LETTERS TO THE EDITOR

The risks and benefits of cisapride

EDITOR—I read with interest the annotation by Lander and Desai discussing cisapride.1 They conclude that the case against cisapride as a safe and useful agent in premature neonates has not been proved. As the three main indications for cisapride in the newborn (gastro-oesophageal reflux, postoperative ileus, and intestinal dysmotility of prematurity) are self-resolving with time, the only useful study design is a randomised controlled trial (RCT).

There are two small published RCTs on the use of cisapride in the newborn. Enriquez et al randomised infants at the initiation of feeds and reported no difference between cisapride and placebo in the time taken to full feeds (CSM) for those with problematic reflux or postoperative ileus, and cisapride when used routinely in 34 preterm infants.1 However, the following were noted: seven of 18 infants given cisapride had no significant gastric residue at any time compared with only one of 16 given placebo (p = 0.04); and only two of 18 given cisapride developed regurgitation compared with eight of 16 given placebo (p = 0.02). These observations are important. Furthermore, two babies with regurgitation were removed from their study and treated openly with cisapride with success. Although they cannot be included in the analysis, they show that the study population was limited to less worrying infants.

Unless the CSM revisits the question of prematurity, robust trials with cisapride, which is still widely used, will not get ethical approval and a good drug may be lost.

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Editors’ comment


Serum bicarbonate and the severity of dehydration in gastroenteritis

EDITOR—I read with interest Booth’s comments1 on my article1 and I take this opportunity to clarify our findings. Macken- zie et al’s study was fundamentally different from ours. The degree of dehydration was assessed by junior doctors and not specialists; all children were inpatients “thought to be” 5% to 10% dehydrated (only 25% were) and no cases of severe dehydration were included. Most were “social” admissions.

During rehydration, children were not fed, and weight loss from catabolism may have led to underestimation of the degree of dehydration. Children’s weight may vary tremend- ously with vomiting or defaecation and those factors were not included; therefore, the weight increase after admission may not be the “gold standard”2. Nine years later, succes- sive editions of most paediatric textbooks from both sides of the Atlantic still rely on clinical parameters to estimate the severity of dehydration, although they are not perfect.

At Booth’s suggestion, we looked at the percentage of weight gain 24 hours after admission for the 64 children who were admitted to hospital, and compared it with their serum CO2 on admission: those with a weight increase of ≤ 5% had a CO2 on admission of 17 mmol/l (range 11–22); those with a weight increase of 5–10% had a CO2 on admission of 16 mmol/l, and those who gained > 10% had a mean CO2 of 19 mmol/l (range 12–20). There was also a poor correlation between weight gain and the degree of dehydration as assessed clinically.

The ideal parameter to estimate the severity of dehydration would be the difference between admission and pre-admission weight. As the latter is often lacking, physicians can rely only on clinical parameters. It would be interesting to know how Booth immediately assesses the degree of fluid loss in a dehydrated child. Perhaps all textbooks will need to be modified if his methods prove to be scientifically valid.

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Cancer in Sotos syndrome

EDITOR.—We greatly enjoyed reading the article by Cole on overgrowth disorders in childhood.2 While the article alluded to the increased risk of malignant disease among children with Beckwith–Wiedeman syndrome (BWS) no mention was made of the increased risk of cancer in Sotos syndrome.

We recently treated a 3 year old boy with Sotos syndrome for abdominal B cell lymphoblastic lymphoma (Murphy stage III) in accordance with United Kingdom children’s cancer study group protocol 9002. Although his lymphoma exhibited only a partial response to standard chemotherapy, he remains disease free two years later following second look surgery and subsequent high dose treatment with autologous bone marrow rescue.

Non-Hodgkin’s lymphoma has also been reported in three other patients with Sotos syndrome.3,4 Malignant disease in this condition is not restricted to lymphoproliferative disorders and several other types of cancer including Wilms’ tumour, neuroblastoma, hepatocellular carcinoma, and acute lymphoblastic leukaemia have been described. The risk of malignant disease in Sotos syndrome has been estimated as 1 in 41 under the age of four years.5

The literature suggests that the incidence of specific tumour types may differ between individual overgrowth syndromes. In Sotos syndrome, non-Hodgkin’s lymphoma constitutes almost one quarter of reported cases; a very different pattern has been observed in children with BWS in whom Wilms’ tumour, neuroblastoma, and neuroblastoma are responsible for the vast majority of observed cancers.6 Although subject to reporting bias these figures suggest that specific overgrowth syndromes are associated with differing, albeit overlapping, patterns of tumour formation. Such an observation may


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Influence of five years of antenatal screening on the paediatric cystic fibrosis population in one region

EDITOR.—The paper describing screening for cystic fibrosis (CF) by Cunningham and Marshall has a number of important flaws. Any screening programme is targeted at a defined population. The title refers to a “population in one region” without being geographically precise, but the study is of defined population. The title refers to a region (in Edinburgh) and fails to amalgamate data. Our aim was to highlight the importance of antenatal screening stated in our paper remains true. In the seven years before screening there were 39 children born with CF (mean 5.57) and in the seven years after screening 38 children born with CF (in Edinburgh only) there were 20 children born with CF in the south east of Scotland (mean 2.85) (including two children born in 1996 and four in 1997 not included in our study).

