Self-management in prevention of pressure ulcers in persons with spinal cord injury: a descriptive cross-sectional study.

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English Abstract

Title: Self-management in prevention of pressure ulcers in persons with spinal cord injury: a descriptive cross-sectional study.

Background: Persons with spinal cord injury (SCI) perform daily activities to prevent pressure ulcers (PUs). Increasing self-management behavior can decrease the impact of a chronic condition on a person's health status. Self-management interventions to prevent PUs should be implemented into chronic SCI care. In order to do so, information is needed on self-management behavior in the SCI population.

Aim: This study explored which personal, SCI related and health related factors influence self-management behavior in persons with SCI. With this knowledge nurses can focus on these main influencing factors to increase the person's extent of self-management behavior.

Research question: What is the nature and extent of self-management behavior in PUprevention in persons with SCI?

Method: The extent of self-management was measured using the PAM 13-Dutch. A 30-item questionnaire was completed by 165 persons with a SCI from two rehabilitation centers in the Netherlands. Correlations and a logistic regression model were used to measure associations between self-management and assumed influencing factors.

Results: Significant correlations were found between the PAM 13-Dutch and the number of PU-prevention behavior, time since injury, self-reported health, education, usual activity (EQ 5D-3L), complete SCI and comorbidity. Completeness of SCI was the main influencing factors on the extent of self-management behavior.

Conclusion: Increased PU-prevention behavior correlates with higher self-management behavior. Complete SCI has most impact on a higher extent of self-management behavior.

Recommendations: Nurses who provide SCI and PU-prevention care should consider the characteristics of the person versus the potential influencing factors in their efforts to increase the patient's self-management behavior. Self-management education and instruction should be tailored to the individual with SCI.

Keywords: tailored self-management intervention, pressure ulcer behavior, patient activation measure.

Background

Persons with a spinal cord injury (SCI) are exposed to a high, lifelong risk of developing pressure ulcers (PUs).¹⁻² A PU is defined as 'a localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear'.³ Due to paralysis and sensory loss, persons with SCI experience less, or no, pain and pressure.² Therefore, they cannot react accordingly to increasing pressure and starting PUs. Accurate PU-prevention is undisputed since PUs are one of the most common complications of SCI.¹ A PU has a great impact on a person's life, as it can lead to loss of self-esteem, and decrease of quality of life and life satisfaction.^{1, 4} Moreover, treatment of PUs can lead to extremely high medical costs.⁵

In Western countries, the prevalence of PUs in persons with SCI is around 35%.⁶⁻⁸ In other terms, up to 85% of these individuals develop a PU at some point during their lifetime.⁹ The SCI results in a chronic disability in many cases, which requires chronic care.¹⁰ The necessary prevention and care of a PU depend heavily on the behavior of the person with SCI involved.¹⁰ PU-prevention behavior varies from daily skin examining, regular pressure relief, and seating evaluation to an adequate lifestyle (healthy nutrition and no smoking).¹ It has been shown that a large proportion of the SCI population has difficulty with following the recommended skin care behavior guidelines.¹¹

Self-management is known as 'the day-to-day tasks a person must undertake to control or reduce the impact of his/her condition on physical health status'.¹² Nursing interventions based on self-management have demonstrated significant improvement in health care outcomes in various populations with a chronic disease.¹³ The extent of self-management abilities differs per person and, thus, requires different types of care.¹⁴ Self-management is best adopted if the education and instruction is tailored to the person's activation and readiness in self-management.¹⁵⁻¹⁶ In case a person experiences inabilities in self-management, it is the nurses' task to meet this person's needs, by providing training and education.¹⁷ In order to implement self-management based care in PU-prevention, information is needed on self-management behavior in the SCI population.

Risk factors of PU development in the SCI population have been widely investigated.¹⁸⁻²² Multiple of these influencing factors as demographics (*e.g.* age²³⁻²⁵, gender²⁵⁻²⁶, education level²³⁻²⁶) and health related factors (*e.g.* comorbidity^{22, 26}, physical PU experience²⁷) are also found to be significantly associated with self-management behavior.

Although the SCI population has difficulty with adherence to skin care behavior guidelines, relationships between the PU risk factors and self-management behavior have not been investigated in the SCI population. Nor have relationships between PU-prevention behavior and the personal extent of self-management behavior been investigated. Investigating these relationships can reflect the nature of self-management in PU-prevention.

Problem Statement

Self-management interventions to prevent PUs should be implemented into chronic SCI care, given that the increase of self-management can improve health care outcomes. PU-prevention performed by persons with a SCI can be improved by increasing the person's extent of self-management behavior. Subsequently, the role of nurses in SCI care will emphasize tailored self-management support and education. To follow through with self-management based PU-prevention care, knowledge of the nature and extent of self-management behavior in the SCI population has to be investigated.

