Original Article

Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples

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Study design: Cross-sectional or psychotherapy, questionnaire.

Objectives: To examine the community needs of people with spinal cord injury (SCI) across four European countries and to identify areas of unmet needs. It is intended that this information will be of use to rehabilitation professionals in fostering greater social participation among SCI individuals.

Setting: United Kingdom, Germany, Austria and Switzerland.

Methods: Self-report questionnaires were sent to 1000 people with SCI resident in the community in the UK, Germany, Austria and Switzerland. Questionnaires measured current needs, community integration, mood, appraisals, coping strategies, functional independence and perceived manageability.

Results: Occupation, sexual activity and pain relief were areas indicative of highest community needs in all four countries. Most participants were psychologically well adjusted and socially integrated into the community. Well-addressed needs were skin management, wheelchair needs and accommodation. Some differences that occurred in certain areas across the four countries were found.

Conclusion: This study has highlighted that the main areas of unmet needs for a European community sample of people with SCI includes levels of occupation, sexual activity and pain relief. The findings will be of interest to those involved in rehabilitation of newly as well as long-term injured people and demonstrate the need to consistently readdress such issues as part of a person's long-term rehabilitation in order to achieve and maximise effective social participation. *Spinal Cord* (2006) 44, 95–105. doi:10.1038/sj.sc.3101787; published online 30 August 2005

Keywords: spinal cord injury; community needs; sexual activity; pain; occupation; reintegration

Introduction

Community needs of people with spinal cord injury (SCI) 'Successful community integration can be defined as being part of the mainstream of family and community life, fulfilling normal roles and responsibilities and being an active and contributing member of ones social groups and society as a whole'.¹ It is viewed as one of the key goals of rehabilitation following an SCI and social participation is also recognised by the World Health Organisation as critical outcome following disability.²

Physical, psychological and social consequences of acquiring an SCI are evident in both the acute and chronic phases of the condition and have the potential to influence reintegration into the community. Some physical consequences pose a lifelong and disruptive health risk. Pressure sores have been reported at the

rates of 33% in a community-based sample of 100 men and 40 women examined at a single time point,³ 10% in a sample of patients at each of three time points in their first, third and fifth year postinjury⁴ and 23% in survivors between 20 and 45 years postinjury,⁵ indicating that this complication remains a long-term challenge. SCI is also associated with increased severity and frequency of bowel dysfunction compared with the general population.⁶ In a study of individuals who had been injured for at least 20 years, 42% reported constipation, 35% reported gastrointestinal pain and 27% complained of bowel accidents.⁶ A range of bowel problems were reported by 50% of outpatients with chronic SCI, and bowel function was reported to be a significant source of distress in 54% of these patients in a study by Glickman and Kamm.⁷ Urinary tract infections (UTIs) have been found to be another major problem. Sapountzi-Krepia, Soumalis and Papadakis⁸

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found that 82% of a sample of paraplegics living in Athens stated that they had at least one UTI during their stay at home following discharge. Chronic pain has also been found to be prevalent in people with SCI who live in the community, with 82% of people reporting persistent, bothersome pain at some time after discharge, many with pain that frequently interferes with daily living.⁹ These medical complications are only a few of the wide-ranging ongoing physical health needs of people with SCI, who are living in the community and highlights the need for ongoing consideration of the physical needs of people with SCI. Such physical health problems can cause disruption to lives and may have negative effects on psychosocial functioning.

A 'need' may be conceptualised as a circumstance requiring a course of action, want or requirement. The need to attend to psychological needs in the community has been indicated.^{10,11} In samples of spinal cord injured persons living in the community, psychological problems have been shown to be present at varying rates. Depressive symptomatology has been reported in 31%,¹² mild depression in 45% and evidence of clinical depression in 15%,¹³ and longitudinal studies have shown depression and anxiety to be prevalent across time.^{10,14} The psychological consequences of SCI have been shown to influence people's interaction within the social environment.^{12,13,15} The psychological needs following SCI are therefore of ongoing concern post-discharge and appropriate psychological care needs to be available within both SCI rehabilitation and community settings.¹⁰

In terms of social participation, the social consequences of SCI produce changes in an individual's social roles and interactions, resulting in need in several areas.¹⁶ In a study examining the unmet needs of people with SCI living in the community, a high or very high need relating to employment was reported by 22% of the sample.¹⁷ Results from such studies vary due to many factors, for example, the characteristics of the sample and the definition of employment used. However, re-employment rates have been reported as ranging from 14 to 44%.¹⁸ Therefore, on the whole, work can be concluded to still be an elusive goal for many,¹⁶ highlighting the need for vocational rehabilitation and careers support to help individuals return to work.^{19,20}

Related to low re-employment figures is the reported need for financial support by people with SCI, living in the community. In a study by Johnson *et al.*,⁴ financial limitations were reported by 25% of their sample and comprised the largest category of nonmedical secondary complications. However, given the vital importance of money in paying for home adaptations, equipment and care when necessary, Johnson may be inaccurate in referring to financial limitations as a 'secondary complication'. Many people with SCI will be dependent for long periods on welfare benefits and due to the complexity of the administration process, may receive substantially less than their entitlement. Thus, there is a need for professional advice on these issues.²¹

Mobility needs in the community can be high^{4,17} and can have a wide-ranging effect on a person's ability to live in the community. According to previous research, impaired mobility is related to unemployment,²² increased secondary conditions²³ and loneliness and low self-esteem.²⁴ The mobility of people with SCI has been acknowledged to be limited due to transport problems, preventing people from increasing their presence in the community.²⁵

Family and personal relationship needs postdischarge have been reported to be met to varying degrees. Needs regarding close relationships with a spouse/partner and child-rearing have been identified as being unmet, although the importance placed upon these needs have varied between studies.^{5,11} Unmet needs for peer recreation and peer support groups have also been found.²⁶

Despite agreement in the literature about the existence of some of the above areas of need postdischarge, agreement about the general level of need and consequently support required by people with SCI living in the community is harder to find. Contrasting studies indicate that, on the one hand, relatively large proportions of their community-based samples have no significant medical or psychosocial problems,²⁷ while others report a diversity of need found in fairly high percentages of people studied, and suggest the need for multidisciplinary outreach teams.¹⁷ Accurate measurement to assess individual need in the community is critical.

