

Results: 274 patients with neuromuscular diagnoses were referred to Martin House (MH) during this time period. This is 18% of total referrals during this time period.

70.1% (192) had a diagnosis of Duchenne Muscular Dystrophy (DMD) with a peak in referrals in the year after the opening of MH, 24.1% (66) Spinal Muscular Atrophy (SMA) and 5.8% (other neuromuscular diagnoses). The mean age at referral was 9.7 years (SD 5.2) but this was significantly higher in DMD (mean 11.6, SD 3.9) than the other two groups although age at referral of DMD patients has decreased from a mean of 16 to 10 years during this period.

The survival patterns differ significantly between the three groups with children with SMA having a steeper curve and therefore a significantly shorter survival time (mean 0.25 years) compared to DMD patients (mean 8.7 years).

Conclusions: Children and young people with neuromuscular diagnosis form a large proportion of the referrals to a children's hospice.

The survival patterns highlight the different palliative care needs of the children and young people with subgroups of neuromuscular disease.

748

END OF LIFE CARE PLANS (ELCP) IN CHILDREN WITH LIFE LIMITING CONDITIONS

S. Raman, N. Gerson-Sofer

*Great Ormond Street Hospital NHS Trust,
London, UK*

Background and aim: Paediatricians face acute situations with children with life limiting illness, wherein resuscitative medical interventions should not be attempted. We aim to survey current prevailing practices on provision of ELCP in children who fulfil the criteria for life limiting illness in the London borough of Haringey, UK.

Methods: Survey was conducted in the last quarter of 2009. A list was compiled of medical conditions deemed as life-limiting in children. Medical notes of all children on the list were reviewed, directing attention to the specific points that were noted as relevant in the audit proforma. Ethical issues were discussed with the clinical governance department at Great Ormond Street Hospital, London, UK.

Results: 18 children with life limiting illness were resident in Haringey. 10 of the 18 (55.5%) children suffered from cerebral palsy. 13 of these children (72.2%) fulfilled criteria for the provision of an End of Life Care Plan (ELCP). 3 children of the 13 (23%) had an ELCP. Only one child had the ELCP documented and communicated to professionals appropriately.

Conclusions: National standards for delivering end of life care for children are currently not being met, and children with complex neurodisabilities are not usually being appropriately considered for ELCP discussion. Professionals are uncomfortable with approaching and addressing the issue of ELCP in eligible candidates. A programme for training and support at all levels of service delivery - consultants, registrars and nursing staff should be developed and implemented.

749

NEONATAL POST-MORTEM RATES: A 10 YEAR EXPERIENCE AT A TERTIARY CENTRE IN THE UK

A. Walker¹, A.K. Ewer^{1,2}, S.V. Rasiah¹

¹Department of Neonatology, Birmingham Women's NHS Foundation Trust, ²School of Clinical & Experimental Medicine, College of Medical and Dental Sciences, University of Birmingham, Birmingham, UK

Background: Post-mortem examination is important in determining cause of death and can add additional information even when the cause is felt to be apparent. The organ retention scandal in 1999 has changed the perception of post-mortems particularly in children.

Aims: To determine the post-mortem rates for babies who have died on our neonatal unit and to see if there are any differences between term and preterm babies.

Methods: All babies who died on our neonatal unit from January 2000 to December 2009 were identified using a combination of our neonatal databases, admissions book and death certificates. Post-mortem examinations were determined from our neonatal database and mortuary records.

Results: There were 329 deaths and 80 post-mortems performed during this period (24%). The yearly post-mortem rate for all babies varies from 13 to 39 percent. Over the 10 year period, rates

were 31 percent for term babies and 23 percent in preterm infants. Rates in extreme preterm infants were only 17 percent. There is a statistically significant difference between the post-mortem rates in term, 29-36 week gestation and extreme preterm infants.

Conclusion: Our post-mortem rates are lower than expected and vary from year to year. The rates are particularly low in the extreme preterm infants. The reasons for this are likely to be complex but include parents feeling they already know why their baby has died and also because they feel they do not wish to put their preterm babies through further suffering.

750

ASSENT IN RESEARCH FOR CHILDREN IS PROBLEMATIC

P. Baines

Department of Professional Ethics, Keele University, Staffordshire, UK

Introduction: Authoritative research guidelines from Europe, USA and Australia suggest that incompetent children ought to assent, when unable to consent. What assent means here is both unclear and morally problematic. I argue that if parents consent (that is choose) the role of the child's assent is unclear.

Problems with assent: Firstly, a practical problem arises if parent and child give incompatible responses to consent and assent. The research will either continue or be withheld. If the child can be over-ruled, then assent seems meaningless. Alternatively, if the parents are overruled then this is not consent. But if consent is the authority to proceed, then assent has no role. Secondly, there are other conceptual problems with assent itself. For example, it is emphasised in research, but is largely ignored in medical treatment. Why? In addition, in many descriptions of assent, what is described is lack of dissent. Thirdly, as well as incoherence, the requirement for assent may cause other moral problems. If parents do choose for their children (and ignore the child's views) or if a child's assent contains a veto over the parents' consent, then we may be introducing tensions into the decision-making within a family.

Some children can consent. Parents of incompetent children must consent (or not) usually consulting with their child. Children should have an input into

their parents' decisions but as one component in the decision, not an independent choice.

Conclusions: The notion of assent is both flawed and morally problematic. Children's research regulations should be reformed.

This Work was Supported by the Wellcome Trust [WT087470MF]

751

QUALITY OF LIFE AS A DECISION CRITERION ON HEALTH CARE (ETHICAL PONDERATION)

A.P. França¹, A.R. Mendes², C. Pinto², A. Ourives², I. Ribeiro², T.R. Sarmento²

¹UNIESEP (Oporto High School of Nursing Resaearch Unit), ²UNIESEP (Oporto High School of Nursing Research Unit), OPorto High School of Nursing, Porto, Portugal

The "Quality of Life", although to be a subjective concept, is frequently used as criterion in the resolution of problems of the clinical practice, nominated in situations of ethical dilemmas in pediatric intensive care units, being able to take the orientation directions that do not dignify the human being. One of the aims of this research is to perceive as "Quality of Life" criterion is used in the resolution of ethical dilemmas in the clinical practice, having for purpose that the health professionals became aware on the use of this criterion and the potential effects of its use in the clinical practice. 152 nurses, attending post-graduation courses in the Oporto High School of Nursing had been inquired about the professional situations where they have been collated with decisions based on the "quality of life" and about the appreciation of the ethical questions raised by these decisions. After content analysis was verified that the told situations are centered in diverse areas as surgical and therapeutic decisions, do not reanimate orders, institution of measures of life advanced support, decisions on internment/discharge and the nursing care plan, among others, and excites questions that are related to bioethical principles: autonomy, justice, beneficence, non-harming, human being dignity and respect, among others, and still with attitudes morally improper as the excessive therapy and the lack of attention to the rights of the sick people. The predominance of its occurrence seems to do itself with the situations of intensive and end of life care.