LETTERS TO THE EDITOR

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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 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 have no LAS, and are excluded (actually, it appears from the graph that some children are assessed at a later age than 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.

3. Hutton *et al*'s results show that, as is well known, IQ and/or poor mobility correlate with reduced life expectancy. In their 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 shorter survival in the persistent vegetative state, which may be regarded as the extreme case of disability.

In neither HCM nor in Dr Hutton’s previous study of the Merseyside area is this possibility mentioned. As a result, the latter study has frequently lead plaintiffs to overestimate survival of children with the most severe disabilities.

1. 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 databases, so the marginal effect of any one of them—that is, when the others are held constant—is smaller. For example, our 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 the ratio 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 precis of the LAS in the 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, 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 a state of extreme immobility and/or incontinence is much more serious than the 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.

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.² The suitability of pre-pubertal testicular tissue is questionable. Even technological 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 harbor immature cells.

The question of prepubertal boys and the use of rectal electrostimulation raises seriously important issues about the pain and psychological effect this procedure as a “first sexual experience” could have on the patient's future sexual development and outlook.² The procedure needs to be performed under anaesthesia. Any suggestion that this approach could be tried on prepubertal 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 classical terms 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 parent 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 negligible regulatory guidance.² With respect to the statement that “fertility preservation procedures for children are experimental”, it is worth stating that the whole field of human assisted reproductive technology (ART), ranging from cryopreservation of sperm, oocyte, embryo, blastocystos, to the use of IVF, ICSI, and PGD has never undergone classical clinical trial evaluation. In this respect ART continues to be experimental, which is partly why the field is uniquely regulated by statute under the HFEA. There are advantages in bringing children's gonadal tissue under regulation by the HFEA. There are advantages in bringing children's gonadal tissue under regulation by the HFEA. There are advantages in bringing children's gonadal tissue under regulation by the HFEA.

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