

# **Life Expectancy Determinations: Cerebral Palsy, Traumatic Brain Injury, and Spinal Cord Injury Analysis and Comparison**

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## **Abstract**

In preparing a life care plan for a disabled individual, a determination of life expectancy is usually necessary. The most common disorders in which life expectancy results have been studied in individuals with chronic, non-progressive neurologic disabilities are cerebral palsy (CP), traumatic brain injury (TBI,) and spinal cord injury (SCI). The interpretation of published results, and their practical application to an individual patient, must be determined by evaluating methodological aspects of the studies, such as when (historically) the data was collected, how long and to what age the study subjects were followed, whether optimal medical care was provided, and whether the study subjects had other significant medical illnesses. In this paper, the methodology for critically analyzing and interpreting the literature on life expectancy in CP, TBI and SCI is presented. The most important determinants of life expectancy are the specific types and degrees of disabilities that an individual has. Despite marked clinical differences in the causes of these three chronic neurologic disorders (CP, TBI and SCI), when appropriately analyzed and applied, these bodies of literature may result in life expectancy determinations that are similar.

*Key words:* cerebral palsy, life expectancy, spinal cord injury, survival rates, traumatic brain injury

## **Introduction**

The term life expectancy is frequently misunderstood as it is not a precise prediction of how long a person will live, but rather a statistical average of future life spans. For example, the current life expectancy of a 20 year old woman in the United States is 81 years of age. That does not mean that all 20 year old women will live to 81 years of age; it means the average life span is 81 years. Out of 100 20-year-old women identified today, 61 years from now approximately 50 will have died, and 50 will still be living. That means some may have died in their 20's, 30's, etc. and some will live well into their 90's and beyond. Life expectancy always refers to an average life span expectation for a group of individuals and can never be an exact prediction of an individual's length of life. The number of years of life expectancy can be expressed as either the number of additional years of life, or the age to which a person is expected to live. Using the example of a 20 year old woman, her life expectancy is an additional 61 years of life, or her life expectancy is 81 years of age.

Life expectancy data is collected and analyzed in the United States by the National Center

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for Health Statistics, a part of the Centers for Disease Control and Prevention. This extremely large database consists of the entire population of the United States. However, this database has not been subdivided into separate categories for individuals with disabilities. When an individual with a chronic neurologic disability is evaluated for a life care plan, the life care planner must rely on the available medical research literature and/or a physician specialist for that specific disorder.

Concerning life expectancy, the most extensively researched neurologic disorders, associated with chronic, non-progressive disabilities, are cerebral palsy (CP), traumatic brain injury (TBI), and spinal cord injury (SCI). Cerebral Palsy is a neurologic motor disorder present from birth, and individuals who have CP can exhibit a wide range of severity of clinical impairment. Traumatic brain injury and SCI occur at any age and can leave an individual severely disabled.

The goal of this paper is to review methodologic issues of importance in determining life expectancy. These include time factors, chronologically, when the study data was collected, until what age the study was conducted, the effect of optimal medical care, and the effect of other significant illnesses on life expectancy determinations. How to determine life expectancy using life tables and survival rate graphs will be discussed and explained. The three bodies of survival rate literature (CP, TBI and SCI) will be analyzed and compared.

### **Methodological Issues**

In statistical terms, life expectancy is the arithmetic average of life spans of a group of individuals, and median survival time is the midpoint of a group of life spans. Because some individuals within any group will live to a much older age, median survival time is usually less than life expectancy. The survival rate is expressed as the percentage of a group's members who are still alive at a given time.

Life tables for the general United States population are prepared by the National Center for Health Statistics, a part of the Centers for Disease Control and Prevention (CDC), and can be used as a basis for what would be normal life expectancy. These tables are also categorized according to gender, race (white, black) and ethnic origin (Hispanic, non-Hispanic).

In using these life tables as a basis of normal life expectancy, in calculating the life expectancy of any medical condition, two approaches may be used. One is based on mortality ratios (MR) and the other on excess death rates (EDR). Mortality ratios are the number of observed deaths, divided by the number of expected deaths, over a defined period of time. For example, in a population of 1,000 patients with a life-long, chronic illness, at the age of 50 years, 100 have died. From the CDC life tables for the general US population, the expected number of deaths at this age is 58. The MR is 1.7 (100 divided by 58). The observed death rate over this time period is 1.7 times greater than what was expected. Using this same example, the EDR, the difference between the observed and expected death rates, can also be calculated. The expected death rate is 0.058 (58 divided by 1,000). The observed death rate is 0.1 (100 divided by 1,000). The EDR is the difference between these two determinations, namely 0.042 (0.1 minus 0.058).

In principle, if one had reliable MR's or EDR's, life expectancy could be calculated using these life tables. Individual studies about life expectancy in chronic neurologic conditions, frequently do not present MR's and EDR's, thus severely limiting the usefulness of these approaches. Another major problem with using the MR's and EDR's is that they can change (increase or decrease) dramatically over time, year by year, significantly affecting any life

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expectancy determination. Above all, given the limitations within any individual research report, adjustments must be made to MR and EDR determinations on the basis of many research and clinical factors. Numeric adjustments to MR's and EDR's are arbitrary and thus, unjustifiable.

