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Predictors of Institutionalisation in Incident Dementia – Results of the German Study on Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe Study)

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Key Words

Institutionalisation · Nursing home placement · Nursing home admission · Predictors · Cognitive impairment · Dementia

Abstract

Background/Aims: In the past few decades, a number of studies investigated risk factors of nursing home placement (NHP) in dementia patients. The aim of the study was to investigate risk factors of NHP in incident dementia cases, considering characteristics at the time of the dementia diagnosis. ***Methods:*** 254 incident dementia cases from a German general practice sample aged 75 years and older which were assessed every 1.5 years over 4 waves were included. A Cox proportional hazard regression model was used to determine predictors of NHP. Kaplan-Meier survival curves were used to evaluate the time until NHP. ***Results:*** Of the 254 incident dementia cases, 77 (30%) were institutionalised over the study course. The mean time until NHP was 4.1 years. Significant characteristics of NHP at the time of the dementia diagnosis were marital status (being single or widowed), higher severity of cognitive impairment and mobility impairment. ***Conclusion:*** Marital status seems to play a decisive role in NHP. Early initiation of support of sufferers may ensure remaining in the familiar surroundings as long as possible.

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Introduction

Dementia is one of the most common and serious disorders in late life. The number of people affected worldwide will double every 20 years to 81 million by 2040 [1]. Due to the progressive deterioration in cognitive and physical functioning in dementia and the resulting burden on informal caregivers [2, 3], dementia is the main cause of nursing home placement (NHP) among the elderly [4]. However, most elderly people prefer to grow old in their familiar surroundings, and caring for these individuals at home can be beneficial for several reasons. To facilitate the application of targeted preventive strategies or to provide opportunities for planning instead of precipitating NHP of individuals when the feasibility of continued home care is threatened, a number of studies in the past few decades aimed to identify risk factors for NHP in dementia patients (for an overview see Luppa et al. [4] and Gaugler et al. [5]). However, since most studies are based on samples of prevalent dementia cases, findings on the time to NHP may be biased, because subjects were included at different stages with high uncertainty about the onset of the disorder, with the result that the time of living in a private home between the onset of the disorder and the diagnosis of prevalent dementia has to be estimated retrospectively. By way of contrast, studies based on incident dementia cases (i.e. new-onset cases), such as the study by Luck et al. [9], treated this methodical problem, looking at subjects with dementia from the onset of their disorder, thus allowing more precise statement concerning the course of the disorder and time until NHP. However, this study also only considered baseline characteristics as risk factors of NHP.

Thus, the present study aimed (1) to evaluate the time until NHP in incident dementia cases derived from a representative German primary care sample aged 75 years and older, which was surveyed between January 2003 and March 2009 – on average every 1.5 years – and (2) to identify risk factors affecting time until NHP, considering characteristics of the subjects at the time of the incident dementia diagnosis.

Methods

Study Design and Sample

The investigated sample of incident dementia cases was derived from a sample of general practice (GP) patients in a prospective longitudinal study on early detection of mild cognitive impairment and dementia in primary care: the German Study on Ageing, Cognition and Dementia in Primary Care Patients. This study was conducted at 6 centres (Bonn, Düsseldorf, Hamburg, Leipzig, Mannheim, and Munich), representing an urban area of cities with a total population ranging between about 300,000 (Mannheim) and 1.8 million (Hamburg). The subjects were recruited between 1 January, 2003 and 30 November, 2004 and reassessed every 1.5 years, in total 4 times over 6 years. Inclusion criteria for GP patients were age 75 years and over, absence of dementia according to the judgement of the GP, and at least one contact with the GP within the last 12 months. Exclusion criteria were GP consultation by home visits only, residence in a nursing home, severe illness with an anticipated fatal outcome within 3 months, German language insufficiency, deafness or blindness, and lack of ability to provide informed consent. About 95% of the subjects in this age group are registered at an office of a GP. Since we used a medical record registry approach rather than a waiting room recruitment strategy, the participants in this study are unselected and can be considered representative of community-dwelling older adults. Detailed information on sampling frame, eligible subjects, and respondents is provided in figure 1.

