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ORIGINAL ARTICLE

Dying at home or in the hospital? An observational study in German general practice

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KEY MESSAGES

- End-of-life care in the last 48 hours by family caregivers and GPs was strongly associated with dying at home.
- Long-term end-of-life care by family caregivers was a risk factor for not dying at home.

ABSTRACT

Background Although determinants of place of death have been investigated in several studies, there is a lack of knowledge on factors associated with dying at home from the general practice perspective.

Objectives To identify factors associated with dying at home for patients in German general practice.

Methods In a retrospective study, general practitioners of 30 general practices were asked to provide data for all patients aged 18 years or older who died within the last 12 months, using a self-developed questionnaire. 'Dying in hospital' was defined as dying in hospital or hospice and 'dying at home' as dying at one's usual residence including the nursing home. Multiple logistic regression analyses were used to determine factors associated with 'dying at home'; odds ratios (ORs) and their 95% confidence intervals (CI) were calculated as measures of effect size.

Results Of 439 deceased patients, 52.2% died at home, and 47.8% died in hospital or hospice. Determinants for dying at home were patients' care in the last 48 hours of life by family members (OR: 7.8, 95% CI: 3.4–18.0), by general practitioners (GPs) (OR: 7.3, 4.2–12.9) and living in a nursing home (OR: 3.8, 1.7–8.3). In the adjusted model, low comorbidity was positively associated (OR: 3.2, 1.4–7.0), and low functional health status (Karnofsky performance status) was negatively associated with dying at home (OR: 0.3, 0.1–0.7).

Conclusion Apart from patient-related factors such as comorbidity and health status, care by family members and GPs respectively, were determinants of dying at home.

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Family practice; terminal care; death; physician-patient relations; family caregivers

Introduction

Although most people prefer to die at home,[1–4] the proportion of people dying at home in western countries remains more or less stable over the last years and does not exceed 50%.[4–6] Determinants for the place of death have been investigated in several studies, often focusing on cancer patients.[7,8] Many of them were based on large datasets of a region or a country with a strong primary care-based health care system in Europe.[4,6,8–10] Although studies differed in study design and sampling, the following factors were consistently identified as predictors for dying at home: a long duration of disease, low health performance status,

good social conditions and support, intensive home care, extended family support and patients' preferences.[1,7,8,10–12]

In Germany, patients have a free choice of provider and an unrestricted access to all healthcare levels.[13] The majority of the population have their own general practitioner (GP) providing primary medical care,[14] although the health system is not primary care-based in the strict sense of the word. GPs are often involved in end-of-life care,[11,12] but there is a lack of knowledge of possibly relevant factors in end-of-life care in general practice. Therefore, GPs were asked to provide data from patients' records and their memory on symptoms,

diagnoses and comorbidities, palliative status, health-care providers and family members involved in the patient's medical care during the last months. These data should allow investigating factors associated with dying at home from the GP perspective.

Methods

This study is a retrospective observational survey on deceased patients in German general practices, performed between January and April 2011, based on data from medical records and the GPs' memory, collected by a 35-item questionnaire. Approval of the ethics committee of the University Medical Centre of Göttingen was obtained (Nr. 7/5/10). Other parts of this study were published elsewhere.[13]

Participating GPs and patient sample

We asked all registered GPs ($n = 162$) in the surrounding of Göttingen and Hannover, two cities in northern Germany, if they were willing to provide data of all adult patients they had cared for at least for 3 months and who had died within the last 12 months. Patients younger than 18 years, and patients who died from an accident, intoxication or suicide were excluded from the study.

Patients' data are not linked to different healthcare providers in Germany. To mitigate the risk of insufficient healthcare data on death circumstances in general practice, patients who were regularly cared for by another GP were excluded.

Place of dying

Nursing homes have become increasingly the place of residence for older and frail people and are therefore often their place of death.[15] Currently, most nursing homes in Germany are not equipped to provide hospice services. Therefore, we dichotomized places of dying as follows: 'dying at home' was defined as dying in one's usual residence including nursing homes. Dying in hospitals or hospices was defined as 'dying in the hospital'.[16]

Data collection

A multidisciplinary team of sociologists, psychologists, research nurses and GPs developed and tested a questionnaire with 35 items largely based on existing literature about relevant determinants of the place of death.[4,6,8–10,17] For each deceased patient identified from electronic patient records basic sociodemographic

data (i.e. gender, age, residence) were collected by the GP. Additionally, GPs provided retrospective information on symptoms, main diagnoses and comorbidities, as well as on institutions, healthcare providers and persons, especially family members involved in the patient's medical care during the last three to six months and in the last 48 h of life. All GPs were asked whether the deceased person was a palliative patient in their view and if an advance care directive was written. Advance care directive is a written document providing health-care decisions for situations in which people are unable to make decisions. In the last few years, these documents became directional for healthcare in Germany.[18] Health status was assessed using the Karnofsky Performance Status Scale (KPSS) and the Charlson Comorbidity Index (CCI).[19,20] Data of health status and of care providers who were involved in the last 48 h were also collected. For most of the data, GPs used the electronic or paper based patient record; only for some information of the questionnaire, such as data on care providers, symptoms or KPSS, we had to rely on the GP's memory. All data were anonymized.

