Living Alone with Dementia: Prevalence, Correlates and the Utilization of Health and Nursing Care Services

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Abstract.

Background: Little is known about the proportion and the characteristics of community-dwelling people with dementia (PWD) living alone in Germany.

Objectives: To analyze the prevalence of PWD living alone (with and without the support of an informal caregiver) and socio-demographical and clinical characteristics as well as health and nursing care utilization associated with living alone.

Methods: DelpHi-MV (Dementia: Life- and person-centered help in Mecklenburg-Western Pomerania) is a general practitioner-based, randomized controlled intervention trial. The present analyses are based on baseline data of 511 patients (≥ 70 years, community-dwelling) who had screened positive for dementia (DemTect < 9).

Results: $N = 251$ (51%) of the patients lived alone. PWD living alone were statistically significantly more often female, older, and more often widowed than those not living alone. About 9% of the patients ($n = 24$) were not supported by any informal caregiver. Regarding the clinical variables (cognitive and functional impairment, depression, falls, number of drug-related problems, malnutrition, quality of life), there were no statistically significant group differences. Patients living alone utilized professional services such as home care, help with medication, home-delivered meals, or housekeeping assistance significantly more often. Multivariate analyses confirmed these findings.

Conclusion: Our results reveal the high proportion of PWD living alone in Germany. PWD living alone did not seem to be at an increased health risk. Our findings indicate that living alone with dementia is possible. In order to ensure the sufficient provision of health and nursing care services for PWD living alone, providers should consider the present results for future planning.

Keywords: Ambulatory care, dementia, living arrangements, primary health care

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INTRODUCTION

About three-quarters of the estimated 1.5 million people with dementia (PWD) in Germany live at home [1, 2]. It is likely that a significant proportion of these people live in single households. For the United States (US) [3] and the United Kingdom (UK) [4],

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it is estimated that up to one-third of community-dwelling PWD live alone. Previous studies showed that PWD living alone tend to be older, more often female, more likely to live in poverty, less cognitively impaired, to have fewer impairments in activities of daily living, and a higher risk to be socially isolated than PWD who do not live alone. In addition, they have more unmet needs, less access to health care, higher risks of problems with medication, untreated medical conditions, falls and injuries, earlier nursing home transition, and inadequate self-care such as malnutrition, poor hygiene, or inadequate clothing or housing. These risks increase with the progression of the disease [3–8].

As people grow older, they are not only more likely to live alone—demographic and societal changes result in an increasing number of PWD who do not have any relative, friend, or neighbor close by who can take care of them. Risks that are associated with living alone are likely to exacerbate even further if PWD live alone without the support of an informal caregiver. So far, very little is known about this group of patients, because the absence of an informal caregiver is often an exclusion criterion in dementia care research. It has been estimated that up to one-third to one-half of PWD live alone without an identifiable caregiver in the US [3].

To our knowledge, there are no primary data available about the proportion and the characteristics of community-dwelling PWD who live alone in Germany. Reliable figures are difficult to determine because the majority (about 60%) of community-dwelling PWD in Germany is not formally diagnosed with dementia [9] and general practitioners (GP) are even less likely to recognize dementia when patients live alone [10].

However, many PWD in Germany wish to remain at their own home as long as possible, even if they live alone [11]. To provide adequate treatment and care according to the individual needs of these PWD, health care and nursing care providers need to know more about this group of patients. The present study aims to contribute empirical data on community-dwelling PWD living alone in Germany. Specifically, we want to determine (1) the prevalence of community-dwelling PWD who live alone as well as the prevalence of PWD who live alone without the support of an informal caregiver and (2) socio-demographic and clinical characteristics as well as health care and nursing care utilization associated with living alone with and without the support of an informal caregiver.

MATERIALS AND METHODS

Study design

The present cross-sectional analyses are based on data derived from the GP-based, randomized controlled intervention trial DelpHi-MV (Dementia: Life- and person-centered help in Mecklenburg-Western Pomerania). The details of the study are described elsewhere [12–14]. The eligible patients (older than 70 years, living at home) were screened for dementia in participating GP practices using DemTect [15]. This personal interview-based instrument includes five tasks (recall of word list, number transcoding task, word fluency task, digit span reverse, delayed recall of word list) and is widely used for dementia screening in GP practices in Germany [16]. All patients who had screened positive for dementia (DemTect-score <9) were informed by their GPs about the study, invited to participate, and asked to provide a written informed consent. If the patient named a caregiver, the caregiver was asked to participate in the study as well. When the patients were unable to provide a written informed consent, their legal representatives were asked to sign the consent form on their behalf (as approved by the Ethical Committee of the Chamber of Physicians of Mecklenburg-Western Pomerania, registry number BB 20/11). Study enrollment into the main study started on January 1, 2012 and ended on December 31, 2014. The participants and their caregivers were assigned to an intervention group (received “Dementia Care Management”) and a control group (received “care as usual”). In both groups, identical, standardized, computer-assisted baseline assessments were conducted as face-to-face interview at the participants’ homes.

