LETTERS TO
THE EDITOR

Rapid responses

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The editors will decide, as before, whether to also publish it in a future paper issue.

Life expectancy in cerebral palsy

Editor,—The recent study by Hutton, Colver, and Mackie in some respects a useful addition to our knowledge of survival in cerebral palsy. Unfortunately there are substantial problems with the paper; we note three of them below.

1. In figure 1A it appears that in the most seriously affected group, who had a Lifestyle Assessment Score (LAS) >70%, there is 100% survival to age 9. This scarcely seems plausible when, as the graph indicates, 20% of these survivors die in the next 9 years. The explanation is that the most severely disabled children, with LAS 70% or more, have to survive to age 5 to be assessed by LAS. Thus the severely disabled children who die before age 5 have no LAS, and are excluded (actually, it appears from the graph that some children are labelled as (value) later than age 5).

2. The resulting bias could have serious consequences. For example, in a lawsuit involving a neurologically devastated 2 year old child a plaintiff may cite Hutton et al to argue for 100% survival over the next seven years. 2. Hutton et al’s results show that, as is well known, low IQ and/or poor mobility correlate with reduced life expectancy. In his commentary, Dr Rosenbloom uses this evidence to argue that the cognitive disability and its variability and in this respect with the variables of the study of the Merseyside area is this possibility mentioned. As a result, the latter study has frequently lead plaintiffs to oversize survival of children with the most severe disabilities.

3. In their table 5, Hutton et al state that in our California study the odds ratios for various hazards were lower than in several other studies. For example, in table 2 of our article we gave a hazard ratio of 3.8 for two year olds who were tube fed, compared with those who were not. Hutton et al then proceeded to speculate at some length on what accounts for the transatlantic difference.

The real reason is simple: the California database has many more variables other data bases, so the marginal effect of any one of them—that is, when the others are held constant—is smaller. For example, our table 5 showed that if no other factors are taken into account the hazard ratio for tube feeding (compared with children who could self feed) was 23.6—a much larger ratio than the above 3.8, and in fact about as large as that in Hutton et al’s table 5. In addition, the definitions of mobility etc in the various studies are very different.

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Reply

We thank David Strauss for his interest in our work but he fails to substantiate his claims that there are “substantial problems” with it.

First, we wish to correct an error in our article on page 470, column 2, line 11: “dying before" should read “surviving until".

With regard to Strauss’s remarks on LAS, both the abstract and the results section include the phrase “survived to age 5", so Strauss has not explained our result, but merely repeated this information. Even the brief précis of the LAS paper makes it clear that it would be difficult, if not impossible, as well as unwise, to attempt to complete it for a 2 year old. That someone might misquote our work is not our responsibility.

With regard to mobility and mental ability, we have reported exactly what is measured, and have referenced other work which includes measures different from ours. It appears that Strauss wishes we had speculated about information we do not have. Note that IQ was constructed to have a mean of 100, and standard deviation of 15. On this scale, IQ less than 50, our definition of severe IQ less than 50, our definition of severe disability. A value which is substantially less than 23.6, and than our results. Further, Strauss states that this lower ratio is for a more disabled group: “But our definitions are very different from yours. Our ‘bad’ group is ‘no functional use of hand’...while your ‘severe functional disability’ group is much more inclusive...". Thus the “reason” Strauss gives fails to explain the difference in results for multivariate analysis.

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Evolving practice

Editor,—I am aware that a respected scientific journal does not normally indulge in political issues but you seem to be setting a precedent by “Reflecting on Redfern”.

As a registrar at the Alder Hey Hospital in the 1980s, I was one of those taking consent for post mortem from parents of children dying in the cardiac unit. It was one of the most difficult jobs I have ever had to undertake. It was done, not to provide specimens for museum, but to provide parents with as much knowledge as possible about why their child died. It was regarded as the parents’ right to have this information, and that was the spirit in which consent was obtained.

It is true that details of the procedure were not volunteered but neither were they withheld if requested, which was hardly ever. As many people have commented, it was not the intention to deceive but to avoid distress. The lack of probing by parents only seemed to confirm their wish not to know. I believe I undertook this task with honesty and integrity. I feel no shame in my actions and have no wish to offer an apology.

