

SUMMARY OF RESEARCH FINDINGS

This research summary is provided as an overview of a research project completed through the Institute for Safety, Compensation and Recovery Research (ISCRR). When published, the full report will provide more detailed findings and will be available from the ISCRR website www.iscrr.com.au.

For people living with spinal cord injury, bladder health and problems with urination can significantly impact on their health, dignity, independence, and participation in social and community life. These urological issues profoundly affect daily life for the person and also lead to increased use of health care services, including emergency care and hospital admissions.

This project was developed to improve urological care for people living with spinal cord injury. To do this, the researchers investigated the barriers and facilitators to bladder care, as well as the impacts of bladder dysfunction at a personal and societal level.

In this project 22 Victorians living with spinal cord injury were interviewed to gain an understanding of their experiences with urological issues since their injury..

WHAT WAS FOUND?

The study identified five key issues that affected bladder management for people living with spinal cord injury:

1. Availability of health care services

- Access to health care professionals with knowledge and specific skills of urological and continence issues related to spinal cord injury is limited, including general practitioners and hospital staff.
- Access to hospital-in-the-home services is also limited but can reduce the need for people living with spinal cord injury to seek hospital admission for bladder related complications.
- People living with spinal cord injury are not always aware of the range of health care and support services available to them.

2. Cost of equipment

- The cost of urological equipment and supplies is a significant burden, with some people resorting to unhygienic methods to prolong the service life of supplies such as catheters.

3. Getting professional help from paid carers

- The high turnover of paid carers results in ongoing loss of knowledge, capability, and practice around urological hygiene and prevention of urinary tract infections for individuals.
- The cost of paid carers is a barrier for people living with non-compensable spinal cord injury.

4. Accessible toilets

- Access to hygienic disabled public toilet facilities is a significant issue which impacts people's ability to maintain a predictable routine.
- Stress and anxiety about incontinence and finding usable toilet facilities is a barrier to participation in activities away from home.
- Inadequate compliance with regulations governing the construction and maintenance of disabled facilities was a key issue.
- Being able to find accessible toilets was a challenge for participants and ideas were proposed for sharing information, such as through reputable apps using GPS location finders for disabled toilets and rating of their cleanliness and usability.

5. Awareness, information and education

- People living with spinal cord injury, their families and their health professionals identified a need for education about issues such as management of urinary tract infections, funding for purchases of equipment, strategies for long-term bladder health, and the range of referral services available.
- Relationship strain was a significant issue resulting from urological complications and there was a need for support groups and resources for family members to help overcome the problems encountered.

WHAT ARE THE IMPLICATIONS OF THE FINDINGS?

Opportunities exist to improve bladder management and decrease the impact on daily life for people living with spinal cord injury. From this study, possible strategies have been identified:

1. Increasing the availability of health care and professional services:

- Enhance GP expertise in management of spinal cord injury.
- Inform people with spinal cord injury of GPs with expertise in care of injuries of this nature through advocacy groups, as part of the discharge process from hospital or rehabilitation.
- Promote optimum use of existing services by addressing identified access barriers, including high turnover rates of paid carers.

2. Help lower the cost of supplies:

- Provide subsidised urological supplies for people with non-compensable spinal cord injury.

3. Increasing access to hygienic disabled toilets

- Work with stakeholders to promote compliance with requirements for the construction and maintenance of disabled facilities, and promote end-user involvement in the process.

4. Raising awareness, providing information and education

- Consider the ongoing role of case managers for people with spinal cord injury.
- Raise awareness of the services currently available through Victorian Spinal Cord Service.
- Inform people living with spinal cord injury and their health professionals about the management of bladder health and urinary tract infections.
- Provide resources to family members of people with spinal cord injury to help manage relationship strain that can occur due to urological complications.

PROJECT OVERVIEW

Project title Bladder management care experiences following spinal cord injury

Themes bladder management, spinal cord injury, disability

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