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National Spinal Cord Statistical Center Cost Figures: A Comparison to the Life Care Planning Approach

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Abstract

The work product of life care planners provides interested parties with a lifetime cost projection of goods and services that are necessary due to disability onset, and the methodology that life care planners follow has been well published in the rehabilitation literature. The final product is a projection of an individual's disability-related needs throughout their life expectancy. This article contrasts the methodology utilized to prepare a life care plan with the methodology to obtain cost estimates published by the National Spinal Cord Injury Statistical Center.

Keywords: life care planning, spinal cord injury statistics

Introduction

In personal injury litigation, the total cost of an individual's life care plan is often contrasted by opposing counsel to aggregate data of individuals with similar disabilities published by various sources. For individuals with spinal cord injuries, one source often presented to contradict a life care planner's projections are published data from the University of Alabama at Birmingham's National Spinal Cord Injury Statistical Center (NSCISC). As life care planners are frequently presented with this data, this article will examine the methodology by which these figures are prepared and explore the differences between this data and the data presented in an individualized life care plan.

Spinal Cord Injury Information

Spinal cord injury (SCI) is defined as an acute, traumatic lesion of neural elements in the spinal canal resulting in sensory and/or motor deficit (NSCISC, 2011). A review of the most recent spinal cord injury statistics from the NSCISC (February 2011) indicates that approximately 12,000 new spinal cord injuries are sustained each year in the United States. Of these, 81% of individuals who sustain injuries are male and since 2005, the average age at injury was 40.7 years. Racial or ethnic differences since 2005 suggests that 67% of persons injured are Caucasian, 27% African American, 2% Asian, and 8.3% Hispanic. The most commonly reported SCI causes include motor vehicle accidents 40%, falls 28%, violence 15%, sports 8%, and other 9% (NSCISC, 2011).

Despite historical increases in life expectancies for individuals with SCI, overall life expectancy for this population continues to remain below that for the general population, ranging from 37.1 years for ventilator dependent with SCI onset at age 20, to 65.2 years for those with paraplegia onset at age 20. For adults with SCI onset at 60 years of age, life expectancy ranges from 61.5 years for persons dependent on ventilator support to 72.8 for those with paraplegia (NSCISC, 2011). Common causes of death specific to the SCI population include renal failure, pneumonia, and septicemia (NSCISC, 2011).

Following rehabilitation, 88% of individuals with SCI are discharged to their pre-injury home which often requires architectural modifications to allow access for wheelchair use. This process may include acquisition of equipment and supplies as well as modification of existing structures and employment of attendant care providers. The life care plan outlines the needs of the individual as well as researched costs for providing these goods and services typically from person's geographic area or when unavailable or not feasible, national vendors (Deutsch & Sawyer, 2002; Weed & Berens, 2010).

Life Care Planning Methodology

Life care planning is a methodology to comprehensively analyze disability and its resulting needs including the frequency, duration and cost of necessary disability-related goods and services. The life care plan was introduced as a case management approach to disability that provided an organized, consistent, and comprehensive method to outline the framework of necessary goods and services that resulted from the onset of disability, usually from a traumatic event (Weed & Field, 1994).

It has emerged as the most comprehensive and widely accepted process for identifying needs and the accompanying economic projections associated with complex medical impairments and catastrophic injuries (Weed, 2007).

With its historical roots in case management, a life care plan is prepared based upon individualized assessment procedures conducted with one individual at a time. A life care plan is specific to the individual's specific medical needs and functional limitations and is not generalized to a type of injury (e.g., spinal cord injury or traumatic brain injury) (Weed & Field, 1994). Both the need for disability-related goods and services and the accompanying cost for these services are typically based upon research for the specific individual. Recommendations for future care come either from a treatment team member and/ or independent medical examiner (Deutsch & Raffa, 1982). The costs associated with goods and services included in a life care plan are obtained at the time that the life care plan is prepared and from local vendors or vendors that are accessible to the client. Because the methodology is individualized and specific to the case being assess, life care planners do not typically rely on aggregate data for cost projections in a life care plan.