Professor Hall was correct to say we should all be looking at what we do now, for which we shall be castigated in the future. Inevitably something will emerge but does this mean we are all currently acting in a paternalistic, arrogant, callous fashion. I do not think so.

If, in the 1980s, I had been required to gain specific permission for organ retention I could have accepted that as a patient consent. However the system and parents did not request that I did. Why is it necessary to effect this change in practice in such an agonising fashion? The answer is in our malevolent British media, who are constantly on the lookout for an evolving practice but need scapegoats and whipping boys.

We need as a profession to respond to changing expectations of society, but must we do so in such a self flagellating manner?

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Fertility preservation in children—scientific advances, research dilemmas, and ethical consent

EDITOR,—The two publications on fertility preservation for children1 raise important issues but several issues need to be clarified.

Specifically, intracytoplasmic sperm injection (ICSI) is not a method to reverse male infertility in whatever circumstance. ICSI provides an effective solution to severe male infertility problem but offspring and partner issues need to be considered carefully.6 7 The suitability of pre-pubertal testicular tissue is questioned in the context of research. Such cryopreservation and in vitro manipulation of prepubertal testicular tissue is stated as being “entirely experimental”. It is also true of adult testicular tissue which may similarly harm prepubertal children.

The question of peripubertal boys and the use of rectal electrostimulation raises serious important issues about the pain and psychological effect this procedure as a “first sexual experience” could have on the patients future sexual development and outlook.8 9 The procedure needs to be performed under anaesthesia. Any suggestion that this approach could be tried on peripubertal patients would be ill advised since aiming to obtain an ejaculate necessarily signifies post pubertal status and one has to be certain this level of maturity has been attained. This technique could be open to abuse, for in strict clinical settings where masturbation is forbidden, a parent could ask and consent to this procedure in post pubertal boys leading to a conflict in the requirement of an “autonomous consent”. Sperm storage under forced conditions will most likely be illegal, with enormous consent. Sperm storage under forced consent is “entirely experimental”. This is also true of prepubertal testicular tissue which may similarly be done by persuading Parliament through professional or patient representation to enlarge the regulatory remit of the HFEA, to help enhance patients interest, and in achieving consistent policies. Furthermore, it should be recalled that the UK legal landscape has changed significantly with the Human Rights Act 1998,10 favouring patients determination and sensitively engaging this Act may become a useful option.

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Life threatening airway obstruction in a newborn following ingestion of sterilising tablets

EDITOR,—Sterilising tablets have been marketed and widely used to sterilise infant feeding bottles for the past 25 years.1 Accidental ingestion commonly results in mild gastro-intestinal irritation.2 Severe airway obstruction has been reported in an older infant.3 Recently a 4 day old infant presented to our hospital with features of acute upper airway obstruction following accidental ingestion of sterilising tablets. The mother had found her struggling to breathe, with profuse secretions and stridor. Following prompt endotracheal intubation and mechanical ventilation for 48 hours. Massive swelling of the epiglottis, tongue, and arytenoids was noted at intubation. Severe stomatitis and oral ulcerations followed, requiring nasogastric feeding for two weeks. In addition to ventilation, treatment involved airway toileting to clear secretions, a short course of corticosteroids, and nutritional support.4 Upper gastrointestinal contrast studies excluded oesophageal stricture. The tablet was given to her by her 4 year old sibling, who was very keen to share babycare since the birth of her little sister. She later admitted to having managed to retrieve the tablets from the kitchen cabinet, unwrap the foil, and feed the baby while her mother was asleep. To our knowledge this is the youngest case reported.

Sterilising tablets are available as paper or foil wrapped strips with dichloroisocyanurate and sodium bicarbonate as contents; labelled for infants and children. They produce an exothermic and effervescence reaction in contact with water, resulting in production of hypochlorite. The combined thermal and chemical injury in situ causes severe oedema of the epiglottis and arytenoids, resulting in airway obstruction. In both our case and a previous report,5 an enthusiastic older sibling was able to unwrap the tablets and feed the baby. There is an urgent need to deliver these tablets in childproof containers and increase parental awareness in order to prevent potentially fatal complications.

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