Aim and Research Question

This study investigates which factors, such as PU-prevention behavior, health related factors and demographics are related to the nature and extent of self-management behavior in the SCI population. The main objective is to delineate the nature and extent of self-management behavior in PU-prevention in the SCI population. Using the obtained knowledge, selfmanagement implemented in nursing care can be tailored to the person's activation and readiness in self-management.

The following research question is formulated: What is the nature and extent of selfmanagement behavior in PU-prevention in persons with SCI?

Method

Design

To examine the nature and extent of self-management in the SCI population, a descriptive study was performed by using a quantitative cross-sectional survey design. Self-reported cross-sectional data were used to perform a tentative exploration of possible relationships between the phenomenon of interest: self-management behavior; and demographics and health characteristics.²⁸

Self-management Behavior

To determine the extent of self-management the Dutch Patient Activation Measure (PAM 13-Dutch) was used. Figure 1 represents the original PAM-13. The PAM is an instrument which assesses patient self-reported knowledge, skills and confidence for self-management of one's health or chronic condition.²⁹ Research has demonstrated that the PAM has strong psychometric properties, including content, construct and criterion validity.^{14, 30} The Dutch translated version of the PAM (PAM 13-Dutch) was also found to be a reliable instrument to measure patient activation.³¹ Using the PAM 13-Dutch respondents were asked to indicate their level of agreement on thirteen items using a four-point Likert scale ranging from 'totally disagree' to 'totally agree', adjusted with 'not applicable'.³¹ The sum of the thirteen PAMitems was converted into an activation score (0-100).³² To facilitate the interpretation of the PAM score, the activation score was classified into four stages: level 1 (score of \leq 47): the person may not yet believe that an active role is important; level 2 (score of 47.1-55.1): the person lacks confidence and knowledge to take action; level 3 (score of 55.2-67.0) the person takes action; and level 4 (score of \geq 67.1): the person actually stays the course even under stress.^{30, 32}

Demographics, SCI-, PU-, and General Health Related Factors

Factors were identified that theoretically and practically could influence self-management behavior in PU-prevention. The factors were classified into four components: demographic factors, SCI related factors, PU related factors and general health related factors.

Three of the measured demographic factors have been found to be related to both PU prevalence and self-management behaviors in previous literature: age^{20, 23-25}, gender^{20, 22, 25-26} and education^{22-26, 33}. Marital status has been found to be significantly associated to PU prevalence.^{20, 22, 33}

Selected SCI related factors have been found to be related to PU prevalence: cause of injury²⁰, level of injury^{4, 34}, time since injury^{22, 33}, completeness of the SCI^{4, 22, 34} and the ability to walk^{8, 34}. To determine the level of the SCI, injury levels were grouped into sections of vertebrae. This categorization was believed to be most conveniently for self-report of the injury level.

PU related factors were PU prevalence, experienced PUs in the past, severity of treatment, physical PU experience and experienced risk to develop a PU. PU-prevention behavior was divided into the number of performed PU-prevention tasks (*e.g.* skin checks, pressure displacement, practicing a healthy lifestyle)¹, frequency and sufficiency of PU-prevention behavior, received PU-prevention instruction and most recent PU related contact with a health care professional (HCP).

Self-reported health, quality of life and comorbidity were measured as general health related factors. Self-reported health (first item on the SF-36)^{23, 25-26} and comorbidity²⁶ have been found to be related to self-management in other studies. Quality of life has been found to be related to self-management³⁵, PU prevalence²⁷ and SCI³⁶. Both the SF 36 and EQ 5D-3L (quality of life measurement) were found to be valid and reliable scales.³⁷⁻³⁸ The item of mobility of the EQ 5D-3L was transformed from "walking around" into "getting about" to be valid for the SCI population.³⁹ Comorbidity was measured using the selected list of 25 chronic conditions of The National Public Health Compass.⁴⁰

The PAM 13-Dutch has also been measured in the Dutch National Panel of People with a Chronic Disease (NPCD).²⁵ Categorization of age, education and self-reported health in this study were applied similarly to the PAM study of the NPCD to compare data of both studies.

Development of the Questionnaire

The questionnaire was developed in three main phases. First, two researchers (AM, EdL) composed the questionnaire containing the PAM-13 Dutch, demographic, SCI related, PU related and general health related questions. Secondly, the questionnaire was presented to a person with SCI, a physician, a wound care nurse specialist and a psychologist. Suggestions were collected for improvement regarding the intelligibility, clarity and acceptability of completion time of the questionnaire. Thirdly, the improved hard copy questionnaire was constructed into an online-version questionnaire using the website program SurveyMonkey®.