The KPSS is widely used for assessment of the functional status of patients. For the statistical analysis, the KPSS was categorized into three groups, based on the Australia-modified KPSS A (for 100–80%), B (for 70–50%) and C (for <50%).[21,22]

The CCI is a validated instrument to predict mortality by weighting comorbidities. For our purpose, we categorized CCI in three groups analogous to Schnell et al., in low (score of 0–1), medium (score of 2–3), and high (score of 4 and more).[23]

Statistical analysis

The statistical software package SAS 9.3 was used for all analyses. First, the influence of different factors for 'dying at home' versus 'dying in hospital' was described, in the case of nominal variables, by absolute and relative frequencies and, in the case of age, by means. The difference of mean age between both groups was tested using the Student's *t*-test. For further analysis, the sample was split into three age groups.

We calculated the effect of all factors on 'dying at home' by univariable logistic regressions, with odds ratios (ORs) and their corresponding 95% confidence intervals (95% CI) as measures of effect size. In the last step, all factors, even if not statistically significant in the univariable model, were entered in a multiple logistic regression model, using the selection forward option.[20] The *P*-values of the Wald chi-squares were used to select a variable for the final model with an entry level of 0.05.[24] We report all factors that were entered

into the model, even if not statistically significant in the final model. Goodness of fit was assessed by the Hosmer–Lemeshow test, with P -values > 0.05 supporting the model's adequacy.

Results

Participating GPs

Of the 162 invited GPs, 30 (19%) participated, 11 of them were female, mean age was 51 years (SD: 6.6). The mean duration of the practice license was shorter in female GPs (11.4 years versus 14.9 years). Of all GPs, 15 (50%) worked in a single-handed practice and 15 (50%) in a group practice.

Deceased patients

Data collection comprised 451 deceased patients, on average 15 patients per practice (SD: 7.3; range: 4–36). The mean age of patients was 79.0 years (SD: 12.6; range: 19–102). In 12 cases, the place of death was neither within our definition of places, nor known. Hence, our valid sample was 439 patients, of whom 229 (52.2%) died at home, including 128 patients living in a nursing home. Two hundred and ten patients (47.8%) died in a hospital or hospice.

Nursing home residents had different characteristics compared to people living at home. They more often were female (70.5% versus 46.3%), they were older (85.6 years, SD: 8.1 versus 75.1 years, SD: 13.1), more often they were immobile (61.5% versus 33.6%), more often had lower scores for KPSS (67.1% versus 33.3%), and more frequently suffered from dementia (62.2% versus 13.4%) and cerebrovascular diseases (45.5% versus 21.2%), respectively. Interestingly, more patients with a low KPSS, i.e. a low functional status and a need for care, received care from their family members in the last 48 h of their life than those with a high KPSS (35.9% versus 19.6%).

Factors associated with 'dying at home'

Patients who died at home were older than patients who died in the hospital (81.3 years; versus 76.1 years; difference 5.2; 95% CI: 2.9–7.5). Other important characteristics that distinguished patients who died at home from those who died in hospital, are shown in Table 1. For example, 43.2% of the patients who died at home, had dementia, compared to 17.1% who died in the hospital. Chronic heart failure, cerebrovascular diseases, confusion and immobility, were also more prevalent among those who died at home (Table 1). Also, environmental factors such as living in a nursing home,

patients' care in the last 48 h by GPs, relatives and district nurses were strongly associated with home death in the univariable analysis. Persons with a low KPSS score were more likely to die at home as well. Duration of disease, frequency of GPs' care and similarly, advanced care directive did not affect the place of death.

The strongest predictor for 'dying at home', in the multivariable model, was family members' care (OR: 7.8; 95% CI: 3.4–18.0). A similar strong predictor was GPs' care in the last 48 h of life. The nursing home as a residence became a stronger factor in the multiple regression model than in the univariable analysis (OR: 3.8 compared to 3.2). Another significant factor was low comorbidity status (OR: 3.2; 95% CI: 1.4–7.0). In contrast, a low and a moderate Karnofsky performance status (C and B) were inversely associated with 'dying at home' in the adjusted model. GP's assessment as palliative was excluded in the final model.

