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Utilizing Research to Determine Life Expectancy: Applications for Life Care Planning

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Abstract

Estimating life expectancy (LE) is an essential component to determining lifetime needs after disability and to project lifetime costs. Our objective was to define LE and describe the types of research utilized in estimating LE, focusing on spinal cord injury as an example. LE is a population parameter, whereas the life care plan is an individualized plan. This makes it essential that research used as the foundation of the LE be matched to key characteristics of the individual to insure the estimate reflects the appropriate population. LE estimates must be adjusted to account for additional mortality related to disability. Behavioral, economic, and health factors also affect LE, with economic factors being particularly important since life care plans are typically developed within the context of litigation (a process of allocating economic resources). Since economics are strongly related to risk of mortality, it is essential to account for favorable economics when estimating LE for a life care plan to produce accurate estimates not biased by the excess mortality observed among those in the population with highly limited economic resources. Failure to account for favorable economics and other selective factors for individuals for whom the life care plan is developed may lead to inaccurate estimations of LE, as the population upon which the LE estimate is derived may be different than that of the individual.

Keywords: life expectancy; life care plan; mortality; spinal cord injury; traumatic brain injury; disability

One of the most difficult, yet important, aspects of the life care plan after severe disability is to estimate life expectancy (LE). While this estimate is not commonly done by life care planners unless they are uniquely qualified to do so, an LE estimate establishes the time limits

of the life care plan. The life care plan is an individualized estimate, whereas LE is a population parameter determined by averages of those with similar characteristics within a population. Therefore, the LE estimate to be used in the life care plan will reflect the average LE for individuals from that population. As applied to life care planning, it is important to use population data most closely approximating the characteristics of the individual for whom the life care plan is being developed.

The purpose of this manuscript is to present an overview of the concepts used to determine LE and their application to life care planning, using scientific data to guide the estimates. We begin with an overview of the general concepts of LE as applied in the general population, followed by applications within life care planning. We conclude with a more detailed discussion of LE after traumatic neurologic injury, with an emphasis on spinal cord injury (SCI), as there has been a particularly strong body of research focusing on this condition. The concepts brought forward with this specific example typically apply to most life care planning cases.

Standard Life Tables

Life expectancy is the number of additional years of life anticipated based on observed mortality in the population. The Centers for Disease Control and Prevention (CDC) publishes standard life tables which are LE estimates for the population, given a particular age and gender (Arias, 2011). However, many characteristics are related to LE that typically are not incorporated into standard life tables. Disability is one such characteristic, with other important characteristics including overall health, health behaviors, and socioeconomic factors.

It is important to understand the nature of population-based LE estimates from standard life tables. First, because they are population-based, they are, conceptually, related to the LE of the average individual within the population. Therefore, they include not only healthy adults but also the representative typical range of health conditions observed within the general population. They also include individuals with the full range of health behaviors and full range of access to healthcare services. Therefore, they do not represent estimates for only healthy adults or those who do not report significant health behavioral issues (e.g., smoking). Standard life tables will overestimate the LE of those who have significant health problems, perform risky behaviors, such as cigarette smoking, and do not have access to care. Conversely, they will underestimate the LE of those with favorable health, health behaviors, and access to healthcare.

How accurate are standard life tables when applied to disability? The answer depends on the extent to which the particular condition is related to an elevated risk of mortality. Standardized mortality ratios (SMR) represent the degree of excess mortality compared with expected mortality based on the general population. The higher the SMR, the lower the LE. Standardized mortality ratios may vary among those with a particular condition, depending on the severity of the condition. In these instances, it is important to account for both the presence of the condition and severity. The quality of research may or may not allow for accurate estimates of LE for a particular condition, much less for a breakdown related to the severity of that condition. Furthermore, for conditions with multiple functional impairments, such as combinations of motor and cognitive deficits, an accurate classification of severity may be difficult to obtain.

