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Life Expectancy for Life Care Planners

Scott J. Kush MD JD MPH, Steven Day PhD, and Robert Reynolds MPH

Abstract

This article examines life expectancy and its relationship to life care planning and economic calculations in litigation. It discusses basic terminology, the standard scientific method, the life table, and essential variables and source data for determining the life expectancy of persons with chronic disabilities or other medical conditions. It describes the Life Expectancy and Expected Present Value models, presents analyses of four sample cases, and discusses the possible effects of quality and quantity of care.

Key words: life expectancy, survival time, life table, essential variables, scientific method, life care planning, mortality, forensic economist, life expectancy expert, life care planner, expected present value, cerebral palsy, spina bifida, spinal cord injury, diabetes, end stage renal disease, quality of care, quantity of care

Introduction

Life expectancy can play an important role in medical malpractice, personal injury litigation, and life care planning. Life expectancy is critical to life care planners for forecasting purposes and is not limited to courtroom care plans as it is also applicable outside of litigation (e.g., in pension and estate planning, and in setting up annuities).

This article will discuss the basic terminology related to life expectancy, the standard scientific method of calculating life expectancy, the basic tool known as the life table, and the essential variables and source data that assist in completing a life expectancy analysis. Then, the *Life Expectancy model* will be compared with the *Expected Present Value model* with respect to calculating certain economic damages. Four examples will illustrate how life expectancy can impact life care planning and the calculation of damages in the context of litigation. Next, the issues of quality and quantify of care will be considered. A discussion of possible future trends and the need for collaboration and further research concludes the article.

Basic Terminology

In medicine and science, the term *life expectancy* is defined as the average survival time in a large group of similar persons. Survival time is the actual number of years, months, days, and hours a person will live. The *median survival time* is the time after which only 50% of a large group of similar persons are still alive. If all the survival times until death are known and are lined up from smallest to largest, the median will be the middle value. Life expectancy is not a prediction of anyone's actual survival time, but is arguably a fair surrogate for that actual survival time in the absence of certain knowledge of the future. It is not possible to accurately predict the ultimate survival time of any living individual.

The National Center for Health Statistics reports that the life expectancy of a U.S. male at birth is 75.6 total years (Arias, 2012). This represents the average (arithmetic mean) survival time of a newborn boy. For a newborn girl the figure is 80.6. The life expectancy is a summary measure of more extensive information contained in a life table, including annual probabilities

of survival and age-specific mortality rates. To repeat, life expectancy is not intended to predict the actual survival time of any individual and we do not expect that a given male born today will die *precisely* at age 75.6 His actual survival time can be longer or shorter than the average, which is intuitively clear if one thinks of their own male acquaintances who have died before the age of 75.6, or who are now older than that.

Life Expectancy Analysis Overview – The Standard Scientific Method

The US life tables published by the National Center for Health Statistics and the Center for Disease Control and Prevention (CDC) account for age, sex, and race or ethnicity in reporting life expectancies; these factors are known to have an impact on mortality rates, and therefore on life expectancy. There are, of course, many other factors not addressed by the standard life tables of the CDC that can affect mortality rates and life expectancy. For example, an overwhelming body of medical and scientific literature demonstrates that mortality rates for persons who have significant limitations in motor functioning due to neurological injury are higher than those of the age- and sex-matched general population. (References for this will be provided below.)

The standard scientific process of calculating the life expectancy of a given individual involves several components. First, one must determine what medical or behavioral mortality risk factors the individual may have. This is typically done by way of review the individual's medical records and other information (e.g., notes from his caregiver(s), independent medical exam(s), and/or a deposition of the individual). Second, one must examine the peer reviewed literature and/or available databases that provide information about the mortality rates and survival probabilities for persons with medical conditions comparable to the individual's. Third, one must extract pertinent information on mortality rates from the literature. Most often this information will come in the form of mortality rates, standardized mortality ratios (SMRs), or excess death rates, and in some cases actual published estimates of life expectancy. Fourth, one must use the information on mortality rates from the literature to construct a life table, or perhaps numerous life tables, each providing a life expectancy that accounts for one or more medical conditions or non-medical risk factors (e.g., smoking habit), and in some cases multiple risk factors simultaneously. When adjustments are made in a life table to account for more than one risk factor, consideration should be given to how the conditions may interact. A full discussion of these issues is beyond the scope of this article, but some information on how various medical conditions interact with each other to affect mortality rates is available in many peer-reviewed studies. Once the work of calculating various life expectancies is completed, expert judgment must be exercised in determining how the life expectancy of the individual in question compares with the (possibly many) results. A life expectancy, or possibly a range of life expectancies, eventually is settled on based on the foregoing process. A life table (or tables) representative of the life expectancy (or life expectancies) can then be produced using the mortality information from the various resources that have been employed (Brackenridge & Croxson, 2006; Anderson, 2002). The standard scientific method allows one to take into account any evidence available regarding factors that influence survival, and can thus adjust for factors such as economic resources and access to needed services, provided sound scientific evidence regarding their impact on survival is available.

The Life Table

A life table summarizes the mortality experience of a population. This analytical tool is used to describe age-specific morality and survival rates for a population. John Graunt is known to have produced what may have been the first life table in the 17th century to analyze whether plague continued to be a problem for London. Life tables are now routinely used by demographers, epidemiologists, pension planners, life actuaries, and medical researchers (to name a few). They describe in table form, most importantly, the number of individuals surviving to any given age, the number of deaths in any given year, the probability of dying in a particular year, and the life expectancy at any age.

Below is an abbreviated life table for males using recent data from the National Center for Health Statistics (Arias, 2012).

