Ethics and law and palliative medicine joint session

G196 ATTITUDES OF PAEDIATRICIANS TOWARDS END OF LIFE MANAGEMENT

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Background: Children commonly die through withholding or withdrawing of life sustaining measures and the RCPCH first produced a framework for practice in 1997. Little is known about its effect on clinical practice.

Aims: To establish the attitudes of paediatricians towards end of life management issues including four key areas: communication, dealing with conflict, active *v* palliative care, and withdrawal of treatment.

Methods: A questionnaire based on four real life cases of children with incurable disease was sent to all consultant paediatricians in the West Midlands. Twenty four statements encompassing the four key areas were included. Responses were rated on an itemised rating scale from strongly disagree to strongly agree.

Results: The response rate was 52% (113 completed questionnaires). Forty five per cent of consultants had more than five patients with incurable disease, but only 22% had received formal training in end-of-life management. Most agreed that early information and understanding about prognosis and management is important for families and their children. Quality of life and intractable symptoms were the most common reasons for stopping active treatment. In dealing with conflict most agreed to maintain dialogue but not to give families the final decision. The majority (57%) would delay seeking a second opinion and most disagreed with using the courts to resolve conflict. Opinions were divided on when care should be switched from active to palliative. Most advocated use of sedation and analgesia during withdrawal and would discontinue or avoid muscle relaxants.

Conclusion: Although clear communication was important for consultants at the end-of-life, there was disagreement on the timing of withdrawal of life sustaining measures and introduction of palliative care. This may be explained by the fact that quality of life was a major determinant in this decision. More extensive training in end-of-life management and early involvement of palliative care services may reduce this variation in practice.

G197 CARE AT THE END-OF-LIFE ON THE PAEDIATRIC INTENSIVE CARE UNIT

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Introduction: The majority of deaths on a paediatric intensive care unit (PICU) can be anticipated. This gives an opportunity to share decisions with parents and manage a child's end-of-life care accordingly. We present a review of deaths on PICU over a 12 month period and three cases to illustrate differences in end-of-life care.

Methods: The ''mode'' of death of all children who died in 2003–2004 was categorised: brain stem death, failure of resuscitation attempts, or withdrawal/limitation of therapy. In the latter, the circumstances leading to this decision was noted along with the process of therapy withdrawal. Specific issues raised by parents or staff regarding a child's care, such as timing and place of therapy withdrawal, were noted.

Results: There were 23 deaths (6%) out of 383 admissions. Twelve children (52%) died following withdrawal or limitation of therapy. Six deaths (26%) followed failed attempts at full resuscitation. Five children (22%) died from brain stem death. In the majority of cases, medical staff initiated discussions regarding withdrawal of therapy, usually several discussions took place. Therapy was withdrawn with family present in all cases. Organ donation was indicated in two cases, it was offered to one family who accepted. The following are examples of end-of-life situations on PICU.

Case 1: A five month old baby with spinal muscular atrophy required prolonged ventilation for respiratory failure. His parents did not want him to be ventilated indefinitely. He was taken home on non-invasive respiratory support and then therapy withdrawn once all family members had said goodbye.

Case 2: A 5 week baby had profound neurodisability and apnoea following meningitis. The decision to withdraw therapy was made, but the process was delayed for 3 days at her parents' request, so her grandparents could see her before she died.

Case 3: Siblings with neurometabolic disease and severe disability were admitted with respiratory failure, one to PICU, the other to the ward. At their parents' request, therapy was withdrawn in the first child and limited in the other. They died together on PICU.

Conclusions: Deaths of children on PICU fall into three categories, and most can be anticipated. End-of-life care is discussed with families, so their wishes can be taken into account when managing children dying on PICU. This is a very emotive and challenging area for intensive care, and raises many complex operational and ethical issues. The quality of care at the end of life should be investigated by examining the family's perceptions of such care.

G198 IMMINENT DEATH AND RESPECT FOR AUTONOMY ON PAEDIATRIC INTENSIVE CARE

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Background: An individual's autonomy underpins their ability to consent and refuse treatment. Where a child is not competent, we often turn to the family to act in his/her best interests. However, a dilemma arises if parental decisions interfere with a competent child's ability to consent.