A better methodologic approach is to extrapolate life expectancy from survival rate graphs. When a survival rate graph drops down to the 50% survival rate, the indicated age is the median survival age, and reasonably approximates life expectancy. Adjustments for other factors, including clinical and research design issues, can then be made to the life expectancy determination in a more straight-forward and understandable fashion. In those cases where the research report graph do not cross the 50% survival rate, the curve of the graph can be extended linearly until it reaches the 50% rate. In all of the research reports discussed in this review, after an initial period of several years during which the rate of death decreases, survival rate curves become linear.

The life expectancy results using this method produce a range of ages, not a specific age. Given all of the research methodology and clinical factors that must be taken into account, it is usually not possible to give a more precise life expectancy determination.

### **Cerebral Palsy: Improved Medical Care since 1985**

Most CP survival rate studies have collected clinical data over many decades. For example, a United Kingdom study by Hutton, Colver, and Mackie (2000) collected data from births starting in 1960. Since 1960 there have been many advances in medical care which have improved survival rates of the general population. More significantly, however, due to implementation of U.S. federal regulations, it was only since 1985 that in the United States infants with disabilities and children started to receive adequate medical care (Plioplys & Peterman, 2004; Plioplys & Peterman, 2005; fully reviewed in Boyle, 1997). Previously, many infants with severe disabilities and children received minimal care and had short life spans. In a report from Cornell Medical Center in New York City concerning the placement of tracheotomies in children, the percentage of tracheotomies for neurologic diagnoses in the five year epoch 1980-1985 was 8.7%, and in 1985-1990 was 33% (Ward, Jones, & Carew, 1995). This four-fold increase suggests that children with neurologic disabilities only started to receive adequate medical care around 1985.

Our own results likewise show a significant improvement in outcome after 1985 (Plioplys, & Peterman, 2004; Plioplys & Peterman, 2005). In a skilled nursing facility dedicated to patients with severe CP, the overall 5-year death rate during 1980-84 was 35%, and during 1985-89 was 20%, a statistically significant reduction. In 1982, only 2% of the patients were fed by G-tube, whereas by 1985 this was 52%. Providing adequate nutrition, without producing aspiration pneumonias, was a major reason for the observed improved survival rates in our skilled nursing facility.

In a study of children with CP in the United Kingdom, it was noted that in the Oxford area of England, there was a significant improvement in survival rates of children born in the 1990's as compared with those born in the 1980's (Hemming, Hutton, Colver, & Platt, 2005). From Table 6 in this report, the 10-year survival rate for children with severe lower limb impairment increased from 83% for those born in the 1980's, to 93% for those born in the 1990's. For those children with severe upper limb impairment, the comparable 10-year survival rate increased from 76% to 90%. It is noteworthy that although the regulatory changes took place in the U.S., the effect was seen internationally. Thus, it is important to analyze when the study data was historically collected.

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### **Cerebral Palsy: Optimal Medical Care**

In most CP survival rate studies there is no data available to assess the presence or absence of optimal medical care that may affect life expectancy results. Optimal medical care means that acute medical problems are addressed in a timely fashion, and that all ongoing chronic medical issues are adequately tended to. Strauss has reported that home and group home settings where access to acute medical care is difficult compared to institutional care, statistically show mortality rates that are 25% higher, irrespective of degree of disability (Strauss, Eyman, & Grossman, 1996). It is in institutional settings, where acute medical care is more easily obtained, that survival rates are significantly better. Similar results have subsequently been observed and reported (Shavelle, & Strauss, 1999; Shavelle, Strauss, & Day, 2005).

In a study of children with CP from Western Australia, there was a significant difference between the survival rates of indigenous and non-indigenous populations, where the non-indigenous had much better survival rates (Blair, Watson, Badawi, & Stanley, 2001). From Figure 6 in this report, 20-year survival rates for children with CP whose mothers were indigenous was 75%, and for non-indigenous mothers, 92%. These results suggest that providing access to acute and chronic medical care improves survival rates. Finally, in a study comparing children with CP in an institutional versus home setting, Henderson et al., (2007) found that an institutional setting provided much better growth and development indices as compared to home settings where access to optimal medical care was problematical.

Recently, in a report from Sweden (Westbom, Bergstrand, Wagner, & Nordmark, 2011) children with CP who were classified as the most severely disabled according to the Gross Motor Function Classification System (GMFCS) level V (immobile, wheel chair confined), had a 20-year survival rate of 60%. This particular study is very intriguing in that important additional demographic information is provided. All the children lived at home and 54% lived in "smaller catchment areas", meaning in smaller cities or rural locations. Those GMFCS level V children living in more rural areas had a hazards mortality ratio 3.18 times higher than those living in larger cities. As the authors discussed, the increased death rate in more rural areas indicates a lack of access to acute and ongoing necessary medical care, an otherwise lack of access to optimal medical care. With this information it is possible to calculate the expected survival rate, as if the entire study population lived in larger cities. This corrected survival rate to 20 years of age is 71%.

