ORIGINAL ARTICLE

Dying With Dementia

Symptom Burden, Quality of Care, and Place of Death

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SUMMARY

Background: No detailed information has been available until now about the care setting, circumstances and place of death, symptom burden, and quality of care of persons with end-stage dementia in Germany.

Methods: This cross-sectional study is based on a random sample of 5000 persons who died in the period from 25 May to 24 August 2008 in the German federal state of Rhineland-Palatinate. Their surviving relatives were contacted and asked to participate in a questionnaire survey. Data were obtained in this way for 310 persons with dementia and 931 persons without dementia.

Results: 42.4% of the persons with dementia died at home. Most patients and their relatives preferred death at home to death anywhere else (94.8% of patients, 77.5% of relatives). Persons living with at least one relative were more likely to die at home (adjusted odds ratio [aOR] 4.69, 95% confidence interval [CI] 2.71–8.11). According to information supplied by the relatives, the overwhelming majority of patients suffered, two days before death, from moderate to severe weakness (94.9%), fatigue (94.4%), disorientation/confusion (86.9%), and appetite loss (86.4%). Other common symptoms were anxiety (61.0%), tension (59.9%), dyspnea (56.7%), and pain (52.5%). The relatives were critical of the quality of care on standard hospital wards, citing the limited temporal availability of staff and limited emotional support.

Conclusion: These data indicate the high symptom burden of persons with dementia in Germany at the end of their lives. They underscore the need for proper palliative care in all of the settings where persons with dementia die. Specialized in- and outpatient palliative care should not be offered only to patients with cancer, but should rather be made available to all who need it.

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Advanced dementia is increasingly being regarded as a terminal disease (1, 2). Studies in English-speaking countries have led to the conclusion that the palliative care of patients with dementia at the end of their lives is now inadequately adapted to their special needs, not only for those dying at home, but also for those dying in hospitals and nursing homes (3, 4). Insufficient symptom control, failure to recognize that the patient is dying, and unnecessary and stressful interventions such as artificial nutrition or physical restraints are common (5, 6). Most of the pertinent studies in Germany have looked only at the symptom burden of persons dying of cancer in palliative care facilities (7, 8). In this article, we make use of data from the EPACS (Establishment of Hospice and Palliative Care Services in Germany) study (9–12) to assemble a more complete picture of the current situation of dying persons with dementia in Germany. We devote special attention to the patients' preferred and actual places of death, symptom prevalence, and quality of care. Data on non-dementia patients are included for comparison.

Methods

Data acquisition

The method of data acquisition has been described previously (11). The EPACS cross-sectional study was conducted from September 2008 to January 2009. A random sample of data was taken concerning 5000 persons who died in the period from 25 May to 24 August 2008 and who were officially registered as residents in one of the communities of the state of Rhineland-Palatinate. Primary residence in the state at the time of death was a criterion for inclusion in the study. Letters addressed to the deceased persons' relatives were sent to their former addresses; in these letters, the relatives were asked to participate in the study by filling out the questionnaire. The study was approved both by the Ethics Committee of the Rhineland-Palatinate State Medical Association and by the designated state official in charge of protecting the confidentiality of personal data.

Questionnaire

A questionnaire was used to determine the deceased persons' sociodemographic characteristics, underlying

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TABLE 1

Sociodemographic and health-related characteristics of the deceased, stratified by disease status