Study sample

Figure 1 shows the flow of the study participants through each stage of the DelpHi-study.

Of 1,167 eligible patients 634 (54.5%) provided informed consent. Of these, 516 patients were assessed at baseline. There were no statistically significant differences between patients assessed at baseline and those who dropped-out before the baseline-assessment regarding the DemTect-score, age, and sex (see Supplementary Table 1). The present analyses are based on the data of 511 patients at 93 GP practices. Not all variables could be assessed completely in all subjects due to the amount of

Fig. 1. Flow of the study participants through each stage of the DelpHi-study.

information assessed and the cognitive impairment of the participants. Missing data were statistically significantly more frequent among patients with more severe cognitive impairment (according to the DemTect-score, see Supplementary Table 2). In the case of missing data the number of participants for the respective variable is provided in the Tables 1 and 2.

Procedures and instruments

For the description of socio-demographic and clinical characteristics of the study sample sex, age, marital status (unmarried, married, divorced, widowed), living in a partnership (yes/no), number of children, presence of an informal caregiver (yes/no), description of the informal caregiver (spouse/partner, daughter/son, daughter/son-in-law, sister/brother, granddaughter/-son, others), availability of help in case of emergency (no/yes, within 24 h/yes, but not within 24 h), formal diagnosis of dementia (yes/no), falls in the past six month (yes/no), malnutrition (loss of body weight ≥ 5 kg over the past three months), number of drug-related problems (DRP), cognitive impairment, depression, functional impairment, quality of life, and the perceived social support were analyzed.

The baseline assessment includes a comprehensive home medication assessment [17] to document all drugs used by the PWD including over-the-

counter medicines. DRPs were classified according to the PI-Doc[®] coding system [18]. The main DRP groups comprise unsuitable drug choice, unsuitable use by the patient (including compliance), unsuitable dosage, drug-drug interactions, adverse drug reactions, other drug-related problems, and patient-related/communication-related/technical and logistic problems. All identified DRPs were summed to the total number of DRPs per patient.

Cognitive impairment was assessed using the German version of the Mini-Mental State Examination (MMSE) [19]. In the analyses we used the total MMSE score as well as a categorization that indicates “no cognitive impairment” (score 27–30), “mild” (score 20–26), “moderate” (score 10–19), and “severe cognitive impairment” (score 0–9). Depression was operationalized using the score of the Geriatric Depression Scale (GDS) [20] as dichotomized variable (“no depression”: Score 0–5; “depression”: Score 6–15). The functional impairment was assessed using the Bayer Activities of Daily Living Scale (B-ADL) [21], which yields a mean score of 1 to 10, where 10 indicates the highest possible impairment. The quality of life was assessed using the mean score of the Quality of Life-AD (QoL-AD) [22], a brief 13-item personal interview designed specifically to obtain a rating of the quality of life from PWD. The measure consists of 13 items, rated on four point scales, with 1 being poor and 4

