Original Research Article

Predictors of Institutionalization of Dementia Patients in Mild and Moderate Stages: A 4-Year Prospective Analysis

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Key Words

Abstract

Background: Institutionalization is the most important milestone in the care of dementia patients. This study was aimed at identifying relevant predictors of institutionalization in a broad empirical context and interpreting them on the basis of the predictor model proposed by Luppa et al. [Dement Geriatr Cogn Disord 2008;26:65–78]. ***Methods:*** At the start of this study, 357 patients with mild to moderate dementia were examined by their general practitioners, and a telephone interview was conducted with their caregivers. Four years later, the outcomes 'institutionalization' and 'death' were determined from health insurance data. Forty-one variables were examined for their predictive influence by univariate and multivariate Cox regression. ***Results:*** The risk of institutionalization increased significantly ($p \leq 0.05$) with older ages of patients [hazard ratio (HR) = 1.05] and caregivers (HR = 1.03), a higher educational level of the caregiver (HR = 1.83), greater use of community health services (HR = 1.59), greater caregiver burden (HR = 1.02), and when the caregiver and patient lived apart (HR = 1.97). ***Conclusion:*** The results show that there is a multifactorial influence on institutionalization of dementia patients by sociodemographic, health-related, and psychological aspects as well as the care situation, thus validating the predictor model by Luppa et al. [Dement Geriatr Cogn Disord 2008;26:65–78]. Caregiver burden was found to be the strongest predictor accessible to interventions.

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Introduction

Institutionalization from an elderly person's point of view often means the loss of their lovely long-term home and their familiar social environment, and the abandonment of memories, identity, independence, autonomy, and dignity. Institutionalization can indeed be considered a 'critical life event', which has varied effects on everyday life and requires the behavioral, cognitive, and emotional reorientation and the adaptation of all persons involved. Often, older patients in advanced stages of dementia are transferred from being cared for at home to long-term care in a nursing home [1], i.e. they are institutionalized, because the care of elderly patients with chronic progressive diseases is a great challenge for their caregivers and families. On the one hand, for the dementia patient, institutionalization may actually have positive effects, such as the improvement of physical symptoms and functional level [2–4]. On the other hand, institutionalization also has the bad reputation of having negative effects on the patient, such as decreased psychological and physical health and increased mortality [5, 6]. Informal caregivers may experience a rapid reduction in their everyday physical and emotional burdens as a result of institutionalization [7–9], but there may also be an increase or possible chronification of stress symptoms or depression [7–14]. Often, the tasks of and the strains on the family members are not solved by the admission of the patient into a nursing home, but are rather shifted to another area, such as visits to the home, care activities that continue, or discussions with the home staff [15–18].

Institutionalization of dementia patients is problematic from 2 perspectives:

(1) In industrial countries like Germany, the majority of care receivers and their caregivers prefer care at home [19, 20]. The caregivers' final decision to institutionalize dementia patients is often difficult and laden with conflict [21, 22].

(2) The institutionalized care of dementia patients represents the largest portion of direct costs in the care of the elderly, both for social care insurance and for the family members themselves [23, 24].

In order to have an effect on the process of institutionalization, such as by postponing it or by helping to make this difficult transition go more smoothly, it is necessary to identify the predictors that can be influenced by interventions. The psychosocial and medical circumstances under which institutionalization takes place have been examined in numerous studies. For one thing, dementia itself is often a strong predictor of institutionalization of elderly people [25–30]. In addition to functional impairment in the activities of daily living (ADL) or instrumental activities of daily living (IADL) [30, 31] and the extent of cognitive impairment [1, 26, 27, 32–34], dementia patients' behavioral problems [19, 33, 35–37], such as aggression [38] or depression [32, 39–41], are important predictors. Like limited physical health or comorbidities [27, 40–42], such as urinary or fecal incontinence [40, 43], unexpected events, such as hospitalization [44], can influence the final institutionalization. Sociodemographic predictors, such as living alone [34], the absence of a spouse [1, 45, 46], older age [26–28, 31, 40, 41], the socioeconomic status [47], the place of residence [34], employment [19], ethnicity [27, 28], or gender [31, 40, 45, 48], can play a role in the process of institutionalization, too. Likewise, characteristics of the care situation are often important predictors, for example, the presence of helpers [19] or the use of community-based care [45]. Caregiver burden has been found to be an important independent predictor [32], on the one hand, and a mediator, on the other [37, 39].

These results indicate that institutionalization is determined multifactorially by a number of single influencing factors. In the literature, predictors of institutionalization have been examined in different ways, both methodologically and qualitatively, often not in theory-based ways, and seldom with multivariate analyses that include a large number of variables.

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Dement Geriatr Cogn Disord Extra 2013;3:426–445

DOI: 10.1159/000355079

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For this reason, the present study followed a methodologically elaborated, theory-based, multivariate research approach.

Based on a literature review, Luppa et al. [49] presented a differentiated model for predicting institutionalization of dementia patients. In accordance with the models proposed by Andersen [50], Pearlin et al. [51], and Pruchno et al. [52], Luppa et al. [49] subdivided the predictors of institutionalization into 'predisposing variables', 'need variables', and 'enabling variables' (fig. 1). The predisposing variables include sociodemographic characteristics of the patients and caregivers, sociocultural aspects, the socioeconomic status, and characteristics of the relationship between the patients and caregivers. The need variables describe the subjective evaluation of the illness by the patients and caregivers and the objectively estimated need for help. Luppa et al. [49] further subdivided the need variables into 'primary stressors' (dementia-related aspects and caregiving-related aspects) and 'secondary stressors' (the caregivers' evaluation of the burden caused by the care situation). The enabling variables denote personal and social resources as well as community-based care offers. Finally, Luppa et al. [49] noted a 'desire for institutionalization', which precedes the final institutionalization. Their predictor model offers a structured overview and categorization of predictors and thus provides a starting point for a comprehensive conceptual elucidation of institutionalization.

