People with Spinal Cord Injury in China

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN CHINA

Only sparse epidemiological data on spinal cord injury (SCI) in mainland China is available. Epidemiological studies are predominantly based on retrospective chart reviews of selected hospitals in particular regions and cities. Prevalence data are currently not available and studies of nontraumatic SCI are largely lacking. China has no central registry for SCI. However, a nationwide trauma registry comprising all military hospitals exists.

Estimates of the incidence of SCI exist for Beijing,[1] Shanghai,[2] and Tianjin.[3,4] Incidence rates ranged from 23.7 per million (Tianjin[3]) and 25 per million (Shanghai[2]) between 2004 and 2008 to 60 per million in Beijing.[1]

Evidence suggests that the incidence of SCI in China increased dramatically during the past decade. A study based on data of the aforementioned trauma registry found a staggering increase of spinal trauma in the period from 2001 to 2007, which was mainly due to an increase of spinal trauma due to motor vehicle crashes and falls.[5] Spinal trauma accounted for 4.68% of all trauma cases, and SCI accounted for 0.74%.[5] A similar trend was found by Ning et al.[3] for the annual incidence of traumatic SCI in Tianjin between 2004 and 2008 based on a retrospective chart review of 15 tertiary hospitals able to treat traumatic SCI. Yang et al.[6] found that the percentage of patients hospitalized in second grade A hospitals located in Guangdong China increased from 7% to 14% from 2003 to 2011.

As in many other countries, males are more likely to have a traumatic SCI than women.[1,3–5,7,8] Male-to-female ratios ranged from 3.1:1 in Beijing[1] to 5.6:1 in Tianjin.[3] The mean age ranged from 41.7 years (SD not reported) in Beijing[1] to mean (SD) 46.0 (14.2) years in Tianjin,[3] with the largest proportion in the age group between 30 and 50 years. Several studies also reported on the occupational status at injury suggesting that most of patients with SCI are unemployed persons,[4] peasants,[1,8,9] or workers.[6]

Only one study from Guangdong reported on nontraumatic SCI[6] indicating a proportion of 10% of nontraumatic cases of all known causes. Main etiologies of nontraumatic SCI in this study were ossification, spinal degeneration, tumors, and inflammation.

Leading etiologies of traumatic SCI were reported to be motor vehicle accidents and falls, both from a height and trivial falls. Evidence suggests that high falls particularly occur in men and in younger age groups, whereas trivial falls are the leading cause of traumatic SCI in the elderly.[3,4,8] Notably, several studies report a relatively high proportion of SCI due to being hit by falling objects ranging from 4.9%[8] to 19.5%,[6] probably related to work accidents and natural disasters such as earthquakes.

Apart from one study from Beijing, which reported the highest proportion of SCI to have lumbosacral lesions,[1] all other studies report the highest proportion of patients with cervical lesions ranging from 44.4% in Guangdong[6] to more than 80% in Tianjin.[4] Most lesions seem to be complete, with American Spinal Injury Association (ASIA) Impairment Scale (AIS) Grade A accounting for up to 32%.[4]

No estimates for the life expectancy of people with SCI are available for study, and only few studies on mortality after SCI have been conducted. A study from Shang[10] followed 131 patients with cervical SCI between 2004 and 2012 in Jinan, 11 (8.40%) died, of which nine were males. Leading cause of death was respiratory failure. Ning et al.[3] looked at in-patient mortality of patients with SCI admitted to hospitals in Tianjin between 2004 and 2008. Twelve patients (1.4% of admitted cases) died; all were tetraplegics, and the leading cause (92 %) was respiratory failure.