A life care plan is 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 healthcare needs. This definition is published in the *Life Care Planning and Case Management Handbook* (Weed & Berens, 2010) and endorsed by the International Association of Life Care Planners. As such, the life care plan outlines disability-related needs of an individual. This is in contrast to the identification of disability-related goods/ services consumption. A review of medical bills or a review of aggregate data will always be a reflection of goods/services consumption. It is often argued by the party being held accountable to fund the life care plan that since the individual with the

disability has not previously consumed the disability-related service, he or she therefore does not need the service recommended in the life care plan. However, life care plans should not be limited to simply reflecting only the goods and services that the individual has previously consumed for two primary reasons: (a) the individual in many instances may likely not have had enough funding to purchase needed items (Rutherford Owen & Marini, 2012); and (b) items found in the life care plan and the costs associated with these projections must be needs-driven rather than a projection of previous consumption only. This often stands in contrast to cost-related data presented by the National SCI Statistical Center. A discussion of this data follows.

SCI Statistical Center Data

In contrast to the individualized approach utilized in life care planning, the National SCI Statistical Center publishes aggregate data collected through the various Model Systems treating individuals with spinal cord injuries. A review of the NSCISC's most recent cost data provides the lifetime cost of health care, living expenses and estimated lifetime costs attributable to SCI. In 2010 dollars, Table 1 provides the average yearly and estimated lifetime costs associated with SCI, based upon level of injury, as published by NSCISC.

The NSCISC's website figures do not include "indirect" costs such as lost wages, productivity or benefits. The NSCISC estimates that this figure has wide variation, but provides a yearly figure of $66,626 (in 2010 dollars) as an estimation of indirect costs with no valid or identified rationale. For life care planners who also provide a vocational component to their life care plan, this figure may also be presented to contradict the estimate of lost earning capacity provided by the life care planner who is also a vocational expert.

Table 1

Lifetime Costs Published by NSCISC

	Average Yearly Expenses (in 2010 dollars)		Estimated Lifetime Costs by Age at Injury (discounted at 2%)	
Severity of Injury	First Year	Each Subsequent Year	25 years old	50 years old
High Tetraplegia (C1-C4)	$985,774	$171,183	$4,373,912	$2,403,828
Low Tetraplegia (C5-C8)	$712,308	$105,013	$3,195,853	$1,965,735
Paraplegia	$480,431	$63,643	$2,138,824	$1,403,646
Incomplete Motor Functional at Any Level	$321,720	$39,077	$1,461,255	$1,031,394

Data Source: Economic Impact of SCI published in the journal *Topics in Spinal Cord Injury Rehabilitation* Volume 16 Number 4 in 2011. *Reprinted with permission.*

SCI Statistical Center Data Collection

The University of Alabama at Birmingham's National Spinal Cord Injury Statistical Center and its predecessor the National Spinal Cord Injury Data Research Center have published data pertaining to spinal cord injuries since 1973. Data are collected from individuals with spinal cord injuries (SCI) who are seen at the various Model Spinal Cord Injury hospitals. The number and location of SCI Model Systems vary based upon a federal selection process. Since 1984, there have been fewer participants in data collection due to fewer systems being funded by National Institute on Disability Rehabilitation Research (NIDRR) than in previous years (NSCISC, 2011). In 2012, there are 14 SCI Model Systems located in Alabama, California, Colorado, Florida, Georgia, Illinois, Kentucky, Massachusetts (two centers), Michigan, New Jersey, Pennsylvania (two centers), Washington state. Additionally, there are five Form II centers that only collect follow-up data located in California, Missouri, New York, Texas and Virginia.

The data published by the NSCISC reflects information from 13% of new SCI cases in the United States. This information was collected from individuals who received initial inpatient rehabilitation at SCI Model Systems within one year of their SCI (NSCISC, 2011). As the same data is collected by various staff members through the Model System Centers, strict data collection processes have been developed to ensure that the data collected are comparable. Data are collected at all SCIMS locations in two sets; Form I which includes data collected during one's initial hospitalization, and Form II which is a follow-up form. Data included in Form I includes demographic data, information about acute care, rehabilitation and outcomes of treatment for qualified patients. Since 2005, criteria for inclusion in Form I data collection, in general, includes presence of a SCI, admission to a Model System within one year of SCI, and residence in the catchment area of the system at time of SCI (NSCISC, 2011).

Form II data is collected at regular intervals from individuals who previously provided Form I information. Typically follow-up continues until death, neurologic recovery or withdrawal of consent. Between 1996 and September 2000, Form II data was collected from most program participants at intervals of one, two, five, ten years and then every five years. A small set of individuals (125) were followed yearly until 2000 when this process was terminated. Also in October 2000, Form II data collection no longer occurred at the two year interval. As of October 2010, the National SCI Database contained information on 27,553 Form I patients and 102,668 Form II records collected by phone, in-person, chart review or surveyed by mail. Approximately 70% of data collection interviews were completed via telephone, 9% were conducted in person, approximately 8% were completed via mail and approximately 8% of interviews were completed using a combination of the methods (i.e., in-person, by phone and/or by mail). The combined total of registry, Form I and Form II records I the National SCI Database is 141,678 records (NSCISC, 2011).

