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P6. Survival Rates of Children with Severe Neurological Disabilities

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Data were collected at three pediatric skilled nursing facilities (SNFs) during the 1985 to 1996 decade in a fashion identical to that used in a previously performed study (*Am J Dis Child* 1993;147:329). We found the survival rates in all six groups of severely disabled children to be significantly better than published data. For example, in Group 1 (cerebral palsy, profound mental retardation, immobile, incontinent, tube fed, not rolling, no hand or arm use), our 8-year survival rate was 66% (previous rate, 5%; $p < 0.001$). In Group 2 (same as in Group 1 but with hand and arm use), our 8-year survival rate was 89% (previous rate, 22%; $p < 0.001$). We obtained significantly better survival rates irrespective of the analysis, including those for patients less than 1 year of age, 1 to 15 years of age, and greater than 15 years of age. The most significant determinant of a reduced survival rate was the presence of other significant diseases (recurrent pneumonias, severe asthma, refractory seizures, cardiac failure, or recurrent bowel obstructions). Those with such diseases had a 10-year survival rate of 45% as compared with 90% in those who were relatively healthy ($p < 0.0001$). There was a significant correlation between reduced survival rates and being immobile and receiving tube feedings, but not with the presence of a tracheostomy tube. Those fed by gastrostomy tube had a better 10-year survival rate than those fed by nasogastric tube (78% vs. 41%; $p < 0.01$). This difference was independent of the presence of other significant medical diseases. Our results confirm those of previous studies showing that immobility, seizures, and tube feedings are associated with decreased survival rates. However, we found survival rates substantially better than those reported in the literature. These improved results most likely stem from the more intense medical management of acute illnesses in SNFs than at home or other residential settings. We also found the survival rate was significantly better in those fed by gastrostomy tube than in those fed by nasogastric tube.