

**Self-management, self-efficacy, and
secondary health conditions in people
with spinal cord injury**



Tijn van Diemen

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university of
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Self-management, self-efficacy, and secondary health conditions in people with spinal cord injury

PhD thesis

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 University of Groningen
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 the decision by the College of Deans.

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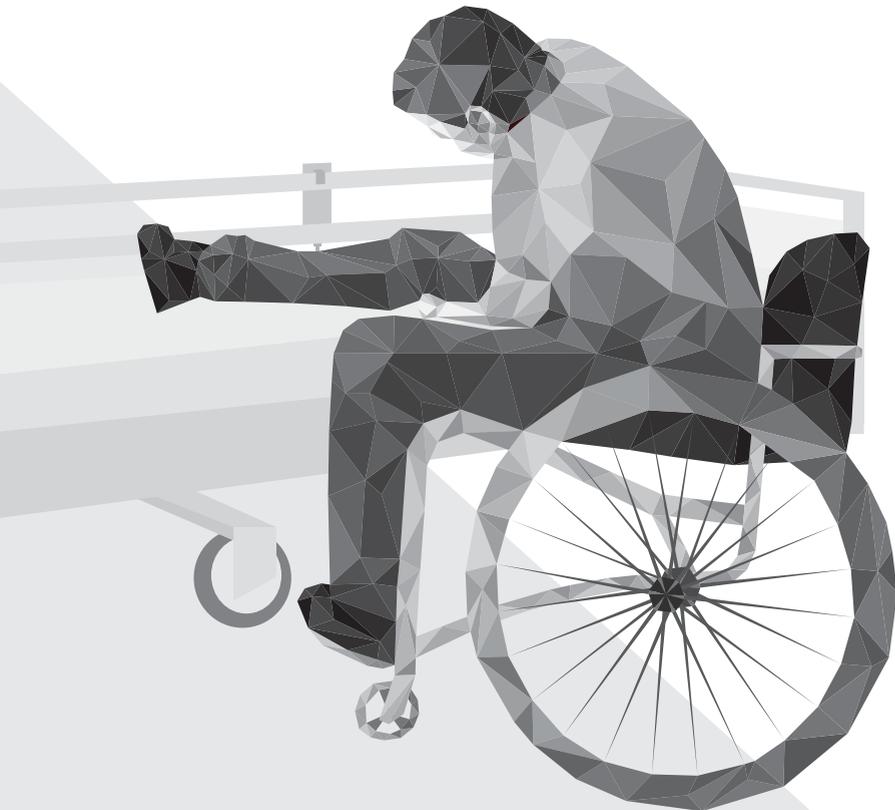
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Chapter 1

General introduction



Objective

The objective of this thesis is to better understand self-management, self-efficacy and their relationship with occurrence of secondary health conditions (SHCs) in people with spinal cord injury (SCI). This chapter serves as an introduction to this thesis. First, the background information about SCI and SHCs will be described. Second, the concepts of self-management and self-efficacy will be presented. This introduction will end with the aim and the outline of this thesis.

Background and relevance

Spinal cord injury is a relatively rare condition, with a global incidence estimated between 40 and 80 new cases per million population per annum.¹ In the Netherlands, every year between 550 and 600 people with SCI, from traumatic or non-traumatic origin, are admitted for the first time to one of the eight specialized rehabilitation centers. The total number of persons living with SCI in the Netherlands is estimated between 10,000 and 15,000.^{2,3} As a result of SCI, people can experience impairments of motor, sensory, and autonomic functions. Further, people with SCI are also at risk for the occurrence of physical SHCs.⁴ In a large Canadian survey of 1549 community-based people living with a traumatic SCI, the following physical SHCs were most commonly reported within 12 months after discharge from the hospital: neuropathic pain (65%), sexual dysfunction (62%), spasticity (60%), urinary tract infections (58%), joint contractures (57%), shoulder problems (53%), bowel incontinence (51%), weight problems (48%), urinary incontinence (46%), pressure injuries (33%), neurological deterioration (33%) and fatigue (32%).⁵ These primary and secondary physical health conditions of SCI urge people with SCI to deal with and adapt to their new situation. Most people manage to incorporate these changes into their lives, without a heavy psychological burden.^{6,7} Those who do have trouble adjusting to their new situation develop psychological SHCs like depression and anxiety.^{6,7} Major depression in people living with SCI has a prevalence of 22.2% (ranging from 7–48%).⁶ This differs strongly from the prevalence in the general population of 3.2% and from the prevalence of depression in people with any other chronic physical disease, ranging from 9.3 to 23%.⁸ It is estimated that 27% (ranging from 15–32%) of people living with SCI develop an anxiety disorder.⁹ In comparison, the prevalence of anxiety disorders in the general population is estimated at 7.3%.¹⁰

Spinal cord injury itself can affect the participation in social activities of a person¹¹ and the occurrence of SHCs (both physical and psychological) may significantly enlarge this impact, including on work participation.^{11–13} Having SHCs is also related to high health care utilization and therefore with increased health care costs, and lower quality of life.^{14,15}

To deal with the primary and secondary health conditions, appropriate self-management is highly important for people with SCI, regardless of whether they are able to do the care themselves or need assistance from formal or informal caregivers.

Self-management and self-efficacy

Self-management is defined as the individual's ability to manage the symptoms, treatment, physical and social consequences, and lifestyle changes in accordance with living with a chronic disease (Chronic Care Model).¹⁶ Within this definition, aspects like self-care, preventing SHCs, having an active lifestyle and participating in social activities are incorporated. These aspects interact with each other, for instance if people perform appropriate self-care, they will, at least partly, prevent SHCs occurring and they might be better able to participate in society.¹³ The execution of self-management by people with a disability depends on knowledge, skills and confidence in managing their condition.¹⁶ This confidence is in the scientific literature often referred to as self-efficacy.

Self-efficacy has been defined as the belief that one can successfully execute the behavior required to produce the desired outcomes.¹⁷ For people with SCI in the chronic phase, levels of general self-efficacy, the belief they have in their ability to cope with difficult situations in life in general, do not differ substantially from people in the general population.^{18–21} Further, levels of self-efficacy among people with SCI are strongly associated with psychological SHCs like depression and anxiety.^{18,20,22,23} The relationship between self-management and self-efficacy leads to the assumption that better self-efficacy will lead to better self-management which in turn may prevent SHCs.

In previous Dutch research, most people with SCI, living in the community in the first year after inpatient rehabilitation, were found to have multiple SHCs.⁴ Also in the long term people with SCI report many different SHCs.²⁴ Further, at the end of inpatient rehabilitation more than 30% of people with SCI experience mild to severe mental problems like a depressed mood or anxiety.²⁵ This high occurrence of SHCs, both physical and psychological, of people with SCI raise the question how they were educated to perform self-management during their rehabilitation process. Moreover, it is still not clear how self-management is related to SHCs, self-efficacy and other possible contributing factors. From a clinical perspective, one could ask how the aspect of self-efficacy could be used as an explicit goal for rehabilitation, in order to improve self-management and diminish physical and psychological SHCs.

Aim of the thesis

The aim of this thesis is to investigate SHCs, self-management, and self-efficacy in people with SCI. The relationship between these aspects is investigated, also, their associations with determinants like SCI characteristics, socio-demographic factors and psychological aspects were subject of investigation. For that purpose, two longitudinal studies were performed. The first study called 'Coping with SCI', was carried out in the rehabilitation center Sint Maartenskliniek, between March 2011 and October 2016. From the 188 eligible people admitted with a recently acquired SCI in this period, 150 agreed to participate. There were three assessments; at admission of the first inpatient rehabilitation; at discharge from inpatient rehabilitation and one year after discharge. The focus of this study was on coping flexibility.

The second study called 'SELF-SCI' was funded by the Dutch rehabilitation foundation (Revalidatiefonds, now Handicap.nl). This study was carried out in all eight Dutch specialized SCI rehabilitation centers between January 2016 and June 2019. Of the 514 eligible people with a recently acquired SCI who were admitted to one of these centers, a total of 285 people agreed to participate of whom 272 actually filled out at least one assessment. There were five assessments; at admission to the first inpatient rehabilitation; at discharge from inpatient rehabilitation; three months after discharge; 6 months after discharge; and one year after discharge. As part of the SELF-SCI study, interviews were held with both participants and team members at five of the rehabilitation centers. They were interviewed about the way people with SCI were taught appropriate self-management. The SELF-SCI study focused on self-management and self-efficacy. In both studies, physical and psychological SHCs were taken into account.

Outline of the thesis

The thesis is in two parts. In the first part, the focus will be on the background information, while in the second part the focus will be on the results from both studies.

In **chapter 2** the protocol of the SELF-SCI study will be described. The quantitative part of SELF-SCI is outlined, with its focus on self-management and self-efficacy and their relationship with SHCs. Based on two theoretical models (Theory of Planned Behavior and The SCI Adjustment Model) a selection of determinants was made and described.

In **chapter 3** the literature about the relationship between self-efficacy and SHCs will be described. A systematic literature search was performed, identifying all quantitative literature investigating the relationship between self-efficacy and physical or psychological SHCs. Meta-analyses were performed whenever the body of evidence was sufficient.

In the last part of this background section, **chapter 4** will describe the validity of scales used for the assessment of self-efficacy of people with SCI. A total of four different self-efficacy measurement were compared for their internal and external (concurrent and divergent) validity.

In the second part, the focus is on the results of both the Coping with SCI study and the SELF-SCI study.

In **chapter 5** the lived experience of people with SCI after their clinical rehabilitation will be described, based on the interviews performed as part of the SELF-SCI study. The aim of the interviews was to explore the way people with SCI experienced how the rehabilitation team thought them to manage their care. An important aspect of this self-management is to prevent SHCs and to act adequately if SHCs occur. Another aspect of the interviews was how people with SCI experienced the way the rehabilitation team helped them gaining confidence in dealing with the consequences of SCI.

Fatigue is mentioned frequently by people with SCI, as an SHC with a great effect on their lives. Over 50% report fatigue severe enough to interfere with functioning.²⁶⁻²⁹ In **chapter 6** fatigue will be explored. The course of fatigue during the rehabilitation phase as well as the correlation between fatigue and possible determinants, will be described.

Although SCI can have a great effect on the way people look at themselves, studies on body image among people with SCI are sparse. Also, most of these studies focus on physical characteristics and/or physical activity.³⁰⁻³⁸ In **chapter 7** the course of body image of people with SCI during their inpatient rehabilitation will be described in terms of awareness of the body in relation to the self. Further, associations between body image and possible determinants, including psychological SHCs, will be described.

In the last part of the results section, **chapter 8** will describe whether coping flexibility at admission to initial SCI rehabilitation can predict distress (a psychological SHC) one year after discharge.

This thesis will end with a general discussion in **chapter 9**. In the general discussion the main results of the different chapters will be described, as well as theoretical considerations, methodological implications and implications for clinical practice are discussed and ideas for future research are presented.

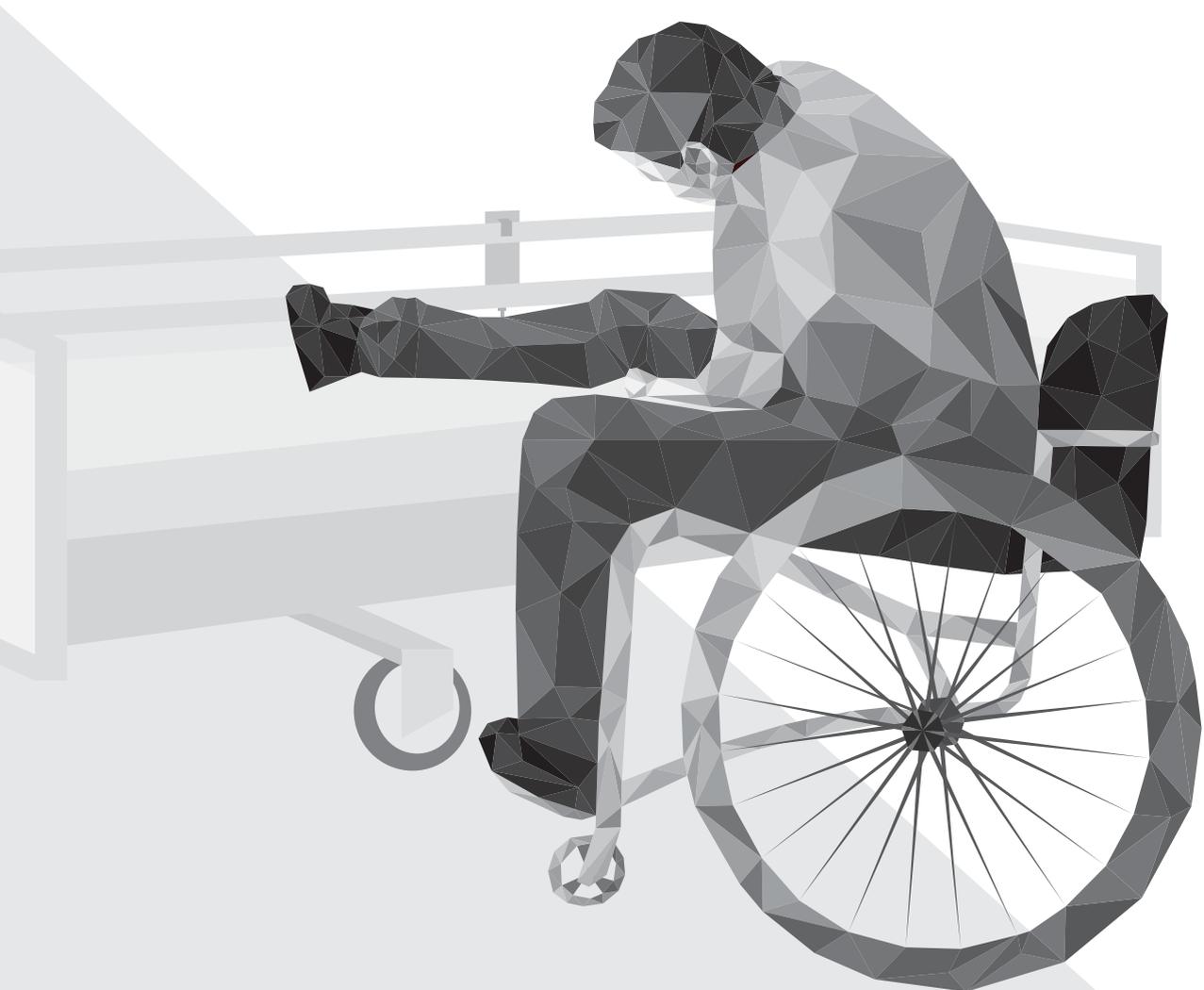
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Part I

Background information

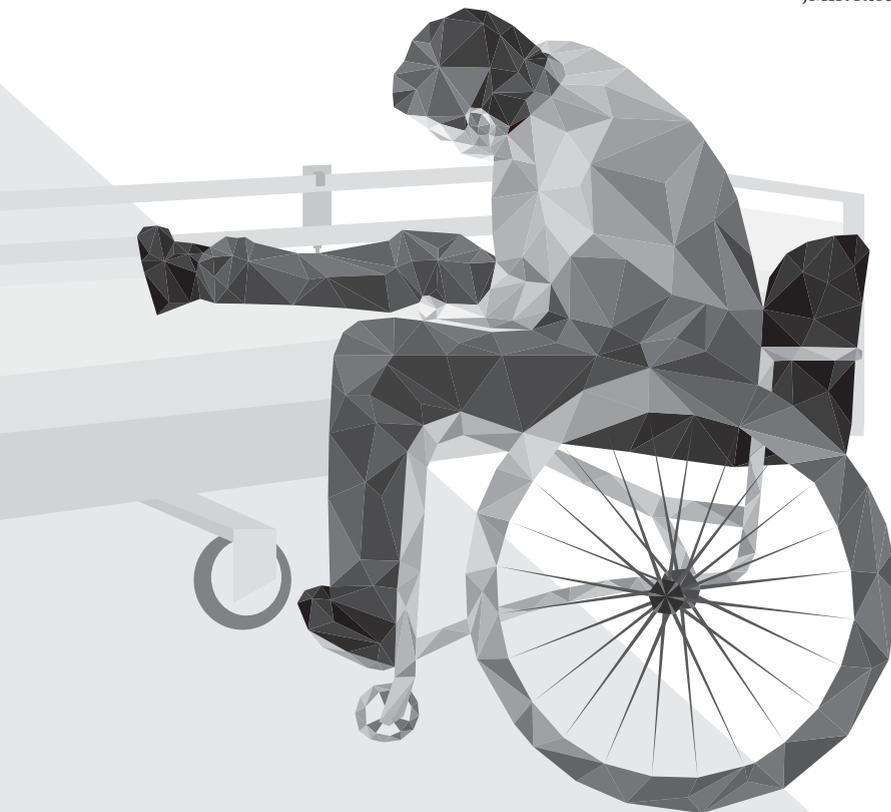


Chapter 2

Self-management and self-efficacy in patients with acute spinal cord injuries: a longitudinal cohort study protocol

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Abstract

Background: People with recently acquired spinal cord injury (SCI) experience changes in physical, social and psychological aspects of their lives. In the last decades, attention has grown for aspects of self-management and self-efficacy in SCI research. However, we still do not know what the self-management and self-efficacy outcomes of first rehabilitation are and whether utilizing these skills may prevent secondary health conditions (SHCs) and increase participation and psychological adjustment early after SCI.

Objective: To describe the course and determinants of self-management and self-efficacy during and after first SCI rehabilitation; and to determine theory-based associations between self-management and self-efficacy with SHCs, participation and psychological adjustment.

Methods: Multicenter prospective longitudinal cohort study. All people with a newly acquired SCI admitted to one of the 8 specialized SCI rehabilitation centers in the Netherlands will be considered for inclusion in this study. Main assessments will take place during the first and last week of admission and 3, 6 and 12 months after discharge. The target sample is 250 participants. The primary outcomes are self-management (knowledge and execution of self-care) and self-efficacy (confidence in the ability to manage the consequences of SCI and of self-care). Secondary outcome measures are SHCs, participation and psychological adjustment to SCI.

Results: The first results with the complete set of data are expected in June 2019.

Conclusion: This protocol describes the SELF-SCI cohort study investigating self-management and self-efficacy of initial inpatient SCI rehabilitation. Second, associations will be investigated with SHCs, participation and psychological adjustment early after onset of SCI, until 1 year after discharge. The results will be used to test theories about motivation to perform health-promoting behaviors and adjustment to SCI.

Introduction

Overview

The global incidence of spinal cord injury (SCI) is estimated between 40 and 80 new cases per million population per annum.¹ In the Netherlands, between 400 and 500 people suffer SCI each year and the total number of persons living with SCI is estimated between 10,000 and 15,000.^{2,3} The primary loss of motor, sensory and autonomic function below the level of injury may lead to several secondary health conditions (SHCs).⁴⁻⁷ These primary and secondary consequences of SCI may affect the functional independence, participation and quality of life (QoL) of the person involved.⁸⁻¹⁰

SHCs are common in people with SCI in the Netherlands,¹¹ and their participation and QoL fall behind those of people without SCI.^{12,13} One and 5 years after discharge from initial inpatient rehabilitation, many people with SCI reported urinary tract infections (57–59%), severe neuropathic pain (40–44%), pressure ulcers (29–46%), problematic spasticity (23–36%), and severe muscle or joint pain (22–35%) among other problems.¹⁴ On the long term (>5 years post-injury), people with SCI report an average of 8 SHCs in the previous year,¹⁵ their participation in employment is lower compared to society as a whole,¹⁶ and more than a third experience mild to severe chronic mental health problems.⁹ These findings are similar to results of studies in other countries.¹⁷⁻¹⁹

The high prevalence and the chronic nature of SHCs, can lead to the conclusion that SCI should be seen as a chronic condition, rather than an incidental trauma. This also focuses attention to the crucial role and responsibility persons with SCI themselves have regarding the lifelong maintenance of their health and participation in the society. During first rehabilitation of people with SCI, learning and practicing self-management skills should therefore be a main concern.

Self-management is defined as the individual's ability to manage the symptoms, treatment, physical and social consequences and lifestyle changes in accordance to a life with a chronic disease (Chronic Care Model).²⁰ To be able to apply self-management, persons with SCI must have knowledge of their physical condition and how to prevent complications or control them if they do occur.^{18,21} The high prevalence of SHCs reported in the SCI literature, however, suggest that at least part of the people with SCI lack sufficient self-management skills or do not use them properly.^{18,22}

Another concept associated with high prevalence of SHCs, especially psychological SHCs, is self-efficacy.²³ Self-efficacy is defined as the belief that one can successfully execute the behavior required to produce the desired outcomes.²⁴ Negative associations are found between self-efficacy and depression and anxiety. The negative association between self-

efficacy and the occurrence of physical SHCs of people with SCI is still unclear.²³ There is, to date, also limited information about the course of self-efficacy and self-management during and after the SCI rehabilitation. Nor do we know if self-management and self-efficacy may prevent SHCs from occurring.

The SELF-SCI study has been designed to investigate this gap. The aims of the SELF-SCI study are: 1) to describe the course of self-management and self-efficacy during and after the first year of clinical SCI-rehabilitation; 2) to examine determinants of self-management based on the theory of planned behavior (TPB); 3) to examine determinants of adjustment after SCI based on the SCI adjustment model (SCIAM).

Theoretical background

To understand how people handle the consequences of their SCI, it is not only important to know the aspects involved in health related behavior, but also the way people adjust to this situation. Therefore we will use two complementary models; the Theory of Planned Behavior (TPB) which has its focus on health-promoting behavior,²⁵ and the SCI adjustment model (SCIAM)²⁶ which describes the way people adjust after SCI.

According to TPB, the intention of people to perform health-promoting behaviors depends on their attitude, subjective norms and perceived behavior control. The scheme of TPB is depicted in Figure 2.1. Attitude is the individual's prospective evaluation of self-performance of a particular behavior.²⁵ Subjective norm refers to the perceived social pressure to perform certain behavior.²⁵ Perceived behavioral control refers to an individual's belief in their ability to succeed in specific situations or accomplish a task, also called self-efficacy.^{25,27}

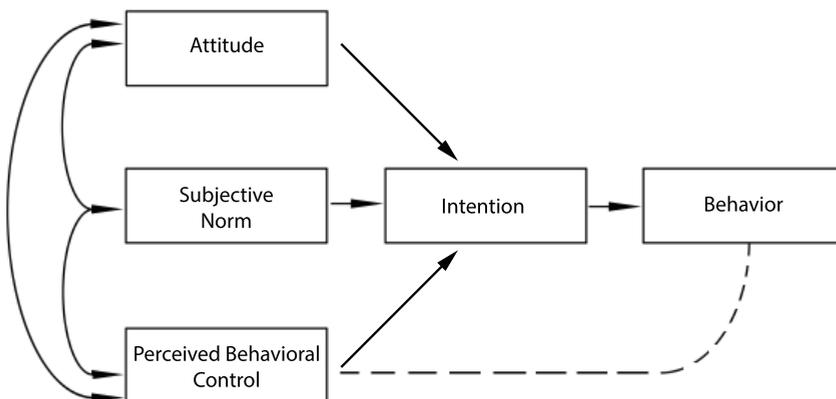


Figure 2.1 Scheme of Theory of Planned Behavior.

The SCIAM (Figure 2.2)²⁶ is based on the notion that adjustment to SCI is influenced by physical aspects, psychological resources and social factors. These aspects interact with each other and influence the person's appraisal of their situation. This will lead to certain ways of coping and levels of motivation. The result will be positive or negative adjustment. Adjustment has a psychological component, reflected in well-being or distress, and a social component, reflected in social engagement/participation.

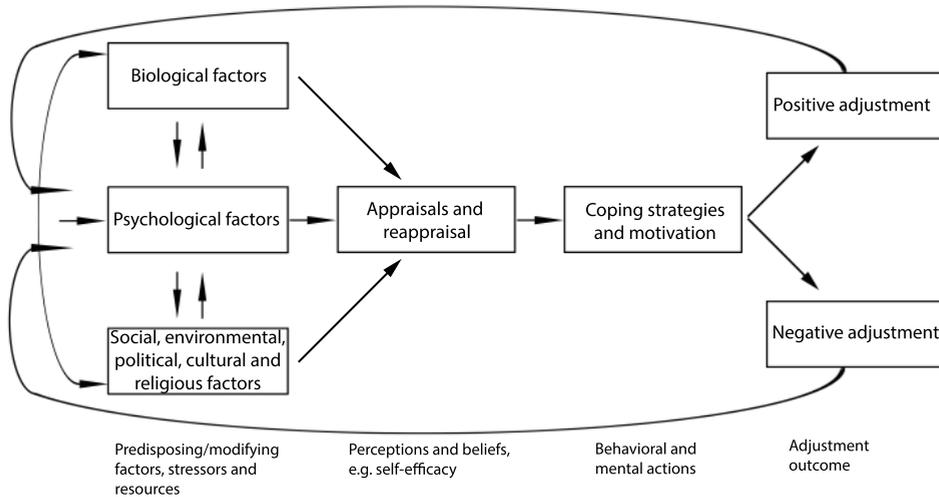


Figure 2.2 Scheme of the Spinal Cord Injury Adjustment Model.

The continuous process of appraisal and re-appraisal of the situation has a central role within SCIAM. First there is the perception of the current situation, the primary appraisal, then there is the secondary appraisal to what extent the person has sufficient resources to deal with this situation. These beliefs are influenced by the aforementioned physical, social and psychological factors. A variety of psychological resources have been associated with adjustment in the literature.^{12,28} Resources with a high potential to predict adjustment and with a minimum of conceptual overlap are: self-efficacy, resilience, personality and meaning in life.¹²

In studies on self-efficacy during and shortly after SCI rehabilitation, moderate relationships between self-efficacy with participation and psychological wellbeing were found.^{23,29,30} In the chronic stage, moderate to strong relationships between self-efficacy with adjustment variables (especially depression and anxiety) were found.^{23,31,32} Self-efficacy can be conceptualized and measured at different levels.²³ General self-efficacy (GSE) refers to the self-beliefs of a person to cope with a variety of difficult commands in general.^{27,33}

Disability management self-efficacy (DMSE) is defined as the confidence that people have in their ability to manage the consequences of their chronic condition.³⁴ Finally, self-care self-efficacy (SCSE) refers to specific beliefs concerning the opportunities to perform appropriate self-care. The specific self-efficacy described within TPB is best categorized at the level of SCSE. The secondary appraisal process in SCIAM is self-efficacy at the level of DMSE. GSE, finally, is considered to be a trait variable that will not change much over time, and therefore is seen as one of the psychological resources as described in SCIAM. DMSE and SCSE are seen as state variables that are more situation-specific and vary over time. From literature as well as from a theoretical point of view self-efficacy seems to play an important role in participation and psychological adjustment.

To investigate the role of both self-management and self-efficacy, TPB and SCIAM were used to design the current study. All the aspects described in both theoretical models were taken into account by measuring each aspect through one or more assessment tools.

Methods

Overview

SELF-SCI is a multicenter prospective longitudinal cohort study during the first SCI inpatient rehabilitation until one year after discharge. To describe the course of self-management and self-efficacy, repeated measures of the main outcome variables are used. In this quantitative study all aspects described in the theoretical models (TPB and SCIAM) are investigated, to examine determinants of self-management and adjustment after SCI.

Data collection tools

First aim

The main outcome variables of the first aim of this study are self-management and self-efficacy. Self-management is operationalized as knowledge and execution of self-care. Self-efficacy is measured at two levels; the level SCSE and of DMSE.

Self-management will be measured with a questionnaire concerning the knowledge and execution of self-care. The 13 questions about the knowledge of self-care can be answered on a 5-point scale ranging from certainly not true to certainly true. An example of a question is: "I know what to do when confronted with a pressure ulcer." The 14 questions about the execution of self-care can be answered on a 4-point scale ranging from never to always. An example of a question is: "I maintain my physical fitness as good as possible." This list

was previously used among community-dwelling people with SCI, with a high internal consistency $\alpha=.80$.³⁵ Because knowledge and execution of self-care must be acquired during rehabilitation, this questionnaire is administered for the first time at discharge.

Self-care self-efficacy will be measured with the Managing Disease in General subscale of the Self-efficacy for Managing Chronic Disease Scale.³⁶ This subscale consists of 5 items with a 0–10 numeric rating scale (NRS) which indicate to what degree participants have confidence in the asked behavior or judgment. The internal consistency is high $\alpha=.87$.³⁶ Some questions have been adapted to get a better fit with the research question. An example of a question is: “How confident are you that you can do all the things necessary to manage your condition on a regular basis?”

Disease management self-efficacy will be measured with the short version of the University of Washington Self-efficacy Scale.³⁴ This 6 item version has a 5-point scale ranging from not at all confident to totally confident. This scale has been validated for people with SCI and multiple sclerosis.^{34,37} The internal consistency of the short version is high ($\alpha=.90$).³⁴ At admission one question will be added concerning the confidence one has about the increase of DMSE during rehabilitation on a 0–10 NRS.

Second aim

The main outcome variable of the second aim is self-management. Main determinants of self-management are SCSE, attitudes towards self-management and subjective norm.

Attitude to perform health behavior in SCI was, to our knowledge, not studied previously. A new scale was constructed, the Motivation for Health Care Scale. Based on the theoretical background of TPB a total of 6 questions were formulated, covering the subject of attitude to perform health behavior in people with SCI. On each question the participants can point out to what extent the given health behavior is important to them on a 0–10 NRS. An example of a question is: “Do you find it important to have an active role in preventing health problems?” Data of the current study will be used to investigate reliability and convergent validity of this scale.

Subjective norm is operationalized as experienced stimulation from the people close to the participant, with respect to self-care. While no such scale existed, a new scale was constructed for this purpose; the Stimulation to Perform Self-care List. On 6 questions with a 0–10 NRS, the participants can state to what extent they are stimulated to perform self-care and health-promoting behaviors by people in their social environment, (e.g.: “My partner/family stimulate me to take good care for myself?”).

Third aim

The main outcome variable of the third aim is adjustment. Adjustment is operationalized as distress, illness cognitions, life satisfaction and participation. Demographic, physical, social aspects and psychological resources are taken into account as determinants of adjustment.

Distress will be assessed using the Hospital Anxiety and Depression Scale.³⁸ This scale is a commonly used measure of distress and contains 14 statements equally divided in two scales; Depressive mood and Anxiety. Participants will be asked to indicate the extent to which they agree with each item, on a 4-point scale.^{38,39}

Illness cognitions will be assessed using an adapted version of the Illness Cognitions Questionnaire.^{40,41} This instrument contains 18 statements divided into three subscales: Helplessness, which measures the aversive cognitive attributions attached to SCI; Acceptance, which measures neutralizing connotations of the condition; and Disease benefits, which measures the positive meaning given to SCI. Participants will be asked to indicate the extent to which they agree with each statement, ranging from 1 (not at all) to 4 (completely).

Life Satisfaction will be assessed using 2 Life Satisfaction questions:⁴² one question about the QoL at this moment with 6 answer categories (ranging from very unsatisfying to very satisfying), and the second question about the comparison of QoL now with the QoL before the SCI with 7 answer categories (ranging from much worse to much better).⁴³

Participation will be measured using the Utrecht Scale for Evaluation of Rehabilitation-P, participation.^{44,45} The scope of this 32-question scale is to investigate the frequency of participation in daily activities, experienced participation restrictions due to SCI and satisfaction with participation. At T1 the questions will somewhat be changed to assess the activity level and the satisfaction with these activities before the SCI, as has been done before.⁴⁶ One year after discharge the original scale will be used.

Participation will further be assessed using two questions from the Craig Handicap Assessment and Reporting Technique.⁴⁷ These two questions (how many hours a day one is out of bed and how many days per week one gets out of the house) are more often used for this purpose.⁴⁸

Determinants of adjustment

SCI characteristics (time since injury; cause of the lesion: divided into traumatic and non-traumatic; level and severity of injury according to the International Standards for Neurological Classification of Spinal Cord Injury)⁴⁹ will be determined by a trained rehabilitation physician at admission and discharge.

Functional independence in self-care and mobility will be measured with the corresponding subscales of the Utrecht Scale for Evaluation of Rehabilitation.⁵⁰ This observation scale consists of 7 items for each subscale, that can be scored by a professional on a 5-point scale. Higher scores indicate higher independence.

Experienced pain and fatigue during the past week will be measured with a NRS ranging from 0–10.

Medical consumption will be measured with questions about the amount of visits to health professionals like physicians, physiotherapists, stay in a hospital and the amount of help from family and friends for the past three months. Other questions will be about the occurrence of medical complications: pressure ulcers, incontinence, urinary tract infections and weight gain or loss.

Influence of SHCs will be measured with the Spinal Cord Injury Secondary Conditions Scale.⁵¹ From the original 16 items, 12 were selected, which can be influenced by the participant with health-promoting behaviors. The participants have to rate on a 4-point scale how much each health problem affected their activities and independence in the last three months.⁵¹

The appraisal of the current situation will be measured with the Appraisal Life Events Scale.⁵² Using 16 adjectives, participants will respond how they appraised their life in the past 3 months on a 6-point scale. The Appraisal Life Events Scale is recently used in a study with community-dwelling people with SCI.³²

The general self-efficacy will be measured with the General Competence Scale, the ALCOS-12, the Dutch version of the General Self-Efficacy Scale from Sherer.³³ The ALCOS-12 consists of 12 questions with a 5-point scale, concerning the confidence to solve problems in general.

Resilience will be measured with the Brief Connor-Davidson Resilience Scale. This short version consists of 10 items with a 5-point scale.^{53,54}

Personality will be measured with the subscale neuroticism of the Eysenck Personality Questionnaire.⁵⁵ This scale consists of 12 dichotomous questions. Neuroticism has a strong association with QoL according a systematic review.¹²

Meaning in life will be measured with the short version of the Purpose in Life Scale.⁵⁶ This scale consists of 4 of the original 20 questions that can be answered on a 7-point NRS.

Coping is operationalized in two different ways, previously be proven to be of influence on adjustment in people post-stroke,⁵⁷ namely passive coping and proactive coping.

To measure the *passive coping*, the passive reaction pattern subscale of the Utrecht Coping List will be used.⁵⁸ This subscale consists of 7 questions with a 4-point scale.

The *proactive coping* style will be measured by the Utrecht Pro-active Coping Competence Scale short version.⁵⁹ This scale measures to what extent the participant is

proficient to anticipate on difficult situations in the future on a 4-point scale. This short version, consisting of 7 of the original 21 items, is recently developed and had a high internal consistency ($\alpha=.90$) and a very high intra class correlation ($=.96$) with the total list (Post in preparation).

Social support will be assessed by the Social Support List-12.⁶⁰ This short version consists of 12 items with a 4-point Likert scale. There are three sub-scales; everyday social support, support in problem situations and esteem support.^{60,61}

The way participants are *empowered* during the rehabilitation phase will be measured with a selection of questions from the Patient Assessment of Chronic Illness Care.⁶² These 8 questions reflect the way in which the participants are involved in decision making during the rehabilitation phase. On a 5-point scale, participants can respond to what extent they were supported by the professionals, in making their own decisions and to perform self-care, during clinical rehabilitation.⁶²

Demographic variables including age, sex, living with a partner, and educational level will be assessed.

An overview of all measurement instruments is shown in Table 2.1.

Ethical considerations

The Medical Ethics Committee of the University Medical Centre Utrecht declared that this protocol does not need formal ethical approval under the Dutch law regulating medical research in human beings (reference number: 15-449/C). The Medical Ethics Committees of all participating rehabilitation centers approved this protocol. The study will be carried out according to the code of conducts formulated by Helsinki code. As part of this code all participants will give written informed consent before entering the study.

