

People with Spinal Cord Injury in Germany

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN GERMANY

In Germany, specific data reflecting the health and care situation on spinal cord injuries (SCIs) are very limited. The results of research primarily relate to diagnostic and therapeutic interventions. Routine data provided by the German Health Surveillance System do not give any information about new cases and their etiology. For that reason, neither the exact number of new cases per year nor the number of people affected by SCI in Germany is known. Furthermore, a nationwide registry like that in Australia¹ or the United States,² including all cases of SCI, does not exist. The extent of disability and rehabilitation needs in Germany is also unknown.

A German working group is providing the first indications about the current situation. They have been collecting data from most SCI-specialized centers in Germany since 1976. From this database, we know that 34,000 new cases of SCI were registered between 1976 and 2002, corresponding to an annual incidence rate of approximately 1,200 to 1,500 cases per year.³ Most patients (70%) were male. The main identified causes of SCI were traffic accidents (31%) and disease (30%), eg, tumor of the spinal cord, certain types of disc herniation, or prenatal impairments like spina bifida.⁴ Thirteen percent of cases involved occupational accidents, and 7% involved swimming and sport accidents. Regarding the paralysis level, there were 37% tetraplegics and 63% paraplegics. Children were rarely affected (1%).³ Currently, Germany lists approximately 80,000 cases of a total of 81.1 million inhabitants.⁵ However, the significance of these figures is limited owing to the partial response of the specialized SCI centers in Germany.

Recent data of the working group (1997–2010) indicate a strong increase in disease-related SCI and a slight decrease of accidental causes. Owing to an increase in age-related diseases in the population, an increase in disease-related SCI up to 50% is expected in the future. Moreover, an increasing percentage of women are expected owing to their higher life expectancy. The mean age of the entire population affected by SCI in 2010 was 60 years.⁵

Life expectancy after traumatic SCI is limited in Germany, despite comprehensive systems of rescue, treatment, and rehabilitation, and the implementation of lifelong aftercare. The mean survival time after the incidence of paraplegia is 29.2 years, the mean survival time after the incidence of tetraplegia, 13.7 years.⁶ A patient's prognosis was worse at the start of the 20th century owing to fewer medical and rehabilitation services.⁷ Today, patients with SCI who survived 20 years after injury have nearly the same life expectancy as the general population. If SCI with a high degree of paralysis is diagnosed, pulmonary complications often lead to premature death.⁶

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

In Germany, a well-developed and comprehensive system of emergency rescue exists to initiate first aid. Normally, in case of an accident, it can be assumed that a rescue team, consisting of paramedics and an emergency physician will arrive within a maximum of 15 minutes at the accident location to initiate the first medical interventions.⁸ Rescuers can acquire knowledge and skills in dealing with patients with a suspected SCI in special courses.⁹ The aim was to transfer the patients to one of the available specialized SCI centers. If this is not possible for reasons of capacity, transport to another emergency care hospital is initiated. Rescue vehicles and helicopters are always equipped to treat seriously injured patients. The choice of transportation, however, depends on availability.⁹

Subsequent intensive care can be carried out in 60% of all hospitals in Germany.¹⁰ Even surgical procedures are possible in many places. Twenty-five years ago, there were only a few hospitals where surgical interventions of the spine could be carried out. Today, even smaller hospitals have spinal surgery departments.¹¹

Transfer to an SCI center for subsequent rehabilitation is desirable. These centers are spread across the country and make regional medical care possible. The mean duration of transport is rather low because most of the large federal provinces in Germany (11/13) provide a specialized SCI center (Fig. 1).¹² The range of services at the facilities is nearly similar. All of them provide physical, occupational, and sports therapy as well as physical medicine. Furthermore, most of them perform surgeries (75%), have an intensive care unit (96%), and provide pain management (93%).¹² In addition, most of them offer all phases of rehabilitation: emergency treatment, integration into the social and professional environment and long-term care. A clear classification for becoming a specialized center for Spinal Cord Injury is not available. Possible criteria could be, for example, the number of SCI patients per year and the specialized know-how of the staff. Although many German

