

## Palliative medicine

### G169 CONTRAST BETWEEN PROTOCOL AND PRACTICE IN THE PRESCRIPTION OF OPIOIDS IN PAEDIATRIC INPATIENTS: AN AUDIT

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**Aim:** To compare current practice with local guidelines for prescribing opioids in children based on the WHO pain ladder.

**Background:** An audit of severe pain management in 2005 demonstrated inadequate documentation of pain assessment and inaccuracies in opioid prescribing. Following dissemination of these findings we are re-auditing practice.

**Methods:** Patients that had received opioids were identified from ward-controlled drug record books. Using the same questionnaire as the 2005 audit, management of the episodes was audited against local guidelines.

**Results:** The audit is ongoing. So far, 27 patients who received strong opioids have been identified. 20 (74%) had acute pain, six of whom were managed by the acute pain team using patient controlled analgesia systems. Five (19%) were palliative care patients with pain and two (7%) received opioids for non-pain indications. We have identified four gaps in practice: failure to administer laxatives preemptively; prescribing incorrect doses of regular opioids; prescribing opioids for use on an as required basis only; and paucity of documentation of the assessment of pain.

**Conclusions:** There remain deviations from recommended practice in the management of severe pain in children at our tertiary paediatric inpatient unit. We plan to implement a teaching intervention and repeat this audit.

### G170 END OF LIFE PLANNING IN A REGIONAL CHILDREN'S HOSPICE SERVICE: REVIEW OF CURRENT PRACTICE AND A FRAMEWORK FOR IMPROVEMENT

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**Aim:** Children accepted on to hospice caseloads are those where there is a reasonable expectation that the child may die before adulthood. These children may have long periods of stable health, but are at risk of rapid deterioration or sudden death, which, despite a diagnosis of a life-limiting condition, may overtake a family's preparation for the death of their child. Our hospice undertook a review of all children's notes, and consultation with their hospice key workers, to identify those where there was clear evidence of advance planning for any possible emergencies or death of the child.

**Method:** Structured notes review and case discussion of 98 children attending two hospice sites, covering several primary care trust and district general hospital catchment areas.

**Results:** Clear documentation of resuscitation discussions were in place for 26 of 98 (26.5%), of which 10 specifically requested full resuscitation. Children without evidence of a decision to limit resuscitation would have been fully resuscitated in any emergency. Thus only 16 children in the hospice had written instructions to allow a natural death to occur without resuscitation. Of these, four plans were at least 1 year old and had not been updated. 18 of 26 (69%) had been written by hospice staff, not by the child's paediatricians. Of the 82 children where full resuscitation would be expected by the family, 13 (16%) had emergency management plans for anticipated problems (primarily convulsions or respiratory distress), all written by the child's paediatricians. Three of these plans needed updating/clarification, and an additional four children were identified who urgently needed clear emergency management plans for common complications, where none existed in their notes.

**Conclusions:** In order to provide appropriate care for children whose health deteriorates while in a hospice, sensitive and timely

discussions about potential complications and their management need to occur, and to be clearly documented. We developed a tool to help hospice staff identify the specific areas for discussion that would be most appropriate for an individual child and family, and to empower staff to open discussions and support families through this process. We worked closely with colleagues in hospital and community services to develop guidance notes and documentation to be shared across all sites. Results of follow-up will be presented.

### G171 DOCTORS' KNOWLEDGE AND AWARENESS OF TISSUE AND ORGAN DONATION IN CHILDREN

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**Background:** Organ and tissue transplants are procedures that change lives for the recipient, and donation is a chance for grieving families to bring something good out of a tragic situation. Organs can be used from children who die in hospital but in addition heart valves and eyes can be collected up to 48 h after death, increasing the number of children who can donate. Specialist transplant co-ordinators are always available to talk to interested families but the initial approach must be made by an involved clinician.

**Aims:** To find out whether doctors who work with children have basic knowledge of tissue and organ donation, which would allow them to discuss the subject with families.

**Methods:** A questionnaire was designed to assess knowledge of basic information that doctors should have before approaching families to discuss tissue and organ donation. This was piloted and then given to doctors of all grades working in a district general hospital as paediatricians or in the intensive care or emergency departments.