Study setting and participants

In the Netherlands 8 rehabilitation centers are specialized in SCI rehabilitation. All 8 centers participate in this study. In this protocol patients are eligible for this study if they have been admitted for inpatient rehabilitation with a clinically confirmed diagnosis of SCI, this is their first inpatient rehabilitation after the onset of the SCI, and this admission will last for at least 4 weeks. Furthermore the patient must be at least 18 years old and be able (with help if necessary due to hand function problems) to complete the self-report questionnaires. Patients with severe cognitive problems are excluded, as well as patients who have insufficient knowledge of the Dutch language to understand and complete the questionnaires. Patients are also excluded from this study if they have a limited life expectancy, for example in case of

cancer-related SCI. There are no restrictions regarding the severity of SCI or maximum age. Decision on in/exclusion is based on the clinical judgment by the rehabilitation physician and will be checked by the research assistant. If the participants are not able to complete the questionnaire because of hand function problems, help is offered by a research assistant.

All eligible patients will be informed about the study by their rehabilitation physician on the first day of admission into rehabilitation. One or two days later the research assistant will inform the patient more extensively. After informed consent is given, the research assistant will provide the participant with the first comprehensive questionnaire (T1). Next, a short 5-item questionnaire will be administered after 4 (T2), 8 (T3) and 12 weeks (T4), if at that time the participant is still admitted for at least two weeks. In the last week of admission the second comprehensive questionnaire (T5) will be administered. Three (T6) and six months (T7) after discharge a brief questionnaire will be sent to the participants, and one year after discharge the final comprehensive questionnaire (T8) will follow. During inpatient rehabilitation, participants will complete paper/pencil versions of the questionnaires. After discharge, the participants can choose whether they want to complete the questionnaire on paper or online (NetQ package). Before the questionnaire is sent after discharge (T6 to T8), the participants will be contacted by phone, further two reminders will be send in case of no response. Participants will not be offered monetary or non-monetary compensation for their efforts.

A total of 250 participants will be recruited. This target number is chosen to allow regression models with 15 determinants with sufficient statistical power per determinant in the model. An estimated 350–400 people who fit the in- and exclusion criteria are admitted to one of these 8 specialized centers each year. Therefore it seems feasible to include the desired 250 participants within the two-year inclusion period from January 2016 till December 2017.

Data analysis

All data will be entered into SPSS statistical program for Windows (version 24). The manually entered data will be checked by a second person. The data from the online questionnaires will be exported and merged with the manually entered data. When all data is entered descriptive statistics will be performed. Outliers and scores out of range of the questionnaires will be double-checked. Next, multilevel analysis, with mixed methods approach, will be performed to estimate differences between the three major assessments (T1, T5 and T8) and between all 8 assessments with a limited number of variables. Next, latent class growth mixture modeling will be used to investigate if there are different trajectories of self-management and DMSE between admission and one year after discharge. Prediction of problems regarding

Table 2.1 Measurement instruments, on the different test occasion

Primary outcome measures	Instrument	T1	T2-T4	T5	T6	T7	T8
Self-management (first and second aim)	Knowledge and execution of self-care			X			X
Self-care Self-efficacy (first aim)	Self-efficacy for Managing Chronic Disease Scale, Managing disease in General subscale			X			X
Disability management Self-efficacy (first aim)	University of Washington Self-Efficacy Scale-Short Form	X		X	X	X	X
Distress (third aim)	Hospital Anxiety and Depression Scale	X		X	X	X	X
Illness cognitions	Illness Cognitions Questionnaire	X		X			X
Life satisfaction (third aim)	Two Life Satisfaction questions	X	X	X	X	X	X
Participation (third aim)	Utrecht Scale for Evaluation of Rehabilitation, participation part	X			X	X	X
Participation (third aim)	Craig Handicap Assessment and Reporting Technique, 2 questions				X	X	X
Determinants of second aim							
Stimulation from environment	Stimulation to Perform Self-Care List			X			X
Motivation to prevent health problems	Motivation for Health Care List			X	X	X	X
Determinants of third aim: Biological and functional determinants							
SCI characteristics		X		X			
Functional independence	Utrecht Scale for Evaluation of Rehabilitation	X		X			
Experienced pain, fatigue and mood	Numeric Rating Scale	X	X	X	X	X	X
Medical consumption	Questions about received help				X	X	X
Experienced complications	Spinal Cord Injury Secondary Conditions Scale			X	X	X	X

Table 2.1 Continued

Primary outcome measures	Instrument	T1	T2-T4	T5	T6	T7	T8
Determinants of third aim: Psychological determinants							
Appraisal	Appraisal Life Events Scale	X		X			X
General self-efficacy	General Competence Scale (ALCOS-12)	X					
Resilience	Brief Connor-Davidson Resilience Scale	X					
Personality	Eysenck Personality Questionnaire, neuroticism subscale	X					
Meaning in life	Purpose in Life Scale (short version)	X					
Passive coping	Utrecht Coping List, passive reaction patron subscale	X					
Active coping	Utrecht Pro-active Coping Competence Scale (short version)	X					
Determinants of third aim: Social determinants							
Social support	Social Support List-12	X					
Demographic determinants							
	Age, sex, level of education, marital status, and other	X					

self-management and DMSE on T8 will be analyzed using multivariate regression models. Also relationships between self-management, DMSE and SCSE on the one hand and SHCs, participation and psychological adjustment on the other will be analyzed using multivariate regression analyses and path analysis.

The first aim of this study is to describe the course of self-management and self-efficacy during the first SCI rehabilitation period until one year after discharge. All available data concerning the three main variables will be used. For the second and third aim (examine the determinants of self-management and adjustment) the theory will be tested using a path analysis.

Discussion

The SELF-SCI Cohort study investigates the changes in self-management and self-efficacy of people with a recently acquired SCI during the first initial rehabilitation until one year after discharge. Next, this study determines, based on theories about motivation to perform health-promoting behaviors and adjustment to SCI, to what extent self-management, DMSE and SCSE are predictors of SHCs, participation and psychological adjustment.

There are several reasons why this cohort study is innovative. First its focus on the changes in self-management, self-efficacy over time, from shortly after the occurrence of SCI until one year after inpatient rehabilitation. Traditionally, much research and rehabilitation care has focused on the physical and functional impact of SCI. Research on psychological impact of SCI is most often cross sectional and performed in community-dwelling people with SCI. In addition, this longitudinal study focuses on the post-acute phase until one year after SCI-rehabilitation. Second, this study will investigate the relationship between self-management and self-efficacy on the one hand and SHCs, participation and psychological adjustment on the other. With a growing amount of older people with SCI, these SHCs and reduced participation in society is of major interest for health workers and policy makers. Thirdly, this study is theory driven. The present study will extensively investigate the influence of motivation to perform health-promoting behaviors and adjustment to SCI on self-management and self-efficacy. All the variables within both theories will be taken into account, as much as possible, in order to be able to test these models for the SCI population.^{31,32} And lastly, this is a nation-wide study including all 8 rehabilitation centers with a SCI specialization in the Netherlands. This means that a broad range of people, who are recently confronted with SCI, including people with traumatic and non-traumatic SCI and irrespective of age and severity of SCI, will be included in this study.

A limitation of this study could be the fact that the outcomes are only measured with self-assessment questionnaires. However, we do not consider this as a problem, because especially DMSE and SCSE are subjective concepts which we will measure with a validated scale.

In conclusion, the information which will be gathered in the present study, especially about the influence of self-management and DMSE on SHCs and participation, will be used to establish better rehabilitation care and to develop new interventions for SCI patients. This should allow people with SCI to make optimal use of their capacity to deal with their new situation.

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Chapter 3

Associations between self-efficacy and secondary health conditions in people living with spinal cord injury: a systematic review and meta-analysis

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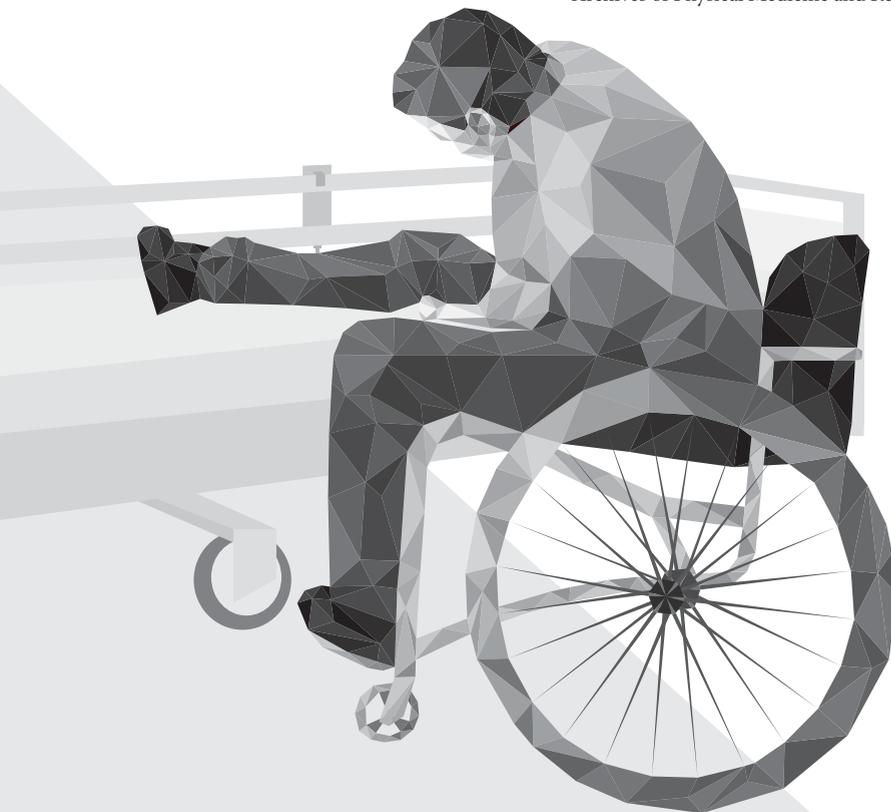
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Abstract

Objective: To describe the association between self-efficacy and secondary health conditions (SHCs) in people living with spinal cord injury (SCI).

Data sources: PubMed, Embase, the Cochrane library and CINAHL were systematically searched from database inception to September 2016.

Study selection: Studies describing patients living with SCI in which self-efficacy was measured by a standardized questionnaire and an association was made with somatic or psychological SHCs.

Data extraction: An independent extraction by multiple observers was performed based on the Strengthening the Reporting of Observational Studies in Epidemiology statements checklist. A meta-analysis concerning the association between self-efficacy and SHCs in people with SCI was performed if a minimum of 4 comparable studies were available.

Data synthesis: Out of 670 unique articles screened, 22 met the inclusion criteria. Seven out of these 22 studies investigated associations between self-efficacy and somatic SHCs. Only a trend towards an association between higher self-efficacy and less pain, fatigue, number of SHCs and limitations caused by SHCs was found. Twenty-one studies described the association between self-efficacy and psychological SHCs. All correlations of higher self-efficacy with fewer depressive (18) and anxiety symptoms (7) were significant and meta-analysis showed a strong negative correlation of $-.536$ ($-.584$ to $-.484$) and $-.493$ ($-.577$ to $-.399$) respectively. A small number of studies (2) showed a trend towards a positive correlation between self-efficacy and quality of life.

Conclusion: Self-efficacy is negatively associated with depressive and anxiety symptoms in SCI. Therefore, self-efficacy seems an important target in the rehabilitation of patients living with SCI. More research is necessary to clarify the associations between self-efficacy and somatic SHCs. Future research should also focus on different types of self-efficacy and their association with SHCs.

Introduction

Spinal cord injury (SCI) is a highly disabling condition that affects many aspects of daily life.^{1,2} A variety of secondary health conditions (SHCs) contribute to the disability people living with SCI may experience.^{1,3} An SHC is defined as a condition that is causally related to a disabling condition (i.e., occurs as the result of SCI) and that can either be a pathology, an impairment, a functional limitation, or an additional disability.⁴ SHCs can be divided into somatic and psychological health problems. In a large Canadian survey of 1549 community based people living with a traumatic SCI, the following somatic SHCs were most commonly reported within 12 months after discharge from the hospital: neuropathic pain (65%), sexual dysfunction (62%), spasticity (60%), urinary tract infections (58%), joint contractures (57%), shoulder problems (53%), bowel incontinence (51%), weight problems (48%), urinary incontinence (46%), pressure injuries (33%), neurological deterioration (33%) and fatigue (32%).⁵ Psychological SHCs most commonly described in people living with SCI include depression, anxiety and poor quality of life.^{6,7} Depression in people living with SCI has a prevalence of 22.2% (ranging from 7–48% in different studies).⁶ This differs strongly from the prevalence in the general population of 3.2% and from the prevalence of depression in people with any chronic physical disease, ranging from 9.3 till 23%.⁸ It is estimated that 27% (range, 15–32%) of people living with SCI develop an anxiety disorder.⁹ In comparison, the prevalence of anxiety disorders in the general population is estimated at 7.3%.¹⁰ In SCI research, most studies, however, measured depression and anxiety using self-rating scales. These measurements reflect subjective mood rather than demonstrate the existence of a depressive or anxiety disorder.¹¹

SCI itself can have an effect on the participation of a person,¹² and SHCs may significantly enlarge this effect, including by effecting work.^{1,2} Having SHCs is also related to high health care utilization, lower quality of life, and increased health care costs.^{13,14} This makes minimizing the occurrence and effect of SHCs an important target for the rehabilitation and the lifelong care of people living with SCI.

A recent review shows that health promotion and self-care of people living with SCI are of great importance in preventing SHCs.² It has also been suggested that in chronic disease, a person's self-efficacy is requisite to performing self-care.¹⁵ Together this leads to the assumption that better self-efficacy will lead to a better self-care, which in turn may prevent SHCs. In the last decades, self-efficacy has gained interest in SCI research. Also in the theory of adjustment after SCI, as postulated in the Spinal Cord Injury Adjustment Model, self-efficacy has a central role. Within this model, enhanced self-efficacy is associated with positive adjustment in the future.¹⁶ Self-efficacy is described as the belief that one can

successfully execute the behavior required to produce the desired outcomes.¹⁷ Self-efficacy can be operationalized at different levels: general self-efficacy is the general belief about one's ability to cope with a variety of difficult situations in life¹⁸; disease management self-efficacy is the ability to manage situations associated with one's problems that arise from disease¹⁹; lastly, self-efficacy can be measured with respect to specific situations. Some examples of SCI-specific self-efficacy are: wheelchair-specific self-efficacy^{20,21} and pressure injury prevention self-efficacy.²² Most research regarding people living with SCI focuses on the association between general self-efficacy or disease management self-efficacy with pain, depression and anxiety.^{23,24,33–40,25–32}

Systematic reviews in people with chronic pain⁴¹ and osteoarthritis⁴² have shown that self-efficacy is an important factor in relation to SHCs. However, to our knowledge, no systematic review on the association between self-efficacy and SHCs in people living with SCI has been performed to date. Therefore, the aim of this systematic review is to describe the evidence on the associations between self-efficacy and SHCs in people living with SCI. All types of self-efficacy and both somatic and psychological SHCs will be discussed. We hypothesized that a higher self-efficacy leads to a lower incidence or less burden of both somatic and psychological SHCs.

Methods

Literature search and inclusion and exclusion criteria

Four relevant electronic medical databases (PubMed, The Cochrane Library, CINAHL, EMBASE) were comprehensively searched from database inception to September 2016. All electronically available, published research regarding self-efficacy in relation to SHCs of people with SCI were taken into account. Terms included spinal cord injury and several synonyms, self-efficacy and related terms (e.g., self-concept, self-esteem, locus of control), and SHCs described in the SCI literature.^{1–3,5,9,43–47} These terms were used to search in all available search fields. Search terms used are shown in Appendix 3.1.

After duplicates were removed, 2 investigators, 1 with a psychological (T.v.D) and 1 with a medical (T.C.) professional background, independently screened the titles and abstract for eligibility. Studies were included if they met the following criteria: (1) Journal article published in English.; (2) study describes people living with an acquired SCI, traumatic or non-traumatic; (3) target population of the study is aged ≥ 16 years; (4) self-efficacy measured using a standardized questionnaire; and (5) a quantitative association with SHCs is reported. The following exclusion criteria were used: (1) study focused on people with

cognitive disorders or malignant tumors; (2) study is a systematic review or a case report; and (3) study does not separate the results of people living with SCI from people with other diagnoses (e.g. multiple sclerosis, cerebral palsy, chronic pain). Studies using data from the same study groups are only included once into the systematic review.

Cohen's kappa was calculated and used to assess interrater agreement on inclusion. To prevent selection bias, the differences were discussed until both investigators reached consensus. The remaining articles' full-texts were further checked for the inclusion and exclusion criteria as described above. In addition, the reference lists from the selected articles were screened for other potentially eligible studies.

Critical appraisal

The completeness of the reported study's design, conduct, and findings of each article was also independently assessed by both investigators using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cohort, case control, and cross-sectional studies.⁴⁸ The STROBE statements checklist consists of 22 items (with 12 additional sub items) that relate to the title, abstract, introduction, methods, results, and discussion sections of an article.⁴⁹ One item – "13(c): Consider use of a flow diagram" – was excluded, for this could not be verified by the investigators reading the article. Omitting this item left a total of 33 items. Twenty-one items were given a dichotomous rating: 1 (present) or 0 (absent). The other twelve items were given a three-point rating: 2 (present), 1 (partially present) or 0 (absent). If an item was not applicable for that study, the maximum score was given. This was applicable for 4 items. The range of the quality score was 0 to 45. The scores from both investigators were then compared, and differences were discussed to reach consensus.

Statistical analysis

Outcome data were extracted from the selected studies. Bivariate Pearson correlation coefficients were the preferable statistics. A meta-analysis was performed if sufficient studies described a correlation between self-efficacy and a particular SHC or a measure of SHCs. No standards regarding the number of articles for a meta-analysis could be found and a minimum of 4 articles was deemed appropriate to perform a meta-analysis, if the used outcome measures were sufficiently similar (e.g., a validated screening measure for depression). Comprehensive Meta-Analysis software^a was used. Correlations were first transformed into Fisher z scores, to calculate the mean. This mean Fisher z scores could then be transformed back into a correlation.⁵⁰ Ninety-five percent confidence intervals and

P-values were calculated by entering the correlations and sample sizes into Comprehensive Meta-Analysis. Because of the differences in study design between the studies, a random-effects model was used to synthesize a mean correlation of the studies.^{51,52} The random-effects model was chosen based on interpretation of the selected studies, rather than on statistical heterogeneity.⁵¹

Results

Selection of articles

A total of 925 articles were found through searching the 4 electronic databases. After the removal of duplicates, a total of 665 articles were considered for inclusion. The intra- and interobserver agreement (Cohen's kappa) on inclusion/exclusion of a study between the two investigators was .38. The investigator with a medical background selected more studies than the investigator with a psychological background, resulting in an only fair level of agreement.⁵³ All discrepancies were discussed, until consensus was reached. From the 665 articles found in the search, 70 were selected for full text analysis, resulting in the exclusion of another 49 articles. Screening of the references of all full-texts revealed 5 additional possibly relevant articles. Of these 5 articles, 1 was deemed eligible and added to the systematic review. The Preferred Reporting Items for Systematic Review and Meta-Analyses flow diagram,⁵⁴ with reasons to exclude each full-text, is shown in Figure 3.1.

STROBE checklists

A total of 22 articles were included in the systematic review and were critically appraised using the STROBE checklist. Table 3.1 shows the scores awarded to each study. Scores varied from 27 to 41 points, with a mean score of 37. Individual item data of the STROBE checklist are summarized in Figure 3.2. As this figure shows, all the found articles in the review explained the scientific background (item 2), gave matching criteria (item 6), described subgroup analysis (if applicable) (item 12B), summarized follow-up time (if applicable) (item 14C), reported categorized variables (if applicable) (item 16B), gave risk estimates (if applicable) (item 16C), reported other analysis (if applicable) (item 17), summarized key results (item 18), and gave overall interpretation of the results (item 20). Non, however, described any sensitivity analysis (item 12E). All but 1 study only gave incomplete information about the limitations of the study and the magnitude of the bias (item 19).

The self-efficacy scales used in the included studies, measure this concept on diverging levels: general self-efficacy (General Self Efficacy Scale); disease-specific or disease

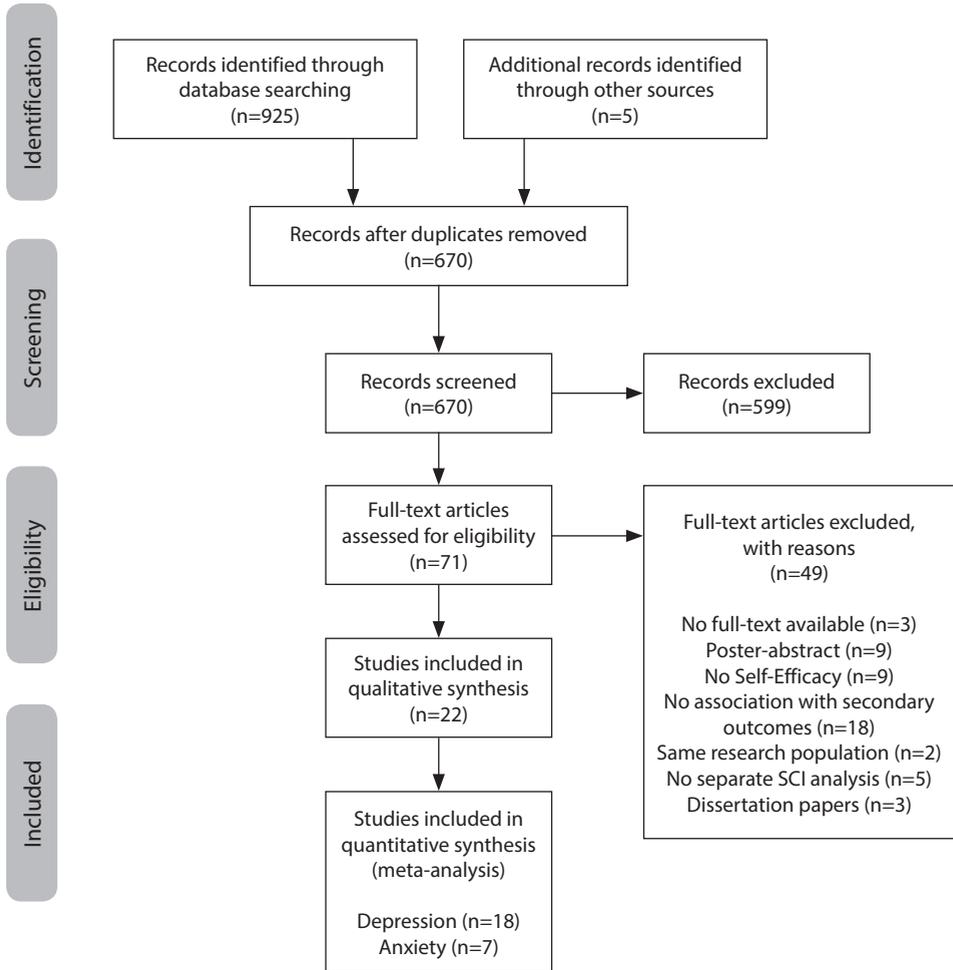


Figure 3.1 Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flow diagram.

management self-efficacy (Moorong Self Efficacy Scale, Chronic Disease Self-Efficacy Scale, Self-Efficacy for Managing Chronic Disease Scale, Beliefs Scale); or a specific type of self-efficacy (Leisure-Time Physical Activity Self-Efficacy Scale).

Somatic SHCs

A total of 7 studies^{25,27,29,34–36,58} described a correlation between self-efficacy and somatic SHCs. All significant and non-significant correlations between self-efficacy and somatic SHCs are depicted in Table 3.2. Somatic SHCs investigated in relation to self-efficacy were pain, fatigue, amount of somatic SHCs and limitations caused by somatic SHCs. Pain was described in a

Table 3.1 Characteristics of included studies

Author, year	Country	Study design	Population	N	STROBE
Munce, ³³ 2016	Canada	Cross-sectional	Community-dwelling individuals	99	40
Driver, ²⁶ 2016	USA	Cross-sectional	Inpatient and community-dwelling individuals	44	39
Peter, ³⁷ 2015	Switzerland	Cross-sectional	Community-dwelling individuals	516	39
Craig, ⁵⁵ 2015	Australia	Cohort	Inpatient and community dwelling individuals	88	38
Craig, ²⁴ 2014	Australia	Cross-sectional	Inpatient, outpatient and community-dwelling individuals	107	35
Sweet, ³⁹ 2013	Canada	Cohort	Community-dwelling individuals	395	40
Kilic, ²⁹ 2013	Australia	Cross-sectional	Community-dwelling individuals	60	39
Craig, ²⁵ 2013	Australia	Cross-sectional	Community-dwelling individuals	70	34
van Leeuwen, ⁴⁰ 2012	The Netherlands	Cohort	Community-dwelling individuals	143	38
Geyh, ²⁷ 2012	Switzerland	Cross-sectional	Community-dwelling individuals	102	39
Bombardier, ²³ 2012	USA	Cross-sectional	Community-dwelling individuals	244	35
Mortenson, ⁵⁶ 2010	Canada	Cohort	Inpatient and community dwelling individuals	93	40
Pang, ³⁶ 2009	Taipei	Cross-sectional	Community dwelling individuals	49	34
Nicholson-Perry, ³⁴ 2009/I	Australia	Cross-sectional	Inpatient	47	41
Nicholson-Perry, ³⁵ 2009/II	Australia	Cohort	Outpatient	45	40
Miller, ³² 2009	USA	Cross-sectional	Community dwelling individuals	162	27
Hampton, ⁵⁷ 2008	China	Cross-sectional	Outpatient	119	35
Suzuki, ⁵⁸ 2007	USA	Cross-sectional	Community dwelling individuals	270	38
Middleton, ³¹ 2007	Australia	Cross-sectional	Community dwelling individuals	106	38
Kennedy, ²⁸ 2006	United Kingdom	Cohort	Community dwelling individuals	35	37
Middleton, ³⁰ 2003	Australia	Cohort	Community dwelling individuals	36	33
Shnek, ³⁸ 1997	USA	Cross-sectional	Community dwelling individuals	80	31

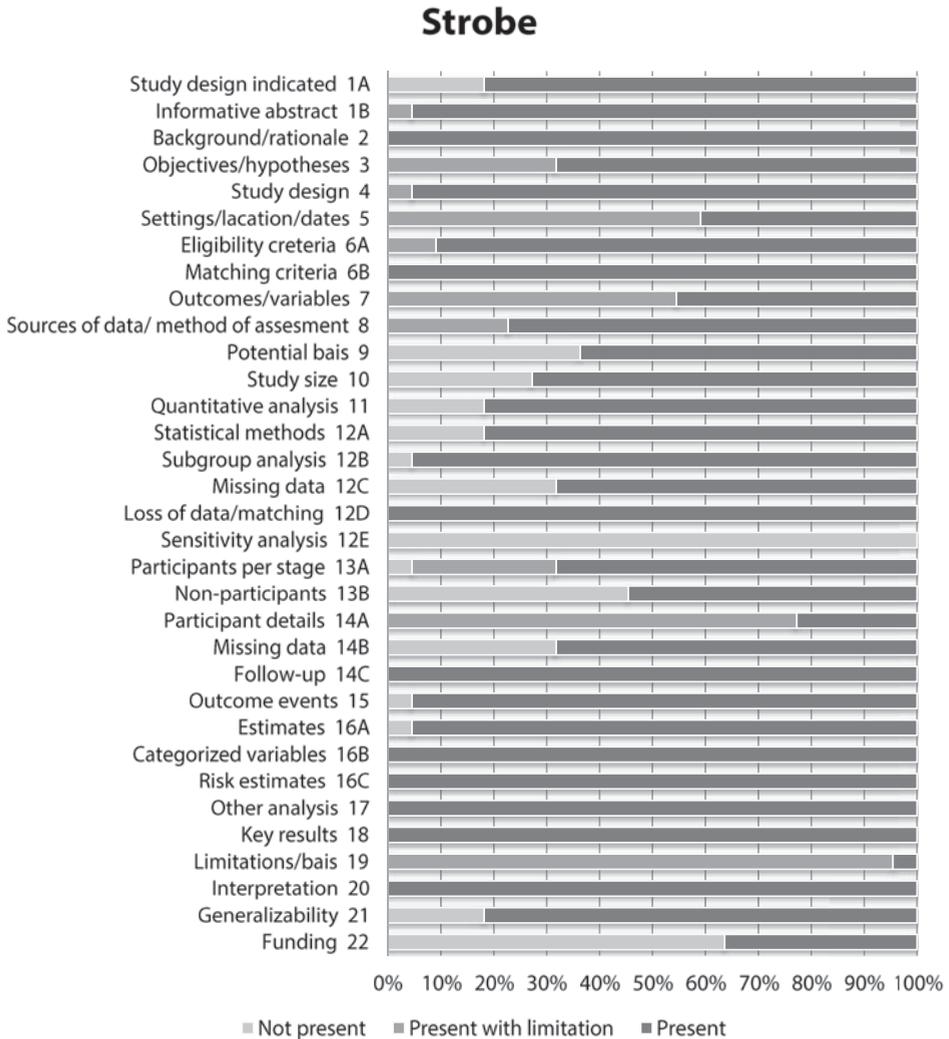


Figure 3.2 Reporting quality assessment with STROBE (N=22).

variety of terms, including “pain”^{25,29,34,35} “pain intensity”^{25,27,34,35} and “pain interference”^{27,36}. One study²⁵ showed an association between self-efficacy and fatigue. Finally, two articles^{27,58} showed a correlation between self-efficacy and a total somatic SHCs score. One article²⁷ used the Secondary Health Conditions Scale, which measures the experienced effect of SHCs, the other⁵⁸ used a list of 18 preselected SHCs in a questionnaire. Pain and pain intensity did not meet the criteria set for a meta-analysis because to diverging outcome measures: questionnaires versus single numeric rating scales (see Table 3.2). For pain interference, fatigue and number/impact of SHCs, the number of studies did not meet the criteria set for a meta-analysis.

Table 3.2 Correlations between self-efficacy and somatic SHCs

Type of SHC	Article	N	SE-scale	Outcome scale	Value
Pain	Kilic (2013) ²⁹	60	MSES	NRS (0–10)	-0.27
	Craig (2013) ²⁵	70	MSES	SFMPQ	-0.54*
	Nicholson-Perry (2009/I) ³⁴	47	MSES	PRSS	-0.28
	Nicholson-Perry (2009/II) ³⁵	45	MSES	PRSS	-0.46*
Pain intensity	Craig (2013) ²⁵	70	MSES	PPI	-0.45*
	Geyh (2012) ²⁷	102	GSES	BPI	NS
	Nicholson-Perry (2009/I) ³⁴	47	MSES	NRS (0–10)	-0.47*
	Nicholson-Perry (2009/II) ³⁵	45	MSES	NRS (0–10)	-0.36
Pain interference	Geyh (2012) ²⁷	102	GSES	BPI	-0.24*
	Pang (2009) ³⁶	49	SEMCD	PIS	-0.59*
Fatigue	Craig (2013) ²⁵	70	MSES	CFS	-0.54*
General SHCs	Geyh (2012) ²⁷	102	GSES	SHCS-L	-0.25*
				SHCS-N	NS
	Suzuki (2007) ⁵⁸	270	BRFSS	18 selected SHCs	-0.13*

NOTE. All Studies showed a correlation between self-efficacy and the outcome. The 18 selected SHCs from Suzuki, 2007,⁵³ include high or too low blood pressure, poor circulation (such as swollen or cold feet or hands, blood clots), contractures, diabetes, fatigue, injuries, osteoporosis, pressure sores, alcohol or other drug overuse/abuse, muscle spasms, urinary tract infection/bladder problems, yeast infections/vaginal infections, pneumonia, repetitive motion pain (carpal tunnel syndrome, shoulder pain), weight management/weight gain, chronic pain, stomach problems, and constipation or bowel problems.

Abbreviations: BPI, Brief Pain Inventory; BRFSS, Behaviour Risk Factor Surveillance System; CFS, Chalder Fatigue Scale; GSES, General Self-Efficacy Scale; MSES, Moorong Self-Efficacy Scale; NRS, Numeric Rating Scale; NS: Non-significant correlational value not shown in study; PIS, Pain Interference Score; PPI, Present Pain Intensity; PRSS, Pain Response Self-Statements Scale; SE, self-efficacy; SEMCD, Self-Efficacy for Managing Chronic Diseases; SFMPQ, Short-Form McGill Pain Questionnaire; SHCS-L, Secondary Health Conditions Scale Limitations; SHCS-N, Secondary Health Conditions Scale Number.

* $P < .05$.

Psychological SHCs

A total of 21 studies^{23,24,33–40,55,56,25,57,26–32} described an association between self-efficacy and 1 or more psychological SHCs. Eighteen studies^{23,24,33–40,25–32} showed significant correlations between self-efficacy and depression, varying from $-.32$ to $-.74$ (Table 3.3). One study²⁶ gave correlations between self-efficacy and depression during initial rehabilitation and 3 months after discharge; on behalf of the homogeneity, the latest is used in the meta-analysis. All studies used validated scales to measure self-efficacy and depression. Assuming that these scales measure the same underlying construct, a meta-analysis was performed. The mean correlation and the forest plot of this meta-analysis are shown in Figure 3.3. The 4 studies using a general self-efficacy scale had a mean correlation of $-.52$. The 13 studies using a disease-specific or disease management self-efficacy scale had a mean correlation of $-.57$. The one³⁹ study using a specific type of self-efficacy scale showed a correlation of $-.32$.

Most of the studies in this review are cross-sectional and used community dwelling patients with SCI. One study,²⁶ however, investigated the correlation between self-efficacy

Table 3.3 Correlations between self-efficacy and psychological SHCs

Type of SHC	Article	N	SE-scale	Outcome scale	Value
Depression	Munce (2016) ³³	99	MSES	HADS-D	-0.56*
	Driver (2016) ²⁶	44	CDSES	PHQ-9	-0.74*
	Peter (2015) ³⁷	516	GSES	HADS-D	-0.54*
	Craig (2014) ²⁴	107	MSES	SF-36†	0.48*
	Sweet (2013) ³⁹	395	LTPA-SE	PHQ-9	-0.32*
	Kilic (2013) ²⁹	60	MSES	DASS-21	-0.63*
	Craig (2013) ²⁵	70	MSES	POMS	-0.64*
	van Leeuwen (2012) ⁴⁰	143	GSES	SF-36†	0.52*
	Geyh (2012) ²⁷	102	GSES	HADS-D	-0.57*
	Bombardier (2012) ²³	244	CDSES	PHQ-9	-0.58*
	Pang (2009) ³⁶	49	SEMCD	CESD-10	-0.46*
	Nicholson-Perry (2009/I) ³⁴	47	MSES	HADS-D	-0.61*
	Nicholson-Perry (2009/II) ³⁵	45	MSES	HADS-D	-0.59*
	Miller (2009) ³²	162	MSES	CESD-10	-0.54*
	Middleton (2007) ³¹	106	MSES	SF-36†	0.41*
	Kennedy (2006) ²⁸	35	GSES	HADS-D	-0.43*
	Middleton (2003) ³⁰	36	MSES	HADS-D	-0.61*
Shnek (1997) ³⁸	80	BS	CESD-10	-0.58*	
Anxiety	Munce (2016) ³³	99	MSES	HADS-A	-0.32*
	Kilic (2013) ²⁹	60	MSES	DASS-21	-0.54*
	Geyh (2012) ²⁷	102	GSES	HADS-A	-0.61*
	Nicholson-Perry (2009/I) ³⁴	47	MSES	HADS-A	-0.52*
	Nicholson-Perry (2009/II) ³⁵	45	MSES	HADS-A	-0.43*
	Kennedy (2006) ²⁸	35	GSES	HADS-A	-0.45*
	Middleton (2003) ³⁰	36	MSES	HADS-A	-0.58*
Quality of Life	van Leeuwen (2012) ⁴⁰	143	GSES	2 LS	0.33*
	Mortenson (2010) ⁵⁶	93	GSES	QLI (3 months) QLI (15 months)	0.62* 0.47*
Affective/subjective disorder	Hampton (2008) ⁵⁷	119	GSES	IPWB	-0.09†
Psychological disorders	Craig (2015) ⁵⁵	88	MSES	MINI-plus	1.05 [§]

NOTE. All studies except for Hampton⁵⁷ and Craig⁵⁵ showed a correlation between self-efficacy and the outcome.

