Not Just Little Adults: A Review of 102 Paediatric Ethics Consultations

The American Academy of Pediatrics statement on institutional ethics committees highlights the importance of paediatric ethics consultation. However, little has been published on actual experience with ethics consultation in paediatrics. The objective of this study was to review and describe topics covered by a large retrospective sample of clinical ethics consultations in paediatric medicine. Methods: We reviewed ethics consultations involving patients of <18 years of age from January 2005 to July 2013 at one institution. Descriptive statistics of the patient population, the reason for the ethics consultation and the consultant’s perceived contribution to the case were generated. Subgroups of patients were compared based on demographic and clinical characteristics using Wilcoxon's rank sum tests, chi-square tests and logistic regression models. Results: Most of the 102 eligible consultations originated from intensive care units and were requested by attending physicians. The most frequent topic leading to consultation was end-of-life issues. Both younger age and male sex were associated with consults for end-of-life issues (p < 0.001 and p = 0.010). Conclusion: This analysis provides important information describing the type of consults requested in paediatric medicine, which is necessary given the movement towards professionalising clinical ethics consultation. Further empirical research is needed on ethics consultation in paediatrics. Acta Paediatr. 2015;104(5):529-534

Talking with Parents about End-of-Life Decisions for Their Children

Retrospective studies show that most parents prefer to share in decisions to forgo life-sustaining treatment (LST) from their children. We do not yet know how physicians and parents communicate about these decisions and to what extent parents share in the decision-making process. Methods: We conducted a prospective exploratory study in 2 Dutch University Medical Centers. Results: Overall, 27 physicians participated, along with 37 parents of 19 children for whom a decision to withhold or withdraw LST was being considered. Forty-seven conversations were audio recorded, ranging from 1 to 8 meetings per patient. By means of a coding instrument we quantitatively and qualitatively analyzed physicians' and parents' communicative behaviors. On average, physicians spoke 67% of the time, parents 30%, and nurses 3%. All physicians focused primarily on providing medical information, explaining their preferred course of action, and informing parents about the decision being reached by the team. Only in 2 cases were parents asked to share in the decision-making. Despite their intense emotions, most parents made great effort to actively participate in the conversation. They did this by asking for clarifications, offering their preferences, and reacting to the decision being proposed (mostly by expressing their assent). In the few cases where parents strongly preferred LST to be continued, the physicians either gave parents more time or revised the decision. Conclusions: We conclude that parents are able to handle a more active role than they are currently being given. Parents' greatest concern is that their child might suffer. Pediatrics. 2015;135(2):e465-e476
Initial Development and Psychometric Testing of an Instrument to Measure Quality of Children’s End-of-Life Care

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The field of pediatric palliative care is hindered by the lack of a well-defined, reliable, and valid method for measuring the quality of end-of-life care. Methods: The study purpose was to develop and test an instrument to measure mothers’ perspectives on the quality of care received before, at the time of, and following a child’s death. In Phase 1, key components of quality end-of-life care for children were synthesized through a comprehensive review of research literature. These key components were validated in Phase 2 and then extended through focus groups with bereaved parents. In Phase 3, items were developed to assess structures, processes, and outcomes of quality end-of-life care then tested for content and face validity with health professionals. Cognitive testing was conducted through interviews with bereaved parents. In Phase 4, bereaved mothers were recruited through 10 children’s hospitals/hospices in Canada to complete the instrument, and psychometric testing was conducted. Results: Following review of 67 manuscripts and 3 focus groups with 10 parents, 141 items were initially developed. The overall content validity index for these items was 0.84 as rated by 7 health professionals. Based on feedback from health professionals and cognitive testing with 6 parents, a 144-item instrument was finalized for further testing. In Phase 4, 128 mothers completed the instrument, 31 of whom completed it twice. Test-retest reliability, internal consistency, and construct validity were demonstrated for six subscales: Connect With Families, Involve Parents, Share Information With Parents, Share Information Among Health Professionals, Support Parents, and Provide Care at Death. Additional items with content validity were grouped in four domains: Support the Child, Support Siblings, Provide Bereavement Follow-up, and Structures of Care. Forty-eight items were deleted through psychometric testing, leaving a 95-item instrument. Conclusions: There is good initial evidence for the reliability and validity of this new quality of end-of-life care instrument as a mechanism for evaluative feedback to health professionals, health systems, and policy makers to improve children’s end-of-life care. BMC Palliat Care. 2015;14(1):1

Full text of this article is freely available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4305389/