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

Patients with SCI are transferred to the nearest hospital within 8 hours after injury in urban areas, whereas in some rural areas, it takes more than one day transferring to a hospital, which is capable of managing patients with SCI. Acute care mainly depends on professional knowledge and the skills of physicians and nurses. Multidisciplinary cooperation between emergency department, neurology department, and rehabilitation department is common in China and helps to provide better treatment during in-patient periods. Nonetheless, postacute SCI rehabilitation in China still has its limitations, that is, some patients are referred to rehabilitation only 2 to 3 months after the acute phase owing to the limited understanding of the importance of postacute rehabilitation. In-patient rehabilitation, which usually lasts for 1 to 2 months mainly, includes physical and occupational

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therapy. Patients are discharged from hospitals and go back to the community when they acquired basic skills of daily living or complications have been cured. Readmission due to complications occurs frequently.

LIVING WITH SCI

Life after SCI in China is not well researched. Only one study on labor market participation of people with SCI living in China was available. The study from Xu et al.[11] followed 161 traumatic patients with SCI from Guangdong for 18 months after injury. The re-employment rate was 31% (80% full time, 20% part time) with a 4.4:1 ratio of paraplegia to tetraplegia.

THE HEALTH AND REHABILITATION SYSTEM

China has recently faced rapid economic growth and its estimated gross national income per head was $11,860 international purchasing power parity in 2013 of which $646 (international purchasing power parity) was spent on health care expenditure per inhabitant. Approximately 44% of health care expenditure was private in 2013 mostly involving out-of-pocket payments (76.7%). The life expectancy of both sexes has increased considerably from 69 years in 1990 to an estimated 75 years with a healthy life expectancy of 68 years in 2013.[12]

In 2009, China had approximately 15 physicians, 15 nurses and midwives, and 42 hospital beds per 10,000 population.[12] The Chinese health system faces challenges, in particular owing to a dramatic rise in noncommunicable disease in recent years resulting from an aging population, increasing income, and urbanization.[13] It is envisioned to achieve universal health coverage by 2020 involving different strategies such as consolidating the fragmented social health insurance schemes to achieve equitable access, investing in training of general practitioners to improve the quality of primary health care delivery, enhancing health system's monitoring capacity, and strengthening the production of evidence to inform clinical decision making.[14]

China has increased investments in clinical rehabilitation massively after the 2008 Wenchuan earthquake.[15] However, those have been mainly concentrated on urban areas.

WHAT IS THE STATE OF SPECIALIZED CARE?

In urban areas, specialized care for persons with SCI is provided in sufficient amounts, and appropriate treatments and devices are available. This is, however, less so in rural areas as well as in economically less developed provinces of China. A major problem regarding SCI treatment in China is that patients are often lost to follow-up upon return to the community, and continuous specialized health care is hardly provided. Additionally, psychological and vocational rehabilitation is rarely provided. Peer counseling is not well developed in China as is professional personal assistance. Thus, caring for and financing of persons with SCI largely depend on their relatives after discharge from in-patient rehabilitation.

THE SOCIAL RESPONSE TO SCI

In 1988, China founded the Chinese Disabled Persons Federation, which is the national umbrella organization for persons with different kinds of disability. China has also signed the United Nations Convention on the Rights of Persons with Disability in 2007 and ratified it in 2008 by revising and amending the 1990 Law on the Protection of Persons with Disabilities (signed by President Jintao Hu on April 24, 2008, and entered into force on July 1, 2008).[16] This law encompasses comprehensive provisions regarding rehabilitation, education, employment, cultural life, social security, and accessibility. Its implementation in practice is, however, another issue and has not been researched to our knowledge.

In China, most recently constructed government buildings, that is, museums, theaters, schools/universities, and hospitals as well as public facilities like subways are well accessible in most cities, but other buildings open to the public such as restaurants or shops and private buildings are not. Moreover, sidewalks are often difficult to maneuver in a wheelchair and streets difficult to cross.

The situation regarding attitudes toward disability and discrimination in employment and in social and community life is unclear owing to lack of research on these issues. Our understanding, however, is that employment is often difficult to find for persons with SCI.

