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Life Expectancy And The Life Care Planner

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Introduction

Many of the costs budgeted in a life care plan are "per year," and the more years of life expected the greater the cost. Thus the life expectancy is a significant factor in the total cost of the plan. For this reason, life care planners are often asked what is the patient's life expectancy.[1] Even if the life care planner will not provide a professional opinion on this issue, having a basic knowledge of the subject area, if offered only for preliminary or informal purposes, is valuable to both the planner and the client.

There is a medical literature on the life expectancy of patients with various conditions, and in particular of those with neurological impairment such as cerebral palsy, traumatic brain injury, or spinal cord injury. In the present article we focus on these three conditions. As would be expected, the more severe the injury, as measured by the degree of disabilities, the greater the reduction from normal life expectancy.

In this article we offer a brief guide to this literature. We begin here with the basics. We then discuss the risk factors associated with survival. We follow with a discussion of the extant literature. We give examples for many medical conditions, to demonstrate that the framework described here is universally applicable.

The Basics of Life Expectancy

The medical literature on prognosis for survival is vast and ever-expanding; there are more than a million survival studies of many millions of persons. Populations of particular interest to life care planners have been extensively studied, and in particular those with cerebral palsy, traumatic brain injury, and spinal cord injury.[2-5]

A few key terms[6] in this literature are:

- Life span or survival time is the total number of additional years a person actually lived or will live.
- Survival percentage refers to the proportion of a cohort (original group) that survive to a given time point. For example, in cancer studies one often cites the 5-year survival percentage.
- Survival percentile is the complement of the above, the time at which a given percentage of a cohort have died. For example, if 90% of the studied cohort have died by time 10 years then the 90th percentile is 10 years.
- Median survival time, a special case of the above, is the time at which half the original members of a given population have died (or are still alive); it is the 50th percentile.
- Life expectancy is the mean (or average) survival time of a large group of similar persons.

It is not possible to predict a person's actual survival time with any accuracy, and people frequently err or show bias when attempting to do so.[7] It is, however, possible to estimate, or compute, various summary measures of survival, including the median survival time and life expectancy. This summary information provides guidance to interested parties as to the "anticipated number of years remaining" for a typical member of a population.

As an example, the federal government life tables for the United States population do not predict survival time, yet they are used extensively in a variety of applications (e.g., the required minimum distribution in a retirement account is often based on the person's remaining life expectancy, and annuity prices are determined by survival rates). For instance, a male aged 70 in the US general population has a life expectancy of 14 years, a median survival time of 13 years, the 10th percentile is 3 years and the 90th is 24 years.6 Due to the large sample size involved, there is great precision to these figures.

Life expectancy and other survival quantities derive from either a life table or a survival curve. A life table summarizes the entire life-long pattern of mortality in a population.[8] The table is constructed with the use of mortality rates for all ages. These may not be available if the study window is short and the sample size is relatively limited, in which case it may be necessary instead to construct survival curves for various study groups.[9] These track cohorts over time, beginning with 100% alive initially and following the group until either (a) all have died, or (b) the study period has ended or the person is lost to follow-up. In the latter case the survival times are said to have been "censored". Using either approach, a life table or a survival curve, one can account for various "risk factors". Discussion of the technical details is beyond the scope of the present article, but further information may be found in any of a number of standard sources.[8-10]

Risk Factors Associated With Survival

Characteristics associated with a given outcome are referred to as "risk factors" for that event. The medical literature documents many factors associated with survival, including demographics, lifestyle, and medical conditions. Chief among these of course is age; for example, the mortality rate for males aged 80 is 12 times larger than at age 50 years. Also, at most ages males have roughly twice the risk of death as females.[6]

In addition there are factors particularly relevant to each disabling condition. In coronary artery disease, for example, it is well known that survival is related to the number of affected vessels (stenosed by 50% or more, say), ejection fraction, and the presence of left ventricular hypertrophy. In diabetes, survival is associated with long-term glycemic control, risk factor control, and especially the presence and severity of the triopathies (retinopathy, neuropathy, and nephropathy). In cancer, the tumour histology, stage, grade, treatment and response are often correlated with short-term and long-term survival.[10]

In brain injury (whether congenital, as in cerebral palsy, or acquired, as in traumatic brain injury), it has been found that gross motor skills and feeding ability are strongly associated with survival.[2-5] For example, the abilities to walk and to self-feed are strongly positive factors for survival. In spinal cord injury the level and grade of injury, etiology and time since injury are important factors. A detailed listing of some of the more salient factors is given in Table 1.

