Epidemiology of Spinal Cord Injury

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Abstract

Worldwide, the average prevalence of spinal cord injury (SCI) is estimated to be 1:1000, and the mean incidence is proposed to be between 4 and 9 cases per 100,000 population per year. Numbers vary substantially for different parts of the world. The mean incidence of SCI in developing countries is estimated to be 25.5/million/year with a range between 2.1 and 130.7/million/year. The incidence of SCI in industrialized countries ranges from 15 in Western Europe to 39/ million/year in the USA. Most common causes for traumatic SCI are traffic accidents, falls, and results of violence, whereas the leading causes of non-traumatic SCI (NTSCI) are degenerative diseases and tumors (developed countries) and infections, particularly tuberculosis and HIV (developing countries). The majority of people with traumatic SCI are males (ratio men/women=3:1), whereas in non-traumatic SCI, genders are almost equally distributed. Worldwide NTSCI increases significantly as well as the number of high-level tetraplegic patients with the need for permanent or artificial ventilation. In general, the percentage of tetraplegic patients has increased and nowadays equals that of paraplegic patients. Additionally, in industrialized countries, the mean age at the time of injury increases continuously, mostly due to older patients also experiencing SCI. The mortality rate in the first phase after SCI is directly linked to the availability and quality of primary care and rehabilitation approaches. Life expectancy is determined by the level of integration into a proper socioeconomic environment after initial treatment and directly related to the availability of qualified medical care in the event of complications such as pressure ulcers or urological problems.

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1.1 Introduction

In order to understand the sociopolitical, health-related, and socioeconomic implication of spinal cord injury (SCI), knowledge about the frequency of occurrence and etiology is required.

This introductory chapter provides basic numbers on prevalence, incidence, mortality, causes of death, and treatment costs of SCI. In particular, the differences between traumatic and non-traumatic causes of SCI and also between regions with high and low income will be elaborated. A correct interpretation of regional differences is of utmost importance, because it allows for a prognosis of the course of numbers in developing and emerging countries.

The presented results are based on the review of the scientific literature and of reports of public administrations of different countries up to 2015 with a strong focus on the most recent available numbers and information.

1.2 Challenges in Interpretation of Epidemiological Data

Unfortunately, a central worldwide registry for the collection of epidemiological data regarding SCI does not exist. Additionally, even industrialized countries do not often have a national SCI registry, in which data, at least from SCI centers about new cases, are collected. Population-based surveys for estimation of the percentage of persons with SCI in the general population are very rare [1]. Most of the epidemiological data on incidence and prevalence represent extrapolations based on the numbers collected by a few clinical centers or based on assumptions about the mean life expectancy of individuals after SCI, respectively. Due to the different methodologies of data collection and various assumptions, epidemiological data available from the literature usually have a high variance, which makes it impossible to compare data from different sources. There is very sparse information if patients with lesions at the level of the cauda equina or conus medullaris, which results in lesion of peripheral nerves, are classified as patients with SCI and are included in the epidemiological data analysis or not. Even though the incidence and prevalence of cauda equina lesions is relatively low [2], it might explain some of the variations of the data between different sources. The same applies to congenital SCI (spina bifida, meningomyelocele), for which the incidence is estimated to range between 2 and 58 per 10,000 population per year [1].

Epidemiological data might change very rapidly and numbers, which were valid a decade ago, might be obsolete nowadays. This becomes most apparent in countries with high average income, where life expectancy has dramatically increased over the last two to three decades [3].

Especially the rapid increase of cases with non-traumatic SCI within the last few years shows that the date of data acquisition is of significant importance and, as a further consequence, renders the comparison of data from different sources rather impossible.

Especially, data on prevalence and incidence of individuals with tetraplegia due to high SCI with the need for permanent mechanical ventilation or a phrenic nerve stimulator is poor. One of the reasons is that those patients die early after SCI in many countries, even in those with high average income, because either the required medical-technical care cannot be provided or the social system does not contribute financially to home-based ventilation.