Age	l(x)	d(x)	q(x)	L(x)	T(x)	e(x)
0	100,000	720	0.0072	99,374	7,559,612	75.6
1	99,280	50	0.0005	99,255	7,460,238	75.1
10	99,088	7	0.0001	99,084	6,567,827	66.3
20	98,598	121	0.0012	98,537	5,578,411	56.6
30	97,246	136	0.0014	97,178	4,599,187	47.3
40	95,666	211	0.0022	95,561	3,634,102	38.0
50	92,449	502	0.0054	92,198	2,691,236	29.1
60	85,447	975	0.0114	84,959	1,797,985	21.0
70	72,277	1,817	0.0251	71,369	1,002,466	13.9
80	48,469	3,079	0.0635	46,930	388,134	8.0
90	16,223	2,775	0.1710	14,835	64,891	4.0
100	844	844	1.0000	1,730	1,730	2.0

Table 1. Life Table of a male.

The columns are:

Age – age in years

l(x) – the number of people surviving to age x

d(x) – the number of deaths that occur during age x

q(x) – the probability of dying during age x

L(x) – the total number of person-years lived by persons age x

T(x) – the total number of person-years lived during year x and all future years (if all rows of the table were included, this would be the sum of all figures in the L(x) column for year x and all future years)

e(x) – the life expectancy (or expectation of life) of persons alive at the beginning of age x

Life tables assist in understanding the mortality dynamics of a population. Using data from the life table, a survivorship curve can be drawn by plotting l(x) on the y-axis and age on the x-axis. Mortality curves can be created by plotting q(x) against age.

Essential Variables and Source Data for Determining the Life Expectancy of Disabled Individuals

When attempting to formulate a life expectancy estimate for a disabled individual, the life expectancy professional needs information about the individual as well as information about survival probabilities, mortality rates, or life expectancies of populations of similarly disabled persons. For both individuals and populations there are variables that are considered essential mortality predictors, and there are common data sources that can assist in determining the impact of these variables on mortality rates and life expectancy.

Demographics are essential in the estimation of life expectancy. Because mortality rates are known to vary by age, sex, race, and nationality, any attempt at estimating life expectancy should take these basic characteristics into consideration.

An individual's medical history can also be critical to life expectancy estimation. Illnesses and injuries can shorten life expectancy, and the absence of illness or injury and particularly healthy lifestyle habits can sometimes lengthen life expectancy. Failure to consider these factors may lead to overly optimistic or pessimistic life expectancy estimates. Information needed varies in relation to particular disabilities or medical conditions, but in general, specifics such as the type and severity of disability and functional profiles, when available, are strongly associated with survival. Functional profiles most often refer to assessments of mobility and physical function, but for those patients who have mild physical disabilities, such assessments may extend into the realms of self-care and cognitive impairment.

Other variables may also impact life expectancy to some degree. Lower socio-economic status (SES) may play a role in long-term survival, perhaps in part because of inadequate funding for reasonable care needs, but also possibly due to other unmeasured variables such as lower compliance or adverse health habits (Strauss, DeVivo, Shavelle, Brooks, & Paculdo, 2008; Krauss, DeVivo, & Jackson, 2004). Recent studies have suggested that more care, above and beyond a necessary level, may not positively impact longevity (Fisher, Goodman, Skinner, & Bonner, 2009; Wennberg, Fisher, Goodman, & Skinner, 2008).

To determine the most accurate life expectancy estimate possible, and one that is sufficient for life care planning and/or litigation purposes, data concerning survival in populations of patients with similar disabilities should be compiled and evaluated. Typically, life expectancy experts will turn to peer-reviewed scientific studies of the mortality and life expectancy of disabled populations. Such studies draw data from sources such as vital statistics registries, research cohorts, and hospital registries to provide estimations of life expectancy or survival probabilities for disabled patients based on clinical, functional, and demographic characteristics. By considering all possible published evidence, and in some cases considering also available sets of data, and taking account of the particulars of the individual, life expectancy experts can arrive at accurate, evidence-based estimates of life expectancy for disabled patients.

Examples of data sources for life expectancy research exist for several disabilities. We will focus, here, on cerebral palsy, traumatic brain injury, spina-bifida, and advanced diabetes with end-stage renal disease. Our example involving spina-bifida will also draw a comparison with spinal cord injury. Evidence on long-term survival of persons with these disabilities and medical conditions, as well as many others, is available in the literature.

Cerebral palsy (CP) has been researched extensively in the US and UK, and to a lesser extent in Australia, Canada, and elsewhere. In the US the primary data source has been the California Department of Developmental Disabilities database (CA-DDS), while in the UK data have been analyzed from the United Kingdom Collaborative Network of Cerebral Palsy Registers (Surman & Bonellie, 2006). In Australia data have been compiled since the 1950s by the Western Australian Cerebral Palsy Register which now contributes data to the Australian CP Register (ACPR Group, 2009).

Traumatic brain injury studies have been conducted using data from the CA-DDS (Shavelle & Strauss, 2000; Shavelle, Strauss, Day, & Ojdana, 2007) and from the National Institute on Disability and Rehabilitation TBI Model systems of care (Harrison-Felix et al., 2012), among other sources of data.

Research into the life expectancy and mortality of spina bifida has been conducted using disease registries in at least 10 US states, including the CA-DDS (Shin 2012). In addition, a cohort of spina bifida patients has been followed completely and continuously in the UK since the early 1970s (Oakeshott, Hunt, Poulton, & Reid, 2010).

The Spinal Cord Injury Model System Information Network at the University of Alabama at Birmingham maintains a large database of patients who sustained and have been treated for spinal cord injuries over many years. The Network is actively conducting research on many aspects of spinal cord injury, including life expectancy (Chen et al., 2011; DeVivo, Krause, & Lammertse, 1999; DeVivo & Ivie, 1995).