While demographic SCI data is collected using the above procedures, the current cost/charge information published on the National SCI Statistical Center's website was derived from research published in 2011 in *Topics in Spinal Cord Injury Rehabilitation*. Historically, the NSCISC collected financial data pertaining to days hospitalized (with associated charges), days in a nursing home (with associated charges), and charges for emergency medical services, physician services, equipment, environmental modifications, attendant care, outpatient therapy, medications, supplies and vocational rehabilitation (DeVivo, Chen, Mennemeyer & Deutsch, 2011). In 1981, data collection as outlined above was discontinued. From 2000 until 2011, the only areas on which financial data were collected in the NSCISC database were acute care, rehabilitation, rehospitalization, nursing home lengths of stay, hours of daily

attendant care, and hours of outpatient therapy services (DeVivo et al., 2011). The only charge-related information care was for initial acute care and rehabilitation (DeVivo et al., 2011).

In order to provide cost-related information as previously published by NSCISC, three cost studies were initiated in the late 1980s and early 1990s (DeVivo et al., 2011). These studies provided the lifetime cost estimates published by NSCISC. However, a primary limitation of the cost studies of the 1980s and 1990s was that the studies considered only what goods and services were received (not what was needed), therefore the figures arguably underestimated the costs of optimal SCI-related care (DeVivo et al., 2011). The purpose of the 2011 DeVivo et al. study was to provide a current estimate of initial and long-term costs of care for persons with SCI included in the Model System. The research included charges of care including initial acute care and rehabilitation, attendant care, and hospitalization. As the NSCISC no longer collects data for emergency medical services, outpatient services, physician fees, medications, supplies, vocational rehabilitation, environmental modifications, and durable medical equipment, these previously collected data were adjusted for inflation to arrive at current cost estimates. The aggregate cost information was then stratified into four neurological categories consistent with the American Spinal Injury Association Impairment (ASIA) Scale: C1-4, C5-8, T1-S5 and AIS- D at any level (DeVivo et al., 2011). Detailed collection information about the four major categories of recent data collection, acute care, rehabilitation, attendant care and hospitalization are discussed.

Acute Care Charges

Length of stay and incurred charges data were collected from 1,508 SCI Model System former patients regarding initial care and 1,599 individuals regarding rehabilitation. These charges were collected from all individuals admitted to the SCI Model Systems within 24 hours of injury between 2000 and 2006 (DeVivo et al, 2011). Inpatient acute care hospital charges reflect the amounts billed to either patients or third parties, typically the hospital's retail price for covered and noncovered services from the hospital's "chargemaster." Physician fees were typically excluded. Acute care costs were derived by applying the cost to charge ratios for each Model System acute care facility to the charge data (DeVivo et al., 2011). Use of cost to charge ratios are recognized in research as the most precise method of estimating a provider's actual 'cost' (Asper, 2009). According to the American Hospital Association (2010), the ratio for calculating cost to charge ratio is:

Cost-to-charge Ratio = Total Expenses Exclusive of Bad Debt
Gross Patient Revenue + Other Operating Revenue

This is the equation utilized in the DeVivo et al. (2011) research, which is the source of cost figures published on the National Spinal Cord Statistical Center's website. Adjustments were made to 2009 dollars using hospital services information in the Consumer Price Index (DeVivo et al., 2011). The resulting figure represented the estimation of acute care costs included in the total estimation of SCI related expenses.

Attendant Care

Additional information was collected from 7,637 individuals pertaining to attendant care services, 8,239 individuals pertaining to number of days in a nursing home, and 8,034 individuals pertaining to days of rehospitalization for secondary medical conditions or follow-

up rehabilitation. These data were self-reported from individuals in the NSCISC database who completed an annual follow-up evaluation between 2000 and 2006. In the previous 1992 SCI cost study, attendant care was priced at $5.00 per hour for both paid and unpaid care received (Harvey, Wilson, Greene, Berkowitz & Stripling, 1992). In the earlier Model Systems study (DeVivo, Whiteneck & Charles, 1995), paid attendant care was based on actual charges paid and unpaid care was based on $5 per hour.