Case: A 14 year old child was admitted to a paediatric intensive care unit (PICU) for mechanical ventilation of acute on chronic respiratory failure. A multidisciplinary meeting including the parents agreed that his lung disease was irreversible and rapidly terminal, leaving withdrawal of intensive care support as the only option. At various points in the admission, the child was unsedated but remained ventilated. During these occasions, he had demonstrated lucid non-verbal communication. The team had the option to wake the child, discuss his terminal condition and allow him to exercise his choices. The parents and many members of the multiprofessional PICU team felt that this would be too distressing for the child. An ethical meeting was held to discuss the dilemma.

Discussion: The ethical principles underlying the case are discussed. This case highlights the increasing complexity of end-of-life decisions on PICU.

G199 ANALYTICAL SURVEY OF STAFF ATTITUDES TO CARE FOLLOWING END-OF-LIFE DECISIONS ON NICU

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Background: End-of-life decisions create dilemmas. Both lingering death and active euthanasia are undesirable. Interventions can hasten death, but what do staff feel are the limits of acceptable practice? Does this accord with recent college guidance? Why do they think like they do?

Method: Structured interview. Drop-in recruitment; all medical and nursing staff in a neonatal unit were invited to participate. Interviews audio-recorded and anonymously transcribed. Answers classified yes/no/don't know/equivocal. Analysis of answer pattern and text performed qualitatively. Ethical principles identified.

Results: 25 participants: 15 nurses, 10 doctors. Summary of answers:

- Q. 1: Aims of care following withdrawal: 80% pain relief, 60% parental need
- Q.2: 76% feel that death can be a desired consequence of withdrawal
- Q. 3: 52% feel that death should never be hastened
- Q. 4: 96% feel that morphine is acceptable after withdrawal
- Q. 5: 72% would give a higher than normal dose of morphine.
- Q. 6: 56% feel that our intentions determine the rightness of our actions in this case even if death results.
- Q. 7–9: 56% would stop paralysis at extubation but not reverse it. 24% would continue paralysis
- Q. 10: 16% would consider a drug that ended life instantly in some cases.

Conclusions: A wide variety of views, but two main positions, the cautious majority and the more proactive minority. Majority position close to that of RCPCH. Apparent contradictions within majority position can be resolved with the doctrine of double effect and the acts and omissions distinction. Implications for policy and academia discussed.

G200 SEX ON THE BRAIN: DILEMMAS IN THE ENDOCRINE MANAGEMENT OF CHILDREN AND ADOLESCENTS WITH GENDER IDENTITY DISORDER

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Aim: To describe ethical and legal dilemmas in the endocrine management of children and adolescents with gender identity disorder.

Methods: Case review.

Results: Gender identity disorder is a condition in which individuals perceive themselves to be of the opposite gender to their biological sex. Treatment is predominantly psychological and social; however, during puberty and adolescence, demands may be made for hormonal interventions to suppress symptoms of puberty (for example menarche, beard growth), suppress normal puberty altogether, and/or to prescribe hormones of the desired sex. We provide an endocrine liaison service to the national Gender Identity Development Unit for management of children and adolescents with gender identity disorder. We used a staged approach to hormonal management. This frequently raises ethical dilemmas and child protection concerns in management, particularly around demands from young people and parents to prevent entry into natural puberty and to prescribe a range of potentially harmful hormones (GnRH analogues, sex steroids, cyproterone acetate) off-licence with no clear ''medical'' indication. Additional difficulties include frequent psychiatric comorbidity (emotional disorders, self-harm, and substance use), social deprivation, refusal to be physically examined, and use of ''black market'' hormones. Further dilemmas are presented by highly active patient support groups and reports of early active hormonal treatment in other European countries. We present background data and case studies demonstrating some of the ethical and moral dilemmas encountered in providing this service.

Conclusions: Medical management of gender identity disorder presents significant moral and ethical dilemmas and child protection concerns. Management should be restricted to specialist teams working in close liaison with specialist psychiatric services.

G201 ATTITUDES ON TREATING PREMATURE BABIES IN A PREDOMINANTLY MUSLIM COMMUNITY

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Aim: To find out what attitudes may exist on the treatment of premature babies in one predominantly Muslim community.