Measurement of community needs

Major components of social participation are: home and family roles and activities, other productive roles (work, school and volunteering), social networks, leisure activities, mobility and economic self-sufficiency.¹ If social participation is considered to be the major aim of outpatient rehabilitation,¹ the extent to which individuals with disabilities lack integration into each of these aspects of life can be considered to constitute a need. Measuring peoples' level of social participation can therefore be used to identify community needs. Very few instruments have been designed to measure social participation comprehensively and even fewer are directly related to the SCI population.

The emphasis when measuring rehabilitation outcome has previously been on measures of impairment and disability to the neglect of handicap outcomes,²⁸ or the closely related concept of community or social integration. The Craig Handicap Assessment and Reporting Technique (CHART) focuses on objectively measuring handicap and is the most commonly used measure in research with people with SCI. In its various forms it has been used in multiple studies. As a measure of societal functioning, or how well individuals are reintegrated back into the community,⁵ it has been used to investigate the relationships between handicap and depression,¹² secondary conditions,⁴ life satisfaction,²⁹ and physical activity³⁰ among others.

Quality of life (QOL) can be conceptualised as a global subjective assessment of well-being. Assessment

of an individual's satisfaction with their health, family relations, friendships, employment and finance, as well as sexual life and leisure time^{31,32} is often used to assess subjective QOL.³³ Social role functioning and interactions with family and friends are likely to be of high significance to an individual;³⁴ therefore, measures of QOL cover content similar to the core aspects of social participation measures (ie role performance and social relationships)¹ Due to their relevance to social participation and handicap, subjective QOL measures can therefore also be considered when assessing community needs.

The research literature reports that various needs remain prevalent in persons with SCI postdischarge⁴ and the provision of support in terms of medical follow-up, treatment of complications, and education of the patient and the family does not cease on discharge.²⁰ In order to provide continuing care following inpatient treatment, the identification of needs is essential. The needs of people with SCI living in the community can be viewed in terms of the success with which they participate socially, the level of handicap they experience and by identifying areas of life (roles, activities and relationships) in which they are disadvantaged in comparison to peers of the same age, gender and culture. The present study will use both objective and subjective instruments to measure QOL, social participation, cognitive appraisals and coping strategies of people with SCI residing in the community and will compare the results across four European countries.

Methods

Participants

Participant data were selected from the database of Manfred Sauer GmbH division Rolli Moden, a department that makes disability aids. It is felt that this client database is comparable to the population sample of Kennedy *et al*'s³⁵ longitudinal study. Questionnaires were sent to selected participants with SCI who resided in Germany (400), the UK (300), Switzerland (150) and Austria (150).

Materials

(i) Demographics

There were 10 questions to obtain personal details such as date of birth and marital status, injury characteristics including cause, date, level and completeness of injury, as well as information on place of rehabilitation and employment status.

(ii) Current needs

A specially designed questionnaire (reviewed by an SCI expert panel) was used to identify the extent to which current needs were being addressed in the following areas: activities of daily living, sense of control over life, management of bowels and bladder, skin management, sexual activity, transfer ability, adjustment, pain relief, wheelchair needs, personal develop-

ment, social activities, employment, recreation, relationships, emotional well-being, life goals and accommodation. Responses were made on an 11 point scale (0 = not at all; 10 = fully achieved). Participants were also asked which of the following resources were most likely to meet their needs; (a) readmission to SCI centres, (b) admission for general rehabilitation care, (c) home-based treatment and rehabilitation, (d) admission to a specialist SCI training centre with psychological and physiotherapeutic care, (e) psychological support and development, (f) general health spa, (g) employment training. Participants were asked to select any of the above which they felt applied to them.

(iii) *The Craig Handicap Assessment and Reporting Technique*³⁶

This measure quantifies individual handicap in terms of five areas: physical independence, mobility, occupation, social integration and finances. The CHART³⁶ has been shown to be reliable, with test-retest correlations from 0.80 to 0.95 for the subscales and 0.93 for the total score. It has also shown to be valid, successfully differentiating between groups of subjects globally evaluated by rehabilitation professionals as having high or low levels of handicap.³⁶ The CHART was applied to a non-US setting through converting the currency in accordance with instruction from authors of the scale.

(iv) *Life Satisfaction Questionnaire (LSQ)*^{37,38}

This measure provides a subjective interpretation of QOL, producing ratings of individuals' satisfaction with life as a whole and in eight other specific areas: self-care, leisure, vocational and financial situations, family life, partnership relations, sexual life, and social contact with friends. Answers could be allocated to one of six categories: 1 = Very dissatisfying, 2 = Dissatisfying, 3 = Rather dissatisfying, 4 = Rather satisfying, 5 = Satisfying, 6 = Very satisfying. Taking into consideration, the typical QOL instrument criteria (ie reliability, validity, responsiveness, interpretability, practicality and cross-country applicability),³⁹ it has been found that the LSQ⁴⁰ is a satisfactory QOL measure. Previous research has used this measure with people with disability including patients with stroke,³⁷ multiple sclerosis,⁴¹ and other physical disabilities⁴² including SCI.³⁸ The LSQ has previously been used in studies with persons with SCI living in the community³⁸ for which a Cronbach's alpha of 0.74 was obtained.