Table 1
Socio-demographic and clinical characteristics of the study sample

	Total sample (n = 511)	Living situation (n = 511)			Living alone (n = 260)		
		Living with another person (n = 251)	Living alone (n = 260)	p-value	with informal caregiver (n = 236)	without informal caregiver (n = 24)	p-value
<i>Sex (female), n (%)</i>	303 (59.3)	117 (46.6)	186 (71.5)	<0.001^a	174 (73.7)	12 (50.0)	0.018^a
<i>Age, mean (SD)</i>	80.3 (5.5)	79.1 (5.2)	81.5 (5.6)	<0.001^b	81.7 (5.5)	79.8 (6.3)	0.172 ^b
<i>Marital status</i>							
Unmarried, n (%)	29 (5.7)	9 (3.6)	20 (7.7)	<0.001^a	14 (5.9)	6 (25.0)	0.010^a
Married, n (%)	215 (42.1)	187 (74.5)	28 (10.8)		27 (11.4)	1 (4.2)	
Divorced, n (%)	36 (7.1)	6 (2.4)	30 (11.5)		26 (11.0)	4 (16.7)	
Widowed, n (%)	231 (45.2)	49 (19.5)	182 (70.0)		169 (71.6)	13 (54.2)	
<i>Living in partnership (yes), n (%)</i>	253 (49.5)	210 (83.7)	43 (16.5)	<0.001^a	41 (17.4)	2 (8.3)	0.388 ^a
<i>Number of children, mean (SD)</i>	2.3 (1.6)	2.5 (1.5)	2.2 (1.7)	0.075 ^b	2.3 (1.7)	1.2 (1.2)	<0.001^b
<i>Support of informal caregiver (yes), n (%)</i>	485 (94.9)	249 (99.2)	236 (90.8)	<0.001^a	–	–	–
<i>Spouse/partner, n (%)</i>	193 (39.8)	168 (67.5)	25 (10.6)	<0.001^a	–	–	–
<i>Daughter/son, n (%)</i>	205 (42.3)	63 (25.3)	142 (60.2)				
<i>Daughter/son-in-law, n (%)</i>	18 (3.7)	4 (1.6)	14 (5.9)				
<i>Sister/brother, n (%)</i>	11 (2.3)	3 (1.2)	8 (3.4)				
<i>Granddaughter/-son, n (%)</i>	9 (1.9)	2 (0.8)	7 (3.0)				
<i>Others, n (%)</i>	49 (10.1)	9 (3.6)	40 (17.0)				
<i>Can somebody help in case of emergency?</i>	<i>n = 510</i>	<i>n = 251</i>	<i>n = 259</i>		<i>n = 235</i>	<i>n = 24</i>	
Yes, within 24 hours, n (%)	453 (88.8)	236 (94.0)	217 (83.8)	<0.001^a	210 (89.4)	7 (29.2)	<0.001^a
Yes, but not within 24 hours, n (%)	38 (7.5)	14 (5.6)	24 (9.3)		21 (8.9)	3 (12.5)	
<i>Perceived social support (FSozu)</i>	<i>n = 479</i>	<i>n = 236</i>	<i>n = 243</i>		<i>n = 220</i>	<i>n = 23</i>	
Score, mean (SD)	4.0 (0.7)	4.1 (0.6)	3.9 (0.7)	<0.001^b	3.9 (0.6)	3.1 (1.0)	0.001^b
<i>Cognitive impairment (MMSE)</i>	<i>n = 468</i>	<i>n = 235</i>	<i>n = 233</i>		<i>n = 212</i>	<i>n = 21</i>	
Score, mean (SD)	22.2 (5.3)	22.2 (5.6)	22.2 (5.0)	0.968 ^b	22.0 (5.0)	23.9 (4.7)	0.103 ^b
No (score, 27–30), n (%)	108 (23.1)	56 (23.8)	52 (22.3)	0.926 ^a	44 (20.8)	8 (38.1)	0.314 ^a
Mild (score, 20–26), n (%)	239 (51.1)	118 (50.2)	121 (51.9)		111 (52.4)	10 (47.6)	
Moderate (score, 10–19), n (%)	107 (22.9)	53 (22.5)	54 (23.2)		51 (24.1)	3 (14.3)	
Severe (score, 0–9), n (%)	14 (3.0)	8 (3.4)	6 (2.6)		6 (2.8)	–	
<i>Diagnosis of dementia (ICD-10)</i>	<i>n = 510</i>	<i>n = 250</i>	<i>n = 260</i>		<i>n = 236</i>	<i>n = 24</i>	
Yes, n (%)	194 (38.0)	101 (40.4)	93 (35.8)	0.316 ^a	83 (35.2)	10 (41.7)	0.513 ^a
<i>Functional impairment (B-ADL)</i>	<i>n = 498</i>	<i>n = 245</i>	<i>n = 253</i>		<i>n = 230</i>	<i>n = 23</i>	
Score, mean (SD)	3.7 (2.6)	3.7 (2.7)	3.7 (2.5)	0.887 ^b	3.8 (2.5)	2.7 (2.2)	0.028^b
<i>Falls (in the past 6 month)</i>	<i>n = 507</i>	<i>n = 250</i>	<i>n = 257</i>		<i>n = 233</i>	<i>n = 24</i>	
Yes, n (%)	143 (28.2)	65 (26.0)	78 (30.4)	0.280 ^a	69 (29.6)	9 (37.5)	0.485 ^a
<i>Depression (GDS ≥ 6)</i>	<i>n = 490</i>	<i>n = 240</i>	<i>n = 250</i>		<i>n = 226</i>	<i>n = 24</i>	
Yes, n (%)	76 (15.5)	35 (14.6)	41 (16.4)	0.619 ^a	36 (15.9)	5 (20.8)	0.562 ^a
<i>Drug-related problems (DRP)</i>	<i>n = 491</i>	<i>n = 244</i>	<i>n = 247</i>		<i>n = 226</i>	<i>n = 21</i>	
Number of DRP, mean (SD)	2.4 (1.5)	2.4 (1.5)	2.4 (1.4)	0.668 ^b	2.4 (1.4)	2.4 (1.7)	0.953 ^b
<i>Malnutrition (loss of weight ≥ 5 kg in past 3 month)</i>	<i>n = 500</i>	<i>n = 246</i>	<i>n = 254</i>		<i>n = 230</i>	<i>n = 24</i>	
Yes, n (%)	62 (12.4)	31 (12.6)	31 (12.2)	0.893 ^a	29 (12.6)	2 (8.3)	0.748 ^a
<i>Quality of life (QoL-AD)</i>	<i>n = 493</i>	<i>n = 240</i>	<i>n = 253</i>		<i>n = 229</i>	<i>n = 24</i>	
Score, mean (SD)	2.8 (0.4)	2.8 (0.3)	2.8 (0.4)	0.263 ^b	2.8 (0.4)	2.6 (0.6)	0.272 ^b

