Specialized Home Palliative Care for Adults and Children: Differences and Similarities

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Abstract

Objective: To compare the provision of specialized home palliative care (SHPC) by the adult and pediatric SHPC teams at the Munich University Hospital.

Methods: All patients treated by one of the SHPC teams and their primary caregivers were eligible for the prospective nonrandomized survey. We analyzed the demographics, the underlying diseases, duration and impact of SHPC on symptom control and quality of life (QOL) as well as the caregivers' burden and QOL.

Results: Between April 2011 and June 2012, 100 adult and 43 pediatric patients were treated consecutively; 60 adults (median age, 67.5 years; 55% male) and 40 children (median age, 6 years, 57% male) were included in the study. Oncologic diseases were dominant only in the adult cohort (87 versus 25%, $p < 0.001$). The median period of care was higher in the pediatric sample (11.8 versus 4.3 weeks; NS). Ninety-five percent of adult and 45% of pediatric patients died by the end of the study ($p < 0.001$), 75% and 90% of them at home, respectively. The numbers of significant others directly affected by the patient's disease was higher in children (mean 3.4 versus 1.2; $p < 0.001$). The QOL of adult patients and children ($p < 0.05$ for both), as well as of their primary caregivers ($p < 0.001$ for both) improved during SHPC, while the caregivers' burden was lowered ($p < 0.001$ for both).

Conclusions: Our results show important differences in several clinically relevant parameters between adults and children receiving SHPC. This should assist in the development of age-group specific SHPC concepts that effectively address the specific needs of each patient population.

Introduction

IN GERMANY, approximately 780,000 adults ($n = 780,883$ in 2011) and 3,500 children ($n = 3,559$ in 2011) die of a life-limiting disease every year.¹ Receiving the diagnosis of an incurable disease always means a grave situation for the patients as well as for their significant others.² Several different palliative care approaches have been established in recent years to achieve the best possible quality of life (QOL) for these patients and their families.^{3–6}

The vast majority of patients prefer to spend their remaining time in their familiar environment, which can lead to a high burden for the primary caregivers.^{7–11} Several concepts to prepare and support the patients and their caregivers in the realization of this desire were evaluated in recent years,^{12,13} and multiprofessional specialized home palliative care (SHPC) teams were established.

A few studies stated the effectiveness of SHPC for adults and children to date,^{14–16} but little data are available on the

specific needs of adult and pediatric palliative care patients and the differences between these patient groups. To our knowledge, this is the first survey comparing SHPC for children and adults at the same center, prospectively and in parallel. Detailed results for each patient group have been reported previously.^{16,17} This article focuses on the meta-analysis of the data, exploring the differences and similarities on the provision of SHPC to adults and children in order to provide the basis for the development of age-appropriate SHPC concepts.

Methods

Study design and subjects

The survey was conducted at the Interdisciplinary Center for Palliative Medicine and the Pediatric Palliative Care Service at the University Hospital in Munich, Germany. In 2009, two multiprofessional SHPC teams, one for adult and

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one for pediatric palliative care, were established. The main tasks of these teams are counseling, coordination, and provision of palliative medical and nursing care, including a 24/7 on-call service, as well as psychosocial support. This service is provided in close cooperation with the local health care professionals (HCPs), e.g., general practitioners (GPs), pediatricians, nursing and hospice services.

All patients treated by one of the aforementioned teams between April 2011 and November 2011 (adults) or June 2012 (children) and their primary caregivers were eligible for the study. Exclusion criteria were patient and caregiver refusal, inappropriate language knowledge or intellectual inability to understand the questionnaire. The study was approved by the Research Ethics Committee of the Munich University Hospital, and all adult participants provided informed consent. We also prepared age-adjusted letters of information for the participating children. The three children who were able to take part gave their consent as well as their parents.

