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Spinal Cord Injuries Australia and the Australia New Zealand Spinal Cord Injury Network's Response to the Senate Community Affairs References Committee Inquiry into Suicide in Australia

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Spinal Cord Injuries Australia (SCIA) and the Australia New Zealand Spinal Cord Injury Network (ANZSCIN) would like to thank the Senate Community Affairs Reference Committee for the opportunity to present a submission into suicide and spinal cord injury (SCI) in Australia.

We would like to acknowledge the assistance of Professor Ashley Craig and Dr Kathryn Nicholson Perry in the preparation of this submission.

Background

More than 10,000 people are living with spinal cord injury (SCI) in Australia. A recent Access Economics Report published in June 2009 revealed that despite its low incidence, SCI in Australia amounts to $2 billion in financial and burden of disease costs annually. The human cost of SCI is incalculable. People with SCI face major ongoing challenges in staying healthy and have a high risk of having a severely reduced quality of life (Middleton et al, 2007). They frequently lose their mobility, their independence and their livelihood.

What were once easy things such as a trip to work, having a schooner of beer with friends, going to the bathroom or popping over to a relative's house are now difficult and can often require careful and precise planning. This is an example of how SCI can become socially isolating. Pain affects approximately 80% of spinally injured people. It can be long lasting and is severe in 50-60% of people with SCI and significantly impairs quality of life and mood (Nicholson Perry et al, 2009a; Nicholson Perry et al, 2009b). Current treatments often have negative side effects, some of which can be as severe as the trauma from injury itself.

Our joint submission will focus on three areas:

1) Medical problems that contribute to increased risk of suicide

2) The psychosocial effects of life reliant on an accessible community; the impact that social factors play increasing the risk of suicide

3) The role that a loss of sexuality and fertility and self have in increasing an individual's risk of suicide.

Submission

Medical problems

The suicide risk of people with SCI is about five fold higher than the rest of the population, particularly for the first five to six years after injury (Middleton et al, 2008). Suicide is responsible for 6-10% of SCI deaths. Notably, a study of patients treated through the Royal North Shore Hospital in Sydney found that suicide occurred more commonly in tetraplegia than paraplegia, with the most common method used drowning (Soden et al, 2000). Presumably, tetraplegic individuals were unable to use any other unassisted methods.

De Leo et al (1999) reported that physical disorder may be a greater risk factor with increasing age, when it affects lifestyle, requires multiple medication, or is accompanied by pain. Daily pain management is a serious issue for a person living with SCI. Middleton et al (2008) list some side effects from key medications required to alleviate pain following SCI as "fatigue, sedation, dizziness, ataxia, tremors, hypertension and abnormal thinking."

Other physical problems for people with SCI include skin breakdown (decubitus ulcers) that often require lengthy hospital readmissions, the requirement to use a ventilator on a daily basis or a CPAP breather at night that (anecdotally) can often lead to feelings of drowning.

All of these health problems can have a contributing effect on an individual's state of mind.

Psychosocial Issues

Psychiatric illness occurs in about 40% of the SCI population, with depression, adjustment disorders and substance abuse most common. Traumatic brain injury is also common in people with SCI and can result in behavioural and cognitive changes (Middleton et al, 2008). Psychosocial adaptation to SCI is complex and includes coping and acceptance as well as a range of environmental factors. Psychological issues can impact on a person's ability to care for themselves resulting in secondary health complications.

Depression is estimated to affect between 20 to 43% of all people with SCI whilst in rehabilitation (Craig et al, 2008; Craig et al 2009). This decreases to around 15% of people living long term in the community. Depressive symptoms include a depressive mood and increased anxiety. Studies have recommended that rates of depression will remain high unless cognitive behaviour therapy becomes a part of rehabilitation (Craig et al, 1997). Whilst ongoing depression statistics are marginally significant when compared to the average population (5-10%) (DSM IVR) what is significant is that depression is relatively non-episodic owing to the ongoing life condition.