Abbreviations: BS, Beliefs Scale; CDSES, Chronic Disease Self-Efficacy Scale; CESD-10 Centre of Epidemiologic Studies Depression Scale; DASS-21, Depression Anxiety and Stress Scale 21; GSES, General Self-Efficacy Scale; HADS-A, Hospital Anxiety and Depression Scale - Anxiety; HADS-D, Hospital Anxiety and Depression Scale - Depression; IPWB, Index of Personal Well-Being; LTPA-SE, Leisure Time Physical Activity Self-Efficacy; MINI-plus, MINI International Neuropsychiatric Interview; MSES, Moorong Self-Efficacy Scale; PHQ-9, Personal Health Questionnaire 9; POMS, Profile of Mood States; 2LS, Two Life Satisfaction questions; QLI, Quality of Life Index; SE self-efficacy; SEMCD, Self-Efficacy for Managing Chronic Diseases; SF-36, Medical Outcome Study 36-item Short Form Health Survey.

* $P < .05$.

† SF-36 describes mental health instead of depression. Therefore outcomes are positive instead of negative. For the meta-analysis, the effect direction was changed to negative.

‡ Hierarchical regression instead of correlation was used as outcome measure.

§ Odds ratio instead of correlation was used as outcome measure.

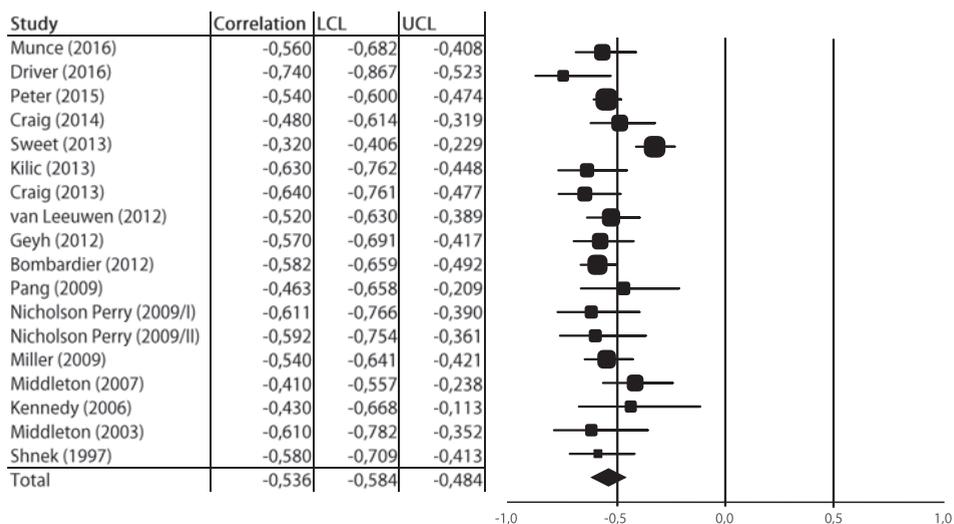


Figure 3.3 Self-efficacy and Depression: forest plot. Abbreviations: LCL, lower confidence limit; UCL, upper confidence limit. Q -value = 39,610; $dg(Q)$ =17,000; P =.001; I^2 =57,082.

and depression on different time intervals. That study showed a nonsignificant correlation during rehabilitation, and the largest correlation found in this review three months post-discharge (-.74).²⁶ Another study used the same scale in a larger population of community-dwelling people with SCI (60% >4 years post injury). The correlation found in that study was more similar to that of the mean correlation (-0.58).²³ The only other longitudinal study⁵⁶ in this review investigated the correlation between self-efficacy and quality of life. That study showed a change from 3 to 15 months of r =.62 to r =.47.

Seven studies^{27–30,33–35} showed a correlation between self-efficacy and anxiety. The scales used to describe self-efficacy varied, but anxiety was measured using only 2 scales: the Hospital Anxiety and Depression Scale (6 articles) and the Depression Anxiety and Stress Scale 21 (1 article). The correlations found varied from -.32 to -.61 and were all significant. The mean correlation and the forest plot are shown in Figure 3.4.

One final study⁵⁵ showed an association between self-efficacy and psychological disorders, determined using the Mini International Neuropsychiatric Interview-Plus. These psychological disorders included: major depressive disorder, bipolar disorder, suicidality, posttraumatic stress disorder, generalized anxiety disorder, alcohol dependence and abuse disorder, drug dependence and abuse disorder and psychosis. The only association with self-efficacy shown in that article was a non-significant odds ratio of 1.05 for the total number of psychological disorders. Because of the different outcomes and the low number

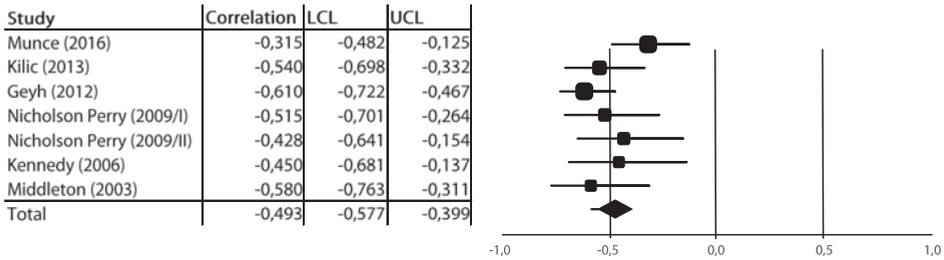


Figure 3.4 Self-efficacy and Anxiety: forest plot. Abbreviations: LCL, Lower Confidence Limit; UCL, Upper Confidence Limit. Q -value = 8,224; $df(Q)$ =6,000; P =.222; I^2 =27,043.

of articles describing quality of life, affective/subjective disorder, and psychological disorders, no meta-analyses were performed.

Correlations between self-efficacy and quality of life were described in 2 studies.^{40,56} One study⁴⁰ used the Life Satisfaction Questions (a 2-item scale with 1 question about the quality of life at this moment, and 1 about the quality of life now compared to life before SCI) to measure life satisfaction, whereas the other used the Quality of Life Index.⁵⁶ Another study⁵⁷ reported no correlations, but a significant regression coefficient of self-efficacy with psychological well-being.

Discussion

A systematic review was performed, resulting in 22 studies describing an association between self-efficacy and SHCs. Seven studies described somatic SHCs, including different pain variables, fatigue, amount of SHCs and effect of SHCs. These studies did not provide solid evidence of an association between self-efficacy and somatic SHCs. Only a trend toward a small negative correlation was found. Based on 21 studies describing an association between self-efficacy and psychological SHCs, a meta-analysis produced strong mean negative correlations between self-efficacy and both depression and anxiety.

The strong mean negative correlations between self-efficacy with depression and anxiety are in accordance with those found in a systematic review⁴² in people with osteoarthritis, and somewhat stronger than found in a review of people with chronic pain.⁴¹ While the study⁴² on people with osteoarthritis did not find evidence of a relation between self-efficacy and pain, the study⁴¹ of people with chronic pain did find a relation between self-efficacy and pain intensity.

In this review, only few studies were found that examined self-efficacy and somatic SHCs. Most of these studies focused on pain. Frequently reported somatic SHCs in the SCI literature, such as pressure ulcers and urinary tract infections, are to our knowledge, never examined in relation with self-efficacy other than being part of a total SHCs score. The occurrence of somatic SHCs may increase with the aging of the SCI population⁵⁹ and with the shortening of initial rehabilitation programs for financial reasons.^{60,61} Such an increase of somatic SHCs will lead to a higher rate of physician and specialist utilization, emergency department visits, and hospital readmissions. This underscores the importance of research into prevention of somatic SHCs and the possible role of enhancing self-efficacy in self-care of persons with SCI.

This review showed limited indication that time since injury might moderate the association between self-efficacy and psychological SHCs.^{26,56} One study found that at inpatient stay, disease-management self-efficacy was not significantly correlated to depression. However, 3 months post-discharge, the correlation was the strongest found in this review. In another study²³ using the same scale in community dwelling patients with SCI, the correlation is somewhat weaker. A longitudinal study⁵⁶ using a general self-efficacy scale to investigate the association with quality of life found a decrease in the correlation from 3 to 15 months. This might suggest that the influence of self-efficacy on psychological SHCs changes over time.^{23,26,56} It might be expected that disease management self-efficacy will increase during inpatient rehabilitation, being a major target of the rehabilitation team. How it changes, and its effect over time on the association with depression, must be clarified in future research. General self-efficacy, on the other hand, is a trait variable that will not change much over time. Its alteration on the effect of the association with psychological SHCs must also be subject for further research.

The forest plot on the meta-analysis of self-efficacy and depression shows that 1 study³⁹ deviates the furthest from the mean. Its negative correlation (-.32) was smaller than any other study, of which the correlations did not get above -.40. An explanation for this difference might be the Leisure-Time Physical Activity Self-Efficacy Scale, which no other study used. Leisure-time physical activity is an aspect of importance for people living with SCI functioning in society. The Leisure-Time Physical Activity Self-Efficacy Scale mostly focuses on the barriers to performing leisure-time physical activities. This may be the reason that the association with psychological SHCs is less strong.³⁹

To date, it is unclear whether the type of self-efficacy scale used influences the associations found with SHCs. The studies included in this review used different self-efficacy scales, measuring diverging levels of self-efficacy. The mean correlation of general self-efficacy scales with depression was somewhat weaker than the mean correlation of a

SCI-specific or a disease management self-efficacy scale with depression. The scale most commonly used is the Moorong Self-Efficacy Scale (10 out of 17).^{24,25,29–33,35,39} The studies in our review all used the Moorong Self-Efficacy Scale total score. The scale was developed with a 2-factor structure, although some discrepant findings have been reported.^{30,32,62,63} In a recently published study,⁶⁴ however, the factor structure of the Moorong Scale was reexamined, showing 3 factors: social function self-efficacy (e.g., I can maintain contact with people who are important to me), personal function self-efficacy (e.g., I can maintain my personal hygiene with or without help), and general self-efficacy (e.g., When I see someone I would like to meet, I am able to make the first contact). The authors consider the first 2 to be SCI-specific variables, whereas the latter is considered to be a general self-efficacy. The reexamining study of the Moorong Self-efficacy Scale showed that the different subscales all had strong correlations with physical health (including pain and vitality) and mental health (the positive equivalent of depression). The most distinct differences are found between the social functioning self-efficacy ($r=.59$) and personal functioning self-efficacy ($r=.42$) on the one hand, and mental health on the other. The total Moorong score showed the strongest correlation ($r=.63$) with mental health.⁶⁴ In a systematic review⁴¹ concerning people with chronic pain, the heterogeneity in the found relationships across studies was, among other things, based on the self-efficacy scale content. Future research is needed to differentiate between the different levels of self-efficacy and their relations to SHCs, and whether these different levels of self-efficacy have a different effect on somatic versus psychological SHCs.

The strong mean correlations found for self-efficacy with depression and anxiety trigger interest in the causal pathway of this effect. Peter et al.³⁷ tested the Spinal Cord Injury Adjustment Model,¹⁶ proposing a multifactorial adjustment process in which biological, environmental, and psychological factors interact and influence the way people with SCI appraise their situation. In this model, appraisal refers to the way a person perceives and interprets a stressful situation, such as their disability. Peter³⁷ found that self-efficacy influences depressive symptoms indirectly via appraisals; self-efficacy relates to the way people appraise their disability, which in turn leads to more or less depressive symptoms. Sweet et al.³⁹ proposed another mechanism, based on their study of leisure-time physical activity self-efficacy. Their hypothesis is that leisure-time physical activity self-efficacy is directly correlated to leisure-time physical activity, which in turn is negatively correlated to depression. Finally, van Leeuwen et al.⁴⁰ found that self-efficacy has a direct pathway to mental health, as well as a mediated pathway through appraisals. These studies describe both a direct and an indirect effect of self-efficacy on SHCs. It is likely that the indirect effect is mediated through appraisals. Future research is needed to clarify the direct and indirect effect, through appraisals, of self-efficacy on SHCs.

The relatively high scores on the STROBE can be explained by the fact that 20 out of the 22 articles are published in the last 10 years. In this last decade, many publishers use the STROBE or similar checklists.

Study strengths and limitations

This is the first systematic review in people with SCI with respect to self-efficacy in relation to SHCs. The search used was extensive, and terms related to self-efficacy were included to avoid missing relevant studies. Also, the reference lists of included studies were screened for additional articles, which accounted for 1 extra study included in the systematic review. The results of this review are representative for people living with SCI in the community. Therefore, the information extracted on psychological SHCs can be generalized for this population.

Unfortunately, for somatic SHCs, not enough data were found to come to a grounded conclusion. Although associations between self-efficacy and pain were examined in six studies, because of the use of significantly different pain scales, no meta-analysis could be performed. It was further impossible to include the non-significant correlations that were mentioned but not stated in 1 article.²⁷

As in every systematic review, there is the risk of publication bias. Non-significant results are less likely to be published, so there is a possibility these data are missed despite our extensive literature search. This may result in an inflation of the effect size estimates.

Clinical implications

Enhancing self-efficacy has been described as a target in the rehabilitation of SCI. This can, for instance, be done by exercise, through improving physical condition and functional abilities,⁶⁵ or by improving the self-management abilities through a creative way of thinking.⁶⁶ Often the outcome discussed in studies focusing on self-efficacy relates to a person's participation.⁶⁷ Our study suggests that increasing self-efficacy can have a positive effect on depressive and anxious symptoms and probably on somatic SHCs. A widely used therapy for both depression and anxiety is cognitive behavioral therapy.⁶⁸ Within this tradition, explicitly adjusting the self-efficacy cognitions of people with SCI may be, based on this review, a very promising approach that should be the subject of further research.

Conclusion

Self-efficacy is negatively associated with depressive and anxiety symptoms in SCI in accordance with the hypothesis. Therefore, self-efficacy seems an important target in the rehabilitation of patients living with SCI to prevent SHCs.

More research is necessary to clarify the associations between self-efficacy and somatic SHCs. Future research should also focus on different types of self-efficacy and their association with SHCs and the changes in self-efficacy over time.

Supplier

- a. Comprehensive meta-analysis software (CMA) [Internet]. [cited 2016 Oct 18]; Available from: <https://www.meta-analysis.com/>

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Appendix 3.1 Search strategy

AND →	AND →	OR →	OR →
"Spinal Cord Injury" "Spinal Cord Trauma" "Cord Trauma, Spinal" "Cord Traumas, Spinal" "Spinal Cord Traumas" "Trauma, Spinal Cord" "Traumas, Spinal Cord" "Injuries, Spinal Cord" "Cord Injuries, Spinal" "Cord Injury, Spinal" "Injury, Spinal Cord" "Myelopathy, Traumatic" "Myelopathies, Traumatic" "Traumatic Myelopathies" "Traumatic Myelopathy" "Spinal Cord Transection" "Cord Transection, Spinal" "Cord Transections, Spinal" "Spinal Cord Transections" "Transection, Spinal Cord" "Transections, Spinal Cord" "Spinal Cord Laceration" "Cord Laceration, Spinal" "Cord Lacerations, Spinal" "Laceration, Spinal Cord" "Lacerations, Spinal Cord" "Spinal Cord Lacerations" "Post-Traumatic Myelopathy" "Myelopathies, Post-Traumatic" "Myelopathy, Post-Traumatic" "Post Traumatic Myelopathy" "Post-Traumatic Myelopathies" "Spinal Cord Contusion" "Contusion, Spinal Cord" "Contusions, Spinal Cord" "Cord Contusion, Spinal" "Cord Contusions, Spinal" "Spinal Cord Contusions" "Spinal Cord Diseases" Paraplegia Paraplegias Quadriplegia Quadriplegias Tetraplegia Tetraplegias	"Self-efficacy" "Efficacy, self" Mastery "Internal-External Control" "Control, Internal-External" "Controls, Internal-External" "Internal External Control" "Internal-External Controls" "Locus of Control" "Control Locus" "Self-concepts" "Concept, Self" "Concepts, Self" "Self Concepts" "Self-perception" "Self-perceptions" "Self Perception" "Perception, Self" "Perceptions, Self" "Self Perceptions" "Self Esteem" "Esteem, Self" "Esteems, Self" "Self Esteems" "Self-assessment" "Self-assessments" "Self Assessment" "Assessment, Self" "Assessments, Self" "Self Assessments" "Self-criticism" "Self-criticisms"	Depression Depressions Depressive Dysthymic Dysthymia Anxiety Anxieties Hypervigilance Nervousness Affective Affection Affections Alexithymia Alexithymias Emotional "Anxiety Disorders" "Anxiety Disorder" "Disorder, Anxiety" "Disorders, Anxiety" "Neuroses, Anxiety" "Anxiety Neuroses" "Anxiety States, Neurotic" "Anxiety State, Neurotic" "Neurotic Anxiety State" "Neurotic Anxiety States" "State, Neurotic Anxiety" "States, Neurotic Anxiety" "Quality of Life" "Life Qualities" "Life Quality" QoL	Comorbidity Comorbidities Multimorbidity Multimorbidities "Secondary Health" SHC SHCs "Pressure Ulcers" "Ulcer, Pressure" "Ulcers, Pressure" Bedsore Bedsores "Pressure Sore" "Pressure Sores" "Sore, Pressure" "Sores, Pressure" "Bed Sores" "Bed Sore" "Sore, Bed" "Sores, Bed" "Decubitus Ulcer" "Decubitus Ulcers" "Ulcer, Decubitus" "Ulcers, Decubitus" "Autonomic Dysreflexia" "Autonomic Dysreflexias" "Dysreflexias, Autonomic" "Hyperreflexia, Autonomic" "Spinal Autonomic Dysreflexia" "Autonomic Dysreflexia, Spinal" "Autonomic Dysreflexias, Spinal" "Dysreflexia, Spinal Autonomic" "Dysreflexias, Spinal Autonomic" "Spinal Autonomic Dysreflexias" "Autonomic Hyperreflexia" "Autonomic Hyperreflexias" "Hyperreflexias, Autonomic" "Dysreflexia, Autonomic" Cardiovascular Circulation Circulatory Bladder Bowel Fecal Incontinence Incontinences "Urinary tract" Infection Sexual Sex Joint Joints Muscle Muscles Contracture Contractures Respiratory Pain Diabetes Spasm Spasms Sleep Nocturnal Apnea

OR →

Chapter 4

The validity of four self-efficacy scales used in people with spinal cord injury; issues of state versus trait self-efficacy

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Abstract

Objective: Self-efficacy (SE) is an important determinant of adjustment following spinal cord injury (SCI) and valid measures of SE are therefore required to enhance our understanding of the adjustment process. The objective of this study was to investigate the internal, convergent, and divergent validity of four SE scales designed to measure different trait versus state levels of SE (general versus domain and task-specific) in a sample of people with SCI.

Research methods: Dutch and Australian adults with SCI (N=140) completed the Moorong Self-efficacy Scale (MSES), General Self-efficacy Scale (GSES), University of Washington Self-efficacy Scale (UW-SES) and a newly developed Self-care Self-efficacy Scale (SCSES) approximately 6 months post-rehabilitation. Internal validity was examined using confirmatory factor analysis (CFA) and convergent/divergent validity using Pearson correlations.

Results: All four self-efficacy scales showed acceptable to good fit in a one-factor model using CFA. The three-factor solution reported in the literature for the MSES could not be confirmed. In assessing the different trait and state levels of SE (general, domain, task), convergent validity was confirmed (correlations 0.50–0.65), although divergent validity was only partly confirmed (correlations 0.31–0.74).

Conclusion: The internal validity for the four SE scales was acceptable to good with strong convergent validity. However, the expected distinction between different levels of SE, the divergent validity, could not be demonstrated. These findings support the need for further research and development of scales better able to measure domain and task-specific state SE for people with SCI.

Introduction

Impact

- This article contributes to our understanding of the concept of self-efficacy (SE).
- Four SE scales were analyzed and showed acceptable internal and convergent validity as one-dimensional scales.
- The strong correlations between SE scales designed to measure divergent aspects of SE suggest that the concept of state versus trait SE constructs requires further investigation.
- Further work is required to develop a SE questionnaire that sensitively measures state aspects of SE.

Spinal cord injury (SCI) affects both physical and psychological functioning and challenges all areas of a person's life. Physical aspects include limitations in strength, function and mobility, loss of sensation, spasm, pain, and changes in bladder, bowel and sexual functioning.¹ These effects are associated with increased dependence on caregivers, reduced social and work participation and diminished quality of life.²⁻⁶ Psychological consequences can include elevated depressive mood, anxiety and fatigue, which also may have a negative influence on quality of life.^{5,7-10} Therefore, it is important to have sensitive clinical measures that can provide an indication of adjustment to these new life challenges, and thus to offer guidance in how to improve adjustment outcomes.⁹

In recent years, there has been increased clinical and research interest in the capacity of self-efficacy (SE) to act as a mediator for adjustment in people with SCI.^{5,11-13} Self-efficacy is defined as the belief that one can successfully execute behavior required to produce the desired outcomes.¹⁴ A recent meta-analysis showed strong associations between low SE and high depressive mood, anxiety and pain in persons with SCI.¹⁵ In addition, SE has been shown to be a key determinant of adjustment after SCI,^{13,16-18} as well as in other chronic health conditions.^{20,21} Self-efficacy is therefore a valuable clinical predictor of adjustment and, arguably, it could be a promising intervention outcome measure to target during the SCI rehabilitation process.^{15,16,22,23} Furthermore, a recent model of adjustment following SCI, called the SCI Adjustment Model or SCIAM,²⁵ incorporating aspects of social learning, stress and coping, and health belief theories, views SE not just as an indicator or predictor of potential to adjust, but also as a key component in the person's appraisal/reappraisal process, labelled the "engine room". This is seen to be a crucial element in a complex, non-linear multifactorial process for adjustment and coping.

State and trait constructs have been widely used in many areas of psychology and the distinction between them has been of considerable importance in psychological theory and

research.²⁶ In its original conceptualization, SE referred to the confidence that people had in their ability to accomplish specific tasks and behaviors within a specific context. This can be seen as 'state-like' SE, believed to be open to change over time as circumstances in someone's life change, and was also believed to be modifiable by training or treatment.²⁷ However, over time, the concept of SE expanded to include a general or 'trait-like' construct, tapping into a more general set of expectations, which is a stable non-specific confidence people may have in managing their life in both routine and novel situations, and believed to be less open to change.²⁷ In a systematic review on the assessment of SE, Sheer²⁸ described three types of SE: trait-like SE (e.g., general stable belief in one's ability to accomplish goals); domain-specific SE (e.g., a belief concerning managing aspects of chronic illness); and task-specific SE (e.g., a belief that is context bound involving a specific behavior). The last two are a further differentiation of the state level described above into domain and task-specific aspects of SE.

In SCI-related research, as well as in other areas of research, efforts have been made to measure SE on different levels, which most likely overlap to some extent.^{15,29,30} General self-efficacy (GSE) is often measured in SCI research using one of the General Self-efficacy Scales (GSES).^{17,19,31,32} A scale that has been used at the level of domain-specific SE in people with SCI and multiple sclerosis, is the University of Washington Self-efficacy Scale (UW-SES).^{33,34} This scale was designed to measure confidence in disability management self-efficacy (DMSE), the person's ability to manage the consequences of their chronic health condition in their daily activities and social life. More recently, a new task-specific scale has been developed to measure self-care SE, the confidence that people with SCI have in their ability to perform appropriate self-care behaviors, called the Self-care Self-efficacy Scale (SCSES).³⁰

The most commonly used SE scale in SCI research is the Moorong Self-efficacy Scale (MSES).³⁵ This scale was originally designed to measure SE at the state level. The factor structure of the MSES has been investigated several times over the years with two-factor and three-factor solutions found.³⁵⁻³⁸ In the latest study, three subscales were identified namely: general SE (MSES-General), social functioning SE (MSES-Social), and personal functioning SE (MSES-Personal),³⁶ which at face value appear similar to the distinctions between GSE, domain-specific and task-specific SE, respectively.

The validity and inter-relationships between these various scales, all designed to measure distinct aspects and levels of SE, have not been empirically tested in SCI research to date and, consequently, the construct of SE employed in SCI research remains unclear. Therefore, the aim of this current study was to clarify the construct of SE by examining the internal, convergent and divergent validity of the four abovementioned SE scales. The hypotheses for this study were: for internal validity (I) the factor structures of the SE scales as described in the literature can be reproduced; for the external validity (II) SE scales that

measure at the same trait or state level, that is, GSE (MSES-General with GSES), DMSE (MSES-Social with UW-SES) and SCSE (MSES-Personal with SCSES) will show strong inter-correlations (>0.5); (III) SE scales that measure SE at different trait and state levels, that is, GSE (MSES-General and GSES) versus DMSE (MSES-Social and UW-SES) versus SCSE (MSES-Personal and SCSES) will show moderate, less strong inter-correlations (between 0.3 and 0.5), as the concepts are different but not fully independent.

Methods

Participants

For this study, people with SCI were recruited in the Netherlands and Australia. The recruitment of the Dutch cohort has been described in detail elsewhere.³⁰ In short, 285 people with SCI, admitted to one of the eight specialized SCI rehabilitation centers in the Netherlands between January 2016 and January 2018, participated in this longitudinal cohort study. To be eligible to enter the study, participants had recently acquired a SCI, were 18 years of age and older, had no severe cognitive impairment due to comorbid brain injury, no severe mental health disorders (such as schizophrenia) and possessed sufficient knowledge of the Dutch language to complete the questionnaires reliably. For the Australian cohort, participants in a SCI Outreach program in Sydney, New South Wales, who were between 3–9 months post-discharge after completing their subacute inpatient SCI rehabilitation in June 2018, were asked to take part in this study. The same inclusion criteria were applied, other than participants in this case needed to possess sufficient knowledge of English language to complete the questionnaires.

Procedure

In the Netherlands, the SE scales were part of the regimen of questionnaires in a longitudinal study, here only reporting the assessment administered 6-months post-discharge. Data collection took place between June 2017 and December 2018. Injury characteristics were recorded by an experienced rehabilitation physician at admission or retrieved from medical files. The Medical Ethics Committee of the University Medical Centre Utrecht declared that the study did not need formal ethical approval under the Dutch law regulating medical research in human beings (reference number: 15-449/C). After that, in accordance with local requirements, the Medical Ethics Committees of all participating Dutch rehabilitation centers approved the execution of the study in their center.

In the Australian arm of the study, participants of the Spinal Outreach Service in Sydney, were invited by postal mail to participate in a survey including the four self-efficacy

questionnaires. In the case of no response (to participate or opt out) being received, a postal reminder was sent out four weeks after the first letter and the participants were telephoned after eight weeks. Injury characteristics were retrieved from medical files. The Human Research Ethics Committee of the Northern Sydney Local Health District approved the project (reference number: LNR/17/HAWKE/269).

The study, in both countries, was carried out in accordance with the code of conduct formulated in the Helsinki code. All participants provided informed consent before entering the study.

Measures

Socio-demographic variables collected included age, sex, presence of a partner, educational level and pre-injury employment. Injury characteristics included: time since injury; traumatic or non-traumatic etiology; paraplegia or tetraplegia; and motor complete (i.e., AIS grades A and B) or motor incomplete (AIS grades C and D) lesion, according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).³⁹

The MSES is a 16-item scale assessing an individual's perception of control over their behaviour for achieving their desired outcomes in relation to their SCI. Responses are provided on a 7-point Likert scale, ranging from 1 (very uncertain) to 7 (very certain). The MSES total scores range from 16 to 112, with higher scores indicating stronger SE. The MSES was translated into Dutch for this study using a translation – back translation procedure.⁴⁰ In the most recent validation study,³⁶ three factors were found, namely: General self-efficacy (e.g., Question 10: I can deal with unexpected problems that come up in life), Social functioning self-efficacy (e.g., Question 7: I can enjoy spending time with my friends) and Personal functioning self-efficacy (e.g., Question 1: I can maintain my personal hygiene with or without help).³⁶ The internal consistency of the total MSES was excellent (Cronbach $\alpha = .91$), while the internal consistency of the MSES-General, MSES-Social and MSES-Personal factors were acceptable to good (Cronbach $\alpha = .81, .77$ and $.80$, respectively).³⁶

The Sherer General Self-efficacy Scale (GSES) was used to measure GSE.⁴¹ The Dutch short version of this scale has 12 items (of the original 17 items).³² Each item can be answered using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). The scores on this scale range from 12 to 60, where higher scores indicate stronger general self-efficacy. The same 12 questions were administered in the Australian cohort. A re-examination of the original GSES version of Sherer, as well as the Dutch 12 item version, found three factors- representing aspects of GSE, Initiative, Effort and Persistence.^{29,32} One of these studies,³² demonstrated an improved fit with a higher order (one factor) model, which

therefore was chosen for this study. Cronbach's alpha of the total score was questionable ($\alpha=0.69$).³²

Self-efficacy in disability management (DMSE) was assessed using the short version of the University of Washington Self-efficacy Scale (UW-SES).³³ This 6-item version has a 5-point scale ranging from 1 (not at all confident) to 5 (totally confident). The scale scores range between 6 and 30, with higher scores indicating greater DMSE. The UW-SES has been validated for people with SCI and multiple sclerosis.^{33,34,42} Prior research investigating the internal validity of the UW-SES 6 item version with confirmative factor analysis and Rasch analysis has confirmed the one-factor structure.^{42,43} The internal consistency of the UW-SES 6 item version was excellent (Cronbach $\alpha=.90$).³³

For assessment of SCSE, an adapted version of the Managing Disease in General subscale of the Self-efficacy for Managing Chronic Disease Scale⁴⁴ was used, referred to as the Self-Care Self-efficacy Scale (SCSES). This scale consists of 5 items with a 0–10 numeric rating scale indicating to what extent participants believe in their capacity to self-manage their health. The scale score ranges between 0 and 50, with higher scores indicating greater confidence in a person's ability for self-care. The internal consistency of the original scale is good (Cronbach $\alpha=.87$).⁴⁴ The first two questions were not altered, asking about confidence in “doing all things necessary to manage the condition on a regular basis” and being able to “judge when to see a doctor”. The other three questions were adapted to read: 3 “How confident are you that you can keep up your physical condition and weight?”; 4 “How confident are you that you can prevent problems like pressure sores or urinary tract infections?”; and 5 “How confident are you that you can do everything necessary, in order to get the right aids and medication?”.

Statistical analyses

Missing items were replaced with the mean score of the (sub)scale. For the MSES Total score, less than 8% of the participants had one or more missing items that needed to be replaced. For the MSES-Social less than 5% and for all other scales less than 2.5%. Three participants had too many missing items to calculate one or more valid (sub)scores. Differences between the two arms of the study (the Dutch and Australian participants) were tested using independent sample t-tests.

Confirmatory factor analyses were conducted to investigate the structure of each of the four scales. Adjustments, such as covariate between uniqueness' (non-shared variance) and removal of questions (with the greatest prediction error) were made to get a better model fit if applicable. Multiple parameters were taken into account with commonly used cut-off

points: Minimum value of the discrepancy function C divided by degrees of freedom (C_{MIN}/DF) < 5 ; Normed fit index (NFI) $> .95$; Comparative fit index (CFI) $> .90$; Root mean square error of approximation (RMSEA) $< .80$; and P -value for testing the null hypothesis of close fit (PCLOSE) $> .05$.

To examine convergent /divergent validity, associations between the four scales, (e.g., MSES with three subscales, GSES, UW-SES and SCSES) as well as certain socio-demographic and injury-related characteristics, were calculated and expressed in Pearson correlations; with correlations up to 0.3 considered weak, between 0.3 and 0.5 as moderate and > 0.5 as strong.⁴⁵ All analyses were conducted using SPSS for Windows (version 25) and SPSS AMOS (version 26) (IBM corp, Armonk, NY).

Results

In the Dutch arm of the study, a total of 119 participants completed all four SE scales. In the Australian arm, 21 of the 37 potential participants agreed to participate and completed all questionnaires. The characteristics of the participants are shown in Table 4.1.

Only time since injury and motor completeness of the SCI were significantly different between the cohorts ($P < .05$). A sensitivity test with only the Dutch cohort did not reveal a different pattern. Given the two cohorts were similar, they were combined for further analysis. The scores of the different SE scales are shown in Table 4.2.

Table 4.1 Characteristics of the study sample

Characteristic	Netherlands	N	Australia	N
Age in years Mean (SD)	55.1 (15.1)	119	60.4 (16.3)	21
Range	19–84		29–81	
Median (IQR)	56 (47–66)		64 (51.5–73.5)	
Sex, male N (%)	79 (66.4)	119	12 (57.1)	21
Having a partner N (%)	85 (73.3)	116	14 (66.7)	21
Education, bachelor degree or higher N (%)	41 (36.3)	113	7 (33.3)	21
Paid employment prior to SCI N (%)	83 (69.7)	119	9 (50.0)	18
Time since injury in weeks Mean (SD)	44.4 (12.5)*	119	55.9 (21.1) *	21
Range	30–95		27–103	
Median (IQR)	41 (36–49)		47 (40.5–70)	
Level of injury, paraplegia N (%)	57 (47.9)	119	10 (47.6)	21
SCI motor complete N (%)	29 (24.6)*	118	8 (38.1)*	21
SCI traumatic cause N (%)	65 (54.6)	119	13 (61.9)	21

NOTE. * $P < .05$ according the independent samples t-test.

Abbreviations: SD: standard deviation; IQR: interquartile range.

Table 4.2 Mean scores of the four Self-efficacy scales, including the sub-scales of the Moorong Self-efficacy Scale, Cronbach's alpha and the percentage of participants with the maximum scores on the scale

Measure (score range)	N	M (SD)	Median	IQR	Cronbach alpha	Maximum score (%)
MSES Total (16–112)	138	86.5 (17.1)	90	75.8–100.0	.91	1.4
MSES-General (4–28)	139	21.8 (4.4)	23	19.0–25.0	.75	5.0
MSES-Social (5–35)	138	28.5 (5.5)	29	24.4–33.2	.74	16.7
MSES-Personal (4–28)	138	21.7 (5.7)	23	19.0–26.0	.75	15.9
GSES (12–60)	140	47.2 (8.3)	49	42.0–54.0	.85	2.9
UW-SES (6–30)	139	17.5 (5.5)	18	13.0–22.0	.90	1.4
SCSES (0–50)	139	38.6 (7.1)	40	35.0–44.0	.81	7.2

Abbreviations: M: mean; SD: standard deviation; IQR: interquartile range; MSES total: Moorong Self-efficacy Scale total score; MSES-General: Moorong Self-efficacy Scale General factor; MSES-Social: Moorong Self-efficacy Scale Social functioning self-efficacy factor; MSES-Personal: Moorong Self-efficacy Scale personal functioning self-efficacy factor; GSES: General Self-efficacy Scale; UW-SES: University of Washington Self-efficacy Scale; SCSES: Self-care Self-efficacy Scale.

Internal validity

Results of the confirmatory factor analyses for the four self-efficacy scales are shown in Table 4.3.

Table 4.3 Fit-indices of confirmatory factor analysis of the four self-efficacy scales

Scale	CMIN/Df	NFI	CFI	RMSEA	PCLOSE
MSES 3 factors *	2.275	.838	.898	.096	<.001
MSES 1 factor **	1.656	.872	.944	.072	.059
GSES 1 factor ***	2.055	.914	.954	.087	.087
UW-SES 1 factor †	1.829	.981	.991	.077	.108
SCSES 1 factor ††	.908	.989	1.000	<.001	.519

* The three factors found in the latest re-examination.³⁶ To get the best possible model fit, covariates between uniqueness' of questions 4 and 9; questions 7 and 9; and questions 10 and 14 were required. In this model the covariance between the factors was strong, ranging between .87 and .94.

** To get the best model fit covariates between the uniqueness' of questions 4 and 9 and between questions 9 and 15 were required. Further questions 7 and 10 had to be removed.

*** Model fit after removal of question 4, 6, 8, 9 and 10.

† Model fit of UW-SES after covariate between the uniqueness' of question 5 and 6 and removal of question 4.

