**Community/Palliative Care**

**PARENTS’ AND SELF REPORTED PERCEPTION OF HEALTH AMONG TEENAGERS IN MAINSTREAM SCHOOL BORN AT EXTREMELY LOW GESTATIONAL AGE (ELGA) AND CLASSROOM CONTROLS**


**Aims:** To compare health status and health related quality of life of teenagers in mainstream school born before 29 weeks of gestation and classroom controls

**Methods:** Of 218 survivors from three regional cohorts (Scotland, former Northern and Oxford regions) born in 1983–84, 174 (80%) were traced and assessed at age 15–16 years. Using the eight attributes of the Health Utilities Index Mark 3, vision, hearing, speech, emotion, pain, ambulation, hand use and cognition, the health status and derived utility score of the 145 teenagers in mainstream school and 107 classroom controls were measured using questionnaires to both parents and the teenagers themselves

**Results:** Parents reported two or more attributes affected in 30.8% index teenagers compared with 18.2% controls (difference 12.6%, 95%CI 1.9—23.3). On self report two or more attributes were affected in 42.8% of index teenagers and 37.4% of controls (difference 5.4%, 95%CI 8.6—17.6). Based on health states reported by parents, a utility score of <0.75 [1.00 = ‘perfect health’ and 0 = ‘dead’] was derived for 25.7% of index teenagers compared with 8.2% of controls (difference 17.6, 95% CI 8.5—26.6). Based on self report, 19.6% of index teenagers and 11.2% of controls had a utility score of <0.75 (difference 8.4, 95%CI −0.6—17.3).

**Conclusions:** Health related problems persist into adolescence in extremely preterm survivors who are in mainstream school. There are differences in proxy reports of health status by parents and the views of teenagers themselves.

**EXPERIENCES OF PARENTS WITH LIFE-LIMITED CHILDREN: A QUALITATIVE STUDY**

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**Background:** Life-limiting conditions other than cancer impose a huge, long-term burden on the family of the affected child. These conditions usually require long term care, with the expectancy of sure but slowly disabling life-limiting conditions.

**Aims:** The study intends to explore the experiences and needs of families with children having life limiting illnesses. It attempts to identify parents’ problems, to match care and support to the family’s needs.

**Methods:** A qualitative study was performed, using in-depth interviews. Purposive sampling was used, selecting parents systematically from the list of a children’s hospice. Triangulation and respondent validation techniques safeguarded the validity.

**Results:** The overall emotional and behavioural patterns were similar to those described by Kubler-Ross. However, the sequence of the recognised stages was frequently different, and several attitudes (such as anger, denial and bargaining) were prolonged and present at the same time.

**Conclusions:** Attitudes were also seen. Emotional distancing, followed by guilt and frustration, were observed when a fatal illness was diagnosed perinatally. A strong need to find a person to blame was seen; mothers accused themselves or professionals—resulting in disbelief in professionals’ judgement. Acceptance of the inevitable loss of the child meant recognising the child’s contribution to the parent’s emotional and personal growth.

**CULTURE, STRESS AND THE PARENT–CHILD RELATIONSHIP**

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**Aims:** This qualitative research project, based on the principles of grounded theory, has used a series of semi-structured interviews with parents to explore parental understanding of the culture in which today’s children are growing up, the influences of that culture on their parenting and the potential impact on their child.

**Methods:** Sixteen mothers and one father whose children are participating in the Avon Longitudinal Study of Pregnancy and Childhood were interviewed. Data from the transcribed interviews were analysed for emerging themes relating to parenting and areas where parenting can go wrong within contemporary culture.

**Results:** Analysis of the data suggested several key areas in which our culture imposes particular stresses on parents and as such does not support families of children. Prominent areas of stress were time pressures, particularly in the work-home arena; expectations of children to be active and achieving; financial pressures, and the impact of consumerism on children and their families. These areas of stress were specifically linked with difficulties in parenting, including child abuse.

**Conclusions:** These data tend to support the notion that parents themselves hold a very positive view of their children, are committed to them and value them as individuals. They do however perceive parenting as being hard work, and this is exacerbated by social structures and attitudes that do not value or support children and their families.

**ATTITUDES TO IMMUINISATION WITH MENINGOCOCCUS C CONJUGATED VACCINE AND MMR**

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**Aims:** To understand how parents decide whether or not to vaccinate their child with two vaccines receiving contrasting publicity.

**Subjects and setting:** 167 parents of children attending community child health clinics during a media campaign promoting the meningococcal type C (MenC) vaccine.

**Study design:** Anonymised questionnaire enquiring about beliefs and experience of Measles, Mumps, Rubella and Meningococcal disease, and beliefs about the vaccines, their side effects and efficacy.