Data sources

The data were collected from a review of the patients' medical charts as well as from two questionnaires. The questionnaires comprised numeric rating scales (NRS) and the following validated scores: For the patients, McGill Quality of Life Questionnaire (MQOL, to assess quality of life), Minimal Documentation System for Palliative Medicine (MIDOS, symptoms) and Palliative Outcome Scale (POS, quality of care); for the caregivers, Quality of Life in Life-Threatening Illness–Family Carer Version (QOLLTI-F, quality of life), Häusliche Pflegeskala (home care scale, burden of care), and Hospital Anxiety and Depression Scale (HADS, anxiety and depression).^{16,17} The questionnaires were completed by the adult patients as well as the primary caregivers of adult and pediatric patients. The assessment of the children by self-report as initially intended could only be accomplished in three children, thus these data were not evaluated.

Both the adult and the pediatric population were surveyed twice during the study. The adults and their caregivers were surveyed during the first week, and then within the following 2 months after involvement of the SHPC team. The pediatric population was surveyed during the first week, and then within the following 6 months of SHPC involvement. The different time frames were selected based on the average periods of SHPC involvement, which were known from clinical experience to be much longer in children than in adults.

The analysis of the patients' period of care and survival was conducted between April 2011 to June 2012 (end of the study period) and December 2012 (6-month follow-up) for both samples. Palliative medicine specialists provided objective data concerning the patients' performance status (Karnofsky Index for the adult patients and Lansky Index for the pediatric patients, both of which were converted for comparison into the Eastern Cooperative Oncology Group [ECOG] score).¹⁸ They also provided information on their current medication at both time points as well as—in the case of the pediatric patients—their actual symptom burden at the first measure point.

Statistical analysis

Descriptive statistics were used to characterize the demographics, objective care data, and evaluation of care. The

significances of the differences before and after involvement of the SHPC teams were calculated using the Wilcoxon signed-rank test for nonparametric data. Equivalency of the variables between the two sample groups was tested by means of the χ^2 test. Kaplan-Meier survival curve and log-rank test were used to describe and compare the patients' duration of SHPC and survival. For all analyses, Bonferroni adjustments were performed. Significance level was set at $p < 0.05$ for single comparisons and on the respective adjusted level for multiple comparisons. The analyses were conducted using the Statistical Package for Social Sciences (SPSS, version 20.0, SPSS Inc., Chicago, IL).

Results

Patients

Of the 100 adult and 43 pediatric patients treated consecutively between April 2011 and November 2011 (adults) or June 2012 (children), 60 adult and 40 pediatric patients were included in the study. Seventeen adult and three pediatric patients were excluded because of exclusion criteria, respectively. Nine adult patients (23%) and their caregivers were excluded due to the patient's and family's best interest. Eight adult patients (20%) could not be surveyed because their death occurred within 24 hours after involvement of the SHPC team. Three adult patients (8%) could not take part because of their poor clinical condition, and their caregivers refused to participate. Two foreign adult patients (5%) and their caregivers immediately left Germany with the aid of the SHPC team to die in their home country, and one patient and his caregiver did not have appropriate language knowledge.

Due to poor clinical condition (16 adults/6 children), young age (15 children), cognitive impairment (2 adults/13 children), or patient refusal (5 adults/3 children), 23 of 60 adult and 37 of 40 pediatric patients did not take part in the study themselves. In these instances, their primary caregivers (i.e., spouses or parents in most cases) answered the questionnaires, with the patient's explicit consent wherever possible. In these cases, only sociodemographic and disease-related data of the patients were collected. Because 5 of the remaining 37 adult patients died between the first and the second assessment, a total of 32 adult patients were assessed by self-report in the study at the second time point.

The median age of the included 60 adult and 40 pediatric patients was 67.5 and 6 years, respectively (range, 32–97 years versus 1 month to 18 years). The patients' characteristics and the initiation of contact with the SHPC team are shown in Table 1. The interval between the first and the second assessment ranged from 2 days to 7 weeks (median, 2.5 weeks) in the adult and from 2 days to 6 months (median, 8.0 weeks) in the pediatric sample.