FSozu, Social Support Questionnaire; mean score 1–5, higher score indicates better social support; MMSE, Mini Mental State Examination, range 0–30; higher score indicates better cognitive functioning; B-ADL, Bayer Activities of Daily Living Scale; range 0–10; lower score indicates better performance; GDS, Geriatric Depression Scale, sum score 0–15; score ≥ 6 indicates depression; QoL-AD, Quality of life in Alzheimer's disease; mean sum score 1–4, higher score indicates better quality of life ^aFisher's exact test; ^bWelch's *t*-test. Bold *p*-values indicate *p* < 0.05.

being excellent. The perceived social support was assessed using the mean score of the 22-item version of the Social Support Questionnaire (FSozu) [23]. The FSozu is a self-report questionnaire to assess

general social support, covering three central characteristics of social support (practical and material support, emotional support, and social integration). Statements regarding perceived or anticipated social

support are rated on a five-point Likert scale, ranging from 1 (does not apply) to 5 (exactly applicable).

For all patients who had provided the respective informed consent, the formal medical diagnoses (ICD-10 codes: F00, F01, F02, F03, G30, and G31) were retrieved from the medical records in their GPs' practice (including the date of the initial diagnosis).

To describe the health care and nursing care utilization in the past 12 months, we analyzed the following variables: Consultation of the GP (yes/no) and number of visits, consultation of neurologist/psychiatrist (yes/no) and number of visits, hospital admission (yes/no) and number of days in hospital, professional home care (yes/no) and number of visits in the past 12 months, attending professional day care (yes/no), professional housekeeping assistance (yes/no), professional help with medication (yes/no), and home-delivered meals (yes/no). These variables were assessed in a standardized personal computer-assisted interview which contained lists of common resources and services to select from in order to minimize the recall bias. For more precise information and to improve data quality, the participant's caregiver (if present) assisted in the interview. In case of missing data, other available proxies, such as documentation of nursing services, were used.

Statistical analyses

Variables that describe the sample were summarized using descriptive statistics. For univariate subgroup analyses, the patients were divided into the following groups: (1) patients living alone versus not living alone, and (2) patients living alone with versus without an informal caregiver ("there is someone who could take care of me on a regular basis" yes/no). To test for the differences between subgroups we used Welch's *t* test (robust to unequal variances) for continuous and Fisher's exact test for categorized variables (significance level 5%). We conducted multivariate regression analyses to analyze the association of living alone (predictor variable) with the following patient outcomes (dependent variables): Presence of informal caregiver, availability of help in case of emergency, self-perceived social support, depression, quality of life, drug-related problems, malnutrition, falls, formal diagnosis of dementia, visit to neurologist/psychiatrist, hospital admission, utilization of professional home care, help with medication, housekeeping assistance, and home-delivered meals. These analyses were performed

unadjusted as well as adjusted for potentially confounding variables (age, sex, cognitive and functional impairment, living in partnership, presence of informal caregiver, depression, and visit of neurologist/psychiatrist).

Because the Delphi-study is a cluster-randomized trial, the dependency of data from participants who belonged to the same cluster (i.e., the same treating GP) had to be considered. Therefore, we applied random effects logistic/generalized least square (GLS) regression models, which can offer consistent estimates in cases of clustered data. Standard errors of the regression coefficients were estimated using the jackknife method for the logistic regression models and the bootstrapping procedure (2,000 replications) for the linear regression models. The statistical analyses were performed using Stata/IC [24].

RESULTS

Socio-demographic and clinical characteristics of the study sample

Table 1 (first column) shows the socio-demographic and clinical characteristic of the study sample.

Patients living alone

Approximately half of all primary care patients screened positive for dementia lived alone (50.9%). Table 1 presents the differences in socio-demographic and clinical characteristics between patients who lived alone and those who lived together with another person.

The socio-demographic characteristics differed considerably between these two groups: Patients who lived alone were statistically significantly more often female (71.5 versus 46.6%; $p < 0.001$), older (mean age (SD): 81.5 (5.6) versus 79.1 (5.2) years; $p < 0.001$), less often married (10.8 versus 74.5%; $p < 0.001$), and more often widowed (70.0 versus 19.5%; $p < 0.001$). Only 16.5% of the patients who lived alone had a partner, in contrast to 83.7% of the patients who did not live alone ($p < 0.001$). More than 90% of the patients living alone were supported by an informal caregiver. Almost two-thirds of these informal caregivers were children or grandchildren of these patients. The vast majority of the patients living alone had somebody who could help them in the case of an emergency (93.1%). The self-perceived social support was significantly lower in patients

Table 2
Utilization of health care and nursing care services (in the past 12 months)