Furthermore, the results of this study (Westbom, Bergstrand, Wagner, & Nordmark, 2011) are similar to previously related published results (Plioplys, 2003; Plioplys, 2004a; Plioplys, 2004b; Plioplys, Kasnicka, Lewis, & Moller, 1998) in that they reported no difference in survival rates on the basis of gender, and that the leading cause of death was pneumonia (61% of identified causes of death in this report, and 76% in our reports). However, in this study, 7% of identified causes of death were from complications from G-tubes. In the Plioplys studies cited above, there were no deaths from G-tube complications. These G-tube deaths further argue that, in some cases, there was a lack of access to optimal medical care. Correcting for this preventable cause of death, and adding it to the previous corrected calculation of residing in a larger city, results in an estimated 78% survival rate at 20 years of age. Since these corrections may have overlapping data points, it may not be accurate to add 7% to the 71%. Thus, the actual survival rate at 20 years of age, corrected for optimal medical care, is perhaps better described as a range between 71% and 78%.

It is worth comparing this survival rate result with Plioplys and associates published data

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(Plioplys, 2003; Plioplys, 2004a; Plioplys, 2004b; Plioplys, Kasnicka, Lewis, & Moller, 1998). In these studies, all six groups (1 through 6) would fit within the designation of GMFCS level V. Using information from the graphs of individuals who survived one year of age and adjusting for the size of the individual groups, results in a 20-year survival rate of 73%. The result is basically identical to the 71% to 78% survival rate results from this recent Swedish study. Thus, the most recent CP survival rate report (Westbom, Bergstrand, Wagner, & Nordmark, 2011) confirms our previously published results. ~~efore applying the results to determining a particular patient's life expectancy.~~

### **Cerebral Palsy: Other Medical Illnesses**

The health status of patients is not addressed in most CP survival rate studies. When we started our study data collecting, we paid particular attention to the presence of other significant medical illnesses, which we defined as, over the previous two years, two or more bouts of pneumonia per year, refractory seizures (more than one per day), recurrent bowel obstruction, severe asthma, cardiac arrhythmia, and progressive cardiac failure. Once we collected and analyzed our results, the most significant other medical illness was recurrent pneumonias. 76% of all the deaths in our study were due to pneumonia, 12% were due to cardiac arrest, 4% were from progressive cardiac failure, and 1% from bowel obstruction. In our own reports (Figure 5 in Plioplys, Kasnicka, Lewis, & Moller, 1998) for the entire studied CP population, the 10-year survival for those with significant medical illnesses was 45%, and for those who were otherwise healthy, the rate was 90%, a statistically significant difference. Life expectancy will be longer for those who are healthy, as compared to those who are not. It should be noted that our studies were the first to evaluate the impact of other medical conditions on survival rates of patients with CP.

Regarding the issue of epilepsy and its effect on life expectancy, our studies were the also the first to show that epilepsy decreases survival in patients with CP, with more frequent seizures producing further reduced survival rates (Figure 6 in Plioplys, Kasnicka, Lewis, & Moller, 1998). In our study, the effect of epilepsy is factored into the overall survival rates data and graphs, since 64% of the studied population had epilepsy. Similarly, in all other CP survival rate reports the issue of epilepsy is not separated out rather it is included in the overall results.

To assess the impact of epilepsy on life expectancy in the general population, a very useful reference is that by Gaitatzis, Johnson, Chadwick, Shorvon, and Sander (2004). In this United Kingdom report about newly diagnosed epilepsy, Table 1 lists the decrease in life expectancy for cases of idiopathic/cryptogenic epilepsy and Table 2 for symptomatic epilepsy. Both tables are stratified according sex, age and years after diagnosis.

### **Spinal Cord Injury: Improved Medical Care**

In a recent extensive report about survival rates of patients with SCI, there was a marked decline in the rate of death over the past three decades (Middleton et al., 2012). From Table 4 in this report, for patients with cervical (C1- C4) ASIA-A tetraplegia (meaning a severe or total SCI), the rate of death during the first 12 months after injury fell from 32.4% (1975-1984), to 20.8% (1985-1994), and finally to 13.5% (1995-2006). Thus, improvement in medical care resulted in a reduction in SCI death rates from 32.4% to 13.5%, with the greatest reduction occurring after 1985.

**Spinal Cord Injury: Optimal Medical Care**

One method to assess access to optimal medical care is to investigate family yearly income. It would be expected that those families with higher incomes would have easier access to acute and ongoing medical care. In a 2002 study, Krause reported that patients with SCI living in families with yearly incomes of less than \$25,000, had a 4.51 times greater rate of mortality, over a 4 year interval as compared to those with an income of \$75,000 or greater (Krause, 2002). Recently, Krause updated his analysis with SCI data from 20 hospitals across the U.S. (Krause, Saunders, & DeVivo, 2011). From Table 1 of this study, patients with SCI living in families with income less than \$25,000 had a mortality rate 2.55 greater than for those with incomes above \$75,000. From Table 3 of this report, for a 25 year old with a C4 SCI of ASIA-A severity, life expectancy was decreased by 10.2 years if the individual lived in a family whose income was less than \$25,000 compared to families earning over \$75,000 per year. This is a 36.3% reduction in life expectancy. From this same table, for a 25 year old with a C6 level SCI, the financial difference resulted in a decrease of 10.5 years in life expectancy, and for a thoracic (T7) level SCI, a decrease of 11.1 years in life expectancy. The authors explained the reason for this: "The tangible benefits include access to resources and health care that can be used to reduce the likelihood of secondary conditions and obtain treatment when needed." (p. 7). The results of this report would appear to suggest that the presence of optimal medical care produces increases in life expectancy of 10.2, 10.5 and 11.1 years if income is indeed linked to optimal medical care.