The current paper refers to a large sample and a broad set of variables from 3 data sources (a baseline caregiver interview, a baseline assessment from the general practitioner, and health insurance data), and it contains the use of different assessment methods. This made it possible to pursue the following aims:

(1) to determine independent predictors of institutionalization by using multivariate regression analysis and

(2) to examine the validity of the predictor model by Luppa et al. [49].

Methods

Design and Participants

The data for the study presented here were obtained from a 3-armed, cluster-randomized, controlled trial called the 'IDA project' (Dementia Care Initiative in Primary Practice), which had been developed to evaluate a counseling program for family caregivers of dementia patients [53] (trial registration: ISRCTN68329593). There was 1 control group (group A: standard treatment by the general practitioners) and 2 intervention groups (group B: standard treatment, a caregiver support group, and family counseling after 1 year, and group C: standard treatment, a caregiver support group, and family counseling from baseline). More information about the counseling program can be found in Grossfeld-Schmitz et al. [54]. In the IDA project, no statistically significant differences were found between the groups [55]. Additional aims of the IDA project were to investigate whether the program had an effect on institutionalization and to examine the costs of care for dementia patients in a community setting [23, 55]. For this purpose, 129 cooperating and trained general practitioners in the region of Middle Franconia, Bavaria, Germany, recruited 390 dementia patients and their

Fig. 1. Capital letters represent variables in the model by Luppa et al. [49]. Variables in our study are in parentheses (…), 39 variables are shown (the adjustment variables study arm B and C are excluded). Significant predictors from our multivariate analysis are given in bold. Some variables cannot be assigned to the predictor model by Luppa et al. [49]: EQ-5D (P), Incalzi Comorbidity Index, antidementia drugs, psychopharmaceutical drugs, and nonpharmacological therapy. Black boxes contain suggestions for modifications of the model by Luppa et al. [49]. Arrows indicate shifts within the modifications. P = Patient; CG = caregiver.

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Predisposing Variables

Sociodemographic and relationship characteristics of patients (Ps) and caregivers (CGs)

AGE
(**Age P, Age CG**)

GENDER
(Gender P, Gender CG)

ETHNICITY

RELIGION

MARITAL STATUS
(Marital status CG)

LIVING SITUATION
(Residence urban/rural)

EDUCATION LEVEL
(**Educational level CG**)

EMPLOYMENT
(Employment CG)

RELATIONSHIP
(Relationship)

INCOME

Need Variables

Primary stressors

(1) Dementia-related aspects

SEVERITY AND TYPE OF DEMENTIA
(Type of dementia, CGI)

COGNITIVE IMPAIRMENT
(MMSE, DemTect, Number of cognitive impairments)

DEMENTIA-RELATED PROBLEMS
(Number of noncognitive impairments, NOSGER-disruptive behavior)

FUNCTIONAL IMPAIRMENT
(Barthel Index, NOSGER-IADL)

UNMET ADL NEED

HOSPITALIZATION

(2) Caregiving-related aspects

(Care of other persons under 18 by CG, **Living in the same house/shared apartment**, Sleep interruption)

CAREGIVING HOURS
(Help from CG in ADL, IADL, supervision, in at least 1 area)

DURATION OF CAREGIVING
(Duration of caregiving)

CAREGIVER'S HEALTH
(Subjective physical health CG)

(3) Psychological aspects

(European Quality of Life-5 Dimensions)

(4) Health-related aspects

(Incalzi Comorbidity Index)

HOSPITALIZATION

Secondary stressors

(1) Psychological aspects

CAREGIVER'S BURDEN
(**BSFC**)

LIFE SATISFACTION

QUALITY OF LIFE

(2) Health-related aspects

CAREGIVER'S HEALTH
(Subjective physical health CG)

HOSPITALIZATION

Enabling Variables

Resources

(1) Personal and social resources

CHILDREN LIVING IN THE AREA

SOCIAL SUPPORT
(Help from other person in ADL, IADL, supervision, in at least 1 area)

COPING STRATEGIES

(2) Community-based care

(**Number of community health services**, Care Level P)

ADULT DAY SERVICE USE

LONG-TERM CARE USE

IN-HOME SERVICE USE

NUMBER OF HOME HEALTH AGENCIES

NUMBER OF NURSING HOME BEDS

NURSING HOME OCCUPANCY RATES

(3) Therapeutic care

(Antidementia drugs, Psychopharmaceutical drugs, Nonpharmacological therapy)

DESIRE TO INSTITUTIONALIZE

INSTITUTIONALIZATION

1

(For legend see p. 428.)

informal caregivers [56]. The intervention program was conducted over a period of 2 years. Patients were only included in the IDA project if they had physician-diagnosed mild or moderate primary dementia, were at least 65 years old, had an AOK Bavaria Statutory Health Insurance, were still living at home, and had an informal caregiver. Additionally, written informed consent of patients and their caregivers was also required before inclusion in the study. Patients were excluded if they had a terminal illness, if institutionalization had already been planned, or if they were not able or willing to provide informed consent. The IDA project was approved by the Ethics Committee at the Bavarian Chamber of Physicians (No. 05029) and was conducted in accordance with the Declaration of Helsinki.

The present study investigated the extent to which variables recorded at baseline could predict institutionalization after a period of 4 years. The baseline data were comprised of a caregiver interview, a general practitioner's assessment, and health insurance data. The sample consisted of those 357 cases from the IDA project for whom all baseline data were available, including the informed consent statements of the patients and caregivers.

Instruments
Mini-Mental State Examination
The Mini-Mental State Examination (MMSE) [57] was used for dementia screening. The score ranges from 0 (= maximal cognitive impairment) to 30 points (= maximal cognitive performance). Patients with mild (18–24 points) or moderate (10–17 points) dementia were included in our study.

