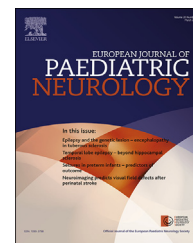




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Official Journal of the European Paediatric Neurology Society



Original article

Symptoms and management of pediatric patients with incurable brain tumors in palliative home care



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ARTICLE INFO

Article history:

Received 23 July 2015
Received in revised form
18 November 2015
Accepted 6 December 2015

Keywords:

Palliative care
Children
pediatric
Home care
brain tumors

ABSTRACT

Introduction: Brain tumors have the highest disease-related mortality rate of all pediatric cancers. The goal of this study was to determine whether all children with incurable brain tumors cared for by a pediatric palliative care team in a home setting suffer from the same symptoms towards the end of their lives or whether there are differences between the tumor localizations with implications for palliative care.

Patients and methods: This study was conducted as a retrospective, single center chart review including all patients treated between January 1st 2000 and December 31st 2013.

Results: 70 children, adolescents and young adults were included in the analysis. Symptom burden was high with a mean number of symptoms of 7.2 per patient. 74% of the symptoms already existed one week before death. Within the last week of life, impaired consciousness (75.7%) most often occurred. Furthermore, symptoms considerably depended on tumor localization. Patients with supratentorial tumors presented more frequently with seizures ($p < 0.05$), coma ($p < 0.01$), nausea and emesis ($p < 0.01$). Ataxia ($p < 0.001$) occurred most frequently in infratentorial tumors and speech disturbances ($p < 0.05$), cranial nerve paralysis ($p < 0.001$), and tetraparesis ($p < 0.001$) in brain stem tumors. 84.3% of the patients needed analgesics, only 64.4% WHO class III analgesics. Anticonvulsants were given more often in supratentorial tumors ($p < 0.01$).

Conclusions: Caring for a dying child suffering from a brain tumor needs increased awareness of the neurological deterioration. The symptom pattern strongly depends on the tumor localization and significantly differs between supratentorial, infratentorial and brain stem tumors.

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Abbreviations: PCA, patient-controlled analgesia; PEG, percutaneous endoscopic gastrostomy; PPCT, pediatric palliative care team.

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<http://dx.doi.org/10.1016/j.ejpn.2015.12.004>

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1. Introduction

Pediatric brain tumors are a quite heterogeneous group of tumor entities. Making up more than 20% of all newly diagnosed pediatric cancers, they are the second most common neoplasms in children. In Germany, approximately 400 children and adolescents are diagnosed with primary brain tumors per year. Despite multi-modal treatment and significantly improved survival rates, approximately 30% of them will ultimately die from their disease.¹

Previous research on children dying of cancer has documented substantial suffering,^{2–6} but a systemic evaluation of the distinct issues of each tumor group is missing. Hence, practice of pediatric palliative care is still based primarily on clinical experience and/or adaptation of best practice delivered in adults. With the aim of the best possible quality of life, local office-based pediatricians and specialized pediatric palliative care teams (PPCT) provide end-of-life care to those children and their families in the home setting.^{7,8}

As is known from adult studies, the end-of-life phase of brain tumor patients is characterized by a high symptom burden and progressive neurological deterioration which is difficult to treat.^{9–13} However, palliative care of children substantially differs from that in adults,¹⁴ but very few studies concerning the distinct issues that children with brain tumors and their families face, are available.^{15,16} Furthermore, a thorough evaluation of differences in the symptom pattern between the distinct tumor localizations is completely lacking. A better understanding of the end-of-life phase of these children and the affected families will help to more successfully address their needs to avoid hospitalization, thus maintaining the maximum quality of life. Furthermore, it will support pediatricians, families, and caregivers in anticipating and managing these difficult situations.

The goal of this study was to determine whether all children with incurable brain tumors cared for by a pediatric palliative care team in a home setting suffer from the same symptoms towards the ends of their lives or whether there are differences between the tumor localizations with implications for palliative care. Additionally, our data allows a resource estimation of intensity of care across tumor types by combining the acquired data on clinical characteristics, supportive treatment, as well as medical devices and equipment.

2. Patients and methods

This study was conducted as single center analysis at Children's University Hospital, Dusseldorf, Germany, between January 1st 2000 and December 31st 2013.

Patients were included who fulfilled the following criteria: previous anticancer treatment (including surgery alone), diagnosis of an incurable, progressive primary brain tumor, discharge from hospital, and home care provided by the specialized pediatric palliative care team of this institution. Patients who died after December 31st 2013 and patients with primary spinal tumors were excluded from this analysis. No other exclusion criterion was defined.

Two physicians of the PPCT retrospectively analyzed the records. All patient charts were assessed for demographic data

and symptoms with respect to time of onset and management. For the sake of clarity, we summarized the neurological impairments symptom-oriented (swallowing and speech difficulties, visual impairment, cranial nerve paralysis, hemiparesis, diplegia, tetraparesis, spasticity, ataxia, incontinence/retention, somnolence, coma). Psychological symptoms were not evaluated as these symptoms were not sufficiently documented. Treatment was summarized drug group-oriented (dexamethasone, analgesics, anticonvulsives, antiemetics, hydration, nutrition, other drugs) for the same reason. The medical equipment available to the patients (wheelchair, homecare bed, stairlift, PCA pump, PEG tube) was recorded.

All patients were categorized according to three tumor localizations (supratentorial (s), infratentorial (i), brain stem (b)) according to their primary tumor or relapse site to particularly analyze symptom patterns resulting from these distinct tumor sites.

Time under investigation was defined as time between the decision for palliative home care and death.

The study was approved by the local ethics committee.

Two \times 3 contingency tables were analyzed with χ^2 -test. Additional pairwise comparisons between tumor localizations were performed with Fisher's exact test (no adjustment for multiple testing). The statistical analysis was performed using the SAS[®]9.2 program (SAS Institute Inc., Cary, NC, USA).

For the resource estimation we scored the symptoms as follows: Tetraparesis (10), Coma (9), Somnolence (8), Pharyngeal palsy (7), Hemiparesis (7), Speech disturbance (6), Spasticity (6), Dyspnea (6), Visual disturbance (5), Diplegia (5), Seizures (5), Cranial nerve paralysis (4), Sensory disturbance (4), Pain (4), Nausea/emesis (4), Urine incontinence/retention (3), Rectal incontinence/retention (3), Ataxia (2), Inappetence (2). If a symptom was recurring, its score was multiplied by three, if it was persistent, its score was multiplied by nine.

Additionally, we scored the treatment as follows: PCA pump (10), Analgesics WHO III (9), Parenteral nutrition (7), Analgesics WHO II (5), PEG/feeding tube (5), Anticonvulsive treatment (4), Antiemetics (3), Intravenous hydration (2), Supportive treatment (2), Analgesics WHO I (1), Dexamethasone (1). If a treatment was administered for longer than one week, its score was multiplied by three, if it was administered for longer than one month, its score was multiplied by nine.

3. Results

3.1. Patient characteristics

In the evaluation period of January 1st 2000 to December 31st 2013, a total of 70 children, adolescents and young adults meeting the inclusion criteria were cared for by the PPCT at home. The mean duration of care was 73 days (range 3–838), the mean number of home visits 7 (range 1–43). Most patients (65; 92.9%) died at home. The demographic characteristics are given in [Table 1](#). 43 (61.4%) patients presented with supratentorial, 11 (15.7%) with infratentorial and 16 (22.9%) with brain stem tumors.

The majority of patients (66, 94.3%) were provided with one or more medical devices, 2 patients required home ventilation (see [Table 2](#)).

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