The sample in this study consists of subjects developing dementia ('incident dementia diagnosis') before NHP during the 6-year course of the study. At baseline, a total of 3,327 selected GP patients were interviewed in their homes by trained investigators (medical doctors, psychologists, gerontologists). Of these 3,327 interviewed subjects, 3,073 (92.3%) were excluded from the following analyses: 2,894 (94.1%) did not develop dementia during the course of the study; 2 (0.1%) fell short of the age limit of 75 years; 120 (3.9%) had incomplete assessments at the time of the dementia diagnosis, due to proxy interviews, and 56 (1.8%) were living in nursing homes (NH) at the time of the incident dementia diagnosis. Thus, a sample of 254 subjects with incident dementia represents the population at risk for NHP in follow-up waves. At the time of the dementia diagnosis, severity of dementia in these subjects was mild in 75.6%, moderate in 20.5%, and severe in 3.6% of cases.

Comparison of socio-demographic characteristics of those living in NH at the time of the dementia diagnosis (n = 56) and those with incomplete assessments (n = 120) with the remaining 254 subjects showed no significant differences regarding gender and educational level. Those living in NH at the time of the dementia diagnosis were more often widowed (70 vs. 50%, $\chi^2 = 9.3$, $p = 0.026$) and older (85 vs. 84 years, $t = -2.4$, $p = 0.017$) compared to the 120 subjects with incomplete assessment.

Instruments

During visits to the participants' homes, structured clinical interviews were conducted, and socio-demographic, clinical and psychometric baseline and follow-up data were collected.

Institutionalisation was defined as entry into an old-age home or NH at any time during follow-ups, with a stay lasting until the end of the study or until death. Typically, the exact date of move into an NH was ascertained when a participant was contacted for follow-up assessment. For participants who had died between two waves, fully structured proxy interviews with an informant were conducted, and the time of institutionalisation was assessed.

In order to diagnose dementia, neuropsychological and clinical assessment was based on the Structured Interview for the Diagnosis of Dementia of Alzheimer Type, Multi-infarct

