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Research Article

Individually Tailored Palliative Care in a Rural Region: A Representative Chart Survey and Physicians' Experiences with Integrated Care

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Background. Dying at home represents a special challenge in rural areas. This representative study describes the palliative care for patients in a rural German region. **Methods.** In a cross-sectional, representative study all physicians of a large rural area were surveyed in terms of their palliative care for a biennial period. In prestructured interviews and chart reviews physicians, practices, and palliative care patients' characteristics were obtained. The data were matched with regional mortality data. **Results.** According to public data 463 inhabitants died during the biennial period: 248 patients (53.6%) died outside the region's borders including all in-hospital patients, while 215 died within this territory (46.4%). Of the latter, a total of 91 patients (42.3%) received care by the 14 physicians surveyed (on average: 6.6 patients per physician). 89% of families were actively involved in care, especially in multigenerational family scenarios. If family members were not involved, nursing services were active instead. Significant predictors for dying at home were the wish to die at home, a cancer diagnosis, and having family support. **Conclusions.** This study shows a physician-based, individually tailored, rural palliative care approach which allowed the majority of patients to die at home. Families were documented as an important social resource.

1. Background

For their end of life, most patients wish to “live a meaningful life” [1] in their familiar setting with “dying at home” [2]. Currently, dying at home is realized for about 13–70% of patients, depending on the setting and available palliative care structures [3–8]. It has been repeatedly shown that structured palliative care home services increase the likelihood to die at home about 3- to 4-fold [9–11]. Various structures of care are developed to improve access to palliative home care [8, 11] spanning ambulatory nursing and palliative care services [7, 12], primary care facility-based interdisciplinary teams [13], and multidisciplinary, hospital-based in- and outpatient services [9, 10, 14]. However, access to programs is often restricted to patients with certain medical or social characteristics (e.g., cancer patients only [7, 9, 11, 14–16], at least one informal caregiver at home [8], and no need for 24-hour services) or rendered difficult due to long distances in rural areas [17]. The issue of fragmented palliative care services has

been the subject of recent discussion [18]. As one solution, reframing of the core ideas of end-of-life care in the concept of integrated palliative care is gaining increasing attention [18]. This concept refocuses on the individual patient and calls for services being tailored to each individual's needs.

As in many other countries, palliative care is an evolving field in Germany. In this two-year, representative, retrospective study we analyze the palliative care in a rural German region representing a physician-based, integrated palliative care approach. Predictors for dying at home in this rural region and the palliative care situations in extended families typical for rural areas were analyzed from the perspective of integrated palliative care.

2. Methods

2.1. Study Design. In this cross-sectional, representative study all physicians of the largest physician district of the Kassenärztliche Vereinigung Nordrhein (publically authorized

TABLE 1: Physician characteristics ($n = 15$).

	N	%*
Physician characteristics		
Licensed for the survey region	15	100.0
Participated in survey	14	93.3
Cared for palliative care patients in the biennial period	13	86.7
Gender		
Male	11	78.6
Female	3	21.4
Age, in years (average, SD, range)	50.6 (6.1)	40–62
Specialty		
Family or internal medicine	11	73.3
Other specialties	4	26.7
Practice type		
Solo practice	8	57.1
Group practice	6	42.9
Palliative patients per physician (average, SD, range)	6.5 (3.7)	0–10
Physician home visits in end-of-life period (average, SD, range)	10.4 (6.1)	1–31
Distance from physician practice to patient, in kilometers (average, SD, range)	5.2 (3.3)	1–18
Physician availability		
24 h availability for all patients of practice	5	35.7
24 h availability for selected patients of own practice	3	21.4
Refers to palliative care patients to physician on duty when own office is closed	6	42.9

* means % unless marked otherwise.

physicians' association), North Rhine-Westphalia, Germany, in the survey year 2009 were surveyed for their palliative care in the preceding two years.

In 2008 this rural area covered a territory of 164 square kilometers with a total of 27,780 inhabitants (population density per square kilometer: 169; for comparison: in North Rhine-Westphalia: 515) [19]. All fifteen physicians (eleven primary care and four specialist physicians (orthopedics, gynecology, pediatrics, and urology)) licensed for this area self-organize the mandatory regional acute care service. This service covers all after-office hours including nights and weekends except emergencies requiring an ambulance. It includes an on-call service for palliative care patients unless the patient's physician chooses to provide palliative care around the clock himself.

