Improved survival in cerebral palsy in recent decades?

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SIR–Reid et al.[1] reported on the long-term survival of persons with cerebral palsy in the Australian state of Victoria. They found that rates, predictors, and causes of mortality were in line with reports from other countries. They also found that 'contrary to expectation, no improvement in survival was seen over the 40 years of the study.' We wish to raise two issues, possibly related, regarding this last point.

The first issue is methodological. The authors' approach was to identify four cohorts according to the decade of birth, the first being the 1970s and the fourth being the 2000s. The authors found no difference in the survival of these cohorts. There are several potential difficulties with this approach. By working with mortality of cohorts followed over several decades rather than with observed mortality in a specific calendar year, it does not answer the question of real interest: is mortality lower in later years – the year 2000, say – than it was in 1975? The children in the 1970s cohort, for example, may contribute data to all four decades. A better approach is to work directly with person-years, as in the California studies cited by the authors.[2,3]

A further methodological difficulty with the authors' approach is that it does not take into account the severity of disabilities, a factor known to be of critical importance to survival. Conceivably, for example, because of advances in neonatal medicine, more of the children with the most extreme disabilities survive infancy in the later decades than in the earlier decades. If that were the case then the comparison of birth cohorts would be biased, as the later cohorts would have a greater proportion of very fragile children. Once again, this problem could have been avoided with the use of the person-year approach.

This brings us to the second issue, the use of gastrostomy feeding. The authors write: 'We did not present data on feeding, as tube feeding is an indicator that an individual has severe problems and a poor prognosis for survival, but it is also performed to improve survival and quality of life.'

We agree with the assertions in the second half of this sentence, but they scarcely constitute a reason to ignore the data on tube feeding. As is well known, the need for tube feeding is a powerful predictor of mortality and the use of gastrostomy feeding has become far more common in recent decades.[2,3] It would therefore be important to take gastrostomy dependence into account, along with a measure of motor function, etc. when examining the mortality data for a possible trend over time.

Had the authors taken a person-year approach that properly took account of motor function, gastrostomy dependence, etc. in addition to calendar year, they may have found improved survival over the decades. At the least, if they still did not observe such a trend it would represent much better evidence that it had not occurred.

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