DemTect
DemTect [58] is another screening instrument for dementia and consists of 5 subtests. They cover the areas 'verbal memory', 'cognitive flexibility', 'word fluency', 'working memory', and 'long-term memory'. The DemTect is more sensitive to mild dementia than the MMSE. The evaluation can be made separately for people <60 versus >60 years of age; the maximum score is 18 points. The sum score allows to draw conclusions concerning suspected dementia (≤8 points), mild cognitive impairment (9–12 points), or age-appropriate cognitive performance (13–18 points).

Incalzi Comorbidity Index
The Incalzi Comorbidity Index [59, 60] is used to weight comorbidities. The procedure assigns a relative mortality risk of 1–6 to a total of 52 diseases. Category 1, which indicates the lowest mortality risk, includes for example hypertension and ulcerative colitis. Category 6, with the highest relative mortality risk, includes for example acute leukemia and stage III multiple myeloma. The sum score for the mortality risk was calculated from the diseases documented in the health insurance data according to the ICD-10.

Clinical Global Impression
The Clinical Global Impression (CGI) [61] records the physician's overall clinical impression. Only the item 'severity of the disease' was used in the present study. The 7-step classification consists of 'healthy' (= 1), 'borderline' (= 2), 'slightly ill' (= 3), 'moderately ill' (= 4), 'obviously ill' (= 5), 'seriously ill' (= 6), 'extremely seriously ill' (= 7), and, additionally, 'cannot be rated' (= 0).

European Quality of Life – 5 Dimensions
The European Quality of Life – 5 Dimensions (EQ-5D) is used to measure the health-related quality of life of patients [62, 63]. The assessment of health according to the EuroQol classification is made for the dimensions 'mobility', 'self-care', 'everyday activities', 'pain/

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discomfort', and 'anxiety/depression' using a 3-step scale (no difficulties vs. moderate or some difficulties vs. extreme difficulties). To calculate the utilities, the German tariff was used, which is based on time trade-off, yielding utility values ranging from –0.02 to 1 [64]. As the self-rating of dementia patients may be invalid or erroneous [65, 66], the evaluation of quality of life was conducted by the caregivers.

Barthel Index

The Barthel Index [67] is a widely used observer rating scale for measuring the independence of patients in fundamental ADL. Basic, everyday, practical abilities are rated on a 2-step (0 or 5 points) to 4-step rating scale (0, 5, 10, or 15 points) for 10 functional areas: 'eating', 'sitting up and changing chairs', 'washing', 'using the toilet', 'bathing and showering', 'getting up and walking', 'climbing stairs', 'dressing and undressing', 'fecal continence', and 'urinary continence'. The sum score ranges from 0 (= dependent in all areas) to 100 points (= completely independent in all ADL functions). The Barthel items were presented in a form that was adequate for the caregivers to rate the functional independence of the patients in the interview.

Nurses' Observation Scale for Geriatric Patients

With the Nurses' Observation Scale for Geriatric Patients (NOSGER) [68], caregivers describe behavioral problems and changes in behavior of geriatric patients with regard to daily functioning on several dimensions: 'memory,' 'IADL', 'ADL', 'mood', 'social behavior', and 'disruptive behavior'. In our study, we used the 2 subscales 'disruptive behavior' and 'IADL', consisting of 5 questions each. The informal caregivers rated the relevant behaviors on a 5-step scale ranging from 1 (= always) to 5 (= never) in reference to the last 2 weeks. The score for each subscale ranged from 5 (= no disturbance/fully independent) to 25 (= maximum disturbance/fully dependent) [69].

Care Time

The Resource Utilization in Dementia (RUD) [70–73] scale, modified by Neubauer et al. [74, 75], is used to determine the time spent on care activities. It is based on a reliable and valid questionnaire recording the time spent on informal care activities by the main family caregiver and other informal caregivers. The informal care activities include the 3 categories ADL, IADL, and supervision. In this study, we used a rough dichotomous division, indicating whether the main family caregiver or another informal caregiver gave any help in these areas.

Burden Scale for Family Caregivers

The Burden Scale for Family Caregivers (BSFC) [76] includes 28 items for the measurement of caregiver burden by self-report. The items cover the entire spectrum of burden causes, especially in the areas 'expenditure of emotional and physical energy', 'relationship between caregiver and patient', 'changes in the socioeconomic situation', 'overload', and 'role identification'. The items are rated on a scale from 0 (= definitely disagree) to 3 (= definitely agree). The sum score ranges from 0 to 84 points with higher values indicating greater caregiver burden. The scale is validated using the increasing risk for psychosomatic symptoms in the case of increasing subjective burden.

Other Measures
Care Level

The level of care in Germany is categorized by the degree of care required due to physical or psychological impairments. Trained experts of the Medical Service of the Health Insurance make the decisions about the Care Level: Care Level 0 indicates no/low impairment, Care Level 1 indicates mild impairment, Care Level 2 indicates moderate impairment, and Care Level 3

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indicates severe impairment. The decision is based on the need for help in ADL and household duties. The daily amount of time spent on the care of patients in Care Level 1 must average at least 1.5 h, it is at least 3.0 h in Care Level 2, and it is at least 5.0 h in Care Level 3. The Care Level determines the amount of financial services paid by the care insurance [77]. The Care Level is strongly associated with impairments in ADL functioning ($\eta = 0.75$ with the Barthel Index in our study), and it is only mildly associated with cognitive decline ($\eta = 0.37$ with the MMSE).

Number of Community Health Services

The variable 'number of community health services' represents the total number of community-based health services used by patients and caregivers (range: 0–10). These are: family counseling, support group, home nursing, home help, Meals on Wheels, voluntary help service, care group, adult daycare, day hospital, and short-term residential care.

Number of Cognitive Impairments

The general practitioners assessed the number of cognitive impairments (range: 0–5); they are: disorientation, agnosia, impaired executive functions, apraxia, and aphasia.