Table 1
Risk factors associated with survival in chronic disability

Brain Injury (cerebral palsy and traumatic brain injury):
- Age
- Gender
- Gross and fine motor function
- Feeding ability (fed by others, self feeds with assistance, self feeds independently)
- Need for a feeding tube
- Dysphagia
- Need for tracheostomy or ventilator support
- Need for frequent suctioning
- Asthma, aspiration pneumonia or other respiratory problems (frequency/severity)
- Epilepsy
- Vision loss
- Mental retardation / cognitive impairment
- Medical complexity (including cardiopulmonary and gastrointestinal complications)
- Bowel and bladder incontinence
- Factors more common in children: Contractures, scoliosis
- Factors more common in adults: Behavioral problems, aggression, frontal lobe syndrome
- Complications of the injury
- Sequelae of immobility
- Co-morbidities (including nicotine dependence, psychiatric diagnoses, overweight)
- Past medical history (heart disease, cancer)

Spinal Cord Injury:
- Age
- Gender
- Etiology of injury
- Level of neurologic injury
- ASIA grade
- Time since injury
- Bowel and bladder function
- Complications (including urinary tract infections, autonomic dysreflexia, respiratory compromise, skin breakdown, DVT, depression, hospitalizations)
- Co-morbidities (including nicotine dependence, overweight)
- Past medical history (heart disease, cancer)

While it may be surprising to some, it is clear from the epidemiologic literature that the disabilities themselves, rather than the exact medical diagnoses, correlate most strongly with survival. The patient's basic motor and self-care skills prove to be especially important. Significant milestones in the pediatric population include the ability to lift the head in prone, roll over, sit, crawl, walk, and self-feed. Parallel capabilities, such as walking, are likewise important in the adult and elderly populations.[6,11] Other markers include the presence of a seizure disorder, sensory losses including blindness and deafness, bowel/bladder incontinence (which may actually reflect motor or intellectual losses) and overall medical complexity and stability.

The impact of severity of disability on life expectancy has a well-documented medical basis. The very sedentary and immobile patient has a clearly increased risk of dangerous complications, including decreased cardiopulmonary function and reserves; increased risk of

vasculopathy, including deep venous thrombosis and pulmonary embolism; demineralization of bone with its effects on the musculoskeletal and urinary systems; skin breakdown with its associated infectious disease risk; insulin resistance; and adverse effects on the immune system. All are well-recognized risk factors for premature death.[12-17]

Advances in medical science in recent decades have reduced mortality, especially among people with severe disabilities, and with regard to respiratory failure and dysphagia. The benefits of these advances, however, are less than many clinicians believe.[18] It is also common for those unfamiliar with the literature to overestimate the actual functional benefits of therapeutic interventions such as physical and occupational therapy in, for example, cerebral palsy.[19-21]

The Medical Literature

As noted, life expectancy is the average survival time in a large group of similar persons. To compute a person's life expectancy thus requires identification of a large group of similar persons whose survival experience is known. We find such groups, and their accompanying survival information, in the medical literature. In each of cerebral palsy, traumatic brain injury, and spinal cord, for example, there are over a dozen recent and relevant studies. In heart disease, cancer, stroke or diabetes, there are often hundreds of relevant studies.[10] The number of studies, and the range of the applicable figures, indicates the precision of the resulting life expectancy figures. In some cases the agreement is remarkable; in other cases the range can be quite wide, reflecting the differing effects of study populations, methods, or treatments.

As a matter of scientific procedure, the matching of a patient to the literature must be done in an unbiased fashion; that is, the same criteria used in the study must be used to evaluate the patient. In cerebral palsy, various motor function scales are used. In the California studies,[6] head control refers to the "ability to consistently and purposefully lift the head in prone." Thus head control in supported sitting does not meet this criteria. Similarly, in the United Kingdom cerebral palsy studies of Hutton and colleagues,[22] a person is said to have a severe ambulatory disability if "wheelchair is required and assistance is needed for its propulsion." Someone entirely bed bound would therefore have a poorer prognosis than the average of this group. Similarly, the criteria for feeding ability, visual disability, and learning disability (or, equivalently, mental retardation level) must be used consistently and carefully.

Regarding traumatic brain injury, one study reports an average reduction in life expectancy of 7 years.[23] It would not be appropriate to ascribe this reduction to someone whose disabilities were much less or more severe than the average (e.g., someone with only a mild cognitive impairment, or someone in the vegetative state). To compute a person's life expectancy one must make a fairly close match of their characteristics to those of the various study populations. Even if this cannot be done, at the very least one can determine appropriate bounds, or ranges, for the life expectancy. For example, based solely on the study cited above,[23] someone severely disabled after traumatic brain injury would have a life expectancy that is reduced by more than (the average) seven years.

In spinal cord injury, the neurologic level of injury is defined by the ASIA as "the most caudal segment of the spinal cord with normal sensory and motor function bilaterally."[4] It would thus be improper in this context to instead use the level of the injured vertebra. For example, persons with a C4 injury generally have limited shoulder movement, no elbow flexion, and can control an electric wheelchair only via chin or "sip and puff" controller. Conversely, persons with a C5 injury generally have good shoulder movement, good elbow

flexion, and can control an electric wheelchair with hand control. Other functional distinctions arise in the respiratory system, personal care, domestic care, and communication domains.

