

## Thesis summary

# Health problems after spinal cord injury rehabilitation: who cares?

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The main aim of the project was to improve follow-up care for persons with spinal cord injury (SCI) after clinical rehabilitation by introducing transmural care in the rehabilitation sector. After discharge from rehabilitation, persons with SCI experience many health problems in daily life, for which they would like to receive better support. We undertook the following activities: (1) a survey assessing health problems experienced after clinical rehabilitation; (2) a literature search regarding follow-up care programmes; and (3) the development, implementation and evaluation of a transmural nursing care model aimed at the prevention of health problems.

The survey illustrated that the respondents (response rate 45.5%, 454 persons) experienced many health problems after finishing clinical rehabilitation. The most frequently occurring problems regarded bowel (61%) and bladder regulation (71%), spasms (57%), pain (55%), oedema (49%) and sexuality (39%). Many limitations were experienced in daily activities and social life due to these problems.

The literature search revealed only twenty-four articles regarding follow-up care programmes for persons with SCI, the effects of which had usually not been studied properly. Five methods of follow-up care were identified: telemedicine, outpatient consulting hours, home visits, case management and mixed types of follow-up care. Although several studies claimed positive effects, it was not possible to draw conclusions on the effects on the occurrence of secondary impairments, well-being or the quality and costs of care.

The core component of our transmural nursing care model consists of a transmural nurse, working as a 'liaison' person between persons with SCI living in the community, primary care professionals, and the rehabilitation team. The transmural nurse had to support persons with SCI and their partner/family; support primary care professionals, promote continuity of care, and give feedback to the rehabilitation team on the basis of the experiences with patients.

Two rehabilitation centres put the model into practice. The process-evaluation showed that it was not fully implemented as planned, with a clear difference between the two rehabilitation centres. Enabling fac-

tors and barriers for implementation were found at the level of the individual professionals (e.g. competencies, attitude and motivation of the transmural nurses), the organisational and financial level (e.g. availability of facilities and funding) and the social context (opinions of colleagues, managers and other professionals involved).

Thirty-one participants who received transmural nursing care in two experimental rehabilitation centres were compared with a matched sample of participants having received usual follow-up care in six other centres. One year after discharge, no differences were found between the intervention and usual care groups in the prevalence of health problems, nor in re-admissions or the perceived quality of care. Since the 'usual' follow-up care was extended in 50% of the 'control' centres during the study period, subgroup analyses were performed. However, these analyses also did not show differences in outcome variables.

The most important conclusion is that persons with SCI may experience a variety of health problems immediately after rehabilitation, as well as in the long-term. No evidence has been found for the effectiveness of follow-up care programmes in the literature. Since our transmural nursing care model had been inconsistently and incompletely implemented in both of the 'experimental' rehabilitation centres, and there were also several methodological and practical limitations, it was not possible to formulate final conclusions regarding its effectiveness. We feel that implementing the transmural nursing care model more strictly may improve its effectiveness. A conclusion relevant for the readers of the IJIC is that implementing a care protocol should be accompanied with a plan to identify barriers for implementation and to deal with these.

Recommendations are given to improve the implementation of this or other interventions in day-to-day rehabilitation practice.

The results presented in this review are based on the authors' thesis presented at the University of Maastricht on 13 October 2006.

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