Discussion

Main findings

This study is the first on factors associated with dying at home carried out in German general practice. Patients' care by relatives and GPs' in the last 48 h of life and living in a nursing home were strongly associated with 'dying at home'. Patients with long-term care provided by relatives died more often in the hospital. While it first seemed that people with lower health status (KPSS $< 50\%$) died more often at home, the adjusted OR showed no association. Advanced care directive did not affect 'dying at home'. Neither the duration of GPs' care nor the contact frequency turned out as a significant factor in the multivariable analysis. Similarly, age, sex, dementia, 'GPs' assessment as palliative', were not significantly associated with 'dying at home'.

Role of family caregivers

The role of relatives in patients' care in the last 48 h was our strongest factor associated with 'dying at home'. [25,26] Nakamurah and colleagues [26] found a stronger influence on the place of death when it was the preference of relatives than the patients' preference. These findings are helpful to understand our results but there are many influencing factors and some ethical aspects to consider as well. Family caregivers often do not feel prepared for end-of-life care. [27] However, advance care planning with patients and their relatives have a positive influence on both the preferred place of death [28] and can reduce the time spent in hospital at the end-of-life. [29]

Table 1. Factors associated with 'dying at home' in Germany, from the perspective of GPs.

Variable ^a	Place of dying		Model predicting dying at home			
	At home <i>n</i> = 229 ^b %	In hospital <i>n</i> = 210 ^b %	Univariable		Multivariable ^{c,d}	
			OR	95% CI	OR	95% CI
Age						
<65 years	10.0	18.1	1	–		
65–84 years	49.3	57.6	1.5	0.9–2.8		
> 84 years	40.6	24.3	3.0	1.6–5.6		
Female	65.1	43.8	2.4	1.6–3.5		
Residence						
Nursing home	47.6	22.4	3.2	2.1–4.8	3.8	1.7–8.3
Not institutionalized	52.4	77.6	1	–	1	–
Advance care directive ^e	28.8	25.7	1.2	0.8–1.8		
Karnofsky performance status scale ^f						
100%–80%	41.4	58.7	1	–	1	–
70%–50%	38.5	61.5	0.9	0.5–1.5	0.3	0.1–0.7
<50%	67.2	32.8	2.9	1.8–4.7	0.5	0.2–1.2
Charlson comorbidity index						
0–1	14.9	10.5	1.4	0.8–2.5	3.2	1.4–7.0
2–3	24.5	30.0	0.8	0.5–1.2	0.9	0.5–1.7
≥ 4	60.7	59.5	1	–	1	–
Diagnoses						
Chronic heart failure	48.5	36.6	1.6	1.1–2.4		
Cancer	34.0	38.1	0.8	0.6–1.2		
Dementia	43.2	17.1	3.7	2.4–5.7	1.8	0.9–3.6
Cerebrovascular diseases	34.9	24.3	1.7	1.1–2.5		
Diabetes mellitus	22.3	32.4	0.6	0.4–0.9		
Chronic pulmonary diseases	23.1	26.6	0.8	0.5–1.3		
Symptoms						
Confusion	34.1	15.2	2.9	1.8–4.6		
Immobility	52.4	33.8	2.2	1.5–3.2		
Anxiety	16.6	14.8	1.2	0.7–1.9		
Nausea	19.2	13.8	1.5	0.9–2.5		
Dyspnoea	33.2	42.4	0.7	0.5–0.99		
Pain	39.3	45.7	0.8	0.5–1.1		
Duration GPs' care ≤ 3 years	33.2	24.8	0.7	0.4–1.0		
Contact frequency ≥ 2 × monthly	28.0	32.4	1.8	1.2–2.8		
Patients' care in the last 3–6 months						
By relatives ^g	44.9	53.9	0.7	0.5–1.0	0.4	0.2–0.8
By district nurses	27.5	30.0	0.9	0.6–1.3		
Patients' care in last 48 h of life						
By relatives ^g	44.0	12.1	5.7	3.5–9.3	7.8	3.4–18.0
By district nurses ^g	23.6	4.4	6.7	3.2–14.1	2.8	1.1–7.1
By GPs	76.4	19.5	13.4	8.5–21.1	7.3	4.2–12.9
GPs' assessment as palliative ^h	65.1	52.2	1.7	1.2–2.5		

^aReference categories.^bIf not otherwise stated, all analyses are based on the full sample.^cGoodness of fit (Hosmer–Lemeshow: *P* = 0.73).^dThe adjusted model comprises all factors that were entered by the 'selection forward' procedure (entry level of 0.05) even if some of the factors were not statistically significant in the final model.^eValid sample: *n* = 401.^fValid sample: *n* = 437.^gValid sample: *n* = 431.^hValid sample: *n* = 438.

