

Psychosocial issues in spinal cord injury: what do we (not) know?

Marcel W.M. Post^{1,2}, Christel M. C. van Leeuwen¹

1 Rudolf Magnus Institute of Neuroscience and Center of Excellence in Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat, Utrecht, The Netherlands

2 Swiss Paraplegic Research, Nottwil, Switzerland

Correspondence: m.post@dehoogstraat.nl

Abstract

Objective: This manuscript reviews literature on subjective well-being (mental health and life satisfaction) in persons with spinal cord injury (SCI) and psychosocial predictors (psychological and social factors) of these outcomes, in order to identify gaps in scientific knowledge and recommend research priorities.

Methods: Narrative review of the literature.

Results: Persons with SCI experience higher levels of distress and lower levels of life satisfaction compared to the general population. Demographic and SCI characteristics do not explain satisfaction and well being (SWB) very well. A set of psychological and social support factors are strongly related to SWB. Intervention studies show promising results, but suffer from methodological weaknesses (e.g., lack of randomization and small sample size).

Conclusions: The authors provide research recommendations to enhance our understanding of mental health issues in this population and interventions that may enhance quality of life.

Introduction

Because of improvements in medical care, the average life expectancy of persons with spinal cord injury (SCI) has considerably increased in the last decades.¹ Most persons who incur SCI may expect to live for many years. However, SCI still is a major life event that leads to serious physical disability and secondary medical problems, which seriously impact the quality of life (QoL) of the persons involved.^{2,3} SCI is associated with abnormal levels of psychological morbidity,⁴ substance abuse and risk of suicide.⁵ Consequently, psychosocial issues have become more prominent in SCI research in the last few decades.

QoL is a broad and ill-defined concept.⁶ QoL has been taken to be synonymous with health status, physical functioning, perceived health status, subjective health, health perceptions, symptoms, need satisfaction, individual cognition, functional disability, psychiatric disturbance, well-being and, often, several of these at the same time.⁷ Three broad approaches to the operationalization of QoL can be found in the literature: (1) by equating quality of life with health, (2) by equating it with well-being, and (3) by treating quality of life as a super-ordinate construct.⁸

Many rehabilitation clinicians and researchers have been surprised by the results of satisfaction and subjective well being (SWB) studies in persons with SCI, showing that SWB in this group is relatively good, at least better than expected for such a serious injury.² However, there are substantial individual differences and a substantial group experiences persistent low SWB.^{9,10} These differences are not well-predicted by the severity of the SCI (level and completeness) and resulting impairments like, for example, loss of bladder control, spasticity and pain.^{2,10-14} Other factors must be taken into account to explain differences in SWB.

The over-all aim of this paper is to clarify SWB (mental health and life satisfaction) in persons with spinal cord injury. Specific aims are: (1) to review the evidence on levels of SWB in persons with SCI, (2) to review the evidence on psychosocial (psychological and social) predictors of SWB in persons with SCI, (3) to review the evidence on interventions aimed at improving

psychosocial functioning in persons with SCI, and (4) to identify gaps in the scientific understanding of SWB in persons with SCI and to make research recommendations.

To focus this review, and to avoid overlap with other papers presented at the State of the Science conference, we restrict our review to SWB outcomes, excluding the literature on participation and health-related quality of life outcomes. We also exclude relevant secondary conditions (e.g., chronic pain), and concomitant traumatic brain injury. Further, we exclude the evidence on relationships between SWB and disablement factors,¹¹ secondary conditions,¹⁵ and environmental factors¹⁶ except for social support.^{17,18} Finally, we exclude evidence on the importance of psychosocial factors as predictors of functional outcomes,¹⁹ pain,²⁰ and other secondary conditions.²¹

The nature of subjective well-being

Subjective well-being (SWB) is defined as how people evaluate their own lives.²² These evaluations can be more focal (e.g., marital satisfaction or satisfaction with one's car) or broader (e.g., life satisfaction or satisfaction with the self). In addition, these evaluations can be cognitive - in terms of satisfaction judgments - or they can be affective (moods and emotions, which are reactions to what is happening in one's life). Moods and emotions are considered more variable over short periods than life satisfaction.²² Mental health, in this manuscript is used as a general term covering mood, emotions and distress, and life satisfaction can be considered two different, but related outcomes of SCI. Figure 1 shows a path model of the relationships between activities, participation, mood, and over-all life satisfaction.²³ This model showed better fit statistics than models with more, or with less, arrows or with arrows in other directions. This means that mental health influences well-being, but not the reverse. This is consistent with theory that SWB is a satisfaction judgment, including judgment of one's mood.²²

Figure 1 about here

Relatively high levels of SWB in persons with SCI are also found in other studies. Brickman et al²⁴ found that lottery winners were only slightly happier than non-winners, and that

people with spinal cord injuries were not as unhappy as one might expect. This observation has led to a discussion about the nature and determinants of SWB, and an understanding of well-being as a stable characteristic of the person, or the Set-point, Hedonic treadmill, or Homeostatically Protected Mood – theory: SWB reflects good and bad events, but with time returns to neutral.²⁵ This point of view has gained momentum by findings of twin studies suggesting SWB has a substantial genetic component.²⁶

Life satisfaction of persons with SCI

Mean life satisfaction scores are instrument-dependent and need a reference to reveal meaningful information. Several studies have compared life satisfaction of persons with SCI to that of the general population (Figure 2). The differences between mean scores in persons with SCI and in the population are expressed as Effect Sizes (ES).²⁷ The mean ES of all studies in Figure 2 is -0.77 (SD 0.55), indicating a strong effect, and meaning that the average level of life satisfaction in persons with SCI corresponds to the 20th percentile in the population. Both statistics indicate a substantial lower life satisfaction in persons with SCI than in the reference population.

Figure 2 about here

The course of life satisfaction after SCI has rarely been studied; only five longitudinal studies in the first years after SCI are available. Three of these studies²⁸⁻³⁰ reported a stable course of life satisfaction, although the time span of these studies varied (the first 6 months after discharge,²⁸ three to 15 months after discharge,³⁰ and one year up to five years after SCI.²⁹ In a small study by Stensman⁹ 17 patients were followed from 6 months up to 5 yrs after SCI. Mean quality-of-life ratings of most subjects improved between 6 months and 1 yr after SCI and remained relatively stable after the first year.⁹ Similarly, a Dutch prospective cohort study³¹ showed that life satisfaction improved during inpatient rehabilitation, especially during the first three months of active rehabilitation, and remained stable during the first year after discharge.

