

Living with cerebral palsy and tube feeding

To the Editor:

Smith et al¹ state that their survival results are similar to those of Strauss et al² but different from those of Eyman et al.³ A closer look at the findings of studies concerned with tube feeding and mobility reveals similar results rather than differences in median years of survival. Strauss et al⁴ found a median survival of 5.7 years for tube-fed children who had no mobility and a median survival of 9 years for children who were tube fed but had some mobility. Their later study indicates a median survival of 7 more years for children with cerebral palsy who were tube fed and had no mobility and a median survival of 12+ years for children with head lift.² Eyman et al³ reported a median survival of 4.8 years for children with no mobility who required tube feeding and 11 more years for tube-fed children who had limited mobility (partial rolling). All studies are in agreement that once tube-fed children can sit independently and move about, the prognosis improves dramatically. Differences in median estimates among these studies are trivial in our view. We believe that mobility or voluntary movement is critical in the presence of tube feeding.

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Reply

To the Editor:

Drs Eyman and Grossman have contributed tremendously to our knowledge of survival of children with severe handicaps. They suggest that our survival data are really not any different from results of their studies, and they may be correct, given our much smaller sample size. Part of the difference may be related to varying proportions of subjects with impaired mobility—a major predictor of mortality in this setting. Our sample is too small for a sub-analysis. On the other hand, our study is truly population-based and theirs is based on subjects who received services from the California Department of Developmental Services—possibly those subjects as a group were more handicapped than ours.

The truth may be somewhere in the middle! Clearly, there is a substantial mortality rate for this group of children, but our families strongly indicated that the risk of eventual death should not influence the decision to insert a feeding tube to improve everyone's quality of life.

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Regarding autism

To the Editor:

I would like to compliment Drs Accardo and Bostwick on their excellent editorial regarding autism.¹ However, I must take issue with their un-referenced statement: "... it is becoming an accepted general rule among parents and professionals other than pediatricians that diagnosis by age 2 years is needed to ensure optimal outcome." Two recent reviews of autism^{2,3} report an onset of symptoms at ages ranging from 18 to 30 months. I interpret this to mean that some children with autism may appear to be developing in a normal fashion at 2 years of age. Thus the above statement of Drs Accardo and Bostwick has the potential, in a legal arena, to impute delayed diagnosis with subsequent poor developmental result when, in fact, the characteristics of autism may not have been present at age 2.

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Reply

To the Editor:

"First...all the Lawyers"
Shakespeare, *Henry VI Part 2*, 4.2.86