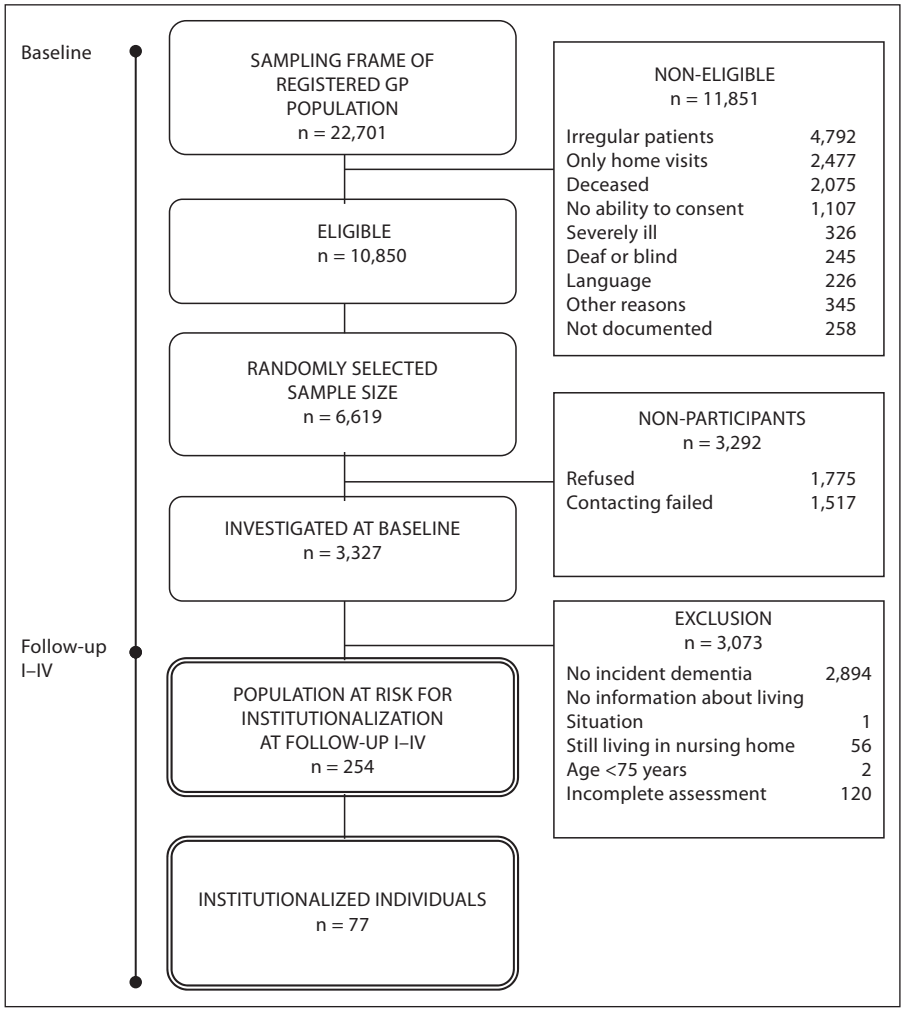

Fig. 1. Sampling frame and sample.

Dementia and Dementia of Other Aetiology according to DSM-IV and ICD-10 (SIDAM) [6]. The SIDAM contains (1) a neuropsychological test battery and (2) a 14-item scale for the assessment of instrumental activities of daily living. The cognitive battery covers 55 items (SIDAM cognitive score), including the Mini-Mental State Examination (MMSE) [7]. To determine impairment of cognitive functioning, German age- and education-specific norms of the SIDAM for the cognitive domains were applied [8].

Statistical Analyses

The data were entered at the centres via an internet-based Remote Data Entry System into a central ORACLE version 9 database. Statistical analyses were performed with SPSS for Windows, version 20.0, and Stata, version 12.0. Differences of characteristics between institutionalised and non-institutionalised subjects at the time of the dementia diagnosis were analysed by means of the χ^2 test and the two-tailed t test, as appropriate.

Incidence of dementia could only be diagnosed at the defined times of follow-up assessments. On average, the exact time of the first possible diagnosis could be assumed at the midway point between the follow-up visit, when dementia was diagnosed, and the previous visit [9, 10]. Accordingly we determined the time point of incidence of dementia. Incidence of NHP was calculated as the number of cases admitted to NH during the follow-up waves divided by the person-years at risk. For those subjects who were not admitted to NH, person-years at risk were calculated as the time between the incidence of dementia and the last follow-up interview the participant had attended.

A multivariate Cox proportional hazards regression model was developed to determine risk factors which were significantly and independently predictive of time to NHP. Risk factors were age, gender, marital status, level of education, severity of cognitive impairment (MMSE score), and impaired mobility, vision and hearing at the time of the dementia diagnosis. Adjusted hazard ratios with 95% confidence intervals (95% CI) were stated. Kaplan-Meier survival analysis was used to determine the time until NHP; the log rank test was conducted to detect differences between survival curves. A p value less than 0.05 was considered statistically significant in all analyses.

Table 1. Sample characteristics of institutionalised and non-institutionalised individuals with a diagnosis of incident dementia (n = 254)

Characteristics	Non-institutionalised (n = 177)	Institutionalised (n = 77)	Test statistic	p value
Age (mean ± SD)	83.5±3.8	84.6±4.6	t = –2.09	0.038
Male, n (%)	64 (36.2)	20 (26.0)	χ^2 = 2.51	0.113
Education[1], n (%)			χ^2 = 0.83	0.662
Low	116 (65.5)	46 (59.7)		
Middle	42 (23.7)	22 (28.6)		
High	19 (10.7)	9 (11.7)		
Marital status, n (%)			χ^2 = 21.16	<0.001
Single	7 (4.0)	10 (13.0)		
Married	81 (46.3)	14 (18.2)		
Divorced	9 (5.1)	5 (6.5)		
Widowed	78 (44.6)	48 (62.3)		
MMSE score (mean ± SD)	21.7 (3.4)	20.4 (4.2)	t = 2.40	0.017
Mobility impairment, Yes, n (%)	120 (68.2)	66 (86.8)	χ^2 = 9.56	0.002
Vision impairment, Yes, n (%)	55 (31.4)	30 (40.0)	χ^2 = 1.72	0.190
Hearing impairment, Yes, n (%)	81 (46.3)	32 (42.1)	χ^2 = 0.37	0.541

[1] Based on the revised version of the international CASMIN educational classification [31].