†† Model fit of the SCSES after removal of question 5.

The confirmatory factor analysis of the MSES showed a better fit for the one-factor solution as compared to the three-factor solution, based on all fit indices. In further analysis, both the three-factor and the higher order model were taken into account. The confirmatory factor analysis with the GSES resulted in an acceptable model fit based on most indices (NFI and RMSEA are just a little below and above the cut-off points respectively), after

eliminating questions 4, 6, 8, 9 and 10. The confirmatory factor analysis with one-factor solution for the UW-SES resulted in a good model fit after deleting question 4 (Confidence in keeping the SCI from being the center of your life) on all fit indices. The confirmatory factor analysis with one-factor solution for the SCSES resulted in an excellent model fit after deleting question 5 (confidence in getting the right aids and medication) on all fit indices.

External validity

Correlations between the SE scales and determinants are shown in Table 4.4.

Table 4.4 Pearson Product Moment correlation coefficients between the four self-efficacy scales or subscales, and participant characteristics

Variable	1	2	3	4	5	6	7
1 MSES Total	1.00						
2 MSES-General	.86**	1.00					
3 MSES-Social	.91**	.74**	1.00				
4 MSES-Personal	.84**	.57**	.64**	1.00			
5 GSES	.53**	.65**	.45**	.34**	1.00		
6 UW-SES	.56**	.54**	.50**	.42**	.31**	1.00	
7 SCSES	.69**	.65**	.60**	.56**	.52**	.42**	1.00
8 Age	-.26**	-.28**	-.25**	-.17*	-.12	-.24**	-.15
9 Sex	-.11	-.15	-.06	-.10	-.21*	-.07	-.13
10 Having a partner	.03	.05	<.01	<-.01	-.11	.20*	-.03
11 Having a paid job	.32**	.22*	.30**	.34**	.25**	.17*	.14
12 Higher education	.12	.08	.10	.18*	.11	.12	.07
13 SCI traumatic	<.01	.06	.08	-.14	.11	.09	.08
14 Paraplegia	-.11	-.02	-.04	-.25**	.11	-.14	-.07
15 Motor complete	-.19*	-.09	-.11	-.27**	-.06	-.05	-.10
16 Time since injury	-.32**	-.21*	-.18*	-.46**	-.09	-.14	-.21*

NOTE. * $P < .05$, ** $P < .01$ according to Pearson correlation analyses.

Abbreviations: MSES total: Moorong Self-efficacy Scale total score; MSES-General: Moorong Self-efficacy Scale General factor; MSES-Social: Moorong Self-efficacy Scale Social functioning self-efficacy factor; MSES-Personal: Moorong Self-efficacy Scale personal functioning self-efficacy factor; GSES: General Self-efficacy Scale; UW-SES: University of Washington Self-efficacy Scale; SCSES: Self-care Self-efficacy Scale; SCI: Spinal Cord Injury.

All the SE scales showed moderate to strong significant inter-correlations. With respect to the second hypothesis predicting strong inter-correlations between scales that measure at the same level, this was confirmed with correlations between 0.50 and 0.65 (circled in Table 4.4). However, the hypothesis that SE scales that measure GSE (MSES-General and GSES) versus DMSE (MSES-Social and UW-SES) versus SCSE (MSES-Personal and SCSES) would show moderate, but not strong inter-correlations could only be partly confirmed, where 7

out of 12 inter-correlations were strong (white in Table 4.4). These strong correlations were seen for the MSES-General with all scales/subscales, for MSES-Social with MSES-Personal, MSES-Social with SCSES and GSES with SCSES.

Age, being employed before the SCI and time since injury showed weak to moderate correlations with most SE scales. The MSES-Personal showed the strongest association with SCI-related variables (neurological level, completeness and time since injury).

Discussion

Self-efficacy is a key concept in theories about adjustment to chronic health conditions, such as spinal cord injury, linking competence beliefs to behavioral outcomes. As such it is an important target for intervention. However, for research as well as in rehabilitation practice, to develop this field further it is crucial to have suitable SE scales that measure general, domain and task-specific aspects.

In the current study, confirmatory factor analyses showed that, with some adaptations, all SE scales had an acceptable to good model fit in a one-factor model. For the MSES, an acceptable model fit for the three-factor structure could not be confirmed.³⁶ The inter-correlations between the three sub-scales of the MSES were high. In previous studies, exploratory factor analyses revealed diverging factor structures with strong inter-correlations between the factors.³⁵⁻³⁸ In most of these studies and the current study, the internal consistency of the MSES Total score was found to be excellent. Using the higher order one-factor total MSES score may therefore be preferred over the use of the three sub-scale scores. This finding is in line with a review showing that subscales resulting from exploratory factor analysis of self-efficacy scales should not be used as independent self-efficacy measures,²⁸ and many researchers using the MSES already only reported the total score.^{12,46-48}

For the GSES, internal consistency was good and the proposed one-factor structure was confirmed with the current data, although only after removal of 5 of the 12 questions.^{29,32} In previous research, a three-factor structure was found beside the one-factor structure within the GSES.^{29,32} This could indicate that a factor structure with more factors might result in a better fit, however, that was not further explored in this study. Similar to the MSES, it is recommended that the GSES be used as one-dimensional scale.²⁸

For the UW-SES, internal consistency was excellent and a one-factor structure with a good model fit was found after deleting one question. In prior studies investigating the internal validity of the UW-SES 6 item version by confirmative factor analysis and Rasch analysis, this one-factor structure was confirmed, without the deletion of question 4.^{42,43}

The SCSES showed an excellent model fit with a one-factor model after deleting one question. The internal consistency of the SCSES is good.

Based on these findings, it can be concluded that the internal validity of the MSES, GSES, UW-SES and the SCSES are all acceptable to good as one-dimensional scales after some adaptations to the scales.

With respect to convergent and divergent validity, the hypotheses could not be fully confirmed. All scales measuring SE at the same level (i.e., GSE, DMSE or SCSE) had strong inter-correlations. However, over half (7 out of 12) of the correlations between scales measuring different SE levels were strong as well. This result indicates better convergent than divergent validity for the SE scale and suggest a common latent construct exists underlying the scales. In previous research this has been argued for general self-efficacy and certain other psychological factors, like locus of control and self-esteem.⁴⁹ From the current study, it is not clear whether the trait scales also measure state aspects or the other way around. Inspection of the separate questions suggests that it is not very likely that the trait scales measure state aspects. The results therefor seem to indicate that it might be difficult to measure state aspects of SE, and that the current “state” questionnaires incorporate trait aspects. It could also be argued that the distinction between trait and state self-efficacy is pure theoretical. In addition, the findings of this present study reflect the complex nature of the SE scales, their factors and items that may incorporate various aspects of physical function, interpersonal relations, social participation, health and psychological wellbeing.

If both state and trait questionnaires tap into a core underlying trait construct it would, from a theoretical point of view, be more difficult to see changes over time. To our knowledge, there are no longitudinal studies in which scales were used that measure only state aspects of SE. A study using the GSES showed no overall changes in mean scores during inpatient rehabilitation, although there were some changes within individual participants.⁵⁰ Another study showed similar GSES scores at discharge (mean 65.6, SD10) and at five years post-discharge from initial inpatient rehabilitation (mean 64.5 SD 11.9).⁵¹ Previous research has shown some variation over time in the MSES total score from admission to discharge from SCI rehabilitation, and 6 months post-discharge.^{16,52} Most participants in the recent study by Craig et al.¹⁶ followed a stable trajectory and only a small percentage showed a decreasing trajectory of which is not clear that the change over time is significant. Another study with the MSES did not find significant change between admission and discharge.⁵³ A study using the Self-Efficacy for Managing Chronic Disease Scale, like the MSES both measuring trait and state aspects of self-efficacy, also did not find any change from inpatient rehabilitation and 3-months post discharge. One study that used the self-rated Abilities for Health Practice

Scale, a domain specific scale like the MSES, that measures both state and trait aspects of SE, did not find any change in scores after an intervention.⁵⁴

Further, the question has been raised whether current self-efficacy measurements actually measure self-efficacy rather than motivation.⁵⁵ By asking participants to indicate whether one “can do” the specific target behaviour, one unintentionally also measures aspects of motivation instead of self-efficacy. The authors argued that controlling for motivation by adding the phrase “if you wanted to” to each question could decrease associations between self-efficacy ratings and motivation.⁵⁵ More research is needed to understand the specific features of state SE and how this concept can be transformed into questions that are sensitive enough to measure changes if the circumstances in a person’s life alter or when receiving an intervention.

Nonetheless, self-efficacy is a central concept in rehabilitation psychology and is predictive of adjustment after SCI.^{9,15,56} These studies were conducted using scales that appear to measure a combination of trait and state aspects of SE. One could argue that scales that explicitly measure state aspects of SE, in which domain-specific knowledge and skills are needed to meet the challenges associated with living with a SCI, would be even more predictive.²⁵ However, it is also possible that GSE may moderate the impact of certain environmental factors on an individual’s domain or task-specific SE. In terms of improved measurement, it has been suggested that custom-made short-forms that measure different levels of SE (e.g., high vs low) may provide greater precision, with the potential to develop separate norms.³³ Within the SCIAM model, a division is made between trait aspects of SE, as part of the psychological factors, and state aspects of SE, as part of the appraisal and reappraisal process, the so called “engine room”. The performance of this latter process is seen as crucially important for adjustment and therefore even more important for predicting adjustment following SCI.

Study limitations

In this study, a relatively small sample size was used, and for this reason the interpretation of results from the confirmatory factor analyses, especially for the MSES with 16 questions, must be approached with some caution. We believed this step, however, was nevertheless necessary to determine whether the data in the current study behaved in a similar way to that in former studies. Further we combined two cohorts, from two countries, while largely the same they had different sample sizes. Lastly, the SCSES was modified from the Managing Disease in General Subscale of the Self-efficacy for Managing Chronic Disease Scale and being a new scale had not been validated prior to this study.

Conclusions

Based on confirmative factor analysis all four scales showed acceptable to good model fit for a unidimensional SE construct, with some minor adaptations, confirming their internal validity. Convergent validity was confirmed, although the expected distinction between SE as a state versus trait construct (divergent validity) involving different levels (GSE, DMSE and SCSE) could not be fully demonstrated. Further research is necessary to find ways to better measure state aspects of SE, which are sensitive enough to capture change over time. If no such scale could be developed, a change in the theoretical model must be considered.

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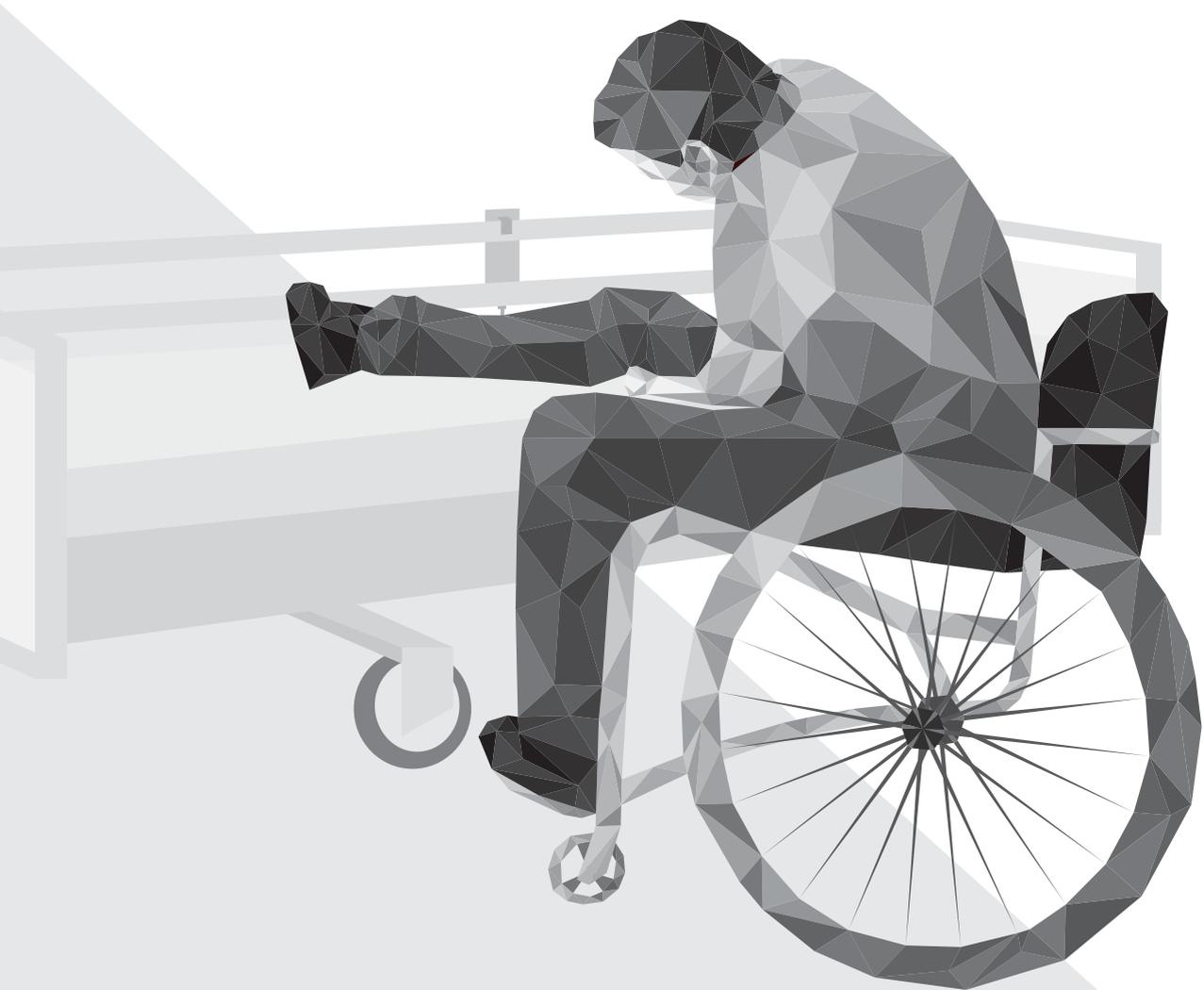
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Part II

Results



Chapter 5

Learning self-management after spinal cord injury: a qualitative study

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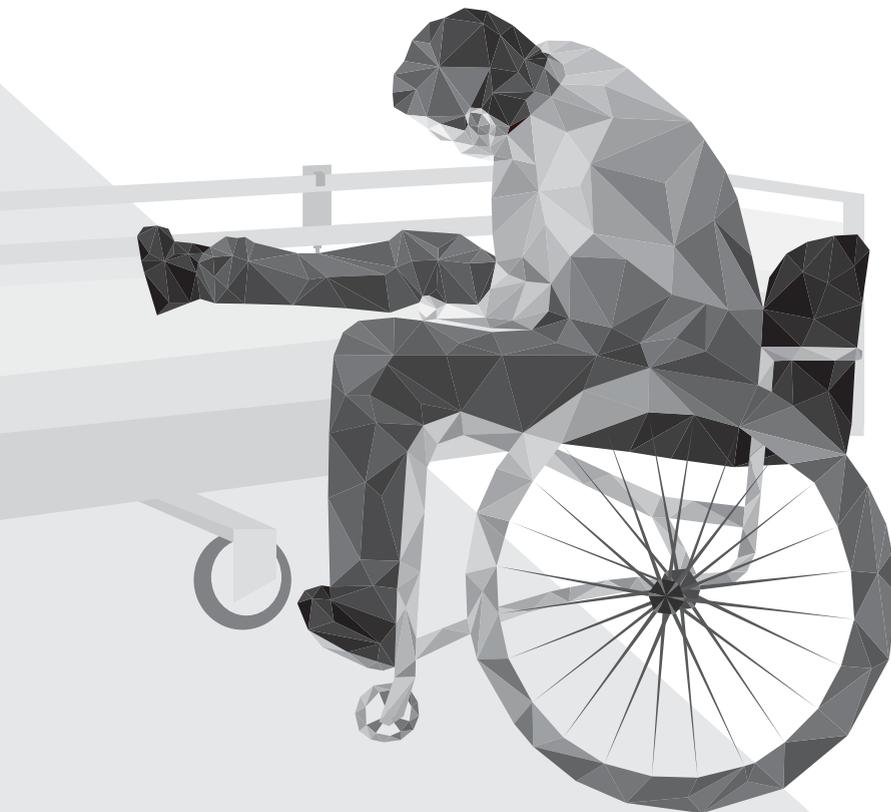
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Abstract

Objective: To describe how people with spinal cord injury (SCI) experienced the process of learning self-management skills during inpatient rehabilitation and the contribution of the rehabilitation team to this process.

Method/design: Individual semi-structured interviews with 15 people with SCI, who were recently discharged from initial inpatient rehabilitation. Interviews were audio-taped, transcribed and analyzed thematically. Nine themes were identified.

Results: Participants underlined the importance of learning how to perform self-management appropriately. This included both the *self-care* and the prevention of *secondary health conditions (SHCs)*. Important themes affecting the participants' *attitude towards learning self-management* were take initiatives and their mindset (think positively and acceptance). *Gaining of confidence* was experienced by most participants as stemming from their own nature. The part that was not seen as their own effort was often described as a team effort. Participants mentioned various strategies employed by the professionals to learn self-management: *learning by doing, motivation and information*. The use of these strategies varied across disciplines. Other factors of influence were: *running out of time* especially the nursing staff and the *interpersonal approach*. Many participants distinguished between therapy and care, e.g. between physiotherapist/occupational therapists and the nursing staff.

Conclusions: The strategies used by the rehabilitation team to help people with SCI to perform their self-management appropriate was also helping the participants to gain self-efficacy. This is in contrast with the idea of the participants that this last part was belonging to their nature. Learning to perform self-management requires an interdisciplinary approach, where segregation between disciplines has no place.

Introduction

Implications for rehabilitation

- Little is known about the way people with spinal cord injury learn to perform appropriate self-management (self-care and prevention of secondary health conditions).
- Learning by doing, used in its different ways, not only improves appropriate self-management it also helps to gain confidence, which in turn will help to improve self-management.
- Learning to perform appropriate self-management is a team effort that enquires all disciplines of the rehabilitation team, including the psycho-social.

Spinal cord injury (SCI) is a highly disabling condition.^{1,2} Besides experiencing motor, sensory and autonomic impairments, people with SCI are also at risk for the occurrence of secondary health conditions (SHCs), such as urinary tract infections, musculoskeletal and neuropathic pain, pressure injuries, edema and spasticity.³ These impairments and SHCs may restrain people with SCI from participating in daily life activities and reduce their quality of life.^{1,4,5} To deal with these impairments and to prevent SHCs, appropriate self-management is highly important for people with SCI, including those who are assisted by formal or informal caregivers.

Self-management is defined as the individual's ability to manage the symptoms, treatment, physical and social consequences, and lifestyle changes in accordance with living with a chronic disease (Chronic Care Model).⁶ The execution of self-management by people with a disability not only depends on knowledge but also on skills and confidence in managing their condition.⁶ Learning self-management skills is an important part of the intensive rehabilitation program most people with a recently acquired SCI receive.⁷ This learning requires involvement of the entire rehabilitation team.⁸

To date, there is not much academic attention for this process of learning self-management skills during initial rehabilitation in the subacute phase. Most studies on self-management among people with SCI focus on the chronic phase, or on a specific aspect of self-management e.g. skincare.⁹⁻¹² In two reviews of qualitative studies on the experience of rehabilitation following SCI, no studies were included that had learning to perform self-management as their primary objective.^{13,14} Nevertheless, certain themes related to learning self-management were identified in these reviews. These themes included the need for support by professionals, the importance of specific staff qualities and their vision on future live possibilities, building self-confidence, and motivation.^{13,14} Participants described the importance of a supportive and encouraging team for successful rehabilitation.¹³ A caring

relationship with the team members helps and has been described as a process in which participants started as passive recipients of information and gradually developed into active agents who had the opportunity to find out what they needed themselves.¹⁵ An increase of self-confidence during rehabilitation was described in multiple studies, within the review. This increase in self-confidence enabled the participants to try new activities or to return to activities they did prior the onset of SCI.¹³ Rehabilitation also played an important role in making the participants mentally and emotionally stronger which in turn helped to increase motivation.¹³ Despite these findings, it is still unclear how self-management skills are taught to people with SCI during inpatient rehabilitation. It has also been noted that developing self-management skills is not always given sufficient priority by team members, because of a primary focus on the physical aspects of rehabilitation, insurance reimbursement policies, and cultural values associated with family caregiving.¹⁶

Therefore the objective of this study is to describe how people with SCI experienced learning self-management skills during initial inpatient rehabilitation and how they experienced the contribution of the rehabilitation team to this learning process.

Materials and methods

Study design

This study had a descriptive qualitative design and data were collected using face-to-face interviews. This approach was employed as there is a paucity of research on how rehabilitation team teaches self-management skills to people with SCI in initial inpatient rehabilitation phase. The qualitative descriptive approach is a good starting point for topics about which little is known.

Participants

The present study is related to a large cohort study in which the development of self-management skills and self-efficacy after SCI is being investigated with quantitative methods (SELF-SCI study).¹⁷ Participants in the SELF-SCI study were recruited for the current study between February and May 2017. Based on the interest in self-efficacy as conditional for performing self-management, participants were purposively selected. By applying this selection, the aim was to get variation in self-efficacy that could be related to the experience of learning self-management.

Procedures

Participants in the SELF-SCI study could indicate in their discharge questionnaire whether they were willing to participate in this qualitative study. As part of the quantitative study all participants filled out the University of Washington Self-efficacy Scale 6 item version (UW-SES-6),^{18,19} a disability-management self-efficacy scale. The scores of this questionnaire were divided into low, average and high. Initially, only potential participants with low or high UW-SES-6 scores were invited. Since the inclusion went slower than anticipated, potential participants with average scores were also invited. After analyzing the data of the first 13 participants, it turned out that most of them expressed confidence in handling the consequence of the SCI, even if they had lower scores on the self-efficacy scale. To investigate if including more people with low scores would give additional information, two more participants with low scores on the UW-SES-6 were invited in November and December 2017. Since the answers of these two did not add substantial new information, saturation was assumed.

Data collection took place in a single face to face semi-structured interview between two and five weeks after discharge from inpatient rehabilitation. The interview took place at the participant's home or a rehabilitation facility, depending on the participants' preference. All interviews were digitally recorded and transcribed verbatim for data analysis. The Ethics Committee of the University Medical Centre Utrecht declared that this protocol did not need formal ethical approval under the Dutch law regulating medical research on human beings (reference number: 15-449/C). Next, in accordance to the local requirements, the Medical Ethics Committees of all participating rehabilitation centers approved this protocol. The study was carried out according to the code of conduct formulated by the Helsinki code, as part of that all participants gave written informed consent before entering the study.

Interview

The interviews lasted between 45–70 minutes and were conducted by the first author, a trained psychologist with 15 years of experience in SCI rehabilitation, assisted by two trained master students. The interview guide consisted of semi-structured open-ended questions. Probes or recursive questioning were used during the interviews to explore issues in greater depth and verify the interviewer's understanding of the information being collected.

The complete list of questions is included in Appendix 5.1. Three major questions were asked by the interviewer concerning how participants; looked after their body; prevented SCHs; and gained confidence during their inpatient rehabilitation. For each of these aspects the participants were asked to describe what they learned and how the rehabilitation team contributed to this learning process.

Data analysis

Data analysis was conducted in an iterative manner using inductive thematic analysis, in order to understand how people with SCI experienced learning self-management skills during inpatient rehabilitation and how the rehabilitation teams facilitate that learning. The first transcripts were independently coded by two master students, giving full attention to all data. The results were discussed with the first author until consensus was reached. After this open coding, axial coding followed in which already existing codes were refined, differentiated and linked with each other. The last step was selective coding, in which the core themes were identified, and other themes were linked together or themes that needed more explanation were developed and refined. The results were discussed with the last author (MP) and adjusted. After this last adjustment, the coding framework was applied for all transcripts. MAXQDA 18.2 (VERBI Software, 2017) was used to organize and analyze the data.

Results

A description of the participants can be found in Table 5.1.

Table 5.1 Description of the participants

Participant	UW-SES-6	Age	Gender	Higher Education*	Having a partner	Height SCI Start (End)**	AIS Start (End)**	Admission in days
A	29 (High)	56	Male	No	Yes	T4 (L1)	D	91
B	26 (High)	64	Female	Yes	Yes	C4 (C3)	D	91
C	25 (High)	56	Male	No	Yes	T4	D	92
D	24 (High)	56	Female	No	Yes	T10	D	44
E	24 (High)	54	Male	No	Yes	C7	C (D)	113
F	24 (High)	42	Female	Yes	No	C3	D	39
G	23 (High)	72	Female	Yes	Yes	C4 (C5)	D	37
H	19 (Middle)	62	Male	Yes	Yes	T9	D	77
I	18 (Middle)	69	Female	Yes	Yes	T11	D	57
J	16 (Middle)	30	Female	Yes	Yes	T1	D	56
K	15 (Low)	79	Female	No	No	T12	C (D)	80
L	14 (Low)	57	Male	Yes	No	C5 (C6)	D	64
M	14 (Low)	65	Male	No	Yes	C3	C	203
N	11 (Low)	69	Male	No	Yes	T11 (L1)	C	85
O	11 (Low)	56	Female	Yes	Yes	C5 (C6)	A	250

NOTE. * Higher education = bachelor degree or higher. ** Start (and end) of inpatient rehabilitation if there is a difference. Abbreviations: UW-SES-6; University of Washington Self-efficacy Scale six item version. SCI; Spinal cord injury. AIS; American spinal cord injury association Impairment Scale.

The themes identified from the interviews will be described in three parts; (I) themes with respect to the general remarks of the participants about self-management, divided into self-care and SHCs. This last theme itself is sub-divided into preventing SHCs and susceptibility to SHCs; (II) themes with respect to the contribution of the participants. In this part the attitude of the participants towards self-management (sub-divided into taking initiative and mindset) and their experience towards gaining confidence (i.d. self-efficacy) will be described; (III) themes regarding the contributions of professionals, including: Learning by doing, Motivation, Information, Running out of time, and Interpersonal approach.

I: Self-management

Self-care: The participants mentioned various aspects of self-care. This ranged from activities of daily living including bathing, clothing, brushing teeth, bladder and bowel management, taking care of their intake, transfers including changing position in bed or wheelchair, to taking enough rest, and responsibility for their medicines. Most participants did not need any assistance with their self-care, or needed just a helping hand from their informal caregivers, mostly their partner. Nevertheless, this took them much more time than they were used to and they had to pay close attention while performing these activities because the automaticity was lost or they had to do it in an adapted way.

Quote participant L: “You have to approach ordinary things in a different way, because they just take much more time. Both showering and getting dressed. You have to think about everything, what you previously did automatically, is not automatic anymore.”

Three participants needed formal caregivers, one because the adaptations to the house were not ready, the other two because of insufficient functionality of their hands and arms. These three participants also had to know what was needed for their care, even if they could not do this themselves, in order to be able to instruct their caregivers to do it for them.

Most people indicated that they regained independence in their self-care because of their remaining skills and the skills they developed during rehabilitation. Multiple participants described how they could not do any self-care activity at the start of rehabilitation, and how they regained the functionality of their body, like the use of their hands or being able to stand or walk.

Secondary Health Conditions: The SHCs most often mentioned were pressure injury, pain, spasms, urinary tract infections and sleep problems (trouble sleeping because of noise on

the ward, or sleeping more and deeper after SCI). Most participants stated that they did not experience much SHCs during their stay in the rehabilitation center. Those who did experience SHCs described this as really disturbing their daily routine or as a major setback.

Quote participant O: “I suffered serious setbacks because I have recurrent skin problems; that is, pressure ulcers. And time and again I get another skin mark, and have to lie in bed another week....[later on] Actually, the worst part of a spinal cord injury is not that you lose the use of your legs. A much bigger problem is pressure sores, lung infection, in-growing toenails, and all that business with your bowels.”

For most participants, the ‘*preventing SHCs*’, or dealing with them if they did occur, was of great importance. More than half of the participants thought they were able to prevent SHCs occurring.

Quote participant E: Interviewer: “But do you think you are able to prevent SHCs?” Participant: “Yes. Because of the information given and because I know what to look out for.”

To prevent SHCs, participants had to be constantly alert about a lot of aspects in their lives. These participants stated that being alert to avoid SHCs was an ongoing process during the day, checking their body or asking others to do that for them, e.g. in case of a possible pressure injury.

The minority of the participants were not all that sure they could prevent SHCs occurring. These participants had some experience with SHCs in the past, despite the preventive actions during the rehabilitation phase. Some learned effective ways to prevent SHCs, others stated that despite their knowledge they were not fully able to prevent SHCs from happening.

Quote participant O: Interviewer: “Do you think you are able to prevent them [SHCs] occurring?” Participant: “Not completely. But of course I can do my very best.”

Only a few participants thought that they were more ‘*susceptible to SHCs*’ now compared to before SCI. The others did not consider themselves as being more susceptible to SHCs as long as they followed the actions they were learned by the rehabilitation team. They had to be more aware of problems that might occur.

Quote participant I: “But I am now very conscious that this [wearing jeans with a back pocket] can produce a mark [pressure injury]. So I have become very aware of this.”

Some participants stated that they did not yet know if they were more vulnerable for SHCs, because of the SCI was relatively recent.

Quote participant B: “So far I haven’t experienced that. But it takes more time to foresee things now, so I’ll have to wait and see. I can’t say anything more, about whether I’m more vulnerable.”

II: Participant’s contribution

Attitudes towards learning self-management: Many participants stated that learning appropriate self-management was very important to them. An important strategy to get this done was ‘*taking initiative*’. This was done in different ways, for some by setting goals for themselves. This helped them to try to do activities themselves before asking for help. To achieve their goals participants needed to be persistent and inventive in finding solutions for things they could not do, and to see that as a challenge.

Quote participant F: (about making a sandwich) “I wanted ... to do everything myself, so I refused help. Thinking: if it takes me half an hour, then it takes me half an hour.”

Quote participant M: “Of course, you’ve got to do everything yourself, also go out on your own. So: as soon as I could manage the wheelchair, I went to the village, and to the beach, and that kind of thing.”

Some participants stated that they thought that other patients on the ward had more need of help from the nurses, and for this reason they did not ask for help.

Quote participant D: “Yes: they [nurses] help you and dress you ... they are so ... they have got also all those people with a complete spinal cord injury, those boys who need much more care. So you try to do as much as possible yourself, in order to spare them [the nurses], so I don’t keep on ringing the bell.”

This initiative of the participants was, according to some, implicitly expected by the team members. Others said that they took the initiative to communicate with the therapists about adaptations, aids or a specific therapy which they believed was necessary at that point of time. Another way of looking for answers was, for some participants, searching for

information concerning their condition or SHCs on the Internet. This own-initiative was time-consuming, but was seen by most of the participants who used these strategies as a way to maximize the outcome of the rehabilitation.

Participants described different ways of thinking or '*mindset*' that helped them to get the best result from rehabilitation treatment, including self-management. One often mentioned mindset was thinking positively, instead of giving in to sad feelings, and of doing nothing which was not seen as directly helping.

Quote participant G: "Even if your body doesn't work, you've got to sure your mental approach. You have to convince yourself you're worthy, that you have something to give."

Quote participant A: "But once again: I've got my illness and I'm going to solve it ... I'm not going to get depressed."

Other participants stated that as part of the mindset they had to accept that there were activities which they might not be able to do anymore. Not being able to do some of activities as previously was confronting. At the same time, clarity about what they still could do and could not do anymore seemed important to some participants to be able to accept their situation. Most of these participants were happy that their condition was not worse. Some participants also mentioned the importance of resetting their priorities about activities that were important in their life, for instance the importance of family above of work. Others talked about enjoying the things they still could do.

Experience towards gaining confidence (self-efficacy): During the interviews, the participants were asked how they gained confidence in doing their self-management and in handling the consequence of SCI during their rehabilitation. From the 15 participants, five scored low on a disability-management self-efficacy scale (see Table 5.1). Some of these low scorers however did not describe themselves as having low confidence during the interviews. They described themselves as being fairly certain about themselves and the way they could handle the consequences of SCI.

Most participants stated that their confidence increased during the rehabilitation. This increase depended partly, according to some participants, on the natural recovery of functions after SCI. On the other hand, physical setback could have a negative influence on confidence. Confidence in self-management and in handling the consequence of SCI was seen by most participants not as a static state of mind, it fluctuated depending on their situation. For the majority of the participants, the growth of confidence was seen as part of their nature, belonging to their personality, and not taught by professionals of

the rehabilitation team. Nevertheless a lot of the participants also mentioned a variety of actions by the rehabilitation team that could be seen as training to gain confidence (see professionals contribution). Confidence and acceptance, but also hope, were mentioned together several times in combination, as if they belong together for these participants. For some, the realization that they could not do all the activities they wanted to do or were used to do was felt as a burden and decreased confidence.

III: Professionals' contribution

When the participants were asked what the contribution of the different disciplines was, with respect to learning bodily care after SCI, most participants answered this by telling what the occupational therapist or the physiotherapist did for them during the rehabilitation period. Most participants did not mention the nursing staff spontaneously when asked which discipline helped them to learn bodily care. When asked directly about the role of the nurses, many participants stated that the nursing staff was (one of) the most important disciplines in learning self-care activities, and also in preventing SHCs. For most participants, physiotherapy seemed to be their favorite discipline for rehabilitation in general. With respect to self-care, some participants attributed a very important role to physiotherapy, while others saw it more as conditional, namely training skills needed for self-care, or did not see a role at all for the physiotherapist. Besides the nursing staff, occupational therapy and physiotherapy, all other disciplines from the multidisciplinary team were also mentioned as contributing to self-management, although not very pronounced.

Learning by doing: One of the most frequently mentioned strategies to teach the participants to perform self-management could be called "learning by doing". The application of learning by doing varied between the disciplines. For the nursing staff, learning by doing was often integrated in their work as a graded activity. The nurses took over complete care in the beginning and showed the participants what to do by telling what they themselves did, and why they did it in this particular way. Depending on their capabilities, the participants were supposed to do more and more of the activity independently over time. Most participants mentioned this strategy as being very smooth, almost natural. Some experienced this approach as a (positive) pressure.

Quote participant G: (about the nurses role in learning self-management)
"For instance when you have to dress yourself you ask the nurse; how can this be done? And she says I will help you less and less."

The occupational therapists used the strategy of learning by doing to compensate for lost functions in day-to-day situations. The participants were told to perform the affected skills in a modified way, or what aids could be used to compensate, then this was put to practice. During the training, tips and tricks were added to get the best functional possibilities. Dependent on the participant's goals, some occupational therapists performed a clinical observation during the morning routine on the ward. This seemed not to be a daily practice in all rehabilitation centers.

Quote participant E: "They [occupational therapists] came and stood next to me, especially in the beginning. Then I had to do it by myself, and they watched what went wrong. Then they intervened and told me how it could be done better, and what was easier."

For the physiotherapists learning by doing was seen, by most participants, as teaching them step-by-step. Within this approach, first information was given about the goal and how it could be achieved, then the first small step was practiced before going to the next. Along the way old and new instructions were given, until the activity was learned.

Quote participant J: "Thru the physiotherapist, who in stages, tries to improve all the arm functions and the leg functions. And to get the strength back."

Quote participant A: (During walking practice) (imitate voice of physiotherapist) "What did we say: get your back straight and ... (in own voice of participant) Yes, I know it (laughing), Don't take big steps"

An important side effect of this learning by doing strategy was that it also increased the confidence of the participants.

Quote participant N: "They [the rehabilitation team] made you aware of your limitations and also of your possibilities."

Quote participant K: "It goes from wheelchair, to rollator, to crutches, to a walking stick, and then to nothing. Every time you increase your self-confidence."

Not only by letting the participants experience what they can do, but also by reminding them about the progress, the team members helped to increase confidence.

Quote participant E: "They [the staff members] point out: ... first you couldn't do that, and now you can."

For participants it was hard to tell which discipline in particular helped them regaining confidence. The part that was not seen as belonging to themselves was often described as a team effort of all team members.