Number of Noncognitive Impairments

The number of noncognitive impairments (range: 0–7) is calculated based on the following symptoms: anxiety, depression, aggression, agitation/restlessness, tendency to run away, insomnia, and delusions.

Events

The events 'institutionalization', 'death', 'dropout', and 'study completion without event' were registered in the 4-year follow-up with the date of the event.

Conceptual Framework

A total of 41 variables were analyzed in this study (fig. 1). These 41 variables consisted of 9 predisposing variables according to the model by Luppa et al. [49], 19 need variables [primary stressors – dementia-related aspects (9), caregiving-related aspects (9), and 1 secondary stressor], 6 enabling variables [resources – personal and social (4) and community-based care (2)], and 7 variables that were not classifiable according to the model by Luppa et al. [49]: EQ-5D (patient), Incalzi Comorbidity Index, psychopharmaceutical drugs, antidementia drugs, nonpharmacological therapy, study arm B, and study arm C.

Data Recording

The assessments by the general practitioners at baseline included sociodemographic information about the patients (urban/rural residence, age, and gender), the inclusion criteria, ICD-10 criteria for dementia, and attendant symptoms (disorientation, agnosia, impaired executive functions, apraxia, aphasia, anxiety, depression, aggression, agitation/restlessness, tendency to run away, insomnia, and delusions). Moreover, the general practitioners performed the screening procedures of the MMSE, DemTect, and CGI as well as the additional medical examinations to clarify the type of dementia. They also assessed comorbidities and the use of drug and non-drug therapy.

In a computer-based telephone interview with the informal caregivers, trained interviewers recorded data on the caregivers' sociodemography, the care situation, the patients' EQ-5D, Barthel Index, and NOSGER, the BSFC and the caregivers' physical health, the care time invested by the informal caregivers as well as the use of community health services. From the health insurance data, we were able to obtain information about whether institutionalization had taken place or the patients had died within the 4-year period.

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Statistical Analysis

General Description

For predictive analyses, the statistical procedure of Cox regression was used [78] with 'institutionalization' as the dependent variable. The events 'death', 'other dropout', or 'end of study' were censored, and the observation period was counted in days from baseline to the occurrence of the target or censoring event. The study arms of the IDA project (groups B and C as dummy variables) and patient's and caregiver's age and gender were used as adjustment variables in all regression analyses. Missing values were imputed based on an expectation-maximization algorithm [79] using available information from the general practitioners' baseline assessments, telephone interviews with the caregivers, and health insurance data. Only single missing items had to be imputed instead of whole interviews.

Generation of Sum Scores

Several single variables were combined into sum scores: 'number of community health services', 'number of cognitive impairments', and 'number of noncognitive impairments'. To justify the summation of these single variables, the direction of the predictive influence of each single variable (i.e. the augmentation or reduction of risk) was checked by Cox regression. If the predictive direction of the single variables was the same or not significantly different, the sum score was computed.

Univariate Analysis

To achieve valid results, the number of variables in the Cox regression had to be limited. Usually, the number of covariates should not make up >10% of the target events [80]. In our case, this meant a limit of 8 covariates for the multivariate model. For this reason, a 'univariate' Cox regression (method *enter*) was first conducted to individually check all 41 independent variables for their influence on the risk of institutionalization. Only those variables with a significant influence (cutoff $p \leq 0.05$) were used in further analyses (in addition to the adjustment variables).

Multicollinearity

To avoid redundancy, the significant variables of the univariate analysis were checked for multicollinearity. Variables with a correlation coefficient of $r < 0.50$ were rated as not multicollinear and were retained in the model. At a moderate correlation of $r \geq 0.50$, multicollinearity was assumed, and those variables with the greatest predictive influence on institutionalization were retained in further analyses, whereas those with lower significance were excluded.

Multivariate Analysis

The remaining variables were then analyzed together in a multivariate Cox regression model. In this predictor model, the adjustment variables were included in the Cox regression in an initial block using the method *enter*, the other covariates were integrated together into the model in a second block using the method *stepwise backward LR* [81]. The inclusion cutoff was set at $p \leq 0.01$ and the exclusion cutoff at $p \leq 0.05$.

Sensitivity Analysis

Two sensitivity analyses were performed. First, we checked the predictive influence of single items from the Barthel Index within the univariate analysis (e.g. urinary and fecal incontinence). Second, in the sensitivity analysis within the multivariate analysis, we changed the inclusion cutoff to $p \leq 0.05$ and the exclusion cutoff to $p \leq 0.10$ in the multivariate Cox regression to test the stability of the multivariate predictor model. IBM SPSS Statistics 19 was used to compute the statistical analyses.

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Table 1. Patient and caregiver characteristics