Caregivers

In the adult sample, a total of 53 primary caregivers (88%) participated in the study. Five patients (8%) were single and in two cases caregivers could not participate due to lack of time. In the pediatric sample, all primary caregivers ($n = 40$) could be interviewed. Primary caregivers were predominantly female in both groups (77% in the adult versus 95% in the pediatric sample). Their age ranged from 29 to 91 years (median, 58 years) versus 18 to 52 years (median, 39 years; NS). In the

TABLE 1. PATIENT'S CHARACTERISTICS AND INITIATION OF CONTACT WITH SPECIALIZED HOME PALLIATIVE CARE

	Adults (n=60) n (%)	Children (n=40) n (%)
Gender		
Male	33 (55)	23 (57)
Female	27 (45)	17 (43)
Religious affiliation		
Christian	48 (80)	35 (88)
Muslim	1 (2)	5 (12)
None	11 (18)	—
Migration background	12 (20)	14 (35)
Initiation of contact with the SHPC team		
Hospital	39 (65)	30 (74)
GP/pediatrician	10 (17)	3 (8)
Hospice service	—	2 (5)
Medical specialist	5 (8)	—
Nursing service	3 (5)	4 (10)
Friends	3 (5)	1 (3)

SHPC, specialized home palliative care; GP, general practitioner.

adult sample, most of the caregivers were spouses (64%), parents (20%), or children (6%) of the patients. Two patients were cared for by a neighbor, and one each by a sister, a distant relative, and a good friend. In the pediatric sample, 92% of the questionnaires were completed by the mothers, 5% by the fathers, and in one case by the cousin of the patient. Eighty-three percent of the caregivers in both groups were married or in a relationship; 17% each were single, widowed, or divorced.

In addition to the primary caregivers, there were often significant others being directly affected by the patient's disease, particularly in the pediatric sample (less than 1 person in 98% of pediatric versus 23% of adult cases, median 3 versus 1 person; $p < 0.001$; Fig. 1).

Spectrum of disease and characteristics of care

A major difference between adult and pediatric patients concerned the underlying diseases. While the majority of adult patients suffered from oncologic diseases, this was true for only a minority of the children receiving SHPC (87% versus

25%; $p < 0.001$; Fig. 2B and 3B). Furthermore, the spectrum of diseases was considerably reduced in the adult sample compared to the actual causes of death in the general population in Germany in 2011. In contrast, the spectrum of diseases in the pediatric sample was closer to the actual epidemiologic data on pediatric deaths in Germany in 2011 (Figs. 2 and 3).¹

After being enrolled in SHPC, the probability of survival at 6 and 12 months was significantly higher in children compared to adults (56% versus 11%, $p < 0.001$, and 31% versus 5%, $p < 0.05$, respectively; Fig. 4). The median period of SHPC was longer in children (11.8 weeks; range, 0.5–58 weeks) than in adults (4.3 weeks; range, 0.5–52 weeks). However, the difference was not statistically significant. Six months from admission, the probability of being still under SHPC was higher in children than in adults (38% versus 8%, $p < 0.001$). After 1 year, no difference could be shown (9% versus 3%, NS).

The most common reason for the end of SHPC was the death of the patient. Fifty-seven adults (95%) and 18 children (45%) died by June 2012 ($p < 0.001$), 75% and 88% of them at home, respectively (NS). Another four children and no adult patient died within the follow-up period (overall pediatric deaths 55%, 90% of them at home; Fig. 4B). Termination of SHPC because of reasons other than death occurred more often in children (8 adult [13%] and 12 pediatric patients [12%, $p < 0.05$]), mostly because of stabilization of the patients' general condition (4/8 adults and 12/12 children). Three adults were transferred to a palliative care unit or a hospice, and 1 patient moved away.

Patients' functional status, symptoms, and medication

The different disease courses were reflected in differences in the adults' and the children's functional status. At the beginning of SHPC, the median ECOG score was 3.0 in the adult and 2.0 in the pediatric sample ($p < 0.05$; Fig. 5A). During the time interval between the first and the second assessment, the adults' ECOG score significantly worsened to a median of 4.0, while the children's median ECOG score was unchanged ($p < 0.001$; Fig. 5B).

For the adult patients, weakness (98%), fatigue/exhaustion (97%), pain (92%), lack of appetite (76%), depressive mood (65%), nausea/vomiting (60%), constipation (57%),

FIG. 1. Number of significant others directly affected by the patients' disease situation.

