An E-Journey through the Life Cycle of Spinal Cord Injury

Jane Moon  
*University of Melbourne, Australia*

Graeme K Hart  
*Austin Health, Australia*

Andrew Nunn  
*Austin Health, Australia*

**INTRODUCTION**

Spinal Cord Injury (SCI) is a traumatic condition where there is a high dependency on medical and social support (ABS, 2013). The average life span after injury is around 40 years and the latest review suggests there has been a significant increase in incidences in the age group over 40 years (AIHW, 2010).

Patients with spinal cord injury have long term treatments and rely heavily on medical and social intervention. Evidence suggests that SCI patients constantly return to hospital for treatment for conditions such as urinary tract infections, pneumonia and a range of other conditions (Guilcher et al., 2013; VNI, 2011). The study suggests that a third of traumatic SCI will be hospitalized each year posing a big burden on health expenditure as well as on quality of life (Jaglal et al., 2009).

Over the years of medical treatment, patients accumulate a large set of medical data at a public (Commonwealth, State and Community) and private level. This distributed data are difficult to identify and key information may not be available to clinicians or to patients at the right time and place as clinical data are kept at different databases (Banfield et al., 2013; Pang & Hansen, 2006).

The aim of this current research is to develop a basis for a systematic approach to working with a mass of health information that is currently not mobilized effectively. This research proposes to investigate the life cycle of information generated from SCI and how it can be linked and integrated to collate and make sense of the data relevant to these incidents to see if it can be used predictively to preempt problems and ultimately improve outcomes for patients with SCI.

The focus of this study will be on trauma centres of SCI in Victoria, following through health information generated by patients of SCI from the first injury to discharge. Identifying stakeholders, roles they play and the needs of technology to evolve to share information by all concerned (Pinsonneault, Dakshinamoorthy, Reidel, & Tamblyn, 2012; Pluye et al., 2013).

**BACKGROUND**

**What is Spinal Cord Injury (SCI)?**

Spinal Cord Injury (SCI) is a traumatic condition. The effect of SCI depends on the type of injury. There are two types of injuries: complete and incomplete. Complete injury is a severe injury where there is no voluntary function or sensation bilaterally below the level of the injury. An incomplete injury has some bodily function below the level of the injury with varying degrees of mobility and sensation. Some patients might have no movement but some sensation or vice versa (Boninger et al., 2012; Fehlings, 2013).

The level of injury is very helpful in predicting which part of the body will be affected. The motalities vary depending on the types of injury and the higher the injury toward cervical nerves, the higher will be the dependency on the medical and social support and prolonged rehabilitation (QSCIS, 2010).

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The American Spinal Injury Association (ASIA) Standards (ASIA, 2013) have been widely used to assess motor function of SCI. Spinal cord injuries are divided into largely four sections: cervical (C1 to C7), thoracic (T1 to T12), lumbar (L1 to L5) and sacral nerve (Sarhan, 2012) as can be seen Figure 1.

Table 1 describes conditions and injury sites of cervical and thoracic, as they are the more serious conditions, to give some reflection of the complexity of the condition and how it could relate to the amount of information generated as a patient experiences the effects of SCI (Fehlings, 2013; Kim, Ludwig, Vaccaro. R.A., & Chang, 2008; Lin, 2003; Merritt, Rowland, & Pedley, 2010).

Australian Institute of Health Welfare survey over period 2007-2008 showed 50-59% accounted for cervical injuries (n=127), the most common one being C4-C5. The next common neurological level was T12/L1 (n=26) of 11%, lumbar and sacral made up for remaining cases (Norton, 2010).

**Prevalence and Incidence of SCI in Australia and Health Expenditure**

According to the Australian Institute of Health Welfare, in the period of 2007-2008 there were 362 new spinal cord injuries. The majority (79%) were due to traumatic causes. The incidence of traumatic SCI in other countries shows variation from 10.4 to 84 cases per million per year (van den Berg, Castellote, Mahillo-Fernadez, & de Pedro-Cuesta, 2010; Wyndaele & Wyndaele, 2006) compared to 15-17 cases per million in Australia.

Thirty percent of injuries reported by AIHW were from the ages 15-24, and the trend showed significant increase in the average age at injury from 38 years...
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