

Original Article

Status Quo of Palliative Care in Pediatric Oncology—A Nationwide Survey in Germany

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Abstract

Cancer is the leading cause of death among the pediatric population with life-limiting conditions. The provision of palliative care at home and on the children's cancer unit has not been surveyed previously on a national scale. A survey of 71 (of 73) German pediatric oncology units (response rate 97%) provided information on the timing of breaking bad news, place of death, orchestrating palliative care at home and on the ward, integration of services and staff, funding of palliative care, bereavement services for siblings and parents, educational needs, level of self-satisfaction, and designated integrated palliative care services for children with cancer. More than 60% of children with malignancies died as inpatients in 2000, fewer than 40% at home. Twenty-nine pediatric cancer departments were able to provide comprehensive medical palliative home care, and nine units incorporate a designated palliative care team or person. Only half of the departments provide bereavement services for siblings. Many health professionals working on pediatric cancer units in Germany provide palliative home care in their free time without any payment. They predominantly use their private vehicles and often are unclear about the legal background and insurance arrangements covering their provision of care. The data suggest an important need for education about palliative and end-of-life care. The majority of children dying from cancer in Germany do not have access to comprehensive palliative care services at home. Our study highlights the necessity of incorporating the palliative paradigm into the care of children with cancer. Barriers to its implementation must be identified and overcome. *J Pain Symptom Manage* 2005;29:156–164. © 2005 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words

Children's cancer wards, pediatric palliative care, home care, nation-wide survey

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Introduction

Cancer is the leading cause of death for children with life-limiting conditions.^{1,2} Of the German population of 82 million people, 13 million are under 18 years and about 2,000 children 0–17 years are diagnosed with a malignancy each year. The five-year survival rate is

74% and the 15-year survival rate is 69%.³ Each year, more than 500 children die of cancer in Germany.

Childhood cancer trends in Germany regarding incidence and mortality mirror those in the U.S.,² Canada,⁴ and Western Europe⁵ (Austria, Denmark, Finland, France, Iceland, Spain, Sweden, Switzerland, The Netherlands, United Kingdom). In the United States alone, approximately 12,400 children and adolescents 0–19 years of age are diagnosed with cancer each year and, in 1995, there were 2,275 deaths from cancer among this group.⁶ In 2000, 1,434 children younger than 15 years of age died (1995: 1,548).⁹ Their five-year survival rates in the U.S. increased from 73.8% in 1989–1994 to 77.1% in 1992–1997.⁷

Each year, 4–5 million adults die of a malignant disease worldwide. Cancer deaths accounted for 25% (or 220,000 people) of all deaths in Germany⁸ and 23% (or 550,000 people) in the United States.⁹ Whereas high-quality palliative care is now an expected standard at the end of life for adults,^{8,10} it is uncertain whether the care of children with malignancies meets this standard.¹² Little is known about the provision of end-of-life care for children with malignancies on a nationwide scale, as the care for dying children can be particularly complex.

Models of care for dying children include freestanding children's hospices with in-bed facilities providing respite and end-of-life care in Australia (2 hospices), Canada (1), Germany (6), The Netherlands (1), United Kingdom (27), and the United States (1), as well as designated pediatric palliative home care programs, which were commenced in the 1980s and 1990s in Costa Rica, Poland, Romania, United Kingdom, United States, Ukraine, and other countries. Little is known about the provision of pediatric palliative care by children's hospitals. To our knowledge this is the first nationwide survey looking into details of the status quo of palliative and terminal care for children with cancer.

There are four key issues we believe should be studied in order to provide baseline information about the current practice of pediatric cancer units with regard to their palliative care services, discussed below.

Proportion of Children Dying at Home

Data from several studies suggest that there is a high correlation between the availability of

comprehensive home care and the number of children with life-limiting conditions dying at home.^{11–13} At Great Ormond Street Hospital for Children (London, UK), only 19% of children with cancer died at home before the Symptom Care Team was established by Ann Goldman in 1987. Within two years of establishing the Symptom Care Team, more than 75% of pediatric oncology patients chose to die at home.^{14,15} The proportion of children dying at home, therefore, may be one indicator about the provision of palliative home care.

Number of Designated Palliative Care Teams

About one of four children with cancer eventually die from their disease.^{3,7} It is, therefore, common for pediatric cancer units to deal with dying children. The care for a dying child and his/her family may be very complex and some issues, like pain control, symptom management, around-the-clock availability of professionals for children dying at home, holistic multidisciplinary provision of palliative care, and follow-up of bereaved parents and siblings, may require the assistance of specially trained specialists. The number of designated palliative care teams, therefore, may reflect the incorporation of palliative care into the daily routine on children's cancer wards.