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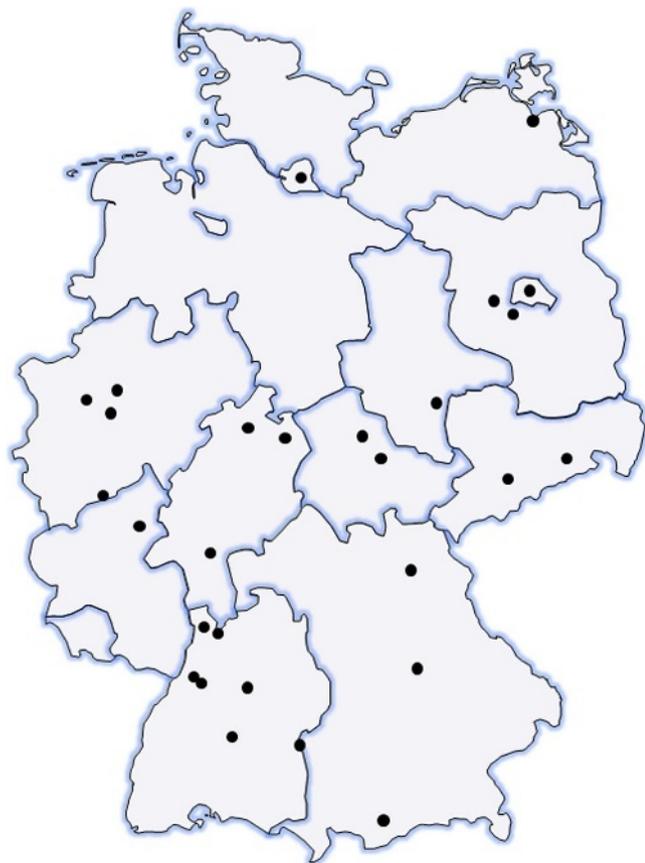


FIGURE 1. German SCI centers, modeled after DMGP 2015.

legal requirements for ensuring a needs-based medical care exist, the realization of these standards has not been explored. There are no studies that give an overview of the actual situation.

LIVING WITH SCI

During the first phase of rehabilitation after the occurrence of SCI, patients are provided with various support such as a wheelchair and aids for emptying the bladder and bowel, etc. The German insurance system bears (most of) the incurred cost, according to the SCI cause. For the period after the first rehabilitation, there are a number of stakeholder organizations, associations, and foundations that work for the interest of patients with SCI. They provide information, advice, and support. To lead an active life in the community, patients can obtain technical support (wheelchairs), support for integration into the environment, home maintenance, home care, as well as assistance to participate in cultural life.

THE HEALTH AND REHABILITATION SYSTEM

Health care in Germany is predominantly financed by the insurance system. Citizens and employers contribute to different obligatory health, nursing care, pension, and accident insurance. Federal grants contribute to the social contributions by tax revenue.¹³ This general legal obligation ensures that all people living in Germany pay into the health care system. In the case of unemployment, social welfare pays the costs. This

arrangement ensures adequate medical care for all people at any time, including in the case of SCI.

The compulsory health insurance covers the costs almost on an equal level. Differences in health care services exist if other institutions bear the incurred cost, such as a private accident insurance company or the employer's liability insurance association. The latter takes care of persons with SCI caused by work-related accidents and is very specific for Germany. With the principle of restoring human health by using all appropriate means, persons with a work-related SCI benefit from high-quality health care.

Table 1 shows the different phases of care of paraplegics and legal support.

WHAT IS THE STATE OF SPECIALIZED CARE?

As previously mentioned, in Germany there are a total of 28 SCI centers assigned to several payers (eg, employer's liability insurance association). They are specialized in medical treatment, rehabilitation, and follow-up care,¹² based on very good personnel and equipment facilities. Almost all centers or hospitals to which these specialized centers are attached provide intensive medical care. Surgical interventions of the spine can be performed in 11 centers directly and in another 9 centers of the attached hospitals over 24 hours. Special surgeries such as urological surgeries or hand surgeries are possible in most of the centers or may be performed nearby.¹³

Throughout the rehabilitation process, clinical psychological care is always provided. Psychologists form an integral part of the team.¹⁴ Social workers also support patients in adapting to their domestic and professional environment.¹⁵ Relatives can participate in care training and consulting services. In addition, the principle of lifelong follow-up care ensures the early detection of health problems and the greatest possible independence.¹⁶ These interventions are mainly carried out in specialized SCI centers because of their knowledge. The frequency of the examinations varies and is adapted to each case.