Sampling and Data Collection

All eight rehabilitation centers in the Netherlands which provide SCI care were approached for participation. Two rehabilitation centers (Sint Maartenskliniek in Nijmegen and Beatrixoord - University Medical Center Groningen) provided consent for taking part in this study. In both rehabilitation centers a contact person supervised the selection of the participants. The selection of participants was based on convenience sampling to recruit as many eligible participants as possible.⁴¹

The eligible participants were hand-picked from the computer system if they met the inclusion criteria; diagnosed with any type of SCI (traumatic or non-traumatic); and aged above 18 years. Persons were excluded from the study if it was determined by the contact person that: they were having insufficient knowledge of the Dutch language; could not complete a questionnaire due to mental incompetence; or had reduced consciousness due to severe illness.

Eligible participants received an information letter by post from their rehabilitation centre. The letter comprised information about the study, the request to complete the questionnaire, a

notification of voluntarily and anonymous participation, the approximated length of time of participation, and the URL where they could fill out the questionnaire. Persons could ask for a hard copy of the questionnaire by filling out their name and address on the reply strip at the bottom of the information letter and returning the reply strip to their rehabilitation centre. Consequently, they received the hard copy questionnaire, including a return envelope.

Due to the anonymous participation it was unknown who completed the questionnaires. Therefore, it was impossible to select the participants who completed the questionnaire previously and who did not. Therefore, all eligible participants received a second request for participation after one month. The questionnaires were completed between February 1st and March 31th 2013.

Ethics

The study was conducted in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). Official approval was gained from the local Medical Research Ethics Committee (No. 2012/486) and waived the need for a written informed consent.

Data Analysis

The main goal of analysis in this study was to identify significant associations between the collected factors and self-management behavior to establish the nature and extent of self-management behavior in PU-prevention.

Associations were tested on statistical significance by using: Spearman's rank-order correlation (ρ_s); Chi-square (X²); phi (Ø); and Pearson's product-moment correlation point-biserial (r_{pbi}), depending on the level of measurement of the variables.

Factors with significant associations with the activation score, supplemented by the assumption of causality with self-management behavior,^{28, 42} were used in a binary logistic regression model.²⁶ The model was used to predict the probability of a low or higher ability of self-management behavior. Therefore, the PAM stage was dichotomized into equal groups with level 1 and 2 as low self-management group, and levels 3 and 4 as the higher self-

management group. The low self-management group contained respondents who have no or little experience and confidence in the ability to self-manage health.³² The higher self-management group represented respondents that have experience and success in making necessary behavior changes and taking action in health behaviors.³²

To compare the data of this study to the data of the NPCD, a t-test for independent samples was used. Since the SDs of the (sub)groups of the NPCD are not described, SDs were calculated from the given confidence intervals (CI), by using the following formula $\bar{Y}\pm 1.96\sigma/\sqrt{n}$.⁴³

Internal consistency and construct validity were measured since the PAM 13-Dutch has not been tested in the SCI population. Internal consistency was measured with Cronbach's α and item-total correlation.²⁸ Construct validity was determined by calculating ρ_s between activation score and 'number of performed PU-prevention tasks' in three levels (0-1 tasks, 2-3 tasks, and > 3 tasks), quality of life on VAS (scale 0-100) and self-reported health.

Within the bivariate tests, missing values were deleted pair wise to enable usage of all observed data.⁴⁴ In case a respondent answered all thirteen PAM items identically with 'totally agree' or 'totally disagree' or in case less than seven PAM items were filled out, the questionnaire was considered as biased response set and excluded from self-management analysis.²⁵

A sample size of at least 155 respondents was needed in the calculation of correlations to reach a power of .80.^{28, 45}

For all tests p<0.05 was considered as statistically significant.

Data were analyzed using IBM SPSS Statistics version 20.0.

Results

In total 441 respondents in the two rehabilitation centers were found to be eligible to participate in the study (Figure 2). A number of 170 questionnaires were returned; 134 were completed online and 36 on paper. Six questionnaires were excluded from analysis which led to a response rate of 39.1%. Two questionnaires were excluded because they did not comply with valid PAM-scores.

Characteristics of the Sample

Table 1 shows the characteristics of the demographic and SCI related factors of the sample. Of the respondents 53.7% was from the Sint Maartenskliniek and 46.3% from the Beatrixoord. Almost two-thirds of the respondents (65.9%) were male and 64.1% of the injuries were caused by trauma. More than half of the respondents had an incomplete SCI (54.5%) and 64.2% was unable to walk.

PU-prevention tasks which were most performed by respondents were: using a special cushion or mattress (57.3%), moving as much as possible (49.4%), keeping a clean and dry skin (47%), and keeping the wheelchair in a correct angle (47%). Regular pressure lifting was performed by 45.7% and skin checks by 43.9%. A low percentage (5.8) of the respondents believes the amount of activities they perform to prevent PUs are insufficient.

Significantly Correlating Factors with Patient Activation

The mean activation score (scale 0-100) was 53.98 (SD=8.14). Respondents were distributed over the PAM stages as follows: level one, 19.1% (n=31); level two, 32.7% (n=53); level three, 42.0% (n=68); and level four 6.2% (n=10).

