

# People with Spinal Cord Injury in the United States

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## EPIDEMIOLOGY OF SPINAL CORD INJURY IN THE UNITED STATES

The incidence of traumatic spinal cord injury (SCI) in the United States is estimated to be 40.1 cases per million,<sup>1</sup> indicating approximately 12,500 new SCI occur each year.<sup>2</sup> The prevalence of SCI is estimated to be 906 cases per million, or 276,000 individuals.<sup>1,2</sup> Males are more likely to experience an SCI than females at a ratio of 2.25:1 and are estimated to account for 80% of all traumatic SCI cases. Between 1993 and 2012, there was an estimated decrease in incidence of SCI from 144 to 87 cases per million in younger males aged 16 to 24 years.<sup>3</sup>

Vehicular accidents are the leading cause of SCI in the United States, accounting for approximately 39.08% of all SCIs between 2005 and 2015. Unintentional falls (29.54%) ranked second, followed by acts of violence (14.41%; 13.01% from gunshot wounds) and sports/recreational activities (8.39%).<sup>4</sup>

The average life expectancy for an individual with SCI has not changed since the 1980s and is significantly lower than an individual without SCI.<sup>2</sup> The leading cause of mortality in SCI individuals is disease of the respiratory system, such as pneumonia, accounting for 21.6% of all deaths.<sup>5</sup> Between 1997 and 2012, there was a significant increase in the incidence of acute traumatic SCIs as a result from unintentional falls.<sup>3</sup> Incidence and prevalence of SCI in individuals older than 60 years have increased, with prevalence increasing at a slower rate because of higher mortality rates in this age group.<sup>6</sup>

## THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

Milestones and expected outcomes are highly dependent on the neurological level of injury as well as whether the injury is complete or incomplete.<sup>5</sup> The prevalence of neurologically complete injuries has decreased, potentially indicating that the immediate postinjury care and surgical response has improved.<sup>6</sup> Between 1973 and 1979, the median number of days spent in an acute care unit was 24.0. That number decreased to 11.0 from 2010 to 2014.

Nine-four percent of patients go directly to an inpatient rehabilitation center.<sup>7</sup> The median stay in inpatient rehabilitation

has decreased from 98.0 days in 1973 to 1979 to 36.0 days from 2010 to 2014.<sup>5</sup> Average stay is longer for those using a wheelchair versus those who are able to walk.<sup>7</sup> During this phase of rehabilitation, it is important to have medical specialists nearby if complications arise. People with SCI are at high risk of pneumonia, deep vein thrombosis, and pressure ulcers, as well as gastrointestinal, respiratory, urogenital, and cardiovascular problems.<sup>8</sup> Following inpatient rehabilitation, nearly 3 quarters of patients are discharged back into the community.<sup>7</sup> A 2004 study by Cardenas et al.<sup>9</sup> found a post-SCI rehospitalization rate of 55% within the first year. Low motor Functional Independence Measure scores at time of discharge from acute care public health insurance coverage correlated with higher rates of rehospitalization.<sup>9</sup>

## LIVING WITH SCI

According to the National Spinal Cord Injury Statistical Center, 91% of people with SCI live in a private residence 1 year after injury, and 4% live in a skilled nursing facility. At 20 years after injury, 97% live in a private residence, and less than 1% live in a skilled nursing facility.<sup>5</sup> Functional Independence Measure scores upon discharge from initial rehabilitation average 55/126, with scores being lower for those with complete (28/126) and incomplete (50/126) tetraplegia and higher for those with complete (65/126) and incomplete (70/126) paraplegia.<sup>5</sup> The largest gains in function are made in the first year after injury as evidenced by an increase in Functional Independence Measure scores from discharge to 1 year after injury, followed by a leveling off of average scores throughout the lifespan.

Societal participation for people with SCI is essential. Using the Craig Handicap Assessment and Reporting Technique, the physical independence subscale scores ranged from 71/100 on year after injury to 88/100 at 35 years after injury. Mobility subscale scores ranged from 73/100 at 1 year after injury to 79/100 at 15 to 25 years after injury. Finally, the social integration subscale mean scores were 86/100 1 year after injury and remained consistent throughout life.<sup>5</sup> These data indicate that people with SCI in the United States are generally independent and are participating in society.