**Results:** Similar numbers were prepared to have their child immunised with MMR and MenC vaccine (87.5% vs. 85%). The decision to vaccinate with MMR was unrelated to experience of Measles in the family, beliefs about Measles mortality rates, disease severity or complication rates or concerns about vaccine side effects. Those that overestimated meningococcal mortality (72%) were more likely to accept MenC vaccine than those that underestimated it (95% vs. 76.5%, p=0.04).

Parents believed that complications were more likely with Measles than Meningococcal disease and death more likely with Meningococ- cus, rating 4.4 vs. 2.1 (p=3 x 1”) in an arbitrary scale out of 10. The vaccines were thought to be similar in terms of their rate of side effects.

Those that had heard publicity for the MenC vaccine were more likely to want the vaccine (90% vs. 38% p=0.00003).

**Conclusions:** The parental decision to vaccinate children is complex but relates to perceived risk and disease severity. Health educationists should emphasise the dangers of the diseases and empower parents to make informed decisions.

**CHILDREN REFERRED FOR SPECIALIST PALLIATIVE CARE: FIRST 25 PATIENTS**

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**Introduction:** Wales has only the second hospital-based tertiary paediatric palliative care service in the United Kingdom. It is based in the Department of Child Health in Llandough, Cardiff, and has close links with the Department of Paediatric Oncology. We report a series of patients referred to the service in its first few months, and make some observations on the contrast between adult and paediatric palliative care models.

**Methods:** Case series of first 25 patients referred to the service date, including source of referral, diagnosis, major symptoms reported, and management approach adopted.

**Results:** There were 16 oncology and 9 non-oncology patients. Four of the patients with non-malignant disease had no clear diagnosis. The remaining five had diverse neuro-degenerative problems. All were under the care of at least one paediatrician. Between one and six additional healthcare professionals were involved. Psychosocial symptoms were recorded in 12 patients. The commonest physical symptoms were pain (15 patients), nausea and vomiting (8 patients), constipation (7 patients) and agitation (9 patients). The palliative care
consultant became the only responsible consultant in one case; care was shared in all the others. 17 patients died: at home (14), children’s hospice (2) or in hospital (1).

Conclusion: While the number of children requiring palliative medicine for cancer is relatively small, the need for symptom control expertise extends well beyond this. There is a role for a specialist palliative care service for children. The adult model of palliative medicine, which serves the needs of cancer patients well, must be extrapolated with caution to children.

**THE ROLE OF AN INTERAGENCY DISCHARGE DIAGNOSTIC OUTCOMES FROM A PILOT PROJECT**

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**Aims:** To map the interventions and strategies used to plan complex discharges; to evaluate good practice models; to identify gaps in service provision; to develop a framework to ensure that discharge is both effective/supported; to deliver a service within a tertiary children’s unit in order to develop working partnerships and facilitate discharge.

**Methods:** A grant from the Northern and Yorkshire Region was used to set up a ‘complex discharge planning team’ (CDPT) comprising hospital social worker and nurse. A child with ‘complex needs’ was defined as ‘one requiring input from more than one agency or group of professionals where communication will be assisted by robust discharge agreements’. Details of case work were recorded and a regional directory of child health services developed for future electronic reference.

**Results:** Over 6 months, 27 children were referred to the CDPT; half came from within the health district (Leeds) and half were from the region. All children had complex social problems (main reason for referral in 10/27); other needs/issues included: nutritional support (70%), severe respiratory disease (52%), >3 complex needs (48%), severe learning disability (37%), and neurological disease (15%). Regular review meetings with action plans defining roles/responsibilities were vital to timely discharge; limited community resources resulted in identified needs not being met, with finding paid carers a major problem.

**Conclusions:** Multidisciplinary discharge planning should start from admission, co-ordinated by a designated ‘care manager’; the time consuming nature of the process is often underestimated by clinical teams. Effective discharge planning can improve discharge planning for children with complex needs.

**DIAGNOSTIC OUTCOMES FROM A PILOT PROJECT OF STATUTORY MEDICALS DONE BY COMMUNITY PAEDIATRICIANS**

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**Aims:** To evaluate the diagnostic yield from a pilot project of Community Paediatrician’s doing the Statutory Medicals for ‘Looked After’ children.

**Method:** A retrospective review of the new and existing diagnoses from 300 medical examinations of 297 children.

**Results:** Previous medical concerns n=115 (39.9%). In this group there were 23 mental health issues (behavioural problems 7, ADHD 3, previous attendance at CAHMS not otherwise specified 13). 20 developmental concerns (generalised developmental delay 15, speech and language delay 2, autism 1, cerebral palsy 1), 84 medical issues including asthma 25, epilepsy 8, one each with arthrogryposis, Angelman’s syndrome, congenital hypothyroidism and foetal alcohol syndrome. 92 new medical diagnoses were made. There were 21 mental health issues identified (behavioural problems 5, encopresis 3, new onset of enuresis 3, ADHD 1, Anorexia nervosa 1, attachment difficulties 6, bullying 1, self harming behaviour 1). 8 new developmental issues were identified, 4 with generalised developmental delay, 3 with speech and language delay and 1 with developmental co-ordination difficulties. 67 new physical health issues identified including short stature 7, asthma 5, eczema 2, food allergies 2, training of residential staff in use of an Epipen 1, strabismus 5, Wardenburg’s syndrome 1 and undescended testes 1.