Provision of Adequate Resources to Orchestrate Palliative Care

Health care professionals looking after dying children in the hospital, at a hospice or at home, fulfill a paramount role in the provision of pediatric cancer care. These services should be adequately funded and well resourced. The current funding of palliative care services may or may not reflect the uttermost importance of the provision of care for dying children.

Implementation of Palliative Care

Palliative care does not equal symptom control in the last days of life. Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social, and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement.¹⁶ The timing of breaking bad news and the timing of

integration of a palliative care team, and holistic aspects like details about sibling work and bereavement, therefore, were important data to be gathered by the survey to reflect the current status quo of pediatric palliative care in pediatric oncology in Germany.

Methods

Survey Process

The survey was conducted from March to November 2002 at all 73 German pediatric cancer departments by the project PATE (Palliative Care, Therapy, and Evaluation in Pediatric Oncology/Hematology), which was initiated by the German Society for Pediatric Oncology/Hematology (GPOH) and financed by the German Children's Cancer Fund (Deutsche Kinderkrebshilfe) and Mundipharma, Limburg. The 6-month time frame was needed to gather all the necessary information from these units. The survey was sent to the head of the oncology department and the head nurse, as we assumed those individuals would have the greatest knowledge of current practice in their unit and would be able to pass the questionnaire on to appropriate staff members. Of 73 pediatric cancer departments, 71 agreed to participate (response rate of 97%). The majority of the surveys were completed and returned by mail; eight were conducted over the telephone.

Questionnaire Development

The questionnaire was developed on the basis of a review of the literature and suggestions from focus groups of health professionals involved in the care of dying children. It included questions about timing of breaking bad news, place of death, orchestrating palliative care at home and on the ward, integration of services and staff, funding of palliative care, bereavement services for siblings and parents, education needs, level of self-satisfaction, and designated integrated palliative care services for children with cancer. A pilot study of five cancer units was performed. During that pilot study, a multidisciplinary team working on the five children's cancer wards agreed to complete the survey. The pilot study allowed user input to test appropriateness of the questionnaire, assess the ease of completion of a nationwide survey, discuss potential logistical problems, review of time spent and resources needed for the survey, and review of

the proposed data analysis technique to uncover potential problems. The majority of questions were formatted in Likert scale answers. Others had a yes or no format or open questions and continuous, non-categorical visual analogue scales (VAS) 1–10.

Analysis

Independent continuous variables were compared using either Mann-Whitney U test or Student's *t*-test. A two-tailed Fisher's exact test was used to compare categorical responses (SPSS 11.5 for Windows). Details about the provision of care, place of death, need of education, and level of satisfaction of care, in regard to the size of the unit and to what degree home care was provided, were compared.

Results

Ninety percent of the surveys were completed by individual respondents and 10% by a group of 2–3 staff members from different professional backgrounds. Pediatric nurses (59%), physicians (34%), and members of the psychosocial team (7%) filled in or answered the questionnaire alone or with a team. The results are based on the information provided by these departments.

Service Profile

Twenty responding departments cared for less than 10 newly-diagnosed children with cancer per year age 0–17 and 15 for more than 50 patients (maximum 120 patients/year) (Table 1). Nearly half of the oncology units (49%) incorporated an outpatient clinic, which provided chemotherapy and transfusions of blood products and 28% had designated beds for children undergoing bone marrow transplants.

Established Palliative Care Teams

Nine children's cancer units in Germany (12%) incorporated a designated palliative care person or palliative care team consisting of 1–6 people. Eight teams employed nurses (3 teams more than 1 nurse), two teams psychosocial staff, and 4 teams a physician (1 team employed 2 physicians). The physicians in 3 teams provided home visits. One team had a pastoral caregiver,

Table 1
71 (of 73) German Pediatric Oncology Departments

| No. of New Cancer Cases per Year | No. of Children's Cancer Wards (%) | No. of Wards with Frequent Home Care (%) | No. of Children who Died in 2000 | No. of Children who Died at Home (%) | No. of Children who Died in the Surveyed Hospital (%) | No. of Children who died in Another Hospital (%) |
|----------------------------------|------------------------------------|--|----------------------------------|--------------------------------------|---|--|
| 1-30 | 42 (59) | 11 (26) | 144 | 51 (35) | 71 (49) | 22 (15) |
| 31-60 | 18 (25) | 10 (56) | 150 | 65 (43) | 65 (43) | 20 (13) |
| >60 | 11 (15) | 7 (64) | 194 | 78 (40) | 94 (48) | 22 (11) |
| Total | 71 (100) | 28 (39) | 488 | 194 (40) | 230 (47) | 64 (13) |

and one team two physiotherapists. Seventy-five percent of the staff working in palliative care received no counseling or supervision. The first contact between the patient and his/her family and the palliative care team / person usually (more than one answer possible) took place at diagnosis (89%), when curative therapy stopped (44%), at time of relapse (33%), or at transition to home care (33%).