Myriad studies have been published describing the impact of diabetes on long-term survival and mortality; we mention here only two that are representative (Hansen, Jensen, & Carstensen, 2012; Milano 2011). In some cases, diabetes can eventually lead to kidney damage and renal failure. Reference tables from the United States Renal Data System (USRDS) provide mortality rates for those with end stage renal disease due to diabetes or other causes, stratified by gender, race, and type of dialysis employed (USRDS, 2012).

Life Expectancy and Expected Present Value

As previously discussed, life expectancy is a summary measure of information contained in or obtainable from a life table. This includes (but is by no means limited to): age-specific annual probabilities of survival; age-specific annual probabilities of death; person-years lived by a hypothetical cohort alive at the beginning of a given age; and cumulative person-years lived by a hypothetical cohort from any given age until all in the cohort have died. In litigation, and in other contexts, the single summary figure of life expectancy is often used for the purpose of determining the expected present value of a potential future stream of payments or receipts. The two most common applications of this involve future annual costs of care for a person having been injured through alleged medical malpractice or other wrongful injury; and potential future annual earnings lost due to wrongful injury or death.

Determining reasonable future annual costs or lost earnings typically requires input from a number of experts. A forensic economist may be relied upon to determine factors influencing the time value of money (e.g., discount rates, inflation rates for medical supplies, equipment and services, and rates of return on savings or other investments). The economist may also play a role in determining reasonable assumptions about the future earning potential of an individual but for a disabling injury or death. A life care planner may be relied upon to determine current costs of medical goods and services, typical replacement schedules for wheel chairs or other durable goods, and other healthcare-related costs. Assuming these issues have all been settled and a court of law has found in favor of a plaintiff on the issue of liability,

it is typical for a lump sum of money to be awarded. In the case of an award for future medical costs, this lump sum is intended to approximate the expected present value of anticipated future medical costs (as part of a possibly more extensive settlement to include such non-economic damages as money for pain and suffering, loss of consortium, and others). Since all potential future payments are uncertain (a plaintiff could die before any future care is actually needed), the calculation of their expected present value is a probabilistic one.

The methods for determining a fair estimate of the expected present value of a stream of potential future payments are similar whether those payments are for medical costs or lost earnings. To simplify our discussion of expected present value and its relationship to life expectancy, we will now focus on costs associated with future medical care and omit further consideration of lost earnings. To illustrate the issues involved in determining a fair estimate of expected present value, or a fair lump sum to represent a future stream of uncertain payments, we will consider a hypothetical and rather simplistic example.

Consider a 50 year-old man who might live 1, 2, 3, or 4 more years. Assume that each of these outcomes is equally likely, so that there is a 1/4 chance that he dies at the end of one year, a 1/4 chance he lives past 1 year then dies at the end of 2 years, and a 1/4 chance he lives past 2 years and dies at the end of 3 years, and so on. The example is thus unrealistic for at least two reasons: this person is guaranteed to live at least one year, and certain to die at the end of four years, if not sooner. Such certainty is impossible in any real-life situation. A life table corresponding to this hypothetical scenario is provided below (Table 2).

Age	l(x)	d(x)	q(x)	L(x)	T(x)	e(x)
50	100,000	25,000	0.25	100,000	250,000	2.5
51	75,000	25,000	0.33	75,000	150,000	2.0
52	50,000	25,000	0.50	50,000	75,000	1.5
53	25,000	25,000	1.00	25,000	25,000	1.0

Table 2. Life Table of a hypothetical 50 year-old male.

Note that for this scenario, the life expectancy is 2.5 years from age 50. Now assume that costs of medical care for this gentleman's remaining years of life (however many he may actually live, 1, 2, 3, or 4) will be $100,000/year. Further assume, for now, that the net discount rate is zero, so that $100,000 four years from now is worth the same as $100,000 today.

The question is, then, what lump sum today will be fair as a substitute for a stream of possible future payments that might be as little as $100,000 or as great as $400,000, depending on how long the individual actually lives?

Generally speaking, the average, or expected, present value under all possible contingencies is considered the fair amount to award. A number of methods for estimating the expected present value have been proposed (Anderson, 2008). In our experience the most common model is what Anderson referred to as the *Life Expectancy* (LE) *model* (Anderson 2008). This model assumes all costs or earnings will be realized with certainty up to an

individual's life expectancy, and that none will be realized thereafter. To put it another way, this model assumes that the plaintiff will live exactly to his life expectancy, and not beyond it. In the pending example, this means we would assume the plaintiff, our 50-year-old gentleman, will live exactly 2.5 years, and no more. He would thus incur, with certainty, 2.5 years of payments, or 2.5 × $100,000 = $250,000 (this calculation makes an assumption that a year's costs are evenly distributed throughout the year and various other assumptions can be accounted for by an economist in an actual case). If there were a non-zero net discount rate in effect, future payments of $100,000, $100,000, and $50,000 would be discounted for 1 year, 2 years, and 2.5 years in determining the total expected present value.

This method is widely used, though incorrect when there is a non-zero discount rate in effect (as we shall see). The simplicity of it is appealing, however, and in some cases the pattern jury instructions explicitly require this method to be used in assessing total healthcare cost-related damages to be awarded.

