



# Surveillance of traumatic spinal cord injury in Australia: the identification of information needs

CE Blumer and S Quine

*Department of Public Health, University of Sydney, Australia*

Monitoring the occurrence of disease through any surveillance program necessarily requires the expenditure of scarce resources. The type of information accessible through surveillance and how it may be obtained deserve careful consideration in order to justify these costs. Therefore before establishing a new system of surveillance it is advisable to ascertain the information needs of potential users and to determine the feasibility of developing a system to meet them. As part of the planning for a national traumatic spinal cord injury surveillance system in Australia these data were sought by conducting a survey of key informants in 1993. The planning and evaluation of health care services, a knowledge of spinal cord injury epidemiology and its sequelae, injury prevention, external demands for information, and facilitation of research, were identified as the most important needs for information. It has been shown that the prevalence of spinal cord injury in Australia is increasing. As this occurs the need for specialised health services will also rise. Therefore, to facilitate the rational planning of services, and to monitor the well-being of the Australian spinal cord injured population, accurate surveillance data are essential.

**Keywords:** spinal cord injuries; surveillance; Australia; survey; health services

## Introduction

Traumatic spinal cord injury (SCI) is a devastating injury, which affects mostly young people in their prime. In Australia in 1987 the incidence of SCI was 25 per million, and just over 400 new cases each year were added to the prevalent population of 6000.<sup>1</sup> Although by 1991 the incidence rate had declined to 15 cases per million,<sup>2</sup> the prevalence of this condition has continued to increase because of increases in survival; paraplegics and quadriplegics may now expect to live for 30 years following their injury.<sup>3</sup> During this time they are a group at high risk of experiencing further morbidity. A knowledge of the size and character of SCI populations and their rate of growth is clearly desirable so that their impacts on the health system may be monitored.

Overseas, the theme of increasing health needs has been discussed by DeJong and Batavia, in their argument for the development of a health services research capacity in SCI. They emphasize the need for an integrated system of service provision, which can assure continuity in the provision of care.<sup>4</sup> In a review of surveillance systems in the United States, Harrison and Dijkers also recognise the role that surveillance can play in facilitating the coordination of health and other services for people with SCI.<sup>5</sup>

DeJong and Batavia observe that the development of services for SCI people living in the community lags behind the organisation of services concerned with the

acute treatment and rehabilitation of recently injured persons.<sup>4</sup> These authors further refer to the tendency for SCI research to focus on the 'front end' of treatment. As an example the report of Price, Makintubee, Herndon *et al* cites the incidence and the costs of acute and rehabilitative care in Oklahoma. They report that these costs were only a small proportion of the total cost of SCI, but there is no consideration of the already existing impact of the prevalent population, nor of its long-term consequences.<sup>6</sup>

Surveillance can be used to assess the needs of a prevalent SCI population, as demonstrated through the recent work of Gerhart, Johnson, and Whiteneck, who used the Colorado surveillance program to follow-up the well-being of people with incomplete SCI living in that State.<sup>7</sup> Thurman, Burnett, Jeppson *et al* also identify the use of surveillance in the evaluation of prevention programs in addition to its role in indicating areas of aetiology that may be researched in more detail.<sup>8</sup>

In Australia spinal units are based on the model developed by Guttmann in Britain during the 1940s. The first spinal unit was established in Perth in 1954.<sup>9</sup> Currently there are six units, which are situated in five of the six State capital cities; Adelaide, Brisbane, Melbourne, Perth and Sydney (with two). Containing 250 beds in total, the units provide the acute care for nearly all people sustaining traumatic SCI in Australia. Rehabilitative care for patients from three of the spinal units is provided at the same site, and for

Correspondence: Charles Blumer, Department of Public Health, A27, University of Sydney, Sydney, NSW 2006, Australia

patients from the other three units this care is provided at a separate metropolitan site. Five of the six rehabilitation services are directed by the spinal unit director and, at the time of the survey, the sixth rehabilitation service was under the direction of a former spinal unit director. No other SCI orientated rehabilitation services exist.

