LETTERS TO THE EDITOR

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Life expectancy in cerebral palsy

EDITOR,—The recent study by Hutton, Colver, and Mackie is 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 are excluded (actually, it appears from the graph that some children are evaluated even later than age 5).

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 usefully asks whether extreme immobility or mental impairment would give an even greater reduction. The answer is clearly yes, as indicated by our own work and is also acknowledged by other workers in the area. Indeed it must be so because an extensive literature shows a much higher survival rate for children who can self-feed compared with children who could not. Hutton et al’s table 1 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 any 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 wishes we had speculated more about 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 understandable, 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, fewer than 4 in 10 000 people would have an IQ less than 50; our definition of severe cognitive disability. Fewer than 5 in 10 million people would have an IQ of less than 20, the number mentioned by Dr Rosenbloom.

It seems obvious that persistent vegetative state or indeed decapitation, is smaller. For example for ventilation twice a year are clearly additional, and largely independent risk factors for death which any court would take into account.

With regard to hazard or odds ratios, our discussion does comment on multivariate versus univariate models. Whether univariate or multivariate, one still has a relative statistic, so that any lack of similarity in the baseline categories will be relevant. Strauss claims that “the real reason is simpl[y]” the difference between multivariate and univariate analyses: he gives hazard ratios for tube feeding, and states that the univariate ratio of 23.6 is “about as large as any in Hutton et al’s table 5”. However, Strauss fails to quote a factor—hand use—which, unlike tube feeding, can be easily compared with our work, and that of South East Thames. In correspondence with Hutton, Strauss stated “re hand use: our multivariate OR was 1.52 and our univariate OR was 5.69”: 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 manual disability’ group is much more inclusive...”. Thus the “reason” Strauss gives fails to explain the difference in results for manual disability.

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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 museums, 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 an 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 difficult job. 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 media, who are not content with evoloving 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 ethics of 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. The suitability of pre-pubertal testicular tissue is questioned. Sperm storage under forced consent is also raised. The suitability of pre-pubertal testicular tissue is questioned because the technique supports cryopreservation and in vitro manipulation of prepubertal testicular tissue is stated as being "entirely experimental". This is also true of adult testicular tissue which may similarly harbour child-like germ cells.

The question of peripubertal boys and the use of rectal electrostimulation raises seriously important issues about the pain and psychological effect this procedure as a "first sexual activity" could have on the patients future sexual development and outlook. The procedure needs to be performed under anaesthesia. Any suggestion that this approach could be tried on peripubertal patients would be ill advised since aim 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 cultural 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 possibilities of assault charges to the person taking the sperm sample. There remains also the probability of having mature sperm even if the patient has not yet reached the Human Fertilisation and Embryology Authority (HFEA) stated Tanner stage II maturity level.

Such a situation would present a legally awkward sperm storage scenario with apparently non-regulatory guidance.

With respect to the statement that "fertility preservation procedures for children are experimental", it is worth stating that the whole field of assisted reproductive technology (ART), ranging from cryopreservation of sperm, oocyte, embryo, blastocysts, in vitro fertilisation and in vitro manipulation of prepubertal testicular tissue is stated as being "entirely experimental". This is also true of adult testicular tissue which may similarly harbour child-like germ cells.

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Arch Dis Child 2001 85: 442
doi: 10.1136/adc.85.5.442a

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