RATIONALE OF THE STUDY

Whereas limited epidemiological data on SCI are available for specific cities and regions of China, research on the lived experience of persons with SCI living in the community, in particular, with regard to activity limitations, participation restrictions, and influencing environmental factors with regard to the International Classification of Functioning, Disability and Health (ICF)[17] as well as quality of life, is, with the exception of some studies on small groups of spinal cord–injured earthquake victims,[18,19] virtually nonexistent. Problems and needs of community dwelling persons with SCI are thus largely unknown for China. To identify the former is, however, a necessary condition to provide respective interventions on the services and policy level.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

The objective of the Chinese SCI Survey of the InSCI survey is to obtain basic epidemiological data and to better understand functioning, social integration, living situation, health care, and quality of life of persons with SCI in China and in comparison to other countries. Based on the results, the authors expect to trigger a policy dialogue in China to improve the living situation of persons with SCI.

THE NATIONAL STUDY PROTOCOL

Design and Ethical Procedures

This is a cross-sectional observational study with the possibility of follow-up after 5 years as indicated by the general design of the International SCI survey.[20]

The study will be conducted according to the principles of the Declaration of Helsinki. The study protocol has been approved by the provincial ethical review boards of Jiangsu,

Yunnan, and Sichuan Province located at the respective provincial hospitals.

Setting

Three provinces representing different levels of economic development within mainland China have been purposefully selected to be able to compare the situation of people with SCI across provinces with differential economic resources: Jiangsu, Yunnan, and Sichuan Province (Fig. 1). Jiangsu province is located northeast of China and with a per capita gross domestic product (GDP) of 14,105 USD in 2014 is one of the higher resourced provinces of China. With a population of approximately 80 million living on an area of 102,600 km^2, it is relatively densely populated. Jiangsu is ethnically homogeneous, with Han Chinese comprising 99.6% of the population.[21] In contrast, Yunnan Province located in the southwest of China is less economically developed (2013 per capita GDP of 4,156 USD) and less densely populated (approximately 46 million population on an area of 394,000 km^2). It is also ethnically more heterogeneous, with Han Chinese making up only approximately 67% of the population.[22] Sichuan Province is located in the middle west of China. It has 81 million inhabitants on an area of 485,000 km^2. It is more economically developed than Yunnan but less than Jiangsu (5,728 USD per capita GDP). Han Chinese make up approximately 95% of the population.[23] Sichuan is also interesting because it is prone to natural disasters, in particular, earthquakes, with the 2008 major Wenchuan earthquake being the most significant.[15]

Eligibility Criteria

Eligibility criteria largely follow the recommendations of the overall InSCI study protocol.[20]

Eligible will be adults aged 18 years or older having sustained a traumatic SCI (including cauda equina syndrome), or SCI of certain nontraumatic etiologies, including vascular causes, infections, and benign tumors. Eligible subjects should be residents of China, able to respond in Mandarin Chinese or one of the dialects with which the interviewers are familiar, and having provided informed consent. Included furthermore are only patients of which electronic records in the succeeding specified databases are available (mostly those having sustained SCI in the past 10 years). Excluded are persons with congenital etiologies, such as spina bifida as well as progressive etiologies, such as autoimmune diseases, malignant tumors, toxic agents, radiation; multiple sclerosis; amyotrophic lateral sclerosis; or peripheral nerve damage, such as Guillain Barré syndrome. Persons who are in-patients receiving first rehabilitation at the time of the study are also excluded.

Sampling Frame

The sampling frame (Fig. 2) will primarily follow the hierarchically organized Chinese hospital system. In China, three levels of hospitals exist with level 3 hospitals (province level) providing the most specialist care according to highest standards. Moreover, it is envisioned to use available data from the Chinese Disabled Persons Federation (CDPF) of the participating provinces.

FIGURE 1. Geographical location of Jiangsu (left), Yunnan (right), and Sichuan (bottom left) within the People's Republic of China (source: wikipedia.org).