**Results:** All respondents knew that children could donate organs through the national register although only half were aware that premature babies were not eligible to donate. 73% knew that children could not donate blood and 60% knew that children could not donate bone marrow through national registries. Only 50% knew that there was no lower age limit for donating heart valves and none knew the correct age limit for donating eyes (3 years). 93% were aware that it was possible to donate tissues if a patient died outside hospital; however, 30% also thought incorrectly that out-of-hospital death was compatible with organ donation. 90% were aware that people with HIV were unable to donate, 37% were unclear about donation in children with cancer. Only 7% and 14% respectively knew how much tissue was removed during the donation of eyes and heart valves; however, about half of respondents for each type of tissue correctly described the appearance of the body after tissue collection has taken place. 83% knew that families are given information about the ultimate use of organs, 67% were aware that this was the case after tissue donation.

**Conclusions:** Most doctors surveyed lacked basic knowledge about organ or tissue donation in children. All paediatricians are involved in the care of dying children. Awareness could be increased during postgraduate education.

### G172 END OF LIFE SYMPTOM PROFILES IN CHILDREN DYING FROM MALIGNANT AND NON-MALIGNANT CONDITIONS

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**Aim:** To ascertain the frequency of significant symptoms in children with malignant and non-malignant conditions during their end of life care.

**Method:** A retrospective case notes review of a series of 130 children, who died over a 2-year period. We looked at all the symptoms reported in the last month of life as well as identifying each child's most predominant symptom.

**Results:** 66 of the 130 children had cancer and 64 had non-cancer diagnoses (35 children had neurometabolic or progressive neurological disease, nine neuromuscular disease, eight congenital abnormalities, six cardiorespiratory diagnoses, three epidermolysis bullosa and three with other condition). Of the 66 children with cancer, 64 (97%) had pain, 36 (55%) reported nausea and vomiting, 15 (23%) had constipation, 15 (23%) had one or more seizures and 12 (18%) had breathlessness. In the non-cancer group, 34 (53%) had pain, 10 (16%) had nausea and vomiting, five (8%) reported constipation, 24 (38%) had one or more seizures and 25 (39%) had breathlessness. This group had 20 (31%) children with excess secretions (vs seven (11%) in the cancer group) and 11 (17%) children with spasms (vs one (2%)). Both groups reported a similar frequency (17%) of agitation. Pain was the most predominant symptom in 58 (89%) of the 66 children with cancer, against 17 (27%) of the 64 with non-cancer disease ( $p < 0.05$ ). Breathlessness was also most prominent in 17 of the non-cancer children. Seizures were most problematic in 14 (22%) of the non-cancer children, unsurprisingly, 13 of them had neurological disease.

**Conclusions:** Our findings suggest that children with non-malignant disease have very different symptoms from children with malignant disease. This study indicates that pain is much less problematic in the non-cancer children. As parents are anxious about pain at the end of life, these data can help better inform them on the basis of their child's underlying diagnosis. It also helps clinicians anticipate symptoms, plan interventions and direct future research.

#### G173 IS THE PATTERN OF REFRACTORY ACUTE LYMPHOBLASTIC LEUKAEMIA CHANGING?

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**Background:** Over the past 10 years, survival rates in children with acute lymphoblastic leukaemia (ALL) have continued to

improve. At the same time, children with refractory ALL are increasingly being offered further therapeutic interventions. Has this changed the course of refractory ALL and palliation of these children?

**Aim:** To retrospectively review all children (<18 years) who died from refractory ALL over a 10-year period. To determine the pattern of the disease, including the palliative care phase and the palliative symptoms experienced.

**Method:** Retrospective review of all children (<18 years) with refractory ALL who died from January 1997 to December 2007. Review of the child's date of confirmed diagnosis, date of death and date of confirmation of a refractory relapse to standard therapies (not including clinical phase 1 and 2), which is defined as "palliation", was documented. Symptoms experienced and blood product requirements during palliation were recorded.

**Results:** Over the period from 1997 to 2007, 52 children with ALL died in our institution, of those, 23 children died on treatment, 28 died from refractory disease and one child died from chronic graft versus host disease. Children with refractory disease over the 10-year period lived on average 30 months longer in 2007 compared with 1997. However, during their 'palliative' phase, their length of survival fell by 50% (from 6 to 3 months) and symptoms and blood product requirements increased.

**Discussion:** Refractory ALL, among other childhood cancers, is beginning to exhibit a chronic illness pattern due to increasing therapeutic interventions with implications to long-term symptom control. With the palliative phase being shorter and increasing symptom support required, the need for interfacing and overlapping services between paediatric palliative care and paediatric oncology teams is emphasised. A paediatric palliative care service needs to be responsive to ensure quality symptom control and care in the family's place of choice; ensuring communication and co-ordination of care and services. The role and co-ordination of blood product support needs to be considered.