THE SOCIAL RESPONSE TO SCI

In Germany, the costs for medical care, rehabilitation, and the changing life circumstances are funded by various organizations and forms of insurance. In cases of disease or private accidents, the compulsory health insurance covers acute care, as well as financial support. Medical rehabilitation is financed by the pension fund as long as the patient is of working age.¹⁷ In case of accident at one's workplace or on the way to work or returning home from work, the employer's liability insurance association assumes all costs associated with restoring health and capacity.¹⁸ The pension fund follows the principle of "rehabilitation before retirement" and includes medical care as well as vocational and social reintegration of the patient.¹⁹ Insurance provides benefits for participation in the work force as well as complementary services to alleviate the effects of disease on the patient's ability to work. If the ability to work and have income is limited owing to SCI, it is possible to obtain a disability pension. Patients with SCI can also retire earlier from work or reduce their weekly working time.²⁰ If the SCI is the result of a third party's fault, all costs are adopted by the private liability insurance of the person who was responsible for the accident. Regarding civil servants, there are special

TABLE 1. Overview of phases of care of paraplegics and legal support

Insurance Company or Support Institution		Health Insurance	Accident Insurance ^a	Pension Insurance	Long-term Nursing Care Insurance ^b	Social Welfare
Legal Basis		GSLC V, IV, IX	GSLC VII, IV, IX	GSLC VI, IV, IX	GSLC XI, IV, IX	GSLC XII, IV, IX
Phase of Care						
Acute Care	Intensive care/Hospital care	X	X			X
	Posttreatment rehabilitation	X	X	X		X
Post-Acute Care/Rehabilitation (mostly inpatient)	Vocational rehabilitation		X	X		X
	Assistive technologies (eg, prosthesis, wheelchairs, crutches)	X	X	X		X
	Community-based health care ^c	X	(X)		X	
	Adopted living and/or working environment	(X) ^d	X	X		X
Long-term Care/Rehabilitation (mostly outpatient)	Home care/Outpatient care	X			X	(X)
	Retraining measures ^e		X	X		X
	Medical rehabilitation	X	X	X		X
	Vocational rehabilitation		X	X		X
	Assistive technologies	X	X	X		X
	Monetary compensation ^f	X	X		X	
Financial Protection	Reduced earnings capacity pension		X	X		X
	Pension payment		X	X		

The direct comparison of the phases is not given between the insurances, and for everything, there are various exemptions in the German Social Law Codes (GSLC). This list only represents an attempt of a schematic collection of possible phases of care and the corresponding responsibilities. Not every paraplegic runs through all phases.

For all legal insurances, there are also private insurances, which stand either in place of the legal insurances or as a supplement. Base is an individual contract. Moreover, it may get in case of liability claims to a recovery of financial expenditure of the legal insurance. E.g. in case of early retirement after an alien-inflicted accident: Not only the pension is taken from the opposing party liability insurance until official retirement age, also the outstanding pension contributions (see SGB X §115ff).

^aResponsible for the elimination of the consequences of an accident on the way to work, on the way from work to home or during work.

^bUsually not 100% financing, but exclusive own contribution.

^cCommunity-based health care is for people of all ages who need health care assistance at home. Community care services include home support, general practitioner, PRM specialist, nursing, physiotherapy, but also other rehabilitation services.

^dBrackets mean that this is only in exceptional cases applicable.

^eThis means retraining measures beyond the vocational rehabilitation.

^fFor example, sick pay, compensation for damages or care allowance.