	Total sample (<i>n</i> = 511)	Living situation (<i>n</i> = 511)			Living alone (<i>n</i> = 260)		
		Living with another person (<i>n</i> = 251)	Living alone (<i>n</i> = 260)	<i>p</i> -value	with informal caregiver (<i>n</i> = 236)	without informal caregiver (<i>n</i> = 24)	<i>p</i> -value
<i>Visit to GP, n (%)</i>	511 (100.0)	251 (100.0)	260 (100.0)	–	236 (100.0)	24 (100.0)	–
Number of visits, mean (SD)	7.0 (6.4)	6.8 (6.1)	7.2 (6.6)	0.519 ^b	7.1 (6.8)	8.0 (4.2)	0.380 ^b
<i>Visit to neurologist/psychiatrist n = 500</i>	<i>n = 500</i>	<i>n = 246</i>	<i>n = 254</i>		<i>n = 231</i>	<i>n = 23</i>	
Yes, <i>n (%)</i>	127 (25.4)	73 (29.7)	54 (21.3)	0.032^a	49 (21.2)	5 (21.7)	>0.999 ^a
Number of visits, mean (SD)	0.8 (2.9)	0.9 (2.1)	0.7 (3.4)	0.333 ^b	0.7 (3.6)	0.7 (1.4)	0.988 ^b
<i>Hospital admission n = 499</i>	<i>n = 499</i>	<i>n = 248</i>	<i>n = 251</i>		<i>n = 227</i>	<i>n = 24</i>	
Yes, <i>n (%)</i>	141 (28.3)	82 (33.1)	59 (23.5)	0.022^a	54 (23.8)	5 (20.8)	>0.999 ^a
Number of days in hospital, mean (SD)	4.0 (9.6)	4.8 (10.9)	3.2 (8.1)	0.058 ^b	3.4 (8.4)	1.6 (3.9)	0.083 ^b
<i>Professional home care n = 508</i>	<i>n = 508</i>	<i>n = 251</i>	<i>n = 257</i>		<i>n = 233</i>	<i>n = 24</i>	
Yes, <i>n (%)</i>	121 (23.8)	34 (13.6)	87 (33.9)	<0.001^a	75 (32.2)	12 (50.0)	0.111 ^a
Number of contacts/ year, mean (SD)	121.3 (289.0)	59.6 (221.1)	181.5 (332.1)	<0.001^b	161.5 (304.1)	374.8 (501.7)	0.052 ^b
<i>Professional day care n = 496</i>	<i>n = 496</i>	<i>n = 246</i>	<i>n = 250</i>		<i>n = 226</i>	<i>n = 24</i>	
Yes, <i>n (%)</i>	21 (4.2)	10 (4.1)	11 (4.4)	>0.999 ^a	11 (4.9)	–	0.607 ^a
<i>Professional help with medication n = 480</i>	<i>n = 480</i>	<i>n = 242</i>	<i>n = 238</i>		<i>n = 219</i>	<i>n = 19</i>	
Yes, <i>n (%)</i>	106 (22.1)	20 (8.3)	86 (36.1)	<0.001^a	78 (35.6)	8 (42.1)	0.622 ^a
<i>Professional housekeeping assistance, n (%)</i>	<i>n = 508</i>	<i>n = 251</i>	<i>n = 257</i>		<i>n = 233</i>	<i>n = 24</i>	
Yes, <i>n (%)</i>	59 (11.6)	22 (8.8)	37 (14.4)	0.053 ^a	28 (12.0)	9 (37.5)	0.003^a
<i>Home-delivered meals n = 508</i>	<i>n = 508</i>	<i>n = 251</i>	<i>n = 257</i>		<i>n = 233</i>	<i>n = 24</i>	
Yes, <i>n (%)</i>	99 (19.5)	31 (12.4)	68 (26.5)	<0.001^a	63 (27.0)	5 (20.8)	0.631 ^a

^aFisher's exact test; ^bWelch's *t*-test. Bold *p*-values indicate *p* < 0.05.

living alone (mean FSozu-score (SD): 3.9 (0.7) versus 4.1 (0.6); *p* < 0.001).

Regarding the clinical variables (cognitive and functional impairment, depression, falls, number of drug related problems, malnutrition, quality of life), there were no statistically significant group differences.

Table 2 shows the utilization of health and nursing care services. Overall, patients living alone utilized more often professional services such as home care (33.9 versus 13.6%; *p* = 0.022), help with medication (36.1 versus 8.3%; *p* < 0.001), home-delivered meals (26.5 versus 12.4%; *p* < 0.001), or professional housekeeping assistance (14.4 versus 8.8%; *p* = 0.053). In contrast, patients living alone utilized certain health care services statistically significantly less often (visit to neurologist/psychiatrist: 21.3 versus 29.7%; *p* = 0.032; hospital admission: 23.5 versus 33.1%; *p* < 0.022).

Patient outcomes associated with living alone

Further multivariate regression analyses were performed to analyze the association of living alone (predictor variable) with different patient out-

comes (unadjusted as well as adjusted for potential confounders). The results of these analyses are summarized in Table 3. The results showed that living alone was statistically significant associated with a lower chance for the presences of an informal caregiver (OR = 0.91, *p* < 0.001; 95% CI 0.06–0.14), the availability of help in the case of an emergency (OR = 0.26, *p* < 0.001; 95% CI 0.13–0.50), and with lower self-perceived social support (regression coefficient (RC) = –0.19, *p* = 0.022; 95% CI 0.35–0.03). On the other hand living alone was statistically significant associated with a higher chance for the utilization of professional home care (OR = 3.62, *p* < 0.001; 95% CI 1.86–7.04), help with medication (OR = 7.17, *p* < 0.001; 2.80–18.39), and home-delivered meals (OR = 2.55, *p* = 0.004; 95% CI 1.37–4.76).