Method: A questionnaire survey was carried out over a 4 week period. The questionnaire was bilingual and contained 25 questions including demographics. Parents, doctors, nurses, and midwives were polled. The survey was carried out in hospital wards, paediatric outpatient clinics, and also in community mother–child health clinics. Data entry and analysis was carried out on an SPSS package.

Results: 413 questionnaires were returned. The worst question non-response rate was 2%. 195 parents, 73 doctors, and 145 nurses/midwives answered. 335 respondents identified themselves as Muslim. Overall, 67% thought we should try to save those babies who have a ''slim chance'' of survival. 1:3 Muslim respondents answered ''no'' to attempting to save slim chance babies. 17% of parents did not think we should try to save slim chance survivors. When given as high as a 50:50 chance of disability, a majority of 78% of all respondents still felt we should try to save the life of that baby. This suggests a possibly higher acceptance of disability. 40% of all respondents did not think the equivalent of £50 000 was justified for babies who might have to spend 3–4 months on the neonatal unit. 49% of parents were of this opinion. Of the 60% of people (246/407) who thought this sum was justified, almost 70% of them (170/246) then said they would change their answer if they had to bear the cost themselves. The vast majority 96% wanted to be informed frankly about poor prognosis. 75% overall said they would be able to take part in the decision to withdraw intensive care, but about half of these said they would actually prefer the doctor to make the decision for them.

Conclusions: Although this was a limited survey, in this predominantly Muslim community at least, not everyone is of the opinion that every preterm baby should be saved at all costs. Health workers in neonatal units should take heed and not allow any preconceived assumptions creep in when dealing with either parents or members of their own staff.

G202 PERSONAL RESUSCITATION PLANS: THE DEATH OF DNARS?

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Aims: Professionals working with children with life threatening or life limiting conditions (for example with profound or progressive neurodisabilities) found the new ''do not attempt resuscitation'' (DNAR) orders unsuitable. Following an idea by the West Midlands Paediatric Palliative Care Network, we aimed to develop a child and family centred alternative: the personal resuscitation plan (PRP).

Methods: Professionals' focus groups were held in the two local hospitals and community settings, and comments sought from a wide range of professionals and individually from selected bereaved parents or guardians. A template (pro forma and aide memoire) with instructions was developed and is being piloted.

Results: Aims of the PRP were identified: to clarify choices for the child or family and help discussions about end of life issues; to respect the child's humanity; to empower the child or family and allow as much choice and control as possible; to be flexible to accommodate changing attitudes and circumstances; to assist clear communication between the family and all carers; to provide a clear record for clinical audit, clinical governance, and legal purposes; and to be developed and improved over time. The properties of the PRP template were: a standard pro forma with ''delete as needed'' options and free fields; clear, detailed, practical instructions on extent of resuscitation required; flexible with no proscribed review dates (but can be changed at any time by the family); helps end of life discussions with the family; requires consultant signature; may be signed by child and parents/legal guardian; and avoids legalistic small print.

Conclusions: A PRP is more acceptable to professionals in caring for children with life threatening or life limiting conditions and their families. Progress of the pilot and implementation will be reported in April 2005.

Acknowledgements: We thank all the professionals and families who have contributed their time, efforts and ideas to the PRP template development and implementation.

G203 DEVELOPING THE LIVERPOOL CARE PATHWAY FOR THE DYING CHILD

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The Liverpool Care Pathway (LCP) for the dying patient was developed to improve standards of care for adults in the last 48 hours of life. It has been awarded NHS Beacon status as a model of good care, and is currently being disseminated and evaluated across the NHS. The benefit of the LCP is obtained as much from the structured process of implementation and education of staff as from the document itself.