Significant correlations were identified between the PAM stage and the number of performed PU-prevention tasks, time since injury, self-reported health, education, usual activity (EQ 5D-3L), completeness of SCI, and comorbidity (Table 2). These seven significantly related factors were explored in relation to PU and PU-prevention related factors (see Table 3). Time since injury, completeness of SCI and number of performed PU-prevention tasks had the most significant correlations with PU and PU-prevention related factors.

Logistic regression Model

The predictor variables used in the logistic regression model were six of the seven significant correlating factors with self-management behavior: time since injury, number of performed PU-prevention tasks, self-reported health, education, completeness of SCI and comorbidity. Usual activity was left out of the model, as the unequal distribution over the three levels within this item led to extreme OR-values. The outcome model (n=145) showed that only a complete SCI predicts a higher self-management level (OR=2.436, p=.011).

Comparison of the PAM 13-Dutch in the SCI-population and the NPCD

Comparison of the mean activation scores between the SCI population and the NPCD indicated a significant difference between almost all (sub)groups of the two populations: overall mean, both genders, all age groups, all education levels, and self-reported health statuses 'good' and 'very good' (Table 4). No respondents qualified their health as 'excellent' in the SCI population.

Internal Consistency and Construct Validity

Cronbach's α of the PAM was 0.793, reflecting the internal consistency. Correlations between items one-seven, and one-nine were negative in the inter-item correlation matrix (for items, see Figure 1). Item one received the highest score of the sample: 3.41 on the PAM level from 1-4. The mean score of items two to thirteen ranged from 2.57-3.02.

Determining construct validity, correlation coefficients found between activation and amount of performed PU-prevention tasks, quality of life on VAS and health were respectively ρ_s =.225 (p=.004), ρ_s =.132 (p=.0.1) and ρ_s =.208 (p=.009).

Discussion

In this study the nature and extent of self-management behavior in relation to PU-prevention in persons with SCI are identified. According to this study, the respondent with a complete SCI is predicted to have higher levels of self-management behavior. The findings also indicate that higher levels of self-management behavior are associated with a higher number of various PU-prevention tasks. This suggests that if a person's self-management behavior is increased the performed preventive behavior to reduce PUs will increase likewise. Nevertheless, due to the cross-sectional nature of this study this causal relationship cannot be assumed.

The results show that longer time since injury and complete SCI are significantly correlated to the experience of more PUs in the past, more severe PU treatment and the experience of higher risk to develop a PU. In addition, these same subgroups perform more frequent and more different types of PU prevention tasks, which seems to indicate that more experience with PUs is related to more PU-prevention behavior. It stands to reason that when a person has experienced a PU in the past; they want to prevent a PU in the future, strengthened by their increased risk to develop a PU.

The PAM-13 has been described as valid and reliable measure to determine selfmanagement behavior, as demonstrated in the NPCD.^{30, 46} This study supports the findings in construct validity as higher self-reported health and a higher number of various PUprevention tasks are significantly associated to higher PAM scores. Also, the measured Cronbach's α of 0.793 can be considered as a good level of internal consistency.⁴⁷ Deflection on the item-total correlations could be explained by the high rating of item one, which indicates that most respondents agree with the statement that he/she is responsible for his/her own health. However, persons with SCI seem to have difficulties with PAM item nine: "I know the different medical treatment options available for my health condition(s)". This is comprehensible given the fact that in most cases there is no treatment for a SCI.⁸ Therefore, it can be said that the PAM 13-Dutch is applicable for the SCI population.

As the PAM-13 is a widely used measure to determine self-management behavior, the selfmanagement behavior in this study population can be compared to self-management behavior in other populations. Remarkably, the SCI population rates their self-management behavior lower than persons with and without a chronic condition in other study populations.^{23, 25, 46, 48} This low extent of self-management behavior might be explained by the fact that persons with SCI tend to suffer from a low self-concept.^{17, 49} Self-concept can be defined as the full set of attitudes, opinions, and cognitions that a person has of himself.⁵⁰ Self-concept, together with attitudes and self-directed behavior, are included in SCI nursing models to improve self-management education¹⁷. These psychological factors should be taken into account in self-management interventions in SCI and PU care.⁵¹

Self-responsibility is defined as one of the basic elements of self-management behavior.²³ The SCI populations generally agree with this item, which seems to indicate that they are opening up to self-management behavior. The mean activation score of 54 indicates that the population have shortage of confidence and knowledge to take action in self-management behavior.²³ This is accompanied with the low guideline adherence to perform PU-prevention tasks. To be effective, self-management interventions for the SCI populations must be tailored to this level of readiness in self-management behavior. However, to move toward tailored care the PAM 13-Dutch can also be used as clinical assessment tool to determine individual self-management behavior. Founders of the PAM developed general guidelines for using PAM to tailor care in individualized care.³²

The findings of this study must be interpreted considering several limitations. The approach of non-random, convenience sampling used within this study might have caused selection bias. For example, the participating rehabilitation centers might apply a different PU care approach regarding self-management, than other rehabilitation centers in the Netherlands, or world-wide. In addition, respondents who chose to participate in the study might reflect the more cooperative and active persons in the SCI population. However, that could indicate the self-management behavior in the SCI population is even lower than reflected in this study since other less active persons with SCI did not participate in this study.