OR: odds ratio; CI: confidence interval.

We believe it is important to differentiate between long-term care and end-of-life care. Long-term care by relatives was surprisingly associated with 'dying in hospital', unlike care by relatives in the last 48 h. In Germany, relatives caring for family members with officially recognized need of care instead of a professional ambulatory nursing service are entitled to financial support. This finding might reflect that long-time care might cause exhaustion of family caregivers at the end of life [30]. Training for family caregivers is not well

established in Germany. Providing such training might reduce undesirable hospitalization at the end of life.[31]

The need to support family caregivers, being frequently still in the labour force, caring temporarily for their relatives in urgent situations was recognized by the German government. Consequently, the Home Care Leave Act (Pflegezeitgesetz) was enacted.[32] This law allows close family caregivers to take unpaid work leave for up to ten days. A preliminary analysis showed that only a few relatives made use of this right.[33]

Role of health status

While patients with a low KPSS died significantly more often at home in the univariable model, this was not true in the multivariable model. Our findings are in some contrast with existing literature.[1,4] For example, Escobar Pinzon and colleagues [4] found that a higher care level—that is comparable to a low KPSS—was associated with ‘dying at home’. In addition, the marital status was associated with ‘dying at home.’ They argued that death does not happen unexpectedly in those, mostly chronically ill patients living with family members, often acting as caregivers, together. Our model suggests, however, an alternative explanation due to an association between family care in the last 48 h of life and the KPSS. Many patients with a low functional status received family care, which proved to be highly significant in the multivariable model. So it seems to be ‘family care’—and not so much the functional status of a person—that matters in end-of-life care and influences the place of dying. Another strong factor for ‘dying at home’ was living in a nursing home. Availability of nursing homes was found as an influencing factor at least in one other study.[10] This might reflect the better availability of nursing resources and a better agreement with family and caregivers regarding the prognosis.[34] A shift from a not significant to a significant OR in patients with less comorbidity was seen in the CCI. We did not find published data to compare this finding.

Role of advance care directives

Only about a quarter of the mostly elderly patients had an advance care directive, which did not influence the chances of ‘dying at home’. The rate of patients with an advance care directive is much higher than observed in another German study from 2007, where only 11% of nursing home residents had an advance care directive. Since then, advance care directives have been actively promoted in the media. This study also found that most advance care directives were invalid and disregarded by nursing home staff.[35] This might explain while unlike in a Dutch study with nursing home residents, where 62% had advance care directive, no effect of advance care directives was found on not ‘dying in a hospital’.[36] One reason for the low proportion of patients with advance care directive in our sample that did not affect hospital admission may be the lack of remuneration for this time-consuming task.[16,37]

Role of GPs

Our findings confirm the key role of GPs’ in end-of-life care when patients wish to die at home as

Des Spence recently emphatically requested.[38] It should be emphasized that the involvement of the GP in the last 48 h is nearly as important as the family’s involvement in end-of-life care and obviously supports the patient and the family in their wish to die at home.

Strengths and limitations

If end-of-life care research is to be useful to clinicians, it needs to be conducted in relevant, rather than atypical, settings.[39] This study on determinants of ‘dying at home’ uses data from primary care practices. The participating GPs used their electronic patient records to include all eligible patients so that the sample of patients seems to be representative for these practices. Moreover, we had access to all relevant patient documents in the participating GP practices, including the GPs’ assessment of the care provided by the family and others so that the study provides an important view of the role of GPs and family members in end-of-life care.

Low response rate is a weakness of our study, however, our response rate is comparable to most studies in general practice in Germany.[40] It is conceivable that GPs with more interest in palliative care agreed to provide data.

The intensity of patients’ care by family members was not specified in the questionnaire. However, we assume GPs used this term in a professional sense.

Another potential source of bias was the retrospective design. Some of the data was reported ‘from the memory’ such as the estimation if palliative, data of contextual factors such as duration of patient care by relatives and might be subject to recall bias. Furthermore, the retrospective design did not allow us to enquire about the patients’ favoured place of death as in other studies.[1,4,5]

Implications for practice and research

To increase the proportion of people ‘dying at home’ long-term family care givers should be made aware of existing means of support and might need more educational support to manage problems that can be anticipated in end-of-life care.

Further research should investigate the role of family caregivers in end-of-life care and their interaction with GPs to enable adequate support for both groups. Better identification of patients in the palliative care situation in the primary care setting is needed to allow organizing the best available service according to their wishes.

Conclusion

Apart from patient-related factors such as comorbidity and health status, family caregivers and GPs were key determinants of 'dying at home' in German general practice.

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Declaration of interest

The authors declare that they have no conflict of interest. The authors alone are responsible for the content and writing of the paper.

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