1.3 Prevalence of SCI

In general, the term prevalence describes the proportion of a population living with a certain condition. It is determined by comparing the number of people found to have the condition with the total number of people studied and is usually expressed as a fraction, as a percentage, or as the number of cases per million people. Point prevalence is the proportion of a population that has the condition at a specific point in time. Period prevalence is the proportion of a population that has the condition at some time during a given period (e.g., 12-month prevalence) and includes people who already have the condition at the start of the study period as well as those who acquire it during that period. Lifetime prevalence is the proportion of a population that a some point in their life have experienced the condition. Lifetime prevalence is the term that is often only called "prevalence" in medicine [4]. It is determined by the number of new cases per year and the life expectancy of people with this condition in years. As a consequence prevalence is, on the one side, an estimate for the hazard potential within a society and, on the other side, an indicator for the effectiveness of secondary preventive measures.

A report of the World Health Organization (WHO) shows that 15% of the world's population is affected by disability, 0.1% by spinal cord injury [1]. Hence, the global prevalence of traumatic SCI is estimated to be 1000/million people [5]. However, this number needs to be treated with caution, because it represents only a rough estimate as valid data are available only for a few countries (Table 1.1). Even less reliable data are available on the prevalence of non-traumatic SCI (Table 1.2).

In general, the incidence of traumatic SCI varies substantially between countries. Among the reasons for these country-level variations are genuine country-level differences in incidence related to differences in risk, standard of living and healthcare systems, merging of data from adolescents and children (studies reporting only adult incidence overestimate the overall population rate), and differences attributable to methodological approaches. A big problem arises regarding the representativeness of the data, because only a few, mostly (small) countries, have a country-wide SCI registry system, such as Finland or Scotland, and therefore incidence estimates are extrapolated from city or regional data that may not be representative for the country as a whole [1]. It is remarkable that the overall prevalence of SCI (traumatic and non-traumatic) in Iran is with 318/million population, one of the lowest worldwide [14].

Fable 1.1 Prevalence of raumatic SCI Image: second secon	Country	Year	Prevalence (cases/million population)
	USA [6]	2013	906
	Canada [7]	2010	1298
	Norway [8]	2002	365
	Finland [9]	1999	280
	Australia [10]	1997	681
	Germany [11]	2015	500
	France [1]	2014	250

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Table 1.2 Prevalence of non-traumatic SCI

Country	Year	Prevalence (cases/million population)
Canada [7]	2010	1120
Australia [12]	2013	455
Germany [11]	2015	300
India [13]	1986	2310

1.4 Incidence of SCI

While prevalence is a measurement of all individuals affected by a condition at a particular time, incidence is a measurement of the number of new individuals who acquire a condition during a particular period of time. The incidence of SCI describes how many people have acquired an injury of the spinal cord within a predefined period of time. It is therefore a descriptive term for the risk of suffering from a certain condition or disease and represents an indirect indicator for the effectiveness of primary preventive measures.

The incidence of SCI including traumatic and non-traumatic lesions is estimated to be between 40 and 83/million/year, with an absolute estimated annual number of new cases worldwide around 250,000-500,000 [15]. The worldwide incidence of only traumatic SCI is estimated to be between 10.4 and 83/million/year [13].

However, these numbers must be interpreted with caution. The determination of the incidence of SCI is highly dependent on a variety of factors, which results in large variations.

Patients with traumatic SCI who die at the scene of the accident or pass away on their way to an emergency room are normally not included in any statistical data evaluation. This also applies to patients with a malignant disease in its final stage involving an SCI. These facts introduce a systematic bias to the overall incidence of SCI resulting in lower estimate.

Similar to the problem of determining a representative value for the prevalence of SCI, the database for determining the incidence of SCI is incomplete and inconsistent. Technical limitations and a systematic bias may be present in data collection in different countries. As a consequence, there are only rough estimates available.