The occupational subscale scores of the Craig Handicap Assessment and Reporting Technique ranged from 49/100 at 1 year after injury to 67/100 at 25 years after injury in 2014<sup>5</sup>; 58.1% of individuals with SCI were employed at the time of their injury; 12.2% were employed 1 year after injury; and 34.4% were employed 20 years after injury.<sup>2</sup> Race, age, sex, education, and other factors were significantly related to employment outcomes after SCI. Race and sex were also found to play a significant role in employment earnings<sup>10</sup>; 15.3% of individuals with SCI were students at the time of injury; 16.1% of individuals attained student status a year after injury,

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whereas only 2.7% were considered students 20 years after injury.<sup>2</sup> Individuals who had completed at least 16 years of education were associated with a \$21,751 increase in conditional earnings.<sup>10</sup> The average yearly cost of SCI ranged from \$42,206 for American Spinal Injury Association (ASIA) level D to \$184,891 for high tetraplegia. Indirect costs (e.g., lost wages) averaged \$71,961.<sup>2</sup>

Rates of marriage and divorce were both found to increase in the years after injury. At the time of the injury, approximately 51.6% of patients were single and had never married. By 40 years after injury, that number was reduced to 14.3%, suggesting that individuals experiencing SCI continue to marry.<sup>2</sup>

Overall satisfaction with life for people with SCI increases throughout the lifespan, ranging from 19/35 at 1 year after injury to 25/35 at 40 years after injury.<sup>5</sup>

### THE HEALTH AND REHABILITATION SYSTEM

Health care in the United States is a combination of private and public, with a bias toward the private sector. In 2014, 63.6% of individuals younger than 65 years were covered by private health insurance, whereas 13.3% were not covered at all; 17.7% of adults between the ages of 18 and 64 were covered through public plans such as Medicaid.<sup>11</sup> All individuals older than 65 years receive public coverage through Medicare, although as of 2013, nearly 1 in 4 of these paid for private supplementary coverage.<sup>12</sup>

Insurance acceptance by health care providers is another problem in the United States. While 90% of general physicians accept new patients with private insurance, only 75% are willing to accept public coverage such as Medicare or Medicaid.<sup>13</sup> In 2012, 2.9% of individuals were told that their health insurance was not accepted; this number jumps to 8.3% for adults aged 18 to 64 years with public coverage.<sup>13</sup>

Persons with SCI require the care of a multidisciplinary team including (but not limited to) physicians, specialists, nurses, physical and occupational therapists, and speech and language pathologists.<sup>8</sup> There are roughly 209,000 physicians, 56,000 nurse practitioners, and 30,000 physician assistants serving in primary care in the United States.<sup>14</sup> A large percentage of primary care professionals practice in urban areas, closely approximating the general population distribution. In some cases, this can create difficulty in finding accessible care for rural populations. The problem becomes much more acute when seeking the care of a specialist: only 11% of specialist physicians practice in rural areas, compared with 22.5% of general practitioners.<sup>14</sup> Numbers are similar for rehabilitation professionals. There are 11,781 physical medicine and rehabilitation physicians (or physiatrists),<sup>15</sup> 204,200 physical therapists, 121,400 physical therapist assistants and aides, 113,200 occupational therapists, and 134,100 speech-language pathologists in the United States.<sup>16</sup> The shortage of health care professionals is concerning for the population with SCI, particularly for those living outside urban centers.

### WHAT IS THE STATE OF SPECIALIZED CARE?

There are currently 14 SCI model systems and 5 form II centers responsible for admitting and advancing the treatment of individuals with SCI.<sup>5</sup> In 2003, Beatty et al.<sup>17</sup> found that

57% of individuals surveyed with SCIs need the assistance of an SCI specialist, but 25% of them indicated that this need had not been met. As of 2014, there were only 635 physiatrists specializing in SCI medicine in the United States.<sup>15</sup>

A wheelchair is by far the most common piece of assistive technology used by people with SCI; figures range from 58% to 80% of this population using a wheelchair at 1 and 30 years after injury, respectively.<sup>5</sup> Selection of a wheelchair is of utmost importance in the mobility of people with SCI. There are many types of chairs available, ranging from lightweight manual models to power wheelchairs and scooters, with several options for customization. Criteria for wheelchair coverage vary widely based on one's insurance plan.<sup>18</sup> There are currently 4180 certified assistive technology practitioners in the United States who are skilled in assessing the needs of people with disabilities and ensuring that they procure the optimal assistive technology.<sup>19</sup> In most cases, the wheelchair evaluation and prescription is done by a physiatrist, physical therapist, or occupational therapist.<sup>20</sup>

