

People with Spinal Cord Injury in Republic of South Africa

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EPIDEMIOLOGY OF SPINAL CORD INJURY IN REPUBLIC OF SOUTH AFRICA

In South Africa, epidemiological data on spinal cord injury (SCI) are scarce, partly owing to the lack of a national registry and a coordinated system of care. A recent study by Joseph et al. provided the first population estimates of the incidence of traumatic spinal cord injury (TSCI), reporting a staggering rate of 75.6 per million persons. The main cause of TSCI in South Africa was found to be assault, which accounted for approximately 60% of all cases, followed by transport-related causes (26%) and falls (12%).¹ This recent report provides an optimal platform for prevention because of its population-based design; however, the data only represent the City of Cape Town and not the entire nation of South Africa. The only other epidemiological study of South Africa, conducted 2 decades ago in Johannesburg, found similar mechanisms of injury² but a lower incidence rate that is probably due to the hospital-based design. Taken together, the 2 studies show a disproportionately high incidence of violent injuries in South Africa, compared to the rest of the world, which is believed to be precipitated by the sociopolitical climate.^{2,3} With regard to prevalence and mortality of TSCI, and nontraumatic spinal cord injury, (NTSCI) generally, there are no available reliable reports, although the QuadPara Association of South Africa estimated in 2009 that approximately 50,000 people in South Africa are living with an SCI.⁴

With the restructuring of the health care system in South Africa, moving toward a universal health insurance, it is essential to firmly establish the epidemiological profile of SCI to redistribute resources for improved service delivery. Many gaps concerning the epidemiology of TSCI and NTSCI remain, especially for mortality and life expectancy after SCI.

THE PATIENT JOURNEY THROUGH THE CHAIN OF CARE

The management of SCI in South Africa has transformed tremendously, having moved toward the provision of

comprehensive care of those who survived the initial ordeal. Having said that, only a few of the 9 provinces in South Africa have the organizational capacity and resources to provide a more comprehensive package of care for survivors of SCI. Typically, those in urban settings and those with private health care insurance have access to better care.

Consistent with the acute clinical practice guidelines of managing SCI, in South Africa, acute survivors are first transferred to the closest Level I trauma unit—hospitals with the capacity and expertise to ensure that persons are medically stable.⁵ However, a recent report found that stabilization surgery for newly injured persons is delayed, with 10 days as the average time to surgery after injury. This is likely due to pressure on specialized services such as neurosurgery and orthopedics. Subsequently, this delay resulted in an increased prevalence of pressure ulcers during acute care.⁶

Specialized inpatient rehabilitation is available for both public and private systems. The public-funded center situated in Cape Town manages approximately 420 persons with SCI annually, constituting 40% of all admissions for the year. Owing to the high need of rehabilitation, persons with SCI are often admitted based on factors such as age, potential to benefit optimally from rehabilitation, and motivation. The length of inpatient rehabilitation of those with tetraplegia and paraplegia is 86 and 68 days, respectively.⁷ The benefits of those selected for rehabilitation are evident in their functional independence and experience of becoming reconnected with and integrated in society.^{7,8}

Based on the emerging evidence-based foundation for developing SCI care in South Africa, it is important to aggressively target primary prevention of SCI, followed by secondary prevention of adverse events that may lengthen acute hospital stay in an already pressurized health care system. Additionally, access to comprehensive care to persons with SCI living in rural areas of South Africa needs to be improved.

LIVING WITH SCI

Inaccessibility of the environment had been identified as the chief barrier to social participation and integration of persons with SCI in South Africa. Already in 1982, a time when little legislation concerning the demands of equalizing employment opportunities existed for persons with disabilities,⁹ a coordinated approach between state departments, provincial and local authorities, and private welfare organizations had been proposed to address this need—equalization of opportunities and effective participation—among persons with SCI. Now, more than 30 years later, the same challenges, including accessibility of the environment and the lack of recreational facilities and transport, persist today with no SCI-specific employment legislation in place. A recent qualitative study