(v) *Hospital Anxiety and Depression Scale (HADS)*⁴³

This scale provides a brief state measure of anxiety and depression enabling detection of clinical cases and assessment of severity without contamination of scores by reports of physical symptomatology. It has been found to perform well in various adult medical populations.^{44,45} A review of papers assessing the validity of the HADS indicated that it has good psychometric properties, with internal consistency varying from 0.68 to 0.93 (mean = 0.83) for the HADS-A and between 0.67 and 0.90 (mean = 0.82) for the HADS-D. Its concurrent validity has been established with other commonly used questionnaires ranging from 0.49

to 0.83 (mean = 0.66).⁴⁵ A psychometric evaluation of the HADS in a sample of 985 adults with an SCI⁴⁶ found the internal consistency for the HADS-A to be 0.85 and 0.70 for HADS-D.

(vi) *Appraisal of Life Events Scale (ALE)*⁴⁷

This scale consists of a checklist of 16 adjectives designed to elicit respondents' cognitive appraisals of stressful life events in terms of threat (6 adjectives), challenge (6 adjectives) and loss (4 adjectives). Participants rated their responses on a six-point scale (0 = not at all to 5 = very much) to indicate the extent to which each of the adjectives described their perceptions of their current circumstances. The maximum score for the threat and challenge subscales was 30 and for the loss subscale, the maximum score was 20. This scale has been shown to have adequate factor structure, good test-retest reliability (ranging from 0.48 to 0.90), acceptable internal reliabilities (ranging from 0.75 to 0.91), and construct validity.⁴⁷

(vii) *Spinal Cord Lesion Related Coping Scale (SCL-RCS)*^{48,49}

This scale was developed specifically for use with individuals with SCI to explore coping processes. It consists of 12 items measuring the utilisation of three coping strategies: acceptance (4 items), fighting spirit (5 items) and social reliance (3 items). The scale has good psychometric properties, with item internal validity correlations ranging from 0.44 to 0.64 and internal reliability coefficients ranging from 0.72 to 0.79 for the three strategies. It is part of a larger scale, the SCL CO-24, which also includes a scale to measure psychological outcome in terms of three variables: helplessness, intrusion, and personal growth.

(viii) *Functional Independence Measure (FIM)*⁵⁰

This disability measure assesses degree of independence in activities of daily living in each of six areas of function: self-care, mobility, sphincter control, locomotion, communication and social cognition. The 18 items of the FIM are scored from 1 (total assistance is required from someone else to achieve the task) to 7 (total independence). It has been widely used in the SCI population¹⁰ and has a good psychometric profile with an internal consistency coefficient of 0.91–0.92 for the total scale and item-total correlations ranging from 0.33 to 0.81 when used with this group.

Procedure

The questionnaires were sent out to people whose names were recorded on the database of Manfred Sauer GmbH division Rolli Moden. A letter was included explaining the purpose of the study. Questionnaires sent out to Germany, Austria and Switzerland were translated into German. The original language of the questionnaire was English and a double backward translation method was used to establish semantic equivalence. Follow-up reminders were sent to the participants 2 weeks after the questionnaires had been distributed. The study was conducted in accordance with local research ethics research governance requirements.

Data analysis

Data were analysed across the whole sample and differences were investigated between the four different countries, using significance tests where appropriate.

Results

Response rate

The overall response rate was 35%. There were 171 responses from participants resident in Germany, accounting for 49% of the returned sample, 44 questionnaires were completed by people resident in Austria (12% of the returned sample), 27 responses (8%) were from Switzerland and 108 (31%) were from the UK. The individual response rates from the four participating countries of Germany, UK, Austria and Switzerland was 43, 36, 18 and 29%, respectively.

Demographics

Across the whole sample, the mean age was 49 years (SD = 12.1, range 15–76 years). This reflected the mean age across the four countries, the average age being 49 (SD = 11.7) in Germany, 51 (SD = 11.3) in Austria, 48 (SD = 12.5) in Switzerland and 48 (SD = 13.0) in the UK. Across the whole sample, the ratio of males to females was approximately 4:1 (277:72). This ratio was found in the UK sample. However, the ratio of males:females in Germany (130:41) and Switzerland (20:7) was roughly 3:1 and in Austria this was increased to approximately 8:1 (39:5).

The majority of participants (60%) were married or living with a partner. A total of 102 (29%) were single and 31 (9%) were divorced or separated. For those participants who were divorced, all, except one had become divorced or separated postinjury. Three people (1%) were widowed. The pattern of marital status of the whole sample was roughly replicated in Germany, Austria and the UK but differed slightly in Switzerland where 56% were single and 44% were married.

Across the whole sample 152 (43%) people had been injured in an RTA (road traffic accident), 51 (15%) people by an accident at work, 30 (8%) by a fall, 53 (15%) through a sporting accident, six (2%) due to medical treatment, 33 (9%) due to illness and 29 (8%) had been injured due to other reasons. Figure 1 shows these demographics across the four countries.

Participants had been injured, on average, for 21 years (SD = 11.2, range 1–59 years), which was representational across the four countries. On average, the participants from Germany, Austria, Switzerland and the UK had been injured for 22, 20, 23 and 19 years, respectively.

Across the whole sample, 160 (48%) participants were classified as having complete paraplegia, 31 (9%) participants had incomplete paraplegia, 84 (25%) participants had complete tetraplegia and 58 (18%) participants had incomplete tetraplegia. This pattern was roughly shown for the four countries except the UK where there were a greater proportion of participants

with complete tetraplegia. Across the whole sample, 147 (46%) participants were injured at the cervical level, 152 (47%) participants at the thoracic level and 23 (7%)

Figure 1 Comparison of the cause of injury across the different countries

Figure 2 Percentages of participants in paid or voluntary employment

*adl – activities of daily living

Figure 3 Mean ratings for current needs for the whole sample

participants at the lumbar level and one (0.3%) at the sacral level. Examining data across the countries, for Germany, Switzerland and Austria, the percentage of participants with a cervical injury ranged from 36 to 42% and the percentage of participants with a thoracic injury was greater, ranging from 51 to 60%. In the UK, there were more participants with a cervical injury (58%) than a thoracic injury (32%).