Although people with SCI might use the physiotherapy or clinical services of other hospitals, which may be rural, none of these services possess any specialist knowledge of SCI, or have links to the spinal units. Thus, for people with SCI, experience of complications will usually result in their readmission to one of the six spinal units. Finally, a number of national and State community support groups provide community and advocacy services, and supply equipment to people with SCI living in the community.

Following the discontinuation of an earlier system of SCI surveillance, due to a lack of ongoing funding and in the absence of any other relevant information base in Australia, a national survey on behalf of the National Injury Surveillance Unit was conducted to explore the needs and views of organisations concerned with the care and well-being of SCI people. The aim of the survey was to ascertain the feasibility and the benefits of establishing a national surveillance system.<sup>10</sup>

## Methods

The National Injury Surveillance Unit, a division of the Australian Institute of Health and Welfare, is responsible for reporting on the occurrence of injury in Australia. In late 1992 the unit funded the Department of Public Health at the University of Sydney to conduct a survey of the needs for information on spinal cord injury.

A semi-structured interview format was developed, and interviews with key informants were conducted in 1993 by one of the authors (CB). These comprised informed individuals prominent in SCI treatment and service provision: directors of all six spinal units and the independent rehabilitation centre (as described above); representatives of the advocacy and SCI

support groups; the person who had developed and managed an earlier system of national SCI surveillance; and State and Commonwealth health department representatives.

Each interview explored the following issues: objectives and benefits of a national surveillance system; how such a system should operate; the specific information needs of individual organisations; and views on the importance of national SCI statistics. This paper presents detailed findings on the specific information needs identified.

## Results

Table 1 shows the stages of recovery that a person with SCI is likely to pass through. For each stage different services are provided by a variety of practitioners, each of whom has differing information needs. Table 1 shows examples of the kinds of measures and indicators that may be used in surveillance. Awareness of this scheme aids the understanding of the various sorts of information that may be sought by the different service providers. Prevention efforts are also services, but aimed at the uninjured community. For people conducting prevention campaigns the incidence and aetiology of SCI are the indicators of most interest.

Eighteen interviews were held, most of which were with one, but some with two or more, key informants ( $n=26$ ). Informants from organisations were asked to present the needs of the organisations they represented, rather than their personal opinions. The interviews obtained information from representatives of: the six spinal units ( $n=8$  interviews), one rehabilitation centre (1), different community support groups (3), State (New South Wales) (1) and Commonwealth (1) health departments, accident research centre (national) (1), an insurance provider (third party compensation, for victims of motor vehicle accidents) (1) and a medical/scientific research foundation (1). The other interview was with John Walsh, who conducted an earlier national Australian system of SCI surveillance, from 1986 until 1992.

From these informants a number of information needs were identified, which could be organised into

**Table 1** Services and measures at each stage of recovery for a person with SCI

<i>Stage</i>	<i>Acute retrieval &amp; initial care</i>	<i>Definitive care and initial rehabilitation</i>	<i>Rehabilitation and reintegration into community</i>	<i>Long-term welfare</i>
Service providers	Emergency services Ambulance service and paramedics	Spinal units Rehabilitation centres	Rehab. centres Support groups Insurance industry	Support & advocacy groups Govt. agencies Insurance groups
Measures and Indicators	Incidence Injury scores Early mortality	Incidence and mortality Prevalence Complication rates Lengths of stay Financial status	Incidence Level of functional independence Outcome measures	Prevalence Complication rate Quality of life Welfare indicators Financial status Survival

five broad areas: (i) service evaluation and planning, (ii) epidemiology, (iii) prevention, (iv) external demands, (v) research.

*(i) Service planning and evaluation*

The need to plan and evaluate services for people with SCI emerged as the most frequently stated information requirement. Service planning was identified at two levels: within the spinal unit where definitive care is provided, and within the community where the long-term well-being of the person with SCI is of most concern.