FIG. 2. Causes of death of **adults** who died of life-limiting diseases in Germany in 2011 ($n=780,883$; **A**) and diagnosis of the adult patients in the present study ($n=60$; **B**). Details in percent (%). The disease groups are ordered clockwise from top. In our sample, the following disease groups were identified: neoplasms (87%), nervous system (8%), circulatory system (2%), and digestive system (3%).

anxiety (57%), and dyspnea (54%) were the most burdensome symptoms (self-rating). The children's palliative medicine specialists identified epileptic seizures (55%), dyspnea (50%), impaired speech (48%), cognitive impairment (48%), pain (45%), weakness (40%), fatigue/exhaustion (30%), spasticity (25%), and nausea/vomiting (23%) as predominant symptoms.

An overview of the medication administered is shown in Table 2. Significant differences between the adult and the pediatric sample showed up concerning the use of nonopioid

analgesics, strong opioids, coanalgesics, antacids, and anti-convulsants.

Quality of life, symptom control, and caregiver burden

The QOL in the adults and children improved significantly through the involvement of the SHPC team as assessed by the primary caregivers (Fig. 6). The spouses rated the adult patients' QOL as significantly lower than the parents did for the children's QOL ($p < 0.05$). Both spouses and parents assessed

FIG. 3. Causes of death of **children** having died of life-limiting diseases in Germany in 2011 ($n=3,559$; except accidents, suicides, and crib death; **A**) and diagnoses of the pediatric patients in the present study ($n=40$; **B**). Details in percent (%). The disease groups are ordered clockwise from top. In our sample, the following disease groups were identified: neoplasms (25%), metabolism (18%), nervous system (33%), circulatory system (5%), and congenital diseases (20%).

FIG. 4. Period of care (A) and survival (B) of adults and children under SHPC (reference period: April 2011 to December 2012). SHPC, specialized home palliative care.

their own QOL as significantly improved after involvement of the SHPC team, without a significant difference between groups.^{16,17}

Despite the partly differing characteristics of the patients' main symptoms, symptom control under SHPC significantly improved in both samples as assessed by adult patients, spouses, and parents. These outcomes were confirmed by the MIDOS scores.^{16,17}

The caregiver burden as well as the levels of anxiety and depression was also significantly lowered in both groups after SHPC.^{16,17} No difference between groups was detected.

Discussion

This study reveals remarkable differences concerning SHPC for adults and children. First of all, there is an evident

FIG. 5. Adults' and children's functional status (ECOG) at the beginning of SHPC (A) and at the second measure point (B). ECOG, Eastern Cooperative Oncology Group; SHPC, specialized home palliative care.

TABLE 2. MEDICATION OF PATIENTS AND CHILDREN BEFORE INVOLVEMENT OF SPECIALIZED HOME PALLIATIVE CARE AND AT THE SECOND MEASURE TIME POINT

Group of drugs	Before involvement of SHPC (in %)		After involvement of SHPC (in %)	
	Adults	Children	Adults	Children
Nonopioid analgesics	68	23 ^a	67	28 ^a
Moderate opioids	12	0	2	3
Strong opioids	52	18 ^b	72	35 ^a
Coanalgesics	25	0 ^b	23	0 ^b
Corticosteroids	23	10	28	20
Antiemetics	30	18	33	20
Antacids	63	28 ^a	43	40
Anticonvulsants	13	43 ^b	12	50 ^a
Sedatives/anxiolytics	23	28	43	40
Antidepressants	18	5	18	0
Laxatives	27	15	37	23
Antibiotics	2	3	2	5
Diuretics	17	10	18	8
Cardiovascular drugs	23	13	13	13
Neuroleptics	3	5	5	3

^a χ^2 test [two-tailed]; Bonferroni-corrected $p < 0.0000625$.