We accept that the data of births to Edinburgh residents is not helpful because this was not the population screened. Given the number of cases found per year prescreening (approximately five), and assuming the UK incidence, there should have been about 12 500 live births per year. The births in Edinburgh were about 5000 per year, suggesting about two CF cases per year. This discrepancy warrants comment by the authors.

The prescreening data raise more issues that they solve. The direct reduction in CF live births is given by the number of abortions. This can only be determined by long term population studies of disease incidence and gene frequency. As the members of a population become better informed about the nature and scope of antenatal screening they will adopt more sophisticated strategies to exploit its potential for their own benefit. It is difficult to anticipate the net effect of these strategies. Organisations such as the UK Screening Committee are more likely to accept the case for CF screening if scrupulously accurate data, properly analysed and clearly interpreted, are available. Anything less leads to confusion and can only damage the case.

Information with regard to carrier frequency in this region has recently been reported. The 1 in 20 frequency quoted was a general introductory statement that we did not attach to this region and did not use in any calculation.

The numbers of screened pregnancies in this area have previously been reported by Professor Brock. Our paper attempted to mirror the time period and population used in Professor Brock’s report, to allow the reader to collate both pieces of information. Edinburgh Sick Children’s Hospital CF centre serves the population of south east Scotland. Even when considering this whole region, the effect of antenatal screening stated in our paper remains true. In the seven years before screening there were 39 children born with CF (mean 5.57) and in the seven years after screening there were 38 children born with CF (in Edinburgh only) there were 20 children born with CF in the south east of Scotland (mean 2.85) (including two children born in 1996 and four in 1997 not included in our study).

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Paediatricians tend to forget that injury is the most common cause of death for young children, responsible for just over a third of deaths in this age group. Even in children aged 1 to 4 years, nearly a quarter of deaths are traumatic in origin. In the past decade there has been increasing interest in the prevention and epidemiology of childhood injuries with advances in initial resuscitation and treatment, which depend on a basic understanding of the underlying pathophysiological processes. Some deaths from trauma result from overwhelming damage and are inevitable. Children with less severe injuries may deteriorate quite rapidly and develop respiratory, circulatory or secondary brain problems with death occurring within several hours. The changes in training of paramedics and improved resuscitation training of doctors and hospital staff have helped improve the outlook for these children while advances in intensive care, improved in transport, and faster high quality imaging have also been of benefit. Finally, there is a smaller number of children who die later from infection, multiple organ failure or brain damage secondary to raised intracranial pressure—some of these are preventable.

Therefore it is timely for Injury in the Young, which tries to bring together the mechanisms of injury and some of the abdominal physiological processes that supervene. The authors review experimental and empirical data to look at more rational treatment regimens for injured children. A wide panel of experts have been brought together in this well edited book, from disciplines including paediatrics, accident and emergency medicine, anaesthetics, and paediatric public health. Although the list of contributors is named and their work places stated it would be helpful to have details of the authors’ current posts to give readers an idea of the diversity of their skills.

The editors have had a difficult job squeezing all this information into a book of just over 300 pages, so they have rightly concentrated on the most common life threatening injuries in children including head injury, near drowning, burns, and chest injury. Unfortunately, they omit severe abdominal trauma; there should have been two or three pages of text about immediate treatment as ruptured spleen, liver or vissus can cause major diagnostic problems and death in the multiply injured child.

What about child abuse? This is covered in almost two pages of text with just two references, one to fractures caused by child abuse and another general reference, both from the BMJ in 1995. This is disappointing, although the final chapter is on children’s rights and child protection.

Overall the book is well laid out and carefully produced. The authors state its targets as accident and emergency specialists, paediatric surgeons, anaesthetists, and intensive care specialists, as well as paediatricians. There is no doubt that trainees and others with an interest in the subject will find the book a useful reference.
source. My preference would have been for more illustrations to complement the text. The academic approach to many topics, such as acute respiratory distress syndrome, will mean that this text is useful for researchers.

The emphasis on primary prevention is covered well. Reducing injury from road traffic accidents is of major interest to community paediatricians. Other paediatricians are likely to be involved in initial resuscitation during the first hour or so of admission to hospital. In many units they will have an ongoing role in the acute management of some patients, such as those with severe head injury. Indeed, injury treatment is rapidly becoming multidisciplinary and no particular doctor has all the answers. If there are to be advances in management, basic mechanisms of injury and secondary damage must be understood. This book helps with this process and will be useful to staff in units treating paediatric trauma patients.