Another way to assess optimal medical care is to investigate the type of medical insurance patient's carry. Patients with SCI who have Workers' Compensation insurance (considered by many to be the most comprehensive type of insurance coverage), evidence a reduction in annual mortality rate of 57% (Krause, DeVivo, & Jackson, 2004). Overall, a number of SCI studies in the literature suggest that access to optimal medical care is an important factor in determining life expectancy.

**Spinal Cord Injury: Other Medical Illnesses**

Recently, in a study of patients with SCI from one medical center in the US, for a 20 year old male who is non-ambulatory, with a non-cervical SCI, the presence of a chronic pressure ulcer reduced the life expectancy by 41.5% (Table 3 in Krause & Saunders, 2011). Any hospitalization during the past year resulted in a 13.6% reduction, and any infection during the past year resulted in a 4.8% reduction. Thus, the SCI literature shows that the general health of the patient is an important factor affecting life expectancy.

**Neurological Disability: Positive Factors**

Many individuals with severe spasticity, from various causes are treated with intrathecal baclofen (ITB) pumps. Given the location of the pump tubing inside the spinal canal, and medicine being administered intrathecally, concerns may be raised that potential side effects of the ITB may decrease survival rates. However, a recent study has shown that the presence of ITB pump in patients with CP does not decrease life expectancy, but actually may increase it (Krach, Kriel, Day, & Strauss, 2010).

In addition, there are other factors that would have a positive impact on life expectancy to anyone with a severe neurologic disability. To mention just a few, these patients will not compromise their health by consuming or abusing alcohol, smoking cigarettes, or using illegal drugs. They will not engage in reckless automobile driving which causes accidents and death. With optimal medical care, the diet will be monitored closely, and obesity, with

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all of its attendant medical complications, will not develop. These additional factors do have a significant negative impact on the life expectancy of the general population.

As a confirming example, many patients with SCI, with less severe disabilities, are able to engage in compromising activities (Krause, & Saunders, 2010). From Table 3 in this report, a 20 year old patient with SCI who smokes cigarettes, has a reduction in life expectancy of 9.29 years, and who engages in binge drinking of alcohol has a 6.82 year reduction. Thus, if one's disability is severe enough to avoid these compromising activities, life expectancy will be longer.

### **Modification to Life Expectancy Determinations**

In assessing the impact of the transition to improved medical care for children with disabilities from 1985 onwards, the previously cited study from England is of benefit (Hemming, Hutton, Colver, & Platt, 2005). From Table 6, the survival rate in the Oxford region, to 10 years of age, for children with severe lower limb impairment, went from 83% for those born in the 1980's, to 93% for those born in the 1990's. For those children with severe upper limb impairment, survival to 10 years of age went from 76% to 90%. Graphing these 10 year survival rates results in life expectancy indicate increases of 25 and 27 years. These results must be tempered because similar improvements were not seen in other areas of England. Our own results shed light on this question (Plioplys, & Peterman, 2004; Plioplys, & Peterman, 2005). In a skilled nursing facility dedicated to patients with severe CP, the 10-year death rate in the 1980's was 45%, and in the 1990's was 26%. Graphing these differences results in life expectancy increase of 8 years.

In comparing outcomes of home versus institutional settings, the mortality rate of children with disabilities was 25% greater in home settings (Strauss, Eymann, & Grossman, 1996). In our studies which took place in skilled nursing facilities, optimal medical care was continuously provided (Plioplys, 2003; Plioplys, 2004a; Plioplys, 2004b; Plioplys, Kasnicka, Lewis, & Moller, 1998). In comparing our actual results for the most disabled group 1, to a group 1 that would have a mortality rate 25% greater, results in an increased life expectancy of 11 years. The report by Hutton, Colver, and Mackie (2000) was based on a general population sample of CP in England where the majority of the patients with CP lived at home. When this same 25% adjustment is applied to Figure 1D, life expectancy is increased by 9 years.

In the most recent CP study (Westbom, Bergstrand, Wagner, & Nordmark, 2011), after making only one adjustment, that of decreased mortality in larger cities, as compared to smaller cities and rural areas, where optimal medical care is more easily provided, and graphing the results, produces an increase in life expectancy of 10 years. Thus, the presence of optimal medical care increases life expectancy by 8, 9, 10 and 11 years, for the most severely disabled patients with CP. Thus, if optimal medical care can be assured for these patients, their life expectancy, when compared to published results, would be increased by an additional 10 years of age.

Concerning optimal medical care, it is of value to recall the above discussion concerning SCI. When optimal medical care was provided, as judged on the basis of family income, from Table 3 (Krause, Saunders, & DeVivo, 2011) for a 25 year old with a SCI at C4 of ASIA-A severity, life expectancy was increased by 10.2 years. For a C6 level the increase was 10.5 years, and for a T7 level, 11.1 years. It is of note that these results basically match the results from the effect of optimal medical care in CP, as discussed above.

