

Selected abstracts from Paediatrics: things you don't grow out of (managing chronic disorders)

CHRONIC RESPIRATORY DISEASE

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Background The chronic respiratory problems that we pass on to our adult colleagues vary from asthma, which is becoming so common that we will soon have to be arranging counselling for non-asthmatics, to a number of much less prevalent syndromes such as ciliary motility disorders and sarcoidosis.

In the middle of this prevalence range is cystic fibrosis, whose management is an excellent exemplar of the approach to many chronic disorders, comprising antenatal and postnatal screening and diagnosis, breaking the bad news, encouraging parental involvement in management and in management decisions, deploying scarce resources as usefully as possible, providing long-term support for patient and family, handling all manner of medical and psychosocial crises and finally providing sensitive and appropriate terminal care.

Methods or theme In common with other chronic disorders, respiratory disorders give rise to a broad range of problems in addition to those related to medical management. Parental fear, guilt and shame attend the child's negative self-image, feelings of isolation and loneliness, and sometimes overt psychiatric disorder. However, although these problems are common to all chronic disease processes, they reflect the complexities inherent to each specific disease, and supportive management requires not only psychological diagnostic and counselling skills but also a detailed knowledge of the disorders themselves.

There is therefore a need not only for skilled counselling and other supportive services to be provided for chronic respiratory disorders, but also for such support to be given by individuals who are knowledgeable about disorders themselves.

In asthma, perhaps the most common problem is impaired quality of life resulting from poor compliance with therapy. This in turn may result from embarrassment about using inhalers in public, or even criticism from others about drug usage. Psychological problems are common, and were probably better managed when asthma was considered a psychosomatic disorder.

In cystic fibrosis, there are major problems with self-esteem and self-image, with the imposition of therapeutic

regimens of great intensity and complexity, with issues surrounding infertility and child-bearing and with issues related to mortality.

Conclusion These conditions should be seen not as simple medical problems to be managed pharmacologically, but as complex multidisciplinary problems.

References

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Keywords: Asthma, cystic fibrosis, complications, counselling, psychosomatic disorder, psychosocial problems

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PAEDIATRIC NEUROLOGY

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Background Established neurological disorders of childhood stay with you for life. There are few chronic neurological disorders that can yet be cured, although progression can be modified and symptoms ameliorated. Survival and life expectancy have improved, and that in itself brings new problems of care and provision of services into young adult life.

There are transient neurological disorders in childhood that disappear spontaneously with time. Examples include global developmental delay at the slow end of the normal spectrum, and benign epilepsies of infancy, which affect a genetically predisposed, immature brain.

Treatment for certain brain tumours now promises cure, but there are still the risks associated with radiotherapy and chemotherapy.

Prevention of acquired brain damage in children has had some success, for instance haemophilus and meningococcal immunisation and seat-belt laws, but there are still too many pedestrian head injuries in the UK and non-accidental brain injuries.

I will discuss three common childhood conditions, two of which are lifelong – cerebral palsy and Duchenne Muscular Dystrophy (DMD). Survival in severe cerebral palsy and DMD is improving, and new cohorts of children are graduating into adult services. This makes

greater demands on health and social support, and introduces ethical issues about getting the balance correct between survival and quality of life.

The third condition, epilepsy, may change and improve as the child goes through adolescence, but still has the potential to affect quality of life in adulthood.

Keywords: Brain tumours, cerebral palsy, Duchenne Muscular Dystrophy, epilepsy, neurological disorders, pedestrian head injuries, transient neurological disorders

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MAKING DIFFICULT DECISIONS: USING AN ETHICAL FRAMEWORK

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Background Ethical dilemmas arise when clinical or other facts cannot determine what should be done, when moral obligations conflict or when the law is ambivalent or silent. They may range in scope from complex end-of-life issues to simple matters of truth-telling over practical procedures, e.g. venepuncture.

The function of ethics is to define and analyse dilemmas, and apply moral theories or principles in an attempt to assist their resolution. There may be more than one or no 'right' answers.

Traditional moral theories include those in which an action's consequences determine its rightness and those

where action is determined by rational consideration of duties. More frequently an analytical approach involving the four *prima facie* principles of beneficence, non-maleficence, respect for autonomy (the right of self-determination) and fairness is used. It may be difficult to determine which principle should be paramount. Good decision-making is characterised by inclusiveness, transparency, reasonableness and accountability.

From the above we can derive two principles that underpin medical practice:

- Act in the best interests of patients
- Obtain valid consent for all interventions

A framework for approaching moral dilemmas includes:

- determining the relevant clinical and social facts
- deciding an appropriate decision-making process
- ascertaining what the law/professional guidance says
- identifying the ethical issues and morally relevant principles
- listing the options and identifying the moral arguments for and against
- choosing an appropriate option and testing whether it can be rebuffed

Outcomes should be reviewed. The experience gained from ethical 'debriefing' may be helpful.

Keywords Accountability, analyse dilemmas, beneficence, conflict, ethical dilemmas, fairness, inclusiveness, law, moral obligations, non-maleficence, reasonableness, respect for autonomy (the right of self-determination), transparency

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