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Evidence-based life expectancy and the physician

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Abstract

Physicians are often asked to opine on life expectancy. Some mistakenly believe that this is a prediction about how long a given patient will live. Others are not familiar with the scientific evidence on the topic, or with how to use it properly. In this article we offer guidance on evidence-based life expectancy. 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.

Keywords: Survival, mortality, life table, science, cerebral palsy, traumatic brain injury, spinal cord injury.

Introduction

Physicians deal with end of life issues as a matter of course: answering patients' and families' questions on prognosis, or providing information to ensure adequate funding for the future needs of injured parties. Too often, however, they misuse terminology or fail to understand the scientific issues. Some are not familiar with the risk factors associated with reductions in survival rates; others inappropriately rely on their anecdotal experience rather than upon the scientific literature.

The physician can avoid these pitfalls by becoming familiar with the science of life expectancy, and the relevant risk factors for a given condition. He can then (1) review the patient's past medical history, (2) gather information from an appropriate physical examination and (3) use these, together with the scientific literature on survival, to estimate life expectancy.

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We begin here with the basics. We then discuss the risk factors associated with survival. We follow with details on how this information should guide physicians in their history-taking and examinations of patients, and in their subsequent use of the scientific literature. We give examples for many medical conditions, to demonstrate that the framework described here is universally applicable. We focus in particular on three common chronic disabilities: cerebral palsy (CP), traumatic brain injury (TBI), and spinal cord injury (SCI).

Basics of life expectancy

The medical literature on prognosis for survival is vast and ever-expanding; there are more than a million survival studies (1) of many millions of persons. Populations of particular interest to pediatricians, physiatrists, and neurologists have been extensively studied, notably including persons with CP, TBI, and SCI (2-6). Proper use of the prognostic information in these studies requires an understanding of the operative scientific terms.

A few key terms 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 related to the above. It is the time at which a given percentage of a cohort are still alive. For example, if 90% of the studied cohort were observed to survive for 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 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 physicians 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. It is this summary information that provides guidance to interested parties as to the "anticipated number of years remaining" for a typical member of a population.

Notably, 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 10^{th} percentile is 3 years and the 90^{th} is 24 years.

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 a myriad of 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, for ages 30-60 years, males have roughly twice the risk of death as females.

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.

In brain injury (whether congenital [CP] or acquired [TBI]), it has been found that gross motor skills and feeding ability are strongly associated with survival. In SCI 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
- 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 perhaps be counter-intuitive, it is clear from the epidemiologic literature that the resulting 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 be reflective of motor or intellectual losses) and overall medical complexity and stability.

The impact of disability on life expectancy has a thoroughly-documented medical basis. While the degree of disability is generally proportional to the degree of neurologic insult, which in turn is associated with a number of medical complications, the disabilities themselves also engender mortality risk. 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 the most severely disabled and particularly with regard to the management of respiratory failure and dysphagia. The benefits of these advances, however, are less than many clinicians believe [18]. It is also common for those not familiar with the literature to overestimate the actual functional benefits of therapeutic interventions such as physical and occupational therapy in certain populations, notably those with cerebral palsy (19-21).

The physical examination

Medical records can be incomplete and conflicting, and prior evaluations by physicians inexperienced with the severely disabled can be misleading, especially if the nomenclature is misused. The exam should focus on the physical, medical, and functional markers of increased or decreased mortality in the relevant populations, along with any unique aspects of the individual. It is appropriate to look for significant pathologies that may be unrelated to the primary diagnosis, such as infection, cardiopulmonary disease, or other co-morbidities.

Each medical specialty has its own tests, procedures, checklists, and comprehensive evaluation techniques. In the case of the physiatric exam, emphasis is placed on the neurological, musculoskeletal and functional components. In addition, other general and organ system evaluations can by useful in identifying complicating medical conditions, and assist in identifying the etiology and extent of the disability.

The head and neck exam should include evaluation for any dysmorphic features. While some cephalic anomalies are to be expected in infants with any severe neurologic compromise, it is important to ensure that no aberrant genetic features have been overlooked. Abnormalities that may interfere with feeding -- such as micrognathia, a highly arched palate, dental abnormalities, drooling or food rejection -- suggest difficulty taking food by mouth, an important prognostic sign.