We are adapting the LCP to make it appropriate for the care of a dying child, whether they are at home, in hospital, or in a children's hospice. In order to inform the development of the pathway document, we undertook a base review of patients cared for either at home by members of the specialist palliative care team or at the local children's hospice. The pathway is now being piloted in the community and at the children's hospice. We will present preliminary information from the pilot and describe some of the challenges we have needed to address during the development process. These include the following issues:

- The rarity of death in childhood means that most health professionals will care for a dying child infrequently. This makes it difficult to ensure that practitioners are aware of the pathway and have adequate support in using it when they need to.
- Symptoms differ between dying adults and children. In particular, many dying children have neurological conditions, and these patients may have severe and sometimes uncontrollable fits.
- The preferred route of drug administration may be different. Drugs are most commonly administered to dying adults via the subcutaneous route, whereas dying children often have a gastrostomy or central line, which would be used in preference.
- Parents often provide the majority of the hands on care for their dying child, so it may be appropriate to involve them in completing the pathway documentation.
- Communication may be particularly challenging, as many dying children are unable to communicate verbally, either because they are too young to speak or because of developmental delay.

- Communication with the parents of a dying child is of vital importance, and the pathway must also ensure that the needs of siblings are addressed.

G204 SPECIALIST REGISTRAR'S EXPERIENCE OF DEBRIEFS FOLLOWING THE SUDDEN OR UNEXPECTED DEATH OF A CHILD

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Aims: A study to look at the use of debriefs following the sudden or unexpected death of a child within the paediatric department.

Background: Mitchell was one of the first to recognise the effects of critical incident stress on emergency teams.[1] Since then much has been written in the literature on debrief, particularly within the emergency setting. We often spend much time with families following a child's death, but how do we prepare and look after ourselves? We often move on to the next task without taking time to assess and confront our own vulnerabilities.[2]

Methods: Following ethical approval a self administered questionnaire was sent to paediatric specialist registrars (SpRs) within the south west region.

Results: 42/56 (75%) questionnaires were returned. Following a death a formal debrief occurred in 13/42 (31%) of cases. Of these, one person found out by accident and two could not attend due to shifts. Of the 29 not involved in a debrief, 22 (76%) would have found it helpful. Most SpRs (32, 76.2%) responded that they have been involved in debriefs before. Good points included: time to reflect and support each other, help to work through the situation, chance to see nothing else could have been done, and learning points for the future. Negative points included: finger pointing exercise, defensive, little attention to junior staff, vulnerable, and strong personalities dominated the session. What would make a debrief useful? External facilitator, involve everyone, protected time, and freedom to be emotional.

Conclusion: SpRs want to be involved in debriefs. Unfortunately the use of debriefs in the paediatric clinical setting is still patchy at best.

Discussion: How can we ensure that debriefs become ''as standard as filling out a death certificate''? A protocol needs to be developed.

1. **Mitchell JT**. *JEMS* 1983;**8**:36–9.
2. **Martin**. *Nursing* May 93 39–41.

G205 DOSE RESPONSE AND SERUM LEVELS: MORPHINE AND M6G IN CHILDREN WITH CANCER

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Aims: To examine the relationship between analgesia and serum morphine and M6G concentrations in children with cancer.

Patients and Methods: Seven patients under the care of the regional paediatric oncology unit in Cardiff and the Vale NHS Trust who were prescribed morphine. Six blood samples were drawn from indwelling venous lines at intervals between administration of morphine and 8 hours after its discontinuation. Morphine was analysed using high performance liquid chromatography (HPLC). Its active metabolite, morphine-6 glucoronide (M6G), was measured using a highly sensitive enzyme linked immunosorbent assay (ELISA). Pain was assessed using a simple Faces scale, each time a sample was withdrawn.

Results: Pharmacokinetic profiles were obtained in seven patients ranging in age from 2.4 to 16.4 years (median 7.6 years). Pharmacokinetic parameters for M and M6-G were comparable with those of previous studies. The half life of M6-G (329 minutes) was considerably larger than that of M (140 minutes). Clearance of M was higher than in adult studies. Side effects were: drowsiness (7/7, 100%), nausea and/or vomiting (4/7, 57%), pruritus (2/7, 28%), and urinary retention (1/7, 14%). There were no reports of respiratory complications. Pain scores varied between 1 and 4 out of 5. There was no correlation with serum concentrations either of morphine or M6-G, or the molar ratio of the two. Maximum serum concentrations were comparable with other studies.

Conclusion: This study provides preliminary data suggesting that children remain in pain despite significant serum concentrations of morphine and M6-G. The relation between serum concentrations of opioid and relief of pain is not straightforward. Some adverse effects, particular nausea and pruritus, may be commoner than is usually thought, while others (particularly respiratory problems) did not occur at all in this series.