Another common method, which is arguably the correct method (Strauss, Shavelle, Pflaum, & Bruce, 2001), is to include all potential annual costs in the present value calculation, discounting each by a discount rate (to account for the time-value of money, including inflation and potential investment earnings) as well as a mortality factor (to account for the possibility that a person may not live to incur costs in a given year in the future). This arguably being the proper method (assuming an accurate life table is available), it is perhaps correct that Anderson et al. refer to it simply as the *Expected Present Value* (EPV) *model* (Anderson 2008). To illustrate this method, consider the example of Table 2. Continuing for now to assume a net discount rate of zero, the expected present value can be calculated as the sum of each possible future payment multiplied by the probability of the individual being alive to incur that cost. For the example in Table 2, probabilities of the gentleman being alive at ages 51, 52, 53, and 54 are obtained from the l(x) column of the life table by dividing each figure by 100,000. Thus the probabilities of surviving 1, 2, 3, and 4 more years from age 50 are: 1.0, 0.75, 0.50, and 0.25, respectively. The expected present value, then, using the EPV method, is:

$$EPV = \$100{,}000 \times (1.0 + 0.75 + 0.50 + 0.25) = \$250{,}000.$$

This is the same result we obtained using the LE method, but if the net discount rate in effect were non-zero, the results from the two methods would be unequal. For example, if the net discount rate were 3%, the LE method would yield $244,217.17 while the EPV method would yield $242,823.87 for the present value in this case.

When mortality rates are particularly high and the net discount rate is positive, the EPV method will often result in lower expected present values than the LE method. While the two methods in this simple example produce quite similar results, in some cases the differences can be substantial (Strauss et al., 2001). Whether the EPV method can be employed in a given case or not will depend on a number of issues, including whether a life expectancy expert is available to provide the necessary full life table, whether the economist is familiar with the method, and whether the court will not simply mandate the LE method by default. In addition to the factors discussed here, more complexities may arise, possibly including federal and state tax issues (Anderson, & Barber, 2010). Coordination between the economic expert and the life expectancy expert may be helpful. The life expectancy expert may be able to provide a life table with added columns to simplify the work of the economist. Such collaboration may result in more accurate estimates of expected present values.

Application: Four Cases

We will now consider four case scenarios and in each example detail the life expectancy analyses. In the first two examples (both involving cerebral palsy), the two expected present value models discussed (LE model and EPV model) will also be demonstrated.

Cerebral Palsy

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behavior, by epilepsy and by secondary musculoskeletal problems. Disabilities associated with cerebral palsy can range from mild to devastatingly limiting. Two examples from opposite ends of the spectrum are considered here.

Case 1: Assessing the life expectancy of a young child with cerebral palsy. A 3 year-old girl with cerebral palsy who is one year status-post Nissen fundoplication and gastrostomy tube placement, is unable to lift her head from a prone position, and is unable to roll, sit, crawl, or walk independently. She takes no nutrition orally, and has intractable seizures, including periodic episodes of generalized tonic-clonic seizures and status epilepticus, and she is cortically blind. Costs of medical and other care associated with this child's disabilities have been estimated at $100,000 per year to age 18, and $150,000 per year thereafter. At a net discount rate of 3%, what is the expected present value of these costs?

It is the consensus of the authors, each of whom has had extensive experience making such assessments professionally and academically, that a reasonable evidence-based estimate of this young girl's life expectancy is in the range of 15 remaining years. While it is beyond the scope of this article to provide all details of calculations leading to this estimate, we believe that anyone applying standard scientific methods based on available evidence in peer reviewed studies of survival of children with cerebral palsy will come to a similar conclusion. Notable sources of scientific evidence for this include a number of studies utilizing the large California Database of children and adults with cerebral palsy (Strauss, Shavelle, & Anderson, 1998; Shavelle, Strauss, & Day, 2001; Strauss, Shavelle, Reynolds, & Rosenbloom, 2007; Strauss, Brooks, & Rosenbloom, 2008); recent studies of long-term survival of children with or without cerebral palsy who have undergone Nissen fundoplication and/or gastrostomy placement (Catto-Smith & Jimenez, 2006; Wockenforth, Gillespie, & Jaffray 2011); a recent study of long-term survival, stratified by Gross Motor Function Classification System (GMFCS) score, of children with cerebral palsy in Sweden (Westbom, Bergstrand, Wagner & Nordmark, 2011), with follow-up comparison of comparable children in California (Brooks 2012); and studies from England (Hutton, Colver & Mackie, 2000; Hutton, & Pharoah, 2002; Hutton, & Pharoah, 2006; Hemming, Hutton, Colver, & Platt 2005). It should be noted that two studies based on the California data contain serious flaws in arithmetic or methodology (Eyman, Grossman, Chaney, and Call, 1990; Eyman, Grossman, Chaney, & Call, 1993; Strauss & Shavelle, 1998), making the reported results unusable without major adjustment, while one study by Plioplys et al. (Plioplys, Kasnicka, Lewis, & Moller, 1998) contains a serious methodological flaw, making the results unusable except perhaps for internal comparisons (e.g., the more severely affected groups in the study apparently had a lower chance of surviving than the less severely affected groups, though the actual survival estimates reported are erroneous) (Strauss, Shavelle, & Day, 2004).

Given the life expectancy of 15 additional years, a life table representing this can be produced under a number of possible assumptions regarding the structure of the mortality rates as compared to those of the general population of girls in the US (Anderson, 2002; Strauss, Vachon, & Shavelle, 2005). We have prepared such a life table under the assumption of proportional life expectancy as explained in Anderson (2002) or Strauss et al. (2005) and determined mid-year survival probabilities at each age. Resulting estimates of expected present values for the anticipated stream of payments for medical care based on the LE method and EPV method are:

LE method: $1,211,568.09
EPV method: $1,200,570.65

It is notable that the difference here is small, even though the first method assumes the child will not live beyond her 18th birthday, and thus will not incur any of the higher expenses indicated for ages 18 and above. The EPV method, by contrast, includes all costs to age 109 years, each discounted by an appropriate mortality factor in addition to the 3% annual discount rate, in the calculation. If the costs in this case were flat throughout the lifetime of the child, the difference between the two methods would have been more pronounced. For example, assuming a flat $100,000 per year at all ages, the LE method estimate remains the same at $1,211,568.09 while the EPV method estimate is reduced to $1,080,024.89.

