

Atoms



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HEARING FROM OUR PATIENTS

Few peer review journals include articles written by patients (or in our case, parents). Some do have 'patient columns', but those articles are usually written by physicians, reflecting their experiences as patients, rather than by patients without training in healthcare. In an attempt to provide patients and parents with a 'voice' in ADC we are pleased to introduce our patient column – BackChat. Harvey Marcovitch, former Editor in Chief of ADC, is actively soliciting the articles. The intent of the column is not to criticise individual physicians or hospitals, but rather to make ADC more patient centred. What is patient centred care? Although numerous groups have offered formal definitions, and Moira Stewart¹ has eloquently discussed the issue of an international definition, from my standpoint, patient centred care represents the 'art of medicine'. It involves listening intently to patients in an attempt to understand what they want from providers and the healthcare system. For some patients this may be just information, for others they may want help interpreting facts, and finally for a small group, it may be to make important decisions on their behalf. In my experience, when children are acutely ill, particularly with a serious illness, parents want information, but also want clinicians to be directive around diagnostic and therapeutic decisions. When the problem is less serious, or chronic, then many parents want to actively participate in decision making. This column should be seen as experimental – our intent is for it to evolve so that ADC can be characterised as a patient centred peer review publication.

THE ORANGE CARD SURVEILLANCE SYSTEM

A wonderful strength of the UK child health research community is the British Paediatric Surveillance Unit, which allows consultant paediatricians to indicate if they have seen a child with a specific condition that is currently under surveillance. The response rate remains above 90%, indicating the importance that paediatricians attach to

this endeavor. In a report by Devereux and colleagues, the number of children with progressive intellectual and neurological deterioration (PIND) is described. A total of 1400 cases were reported during the five year surveillance period. Of these, 798 had PIND. Additional information about geographic distribution of cases, and the relationship between PIND and ethnicity and consanguinity are in the report.

See page 8

BREASTFEEDING: THE LEGEND GROWS

The list of benefits of breastfeeding in developed countries continues to grow. It has been well documented that breastfed infants are less likely to develop respiratory related illnesses during the first year of life. The benefit for women may be even more pronounced – women who breastfeed for long periods of time are less likely to develop breast cancer.² Horne and colleagues report that breastfed infants are significantly more arousable than formula fed infants at two to three months of age. This may explain the epidemiologic data that suggest breastfed infants are less likely to die from sudden infant death syndrome than formula fed infants. Sadly, the US and UK have made only marginal progress in the campaign to increase breastfeeding rates. While six month breastfeeding rates exceed 80% in Sweden and Norway, they are around 25% in the US and UK. It is no mystery how to impact on initiation rates – when a hospital achieves Baby Friendly status, early breastfeeding rates nearly double. After my institution became Baby Friendly in 1999, breastfeeding initiation rates rose from 58% to 87%. We became Baby Friendly because of the dynamic leadership of a single paediatrician – Bobbi Philipp. There are only 38 Baby Friendly hospitals (of 3500) in the US. Unfortunately, impacting on duration of breastfeeding is more complicated, but we must start with a concerted effort to increase initiation rates.

See page 22

SHORT STATURE: ARE THERE LONG TERM CONSEQUENCES?

The recent approval of growth hormone for use in healthy (but short) US children is controversial. The cost (about \$25,000 per year) need for daily injections, and some concerns about long term complications (for example, changes in insulin sensitivity) make widespread use unlikely. One of the major justifications of use is related to the impact of height on psychosocial functioning. In a report from the Wessex Growth Study, a group of children, both short and normal, have been followed until the age of 18–20 years. Poorer social functioning, in a number of domains, was related to gender and socioeconomic status, but not adult height. Long term, prospective, community based longitudinal cohorts, like the Wessex Growth Study, are necessary if we are to understand the consequences of normal growth and development, as well as disease.

See page 17

ECONOMIC EVALUATIONS STUDIES

I find reading the various types of economic evaluation studies difficult. There always are many assumptions, the terminology is often mystifying, and I am anxious about viewing issues related to child health in terms of dollars and cents, particularly since we spend so little on child health in comparison to adult disease. Nevertheless, I recognize that paediatric economic evaluations have become part of the landscape of child health research. Ungar and Santos describe the growth of published studies in this area. They evaluated the number of cost benefit, cost effectiveness, cost minimisation, and cost utility analyses reported between 1980 and 1999. There were a total of 61 reports published between 1980 and 1984 in contrast to 440 between 1995 and 1999. Whether these studies have impacted on either clinical or health policy decisions is uncertain.

See page 26

REFERENCES

- 1 Stewart M. Towards a global definition of patient centred care. *BMJ* 2001;**322**:444–5.
- 2 Collaborative group on hormonal factors in breast cancer. Breast cancer and breastfeeding: collaborative reanalysis of individual data from 47 epidemiological studies in 30 countries, including 50302 women with breast cancer and 96973 women without the disease. *Lancet* 2002;**360**:187–95.