Palliative care

G231 USE OF INTRANASAL/ORAL MIDAZOLAM IN PAEDIATRIC PALLIATIVE CARE

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Aims: To reduce child's distress/anxiety without intramuscular/subcutaneous injections. To enable parents to have some control over relieving their child's symptoms.

Methods and Patients: Case presentations. The authors would like to present their experience in the use of intranasal Midazolam in 4 patients dying at home. Cases A, B, & C were aged 8 months, 2yrs, and 5yrs. Case D was a 24yr old, who had started treatment when aged 19yr, hence continued to have input from the paediatric service. In cases A, B, & C there was reluctance from parents for their children to receive extra injections for relief of symptoms. In case D it was the choice of the patient.

Discussion: Reasons for using Midazolam intranasally: To provide more immediate symptom relief so that parents can give medication without having to wait for CNS/GP to arrive. Symptoms treated were agitation of the child not responding to extra pain relief and in case D, extreme anxiety related to increased pain and imminent death. Experience of authors has shown this to be an effective route for the administration of Midazolam as uptake of the drug was more immediate than previous intramuscular/subcutaneous administration.

Conclusion: Inranasal Midazolam is effective in treating anxiety/agitation quickly in dying children and therefore helps parents feel involved in their child's care during a very traumatic time.

G232 CORTICOSTEROIDS IN THE PALLIATIVE PHASE OF PAEDIATRIC BRAIN TUMOURS

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Introduction: Brain tumours are the second commonest childhood tumours. Long term survival is only 50% so effective palliative care is important.

Aim: To assess the benefit and risks of corticosteroids in symptom management in children with progressive brain tumours.

Method: A case note review of medical and nurse specialist notes, looking at the use of steroids in palliative care of children who died between 1998 and 2001, attending Great Ormond Street Neuro-Surgery Unit.

Results: 60 children died, aged 8 months to 16 years (median 6 years). Complete information was collected for 47 (78%). 33 (70%) received steroids as symptom management and all received analgesics and anti-emetics. 19 (57%) children received a prolonged course of steroids, range 5 to 90 day (median 29 days). 14 (42%) children received a short course of steroids, 7 were travelling on holiday. 14 (42%) children had documented relief mainly of headache, vomiting and irritability. However cranial nerve palsies, dysarthria and limb weakness, did not respond as well. 10 (33%) experienced a range of adverse effects; most commonly weight gain, increased appetite and moodiness. All children with adverse effects had a prolonged course.

Conclusions: 1: There was no systematic approach in prescribing the drug.

2: Symptom relief occurred in just under half of the children, and there was a suggestion that ataxia, dysarthria and limb weakness did not respond as well as headache, vomiting and irritability. It was unclear how long the improvement lasted.

3: Side effects occurred in a third of the patients, all of whom had received a prolonged course of steroids.

Prospective assessment is required in order to produce guidelines for the use of corticosteroids in the terminal stages of brain tumours.

G233 PAEDIATRIC PALLIATIVE CARE MANAGEMENT ISSUES IN LATE INFANTILE BATTENS DISEASE—A CASE REPORT

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Background: Battens disease is an extremely rare condition with autosomal recessive inheritance and is a progressive neurodegenerative condition with no known treatment.

Aims: To discuss the difficulty in identifying the terminal phase of the illness and the ethical issues of life prolonging interventions and symptom control measures.

Method: A case report of a child now aged 9 years who was diagnosed with late infantile Battens disease when he was 4 years old.

Results: This boy was admitted to hospital in status epilepticus, he was transferred to PICU when therapy caused respiratory depression. Artificial ventilation was deemed inappropriate and he was transferred to Martin House for terminal care in May 1999. Seizure control was poor and he had frequent apnoeic attacks. While potentially a terminal situation a decision was made to treat his seizures actively. Seizure control was finally achieved with subcutaneous infusions of midazolam and phenobarbitone, gastrostomy administered chlormethiazole and fosphenytoin injections and also by alteration of background anticonvulsant therapy.

Subsequent admissions highlighted further dilemmas regarding the degree of intervention for recurrent haematemesis, buttock abscess and pyrexia of unknown origin.

Conclusion: This case study illustrates the difficulties in the identification of the terminal phase and in the assessment of the degree of intervention required in children with chronic life limiting illness.

G234 DO NOT RESUSCITATE (DNR) ORDERS IN A CHILDREN'S UNIT: PREVALENCE AND PROCEDURE

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Aims: To determine i) the number of children with Do Not Resuscitate (DNR) orders at the time of death ii) the recorded process of decision-making.

Methods: Retrospective case note review of all children dying between April 1999 to March 2000.

Results: Hospital records of 36 of 58 patients were available: 13 were neonates (<28 days), 8 infants (<1yr), 3 children (1–11 yrs) and 6 adolescents (>11yrs). Using RCPCH criteria, decisions to discuss changing aims of treatment were based on: brain stem death in 5, "no chance" in 17, "no purpose" in 13 and unbearable in 1. DNR orders were written in 30 (by consultant in 21 and SpR in 9), reviewed 48 hourly in 6, but only once in 21, and more likely to be written about neonates than older children. Written evidence of families' agreement to DNR was noted in 25, with understanding of the child's condition in 24. Multidisciplinary meetings were held in 13 and the involvement of advocates and social workers recorded in 8 and 9 respectively.

Conclusions: DNR orders were written for most children in whom records were located. Review of notes suggested that documentation might not be sufficient for UK human rights legislation.

G235 RESUSCITATION POLICY IN CHILDREN'S HOSPICES

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Aims: The aim of this study was to ascertain the presence of absence of resuscitation policies in Children's Hospices on mainland UK.

Methods: The Heads of Care at a total of twenty-three children's hospices were contacted by letter, and information on their resuscitation policy requested.

Results: There were responses from seventeen hospices. Thirteen of these were written replies and four were telephone calls to the lead nurse of the investigating hospice. Salient points from the discussion were noted. A written policy was in place in nine of the seventeen hospices, including written documentation of parents' wishes. Resuscitation was actively discussed by twelve of the seventeen respondents. In seven of the respondents a discussion covering resuscitation policy occured at each visit. None of the respondents indicated whether the child's views was sought. Seven hospices were examining their policy at the time of the study. A number of replies highlighted the difficult ethical and practical issues raised when discussing resuscitation of children in the hospice setting.

Conclusions: This preliminary study suggests there are wide national differences in resuscitation policy in children's hospices. There is a need for a more detailed study examining resuscitation practices in the Children's Hospice setting. Guidelines are reqired to ensure minimum standards.