2.2. Data Collection. The study data were obtained in pre-structured physician interviews performed by this physician. Each interview consisted of a cross-sectional physician survey and a retrospective analysis of the charts of all deceased palliative care patients that a physician had cared for during the years 2007–2008. All interviews were performed between May and July 2009.

The interviews were based on two prestructured survey instruments which requested the following information:

- (1) Physician and practice sheet: for example, physician's age, gender, years in practice, medical specialty, practice size, physician's availability for his own palliative care patients, and physician's experiences with palliative care. For details see Table 1.

- (2) Chart review sheet: during the chart-based interviews the physicians answered the various questions about each of their deceased palliative care patients: for example, age, gender, primary diagnosis, additional diagnoses relevant to palliative care, location where the patient was cared for, hospital days if required, place of death, and patient's wishes for end-of-life care; involvement of family members; physician's activities including the number of home visits, issues discussed with patient and family, and details on the medical care provided. At the end of each chart interview the physician was asked for his personal experiences in the palliative care for this patient and challenges faced. For details see Tables 2–5.

Using regional public mortality data the percentage of patients who had received palliative care by one of the physicians involved in relation to all the deceased in this biennial period was calculated. Based on registry data on the place of death, the percentage of palliative care patients who died at home in relation to all who died was calculated.

2.3. Data Management, Statistical Analysis, and Ethics' Statement. The study design and data management were performed at the Institute for General Medicine, University of Duisburg-Essen, Essen, Germany. Participation in this retrospective study was voluntary. To maintain confidentiality the physician interviewer did not have access to the patients' charts which were under review by the physician who had provided medical care only. The Ethics Committee

TABLE 2: Characteristics of palliative care patients ($n = 91$).

	N	%*
Gender		
Male	40	44.0
Female	51	56.0
Age, in years (average, SD, range)	70.9 (16.8)	6–98
Health insurance		
Statutory	83	91.2
Private	8	8.8
Nursing care insurance granted		
None	32	35.2
Level 1	18	19.8
Level 2	29	31.9
Level 3	12	13.2
Primary diagnoses		
Carcinoma/hematologic malignancy	56	61.5
Neurological disease	18	19.8
Cardiac disease	7	7.7
Pulmonary disease	5	5.5
Renal insufficiency	4	4.4
Hepatic disease	1	1.1
Secondary diagnoses relevant for palliative care**		
None	39	42.9
COPD	8	8.8
Cardiac disease	6	6.6
Peripheral vascular disease	5	5.5
Diabetes mellitus	4	4.4
Dementia	4	4.4
Stroke/epilepsy	3	3.3
Obesity	2	2.2
Dialysis	2	2.2
Cachexia	2	2.2
Alcoholic disease	2	2.2
Ascites	1	1.1
Nicotine drug dependency	1	1.1
Other (e.g., deafness)	12	13.2
Patient's wishes**		
No pain	50	54.9
No unnecessary therapies	39	42.9
To die at home	26	28.6
No breathlessness	10	11.0
No anxiety	8	8.8
Wanting to die with dignity	6	6.6
Christian services	1	1.1
Aesthetic appearance	1	1.1

* means % unless marked otherwise; ** means multiple answers possible.

of the University Clinic Essen, University of Duisburg-Essen, Germany, had agreed to this approach.

The statistical analyses were performed with IBM SPSS Statistics for Windows, Version 21.0 (Armonk, New York: IBM Corp.). The primary endpoint was the percentage of palliative care patients who died at home. Secondary endpoints were the frequencies of the various aspects of palliative care provided. Active involvement of the next of kin was defined as taking over five or more elements of palliative care. Univariate

analysis, χ^2 -statistics, and a logistic regression model were used to determine predictors for dying at home. Statistical significance was assigned at the level of $p < 0.05$.

3. Results

3.1. Physician Characteristics. All but one of the fifteen physicians volunteered for the study; the nonparticipating GP was not interested in this study (participation rate 93.3%). The physicians' average age was 50.6 years, 87.6% were male, and 42.9% were working in a group practice. During the biennial period each physician cared for 6.5 patients on average, who required a mean of 10.4 home visits each in a distance of up to 18 kilometers from the physician's office. For details see Table 1.