Patients living alone without the support of an informal caregiver

About 9% (*n* = 24) of the patients lived alone without the support of an informal caregiver. The socio-demographic characteristics of these patients differed noticeably from the patients living alone

Table 3

Patient outcomes associated with living alone (each line represents a separate regression analyses; unadjusted and adjusted for the respective covariates)

Dependent variable in regression analyses	Unadjusted					Adjusted				
	OR/RC	t/z	p	95% CI		OR/RC	t/z	p	95% CI	
Presence of informal caregiver (yes) ¹	0.04	12.35	<0.001	0.03	0.07	0.91	12.08	<0.001	0.06	0.14
Help in case of emergency (yes) ²	0.06	7.13	<0.001	0.03	0.14	0.26	4.09	<0.001	0.13	0.50
Perceived social support (FSozu) ³	-0.25	2.84	0.004	-0.42	-0.08	-0.19	2.28	0.022	0.35	0.03
Depression (GDS ≥ 6) ⁴	1.16	0.47	0.641	0.63	2.13	0.85	0.46	0.648	0.42	1.72
Quality of life (QoL-AD) ⁵	-0.05	1.22	0.222	-0.12	0.03	0.03	0.72	0.472	-0.06	0.12
Drug-related problems ⁶	-0.05	1.23	0.218	-0.12	0.03	-0.14	0.72	0.469	-0.50	0.23
Malnutrition ⁷	0.88	0.45	0.654	0.50	1.54	0.85	0.53	0.594	0.46	1.56
Falls ⁸	1.33	1.37	0.173	0.88	1.99	0.79	0.90	0.369	0.46	1.34
Diagnosis of dementia ⁹	0.77	1.23	0.223	0.50	1.18	0.79	0.90	0.369	0.46	1.34
Visit to neurologist/psychiatrist (yes) ¹⁰	0.70	1.36	0.177	0.42	1.18	0.99	0.02	0.980	0.56	1.77
Hospital admission (yes) ¹¹	0.61	2.16	0.034	0.38	0.96	0.67	1.53	0.130	0.39	1.13
Professional home care (yes) ¹²	3.68	4.45	<0.001	2.06	6.58	3.62	3.83	<0.001	1.86	7.04
Professional help with medication (yes) ¹³	7.52	4.71	<0.001	3.21	17.63	7.17	4.16	<0.001	2.80	18.39
Professional housekeeping assistance (yes) ¹⁴	2.10	2.01	0.048	1.01	4.37	1.39	0.82	0.412	0.63	3.11
Home-delivered meals (yes) ¹⁵	2.77	3.17	0.002	1.46	5.25	2.55	2.99	0.004	1.37	4.76

Random effects logistic/generalized least squares (GLS) regression analyses, OR, odds ratio; RC, regression coefficient; CI, confidence interval; FSozu, Social Support Questionnaire; mean score 1–5; higher score indicates better social support; MMSE, Mini Mental State Examination; range 0–30; higher score indicates better cognitive functioning; B-ADL, Bayer Activities of Daily Living Scale; range 0–10; lower score indicates better performance; GDS, Geriatric Depression Scale, sum score 0–15; score ≥ 6 indicates depression; QoL-AD, Quality of life in Alzheimer's disease; mean sum score 1–4, higher score indicates better quality of life. ¹459 observations; 90 cluster: $F(6,88) = 37.15$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, living in partnership); ²458 observations; 90 cluster: $F(6,88) = 17.86$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, living in partnership); ³436 observations; 90 cluster: Wald $\chi^2(7) = 46.47$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ⁴450 observations; 90 cluster: $F(6,89) = 5.41$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, presence of informal caregiver); ⁵451 observations; 90 cluster: Wald $\chi^2(6) = 56.85$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, presence of informal caregiver); ⁶458 observations; 90 cluster: Wald $\chi^2(6) = 8.73$, $p = 0.190$ (adjusted for age, sex, cognitive/functional impairment, presence of informal caregiver); ⁷443 observations; 90 cluster: $F(7,89) = 2.89$, $p = 0.009$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ⁸456 observations; 90 cluster: $F(5,89) = 8.45$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment); ⁹440 observations; 90 cluster: $F(7,89) = 5.78$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, visit to neurologist/psychiatrist); ¹⁰441 observations; 90 cluster: $F(7,89) = 5.43$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ¹¹441 observations; 90 cluster: $F(7,89) = 2.54$, $p = 0.020$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ¹²447 observations; 90 cluster: $F(7,89) = 9.43$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ¹³443 observations; 87 cluster: $F(7,86) = 5.37$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver); ¹⁴456 observations; 90 cluster: $F(6,89) = 12.03$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, presence of informal caregiver); ¹⁵447 observations; 90 cluster: $F(7,89) = 5.30$, $p < 0.001$ (adjusted for age, sex, cognitive/functional impairment, depression, presence of informal caregiver). Bold p -values indicate $p < 0.05$.