However, average scores can obscure individual differences. Stensman et al⁹ found 4 distinct patterns of life satisfaction early after SCI: low, high, recovery, and fluctuating. A recent study¹⁰ using statistical modeling showed 5 distinct patterns from the start of active rehabilitation to 5 years after discharge (Figure 3): a low LS trajectory (27%), a high life satisfaction trajectory (16.5%), a recovery trajectory (23.3%), a deterioration trajectory (2.4%), and an intermediate life satisfaction trajectory (30.6%) that included less distinctive or variable patterns of life satisfaction.¹⁰

Figure 3 about here

Satisfaction with different life domains has also been the subject of research. Kemp and Krause³² studied 177 persons with SCI using a 1-4 point scale and found highest satisfaction scores with housing (3.5), friendships (3.2), emotional health (3.2) and life as a whole (3.2), and least satisfaction with health (2.4), finances (2.9) and community life (2.9). Van Koppenhagen et al.¹⁴ compared several European studies in which the Life Satisfaction Questionnaire (LiSat-9) was used. This measure consists of one question about satisfaction with life as a whole, and eight questions about domain satisfaction, all rated on a scale from 1 (very dissatisfying) to 6 (very satisfying). The results of these studies are displayed in Figure 4.¹⁴ The figure shows varying life satisfaction with different life domains. Persons with SCI were most satisfied with their social relationships (relationships with partner, family, friends), and least satisfied with their sexual life. Similar results have been reported from a large longitudinal study in the US.³³

Figure 4 about here

Mental health of persons with SCI

Conceptual and methodological problems hamper research into mental health of persons with SCI.³⁴ We collected figures on the prevalence of depression, anxiety and post-traumatic stress disorder in persons with SCI (Tables 1-3).

Depression has been subject of many studies, showing a wide range of estimates, from 8.8% up to 60%. These estimates are affected by the type of instruments, definition of depres-

sion (e.g., possible, probable, major), and sample characteristics (gender, age, time after SCI). Figure 2 displays studies since 1997. Studies using the Patient Health Questionnaire (PHQ-9) yielded lower estimates than studies using the Hospital Anxiety and Depression Scale (HADS) or the Beck Depression Inventory (BDI). Despite these differences, all studies show elevated prevalence of depression in persons with SCI, although it is important to stress that most persons with SCI fall well within the normal range.

All of these questionnaires measure depressed mood and have been used to screen for possible depression. A diagnosis of depression disorder, however, can only be confirmed in a clinical diagnostic interview. Craig (2009)⁵ found five studies that applied a structured diagnostic interview during the rehabilitation or hospitalization phase, reporting 20%-43% having minor or major depression disorder. No studies were found applying such an interview after completion of rehabilitation.⁵

The course of depression after SCI is unclear. One study in inpatient rehabilitation found a decline of depression scores between 6 and 12 weeks after SCI,³⁵ but other studies showed an increase of depression with increased length of rehabilitation,³⁶ or did not find any change during inpatient rehabilitation.³⁷ A recent publication from the SCI Model Systems (n=1035)³⁸ revealed similar proportions of persons with probable major depressive disorder at 1 year post-injury (20.6%) and at 5 years post-injury (18.1%), although there was considerable individual change in depression status over time.

Table 1 about here

Anxiety has been examined less often. Proportions with clinically significant symptoms range from 13.2% up to 35%. Kennedy et al.,^{35,36} used longitudinal designs during and after initial inpatient rehabilitation, and did not find a consistent course of anxiety over time.

Table 2 about here

Post-traumatic stress disorder (PTSS) was examined in 6 studies. Estimates of the prevalence of PTSS vary widely, from 7.2 up to 61.8%. Four studies showed lower prevalence

(7.2% – 24%), and two studies showed much higher prevalence (44%-61.8%). The reasons for this difference are unclear.

Table 3 about here.

Psychological predictors of mental health and life satisfaction after SCI

Recently, we reviewed psychological determinants of mental health and life satisfaction after SCI.³⁹ A total of 48 studies were included, and their results are summarized here. All associations reported in these studies were taken into account. Psychological variables were classified as consistent determinants if all bivariate associations reported were statistically significant, and if most of these associations were moderate (0.3-0.5) or stronger. Variables were classified as inconsistent determinants if only some of the associations were statistically significant, or if most significant associations were weak. Variables were classified as unrelated to mental health and life satisfaction if all, or nearly all, associations were non-significant.³⁹

Consistent Determinants of mental health and life satisfaction were: perceived control in life (range of correlations 0.49 – 0.69), experienced sense of coherence (0.32 – 0.76), endorsed positive factors such as hope (0.27 – 0.64) and purpose in life (0.50 – 0.71), reported feelings of self-worth such as self-efficacy (0.23 – 0.62) and self-esteem (0.33 – 0.73), reported positive (0.42 – 0.52) but not negative (0.35 – 0.73) affect, and reported posttraumatic cognitions (0.35 – 0.65).

Inconsistent Determinants included appraisals (17 out of 21 (17/21) correlations were statistically significant; 13 correlations were > 0.30), subscales of locus of control (6/15, 2 > 0.30), attribution of blame (8/19; 2 > 0.30), spirituality (1/12; 1 > 0.30), personality characteristics (4/14; 2>0.30), emotion-focused coping styles (32/51; 21 > 0.30), and passive coping styles (37/66; 24>0.30). Of the attribution of blame variables, self-blame and perceived avoidability of the SCI were most frequently, but weakly associated with QOL. For spirituality, research has focused more on religious than existential aspects, yet existential spirituality was strongly asso-

ciated with QOL in one study. Personality variables were only examined in two studies, and only neuroticism and extraversion were associated with QOL.