Quote participant B: “An effort of everyone [in the rehabilitation team], whereby you start doing things again as soon as possible – and dare to do and are not afraid of ... That applies also for the peer supporters. Actually to everybody, they all had a positive contribution.”

Some participants stated confidence might have increased as a result of a combination of their own initiative, the contribution of others (team members, peers as well as family members) together with the experience of doing different activities and returning to activities participants did before SCI.

Quote participant E: (After talking about gaining confidence and the help from team members and partner) Interviewer: “What has given you back the most confidence? What has helped most?” Participant: “I can’t say what has helped me most. I think that it’s everything together. All the disciplines together. And yes – once again – my wife, she too was very important.”

Quote participant I: Participant: “I’ve got quite a lot of confidence in myself.”

(Later on in the interview) Interviewer: “how has [name of the rehabilitation center] contributed?” Participant: “By stimulating you in all sorts of ways. And creating the conditions under which you can make progress ... I mean: it’s there and it is offered to you. They see things sooner that you can.”

A specific aspect of learning by doing applied to the participants who could not do the self-care themselves, they had to learn how to instruct the (in)formal caregivers to do the care for them. This part of self-management was mostly learned by experiencing the care in the rehabilitation center during the normal routine, mostly by the nursing staff. While undergoing these daily routines the participants were taught how to instruct their future caregivers.

Quote participant O: “... and they [the team members] have always made clear: you are in control. That’s the way they bring you up. YOU are the specialist and actually it’s for you to teach the home carers. You must say precisely what you want; even though that’s sometimes irritating. You don’t want to have to explain it 100,000 times. But if you don’t say it; and if, for example, the catheter is lying under your leg, then

you know for sure that you'll be on your back for two weeks. So you've just got to notice it yourself."

Motivation: A strategy that was mentioned by different participants concerning learning self-management, used by different disciplines, was motivation. Motivation consisted of two aspects: stimulating the participants to take actions that they did not think were possible, and second ensuring the participants that the professional believed they could do it. This second part tapped directly into the self-efficacy of the participants. This strategy of motivation was used by different disciplines in different situations. For instance, the nursing staff applied this strategy by challenging the participants. This sometimes confrontational way helped the participants to realize they could do more than they imagined.

Quote participant C: "At a certain moment they [nursing staff] challenge you. You did it last week, you did it yesterday also, ... so now you can do it yourself. And you can!"

On the other hand, team members were also protecting the participants against their desire to do too much themselves.

Quote participant I: "And then the nurses point out: Watch it! You are asking too much from yourself. Call one of us to help you."

Information: The participants found information on self-management, given by the professionals during the rehabilitation treatments and during the formal information meetings, very important. The information given was helpful in understanding the importance of self-management and especially in how to prevent SHCs. Further, the information helped to gain confidence in handling these consequences of SCI. Also the information about the expectancy of recovery, and the influence of therapy, helped some to increase confidence. This information only could be given by the team members because they had the specific knowledge about SCI and possible complications. The team members gave this information, understanding well the participants needs. A strategy that was mentioned in combination with providing information was learning to recognize the changed signs and signals from the body.

Quote participant C: "Everything ... so much in my body feels different from before. And if I go to the toilet, that too feels different. I've got to learn it again, to recognise it again."

Running out of time: Another factor mentioned, especially in relation to the nursing staff, is shortage of time. This is not a strategy that seems to be used intentionally, but derives from the fact that especially nurses but, also some occupational therapists, were so busy that they did not have time to respond immediately to every request. While waiting, a lot of the participants tried to do the activity themselves and found out ways to accomplish the task they were asking help for.

Quote participant F: “And then I went to the toilet. I remember that I had just entered [name hospital], and I couldn’t wipe myself. And there I sat forgotten on the toilet. And then I thought: OK, I can’t do it well myself, but I’ll do it. Even if it takes me half an hour. I think that helped me a lot.”

Interpersonal approach: An aspect that was mentioned by different participants as influencing learning self-management was the interpersonal approach of the professional. The professionals were often described as resolute in their approach.

Quote participant N: “And you’re inclined to say: today is an off-day, we shan’t do much. The physiotherapist knows how to handle that. (Laughing) They keep you to it ... and that’s good.”

Other professionals were described as tough (sometimes too tough) and confrontational, while others were described as having the soft touch or being encouraging. One participant described how the different approaches by different physiotherapists worked for her.

Quote participant G: “The soft and the hard complement each other. He [male physiotherapist] was the unspoken force and they [two female physiotherapists] gave encouragement: you can do it, you’ve done it so far, come on.”

In addition, professionals were described as being practical and not too cautious or afraid something might go wrong.

Quote participant A: (About the nursing staff) “And they [nurses] weren’t afraid and not like ‘ieehh’ ... No they just did it. Like myself, they have the attitude do it, and if you can’t, then you can’t we’ll see it from there.”

Several participants stated the normalizing attitude of the professionals (e.g. nursing with regard to incontinence) helped them to overcome shame, gain confidence and therefore better be able to learn self-management.

Quote participant L: “In particular with bowels and urine. If that goes badly, you’re ashamed of yourself. They say: you can’t do anything about it, we’re here to help you. They put you at ease and you needn’t be embarrassed.”

Some participants described a special mutual bond they had with one or some team members. These team members made them feel special. More in general most participants described the relationship with the different team members as respectful, based on mutual respect. From this respect participants were able to receive emotional support from different team members.

Quote participant L: (about treatment from psychologist) “It is indeed important. Because I tell my story to family and friends. But it’s good also to tell it to someone with whom you have totally different connection. ... (further on) That gives you a bit of peace actually, it’s the most important.”

Discussion

To understand how people with SCI experienced learning appropriate self-management skills during inpatient rehabilitation and the contribution of the rehabilitation team to this learning process, 15 people who had been recently discharged from clinical SCI rehabilitation were interviewed. Participants found it helpful for learning appropriate self-management to take initiatives, think positively and accept the current situation. Gaining of confidence was experienced by most participants as stemming from their own nature, the part that was not seen as their own effort was often described as a team effort. Participants mentioned various strategies employed by the professionals to learn self-management. Most frequently mentioned was learning by doing. Further strategies were motivation and information. The use of these strategies varied across disciplines. Other factors of influence were: running out of time especially for the nursing staff and the interpersonal approach. Many participants distinguished between therapy and care, e.g. between physiotherapist/occupational therapists and the nursing staff.

Almost all participants found it very important to learn and to perform self-management appropriately. This included both the self-care and the prevention of SHCs. Most participants did not experience themselves as being susceptible to SHCs, as long as they did the things they were taught by the rehabilitation team. Further, almost half of the participants were not certain that they could prevent SHCs from occurring. One factor explaining this discrepancy might be the relatively short duration of rehabilitation and thereby the participant’s limited

experience with SHCs. Without actual experience of having SHCs, it might be difficult to learn how to handle them or to remember and use the information provided. People with SCI living in the community state that more information about SHCs is necessary.²⁰⁻²² Although the participants in the current study did not seem to think that there was a leak of information, it is important to be critical how education during rehabilitation can be optimized and integrated into the rehabilitation program.²³ It has been suggested to do this by increasing the number of opportunities for learning.²⁴ Another explanation for the found discrepancy, might be that in Dutch the word for susceptibility has a negative connotation, associated with weakness of the person and that the participants do not want to see themselves this way. For the professionals working with people with SCI it is important to recognize the difference between the experienced susceptibility and the vulnerability. Rehabilitation teams should especially be alert for almost half of the group of participants that stated they were not certain they could prevent SHCs from occurring. For this group it would be recommended to check if the given information has been delivered well and the necessary skills were learned adequately.

With regard to their attitude towards performing self-management, many participants stated that it helped them to take initiative, set goals for themselves, e.g. by doing before asking, and by finding solutions for problems that they might encounter. Their mindset by thinking positively and accepting the fact that they could not do everything anymore was frequently mentioned as a helpful attitude for successful SCI rehabilitation in general and self-management as part of that. These aspects not only seem to be beneficial for learning self-management they were described as benefits of rehabilitation in general.¹³ Some participants said that this attitude was implicitly expected by the rehabilitation team. Awareness of these aspects as being an important rehabilitation outcome, could make them a point of engagement for the whole rehabilitation team, including the psycho-social disciplines.

Most participants stated that their confidence increased during the rehabilitation, and they attributed this increased confidence to their own personality and efforts. In a review of qualitative studies concerning the experiences with rehabilitation, an increase in self-confidence was seen as the basis for participants to try new activities, or return to activities they previously enjoyed.¹³ Based on theory and therapeutic experience, it would seem to be the other way around.²⁵ Either way, the experiences which the rehabilitation team offers, as part of their treatment, break the circle and will lead to an increase of confidence. This increase in confidence will make it easier for the participants to undertake more or new activities which will increase confidence further. This process seems so incorporated and natural to the participants that they initially indicated that gaining confidence came from their own personality, rather than being a result of the rehabilitation treatment. A more nuanced view was described by some of the participants when the interview got into more

depth. These participants stated that gaining confidence came from a combination of their own initiative, the contribution of others (team members, peers as well as family members) together with the experience of doing different activities during their rehabilitation program. The contribution of the rehabilitation team was more seen as a team effort rather than coming from one or more disciplines. This combination of factors was also in previous qualitative studies identified as important factors of rehabilitation.^{13,26} Gaining confidence is important because of the strong association between high self-efficacy with lower depression and anxiety and a higher quality of life.^{27,28}

Not all the participants with low scores on a disability-management self-efficacy scale talked about themselves as being insecure in self-management or in handling the consequence of SCI during the interview. This could be explained by the fact that in a questionnaire specific behavior is being questioned. Furthermore, people might be less inclined to admit that they were insecure during an interview that during (an anonymous) questionnaire. Most participants who had doubts about their confidence were not able to do the care themselves (at the time of the interview). This required a different self-management, in which they had to develop management skills to instruct their formal caregivers. These participants did not describe substantial different teaching methods by the team members. Although they were taught somewhat different skills, the used strategies were basically the same. The fact that most participants who described themselves as uncertain during the interview also needed help from formal caregivers, might be based on coincidence. In literature, there is no correlation found between self-efficacy and level or completeness of SCI.^{19,29}

With respect to the role of the multidisciplinary team, the nurses, occupational therapists and physiotherapists were the most important disciplines that learned self-management skills, according to the participants. The most frequently mentioned strategy which these three disciplines used in different ways, was learning by doing. Within this learning by doing, all therapists used verbal instructions and demonstrated what was expected. In this way the three important learning styles of (adult) learners were met; visual, auditory and kinesthetic.³⁰

Other important strategy, according to the participants, used by the professionals to teach self-management, was motivation. The motivation consisted of two aspects: stimulating the participants to take actions that they did not think were possible and second to assure the participants that the professional believed they could do it. Motivation was found in a review of qualitative studies to be one of the main themes of physical rehabilitation of people with SCI.¹³

Another aspect that helped participants to learn self-management was shortage of time, especially by the nursing staff but also by occupational therapy. This strategy was not

intentionally used, but helped the participants to try to do activities for themselves instead of waiting for the professionals. While trying participants found ways of accomplish the task they were asking help for.

The last theme mentioned as helpful to learn self-management was the interpersonal approach of the team members. Although there were large differences in their interpersonal approach between the individuals in a professional team, the participants spoke in general with a lot of respect for the team members and that respect was felt as mutual. In former research, the support from the rehabilitation team, and working together as a team with the professions, were found to be important aspects of rehabilitation.¹³ In other studies, a respectful professional caring relationship was found the base for learning in rehabilitation.^{15,31}

A more general message from the interviews was that most participants seem to associate the rehabilitation process of learning new skills, including self-management, with the occupational therapists and physiotherapists and not with the nursing staff. In former literature, the key role of the physiotherapist and the complementary role of the occupational therapist in SCI rehabilitation, according to patients, has been described.³² Also, the segregation between allied health professions and nursing staff has been found before, although this was from the professionals' point of view.³³ As a result of this segregation nurses and allied health professionals were frequently not working effectively towards the common goals, this is the goals of the people with SCI.³³

Limitations

During the inclusion period, to recruit participants was harder than expected. For this reason, not only people with high or low scores on a disability-management self-efficacy scale were invited, also people with a middle score. This resulted in a relatively few participants with low self-efficacy scores. It seemed that people with low self-efficacy scores were less willing to be interviewed. However, inclusion of two more participants with low scores after the initial inclusion period, did not bring up new themes and therefore we think this will not have influenced the results.

Further the participants were recruited from different rehabilitation centers. This resulted in small numbers of participants per center. These small numbers made is hard to give well-grounded differences between the centers. Although there might be some slight differences in approach there were not found substantial difference between the rehabilitation team. On the other hand are the found results not depending on only one center and therefore more applicable for all people after their initial SCI rehabilitation.

Conclusion

The strategy most frequently mentioned by the participants, used by the rehabilitation team to help them to perform their self-management appropriately, could be called “learning by doing”. This strategy was performed in different ways by the different disciplines. By using this strategy the disciplines let participants experience various activities, which was a very important aspect of gaining confidence.^{25,34} The way the rehabilitation team practices this learning by doing was for most participants so natural that they do not experience this as therapy for gaining confidence. Most participants thought that this gaining of confidence comes from themselves.

Many participants distinguish between therapy and care, e.g. between physiotherapists / occupational therapists and the nursing staff. However learning appropriate self-management skills requires both sides; learning in a systematic way how to take of a body with limitations, how to prevent SHCs and how to manage all consequences of SCI. In the process of learning self-management, segregation between nursing staff and allied health professionals is not being helpful. Further the psycho-social disciplines can support the process of learning appropriate self-management by tapping into the attitude and mindset of people with SCI. An interdisciplinary approach, with all disciplines working together in teaching self-management skills is highly recommended.

Supplier

VERBI Software. (2017). MAXQDA 2018.2 [computer software]. Berlin, Germany: VERBI Software. Available from <https://www.maxqda.com>

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Appendix 5.1

Topic list

How are you today? What makes it good/bad?

1. How do you take care of your body?
 - What do you do yourself, and what is done by others?
 - How was this accomplished by [Name rehab center] during the rehabilitation?
 - Which disciplines had contributed?
 - How did these disciplines contribute?
 - What has been helpful for you, in learning to take care of your body?
 - What have you experienced as a barrier learning how to take care of your body?
 - How did the spinal cord injury peer supporters contribute to learning how to take care of your body?
 - How did your family/friends play a role in this process?
 - What did [Name rehab center] teach your family/friends regarding your needed care?
 - To what extent do you have the confidence that you can take care of your own body?
 - Has the approach to treatment changed during the rehabilitation process?
 - Have you missed anything in this process? What could be improved?

2. A spinal cord injury may lead to several health related problems, such as pressure injuries, pain, urinary tract infections or spasm. Do you recognize any of these problems yourself? Or do you have any other health related problems? What have you learned in the rehabilitation center to prevent these problems or to handle them if they occur?
 - How was this accomplished by [Name rehab center] during the rehabilitation?
 - Which disciplines had contributed to that?
 - How did these disciplines contribute?
 - How did the spinal cord peer supporters play a role in this?
 - How did your friends/family play a part in this?
 - How susceptible do you think you are for these health problems?
 - Have you missed anything in this process? What could be improved?

3. People with a spinal cord injury may have different levels of confidence in how to live their life. How do you perceive the confidence you have in handling the consequences of the spinal cord injury?
 - How was this accomplished by [Name rehab center] during the rehabilitation?

- Which disciplines contributed to that?
- How did these disciplines contribute?
- How did the spinal cord peer supporters play a role in this?
- How did your friends/family play a part in this?
- What did [Name rehab center] teach your family/friends with regard to your self-management?
- What has been helpful in handling the situation?
- What was a barrier to handling the situation?
- Has the approach to treatment changed during the rehabilitation process?
- Have you missed anything in this process? What could be improved?

Chapter 6

Multidimensional fatigue during rehabilitation in persons with recently acquired spinal cord injury

Tijn van Diemen

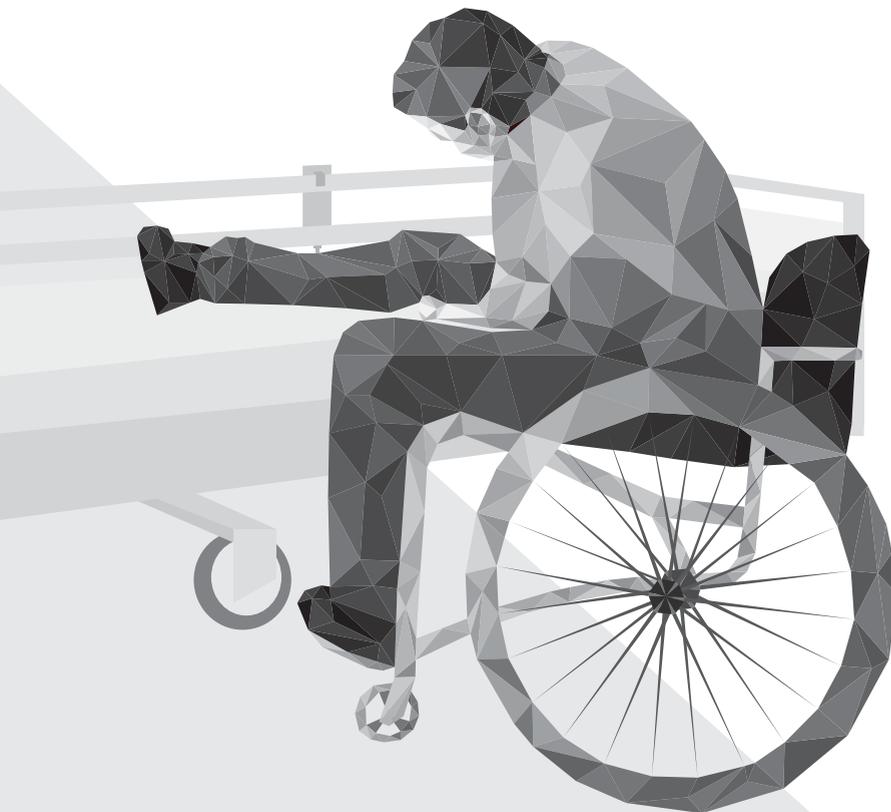
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Abstract

Objectives: To examine the change in multidimensional fatigue in people with a spinal cord injury during post-acute rehabilitation, and to compare these scores with those of healthy adults. Furthermore, to examine correlations between different dimensions of fatigue at discharge and demographics, injury-related variables and indices of psychological adjustment.

Design: Longitudinal cohort study.

Subjects: From 86 patients admitted for spinal cord injury rehabilitation, between June 2011 and January 2013, 78 patients met the inclusion criteria, and 70 (90%) agreed to participate.

Methods: Self-reported questionnaires were completed at admission, and in the week before discharge. Questionnaires used assessed demographics, injury related variables, multidimensional fatigue, and psychological adjustment.

Results: At admission, fatigue scores were very high and decreased significantly during rehabilitation. At discharge, fatigue scores were still significantly higher than those of healthy adults. The fatigue total score at discharge was weakly associated with demographic variables and injury related variables. Psychological adjustment variables explained the largest proportion of variance of the fatigue total score and each of the subscales.

Conclusion: Fatigue is an important consequence in people with recently acquired spinal cord injury. Associations between fatigue and psychological adjustment suggest that psychological interventions might be useful to diminish fatigue.

Introduction

Fatigue can be defined as a state of excessive chronic tiredness and a pervasive feeling of exhaustion.¹⁻³ In the last decade, a growing number of qualitative and quantitative studies have underlined the importance of fatigue in persons with spinal cord injury (SCI). Jensen et al.⁴ found that 67% of people with chronic SCI reported fatigue, of whom 18% reported severe fatigue. Saunders and Krause⁵ reported considerably lower percentages, of 46.4% and 8.3% respectively. In other studies, over 50% of people with SCI reported fatigue severe enough to interfere with functioning.^{1,6-8}

Qualitative studies have shown that fatigue is very commonly experienced by people with a SCI,⁹ and is perceived as having a negative effect on patient's life.¹⁰ This is corroborated in quantitative cross-sectional studies, which report negative associations of fatigue with quality of life,^{1,11} social and psychological functioning,⁴ and rehabilitation outcomes.¹² In addition, fatigue has been reported to be associated with pain,^{1,3,6} depression,^{2-3,7,13-15} anxiety,² injury severity,⁵⁻⁶ age,^{5,11,16} and medication.^{5,8,14}

Some issues related to fatigue in people with SCI have, however, not been addressed in the literature to date. First, the prevalence of fatigue in people with SCI in post-acute rehabilitation is unclear. Most previously published studies into fatigue have been about the chronic situation. Studied into the post-acute phase call for more research into the nature and impact of fatigue and other factors that complicate treatment sessions.¹² Secondly, little is known about the course of fatigue in people with SCI. Some cross-sectional correlation studies have reported higher levels of fatigue in patients with shorter duration of SCI,^{1,3,11} while other studies failed to support these findings.^{4,15,17} Longitudinal studies are therefore needed to draw conclusions about the course of fatigue over time. Thirdly, fatigue in SCI is commonly assessed with single-item measures of the subjective level of fatigue^{6-7,15,18} or with unidimensional questionnaires, such as the Fatigue Severity Scale (FSS),^{6-8,10,13,19} that measure the impact of fatigue on functioning. Lidal et al.¹⁴ and Craig et al.³ have used a multidimensional questionnaire that included both physical and mental fatigue subscales. Hammell et al.¹⁰ showed that fatigue also has cognitive and emotional dimensions. Fourthly, it is unknown whether and how these various dimensions of fatigue are associated with psychological functioning in people with SCI.

The first aim was to examine the change in fatigue between admission and discharge from the first inpatient rehabilitation phase, and to compare fatigue scores at discharge with reference scores of healthy adults. It is hypothesized that levels of fatigue will be high at the start of the rehabilitation and will decrease over time, but will still be higher at discharge compared with fatigue in healthy adults.^{1-2,4-8,10,16-18} The second aim was to examine

correlations of different dimensions of fatigue at discharge with demographics variables, SCI-related variables and several psychological adjustment indices, and to assess the amount of explained variance of these determinants. It is hypothesized that fatigue is not related to demographic variables,^{1-2,5,8,14} only moderately related to the SCI-related variables^{1,3,5-6,10} and strongly related to the psychological adjustment variables.^{2-3,7,10,13-15}

Methods

Participants

All patients with a recently acquired SCI who were admitted for inpatient rehabilitation to the Sint Maartenskliniek in Nijmegen, the Netherlands, between June 2011 and January 2013 were considered for inclusion in the present study, with the exception of patients with cancer-related SCI who had a short life expectancy. This clinic is one of 8 sites in the Netherlands that specialize in SCI rehabilitation. In this period, a total of 86 people with a recently acquired SCI were admitted to the rehabilitation centre. Patients were excluded from this study if they were delirious during the first weeks of admission, had severe psychiatric, cognitive or intellectual problems, or if they were not able to read Dutch according to the rehabilitation physician and the ward psychologist. For the present study, only cases with complete data on admission and discharge were analysed.

Procedure

The ward psychologist contacted the patients in the first week of their admission in the Sint Maartenskliniek, and patients were asked to complete a set of psychological questionnaires for diagnostic purposes as part of routine care. At the same time, patients were informed about the purpose and contents of this study. It was explained to them that enrolment in the study would mean that their responses would be used for research purposes, and that they would be asked to complete the same set of questionnaires in the week before discharge. A patient who was not able to write because of hand function problems was asked to complete the questionnaires with help of a partner or other trusted person. If no such person was available, a clinical psychologist's assistant supported them.

All participants gave written informed consent. The local medical ethics committee approved the research protocol.

Measures

Demographic variables. Age, sex, living with a partner, educational level and work were assessed.

SCI characteristics. Time since injury; cause of the lesion: divided into traumatic (traffic accident, industrial accident, sports accident, fall from height, gunshot – or stab wound) and non-traumatic (disease-related or resulting from medical procedure); level and type of injury according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade A, B, C or D of the SCI were determined by a trained rehabilitation physician at admission.

Pain. Pain was measured with a visual analogue scale (VAS 100 mm).

Multidimensional fatigue. The Checklist Individual Strength (CIS) was used to measure fatigue. This 20-item questionnaire consists of 4 scales: Subjective experience of fatigue (8 items); Reduced concentration, referring to the cognitive aspects of fatigue (5 items); Motivation, referring to the emotional aspects of fatigue (4 items); and Physical activity level (3 items). Each item is scored on a 7-point Likert scale ranging from “Yes, that is true” to “No that is not true”. In addition to the 4 scale scores, a total score of all the 20 items can be calculated. Higher scores on a (sub)scale reflect a higher degree of fatigue. The psychometric properties in various patient groups (including neurological disorders, other than SCI) and healthy adults are excellent.²⁰⁻²²

Psychological adjustment. This was operationalized as distress and illness cognitions.

Distress was assessed using the Hospital Anxiety and Depression Scale (HADS). The HADS is a commonly used measure of distress and contains 14 statements with 7 items each measuring depressive mood or anxiety. Participants were asked to what degree they agreed with each statement on a 4-point scale.²³⁻²⁴ Higher scores on a scale reflect more symptoms of anxiety and depression, respectively. The HADS has been shown to be a reliable and valid instrument in SCI research.²⁵⁻²⁶

Illness cognitions were assessed using an adapted version of the Illness Cognitions Questionnaire (ICQ).²⁷⁻²⁹ This instrument contains 18 statements divided into 3 scales: Helplessness, which measures the aversive cognitive attributions attached to the SCI; Acceptance, which measures neutralizing connotations of the condition; and Disease benefits, which measures the positive meaning given to the SCI. Participants were asked to what degree they agreed with each statement, ranging from 1 (not at all) to 4 (completely). A higher score on the Helplessness scale reflects more negative cognitions, while on the other 2 scales a higher score reflects more positive illness cognition. With the adapted version of the ICQ used here, Wollaars et al.²⁹ found good internal consistency of the different scales in persons with SCI.

Statistical analyses

The sample is described by numbers and percentages for categorical variables, and median, and quartiles for continuous variables. Because this is the first time that the CIS has been used to assess fatigue in SCI, internal consistency of the CIS scales was assessed using Cronbach's alpha. All the assessment scales used in this study have ordinal scores; therefore we used only non-parametric statistics.

To analyse changes in scores between admission and discharge, Wilcoxon signed-ranks tests were used. Wilcoxon signed-ranks tests were used also to compare the scores on the CIS with healthy adults (described by Vercoulen et al.²²).

Secondly, we used the discharge data to analyse the relationships between the CIS scores and demographic, SCI-related, and psychological adjustment variables. Associations were expressed in Spearman correlations; correlations up to 0.3 are considered as weak, between 0.3 and 0.5 as moderate and above 0.5 as strong.³⁰ To determine which independent variable should be used in a multivariate regression analyses, univariate regression analyses were performed with all potential independent variables. The variables with a *P*-value below .25 were used in a multivariate regression analyses and entered block-wise. First, all the relevant demographic variables were entered simultaneously. In the second block all relevant SCI-related variables were entered simultaneously and, finally, all relevant psychological variables. Associations between the 3 blocks of variables and fatigue scores were expressed as the percentage of variance (R^2) explained by all variables in that block corrected for the variables in the previous block(s). R^2 up to 0.25 are considered as small associations, from 0.25 to 0.40 as moderate, and above 0.40 as large.³⁰

P-values less than 0.05 were considered statistically significant in the analyses. All analyses were conducted using SPSS statistical program for Windows (version 16.0). (SPSS Inc, Chicago Ill.).

Results

Of the 86 eligible patients, 8 were excluded from the study: 2 were delirious, 2 could not read Dutch, 3 had cognitive or intellectual problems, and 1 was transferred because of serious medical complications soon after admission. The remaining 78 patients were invited to participate, 70 (90%) agreed to do so and 67 completed the questionnaires for the second time in the week before discharge (2 patients did not return the questionnaire, and 1 was admitted for only a short period of time). Table 6.1 gives the characteristics of the patients with complete data on both measurements (N=64).

Table 6.1 Characteristics of the patients in the study (n=64)

Characteristics	
Age, years, mean (SD) [range]	55.2 (14.7) [22–80]
Duration of injury at admission, days, mean (SD) [range]	43.8 (34.6) [11–153]
Duration of stay, days, mean (SD) [range]	75.0 (52.6) [12–289]
Sex (male), n (%)	33 (51.6)
Injury level, n (%)	
Cervical	26 (40.6)
Thoracic	24 (37.5)
Lumbo-sacral	14 (21.9)
Completeness, n (%)	
AIS A	19 (29.7)
AIS B	4 (6.2)
AIS C	10 (15.6)
AIS D	31 (48.4)
Cause of injury (traumatic), n (%)	24 (37.5)
Living with a partner, n (%)	47 (73.4)
Education level, n (%)	
Higher education	15 (23.4)
Medium education	29 (45.3)
Lower education	20 (31.3)
In paid employment before SCI, n (%)	22 (34.4)

NOTE. AIS: ASIA Impairment Scale; SCI spinal cord injury; SD standard deviation.

Table 6.1 shows that the mean age in this sample was relatively high, and few people had a paid job at the time of the SCI, in part because many were already in (early) retirement. Differently from most other SCI studies, sex was almost equally divided in this sample. The education level was as expected in the Netherlands.

The internal consistency of the CIS scales was satisfactory to excellent, with Cronbach's alpha at admission of 0.93 for subjective experience of fatigue; 0.91 for reduced concentration; 0.83 for motivation; 0.69 for physical activity level; and 0.93 for the total CIS score.

Table 6.2 shows the median and interquartile range at admission and discharge for the CIS and for the psychological adjustment variables.

Between admission and discharge, all scores on the CIS decreased significantly, with the largest decrease reported in subjective experience of fatigue and the smallest for reduced concentration. Significant differences between assessment at admission and discharge were also observed in the pain score (VAS) and all the adjustment variables.

Compared with healthy adults,²² the scores on all the fatigue scales were significantly higher both at admission and at discharge (at discharge: total $Z=5.2$, $P<.001$; subjective $Z<5.0$, $P=.001$; concentration $Z=3.4$, $P=.001$; motivation $Z=4.4$, $P<.001$; activity $Z=5.1$, $P<.001$).

Table 6.2 Median and interquartile range (IQR) at admission and discharge for the fatigue scales, pain and the psychological adjustment scales, the Z-value according to the Wilcoxon signed-ranks test (n=64). For the Checklist Individual Strength (CIS) the reference scores are displayed.

	Admission		Discharge		Wilcoxon		Reference
	Median	IQR	Median	IQR	Z-value	P	Mean (SD)
Fatigue (CIS)							
Total fatigue score	83.5	65.0;102.25	62.0	44.5;83.75	-4.60	.000**	41.5 (19.8)
Subjective experience	38.0	28.0;48.75	26.0	16.0;37.5	-5.29	.000**	17.3 (10.1)
Concentration	16.0	7.25;24.0	12.5	6.0;21.0	-2.11	.035*	9.5 (5.0)
Motivation	13.0	9.25;17.75	10.0	7.25;17.0	-3.09	.002**	7.9 (4.1)
Physical activity level	15.0	11.0;18.0	10.0	7.0;15.0	-4.09	.000**	6.6 (4.5)
Pain (VAS)	21.0	7.0;45.0	12.0	3.0;23.0	-3.55	.000**	
Psychological adjustment							
Depression	6.0	4.0;10.0	5.0	2.0;7.75	-3.05	.002**	
Anxiety	6.0	3.0;10.0	4.0	2.0;8.0	-3.08	.002**	
Acceptance	12.0	10.0;15.0	15.0	13.0;18.0	-4.79	.000**	
Helplessness	15.5	12.0;19.0	13.0	10.0;17.0	-4.40	.000**	
Disease benefits	13.0	10.0;17.0	15.0	13.0;18.0	-3.55	.000**	

* $P < .05$, ** $P < .01$ according to Wilcoxon signed ranks test.

VAS: visual analogue scale; SD: standard deviation.

Also, reported levels of distress in the sample were high. Using cut-off scores of 8 points on both HADS subscales,³¹ 31% of the people in this sample showed probable depression and 34% showed probable anxiety disorder at admission. At discharge these percentages were 16% and 20%, respectively.

In Table 6.3 the Spearman correlations coefficients are depicted between the potential independent variables and the fatigue scales.

Table 6.3 Spearman correlation coefficients between the potential independent variables and the fatigue scales (n=64)

	CIS Total	CIS Subjective	CIS Concentration	CIS Motivation	CIS Physical activity
Age	0.13	0.09	0.12	0.09	0.07
Gender	0.25*	0.24	0.23	0.21	0.14
Partner at discharge	0.21	0.10	0.19	0.32**	0.21
Education	-0.21	-0.18	-0.14	-0.23	-0.03
Paid job	0.13	0.06	0.09	0.14	0.14
Level of SCI	0.10	0.12	-0.05	0.17	0.15
Completeness of SCI	-0.03	-0.01	-0.03	0.04	-0.02
Traumatic SCI	0.08	-0.02	0.22	0.01	-0.04
Duration of stay	0.24	0.17	0.22	0.28*	0.19
Pain (VAS)	0.35**	0.43**	0.21	0.19	0.07
Depression	0.66**	0.57**	0.56**	0.56**	0.39**
Anxiety	0.66**	0.59**	0.55**	0.67**	0.36**
Acceptance	-0.45**	-0.40**	-0.37**	-0.44**	-0.36**
Helplessness	0.35**	0.28*	0.20	0.31*	0.40**
Disease benefits	-0.24	-0.10	-0.27*	-0.28*	-0.28*

* $P < .05$, ** $P < .01$ according to Spearman correlation analysis.

CIS : Checklist Individual Strength; VAS: visual analogue scale; SCI spinal cord injury.

Most demographic variables showed weak associations with the fatigue variables, except for “having a partner at discharge”, which showed moderate associations. From the SCI-related variables only pain was moderately associated with the total fatigue scale and with the subjective experience of fatigue. Depression and anxiety had the strongest and almost equal associations with CIS scores, reflected in moderate to strong correlations with all fatigue subscales. Higher levels of acceptance were associated with lower levels of fatigue. Acceptance was moderately associated with each of the fatigue subscales. Helplessness and Diseases benefits were moderate to weakly associated with CIS total score and the subscales.

Table 6.4 shows the results of the multivariate regression analyses. The block of demographic variables explained a small proportion of the variation of fatigue at discharge (13% of the CIS total score). Females, on average, reported higher levels of fatigue on the CIS

Table 6.4 Regression analyses with the fatigue scales as dependent variables, entering block wise the demographic, spinal cord injury (SCI)-related variables and the psychological adjustment variables. R² depicted for each group of variables, corrected for the variables in the previous block(s) (n=64).

CIS	Total	Subjective	Concentration	Motivation	Physical activity
Demographics variables	Gender			Gender	Gender
	Partner at discharge		Partner at discharge	Partner at discharge	Partner at discharge
	R ²	0.13*	0.10*	0.20**	0.06
SCI-related variables			Level of SCI		Completeness of SCI
	Pain	Pain	Traumatic SCI	Pain	Duration of stay
	R ²	0.12**	0.12*	0.04	0.10*
Psychological adjustment	Depression	Depression	Depression	Depression	
	Anxiety	Anxiety	Anxiety	Anxiety	Anxiety
	Acceptance	Acceptance	Acceptance	Acceptance	Acceptance
	Helplessness	Helplessness	Helplessness	Helplessness	Helplessness
	Disease benefits	Disease benefits	Disease benefits	Disease benefits	Disease benefits
R ²	0.31**	0.24**	0.27**	0.27**	0.16*

* $P < .05$, ** $P < .01$.

total score (median 79.0 vs 55.0, Mann-Whitney U test $Z=-2.0$, $P=.047$), subjective experience of fatigue (32.0 vs 23.0, $Z=-1.9$, $P=.063$), reduced concentration (16.0 vs 10.0, $Z=-1.8$, $P=.066$), and motivation (14.0 vs 9.0, $Z=-1.7$, $P=.092$). Patients with a partner reported lower levels of CIS total fatigue (54.5 vs 78.0, $Z=-1.7$, $P=.089$), concentration (11.5 vs 18.0, $Z=-1.5$, $P=.139$) and motivation (8.5 vs 16.0, $Z=-2.6$, $P=.011$).