G206 END OF LIFE CARE IN CHILDREN WITH CYSTIC FIBROSIS: A PALLIATIVE CARE TEAM VIEWPOINT

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Background: Cystic fibrosis is a life limiting disease posing numerous challenges for end of life care. This study identifies some of these.

Method: Retrospective case review of four children with cystic fibrosis referred to the paediatric palliative care team at our children's hospital.

Results: Three female and one male (3–17 years) patients were studied. Three died in hospital and one at home. Time from referral to death was 3 weeks to 6 months. One patient was 2 years post-transplantation, in two it was not applicable and one was unsuitable. None was for active resuscitation, and in all preventive and therapeutic treatments were continued, as well as symptom control measures. In two cases the family and/or child voiced concerns about the use of morphine, as they thought that this might hasten death. In two cases ward staff expressed concern that the use of morphine would depress respirations and hasten death.

Discussion: This study reflects the end of life experience for children and young adults with cystic fibrosis at a tertiary centre. Most died in hospital, reflecting their institutionalisation and their carers' lack of confidence in managing their treatments at home. The patients were referred shortly before their deaths, highlighting practical difficulties such as liaising with local professionals not known to the family in the terminal phase. Ward staff who had formed close relationships with the families found the terminal phase stressful and confusing. We experienced resistance to the use of opiates for symptom relief. In cystic fibrosis it is difficult to predict short term prognosis and patients rely psychologically on preventive and therapeutic measures. As a result a model of end of life care is emerging where preventive, therapeutic, and comfort measures are adopted simultaneously. A collaborative approach by the paediatric palliative care and respiratory teams may result in improved end of life care for children and young adults with cystic fibrosis.

G207 THE PALLIATIVE CARE NEEDS OF CHILDREN WITH END STAGE CARDIAC DISEASE

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Aims: The aim of this study was to identify the palliative care needs of children with fatal cardiac conditions and to determine how these can be met by a palliative care service

Method: The study was a retrospective case note review of patients referred to a tertiary centre palliative care team over a 2 year period.

Results: Eighteen patients were referred to the palliative care service. One referral was made antenatally at 32 weeks gestation, seven referrals were of children age under 1 year, and 10 referrals were of children age 1.9–17.5 years (median 6.5 years). Only four referrals were specifically for support with symptom management, the other 14 referrals being for general support with continuing care. Two of the children referred for symptom management were under 1 year and had episodes of acute onset severe cardiac pain, which was controlled using buccal diamorphine. Two other children were referred because of generalised discomfort and restlessness, which was observed in an additional eight children during the last few days of life. This was managed with oral analgesia in eight children and with a subcutaneous infusion in two children. Two children developed severe oedema, which was controlled with oral diuretics. Sixteen children died, 11 at home. For social reasons three of the deaths were in hospital, with a further two deaths in intensive care. Palliative care at home was provided by a multi-professional team which included locally based paediatric community or hospice nurses and the family doctor, supported by outreach from the tertiary centre by a cardiac liaison nurse and palliative care specialist. During home visits most families sought emotional and practical support, rather than support for symptom management.

Conclusion: Symptom management in end stage cardiac disease is not usually problematic and the main focus of a multi-professional team should be to provide emotional and practical support to the child and family throughout the illness, death, and bereavement.

G208 CARE AT THE END OF LIFE—COMMUNITY NURSING IN NON-ONCOLOGICAL DISEASE

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Background: The Lifetime Service provides community nursing to children with life limiting conditions. Little work has been done to look

at the workload of community nurses at the end of life for children with non-oncological diagnoses.

Aim: To explore the range and nature of the work of community nurses in children's terminal care.

Methods: Analysis of nursing records for children who died during a 5 year period 1999–2004 to establish the number of visits and calls made in the 2 months leading up to a child's death and following death.