Variables unrelated to SWB included some popular concepts. While acceptance was one of the most consistent determinants of QOL, the majority of emotion-focused coping styles were not associated with QOL. Of the passive coping styles, only helplessness was consistently related to QOL. While behavioral disengagement, denial, avoidance, and social reliance were moderately to strongly related to QOL in some studies, they were not consistently related to QOL across studies. None of the active problem-focused coping variables were consistently associated with QOL outcomes (14/59; $9 > 0.30$). Some of the coping variables, such as confrontation and seeking social support, were assessed in only a few studies, which may explain the lack of a consistent association with QOL outcomes. Other variables, such as suppressing of competing activities and positive reinterpretation, were studied more intensively and have not been associated with QOL outcomes.

An earlier study⁴⁰ found that, in situations where goals are blocked such as is the case with an SCI, actively adjusting life circumstances to one's personal preferences is not effective. In such situations, adjusting personal preferences and goals to situational changes is more effective and more positively related to adjustment. This finding might explain why no relationships were found between active problem-focused coping variables and QOL.

Social support as predictor of mental health and life satisfaction after SCI

Social support in SCI is a well-investigated topic. Social support is defined as an exchange of resources between individuals intended to enhance the well-being of the recipient.⁴¹ It conveys the information of being loved, cared for, esteemed, valued and belonging.⁴² Different dimensions of social support are type, source, and qualifier. Types of social support are instrumental (e.g., tangible assistance), emotional (e.g., exchange with a close friend), and informational (e.g., advice from a peer). Sources of social support can be family members, in particular the spouse, and friends and acquaintances, and others. Support by professionals is also in-

cluded in some social support measures.⁴³ Social support can be described from a quantitative (e.g., network size) or qualitative (e.g., satisfaction with support) perspective.

A main source for social support is the spouse.⁴⁴ Marriage is a major source of support and well-being. Unfortunately, US-figures showed that the majority of persons with SCI (54.2%) are single at discharge from rehabilitation, and divorce rates in persons with SCI are higher compared to the population of the same age and gender.⁴⁵ Another SCI Model Systems study showed that the proportion of married persons with SCI varied from 31% at 5 years post-SCI to 43% at 25 years post-SCI.⁴⁶ Kreuter.⁴⁷ reported 37.7% married or cohabiting persons with SCI in Sweden. Estimates of married or cohabiting persons with SCI in the Netherlands are much higher, from 56.3%¹⁰ up to 65.9%⁴⁸.

A recent review identified no less than 58 studies about social support and SCI.¹⁸ Six of these studies found correlations between social support and life satisfaction (range 0.21-0.75), and 16 studies found associations between social support and mental health problems (range -0.21 – -0.75). These studies show that social support is important to persons with SCI.

Interventions to enhance life satisfaction and mental health after SCI

No *interventions aimed at enhancing well-being* were found, although well-being was included as secondary outcome in some studies of interventions to enhance mental health described, as described below.

The SCIRE group reviewed *interventions for treatment of depression* following SCI, including cognitive behavioral therapy (CBT).^{34,49} CBT strategies can include addressing “irrational” or negative thoughts, increasing opportunities for participating in rewarding activities, and instruction in relaxation. Issues of assertiveness, social skills and discussions of sexuality have also been included. Employing a group setting to provide CBT can also be a cost effective opportunity for peer support, practice of social skills and the opportunity for gaining additional viewpoints.³⁴ The SCIRE group included nine studies including two RCT’s, six prospective controlled trials, and one cohort study. They found level 1 and level 2 evidence supporting the use

of specialized CBT protocols, and concluded that CBT is moderately effective in improving outcomes related to depression, anxiety, adjustment and coping. Its effectiveness in improving anxiety outcomes was not established.⁴⁹

Few studies examined the *effectiveness of psychological interventions during initial inpatient rehabilitation*. Dorstyn et al.⁵⁰ reported a non-randomized controlled trial. Eleven persons with moderate or severe distress were offered CBT in fortnightly individual consultations of 30-60 min duration with a psychologist. The matched control group (n=13) consisted of persons with without distress who received standard psychological care (assessment and monitoring only). Mean scores on depression, anxiety and stress scales (DASS-21) in the CBT group decreased between start and end of the intervention, but were not maintained at the 3 month follow-up. Scores in the control group did not change.⁵⁰

Craig et al.⁵¹ reported a non-randomized controlled trial, in which CBT was offered to persons with SCI in initial inpatient rehabilitation (n=28); they were compared to a control group of persons with recent SCI who did not receive CBT (n=41). CBT was conducted over 10 weeks in small groups for 1.5-2 hours per week. Results showed a significant decrease of depressive symptoms in both groups, but this decrease was not significantly stronger in the CBT group than in the control group, and no decrease of anxiety was found in either group. Subgroup analyses showed that, for persons with baseline levels of depression in the clinical range, the CBT group improved more than the control group. For persons with anxiety scores in the clinical range at baseline, decreases in anxiety were observed in both groups.⁵¹

Kennedy et al.^{52,53} adapted a coping effectiveness training (CET) for people with SCI. CET consisted of seven 60-75 minutes sessions provided twice a week in small groups of 6-9 persons. Themes addressed were appraisal skills, problem solving, awareness of stress reactions, and negative assumptions, thoughts and expectations and how to challenge them, and choosing appropriate ways of coping. In a non-randomized pilot study,⁵² persons with SCI in initial inpatient rehabilitation (n=19) received the CET and were compared to historical controls.

Treatment effects on depression and anxiety were found, with a decrease of depression and anxiety in the CET group, but not in the control group. In larger subsequent non-randomized clinical trial (45 CET participants and 40 controls),⁵³ the authors reported a non-significant decrease in depression for the CET group ($p=0.058$). No treatment effects on anxiety were found, although a decrease in anxiety was found in the CET group that was not found in the control group. No effects on the use of coping strategies were found. The authors hypothesized that their intervention might have worked by changing participants' negative appraisals of the implications of SCI, increasing the perceived manageability of its consequences, thereby improving mood.⁵³

*Duchnick et al.*⁵⁴ evaluated Kennedy's CET in the only randomized clinical trial published. Rehabilitation inpatients with SCI ($n=41$) were randomized to CET or to supportive group therapy. They reported a significant decrease in depression at discharge but not at 3-month follow-up, and a significant decrease of anxiety at discharge and at follow-up; however, the groups did not differ at any time point. The effects of CET may have been attenuated by providing Supportive Group Therapy (SGT) to the comparison group. SGT consisted of minimally structured, emotion-focused SGT sessions. Sixty-minute sessions were provided weekly, and members were encouraged to attend until discharged. SGT sessions emphasized sharing of experiences and information surrounding injury-related topics, exploration of emotional and cognitive reactions, and the opportunity for support and education from peers and psychologists. SGT may be equally effective in reducing depression and anxiety as CET.⁵⁴