	Demented	Not demented	Overall deaths
Characteristics of the deceased	310 (25.0%)	931 (75.0%)	1 241 (100.0)
Age at death (mean, in years)^{*1}	85.6	75.0	77.7
≤ 49 years	0.0%	3.7%	2.7%
50–59 years	0.0%	8.0%	6.0%
60–69 years	1.6%	18.3%	14.1%
70–79 years	12.3%	28.4%	24.3%
80–89 years	58.4%	32.1%	38.7%
≥ 90 years	27.7%	9.7%	14.2%
Sex^{*2}			
Male	34.2%	47.8%	44.4%
Female	65.8%	52.2%	55.6%
Marital status^{*2}			
Married	30.3%	54.0%	48.1%
Widowed	61.3%	37.0%	43.0%
Divorced	2.9%	3.5%	3.4%
Single	5.5%	5.5%	5.5%
Financial situation^{*3}			
Good	33.2%	36.2%	35.5%
Average	45.5%	43.8%	44.2%
Bad	17.1%	14.2%	14.9%
Don't know / No response ^{*4}	4.2%	5.8%	5.4%
Did the deceased live together with at least one relative?^{*2}			
Yes	44.2%	59.8%	55.9%
No	54.8%	39.1%	43.0%
Don't know / No response ^{*4}	1.0%	1.1%	1.1%
Highest level of nursing care delivered in the four weeks preceding death^{*2}			
None	2.9%	36.8%	28.4%
Levels 0 and I	18.7%	15.3%	16.1%
Level II	41.0%	33.2%	35.1%
Level III	36.1%	10.6%	17.0%
Don't know / No response ^{*4}	1.3%	4.1%	3.4%
Care by outpatient hospice service in the four weeks preceding death^{*2}			
Yes	1.3%	6.7%	5.3%
No	79.0%	72.5%	74.1%
Don't know / No response ^{*4}	19.7%	20.8%	20.6%
Major financial burden caused by costs of nursing and treatment^{*2}			
Definitely or mostly true	39.7%	25.7%	29.2%
Partly true	24.2%	23.5%	23.7%
True to a small extent or not at all	32.3%	47.6%	43.8%
Don't know / No response ^{*4}	3.9%	3.2%	3.4%

^{*1}p<0.001 by Mann-Whitney U test; ^{*2}p<0.001 by Pearson's chi-square test

^{*3} For this variable, the relatives were asked to assess the financial situation of the deceased four weeks before death.

The potential responses were "very bad," "relatively bad," "average," "relatively good," and "very good." In further processing of the data, the distinction between very bad and relatively bad (resp. good) was eliminated, so that the three categories indicated in the table remained.

^{*4} Missing data were not considered in the statistical analysis.

diseases, preferred and actual place of death, symptom burden, and quality of care in both in- and outpatient settings.

Construction of variables

To determine the deceased persons' underlying diseases, their relatives were asked what diseases they had suffered from in the four weeks leading up to death.

To determine the place of death, the relatives were asked, "Where did your relative die?" The possible answers were "at home," "on an intensive care unit of a hospital," "on a palliative care unit of a hospital," "on a standard hospital ward," "in a nursing home," "in a hospice," and "elsewhere." Similarly, the following questions were asked to determine the place of death that patients had wanted for themselves and that their relatives had wanted for them: "Did your deceased relative ever say where he or she wanted to die? If so, where?" "What place of death would you have wanted for your deceased relative?" The possible answers to these questions were "at home," "in the hospital," "on a palliative care unit of a hospital," "in a nursing home," "in a hospice," and "elsewhere." The two places of death "on a palliative care unit of a hospital" and "in a hospice" were combined as "in a palliative care facility."

To determine the burden of symptoms, the relatives were asked to say which of a total of 16 symptoms their deceased relative had suffered from in the two days before death, and to what degree. The answer categories were "not at all," "mild," "moderate," and "severe." The items were taken from the symptom and problem checklist of the Hospice and Palliative Care Evaluation (Hospiz- und Palliativhebung, HOPE). This is a standardized documentation form used in palliative care facilities to collect information on both cancer patients and non-cancer patients; since its creation by an interdisciplinary working group in 1996, it has been used in a number of studies in Germany (8, 13–15).

To assess the quality of care, the relatives were asked to agree or disagree with statements about the care provided by physicians and nurses in different settings.

Statistical analysis

All statistical analyses were performed with the STATA/IC 10.1 program. Disease-specific differences between persons with and those without dementia were studied with chi-square and Mann-Whitney U tests. $p < 0.05$ was used as the criterion for statistical significance. Multivariate logistic regression was used to identify factors influencing where persons with dementia die. For the model, we chose automatic backward selection, with $p < 0.05$ as the criterion for exclusion. The dependent variable took on the value "1" for death at home or "0" for death in any type of institution (hospital, nursing home, or palliative care facility).