Results: Sixty six children under the care of the service died during this period. Nursing records were available for 63 (95%). Age at death ranged from 7 days to 18 years, median 2.8 years. Forty three (68%) had primarily neurological disease with smaller numbers having cardiac, gastrointestinal, chromosomal, and other diagnoses; 36 (59%) died in hospital, 5 (8%) in a hospice, and 16 (26%) at home. In total 604 visits were made, range per child 0–50 (median 8). Before death, the range was 0–29, after death 0–21; 52% were home visits and 30% were to visit the child and family in hospital. Other places visited ranged from funeral directors and funerals to pharmacies, and a father's employer. A total of 1654 telephone calls were made or received by the nurses, range per child 0–130 (median 20). Range before death was 0–77 and after death 0–75. Calls to the family accounted for 29%. Other calls included to medical equipment and domestic appliance suppliers, parent support groups, and benefit offices.

Conclusions: A few children had little or no documented contact with nurses around death, sometimes because death was sudden and unexpected even though the child had a known life limiting condition. Other families had a large amount of input. Much of the work is undertaken by the community nurse who has a relationship with the child, even when they are in hospital for long periods. Nurses undertake a wide range of tasks and liaise with a large number of professionals on behalf of many families in the pre- and post-death period. Service managers and commissioners need to be made aware of this important aspect of nursing work that does not correlate with traditional ways of recording community nursing activity.

G209 DEVELOPMENT OF AN EAST MIDLANDS CHILDREN'S PALLIATIVE CARE NETWORK

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Aims: With the recent growth in local children's palliative care services we were keen to help coordinate efforts, avoid duplication, benefit from shared learning, and develop standards, clinical audit, and clinical research across the region.

Methods: Informal networking identified a core group of multi-disciplinary and multiagency professionals and a centrally situated children's hospice. Exploratory email contact was followed by an initial scoping meeting in October 2003. No specific funding was identified for this initiative.

Results: At the first meeting were medical, nursing, teaching, and other care workers involved in children's palliative care from primary, community, and secondary and tertiary hospital and children's hospice settings from the region. It was decided that the network would act as a forum for sharing problems and solutions, developments, audit, guidelines, and research. It would contribute to the development of evidence based practice within the field of children's palliative care. We agreed to meet four times a year and work on progressing a number of priorities through agreed action plans. Key work in the first year focused on developing a symptom control assessment tool, a symptom control box, a post-bereavement questionnaire, a template for personal resuscitation plans, a directory of local services, and network map.

Conclusions: Diverse professionals have been able to work together to establish the network and progress a number of priorities. This will support those currently geographically or organisationally isolated, promote the children's palliative care movement, and we hope improve services.

G210 DEVELOPMENT OF AN AUDIT TOOL FOR CHILDREN'S PALLIATIVE CARE

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Aims: Death, especially of a child, is a very sensitive issue and professionals have been reluctant to measure the outcomes of palliative care from the bereaved's point of view. The RCPCH and ACT have published a number of recommendations for children's palliative care services. We aimed to develop and pilot a questionnaire for bereaved parents and carers to assess the quality of the palliative care experienced.

Methods: This survey of parents/carers experiences of their child's palliative care was registered with the trust's clinical audit department. A literature review and discussions with colleagues led to us piloting a first draft bereavement questionnaire in selected bereaved families 2 to 24 months after the loss of their child. The questionnaire includes a section on how the questionnaire itself was to fill in and whether this kind of audit should be undertaken.

Results: The questionnaire was modified after the first three assessments, undertaken by the paediatrician known well to the bereaved. A further four families have been assessed. The main themes focussed on preparation for the death, autonomy, and empowerment of the family and child, symptom control, and what happened after the death. Although several families found the questionnaire hard or upsetting, all so far were positive about the experience and thought it was a good idea.

Conclusions: It is possible to audit directly the bereaved parents/carers views of the palliative care their child received. Preliminary data from selected families suggest they can view this positively. Further families' responses and views will be elicited before the questionnaire is used routinely, for example at bereavement counselling and follow up visits.

G211 THE PREVALENCE OF NON-MALIGNANT LIFE THREATENING CONDITIONS IN A MULTICULTURAL POPULATION OF CHILDREN IN THE NORTH OF ENGLAND

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Background: Limited information is available about the prevalence of non-malignant, life-threatening conditions among UK children. A recent paper gave useful data about the child population of Bath.[1] There are concerns, however, that there may be significant variation in prevalence between English districts.