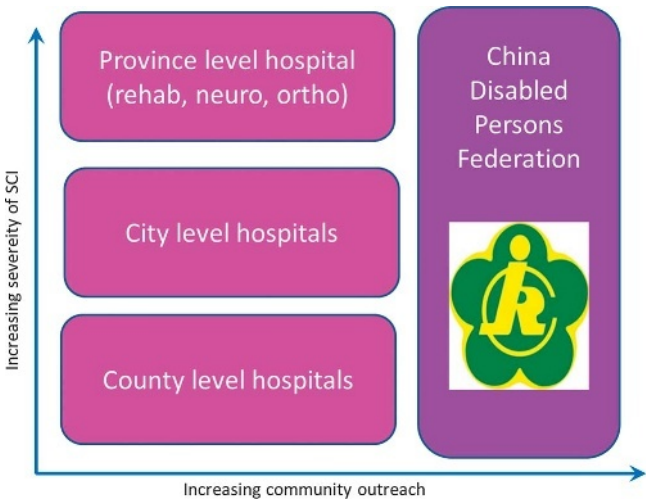

FIGURE 2. Sampling frame.

In each province, at least one provincial hospital, one city level hospital, and one county level hospital will be selected. The rationale behind this is to capture cases of different severity, as more severe cases are usually referred to higher-level hospitals. Moreover, the provincial disabled persons federations (DPFs) will be contacted to identify SCI cases from their databases. People with particular health conditions can apply for disability benefits at DPF.

In Jiangsu province, potential survey participants will be identified through combining databases from the Jiangsu Province Hospital's rehabilitation orthopedic and neurological ward, the International Tongren Rehabilitation Hospital, the Wuxi Rehabilitation Hospital, the Xuzhou Rehabilitation Hospital at the city level, the Zhoushi Community Hospital in Suzhou at the county level, and the Jiangsu Disabled Persons Federation.

In Yunnan, the Yunnan Province Hospital, the Zhaotong People's Hospital at city level, the Ludian Hospital at county level, and the Yunnan Disabled Persons Federation are envisioned sources of cases.

In Sichuan, the West China (Huaxi) Hospital at province level, the Mianyang Hospital at city level, and the Mianzhu People's Hospital at county level and the Sichuan Disabled Persons Federation have been envisioned as data sources.

In all provinces, potential SCI cases will be identified by searching the respective databases for relevant ICD codes[20] and SCI related keywords in Mandarin such as "spinal cord", "paraplegia", etc.

If necessary, charts will be reviewed in detail. Data on contact details (addresses and telephone numbers) of eligible cases will be extracted. Moreover, where applicable data on demographics (age, sex, education, and marital status) and SCI characteristics (level of lesion, etiology, rehabilitation [yes/no], date of onset, spinal stabilization method [surgical vs conservative]) will also be extracted, in particular, with respect to later analysis of unit nonresponse. Finally, the patients' Chinese national ID number will be extracted to serve as local unique and stable case identifier.

Data extracted from different sources will be combined in a new database and duplicates identified.

Recruitment Strategies and Reminder Management

Featuring posters of the upcoming survey in the participating hospitals and offices of the CDPF will sensitize the source population. Information on the upcoming survey will also be posted on the hospitals' and CDPF's website. Eventually, popular social media in China such as Weibo, QQ, and Wechat will be used.

Initial contact with the potential study participants identified from the databases as previously specified will be made by telephone. Informed consent will be obtained verbally and recorded. Per request of the participants, different data collection methods as detailed later will be offered.

Two reminders of participants who have not responded at 1 and 2 months, respectively, after dispatch of the mailed survey invitation are planned. The first reminder will be by mobile text message and the second reminder by telephone call. Up to five attempts to reach potential participants by telephone will be made before a case is considered a nonresponder. The telephone contact attempts also serve the inclusion of illiterate persons in the study.

Real-time monitoring of response based on a tracking system in the central local database will be used to identify persons who have not responded at predefined dates to accurately target the reminders.

To increase the response rate, a lottery among survey participants will be announced within which three iPads can be won.