The SCI-related variables together explained an additional 12% of the variance of the total CIS score corrected for the relevant demographic variables.

All psychological adjustment variables together explained an additional 31% of the variance of the total CIS score and 16–27% of the scores on the subscales.

The 25% of the participants ($n=16$) who improved the most on the total fatigue scale from admission to discharge did not significantly differ in any of the demographic or SCI-related variables from the rest of the participants. Pain nearly reached significance, with less pain for the participants who improved the most. From the psychological adjustment variables only anxiety reached significance, and depression approached significance.

Discussion

This is the first longitudinal cohort study into multidimensional fatigue in the sub-acute phase of people with SCI in relation to psychological adjustment.

The first aim was to examine the change in the different dimensions of fatigue during post-acute rehabilitation, and to compare these scores with scores of healthy adults. At the start of inpatient rehabilitation, people with a recently acquired SCI reported levels of fatigue almost twice as high as healthy adults on all CIS scales. During rehabilitation there was a significant decrease in all CIS scores. Despite this decrease, fatigue scores were still significantly higher than those of healthy adults at discharge. These findings corroborate earlier studies reporting high levels of unidimensional fatigue in people with SCI more than one year after the injury.^{1–2,4–8,10,16–18} Our findings also indicate that fatigue at the start of the rehabilitation is higher than fatigue reported in the chronic phase of SCI, for all dimensions.

The second aim was to examine correlations of different dimensions of fatigue with demographics variables, SCI-related variables and the psychological adjustment indices at discharge, and to assess the amount of explained variance of fatigue. The psychological adjustment variables taken together explained the largest proportion of variation in fatigue (an additional 31% of the CIS total after correction for demographic and SCI-related variables). Depression and anxiety in particular, had strong correlations with the fatigue total score, and moderate to strong associations with all the fatigue subscales. Low levels of

anxiety seems to play an important role in improving from fatigue. The illness cognitions had a moderate to weak association with the CIS total score and the subscales. The blocks of demographic- and SCI-related variables explained small proportions of the variations in some of the CIS (sub)scales. It seems that psychological adjustment plays an important role in all the different dimensions of fatigue. The same was found in another study that used a multidimensional fatigue scale.¹⁴

Of the SCI related variables, pain was moderately correlated with two fatigue scales (total fatigue and subjective fatigue). The influence of pain on fatigue is corroborated in earlier studies.^{1,3,6} The strong relation between psychological adjustment and fatigue has been observed before in patients with SCI in the chronic phase.^{2-3,13-15} Craig et al.³ found that depressed mood contributed, independently from pain, to the experience of fatigue. Our data suggest that not only depression, but also anxiety and illness cognitions are related to fatigue in the rehabilitation phase.

The correlation of the total CIS score with the demographic variables was mostly due to reduced concentration and motivation. For the SCI related variables, the correlation with the total CIS score was mostly due to subjective experience of fatigue and reduced concentration. For the correlation of the psychological adjustment indices with the total CIS score, all subscales contributed, although not all to the same extent. These results suggest that the different subscales measure different aspects of fatigue, and together provide more comprehensive information about fatigue than does a unidimensional measurement like the FSS.^{7,10}

One of the limitations of the study is that the sample size of this study is small; only 64 people with a recently acquired SCI. To draw stronger conclusions about the course of fatigue over time, a larger sample is needed, also a longer follow-up period, for instance one year after discharge. The study sample is representative for people in inpatient rehabilitation in the Netherlands, but compared to the international literature^{1-2,4-11,13-16,18} this sample is relatively old, and contains a higher proportion of females. This difference can partly be explained by the high proportion of patients with non-traumatic SCI. However, patients with traumatic SCI in this study did not differ in fatigue from patients with non-traumatic SCI. Nonetheless, one should be careful about generalising from these findings. Another limitation is that physical capacity was not measured in this study, nor did we have information about medication, sleep(quality), spasms or bladder and bowel function, or other secondary complications (except pain) that may influence the experience of fatigue. Furthermore, the influence of other psychological factors, such as coping with the SCI, has not been taken into account.

It would be desirable to make a distinction between fatigue that improves over time and a more chronic fatigue. Further research with the CIS could be focused on this subject.

Fatigue is an important variable in rehabilitation outcome,¹² showing negative associations with quality of life.¹¹ Therefore, it is important to identify people with high levels of fatigue early in the rehabilitation. As yet, there are no specific interventions for the treatment of fatigue in SCI, besides reconditioning. Cognitive behavioural therapy (CBT) can be used to reduce negative feelings through cognitive restructuring. In the treatment of chronic fatigue syndrome, CBT has been shown to be effective.³² In SCI, the early treatment of fatigue is important for the rehabilitation process itself, and in order to reduce stay in the rehabilitation.¹² In SCI, an early treatment of fatigue is especially of interest because persons with SCI who are fatigued in the chronic phase remain fatigued.⁴

In conclusion, fatigue is an important consequence of SCI. Different aspects of fatigue can be distinguished. At discharge, psychological adjustment explains a large proportion of the variance in fatigue. This suggests that psychological interventions might help to diminish the experience of fatigue in this group. Further research is needed to investigate effective ways to treat fatigue for people with SCI. Although the different scales for psychological adjustment used in this study depict partially overlapping constructs, it is safe to conclude that there is an important role for psychological variables in SCI related fatigue.

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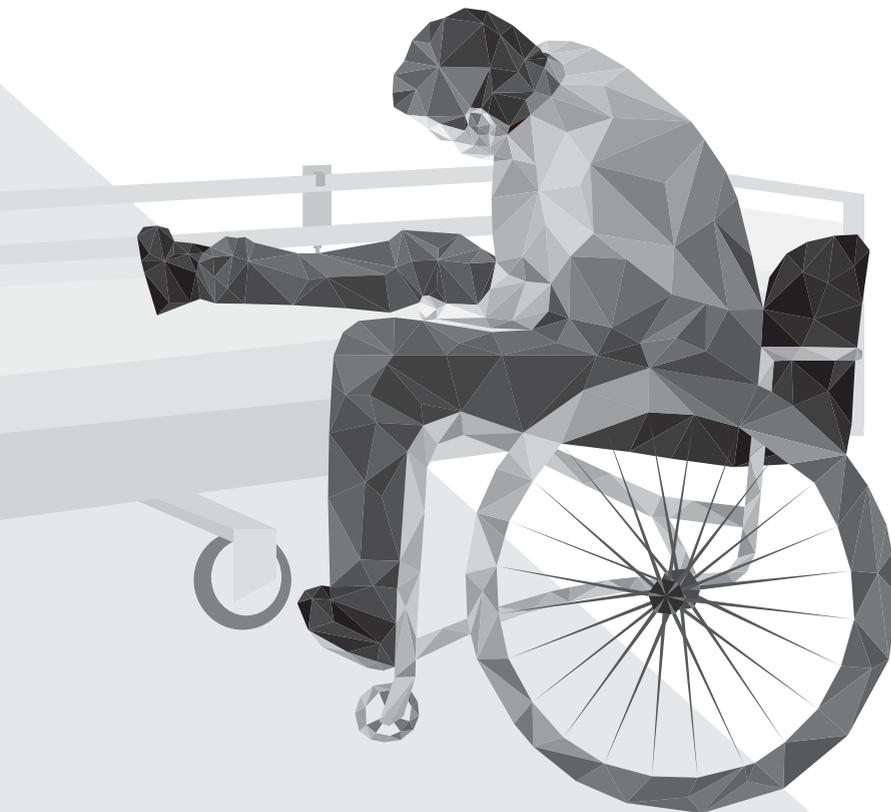
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Chapter 7

Body image in persons with spinal cord injury, during inpatient rehabilitation

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Abstract

Objectives: (1) To investigate the course of body image in persons with spinal cord injury (SCI) during their first inpatient rehabilitation; and (2) to explore the association between demographic and injury-related variables and body image and the association between body image and psychological distress.

Design: Longitudinal inception cohort study.

Setting: Rehabilitation center.

Participants: Of the 210 people admitted for the first inpatient SCI rehabilitation program (between March 2011 and April 2015), 188 met the inclusion criteria. Of these, N=150 (80%) agreed to participate.

Interventions: Not applicable.

Main outcome measures: The Body Experience Questionnaire was used to measure 2 dimensions of body image: Alienation and Harmony.

Results: Mean scores on the Body Experience Questionnaire alienation subscale decreased significantly during the rehabilitation program. Mean scores on the Body Experience Questionnaire harmony subscale did not increase significantly but showed a trend in the hypothesized direction. The 2 subscales showed weak correlations with demographic and injury-related variables. The 2 subscales together explained 16% and 14% of the variance of depression and anxiety, respectively, after correction for demographic and injury-related variables.

Conclusion: During participants' first inpatient rehabilitation stay after SCI, body image progressed towards a healthier state. Body image explains parts of the variance in depression and anxiety and the entire rehabilitation team should be targeting interventions to improve body image.

Introduction

A spinal cord injury (SCI) involves changes in motor activity and movement patterns and sensory input.¹ Depending on the location and completeness of the SCI, further limitations may occur.¹ Furthermore, a number of secondary complications (e.g., pain, fatigue) affect the well-being of people with SCI.² Influenced by both physical and psychological aspects, changes can occur in a patient's body image after SCI.³⁻⁵ From a cognitive behavioral perspective,⁶ body image refers to the multifaceted psychological experience of embodiment and especially but not exclusively refers to physical appearance. Body image encompasses body-related self-perceptions and self-attitudes, including thoughts, beliefs, feelings and behaviors. Within this framework, negative body image experiences unfold as the cumulative result of developmentally predisposing influences and specific events that provoke and sustain maladaptive processes.⁷ Having a SCI, and dealing with its complications, is such an events. Further, this framework state that different facets of body image are associated with psychosocial functioning and emotional stability.⁸

Most of the studies on body image of patients with SCI focus on physical characteristics and/or physical activity.^{3,4,9-15} From these studies, it becomes clear that SCI has consequences on the way patients with SCI perceive themselves and interact with their surroundings, including potential partners.^{4,10,12,13} Other studies suggest that satisfaction with the body improves over the years after SCI.^{3,12,15} The at age at injury does not have any influence on body image.¹¹ However, some studies have found that the satisfaction with appearance after SCI was not different from a reference group.^{9,14}

One way to study body image from a cognitive behavioral point of view is to explore how people experience the relation between their body and self. According to Bode,¹⁶ this experience consists of 2 different aspects, namely alienation and harmony. Alienation is the split between the body and the self, whereas harmony is the degree in which the body is unified with the self. In healthy conditions, it is assumed that body and self are in harmony.^{5,17} Harmony can be disturbed by a chronic condition.^{5,13,16,17} Because of chronic conditions or complications (e.g., pain, fatigue), patients with SCI can be aware of the difference between the body and self.^{16,17} This process is referred to as a body-self split or alienation.¹⁶ So far, alienation and harmony have only been studied in other diagnostic groups.^{16,18} To date, it is not known if this disturbance of alienation and harmony also occurs in people with SCI.

Studies in other diagnose groups and healthy people have found a positive correlation between body image and quality of life.¹⁹⁻²¹ Also, in studies with SCI, body image is one of the factors contributing to quality of life.^{3,9,12,22} Although studies in SCI suggest a relation between body image and emotional aspects of adjustment to SCI,^{4,9,10,22} none have examined

this relation explicitly. To our knowledge, there are no studies investigating body image during the inpatient rehabilitation phase and no studies about the possible influence of body image on the experienced distress of people with SCI.

The aims of this study are (1) to describe the course of body image during patients' first inpatient rehabilitation stay after the onset of SCI; (2) to explore the associations between demographic and injury-related variables and body image; and (3) to explore the associations of body image with psychological distress, controlling for the influence of injury-related variables and demographic factors at discharge.

We hypothesized that (1) during inpatient rehabilitation, the mean alienation scores will decrease, whereas the harmony scores will increase. In other words, participants will progress toward a healthier body image. We also hypothesized that (2) body image is associated with injury and demographic variables, and having a more severe SCI and more complications is associated with more alienation and less harmony. Finally, (3) in line with Cash's theory,^{6,7} we hypothesize that body image is associated with psychological distress after correction of demographic and injury-related variables.

Methods

Participants

All people with SCI, admitted for their first inpatient rehabilitation stay to the Sint Maartenskliniek in Nijmegen, The Netherlands, between March 2011 and April 2015, were considered for inclusion in this study. During this period, a total of 210 patients with SCI were admitted for their first rehabilitation program. People with cancer-related SCI with a short life expectancy excluded from the study. Further, people were excluded if they were delirious during the first week of admission; had severe psychiatric, cognitive, or intellectual problems; or if they were not sufficiently able to read Dutch language as assessed by the rehabilitation physician and ward psychologist. Admitted patients receive physiotherapy and occupational therapy daily, and each is seen for an intake with a social worker and psychologist. Psychological treatment was given necessary after this evaluation. An average inpatient rehabilitation program consists of 12.6 hours of therapy a week. The average stay on this ward is 90.7 days. A stay of ≤ 21 days, for patients' first SCI rehabilitation, is considered as short. Characteristics are displayed in Table 7.1.

Table 7.1 Details of participants with a complete dataset at admission (n=134)

Characteristic	Value
Age (y)	54.2±15.2 (20–88)
Duration of injury at admission (d)	31.5±33.9 (0–220)
Duration of stay (d)	95.3±53.0 (16–309)
Sex, male	86 (64.2)
Injury level	
Cervical	55 (41.0)
Thoracic	55 (41.0)
Lumbosacral	24 (17.9)
Completeness	
AIS grade A	38 (28.4)
AIS grade B	14 (10.4)
AIS grade C	26 (19.4)
AIS grade D	56 (41.8)
Cause of injury, traumatic	56 (41.8)
Living with a partner	102 (76.1)
In paid employment before SCI	56 (41.8)
Education level	
College or university	35 (26.1)
High school	60 (44.8)
Secondary school or less	39 (29.1)

NOTE. Values are mean ± SD (range) of frequency (%).

Abbreviation: AIS, American Spinal Injury Association Impairment Scale.

Procedure

The ward psychologist contacted the patients with SCI in the first week of their admission and asked them to complete a set of psychological questionnaires for diagnostic purposes, as part of routine care. During that same evaluation, potential participants were informed about the purpose and contents of this study. It was explained to them that enrollment in the study would mean their responses would be used for research purposes and that they would be asked to complete the same set of questionnaires in the week before discharge. Participants with a short stay were asked if they would complete the discharge questionnaire; if they stated that there were little or no changes in their psychological functioning, they did not. If the participant was not able to write because of limited hand function, they were asked to complete the questionnaires with help of a partner or other trusted person. If no one was available, a clinical psychologist's assistant provided support. All participants gave written informed consent. The local medical ethics committee approved the research protocol. In this study, only cases with complete data on admission and discharge were analyzed.

Measures

Demographics. Age, sex, living with a partner, educational level, and work were assessed.

SCI characteristics. Time since injury, cause of the lesion (traumatic [traffic collision, industrial accident, sports accident, fall from height, and gunshot or stab wound] or nontraumatic [disease related or resulting from medical procedure]), and level and type of injury according to American Spinal Injury Association Impairment Scale grade (A, B, C or D) were determined by a trained rehabilitation physician.

Pain. Pain was measured with a 100-mm visual analogue scale.

Fatigue. Fatigue was measured with a 100-mm visual analogue scale.

Body image. Body image was measured using the Body Experience Questionnaire.¹⁶ Given the lack of validated measures on body image in SCI, the Body Experience Questionnaire was chosen given its length and face validity. The Body Experience Questionnaire contains 10 statements, 6 of which form the alienation subscale. This subscale captures the split between the body and self. The other 4 statements form the harmony subscale, which is indicative for the degree in which the body is unified with the self.¹⁶ Respondents were asked to what degree they agreed with each statement on a 4-point scale ranging from 1 (totally disagree) to 4 (totally agree).¹⁶ In a previous study in people with rheumatic diseases (RDs), both scales had acceptable to good internal consistency (alienation $\alpha=.84$; harmony $\alpha=.76$).¹⁶ In this same study, a strong negative correlation was found between alienation and self-esteem, and a moderate positive correlation was found between harmony and self-esteem. Strong positive correlations were also found for alienation and functional limitations and helplessness, and a moderate positive correlation was found alienation and pain intensity. The Body Experience Questionnaire fully mediated the relation of functional limitations and self-esteem. Illness cognition partially mediate this relation. Cronbach α of the alienation subscale was .81 and .84 and Cronbach α of the harmony subscale was .63 and .64 at admission and discharge, respectively. A factor analysis was performed on the current data and resulted in almost the same 2-factor structure described by Bode et al.¹⁶ The eigenvalues of alienation and harmony are 3.65 and 1.56, respectively, and all items showed factor loadings $>.55$ on the expected factor. Only question 10 (table 2) did not load on the factor (-.48).

Distress. We assessed distress using the Hospital Anxiety and Depression Scale (HADS). The HADS is a commonly used measure of distress and contains 14 items, with 7 items measuring depressive mood and 7 items measuring anxiety. Respondents were asked to what degree they agreed with each statement on a 4-point scale.²³⁻²⁵ The Cronbach α for both subscales of the HADS is between .82 and .83.

Statistical analyses

The sample was described by numbers and percentages for categorical variables and means and SDs for continuous variables.

Because of the nonnormal data distribution (according the Shapiro-Wilk test) and the ordinal measurement levels, nonparametric tests were used. Changes in scores between admission and discharge were analyzed using Wilcoxon signed-ranks tests. Because body image scores changed during rehabilitation, we used the discharge data to analyze associations between the Body Experience Questionnaire scores and demographic, SCI-related, and psychological distress variables. Associations were expressed in Spearman correlations for continuous data and in η values categorical data; correlations ≤ 0.3 are considered as weak, between 0.3 and 0.5 are considered moderate and correlations ≥ 0.5 are considered strong.²⁶ To examine the independent associations between Body Experience Questionnaire scores and the psychological distress measures, hierarchical regression analyses were performed. Preliminary analyses to check for violations of the assumptions of normality, outliers, linearity, multicollinearity, and homoscedasticity were performed. All demographic and injury-related variables were entered simultaneously in the first block, and the 2 Body Experience Questionnaire subscales were entered in the second block. The percentage of variance (R^2) was computed. R^2 values $< .25$ are considered small associations, values between .25 and .40 are considered moderate, and values $> .40$ are considered large.²⁶ P -values $< .05$ were considered statistically significant. All analyses were conducted using SPSS statistical program for Windows (version 23).^a

Results

Of the 210 people with SCI admitted during the inclusion period, 8 did not speak or read Dutch and 14 had cognitive or intellectual problems that made it impossible to complete the questionnaires in a reliable way. Of the remaining 188 persons, 150 (80%) agreed to participate in the study. At discharge, 10 patients did not return the questionnaire; of these 6 had been admitted for only a short period of time (< 21 d). A further 6 participants missed ≥ 1 items. Table 7.1 displays the characteristics of the sample with a complete dataset ($n=134$).

The differences between the participants with and without complete data were not significant. The mean age in this sample was relatively high, and relative few people had a paid job at the time of the SCI, in part because many were in (early) retirement.

Table 7.2 shows the 10 Body Experience Questionnaire statements and the response distributions, dichotomized into disagree (where 1 is totally disagree and 2 is disagree) and agree (where 3 is agree and 4 is totally agree), at both test occasions.

Table 7.2 Distribution of answers on the Body Experience Questionnaire questions subscales (n=134)

Body Experience Questionnaire		% Agree	
Alienation		t1	t2
2.	My body is a burden to me	59.7	42.5
3.	It feels as if my body doesn't belong to me	47.0	29.1
4.	I don't feel complete	58.2	44.0
6.	My body is unpredictable	64.9	50.7
7.	I feel betrayed by my body	29.1	24.6
8.	I would like to have a different body	37.3	29.1
Harmony			
1.	I reflect on what is good for my body	91.0	93.3
5.	My body lets me know what is good for me	70.1	78.4
9.	I am sensible to my body	78.4	84.3
10.	My body feels familiar to me	59.0	56.7

Abbreviations: t1, inpatient rehabilitation admission; t2, inpatient rehabilitation discharge.

Table 7.3 shows the score distributions of the main variables at admission and discharge. The mean score for alienation decreased significantly during the rehabilitation. The mean harmony score increased, but not significantly. The pain, fatigue, and distress scores all decreased significantly between admission and discharge.

Table 7.3 Mean admission and discharge scores for variables

Variable	Admission	Discharge	Wilcoxon-Signed Rank Test	
			z	P
BEQ				
Alienation (range 6–4)	14.3±4.7	12.5±4.7	-4.79	<.001
Harmony (range 4–16)	11.8±2.6	12.2±2.3	1.95	.052
Injury-related variables				
Pain (VAS)	29.6±25.2	20.1±21.9	-4.82	<.001
Fatigue (VAS)	53.5±24.6	39.0±23.1	-5.33	<.001
Psychological distress				
Depression	7.4±4.5	5.7±4.0	-5.34	<.001
Anxiety	6.7±4.3	4.7±3.7	-5.66	<.001

NOTE. Values are mean ± SD or as otherwise indicated.

Abbreviations: BEQ, Body Experience Questionnaire; VAS, visual analog scale.

In Table 7.4, the correlations coefficients are depicted between the determinants and the distress and body image variables at discharge. Higher scores on the Body Experience Questionnaire alienation subscale were weakly associated with female sex, complete SCI, and higher pain and fatigue scores. There was a moderate positive correlation with the duration of stay. The harmony subscale was weakly associated with pain, fatigue, and duration of stay.

There was a strong positive association between alienation and depression and a moderate positive association between alienation and anxiety. There were moderate negative associations between harmony and the HADS subscales.

Table 7.4 Spearman correlation coefficients between the determinants and the distress and body image variables at discharge (n=134)

Variable	Depression	Anxiety	Alienation	Harmony
1. HADS depression				
2. HADS anxiety	.70*			
3. BEQ alienation	.52*	.47*		
4. BEQ harmony	-.41*	-.38*	-.45*	
5. Higher age	.17	.16	.12	-.15
6. Sex (female) (η)	.04	.08	.18 [†]	.10
7. Having a partner (η)	.09	.14	.04	.16
8. Higher education (η)	.15	.21	.19	.12
9. Having a paid job (η)	.21 [†]	.15	.13	.13
10. Having a complete SCI (η)	.12	.09	.29*	.12
11. Traumatic (η)	.06	.14	.01	.06
12. Higher level of SCI	.03	.04	.02	-.10
13. Duration of stay	.24*	.18 [†]	.37*	-.25*
14. Pain (VAS)	.31*	.34*	.24*	-.18 [†]
15. Fatigue (VAS)	.45*	.44*	.28*	-.21 [†]

NOTE. For the variables, the measure of association is expressed by Spearman correlation coefficients, or as otherwise indicated.

Abbreviations: BEQ, Body Experience Questionnaire; VAS, visual analog scale.

* $P < .01$ according to Spearman correlation analyses or based on analysis of variance for the η values.

[†] $P < .05$.

Table 7.5 shows the results of the regression analyses with the distress scales as dependent variables. All demographic and injury-related variables together explained a moderate 32% of the variance of both HADS subscales. The Body Experience Questionnaire subscales together explained an additional 16% and 14% of the depression and anxiety scales, respectively.

Table 7.5 Regression analysis with the HADS subscales as dependent variables, with demographic and SCI-related variables in the first block and BEQ subscales in the second block

	HADS Depression						HADS Anxiety					
	Model 1			Model 2			Model 1			Model 2		
	B	SE	β	B	SE	β	B	SE	β	B	SE	β
Age	0.01	.02	.05	0.00	.02	.01	0.03	.02	.14	0.02	.02	.10
Sex, female	-0.62	.72	-.08	-1.29	.65	-.16	0.98	.67	.13	0.44	.61	.06
Having a partner	-0.48	.71	-.06	-0.18	.65	-.02	-0.64	.65	-.08	-0.31	.60	-.04
Level of education	-0.26	.21	-.10	-0.34	.19	-.13	-0.28	.19	-.12	-0.36*	.17	-.15
Having a paid job	-1.33	.72	-.16	-1.26	.64	-.15	-0.13	.66	-.02	-0.07	.59	-.01
Having a high SCI	-0.08	.05	-.15	-0.07	.04	-.13	-0.07	.04	-.14	-0.06	.04	-.11
Having a complete SCI	-0.26	.29	-.08	-0.39	.26	-.12	-0.25	.27	-.08	-0.34	.24	-.12
Traumatic SCI	0.18	.74	.02	0.35	.66	.04	1.38*	.68	.19	1.55*	.61	.21
Duration of stay	0.02 [†]	.01	.24	0.01	.01	.08	0.02*	.01	.22	0.01	.01	.07
Pain	0.03*	.02	.18	0.02	.01	.11	0.03	.01	.16	0.02	.01	.10
Fatigue	0.06 [†]	.02	.32	0.04 [†]	.01	.24	0.05 [†]	.01	.32	0.04 [†]	.01	.24
R ²			.32 [†]						.32 [†]			.32 [†]
Adjusted R ²			.25						.26			.26
BEQ alienation				0.33 [†]	.07	.39				0.25 [†]	.07	.32
BEQ harmony				-0.27*	.13	-.15				-0.31*	.12	-.19
R ²						.48						.46
Adjusted R ²						.42						.40
R ² Change						0.16 [†]						.14 [†]

NOTE: R² (change) is depicted for each group of variables, corrected for the variables in the previous block (n=134). Abbreviations: β , standardized beta; B, unstandardized beta; BEQ, Body Experience Questionnaire.

* P<.05.

[†] P<.01.

Discussion

To our knowledge, this is the first longitudinal cohort study on body image in patients with SCI during their first inpatient rehabilitation stay. During this period, the average body image scores improved towards a healthier state. Body image was positively associated with completeness of SCI, secondary conditions, duration of stay, and sex. Most importantly, body image explained a small but significant amount of the variance of the distress variables, after correction for demographic and injury-related variables.

As expected, levels of alienation were significantly higher at admission than discharge. The levels of harmony increased during rehabilitation, also as expected, but this change was not significant. These results show that body image changes towards a healthier state during inpatient rehabilitation. This finding corroborates earlier studies in the chronic phase, which shows that over time, patients with SCI seem to adjust to their changed bodies.^{3,4,15,27}

Our hypothesis that alienation and harmony would be associated with demographic variables was only partly confirmed. Associations between alienation and harmony and the injury-related variables were stronger. Overall, there were more and stronger correlations with the alienation scale than the harmony scale. These findings correspond with the study of the Body Experience Questionnaire by Bode et al.¹⁶ Based on these differences, they concluded that both scales reflect divergent concepts. However, an alternative explanation could be that the harmony subscale is not as sensitive to change because of its lower Cronbach α value in this study. The association between body image and the severity of the physical impairment and secondary conditions also corroborate earlier studies.^{15,16} The weak associations of alienation and harmony with functional impairment and secondary conditions can be understood by the cognitive behavioral model of body image.^{3,6} This multidimensional paradigm considers all the constructs that may be related to the development of body image. The Body Experience Questionnaire only measures a part of the cognitive and affective aspects of body image. The finding that women report more alienation may be because appearance is in general more important for women than for men.³

The alienation and harmony subscales together explained a unique 16% of the variance of depression. This is comparable with percentages found for other psychological constructs (e.g., locus of control [$\Delta R^2=.16$]²⁸; self-efficacy [$\Delta R^2=.18$]²⁹) after correction of some disability-related variables or demographic variables; however, it is much lower than sense of coherence ($\Delta R^2=.33$).²⁹ In the same study, Kennedy et al.²⁹ found for sense of coherence a comparable percentage of explained variance of anxiety ($\Delta R^2=.12$) as we did for body image.

In this population, the mean of the alienation score at discharge was equal to the mean found in an earlier study in community-dwelling people with RD.¹⁶ The mean harmony score

at discharge in this study stayed significantly lower than what was found in the previous study.¹⁶ Because RD and SCI are 2 very different conditions, these similarities and differences are hard to interpret. Bode et al.¹⁶ speculated that harmony is an indicator of successful coping with functional impairment, whereas alienation is a measure of the direct relation between body and self. If this is correct, then the rehabilitation phase may have an adequate length to decrease the feelings that body and self are 2 different phenomena; however, the rehabilitation phase may not be long enough to successfully cope with functional impairment. Further research (e.g., 1y follow-up after inpatient rehabilitation) would be necessary to test this hypothesis. Another explanation for the nonsignificant change in the mean harmony score can be in the subscale itself. The internal consistency of the harmony subscale was low in this population. The harmony subscale may not be a reliable measure to detect changes during this period of time.

Clinical implications

This study showed body image progressed toward a healthier state during patients' first rehabilitation phase. Decreases in pain and fatigue scores, which were found in this study, may be of influence on this positive course.¹⁶ Further, participants gain a lot of experience with their changed bodies during rehabilitation²² because of physical (training) activities, sports, learning to perform self-care, and other activities of daily living. All disciplines of the rehabilitation team play a role in this process of improving the patients' body image, minimizing feelings of depression and anxiety. The physical disciplines of rehabilitation may assist in body image more than they may be aware.⁴ A simple instrument such as the Body Experience Questionnaire to measure body image can help to identify people experiencing (problematic) alienation. These people can be referred to a cognitive behavioral therapy program for body image, which is an evidence-based therapy for body image disturbances.^{21,30}

Study limitations

The validity of the Body Experience Questionnaire has not been extensively examined in previous studies; further research is needed to establish its validity. With respect to the reliability of the harmony scale in this population, the internal consistency was low. This is most likely because the mean interitem correlation was sufficient.

To draw stronger conclusions about the course of body image over time, a longer follow-up period (e.g., 1y after discharge) is needed. The study sample is representative for patients with SCI in inpatient rehabilitation in The Netherlands, but compared with the international literature,³¹⁻³⁴ this sample's is older and contains a higher proportion of women, which may have an effect on body image scores.

We also do not know the influence of having the questionnaire filled out with help from a proxy. Furthermore, we did not gather information about the contents of the rehabilitation program. We also did not have information about other secondary conditions than pain and fatigue and other psychological constructs that may be of influence on body image^{10,13,15}; we did not have information about the premorbid body image.

Conclusion

Body image progressed towards a healthier state during the patients' first inpatient rehabilitation stay after the occurrence of SCI. Body image explains a small but significant amount of the variance of both depression and anxiety, after correction for demographic and injury-related variables. Positive changes in body image and psychological distress may be the result of the efforts of the whole multidisciplinary rehabilitation team.

Supplier

a. SPSS for Windows (version 23); IBM.

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Chapter 8

Coping flexibility as predictor of distress in persons with spinal cord injury

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Abstract

Objectives: Examine whether coping flexibility at admission to first spinal cord injury (SCI) rehabilitation was predictive of distress 1 year after discharge.

Design: Longitudinal inception cohort study.

Setting: Rehabilitation center.

Participants: Of the 210 people admitted to their first inpatient SCI rehabilitation program, 188 met the inclusion criteria. n=150 (80%) agreed to participate; the data participants (N=113) with a complete dataset were used in the statistical analysis.

Interventions: Not applicable.

Main outcome measures: Coping flexibility was operationalized by (1) flexible goal adjusting (FGA) to given situational forces and constraints and (2) tenacious goal pursuit (TGP) as a way of actively adjusting circumstances to personal preference. The Assimilative-Accommodative Coping Scale was used to measure FGA and TGP. The Hospital Anxiety and Depression Scale was used to assess distress.

Results: Scores on FGA and TGP measured at admission were negatively associated with the scales depression ($r=-.33$ and $-.41$, respectively) and anxiety ($r=-.23$ and $-.30$, respectively) 1 year after discharge. All demographic and injury-related variables at admission together explained a small percentage of the variance of depression and anxiety. FGA, TGP and the interaction term together explained a significant additional 16% of the variance of depression and 10% of anxiety.

Conclusion: The tendency to pursue goals early postonset of the injury seems to have a protecting effect against distress 1 year after discharge. People with low TGP may experience protection against distress from high FGA.

Introduction

Spinal cord injury (SCI) is a condition affecting physical as well as social and psychological functioning of the person involved.¹ People recently confronted with SCI need to adapt their lives to paralysis, sensory deficits, and bladder, bowel and sexual problems. These changes affect mobility and social participation, such as work or leisure time activities. People with SCI need to cope with changes in all these different domains. Moreover, goals they had in their lives before the occurrence of the injury may be blocked if these were dependent on pre-injury capabilities.² A substantial proportion of people with SCI have difficulties adjusting to their new situation. In community-dwelling people living with SCI, the estimated prevalence of depressive mood is 22% (ranging from 7% to 48% in different studies)³ and the estimated prevalence of anxiety is 27% (ranging from 13% to 36%).^{4,5} Levels of psychological distress vary strongly among people with SCI, and these can only be partly explained by demographic factors or characteristics of the SCI.⁶ An attempt to explain this variance is to study the effect of different kinds of coping styles.⁷⁻¹⁰ However, correlations found between coping styles and distress are only weak to moderate.¹¹ This low association may result from the way coping styles are measured in most studies, namely as the person's preference for dealing with problems in general. In these questionnaires, changes in circumstances of a person's life are not taken into account, whereas it makes sense to suppose that people might use different coping mechanisms in different circumstances.

In a previous study with community-dwelling people, the dual-process coping theory was applied to better understand determinants of distress after SCI.² The dual-process coping theory describes the way persons attempt to match goal-related coping with situations in which goals are blocked, for instance, due to loss of physical functioning or as part of aging.¹² This theory distinguishes 2 coping mechanisms: accommodative coping, which is reflected in flexible goal adjustment (FGA), and assimilative coping, which is reflected in tenacious goal pursuit (TGP). FGA entails adjusting personal preferences and goal orientations to given situational forces and constraints. This can involve either the devaluation or reevaluation of a particular goal, or the positive reappraisal of an emerging loss or limitation, as well as the consideration of alternative feasible goals. FGA should be considered as a neutralization rather than as an active solution of the problem.¹² The other coping mechanism, TGP, implies actively adjusting development and life circumstances to personal preferences, in other words maintaining goals. This can include activities such as acquiring relevant knowledge and skills, using compensatory means, or implementing basic lifestyle changes.^{13,14} Both FGA and TGP aim at eliminating discrepancies between actual life perspectives and salient concerns of personal development. From theoretical point of view, these scales are most

often antagonistic, although they can synergistically complement each other in concrete episodes of coping. Problems such as bodily impairment, chronic illness, or bereavement generally pose multiple adaptive problems on different levels that often call for different coping mechanisms.¹³ Therefore, both scales may not be seen as the opposite ends of same dimension. If a discrepancy between the desired and factual situation appears, a person will usually employ TGP first, trying to actively reduce the gap. If there are no means to actively attain the desired aim, a person is most likely to adjust standards or priorities to the given circumstances.^{12,14} Thus, whereas TGP is prominent in aiming at improvement or maintenance of functioning, the reorientation effort of FGA becomes more beneficial in accepting permanent loss or constraint.¹²⁻¹⁴ There is, however, a large individual variation in the way people apply both mechanisms in their life.

Stemming from aging research, the concept of coping flexibility has been used in studies in people with a sudden onset of physical problems like amputation, SCI and stroke in the last decade.^{2,15,16} The results are not unambiguous. In aging studies, a negative bivariate correlation was found between FGA and distress.¹⁷ In a cross-sectional study with community-dwelling people living with SCI, both FGA and TGP showed negative bivariate correlations with distress.² In that same study, FGA explained a significant percentage of the variance of distress in a regression analysis, after correction for demographic and SCI-related variables, social support, and task-oriented coping, whereas TGP did not.² Similar results were found in a study among people who sustained stroke. Only FGA, not TGP, measured at the end of their initial rehabilitation period was predictive for their quality of life (QoL) 1 year later.¹⁶ A different pattern was found in a study among people with a lower limb amputation in the initial rehabilitation phase. Although that study showed a positive correlation between both FGA and TGP with physical and psychological QoL, TGP more strongly predicted higher scores on physical and psychological QoL 6 months postdischarge.¹⁵ FGA predicted higher environmental QoL 6 months postdischarge, whereas TGP did not.¹⁵ The differences in results in the presented studies might be caused due to differences in diagnostic groups or differences in time of measurement.