Studies using samples of community-living persons with SCI are rare. *Kemp et al.*⁵⁵ evaluated the combined use of medication and CBT in persons with SCI ($n=28$) in a non-randomized design. Treatment was offered to 43 persons, and the 15 persons who declined treatment served as the control group. After exclusion of 8 persons in the intervention group who discontinued treatment or developed medical complications, depressive symptoms de-

creased significantly in the intervention group, whereas no change in depressive symptoms occurred in the control group.⁵⁵

Gaps in our knowledge and recommendations

Mental health and life satisfaction: There is sufficient and convincing evidence that the prevalence of depression, anxiety and PTSS is elevated in persons with chronic SCI, and that their average life satisfaction is substantially below that of the general population. However, the large majority of published studies are from the United States, Canada, and Northern and Western Europe. There is a lack of studies providing information on persons with SCI elsewhere in the world, as results may not generalize to other countries and cultures. Few studies have compared samples across countries. These limitations apply to all of the following issues.

Recommendations: To perform SWB studies in countries currently not well-represented in this review and to perform comparisons between countries and cultures.^{56,57}

The course of life satisfaction after SCI: Life satisfaction improves from a low level early after SCI and remains relatively stable in later years. Distinct trajectories in the course of life satisfaction have been identified, but additional research is needed to support these findings.

Recommendation: To study distinct patterns of life satisfaction after SCI and its determinants.

The course of mental health after SCI: Conflicting research findings have been reported; further research is needed to enlighten this issue.

Recommendation: To study the course of depression, anxiety and PTSD after SCI, and their determinants.

Psychological predictors of SWB: Personal resources, for example, self-esteem, and a feeling of purpose in life, are strongly and consistently associated with SWB after SCI. Interestingly, one of the most popular topic among psychologists, coping behaviors, showed much less consistent results warranting further study. Psychological terminology is inconsistent, especially with respect to coping and appraisals.³⁹ Acceptance, for instance, is used both as a coping variable and as an appraisal. A second limitation is the conceptual proximity between dependent

and independent variables. For instance, perceived stress is employed as an emotion-based coping variable in one study, and as a QoL outcome in others. Another example is the use of 'posttraumatic cognitions' which, as a determinant entered in analysis, is suspiciously close to the outcome of posttraumatic stress. Other limitations concern the wide variety of questionnaires used, and the overrepresentation of small studies and of studies with a cross-sectional design.³⁹

Recommendations: To perform longitudinal studies with sufficient sample size, to harmonize the use of measures, and to specify and operationalize constructs clearly. To measure psychological and social factors early after SCI to test the predictive value of these factors for long-term adjustment.

Social support has shown a predictor of SWB in persons with SCI.

Interventions to enhance SWB: Most studies sought to minimize distress (depression and anxiety) and none targeted life satisfaction. Some promising results were reported, but effects were inconsistent, possibly because studies used small samples. A major weakness is the lack of patient randomization. Only one study included a social support intervention. No studies aimed to enhance well-being.

Recommendations: A variety of intervention studies are needed to identify optimal psychological support for persons with SCI. In particular, studies are needed in the chronic phase of SCI, studies targeted to strengthening personal resources of persons with SCI,⁵⁸ and studies targeted to the family of persons with SCI.⁵⁹

References

1. Strauss DJ, DeVivo MJ, Paculdo DR, Shavelle RM. Trends in life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2006;87:1079-85.
2. Dijkers MP. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005;42:87-110.
3. Post M, Noreau L. Quality of life after spinal cord injury. *J Neurol Phys Ther* 2005;29:139-46.
4. North NT. The psychological effects of spinal cord injury: a review. *Spinal Cord* 1999;37:671-9.
5. Craig A, Tran Y, Middleton J. Psychological morbidity and spinal cord injury. *Spinal Cord* 2009; 47: 108-14.
6. Hill MR, Noonan VK, Sakakibara BM, Miller WC. Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review. *Spinal Cord* 2010; 48: 438-50.
7. Hunt SM. The problem of quality of life. *Qual Life Res* 1997; 6: 205–212.
8. Post M, De Witte L, Schrijvers A. Quality of life and the ICIDH: towards an integrated conceptual model for rehabilitation outcomes research. *Clin Rehabil* 1999;13:5-15.
9. Stensman R. Adjustment to traumatic spinal cord injury: a longitudinal study of self-reported quality of life. *Paraplegia* 1994;32: 416-22.
10. van Leeuwen CM, Post MW, Hoekstra T, van der Woude LH, de Groot S, Snoek GJ, Mulder DG, Lindeman E. Trajectories in the course of life satisfaction after spinal cord injury: identification and predictors. *Arch Phys Med Rehabil* 2011;92:207-213.
11. Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. *Spinal Cord* 1997;35: 829-40.
12. Dijkers MP. Correlates of life satisfaction among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999;80:867-76.
13. Post MW, de Witte LP, van Asbeck FW, van Dijk AJ, Schrijvers AJ. Predictors of health status and life satisfaction in spinal cord injury. *Arch Phys Med Rehabil* 1998;79:395-401.
14. van Koppenhagen CF, Post MW, van der Woude LH, de Groot S, de Witte LP, van Asbeck FW, van den Heuvel WM, Lindeman E. Changes and determinants of life satisfaction after spinal cord injury: a cohort study in The Netherlands. *Arch Phys Med Rehabil*. 2008;89:1733-40.
15. Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: aging, secondary conditions and well-being. *Arch Phys Med Rehabil* 1999;80:1429-34.
16. Richards JS, Bmbardier CH, Tate D, et al. Access to the environment and life satisfaction after spinal cord injury. *Arch Phys Med Rehabil* 1999;80:1501-6.
17. van Leeuwen CM, Post MW, van Asbeck FW, van der Woude LH, de Groot S, Lindeman E. Social support and life satisfaction in spinal cord injury during and up to 1 year after inpatient rehabilitation. *J Rehabil Med* 2010;42:265-71.
18. Müller R, Peter C, Cieza A, Geyh S. The role of social support and social skills in people with spinal cord injury - A systematic review of the literature. Submitted for publication
19. Kennedy P, Lude P, Elfström ML, Smithson EF. Psychological contributions to functional independence: a longitudinal investigation of spinal cord injury rehabilitation. *Arch Phys Med Rehabil* 2011;92:597-602.
20. Jensen MP, Moore MR, Bockow TB, Ehde DM, Engel JM. Psychosocial factors and adjustment to chronic pain in persons with physical disabilities: a systematic review. *Arch Phys Med Rehabil* 2011;92:146-60.