Case 2: Assessing the life expectancy of a teenager with cerebral palsy. A 15-year-old boy with cerebral palsy is able to walk independently without the need for any supportive devices and can run, albeit more slowly than most of his peers. He has some mild fine motor impairment but is able to dress and feed himself, and carry out other personal care activities independently. He has been seizure-free since birth. He is in a normal academic program in high school and is earning average to above-average grades. He requires some assistance with note-taking and uses a computer with an adaptive keyboard and mouse. Annual costs of care associated with this child's cerebral palsy have been estimated at $10,000 per year for life. At a net discount rate of 3%, what is the expected present value of these costs?

It is the consensus of the authors, based on the information available, that this child's life expectancy is essentially normal (or nearly so). At age 15, life expectancy of boys in the US is 61.3 remaining years (Arias, 2012). A life table for this life expectancy is available from the CDC and mid-year survival probabilities derived from this table were used here for the calculation of the EPV model estimate of expected present value (Strauss et al., 2001). The two estimates of expected present values for the stream of payments in this case are:

LE method: $268,392.45
EPV method: $274,026.99

It is worth observing here that we have considered two rather extreme examples of cerebral palsy. The examples illustrate a common give-and-take that occurs to varying degrees in such cases: The more severely disabled a child is, the higher the annual costs of care, but the lower the life expectancy. The evidence for this is indisputable. This general fact is something that must be borne in mind by both sides in litigation as they gather and present the evidence as to the severity of a given plaintiff's injuries, and as they attempt to put a fair dollar figure on the potential economic damages involved.

Spina Bifida (meningomyelocele)

Spina bifida (SB) is a general term for birth defects in which the vertebrae, spinal canal, or skin does not fully close over the spinal cord. While the term spina bifida may refer to an array of such defects, we focus here on meningomyeloceles, since these are the most common and severe of the debilitating defects labeled as spina bifida or open spina bifida (Vogel, Betz, & Mulcahey, 2003; Mitchell et al., 2004).

Meningomyeloceles are lesions in which the both the spinal column and spinal canal fail to close, leaving the spinal cord of an infant's body exposed to the outside (Vogel 2003; Mitchell 2004). Though most lesions are surgically closed within 48 hours of birth, this form of SB most often leaves the infant with neurological damage in the spinal cord that impairs motor function. Many infants with meningomyeloceles also develop hydrocephalus after closure of the lesion, particularly those with thoracic lesions. Most often hydrocephalus requires ventriculoperitoneal (VP) shunting, adding further medical complication (Mitchell et al., 2004).

The physical disabilities resulting from meningomyeloceles are similar to those from spinal cord injury (SCI), and, as in SCI, the level of the lesion determines the type and severity of disability. In general, the higher on the spine the lesion occurs the more severe the disability (Vogel 2003; Mitchell 2004). The level of the lesion has even been found to be a good predictor of long-term disability and functional profile (Oakeshott, Hunt, Poulton, & Reid, 2012).

Case 3: Assessing the life expectancy of a child with Spina Bifida (meningomyelocele). A 10-year old boy with spina bifida had a meningomyelocele at the L1 level of the spine (1st lumbar vertebrae) surgically closed within the first 24 hours after birth. The child has complete paralysis (loss of both motor function and sensation) below the waist, and thus is unable to walk and is incontinent. He developed hydrocephalus as an infant and received a VP shunt. His IQ has been formally assessed and is estimated to be 50. Because of his paralysis, he will likely be in a wheelchair for his entire life.

Data for the life expectancy estimates of SB come from studies of the survival of SB patients in both the UK and the US (Oakeshott et al., 2008; Oakeshott, Hunt, Poulton, & Reid, 2010; Shin et al., 2012). This research has demonstrated that infants born with open SB are subject to greater than usual mortality rates across the lifespan, and thus experience reduced life expectancy at all ages (Oakeshott et al., 2008; Oakeshott et al., 2010). A long-term English cohort study revealed that more than a third of children with SB died before age 5, while another quarter of the patients died by age 40 (Oakeshott 2008). Comparative studies of more recent SB patient cohorts in the United States have shown lower mortality in the early childhood years but similar adult mortality (Oakshott et al., 2008; Shin et al., 2012). As the American patients were born more recently than the English patients, this suggests that mortality rates for children with SB improved since the 1960s, and these improvements appear to differ by race (Oakeshott et al., 2008; Shin et al., 2012).

The life expectancy for a 10-year old boy in the US, accounting for age and gender only, is 66.3 additional years (Arias, 2012). With the level of meningomyelocele and resultant disabilities listed above, we estimate life expectancy for this young man to be 41 remaining years, a reduction of around 25 years. As a comparison, a recent study (Shavelle et al., 2007) found that 10-year old males with slightly less severe incomplete spinal cord injuries but with equivalent paraplegia would have a life expectancy of 47.8 additional years (and a reduction of 18.5 years). Since the paraplegia is similar in consequence to the life course of both patients (i.e., the spinal cord injured patient and the patient with spina bifida) it is expected that these

estimates should be somewhat close to one another. However, the more severe nature of the meningomyelocele compared to an incomplete spinal injury of American Spinal Injury Association grade B or C, and the mortality risk posed by hydrocephalus and VP shunts in SB patients both create additional mortality risk across the lifespan. This in turn yields a lower life expectancy for children with SB in comparison to those with SCI.