GSLC, German Social Law Code (dt. Sozialgesetzbuch (SGB)).

arrangements in Germany.²¹ Social welfare takes over if the payment from all insurance is rejected. Nursing care insurance only assumes the costs if the need for care was formally confirmed.²²

There are a number of legal regulations regarding the lives of people with disabilities in Germany. The Act on Equal Opportunities for Disabled Persons, in place since 2002, ensures equality and accessibility in the public sector to prevent discrimination.²³ It regulates, that “buildings or other facilities, public ways, squares and streets as well as public traffic facilities and means of public transportation should be accessible.” Although the law was passed 13 years ago, it has not yet been fully implemented.²⁴

Finally, the ninth volume of the German Social Insurance Code mandates that disabled persons receive certain benefits to participate independently and adequately in social life.²⁵ This provision also deals with issues of participation in the work force, the redesign of the workplace, job assistance, wheelchair access, automobile assistance, and accessibility of facilities and homes. If re-entering into the primary profession is not possible, further education or retraining may be granted. Private and public employers with at least 20 jobs available monthly, per year on average, must offer 5% of their jobs to people with a severe disability. If this integration does not occur, a compensation charge must be paid. Despite these provisions, job integration after SCI has reached a proportion of 60%.²⁶

Since traffic accidents are the main cause of SCIs in Germany, the information campaign, “Slow down,” was initiated. Numerous posters on highways and country roads have promoted public awareness of the consequences of risky behavior to reduce the number of serious traffic accidents involving fatalities.²⁷ The prevention campaign of the German foundation for patients with SCI, “Risk makes no sense,” provides information about risks associated with sporting activities. School projects advise children and adults of the risks and consequences of risky behaviors.²⁸

A campaign to improve the folic acid intake of the German population to reduce neural tube defects was initiated in 2006 but was not implemented successfully.²⁹ Although the number of prenatal neural tube defects in Germany compared to other European countries is very high (12.36 new cases per 10,000 child births in Germany compared to 7.88 new cases per 10,000 child births in Europe),³⁰ there are only recommendations for folic acid supplementation before conception. A program for folic acid fortification for food has not yet been established.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

Although the overall situation for persons with SCI in Germany is fairly good, it is always possible to improve medical care and extend the social response to improve their lives. We eagerly await the information to be gathered from the German national study using the InSCI protocol so that gaps in the picture of those living with SCI in Germany are filled, and better policies can be devised.

The National Study Protocol

The German research project, “Spinal Cord Injury in Germany—A Study on the Health and Living Conditions of Affected People,” is a partial project of the ISPRM/WHO collaboration plan (2014–2017). It is designed as an exploratory cross-sectional study based on the design of the Swiss Spinal Cord Injury Cohort Study (SwiSCI-Study) of Swiss Paraplegic Research. It provides, for the first time, an overview of the general health situation, medical care, and job situation as well as social participation in Germany. This promotes the recognition of current problems as well as the implementation and control procedures of health and social policy.

For data collection, contact with cooperating partners, namely, the SCI specialized centers, is planned. The existing address database is used to invite those who meet the inclusion criteria. The use of the database will allow for the inclusion of a large number of patients, will probably establish confidence, and could increase the willingness to participate. Included are persons with SCI (traumatic or nontraumatic, including vascular, inflammatory, and tumor-related causes, as well as congenital SCI) who have already completed their first rehabilitation. Study participants must be at least 18 years old and live in Germany. The questionnaire will be available both in German and English.

Data collection is based on a semistandardized questionnaire, which will be Web-based or paper-based, depending on

the preference of the participants. It is also possible to complete the questionnaire with the help of the study staff by calling the study coordinators if an independent completion of the questionnaire is not possible owing to a functional limitation.

The cooperating SCI centers will send the study documents to their clients, including an invitation to participation in the study, subscriber information, the questionnaire, a Web link, and an online access code for the possibility of Web-based completion, and a return envelope. Study participants will decide which form—paper or online-based—they will use. Participating in the study means completing and sending the questionnaire to the center of the study, and participants agree to follow the study conditions. A written reminder will be sent 4 to 6 weeks after the first letter, depending on the response rate. If the online-based questionnaire is not completed in full, these incomplete questionnaires can be identified by the ID number. The cooperating partners then will inform the study participants again.

CONCLUSION

The improved medical care and social response allowed an independent and integrated life in Germany, even with spinal cord injury. Legal regulations make the realization of appropriate care possible, so that medical care as well as social participation is ensured. However, it is still unknown whether these regulations are being implemented. Furthermore, there is no reliable data about the subjective health or life situation of affected people. The planned study should offer a very first overview about the current situation and could be used to provide a hypothesis and to initiate new research projects.

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