21. Voerman GE, Erren-Wolters CV, Fleuren JF, Hermens HJ Geurts AC. Perceived spasticity in chronic spinal cord injured patients: associations with psychological factors. *Disabil Rehabil* 2010;32:775-80.
22. Diener E. The science of happiness and a proposal for a national index. *Am Psychol* 2000;55:34-43.
23. van Leeuwen CM, Post MW, Westers P, van der Woude LH, de Groot S, Sluis T, Slootman H, Lindeman E. Relationships between activities, participation, personal factors, mental health, and life satisfaction in persons with spinal cord injury. *Arch Phys Med Rehabil* (resubmitted).
24. Brickman P, Coates D, Janoff-Bulman R. Lottery winners and accident victims: is happiness relative? *J Pers Soc Psychol* 1978;36:917-27.
25. Cummins RA. Subjective Wellbeing, homeostatically protected mood and depression: a synthesis. *J Happiness Stud* 2010; 11-17.
26. Bartels M, Boomsma DI. Born to be happy? The etiology of subjective well-being. *Behav Genet* 2009;39:605-15.
27. Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd ed. Hillsdale: Erlbaum; 1988.
28. Kennedy P, Rogers B. Reported quality of life of people with spinal cord injuries: a longitudinal analysis of the first 6 months post-discharge. *Spinal Cord*. 2000 Aug;38:498-503.
29. Putzke JD, Barrett JJ, Richards JS, et al: Life satisfaction following spinal cord injury: Long-term follow-up. *J Spinal Cord Med* 2004;27:106–10.
30. Mortenson WB, Noreau L, Miller WC. The relationship between ** and predictors of quality of life after spinal cord injury at 3 and 15 months after discharge. *Spinal Cord* 2010;48:73-9.
31. van Koppenhagen CF, Post MW, van der Woude LH, et al. Recovery of life satisfaction in persons with spinal cord injury during inpatient rehabilitation. *Am J Phys Med Rehabil* 2009;88:887-95.
32. Kemp BJ, Krause JS. Depression and life satisfaction among people ageing with post-polio and spinal cord injury. *Disabil Rehabil* 1999;21:241-9.
33. Krause J. Adjustment after spinal cord injury: a 9-year longitudinal study. *Arch Phys Med Rehabil* 1997; 78: 651-7.
34. Orenczuk S, Slivinski J, Mehta S, Teasell RW. Depression following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC et al (eds). *Spinal Cord Injury Rehabilitation Evidence Version 3.0*. 2010.
35. Kennedy P, Lude P, Elfström ML, Smithson E. Cognitive appraisals, coping and quality of life outcomes: a multi-centre study of spinal cord injury rehabilitation. *Spinal Cord* 2010;48:762-9.
36. Kennedy P, Rogers BA. Anxiety and depression after spinal cord injury: a longitudinal analysis. *Arch Phys Med Rehabil* 2000;81:932-7.
37. Cushman LA, Dijkers MP. Depressed mood in spinal cord injured patients: staff perceptions and patient realities. *Arch Phys Med Rehabil* 1990;71:191-6.
38. Hoffman JM, Bombardier CH, Graves DE, Kalpakjian CZ, Krause JS. A longitudinal study of depression from 1 to 5 years after spinal cord injury. *Arch Phys Med Rehabil*. 2011;92:411-8.
39. van Leeuwen CM, Kraaijeveld S, Lindeman E, Post MWM. Which psychological variables are associated with quality of life in persons with spinal cord injury? A systematic review. Submitted for publication.
40. Brandtstädter J, Renner G. Tenacious goal pursuit and flexible goal adjustment: explication and age-related analysis of assimilative and accommodative strategies of coping. *Psychology and aging* 1990;5:58-67.

41. Shumaker S, Brownel IA. Toward a theory of social support: closing conceptual gaps. *J Soc Issues* 1984;40:11-36.
42. Cobb S. Social support as a moderator for life stress. *Psychosom Med* 1976;38:300-14.
43. Post MWM, Ros WJG, Schrijvers AJP. Impact of social support on health status and life satisfaction in people with a spinal cord injury. *Psychol Health* 1999;14:679-95.
44. Holicky R, Charlifue S. Ageing with spinal cord injury: the impact of spousal support. *Disabil Rehabil* 1999;21:250-7.
45. DeVivo MJ, Hawkins LN, Richards JS, Go BK. Outcomes of post-spinal cord injury Marriages, *Arch Phys Med Rehabil* 1995;76:130-8.
46. Charlifue S, Lammertse DP, Adkins RH. Aging with spinal cord injury: changes in selected health indices and life satisfaction. *Arch Phys Med Rehabil* 2004;85:1848-53.
47. Kreuter M, Sullivan M, Dahllöf AG, Siösteen A. Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury. *Spinal Cord* 1998;36:252-961.
48. Bloemen-Vrencken JH, Post MW, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the Netherlands. *Disabil Rehabil* 2005;27:1381-9.
49. Mehta S, Orenczuk S, Hansen KT, Aubut JA, Hitzig SL, Legassic M, Teasell RW; Spinal Cord Injury Rehabilitation Evidence Research Team. An evidence-based review of the effectiveness of cognitive behavioral therapy for psychosocial issues post-spinal cord injury. *Rehabil Psychol* 2011;56:15-25.
50. Dorstyn DS, Mathias JL, Denson LA Psychological intervention during spinal rehabilitation: a preliminary study. *Spinal Cord* 2010;48:756-61.
51. Craig AR, Hancock K, Chang E, Dickson H. Immunizing against depression and anxiety after spinal cord injury. *Arch Phys Med Rehabil* 1998;79:375-7.
52. King C, Kennedy P. Coping effectiveness training for people with spinal cord injury: preliminary results of a controlled trial. *Br J Clin Psychol* 1999;38:5-14.
53. Kennedy P, Duff J, Evans M, Beedie A. Coping effectiveness training reduces depression and anxiety following traumatic spinal cord injuries. *Br J Clin Psychol* 2003;42:41-52.
54. Duchnick JJ, Letsch EA, Curtiss G. Coping effectiveness training during acute rehabilitation of spinal cord injury/dysfunction: a randomized clinical trial. *Rehabil Psychol* 2009;54:123-32.
55. Kemp BJ, Kahan JS, Krause JS, Adkins RH, Nava G. Treatment of major depression in individuals with spinal cord injury. *J Spinal Cord Med* 2003;27:22-28.
56. Ide M, Fugl-Meyer AR. Life satisfaction in persons with spinal cord injury: a comparative investigation between Sweden and Japan. *Spinal Cord* 2001;39:387-93.
57. Krause JS, Saladin LK, Adkins RH. Disparities in subjective well-being, participation, and health after spinal cord injury: a 6-year longitudinal study. *NeuroRehabilitation* 2009;24:47-56.
58. Sin NL, Lyubomirsky S. Enhancing well-being and alleviating depressive symptoms with positive psychology interventions: A practice-friendly meta-analysis. *J Clin Psychol: In Session* 2009;65:467-487.
59. Elliot TR, Berry JW. Brief problem-solving training for family caregivers of persons with recent-onset spinal cord injuries: a randomized controlled trial. *J Clin Psychol* 2009; 65: 4-6-22.