The objective of this study was to examine whether FGA and TGP, measured at admission to first SCI rehabilitation, were predictive of distress 1 year after discharge, controlling for baseline scores of sociodemographic and SCI-related variables. Based on most studies published to date, it was hypothesized that higher levels of FGA and TGP at admission would be related to less distress, and that FGA compared to TGP would explain more variance in both depression and anxiety, 1 year after discharge.

Methods

Participants

The cohort used for this study has been described in a previous study.¹⁸ In brief, people with SCI were included who were admitted for their first inpatient rehabilitation to the Sint Maartenskliniek, a specialized SCI rehabilitation clinic in the Netherlands, between March 2011 and April 2015. Excluded were people with cancer-related SCI with a short life expectancy, people who were not sufficiently able to read Dutch, or had severe psychiatric or cognitive problems, such as active psychosis, mental retardation, or severe traumatic brain injury that made it impossible to fill out the questionnaire reliably.

Procedure

The ward psychologist contacted the people with SCI in the first week of their admission and asked them to complete a set of psychological questionnaires for diagnostic purposes. During that same appointment, potential participants were informed about the purpose and contents of this study. All participants gave written informed consent. One year after discharge the same set of questionnaires was sent by postal mail to the home address, including a prepaid return envelope. If the participant was not able to write because of hand function problems, he/she was asked to complete the questionnaires with help of a partner or other trusted person. If no one was available, a clinical psychologist's assistant supported him/her. The local medical ethics committee approved the research protocol (reference number: 15-449/C). The participants received care as usual, which means all were invited for an intake with the ward psychologist in the first 2 weeks after admission. If treatment was indicated this was offered by the psychologist. Incidentally a psychiatrist was consulted for instance in case of antidepressant medication.

Measures

Demographics. Age, sex, living with a partner, educational level, and work were assessed at admission.

SCI characteristics. Etiology of the lesion was divided into traumatic and non-traumatic. Level and completeness of injury were determined according to the International Standards for Neurological Classification of Spinal Cord Injury (<http://asia-spinalinjury.org/learning/>) by a trained rehabilitation physician at admission and discharge.

Pain and fatigue. Pain intensity and fatigue during the past week were measured with visual analogue scale (VAS) at admission. The scales ranged from 0 (no pain/no fatigue) to

100 (unbearable pain/most severe fatigue ever experienced (VAS; 0–100 mm)).¹⁹ VAS scales have been recommended for use in the SCI population in previous research.²⁰

Coping. To assess FGA and TGP, the Assimilative-Accommodative Coping Scale was used at admission. This scale consists of 30 statements equally divided in 2 scales.¹² Both scales consist of 15 items. An example of an FGA item is “I adapt quite easily to changes in plans or circumstances”.¹² An example of a TGP item is “When faced with obstacles, I usually double my efforts”.¹² The participant is asked to indicate the extent to which they agree with each statement on a 5-point scale; 1 (strongly disagree), 2 (disagree), 3 (nor agree nor disagree), 4 (agree), or 5 (strongly agree). The scale scores range from 0 to 60, with higher scores indicating more FGA and TGP, respectively. This scale has been used before with community-dwelling patients with SCI.² The Cronbach alpha for the FGA and TGP scales at admission were 0.80 and 0.69, respectively, in this study.

Distress. Distress was assessed using the Hospital Anxiety and Depression Scale (HADS), 1 year after discharge. The HADS is a commonly used measure of psychological distress in SCI Studies.²¹ It contains 14 statements with 2 scales; depression and anxiety with 7 items each. Respondents were asked to indicate the extent to which they agree with each statement on a 4-point scale. The score ranges from 0 to 21, with higher scores indicating more feelings of depression and anxiety.^{22–24} The Cronbach alpha for both depression and anxiety 1 year after discharge were 0.86 in this study.

Statistical analyses

Only participants with a complete dataset were used in the analysis. Because of the ordinal measurement levels of most scores, nonparametric tests were used as much as possible. Associations between scores on FGA and TGP, demographic and SCI-related variables at admission with depression and anxiety 1-year post-discharge were expressed in Spearman coefficient. Correlations less than 0.3 are considered as weak, between 0.3 and 0.5 as moderate, and above as strong.²⁵

Next, bivariate regression analyses with depression and anxiety as dependent variables were performed for all the demographic and injury-related variables. To minimise the number of determinants in the multiple regression analysis and minimize the chance of rejecting variables that may show an association in the multiple regression analysis, a significance level of 0.20 was used as cut-off. In a hierarchical regression analysis, all demographic and injury-related variables that met these criteria were entered simultaneously in the first block with depression and anxiety as dependent variables. In the second block, the FGA and TGP scales were entered. Finally, based on the theoretical assumption that FGA and TGP are two

different coping mechanisms, this last step was redone, including the interaction term of FGA and TGP. Preliminary analyses to check for violations of the assumptions of outliers, linearity and multicollinearity and of normality and homogenous of the residuals were performed. The percentage of variance (R^2) was computed. Values of R^2 below 0.25 are considered as small associations, from 0.25 to 0.40 as moderate, and above as large.²⁵ To further explore the possible interaction effect and to make it possible to visualize this effect, FGA and TGP scores were dichotomized into a low and high coping group, using the mean score as cut-off.

P-values <.05 were considered statistically significant. All analyses were conducted using SPSS statistical program for Windows (version 23).^a

Results

During the inclusion period, a total of 210 people who sustained SCI were admitted. Of them, 8 were excluded because they did not read or speak Dutch and 14 because of severe cognitive or intellectual problems. From the remaining 188 people, 150 (80%) agreed to participate in this study. One year after discharge 115 participants returned the questionnaire. A total of 113 participants had a complete dataset and were used for further statistical analysis. No statistical differences were found between the group with a complete and incomplete dataset. Table 8.1 gives the characteristics of the participants at admission.

Table 8.1 Participants characteristics (N=113) at admission

Characteristic	Mean±SD	Range
Age (y)	55.5±14.0	20–79
Days since injury at admission	33.7±33.4	0–220
Time of admission (d)	90.2±49.3	16–207
	Frequency	Percentage
Sex (male)	75	66.4
Living with a partner	91	80.5
In paid employment at the time of SCI	44	38.9
Higher education level	34	30.1
Injury level		
Cervical	45	39.8
Thoracic	43	38.1
Lumbosacral	25	22.1
Motor complete	41	36.3
Cause of injury (traumatic)	45	39.8

NOTE. Higher education = college or university.

Table 8.2 depicts the score distributions of the main variables at admission or 1 year after discharge.

Table 8.3 shows the correlations between the determinants, FGA and TGP, and the distress variables. Higher scores on both FGA and TGP, reflecting more use of these coping mechanisms, were associated with lower scores on depression and anxiety. Pain was moderate, positively associated with both depression and anxiety. Having a paid job was weakly associated with less depressive mood. Further there was a significant moderate positive association between FGA and TGP.

Table 8.2 Mean \pm SD at admission for the FGA and TGP scales, pain and fatigue and the scores of distress scales 1 year after discharge (N=113)

Variable	Mean \pm SD
FGA (range 0–60)*	38.1 \pm 7.4
TGP (range 0–60)*	35.4 \pm 6.5
Pain (VAS 0–100)*	28.3 \pm 24.8
Fatigue (VAS 0–100)*	51.2 \pm 24.6
Depression (range 0–21) [†]	6.0 \pm 4.5
Anxiety (range 0–21) [†]	5.2 \pm 4.1

* Score at admission.

[†] Score one year after discharge.

Table 8.3 Spearman correlation coefficients between FLEX, TEN and the determinants at admission, and the distress variables one year after discharge (N=113)

Variable	FGA	TGP	Depression	Anxiety
1. FGA	NA	0.43*	-0.33*	-0.23 [†]
2. TGP	0.43*	NA	-0.41*	-0.30 [†]
3. Depression	-0.33*	-0.41*	NA	0.70*
4. Anxiety	-0.23 [†]	-0.30 [†]	0.70*	NA
5. Sex (male)	0.07	0.21 [†]	-0.05	-0.02
6. Higher age	-0.01	-0.07	0.11	0.05
7. Having a partner	0.26*	0.16	-0.11	-0.10
8. Completed higher education	0.08	0.10	-0.15	-0.08
9. Having a paid job	0.08	0.12	-0.23 [†]	-0.12
10. Having a higher level of SCI	-0.05	-0.05	0.03	-0.07
11. Having a complete SCI	-0.06	0.01	0.09	0.15
12. Sustained a traumatic SCI	0.20 [†]	0.15	-0.14	-0.06
13. Pain (VAS)	-0.22 [†]	-0.04	0.31*	0.32*
14. Fatigue (VAS)	-0.10	-0.02	0.07	0.14

Abbreviation: NA, not applicable.

* $P < .01$ according to Spearman correlation analyses.

[†] $P < .05$.

The bivariate regression analyses with depression as dependent variable showed associations with education, paid job, traumatic SCI, and pain at an alpha level of .20. For anxiety only, an association with pain was found at this alpha level. Table 8.4 shows the results of the multiple regression analyses with these variables and the HADS depression and anxiety scales as dependent variables. The relevant demographic and injury-related variables at admission together explained a small 14% and 12% of the variance of depression and anxiety, respectively. FGA, TGP, and the interaction term together explained an additional 16% and 10% of the variance of the depression and anxiety scales, respectively.

Table 8.4 Regression analyses with the distress scales as dependent variables, entering in the first block the demographic and SCI-related variables and the TGP and FGA scales and the interaction term in the second (N=113)

Variable	Depression		Anxiety	
	β	<i>P</i> -value	β	<i>P</i> -value
Model 1				
Having high education	-0.08	.39	N.A.	
Having a paid job	-0.11	.25	N.A.	
Having traumatic SCI	-0.12	.17	N.A.	
Pain	0.29	<.01	0.34	<.01
R ²	0.14	<.01	0.12	<.01
Model 2a				
Having high education	-0.08	.37	N.A.	
Having a paid job	-0.06	.51	N.A.	
Having traumatic SCI	-0.07	.41	N.A.	
Pain	0.29	<.01	0.34	<.01
FGA	-0.08	.40	-0.01	.94
TGP	-0.32	<.01	-0.26	<.01
R ² change	0.13	<.01	0.07	.01
Model 2b				
Having high education	-0.10	.23	N.A.	
Having a paid job	-0.03	.74	N.A.	
Having traumatic SCI	-0.11	.22	N.A.	
Pain	0.29	<.01	0.35	<.01
FGA	-0.91	.02	-0.76	.05
TGP	-1.09	<.01	-0.96	<.01
FGA × TGP	1.37	.03	1.25	.04
R ² change	0.16	<.01	0.10	<.01

The dichotomized coping scores were used to visualize the interaction between FGA and TGP (Figure 8.1).

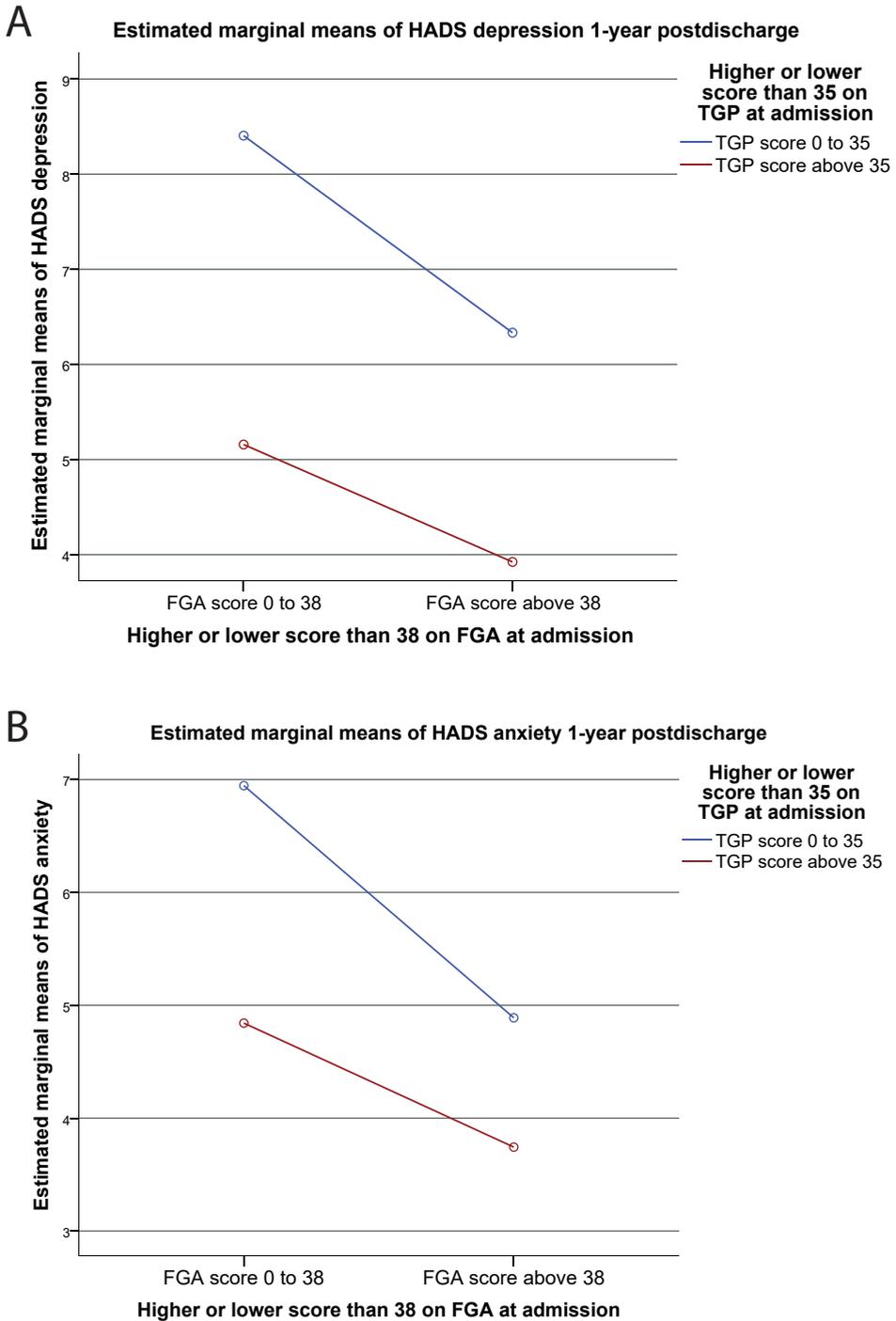


Figure 8.1 Interaction between high and low scores on FGA and TGP with respect to the scores on the HADS.

The significant interaction indicates that the association between FGA and depression/anxiety is dependent on the level of TGP (and vice versa). Figure 8.1 shows that people with a high score on both FGA and TGP have the lowest scores on depression and anxiety. In the group with a high score on TGP, the differences in depression/anxiety between those with high versus low score on FGA are smaller (red line) than for the group with a low score on TGP (blue line).

Discussion

This is the first longitudinal cohort study into coping flexibility of people with SCI. Results showed that the scores of FGA and TGP at admission were both negatively associated with depressive mood and anxiety 1 year after discharge. Together, FGA, TGP, and the interaction term explained a significant additional percentage of the variance in both depressive mood (16%) and anxiety (10%) after controlling for demographic and SCI related variables.

Contrary to the hypotheses and the results from a previous cross-sectional study,² not FGA but TGP explained in this study the largest proportion of variance of both depressive mood and anxiety 1 year after discharge. This is, however, in line with a study of people with an amputation during and shortly after their initial rehabilitation. In that study higher scores on TGP were associated with higher scores on QoL in the physical and psychological domain 6 months after discharge.¹⁵ However, in a study with people with stroke, FGA at discharge of their initial rehabilitation corresponded to higher levels of QoL 1 year after.¹⁶ These differences are unlikely due to the use of different outcome measures, because QoL and distress are strongly associated concepts.^{6,11} Alternatively an explanation of the difference between the studies could be found in the time of the first measurement. Both in the current study and the amputation study,¹⁵ the first measurement took place at the start of rehabilitation. In the stroke study, the first measurement took place at the end of the rehabilitation phase.¹⁶ In the stroke study and in the cross-sectional study of people with SCI in the chronic phase,² FGA rather than TGP was associated with better psychological outcome. These findings combined suggest that shortly after the onset of an intrusive event, like SCI or amputation, the tendency to pursue goals is a protective factor. However, as time passes, flexibility to adjust to blocked goals may become more important for adjusting well. This is in line with the theory that a person will usually employ TGP first when confronted with situations such as bodily impairment, chronic illness, or bereavement.^{13,14} People with higher scores on TGP might be more active in pursuing their goals during their rehabilitation phase. By doing so they might have become more experienced by undertaking different

kind of activities, at the end of rehabilitation. Further research is necessary to clarify the course of TGP and FGA.

More use of FGA and TGP was associated with less depressive mood and less anxiety in this study. These associations have been reported before,^{2,12,16,26} and are in line with the hypothesis. Further, this study showed a moderate positive correlation between FGA and TGP, indicating these concepts are not the opposite ends of the same dimension. These results are in line with some,^{15,27,28} but not with all research previously done.^{12,26,29} Further there seems to be an interaction effect between FGA and TGP, as has been reported before.^{27,28} This interaction suggest that if TGP is high at admission the score of FGA is of less importance. On the other hand, when TGP is low, a high score on FGA might be protective towards distress 1-year postdischarge.

Of the demographic variables at admission only having a job had a small negative association with depressive mood. Pain had a moderated association with both depressive mood and anxiety and a small negative association with FGA. Both findings are in line with previous research.^{27,30}

Clinical implications

Based on the results of this study it is important to realize that people with a high tendency to pursue their goals, may do well in the long term. In clinical practice, this attitude is not always considered the most favorable and sometimes even seen as counterproductive. Rehabilitation in the Netherlands is based on the assumption we have to strive for realistic goals, this is in the eyes of the professionals. These professionals might be afraid that the process of rehabilitation will be difficult if a person strives for higher goals, for example, walking without walking canes, although this is not realistic from a professional point of view. In these cases, the team may try to downsize the patients' goals, which may result in lowering TGP. Probably, rehabilitation is generally focusing on stimulating FGA and too little on strengthening TGP, especially in the first part of rehabilitation. More research is needed to clarify the course of FGA and TGP during and after rehabilitation. If research confirms our hypothesis, stimulating TGP in the first period postonset of SCI might be more effective than diminishing this tendency.

Study limitations

In this study, we did not gather information about the contents of the rehabilitation program. Neither did we have information about other secondary conditions than pain and fatigue, premorbid health conditions, and other psychological constructs that may influence

depressive mood or anxiety. Nor did we gather information about the social economic status of the participants and the help received from formal and informal caregivers. Nor don't we know what the influence may have been of filling out the questionnaire with help from a proxy.¹⁸

For the interaction model, we used the rather arbitrary mean scores as a cut-off, in the absence of established cut-off scores for both coping scales for instance based on a reference group.

Further, the validity of the measurement of FGA and TGP has been point of debate.²⁸ In this study, we found a good internal consistency and a moderate positive correlation between the two coping scales. The latest indicates the scales measure different concepts. Further the results are in line with the theoretical background, as well as a study with patients who had a recent amputation shortly postonset.^{14,15}

Conclusion

The findings of this study indicate that a high score of TGP at admission is protective for distress 1 year after discharge. For people with a low score on TGP a high FGA score may have a buffering effect. In the first period after an intrusive event like SCI, tenacity is most helpful, while time passes, flexibility seems to become more helpful. During rehabilitation, there should be more attention for this shift over time and the most helpful tendency.

Supplier

a. SPSS for Windows, version 23; IBM.

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Chapter 9

General discussion



The aim of this thesis was to investigate secondary health conditions (SHCs), self-management, and self-efficacy in people with spinal cord injury (SCI). Relationships between these features and their associations with possible determinants like SCI related factors, socio-demographic factors and psychological aspects were subject of investigation. The results were presented in the previous chapters. This final chapter starts with an overview of the main findings and conclusions. Subsequently, theoretical considerations, methodological implications, and implications for clinical practice will be discussed. Finally, ideas for future research will be presented, to end with a conclusion.

Main findings

Part I Background information

In **chapter 2** the protocol of the quantitative part of the SELF-SCI study is described. This cohort study investigated self-management and self-efficacy of people with SCI during their initial inpatient rehabilitation until 1 year after discharge. The study is based on theories about motivation to perform health-promoting behaviors (Theory of Planned Behavior) and on a theory about adjustment to SCI (SCI Adjustment Model). All constructs used in these models are measured. The found data will be used to investigate the associations between the different constructs and to test the underlying theories.

The literature about the associations between self-efficacy and physical and psychological SHCs was described in **chapter 3**. Only a few studies (seven out of 22) investigated associations between self-efficacy and physical SHCs. The results showed a trend towards a negative association. The majority of the studies (21 out of 22) described associations between self-efficacy and psychological SHCs, showing strong negative correlations in the meta-analysis. Therefore, self-efficacy seems an important target for intervention during rehabilitation. Further, this literature review suggested the possibility of operationalizing the construct of self-efficacy at different levels of specificity. This was the basis for the next chapter.

In **chapter 4**, four often used self-efficacy scales for people with SCI were investigated for their internal and external (convergent and divergent) validity. The internal validity of these four scales was acceptable to good in one-factor models. The convergent validity of the scales could be confirmed, however the divergent validity could only be partly confirmed. The hypothesis that self-efficacy can be measured at different levels of specificity could not be fully confirmed. The investigated self-efficacy scales are not sensitive enough to capture the state aspects of self-efficacy.

Part II Results

As part of the SELF-SCI study participants were interviewed to understand how the rehabilitation team taught them to perform appropriate self-management and gain confidence (self-efficacy). These qualitative results are described in **chapter 5**. Participants mentioned various strategies employed by the professionals to teach self-management and the factors influencing this learning process. The use of these strategies varied across disciplines. These strategies and the interpersonal approach of the professionals helped participants to gain confidence (self-efficacy) also. Participants further distinguished between therapy and care, associating rehabilitation and learning new skills with physiotherapy and occupational therapy rather than the nursing staff. Learning to perform self-management requires an interdisciplinary approach where segregation between disciplines is undesirable.

In **chapter 6**, results from the Coping with SCI study regarding fatigue were presented. Fatigue is a frequently mentioned as a burdensome SHC for people with SCI. Although fatigue scores significantly decreased during rehabilitation, these scores were at discharge still significantly higher than those of healthy adults. Fatigue scores at discharge could largely be explained by psychological adjustment variables (including psychological SHCs). Associations between fatigue and psychological distress suggest that psychological interventions might be effective in diminishing fatigue.

As a result of SCI, the way people involved look at themselves might change. To investigate the course of body image and its association with psychological SHCs, **chapter 7** described these results from the Coping with SCI study. In this study two different aspects of body image were used, namely alienation and harmony. During rehabilitation, body image of people with SCI increased towards a healthier state, alienation decreased significantly, and harmony increased (but not significantly). Body image explained an important part of the variance in depressive mood and anxiety and can be a target of interventions by all members of the rehabilitation team.

At the end of part II, in **chapter 8**, the coping flexibility results of the Coping with SCI study were described. This study used the dual-process coping theory, which distinguishes two coping mechanisms: flexible goal adjustment (FGA) and tenacious goal pursuit (TGP). Both FGA and TGP, measured at admission, showed negative associations with depressive mood and anxiety one year after discharge. Pursuing goals soon after the onset of the injury seems to have a protecting effect against distress (psychological SHCs) one year after discharge. During initial rehabilitation for SCI this tenacious attitude of people is often qualified as a lack of adjustment and seen as a problem for the team. This study illustrates that the team members should embrace this attitude.

Theoretical considerations

After having discussed the main findings of this thesis I would like to focus on the concept of self-efficacy. In chapter 3 to 5 it can be read that self-efficacy is a central concept in multiple health behavioral theories.¹⁻³ Nevertheless it is still not completely clear what we measure with the current self-efficacy scales. In the following part I will discuss the concept of self-efficacy. First, some background about the concept of self-efficacy and about a theoretical model of adjustment after spinal cord injury (SCIAM), that incorporated this concept. Next, the place of self-efficacy within SCIAM will be explored and discussed. Finally, I will discuss how self-efficacy is linked to other psychological constructs described in this thesis, like body image and FGA.

Self-efficacy

In recent years, the clinical and research interest in self-efficacy of people with SCI has increased.⁴ In its original concept, self-efficacy was defined as the belief that one can successfully execute behavior required to produce the desired outcomes.⁵ Within this definition, the scope of self-efficacy is task specific and therefore self-efficacy will act as a state variable that fluctuates as circumstance in peoples life change.⁶ In the last decades, however, the development of self-efficacy scales has focused on measuring general self-efficacy, which can be seen as a trait variable that will not change much over time.⁶ Another distinction made between different kinds of self-efficacy scales is: general, domain specific, and task specific self-efficacy.^{7,8} These last two can be seen as a refining of the state aspect of self-efficacy.

Self-efficacy is a central concept in rehabilitation psychology and predictive of adjustment after SCI.⁹⁻¹¹ A widely used model for adjustment after SCI has incorporated both state and trait self-efficacy.³

SCIAM

The Spinal Cord Injury Adjustment Model (SCIAM) (Figure 9.1)³ is based on the notion that adjustment to SCI is influenced by physical aspects, psychological resources and social factors. These aspects interact with each other and influence the person's appraisal of their situation. First there is the perception of the current situation, the primary appraisal, then there is the secondary appraisal of the extent to which the person has sufficient resources to deal with this situation. This will lead to particular ways of coping and levels of motivation to take action. The continuous process of appraisal and re-appraisal of the situation and the way people cope

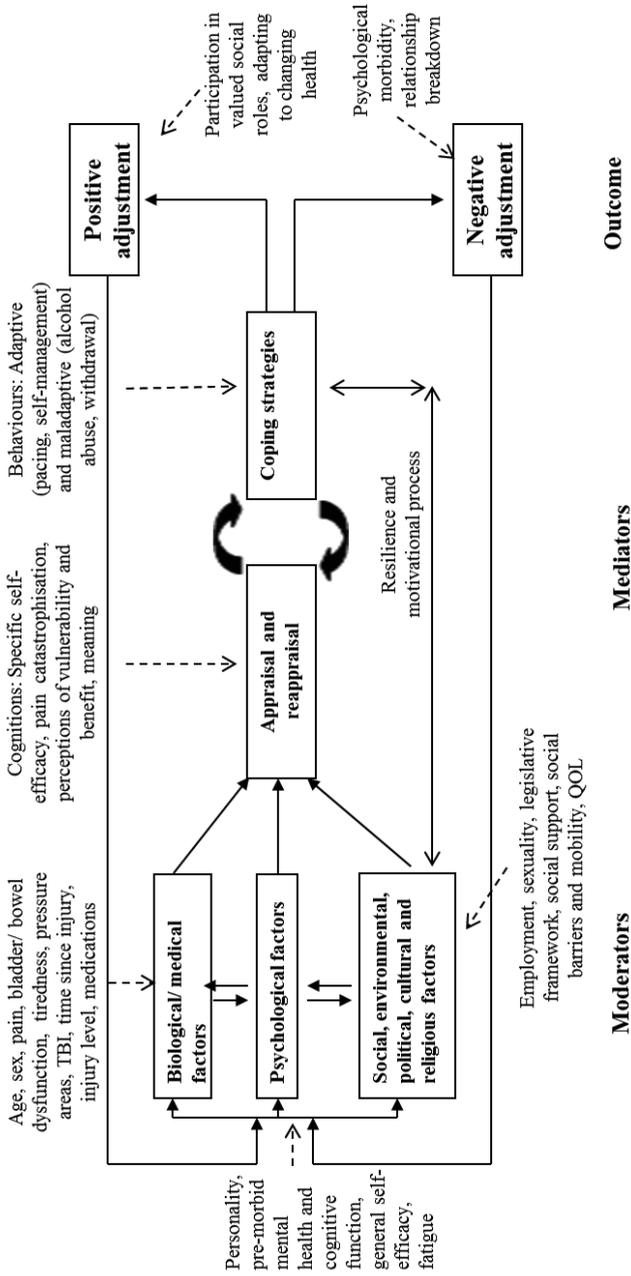


Figure 9.1 Spinal cord Injury Adjustment Model. With permission printed from Craig et al.³

with the situation have a central role within SCIAM and could be seen as the ‘engine room’ of the model. According to SCIAM, the result of this whole process will be positive or negative adjustment. Adjustment has a psychological component, reflected in well-being or distress (psychological SHCs), and a social component, reflected in social engagement/participation. Positive adjustment will be expressed in a good quality of life, low distress and a satisfactory social and community participation, negative adjustment in the opposite.

Self-efficacy in SCIAM

Within SCIAM a distinction is made between general self-efficacy (trait variable) as part of the psychological factors and domain specific self-efficacy (state variable) as part of the perceptions and beliefs of a person.³ According to SCIAM, people have a more or less fixed level of general self-efficacy, regardless of their situation. Self-efficacy as a state variable, like domain specific self-efficacy, is placed in the appraisal and reappraisal box of the model (Figure 9.1). While trait and state aspects of self-efficacy are not fully independent, it can be presumed that high levels of general self-efficacy will lead to higher levels of domain specific self-efficacy.⁶ Further, high levels of general self-efficacy could ensure that the levels of domain specific self-efficacy will bounce back sooner after a major aversive situation like SCI. Although this seems logical from a theoretical point of view, it is not yet confirmed in clinical research. In chapter 3 we found many studies confirming an association between self-efficacy (both general and domain or task specific) and psychological adjustment variables like anxiety and depressive mood. From these studies, no clear differentiation could be made between trait and state scales. Except for one task specific scale (leisure-time self-efficacy),¹² all domain and general self-efficacy scales had approximately the same association with depression and anxiety. Also in chapter 4 no clear differentiation between trait and state self-efficacy scales could be found. Further, little evidence could be found of scores from scales measuring state aspects of self-efficacy varying over time. The few longitudinal studies done with a general self-efficacy scale and with a combined domain specific and general self-efficacy scale, showed only little fluctuation over time.^{13–16} In one of these studies, most participants followed a relative stable trajectory and only if the statistic criterion indices were interpreted leniently, a small percentage showed a decreasing trajectory.¹⁶ To date, scales measuring state aspects of self-efficacy seem unable to capture the variability assumed for this variable, which therefore acts like a trait variable. Although the division in state and trait aspects of self-efficacy is justified from a theoretical point of view, in current clinical and research practice we are not able to distinguish between these two levels of self-efficacy. The development of a sensitive scale for state self-efficacy is necessary in order to be able to test the theory and investigate if the

division in different self-efficacy levels is maintainable. Till then, it does not seem to matter what kind of scale we use, they all measure trait-like aspects of self-efficacy. Considering the length of the scales the short form University of Washington Self-Efficacy Scale seems for now the best choice. On the other hand, for people used to work with other scales, and who are familiar with their outcomes, there seems no need to change.

Another theoretical aspect concerning state aspects of self-efficacy, is related to the experience of people with the investigated behavior or task. If, for instance, someone who has never been confronted with a pressure injury (wound resulting from prolonged pressure on the skin) is asked how confident this person is in preventing a pressure injury, what are we actually measuring? Is this confidence or could it also be a measure of unawareness? In the other direction, people who have experienced a pressure injury in the past can no longer deny that this can happen to them. So, if they score lower on disability-management self-efficacy is this because their confidence is less or are they just more realistic? Nevertheless, comparing people who have never experienced the behavior of investigation with people who have, is a tricky business as long as we do not know what we actually are measuring.

Self-efficacy and other psychological aspects

In this thesis, besides self-efficacy also body image was subject of investigation. According to the more general cognitive behavioral perspective,¹⁷ body image refers to the multifaceted psychological experience of embodiment, especially but not exclusively one's physical appearance. It encompasses one's body-related self-perceptions and self-attitudes, including thoughts, beliefs, feelings and behaviors. From this broad definition it becomes clear that body image has to do with perceptions and beliefs about the body. The body image scale described in chapter 7, focuses on the thoughts and beliefs of people regarding the unity of body and self.¹⁸ This perception of how your body belongs to who you are should, according to SCIAM, be placed in the appraisal box (Figure 9.1). Since this box is also the place where domain specific self-efficacy is placed, one could ask to what extent this scale measures the concept of body-image self-efficacy. The Harmony part of the questionnaire in particular refers to this aspect of feeling familiar with your own body.¹⁸ In the Dutch version used in the study of chapter 7 this is even more so because in Dutch the words for familiar and confidence stem from the same word.

Another subject of investigation was FGA which is defined as adjusting personal preferences and goal orientations to given situational forces and constraints. This can involve either the devaluation or re-evaluation of a particular goal, or the positive reappraisal of an emerging loss or limitation, as well as the consideration of alternative feasible goals.¹⁹

Within this definition the (re)appraisal of loss and of formal goals has a prominent place. As discussed before the (re)appraisal of one's situation is, according to SCIAM, placed in the box where also the domain-specific self-efficacy is placed (Figure 9.1). If self-efficacy and appraisals are so interlinked one could raise the question to what extent this scale and all other scales aiming to measure appraisals are in fact measuring the confidence that people have. In case of FGA this would be the confidence people have in the way they are able to change the way they think about their situation, and their goals, and the confidence to change them in accordance with their new possibilities.

Psychological constructs

In the literature, a variety of psychological resources have been associated with adjustment to SCI.^{20,21} These different resources show strong inter-relationships with self-efficacy; self-efficacy and hope ($r=.54$),²² self-efficacy and resilience ($r=.54$),²³ ($r=.68$),²⁴ self-efficacy and self-esteem ($r=.57$);²⁵ self-efficacy and locus of control ($r=.56$);²⁴ self-efficacy and purpose in life ($r=.55$);²⁶ and self-efficacy and mastery ($r=.42$).²⁷ Further some of these resources and the adjustment indices (depression, anxiety and quality of life) show more or less the same pattern, whereby the most people with SCI score well on these measures. The percentages are depending on the measurement and the used cut-off scores. For instance, for depression in people living with SCI a mean prevalence of 22.2% (ranging from 7–48%) was found.²⁸ For anxiety it was found that 27% (ranging from 15–32%) of people living with SCI develop an anxiety disorder.²⁹ In both examples, most people showed a non-pathological reaction after SCI. This is reflected in high percentage (57%) of satisfaction with life as a whole of people with SCI.³⁰ For resilience, it was found that 58%²⁴ of the research population showed a high score. In a study about post traumatic growth between 54 and 79% of the sample reported at least some positive change (average 67%)³¹ Given the fact that the inter-correlations are high that and they show a comparable pattern in people with SCI the question is justified if these psychological resources are truly independent of each other. It seems that all these different concepts have some kind of underlying construct. It would be good for researchers and clinically working psychologists to seek for this underlying construct instead of creating new ones.

Methodological considerations

For this thesis two separate studies were carried out, the Coping with SCI study, and the SELF-SCI study. Some of the limitations to these studies have already been described. Here I will make some general considerations about methodological issues.

Coping with SCI study

The Coping with SCI study was carried out in one of the eight rehabilitation centers in the Netherlands with a specialization in SCI. This means that generalizations can less easily be drawn than from the SELF-SCI study carried out in all eight specialized rehabilitation centers. In the Coping with SCI study the inclusion rate was very high, with 80% of the eligible participants actually participating in the study. The fact that the prime investigator/clinician recruited the participants for this study himself certainly helped to reach this high response.

As described in chapter 7, the Coping with SCI study used a relative new body image scale for there was no validated scale for people with SCI. It had been hoped that over the years more validity studies had been carried out and published. This was in fact not the case. The scientific proof of the reliability and validity of this new scale, especially when applied to people with SCI, is limited to the results from chapter 7. During the analysis of the data it seemed that the two scales (alienation and harmony) were not fully independent from each other and might be the two ends of the same dimension. In the original validation study two factors were found, an explanation could be that the questions of the alienation scale were mostly negative formulated, while the questions of the harmony scale were positively formulated. Probably the factors were formed by this direction of the questions, rather than by the content.

