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Non-cancer patients in specialized palliative care in Germany: What are the problems?

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Abstract

To determine the role of non-cancer palliative care in inpatient services in Germany, data from the Hospice and Palliative Care Evaluation (HOPE) were analysed. Since 1999, a three-month census has been conducted annually in German palliative care units. Pooled data from 2002–2005 were tested for differences between non-cancer patients (NCs) and cancer patients (Cs). A total of 4182 patients (NC: 3.5%; C: 96.5%) were documented; functional status (using Eastern Cooperative Oncology Group (ECOG) measures) in NCs was lower compared to Cs ($p = 0.009$). NCs suffered more often from dyspnoea (40%; C: 29%; $p = 0.004$), weakness (92.3%; C: 84.5%; $p = 0.011$) and tiredness (75.4%; C: 66.7%; $p = 0.03$) and less from nausea (17.1%; C: 28.9%; $p = 0.002$), vomiting (8.2%; C: 19.4%; $p = 0.001$) or loss of appetite (55.5%; C: 67.9%; $p = 0.002$). There were no differences in pain and constipation. Other problems (nursing, psychological) were more frequent for NCs, in particular the need for support in the activities of daily life (90.3%; C: 72.8%; $p < 0.001$) and disorientation/confusion (32.1%; C: 17.2%; $p < 0.001$). There were no differences in social problems. NCs are still rare in specialized inpatient palliative care institutions in Germany. The palliative care needs in patients with non-malignant disease will challenge the health care system as the workload for these services will grow over proportionally.

Keywords

Documentation, epidemiology, non-cancer, palliative care

Introduction

The integration of palliative care into the health care system has undergone a dynamic development over the last 40 years.¹ Catalysed by the upcoming hospice movement in the late 1960, cancer has emerged as a model² to show that a holistic palliative care approach can be beneficial during the non-curative phase of the illness.³

The beginning of palliative care in Germany was delayed by almost 20 years. The first palliative care

unit linked to a hospital opened in 1983 in Cologne. Since then a wide range of services for inpatient and outpatient palliative care has been established. Parallel to the hospital-based palliative care units for acute care (funded exclusively by the health insurances), free standing hospices (funded on a mixed basis – health and nursing insurances, charity) for long-term care developed.

Nationally and internationally it has been claimed repeatedly that the palliative care approach must not

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be offered exclusively for patients with a particular diagnosis, but services should be open to all patients in need with progressive and life-limiting diseases.^{4,5} This philosophy of generalization of palliative care independent from the underlying disease is emphasized again by the current World Health Organization (WHO) definition.⁶ Accordingly, expertise within palliative care is focussing on needs rather than disease, and it has been suggested that there is a common pathway at the end of life independent from the underlying illness.⁷

In reality – contradicting these statements – only a minority of patients cared for within palliative and hospice services suffer from non-malignant diseases⁸ and some possible barriers have been identified lately. One concern is the implication on the health care system through the increase in patient numbers by at least 70%.⁵ Furthermore, the providers of the existing palliative care services do not feel well prepared for these patients.⁹

We performed this study firstly to determine the role of non-cancer palliative care in specialized inpatient palliative care services in Germany and secondly to clarify how palliative care can meet the needs of this patient group in terms of work load and resource planning.

Methods

Since 1996, a standardized basic documentation tool (**H**ospice and **P**alliative care **E**valuation – **H**OPE) for palliative care patients has been developed, evaluated and amended accordingly by a multiprofessional working group. Each year, German inpatient palliative care services are recruited to participate in a three-month census. Between 2002 and 2005 an average of more than 50% of all existing German palliative care units (2002: 79 units; 2004: 106; 2005: 116) participated. (Due to the fact that data analysis, feedback to the

institutions and discussion about modification of the instrument lasted 15 months on average, no census was performed in 2003. Since 2005, the census has been repeated annually, as the infrastructure is now optimized and the instrument can be used as a standard documentation tool.) The institutions are asked to document up to 30 consecutive palliative care patients at admission to the service and at the time of discharge or death. The anonymized data can be submitted via use of an online database or a two-page paper questionnaire and is processed centrally.

For this study, data on age, gender, diagnosis, metastases, concomitant diseases, functional status, prevalence and intensity of symptoms, as well as psychological, nursing and social problems was pooled and analysed. Symptoms and problems were assessed by staff via an integrated symptom checklist (Table 1) using a four-point grading scale (0 = none, 1 = mild, 2 = moderate, 3 = severe). This symptom checklist was constructed as part of the documentation tool for a general palliative care population, serving to document a patient's status and not to reflect specific diagnoses (for example 'feeling depressed' and not 'depression'). Detailed information on the development of the documentation tool has been published previously.^{10,11} HOPE was used in several epidemiological surveys in Germany.^{10,12–15} Further evaluation of the psychometric properties is currently being performed.