who stated that they had an informal caregiver (see Table 1). Patients without an informal caregiver were statistically significantly more likely to be male (50.0 versus 26.3%; $p = 0.018$), they were more often unmarried (25.0 versus 5.9%), and less often widowed (54.2 versus 71.6%) or divorced (1.7 versus 11.0%; $p = 0.010$) as compared to patients with an informal caregiver. They had fewer children (mean score (SD): 1.2 (1.2) versus 2.3 (1.7); $p < 0.001$), and had less often somebody who could help them in a case of emergency (41.7 versus 98.3%; $p = 0.001$).

The self-perceived social support was significantly lower in patients without an informal caregiver (mean FSozu-score (SD): 3.1 (1.0) versus 3.9 (0.6); $p < 0.001$).

Regarding the clinical variables there was only one statistically significant difference between both groups: Patients without an informal caregiver were less impaired in their activities of daily living (mean B-ADL- score (SD): 2.7 (2.2) versus 3.8 (2.5); $p = 0.028$).

The utilization of health care and nursing care services is shown in Table 2. Patients without an informal caregiver utilized more often professional services such as home care (50.0 versus 32.2%; not significant), help with medication (42.1 versus 35.6%; not significant), or housekeeping assistance (37.5 versus 12.0%; $p = 0.003$). Regarding the utilization of health care services there were no statistically significant differences between both groups.

DISCUSSION

This is the first study that provides empirical data on the proportion and characteristics of German primary care patients screened positive for dementia who live alone. The analyses revealed that approximately half of all community-dwelling patients with dementia lived alone, and about 9% of them were not supported by an informal caregiver. For the US, it is estimated that about 15–35% of PWD live alone and up to one-half of PWD have no identifiable caregiver [3]. Compared to the US, the proportion of PWD who live alone was higher, but the percentage of patients without an informal caregiver was noticeably lower in our German sample. One reason for this difference might be the fact that most studies on PWD include only patients who are formally diagnosed with dementia, thus omitting about 50–80% of PWD without a formal diagnosis of dementia from the analyses [25]. In the present sample, 62% of PWD were not formally diagnosed with dementia by their GP.

Not surprisingly, the socio-demographic characteristics of PWD who lived alone differed considerably from those patients who lived together with another person. Overall, PWD living alone tended to be older and more often female. The majority of these patients were widowed (70%), implying that a major reason for living alone was the death of the patients' spouse. These findings are in line with the results of previous studies [3, 5–7]. Surprisingly, regarding the clinical variables examined we did not find any statistically significant differences between PWD who lived alone and those who did not. PWD living alone were neither cognitively nor functionally less impaired. In addition, our data indicate that PWD living alone did not seem to have more health risks—they did not differ from those not living alone regarding depression, quality of life, falls, drug related problems, or malnutrition. Thus, our findings do not agree with the results of former studies that showed that PWD living alone are less cognitively and functionally impaired, and at the same time are at a higher risk for health problems [3, 5–7]. A possible explanation for these discrepancies could be differences in the study samples. The participants of this study were on average less cognitively impaired than the participants in comparative studies. In addition, only 38% of the positively screened patients had been formally diagnosed with dementia by their GP, and just 25% of the patients underwent a visit to a neurologist or psychiatrist. Thus, the proportion of

patients who lacked a (specialist) diagnosis was relatively high. Some study participants might have been cognitively impaired due to other causes than dementia (e.g., depression or vitamin B12-deficiency). This could have skewed the results. However, the present diagnosis rate is comparable to international rates in the primary care setting (20–50%) [25].

To enable PWD to remain safely at home as long as they wish, they need access to adequate medical treatment and professional in-home care services. A major reason for the present study outcomes regarding the clinical variables could be that patients living alone were utilizing more often professional health care and nursing care services such as home care or help with medication. The utilization of such professional services might substitute the support by an informal caregiver who lives in the same household. Univariate analyses showed that the utilization of certain health care services (e.g., specialist doctor; hospital) was negatively associated with living alone. However, multivariate analyses that were adjusted for confounding variables did not confirm these associations. Our findings are in line with previous studies that showed that PWD living alone utilize health care offers less frequently, but professional services more often than PWD who are not living alone [3, 6, 7]. A possible reason for the differences in the study outcomes regarding clinical variables could be that German PWD living alone may have better access to professional services than PWD in countries like the US. The utilization of such services is mostly covered by health and nursing care insurances that are mandatory for every German citizen. Thus, the utilization of such services is largely independent of the individual financial status of the patients.