Sociodemographic and relationship characteristics of P and CG	
Age P, years	80.2±6.7
Female P	241 (67.5)
Age CG, years	59.2±13.4
Female CG	262 (73.4)
Relationship (spouse)[a]	115 (32.2)
Marital status CG (married)[b]	289 (81.0)
Educational level CG (higher than elementary)[c]	117 (32.8)
Employment CG (employed)	128 (35.9)
Residence CG (urban)[d]	68 (19.0)
Primary stressors – dementia-related aspects	
Type of dementia (degenerative)[e]	258 (72.3)
Dementia screening with MMSE	18.7±3.8
Dementia screening with DemTect	5.7±3.5
Cognitive impairments[f]	2.1±1.3
Noncognitive impairments[g]	1.6±1.6
CGI	4.2±1.1
NOSGER – disruptive behavior	9.5±3.5
NOSGER – IADL	15.8±5.4
Barthel Index	73.0±26.5
Primary stressors – caregiving-related aspects	
CG and P living in the same house/shared apartment (yes)	244 (68.3)
Duration of caregiving by the CG until baseline, months	37.8±48.0
Care of other persons under 18 years by CG (yes)	86 (24.1)
Help from CG in ADL (yes)	245 (68.6)
Help from CG in IADL (yes)	331 (92.7)
Help from CG in supervision (yes)	135 (37.8)
Help from CG in at least 1 area (ADL, IADL, or supervision) (yes)	331 (92.7)
Sleep interruption for CG due to care activities (yes)	122 (34.2)
Subjective physical health CG (good/very good)[h]	217 (60.8)
Secondary stressors	
BSFC	24.9±17.3
Resources – personal and social	
Help from other informal CG in ADL (yes)	115 (32.2)
Help from other informal CG in IADL (yes)	180 (50.4)
Help from other informal CG in supervision (yes)	68 (19.0)
Help from other person in at least 1 area (ADL, IADL, or supervision) (yes)	212 (59.4)
Resources – community-based care	
Community health services[i]	0.6±0.9
Care Level P (Level 1, 2, or 3)	153 (42.9)
Not classifiable by the model by Luppa et al. [49]	
EQ-5D, health-related quality of life P	0.55±0.31
Incalzi Comorbidity Index P	3.6±2.1
Antidementia drugs[j] P (yes)	170 (47.6)
Psychopharmaceutical drugs[k] P (yes)	107 (30.0)
Nonpharmacological therapy[l] P (yes)	46 (12.9)
Study arm B	103 (28.9)
Study arm C	102 (28.6)

(For footnote see next page.)

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Dement Geriatr Cogn Disord Extra 2013;3:426–445

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DOI: 10.1159/000355079

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Results

Sample Characteristics

The patients' mean age was 80.2 years; two-thirds (67.5%) were women (table 1). According to the MMSE, mild dementia was present in 64.1% (n = 327) of the cases and moderate dementia in 35.9% (n = 30). In 42.9% of the dementia patients, the impairment in ADL was so great that they attained a Care Level under the German health system and thus received support from the health care insurance. Care Level 1 (= mild impairment) was assigned to 16.0% (n = 57), Care Level 2 (= moderate impairment) to 18.5% (n = 66), and Care Level 3 (= severe impairment) to 8.4% (n = 30) of the patients. Although dementia was diagnosed in all patients, only about half of the patients were being treated with antidementia drugs (47.6%). After 4 years, 23.5% (n = 84) of the patients were institutionalized, 34.7% (n = 124) had died at home, and 9.2% (n = 33) had died after institutionalization. For 40.3% (n = 144) of the patients, the study ended without any event, and 1.4% (n = 5) of the patients dropped out because of the revocation of the informed consent.

The caregivers' mean age was 59.2 years; 73.4% were women. The majority was married (81%), not employed (64.1%), and had a low (67.2%, n = 240) or moderate (24.4%, n = 87) educational level. In 68.3% of the cases, the caregiver lived in the same house as the patient or in a shared apartment. At baseline, 92.7% of the caregivers assisted the dementia patients in the area ADL, IADL, or supervision; in 59.4% of the cases, another informal caregiver helped in 1 of these areas. 34.2% of the caregivers reported interruptions in their sleep at night because of care-related activities.

Univariate Analysis

The results of the univariate analysis of the total number of independent study variables (n = 41) are given in table 2. The following 13 covariates emerged as significant (p ≤ 0.05) and were therefore retained in further analyses as potential predictor variables: patient's age,

(Footnote to table 1.)

P = Patient; CG = caregiver.

The results are given as numbers with percentages in parentheses or as means ± SD (= standard deviation).

[a] Non-spouse: mother, mother-in-law, father, father-in-law, other.

[b] Not married: single, widowed, divorced.

[c] Higher than elementary: standard certificate, high school, university.

[d] Urban: 100,000 residents or more.

[e] Degenerative: Alzheimer's dementia, other degenerative dementia, mixed forms.

[f] Cognitive impairments: disorientation (201; 56.3%), agnosia (76; 21.3%), impaired executive functions (294; 82.4%), apraxia (105; 29.4%), aphasia (89; 24.9%).

[g] Noncognitive impairments: anxiety (123; 34.5%), depression (117; 32.8%), aggression (55; 15.4%), agitation/restlessness (97; 27.2%), tendency to run away (30; 8.4%), insomnia (147; 41.2%), delusions (17; 4.8%).

[h] Suboptimal/poor = 0.

[i] Community health services: family counseling (10; 2.8%), support group (7; 2.0%), home nursing (79; 22.1%), home help (27; 7.6%), Meals on Wheels (24; 6.7%), voluntary help service (5; 1.4%), care group (4; 1.1%), adult daycare (10; 2.8%), day hospital (5; 1.4%), short-term residential care (25; 7.0%).

[j] Donepezile, galantamine, rivastigmine, and memantine, others: piracetam, gingko, and biloba.

[k] All other drugs with psychotropic effects.

[l] Cited were: occupational therapy, movement therapy, cognitive stimulation, social activation, diet, and massages.

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Dement Geriatr Cogn Disord Extra 2013;3:426–445

DOI: 10.1159/000355079

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Table 2. Results of the univariate predictor analysis