The program packet SPSS 14.0 (SPSS Inc, Chicago, IL, USA) was used for statistical evaluation. Prevalence of symptoms and problems with higher intensity (grade 2 and 3/moderate and severe) at the time of admission was determined. Group differences for these symptoms/problems, as well as for gender, levels of nursing care (Table 2) and low functional status (Eastern Cooperative Oncology Group (ECOG) measures 3–4) were tested with chi square, differences for ECOG results, age and length of stay were tested with an

Table 1. Symptoms and problems assessed with HOPE.

This classification was the result of the tool development, as in an earlier series participating units were asked to document symptoms and problems solely in free text under given categories. The most commonly stated symptoms and problems were defined and transferred into checklists. Detailed information on recoding of free-text entries and categorization methodology has been published previously.^{11,20}

Physical	Pain, nausea, vomiting, dyspnoea, constipation, weakness, loss of appetite, tiredness
Nursing	Wound care, activities of daily living
Psychological	Depression, anxiety, emotional strain, disorientation/confusion
Social	Need for social support, overburden of family

Table 2. Nursing levels according to the German long-term care legislation

Grade 1	Support is necessary for at least two activities in the areas of body care, eating and mobility (at least once daily) as well as housekeeping (at least several times a week) with an overall average duration of at least 90 minutes daily
Grade 2	Support is necessary at least three times daily with an overall average duration of at least three hours daily
Grade 3	Support is necessary around the clock, including nights, with an overall average duration of at least five hours daily
Grade 3+	Cases of hardship with exceptionally high need for support

analysis of variance (ANOVA). For statistical significance we used $p < 0.05$ in all tests.

Results

A total of 4182 patients admitted to palliative care units were documented. The majority of patients suffered from cancer (96.5%) and 3.5 % from a non-cancer disease (Table 3). The proportion of non-cancer patients (NCs) cared for in the participating units varied broadly (0–30%); in 39 units (41%) no NCs were documented. The most common non-malignant diagnoses were related to the nervous system (29.9%), followed by the cardiovascular system (20.4%) and the lung (8.8%). The most common individual diagnoses were motoneuron disease and chronic heart failure (8.1% each).

Functional status (ECOG) and the need for nursing differ significantly between cancer patients (Cs) and NCs. NCs showed more frequently a poor functional status (ECOG 3–4) compared to Cs ($p = 0.009$). A high need for nursing support (grade III) was documented more often in case of non-malignant diseases

Table 3. Distribution of non-cancer diseases $n = 147$

Disease	<i>n</i>	%
Nervous system	44	29.9%
Motoneuron disease	12	
Apoplexy	10	
Dementia	6	
Multiple Sclerosis	4	
Other	10	
Cardiovascular and circulatory disorders	30	20.4%
Chronic heart failure	12	
Arterial occlusive disease	10	
Myocardial infarction	4	
Other	4	
Pulmonary diseases	13	8.8%
Pneumonia	5	
COPD	4	
Other	4	
Musculoskeletal system	12	8.2%
Osteoporosis	5	
Spinal	3	
Other	4	
Urogenital system	10	6.8%
Renal failure	8	
Other	2	
Hematopoietic system	9	6.1%
Liver disease	6	4.1%
Digestive system	6	4.1%
Other	17	11.6%

Table 4. Comparison of sociodemographic and nursing characteristics between patients with non-cancer and cancer diagnoses

Group Item	Non-cancer (<i>n</i> = 147)	Cancer (<i>n</i> = 4035)	Differences <i>p</i>
Gender			
Female	62.6%	51.1%	0.019
Age (mean; SD)	75 y (13.8)	67.4 y (12.4)	<0.001
Levels of care			
None	29.9%	46.2%	<0.001
Applied for	10.2%	15.5%	
Step I	14.3%	11.3%	
Step II	15.6%	9.3%	0.01
Step III	17.0%	2.4%	<0.001
Step III+	1.4%	0.3%	
ECOG (mean; SD)	3.24 (1.3)	2.89 (1.25)	0.001
ECOG 3 or 4	85.0%	75.3%	0.009
Length of stay (mean)	10.2 d	12.7 d	0.008
Death	57.2%	44.9%	0.004

Table 5. Comparison of moderate-to-severe symptoms and other problems between patients with non-cancer and cancer diagnoses