Type of Palliative Home Care

Fifty German children's cancer departments (70%) have provided or orchestrated palliative home care for some of their children according to the information given by the respective departments. A slight majority of those palliative children received frequent care by nurses and physicians (Table 2). The most common services provided by nurses were instructing family members in the provision of care and offering psychosocial support (Table 3). Physicians working in the departments engaged in palliative home care mostly were involved in prescribing drugs and offering psychosocial support. A minority of physicians provided hands-on care of the dying child at home, for example, physical examination (Table 4). Thirty-nine percent

of pediatric cancer departments provided palliative home care for their patients with frequent home visits by nurses and physicians (Table 1).

Orchestrating Palliative Home Care

Most cancer units included the local pediatricians, when a palliative child was discharged home (Table 5). Twenty-six percent of the palliative children requiring blood or platelet transfusions received them at home, with 74% returning to their hospital for them. More than one-third (38%) of the surveyed departments reported legal or organizational difficulties in providing transfusions at home.

Frequently used medical equipment at home included infusion pumps (by 40 from 50 units), wheelchairs (38/50), special beds (35/50), suction (29/50), oxygen concentrators or containers (28/50), toilet chair (28/50), feeding pump (26/50), and patient-controlled analgesia pumps (26/50).

Table 3
Specific Services Frequently Performed by Nurses (n = 50 Pediatric Cancer Departments) Providing Palliative Home Care for Children with Cancer ("Often" or "Very Often")

| Services | Number (%) |
|---|------------|
| Instructing family members in care | 31 (62) |
| Psychosocial support | 28 (56) |
| Coordination of care | 23 (46) |
| Drawing blood | 22 (44) |
| Care of Broviac/Hickman line or Infusaport access | 21 (42) |
| Dressing change | 21 (42) |
| PCA pump control and adjustment | 19 (38) |
| Applying NG tube | 17 (34) |
| Basic care | 16 (32) |
| Injections IV, SC, IM | 14 (28) |
| Suction | 14 (28) |

PCA = patient-controlled analgesia; NG = nasogastric; IV = intravenous; SC = subcutaneous; IM = intramuscular.

Table 2
Provision of Palliative Home Care for Children with Cancer in Germany Orchestrated by 50 Pediatric Cancer Departments: Number of Hospital-Based Professionals Involved in the Care "Often" or "Very Often"

| Profession | Number (%) |
|---------------------|------------|
| Nurses | 28 (56) |
| Physicians | 27 (54) |
| Social worker | 14 (28) |
| Psychologist | 10 (20) |
| Pastoral carer | 7 (14) |
| Art/Music therapist | 2 (4) |

Table 4

Specific Services Performed by Physicians ($n = 50$ Pediatric Cancer Departments) Providing Palliative Home Care for Children with Cancer ("Often" or "Very Often")

| Services | Number (%) |
|---------------------------------|------------|
| Prescribing drugs | 29 (58) |
| Psychosocial care | 24 (48) |
| Coordination of care | 20 (20) |
| Physical examination | 12 (24) |
| Injections IV | 10 (20) |
| Drawing blood | 9 (18) |
| Cannulating vein | 8 (16) |
| PCA pump control and adjustment | 7 (14) |
| Transfusions | 6 (12) |

PCA = patient-controlled analgesia; IV = intravenous.

Most departments saw the majority of their patients at home if they lived within a 30-mile (50-kilometer) radius of the hospital (73%). Some (26%) would travel up to 60 miles, although single departments reported distances further than 125 miles for a single home visit. The staff providing the home visits predominantly used their own cars (60%), some hospital cars (13%), and vehicles financed by donations (10%). About 5% frequently used public transport for their home visits. Insurance coverage, such as third-party for mode of transport and medical indemnity for the home care, was not established or was unclear in 41% of the surveys.

Funding and Reimbursement of Services

Home care was most commonly provided by hospital staff voluntarily without any payment (38% of cases) or was covered by overtime (26%), health insurances (22%), or donations (14%).