Results

After the removal of redundant addresses from the random sample of 5000 deceased persons, 4967 questionnaires were sent, of which 3833 were

FIGURE 1

The place of death of persons with and without dementia

*1,2 No data on place of death were available from one person with dementia and four persons without dementia; these persons were not considered in the creation of this figure

*3 $p < 0.001$ for Pearson's chi-square test

TABLE 2

Multivariate logistic regression analysis to determine factors affecting whether persons with dementia die at home (= 1) or in an institution (= 0)

Multivariate regression analysis (n = 280)			
Variable	aOR	95% CI	p-value
Lived with relative(s) in the same household			
Yes	4.69	2.71–8.11	<0.001
No (reference category)	–	–	–
Level of nursing care			
Levels 0 and I	0.96	0.16–5.82	0.969
Level II	2.64	0.47–14.7	0.268
Level III	4.08	0.73–22.7	0.108
None (reference category)	–	–	–
Major financial burden caused by costs of nursing and treatment			
Definitely or mostly true	1.30	0.69–2.44	0.413
Partly true	2.38	1.18–4.78	0.015
True to a small extent or not at all (reference category)	–	–	–

The variables age at death, sex of the deceased, marital status, size of the city where the deceased had lived, duration of need for help with self-care, relationship of deceased to surviving relative, age of surviving relative, sex of surviving relative, and occupational status of surviving relative were incorporated in the model but eliminated by backward selection.

aOR, adjusted odds ratio; CI, confidence interval

FIGURE 2

Moderate to severe physical, psychological and social burden of persons with and without dementia two days before death.

*¹p<0.05 for Pearson's chi-square test; *²p<0.01 for Pearson's chi-square test; *³p<0.001 Pearson's chi-square test; the numbers in parentheses indicate how many relatives answered the item in question (missing values not shown), stratified by disease status. For example, "(237/723)" under "Weakness" indicates that 237 of the surviving relatives of persons with dementia, and 723 of those persons without dementia, gave information on the severity of weakness (if any) in their deceased relative

delivered to the given address and 1134 were returned to sender. A total of 1378 questionnaires were filled out, yielding a response rate of 36.0% in relation to the questionnaires that were actually delivered or 27.7% in relation to those that were initially sent. 137 persons were excluded from the analysis because of a lack of data about their illness. The following analysis is based on data about 310 persons with and 931 persons without dementia.

Sociodemographic and health characteristics

The age-stratified prevalence of dementia in the sample was 4.4% (age 65–69), 9.5% (age 70–74), 15.6% (age 75–79), 33.5% (age 80–84), 42.0% (age

85–89), 49.6% (age 90–94), and 47.1% (age 95 and above). The sociodemographic and health characteristics of the sample, both as a whole and stratified by type of illness, are shown in *Table 1*.

Persons with dementia, compared to persons without dementia, were about ten years older on average and were more likely to be female (65.8% versus 52.2%) and widowed (61.3 % versus 37.0%). Persons with dementia were less likely to be living in the same household with one or more relatives (44.2% versus 59.8%) and more likely to be receiving nursing care at level II (41.0% versus 33.2%) or level III (36.1% versus 10.6%). Moreover, the relatives of people with dementia were more likely to state that the costs of nursing and treatment were a major financial burden (39.7% versus 25.7%).

Most of the questionnaires were filled out by the children (62.3%) or spouses (16.1%) of the deceased. The surviving relatives of patients with dementia were 59 years old on average, and mostly female (62.3%).

Preferred and actual place of death

The place of death of persons with and without dementia is shown in *Figure 1*. Persons with dementia most often died at home (42.4%), followed by in nursing homes (26.9%) and in hospitals (standard hospital ward 20.4% + intensive care unit 5.8% = 26.2%). Persons without dementia most often died in the hospital (standard hospital ward 26.7% + intensive care unit 15.9% = 42.6%); 35.8% died at home, and 10.0% died in a palliative care facility.

