General introduction

Spinal cord injury

A spinal cord injury (SCI) is damage to any part of the spinal cord. SCIs often result in the permanent loss of motor, sensory and autonomic function below the site of the injury, with the lowest unharmed part of the spinal cord referred to as the neurological level of the injury. In addition to the neurological level, the severity of the injury is indicated by its completeness: a complete SCI results in the loss of all sensory and motor function below the injury; with an incomplete SCI, some sensory and/or motor function is retained. Tetraplegia indicates that the arms, hands, trunk, legs and pelvic organs have all been affected by the SCI. With paraplegia, arm function is spared but all or part of the trunk, legs and pelvic organs are affected.[1] SCIs can be the result of a traumatic insult, such as a fall or a traffic or work accident, or they can have a non-traumatic aetiology, such as being due to a vascular disease or tumour.[2] In the Netherlands, the incidence of traumatic SCI is estimated to be 14 per million people per year; the incidence of non-traumatic SCI is similar.[2]

SCIs not only result in loss of motor, sensory and autonomic function, but also in secondary health conditions (SHCs), being defined as "physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment".[3] SCIs can be associated with SHCs such as bladder and bowel disorders, pressure ulcers, spasticity, upper-extremity pain, and cardiovascular and respiratory problems.[3, 4] Compared to the general population, individuals with an SCI are at greater risk of being overweight[5] and of developing cardiovascular diseases and type 2 diabetes.[6] When an SCI is long-standing, there can be additional problems. For instance, ageing with an SCI can be accompanied by the development of SHCs or an increase in their number.[7] Compared with individuals with a recent SCI, those with a long-standing SCI experience more SHCs[3] and have lower levels of physical activity.[8, 9] Therefore, attention to these problems is needed to help people with SCI to stay healthy as they age.

Physical activity with a chronic SCI

Many individuals with a long-standing SCI have a seriously inactive lifestyle.[4, 10, 11] Because they have fewer opportunities to be active, and they experience more barriers to activity, their risk of inactivity is higher than for able-bodied people and for those with other chronic disorder. [12] An inactive lifestyle with SCI is associated with physical deconditioning and the increased incidence of SHCs;[13-16] conversely, a higher activity level has been found to be associated with several physiological and psychological benefits. [17-19] For instance, a recent study showed that increasing physical activity levels led to an increase in physical capacity and a decrease in the incidence of SHCs.[20] Therefore,

improving their level of physical activity is an important treatment goal for individuals with SCI.

A logical consequence of the importance of physical activity is the need for methodologically sound ways to measure it for research and clinical practice. Various methods and devices are available for the measurement of physical activity. A common approach is via a self-reported questionnaire; however, this has limitations, such as its subjectivity, the risk of recall bias and a tendency of individuals to overestimate their levels of physical activity.[12] In recent decades, activity monitors have been developed and applied to obtain objective measurements; it is generally accepted that this method provides more valid measurements of daily physical activity. [21] However, for individuals confined to wheelchairs, the variety of activities that can be measured with an activity monitor is limited. This needs further development.

Behavioural intervention for a more active lifestyle

A major challenge for clinical practice is how to achieve behavioural change that results in a patient adopting a more physically active lifestyle. It is sometimes assumed that such a behavioural change can be achieved through interventions that focus only on the physical aspects of increasing the patient's fitness and physical capacity, such as hand cycle training. However, studies have shown that this approach does not result in higher levels of physical activity over the long term.[8, 9, 12] Thus, further strategies or techniques are necessary to promote behavioural change.

One option is to use interventions directly aimed at changing the individual's behaviour. Theoretical models can provide a fundamental basis for such behavioural interventions. For example, the Transtheoretical Model of Change, Theory of Planned Behaviour, proactive coping theory and social cognitive theory have been applied in health-related behavioural change interventions. The Theory of Planned Behaviour[22] assumes that intention is required to perform a new behaviour, and that this intention is influenced by attitude, subjective norms and the individual's perceived level of behavioural control (self-efficacy). The Transtheoretical Model of Change[23] can be used to assess an individual's stage of readiness to act with regard to a new behaviour, such as a more physically active lifestyle. In this model, the five stages of change start with pre-contemplation (such as a lack of intention to change exercise behaviour) and end with maintenance (where the individual has changed his or her behaviour and maintained this change for more than 6 months).[24] Proactive coping[25] is a specific form of problem-focused coping in which an individual takes action to prevent unwanted behavioural events, such as by making action plans. Social cognitive theory[26] holds that an

individual can directly obtain part of their knowledge through observing other people within the context of social interactions, experiences and external media influences.

There is overlap in the determinants of change in these models. One of the most modifiable of the determinants is self-efficacy,[27] which is the confidence of an individual in his or her ability to perform a desired behaviour, such as regular physical activity. Determinants such as self-efficacy can be influenced by applying the behavioural change techniques described in the models, such as motivational interviewing, self-monitoring, mastery experiences, action planning and goal-setting. These may therefore offer promising techniques for changing the behaviour of individuals with SCIs.[28-30] Combining these techniques may be more successful than using a single strategy. [29]

Studies have demonstrated positive effects of behavioural interventions aimed at increasing physical activity in people with SCIs.[31-33] However, there are still some gaps in our knowledge. First, most of these studies included subjects with a relatively recent SCI (<5 years post-injury). Their results cannot be generalized to individuals with a more long-standing SCI, whose behaviour may need to be addressed in a different way. For instance, these people may have grown accustomed to living with their SCI, and their behaviours may have developed into habits that are not easily changed.[34] Second, most of these previous studies were based on a single theory or theoretical model. It is questionable whether this approach results in the most effective treatment; a more eclectic approach may be better. Finally, most of these studies did not report long-standing effects. A minimum of six months may be needed to evaluate whether behavioural change has been maintained.[35]

In the main study described in this thesis, we did not favour a single, specific theoretical behavioural change model. Instead, we combined the Transtheoretical Model of Change, the Theory of Planned Behaviour and proactive coping theory into one model (figure 1). We believe this combined model covers every aspect of behavioural change towards a more active lifestyle. Furthermore, the combined model allowed us to develop a pragmatic behavioural intervention from various individual and combined evidence-based behavioural change techniques.