Diabetes leading to End-Stage Renal Disease

Diabetes type II is characterized by a defective response of the body tissue to insulin (insulin resistance). Increased mortality results from both macrovascular and microvascular processes. From a macrovascular standpoint, there is an increased risk of death due to cardiovascular disease, stroke, and peripheral vascular disease. From a microvascular standpoint, there are additional risks from retinopathy (possibly causing blindness), neuropathy (causing damage to the nervous system and leading to potential amputation), and nephropathy (kidney disease).

Diabetes is associated with increased mortality rates compared to those of age- and sex-matched general populations (Hansen, Jensen, & Carstensen, 2012; Milano 2011). With careful diet, regular exercise, weight control, and, when necessary, regular medication (possibly including insulin injections), the risk of complications and mortality can be lessened. However, when diabetes has resulted in end-stage renal disease (ESRD), it has a profound impact on life expectancy. The United States Renal Data System (USRDS), funded by the National Institutes of Health and the National Institute of Diabetes and Digestive and Kidney Diseases, is the national data registry that collects, analyzes, and distributes information on the ESRD population in the U.S., including treatments and outcomes. Their reference tables provide mortality rates for those with end stage renal disease due to diabetes, stratified by gender, race, and type of dialysis (USRDS, 2012).

Case 4: Assessing the life expectancy of a Senior Citizen with Diabetic End Stage Renal Disease. A 72 year-old elderly female has had diabetes for over twenty years and is now having a life care plan prepared. She has had comprehensive health care coverage during the entire course of her diabetes. In the first few years after her diagnosis (at age 50) she attempted to control the diabetes with diet and exercise. By age 54 she started metformin (an oral medication) and then by age 57 she required insulin for good glucose control and began to show some neuropathy. By age 62 she had problems with retinopathy and her kidneys began to malfunction. Over the course of the next ten years she proceeded through the five stages of Chronic Kidney Disease and ultimately reached stage 5, ESRD. She is morbidly obese and her clinicians have indicated that she will not be a candidate for a transplant unless she can lose significant weight. She has expressed that she has no interest in working with a bariatric endocrinologist. She will receive regular hemodialysis treatments for the remainder of her life.

For a woman age 72, the general population life expectancy is 15.4 additional years (Arias, 2012). However, considering her diabetic ESRD and utilizing the comprehensive mortality data (stratified by etiology and gender) from the current USRDS, her life expectancy is now calculated to be 3.7 additional years. This is a reduction of 11.7 years (approximately 76%). A diabetic etiology to ESRD carries the highest mortality rates (closely followed by hypertensive ESRD) and is quite serious at any age.

Quality and Quantity of Care

It is perhaps an axiom that poor quality care or a complete lack of care (as compared to reasonable and necessary care) is detrimental to life expectancy. As one might imagine, however, in industrialized countries, poor care or complete lack of care seldom applies to persons who are the subjects of studies of survival published in peer-reviewed medical journals. Beyond an axiomatic interpretation of quality (i.e., that better quality care is that which results in longer life expectancy), the question of quality of care is complex. The Dartmouth Atlas Project, which has studied extensively the question of quality, cost, and efficiency of healthcare in the US, distinguishes three categories of care: effective, preference-sensitive, and supply sensitive.

> *Effective care consists of evidence-based services such as hemoglobin A1c testing for diabetics. Variations in effective care reflect failure to deliver needed care. Preference-sensitive care encompasses treatment decisions where the options have quite different risks and benefits and where patients' attitudes toward these risks may vary. For example, the decision to undergo bypass surgery for heart disease is likely to improve chest pain but carries a small but real risk of causing memory loss. The Dartmouth Atlas Project has long argued for informed patient choice: ensuring that patients are able to choose based on their own preferences. Finally, supply-sensitive care refers to services where the supply of a specific resource (such as the number of hospital beds per capita) has a major influence on utilization rates (Fisher, Goodman, & Chandra 2008).*

The DAP has consistently found that higher health care spending does not result in better quality of care or better patient perceptions and experience (Fisher et al., 2008; Fisher et al. 2009, Wennberg et al., 2008; Fisher, Goodman, & Chandra 2008, Goodman, Brownlee, Chang, & Fisher 2010). The DAP concluded, for example, that Medicare patients in higher spending regions are somewhat less likely to receive evidence-based treatments (effective care) and are no more likely to receive elective major surgical procedures than those in lower spending regions. In addition, while it may seem counterintuitive, DAP research suggests that for persons availing themselves of the healthcare system at one level or another, higher expenditure on care, and greater quantity or frequency of care do not typically equate to longer life expectancies. The DAP has conducted and reviewed hundreds of studies of differences in the cost and frequency of care and their impact on quality of care and life expectancy. The DAP's conclusion, based on currently available evidence is that care above and beyond what is *reasonable, effective, and necessary* does not result in higher life expectancies. On the contrary, the DAP found that in some cases outcomes can actually suffer with higher frequency of care or more extensive testing or other interventions, in part because of a corresponding increase in the likelihood of mistakes and because a hospital can be a dangerous place if you do not need to be there (Fisher et al., 2009; Fisher, 2012).