The relatives stated that 174 of the persons with dementia had expressed a preference for dying in a particular place, and that 94.8% of these persons had wanted to die at home. The corresponding percentage among persons without dementia was nearly the same (92.6% of 502 persons expressing a preference). Likewise, among the relatives who expressed a preference (249 relatives of persons with dementia and 673 relatives of persons without dementia), most said they had preferred that their relative should die at home (77.5% for persons with dementia, 81.3% for persons without dementia). The second place of death preferred by the relatives was the nursing home (14.9 % for persons with dementia, and a palliative care facility (9.1%) for persons without dementia.

To determine the factors affecting the place of death, a multivariate logistic regression analysis was performed. The results are displayed in *Table 2*.

The single factor making death at home most likely was neither a disease-related feature nor a patient-related one, but rather living together with at least one relative (adjusted odds ratio [aOR] 4.69, 95% confidence interval [CI] 2.71–8.11).

Symptom prevalences

The prevalences of various symptoms among persons with and without dementia two days before death are shown in *Figure 2*. With respect to physical symptoms,

TABLE 3

Assessment of physicians and nurses in various settings by the relatives of persons with dementia and by the relatives of persons without dementia (the latter in parentheses)

	n	Fully / mostly agree (%)	Partly agree (%)	Agree to a small extent or not at all (%)
Item				
The physicians seemed competent to me				
Patient's home	104 (303)	81.7 (77.6)	13.5 (12.2)	4.8 (10.2)
Nursing home	58 (68)	74.1 (69.1)	12.1 (16.2)	13.8 (14.7)
Standard hospital ward	68 (360)	67.7 (72.5)	17.7 (16.4)	14.7 (11.1)
The nurses seemed competent to me				
Patient's home	97 (232)	83.5 (79.3)	14.4 (15.5)	2.1 (5.2)
Nursing home	87 (94)	72.4 (77.7)	19.5 (16.0)	8.1 (6.4)
Standard hospital ward	72 (356)	68.1 (67.1)	20.8 (24.2)	11.1 (8.7)
The physicians had enough time				
Patient's home	100 (300)	68.0 (68.7)	19.0 (20.0)	13.0 (11.3)
Nursing home	77 (85)	61.0 (55.3)	22.1 (23.5)	16.9 (21.2)
Standard hospital ward	72 (376)	34.7 (49.5)	29.2 (23.4)	36.1 (27.1)
The nurses had enough time				
Patient's home	94 (243)	71.3 (65.8)	18.1 (23.1)	10.6 (11.1)
Nursing home	90 (96)	54.4 (63.5)	27.8 (24.0)	17.8 (12.5)
Standard hospital ward	76 (378)	40.8 (49.2)	22.4 (24.9)	36.8 (25.9)
The physicians gave helpful emotional support				
Patient's home	85 (283)	60.0 (64.7)	11.8 (14.1)	28.2 (21.2)
Nursing home	50 (61)	58.0 (45.9)	16.0 (23.0)	26.0 (31.2)
Standard hospital ward*	55 (309)	32.7 (50.8)	18.2 (16.5)	49.1 (32.7)
The nurses gave helpful emotional support				
Patient's home	82 (213)	65.9 (67.6)	18.3 (19.3)	15.9 (13.2)
Nursing home	76 (83)	73.7 (72.3)	15.8 (15.7)	10.5 (12.1)
Standard hospital ward	61 (319)	50.8 (53.0)	19.7 (21.0)	29.5 (26.0)
I was satisfied with the treatment that my relative received				
Patient's home	117 (348)	82.1 (73.6)	10.3 (18.7)	7.7 (7.8)
Nursing home	94 (96)	67.0 (72.9)	22.3 (19.8)	10.6 (7.3)
Standard hospital ward	83 (391)	50.6 (62.4)	25.3 (18.7)	24.1 (18.9)

Palliative care facilities and intensive care units are not included in this table because of low case numbers.