^b χ^2 test [two-tailed]; Bonferroni-corrected $p < 0.003125$.
SHPC, specialized home palliative care.

discrepancy in the predominant underlying diseases as well as in the disease distribution of SHPC patients as compared to the epidemiologically ascertained causes of death in Germany.¹ The high percentage of oncologic diseases in the adult patients of our survey corresponds to the outcomes of former SHPC surveys.^{19–21} Therefore, our outcomes do not seem to be caused by a referral bias to the SHPC team of a university hospital. Patient selection in the adult cohort reflects the historical bias of adult palliative care toward cancer patients,²² while the spectrum of diseases cared for in pediatric SHPC is much larger and appears closer to clinical reality.

Children's survival time under SHPC was more variable and on average markedly longer (with lower and more stable

ECOG scores) compared to adult patients. This might be due to the fact that patients with mainly oncologic diseases in the adult group have a different disease progression compared to nononcologic, predominantly rare and congenital diseases that were prevalent in the pediatric cohort. The latter diseases show highly variable courses, requiring a specific knowledge over a multitude of disorders, some of which are poorly characterized.^{23–27} In our experience, the children's courses of disease are often characterized by recurrent crises, requiring frequent support by the SHPC team, which are interrupted by more stable phases with less SHPC contact. In contrast, SHPC for adult patients often starts in an acute phase late in the disease course with intense involvement of the SHPC team and a rather short time to death.

The characteristics of the patients' main symptoms also differed. In children, dyspnea was more prevalent than pain, and neurologic symptoms such as epileptic seizures, impaired speech, and spasticity were predominant. This is likely a consequence of the different disease spectra, and points to the increased need of specific skills in treating neurologic symptoms in pediatric SHPC.

The noted differences in medication patterns between adult and pediatric SHPC were likely due in part to the differences in symptom distribution (e.g., for anticonvulsants). However, the consistently lower levels of analgesic medication (especially nonopioids and coanalgesics) in children raises the question of a possible underrecognition of symptoms in neurologically impaired children²⁸ or underutilization due to off-label use.^{29,30}

Family dynamics appears to play a major role in pediatric palliative care.³¹ The numbers of significant others directly affected by the patients' disease was significantly higher in the pediatric sample, which increases the risk of having their needs unattended.^{19,32–35}

Our results impressively show a positive impact of SHPC on the quality of life and care for the adult patients and their caregivers as well as the children's caregivers. According to the parents' ratings, this seems also to hold true for the pediatric patients, despite the lack of self-assessment. This is in agreement with previously published results.^{6,36–38} The burden of care for spouses and parents was significantly

FIG. 6. Adults' (A) and children's (B) quality of life according to their primary caregivers' ratings. Assessed by NRS. SHPC, specialized home palliative care; NRS, numeric rating scales.

reduced, and a very high percentage of patients in both groups were able to die at home.^{39,40}

This study has several limitations. The collected data of the pediatric sample are based solely on the assessment of the parents and the attending palliative medicine specialists, while more than half of the adult patients were able to provide a self-assessment.⁴¹ In addition, although not a member of the SHPC team, the interviewer was not blinded to the responses and might therefore unconsciously have influenced their direction. Since this study was conducted at a single center, only a small absolute number of patients could be enrolled. Therefore, no control group could be included and generalizability is limited. On the positive side, due to the conduct of the survey in dialogue form, a high response rate was achieved and no missing data arose.

Conclusion

The data show a remarkable effectiveness of SHPC in improving QOL in adult and pediatric patients and their primary caregivers.^{16,17} Important differences were observed between adults and children concerning disease and symptom spectra, course and duration of SHPC, administered medication, survival time, and family dynamics. These findings could form the basis for the development of age-group specific models of care that address the special needs of, for example, young children with predominantly non-oncologic disorders. Adequate reimbursement schemes for SHPC will also need to take these differences into account.

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Gesa Groh developed the conception and design of the study, collected, analyzed and interpreted the data, and drafted the manuscript. Gian Domenico Borasio and Monika Führer significantly contributed to the conception and design of the study, analyzed and interpreted the data, and revised the manuscript. Berend Feddersen made contributions to this study in acquisition of data and also revised the manuscript. All authors approved the final version of the article.

Author Disclosure Statement

No competing financial interests exist.

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