Variable	B	SE	Wald	Sign	Exp(B)	95.0% CI for Exp(B)	
						lower	upper
Sociodemographic and relationship characteristics of P and CG							
Age P	*0.07*	*0.02*	*15.28*	*<0.001*	*1.07*	*1.04*	*1.11*
Gender P	0.34	0.31	1.16	0.28	1.40	0.76	2.58
Age CG	*0.02*	*0.01*	*4.24*	*0.040*	*1.02*	*1.00*	*1.04*
Gender CG	0.18	0.28	0.41	0.52	1.20	0.69	2.07
Relationship[a]	*−1.15*	*0.50*	*5.32*	*0.021*	*0.32*	*0.12*	*0.84*
Marital status CG	−0.13	0.27	0.24	0.62	0.88	0.52	1.48
Educational level CG	*0.79*	*0.24*	*10.94*	*0.001*	*2.19*	*1.38*	*3.49*
Employment CG	0.49	0.30	2.74	0.10	1.63	0.91	2.92
Residence (urban/rural) CG	*0.52*	*0.26*	*3.91*	*0.048*	*1.67*	*1.01*	*2.79*
Primary stressors – dementia-related aspects							
Type of dementia	0.35	0.27	1.63	0.20	1.41	0.83	2.41
MMSE	−0.05	0.03	2.73	0.10	0.96	0.91	1.01
DemTect	*−0.08*	*0.03*	*5.99*	*0.014*	*0.92*	*0.86*	*0.98*
Cognitive impairments	0.01	0.08	0.01	0.91	1.01	0.86	1.19
Noncognitive impairments	0.05	0.07	0.50	0.48	1.05	0.92	1.21
CGI	0.13	0.10	1.62	0.20	1.14	0.93	1.39
NOSGER – disruptive behavior	0.03	0.03	0.72	0.40	1.03	0.97	1.09
NOSGER – IADL	*0.04*	*0.02*	*3.96*	*0.047*	*1.04*	*1.00*	*1.09*
Barthel Index	0.00	0.00	0.07	0.80	1.00	0.99	1.01
Primary stressors – caregiving-related aspects							
Living in the same house/shared apartment	*−0.80*	*0.26*	*9.75*	*0.002*	*0.45*	*0.27*	*0.74*
Duration of caregiving	0.00	0.00	0.00	0.96	1.00	0.99	1.00
Care of other persons under 18 by CG	−0.17	0.32	0.29	0.59	0.84	0.45	1.58
Help from CG in ADL[b]	*0.53*	*0.27*	*3.91*	*0.048*	*1.70*	*1.01*	*2.87*
Help from CG in IADL	0.97	0.59	2.67	0.10	2.63	0.82	8.39
Help from CG in supervision	0.22	0.23	0.93	0.34	1.25	0.80	1.95
Help from CG in at least 1 area	0.97	0.59	2.67	0.10	2.63	0.82	8.39
Sleep interruption	0.13	0.24	0.28	0.60	1.13	0.71	1.81
Subjective physical health CG	0.31	0.23	1.72	0.19	1.36	0.86	2.14
Secondary stressors							
BSFC	*0.02*	*0.01*	*7.70*	*0.006*	*1.02*	*1.01*	*1.03*
Resources – personal and social							
Help from other informal CG in ADL	0.13	0.23	0.32	0.57	1.14	0.72	1.81
Help from other informal CG in IADL[c]	*0.52*	*0.23*	*5.16*	*0.023*	*1.68*	*1.07*	*2.63*
Help from other informal CG in supervision	0.23	0.28	0.67	0.41	1.25	0.73	2.16
Help from other informal CG in at least 1 area	*0.59*	*0.24*	*6.02*	*0.014*	*1.80*	*1.13*	*2.89*
Resources – community-based care							
Community health services	*0.61*	*0.09*	*42.74*	*<0.001*	*1.85*	*1.54*	*2.22*
Care Level P	0.21	0.23	0.85	0.36	1.23	0.79	1.93
Not classifiable by the model by Luppa et al. [49]							
EQ-5D P	−0.43	0.36	1.49	0.22	0.65	0.32	1.30
Incalzi Comorbidity Index	−0.00	0.06	0.00	0.98	1.00	0.90	1.11
Antidementia drugs	0.37	0.22	2.69	0.10	1.44	0.93	2.24
Psychopharmaceutical drugs	0.32	0.24	1.84	0.18	1.38	0.87	2.20
Nonpharmacological therapy	0.14	0.33	0.18	0.67	1.15	0.60	2.21
Study arm B	0.14	0.27	0.26	0.61	1.15	0.67	1.96
Study arm C	0.18	0.26	0.44	0.51	1.19	0.71	2.00

(For footnote see next page.)

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caregiver's age, relationship, caregiver's educational level, urban/rural residence (all predisposing variables), DemTect, NOSGER – IADL, living in the same house/shared apartment, help from the caregiver in ADL, BSFC (all need variables), help from other informal caregivers in IADL, help from other informal caregivers in at least 1 area, and the number of community health services (all enabling variables).

To test the predictive influence of urinary and fecal incontinence on institutionalization, a univariate sensitivity analysis of the single Barthel items was conducted, but only the 'bathing/showering' item (dichotomized) reached statistical significance (B = 0.53, SE = 0.27, Wald = 4.01, d.f. = 1, p = 0.045, Exp(B) = 1.71, 95.0% CI = 1.01–2.87).

Multicollinearity

Due to multicollinearity (with correlations between r = –0.58 and 0.83, see the legend of table 2), 3 variables dropped out from further analyses: relationship (predisposing variable), help from the caregiver in ADL (need variable), and help from other informal caregivers in IADL (enabling variable).

Multivariate Analysis

The Cox regression of the remaining variables (6 adjustment variables in addition to 8 univariate significant variables) revealed 6 significant predictors of institutionalization after 4 years (table 3): (1) educational level: with a higher educational level of the caregiver, the risk of institutionalization increased; (2) living in the same house/shared apartment: if the caregiver and patient lived apart, the risk increased; (3) BSFC: a high subjective caregiver burden increased the risk; (4) the number of community health services: the more formal community-based health care services were used by the patient and caregiver, the greater the risk, and the 2 adjustment variables (5) patient's age and (6) caregiver's age were also found to be significant in this analysis – as they increased, so did the risk of institutionalization. The significant predictors in the multivariate analysis are presented in bold print in figure 1.

Finally, a sensitivity analysis with more generous cutoffs (inclusion cutoff p ≤ 0.05, exclusion cutoff p ≤ 0.10) was performed to test the stability of the model. The Cox regression was found to be stable as the 6 known covariates once again reached statistical significance in predicting institutionalization. One additional variable remained in this model: DemTect (B = –0.07, SE = 0.03, Wald = 3.72, d.f. = 1, p = 0.054, Exp(B) = 0.94, 95.0% CI = 0.88–1.00).