Table 1 Prevalence of depression in persons with Spinal Cord Injury

Study	Prevalence (%)	Measurement instrument (cut-off)
<i>(prob)MDD</i>		
Kemp & Krause (1999)	17	OAHMQ (score 11-22)
Kemp et al. (1999)	19	OAHMQ (score 11-22)
Krause et al. (2000)	24	OAHMQ (score 11-22)
Bombardier et al. (2004)	11,4	PHQ-9 (criteria for MDD)
Kalpakjian & Albright (2006)	8,8 9,9	PHQ-9 (criteria for MDD) PHQ-9 (criteria for ODD)
Richardson and Richards (2008)	12-21***	PHQ-9 (≥10)
Krause et al (2010)	19 11.7	PHQ-9 (≥10) PHQ-9 (criteria for MDD)
Hoffman et al. (2011)	18-21***	PHQ-9 (≥10)
Fann et al. (2011)	23	PHQ-9 (≥10)
Kreuter et al. (1998)	22	HADS-D (criteria for clinical depression)
<i>(clinical) significant symptoms</i>		
Kemp et al. (1999)	23	OAHMQ (score 6-10)
Kemp & Krause (1999)	24	OAHMQ (score 6-10)
Krause et al. (2000)	24	OAHMQ (score 6-10)
Kemp et al. (2003)	20	OAHMQ (score 6-10) Hamilton Depression Scale
Woolrich (2006)	21	HADS-D (≥ 8)
Kennedy, Evans and Sandhu,(2009)	26	HADS-D (≥ 8)
Kennedy et al. (2010)	16.9-26.3*	HADS-D (≥ 8)
Kennedy et al. (2011)	41.7	HADS-D (≥ 8)
Craig et al. (2008)	18.2	POMS
Scivoletto et al. (1997)	16-19***	QD (norm of healthy persons + 1SD)
Kennedy et al. (2000)	25-35**	BDI (>14)
Kennedy & Rogers (2000)	27-60* 14-35***	BDI (>14)
Beedie & Kennedy (2002)	26-42*	BDI (≥14)
Lude et al. (2005)	UK: 32 CH/DE: 17	BDI (>14)
Pollard and Kennedy (2007)	35-38**	BDI (≥14)
Migliorini and Tonge, (2009)	37	DASS-21
<i>Treated for depression</i>		
Dryden et al. (2005)	28,9	ICD-9-CM codes

PHQ-9: Patient Health Questionnaire; OAHMQ: Older Adult Health and Mood Questionnaire; HADS: Hospital Anxiety and Depression Scale; POMS: Profile of Mood States; BDI: Beck Depression Inventory; QD: Depression Questionnaire (QD) of the Cognitive Behavioral Assessment, DASS-21: Depression Anxiety Stress Scale-21, ICD-9-CM codes: The International Classification of Diseases, 9th Revision, Clinical Modification.

* several measurement occasions, during rehabilitation

** several measurement occasions, during rehabilitation and after discharge

*** several measurement occasions after discharge

Table 2 Prevalence of anxiety in persons with Spinal Cord Injury

Study	Prevalence (%)	Measurement instrument (cut-off)
<i>(clinical) significant symptoms</i>		
Woolrich (2006)	32	HADS (score of 8 or more)
Kennedy et al. (2009)	35	HADS (score of 8 or more)
Kennedy et al. (2010)	13.2-19.7*	HADS (score of 8 or more)
<i>Above cut-off score</i>		
Scivoletto (1997)	15-18***	STAI (norm of healthy persons + 1SD)
Kennedy and Rogers (2000)	20-35**	SAI>48
Migliorini and Tonge (2009)	30	DASS-21

HADS: Hospital Anxiety and Depression Scale, STAI: State-Trait Anxiety Inventory, SAI: State Anxiety Inventory, DASS-21: Depression Anxiety Stress Scale-21