	Non-cancer (<i>n</i> = 147)	Cancer (<i>n</i> = 4035)	Differences <i>p</i>
Physical symptoms			
Pain	49%	55.8%	
Nausea	17.1%	28.9%	0.002
Vomiting	8.2%	19.4%	0.001
Dyspnoea	40%	29%	0.004
Constipation	34%	35%	
Weakness	92.3%	84.5%	0.011
Loss of appetite	55.5%	67.9%	0.002
Tiredness	75.4%	66.7%	0.03
Nursing problems			
Wound care	40.3%	21.7%	<0.001
Activities of daily life	90.3%	72.8%	<0.001
Psychological problems			
Depression	35.9%	33.8%	
Anxiety	45.9%	39.8%	
Emotional strain	51.9%	44.7%	
Disorientation/confusion	32.1%	17.2%	<0.001
Social problems			
Social support	55.4%	49.4%	
Overburden of family	59.4%	56.6%	

($p < 0.001$). Time between admission and discharge or death is significantly shorter for NCs compared to Cs ($p = 0.008$); these patients died significantly more often during the monitored period ($p = 0.004$) and were significantly older ($p < 0.001$) (Table 4).

Comparison of symptom burden showed that NCs suffered more often from moderate to severe dyspnoea ($p = 0.004$), weakness ($p = 0.011$) and tiredness ($p = 0.03$) and less often from nausea ($p = 0.002$), vomiting ($p = 0.001$) or loss of appetite ($p = 0.002$). No differences were seen in pain and constipation. Symptoms and problems in other categories (nursing, psychological) were more frequent in NCs, in particular the need for support in the activities of daily life ($p < 0.001$) and disorientation/confusion ($p < 0.001$). Social problems showed no difference (Table 5).

Discussion

Despite the growing awareness that patients dying from non-malignant diseases have extensive palliative care needs,¹⁶ the overall number of NCs in specialized inpatient palliative care in Germany is still low. This national situation is consistent with the situation in Europe, where only a minority of patients receiving palliative or hospice care suffer from non-malignant diseases (e.g. UK, Spain, France 10%, Poland 11% Netherlands 20%, Italy 40%).⁸ This ratio is more than inversely proportional to the causes of death in Europe, where non-malignant diseases are twice as common as cancer (cancer 25%, non-malignant cardiovascular, respiratory and gastrointestinal diseases 53%, others 22%).¹⁷ The reason for this evident mismatch is not well understood. In a recent survey conducted by O'Leary and Tiernan,⁹ the unpredictable disease trajectory, the resulting differences with referral criteria and the lack of specific expertise were discussed as possible barriers.

Above this, referral may be restricted by concerns that further opening of the services for this patient population would multiply the number of patients and work¹⁸ where resources, particularly in terms of staffing and time, might be perceived as inappropriate. The increase in case load has been estimated already 10 years ago by Addington-Hall et al.⁵ to be as high as 79% and this overall increase in the number of patients is well acknowledged.

However, in addition to the increase in patient numbers, a more intense need of palliative care in the non-cancer population may to be considered as well. In our study patients suffering from non-cancer diseases are in a considerably lower functional status than Cs and need more support in the activities of daily living (ADL). These findings are confirmed by the fact that more patients are assigned to higher nursing levels according

to the German long-term care legislation. This implies a higher ratio of patients with reduced mobility until being bedridden, possibly aggravated by disorientation. These findings can have different causes. On the one hand NCs may have higher needs by nature of their diseases. On the other hand it can be argued that the symptoms predominantly experienced by the NCs were those of dying patients with increasing dependence. Tardy recognition leading to a late referral of patients with non-malignant diseases to palliative care services could explain this trend. This is supported by recent evidence from the UK showing that NCs are more likely to be moved from home to hospital in the last week of life.¹⁹ This again may be due to a felt or true unpredictability of the disease trajectory.⁹ Overall the awareness in referrers that palliative care can be appropriate earlier in the course of the disease for incurable patients without cancer seems to be missing. All of these facts have to be considered for appropriate resource planning for palliative care services willing to admit more patients with non-cancer diseases.

This study has the following limitations. Firstly, the documentation tool was developed with an unspecified sample of palliative care patients. Issues specific for patients with non-cancer diagnoses may therefore still be underrepresented, which would argue that true needs are even higher than those described in our study. Secondly, the documented symptoms and problems were assessed by the staff, not by the patient. However, as many of the patients in our study were cognitively impaired, selection bias in favour of patients with better cognition can be assumed if data were collected by self-assessment. Thirdly, the relatively small number of NCs does not allow for differentiating between different diseases, and some generalizations had to be made here. Therefore, more detailed studies will be further needed.

Conclusion

Access to palliative care is still difficult for NCs in Germany. Meeting the specific palliative care needs in non-malignant diseases appropriately will challenge the health care system, as in addition to the expected increase in the number of patients, the workload for the services may grow over proportionally. Only an adequate resource planning for services and improvement in the awareness of the specific needs will facilitate an appropriate and timely integration of palliative care into the care of NCs in their last phase of live.

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