Estimates of LE after Traumatic Neurologic Injury

Spinal cord injury and traumatic brain injury (TBI) are examples of conditions associated with differential risk of mortality. The primary data used to estimate LE after SCI has been the National SCI Statistical Center (NSCISC) database (Strauss, Shavelle, & Brooks, 2012). DeVivo (2002) outlined three alternative methods for estimating LE within the life care planning process. These include: life table method, SMR method, and logistic regression analysis. Method 1 uses a similar approach to the general population in generating a life table. Method 2 employs an SMR approach where the observed number of deaths is recorded and compared with the expected number of deaths according to the general population. Method 3 is a logistic regression modeling approach where a formula is created based on selected variables (i.e. age, gender, injury severity), and an LE estimate is generated based on the probability of survival generated by the model. The most common method employed is Method 3. Regardless of technique, the quality and accuracy of estimation will be directly related to the quality of the research data used to derive the estimate.

Several publications specific to LE after neurologic injury provide the general background from which to apply LE estimates for individuals with particular injury characteristics. In SCI literature, LE is broken down by ventilator-dependent status, as persons who are ventilator-dependent typically have a much lower LE (DeVivo & Ivie, 1995; Shavelle et al., 2006). Factors included in those analyses were year of injury, gender, race, age, and injury severity (level and completeness; DeVivo & Ivie, 1995). Shavelle et al. (2006) developed a model for persons who are ventilator-dependent and survived at least one year post-SCI. In their model, only age, years post-injury, and injury severity were included. In studies of persons not ventilator-dependent, LE is found to vary by both injury level and Frankel or ASIA grade (DeVivo, Krause, & Lammertse, 1999; McColl, Walker, Stirling, Wilkins, & Corey, 1997; Shavelle, Devivo, Paculdo, Vogel, & Strauss, 2007; Strauss, DeVivo, Paculdo, & Shavelle, 2006).

Very few studies have published on LE after TBI. Life expectancy reduction has been seen after TBI when using the Disability Rating Scale (Harrison-Felix, 2004; Strauss, 2004). While not publishing LE estimates, other studies have found differences in risk of mortality by injury severity (Donohue, Clark, & DeLorenzo, 2007; Harrison-Felix et al., 2009; Selassie, McCarthy, Ferguson, Tian, & Langlois, 2005; Ventura et al., 2010) or disability (Ratcliff, Colantonio, Escobar, Chase, & Vernich, 2005). Studies of TBI do not universally use comparable measures of injury severity as are usually found in studies of SCI, and some studies do not use injury severity or disability status at all when assessing mortality (Egede, Dismuke, & Echols, 2012).

The aforementioned studies have several common elements. They typically use basic demographic characteristics, in particular, chronologic age and gender, to develop the estimates. Race-ethnicity is also frequently used, although somewhat more controversial in that it may result in generating lower estimates for individuals from particular populations. Each of these characteristics is ultimately used to match the characteristics of the individual for whom the estimation is drawn and the LE estimates generated. While demographic, and to some extent injury, characteristics are most readily available for inclusion in LE estimates, other pertinent variables can influence estimates.

Consideration of Factors in Addition to Disability

A wide range of other factors will affect LE, other than demographic characteristics typically used in standard life tables (i.e., age, gender) and disability characteristics. The onset

of the disability is often not a random event. In the case of traumatic neurologic injury, including SCI or TBI, there are often characteristics that lead to the injury itself. Etiologies have been associated with differential risk of mortality and differential LE. For instance, violent etiologies have been associated with a greater risk of mortality after both SCI and TBI (DeVivo et al., 1999; Strauss et al., 2006; Ventura et al., 2010), such that LE estimates in litigation often account for this factor. With TBI, a greater risk of mortality has also been associated with falls (Colantonio et al., 2008; Ventura et al., 2010).

Many other factors are associated with SCI, including alcohol intoxication (Bombardier & Rimmele, 1998; Garrison et al., 2004; Kolakowsky-Hayner et al., 1999; O'Donnell, 1981). For instance, one study found that, among 54 patients on a spinal cord injury unit, 68% reported alcohol or other drug use at the time of injury (O'Donnell, 1981). Bombardier and Rimmele (1998) found alcohol involvement at the time of injury for 28% of their study sample (n=58). Other studies indicate high risk behaviors contributing to injury, with these first identified more than half a century ago (Fordyce, 1964). Alcohol intoxication has also been associated with a greater risk of TBI (Bombardier, Rimmele, & Zintel, 2002; Corrigan, 1995; Parry-Jones, Vaughan, & Miles Cox, 2006). In a study of 142 persons consecutively admitted with recent TBI, Bombardier et al. (2002) found 42.3% of their study sample had a positive blood alcohol level upon admission, and 32.3% had a blood alcohol level considered to be intoxication (at or above the legal limit of 100mg/dL).