* several measurement occasions, during rehabilitation

** several measurement occasions, during rehabilitation and after discharge

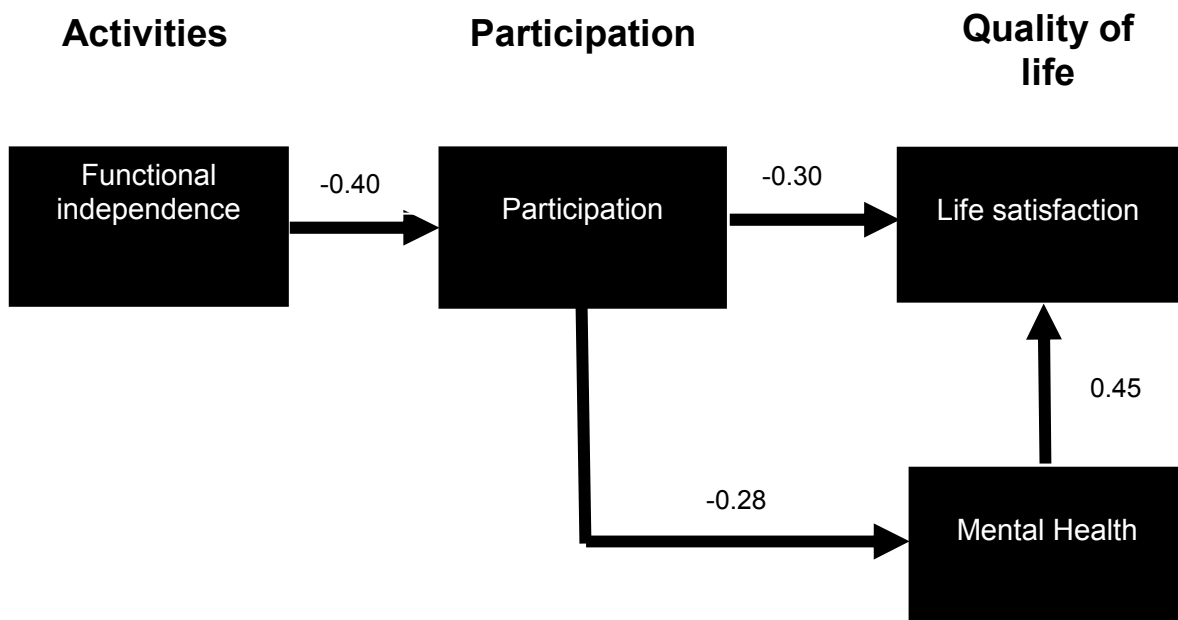
*** several measurement occasions after discharge

Table 3 **Prevalence of post-traumatic stress disorder in persons with Spinal Cord Injury**

Study	Prevalence (%)	Measurement instrument (cut-off)
<i>(clinical) significant symptoms</i>		
Hatcher, Whitacker and Karl (2009)	61.8	IES (i.e. a score of >=20 out of 40)
<i>Above cut-off score</i>		
Lude et al (2005)	UK: 15.3; CH/DE:7.1	IES intrusion (i.e., a score of >20)
	UK: 18.8; CH/DE: 8.6	IES avoidance (i.e., a score of >20)
Chung (2006)	44 full-blown PTSD 42 partial PTSD 14 no PTSD	PCL
Agar (2006)	24	PDS
Migliorini and Tonge (2009)	8.4	DASS-21
Krause et al (2010)	7.2	PPTSD-R

IES-R: Impact of Events – Revised, PCL: Posttraumatic Stress Disorder Checklist, PDS: Post-traumatic Diagnostic Scale, DASS-21: Depression Anxiety Stress Scale-21, PPTSD-R: Purdue Posttraumatic Stress Disorder Scale-Revised

Figure 1: relationships between activity levels, participation restrictions, mental health and life satisfaction.



All standardized path coefficients were significant at $p < 0.05$

From: van Leeuwen CM, Post MW, Westers P, van der Woude LH, de Groot S, Sluis T, Slootman H, Lindeman E. Relationships between activities, participation, personal factors, mental health, and life satisfaction in persons with spinal cord injury (resubmitted).

Figure 2. Life satisfaction of persons with SCI expressed as standardized deviation from a reference group (Note: mean score reference population minus mean score SCI divided by the standard deviation in the reference population)