The nine established palliative care teams or the single palliative care person were predominantly financed (more than one answer possible) by donations or charities (56%), by

unrostered overtime (44%), voluntary/not financed (22%), or health insurance (22%).

Timing of Breaking News

The majority of the participating health professionals (77% of physicians and 60% of nurses) believed the right time was chosen to talk about death and palliative care. Fewer of the health professionals (23% of physicians and 40% of nurses) thought the issue was brought up too late in the course of the disease.

Place of Death

Of the 488 children who died in 2000 due to cancer under the care of the participating 71 pediatric cancer units, 39.8% died at home and 60.2% died in the hospital (Table 1). There was no statistical difference regarding the place of death and the number of patients cared for on the unit. Cancer units that provided frequent or infrequent home care had a higher percentage of children dying at home than cancer departments, that did not provide home care ($P = 0.015$).

Sibling Work and Bereavement

Nearly three-fourths of the German pediatric cancer departments provided formal bereavement services for parents (74%) and similar services were offered to 51% of the siblings. Those units that did offer sibling bereavement services did so by means of bereavement groups (33%), self-help and support groups (30%), and individual counseling by trained staff such as psychologists, pastoral caregivers, or similar (30%).

Education

On a continuous VAS 1–10 (anchors being 1 = no need for education; 10 = very high need for education), German pediatric oncology units already providing palliative home care assessed their need for ongoing education in pediatric palliative cancer care significantly lower (VAS 6.4) than those units not providing any home care (VAS 8.7) ($P < 0.01$).

Departmental Satisfaction with Provision of Palliative Care

The majority of 50 cancer departments, which provided palliative home care at some stage, were satisfied ("content" or "very content") with the level of palliative care provided

Table 5

Frequent ("Often" or "Very Often") Integration of Professionals or Services by 71 German Children's Cancer Units, When a Palliative Child Was Discharged Home

| | No. of Cancer Wards (%) |
|-----------------------------------|-------------------------|
| Local pediatrician | 61 (86) |
| General practitioner | 43 (61) |
| Local nurse-led home care service | 37 (52) |
| Physiotherapist | 14 (20) |

in their unit by nursing staff (77%), physicians (67%), and allied psychosocial staff (51%). The level of satisfaction was lower for cancer departments not providing palliative home care for nursing staff (67%), physicians (60%), and psychosocial staff (40%). This is a significant difference for nurses and physicians ($P < 0.05$) and non-significant for members of the psychosocial team.

Discussion

We sought to evaluate the provision of palliative and terminal care for children with cancer in Germany. Key figures, like number of newly diagnosed children and number of children dying in 2000 match the data of the German Pediatric Cancer Register³ and hence imply reliability of this survey.

Proportion of Children Dying at Home

Surprisingly, more than 60% of pediatric patients with malignancies died in a German hospital in 2000. No child died in a free-standing children's hospice and less than 40% of the children died at home. In Washington State (U.S.), the number of children with cancer dying at home is as low as 20%,¹⁷ in Poland 23%,¹⁸ and in England and Wales 52%.¹⁹ As mentioned above, studies from Finland,¹¹ the U.S.A.,¹² and Germany¹³ demonstrate a high correlation between the availability of comprehensive home care and the number of children with life-limiting conditions dying at home. Evidence suggests that the long-term problems of bereaved parents and siblings may be reduced when they have been involved in caring for the dying child at home.²⁰ Although there cannot be a benchmark regarding a proportion of children dying outside the hospital, the Great Ormond Street Hospital for Children (London, UK) provides impressive data: More than 75% of pediatric oncology patients chose to die at home, after the Symptom Care Team had been established.^{14,15} In comparison to these figures, the relatively high number of children with cancer dying in German hospitals might make a case for the improvement of pediatric palliative care services.

Number of Designated Palliative Care Teams

Although a majority (70%) of the 71 German pediatric cancer departments do provide some

palliative home care for some of their patients, only 39% can provide physicians and nurses for home visits to their palliative patients. A much higher number would be needed, as many children with cancer require active medical intervention in order to be at home and to live as well as possible with their terminal disease.²¹ The quality of the home care was not evaluated in this survey and will be addressed in a future study.

Most of the German children's cancer units appeared to have no systematic plan of palliative care. Only nine (13%) were able to provide a designated team or person for palliative care.