In the cardiopulmonary exam certain findings such as non-innocent murmurs may suggest congenital abnormalities. Evidence of reduced ventilatory excursion is commonly seen in spinal cord injury and other neuropathology. Stridor and any oropharyngial ventilatory discoordination should be documented, as pulmonary complications are a leading cause of death in the severely disabled (22).

The abdominal exam includes assessment for hernias, dysmotility, and ostomy condition, if present. This part of the exam also serves as a reminder to note the patient's overall nutritional status.

An important aspect of the physical exam, particularly in infants, is the integument component. This should focus on identification of café au lait spots, spinal dimpling, unusual hair patterns or other neurocutaneous manifestations of disease. Of course, all patients should be evaluated for risk of skin breakdown.

In addition to documenting any dysmorphia, the musculoskeletal exam should focus on the issues, both reversible and irreversible, that interfere with mobility and self care, most notably contractures. Limb deficiencies are noted, of course, but their effects on life expectancy in and of themselves are insignificant except when associated with other morbidities, notably vasculopathy.

The neurologic and functional exams frequently overlap. Cranial nerve examination should focus on identification of any visual and auditory losses. Evaluation of dysphagia also is commonly done at this point in the exam. A major predictor of survival in the most severely disabled pediatric population is head control. Age-appropriate assessment includes evaluation of head lag when a patient is elevated from the supine position, testing the ability to extend the neck and lift head when prone, and noting general head control during perturbations and visual tracking. The remaining motor and sensory exams are done to ensure that proper diagnostic terminology is ultimately used (e.g., persistent vegetative state, tetraplegia, and complete versus incomplete spinal cord injury, all of which have implications for survival and outcome). The findings should be incorporated and found consistent with evaluation of functional capability. Specific items to be evaluated

include the ability to swallow, to self-feed (an assessment of fine motor skill), and to manage bowel and bladder (when age appropriate). Perhaps most significant is the assessment of age appropriate gross motor function, particularly mobility. Functional capability must be demonstrated independently, consistently, and purposefully, as opposed to, say, rolling over as a result of opisthotonos or ATNR. Similarly, a reflex stepping pattern in fully supported standing resulting from pathologic persistence of a primitive reflex should not be mistaken for true ambulation. Finally, "ambulation" with the help of a weight-bearing device is evidently quite different from walking with the help of Canadian crutches or a rolling walker, or without any aids.

Using the scientific 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 CP, TBI and SCI, for example, there are over a dozen recent and relevant studies. In heart disease, cancer, stroke or diabetes, there may be hundreds of relevant studies.

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. For example, in CAD one must use the same criteria for "an affected vessel" that is used in the index study (e.g., stenosed by 50%). And in cancer studies one must be careful to use the appropriate clinical or pathological diagnosis. The same can be said in the various other medical sub-disciplines. We now consider in particular the literature on survival in CP, TBI, and SCI.

In CP, 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 CP studies of Hutton and colleagues (23), 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, medically precluded from wheelchair use, would therefore be much worse off 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.

In TBI, one study reports an average reduction in life expectancy of 7 years (24). It would be inappropriate 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, respectively). To properly compute a person's life expectancy is in essence to fairly match their characteristics to those of the various study populations. To the extent 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 immediately above (24), someone severely disabled after TBI would have a life expectancy that is reduced by more than (the average) 7 years.

In SCI, 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 CP (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 3 reports life expectancy after TBI (5). In light of the above discussion regarding

etiology, these figures may also be taken 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 mere limitation in walking is associated with an up to 8-year reduction in life expectancy compared with the general population. And children age 10 with severe disabilities have a life expectancy of only 27 years, even if they are not in the vegetative state.

Table 4 reports life expectancies in SCI (4). The level and grade of injury are seen to be key factors.

Table 2. Life expectancy in cerebral palsy by age and disability

Sex /	Cannot Lift Head			Lifts Head or Chest			Rolls/Sits, Cannot Walk			Walks	General
Age	TF	FBO	SF	TF	FBO	SF	TF	FBO	SF	Unaided	Population
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. Used with permission [6].

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. Used with permission [5].

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

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. Used with permission [4].

Other than short term improvements over the first few years post injury, there is no evidence of a significant secular trend in survival over the past 30 years (4). Not shown in the table, but implicit in the study results, is the fact that age and gender are also key factors. As is obvious from the table, even the mildest grade of SCI (grade D) is associated with a significant reduction in life expectancy.

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 the disabled. Physicians are often asked to opine on this important topic. 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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