Published data from different countries show enormous differences in the average incidence of SCI [7, 16, 17]. These differences might be explained by different age distributions, hazard potentials, and different levels of emergency treatment. According to a study, the annual incidence of new traumatic SCI rose significantly in persons 55 years and older. The proportion of tetraplegia and of incomplete injuries also increased. Additionally traumatic SCI occurs mostly at a young age, below 30 years [18, 19], whereas non-traumatic spinal cord disease affects people at a higher age, above 55 years.

In war zones or countries with a widespread availability of weapons or a high crime rate, the number of traumatic SCI is high, whereas gunshots or other forms of violence as causes for SCI play only a minor role in countries with restrictive laws on fire arms [20, 21]. The incidence of traumatic SCI in the mentioned countries and regions (Table 1.3) varies between 12 and 53/million [7, 10, 17, 24]. Even if data on the overall incidence are available for a large country, the regional incidence may vary to a large extent due to differences in industrialization and medical infrastructure, e.g., rural areas versus cities.

The incidence of non-traumatic SCI varies between 12 and 76/million population [7, 10, 26–28] (Table 1.4). In western industrial countries, the demographic change toward a dramatic increase in the elderly population has an enormous

Country	Year	Incidence (cases/million population/year)
Germany [11]	2015	13
Canada [7]	2010	53
Scotland [20]	2015	15.9
Australia [22]	2015	21–32
Finland [23]	2014	25
Netherlands [24]	1994	12
WHO region	Year	Incidence (cases/million population/year)
Western Europe median [25]	2011	16
North America, high-income median [25]	2011	40
Asia Central [6]	2011	25
Asia South [6]	2011	21
Caribbean [6]	2011	19
Latin America Andean [6]	2011	19
Latin America Central [6]	2011	24
Latin America Southern [6]	2011	25
Sub-Saharan Africa Central [6]	2011	29
Sub-Saharan Africa East [6]	2011	21

Table 1.3 Incidence of traumatic SCI in individual countries and WHO regions

Country	Year	Incidence (cases/million population/year)
Germany [11]	2015	12
Canada [7]	2010	68
Scotland [20]	2015	2.8
Australia [10]	2005	26
Spain [29]	1999	11
WHO region	Year	Incidence (cases/million population/year)
Western Europe median [27]	2011	6
North America, high-income median [27]	2011	76
Australasia [27]	2011	26
Asia Pacific [27]	2011	20
Oceania [27]	2011	9

Table 1.4 Incidence of non-traumatic SCI in individual countries and WHO regions

Table 1.5 Distribution of gender in traumatic SCI

Continent	Year	Male [%]	Female [%]
Europe (Germany) [11]	2015	76.8	23.7
Africa [31]	2013	81.1	18.9
Canada [7]	2012	71.6	28.4
Asia [32]	2015	70.2	29.8
North America [33]	2004	74.6	25.4
Latin America [21]	2015	78.2	21.8
Australia [34]	2011	71.6	28.4

Table 1.6 Distribution of gender in non-traumatic SCI

Year	Male [%]	Female [%]
2014	60.4	39.6
1994	67.9	32.1
2010	57.2	42.8
2013	67.3	32.7
1999	66.3	33.7
2011	50.5	49.5
2013	53.9	46.1
	Year 2014 1994 2010 2013 1999 2011 2013	Year Male [%] 2014 60.4 1994 67.9 2010 57.2 2013 67.3 1999 66.3 2011 50.5 2013 53.9

influence on the etiology of SCI, meaning that the percentage of non-traumatic SCI is constantly growing over the last decade [30].

With regard to gender, men are by far more affected by traumatic SCI [7, 24, 31] (Table 1.5). In case of non-traumatic SCI, the proportion of females is nearly equal to males [12, 29, 35] (Table 1.6). Respective gender proportions are robust and comparable in all countries worldwide.