More than 90% of the patients who lived alone were supported by an informal caregiver, mostly their child or grandchild. However, there was a small group of patients (about 9%) who lived alone without having any informal caregiver. Only 29% of these patients had somebody who could help them within 24 hours in the case of an emergency. This lack of informal support can put these patients at special risks in the case of a personal or health crisis; under such circumstances, there is a high probability that these patients have to move to a nursing home rashly and unplanned.

The socio-demographic characteristics differed considerably between the PWD who lived alone with and without an informal caregiver. Patients who were not supported by an informal caregiver tended to be more often male, unmarried, and they had a lesser number of children. One might assume

that these patients did already live alone for a longer period of time; they might be used to manage their everyday life on their own. Regarding the clinical variables there were no statistically significant group differences with the exception that patients who had no caregiver were less functionally impaired. Although the descriptive data indicated that patients without an informal caregiver did utilize professional services more often, there were no statistically significant differences between both groups apart from professional housekeeping assistance. However, because the group of patients without an informal caregiver was small, the statistical power might not have been sufficient to detect significant differences.

Compared to PWD who lived together with another person, the self-perceived social support was significantly lower in patients living alone, especially in those who had no informal caregiver. Therefore, these patients should get better access to social activities and social support. In order to ensure social participation, patients should be encouraged and enabled to visit day care facilities more often. Our results showed that these institutions were used by only 4-5% of the study participants, with no difference between the groups.

So everything is fine, no need for action? Probably not. Previous analyses of our data showed that community-dwelling PWD had on average about nine unmet needs that should be addressed, and there were no significant differences in the number of unmet needs between patients who lived alone and those who did not [26]. Other studies demonstrated that PWD who lived alone had even more unmet needs than those living together with another person [4, 8]. PWD who live alone, particularly if they have no informal caregiver, may require special support in order to gain access to the treatment and care services that address their individual needs comprehensively. New care concepts for PWD such as the Dementia Care Management (DCM) tested within the present Delphi-trial aim to integrate multi-professional and multimodal strategies to optimize the individual treatment and care of PWD within the framework of the established health care and social service system in close cooperation with the treating GP [12, 13]. However, dementia is a progressing disease and at a certain point it is hardly possible to continue to live safely alone. Thus, it is important to find the appropriate time and means to arrange the transition to formal care, e.g. in a nursing home. This process could be supported by a DCM.

Further analyses of our data will enable us to determine prospective associations of living alone with relevant patient outcomes as well as the utilization of health and nursing care services. In addition, we can determine to what extent unmet needs of PWD can be addressed in the course of the Dementia Care Management and what impact the intervention will have on clinical patient outcomes and resource utilization.

Limitations and generalizability of results

The analyses are based on data that were mainly self-reported by patients with dementia. This might have reduced the validity and reliability of the assessment, especially among more severely cognitively impaired patients. In addition, the baseline assessment was very demanding for cognitively impaired patients, thus not all variables could be assessed completely in all subjects, resulting in missing data. Missing data occurred more frequently among more severely cognitively impaired patients, thus these patients were underrepresented in the analysis. However, the effect was quite similar in PWD living alone and those who were not (see Supplementary Table 2).

In the context of the Delphi-trial, 17.1% of 6,838 community dwelling primary care patients (≥ 70 years) had screened positive for dementia. A previous study in Seattle (US) found comparable prevalence rates among primary care patients aged 65 years or older (18%) [27]. In a population-based study sample of older adults in Leipzig (Germany) aged 75 or older, the prevalence of dementia according to the ICD-10 criteria was 12.4% [28]. Of 1,167 eligible patients 54.4% could be enrolled into the study. This rate is comparable with the rate of a study on screening and diagnosis of dementia in Indianapolis (US): 52.3% of 434 positively screened patients aged 65 or older agreed to participate in the further study [29].

False-positive cases of dementia might have been included into the study sample. Twenty-three percent of the primary care patients who had screened positive (DemTect-score < 9) were not categorized as cognitively impaired according to their MMSE-score (27–30; assessed at baseline). A certain proportion of these patients might have been screened false-positive. However, previous studies showed that the MMSE is less sensitive for detecting milder forms of cognitive impairment than the DemTect [15, 30]. Thus the rate of false-positive screenings may be lower than 23%.

Overall, the representativeness of our data for primary care patients screened positive for dementia in the region of Mecklenburg Western-Pomerania (Germany) seems to be acceptable for patients with mild to moderate cognitive impairment.

CONCLUSIONS

The present study revealed the high proportion of PWD who live alone in Germany. Since the German society is rapidly aging, this figure will probably increase. In our study, PWD living alone did not seem to be at an increased risk for their health, even if they lacked the support of an informal caregiver. Our findings indicate that living alone with dementia is possible, even at more advanced stages of the disease. Probably these patients are able to compensate the lack of informal caregiver support by utilizing professional nursing care services more often. In order to ensure the sufficient provision of health and nursing care services for PWD living alone, providers should consider the present results for future planning.

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SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: <http://dx.doi.org/10.3233/JAD-151058>.

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