Conceptual Framework

The results confirm the multifactorial significant influence from statistically independent variables on institutionalization, representing all areas of the model by Luppa et al. [49] (see fig. 1): predisposing variables (patient's age, caregiver's age, educational level); need variables – primary stressor (living in the same house/shared apartment) and secondary stressor (BSFC), and enabling variable (the number of community health services).

(Footnote to table 2.)

P = Patient; CG = caregiver.

B = Regression coefficient; SE = standard error; Wald = Wald significance test; Sign = significance level (p); Exp(B) = hazard ratio; CI = confidence interval.

n = 357, d.f. = 1.

Variables in italics are statistically significant; p ≤ 0.05.

Multicollinearity analysis: dropped out due to multicollinearity: [a] correlation with Age CG – r = 0.74 and correlation with Gender P – r = –0.58; [b] correlation with NOSGER – IADL – r = 0.66; [c] correlation with Help from other informal CG in at least 1 area – r = 0.83.

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Table 3. Results of the multivariate predictor analysis

Variable	B	SE	Wald	Sign	Exp(B)	95.0% CI for Exp(B)	
						lower	upper
Sociodemographic and relationship characteristics of P and CG							
Age P	*0.04*	*0.02*	*5.75*	*0.016*	*1.05*	*1.01*	*1.08*
Gender P	−0.07	0.31	0.05	0.82	0.93	0.51	1.70
Age CG	*0.03*	*0.01*	*6.81*	*0.009*	*1.03*	*1.01*	*1.06*
Gender CG	0.03	0.28	0.01	0.91	1.03	0.60	1.79
Educational level CG	*0.61*	*0.24*	*6.63*	*0.010*	*1.83*	*1.16*	*2.90*
Residence CG	0.37	0.27	1.92	0.17	1.44	0.86	2.43
Primary stressors – dementia-related aspects							
DemTect[a]	−0.07	0.03	3.72	0.05	0.94	0.88	1.00
NOSGER – IADL	−0.00	0.03	0.01	0.94	1.00	0.95	1.05
Primary stressors – caregiving-related aspects							
Living in the same house/shared apartment[b]	*−0.68*	*0.28*	*5.81*	*0.016*	*0.51*	*0.29*	*0.88*
Secondary stressors							
BSFC	*0.02*	*0.01*	*7.75*	*0.005*	*1.02*	*1.01*	*1.03*
Resources – personal and social							
Help from other informal CG in at least 1 area	0.15	0.26	0.35	0.56	1.17	0.70	1.94
Resources – community-based care							
Community health services	*0.46*	*0.10*	*20.73*	*<0.001*	*1.59*	*1.30*	*1.94*
Not classifiable by the model by Luppa et al. [49]							
Study arm B	0.14	0.27	0.29	0.59	1.16	0.68	1.97
Study arm C	0.28	0.27	1.02	0.31	1.22	0.71	2.09

P = Patient; CG = caregiver.

B = Regression coefficient; SE = standard error; Wald = Wald significance test; Sign = significance level (p); Exp(B) = hazard ratio; CI = confidence interval.

n = 357, d.f. = 1.

Variables in italics are statistically significant; $p \leq 0.05$.

[a] p = 0.054.

[b] When the variable was recoded (living together = 0, living apart = 1), Exp (B) = 1.97.

Discussion

The following characteristics were shown to be significant predictors of institutionalization in the multivariate Cox regression: the dementia patient's and caregiver's age, cohabitation of the patient and caregiver, the educational level of the caregiver, caregiver burden, and the use of community-based health services.

Age

Both age variables were found to be stable predictors of institutionalization, even if they were no longer treated as adjustment variables. In order to determine how the predictive effect of the variable 'age' could be explained, we performed further multivariate analyses for the caregiver groups 'spouse' and 'non-spouse'. For the non-spouse group (mainly children or children-in-law), the caregiver's age remained a significant predictor of institutionalization (p = 0.013), but the patient's age did not (p = 0.23). This means that the children/children-in-law, in particular, cared for the patient at home, regardless of how old the patient was. Only

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the caregiver's age seemed to determine institutionalization of the patient: the older the caregiver, the more likely became institutionalization. We found no moderate or strong correlation between the non-spouse's age and other variables, not even with self-rated physical health (r = –0.20). This indicates that the relation between age and institutionalization among non-spouse caregivers was largely independent of a subjective deterioration of physical health with increasing age. What makes older non-spouses willing to institutionalize their demented family members remains a topic for future research.

In the group of caregiving spouses, neither the caregiving spouse's age (p = 0.17) nor the patient's age (p = 0.40) remained significant. This means that spouses continued to care at home, independent of their own age and independent of the patient's age. Age was thus not decisive for institutionalization; whereby for other (non-spouse) caregivers, only the caregiver's age played a role. This leads to the conclusion that caregiving spouses differ from other informal caregivers. It seems as if caregiving spouses, unlike caregiving children (-in-law), remain relatively uninfluenced by age or age-related aspects. They seem to remain uninfluenced by external conditions and their own needs in their decisions concerning institutionalization [45, 46].

Living Situation

The cohabitation of the patient and caregiver was found to be another significant predictor of institutionalization. In a differentiated analysis, however, this variable was significant only for non-spouse caregivers (p = 0.016) and not for caregiving spouses (p = 0.99) who lived together in most cases. This group difference may be a result of low variance in the caregiving spouse group. The risk of institutionalization increased for dementia patients who did not live in the same house or apartment with the caregiving children (-in-law). This can be explained, on the one hand, by the greater investment of time and effort necessary to provide care arising from the spatial distance. On the other hand, this may also be explained by the emotional bond which is less pronounced in caregivers and patients who live apart and stronger in caregivers and patients who live together. The separation resulting from institutionalization may be more difficult to cope with for someone who lives together with a demented family member than for someone who is 'used to' the distance in home care.