1.5 Etiology of Traumatic SCI

The most common global causes for traumatic SCI are road traffic accidents followed by falls and violence. The proportion of road traffic accident-related SCI varies to a great degree for different regions of the world. The number of road traffic accidents is directly related to the population and traffic density but also depends on regionally quite differently developed road safety measures. In Africa, for instance, the proportion of traffic accident-related SCI (57%) is almost twice as high as in Europe [31, 40], whereas the probability of a fall-related SCI in Europe is nearly twice as high as compared to Africa [31, 35]. A Chinese study shows that rapid progress in industrialization and the associated increase of traffic substantially influence the incidence and causes of traumatic SCI. Between 2000 and 2010, an increase of road traffic accident-related SCI to 51.2% has been reported [41]. In other developing countries, traffic accidents are by far the most prominent cause of traumatic SCI (77% in Lagos [42]). With 85% the highest proportion of traffic accidentrelated SCI can be found in Saudi Arabia [43].

In children and juveniles, traffic accidents are the most common cause of paralysis worldwide. In the group of children with an age below 12 years, traffic accidents are the most frequent cause of traumatic SCI, higher than all other causes together [18, 19]. In the subpopulation with an age below 45 years, traffic accidents are the most common cause of SCI. However, after the age of 45, falls are the most likely cause for an SCI [20].

However, those numbers need to be seen from the perspective of regionally different populations. As an example, the high percentage of fall-related SCIs in older people in Europe can be easily explained by the demographic population structure in European countries [1]. This development is also found in the USA ("mean age at injury increased 9 years since the 1970s") [43], in Canada ("significant increase in the mean age at injury from 30.23 to 45.768 years of age") [44], and in Australia reporting a significantly increasing rate of fall-related injuries in elderly males [45].

People's recreational and sport-related activities influence both the rate of SCI and the associated patterns of injury. The percentage of sport-related SCI in the overall traumatic SCI population is 1.7% in Nigeria, 4.0% in Germany, 10.0% in the USA, and 14.1% in the Netherlands [11, 28, 42, 46]. According to the available literature, there are six countries in which sports accounts for over 13% of SCI (highest to lowest: Russia, Fiji, New Zealand, Iceland, France, and Canada). Diving, skiing, rugby, and horseback riding were identified as individual sports with the highest risk for SCI. For hockey, skiing, diving, and American football, almost all injuries are located at the cervical spinal cord level, while over half of horseback riding and snowboarding injuries are at the thoracic or lumbosacral level [47].

The number of traumatic SCI caused by firearms varies to a large extent in different countries. In Northern Europe the percentage is below 1% of the overall traumatic SCI population, whereas in Brazil injuries of the spinal cord by the use of firearms are a common cause accounting for 16.9% of all traumatic SCI cases [48]. As mentioned above the incidence represents, among other things, a good indicator in terms of effectiveness of primary measures for the prevention of SCI. For the validity of this statement, there are both positive and negative examples: in Germany the costs of treatment after accidents during work will be covered by a separate statutory accident insurance (workmen's compensation). This is somehow a unique approach in the international context. The data from Germany show that the proportion of SCI caused by workplace accidents has decreased from 22 to 7% of the total traumatic SCI population from 1985 to 2013 [11]. This can be attributed both to the lower risks for workplace-related injuries due to the general trend toward a modern industrial and information society with more indoor work places and also to the implementation of stricter occupational safety regulations. The latter is without doubt an example of successful primary prevention.

However, in another cause of traumatic SCI, diving into shallow water, primary preventive measures seem to be less effective. Data from Germany show that the percentage of cervical lesions resulting from shallow water diving persists on a constant level from 1985 to 2013 [11]. The proportion of SCI related to shallow water diving accounts for approximately 4% of traumatic SCI. The introduction of several prevention campaigns did not yield a lower incidence. In contrast, prevention programs in the USA and Canada have been reported to successfully promote reduced rates of diving into shallow water accidents [49].

1.6 Etiology of Non-traumatic SCI

Few studies provide epidemiological data on non-traumatic SCI. Non-traumatic SCI has received more and more attention over the recent decades, whereas until the mid of the twentieth century, the percentage of traumatic SCI was reported to be more than 90 % with only few cases due to non-traumatic causes. The increase of non-traumatic SCI – a disease of the elderly – can, for the most part, be explained by the increase in life expectancy of the population in developed countries. This trend is normally linked to the occurrence of age-related diseases such as cardiovascular disorders, tumors, and infections of the spinal column or spinal cord itself. Developing countries tended to have a higher proportion of infections, particularly tuberculosis and HIV, although a number also reported tumors as a major cause [27].