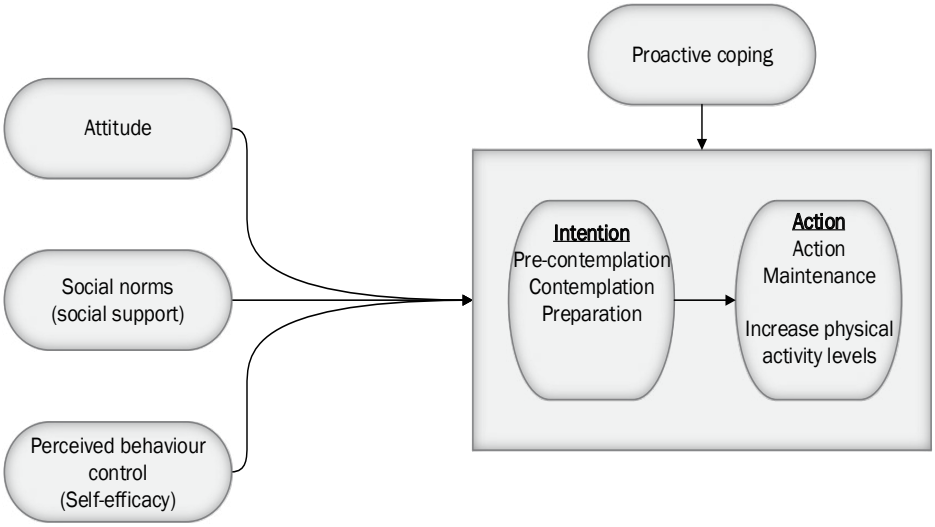

Figure 1 Theoretical model

HABITS and ALLRISC studies

A behavioural intervention based on the combined model of behavioural change was implemented and evaluated in a randomized controlled trial (RCT), the HABITS (Healthy Active Behavioural IntervenTion in SCI) study. The aim of this study was to evaluate the effectiveness of a structured self-management intervention to promote an active lifestyle in inactive individuals with a long-standing SCI.

The HABITS study formed part of the wider ALLRISC (Active LifestyLe Rehabilitation Interventions in aging SCI) research programme, which was developed to address problems related to physical activity, deconditioning and SHCs in people who had lived with an SCI for at least 10 years. [36] This multicentre national programme (started in 2010) was embedded within The Netherlands' SCI clinical rehabilitation research network (www.scionn.nl). It was a continuation of the Umbrella project, a longitudinal cohort study that followed patients with SCIs during their initial clinical rehabilitation and for up to five years after this. [36]

ALLRISC considered several aspects of increasing physical activity in people with SCIs: the long-term consequences of SCI; the preservation of an active lifestyle and fitness; the prevention of SHCs to increase activities, participation, health, and quality of life in individuals living into old age with an SCI; and interventions to improve these aspects in the context of rehabilitation follow-up care. Its main objectives were as follows:

1. To obtain a better understanding of the importance and requirements of regular rehabilitation aftercare in the context of the long-term preservation of an active lifestyle and fitness, to prevent SHCs, and to increase activities, participation, health and quality of life in people living into old age with a chronic SCI;
2. To develop evidence-based components and guidelines for an SCI rehabilitation aftercare system in The Netherlands.

ALLRISC established four studies to provide information on the prevalence and impact of an inactive lifestyle, deconditioning and SHCs on functioning and quality of life in individuals with a long-standing SCI, as well as on the preventive role of fitness, an active lifestyle and behavioural management. The four studies were conducted within a multidisciplinary, multicentre collaboration of eight Dutch rehabilitation centres with an SCI unit and four research groups.

The studies included three RCTs and one cross-sectional study. The aim of the cross-sectional study was to establish the prevalence and impact of SHCs in people with a long-standing SCI and to examine possible determinants for the SHCs. [37] HABITS was the first of the three ALLRISC RCTs. The aim of the second RCT was to investigate the effects of low-intensity wheelchair training on wheelchair-specific fitness, wheelchair performance, physical activity level and propulsion techniques in physically inactive people with a long-standing SCI. [38] The aim of the third RCT was to examine the effects of a 16-week programme of exercise using a hybrid cycle or hand cycle on cardiovascular disease risk factors in people with a long-standing SCI. [39]

Outline of this thesis

This thesis describes studies that developed and evaluated the 16-week HABITS intervention, a structured self-management active lifestyle intervention for people with a long-standing SCI, and investigated the mechanisms underlying the results of the intervention. In addition, the thesis describes the development and validity testing of a new objective measure of physical activity. For further insight, the association between exercise self-efficacy and physical activity is examined in a larger similar population, the ALLRISC cross-sectional study.

Chapter 2 describes the design of our HABITS RCT study. In **chapter 3** we studied the validity of an activity monitor that detects self-propelled wheelchair driving as a measure of physical activity. In **chapter 4** we studied the relationship between self-efficacy and physical activity, based on cross-sectional data from the ALLRISC study. In **chapter 5** we describe the results of the randomized controlled trial of the effective-

ness of a self-management intervention called HABITS on behavioural and secondary outcomes. Based on the data of the HABITS study, **Chapter 6** focusses on the underlying working mechanisms of our theoretical model. **Chapter 7** contains the general the discussion wherein the main findings are summarized and discussed.

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