Ethical Approval

The ethics committees of the participating centres approved the study. Written informed consent was obtained from all participants and/or from their respective guardian.

Results

Institutionalisation Rates

Of the 254 subjects representing the population at risk for institutionalisation in follow-up waves, 77 (30.3%) individuals were admitted to an NH. The mean time to NHP was 4.1 years (95% CI 3.7–4.5). The incidence of NHP was 153 per 1,000 person-years (95% CI 121–192). The characteristics of institutionalised and non-institutionalised individuals at the time of the dementia diagnosis are shown in table 1. Institutionalised individuals were somewhat older, more often single or widowed, had a lower cognitive status (MMSE score), and were more often mobility-impaired than non-institutionalised.

Risk Factors of NHP

In table 2, the results of the Cox proportional hazards regression are shown. The variables found to be signifi-

Table 2. Predictors of time to NHP in individuals with a diagnosis of incident dementia – multivariate Cox proportional hazards regression model

	Exp(B) (95% CI)	p value
Age, per year	1.04 (0.98–1.10)	0.161
Gender (ref. male)	0.64 (0.34–1.20)	0.166
Marital status (ref. married)		
Single	8.02 (3.15–20.39)	*<0.001*
Divorced	3.40 (0.89–12.97)	0.074
Widowed	4.60 (2.20–9.61)	*<0.001*
Level of education (CASMIN)[1] (ref. low)		
Middle	1.75 (0.99–3.06)	0.052
High	1.65 (0.74–3.68)	0.220
Cognitive status, per point MMSE	0.92 (0.86–0.97)	*0.005*
Mobility impairment (ref. no) Yes	2.60 (1.29–5.21)	*0.007*
Vision impairment (ref. no) Yes	1.45 (0.85–2.49)	0.175
Hearing impairment (ref. no) Yes	0.69 (0.41–1.17)	0.172

Figures in italics are significant.

[1] Revised version of the CASMIN educational classification [31].

Fig. 2. Kaplan-Meier survival curves according to marital status.

cantly associated with shortened time to institutionalisation were being single or widowed (compared to being married), a higher severity of cognitive impairment, as well as mobility impairment. The χ^2 difference between the null model and the model containing predictors of 51.22 was significant at the $p < 0.001$ level. Figure 2 shows the Kaplan-Meier survival curves according to marital status. The mean time until NHP was 4.7 years (95% CI 4.4–5.1) for married individuals, compared to 2.0 (95% CI 1.4–2.7), 3.1 (95% CI 2.6–3.5), and 3.7 (95% CI 2.2–5.3) for single, widowed and divorced individuals (log rank test $p < 0.001$).

Discussion

The aim of the study was to determine the time until NHP among individuals with incident dementia in a German primary care sample aged 75 years and older, and to identify risk factors affecting time until NHP. As the first study to do so, we investigated risk factors of NHP taking into account information at the time of the dementia diagnosis, which provide higher predictive validity than do baseline characteristics. Significant predictors of NHP for individuals with a diagnosis of incident dementia were particularly marital status, severity of cognitive impairment, and mobility impairment. Thus, if a patient with a diagnosis of incident dementia was single or widowed at the time of that diagnosis, the risk of NHP was increased by a factor of 8 and 5, respectively. In the German population-based study [9], marital status also increased the risk by the factor of 5 if the individual was widowed or divorced at baseline, but only in the univariate analysis. Due to the lower number of cases (n = 109) and the inclusion of only baseline information in this study, the predictive power of the effect may have been restricted. The reason why the risk for single patients was considerably higher than for the widowed may be due to the fact that – in this generation – widowed patients are more likely than single patients to have children available as potential caregivers. Another study [11] investigating marital status in detail showed a higher risk of the single compared to the widowed, too, but only in univariate analysis and not to this degree (hazard ratio of 2.5 for the single and of 1.6 for the widowed), which may be due to inclusion of baseline characteristics in this study. Overall, the literature shows that being unmarried (single, widowed or divorced) deemed to increase the risk of NHP (for an overview, see Luppa et al. [4], Gaugler et al. [12] and Ebly et al. [13]). Present challenges resulting from these findings include an improved identification of individuals which are at high risk for NHP due to lack of a potential caregiver, which should be more intensively addressed in the future by the responsible GP as well as by consulting a professional case manager providing multicomponent interventions aiming at the optimisation of a holistic, comprehensive and collaborative care for these patients [14]. Future interventional studies in this field should take into consideration this special high-risk group.