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by Joseph et al. focusing on the path to *participation* of long-term survivors of TSCI found that participants acknowledged that barriers are always present and *participation* and integration depended on the ability of dealing with the “new-self,” negotiating challenges, identifying facilitators, and becoming an agent.¹⁰ Survivors of SCI generally expressed their need to be seen as equals in society, people who can contribute in a meaningful way, and people who would like responsibility and not only rights. This understanding is, however, not always observed in the able-bodied persons of society. Participants further expressed that their personal relationships are affected after an SCI, owing to the fact that the consequences of injury can negatively affect intimacy, mobility, and energy. Survivors of SCI further describe their involvement in community life as much less than in the past, mainly due to physical barriers, lack of adequate transport, and negative attitudes of the general population.¹⁰

THE HEALTH AND REHABILITATION SYSTEM

In South Africa, both public- and private-funded health care systems are available, with approximately 80% of South Africans using the public system. The public health care system of South Africa has undergone radical changes after 1994 in the aftermath of apartheid, with core principles and concepts focusing on the availability of health care as a basic human right and having access to affordable care that is of quality. Primary health care has been identified as the primary vehicle for health services delivery (especially to those in rural areas), with rehabilitation as an important component of the primary health care service.¹¹ It is against this backdrop that the National Rehabilitation Policy was developed and published in 2000.¹² A national report of 2014 revealed that 94% of persons with private medical aid were very satisfied with services and facilities compared to only 60% using public care.¹³ A recent community-based study by Maart and Jelsma¹⁴ concerning access to public health and medical rehabilitation services found a high percentage of unmet rehabilitation needs. The proportion of unmet needs for services was as follows: 54% for home-based care; 34.5% for assistive devices; 28.9% for medical rehabilitation services; and 2.5% for health services. The main problems with accessing services included inadequate finances (71%) and transport problems (72%).

WHAT IS THE STATE OF SPECIALIZED CARE?

Specialized health care and SCI rehabilitation services in the larger urban areas are available, although the public sector has major transport problems.¹² There are also large discrepancies between the public and the privately funded SCI sector regarding accessibility: there are only a few public SCI rehabilitation centers and even fewer public acute SCI care facilities, while multiple privately funded rehabilitation and acute care centers are available throughout the country. Owing to the lack of specialized SCI health and rehabilitation services in other areas of the country, patients are screened based on their potential to benefit, with the result that not all spinal cord-injured persons will receive specialized rehabilitation. Recently, the country made available an Integrated Disability

Management and Rehabilitation Pathway document indicating that persons with SCI should receive adequate acute care, followed by 15 to 90 days of high-intensity rehabilitation. Furthermore, outpatient rehabilitation should be received between 1 and 3 hours per week, focusing on individualized goals and development of strategies to facilitate integration and social participation.¹⁵

Assistive technology is available to people with SCI, but this differs from facility to facility, with excellent services being available at some and, mostly in rural areas, no available budget for assistive devices. Training in the use of assistive devices occurs, but this is still in the developmental stages. Furthermore, national wheelchair-seating guidelines are available, and most therapists working with SCI and other neurological health conditions are encouraged and subsidized to complete these courses that are offered at a basic, intermediate, or advanced level. Concerning peer support for newly injured survivors of SCI, this model had been found to assist acute survivors to make a positive adjustment in the light of the new body; however, rehabilitation centers are no longer able to afford the appointment of this level worker. In a recent qualitative study, participants, including founders of nonprofit organizations, expressed the need to continue this service and counseling platform, since survivors are more willing to share their stories with their peer that made a positive adjustment to life.¹⁰

THE SOCIAL RESPONSE TO SCI

South Africa developed its own National Rehabilitation Policy and ratified the UN Convention on the Rights of Persons with Disabilities in November 2007, with the focus of promoting, protecting, and ensuring the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities. South Africa remains committed to accelerate its national agenda for the progressive realization of rights of persons with disabilities by, among others, strengthening its mainstreamed legislative and policy framework and by accelerating the implementation of policies and programs that aim to provide equal access to persons with disabilities, including disability-specific programs aimed at addressing barriers to participation. Many challenges remain today as survivors of SCI echo the inaccessibility of public spaces, for example, lack of elevators at train stations and the narrow aisle of supermarkets. Public transport is another major issue, since the lack of accessible transport resulted in numerous survivors not being able to attend health and rehabilitation appointments or their jobs.¹⁰ Another issue that persists is the portrayal of negative attitudes toward persons with SCI and disability in general. A need exists to sensitize the public toward inclusion of persons with disabilities as equal members of society. Concerning prevention of SCI, 3 SCI-related campaigns have been launched, one for diving accidents,¹⁶ one accentuating the use of seatbelts and road safety,¹⁷ and the other the BokSmart National Rugby Safety Programme (rugby-related).¹⁸ We have seen a low incidence of diving and sport-related injuries in the latest epidemiological study.¹ However, no local or national campaign concerning the main cause of injury, namely, assault (gunshot and stabs), has been launched.