An example of care dramatically above what is *reasonable and necessary* might be found in the case of Christopher Reeve. Mr. Reeve suffered a devastating cervical level SCI in a 1995 horseback riding accident which resulted in him becoming a quadriplegic (requiring a wheelchair and ventilator for the remainder of his life). Mr. Reeve received an extremely advanced level of care for his injury. His treatments, often intense, included activity-based recovery, functional electrical stimulation, aqua therapy, electrode implant procedures, diaphragm pacing, and experimental drugs. He arguably received the highest quality and

quantity of care in history for someone with this type of injury. He survived approximately 9.5 years, until 2004, when he died of severe sepsis (caused by a pressure sore) ultimately leading to cardiac arrest. Two years post injury, his actual survival time (approximately 7.5 years) was more than four years lower than the life expectancy for someone of his age with a comparable spinal cord injury (approximately 12 additional years) based on evidence available at the time (DeVivo & Ivie, 1995; DeVivo et al., 1999) or on more recent evidence (Shavelle et al., 2006).

As the DAP investigations suggested, in some cases, excessive care can actually be harmful and lower life expectancy. This was illustrated with the provision of full body CT services found in some shopping malls for a period of time. The idea was for an individual to have a convenient annual CT scan (not covered by insurance) to catch any anomalies in the body early. However, exposure to this annual radiation was found to increase the risk of lifetime cancer by a factor of over 20 (Brenner & Elliston, 2004). And false positives and incidentalomas (benign growths) ultimately greatly increased the risk of having unnecessary medical procedures. With the out-of-pocket cost prohibitively high and given the above risks, it is no surprise that these companies ultimately and voluntarily stopped providing this service and/or went out of business.

In spite of the evidence that excessively frequent testing or unnecessary trips to the hospital may actually increase the risk of mortality and therefore result in a reduction in life expectancy, it is entirely reasonable that some concept of better care may result in prolonged life – indeed this is one of the main goals of medical science and certainly great improvements in care have been achieved over the last few centuries. When techniques of care or new treatments are developed that prove to be more efficacious than those previously available, they generally become the new standard, and eventually spread widely across care settings, at least in industrialized countries. There are undoubtedly exceptions to this, but this has generally been the rule over time. Such care is what the DAP would refer to as effective, or evidence-based, care. The question of interest here is not whether a particular drug or medical procedure might improve the outcome of a given patient, but rather whether a certain care regimen, perhaps as described in a life care plan and as may be implemented in practice for one individual, might result in better outcomes, and in particular longer life, than is typical for similar patients who were involved in published studies of survival or life expectancy. Evidence to illuminate this question is apparently scant. Nevertheless, we shall consider the possible impact on life expectancy of better levels of care that might be provided for in some life care plans.

There are several possibilities for the form of the relationship between care quality and life expectancy. For highly accurate modeling of the care quality or care quantity relationship with life expectancy, a variety of curvilinear functions may be useful. Such models often produce modest gains in accuracy at the cost of greatly increased complexity, however, and therefore may not be worth the extra effort involved in their use. We limit the discussion here to a few simple models which describe the most basic possible relationships.

Perhaps the simplest model is the threshold model (Figure 1-a). In this model life expectancy is constant above and below a critical threshold value of care quality/care quantity. Increasing the quality of care/quantity of care beyond the threshold value does not yield further improvements in life expectancy. Conversely deteriorating quality of care or lowering overall quantity of care does not lead to additional decreases in life expectancy once care is below the threshold.

Another simple model of the relationship between care quality/care quantity and life expectancy is that of the linear-no threshold model (Figure 1-b). In this model any incremental

change in the quality/quantity of care yields a constant change in life expectancy. This is true across the entire possible range of quality/quantity of care. While the linear model may be more appealing than the threshold model, it too is likely to be a poor fit to the reality of the care quality/quantity and life expectancy relationship, especially at the high and low ends of care (note: a special case of the linear model exists when care quality/quantity does not influence life expectancy at all, in which case the line is horizontal).

A hybrid model is the linear-threshold model. Here the quality/quantity of care has a "floor," a "ceiling," or both (Figure 1-c). The floor represents a certain quality level of care or quantity of care below which life expectancy does not change, but above which life expectancy increases linearly with change in care. The ceiling is a complement to the floor value; it is a level of care above which increases in care quality/quantity no longer yield increases in life expectancy. It should be noted that the linear-threshold model may have only one threshold (e.g. an upper or a lower), or may have both, as pictured in Figure 1-c.

When there is both an upper and lower threshold in a linear-threshold model then this model becomes a close approximation of a logistic curve, like that shown in Figure 1-d. A logistic curve may in fact be a better representation of the relationship between life expectancy and quality of care in such situations, but is admittedly more complex in form.

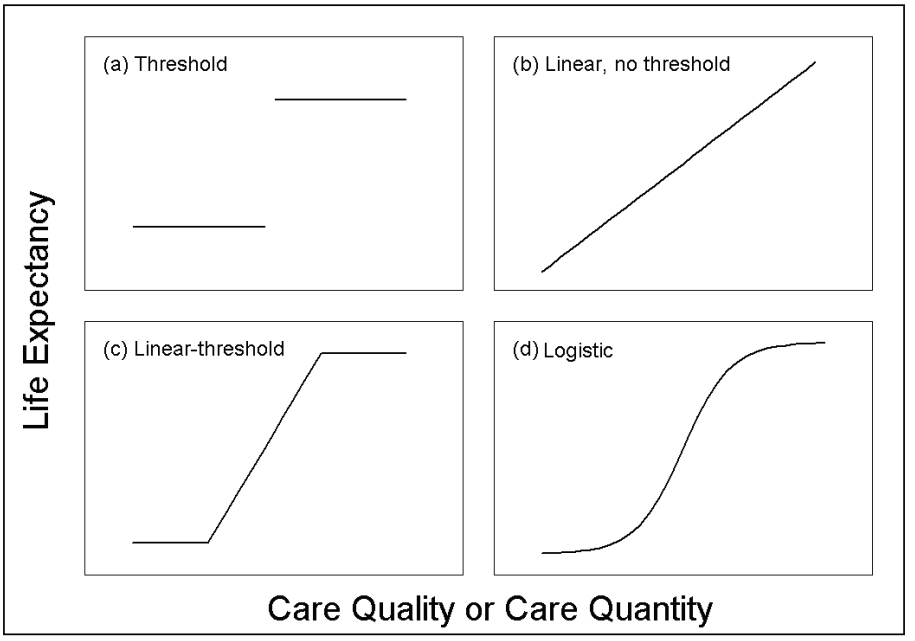

Figure 1. Functional Models Relating Quality of Care and Life Expectancy.