A sample size of approximately 2,000 participants is envisioned. Given that we aim to extract data from three provinces including three major provincial hospitals, four city level hospitals, and four county level hospitals as well as provincial DPFs, this is a rather conservative estimate. Provincial hospitals alone usually treat at least 200 cases of SCI per year, which adds up to 6,000 cases for the past 10 years. A sample size of 2,000 means that we would be able to recruit one third of this population.

Data Model and Questionnaire

The data model and questionnaire follow the InSCI standard as detailed in an accompanying paper.[24] The data model is primarily based on ICF[17] and the ICF core sets for SCI for the long-term context.[25] The questionnaire in English has been translated into simplified Mandarin Chinese (Hanyu) by two members of the national study team (Y.Z. and S.L.). In case of disagreement, a third member of the study team (X.L.) was consulted. Finally, the questionnaire was again reviewed by a fourth author who is a US citizen but has been born and raised in China (H.L.). All Chinese-speaking authors approved the final translation.

Data Collection

Data will be collected by mixed modes. Participants can choose to fill a paper-pencil or an app-based online version of the questionnaire. In addition, telephone interviews and visits at the participating hospitals for face-to-face interviews will also be offered. This is of particular importance to include illiterate persons and the elderly. Telephone and face-to-face

interviews will be computer assisted using the online data-entry tool.

Data Management

A local database with contact information, demographics, and SCI characteristics as extracted from the databases of the participating institutions will be established and hosted on the servers of the participating provincial hospitals. The Chinese national ID number will serve as the unique and stable person identifier. The local database will be password protected. There will be three levels of data input and access: (level 1) database access for student assistants and study nurses who are responsible for data input, for example, response status (permission for writing of data), (level 2) database access for two supervisors for each site (permission for reading and writing of data for site-specific database), and (level 3) database access to national study leader (permission for reading and writing for all data). Automated data backup on a second server will be performed on a daily basis.

In this local database, each local ID will be linked with a unique international survey ID provided by the international study center. A standard operating procedure for linking the local ID with the international ID will be developed. This unique international ID will be printed on the paper and pencil questionnaires and also be used for online data entry.

Anonymous survey data will be hosted by Swiss Paraplegic Research in Nottwil, Switzerland, which guarantees full-data confidentiality and security.

Data from paper-pencil questionnaires will be entered into the online system provided by Swiss Paraplegic Research. Two assistants will independently enter data from each questionnaire. Inconsistencies will be resolved by reviewing the original questionnaire or consultation of the responsible study supervisor. Swiss Paraplegic Research will provide the Chinese study team with a standard operating procedure for data entry.

Paper-pencil questionnaires will be sorted by international ID and filed. Apart from data entry (at hospital), they will be locked in the hospitals' archives at all times.

CONCLUSION

The upcoming study will be the first comprehensive research on functioning and living conditions of people with SCI in China. The study will provide an opportunity for discovering unmet needs of people with SCI with regard to functioning including social participation, health care, and environmental factors based on which a policy dialogue can be started to improve the living conditions of people with SCI in China. The contact database built for the purpose of this study can be used for regular follow-up and monitoring of future interventions. It is also envisioned that additional hospitals and provinces will participate in future repetitions of the survey.