**Conclusion:** Children looked after by the Local Authority often have a history of neglect of their medical needs. We identified 92 new diagnoses in 297 patients. The mental health diagnoses are significantly under represented compared to previous research. Further work on improving our mental health diagnostic skills is necessary.
**Method:** A case report of a 13 year old girl who died of Juvenile onset Huntington's Disease in a children's hospice.

**Results:** This child died 3 years after her diagnosis and 8 years after she first presented with symptoms of this rare dominantly inherited condition, proving a challenge for both diagnosis and management. Her major symptoms in the terminal phase included pain, dystonia and muscle spasm, agitation and excessive respiratory secretions. 30% of the drugs that were required to control her symptoms were used ‘off licence’. There is a lack of evidence-based treatments in Palliative Care, and a need to use drugs ‘off licence’. The report also considers other ethical issues that arise in Paediatric Palliative Care, such as gastrostomies for children with neurodegenerative conditions, and the dilemma of withdrawing treatment.

**Conclusion:** Paediatric Palliative Care is usually discussed with reference to children with malignant conditions, however far more children die from non-malignant conditions and this report offers the opportunity to consider the palliative care management of a child with a neurodegenerative condition.

**G191**

**CUTANEOUS GRANULOMATA AS A PRESENTATION OF IMMUNE DYSGREGULATION**


Cutaneous granulomata can occur as a component of a number of diseases including typical and atypical mycobacterial infections, sarcoidosis, granuloma annulare or as a manifestation of immunodeficiency.

We describe four cases of granulomatous skin disease in children. All four presented with skin lesions before the age of eighteen months. The cutaneous lesions in each child were stereotyped, manifesting as red/purple papules with central atrophy and scarring, affecting the face and limbs but sparing the trunk. Biopsy showed intradermal granulomata with histological features not consistent with mycobacterial infection. Furthermore, lesions did not respond to atypical or typical antimycobacterial agents.

At presentation all children had overtly normal immune function. All four subsequently developed abnormalities in quantitative and/or qualitative aspects of immunity: hypogammaglobulinaemia, low numbers of CD8 positive T cells and overt immune dysregulation with life threatening haemophagocytic syndrome.

All cases responded to oral corticosteroid therapy but the patients developed significant side effects and required steroid-sparing agents. Responses to the latter, which included intravenous immunoglobulin and azathioprine, were variable and all alternative agents were less efficacious than steroids.

Granulomatous skin lesions are an important early sign of possible immunodeficiency, and long term dermatological and immunological monitoring is recommended.

**G192**

**THE PARENTAL VIEW OF ECZEMA AND ITS MANAGEMENT**

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**Aims:** To assess a range of parental concerns and perceptions regarding eczema. The areas concentrated on were 1) adherence to management regimes 2) effect of eczema on the sleep of children and carers 3) satisfaction with the medical care 4) parental attitudes towards steroid creams 5) attitudes towards, perceived curative qualities and use of “alternative therapies” 6) parental perception of their child’s allergies and food intolerances.

**Methods:** Questionnaires were distributed to parents of eczema-tous children at outpatient appointments and were completed whilst in the waiting area.

**Results:** 128 questionnaires completed. 1) Strict adherence to treatment rose from 38% of respondents to 83% when symptoms worsened. 2) 70% of children lost sleep each week (median hours lost = 8.5). 60% of carers sleep was affected (median hours lost = 10). 3) 79% of parents were satisfied with their child’s care. 14% of parents felt that their expectations for the consultation were not met. 4) 22% of parents did not perceive any effect of steroid creams. 48% were less happy to give their children steroid creams than other medicines. 58% gave it “exactly as prescribed”. 5) 78% of parents believe that alternative therapies could help eczema. 6) 66% believed that food affects eczema. 77% believed that allergies affect eczema. 47% believed that allergies cause eczema.

**Conclusions:** Parents harbour misconceptions about eczema, they do not treat it consistently or adequately and have faith in alternative therapies. Unless these issues are addressed, there will continue to be a high rate of non-compliance with eczema treatment.

**G193**

**A CASE OF TRICHORHNOPHALANGEAL SYNDROME IN MONOZYGOTIC TWINS**

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Patients with Trichorhnohalangeal Syndrome commonly present to dermatology clinics with curly, sparse, brittle, slow growing scalp hair.