

AN UPDATE ON SURVIVAL RATES OF DISABLED CHILDREN

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Introduction Accurate survival rates of children with neurologic disabilities is important when third party insurance payers are planning future medical expenses. This is of particular importance to pediatric skilled nursing facilities (SNF) that depend on financial support from governmental sources. Eyman and Grossman published survival rate results from California that were extremely pessimistic and not in keeping with our clinical impressions. This led to a thorough review of our survival rates, which were published (1). Our results were much better than those reported by Eyman. For example, the most dramatic difference was in the most disabled group (group 1). The 8-year survival rate, starting with less than 1 year of age, was 5% according to Eyman and 66% according to our data.

Since our study was published (1), a large number of reports have appeared from many different countries, and also from California using an expanded data base. The survival rate data that we had obtained remains consistently better than more recent reports. For example, 10-year survival rates for the most disabled group 1, was reported from California in 1993 to be 32%, and in 1998 45%, with our result being 73%. 8-year survival rates for group 1, was reported from California in 1993 to be 38%, in 2000 63%, with our result 73%.

We felt that the reasons for our better survival rates are multiple, including the fact that all of our patients were in SNF's where prompt medical care for acute illnesses was always provided (only 3.5% in California were in SNF's). Also, there were many methodologic and statistical errors contained in the California data, which have been reviewed (2, 3, 4). In order to shed more light onto why our survival rates are consistently better than more recent publications, we further investigated survival/death rates of disabled children at Marklund.

Objectives: In 1982 an infant with Down Syndrome, Baby Doe, was allowed to die without necessary surgery. Strong public outcry resulted in the US Department of Health and Human Services passing regulations to prohibit discrimination against individuals with disabilities. This was followed in 1985 by amendments to the Child Abuse Prevention Act which were passed by the US Congress. These regulations and laws should have resulted in increased medical care provided to disabled children, and in decreased death rates. In this study we analyzed death rates of severely disabled CP children from 1970 to 2002.

Measurements: The number of children who were died from 1970 through 2002 was ascertained on a yearly basis. Also, their ages of death, the age at admission, and length of stay before death were recorded. The number of deaths was tallied for 5-year and 10-year intervals. For statistical analysis Chi-square and PROC MULTTEST were used.

Results: There was a dramatic drop in death rates over the time of this study. In the 1970 decade the death rate was 72%, 1980 decade 45% and 1990 decade 26%. The death rates between the 1970 and 1980 decades were significantly different ($p < 0.0005$) as were the rates between the 1980 and 1990 decades ($p < 0.001$). During the time period 1980-84 the rate was 35%, and in 1985-89 it was 20% ($p < 0.01$). Since 1985 the death rate has not significantly changed.

In comparing our death rates to previous publications, startling comparisons were obtained. Adjusting for the distribution of our patients from groups 1 through 3, over ten years, the death rate according to Eyman would have been 88% (note that our 1970's 10 year death rate was 72%). When comparing to Strauss's correction of Eyman's data, the 10 year death rate would be 46% (note that our 1980's 10 year death rate is 45%). Finally, when using our published data (1), the expected 10 year death rate would be 27% (the 1990's 10 year death rate was 26%).

There was also an increase in the median age of death. In the 1970 decade it was 1 year and 1 month, 1980 decade 3 years and 8 months, and 1990 decade 4 years and 8 months.

The most important factor explaining the decreased death rates was the progressive use of G-tubes. Almost all deaths in the 1970's were due to aspiration pneumonia. The first G-tube was placed in 1978. In 1980 2% of residents were fed by G-tube. By 1985, 52% were receiving G-tube feedings, and 9% NG-tube feedings.

All of this data indicates conclusively that the better medical care provided to disabled children, the better the survival rates. Of considerable importance is that the publications by Eyman have a survival rate comparable to our result in the 1970's when negligible medical care was provided. Strauss's correction of Eyman corresponds to the 1980's when intermediate care was provided. Our data (1) corresponds to high quality medical care which is consistently provided.

Conclusion: The US federal laws and regulations fostered an atmosphere of providing disabled children with full access to medical care. When these children's basic medical care needs were met (including nutrition through tube-feedings and thus preventing aspiration pneumonias), there was a dramatic decrease in the death rates of severely disabled CP children. Also, with adequate and appropriate medical care disabled children have much better survival rates.

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