In a review of the literature by Corrigan (1995), the percentage of persons with TBI who were intoxicated at the time of injury ranged from 36-51% across multiple studies. Parry-Jones et al. (2006) similarly found 37-51% of persons with TBI were intoxicated at the time of injury in the studies they reviewed from 1994-2004. Unfortunately, despite the almost certain relationship between these behavioral factors and mortality, they are rarely, if ever, accounted for within LE estimates, as data on these factors is not available in the larger data sets typically used to estimate LE in life care plans (i.e., the SCI and TBI Model Systems) (Model Systems Knowledge Translation Center, 2013a; 2013b). More recent studies have found prescription medication use, binge drinking, and smoking to be related to mortality after SCI, even after accounting for injury, demographic, and other psychological, environmental, and health factors (Krause & Saunders, 2012; Krause, Zhai, Saunders, & Carter, 2009).

The inability to include particularly important behavioral factors raises important considerations regarding the appropriateness of the use of these data sets in generating LE estimates. The estimates are the average LE of all cases within a data set. Therefore, estimates for a given individual will be based on those with similar characteristics used in the analysis (typically, age, gender, injury severity). The LE of individuals with characteristics not included in the analysis who are at greater risk of mortality will be overestimated. Conversely, the LE estimates of those who do not have these characteristics placing them at greater risk will be underestimated.

The primary implication for life care planning for forensic cases is that, in these cases, the injury itself is typically due to an allegation of an outside party having responsibility or fault, making it less likely that any particular individual's injury and subsequent disability will have resulted from their own behavior. Estimates of LE generated for life care plans and used in litigation typically do not differentiate or exclude individuals whose injuries were directly the result of high risk behaviors. This raises a significant threat to the validity of the LE estimates, as the population of people for whom life care plans are developed within a forensic setting systematically differs from that of the population upon which the LE estimates are based. Of course, in some cases, litigation is based on medical practices that exacerbate an injury, such

that an individual may have behaviors that contributed to the SCI, but these cases no doubt are less common.

Health status, above and beyond disability, is also related to mortality after neurologic injury. Even basic measures of self-rated health show increased odds of mortality (Krause & Saunders, 2012). Specific health complications such as pressure ulcers, fracture/amputations, and depressive symptoms are related to mortality after SCI (Krause, DeVivo, & Jackson, 2004; Krause et al., 2009). Studies have also quantified health by counting the number of comorbidities and found more comorbidities resulted in increased risk of mortality (Colantonio et al., 2008; Selassie et al., 2005).

Economic Factors

Within the general population, socioeconomic position is a fundamental cause of health and longevity (Link & Phelan, 1995). A large body of research indicates socioeconomic factors, particularly income, are strongly related to longevity, with greater LE among those in higher income brackets (Lantz, Golberstein, House, & Morenoff, 2010; Lin, Rogot, Johnson, Sorlie, & Arias, 2003; Rask, O'Malley, & Druss, 2009; Stringhini et al., 2011; Stringhini et al., 2010; Suresh, Sabanayagam, & Shankar, 2011). Although some of this relationship is due to differential health behaviors related to socioeconomic status, with more risky health behaviors among those in lower income groups (Lantz et al., 2010; Rask et al., 2009; Stringhini et al., 2011; Stringhini et al., 2010), the importance of economic factors is demonstrated above and beyond its relationship with health behaviors, health status, and disability (Lantz et al., 2010). Therefore, standard life tables will typically overestimate the LE of those with low income and underestimate the LE of those in higher income brackets. Related to income, employment is associated with increased LE after SCI above and beyond income and education (Krause, Saunders, & Acuna, 2012).