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Consultant Paediatrician


“. . .it is not uncommon for the day to start at 5.30 am with preparation of breakfast and attendance to the personal needs of the parent. The child may call home at midday to toilet the parent and prepare lunch. In the evening shopping, cooking and cleaning may take priority over school homework. Often a child puts the parent to bed and sleeps in the same room in order to turn her during the night. The involvement in personal care such as changing of sanitary towels and catheter management has also been reported."

A day in the life of a child caring for a parent with multiple sclerosis.

Children caring for their parents or other children in the family are familiar to those who have worked in the third world but even with the UK’s welfare service and safety net there are between 15 and 40 000 child carers nationwide. Oddly, just before starting to read this book I attended a meeting at a local school where we have begun a system of multiagency review of pupils not in school; the first young person discussed was caring for a parent and grandparent. We need to be more aware of this problem—hence this academic overview is welcomed.

Written by a trio of sociologists the book comes from a community and family based perspective but there is much of value to paediatricians. The authors first describe three perspectives on child carers: the impact of disability on the family, which is mainly medical; the children’s rights angle; and the view of the disability rights movement. The first is viewed rather negatively as being narrow, but to me portrays the emotional and educational impact on the child of being a carer: “Every child needs to grow up in a stable environment characterised by consistent relationships. Many children are instead subjected to unending crises stemming from a parent’s illness and repeated hospitalisation which provoke chronic uncertainty and unresolved grief that can be more stressful to a child than the loss of a parent through divorce or death.” Thus the role of carer can restrict the child’s education, can create physical burdens that their bodies are unprepared for, and confront them with a picture of suffering that has long term harm.

The children as carers literature tells us children take on care giving roles: a major factor is lone parenthood, another is reluc-
tance of their father to take on caring activity; sadly the failure of services to recognise the needs of children and indeed sometimes to withdraw their provision is a notable factor. Inevitably, poverty is an ever present contributor. We learn of the involvement of young carers in intimate tasks; one girl cared for her father from the age of 9 following a stroke: “I did stop showering him at about 14 or 15, but recently that’s started again. I didn’t like showering him any more. You know, I thought ‘I want my privacy, I’m sure he wants his’, and I’m sure he doesn’t like me having to shower him and I certainly don’t like doing it. I suppose it was embarrassment. You know—it takes up so much time, it takes about an hour from start to finish, you know, get him in the shower and get him out and dressed.”

Children carers have little power or status and families assume that what has begun voluntarily will become embedded in their habits, even though the young person would rather relinquish the role.

School attendance and performance is poor among young care givers; one study found that one in four were missing school. It is a poor reflection on school health services that support has not been provided to help these children back into school. I found that the authors take a long time to make a few simple points. Having learned that caring is common and not beneficial for children, I wanted to know what I should do but there are no clear messages. The UN Convention on the Rights of the Child should underpin policy, but its impact in the UK has been limited. Only 11 of 71 local authorities defined these children as in need under the Children’s Act. The Carers Act 1996 ensures that children may request to have their needs assessed but in a typical British Catch 22, the Act does not oblige departments to provide any services.

A useful type of support are the Young Carers’ Projects with now over 100 in the UK. These raise awareness, develop supportive services, act on behalf of young carers to ensure that they receive appropriate benefits, and arrange leisure activities.

The authors identify the need to inform young carers on medical conditions, pointing out that this is woefully inadequate and that many children know so little about their parents’ medical condition that they had invented their own version of diagnosis, prognosis, and consequences.

It saddened me that in the section on the role of professionals in identifying and assisting young carers, there is no mention of paediatricians. Is this because they are seen as purely medical, or because they have little contact with young carers? I suspect that it is the former, and that we need to be more outspoken about our wish to work across disciplines on behalf of children’s health. We also need to look out for child carers in the families whom we see.

What I searched for was a child or young person’s perspective, to try and understand some of the positive aspects of caring. I found little, perhaps because little has been done. Usually children have pretty good answers to difficult questions. Searching hard, I found a reference to a national survey of young people in which they thought that children of 10 should make their own bed and help with the washing up, children of 14 could take a part time job, young people at 16 could baby sit a child of 5, and 18 year olds could marry and vote. Caring for a parent was not mentioned.

So what might paediatricians take away from this book? First, an understanding that children who are carers are around and are being harmed; second, that they are often invisible to the agencies who should be helping; and third, that we have a role in highlighting this type of exploitation, as well as looking out for young carers among our patients. We would do well to network with the agencies locally who have young carers’ projects. Only when I was writing this did I discover who they are in my district.

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The risks and benefits of cisapride

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Updated information and services can be found at:
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