Each year, a significant proportion of people with SCI have at least 1 emergency room visit. A 2011 study found that 47% of emergency room residents had generally poor knowledge of the 6 categories essential to post-SCI care: autonomic dysreflexia, urinary tract infection, posttraumatic syringomyelia, gastrointestinal system problems, pulmonary disturbances, and cardiac complications.<sup>21</sup>

### THE SOCIAL RESPONSE TO SCI

The American with Disabilities Act (ADA) was created in 1990 to protect individuals with disabilities, including SCI, in areas of employment, state and local government programs, public accommodations, commercial facilities, transportation, and telecommunications. It stipulates that parks, transportation, public housing, emergency transport, treatment, and education must be made available to all.<sup>22</sup>

Although the ADA requires significant social accommodations for people with disabilities, there remains a gap in implementation of the law. In 2012, there were 60,000 claims related to accessibility in the United States.<sup>23</sup> According to a Bureau of Transportation survey in 2002, 3.5 million people never left their homes. Of these, 1.9 million were persons with disabilities. The homebound in this category were older (average age of 66 years) and had more severe disability than those disabled who left home at least once per week, and many of them had more difficulty accessing transportation (29% as opposed to 11%).<sup>24</sup> It can be supposed that access to public transportation could also be more lacking in rural areas than in urban areas.

The Social Security Administration offers two benefit programs for persons with disabilities. Individuals who cannot return to work for at least 1 year are eligible to receive Social Security Disability Insurance and Supplemental Security Income to reduce poverty and social isolation.<sup>25</sup> It is unknown how many people with SCI benefit from these services.

Several advocacy and support groups exist for people with SCI. Their purposes span the social, political, educational, and philanthropic spectrum. The largest are the National Spinal Cord Injury Association (ASIA), Paralyzed Veterans of America, and the United Spinal Association.<sup>26</sup> Professional groups such as ASIA and the American Paraplegia Society have formed to

pursue educational or scientific goals. The Miami Project, Christopher Reeve Paralysis Foundation, and others have materialized with the goal of finding a cure for SCI or reversing its effects.<sup>26</sup> The American Spinal Injury Association, the United Spinal Resource Center, and the American Association of Neurological Surgeons have published materials on prevention of SCI.<sup>27–29</sup>

## THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

### What Do We Hope to Gain from Participating in the InSCI Study?

Through participation in the International Spinal Cord Injury Study, we hope to gain insight into the functional ability and quality of life of people with SCI both in the United States and around the world. This valuable information will aid in continued improvement to health care resources, community accessibility, and public policy affecting this population.

### The National Study Protocol

The study will encompass traumatic SCI and certain non-traumatic etiologies, including vascular, infection, and benign tumor. Other inclusion criteria are adult age ( $\geq 18$  years) at time of onset, community dwelling (not in first rehabilitation), resident in the participating country, able to respond in one of the available language translations of the survey questionnaire, and having no notable cognitive impairment. Exclusion criteria are progressive etiologies, including other nontraumatic etiologies, such as congenital, inflammatory, and autoimmune diseases; malignant tumors; toxic agents; and radiation. Sample recruitment tactics will include both online and offline strategies such as notices on the Web sites of hospitals and Disabled Persons Organizations (DPOs), social media, national study Web site, DPO newsletters, posters and flyers in hospital waiting areas, and direct contact via phone, e-mail, and social professional networks.

## CONCLUSION

Although attitudes toward treatment of and outcomes for SCI have changed drastically in the past 100 years,<sup>26</sup> there remains significant work to be done. A general shortage of qualified health care professionals coupled with problems in insurance coverage may create an atmosphere of inferior care for sections of this population. The discrepancy between public and private insurance coverage and the scarcity of health care resources in rural areas have resulted in varying standards of care by region and socioeconomic status. Further improvement of accommodations in public transportation, workplaces, and communities can still occur. Yet despite these shortfalls, enormous strides have been made. The ADA and the disability benefits of the Social Security Administration have gone far in improving quality of life. Advocacy and support for people with SCI, along with research into new treatments and potential cures, are strong. With continued development in these areas, treatment and quality of life for people with SCI will continue to improve in the future.

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