THE INTERNATIONAL SPINAL CORD INJURY (InSCI) COMMUNITY SURVEY

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

Limited research investigating health and functioning of survivors of SCI has been conducted in South Africa. A description of TSCI in South Africa is emerging, whereas little remains known about NTSCI. Participating in the InSCI Survey affords the opportunity to gain information on the health and rehabilitation requirements to respond to the unmet needs of survivors of SCI. The survey items for this purpose were selected from current criterion standard measures in the SCI field, which cover the entire spectrum of ICF domains and the prototypical aspects often altered after injury. Furthermore, having other countries, both high- and middle-income participating in this endeavor, much is to be learned about the successes of restructuring and reallocating resources for survivors of SCI. Our team that consists of academics, clinicians, consumers of health services, and the management of the South African Spinal Cord Association has a clear vision of promoting and ensuring full participation, and is committed to improving the lives of those with SCI. We will further use other data sets for SCI to gain a broader perspective on functioning and the needs of survivors in South Africa. We remain confident that our participation in this study may contribute to the long-term aim of developing a national competence guideline for SCI care in South Africa.

THE NATIONAL STUDY PROTOCOL

We plan to include the entire sample from an ongoing regional population-based epidemiological study in Cape Town, South Africa, among survivors of TSCI. With the start of the International Survey in 2017, this cohort will be 3 years after injury, providing the additional benefit of investigating mortality and factors affecting it, data that are much needed for South Africa. In addition, we will recruit eligible participants from Pretoria, Durban, and the Eastern Cape, which is likely to represent the SCI population in South Africa. This sampling frame will result in the recruitment of survivors from urban, periurban, and rural localities, which will account for the presence or absence of health care services both with regard to accessibility and quality. Furthermore, the recruitment of subjects from these provinces will ensure variation with regard to personal factors, such as ethnicity and socioeconomic status, which need to be addressed within the South African context. We will include adults with TSCI, older than 18 years, surviving 3 years or more. We will also endeavor to include a sample that received private medical care with the same inclusion criteria.

Since knowledge available on NTSCI in South Africa is limited, we strive to retrospectively and prospectively learn concerning its epidemiology. Similarly, inclusion of participants will be based on survival time after diagnosis. We will also include the centers in the 4 provinces.

Contact details of eligible participants will be retrieved from the hospital records, upon approval of the study, and participants will be contacted by telephone to ascertain their intention to participate. Owing to the numerous official languages spoken in South Africa, and high levels of illiteracy (because

of no education), participants will be asked to complete the questionnaire in their preferred language and whether a proxy will be available to assist with its completion. Questionnaires will be sent to participants via postal mail, and 2 to 4 weeks will be given to return completed measures to the Secretary of the South Africa Spinal Cord Association in Durban, where it will be safely stored in accordance with good practice.

CONCLUSION

The South African Department of Health adopted various frameworks and policies to ensure the health and well-being of those with disabilities. This is further evident with the establishment of a limited number of specialized acute and rehabilitation facilities in the country. However, these services are not easily accessible for persons residing in rural areas. It is promising to see the first reports of TSCI epidemiology in a region in South Africa, which could be used to advocate for the adequate distribution of resources and facilities. To date, no epidemiological data are available for the rest of the country (8 of the 9 provinces) and none for NTSCI, which are thought to be on the rise. More studies are needed, especially in the rural areas, to investigate aspects concerning access to health and rehabilitation care, long-term unmet needs, and participation and integration. Participation in this international project may be the platform that is required for strengthening the health care system for SCI in South Africa.

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