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Title: The feasibility of the community questionnaires for identifying secondary complications in spinal cord injuries

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Introduction:

People living with spinal cord injuries (SCI) experience a range of different secondary health complications (SHCs). Each of these bring a large cost to the health system, which may be amplified if they are not treated quickly.

Currently, patients in the community complete self-report questionnaires through which secondary health complications can be identified, assisting referrals to relevant health care services for treatment. The Burwood Spinal Unit (BSU) and the Auckland Spinal Rehabilitation Unit (ASRU) have their own questionnaires which are currently sent to patients between on-site follow ups. From 2018, patients enrolled in the New Zealand Spinal Cord Injury Registry (NZSCIR) will receive community questionnaires at one, two, five years post injury and then at five years intervals.

The BSU questionnaire is a clinically focused questionnaire, investigating a narrow range of commonly experienced conditions for people living with SCI. Comparatively, the NZSCIR is a research focused questionnaire, focussing on a wider range of conditions to gain a picture of the patient's general health status. The BSU questionnaire has not been validated.

A study has been proposed in association with the Rick Hansen Spinal Cord Injury Register in Canada. In this study, a series of questionnaires (including the NZSCIR, as well as additional outcome measures) will be administered to participants across a two-year period to describe and understand factors related to SHCs, for New Zealanders with SCI.

Aim:

To test the feasibility of the proposed questionnaires study by ensuring that the questionnaires cover all relevant secondary health complications, as well as testing the participant burden created by the additional questionnaires.

Impact:

There is currently poor understanding of secondary complications following SCI in NZ. This study will inform a larger project aiming to quantify the incidence of symptoms and secondary complications following SCI; and to determine which individuals are at greater risk of these and why.

In addition, this study will provide the opportunity for further investigation, comparing the data collected by the existing BSU self-report questionnaire and the secondary health condition questionnaires to look at clinical applications of the NZSCIR questionnaire.

Methods:

A mapping exercise was used to compare the BSU remote questionnaire and the ASRU questionnaire to the NZSCIR questionnaire; and to compare them to the SHCs identified in the literature. This was the first measure to ensure that all relevant SHCs were covered.

An audit was then conducted for all patients sent the BSU remote questionnaire over the previous two years. This acted as a further measure to ensure all relevant SHCs were covered.

The proposed questionnaires were tested on four volunteers with SCI. They were asked specific questions relating to the pragmatics and the burden caused by the questionnaires. This acted as the final measure to assess the feasibility of the proposed questionnaires.

Data was recorded on excel and analysed descriptively.

Results:

The mapping exercise showed the ASRU and BSU questionnaires identified no SHCs that were not mentioned in the proposed research questionnaires.

The audit of the BSU questionnaire contained 82 responses (46% response rate) and tended to reflect the literature with spasms (51.7%), shoulder problems (42.6%), skin problems (24.3%) and bowel problems (44%) all being reported as some of the most common secondary health conditions faced by people living with SCI. Of note was the lack of current urinary tract infections (UTIs), although this was accounted for in the “UTI number over the past 12 months”, as the 82 patients suffered a total of 117 UTIs. There was no question regarding pain, despite this being one of the most prevalent SHCs in people with SCI.

The participant interviews indicated that there were no conditions missed in the proposed questionnaires and that they were, in general, very well written (although some minor clarifications were suggested). While completing the questionnaires was time-intensive the participants noted that, once broken down as they would be during the study, the questionnaires were easily manageable. One participant did note, however, that the questionnaires had a very negative focus and did not allow for positive responses, particularly regarding emotional wellbeing.

Conclusion:

The proposed questionnaires covered all important SHCs raised by the literature, mapping and the audit. Participants were pleased with the questionnaires and thought that they were understandable and covered a wide range of conditions. These responses indicate that the questionnaires are feasible for the proposed study.