Educational Level

With respect to educational level, a higher educational level of the caregiver was found to indicate a significantly higher risk of institutionalization. This can be interpreted as due to the fact that, in the German health care system, payments out of pocket must always be made by patients or their family members for institutional care because only about 50% of the costs are financed through the nursing care insurance. Those private costs can probably be more easily paid by caregivers with a higher educational level and the attendant better-qualified professions with higher incomes. Other studies, in contrast, have reported no influence of socioeconomic predictors or inconsistent findings [27, 40].

Subjective Caregiver Burden

Furthermore, a higher subjective burden of the informal caregiver was coupled with a higher risk of institutionalizing the dementia patient. This indicates that the subjective evaluation of the care situation is an important predictor of the desire to institutionalize. The subjective burden has also been found to be a significant mediator [37, 39] or resilience factor [82]. In principle, the subjective burden can be influenced externally and therefore represents an effective starting point for interventions, see for example Etters et al. [83].

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Use of Community Health Services

The use of community health services was found to be the strongest predictor in our analysis: the more formal services were used, the higher the risk of institutionalization. The use of community health services can be regarded as part of the process that leads to institutionalization. The use of formal services may possibly be one section of the difficult adaptation process of placing the demented family member in a nursing home. It requires a reorientation, a redefining of roles, and turning the care over to others. By that, the family caregiver successively 'practices' handing over responsibility and partially learns how to 'let the patient go'. Research findings support this hypothesis [44, 84]. Additionally, in 2011 Lloyd and Stirling [85] demonstrated that the use of formal services may also have negative consequences, such as an emotional strain on the family caregiver, which may be an evidence of the (emotional) release process. The results published by Haley et al. [86] also support this hypothesis, such that the caregivers who had institutionalized their spouse experienced a reduction in depressive symptoms, which continued after the patient's death. These findings suggest that the use of formal services may possibly provide an essential preparatory stage for institutionalization and that institutionalization may provide an essential preparatory stage for losing the dementia patient to death.

Incontinence

Contrary to the findings of previous studies [40, 43, 87, 88], urinary and fecal incontinence did not show a significant association with institutionalization in our study. This leads to the conclusion that the role of many single variables (e.g. incontinence or time required for care) as independent predictors and existing interactions among them have not yet been definitively clarified.

Conceptual Framework

Luppa et al. [49] presented a model for predicting institutionalization of dementia patients. They combined elements of the predictor models by Anderson [50], Pearlin et al. [51], and Pruchno et al. [52] with a review of empirical studies. The results of our study confirm the significant influence of 6 predictor variables, which statistically independently represent all of the main areas in the model by Luppa et al. [49]. By recording a wide range of variables across various data sources and methods, and by excluding multicollinearity, our data validate the subdivision by Luppa et al. [49] in principle. But not all potential predictors could be integrated into the original model. Figure 1 also contains suggestions for modifications. The model should be expanded by 'psychological aspects' for both caregivers (e.g. caregiver burden) and patients (e.g. the patients' quality of life). In our study, caregiver burden was found to be the second strongest predictor, which confirms that psychological aspects are very important for institutionalization in the area of the need variables [89, 90]. We suggest an additional expansion of the model by Luppa et al. [49] by adding the area of 'health-related aspects', e.g. for the patient's comorbidities and the caregiver's physical health (see fig. 1). Other studies have found that, in addition to dementia, physical illness is an important predictor of institutionalization, too [91, 92]. As the caregiver's health may change both due to caregiving and independently of it, it should be assigned not only to caregiving-related aspects, as it is done in the original model. The same applies to the hospitalization of patients and caregivers. Moreover, in the model by Luppa et al. [49], the potential influence of therapeutic measures on institutionalization is not taken into account, e.g. drug and non-drug therapy. There is evidence for the delay of institutionalization due to medication-based treatment [93] and nonpharmacological interventions [94, 95]. In the same way, drugs affect the predictors themselves and may therefore have an indirect effect on institutionalization [96, 97]. Finally, the expanded model offers

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DOI: 10.1159/000355079

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the possibility of integrating additional variables from other models, such as 'caregiver's self-esteem' [51], 'number of children of the patient' [52], 'genetic factors', or 'health beliefs' [50].

Strengths and Limitations

Some of our study's strengths are the large number of cases and the observation period of 4 years. Moreover, the sample did not consist of highly selective patients recruited from specialized inpatient or outpatient facilities, but the patients were recruited via their general practitioners. Furthermore, the study used several data sources with a large number of variables. This enabled extensive analyses of potential predictor variables, on the one hand, and the validation of the model by Luppa et al. [49], on the other. The sensitivity analysis revealed a stable predictor model.

The sample is not representative of all home-dwelling dementia patients in Germany. A reason for that may be the focus on mild or moderate dementia in the primary study. However, other selection biases, as described above, were avoided. Another limitation is that, despite the broad data set, it was not possible to test all variables in the model by Luppa et al. [49]. Additionally, single events, such as hospitalization, may have a special influence on the risk of institutionalization. Such dynamic effects on institutionalization have to be considered in future research.

Conclusion

Our study shows that institutionalization is determined multifactorially by only a few significant variables, and thus complex prediction models may have been overestimated so far [32]. These variables seem to have diverse influences on different subgroups. It appears reasonable to distinguish in particular between caregiving spouses and non-spouses. Our results provide evidence that interventions intended to postpone institutionalization are more promising for caregiving children (-in-law) than for spouses. Of the 41 variables analyzed, 6 remained significant predictors; only 1 of these (caregiver burden) can really be influenced externally. This means that interventions that reduce the caregiver burden should be in a position to effectively change the institutionalization process [83, 98].

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Disclosure Statement

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DOI: 10.1159/000355079

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