3.2. Palliative Care Patient Population and Public Mortality Data. In the years 2007 and 2008 a total of 463 inhabitants of the region died: 215 (46.4%) deceased within and 248 (53.6%) outside the city limits. A total of 19.7% of all deceased inhabitants had received palliative care by the physicians surveyed (91 of 463). Dying at home was made possible for 60.4% (55 of 91) of these patients. In addition, all long-term nursing home residents died in their "second home" (13 of 91; 14.3%), increasing the rate of patients dying at home to 74.7% (68 of 91). For details see Table 3.

3.3. Palliative Care Patient Characteristics. During the biennial study period one specialist physician did not have any palliative patient. Thus, data on 91 patients from thirteen physicians were analyzed. The mean age of the patients was 70.9 years (range: 6–98), and 56.0% were female ($n = 51$). There was no access limitation to the services which addressed patients with cancer (61.5%) and noncancer patients (38.5%). Stratified by main diagnosis, patients with malignancies (40 of 56; 71.4%) and neurological diseases (11 of 18; 61.1%) were most likely to die at home, followed by those with cardiac (4 of 7; 57.1%), pulmonary (2 of 5; 40%), and renal diseases (2 of 4; 50%). One patient with a hepatic disorder died apart from home. For details see Tables 2 and 3.

At the time when a physician considered the patient to receive palliative care, 41.8% of the patients were unable to work and bedridden some time of the day ($n = 38$). The most frequent patient preferences for palliative care were not to suffer from pain (54.9%), to avoid unnecessary therapies (42.9%), and to die at home (28.6%). For details see Table 2.

3.4. Living Circumstances of Palliative Care Patients and Their Families. About 40% of the patients lived in two-generation and about 20% in three-generation households, while only 2% lived alone. The multigenerational households were typically found in farm houses in small villages or in isolated cottages in the countryside. During the terminal phase, 52.7% of the families changed the patient's living circumstances or their private living space to enable the patient to stay at home ($n = 48$), for example, bathroom reconstruction ($n = 35$, 38.5%) or moving the patient's bed into the family's living room ($n = 9$, 9.9%). Two patients moved to a nursing home

TABLE 3: Characteristics of end-of-life period (*n* = 91 patients).

	<i>N</i>	%*
Functional status when palliative care started		
Bedridden, dependent	10	11.0
Limited self-care, bedridden >50% of time awake	14	15.4
Unable to work <50% time bedridden	14	15.4
Able to work, some daily activities possible	16	17.6
Normal activity possible	37	40.7
Patient's location when palliative care started		
Within town (village)	26	28.6
Farm house beyond the towns' limits	51	56.0
Nursing home or hospice	14	15.4
Generations in household		
Patient alone (with nursing support)	2	2.2
One-generation household (e.g., partner)	35	38.5
Two-generation household	36	39.6
Three-generation household	18	19.8
Hospital care		
Hospital care required	46	50.5
Temporarily	19	34.5
Place of death		
At home	55	60.4
Nursing home or hospice in nursing home	13	14.3
Hospital, rehabilitation facility, or hospital palliative care unit	23	25.3
Symptoms requiring intervention**		
Weakness	71	78.0
Loss of appetite	65	71.4
Fatigue	56	61.5
Pain	50	54.9
Family problems	40	44.0
Needing support with daily activities	39	42.9
Nausea	37	40.7
Shortness of breath	32	35.2
Difficulties coping with situation	32	35.2
Constipation	25	27.5
Vomitus	19	20.9
Wounds	18	19.8
Medication during end-of-life care**		
Opioids WHO III	60	65.9
Opioids WHO II	19	20.9
Nonopioid analgesics	60	65.9
Proton inhibitors	62	68.1
Sedatives	48	52.7
Laxatives	38	41.8
Corticosteroids	51	56.0
Neuroleptics	16	17.6
Diuretics	25	27.5
Antidepressants	17	18.7
Cardiac medication	12	13.2
Duration of palliative care, in months (average, SD, range)	5.3 (4.2)	0–20

* means % unless marked otherwise; ** means multiple answers possible.

TABLE 4: Care provided by next of kin ($n = 91$).