Conclusion

A positive relation is found between higher self-management behavior and performing a higher number of various PU-prevention tasks. Persons with a complete SCI are predicted to have higher levels of self-management behavior compared to those with an incomplete SCI. Both, complete SCI and longer time since injury demonstrate better PU preventive behavior. Nonetheless, the SCI population in total indicates to have shortage of confidence and knowledge to take action in self-management behavior. Therefore their readiness and activation in self-management must be taken into account in PU-prevention interventions to improve health care outcomes.

Recommendations

Further research is needed to investigate the influencing factors to the low levels of selfmanagement behavior in the SCI population. For the clinical practice it is recommended to stimulate self-management behavior in PU-prevention care. The PAM-13 is a tool which can be used to measure baseline and follow-up levels of self-management behavior. Nurses could play a prominent role in increasing self-management behavior as educator and personal coach.

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PAM items

- 1. When all is said and done, I am the person who is responsible for managing my health condition(s)
- 2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.
- 3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health condition(s).
- 4. I know what each of my prescribed medications does.
- 5. I am confident that I can tell when I need to go to get medical care and when I can handle a health problem myself.
- 6. I am confident I can tell a doctor concerns I have even when he or she does not ask.
- 7. I am confident that I can follow through on medical treatments I need to do at home.
- 8. I understand the nature and causes of my health condition(s).
- 9. I know the different medical treatment options available for my health condition(s).
- 10. I have been able to maintain the lifestyle changes for my health condition(s) that I have made.
- 11. I know how to prevent further problems with my health condition(s).
- 12. I am confident I can figure out solutions when new situations or problems arise with my health condition(s).
- 13. I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress.

Figure 1. Patient Activation Measure (PAM-13)