For example, at the level of the spinal unit the admission policy is determined by the availability of vacant beds. The determination of the appropriate number of beds should reflect the number of acute admissions occurring and the rate of complications in the prevalent population that the unit services. All directors of spinal units said that about half the beds in their units were occupied by cases re-admitted for complications. As the prevalence of the condition increases and the SCI population ages the occurrence of complications requiring hospital care will also increase. This is despite the probable decrease in the incidence of SCI that is occurring in Australia.

As spinal units are accountable to the hospitals within which they are situated information is also required to enable the units' services to be evaluated. There is a need, for example, for spinal units to report routinely on the number of occupied beds, the injury levels and presence of complications in patients occupying the beds, in order to determine or justify staffing levels. The introduction of case-mix (diagnosis-related groups) funding into Australian hospitals (mentioned by two informants) will result in additional pressures for the collection of such information.

One informant reported that in order for spinal units to provide the best possible treatment for patients, information on outcomes should also be obtained. He suggested that the occurrence of future complication rates following discharge might be used to indicate the efficacy of various treatment and preventive regimes used by the different units.

Information to assist in the planning of services for people living with SCI in the community was also frequently mentioned, especially by the support organisations. Key informants from a State health department and disability support groups reported using data from an earlier surveillance system to determine levels of need and to justify various services for people with SCI, such as home care service provision at a local level.

Two of the three support group informants and Walsh believed that the key emerging issue, because of increasing prevalence, is the long-term welfare of people with SCI. A related observation was that, while the needs of people with SCI were well understood, the most urgent information need was

for specific data on occurrence so that appropriate services could be directed towards areas of greater need.

*(ii) Epidemiology*

The epidemiology of SCI was mentioned by several informants across the range of organisations. Aspects mentioned included incidence and prevalence, survival and aetiology. While information on incidence and prevalence is of direct relevance to the planning and evaluation of services, it is desirable also to consider other aspects of the natural history of SCI that are of particular interest. The increasing survival of people who have sustained SCI was mentioned many times. Two informants noted the recent appearance of a cohort of high-level ventilator-dependent quadriplegics.

Two informants referred to variation in aetiology as a further reason for conducting surveillance. In 1992 across Australia for example a larger number of cases than expected among the elderly was cited. Another informant identified variation between the States in the causes of SCI as a means of initiating more detailed aetiological investigations, and to develop locally relevant preventive strategies. One informant however said that the aetiological parameters used should be consistent with those being used in other injury surveillance, such as within hospitals.

A further aspect of SCI epidemiology concerns the high rates of complications experienced by people with SCI, which was identified by seven of the informants. The impact of SCI associated morbidity is a major issue because of the increase in rates as the population ages, and the direct consequences this has for spinal units. The rate of morbidity was also cited as a useful indicator of the general welfare of the prevalent SCI population. Some of these informants also sought more specific information in order to plan service requirements of the population, and to evaluate the efficacy of services in preventing morbidity. Identification of changes in the occurrence of complications, or the emergence of new conditions, so that medical care could be directed accordingly, was also mentioned as a reason to monitor morbidity.

*(iii) Prevention*

The need to prevent SCI was mentioned by a wide range of informants. Aetiological information on SCI was seen as being essential for the conduct of prevention. Three informants judged an earlier surveillance system to have been successful because it provided information on the causes of SCI and thus supported a State-wide preventive program in New South Wales. Three other informants commented that, now that the most obvious risks and measures to counter them, such as motor vehicle accidents and seat-belt wear, have been identified, it is much harder to discern the more subtle risks for SCI, and therefore that there was a need for detailed causal data. A

further informant noted particularly the role of a SCI register in supporting aetiological research, and the work conducted towards that end.<sup>11</sup>

*(iv) External demands*

In addition to the agencies directly concerned with the provision of medical and community/support services, there exists a large range of other users, such as the insurance industry, the National Injury Surveillance Unit, educators in the health sciences, and the media, which request information on the occurrence of SCI. These requests may be described as external demands. Notable among these requestors is the insurance industry because of its role in the compensation of victims of motor vehicle accidents. Trends in incidence, information on the financial well-being of people with SCI, and their life expectancy, were the information needs that were particularly identified.

