



Interventions in the operating room for children near end of life: A multidisciplinary approach

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ABSTRACT

Introduction: Pediatric surgeons are often involved in the management of severely or terminally ill patients. However, articles addressing their specific roles in the context of palliative care are almost inexistent. We sought to characterize the involvement of pediatric surgeons caring for children near end of life.

Methods: Chart review of children who had a procedure under general anesthesia within 6 months of their death over a five-year period at a tertiary children's hospital (excluding traumas and neonatology cases). In addition to demographic and clinical data, we recorded the aim of the procedures performed, the involvement of the palliative care service, and presence of DNAR orders.

Results: The analysis included 83 patients (mean age: 8 years). Forty-four children had more than one procedure (range 2–10). Pediatric palliative care service was involved in 66 cases (80%). A majority of patients had cancer (50%), and the most frequent cause of death was oncologic progression (46%). Ten patients died of a complication following their intervention. The aim of the procedure was palliative in 48 cases (29 for symptoms control and 19 to facilitate care), diagnostic in 16, and curative in 19. Forty-five procedures were performed urgently and 14 despite DNAR orders.

Conclusion: Surgeon involvement with children near end of life is not infrequent. The procedures performed are varied and can be categorized according to their aim. Lack of formal palliative care training by surgeons highlights the need for increased collaboration with palliative care services to provide children optimal care when they need it most.

Level of Evidence: IV.

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While palliation was a main goal of surgery for most of its history [1], modern surgeons aim to cure, to restore health and to improve their patients' conditions permanently. Assessment of outcomes in surgery is frequently based on survival rate and functional outcomes. Morbidity and mortality conferences are a core educational tool in surgery and exemplifies the traditional surgeon's goals of prolonging life rather than improving the quality of life left [2,3]. It is not surprising then that involvement in palliative care has not been commonly embraced by surgeons [4]. This may be in part due to typical character traits [5], but could also stem from lack of formal exposition to the benefits of palliative care as a specialty. Within the last decade, the American College of Surgeons has actively promoted palliative care in modern surgery [6] and in an era where patient-centered decision making is gaining in

importance, palliative care is considered by many not merely an option but rather as the new standard of care for patients facing severe, potentially fatal conditions.

Benefits of palliative care for surgical patients have been clearly documented. For the institutions supporting the role of palliative care services, significant advantages in terms of cost and length of stay have been demonstrated [7]. However, the literature on the subject addresses quasi-exclusively the adult population and few studies have assessed the specific involvement of surgeons for children near the end of life.

The objective of this study was to identify and characterize palliative care patients for whom the surgical team was involved.

1. Methods

This is a single institution retrospective study performed at CHU Ste-Justine, a free-standing children and obstetrics tertiary hospital of 450 beds in Montreal, Québec. We included all patients who underwent a

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procedure under general anesthesia (GA) within 6 months of their death. This was done using 1) the archive services of our institution and 2) the pediatric palliative care service (PPCS) database which keeps a record of all the patients consulted by this service. All patients younger than 21 years at time of diagnosis were included. Trauma cases, neonatology patients and children receiving GA for radiation therapy or for diagnostic imaging were excluded. The study covered a 7-year period from 2009 to 2016.

Data collection included: demographic data, primary diagnostics, age at the time of the intervention, number of procedures within 6 months prior to death, aim of the procedure, surgical details of the procedure, cause and place of death, presence of “do not attempt resuscitation” (DNAR) orders and involvement of PPCS.

Demographic data are expressed as number and proportion (%) for categorical data and mean (\pm standard deviation) or median (range) for continuous data. Descriptive statistics using Fisher exact test or chi-square as appropriate were used to compare patients with or without PPS involvement.

2. Results

We identified 94 patients meeting the inclusion criteria. There was incomplete or missing data for 11 patients that had mainly been treated elsewhere. Consequently, the analysis included 83 patients with a median age of 6.5 years at time of death (range 4 months to 23 years).

