

## Palliative medicine

### G86 USE OF STRONG OPIOIDS AT THE END OF LIFE IN CANCER PATIENTS

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**Objective:** To investigate and quantify use of strong opioids at the end of life in children with cancer.

**Design and Setting:** Retrospective review of case notes at a large cancer centre in Sutton, Surrey, UK.

**Subjects:** Children aged 1 month–19 years under the care of the paediatric oncology outreach service at the study centre, who had reached the palliative phase of their illness and died between 01 January 2001 and 01 January 2003.

**Results:** 40 cases were available for analysis. Thirty five patients received strong opioids during the last illness (brain/spinal n = 10; solid tumours n = 15; leukaemias n = 10). Diamorphine was the most common preparation used, given via the intravenous route. Dose and duration of treatment varied widely. Weights were available for 25/35 patients and for this group the median dose on the day strong opioids were started was 1.0 mg/kg/day oral. Morphine equivalent (OME) (mean 6.2 mg, 0–58.2 mg), and on the last day of life was 4.8mg/kg/day OME (mean 55.8 mg, range 0–1100 mg).

**Conclusions:** Strong opioids were required by most but not all children at the end of life. Those with solid tumours required treatment for the longest period, those with leukaemias required the highest dose on the last day of life, and those with brain/spinal tumours the lowest.

### G87 A STUDY OF THE SYMPTOMS AND INTERVENTIONS DURING THE PALLIATIVE PHASE IN CENTRAL NERVOUS SYSTEM (CNS) TUMOURS

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**Introduction:** CNS tumours are the commonest cause of oncological death in the paediatric population. Palliative symptom management is a vital part of the holistic care of these children. Many of the symptoms differ from those of other malignancies and present unique challenges to providing effective palliative care.

**Aims:** To document the demographics, symptoms, and interventions of children that died of CNS tumours over a 5 year period.

**Methods:** We reviewed the medical and nursing records of all paediatric patients with CNS tumours at the Royal Marsden Hospital who died between 1997 and 2003. Demographics, symptoms, interventions, and the healthcare professionals involved in the final 3 months of their illness were documented.

**Results:** 52 patients were identified; 56% were male, mean age at diagnosis was 7.6 (range 1.1–15.4) years and at death was 9.0 years. The mean time to death from diagnosis was 15.8 months. The diagnoses included high grade glioma (32.7%), brainstem glioma (30.8%), medulloblastoma/PNET (13.5%), ependymoma (11.5%), and others (11.5%). 60% died at home, 36% in hospital, and 4% in a hospice. Preliminary analysis demonstrated the following incidence of symptoms/problems: speech and communication (62%), vomiting (62%), mobility (60%), nutrition (62%), headaches (53%), sensory loss (53%), swallow (46%), and seizures (38%). Interventions implemented and healthcare professional involved will be presented at the meeting.

**Conclusions:** The study demonstrates a high incidence of neurological symptoms that can be very distressing for patients, families, and carers alike. Although often difficult and challenging to manage, the majority of children can receive their palliative care in the home setting.

### G88 DOES THE PAEDIATRIC PALLIATIVE CARE SERVICE HAVE A ROLE IN PICU?

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**Aim:** Developing the role for paediatric palliative care teams within the paediatric intensive care unit (PICU).

**Method:** A member of the paediatric palliative care team attended the PICU wardround twice weekly for 12 months. The number of children referred, their diagnosis, and the reasons for referral were reviewed.

**Results:** Twelve children age 10 days–15.3 years were referred to the palliative care service. Two previously well children suffered unexpected cerebral or cardiac events. Three children were referred <1 month old with necrotising enterocolitis, CHARGE association, and an intracranial bleed. Seven children had previously identified problems: fatal metabolic disorders (2), chromosomal disorder (1), progressive neurological impairment (2), spinabifida (1), and an unidentified syndrome (1). Clear reasons for referral included support for the family in the decision to withdraw ventilation (1) and terminal symptom management (2). No specific reasons were identified for nine referrals, although all children were clearly life limited.

**Outcomes:** Only four of the children died prior to discharge home, two on the day of referral. Eight continued to receive palliative care; three died 2–5 months from referral; and five remain alive 1–10 months after referral.

**Conclusions:** There is a role for PICU and palliative care teams to work together, particularly in the continuing care of life limited children.

### G89 A STUDY LOOKING AT PAEDIATRIC SpRs' EMOTIONAL RESPONSES TO A PATIENT'S DEATH

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**Aims:** A pilot study looking at current practice following a child's sudden or expected death in particular who SpRs seek support from, who they need to support, the use of debriefs, and the involvement of bereavement counsellors.