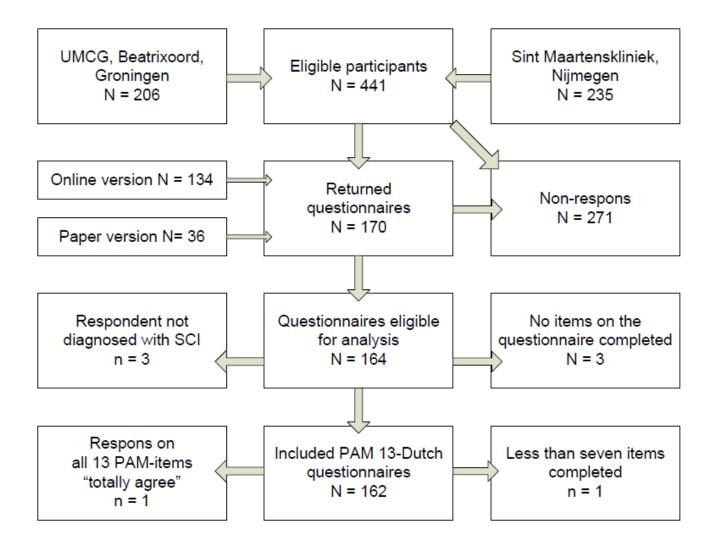


Figure 2. Flowchart of study respondents

| Time since injury 13.0 11.6 Variable N % Rehabilitation clinic Sint Maartenskliniek 87 53.7 Beatrixoord 75 46.3 Gender 75 46.3 Male 108 65.9 Female 56 34.7 Living situation 50 30.8 Living together 114 69.5 Education level * 114 69.5 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 100 64.7 Non-trauma 56 35.5 Level of SCI 30 19.5 Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 58 35.8 <th>Variable</th> <th>Mean</th> <th>SD</th> | Variable | Mean | SD |
|--|-----------------------|------|------|
| Variable N % Rehabilitation clinic Sint Maartenskliniek 87 53.7 Beatrixoord 75 46.3 Gender 75 46.3 Male 108 65.9 Female 56 34.7 Living situation 50 30.5 Living together 114 69.5 Education level * 114 69.5 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 100 64.7 Non-trauma 56 35.5 Level of SCI 30 19.5 Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 58 35.8 | Age | 57.0 | 13.6 |
| Rehabilitation clinic 87 53.7 Beatrixoord 75 46.3 Gender 75 46.3 Male 108 65.9 Female 56 34.7 Living situation 50 30.5 Living together 114 69.5 Education level * 30 18.4 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 70 64.7 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 58 35.8 | Time since injury | 13.0 | 11.6 |
| Sint Maartenskliniek 87 53.7 Beatrixoord 75 46.3 Gender 108 65.9 Male 108 65.9 Female 56 34.7 Living situation 114 69.5 Living together 114 69.5 Education level * 20 30 18.4 Middle 95 58.3 38 23.3 Cause of SCI 7 7 46.3 30 18.4 Middle 95 58.3 58 35.5 55.5 Low 30 18.4 38 23.3 Cause of SCI 7 7 46.5 55.5 Level of SCI 100 64.7 95.5 55.5 Level of SCI 30 19.5 55.5 55.5 Level of SCI 30 19.5 32.2 21.5 Cauda Equina Syndroom 14 9.3 32.2 21.5 Complete 70 | Variable | Ν | % |
| Beatrixoord 75 46.3 Gender 108 65.9 Male 108 65.9 Female 56 34.7 Living situation 114 69.9 Living lone 50 30.9 Living together 114 69.9 Education level * 114 69.9 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 100 64.7 Non-trauma 56 35.9 Level of SCI 100 64.7 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 70 45.5 | Rehabilitation clinic | | |
| Gender 108 65.9 Male 56 34.7 Living situation 50 30.8 Living together 114 69.8 Education level * 114 69.8 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 7 Trauma 100 64.7 Non-trauma 56 35.9 Level of SCI 9 55.35 Level of SCI 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 78 58 35.8 | Sint Maartenskliniek | 87 | 53.7 |
| Male 108 65.9 Female 56 34.4 Living situation 50 30.8 Living together 114 69.8 Education level * 30 18.4 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 7 Trauma 100 64.7 Non-trauma 56 35.9 Level of SCI 9 56.35.9 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 78 58 35.8 | Beatrixoord | 75 | 46.3 |
| Female 56 34.4 Living situation 50 30.5 Living together 114 69.5 Education level * 20 30 18.4 Low 30 18.4 95 58.3 High 30 18.4 95 58.3 High 30 18.4 95 58.3 Cause of SCI 77 77 78.5 32.3 Level of SCI 100 64.7 95 58.5 Level of SCI 100 64.7 95 58.5 Level of SCI 100 64.7 95 55.5 Level of SCI 30 19.9 95 55.5 Low 30 19.5 32.21.5 32.21.5 Cauda Equina Syndroom 14 9.3 9.3 9.3 SCI wholeness 70 45.5 <td< td=""><td>Gender</td><td></td><td></td></td<> | Gender | | |
| Living situation Living alone 50 30.5 Living together 114 69.5 Education level * Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI Trauma 100 64.7 Non-trauma 56 35.5 Level of SCI Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.6 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.3 SCI wholeness Complete 70 45.5 Incomplete 84 54.5 Able to walk Yes 58 35.8 | Male | 108 | 65.9 |
| Living alone 50 30.5 Living together 114 69.5 Education level * 30 18.4 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 7 7 Trauma 100 64.7 Non-trauma 56 35.5 Level of SCI 7 7 Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 7 45.5 | Female | 56 | 34.1 |
| Living together 114 69.5 Education level * 30 18.4 Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 7 7 Trauma 100 64.7 Non-trauma 56 35.5 Level of SCI 7 7 Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.6 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 7 45.5 | Living situation | | |
| Education level * 30 18.4 Low 95 58.3 Middle 95 58.3 High 38 23.3 Cause of SCI 7 7 Trauma 100 64.7 Non-trauma 56 35.9 Level of SCI 95 58.3 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.6 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 7 58 35.8 | Living alone | 50 | 30.5 |
| Low 30 18.4 Middle 95 58.3 High 38 23.3 Cause of SCI 7 38 23.3 Trauma 100 64.7 64.7 Non-trauma 56 35.9 Level of SCI 7 7 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 70 45.5 Able to walk 7 45.5 | Living together | 114 | 69.5 |
| Middle 95 58.3 High 38 23.3 Cause of SCI 7 Trauma 100 64.7 Non-trauma 56 35.9 Level of SCI 95 58.35 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Education level * | | |
| High 38 23.3 Cause of SCI Trauma 100 64.7 Non-trauma 56 35.9 Level of SCI 0 19.9 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Low | 30 | 18.4 |
| Cause of SCI 100 64.7 Non-trauma 56 35.5 Level of SCI 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Middle | 95 | 58.3 |
| Trauma 100 64.7 Non-trauma 56 35.5 Level of SCI 30 19.9 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.8 Incomplete 84 54.8 Able to walk 58 35.8 | High | 38 | 23.3 |
| Non-trauma 56 35.5 Level of SCI 30 19.5 Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.6 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Cause of SCI | | |
| Level of SCI 30 19.9 Up to C4 30 19.9 C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.8 Incomplete 84 54.8 Able to walk 58 35.8 | Trauma | 100 | 64.1 |
| Up to C4 30 19.5 C5-C8 38 25.2 T1-T6 36 23.6 T7-L3 32 21.5 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Non-trauma | 56 | 35.9 |
| C5-C8 38 25.2 T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | Level of SCI | | |
| T1-T6 36 23.8 T7-L3 32 21.9 Cauda Equina Syndroom 14 9.3 SCI wholeness 70 45.8 Incomplete 84 54.8 Able to walk 58 35.8 | Up to C4 | 30 | 19.9 |
| T7-L3 32 21.5 Cauda Equina Syndroom 14 9.5 SCI wholeness 70 45.5 Incomplete 84 54.5 Able to walk Yes 58 35.8 | | | 25.2 |
| Cauda Equina Syndroom149.3SCI wholeness9.3Complete7045.5Incomplete8454.5Able to walk5835.5 | | | 23.8 |
| SCI wholeness7045.5Complete7045.5Incomplete8454.5Able to walk5835.8 | T7-L3 | 32 | 21.9 |
| Complete 70 45.5 Incomplete 84 54.5 Able to walk 58 35.8 | | 14 | 9.3 |
| Incomplete8454.5Able to walk5835.6 | | | |
| Able to walk Yes 58 35.8 | | | 45.5 |
| Yes 58 35.8 | | 84 | 54.5 |
| | | | |
| No 104 64.2 | | | 35.8 |
| | No | 104 | 64.2 |