	N	%
Family members helped with the following*		
Oral medications	66	72.5
Positioning	54	59.3
Providing liquids	43	47.3
Symptom control	40	44.0
Nutritional support	39	42.9
Urine and stool management	38	41.8
Injecting subcutaneous medications	33	36.3
Administrative arrangements	16	17.6
Bowel clearing	15	16.5
Physiotherapy	13	14.3
Wound care	13	14.3
Supply of oxygen/inhalation	8	8.8
Music therapy	7	7.7
Feeding tube management	5	5.5
Intravenous nutrition	3	3.3
Coordination of feeding tube management	3	3.3
Changing of urinary catheter	3	3.3
Art therapy	2	2.2
Dialysis	2	2.2
Next of kin involved in care	81	89.0
≥ 5 aspects of care	59	64.8

* means multiple answers possible.

or a hospice within a nursing home for end-of-life care. Most family members were actively involved in care: help with oral medications (72.5%) and positioning (59.3%). The most frequent medications were pain medications (opioids and nonopioid analgesics). For details see Tables 3 and 4.

3.5. Physicians' Roles, Experiences, and Preferences in End-of-Life Care. In addition to providing typical medical care, physicians were actively involved in various other issues, such as help with administrative topics (44%), emotional support of relatives (69.2%), and spiritual support (14.3%). In nearly 40% of the patients, physicians reported that they were needed to "be present as human being" ($n = 35$; 38.5%). For details see Table 5.

In the majority of scenarios the family members were seen as positive contributors ($n = 76$; 83.5%). In 20% of the cases, physicians were very satisfied with the collaboration with the professional nursing services ($n = 21$; 23.1%) but would have liked more support by family members ($n = 8$; 8.8%) and/or better communication with hospitals ($n = 5$; 5.5%). Nearly 20% complained about difficulties to receive benefits from the nursing care insurance and its medical advisory organization ($n = 16$; 17.8%). For details see Table 5.

3.6. Predictors for Dying at Home. In the univariate analyses the following four independent variables were significant predictors for dying at home: family members were actively involved in care ($p < 0.001$), cancer diagnosis ($p = 0.007$), palliative care in a farm outside the village ($p < 0.001$), and

the patient's wish to die at home ($p = 0.012$). An inpatient stay during the palliative care period was a negative predictor for dying at home ($p < 0.001$). There was no influence of the patient's gender, age ($\leq / > 72$ years), and functional status. Multicollinearity was observed between the variable "palliative care in a farmhouse outside the village" and all other positive predictors, so that this variable was excluded from the final regression model. Thus, the following three positive predictors for dying at home were cancer diagnosis (Odds Ratio (OR) 4.07; 95% confidence interval (CI) 1.27–13.03), family members actively involved in care (OR 5.7, 95% CI 1.81–18.25), and the patient's wishing to die at home (OR 5.54; 95% CI 1.38–22.23). In contrast, a hospital stay during end-of-life care was a negative predictor for dying at home (OR 0.08; 95% CI 0.02–0.29).

4. Discussion

Our representative study of rural palliative care in a German region showed that 60.4% of those patients receiving palliative care died at home according to their wishes. In contrast to many other palliative care settings, the approach described in our study is not prestructured externally but results from individually tailored palliative care self-organized by the locally licensed physicians under integration of family and nursing service resources.

4.1. Predictors for Dying at Home in Rural Regions. The percentage of patients who died at home in our study is well within the range of the 36–80% reported from other scenarios [7, 11, 15, 16]. Our study confirmed the diagnosis of a malignancy, the wish to die at home, and next of kin actively involved in care as significant positive predictors for dying at home [2, 6, 15, 20]. Just as in other studies, a hospital stay during end-of-life care was determined as a negative predictor for dying at home in our study [2, 8]. Similar to the 31.3% reported by Fukui et al. [7], 34.5% of the patients in our survey who died at home required a temporary hospital stay. While some studies found no difference between urban and rural areas [3, 7, 11], others concluded that rural patients were less likely to die at home due to a lack of ambulatory services [17, 21, 22]. Although we did not compare urban and rural areas, our rate of 60% of patients dying at home is consistent with findings from other palliative care settings.