**Background:** There is little written on the grief responses and coping mechanisms used by doctors at these times. It has been well documented that families clearly remember the details surrounding their child's death including actions and attitudes of staff. Many nursing journals recognise that over time our resources to deal with dying infants and children may be depleted. A recent themed issue of the *BMJ* on death highlighted the need for research in this area (*BMJ* 2003/327).

**Methods:** A self administered questionnaire was handed out to paediatric SpRs to be completed before a related teaching session in a large DGH.

**Results:** 10 SpRs completed the questionnaire. All had been involved with neonatal and childhood patient deaths. Regarding the last death they had attended, nine had spoken to parents around the time of death (four without consultant present); seven had been involved in supporting colleagues and had felt initially supported themselves. Four had been involved in a debrief, those not offered a debrief would have found it helpful. Looking at more formal support only three had been offered any ongoing support (by consultant and chaplain). All, however, spoke to someone (staff, chaplain, partner, friends, or family) about the death and found this useful. Nine still think about unresolved issues relating to the death. Seven would speak to a bereavement counsellor if available. Seven had received training on breaking bad news. Longer term all still reflected on certain deaths they had been involved with.

**Conclusions:** This pilot study was received very favourably. SpRs commented they found completing the questionnaire therapeutic. We plan to extend this study to a multicentre study involving SpRs within the south west region. We aim to learn "what works well" so we can disseminate good practice to colleagues.

### G90 "A PAEDIATRIC OPTION"? THE DIPLOMA IN PALLIATIVE MEDICINE 3 YEARS ON

R. D. W. Hain, F. Rawlinson, I. Finlay. University of Wales College of Medicine, Cardiff

**Aim:** This is a report on the Diploma in Palliative Medicine paediatric option. It will describe the initial design of the course, how it has evolved, and how it should now develop based on emerging research and feedback from students on the course.

**Methods:** This is a retrospective analysis of students embarking on the Diploma in Palliative Medicine to do the paediatric option since its inception in the summer of 2000.

**Results:** Twenty three students have enrolled on to the diploma course. Twelve (54%) were consultant paediatricians or specialist registrars. The remaining 11 were general practitioners, almost all working in a children's hospice. Five students (23%) came from outside the UK. Students came from Greece, the US, Ireland, and Switzerland. Feedback from the students suggests general satisfaction with the course, but identified their need to be seen as distinct from colleagues doing the adult option.

**Conclusion:** This is the UK's first specifically paediatric course in palliative medicine. It appears to be relevant to doctors from diverse backgrounds. Although designed with the needs of UK doctors in mind, it has proven to be of value to foreign graduates. Future developments must reflect the training and backgrounds of students, the evolution of paediatric palliative medicine as a speciality, and on going educational research that identifies learning needs among all doctors working with children with life limiting conditions.

#### G91 ETHICAL DIMENSIONS OF PALLIATIVE CHEMOTHERAPY

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**Aims:** To assess the intention and outcome of palliative chemotherapy (PC) in incurable childhood cancer.

**Method:** Retrospective observational study, using casenotes, examined reasons given by clinicians for offering PC to 35 young people.

**Results:** 35 patients were offered palliative chemotherapy and 11 declined. Survival was 10.4 months and 40 days in those who received and declined PC, respectively. In 14 cases no reason was given for PC. For the remainder, reasons included possible cure (2), research trial (3), and "to buy time" (4). In six cases there was clear intent to improve quality of life. Seventeen courses were of low toxicity, three were trials, and nine involved chemotherapy with significant adverse effects. Clinical outcomes (improvement in symptoms or quality of life) could not usually be assessed from the notes.

**Conclusions:** Chemotherapy was given in the palliative phase for a variety of different reasons including symptom control, research, and in hope of a cure. The ethical dilemmas of this approach are discussed.

#### G92 DEVELOPING END OF LIFE PLANS

F. Finlay, M. Poon, M. Lewis, S. Lenton. *Community Child Health Department, Newbridge Hill, Bath BA1 3QE*

**Introduction:** Producing written plans assists with the process of making important decisions around the end of life. Plans may incorporate the views of children, parents, and professionals.

**Aim:** To review current plans for children with life threatening conditions, to develop guidance to assist writing future plans, and then subsequently evaluate use of the guidance.

**Method:** Eight plans were reviewed and their contents analysed.

**Results:** There were eight children aged 2 months to 16 years with end of life plans. Four children had cerebral palsy, one chromosomal abnormality, one spina bifida, one metabolic disorder, and one cardiac abnormality. Pre (death plan): no plan documented for any of the eight children. Time of death plan: all children had plans which included views on acute resuscitation, symptom control, and views on long term ventilation. The favoured place of death was documented for six children: at home (3), on the ward (1), and in a hospice (1). Post death plan: no plan documented for all eight children.