*p<0.05 for Pearson's chi-square test for the comparison of persons with and without dementia

the relatives stated that the persons with dementia had suffered most commonly from moderate to severe weakness (94.9%), followed by fatigue (94.4%) and appetite loss (86.4%). Further common symptoms were dyspnea (56.7%) and pain (52.5%). Likewise, in persons without dementia, the common symptoms included weakness (92.8%), fatigue (90.3%), and appetite loss (85.5%). As for psychological symptoms, 86.9% of the persons with dementia were moderately to severely disoriented, while 61.0% suffered from anxiety, 59.9% from tension, and 45.9% from depres-

siveness. The more common psychological symptoms in persons without dementia were anxiety (61.4%), tension (57.8%), and depressiveness (44.1%).

As for social burden, the overwhelming majority of relatives of persons with or without dementia (88.8% and 86.0%, respectively) said that the deceased person had a moderate or severe need for help in daily activities in the last two days before death. The persons with dementia were significantly more likely than the ones without dementia to have had medical problems leading to a greater need for nursing care, such as

decubitus ulcers or disorientation/confusion, and were more likely to have had problems with organization of care.

The relatives' assessment of the quality of care

The quality of care was assessed by the relatives as shown in *Table 3*. The relatives were asked to judge the care provided by the treating physicians and nurses in the facilities where the deceased had been treated in the four weeks leading up to death.

General satisfaction was greatest with treatment in the patient's own home. Only slightly more than half of the relatives of persons with dementia were satisfied with their care in standard hospital wards. Most of the relatives considered the physicians competent but complained of deficiencies in temporal availability and emotional support. Fewer than half of the relatives of persons with dementia said that physicians in hospitals had taken enough time for the patient. Although physicians and nurses received similar ratings on many items, nurses were rated somewhat higher than physicians with respect to emotional support. The relatives of persons with dementia gave treatment in the hospital a worse rating than the relatives of patients without dementia did. There were a number of interesting differences between the ratings of treatment on standard hospital wards by the relatives of patients with and without dementia, even if most of these differences failed to reach statistical significance: overall satisfaction 50.6% versus 62.4% ($p = 0.134$), temporal availability of physicians 34.7% versus 49.5% ($p = 0.070$), temporal availability of nurses 40.8% versus 49.2% ($p = 0.148$), emotional support from physicians 32.7% versus 50.8% ($p = 0.033$).

Discussion

Main findings

The purpose of this article was to describe the circumstances in which persons with dementia die in Germany. Many of the persons with dementia in this study (42.4%) died at home—in fact, persons with dementia were found to be more likely to die at home than persons without dementia (35.8%). In comparison with studies from other countries, the percentage of persons with dementia dying at home in Germany seems extraordinarily high: In the USA, for example, a study based on death certificates that named dementia as a cause of death revealed that 82.5% of persons with dementia died in a nursing home or hospital (16). In another study based on death certificates in five European countries (Belgium, the Netherlands, England, Wales, and Scotland), the corresponding percentages ranged from 88.6% to 94.9% (17). Overall, 77.5% of relatives of persons with dementia expressed a preference for death at home. This is an impressively large fraction in view of the marked burden that dementia can place on a family and the long duration of care. In contrast, only a relatively small percentage of persons with dementia die in special palliative care facilities.

As expected, a significantly higher percentage of persons with dementia than persons without dementia

were moderately or severely disoriented in the last few days before they died, but the symptom burdens of persons with and without dementia were otherwise quite similar. It is noteworthy that symptoms traditionally associated mainly with end-stage cancer, such as pain and dyspnea, were also common among persons with dementia in their last days. These findings accord with recent research showing that physical symptoms are common among persons with dementia and even more common in the time leading up to death (18, 19). This is particularly true for pain, from which more than half of all persons with dementia suffered in moderate to severe intensity two days before they die. Lack of recognition that the patient is in pain and inadequate administration of analgesic drugs are typical sources of undertreatment for dying persons with dementia (20–22).