High, professional higher education or university

| Table 2. Significant association in Bivariate analysis | | | | | | | | | |
|--|-----|----------------------------|---------|--|--|--|--|--|--|
| | n | Correlation coefficient | p-value | | | | | | |
| PAM stage | | | | | | | | | |
| Pressure ulcer prevention tasks | 163 | ρ _s .176 | 0.028 | | | | | | |
| Time since injury | 150 | ρ _s .169 | 0.040 | | | | | | |
| Self-reported Health | 157 | ρ _s .173 | 0.030 | | | | | | |
| Education level 1 | 163 | ρ _s .179 | 0.023 | | | | | | |
| Euroqol - Usual Activity ₂ | 158 | ρ _s 190 | 0.017 | | | | | | |
| PAM dichotomous | | | | | | | | | |
| Completeness SCI | 154 | Ø.194 | 0.017 | | | | | | |
| Comorbidity ₃ | 164 | Ø .155 | 0.048 | | | | | | |

PAM stage ordinal variable levels 1 to 4

PAM dichotomous

1 indicates activation level 1 and 2

2 indicates activation level 3 and 4

1 Education

Low, no or primary school

Middle, secondary or vocational education

High, professional higher education or university

2 Usual Activity

0 indicates having no problems with performing usual activities ‰

1 indicates having some problems with performing usual activities

2 being unable to perform usual activities

3 Comborbidity

- 0 indicates having no comorbidities
- 1 indicates having one or more comorbidities
- ρs, Spearman's rank correlation coefficient
- Ø, Phi

| Table 3. Associations betwee | | 0 | | | | /ith self-mar | | | | | | | | |
|--|------------------|----------------------|------------------|-------------|-----------------------|---------------|--|-------------|--|-------|---------------------------------|--------------|--------------------------------|-------------|
| PU-prevention behavior | | Time since Education | | cation 5 | 0 | | Self- reported health ₇ | | Number of performed PU-prevention tasks | | Comorbidity ₁ | | Usual Activity ₈ | |
| PU(s) in the past 1 | ρs | .430* | ρs | 136 | r _{pbi} | .416* | ρs | 038 | ρs | .291* | r _{pbi} | .096 | ρs | 101 |
| | p | .000 | p | .087 | p | .000 | p | .636 | p | .000 | p | .226 | p | . 208 |
| PU prevalence 1 | r _{pbi} | .280* | r _{pbi} | .105 | Ø | .125 | r _{pbi} | 101 | r _{pbi} | .117 | Ø | . 044 | r _{pbi} | .037 |
| | p | .001 | p | .190 | p | .129 | p | .211 | p | .144 | p | .582 | p | 653 |
| PU operations 1 | r _{pbi} | .351* | r _{pbi} | .055 | Ø | .319* | r _{pbi} | .034 | r _{pbi} | .115 | Ø | 061 | r _{pbi} | 099 |
| | p | .003 | p | .629 | p | .006 | p | .769 | p | .314 | p | .585 | p | .393 |
| Experienced risk to develop a PU ₂ | ρs | .295* | ρs | 034 | r _{pbi} | .303* | ρs | 206* | ρs | .346* | r _{pbi} | .211* | ρs | 051 |
| | p | .002 | p | .710 | p | .001 | p | .025 | p | .000 | P | .020 | p | .686 |
| Number of performed PU- prevention tasks $_3$ | ρs p | .256* .002 | ρs p | 080 .312 | r _{pbi} p | .249* .002 | ρs p | 015 .857 | | | r _{pbi} p | .058 .410 | ρs p | 141 .079 |
| Most recent PU related contact with a HCP ₄ | ρs | .170 | ρs | 112 | r _{pbi} | .290 | ρs | .085 | ρs | .284* | r _{pbi} | 001 | ρs | 131 |
| | p | .087 | p | .236 | p | .002 | p | .371 | p | .002 | p | .988 | p | .168 |

*= significant correlation

 $_{1}$: no = '0', yes = '1'.