**Conclusion:** End of life plans have not developed to their full potential. Pre-death wishes, for example taking photos and going on trips, were not recorded at all but instead all plans focused on acute resuscitation. Only one plan addressed action if death occurred at school or outside the home. Many of these children spend time with respite carers and some have parents who are separated or live with foster parents and their views should be considered. No plans incorporated wishes after death (for example memorial services and grief counselling). Following the study guidance was developed to act as an aid memoiré to discuss with families when preparing end of life plans offering children and parents the opportunity to actively influence decisions improving end of life care. To date this aid memoiré has proved helpful.

#### G93 A CARE PATHWAY FOR THE TRANSITION FROM PAEDIATRIC TO ADULT SERVICES IN PALLIATIVE CARE

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**Introduction:** Life limited children are living longer with a small, but significant number, now achieving adulthood. At this critical phase in the disease trajectory the implementation of a care pathway assumes enormous importance in the transition from paediatric to adult services.

The speaker will outline methods adopted at her children's hospice to improve service provision to this specific client group.

**Method:** Using case study presentation, examples of successful and suboptimal transference of responsibility will graphically demonstrate the benefits of early identification of, and collaborative multi-agency planning for, individuals for whom transition will be necessary.

**Results:** In the UK in 2003, the Association of Children's Hospices identified from its client group some 432 individuals potentially in need of such. This can only be a portion of the actual total, as not all life limited youngsters use a children's hospice.

**Conclusion:** The number of life limited children reaching majority is likely to increase. A care pathway enables us to focus on the individual and not the condition, and events out what is too often a bumpy road.

#### G94 PARENTS' VIEWS OF THE COMMUNITY PAEDIATRIC NURSING AND PSYCHOLOGY SERVICE

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**Aim:** to obtain the views of parents about the community paediatric nursing and psychology service offered when a child has a non malignant life limiting condition. Parents were asked to list both negative and positive aspects of the service, the aim being to try to eliminate negative aspects and build on the positives with subsequent re-evaluation of the service.

**Methods:** Self completed questionnaire.

**Results:** Common themes emerged from the respondents. Positive aspects of the service included: reducing hospitalisation by having treatment at home, for example intravenous and antibiotics; obtaining equipment for use at home; providing support and encouragement; co-ordinating care and contacting other professionals on parents behalf; finding sources of information from other professionals (for example private sector and voluntary organisations); help with filling in DLA application and other forms; training carers, school staff, and social staff in specific aspects of care enabling the child to lead as normal a life as possible; psychology advice and support valuable at addressing all the families needs; and prompt response to queries/emergencies. Aspects of the service which were not so good: no out of hours cover at night, weekends, or public holidays; staff with very heavy workloads thereby increasing response time; in some areas frequent staff changes; and long waits for a psychology appointment. When asked for one improvement to the service, the main requests were for more "sibling" and "sick children" groups and more social events, giving networking opportunities for families; to be able to contact nurses directly via their mobile phones without having to contact the administration team first; and to provide an inpatient unit for young people over 18 with life limiting/threatening illnesses. Areas of need were highlighted and these are currently being addressed.

#### G95 ANALGESIC PRESCRIBING IN A PAEDIATRIC ONCOLOGY CENTRE

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**Aims:** Pain is a serious problem for many children with malignant disease. The source of pain may be multifold, including pain secondary to their primary malignancy or metastatic spread. Iatrogenic causes of pain and discomfort are also frequent especially as a result of chemotherapy. Many children require regular analgesia including strong opioids such as morphine. The World Health Organization (WHO) produced a booklet of guidelines in 1998<sup>1</sup> incorporating the analgesic ladder, a rational, simple, and stepwise approach to pain. Ideally all children should have analgesia prescribed in accordance with these guidelines.

**Methods:** Permission was sought from the local audit department. A prospective study was carried out on all children requiring analgesia over a 4 week period on the paediatric oncology unit. Basic information such as age, sex, background diagnosis, and status of treatment was recorded. The reason for prescribing analgesia as well as dose and frequency of administration were noted. Evidence of knowledge of the WHO pain ladder and use of analgesia as recommended by it was duly recorded.

**Results:** There was no evidence that children in pain were denied access to adequate doses of opioids. There was a good understanding of the distinction between simple analgesia, weak opioids, and strong opioids. Understanding of the other principles of the WHO pain ladder was often inadequate.

**Conclusions:** The principle of analgesic prescribing as per the WHO pain ladder should be emphasised more in our paediatric units, particularly our oncology departments where analgesic requirements are high. All medical and nursing staff should be able to adapt it with comfort in their daily practice.

1. *Cancer pain relief and palliative care in children*. World Health Organization: Geneva, 1998.

**G96** WITHDRAWN