In the 2011 study, both paid and unpaid attendant care was priced at the 2009 national average cost of an agency provided private pay home health aide, or $21 per hour. The daily cost for nursing home care was priced at $198 per day based upon the national average cost of a semi-private room in 2009. These figures were included in the calculation of yearly expenses and lifetime costs on the National Spinal Cord Injury Statistical Center's website (NSCISC, 2011).

Other Costs

One additional cost calculated was daily hospitalization, based upon research conducted by DeVivo and Farris (2011). To calculate this cost, a review of hospital billing records from Alabama hospitals (including UAB) and Alabama Medicaid computer listings was made. Hospital cost estimates were derived through weighted statewide average cost to charge ratios for urban and rural hospitals in the state where the individual was hospitalized (DeVivo et al., 2011).

As noted above, the NSCISC database no longer collects new information for cost categories including emergency medical services, outpatient services, and physician fees, medications, supplies, vocational rehabilitation, architectural modifications, durable medical equipment, and other miscellaneous costs. Therefore, current costs for these goods and services were calculated by adjusting the previously collected data for inflation in 2010. As a result, the calculation does not account for new treatments, practices, equipment or other innovations introduced since the 1980s.

When added together, the above costs provide the yearly expense and lifetime cost estimates outlined in Table 1 and published on the NSCISC's website. The lifetime cost for individuals with C1-C4 SCI incurred at age 25 is estimated at $4,373,912. These figures represent all individuals who met the criteria outlined above including race and ethnicity, gender, socioeconomic background, and those with co-morbid health conditions such as diabetes or hypertension. As such, the cost information provided is aggregate data.

When compared to the needs identified in a specific individual's life care plan, one would expect lifetime costs to vary widely from the NSCISC figures. Not only are the costs incurred for services consumed very different from identified needs and associated charges, but the costs incurred by the 13% of individuals with SCI included in the NSCISC database may not be the same costs incurred by the individual described in a specific life care plan. Both the purpose of the database and the methodology by which the calculations are developed are very different.

SCI Data vs. Life Care Planning Data

As life care plans are prepared for a specific individual and his or her medical and functional limitations based generally on cost research in the person's geographic area of residence, the figures derived should be a better estimate of an individual's anticipated SCI related costs over his or her lifetime than reliance on aggregate data. DeVivo et al. (2011) note that the estimate of NSCISC charges and costs "cannot substitute for a professionally

developed life care plan based on the actual needs of the individual and the costs of providing those needed services in the community where the individual resides" (p.8). Figures published on the NSCISC website are not intended to substitute or substantially account for an individualized assessment by a life care planning professional.

While utilizing the published figures from the NSCISC database to estimate a specific individual's future cost is not advisable, the data published by the NSCISC may be useful to life care planners in other ways. First, aggregate data provides information about a portion of the population of individuals with SCI in the United States both in terms of demographic information and patterns within the population. For example, the NSCISC notes that inpatient care and attendant care were the largest categories of lifetime costs (NSCISC, 2011). This is consistent with the experience of most life care planners, where it is noted that attendant care is often the largest single item in terms of expense in the life care plan (Deutsch, Weed, Kitchen & Sluis, 1989; Harrell & Krause, 2002; Pomeranz, Shaw, Sawyer & Velozo, 2006). Second, as the life care plan is essentially an educational tool and life care planners are often asked to explain the plan to lawyers, judges, jurors and family members of the person with the disability, the NSCISC population data may be helpful in framing SCI-related issues for individuals unfamiliar with the disability. Additionally, DeVivo et al. (2011) noted that their estimates can be helpful in assessing the costs/ benefit of new interventions and prevention programs. Finally, the data pertaining to future hospitalizations may be a guideline in assessing future hospitalizations for individuals for whom a plan is developed since potential secondary complications can not otherwise be accounted for in projected costs.

Summary

The data presented on the NSCISC's website regarding yearly and lifetime SCI-related costs can be a helpful tool for rehabilitation professionals and life care planners. The data provide demonstrative evidence about charges/costs incurred by thousands of individuals with spinal cord injuries in America. However, it should not be used in the place of an individualized life care plan which is developed based upon methodologically sound research and assessment of the needs of a specific individual following disability onset. For a specific individual, the life care plan continues to provide the most accurate assessment of future needs and associated costs for the individual with a disability.

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