In our study, the risk of NHP increased by 8% with every point less on the MMSE score. That means the risk of NHP increased with rising severity of cognitive impairment or severity of dementia, respectively, a result found consistently in previous studies as well [11, 15–17]. A further significant predictor of shorter time to NHP was mobility impairment, as opposed to neither vision nor hearing impairment. In this regard, it is well investigated that functional impairment significantly predicts NHP (for an overview, see Luppa et al. [4]). But the concept of functional impairment comprises a wide range of activities which could be limited and provide no detailed information about the type of limitation. Our in-depth analysis of different physical functions showed that mobility function rather than impairment of sensory functions increased the risk of NHP; a similar result was found by Hope et al. [18].

In total, 30% of the population at risk among individuals with a dementia diagnosis were institutionalised. The only study with comparable methodical characteristics conducted in the German general population [9] reported a markedly higher rate of 48% after a study period of 7 years. Studies with prevalent dementia cases report-

ed still higher rates of 20–29% 1 year after study entry [19–22], and of 33–50% 2 years after study entry [23, 24] within the clinical context. Population-based studies reported rates of 33% 1 year [25] after study entry, and 51% 5 years thereafter [26]. However, in studies with prevalent dementia cases, NHP rates and time until NHP are shortened, because individuals were included at different stages of the dementia disorder, not at its onset. In our study, the mean time until NHP was 4.1 years. Luck et al. [9] reported a somewhat shorter mean time of 2.9 years. However, that study was conducted in the nineties; meanwhile the social structure of the group of NH residents has changed: mean age at entry has increased, length of residence has shortened, and an increase in need of care is frequently expected before transition to NHP. Moreover, the individuals in this population-based sample were on average 2 years older at baseline, which also may have affected the shorter time to NH and the higher institutionalisation rate. Other studies including prevalent dementia cases reported shorter mean times to NHP of 3.3 [27] or 3.4 years [26, 28] than our study, but started from the study entry of individuals not from their estimated onset of dementia.

Limitations

Although the inclusion of incident dementia cases could be valued as a strength of the study, since cases were also derived from a large representative German primary care sample, the sample size was rather low, limiting statistical power and the number of includable predictors. Moreover, 179 individuals with a dementia diagnosis had to be excluded for different reasons (fig. 1). Because individuals living in NH at the time of the dementia diagnosis were somewhat older and more often widowed than the investigated sample, our results should be seen as rather conservative estimates referring to institutionalisation rate and the effects of age and marital status on risk of NHP. Further, because the exact onset of dementia between the follow-up visit, when dementia was diagnosed, and the previous follow-up is unknown, we set it at the midway point between these two time points following practices in other studies [9, 10]. Post hoc analyses postponing time of onset of dementia to the previous follow-up or to the follow-up when dementia was diagnosed showed only marginal changes in predictors of NHP. Furthermore, a differentiation between types of dementia was also restricted by the low number of cases, and there was a lack of any neurological investigation, imaging or autopsy. Moreover, since we did only obtain information about potential informants if a proxy interview would be indicated, instead of obtaining information about the presence of a caregiver of patients, no information about caregivers' characteristics known to have an essential impact on NHP could be included in the analyses.

Conclusion

The inclusion of patient's characteristics at the time of the dementia diagnosis provides more valid information on risk factors of NHP. Our findings indicate that in this generation, particularly marital status at the time of the dementia diagnosis plays a decisive role, because it concerns the question pertaining to the potential informal caregiver, which is mainly the spouse, followed by children, so that single and widowed patients showed the highest risk of NHP. Conclusively, the early initiation of steady support in requirements of daily living in terms of community-based home care or informal care provided by a non-relational network of patients with nascent cognitive impairment should be understood as a major endeavour of the caring GP [29, 30]. Additionally, consulting of a professional case manager using comprehensive assessment, collaborative approaches, and best practice fundamentals set the stage for saving continuity of care and stability of services, thus ensuring that sufferers stay able to remain in their familiar surroundings as long as possible [14].

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