Aims: We aimed to determine the prevalence of non-malignant, life-threatening conditions in a multicultural population served by a district child development centre in the north of England, and to compare with the reported prevalence from Bath. We focused on four of the diagnostic groups used in Bath: central nervous system (CNS) abnormality, CNS degeneration, syndromes, and neuromuscular degeneration.

Method: A review of both databases and medical records held at our child development centre was performed to identify those children thought to have a life threatening condition. Although a clinic based study, only those living within the area of our three local primary care trusts were included. Children were classified according to previous definitions used by Lenton and colleagues. Prevalence estimates were calculated per 1000 population using 2001 census derived population data, and examined by ethnicity (South Asian or not). Ethnic group was assigned using information from the medical records and verified using a software algorithm to examine the individual's full name.

Results: 148 children were identified as having a non-malignant, life threatening condition. 16 were excluded from this report, as their primary life threatening condition was not neuro-developmental. For the four categories of neurodisability, 132 children (prevalence 1.25/1000, 95% CI 1.04 to 1.48) were identified as having a non-malignant, life threatening condition. This was significantly higher than the prevalence reported from Bath (0.57, 0.43 to 0.74, $p<0.001$). 87 of our subjects were South Asian (2.39, 1.91 to 2.94), representing a significant excess compared with 45 non-South Asian children (0.65, 0.47 to 0.87).

Conclusion: Our data confirm that there are significant variations in the prevalence of non-malignant, life threatening conditions among children in England. In our district, this increase is mainly the result of a high prevalence among our South Asian, mostly Pakistani, patients. Further work is needed to clarify the importance of socioeconomic factors and of genetic influences.

1. **Lenton S**, *et al. Child Care Health Dev* 2001;**27**:389–98.

G212 LIFEFORCE: COMMUNITY PAEDIATRIC PALLIATIVE CARE. HAVE WE MADE A DIFFERENCE?

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Aims: To discuss how Lifeforce was established (the current structure and aims of the team) and to identify what community support existed for children with life limiting/life threatening diseases prior to development of the team. One year on, to identify enhancement in care provision.

Methods: A scoping exercise was performed, in all three primary care trusts, to identify what services each family was currently receiving and to identify what gaps in services, were present. A steering group was established and a successful bid was achieved from the New

Opportunity Fund (The Big Lottery Fund). A database review was undertaken, to identify the level of support the families received from Lifeforce. This was compared with pre-existing services. A case discussion was held, to illustrate the specialist service currently provided by the Lifeforce team.

Results: Considerable improvement in liaison between both community and hospital teams involved in the palliative care of children in these three PCTs; specifically, enhancement of respite services. There was recognition of the keyworker role, involved in coordination in the holistic care of the family and an increase in choice for family and child at end of life care.

Conclusions: A multidisciplinary team is now established providing specialist palliative care to the families. The first year of a three year funding has now been completed and the team are in the process of identifying formal evaluation mechanisms to fully assess the benefits of the Lifeforce team.

G213 THE DEGR SCALE: A TOOL TO MEASURE CHRONICITY OF PAIN IN CHILDREN WITH CANCER

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Aims: To compare a novel pain scale in children with a standard one and to use the new tool to document emergence of ''chronic pain''.

Background: Many studies[2] rely on the child's ability to report pain, while others rely on observation of behaviour patterns. These may not always correlate with the child's own estimate of pain or distinguish between the patterns of behaviours that accompany an actual response to acute or chronic pain. The DEGR scale[3] has identified a syndrome of chronic pain expression among children which resembles depression in adults, termed ''psychomotor atonia''. The DEGR is a scale that assesses both the intensity and chronicity of pain.

Patients and Methods: A comparison of the DEGR with Oucher. Sample, approximately 40 children aged 3–19 years of age starting analgesia. Clinical staff will use DEGR and the research nurse will use Oucher to assess pain twice daily.

Analysis: We will examine correlation between the two scores. Results will be analysed to show emergence of pain chronicity.

Results: The DEGR seems to accurately reflect observations of experienced professionals and is practical in a ward environment.

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3. **Gauvain-Picquard A**, Rodary C, Francois Rezvani A, *et al*. Validity assessment of DEGR scale for observational rating of 2–6 year old child pain. *J Pain Symptom Manage* 1991;**6**:171.