4.2. Setting-Tailored Rural Palliative Care and the Role of Multigenerational Families. The patients described in our study died in quite different rural settings, ranging from a single patient in his trailer home supported by a nursing service to multigenerational family scenarios in farm houses. In the latter scenario even 80% of our patients were able to die at home which we attribute to the patients' strong wish to remain within their family setting and an extraordinary commitment of the multigeneration families. The specific social structures in this rural area are obvious when comparing to nationwide statistics: 25% of the patients in our study lived in families spanning at least three generations as do only 0.5% of the general population [23]. Canadian and Australian studies describe family members of palliative

TABLE 5: Physicians' roles, preferences, and experiences ($n = 91$).

	N	%
Physicians' roles*		
Information on end-of-life course	69	75.8
Coordination of care	65	71.4
Emotional support of relatives	63	69.2
Emotional support of the patient	59	64.8
Help with administrative regulations	40	44.0
Crisis intervention	39	42.9
Being there as human being	35	38.5
Answering questions on advanced directives	26	28.6
Advice regarding palliative care unit transfer	16	17.6
Spiritual support	13	14.3
Physicians wishing for more support or better cooperation *		
Health/nursing insurance and MDK	16	17.6
Patients' family members	8	8.8
Hospitals	5	5.5
Physician peers	3	3.3
Administrative issues	2	2.2
Nursing services	2	2.2
Physicians valuing the following aspects as particularly good*		
Family members as positive contributors	76	83.5
Feeling welcome in the patients home by the family members	24	26.4
Care of nursing service	21	23.1
Control of symptoms	15	16.5
Patient able to die at home	10	11.0
Cooperation of all involved parties	6	6.6
Communication with family members	4	4.4
Cooperation with hospital	1	1.1
Problems during end-of-life care*		
Next of kin not supportive	11	11.0
Family members unable to help due to own mental or physical overburden	7	7.7
Family members lacking interest	2	2.2
Next of kin being additional stressor	1	1.1
Reasonable therapies denied for religious reasons by a caregiver	1	1.1
Disagreement on the concept of care with a relative who was also physician himself	1	1.1
Moments of insecurity during palliative care*		
Due to own personal involvement	6	6.6
Due to extraordinary support required	5	5.5
Due to psychological situation, disease process, or lack of medication response	5	5.5

* means multiple responses possible.

care patients who reported that they felt burdened by being forced into providing palliative care [22] due to a shortage of professionals and long distances [17, 22]. In our study family members took part in the patient's care in 89% of the situations but nursing services supported 91% of these scenarios. This rate is much higher than the 26–51% nursing service involvement reported in other studies [3, 24, 25].

4.3. Physicians' Roles and Experiences in Rural Palliative Care. Several studies showed that patients wish to be supported by the same physician for their end-of-life care [26], which

was realized for 43% of our study patients. In contrast to other structures of palliative care, which are predominantly nurse-driven [17, 22], the physicians are the key coordinators in our region who supported patients and next of kin in a comprehensive way. While the physicians reported mainly positive experiences with families and nursing services, they expressed a desire for better communication with hospital physicians and/or health care insurances. In the service structure surveyed the shift to palliative care is often not as clear-cut as in situations where a shift to a specialized palliative care service is associated with a change of care provider.

4.4. Conclusions, Limitations and Perspectives. Our retrospective survey of a rural physician-based, interdisciplinary care documented an integrated palliative care approach tailored to the patients' preferences and social situations. As one of the first reports we shed a special light on palliative care scenarios in social structures typical for rural regions and showed an extraordinary involvement of multigenerational families; yet further studies are of interest. As in other retrospective studies, we cannot exclude potential recall biases or socially expected answers on behalf of the participants. Future studies on such integrated care models [18] should include the perspectives of patients, caregivers, and nursing services.

Abbreviations

CI: Confidence interval
OR: Odds Ratio.

Competing Interests

The research project forms the basis of the doctoral thesis of André Terhorst. All other authors declare that there are no competing interests.

Authors' Contributions

André Terhorst developed the study question. Birgitta Weltermann developed the study idea, the study concept, and supervised the data management. André Terhorst helped in study design, performed the data collection and the data management, and supported the interpretation of the results and literature search. Helena Albrecht performed the literature search and the data analysis. Birgitta Weltermann and Helena Albrecht reviewed the literature and drafted the first version of the paper. All authors critically reviewed the first draft and provided feedback on it. All authors read and approved the final paper.

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