As related to disability, socioeconomic factors may be particularly important. We replicated the methodology used by Lantz et al. (2010) to identify the relationships of socioeconomic factors and mortality in the general population by applying similar data analytic techniques with data from those with SCI. We found that income was income inversely related to risk of mortality, even after controlling for the effects of health behaviors, health, and disability (Krause & Saunders, 2012). The findings suggested that the effects of income were even greater among those with SCI after controlling for essentially the same set of factors and more refined measures of disability (i.e., SCI severity indicators). The specific underlying mechanisms by which favorable economics is associated with greater LE were not defined in this study, although conceptually, they include both tangible factors, such as access to care and ability to purchase items required to maintain health (e.g., healthy foods, equipment/resources needed to promote exercise and fitness), as well as intangible factors, such as reduced stress associated with low income (Krause & Saunders, 2010).

A life care plan has been defined as a “dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs.” [Source: Combined definition of the University of Florida and Intelicus annual life care planning conference and the American Academy of Nurse Life Care Planners (now known as the International Academy of Life Care Planners) presented at the Forensic Section meeting, NARPPS annual conference, Colorado Springs, CO, and agreed upon April 3, 1998]. Developing a life care plan is not an academic exercise, as it is intended to serve as a guide for allocation of resources needed to

meet the lifetime needs of the individual. Few life care planners would debate the benefits of successfully developing and implementing a life care plan on the health, quality of life, and longevity of the individual for whom the plan was developed.

Life expectancy estimates are developed using larger data sets with individuals who, with some exceptions, do not have resources consistent with those proposed and frequently funded based on the life care plan. Ideally, LE estimates would be based on data using people for whom life care plans were developed. This would serve the dual purpose of accounting for the general nature of the cases (i.e., the injury or chronic health issue is less likely to be directly related to the individual's own behavior), and it would ensure the estimates account for the favorable effects of the economic benefits resulting from the life care plan and litigation. In particular, it would ensure the LE is not biased by higher mortality rates among those with relatively few economic resources.

Given the fundamental relationship between the life care plan, litigation, and the allocation of economic resources, as well as the relationship between favorable economics and LE, it is important to consider the favorable economic situation generally produced by the life care plan and litigation in developing the LE estimate. This requires assumptions regarding economics and mortality for a given condition or the availability of data on income from which to draw prediction.

In the area of SCI, recent publications have differentiated risk of mortality related to income, which can be translated into LE estimates (Krause & Saunders, 2010; Krause & Saunders, 2012; Krause et al., 2012; Krause, Saunders, & DeVivo, 2011). In essence, using this information selects only individuals with favorable economics (high income within the data set) and eliminates the effects of excess mortality among those with limited financial resources. The mathematics for calculating such effects are the same as those used in standard LE estimates accounting for age and severity of disability, and these equations control for these factors. Some assumptions need to be made as to which reference group to use as the most appropriate comparisons. The failure to account for favorable economics, a central condition of the life care plan and litigation process, will lead to underestimates of LE in cases where favorable economic assumptions are justified.

A recent paper demonstrated the differences in LE between income groups (Krause et al., 2011). The relative mean difference (RMD) was calculated as the difference between two LEs divided by their average (RMD=[Mean difference/arithmetic mean]). For example, comparing LE for high and low income for a white male, 50years of age with a C4, neurologically complete injury (based on the American Spinal Injury Association Injury Scale: AIS A), the RMD was 50.2% and absolute difference was 6.5 years (high income = 16.2; low income = 9.7). Comparing middle to low income for the same example, the RMD was 23.6% and absolute difference was 2.6 years (middle income = 12.3; low income = 9.7).

Conclusions

Developing valid estimates of LE relies on the availability of research with any given condition, the quality of that research, and the appropriate application of the research to the LE estimate. The amount of research available for use in estimating LE varies across conditions. This makes estimations more difficult for those conditions for which the data is sparse or for which the data do not as easily translate into measuring variations in severity of disability.

The situation presented by litigation and the circumstances requiring the life care plan make LE estimates more complex. Simply using estimates accounting for only a small set of demographic factors, such as gender and age, and disability characteristics, such as severity,

will not account for the specific circumstances surrounding the disability and the availability of resources which typically are high in the life care plan to help the individual maintain his or her health and longevity. Life expectancy estimates not accounting for, or attempting to adjust for, the unique circumstances of the individual for whom the life care plan is being developed will be of questionable validity. It is incumbent upon those who make LE estimates from life care plans to use the widest possible range of available information and to make critical adjustments to the LE estimates that account for variations in economic factors which are inherent to the life care plan. This is challenging but necessary.

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