Metric Units and the Preferred Dosing of Orally Administered Liquid Medications

American Academy of Pediatrics

Medication overdoses are a common, but preventable, problem among children. Volumetric dosing errors and the use of incorrect dosing delivery devices are 2 common sources of these preventable errors for orally administered liquid medications. To reduce errors and increase precision of drug administration, milliliter-based dosing should be used exclusively when prescribing and administering liquid medications. Teaspoon- and tablespoon-based dosing should not be used. Devices that allow for precise dose administration (preferably syringes with metric markings) should be used instead of household spoons and should be distributed with the medication. Pediatrics. 2015;135(4):784-787

Full text of this article is freely available at http://pediatrics.aappublications.org/content/135/4/784.full.pdf+html
Patient-Controlled Analgesia for Children at Home
Mherekumombe M, Collins J

Pain is a common and significant symptom experienced by children with advanced malignant disease. There is limited research on pain management of these children at home. Objectives: To describe and review the indications for using patient-controlled analgesia (PCA) in the form of a Computerized Ambulatory Drug Delivery device (CADD®) in the home setting. Methods: A retrospective chart review was conducted in children discharged home with opioid infusions using a CADD. Charts from January 2008 to February 2012 were surveyed. Results: Thirty-seven CADDs were dispensed during the study period, and of these, 33 were prescribed for patients with cancer-related pain. A third of the CADDs were commenced at home and almost all PCA CADDs were used for end-of-life care. Hydromorphone was the most commonly prescribed opioid. Patients remained at home and pain control was achieved by either increasing the opioid dose or switching the opioid and using adjuvant therapy. Sixteen patients were readmitted to hospital from home and three admissions were related to pain. The median duration on a PCA CADD at home was 33.7 days (range, 1-150 days), and the mean morphine equivalent dose was 2.13 mg/kg/day. Conclusion: PCA with a CADD can be used to manage pain in the home setting. Dose adjustments and opioid switches were performed with no adverse incidents. Am J Hosp Palliat Med. 2015;49(5):923-027

Survival and Quality of Life for Children with End-Stage Heart Failure Who Are Not Candidates for Cardiac Transplant

Some pediatric patients referred for heart transplant (HTx) are sub-optimal candidates. Their outcomes without HTx are presumed to be dismal, but have not been well described. Knowledge about their outcomes is critical when weighing the risks between a high-risk transplant and “terminal” palliation. Methods: We retrospectively reviewed all HTx referrals from January 2005 to July 2013. We excluded those who were listed for HTx, or who were denied HTx due to being “too well,” seeking only those who were in need of but not suitable for HTx. End-points included mortality and length of survival. Results: Of 212 referrals, 39 (19%) (age 0 to 19 years, median 3.5 years) were denied HTx for reasons other than being too well. Twenty-eight (72%) had palliated congenital heart disease. Overall mortality during the follow-up period was 38% (n = 15) with a median follow-up time of 195 days (8 to 2,832 days). Ten patients received subsequent cardiac surgery with 1 death (10%) and median follow-up of 2.6 years. Mortality risk was not influenced by age, weight, growth failure, congenital heart disease or single-ventricle physiology. Mechanical ventilation (hazard ratio 6.31, p = 0.001) and inotrope dependence (hazard ratio 4.79, p = 0.006) were associated with the highest risk of mortality. Quality of life was measured with the PedsQL cardiac module and completed by 11 of 16 eligible patients with an overall average score of 70.2 ± 23.9. Conclusions: An advanced heart failure program can achieve satisfactory results for pediatric patients who are not suitable candidates for HTx. For some children, high-risk palliative surgery can result in better outcome than high-risk HTx. Mortality was related to the degree of heart failure at presentation rather than underlying heart disease. J Heart Lung Transplant. 2015 Jan 16: epub ahead of print.
Improved Quality of Life at End of Life Related to Home-Based Palliative Care in Children with Cancer
Friedrichsdorf S, Postier A, Dreyfus J, Osenga K, et al

Nearly 2000 children die due to a malignancy in the United States annually. Emerging data suggest that home is the desired location of care for children with cancer at end of life. However, one obstacle to enrollment in a pediatric palliative care (PPC) home care program may be fear that distressing symptoms at end of life cannot be adequately managed outside the hospital. Objective: To compare the symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a PPC home care program (PPC/Oncology) with that of those who died without exposure to the PPC program (Oncology). Methods: We conducted a retrospective survey study of a cohort of bereaved parents of children who died of cancer between 2002 and 2008 at a U.S. tertiary pediatric institution. Results: Sixty bereaved parents were surveyed (50% PPC/Oncology). Prevalence of constipation and high distress from fatigue were more common in the PPC/Oncology group; other distressing symptoms were similar between groups, showing room for improvement. Children who received PPC/Oncology were significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%). Conclusions: This is the first North American study to assess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a PPC home care program appear to have improved quality of life and are more likely to die at home. J Palliat Med. 2015; 18(2):143-150