The National Injury Surveillance Unit also has an interest in information relating to the occurrence of SCI. The main function of the unit is to act as a clearing house for information on all aspects of injury. Because of the large impact of SCI, being able to provide information on trends in its occurrence is therefore an important function that it may fulfil. A further informant, on the collation of national statistics, said that they should be consistent with those reported internationally.

Information required for educational purposes, based on incidence, prevalence and mortality data, was another need that could be identified as external. Such purposes included teaching material in nursing and medical courses, and back-ground data for post-graduate degrees in the health sciences.

*(v) Research*

Several informants remarked on the suitability of the Australian SCI population, which because of its size and the way in which medical care is organised, offers ideal opportunities for research into all aspects of care and the long-term outcomes of people with SCI.

Especially cited were the ease of follow-up, and the ability to relate differing outcomes or levels of well-being to the varying treatment regimes of the six different spinal units. The publication of findings by one of the spinal units, on the results of a new test for the detection of thromboembolic disease, provides a good example.<sup>12</sup>

## Discussion

From the interviews it was apparent that widespread support for a system of surveillance exists, and that a number of important information needs were identified. However, it was also apparent in some responses that the need for surveillance data and research needs, that are based on surveillance data, were not distinguished by respondents. The means of

surveillance envisaged by some informants was a register of people with SCI, which they regarded as also having a use for research, and this may explain the noted lack of distinction between surveillance and research needs.

Wigglesworth, for example, demonstrates this use, of how surveillance data may be used to conduct research. Using a national register of SCI, which primarily was developed to monitor incidence and aetiology, he first identified cases arising from motor vehicle accidents. He then linked these cases to police traffic accident reports, which contained detailed causal information, and hence was able to identify vehicle roll-overs and accidents occurring on rural roads as the predominant causes of motor vehicle accident related SCI.<sup>13</sup> In contrast to research, the aim of surveillance is to monitor, over time, basic information that relates to the cause, occurrence and outcome of SCI.

Amongst the identified needs was information which may be used to prevent SCI. Several informants noted the reliance on surveillance-derived aetiological data of a schools based preventive program.<sup>14</sup> A number of other programs aimed at preventing trauma, including SCI, have been described by Bedbrook, who also emphasised the need to base these programs on aetiological data obtained from surveillance.<sup>15</sup>

However, despite efforts at prevention, SCI will continue to occur, and people whose lives have been so affected are now likely to live for many years with their injury. Although few studies on SCI prevalence have been conducted<sup>16</sup> there is little doubt that the prevalence of SCI in Australia and internationally is increasing.<sup>1,17</sup> It is necessary therefore that the SCI population size, and its rate of increase, are both monitored. Further, as this population is highly vulnerable and experiences high rates of morbidity, the need to monitor the well-being of its members and their health care requirements warrants special attention.<sup>18-20</sup> The needs identified above are supported by the findings in our study, particularly the identification by informants of the increasing needs of the prevalent SCI population.

One other benefit of conducting surveillance of the prevalent population is the possibility of identifying new complications. The prevention and treatment of the most commonly observed complications, such as urinary tract infections and pressure sores, have become routine. However, as the SCI population ages the profile and occurrence of these complications may change, and new complications may appear, which will require description and the development of new prevention and treatment practices.

In Australia the provision of care through six specialised spinal units allows nearly all cases of SCI to be recorded. With coordination amongst the units, and with a well-defined population, it is inherently possible to accurately measure and monitor the rate of SCI and other aspects of its epidemiology in Australia.

## Conclusion

Through this survey, which comprehensively has obtained the views of people concerned with provision of SCI services, wide-ranging support for the establishment of a national system of SCI surveillance in Australia was demonstrated. A number of information demands that justify this support were also identified. A further part of the main survey identified how these differing demands may be met.<sup>10</sup>

In Australia a pilot study to monitor the rate of SCI incidence is currently being conducted, with independent case registers maintained within the six spinal units. These units will also report to a national register for the compilation of national statistics. Given the increasing prevalence of SCI in Australia<sup>1</sup> the need to monitor the long-term welfare of this population is becoming increasingly important. It is recommended that once the incidence monitoring component is established, an integrated surveillance system, which emphasises SCI prevalence and the well-being of people with SCI, should be developed.