**Life Expectancy Case Study for Someone with Intracerebral Hemorrhage**

In order to illustrate the practical application of these research results, they will be applied to a specific case. For this illustrative example, an actual patient will be discussed. She is currently 20 years old, having suffered a spontaneous intracerebral hemorrhage two years previously. She is able to roll, with assistance, sit with support, but cannot walk or crawl. She does have some functional hand use, and can feed herself cookies, but cannot handle a spoon or fork. She is receiving minimal feedings through a G-tube, and this tube will be removed soon. She has not had seizures. She is able to hear and see. She is able to communicate in short sentences, and her cognitive skills are moderately impaired. She has had no pneumonias, or any other infections over the past two years. There is no published survival rate literature concerning patients with intracerebral hemorrhage. Thus, it is necessary to use life expectancy results from similarly disabled CP, TBI and patients with SCI.

*Applying the Cerebral Palsy Literature on Life Expectancy*

In a study from the United Kingdom, children with CP, born between the years of 1960 and 1990, who had severe ambulatory disabilities, had a survival rate of 60% at 35 years of age (Figure 1D in Hutton, Colver, & Mackie, 2000). This study was carried out only to 35 years of age. In determining life expectancy, the results of this study must be interpreted keeping in mind the issues of when the research data was collected, whether optimal medical care was provided, and the general health of the patient. Our case has severe ambulatory disabilities according to the criteria of this study. Extrapolating the graph in Figure 1D, linearly to reach the 50% survival rate, results in a life expectancy in the late 40's years of age. Given the discussion above, concerning the effects of optimal medical care increasing life expectancy by 10 years, this result should also be increased by 10 years. Thus, the results of this study produce a life expectancy into the late 50's years of age.

In a study from Western Australia of children with CP born between the years 1958 and 1994, where 70% of the births were before 1986, 65% of those with severe CP survived to 25 years of age (Figure 3 in Blair, Watson, Badawi, & Stanley, 2001). Our case has severe CP according to the criteria of this study. For this group the study was carried out to 25 years of age. Extrapolating the graph in Figure 3, linearly to reach the 50% survival rate, results in a life expectancy into the late 40's years of age. Given the discussion above, concerning the effects of optimal medical care increasing life expectancy by 10 years, this result should also be increased by 10 years. Thus, the results of this study also produce a life expectancy into the late 50's years of age.

In a more recent study from the United Kingdom, for CP children with three severe disabilities, 70% survived to 25 years of age (Figure 1 in Hemming, Hutton, Colver, & Platt, 2005). According to the definitions of this study, our case has three severe impairments: upper limb, lower limb, and intellectual. This population was studied only until 25 years of age. Extrapolating the graph in Figure 1, linearly to reach the 50% survival rate, results in a life expectancy into the late 40's years of age. Given the discussion above, concerning the effects of optimal medical care increasing life expectancy by 10 years, this result should also be increased by 10 years. Thus, the results of this study produce a life expectancy into the late 50's years of age.

Strauss updated and corrected previous life expectancy results for patients with CP (Strauss, Brooks, Rosenbloom, & Shavelle, 2008). From Table 1 in this study, a 15 year old female, who is able to roll and is fed by others, has a life expectancy of an additional 35

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years. From that same table, a 30 year old female with the same degree of disability, has a life expectancy of an additional 34 years. For a 20 year old disabled female, this results in a life expectancy of 55 years of age. In this particular report, the necessary information was provided in the table, and it was not necessary to extrapolate life expectancy determinations from a graph.

It is worthwhile comparing the above cited literature results, concerning the life expectancy of patients with CP, to studies where access to optimal medical care is accounted for (Plioplys, 2003; Plioplys, 2004a; Plioplys, 2004b; Plioplys, Kasnicka, Lewis, & Moller, 1998). In these studies acute medical care was available 24 hours a day, 7 days a week, chronic medical issues were addressed expeditiously. Although the circumstances were always difficult and limited, the quality of the care provided was the best possible. The degree of severity of cerebral palsy can be subdivided into six groups. Group 1 was defined as having profound mental retardation, total immobility, being incontinent, fed by G-tube, and without functional hand use. This group was the most numerous with a study number of 163. For those who had survived at 1 year of age, there was a 63% survival rate through 34 years of age (middle tracing in Figure 1 in Plioplys, Kasnicka, Lewis, & Moller, 1998). Extrapolating the graph in Figure 1, linearly to reach the 50% survival rate, results in a life expectancy in the late 50's years of age. Using these particular results, where optimal medical care was provided, results in a life expectancy result that does not require further adjustments, and is in keeping with the previous results from the studies discussed above.

In a recent study from Sweden (Westbom, Bergstrand, Wagner, & Nordmark, 2011), children with CP who had the most severe degree of disability, Gross Motor Function Classification System (GMFCS) level V (immobile, wheel chair confined), had a 20-year survival rate of 60%. As discussed above, this particular study is very intriguing in that GMFCS level V children living in smaller cities had a hazards mortality ratio 3.18 times higher than those living in larger cities. As the authors discussed, the increased death rate in smaller cities indicates that there is a lack of access to acute and ongoing necessary medical care in more rural areas. In this study, for level V patients, when Figure 1 is linearly extended, to reach the 50% survival rate, results in a life expectancy into the late 40's years of age. Only applying one correction, that due to better outcomes in more urban settings (the 20-year survival rate then becomes 71%), and then linearly extending the graph to reach the 50% survival rate, results in a life expectancy into the late 50's years of age. Thus, multiple different CP life expectancy reports, when evaluated appropriately and applied to our case, produce identical life expectancy results.