Care in the patient's own home and in the nursing home was judged to be the best. It is noteworthy that the relatives drew a clear distinction between care at home or in a nursing home on one side, and care in a standard hospital ward on the other. Their critical judgment of care in standard hospital wards is particularly worrisome because this was where 20.4% of the persons with dementia died. Possibly, the relatively poor rating of the standard hospital wards was accountable, at least in part, to increasing staff workload (23). The resulting lack of time could have particularly negative consequences for the time-consuming care of persons with dementia in the unfamiliar hospital environment. Advanced dementia is now increasingly considered a terminal illness (18, 19); in view of this fact and the structural problems besetting standard hospital wards, the findings of this study imply that measures ought to be taken to spare persons with dementia the stress of emergency hospitalization in the time just before death. One possibility would be to make ambulatory palliative services more broadly available, so that persons with advanced dementia would be covered as well. The legal basis for such a step can be found in §37b SGB V (Book V of the German Code of Social Law, which deals with statutory health-insurance coverage). The staff providing such services could also lend support with the ethical questions that inevitably arise in connection with complications such as infection or inadequate food intake. This, in turn, could lighten the burden of the physicians and nurses that provide basic medical care in the patient's home and in nursing homes (24).

The limitations of this study

One major limitation of this study is that deceased persons were classified as having been demented on the basis of information supplied by their surviving relatives, rather than the findings of diagnostic tests that had been performed while they were alive. Perhaps some of the patients classified as demented had actually suffered from other diseases of old age whose manifestations can be confused with those of dementia. We can be reasonably confident, however, that most patients were given a diagnosis of dementia as part of the professional assessment of their need for nursing care, and that this

diagnosis was then communicated to, and accepted by, the relatives. The age-stratified prevalence figures obtained here closely correspond to those obtained in a British study, which, like this one, assessed the prevalence of dementia shortly before death (25).

We cannot exclude sample bias as a potential source of error in the distribution of places of death for persons with dementia, as revealed by this study. Persons who die at home generally have at least one near relative who can provide informal care, and this (or these) same relative(s) would presumably be available to participate in studies such as EPACS by filling out questionnaires. Persons dying in institutions might have no such relative. Thus, persons with dementia who died at home may have been overrepresented in this study.

Further limitations include the response rate of 27.7%; potential bias because of the time elapsed since the events that the informants were asked to describe (recall bias); and the subjectivity of judgments of symptom burden, because of which the relatives' notion of the symptoms suffered by the patients may well have differed from the perceptions of the patients themselves.

Overview

Persons with dementia often die under difficult conditions because the health-care system is ill-equipped to deal with their special needs (3). The data presented here illustrate some of the problems in this area in Germany today. A number of ways to give persons with dementia better care at the end of their lives by improving informational strategies, care organization, symptom monitoring and treatment, and support for surviving relatives have been described in detail by Förstl et al. and by Alzheimer Europe (26, 27). Further research on the implementation and assessment of these interventions is urgently needed. Persons with advanced dementia and related problems should be cared for by professionals with special competence in palliative medicine; geriatric psychiatrists and palliative-medicine specialists should work closely together with these persons' family physicians to deliver the care they need.

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Conflict of interest statement

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KEY MESSAGES

- In the German federal state of Rhineland-Palatinate, persons with dementia are most likely to die at home, and less likely to die in a hospital or nursing home.
- The vast majority of persons with dementia would prefer to die at home. Their relatives also desire this for them.
- In the time leading up to death, persons with dementia suffer from many different physical symptoms at moderate to severe intensity. Weakness, fatigue, and appetite loss, but also symptoms that are more usually thought of in connection with end-stage cancer, such as pain and dyspnea, are very common among persons with dementia who are dying.
- Moderate or severe psychological symptoms such as disorientation, anxiety, tension, and depressive mood are also very common shortly before death in persons with dementia.
- The relatives of persons with dementia were most critical of the quality of care in standard hospital wards, citing the inadequate temporal availability of staff and a lack of emotional support.

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