Provision of Adequate Resources to Orchestrate Palliative Care

The main barriers to the provision of more home care facilities include financial limitations and subsequent understaffing. A significant number of hospital staff currently provide palliative home care in their own time, without payment and only in a few cases are any costs covered by health insurance. This is despite the fact that Italian and U.S. studies show a significant decrease in cost by providing home care, even for technology-dependent children with cancer.^{21,22} German health insurance often does not cover the expenses for providing palliative home care. Many health professionals working on pediatric cancer units in Germany provide palliative home care in their free time without any payment, predominately use their private vehicle, and often are unclear about the legal background and insurance arrangements covering their provision of care.

Implementation of Palliative Care

One may speculate that strict barriers between hospital and home care, enforced by health care regulators in Germany, led to fairly comprehensive palliative care inside the hospital and rather limited resources for home care. This is despite the fact that many palliative children and their families prefer spending the end-of-life period at home.^{23,24} Another obstacle may be the focus on cure of cancer by the pediatric oncologist. Curative therapy and palliative care might be seen as dichotomous. Considerations of the toxicity of therapy and quality of life are usually secondary to this goal. As a result, it may be difficult for physicians to change their focus even when

there is little hope of a cure.¹² Additional barriers to the integration of palliative care were identified elsewhere^{25,26} as lack of formal courses in pediatric palliative care, trial and error learning in caring for dying children, lack of strong role models, and lack of access to pain and palliative care services.

Different models have been proposed for the integration of palliative care into the daily routine of pediatric clinical oncology.¹⁶ Many professionals would probably prefer the integration of a "palliative" or "symptom" care team at diagnosis with a "crescendo" or "blending-in" over time. Data from this survey effectively indicate the incorporation of this model into practice by the nine existing palliative care teams or palliative care individuals, as the vast majority often established first contact with a palliative child and his or her family at diagnosis. Outside of designated palliative care settings, it seems to be common practice to institute palliative care only after life-prolonging care is no longer available.²⁷

The death of a child causes intense and prolonged bereavement in both parents.²⁸ Formal strategies to support parents in processing the pain and grief, and adjusting to a life without their child are offered by the majority of German cancer departments. Siblings of children with cancer may feel neglected, angry, and jealous of the attention given to the dying child and at the same time feel guilty for having such feelings.²⁹ Siblings might be under the impression that they have caused the disease or of being at risk to die as well. Our data suggest siblings of a child dying of cancer may not only be neglected by their parents, but also by the German health system, as only half of the cancer units offer formal support groups or services for bereaved siblings.

As the majority of responding health professionals, notably more physicians than nurses, believed the right time was chosen to talk about death and palliative care, we are going to address this issue in a subsequent survey with bereaved parents to rule out a possible bias. Wolfe et al.³¹ could not only demonstrate a considerable delay in parental recognition that their children had no realistic chance for cure, but also that earlier recognition of this prognosis by both physicians and parents was associated with a stronger emphasis on treatment directed at lessening suffering and greater integration of palliative care.

The degree of satisfaction about the level of palliative care service provided by the departments in this survey was higher among units providing palliative home care, but even units without home care were largely satisfied with their palliative care. Bereaved parents did not echo this degree of satisfaction. Joanne Wolfe and her team could not only demonstrate a great deal of suffering among children dying of cancer, but most of their distressing symptoms in the end-of-life period were either not treated at all, or when treated, more often than not treated unsuccessfully.¹² Several studies^{30,31} contradict the impression of most doctors and nurses in this survey for having chosen the right time for breaking bad news and discussing death and palliative care.

One potential limitation of this study is that typically it was one individual from each institution who provided answers to the questionnaire. As such, answers to questions, which include opinion as well as information about service delivery and performance, may be biased. The direction of bias may overestimate the truth about actually provided palliative home care, but the data of this survey still provided important baseline information. To address this potential limitation, data provided by the departments were double-checked against other information sources available to the authors, including the German Pediatric Cancer Register, service Web sites or written information of oncology units, respective guidelines of provision of care, and written and online information provided by parental organizations for children with cancer and bereaved parents and self-help groups. No discrepancies between provided and available information were identified.

The survey, therefore, provides a snapshot about the status quo of pediatric palliative care in German oncology patients. It may be appropriate to use the results of this study as a descriptive baseline for a national palliative program, which will subsequently address questions about access and provision of palliative care for children with cancer in Germany.

Conclusions

The majority of children dying from cancer in Germany do not have access to comprehensive palliative care services at home. Even in

oncology units the notion of palliative care is rarely considered as an integral part of the care package. The paradigm of palliative care is a vital component of the care of children with cancer. Barriers to its achievement must be identified and overcome.

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