#### *Applying the Traumatic Brain Injury Literature on Life Expectancy*

The above cited CP life expectancy literature deals with children and adults who have had severe disabilities since the time of birth. In the case of a 20 year old female with TBI, the disability would have arisen suddenly after 20 years of normal neurologic development. A TBI at this age would argue for a longer life expectancy than the CP literature. For example, a 20 year old patient with TBI will not develop scoliosis, nor need surgery for this common orthopedic condition in the CP population. Further, with good mobility for 20 years, the extent and degree of osteoporosis will be less, producing a reduced risk of fractures, as compared to similarly aged and similarly disabled individuals with CP.

Unfortunately, the available TBI literature has limited applicability. For example, two of the most recent studies concerning life expectancy after TBI (Table 2 in Harrison-Felix et al., (2009); Table 4 in Ventura et al., 2010), for a 20 year old woman, provide life expectancies

of additional 52 and 55 years of life. In both these references the life expectancy results are presented in tables, not as survival rate graphs. These two results would produce life expectancies, in our case, of 72 and 75 years of age, which is very close to the normal life expectancy of 81 years of age. The difficulty with using these results, as it is with the majority of the literature concerning TBI, is that the types and degrees of disability after TBI are not separated out. The majority of persons with TBI have mild injuries, and thus have a normal life expectancy. Thus, when aggregate data is evaluated, the life expectancy numbers obtained are artificially large.

There are a few life expectancy reports categorizing persons with TBI according to degrees of disability. For a 20 year old female having suffered TBI who is unable to walk and needs to be fed by others, the life expectancy is an additional 26 years of life (Table 17-2 in Shavelle, Strauss, Day, & Ojdana, 2007). For our case, this would produce a life expectancy of 46 years of age. However, there are significant limitations in the basic data that was used in this report, including lack of reliable clinical information about patients, and lack of information about the presence or absence of optimal medical care (reviewed in Plioplys, 2004a; Plioplys, 2004b). These factors artificially decrease life expectancy in this report.

Another study by the same authors deals with patients with TBI who received services from 1987 through 1995 (Strauss, Shavelle, & Anderson, 1998). From Table 4 in this study, for 20 year old males who had no mobility, the life expectancy was an additional 14.4 years, and if the mobility was “poor” the life expectancy was an additional 32.3 years. Data concerning females was not presented. In this study there was no further analysis according to other clinical parameters—only mobility was studied. The most severely injured patients with TBI, those with no mobility will also include those with persistent vegetative state (PVS), a condition that has a markedly reduced life expectancy (Ashwal, 2004; Ashwal, 2005). Including results from PVS patients would artificially decrease survival rates of the group. Thus, it would not be correct to use data of patients with TBI that includes no mobility in determining the life expectancy of our case. Alternatively, using the “poor” mobility category would be a more accurate application of this study’s results. Thus, using the data in this report appropriately, the life expectancy would be 52.3 years of age.

In summary, there are two TBI reports which provide information that can be used to determine life expectancy. For our case these determinations are 46 and 52.3 years of age. The multiple factors that were discussed in relation to the CP literature (when the data was collected; optimal medical care; general health of the patients) are fully applicable to the TBI literature. When these factors are applied, an increase in the determined life expectancy is also necessary.

#### *Applying the Spinal Cord Injury Literature on Life Expectancy*

In a report summarizing SCI outcomes from 26 regional centers across the US, from Table 14-3 in DeVivo and Stover (1995), the life expectancy for a 20 year old individual, one year after the injury, for a cervical 1 to 4 level injury, was 32.8 additional years of life, and cervical 5 to 8 level injury, was 38.6 additional years of life. Almost identical results were reported in a follow-up study several years later (Table 3 in DeVivo, Krause, & Lammertse, 1999). Thus, in our case, these numbers would give life expectancies of 52.8 and 58.6 years of age.

Strauss, DeVivo, Paculdo, and Shavelle (2006) gave a more detailed breakdown in life expectancies as a function of degree of disability. Table 4 in this study applies to 25 year old males with SCI, who had already survived 3 years. For those who had a C5 grade ASIA-A

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lesion, the number of additional years of life expectancy is 30.0. For those with an ASIA grade B or C (incomplete SCI) C5 lesion, the number of additional years of life expectancy is 35.7. In this report, life expectancy results are presented in a table, and do not need to be derived from a graph. Applying these numbers to our case, results in life expectancies of 50.0 and 55.7 years of age.

In another report using the same data base for a 20 year old male, having been injured at an age greater than 16 years and suffering a severe cervical 5 level injury (grade ASIA-A C5), the life expectancy is an additional 34.2 years of life (Table 4 in Shavelle, DeVivo, Paculdo, Voget, & Strauss, 2007). This results in a life expectancy of 54.2 years of age. Thus, the cited SCI survival rate studies, using data from across the US, give life expectancies for our case in a range from 50.0 to 58.6 years of age.