Just over half of the participants (185, 52%) were currently in paid or voluntary employment. Figure 2 shows the percentages across the different countries.

Current needs

The extent to which different needs are addressed across the whole sample is presented in Figure 3.

Across the whole sample, sexual activity had the lowest mean score of 4.01 (SD=3.66), followed by employment (5.58, SD=3.77) and pain relief (5.94, SD=3.17). The three needs least met in Austria, Switzerland and Germany were sexual activity, employment and pain relief. Participants from the UK indicated that sexual activity and employment were not being adequately addressed but also indicated that recreation and pain relief were poorly addressed needs.

In total, 72% of participants (252) stated that they were satisfied with their current life circumstances. A residential SCI training centre with specialist psychological and physiotherapeutic care was seen the treatment most likely to meet participants' needs (23% of responses). This was closely followed by a general health spa, which was indicated by 22%. Home-based treatment and rehabilitation was the treatment of choice for 20% of responses, and 17% of responses indicated psychological support and development. Admission for general rehabilitative care accounted for 10% of responses. Employment training and readmission to an SCI rehabilitation centre accounted for only 4 and 3%, respectively. There were no significant differences between countries except for one treatment, specialist SCI residential training with psychological and physiotherapeutic care. The majority

Figure 4 Resources reported as most likely to meet participants' needs for the whole sample

Table 1 Mean scores for the CHART subscales

Mean (SD)	Physical independence	Mobility	Occupation	Social interaction	Economic self-sufficiency
Germany	85.84 (20.14)	90.04 (15.19)	67.69 (31.15)	91.80 (17.86)	76.81 (37.42)
Australia	85.86 (22.67)	83.85 (20.91)	65.13 (33.47)	91.93 (17.77)	65.97 (40.16)
Switzerland	88.51 (20.85)	89.24 (14.19)	67.13 (24.24)	91.96 (17.30)	65.38 (42.47)
UK	66.32 (32.84)	83.86 (19.12)	64.24 (33.79)	85.79 (21.33)	83.95 (30.49)
Total	78.92 (27.34)	87.30 (17.37)	66.26 (31.68)	89.91 (19.12)	76.78 (36.61)

of German participants (69%) stated that this treatment would meet their needs, whereas only 16% of Austrians and less than 10% of Swiss (5%) and British (9%) participants indicated this to be the case. The resources reported as most likely to meet participants needs across the whole sample are presented in Figure 4.

Craig Handicap Assessment and Reporting Technique

The mean score for each subscale was calculated and presented in Table 1.

A Kruskal–Wallis test revealed significant differences between the mean scores across the countries for the subscales, physical independence and economic self-sufficiency ($P < 0.01$) and social participation ($P < 0.05$). Participants from the UK indicated significantly less physical independence and social interaction but significantly greater economic self-sufficiency.

Life Satisfaction Questionnaire

Tests of significance only found a significant difference between countries for the domain, satisfaction with leisure situation. Looking at the percentages of those who were dissatisfied and satisfied, it appeared that respondents from the UK were considerably more satisfied with their leisure situation than respondents from the other countries.

Hospital Anxiety and Depression Scale

A χ^2 test compared the anxiety subscale with the depression subscale. Significant differences were found

($P < 0.01$) between the scores across the whole sample for both anxiety and depression. Over two-thirds of respondents showed normal levels of anxiety and depression. These figures were significantly lower for mild, moderate and severe levels of anxiety and depression. When comparing levels of anxiety and depression directly, there was a greater percentage of respondents indicating mild, moderate or severe anxiety in comparison with the percentage of respondents indicating such levels of depression. However, the percentages indicating mild, moderate or severe levels of anxiety and depression were low overall.

A Kruskal–Wallis test showed that there were significant differences ($P < 0.01$) between the number of people exhibiting normal, mild, moderate and severe depression and anxiety across the different countries. Comparing the data across the four countries, it seems that a greater percentage of participants from the UK indicated anxiety and depression at the moderate level, suggesting that UK participants were experiencing slightly higher levels of anxiety and depression than participants from other countries.

Appraisal of Life Events Scale

Across the whole sample, the mean scores for the threat, challenge and loss scales were 5.81 (SD = 6.39), 15.82 (SD = 6.89) and 4.04 (SD = 4.40), respectively.

A Kruskal–Wallis test showed that there was a significant difference ($P < 0.01$) between the mean scores across the different countries for the challenge and loss subscales. The challenge subscale showed substantial

differences. Swiss respondents gave, on average, higher scores than the respondents from the three other countries. For the loss subscale, distinct differences were apparent between the mean scores given from the respondents from the UK who indicated greater loss than participants from the other countries.

Spinal Cord Lesion Related Coping Scale

The mean scores for the three scales of acceptance, fighting spirit and social reliance were 3.23 (SD = 2.38), 4.22 (SD = 2.27) and 2.81 (SD = 2.05).

A Kruskal–Wallis test found that there were significant differences between the different countries' scores for each subscale. The respondents from the UK showed less acceptance and fighting spirit and greater social reliance. Austrian respondents showed the greatest degree of acceptance whereas German and Swiss respondents showed the highest (and almost equal) degree of fighting spirit and lowest levels of social reliance. Mean scores for SCL RCS subscales for each country are presented in Table 2.