The ability to develop such a coordinated system of long-term care for people with SCI is especially promising in Australia because of its small population size, and the centralised system of treatment and care provision that is based within a small number of SCI centres.

Although these findings are based on Australian SCI surveillance needs, they are relevant overseas in that they not only confirm research reported in the international literature, but also extend on it by identifying issues such as the increasing rate of complications, and the impact of this on SCI services, units and people with SCI.

## Acknowledgements

The support for CB to conduct this survey, through a grant from the Australian Institute of Health and Welfare, is gratefully acknowledged. Useful comments on the final draft were received from Dr Peter Lloyd, Department of Public Health and Community Medicine, University of Sydney.

## References

- 1 Walsh J. Costs of spinal cord injury in Australia. *Paraplegia* 1988; **26**: 380–388.
- 2 Walsh J. Actuarial research into physical disability. *QuadCare* (Sydney), Nov 1992.
- 3 DeVivo MJ, Fine PR, Maetz HM, Stover SL. Prevalence of spinal cord injury. *Arch Neurol* 1980; **37**: 707–708.
- 4 DeJong G, Batavia AI. Toward a health services research capacity in spinal cord injury. *Paraplegia* 1991; **29**: 373–389.
- 5 Harrison CL, Dijkers M. Spinal cord injury surveillance in the United States: an overview. *Paraplegia* 1991; **29**: 233–246.
- 6 Price C, Makintube S, Herndon W, Istre GR. Epidemiology of traumatic spinal cord injury and acute hospitalization and rehabilitation charges for spinal cord injuries in Oklahoma, 1988–1990. *Am J Epidemiol* 1994; **139**: 37–47.
- 7 Gerhart KA, Johnson RL, Whiteneck GG. Health and psychosocial issues of individuals with incomplete and resolving spinal cord injuries. *Paraplegia* 1992; **30**: 282–287.
- 8 Thurman DJ, et al. Surveillance of spinal cord injuries in Utah, USA. *Paraplegia* 1994; **32**: 665–669.
- 9 Bedbrook GM. The development and care of spinal cord paralysis (1918 to 1986). *Paraplegia* 1987; **25**: 172–184.
- 10 Blumer CE. A review of the needs and opportunities for the surveillance of spinal cord injury (NSCI-R1). Canberra: Australian Institute of Health, 1995.
- 11 Wigglesworth EC. Towards prevention of spinal cord injury: The role of a national register. *Paraplegia* 1988; **26**: 389–392.
- 12 Engel S, et al. D-dimer in the early diagnosis of thromboembolic disease in acute spinal injuries. *Med J Aust* 1993; **158**: 705–706.
- 13 Wigglesworth EC. Motor vehicle crashes and spinal injury. *Paraplegia* 1992; **30**: 543–549.
- 14 Yeo JD. Prevention of spinal cord injuries in an Australian study (New South Wales). *Paraplegia* 1993; **31**: 759–763.
- 15 Bedbrook GM. Update on spinal cord paralysis: A preventable injury, a surgical challenge? *Aust NZ J Surg* 1991; **61**: 478–481.
- 16 Blumer CE, Quine S. Prevalence of spinal cord injury: An international comparison. *Neuroepidemiology* 1995; **14**(5): 258–268.
- 17 Lasfargues JE, et al. A model for estimating spinal cord injury prevalence in the United States. *Paraplegia* 1995; **33**: 62–68.
- 18 Whiteneck GG, et al. Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992; **30**: 617–630.
- 19 DeVivo MJ, et al. A cross-sectional study of the relationship between age and current health status for persons with spinal cord injuries. *Paraplegia* 1992; **30**: 820–827.
- 20 Brittell CW. Outcomes for spinal cord injury: the long view [editorial]. *J Am Paraplegia Soc* 1992; **15**(1): 1–2.