REFERENCES

1. Li J, Liu G, Zheng Y, et al: The epidemiological survey of acute traumatic spinal cord injury (ATSCI) of 2002 in Beijing municipality. *Spinal Cord* 2011;49:777–82
2. Pan JLX, Zeng C, Qian L, et al: Retrospective study of acute spinal cord injury between 2005 and 2007 in Pudong New Area, Shanghai. *Journal of Tongji University* 2009;30:131–5
3. Ning GZ, Yu TQ, Feng SQ, et al: Epidemiology of traumatic spinal cord injury in Tianjin, China. *Spinal cord* 2011;49:386–90
4. Feng HY, Ning GZ, Feng SQ, et al: Epidemiological profile of 239 traumatic spinal cord injury cases over a period of 12 years in Tianjin, China. *J Spinal Cord Med* 2011;34:388–94
5. Liu P, Yao Y, Liu MY, et al: Spinal trauma in mainland China from 2001 to 2007: an epidemiological study based on a nationwide database. *Spine (Phila Pa 1976)* 2012;37:1310–5
6. Yang R, Guo L, Wang P, et al: Epidemiology of spinal cord injuries and risk factors for complete injuries in Guangdong, China: a retrospective study. *PloS One* 2014;9:e84733
7. WHO: *International Perspectives on Spinal Cord Injury*. Geneva, WHO Press, 2013
8. Wu Q, Li YL, Ning GZ, et al: Epidemiology of traumatic cervical spinal cord injury in Tianjin, China. *Spinal cord* 2012;50:740–4
9. Wang HF, Yin ZS, Chen Y, et al: Epidemiological features of traumatic spinal cord injury in Anhui Province, China. *Spinal Cord* 2013;51:20–2
10. Shang MFYD, Wang R, Zhao TB: Clinical research of early death in cervical spinal cord injury. *TheJournal of Cervicodynia and Lumbodynia* 2013;34:181–3
11. Xu YW, Lam CS, Tang D: Contributors of return to work for a cohort of spinal cord injured workers. *Chin J Rehabil Theory Pract* 2010;16:678–82
12. WHO: China: WHO statistical profile. 2015. Available at: http://www.who.int/gho/countries/chn.pdf?ua=1. Accessed May 30, 2016
13. Yang G, Wang Y, Zeng Y, et al: Rapid health transition in China, 1990-2010: findings from the Global Burden of Disease Study 2010. *Lancet* 2013;381:1987–2015
14. Meng Q, Fang H, Liu X, et al: Consolidating the social health insurance schemes in China: towards an equitable and efficient health system. *Lancet* 2015;386:1484–92
15. Zhang X, Reinhardt JD, Gosney JE, et al: The NHV rehabilitation services program improves long-term physical functioning in survivors of the 2008 Sichuan earthquake: a longitudinal quasi experiment. *PLoS One* 2013;8:e53995
16. CDPF: Chinese Law on the Protection of People with Disabilities. 2008. Available at: http://www.cdpf.org.cn/english/Resources/lawsregulations/201603/t20160303_542879.shtml. Accessed June 14, 2016
17. WHO: *International Classification of Functioning Disability and Health*. Geneva, WHO Press, 2001
18. Hu X, Zhang X, Gosney JE, et al: Analysis of functional status, quality of life and community integration in earthquake survivors with spinal cord injury at hospital discharge and one-year follow-up in the community. *J Rehabil Med* 2012;44:200–5
19. Li Y, Reinhardt JD, Gosney JE, et al: Evaluation of functional outcomes of physical rehabilitation and medical complications in spinal cord injury victims of the Sichuan earthquake. *J Rehabil Med* 2012;44:534–40
20. Gross-Hemmi MH, Post MWM, Ehrmann C, et al: Study protocol of the International Spinal Cord Injury (InSCI) Community Survey. *Am J Phys Med Rehabil* 2017;96(Suppl):S23–34
21. Wikipedia article: Jiangsu. 2016. Available at: https://en.wikipedia.org/wiki/Jiangsu. Accessed June 6, 2016
22. Wikipedia article: Yunnan. 2016. Available at: https://en.wikipedia.org/wiki/Yunnan. Accessed June 6, 2016
23. Wikipedia article: Sichuan. 2016. Available at: https://en.wikipedia.org/wiki/Sichuan. Accessed August 29, 2016
24. Fekete C, Post MWM, Bickenbach J, et al: A structured approach to capture the lived experience of spinal cord injury: data model and questionnaire of the International Spinal Cord Injury Community Survey. *Am J Phys Med Rehabil* 2017;96(Suppl):S5–16
25. Cieza A, Kirchberger I, Biering-Sørensen F, et al: ICF Core Sets for individuals with spinal cord injury in the long-term context. *Spinal Cord* 2010;48:305–12