 $_2$: never = '0', rarely = '1', sometimes = '2', often = '3', very often '4'.

3: less than one a week = '0', once a week = '1', multiple times a week = '2', once a day = '3', multiple times a day = '4'.

 $_{4}$: longer than a year ago = '0', last year = '1', last 6 months = '2', last week = '3'.

5:no/primary school = '0', secondary or vocational education = '1', professional higher education or university = '2'

 $_{6}$: incomplete = '0', complete = '1'

 $_7$: poor = '0', fair = '1', good = '2', very good = '3', excellent = '4'.

8: no problems with performing usual activities = '0', some problems with performing usual activities = '1', unable to perform usual activities '2'

HCP: Health Care Professional

ρs, Spearman's rank correlation coefficient

Ø, Phi

r_{pbi} Pearson's product-moment correlation point-biserial

| | | SC | l populat | ion | | PAM NPCD (NL) | | | | Independent samples t-test | | |
|---------------|-----------|-----|-----------|-------------|------|---------------|------|-----------|-------|----------------------------------|--------|--|
| | | Ν | Mean | 95% CI | SD | Ν | Mean | 95% Cl | SD | T-value | P-valu | |
| Mean activati | on score | 162 | 54.0 | 52.72-55.24 | 8.14 | 1837 | 61.3 | 60.6-62.0 | 15.32 | 5.9898 | < 0.01 | |
| Gender | | | | | | | | | | | | |
| | Male | 107 | 54.4 | 52.83-56.05 | 8.40 | 804 | 62.9 | 61.8-63.9 | 15.19 | 5.6722 | < 0.01 | |
| | Female | 55 | 53.1 | 51.02-55.14 | 7.62 | 1033 | 60.0 | 59.1-61.0 | 15.58 | 3.2627 | < 0.0 | |
| Age groups | | | | | | | | | | | | |
| | <55 | 60 | 54.2 | 52.51-55.84 | 6.44 | 625 | 61.5 | 60.3-62.8 | 15.94 | 3.5180 | < 0.0 | |
| | 55-64 | 48 | 55.2 | 52.39-57.56 | 8.78 | 476 | 62.4 | 60.9-63.8 | 16.14 | 3.0860 | < 0.0 | |
| | 65-74 | 36 | 53.4 | 50.23-56.04 | 8.83 | 428 | 60.5 | 59.1-61.9 | 14.78 | 2.8382 | < 0.0 | |
| | >74 | 18 | 51.3 | 46.48-59-48 | 9.91 | 308 | 60.0 | 58.3-61.7 | 15.22 | 2.3937 | 0.02 | |
| Education 1 | | | | | | | | | | | | |
| | Low | 30 | 52.9 | 49.21-56.92 | 9.92 | 544 | 58.4 | 57.2-59.7 | 14.88 | 1.9993 | 0.05 | |
| | Middle | 94 | 53.4 | 51.86-55.03 | 7.72 | 731 | 62.3 | 61.1-63.5 | 16.55 | 5.1172 | < 0.0 | |
| | High | 37 | 56.2 | 53.72-58.73 | 7.51 | 430 | 62.5 | 61.1-63.9 | 15.87 | 2.3900 | 0.02 | |
| Self-reported | health | | | | | | | | | | | |
| | Excellent | 0 | | | | 36 | 74.2 | 68.2-80.2 | | | | |
| | Very good | 16 | 54.1 | 50.98-57.29 | 5.92 | 195 | 71.6 | 69.4-73.9 | 16.03 | 4.3345 | < 0.0 | |
| | Good | 75 | 56.7 | 53.77-57.54 | 8.20 | 1010 | 62.3 | 61.4-63.2 | 14.59 | 2.6114 | < 0.0 | |
| | Fair | 47 | 53.7 | 51.09-56.04 | 8.44 | 525 | 55.8 | 54.4-57.0 | 15.20 | 0.9339 | 0.35 | |
| | Poor | 19 | 49.9 | 46.38-53.37 | 7.26 | 65 | 52.6 | 49.4-55.8 | 13.16 | 0.8546 | 0.40 | |

Table 4. Comparing the PAM in the SCI population and the National Panel of Chronic Diseases (Netherlands)

Middle secondary or vocational education High professional higher education or university High