In chapter 8 a scale measuring FGA and TGP was used. Just after the start of the Coping with SCI study, a critical study about the validity of the scale appeared.³² That new study concluded that neither subscales clearly distinguished between FGA and TGP. The direction in which the questions were formulated was just as important as what was being measured.³² This was especially for TGP problematic, while the variance of the item scores was not well explained by the latent coping factor and was better explained by the direction in which questions were formulated. The fact that the direction of the question is important for the factor structure of a scale is a well-known methodological problem.³³⁻³⁵ A way to overcome this problem might be to use as many positive formulated questions as negative formulated questions for each scale.

The SELF-SCI study

The SELF-SCI study was carried out in all eight Dutch rehabilitation centers with a specialization in SCI. The results from this study can therefore easily be generalized to all people with SCI in the Netherlands during and the first year after their initial rehabilitation. On the other hand, the inclusion rates were not equally high in all centers. Despite all efforts from the research team three out of eight centers were not able to provide more than 15 participants each during the

2 year inclusion period. In the remaining 5 centers inclusion rates varied. In the two centers, where researchers of SELF-SCI were working, the inclusion rates were considerably higher. We cannot rule out that different research assistants used the inclusion criteria differently, or were for practical reasons not able to inform and ask all potential participants.

Another issue is the concept of resilience as being used within SCIAM. In the first version of SCIAM,³⁶ used for the design of SELF-SCI, the psychological factors were not completely elaborated. In this first model it was assumed that resilience would be one of the psychological factors, that would not change (much) over time. In the recent version of SCIAM,³ resilience is an explicit part of the mediating factor and therefore a variable that might change over time. In this recent version, resilience is no longer seen as a potential protective quality of a person, but as a moderator of adjustment after SCI.³ Resilience being seen as a moderator would justify repeated measurement over time to determine different possible trajectories.³⁷

Because we wanted to cover all the aspects in both TPB and SCIAM a lot of different scales were included in the assessment. We tried to include as many valid questionnaires as possible. For a few aspects no such scale existed and new ones had to be developed. Because of the limited time for this project, it was not possible before the start of the study to investigate these scales for their validity.

Comparison of the two studies

There were some validated questionnaires that were used in both studies: especially the outcome measures like distress (HADS), illness cognitions (ICQ), quality of life (2LS) but also sociodemographic variables, SCI-related variables and social support were the same in both studies. On the other hand body image and coping flexibility were not incorporated in SELF-SCI for several reasons. First because of their validity problems as discussed before, and further because the scope of the SELF-SCI study was about self-management and self-efficacy not on coping flexibility or body image. This focus on self-efficacy in the SELF-SCI study has its origin in the Coping with SCI study, just as the choice for SCIAM as underlying theoretical model.

Clinical implications

Interdisciplinary working

Rehabilitation of SCI is in most western countries organized as a multidisciplinary approach. Different disciplines work together with the people with SCI towards the same goals. Historically, the rehabilitation approach has been mostly medical and physically oriented.

From this perspective a lot of outcome measures used in rehabilitation are physical in nature (for instance: balance, mobility, physical independence or wheelchair skills). Although the psychosocial aspects are getting more and more attention, the contribution of team members working on these aspects cannot be reflected in these physical oriented goals. One step further than multidisciplinary working will be interdisciplinary; literally working together in the same room with the people with SCI towards the same goals. To attain this interdisciplinary working together, it is helpful to seek for goals that suit this approach. The confidence that people have in their ability to perform certain behavior, for instance walking or wheelchair skills, could be such a goal. Working together as a team to increase self-efficacy will serve more than one purpose. First, it will stimulate interdisciplinary working as a team approach. Second, self-efficacy has proven to be an important aspect in the adjustment and social and community participation of people with SCI. This interdisciplinary goal of self-efficacy, will help people with SCI to adjust better and be more socially active. Participation is seen as one of the most important outcomes within the main theoretical framework of rehabilitation: the International Classification of Functioning. And, finally, increasing self-efficacy as goal for rehabilitation will emphasize all team members on their therapeutic possibilities to improve self-efficacy of people with SCI.

In current rehabilitation practice, all team members work on the aspect of confidence. They do a lot of good things with regard to the self-efficacy of the people they work with. However, they do not always seem to be aware of what they are doing to improve self-efficacy and they certainly do not use therapy as a means to increase self-efficacy. They are capable of doing this but are not aware how they can. The four sources of self-efficacy, formulated by Bandura,³⁸ (performance accomplishments, vicarious experience, verbal persuasion, and physiological feedback) form a good base to develop strategies that could be incorporated in existing therapies aimed to improve self-efficacy.

Interdisciplinary working to improve self-efficacy will probably increase patient's adjustment to SCI. As been shown in this thesis there is a strong correlation between adjustment and fatigue but also between adjustment and body image. Improving self-efficacy, for instance by experiencing new or presumed impossible activities, might reduce depressive mood, and may also have a beneficial effect on body image and decrease fatigue.

Tenacious Goal Pursuit

In clinical practice, when people with SCI try to pursue their former goals, goals that given the current impairments the team regard as impossible to achieve, this is often seen as refusing to accept the consequence of SCI. For this reason people with strong TGP can

be experienced as “difficult patients”, because they ask so much, refuse to use help or aids for their affected skills, or they do not want to make a decision for instance about home improvements. From chapter 8 we know that strong TGP protects people from distress one year after discharge from inpatient rehabilitation. In the present time, where there is limited time per person for rehabilitation, a strong TGP might not be favorable from the perspective of the rehabilitation team. In the eyes of the people with SCI, who have to live with their impairments long after rehabilitation, this might be the right attitude and therefore should be endorsed by the team.

Directions for future research

In this thesis some results of the SELF-SCI study are described. These are, however, only the first analyses of an enormous amount of the collected data. The main aims of the study, to determine the course of self-management and self-efficacy and to test the two models TPB and SCIAM, have not yet been fully achieved. Secondary analysis of the data might give us much more insight into self-management and self-efficacy and into their association with a variety of psychological factors and physical or psychological SHCs. Further, professionals at five rehabilitation centers in the Netherlands and three in Australia have been interviewed. Their response about how they teach people with SCI to perform self-management should be further analyzed and described.

The results in this thesis support the idea that all the current self-efficacy scales measure trait aspects, not the state aspects. The development of a new sensitive self-efficacy scale that is able to capture fluctuation over time would be an enormous step forwards. Therefore, we should develop questions that ask for confidence about domain or task specific behavior, that may change over time, without asking for motivation to perform that behavior.³⁹ For examples of questions, see Box 9.1.

Box 9.1 Example questions for state aspects of self-efficacy

- How confident are you that you have sufficient knowledge, at the moment, about your spinal cord injury and its consequences?
- How confident are you that you can maintain your physical condition (strength and endurance) on a regular basis, if you wanted to?
- How confident are you that you can divide your energy during the day to prevent fatigue, if you wanted to?

Finally, SCI research concerning self-efficacy, should focus on the therapeutic possibilities of improving self-efficacy of people with SCI. To date, different self-efficacy programs have been developed for different health conditions (see for a review Marks et al.),^{40,41} including for people with SCI.^{42,43} All these programs focus on the people with a chronic disease or, in a select cases, on their caregivers. These programmes were guided by either health care professionals or by peer supporters. In this last case one of the four sources of self-efficacy, vicarious experience, is used.³⁸ A new approach would be to train the whole rehabilitation team about the principals of self-efficacy enhancing strategies and how to apply them throughout the inpatient and outpatient rehabilitation program. Research with regard to such an approach, should focus not only on effecting people's self-efficacy and adjustment, but also on the implementation process.

Conclusions

The findings of the present thesis contribute to our understanding of SHCs, self-management and self-efficacy during the initial SCI rehabilitation and the first year after discharge. Self-efficacy is a central aspect in the adjustment to SCI with strong correlations with psychological SHCs and probably with physical SHCs. These findings are robust notwithstanding the fact that the current self-efficacy scales measure on a trait level not on a state level. I would expect this association to be stronger if we are able to measure self-efficacy on state level. Self-efficacy as the goal for people during their SCI rehabilitation will improve interdisciplinary working, adjustment, participation, and diminish SHCs.

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Summary



Spinal cord injury (SCI) is a relatively rare condition, resulting in impairments of motor, sensory, and autonomic functions. Beside these primary impairments, people with SCI are also at risk for the occurrence of physical and psychological secondary health conditions (SHCs). Some common physical SHCs are: neuropathic pain, urinary tract infections and pressure injuries. The psychological SHCs mainly consist of depressive mood and anxiety. The primary and secondary impairments of SCI are related to high health care utilization, lower participation in social activities and lower quality of life. To deal with the primary and secondary health conditions, appropriate self-management is highly important for people with SCI.

Self-management can be seen as the individual's ability to manage the symptoms, treatment, physical and social consequences, and lifestyle changes in accordance with living with a chronic disease. Self-management incorporates aspects like self-care, preventing SHCs, having an active lifestyle and participating in social activities. The execution of self-management by people with a disability depends on knowledge, skills and confidence in their ability to manage their condition. This confidence is in the scientific literature often referred to as self-efficacy. How self-management, self-efficacy and SHCs exactly evolve during rehabilitation and how they interact with each other is not clear to date.

This thesis aims to investigate self-management, self-efficacy, and SHCs in people with SCI. Besides the relationship between these features, their associations with possible determinants like SCI characteristics, socio-demographic factors and psychological aspects were subject of investigation.

Chapter 1 provides an overview of the context of this thesis. The consequences of SCI are discussed as well as the importance of self-management and self-efficacy in handling the consequences of SCI. Further, the two studies used for this thesis are briefly described, the "Coping with SCI" study and the "SELF-SCI" study.

Part I Background information

In **chapter 2**, the protocol of the quantitative part of the SELF-SCI study is described. This cohort study investigated self-management and self-efficacy of people with SCI in their initial inpatient rehabilitation, until one year after discharge. In this chapter it is described how associations would be investigated, in accordance with two theoretical models, with SHCs, participation and psychological adjustment. The first model has its focus on motivation to perform health behavior, the second on adjustment after SCI. The assessments started early after admission to one of the eight participating rehabilitation centers specialized in

SCI. The next assessment took place in the week before discharge, then three months later, six months after discharge and one year after discharge. The protocol describes how the results will be used to investigate the associations between the different constructs and to test both theories.

The literature about the association between self-efficacy and physical and psychological SHCs is described in **chapter 3**. In a systematic literature review 670 unique articles were screened, of which 22 met the inclusion criteria. Seven out of these 22 studies investigated associations between self-efficacy and somatic SHCs. Only a trend towards an association between higher self-efficacy with less pain, fatigue, number of secondary health conditions and limitations caused by secondary health conditions was found. Twenty-one studies described the association between self-efficacy and psychological SHCs. All correlations of higher self-efficacy with fewer depressive (18 studies) and anxiety symptoms (7 studies) were significant. Meta-analyses showed strong negative correlations of $-.54$ and $-.49$ for depressive mood and anxiety, respectively. A small number of studies (2) showed a trend towards a positive correlation between self-efficacy and quality of life. Based on these findings self-efficacy should be an important target for intervention during rehabilitation. More research is necessary to clarify the associations between self-efficacy and somatic SHCs. Based on this literature review the recommendation was done to further investigate different types of self-efficacy. This was the basis for the next chapter.

In **chapter 4**, four often used self-efficacy scales for people with SCI were investigated for their internal and external (concurrent and divergent) validity. All four self-efficacy scales showed acceptable to good fit in one-factor models, using confirmative factor analysis. The three-factor solution reported in the literature for the Moorong Self-Efficacy Scale could not be confirmed. To investigate the external validity two models for self-efficacy were used. First a subdivision in two levels, trait and state levels of self-efficacy. The other in three levels, general, domain-specific, and task-specific self-efficacy. Scales measuring self-efficacy at the same level show, as expected, strong correlations, confirming convergent validity (correlations $.50$ – $.65$). Although divergent validity, an expected weak correlation between scales measuring at different levels, could only partly be confirmed (correlations $.31$ – $.74$). These findings support the need for further research and development of scales better able to measure domain and task-specific state self-efficacy for people with SCI.

Part II Results

As part of the SELF-SCI study participants were interviewed to understand the way they gained confidence and were thought to learn self-management skills by the rehabilitation team. These qualitative results are described in **chapter 5**. Participants underlined the importance of learning how to perform appropriate self-management. This included both the self-care and the prevention of SHCs. Important themes affecting the participants' attitude towards learning self-management were: taking initiative, and their mindset (thinking positively and acceptance). Gaining of confidence was experienced by most participants as belonging to them as a person. The part that was experienced as external was often described as a team effort of the rehabilitation professionals. Participants mentioned various strategies employed by the professionals to teach self-management: learning by doing, motivation by the professionals, and getting information. The use of these strategies varied across disciplines. Other factors of influence were: running out of time, especially the nursing staff, and the interpersonal approach of the professionals towards them. The strategies used by the rehabilitation team to help people with SCI to perform their self-management appropriately was also helping the participants to gain confidence. This is in contrast with the idea of the participants that this last part was belonging to their nature. Many participants distinguished between therapy and care, e.g. between physiotherapist/occupational therapists and the nursing staff. Learning to perform self-management requires although an interdisciplinary approach, where segregation between disciplines is undesirable.

In **chapter 6**, results from the Coping with SCI study regarding fatigue are presented. Fatigue is a frequently mentioned and burdensome SHC for people with SCI. At admission of clinical rehabilitation, fatigue scores were very high and these scores decreased significantly during rehabilitation. At discharge, fatigue scores were still significantly higher than those of healthy adults. The fatigue total score at discharge was weakly associated with demographic variables and SCI characteristics. Psychological adjustment variables (illness cognitions, depressive mood and anxiety) explained the largest proportion of variance of the fatigue scores. Fatigue is an important consequence in people with recently acquired spinal cord injury. Associations between fatigue and psychological adjustment suggest that psychological interventions might be useful to diminish fatigue.

As a result of SCI the way people involved look at their selves and their body might change. To investigate the course of body image and its association with psychological SHCs, **chapter 7** describes these results from the Coping with SCI study. In this study two different aspects of body image were used, namely alienation and harmony. Alienation can be understood as a split between the body and the self, whereas harmony is indicative for

the degree in which the body is considered as a partner of the self. The mean scores on the alienation scale decreased significantly during the rehabilitation program. Mean scores on the harmony scale did not increase significantly, but showed a trend in the hypothesized direction. The two scales showed weak correlations with demographic variables and SCI characteristics. The two scales together explained 16% and 14% of the variance of depressive mood and anxiety respectively, after correction for demographic variables and SCI characteristics. It was concluded that during the first inpatient rehabilitation after SCI, the course of body image increased towards a healthier state. Body image explains parts of the variance in depressive mood and anxiety and can be a target of interventions by the whole rehabilitation team.

At the end of the results section, in **chapter 8**, the results of the Coping with SCI study, regarding coping flexibility, is described. This study used the dual-process coping theory, which describes the way persons attempt to match goal related coping with situations in which goals are blocked, for instance due to loss of physical functions. Two coping mechanisms are distinguished within this theory: flexible goal adjustment (FGA) and tenacious goal pursuit (TGP). FGA entails adjusting personal preferences and goal orientations to given situational forces and constraints. While TGP implies actively adjusting development and life circumstances to personal preferences, in other words maintaining the goals. The scores on FGA and TGP measured at admission were negatively associated with the scales depressive mood and anxiety one year after discharge. All demographic variables and SCI characteristics at admission together explained a small percentage of the variance of depressive mood and anxiety. FGA, TGP and the interaction term together explained a significant additional 16% of the variance of depressive mood and 10% of anxiety. It was concluded that the tendency to pursue goals early after onset of the injury seems to have a protecting effect against distress one year after discharge. For people with low TGP at the start of rehabilitation a high score on FGA may have a protective effect against distress one year after discharge.

At the end of this thesis in **chapter 9**, the main findings are described. Next theoretical considerations are made by focussing on self-efficacy and SCHs, especially within the SCI adjustment model. This model was one of the theories used as base for the SELF-SCI study, as described in chapter 2. Further, methodological considerations with respect to the two used studies are debated. Finally clinical implications and directions for future research are provided.

The present thesis contributes to our understanding of the concept of self-efficacy, its relationship with other psychological constructs and its value in the rehabilitation of people with SCI. We plead that self-efficacy should be used as rehabilitation goal, to be used by the whole rehabilitation team. The use of self-efficacy as a rehabilitation goal may stimulate and improve interdisciplinary working and by that improve the rehabilitation of people with SCI.

Summary in Dutch



Een dwarslaesie is een relatief zeldzame aandoening die leidt tot stoornissen in de motor-, gevoels- en autonome functies. Naast deze primaire gevolgen hebben mensen met een dwarslaesie een verhoogde kans op bijkomende (secundaire) stoornissen op lichamelijk en mentaal gebied. Enkele veel voorkomende lichamelijke secundaire stoornissen zijn neuropathische pijn, urineweginfecties en doorligwonden. De mentale secundaire stoornissen bestaan voornamelijk uit depressieve gevoelens en angst. Door deze primaire en secundaire stoornissen is er bij mensen met een dwarslaesie vaak sprake van een hogere medische consumptie, verminderde deelname aan sociale activiteiten en een lagere kwaliteit van leven. Om de primaire en secundaire stoornissen het hoofd te kunnen bieden is het van groot belang dat mensen met een dwarslaesie op een adequate wijze leren de zorg voor hun gezondheid te managen.

Zelfmanagement staat voor het kunnen omgaan met alle lichamelijke, mentale en sociale gevolgen van een chronische aandoening, de behandeling hiervan, als ook de veranderingen in levensstijl die daarbij horen. Bij zelfmanagement gaat het om zelfzorg, het voorkómen van secundaire stoornissen, en het hebben van een actief leven en deelnemen aan sociale activiteiten. De uitvoering van zelfmanagement door mensen met een chronische aandoening is afhankelijk van hun kennis, vaardigheden en het vertrouwen in het kunnen omgaan met hun aandoening. Dit vertrouwen wordt ook wel zelf-effectiviteit genoemd, en in de Engelstalige literatuur aangeduid met *self-efficacy*. Hoe zelfmanagement, self-efficacy en secundaire stoornissen zich precies ontwikkelen tijdens de revalidatie en hoe zij elkaar beïnvloeden is tot op heden nog niet helemaal duidelijk.

Dit proefschrift heeft tot doel om zelfmanagement, self-efficacy en secundaire stoornissen bij mensen met een dwarslaesie te onderzoeken. Naast de onderlinge relaties tussen deze aspecten zullen ook factoren die invloed kunnen hebben op deze aspecten, zoals dwarslaesiekenmerken, socio-demografische factoren en mentale aspecten worden onderzocht.

In **hoofdstuk 1** wordt een overzicht gegeven van de opbouw van dit proefschrift. Eerst worden de gevolgen van een dwarslaesie beschreven. Vervolgens wordt ingegaan op het belang van zelfmanagement en het vertrouwen in het kunnen omgaan met de gevolgen van een dwarslaesie. Verder worden hier de twee studies kort beschreven waarvan de gegevens gebruikt zijn voor dit proefschrift, de 'Omgaan met een dwarslaesie' en de 'ZELF-DOEN' studies.

Deel I Achtergrondinformatie

In **hoofdstuk 2** wordt het protocol van het kwantitatieve deel van de ‘ZELF-DOEN’ studie beschreven. Deze cohortstudie onderzoekt zelfmanagement en self-efficacy van mensen met een dwarslaesie tijdens hun eerste klinische revalidatie tot een jaar na ontslag. In het hoofdstuk is beschreven hoe aan de hand van twee theoretische modellen de relaties met secundaire stoornissen, deelname aan sociale activiteiten en mentale aanpassing worden onderzocht. Het eerste model heeft betrekking op de motivatie om gezondheidsgedrag te vertonen, het tweede op de wijze waarop mensen zich aanpassen na een dwarslaesie. Verder wordt beschreven hoe de studie is uitgevoerd. De eerste meting was vlak na opname in een van de acht gespecialiseerde dwarslaesie revalidatiecentra in Nederland. De volgende meting vond plaats aan het eind van de klinische opname, dan drie maanden nadien, zes maanden na ontslag en een jaar na ontslag. Het protocol beschrijft hoe de resultaten van het onderzoek gebruikt zullen worden om de verbanden tussen de verschillende constructen te onderzoeken, en om beide theorieën te toetsen.

De literatuur over de samenhang tussen self-efficacy en lichamelijke en mentale secundaire stoornissen wordt beschreven in **hoofdstuk 3**. In dit systematische literatuuroverzicht werden 670 unieke artikelen gevonden. Hiervan voldeden er 22 aan de inclusiecriteria. Zeven van de 22 studies onderzochten relaties tussen self-efficacy en lichamelijke secundaire stoornissen. De resultaten laten zien dat er geen sterke samenhang maar hooguit een trend in de richting van een samenhang te zien is tussen hoger vertrouwen met minder pijn, minder vermoeidheid, kleiner aantal lichamelijke secundaire stoornissen. Eenentwintig studies onderzochten relaties tussen self-efficacy en mentale secundaire stoornissen. Deze studies laten wel een sterk verband zien. Alle relaties tussen hogere self-efficacy met minder depressieve gevoelens (18 studies) en angst (7 studies) waren significant. Meta-analyses komen uit op sterke negatieve correlaties van $-.54$ en $-.49$ voor respectievelijk depressieve gevoelens en angst. Een beperkt aantal studies (2) laat een trend zien in de richting van een positieve relatie tussen self-efficacy en kwaliteit van leven. Op basis van deze bevindingen zou self-efficacy een belangrijk thema tijdens de revalidatie en voor het gehele revalidatieteam moeten zijn. Meer onderzoek is nodig om zicht te krijgen op de relatie tussen self-efficacy en de verschillende lichamelijke secundaire stoornissen en op verschillende vormen van self-efficacy. Dit laatste vormt de basis voor het volgende hoofdstuk.

In **hoofdstuk 4** worden vier veel gebruikte self-efficacy schalen onderzocht op hun interne en externe (concurrente en divergente) validiteit. Alle vier de schalen passen op een acceptabele tot goede manier in een een-factor model volgens bevestigende factoranalyse, wat betekent dat ze één dimensie meten. De in de literatuur beschreven drie-factor oplossing voor

de Moorong Self-Efficacy Scale kon niet worden bevestigd. Voor de externe validiteit van de vier schalen werd gekeken naar twee modellen van self-efficacy. Ten eerste een tweedeling op het niveau van karakter van de persoon (trait) of de toestand waarin de persoon zich bevindt (state). Daarnaast een driedeling in algemene, domein/aandoenings specifieke of taakspecifieke self-efficacy. Schalen die self-efficacy op hetzelfde niveau meten vertonen zoals verwacht een sterke relatie met elkaar en daarmee kon hun convergente validiteit bevestigd worden (correlaties .50–.65). Daarentegen kon de divergente validiteit, een verwachte zwakke relatie tussen schalen van verschillend niveau, slechts gedeeltelijk bevestigd worden (correlaties .31–.74). Deze bevindingen bevestigen de behoefte aan verder onderzoek en de ontwikkeling van schalen die beter in staat zijn om de domein- en taakspecifieke aspecten van self-efficacy bij mensen met een dwarslaesie te meten.

Deel II Resultaten

Als onderdeel van het ‘ZELF-DOEN’ onderzoek werden deelnemers geïnterviewd over hoe zij tijdens de revalidatie leerden om hun vertrouwen te herwinnen en hoe het revalidatieteam hen leerde om goed zelfmanagement toe te passen. Deze kwalitatieve resultaten zijn beschreven in **hoofdstuk 5**. Deelnemers benadrukten hoe belangrijk het voor hen was om te leren zelfmanagement op een goede manier uit te voeren, waarbij zowel de zelfzorg als het voorkomen van secundaire stoornissen voor hen belangrijk was. Belangrijke thema's die werden aangedragen ten aanzien van hun eigen houding waren het nemen van initiatief en hun manier van denken (positief blijven en aanvaarden van de situatie). De toename van vertrouwen werd door de meeste deelnemers gezien als een gegeven dat bij hen als persoon hoorde. Het deel dat buiten hen lag, werd veelal gezien als een inspanning van het gehele revalidatieteam. Deelnemers noemden meerdere strategieën die door de teamleden werden gebruikt om hen te leren op een adequate wijze zelfmanagement uit te voeren: leren door doen, gemotiveerd worden door teamleden en het krijgen van informatie. Het gebruik van deze strategieën verschilt per discipline. Andere factoren die van invloed waren: geen tijd hebben, wat vooral speelde bij de verpleging, en het interpersoonlijke contact dat zij hadden met professionals. De strategieën die gebruikt werden door de teamleden om de deelnemers te leren goed zelfmanagement uit te voeren, waren ook helpend om vertrouwen terug te krijgen. Dit is in strijd met het idee van de deelnemers die het herwinnen van vertrouwen vooral zien als iets dat bij hen, als persoon, hoort. Verder maken veel deelnemers een onderscheid tussen therapie en zorg, dus tussen de fysiotherapeut of ergotherapeut en de verpleegkundigen. Het aanleren van zelfmanagement vraagt echter om een interdisciplinaire aanpak, waar een ervaren onderscheid tussen disciplines onwenselijk is.

In **hoofdstuk 6** worden de resultaten uit de ‘Omgaan met een dwarslaesie’ studie met betrekking tot vermoeidheid beschreven. Vermoeidheid wordt door mensen met een dwarslaesie vaak gemeld als een secundaire stoornis met grote invloed op hun leven. Bij opname in het revalidatiecentrum waren de scores op vermoeidheid zeer hoog en deze scores namen gedurende de opname significant af. Bij ontslag waren de scores echter nog steeds significant hoger dan bij gezonde volwassenen. De ernst van de vermoeidheid bij ontslag uit klinische revalidatie had geen duidelijke relatie met demografische en dwarslaesiekenmerken. Mentale aanpassingsvariabelen (ziekte cognities, depressieve gevoelens en angst) verklaarden in grote mate de variantie van de vermoeidheidsscores. De relatie tussen vermoeidheid en mentale aanpassing suggereert dat psychologische behandeling een positief effect zou kunnen hebben op de ervaren vermoeidheidsklachten.

Een van de gevolgen van een dwarslaesie kan zijn dat het beeld dat mensen hebben van zichzelf en hun lichaam verandert. In **hoofdstuk 7** wordt met gegevens uit de ‘Omgaan met een dwarslaesie’ studie onderzocht hoe het lichaamsbeeld zich bij mensen met een dwarslaesie ontwikkelt en met welke secundaire mentale stoornissen dit samenhangt. In deze studie worden twee verschillende aspecten van lichaamsbeeld gebruikt, namelijk vervreemding en harmonie. Vervreemding kan gezien worden als de ervaren scheiding tussen lichaam en geest, terwijl harmonie staat voor de mate waarin het lichaam als een geïntegreerd onderdeel van het zelf wordt beschouwd. De gemiddelde scores van vervreemding verminderden significant gedurende de klinische revalidatieopname. De gemiddelde score op harmonie nam niet significant toe, maar toonde wel een trend in de verwachte richting. De twee schalen vertoonden een zwakke relatie met demografische en dwarslaesiekenmerken. Na correctie voor demografische en dwarslaesiekenmerken, verklaarden de twee schalen samen 16% en 14% van de variantie in respectievelijk depressieve gevoelens en angst. Er werd geconcludeerd dat tijdens de eerste klinische revalidatie na het ontstaan van een dwarslaesie het lichaamsbeeld zich ontwikkelt in een gezonde richting. Het lichaamsbeeld van een persoon met een dwarslaesie verklaart een deel van de variantie van depressieve gevoelens en angst en kan voor alle disciplines dienen als aangrijpingspunt voor behandeling gedurende de revalidatie.

Het einde van de resultatensectie wordt gevormd door **hoofdstuk 8**, waarin de resultaten met betrekking tot de copingflexibiliteit worden beschreven uit het ‘Omgaan met een dwarslaesie’ studie. In deze studie wordt gebruikt gemaakt van het duale procesmodel van coping. Dit model beschrijft hoe personen proberen hun coping met betrekking tot doelen kloppend te maken in situaties waarin hun doelen geblokkeerd worden, bijvoorbeeld door verlies van lichamelijke functies. Binnen deze theorie worden twee copingmechanismen onderscheiden: flexibel omgaan met doelen (FLEX) en volhardend streven naar doelen (VOL). FLEX houdt het aanpassen van persoonlijke voorkeuren en na te streven doelen aan

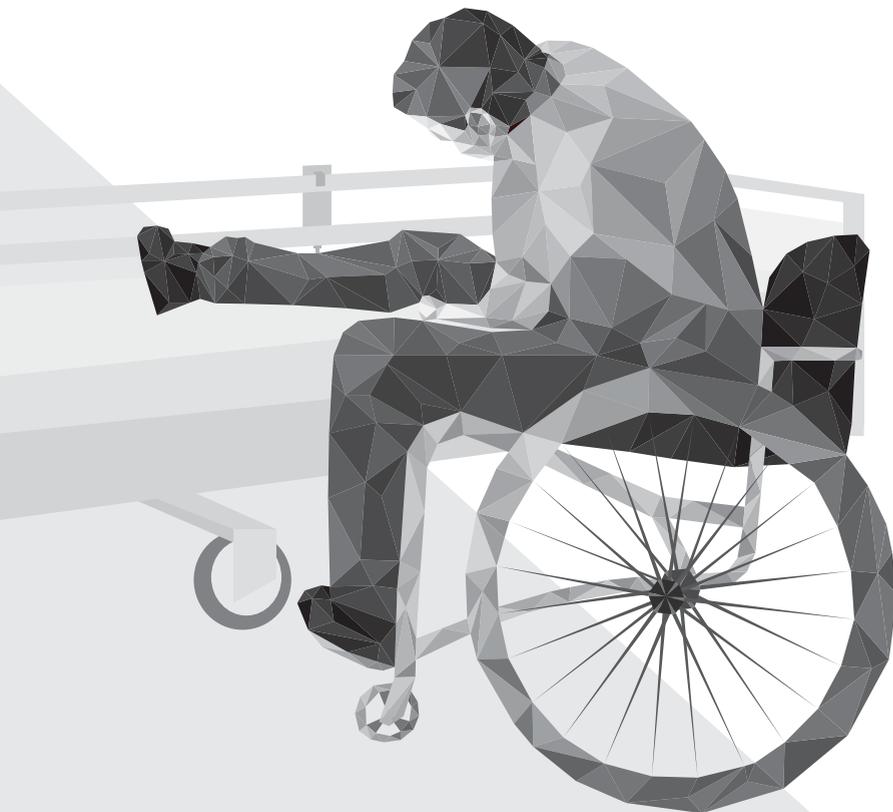
de gegeven omstandigheden en beperkingen in, terwijl VOL staat voor het actief aanpassen van ontwikkelingen en levenssituaties aan de persoonlijke voorkeur, oftewel het vasthouden aan bestaande doelen. De scores op FLEX en VOL, gemeten bij mensen met een dwarslaesie bij opname in het revalidatiecentrum, waren negatief geassocieerd met de schalen depressieve gevoelens en angst een jaar na ontslag uit de klinische revalidatie. Alle demografische en dwarslaesiekenmerken samen verklaarden slechts een klein percentage van de variantie van depressieve gevoelens en angst. FLEX en VOL, samen met de interactieterm, verklaarden een extra 16% van de variantie van depressieve gevoelens en 10% van de variantie van angst. Er werd geconcludeerd dat het volhardend nastreven van doelen in het begin van de revalidatie een beschermend effect lijkt te hebben op het ontstaan van mentale problemen een jaar na ontslag. Voor mensen met een lage VOL in het begin van de revalidatie kan een hoge score op FLEX hen beschermen tegen deze mentale problemen een jaar na ontslag.

Aan het einde van dit proefschrift in **hoofdstuk 9** worden de belangrijkste bevindingen beschreven. Hierna wordt er ingegaan op enkele theoretische overwegingen met betrekking tot self-efficacy, in het bijzonder binnen het theoretisch model dat het aanpassen aan de dwarslaesie beschrijft. Deze theorie vormde mede de basis voor het 'ZELF-DOEN' onderzoek, zoals beschreven in hoofdstuk 2. Vervolgens worden er methodologische overwegingen beschreven ten aanzien van de twee gebruikte studies. Ter afsluiting worden er klinisch relevante implicaties en suggesties voor vervolgonderzoek gegeven.

Dit proefschrift draagt bij aan ons begrip van het concept self-efficacy, hoe dit zich verhoudt tot andere psychologische constructen en de waarden die het heeft binnen de revalidatie van mensen met een dwarslaesie. We pleiten voor het gebruik van self-efficacy als revalidatiedoel door het gehele revalidatieteam. Het gebruik van self-efficacy als revalidatiedoel zal het interdisciplinair werken stimuleren en verbeteren, hetgeen de revalidatie van mensen met een dwarslaesie ten goede zal komen.

Dankwoord

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De reis, die met dit boek eindigt, begon voor mij zo'n 10 jaar geleden. Op deze reis ben ik veel mensen tegengekomen, sommigen zijn een stuk met me mee gelopen, anderen hebben me even geholpen, van advies voorzien of waren geïnteresseerd in de vorderingen. Al deze collegae, familie, vrienden, kennissen, geitenbreiers en patiënten, wil ik van harte bedanken. Hieronder wil ik een aantal mensen in het bijzonder noemen.

Mijn eerste onderzoek, een cross-sectionele studie, deed ik nu ongeveer 10 jaar geleden. Zonder de begeleiding en hulp van Wim van Lankveld zou mijn reis daar ter plaatse zijn gestrand. Door zijn inzet en enthousiasme voor onderzoek ben ik daarna een longitudinale studie op gaan zetten (Omgaan met dwarslaesie) die mede de basis vormt van mijn proefschrift. Dat heb ik kunnen doen dankzij de steun van mijn toenmalige leidinggevenden, Ted van den Boom en Dirk van Kuppevelt.

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About the author



Curriculum vitae

Tijn van Diemen was born in Eindhoven, the Netherlands, on the 14th of September 1969. He finished high school (VWO) in Eindhoven in 1988. The same year he started his study psychology at the current Radboud University in Nijmegen. In 1994 he obtained his doctoral students' degree with specialisation in neuropsychology and rehabilitation psychology. In 1999 he obtained the predicate healthcare psychologist. In 2007 he completed his education cognitive behavioral therapy. In 1994 he started working as a neuropsychologist, first in a private practice, later in a general hospital, a psychiatric hospital, and in a nursing home for young people. In 2003 he started as healthcare psychologist in rehabilitation center Sint Maartenskliniek in Nijmegen. First both on an outpatient unit for people with brain injury and on the spinal cord injury ward, later only for people with spinal cord injury. From 2016 to 2020, as part of his PhD, he also worked at rehabilitation center de Hoogstraat. Currently, he is still working as healthcare psychologist at the spinal cord injury ward and for the research department of the Sint Maartenskliniek.

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- 2019 Presentation pre-conference ISCOS psychological workforce in Nice. Title: Psychological outcome measures in persons with SCI: what do / can / should we do?
- 2019 Presentation ESPA meeting in Zurich. Title: Validity of the Moorong Self-efficacy Scale.
- 2018 Presentation pre-conference ISCOS psychological workforce in Sydney. Title: Self-efficacy and recovery after spinal cord injury.
- 2017 Presentation ESPA meeting in Oxford. Title: Body image of people with a spinal cord injury.
- 2017 Workshop ESPA meeting in Oxford. Title: Self-efficacy: Concept, measurement and relevance for SCI rehabilitation.
- 2016 Workshop DCRM congress in Maastricht. Title: Psychosocial rehabilitation of people with a spinal cord injury.
- 2014 Presentation ISCOS 2014 in Maastricht. Title: Multidimensional fatigue during the rehabilitation of SCI.
- 2013 Presentation ESPA meeting in Oslo. Title: Fatigue during the rehabilitation of SCI.
- 2007–2018 Multiple presentations at the annual Dutch-Flemish Spinal Cord Injury Society meetings.

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