2.1. Diagnosis

We categorized primary diagnosis as follows: 42 patients had cancer (51%), 13 had neurologic conditions (16%), 11 had a cardiac disease (13%), 6 had gastro-intestinal disease (7%), 5 had pulmonary disease (6%) and 4 patients had congenital metabolic disease (5%). The remaining two patients both had a poly-malformative syndrome within the VACTERL spectrum.

2.2. Involvement of the PPCS team

A majority of these patients were known from the PPCS of our institution (66/83; 79.5%). The PPCS team is readily available at any given time. It is composed of two clinical nurses, of several medical subspecialists (pediatricians, hemato-oncology, neonatology, surgery, and obstetrics-gynecology) and of one medical psychologist. It collaborates actively with various health care professionals (physical and occupational therapy, social workers, spiritual consultants and psychologists). Weekly interdisciplinary clinical meetings are held and provide an opportunity for clinical teachings and allow discussion of more challenging cases.

2.3. Procedures under GA

All procedures were performed in the operating room with a pediatric anesthesiologist managing the GA. A total of 197 procedures under GA were performed for these 83 patients within 6 months of their deaths (median 2, range 1–10). Forty-four patients had more than one

Table 2

Definitions and examples of each category of intervention.

Curative	Intervention to cure or to offer long term improvement of primary diagnosis Examples: Liver transplant, cardiac surgery, tumor resection, metastasectomy
Diagnostic	Diagnostic intervention addressing the primary diagnosis or subsequent conditions Examples: Bronchoscopy, tumor biopsy, intestinal biopsy in context of GVH disease
Palliative to facilitate care	Intervention to support care providers in management of the patient's conditions Examples: Gastrostomy, vascular access
Palliative for symptom control	Intervention aimed directly at improving patient's wellbeing Examples: VPD shunt revision, cystoscopy for hemorrhagic cystitis, effusion drainage

GVH = Graft versus host, VPD = ventriculo-peritoneal derivation.

procedure and 55 patients had at least one procedure within 3 months of their death (median 1, range 0–6).

During the study period, a total of 85,339 cases were performed in the operating room at the CHU Ste-Justine (excluding gynecology-obstetrics and dental surgery). Thus, even when performing a rough estimate, the relative frequency of these types of procedures is less than 1% on a yearly basis.

For the purpose of this study, we further analyzed the last procedure (closest to time of death) each patient underwent. Pediatric specialties performing these procedures included: general surgery (29), neurosurgery (9), otorhinolaryngology (7), cardiac surgery (7), gastroenterology (7), interventional radiology (7), urology (6), respiratory (4), cardiology (3), dentistry (2), orthopedics (1) and oncology (1) for a total of 83 procedures analyzed.

The aim of the last procedure was categorized as follows: palliative, diagnostic or curative (Table 1). The palliative category was further divided into palliative procedure to facilitate care or palliative procedure to alleviate symptoms. Table 2 presents typical examples of each category. A significant proportion of procedures were performed urgently ($n = 38, 46\%$) and 26 of these involved children admitted to the pediatric intensive care unit (PICU). Among the 45 cases performed electively, 21 patients were treated as outpatients.

2.4. DNAR orders

DNAR order were clearly documented for 49 patients overall. For 14 patients, the DNAR orders were established and documented prior to the procedure under GA with a median time between DNAR decision and procedure of 68 days (range 1 day – 8 years). For these 14 patients, the procedure took place despite the DNAR orders following discussion between the family, the PPCS and the treating physician to agree on management in case of acute vital deterioration during the procedure.

2.5. Cause and place of death

The median time interval between last intervention and time of death was 56 days (range: 0 days – 6 months). The cause of death was most frequently attributed to progression of the oncologic condition. Importantly, for 10 patients the cause of death was attributed to

Table 1

Aim of the last procedure performed for each patient, by category.

	Surgery < 3 months prior to death	Surgery 3–6 months prior to death	Total
Palliative	31	17	48 (58%)
To facilitate care	9	10	19
For symptom control	22	7	29
Diagnostic	14	2	16 (19%)
Curative	10	9	19 (23%)
Total	55	28	83

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