A detailed analysis of over 1000 cases of non-traumatic SCI in 2012 in Germany attributed 26% to tumors compressing the spinal cord, 20% to infectious disease, and 16% to ischemia. The most common non-traumatic cause (41%) was degenerative spine diseases with associated spinal canal stenosis [11]. These proportions are comparable for all industrialized countries [26].

Non-traumatic SCI results much more often in incomplete paralysis compared to traumatic SCI [9, 11, 12, 26, 28, 29, 41, 42] (Tables 1.7 and 1.8).

		Tetraplegia		Paraplegia		
Continent	Year	Complete (AIS A) [%]	Incomplete [%]	Complete (AIS A) [%]	Incomplete [%]	
Europe (Germany) [11]	2015	28.6	25.0	30.1	16.3	
Middle East [50]	2012	21.0	31.0	29.0	18.0	
Asia [41]	2013	26.8	25.7	23.7	8.3	

Table 1.7 Distribution of lesion level and severity in traumatic SCI

Table 1.8	Distribution	of lesion	level and	severity i	in non-traumatic	SCI
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		Tetraplegia		Paraplegia	
Continent	Year	Complete (AIS A) [%]	Incomplete	Complete (AIS A) [%]	Incomplete
Europe (Germany) [11]	2015	7.3	20.6	29.7	42.2
Middle East [50]	2010	11.9	25.1	15.9	47.1
Australia [12]	2013	19.4	11.3	20.2	49.1

1.7 Trends, Mortality, and Life Expectancy in SCI

Until the beginning of the twentieth century, an SCI was a devastating condition leading to death due to pneumonia, pressure sores, or lower and upper urinary tract infections within days to months depending on the lesion level and severity. In particular, in high cervical cord lesions very soon after the injury, pneumonia occurred due to the impairment of respiratory function, which in the long run, led to death due to the lack of therapeutic interventions. The progress in the second half of the twentieth century in the development of surgical stabilization options and intensive care medicine as well as a strong desire to not accept the unavoidable fate of SCI victims, resulted in the introduction of dedicated rehabilitative and neurological therapies. These factors promoted a fundamental change in the situation of individuals suffering from the sequels of SCI.

As a consequence, the life expectancy of people with traumatic SCI has continuously increased over the last 70 years [51]. However, compared to the general population, mortality is increased in the SCI population. The life expectancy (LE) of people with SCI is still lower compared to age-matched able-bodied individuals. The highest estimated lost LE was associated with chronic pressure ulcers (50.3 %), followed by amputations (35.4 %), one or more recent hospitalizations (18.5 %), and the diagnosis of probable major depression (18%). Symptoms of infections were associated with a 6.7 % reduction in LE for an increase in infectious symptoms [52]. For patients with traumatic SCI, the highest mortality risk is during the first year after the date of injury and the onset of SCI [53, 54]. The mortality rate and life expectancy after SCI differ substantially in different parts of the world mainly due to enormous differences in the standard of care. This includes, on the one hand, the availability and effectiveness of emergency units and, on the other hand, the quality of lifelong care [55]. The quality of emergency and primary care and the subsequent medical-rehabilitative therapy affect mortality rates to a great extent. Particularly in low-income countries, many people today still die from complications that could easily be avoided with a higher standard of care.

In addition to the level and severity of the SCI, the presence and extent of concomitant injuries and trauma strongly influence the mortality risk. Age substantially influences the prognosis of survival due to the presence of comorbidities [56].

The mean life expectancy of people with tetraplegia is lower than of persons with paraplegia. A complete SCI results more often in earlier death than an incomplete SCI. This was shown in a number of countries by comparing mortality rates with the general population [53, 57].