It remains to be seen whether there is currently a *standard of care* for persons with severe or chronic disabilities, and whether anything above and beyond that standard will improve quality or quantity of life. It may be that improving quality and quantity of life are actually at odds in some cases (e.g., giving tastes of food to a person with severe dysphagia may increase quality while decreasing average quantity of life due to choking and aspiration risks).

Currently we are aware of no evidence that receiving higher quality of care or a greater quantity of care and exceeding that which is already considered *reasonable and necessary*, or that which is provided routinely in industrialized settings, carries any significant life expectancy benefit. Were such evidence available, it would allow for adjustments to analyses of life expectancy using standard scientific methods to account for such advanced care. The paucity of such evidence suggests that the health care system may be working under the logistic curve illustrated in Figure 1-d where the ceiling is represented by the reasonable and necessary standard of care currently provided. While incremental improvements, or even substantial improvements, may occur in the future, it likely that when such breakthroughs occur, and when evidence of their efficacy becomes available (via peer reviewed research or other scientifically sound methods), they may quickly become part of the standard.

So while it may seem intuitive or even customary to a life care planner that ramping up a care plan with many extras on top of already providing stellar care might make a difference in longevity, available evidence to support this is largely lacking, or in some cases suggests otherwise. Were evidence to become available that supports the idea that a particular plan of care for an individual will result in better survival than that of persons involved in a particular study, adjustments to the analysis of life expectancy based on that study could be made using standard scientific methods. As of now, the question of whether there might be a type of care that actually will increase life expectancy is not fully understood, and evidence that one regimen might be better than another is quite sparse. There is a definite need for further research in this area. Outcomes-based research on the care regimens implemented in accordance with various life care plans would go a long way towards codifying the quality, quantity, and types of care that could be most impactful.

Conclusion

Though no one can precisely predict how long an individual person will live (survival time), much can be conveyed about an individual or group's *average survival time* or *life expectancy*. Life expectancy experts use individual information in tandem with data from populations with similar characteristics to compute scientifically accurate life expectancies. Such calculations are important in litigation, where life expectancy and annual probabilities of survival may contribute to the determination of expected present value of future costs of care or lost earnings. Life care planners ought to have a keen interest in the question of life expectancy as well. Assuming that the life care plan may have an impact on a patient's longevity is not enough. As life care planners become more familiar with the concept and science of life expectancy, we are hopeful that collaborative efforts to advance the knowledge of the impact of one on the other may take place, and real scientific evidence may emerge.

As we have seen in this brief report, considerable evidence currently exists regarding the survival probabilities and life expectancies of persons with a number of different disabilities or medical conditions; we have only scratched the surface. There are now myriad studies of the survival or mortality of persons suffering from wide-ranging disabilities or medical conditions. Emerging studies and the resulting increases in understanding of disease processes continue to allow refinements of the analysis of life expectancy for persons with many different injuries, disabilities, or medical conditions. A set of key variables impacting survival and life expectancy of neurologically injured persons, and of persons with a variety of other common medical conditions, has emerged and will continue to be refined. Every day, new studies reveal further information about the impact of these variables and other factors that may influence longevity. A trained and experienced expert in this growing field can often make use of this

literature to provide accurate, evidence-based estimates of life expectancy of injured plaintiffs.

In personal injury litigation, economic damages can often be the largest part of a potential award or settlement. Costs of implementing life care plans can run into the tens of millions of dollars depending on a plaintiff's injuries, health care needs, and expected survival time. Determining a single sum of money to award (in lieu of annual payments for life) as compensation for those uncertain costs requires input from experts in multiple disciplines, including life care planning, forensic economics, and life expectancy. The life expectancy expert, working in collaboration with the life care planner and/or the economist, can provide input valuable to achieving as accurate and as fair an estimate as possible. A life care plan, used in conjunction with a life expectancy and full life table reflecting the annual probabilities of survival or death associated with it, can be used by forensic economists in carrying out their own calculations of expected present value of future healthcare costs and potential future earnings lost due to injury or death.

Advances in medical care and treatment are expected to continue to improve the longevity and quality of life outlook for many medical conditions even as occasional set-backs occur (e.g., new virulent and drug-resistant strains of bacteria increasing the risk of mortality associated with infections). We hope that future studies of survival will take into consideration healthcare types, quality, and quantity as possible predictors. The extent to which such factors may influence longevity is not well understood. Careful studies of the impact of such factors will allow for further refinement of life expectancy calculations, but more importantly it will improve our understanding of the impact of differing medical care regimens thus improving health care for everyone.

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Author Bios

Dr. Scott Kush founded the Life Expectancy Group and studies life expectancy in general medical conditions, vegetative state, brain & spinal cord injuries, and developmental disabilities.

Dr. Steven Day studies mortality and other epidemiological topics, often focused on developmental disabilities, neurological injuries, or occupations (e.g., professional sports). He provides related professional services.

Robert J. Reynolds is an epidemiologist and biostatistican whose research interests include the patterns and determinants of mortality in unique occupational and patient populations.