The research program ‘Physical strain, work capacity and mechanisms of restoration of mobility in the rehabilitation of individuals with spinal cord injury (SCI)’ investigates the development and outcome of the rehabilitation process of people with a SCI with respect to mobility in the broadest sense. This multi-center and multi-disciplinary research program is a strong collaboration between 8 SCI-specialized rehabilitation centers and 5 research groups in The Netherlands. The program is funded by the ZonMw-Rehabilitation program as well as other smaller third money partners. At the moment, the program consists of the national umbrella project and many highly complementary locally performed research (sub)projects, which focus on specific aspects of restoration of mobility in SCI rehabilitation. The research program collaborates with the Dutch-Flemish Society of Paraplegia and among others the Swiss Paraplegic Research Center in Notwill. With this newsletter we inform you about the current status of the research program.

The Program
Restoration of mobility during rehabilitation of persons with a spinal cord injury (SCI) is generally directed to a wheelchair bound daily life. SCI implies an acute change from leg to arm work. This has a major impact onto the cardiovascular, respiratory, neuromuscular and skeletal systems, as well as for overall functionality in daily life. A SCI affects physical strain of simple every day activities and the individual work capacity, as well as the opportunities to be functionally mobile and active in daily life. Many (neuro-) physiological and biomechanical changes take place as a mere consequence of SCI or the role of rehabilitation, apart from the mental and cognitive changes. Little is known of the complex adaptations in the organ systems that are basic to the restoration of mobility. Although with a strong focus on these biomedical issues of mobility, the program does not restrict itself to that. It also addresses mobility issues at the level of function as well as activities and participation and their impact of quality of life.

This research program is, therefore, directed to the following main objectives:
1. Development of fundamental and clinical knowledge of adaptations in organ systems and the mechanisms of restoration of mobility from a (neuro-)physiological, biomechanical and rehabilitation technology perspective.
2. Development of a knowledge base of the effects of rehabilitation and protocols of physical training on overall work capacity as well as functional progress.
3. Analysis of associations between impairment, disability and handicap in this respect.
4. Understanding of material, physical and process requirements for an optimal restoration of mobility during and after the rehabilitation of patients with SCI.

The program started initially with 5 projects but currently consists of the national umbrella project and many other PhD and subprojects.

Upcoming PhD defense
The handbike is a commercially available alternative for outdoor wheeled mobility that does not seem to have the disadvantages of hand rim wheelchair use. Hand cycling is characterized by a synchronic cyclic movement of both arms. Especially persons with a low physical capacity of the arms (cervical SCI), are expected to benefit from the handbike. Only very few experimental studies on handbike use were conducted. Based on these studies, it is expected that handbike use leads to a much more favorable lower level of cardiovascular strain and a strongly reduced mechanical strain to the upper body musculo-skeletal system. The PhD-project of Linda Valent (figure 1) focuses on the possible advantages of handbike use and training in persons with SCI during and after 1 year of inpatient rehabilitation. Linda’s project focused on the effect of regular hand cycling on the physical capacity, functioning, health and quality of life. Linda will defend her thesis on May 15, 2009.

Other PhD projects
Besides the handbike project, there currently are 4 other PhD projects well on their way focussing on different aspects of SCI rehabilitation:
1) Upper extremity task performance in high SCI
   - Annemie Spooren
2) Classification of paramedical intervention
   - Sacha van Langeveld
3) Quality of Life during and after rehabilitation
   - Christel van Leeuwen
4) Respiratory complications and physical inactivity after SCI
   - Karin Postma
The Umbrella project
The Umbrella Project is a national multi-center prospective cohort study that focuses on the outcome of SCI rehabilitation with respect to mobility restoration. The study is performed in 8 SCI-specialized rehabilitation centers. In each center a trained paramedical research assistant conducts several tests on 4 occasions. Subjects were tested:

1) at the start of active rehabilitation;
2) three months later;
3) at discharge of clinical rehabilitation,
4) 1 year after discharge.

The tests measure, among others, the performance of wheelchair skills, physical capacity, daily functioning, comorbidity and secondary health problems, sickness impact, and the quality of life during and after rehabilitation.

Umbrella project continued – Quality of Life
Although many persons with SCI regain good quality of life, compared to the general population the prevalence of psychosocial problems is substantially higher and societal participation lags behind. The over-all aim of this project is to provide detailed knowledge about the development of quality of life (mental health and well-being) during clinical rehabilitation up to five years after discharge. This quality of life study consists of an extra follow-up measurement five years after discharge of all persons with SCI who participated in the Umbrella project, with a special focus on quality of life issues. This study will also make use of the quality of life data gathered in the Umbrella project. The measurement will consist of physical tests, oral interview and self-report questionnaires. In 2009 the last measurements will be performed and data analyses and writing will start.

Future plans
No regular long-term rehabilitation aftercare system is currently operational in the Netherlands, nor have relationships between inactive lifestyle, de-conditioning, and secondary complications been systematically evaluated in chronic SCI. In the future we would like to address these issues in people aging with SCI with self-management and physical exercise interventions. It is hypothesized that self-management and physical exercise are effective interventions to enhance active life style and fitness, and prevent some of the secondary complications, since “self-management is power” and “exercise is medicine”.

New website
Last month we have launched our new website www.scionn.nl. SCIONN is the abbreviation of Spinal Cord Injury investigatiOn Network Netherlands or in (partly) Dutch 'Spinal Cord Injury OnderzoeksNetwerk Nederland'. Scion also means a shoot or sprout of a plant. In that sense it is a metaphor for research that is a scion, and hopefully leads to improved rehabilitation in the near future!

Patient monitoring
Currently we are working on the implementation of the measurements in the SCI rehabilitation with as main purpose to improve the quality of rehabilitation by objective evaluation. Subsequently, we would like to collect these future data to enlarge the database. More subjects are needed to calculate valid normative values (Figure 2) of, for example, physical capacity of subjects with different lesion levels or completeness at several times during rehabilitation.

Figure 2. Normative data for the maximal aerobic power capacity (as a measure of physical fitness), developed with data from the umbrella project.

Contact
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For more information about the research program we would like to direct you to our website:

www.scionn.nl