Functional Independence Measure

The mean score for the motor scale was 63.57 (SD = 24.54) and the mean score for the cognitive scale was 33.75 (SD = 4.05) and the mean score for the total score was 97.30 (SD = 25.6). The mean total score was slightly less than that found in previous research,¹⁰ which found that total FIM scores remained relatively stable at around 105 between 1 month and 2 years postdischarge. The mean time since injury in the present study was 21 years, thus it is expected that the participant sample would be comparatively older in the current study and therefore the total FIM score would likely to be less. Mean total FIM scores for each country are presented in Table 3.

A Kruskal–Wallis test found no significant differences between the scores across the four countries for the cognitive, motor or total FIM scales.

Table 2 Mean scores for SCL RCS subscales

Mean (SD)	Acceptance	Fighting spirit	Social reliance
Germany	13.15 (2.25)	17.05 (2.25)	8.08 (2.11)
Austria	13.69 (2.36)	16.69 (2.92)	8.47 (2.43)
Switzerland	12.72 (2.92)	17.08 (2.12)	8.38 (2.32)
UK	11.94 (2.78)	16.27 (2.42)	9.00 (1.75)
Total	12.81 (2.56)	16.76 (2.40)	8.44 (2.09)

Table 3 Mean FIM scores

	Germany	Austria	Switzerland	UK	Total
Mean (SD)	99.47 (23.726)	99.95 (27.410)	96.96 (25.987)	92.83 (27.031)	97.29 (25.511)

Discussion

This study examined aspects of QOL, mood, life satisfaction, coping and perceived needs in a community sample of people with SCI from four European countries. Generally, while participants are well integrated into the community, this was not reflected in all areas, such as occupation and economic self-sufficiency. It was found that participants were psychologically well-adjusted, indicating normal levels of anxiety and depression, exhibiting positive psychological reactions to their circumstances and using effective coping strategies. The needs identified as being addressed least satisfactorily were in the areas of occupation, sexual activity and pain relief.

The overall demographics of this community sample were similar across the four European countries, with only marital status, cause of injury and employment status showing significant differences. This community sample is comparable to that of previous research conducted in the UK⁵¹ and Switzerland⁵² in terms of demographics and injury characteristics. Highest perceived needs were associated with sexual activity, pain relief and employment. Such dissatisfaction with employment needs was reflected in the CHART³⁶ scale, where it was found that occupation scored the lowest mean score (66.31) and only just under a quarter of participants (25%) scored the maximum score of 100. This suggests that, with respect to occupation and employment, full social participation was limited for the majority of participants. The occupation subscale of the CHART³⁶ showed this to be the lowest degree of community integration across all four countries. Economic self-sufficiency also showed low levels of social participation, although participants from Germany and the UK indicated significantly higher levels than Austrian and Swiss participants, a factor possibly related to how health services are funded and consequently how much the individual may have to pay for health care.

Participants were most satisfied with their family life, contact with friends and acquaintances and relationship with their partners. In total, 70% of participants were dissatisfied with their sexual lives, an area that was clearly not being addressed. Participants' leisure situation and ability to manage their self-care did not elicit such strong views but still, just under half of the participant sample were dissatisfied with these two life domains. Comparing the results across the countries, significant differences were found for only one domain, participants' leisure situation. Participants from the UK were considerably more satisfied with their leisure situation than respondents from the other countries.

Just under 45% of participants were dissatisfied with their employment situation.

Satisfaction with different life domains for people with SCI has been previously investigated. It has been found that pain relief is a common health-related issue for people with SCI. Anke *et al*⁵³ stated that 46% of the sample 'developed pain of moderate or severe intensity', a figure echoed by others who state that chronic pain is prevalent in 25–45% of people with SCI.^{54,55} The importance of effective pain relief for people with SCI is highlighted in a study conducted by Putzke *et al*.⁵⁶ It was found that pain in individuals with SCI had a 'consistent detrimental impact on functioning across multiple QOL domains' and chronic pain was a 'major factor that complicates adjustment and compounds the individual's sense of burden'. A further study by Putzke *et al*⁵⁷ found that people developing pain between 1 and 2 years postinjury reported decreased life satisfaction, physical health and mental health and those that experienced an improvement in pain relief reported an increase in those domains. Interestingly, a change in pain interference did not result in a change in people's self-reported handicap.

Sexual needs of people with SCI have previously been examined by White *et al*.⁵⁸ A sample of 40 females resident in the community ranked 11 areas of their life in terms of importance and satisfaction. Sex life was ranked 10th in terms of both importance and satisfaction. It was found that compared to a previously studied male group, the women had distinctive needs that were not being addressed.

Although figures do vary, dissatisfaction with employment and occupation status has been previously acknowledged by Creek *et al*,⁵⁹ who found that in a British sample only 50% were in employment 5 years postinjury, compared to an employment figure of 97% at the time of injury. Employment satisfaction is a crucial factor in a person's rehabilitation and it has been stated that employment is 'a useful definition of successful rehabilitation'.⁵¹

When asked what treatment would most likely to address the participants' needs, the most frequent answer, which accounted for 23% of responses was residential training in a specialist SCI centre with psychological and physiotherapeutic care. Readmission to an SCI rehabilitation centre, treatment which the majority of participants would have likely to have received when they were initially injured, accounted for only 3% of responses. It appears that the majority of participants believe that specialist treatment or home-based care rather than general rehabilitation would meet their needs.

Analysis of the ALE scale demonstrated that across the whole sample, participants gave low scores for threat suggesting that participants were not appraising their environment as anxiety provoking (ie physically harmful and hostile). Participants across the whole sample gave high scores for the challenge subscale (Swiss participants gave significantly higher scores than other participants) indicating that they perceive their environment as one

that they can learn and develop from (eg informative and stimulating). Overall, low scores were given for loss, although participants from the UK gave significantly higher scores, suggesting that the degree to which participants from the UK perceive their current circumstances as depressing was higher than participants from the other countries. Given that the participant sample indicated low appraisal scores for threat and loss and high appraisal scores for challenge, it could be inferred using the Lazarus and Folkman's⁶⁰ model of stress, that the participants are showing evidence of positive psychological reactions.

