

PEDIATRIC NEUROLOGY

Correspondence

Survival Estimates of Severely Disabled Children

To the Editor:

In our article [1] we had not explained the methodologic mistake in the article by Eyman et al. [2], but it may be helpful to do so now. We emphasize that the issue is *not* a matter of choice but rather of mathematical correctness.

Grossman and Eyman state that in their study "Groups of people with varying degrees of disability were formed and followed for 11 years." This is not the case, however. People were followed for up to 11 years and then, *on the basis of outcome*, the groups were formed. In particular, only children whose condition did not change were included. Because a child observed for a short period is less likely to display change than one observed for a long period, those who die early are more likely to be included. This accounts for the generally pessimistic prognoses in their study.

As an example, we consider children aged 1-3 years in their group 3. Criteria for this group were: immobile, fed by others (not tube-fed), unable to roll, incontinent, no arm-hand use, and severe, profound, or suspected mental retardation. Data were taken from the period 1984-1996. The solid line in the accompanying figure shows the survival curve for this group. This analysis correctly follows a cohort of infants who initially met the criteria. If we use the procedure of Eyman et al. [2], however, and retain only children who meet the criteria *throughout* the study, we include 100% of the children who die quickly but only 17% of those who survive 10 years—hence, the much more pessimistic prognosis (dashed line).

We agree with Grossman and Eyman that the etiology of mental retardation is frequently unknown. Readers of this journal may, however, be surprised to learn that a diagnosis of cerebral palsy is "notoriously unreliable." Our data on cerebral palsy were based on evaluations of pediatricians, occupational and physical therapists, and developmental psychologists. As noted in our article, we found very high inter-item reliability for variables indicating cerebral palsy.

In their comparison of our results with those of a previous article [3], Grossman and Eyman unfortunately did not give any specifics. To the limited extent that the two articles can be compared (e.g., cohort A in Fig 1 of the earlier article [3] and in Fig 3 of the present one [1]) the results are quite similar. As they note, however, the two articles deal with different etiologies and age groups.

David J. Strauss, PhD
Robert M. Shavelle, PhD
Department of Statistics
University of California, Riverside

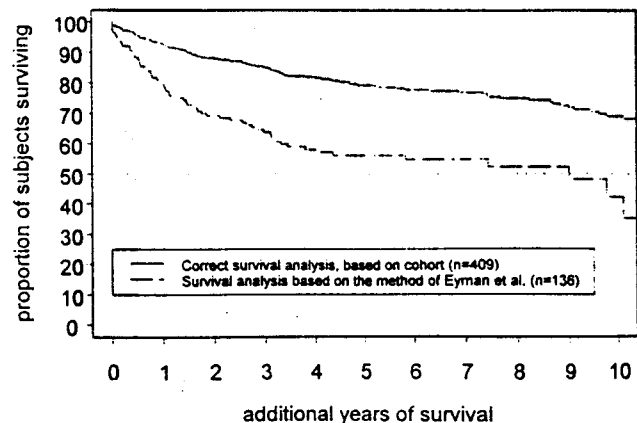


Figure 1. Survival analysis for children aged 1-3 years, using criteria of group 3 of Eyman et al. [2].

References

- [1] Strauss DJ, Shavelle RM, Anderson TW. Life expectancy of children with cerebral palsy. *Pediatr Neurol* 1998;18:143-9.
- [2] Eyman RK, Grossman HJ, Chaney RH, Call TL. Survival of profoundly handicapped people with severe mental retardation. *Am J Dis Child* 1993;147:329-36.
- [3] Strauss DJ, Ashwal S, Shavelle R, Eyman, RK. Prognosis for survival and improvement in function in children with severe developmental disabilities. *J Pediatr* 1997;131:712-7.