There are also several international studies concerning life expectancy in patients with SCI. In a report from Australia, for a 25 year old who suffered a severe (ASIA-A) cervical cord injury, life expectancy is an additional 34.9 years of life (Table 6 in Yeo et al., 1998). In our case, this results in a life expectancy of 54.9 years. In a report from England, for a 20 year old female, who suffered SCI resulting in tetraplegia, life expectancy is an additional 38.8 years of life (Table 4 in Frankel, et al., 1998). In our case, this results in a life expectancy of 58.8 years.

An extensive, 50-year life expectancy study has been recently reported from Australia. For a 25 year old sustaining a C1- C4 SCI of ASIA-A, B or C severity resulted in a life expectancy of 38.7 additional years (Table 1 in Middleton et al., 2012). In our case, this results in a life expectancy of 58.7 years of age.

In summary, the published literature concerning SCI life expectancy for cases that have neurologic disabilities comparable to our case result in the following life expectancies: 50.0, 52.8, 54.2, 54.9, 55.7, 58.6, 58.7 and 58.8 years of age. This spectrum of ages is a vivid example that when research data is applied to determine the life expectancy of an individual, a specific age cannot be determined, just a range of ages. It is notable that this spectrum of ages is identical to the life expectancy results that were obtained for our case when the CP and TBI survival rate literature results are analyzed and appropriately applied.

## **Conclusion**

In using the published life expectancy literature, it is important to evaluate each study regarding a number of different factors, which include: when the research data was collected; until what age the study was conducted; whether optimal medical care was provided; whether the patient has other significant medical illnesses that would compromise life expectancy. In the particular clinical case discussed of a neurologically disabled 20 year old woman, all three bodies of life expectancy literature (CP, TBI and SCI), when appropriately analyzed and applied, produced similar life expectancy results.

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**References**

- Ashwal, S. (2004). Pediatric vegetative state: Epidemiological and clinical issues. *NeuroRehabilitation*, 19, 349-360.
- Ashwal, S. (2005). Recovery of consciousness and life expectancy of children in a vegetative state. *Neuropsychological Rehabilitation*, 15, 190-197.
- Blair, E., Watson, I., Badawi, N., & Stanley, F. J. (2001). Life expectancy among people with cerebral palsy in Western Australia. *Developmental Medicine and Child Neurology*, 43, 508-515.
- Boyle, R. J. (1997). Decisions about treatment for newborns, infants and children. In J. C. Fletcher, P. A. Lombardo, M. F. Marshall & F. G. Miller (Eds.) *Introduction to Clinical Ethics: Second Edition* (pp. 181-204). Hagerstown, Maryland: University Publishing Group.
- DeVivo, M. J., Krause, J. S., & Lammertse, D. P. (1999). Recent trends in mortality and causes of death among persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 80, 1411-1419.
- DeVivo, M. J., & Stover, S. L. (1995). Long-term survival and causes of death. In S. L. Stover, J. A. DeLisa, & G. G. Whiteneck (Eds.), *Spinal Cord Injury* (pp. 289-316). Gaithersburg, MD: Aspen.
- Frankel, H. L., Coll, J. R., Charlifue, S. W., Whiteneck, G. G., Bardner, B. P., Jamous, M. A., Krishnan, K. R., Nuseibeh, I., Savic, G., & Sett, P. (1998). *Spinal Cord*, 36, 266-274.
- Gaitatzis, A., Johnson, A. L., Chadwick, D. W., Shorvon, S. D., & Sander, J. W. (2004). Life expectancy in people with newly diagnosed epilepsy. *Brain*, 127, 2427-2432.
- Harrison-Felix, C. L., Whiteneck, G. G., Jha, A., DeVivo, M. J., Hammond, F. M., & Hart D. M. (2009). Mortality over four decades after traumatic brain injury rehabilitation: a retrospective cohort study. *Archives of Physical Medicine and Rehabilitation*, 90, 1506-1513.
- Hemming, K., Hutton, J. L., Colver, A., & Platt, M.-J. (2005). Regional variation in survival of people with cerebral palsy in the United Kingdom. *Pediatrics*, 116, 1383-1390.
- Henderson, R. C., Grossberg, R. I., Matuszewski, J., Menon, N., Johnson, J., Kecskemethy, H. H., Vogel, L., Ravas, R., Wyatt, M., Bachrach, S. J., & Stevenson, R. D. (2007). Growth and nutritional status in residential center versus home-living children and adolescents with quadriplegic cerebral palsy. *Journal of Pediatrics*, 151, 161-166.
- Hutton, J. L., Colver, A. F., & Mackie, P.C. (2000). Effect of severity of disability on survival in north east England cerebral palsy cohort. *Archives of Diseases of Childhood*, 83, 468-474.
- Krach, L. E., Kriel, R. L., Day, S. M., & Strauss, D. J. (2010). Survival of individuals with cerebral palsy receiving continuous intrathecal baclofen treatment: A matched-cohort study. *Developmental Medicine and Child Neurology*, 52, 672-676.
- Krause, J. S. (2002). Accuracy of life expectancy estimates in life care plans: Consideration of non-biographical and injury related factors. *Topics in Spinal Cord Injury Rehabilitation*, 89, 572-574.
- Krause, J. S., DeVivo, M. J., & Jackson, A. B. (2004). Health status, community integration, and economic risk factors for mortality after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 85, 1764-1773.
- Krause, J. S., & Saunders, L. L. (2010). Risk of mortality and life expectancy after spinal
-