Previous research has indicated that the way in which the environment is appraised and the type of coping strategy used is related to some degree.⁶¹ Ferguson *et al*⁴⁷ demonstrated that avoidance and emotion-focused coping (as measured by the Endler and Parker's⁶² Coping Inventory for stressful situations) was associated with increased threat and loss appraisals (as measured by the ALE scale) and task-focused coping was positively associated with challenge appraisals, but this did vary according to the situation.

Across the whole sample, results indicated that participants utilised fighting spirit and acceptance coping strategies more than social reliance. Examining the degrees to which different countries utilised each coping strategy, it was found that participants from the UK showed less acceptance and fighting spirit and greater social reliance. This suggests that fewer of the participants from the UK were accepting their situation or approaching it with a fighting spirit, in comparison to participants from other countries. The higher social reliance scores indicated that more participants from the UK seemed to be externalising the control for stressors to other people or relying on bridging the gap between situational demands and their own personal capacity,^{48,49} in comparison to participants from other countries.

SCL-related coping factors such as the three factors of the ALE scale have been shown to predict psychological outcome in SCL.^{48,49} Acceptance has been shown to be particularly associated with less psychological distress and more positive morale, whereas the coping factor of social reliance has been shown to be related to increased psychological distress. Elfström *et al*^{48,49} offer an explanation, suggesting that low acceptance involves externalising control, and that 'elevated control attributions have been associated with higher levels of psychological distress'. Fighting spirit has been found to predict psychological outcome less well^{48,49} although high levels of internal control, indicated by high levels of fighting spirit are linked to less psychological distress and better well-being among people with SCI.⁶³ The relationship between utilising positive primary appraisals and effective coping strategies and exhibiting less psychological distress has been indicated in this participant sample. The relationships between coping and psychological adjustment have been previously highlighted by Kennedy *et al*.³⁵ The study examined psychological impact and coping in people with SCI

during their early treatment, through rehabilitation and up to 2 years after discharge, demonstrating the existence of a significant predictive relationship between coping strategies and psychological distress.

The FIM mean total score was slightly less than that found in previous research,¹⁰ which found that total FIM scores remained relatively stable at around 105 between 1 month and 2 years postdischarge. The mean time since injury in the present study was 21 years, thus it is expected that the participant sample would be slightly older in the current study and therefore the total FIM score would likely to be less. The FIM⁵⁰ showed that across the whole sample, participants, on average scored close to the maximum score for cognitive independence but scored a lower mean score for motor independence, indicating that on average minimal assistance was required with activities of daily living that required motor function. No significant differences were found for either the total, motor or cognitive scores across the four countries. The results mirror those found by a study conducted by Hall *et al*,⁶⁴ who reported that 89–97% of cognitive scores showed a ceiling effect, that is scored 6 or 7 1 year after discharge and virtually all cases were independent 2 years after discharge. In contrast, motor scores varied by level of injury and time postinjury, 'providing information on functional independence across a continuum'.⁶⁴ This led to the authors' conclusion that for people with SCI, the motor subscale of the FIM is a valid tool but the cognitive subscale lacks the sensitivity to measure subtle changes.⁶⁴

There seem to be few studies examining the community needs of individuals with SCI in Germany, Austria or Switzerland and even fewer studies that appear to compare the needs of individuals across these countries. It is therefore difficult to state whether the results from the countries and significant differences that were found are valid and representative of the general population in these identified countries, or whether the results have been distorted due to small numbers of participants. It is possible that some of the inter-country differences found may be attributable to differences in language and culture.

It is also important to address the needs of partner and family members. Every participant except one was divorced or separated after their injury, a result which is indicative of the problems that partner and family members can face after a person has an SCI. When partner and family needs are seriously taken into account, these become essential factors during long-term adjustment.^{65,66} A limitation of this study is the inability to compare participants who returned the questionnaire with those who did not, leading to selective attrition. This is an inherent difficulty with study designs of this type. Although further analysis is required to examine the relationship between psychological adjustment, mood, QOL, appraisal and coping strategies, this study has highlighted as previous research has carried out, the dissatisfaction people with SCI have with life domains such as occupation, sexual activity and pain relief. This

study's findings will be of interest to those involved in the rehabilitation of newly as well as long-term injured people, highlighting the issues that may be addressed, and in doing so, helping to achieve and maximise effective social participation. It can be concluded that, up to the present time, social participation seems to be a long-term process in which three areas of unmet needs have been identified as occupation, sexual activity and pain relief. These key issues have to be consistently addressed and such needs met.