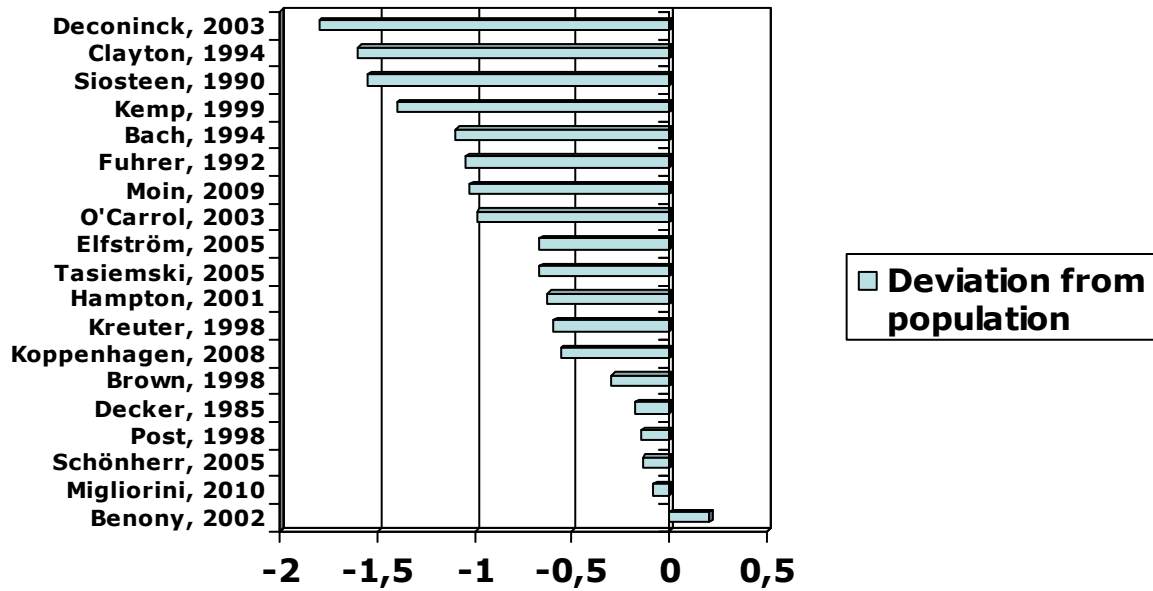
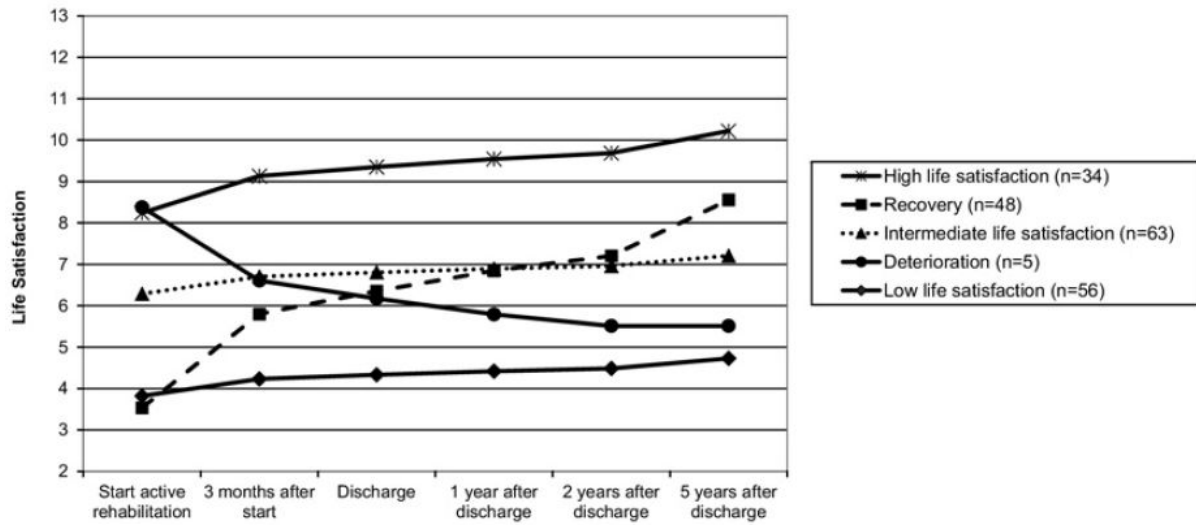
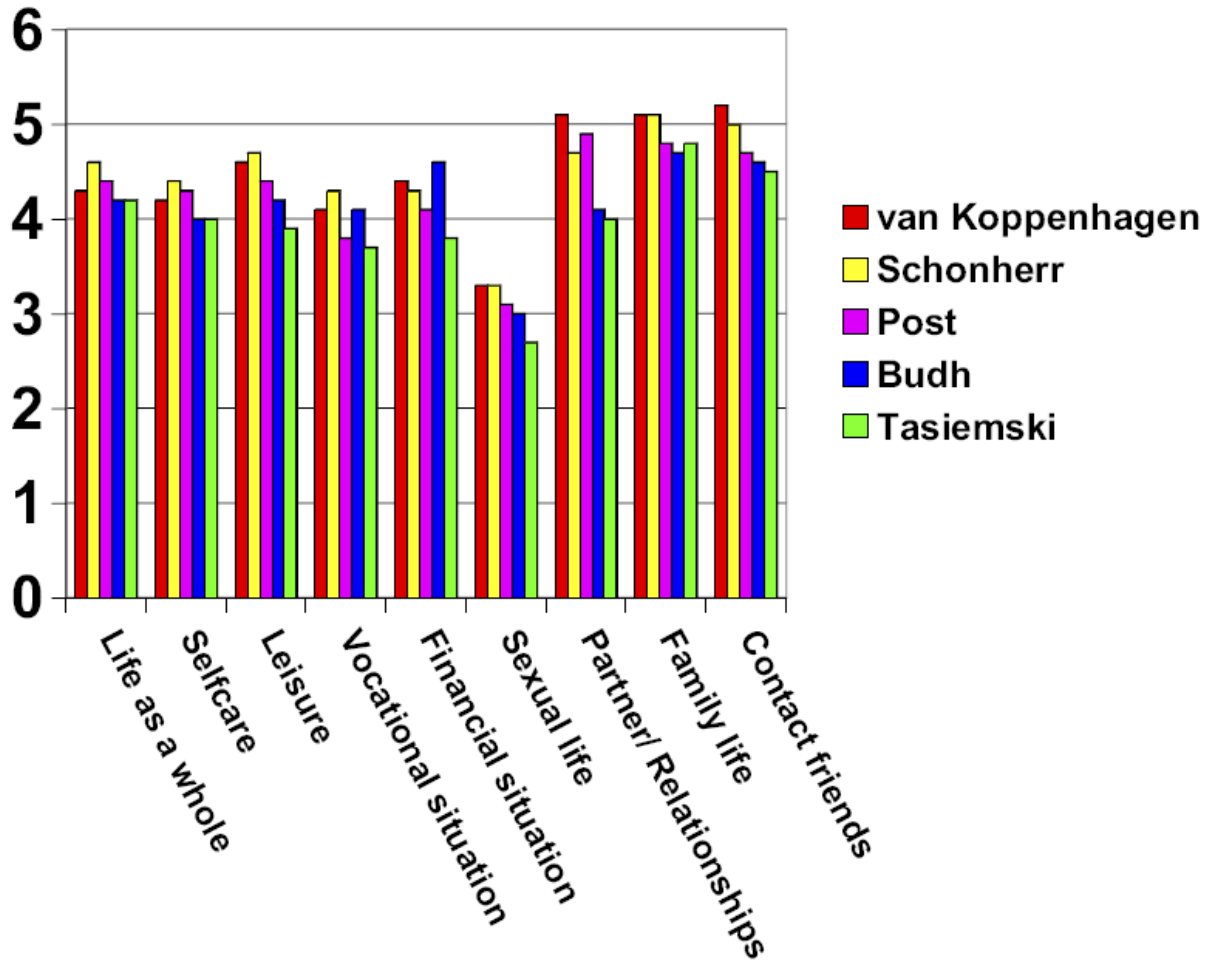


Fig 3. Five estimated trajectories in life satisfaction between the start of active rehabilitation and 5 years after discharge from inpatient rehabilitation (N=206).



From: van Leeuwen CM, Post MW, Hoekstra T, van der Woude LH, de Groot S, Snoek GJ, Mulder DG, Lindeman E. Trajectories in the course of life satisfaction after spinal cord injury: identification and predictors. Arch Phys Med Rehabil 2011;92:207-213.

Figure 4. Satisfaction with life domains in five European studies



From: van Koppenhagen CF, Post MW, van der Woude LH, de Groot S, de Witte LP, van Asbeck FW, van den Heuvel WM, Lindeman E. Changes and determinants of life satisfaction after spinal cord injury: a cohort study in The Netherlands. Arch Phys Med Rehabil. 2008;89:1733-40.