Several studies show that in people with paraplegia, the causes of death become similar to those of the general population [53, 58]. Most common causes of death are nowadays ischemic events such as cardiac arrest or stroke, tumors, and chronic obstructive pulmonary disease (COPD). However, approximately 15% of SCI patients still die because of pressure sores and their medical consequences [58, 59].

The causes of death in people with tetraplegia are very different to those with paraplegia. In the international literature, high numbers of pulmonary complications are found consistently to be a leading cause of death in people with tetraplegia [30, 60–62]. This is obvious and, particularly in case of very high lesions with an extended paralysis, unavoidable to some extent. In any case, patients suffering from very high cervical SCI require permanent mechanical ventilation and form a special group. Unlike any other group, their mortality depends on the availability of medical-technical equipment and nursing care. Therefore, the mortality rate of these very high-lesioned patients may serve as an indicator of how much a society is technically and economically able to provide a high-level of community-based care [63].

Independent from the severity and the level of the lesion, there is evidence that the incidence of suicide as a cause of death is higher in the SCI population than in the general population [64]. This might be related to the fact that a suicide attempt was quite often the cause of the SCI [65].

Other typical paralysis-related causes of death are chronic obstipation related to neurogenic bowel dysfunction and urosepsis as consequences of neurogenic bladder dysfunction. Not infrequently, urothelial carcinoma of the bladder can represent a death-related cause in SCI patients [50].

The notable shift in traumatic SCI toward older patients has a huge impact on rehabilitation approaches, because older people have age-associated comorbidities limiting their rehabilitation potential [46, 66, 67]. This problem will become even further apparent due to the ongoing demographic change in industrial countries. A German population of over 3.000 SCI patients collected over a 25-year period showed that 84 % of the patients suffered from comorbidities such as cardiovascular diseases and tumors, which required additional treatment [11].

Trends in the growth of the proportion of non-traumatic SCI can be seen in the German database, to which all German SCI centers contribute. In the beginning of data acquisition (1976), the proportion of non-traumatic SCI was 14%. In 2012, the percentage of non-traumatic SCI was 54% [11], with an average of 37% between 1976 and 2012.

1.8 Costs of SCI

SCI does not only put additional burden on to affected individuals, but it generates substantial costs for health care and professional reintegration. In many instances, the severity of the functional impairments with required lifelong care substantially contributes to this figure. The costs on the social system are very high due to permanent paralysis. Here, one has to differentiate between costs directly related to the injury and the expenses of the treatment of the lifelong consequences of the SCI impairment, which also include financial commitments of social reintegration.

Basically, direct costs in the acute phase after the injury consist of:

- Expenses resulting from rescue and emergency services in the case of traumatic SCI
- · Costs for inpatient surgical and conservative treatments and care
- Costs for outpatient care, medication, physical/occupational therapy, assistive devices such as wheelchairs, and consumables such as catheters

Costs related to comprehensive care are mainly generated by:

- · Setup of an accessible home and eventually also a working environment
- Loss of tax and/or welfare expenses in case professional reintegration is not successful

It is clear that both the severity of the functional impairment and the outcome of the primary medical treatment and the medical and professional rehabilitation have an impact on both direct and indirect costs. The highest costs occur during the first year after injury, whereas the total costs are determined by the life expectancy.

Published data regarding lifetime costs of SCI are inconsistent and often untransparent regarding the method of estimation [1]. The available numbers often seem to be outdated and in any case need to be interpreted with caution. Therefore, no precise numbers are provided within this chapter.

Conclusions

Epidemiological data on incidence, prevalence, and etiology of traumatic and non-traumatic SCI are subject to substantial regional variations. These numbers are influenced by multiple factors, most importantly the level and availability of emergency and life-saving services as well as SCI-specific surgical, rehabilitative, and home care institutions. Trends in the incidence of traumatic SCI over time may serve as an indicator for the success of preventive measures. The increase in life expectancy of the general population in societies with high average income results in an increase of non-traumatic SCI. More population-based studies are needed to obtain more reliable data about SCI epidemiology and trends over time.

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