP patients spend the same amount of time in LTC, GP patients tend to be diagnosed at a later stage of the disease. The second explanation is that the difference between NP patients and GP patients in terms of the amount of time it takes them to transition to LTC is attributable to the different treatments they receive. A diagnostic workup by an NP is more likely to conform to the guidelines, which may lead to a more accurate diagnosis of the dementia type (Stoppe et al. 2007), and thus to a more appropriate treatment being prescribed. The present study only looks at the effect of the diagnosing physician in the quarter in which the initial diagnosis was made. It is possible that patients who were first diagnosed by a GP only were referred to and treated by a specialist in the following quarters. A study by van den Bussche et al. (2011b) showed that one-third of all incident dementia patients saw an NP during the year

of incidence. We can therefore assume that the real difference between GP patients and NP patients may have been even greater, since the group of GP patients included patients who were referred to an NP after the incidence quarter.

Contrary to the initial hypothesis that patients who received antidementia drug treatment had a lower risk of LTC, the analysis showed that patients who underwent antidementia drug therapies had an increased risk of LTC. This was found to be the case for both GP and NP patients. Other studies have shown that antidementia drugs protect against cognitive and functional decline (Atri et al. 2013; Förstl 2008; Koch et al. 2005; Lopez et al. 2002; Reisberg et al. 2003; Rogers et al. 1998; Sano et al. 2003). One possible explanation for our finding is that the prescription of antidementia drugs was an indicator of the severity of the disease: i.e., that the patients in our study who were more affected by dementia were more likely to be prescribed antidementia drugs, but also had an increased risk of LTC. Moreover, our study did not distinguish between the use of cholinesterase inhibitor and memantine therapies. Whereas cholinesterase inhibitors are approved for mild to moderate Alzheimer's disease, memantine is used to treat the more severe forms (Förstl 2008). Thus, if it was possible to differentiate  between these two medications, using them as indicators for the severity of the illness, we may be able to resolve this apparent contradiction. However, a study by van den Bussche et al. (2011a) showed that only 8% of all treated patients received an appropriate dose of either cholinesterase inhibitor or memantine, which leads us to assume that the increased risk of LTC may have been a result of a high proportion of patients receiving inappropriate antidementia drug treatments.

We found a strong age effect, with an exponential increase in the risk of needing LTC with a rising age at the time of the first dementia diagnosis. This finding is in line with the results of other studies that analyzed risk factors for limitations in ADL and disability (Agüero-Torres et al. 1998; Boult et al. 1994; Moritz et al. 1995; Sauvaget et al. 2002).

In addition, women were shown to be more likely than men to require LTC. This result is in line with the findings of other studies which showed that women are more likely to be functionally impaired than men (Oksuzyan et al. 2008; Leveille et al. 2000, Arber & Cooper 2006). However, this could also be an effect of marital and/or cohabitation status, which we cannot control for. Women are more likely than men to be widowed and live alone (Statistisches Bundesamt 2012; 2013b), which means that they are less likely to have a potential caregiver in the household who can meet their care needs, even in the early stages

of dementia. As a consequence, women might apply earlier than men for benefits from the statutory long-term care insurance scheme in order to obtain professional help.

As expected, we found that cardiovascular comorbidities, like diabetes mellitus, cerebrovascular diseases, and atrial fibrillation, were related to a higher risk of LTC. Although dementia is a leading cause of functional limitations and care need (Agüero-Torres et al. 1998), other chronic comorbidities may also lead to a need for LTC (Boult et al. 1994). This is an inherent result, as the construction of the dependent variable was based on limitations in ADL, which are induced by chronic diseases. The presence of hypertension and ischemic heart disease did not show any significant effects. By contrast, dementia patients with hypercholesterolemia had a significantly reduced risk of LTC. This may be an effect of the treatment of hypercholesterolemia with statins. Studies have shown that the use of statins can reduce the risk of the onset of dementia, and is correlated with a reduced prevalence of dementia (Haag et al. 2009; Hajjar et al. 2002). Furthermore, the use of statins has been shown to delay the progression of cognitive impairments (Hajjar et al. 2002), and therefore to reduce the risk of LTC among patients with dementia.

The present study has some limitations. The data do not allow for meaningful distinctions between dementia subtypes, as 45% of the cases were coded as "unspecified dementia," and 27% of the cases were of the type of Alzheimer's disease which does not correspond to other epidemiological studies (Bickel 2000; Ott et al. 1995; Weyerer 2005). However, a sensitivity analysis which took only incident cases with Alzheimer's disease into account led to comparable estimates. Only care needs based on entitlement to benefits from the statutory long-term care insurance scheme were considered. However, this entitlement is dependent on the patient or the patient's family making an application for benefits, and assumes that the family members know about the existence of these benefits. In addition, a successful application for benefits is based on impairments in ADLs, but dementia patients experience limitations in ADLs rather late in the progression of their illness, even though the need for care may arise due to certain behaviors, such as a tendency to wander. Since 2008, patients have been able to obtain funds if a care need is ascertained, even with no (or not enough) limitations in ADLs. However, this information was not in the data. Because of the use of routine data, the set of explaining variables was limited to basic demographic variables and medical information that were relevant for the claims process. Therefore, it was not possible to control for other confounding factors, like life style variables.

The strength of the present study is the large number of cases available for analysis. Even after data cleaning, over 13,000 dementia patients without entitlement to benefits or services from the statutory long-term care insurance could be included in the data set. Bias effects due to attrition for reasons other than death were marginal thanks to the completeness of the data over time, and the low rate of shifts between public health insurance funds, especially at old ages. There was no selection bias by health care providers or self-selection into the study. All insured persons were included in the study, regardless of their functional and cognitive status. There was no recall bias of the medical diagnoses.

The World Alzheimer Report 2011 has emphasized the importance of early dementia diagnosis. An early diagnosis allows patients to plan for the future and make important decisions in conjunction with their relatives. Moreover, drug and non-drug therapies can be started earlier in order to preserve cognitive functions as long as possible and improve the patient's quality of life. This may result in a delay in care dependence, and thus lessen the costs associated with care provision (Alzheimer's Disease International 2011). Of the 244,000 new dementia cases in Germany each year (Ziegler and Doblhammer 2009), about 100,000 are diagnosed by a GP. Assuming the lowest possible benefit from the statutory long-term care insurance fund of 235 euros per month, a postponement of the transition into LTC of just two months would lead to a cost savings of about 47 million euros per year. This is likely the minimum amount that could be saved in the nursing care sector. Our results imply that a higher rate of involvement of specialists in the treatment of dementia patients would not only be meaningful for the patients, who would benefit from earlier and more accurate diagnoses and treatments; but also for society, as the need for costly LTC is postponed.

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