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References

- 1 Dijkers M. Community integration: conceptual issues and measurement approaches in rehabilitation research. *Top Spinal Cord Injury Rehabil* 1998; **4**: 1–15.
- 2 World Health Organization. *International Classification of Functioning, Disability & Health (ICF)*. World Health Organization: Geneva 2001.
- 3 Fuhrer MJ, Garber SL, Rintala DH, Clearman R, Hart KA. Pressure ulcers in community resident persons with spinal cord injury: prevalence and risk factors. *Arch Phys Med Rehabil* 1993; **74**: 1172–1177.
- 4 Johnson RL, Gerhart KA, McCray J, Menconi JC, Whiteneck GG. Secondary conditions following spinal cord injury in a population-based sample. *Spinal Cord* 1998; **36**: 45–50.
- 5 Whiteneck GG *et al*. Mortality, morbidity and psychological outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992; **30**: 617–630.
- 6 Menter R, Weitzenkamp D, Cooper D, Bingley J, Charlifue S, Whiteneck G. Bowel management outcomes in individuals with long-term spinal cord injuries. *Spinal Cord* 1997; **35**: 608–612.
- 7 Glickman S, Kamm MA. Bowel dysfunction in spinal-cord-injury patients. *Lancet* 1996; **347**: 1651–1653.
- 8 Sapountzi-Krepia D *et al*. Post traumatic paraplegics living in Athens: the impact of pressure sores and UTI's on everyday life activities. *Spinal Cord* 1998; **36**: 432–437.
- 9 Turner JA, Cardenas DD, Warms CA, McClellan CB. Chronic pain associated with spinal cord injuries: a community survey. *Arch Phys Med Rehabil* 2001; **82**: 501–508.
- 10 Kennedy P, Rogers BA. Anxiety and depression after spinal cord injury: a longitudinal analysis. *Arch Phys Med Rehabil* 2000; **81**: 932–937.
- 11 Kennedy P, Rogers BA. Reported quality of life of people with spinal cord injuries: a longitudinal analysis of the first 6 months post-discharge. *Spinal Cord* 2000; **38**: 498–503.
- 12 Fuhrer MJ, Rintala DH, Hart KA, Clearman R, Young ME. Depressive symptomatology in persons with spinal cord injury who reside in the community. *Arch Phys Med Rehabil* 1993; **74**: 255–260.

- 13 MacDonald MR, Nielson WR, Cameron MG. Depression and activity patterns of spinal cord injured persons living in the community. *Arch Phys Med Rehabil* 1987; **68**: 339–343.
- 14 Craig AR, Hancock KM, Dickson HG. A longitudinal investigation into anxiety and depression in the first 2 years following a spinal cord injury. *Paraplegia* 1994; **32**: 675–679.
- 15 Tate D, Forchheimer M, Maynard F, Dijkers M. Predicting depression and psychological distress in persons with spinal cord injury based on indicators of handicap. *Am J Phys Med Rehabil* 1994; **73**: 175–183.
- 16 Dijkers M, Abela NB, Gans BM, Gordon W. The aftermath of spinal cord injury. In: Stover SL, Delisa JA, Whiteneck GG (eds) *Spinal Cord Injury. Clinical Outcomes From the Model Systems*. Aspen: Baltimore 1995, pp 185–211.
- 17 Cox RJ, Amsters DI, Pershouse KJ. The need for a multidisciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil* 2001; **15**: 600–606.
- 18 Krause JS. Years to employment after spinal cord injury. *Arch Phys Med Rehabil* 2003; **84**: 1282–1289.
- 19 DeVivo MJ, Richards JS. Community re-integration and quality of life following spinal cord injury. *Paraplegia* 1992; **30**: 108–112.
- 20 Brown DJ, Judd FK, Ungar GH. Continuing care of the spinal cord injured. *Paraplegia* 1987; **25**: 296–300.
- 21 Bamford E, Grundy D, Russell J. ABC of spinal cord injury. Social needs of the patient and his family. *Br Med J* 1986; **22**: 546–548.
- 22 Fiedler IG, Indermuehle DL, Drobac W, Laud P. Perceived barriers to employment in individuals with spinal cord injury. *Top Spinal Cord Injury Rehabil* 2002; **7**: 73–82.
- 23 Meyers AR, Mitra M, Klein-Walker D, Wilber N, Allen D. Predictors of secondary conditions in a sample of independently living adults with high-level spinal cord injury. *Top Spinal Cord Injury Rehabil* 2000; **6**: 1–8.
- 24 Tzonichaki I, Kleftaras G. Paraplegia from spinal cord injury: self-esteem, loneliness, and life satisfaction. *Occup Participation Health* 2002; **22**: 96–103.
- 25 Harrison C, Kuric J. Community reintegration of SCI persons: problems and perceptions. *SCI Nurs* 1989; **6**: 44–47.
- 26 McAweeney MJ, Forchheimer M, Tate DG. Identifying the unmet living needs of persons with spinal cord injury. *J Rehabil* 1996; **62**: 29–34.
- 27 Gehart KA. Spinal cord injury outcomes in a population-based sample. *J Trauma* 1991; **31**: 1529–1535.
- 28 Hall KM, Dijkers M, Whiteneck G, Brooks CA, Krause JS. The Craig Handicap Assessment and Reporting technique (CHART): metric properties and scoring. *Top Spinal Cord Injury Rehabil* 1998; **4**: 16–30.
- 29 Vogel LC, Klaas SJ, Lubicky JP, Anderson C. Long-term outcomes and life satisfaction of adults who had paediatric spinal cord injuries. *Arch Phys Med Rehabil* 1998; **79**: 1496–1503.
- 30 Manns PJ, Chadd KE. Determining the relation between quality of life, handicap, fitness, and physical activity for persons with spinal cord injury. *Arch Phys Med Rehabil* 1999; **80**: 1566–1571.
- 31 Pentland W, McColl MA, Rosenthal C. The effect of aging and duration of disability on long term health outcomes following spinal cord injury. *Paraplegia* 1995; **33**: 367–373.
- 32 Fuhrer MJ, Rintala DH, Hart KA, Clearman R, Young ME. Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. *Arch Phys Med Rehabil* 1992; **73**: 552–557.
- 33 Whiteneck GG. The 44th annual John Stanley Coulter Lecture. Measuring what matters: key rehabilitation outcomes. *Arch Phys Med Rehabil* 1994; **75**: 1073–1076.
- 34 Dijkers MP, Whiteneck G, El-Jaroudi R. Measures of social outcomes in disability research. *Arch Phys Med Rehabil* 2000; **81**: S63–S80.
- 35 Kennedy P, Marsh N, Lowe R, Grey N, Short E, Rogers B. A longitudinal analysis of psychological impact and coping strategies following spinal cord injury. *Br J Health Psychol* 2000; **5**: 157–172.
- 36 Whiteneck GG, Charlifue SW, Gehart KA, Overholser JD, Richardson GN. Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Phys Med Rehabil* 1992; **73**: 519–526.
- 37 Viitanen M, Fugl-Meyer KS, Bernspang B, Fugl-Meyer AR. Life satisfaction in long-term survivors after stroke. *Scand J Rehabil Med* 1998; **20**: 17–24.
- 38 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.
- 39 Hallin P, Sullivan M, Kreuter M. Spinal cord injury and quality of life measures: a review of instrument psychometric quality. *Spinal Cord* 2000; **38**: 509–523.
- 40 Fugl-Meyer AR, Branholm IB, Fugl-Meyer KS. Happiness and domain specific life satisfaction in adult northern Swedes. *Clin Rehabil* 1991; **5**: 25–33.
- 41 Lundmark P, Branholm IB. Relationship between occupation and life satisfaction in people with multiple sclerosis. *Disabil Rehabil* 1996; **18**: 449–453.
- 42 Fugl-Meyer AR, Eklund M, Fugl-Meyer KS. Vocational rehabilitation in northern Sweden. III. Aspects of life satisfaction. *Scand J Rehabil Med* 1991; **23**: 83–87.
- 43 Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; **67**: 361–370.
- 44 Flint AJ, Rifat SL. Factor structure of the hospital anxiety and depression scale in older patients with major depression. *Int J Geriatr Psychiatry* 2002; **17**: 117–123.
- 45 Bjelland I, Dahl AA, Haug TT, Necklemann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosomatic Res* 2002; **52**: 69–77.
- 46 Blaikely R, Kennedy P. A psychometric analysis of the Hospital Anxiety and Depression Scale. *Psychology, Health & Medicine* (in press).
- 47 Ferguson E, Matthews G, Cox T. The appraisal of life events (ALE) scale: reliability and validity. *Br J Health Psychol* 1999; **4**: 97–116.
- 48 Elfström ML, Kreuter M, Rydén A, Persson L-O, Sullivan M. Effects of coping on psychological outcome when controlling for background variables: a study of traumatically spinal cord lesioned persons. *Spinal Cord* 2002; **40**: 408–415.
- 49 Elfström ML, Rydén A, Kreuter M, Persson L-O, Sullivan M. Linkages between coping and psychological outcome in the spinal cord lesioned: development of SCL-related measures. *Spinal Cord* 2002; **40**: 23–29.
- 50 Hamilton BB, Granger CV. *Guide for the Use of the Uniform Data Set for Medical Rehabilitation*. Buffalo: New York 1990.