- cord injury: The role of health behaviors and participation. *Topics in Spinal Cord Injury Rehabilitation*, 16, 53-60.
- Krause, J. S., & Saunders, L. L. (2011). Health, secondary conditions, and life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 92, 1770-1775.
- Krause, J. S., Saunders, L. L., & DeVivo M. (2011). Income and risk of mortality after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 92, 339-345.
- Middleton, J. W., Dayton, A., Walsh, J., Rutkowski, S. B., Leong, G., & Duong, S. (2012). Life expectancy after spinal cord injury: A 50-year study. *Spinal Cord*, (advance online publication, May 15, 2012) doi:10.1038/sc.2012.55.
- Plioplys, A. V. (2001). An ethical response to Peter Singer. *Caring for the Ages*, 2, 11-13.
- Plioplys, A. V. (2003). Survival rates of children with severe neurologic disabilities: A review. *Seminars in Pediatric Neurology*, 10, 120-129.
- Plioplys, A. V. (2004a). Pediatric skilled nursing facilities: Improved survival rates. In P. R. Katz, M. D. Mezey, & M. B. Kapp (Eds.) *Vulnerable Populations in the Long Term Care Continuum* (pp. 109-131). New York: Springer.
- Plioplys, A. V. (2004b). Life expectancy of severely children with disabilities: A brief review. In S. Riddick-Grisham (Ed.) *Pediatric Life Care Planning and Case Management* (pp. 781-795). New York: CRC Press.
- Plioplys, A. V., Kasnicka, I., Lewis, S., & Moller, D. (1998). Survival rates of children with severe neurologic disabilities. *Southern Medical Journal*, 91, 161-170.
- Plioplys, A. V., & Peterman, P. (2004). Effect of government regulations on death rates of severely disabled cerebral palsied children.. *Annals of Neurology*, 56 (suppl 8), S125.
- Plioplys, A. V., & Peterman, P. (2005). Effect on government regulations on death rates of severely disabled cerebral palsied children. *Journal of the American Medical Directors Association*, 6, B15.
- Shavelle, R. M., DeVivo, M. J., Paculdo, D. R., Voget, L. C., & Strauss, D. J. (2007). Long-term survival after childhood spinal cord injury. *Journal of Spinal Cord Medicine*, 30, (suppl. 1), S48-54.
- Shavelle, R. M., & Strauss, D. J. (1999). Mortality of persons with developmental disabilities after transfer into community care: A 1996 update. *American Journal on Mental Retardation*, 104, 143-147.
- Shavelle, R. M., Strauss, D. J., & Day, S. M. (2005). Deinstitutionalization in California: Mortality of persons with developmental disabilities after transfer into community care, 1997-1999. *Journal of Data Science*, 3, 371-380.
- Shavelle, R. M., Strauss, D. J., Day, S. M., & Ojdana, K. A. (2007). Life expectancy. In: N. D. Zasler, D. Katz, & R. Zafonte (Eds.), *Brain Injury Medicine: Principles and Practice* (pp. 247-261). New York: Demos Medical Publishing.
- Strauss, D., Brooks, J., Rosenbloom, L., & Shavelle, R. (2008). Life expectancy in cerebral palsy: An update. *Developmental Medicine and Child Neurology*, 50, 487-493.
- Strauss, D. J., DeVivo, M. J., Paculdo, D. R., & Shavelle, R. M. (2006). Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 87, 1079-1085.
- Strauss, D., Eyman, R., & Grossman, H. (1996). Predictors of mortality in children with severe mental retardation: The effect of placement. *American Journal of Public*
-

- Health, 86, 1422-1429.
- Strauss, D. J., Shavelle, R. M., & Anderson T. W. (1998). Long-term survival of children and adolescents after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation, 79*, 1095-1100.
- Ventura, T., Harrison-Felix, C., Carlson, N., DiGiuseppi, C., Gabella, B., Brown, A., DeVivo, M., & Whiteneck, G. (2010). Mortality after discharge from acute care hospitalization with traumatic brain injury: A population-based study. *Archives of Physical Medicine and Rehabilitation, 91*, 20-29.
- Ward, R. F., Jones, J., & Carew, J. F. (1995). Current trends in pediatric tracheotomy. *International Journal of Pediatric Otorhinolaryngology, 32*, 233-239.
- Westbom, L., Bergstrand, L., Wagner, P., & Nordmark, E. (2011). Survival at 19 years of age in a total population of children and young people with cerebral palsy. *Developmental Medicine and Child Neurology, 53*, 808-814.
- Yeo, J. D., Walsh, J., Rutkowski, S., Soden, R., Craven, M., & Middleton, J. (1998). Mortality following spinal cord injury. *Spinal Cord, 36*, 329-336.

**Author Bio**

Dr. Plioplys has provided 30 years of service as a child neurologist. The last 20 years of his medical career were devoted to caring for children and adults with the most severe forms of cerebral palsy. During this time period he amassed more clinical experience in caring for this population than any other physician in North America. He can be reached at [plioplysav@sbcglobal.net](mailto:plioplysav@sbcglobal.net).

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