Table 2 reports life expectancies in cerebral palsy.[6] As can be seen, the life expectancy varies by age, sex, feeding ability, and gross motor function, the latter two being the most significant. At age 30, for example, males who can roll or sit, but who cannot independently walk or feed themselves, have a life expectancy of 31 additional years, whereas those who can walk have a life expectancy of 39 years, or 8 years higher.

Table 2
Life expectancy (additional years) in cerebral palsy by age and disability

Sex / Age	Cannot Lift Head			Lifts Head or Chest			Rolls/Sits, Cannot Walk			Walks Unaided	General Population
	TF	FBO	SF	TF	FBO	SF	TF	FBO	SF		
Female											
15 y	13	16	-	16	21	-	21	35	49	55	65.8
30 y	14	20	-	15	26	-	16	34	39	43	51.2
45 y	12	14	-	13	16	-	14	22	27	31	37.0
60 y	-	-	-	-	-	-	-	-	16	20	23.8
Male											
15 y	13	16	-	16	20	-	19	32	45	51	60.6
30 y	14	19	-	15	24	-	16	31	35	39	46.5
45 y	12	14	-	13	15	-	14	20	23	27	32.8
60 y	-	-	-	-	-	-	-	-	13	16	20.4

TF = tube fed, FBO = fed by others, without feeding tube, SF = self-feeds

From: Strauss DJ, Shavelle RM, Rosenbloom L, Brooks JC. Life expectancy in cerebral palsy: An update. Developmental Medicine & Child Neurology 2008; 50:489.

Table 3 reports life expectancy after traumatic brain injury.[5] Given that the precise cause of the injury is usually only a minor factor, these figures may also be taken roughly to apply to anoxic/hypoxic brain injury (though stroke, which may reflect a systemic condition and may recur, tends to have a worse outcome). The table shows that a limitation in walking is associated with an up to 8-year reduction from the general population life expectancy. And children age 10 with severe disabilities have a life expectancy of only 27 years, even if they are not in the vegetative state (persons with no purposeful motor function or ability to communicate).

Table 3
Life expectancy after traumatic brain injury by age and severity of disability

Females		Cannot Walk		Some	Walks	General
Age	PVS[a]	Fed by Others[b]	Self Feeds[c]	Walking Ability[d]	Well Alone[e]	Population
10	12	27	46	57	62	70
20	11	26	40	48	53	60
30	10	22	33	41	45	51
40	9	16	26	31	36	41
50	7	11	20	23	27	32
Males						
10	12	27	45	50	56	64
20	11	26	40	45	50	55
30	10	22	33	37	42	45
40	9	16	25	26	31	36
50	7	11	19	18	23	27

[a]Permanent vegetative state: No purposeful motor or cognitive function. Requires a feeding tube.
[b]Does not feed self, must be fed completely (either orally or by a feeding tube).
[c]Can feed self with fingers or utensils, with assistance and/or spillage.
[d]Walks with support, or unsteadily alone at least 10 feet but does not balance well.
[e]Walks well alone for at least 20 feet, and balances well.

From: Shavelle RM, Strauss DJ, Day SM, Ojdana KA. Life Expectancy. In: Zasler ND, Katz DI, Zafonte RD, eds. Brain injury medicine: Principles and practice. New York: Demos Med Publ 2007; page 253.

Table 4 reports life expectancies in SCI.4 The level and grade of injury are seen to be key factors. Other than short term improvements over the first few years post injury, there is no evidence of a significant secular trend towards improved survival over the past 30 years.[4] This is contrary to to some fairly widespread beliefs in the rehabilitation field. As is clear from the table, even the mildest grade of SCI (grade D) is associated with a significant reduction in life expectancy.

Table 4
Life expectancy following spinal cord injury, by injury level and ASIA grade: 25 year-old white men with non-violent etiology, time since injury 3 years

Group	Life Expectancy
General Population	51
C1-3, grade A	25
C1-3, grades B and C	32
C4, grade A	26
C4, grades B and C	35
C5, grade A	30
C5, grades B and C	36
C6-8, grade A	35
C6-8, grades B and C	37
T1-S5 (paraplegia), grades A, B, and C	38
All grade D	45

From: Strauss DJ, DeVivo MJ, Paculdo DR, Shavelle RM. Trends in life expectancy after spinal cord injury. Archives of Physical Medicine and Rehabilitation 2006; 87:1082.

The scientific evidence on life expectancy, as reported in the medical literature, should at least be the starting point for a rational discussion of life expectancy. One can then determine whether additional adjustments are warranted.[5] Too often, however, the existing evidence is not identified, or is too readily dismissed as irrelevant by those who have not properly considered it.

Conclusions

Life expectancy is used in social and economic planning, public health management, and in assisting families and care givers in their preparations for meeting the needs of people with disabilities. While we cannot predict exactly how long any one person will live, we can compute various summary measures of survival such as the life expectancy, often with considerable accuracy. This requires knowledge of the patient's history, medical conditions, and functional deficits, together with an understanding of the basics of life expectancy, the factors related to survival, and how to use the available scientific literature. An evidence-based opinion on survival is greatly preferable to reliance on anecdotal experience or gut feelings.

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