Access to services is a major issue. Many people with SCI have few economic resources and are not eligible for compensation as a result of their injury. They are therefore unable to cover the cost of private treatment. Many do not meet the criteria to access public services as they do not have a serious mental illness such as bipolar disorder. In addition, the knowledge and skills required to deal with the difficulties experienced by people with SCI are not well developed in the mental health workforce and it can be very difficult to find knowledgeable practitioners.

It is not only isolation from the community comprising factors such as transport and the built environment that are problematic. It is also access to core services that have been put in place to provide support for people to live independently that can be challenging. Access to services such as in home care and aids, and equipment can be difficult.

Studies have looked into the links between the often socially isolating effect of a SCI and pain experiences (Siddall et al, 2000) These studies have revealed that the ongoing pain of a SCI that is a regular part of every day life is perceived to be felt greater when social factors impact on the individual rather than when not. This research shows us that an isolating community has a detrimental effect on a person with SCI leading to a greater risk of suicide.

Research has identified a particular risk for individuals developing pressure sores owing to poor access to care services (Middleton et al, 2008). There is a cost to the individual and also to the state. In 2003/04 the cost of a hospital bed typically used to treat pressure sores was $864 per day. Pressure sores can often take many months to heal.

Being isolated from the community has also been shown to lead to increased substance abuse and smoking leading to other related health risks (Middleton et al, 2008).

Access to employment for a person with SCI is difficult, with Australia recording an OECD reported employment rate in 2009 of only 9.5% across all disabilities. Many people with SCI are injured as young people when most likely to be studying. This means they may have fewer opportunities because they have not been able to complete their education.

Sexuality and Fertility Effects

As a subject this is very important and needs to be considered. When a person acquires a SCI there are many social changes that occur or are at least perceived to be occurring. Relationships can breakdown as the trauma of an injury starts to erode what were once strong family bonds. The injured person may fear a role reversal within the relationship going from a male provider to a person that is cared for and almost relegated to the role of a child.

The physical self will undergo changes and weight loss may occur with changes in posture owing to the declining of strength in some muscles. The use of a mobility aid may be necessary (but not always) will bring unique challenges to how you interact with your partner.

Bladder and bowel complications changes what was once a very private affair to one that is public and your partner may need to assist you with toileting. This can have a detrimental affect on a sexual relationship.

All of these things can have a detrimental effect on the self and have been identified as suicide risk factors (Hanson et al, 1993).

Summary

The high levels of suicide in the SCI population highlight the need for increased awareness of depression and psychological adjustment difficulties by rehabilitation staff and general practitioners. These issues should be given special attention during rehabilitation and follow up. Regular clinical follow-up and early recognition of symptoms leading to suicide is vital to allow prompt referral to an experienced mental health clinician. It is also important to identify and facilitate sources of support for the patient.

Future research is required to more fully understand the extent and nature of psychological morbidity following SCI. More research is needed to clarify specific risk factors in order to better develop more targeted strategies to prevent suicide. For example, persistent pain increases the risk of suicide in people with SCI but it is not clear whether it is the pain itself or other aspects that are important, such as thoughts about the pain or coping strategies.

Our Recommendations

- That there is recognition of the increased risk of suicide for many people with a disability within the National Suicide Prevention Strategy. In particular, people with SCI have five times the risk of committing suicide compared to able-bodied people

- That more research is needed to target interventions at factors that may be associated with increased chances of low mood / suicide. For example multidisciplinary management of pain

- That more research is needed into the benefits of continuing rehabilitation for people with SCI for longer post-discharge from a formal rehabilitation setting than currently available. Ideally ongoing rehabilitation should be flexible enough to be self-directed and be available for a period up to 20 years

- That more research is needed into the relationship between increasing pain levels in people with a SCI and psychosocial factors such as: lack of timely access to items of supportive equipment, social isolation from the community environment and access to employment

- That the federal government consider specialist intervention support services for people with acquired disabilities with an aim of ensuring that where a person is in crisis and recognised to be at risk formal support will seamlessly support the individual.

Thank you for the opportunity to provide a submission:

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