- 51 Kennedy P. Spinal cord injuries. In: Bellack AS, Hersen M (eds). *Comprehensive Clinical Psychology*. Pergamon Press: New York 1998.
- 52 Znoj HJ, Lude P. Regulation of emotion and psychological symptoms in people with spinal cord injury. *Swiss J Psychol* 2002; **61**: 203–210.
- 53 Anke AG, Stenehjem AE, Stanghelle JK. Pain and life quality within 2 years of spinal cord injury. *Paraplegia* 1995; **33**: 555–559.
- 54 Britell WW, Mariano AJ. Chronic pain in spinal cord injury. In Walsh NE (ed). *Physical Medicine and Rehabilitation; Rehabilitation of Chronic Pain*. Hanley and Belfus: Philadelphia 1991 pp 71–82.
- 55 Kennedy P, Frankel H, Gardner B, Nuseibeh I. Factors associated with acute and chronic pain following traumatic spinal cord injuries. *Spinal Cord* 1997; **35**: 814–817.
- 56 Putzke JD, Richards JS, Dowler RN. The impact of pain in spinal cord injury: a case-control study. *Rehabil Psychol* 2000; **45**: 386–401.
- 57 Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Interference due to pain following spinal cord injury: important predictors and impact on quality of life. *Pain* 2002; **100**: 231–242.
- 58 White MJ, Rintala DH, Hart KA, Fuhrer MJ. Sexual activities, concerns and interests of women with spinal cord injury living in the community. *Am J Phys Med Rehabil* 1993; **72**: 372–378.
- 59 Creek G, Moore N, Oliver V, Silver J, Zarb G. *Personal and Social Implications of Spinal Cord Injury*. Thames Polytechnic: London 1998.
- 60 Lazarus RS, Folkman S. *Stress, Appraisal and Coping*. Springer: New York 1994.
- 61 Vitaliano PP, DeWolfe DJ, Maiuro RD, Russo J, Katon W. Appraised changeability of a stressor as a modifier of the relationship between coping and depression: a test of the hypothesis of fit. *J Personality Soc Psychol* 1990; **59**: 582–592.
- 62 Endler NS, Parker JD. Multi-dimensional assessment of coping. A critical evaluation. *J Personality Soc Psychol* 1990; **58**: 844–854.
- 63 Schulz R, Decker S. Long-term adjustment to physical disability: the role of social support, perceived control, and self-blame. *J Personality Soc Psychol* 1985; **48**: 1162–1172.
- 64 Hall KM, Cohen ME, Wright J, Call M, Werner P. Characteristics of the functional independence measure in traumatic spinal cord injury. *Arch Phys Med Rehabil* 1999; **80**: 1471–1476.
- 65 Lude-Sigrist Y. Querschnittlähmung: Der Verarbeitungssprozess bei Angehörigen bzw. Nahen Bezugspersonen. Ergebnisse einer Längsschnitt- und einer Querschnitt-Studie. (Spinal cord injury: the adjustment process of relatives and close persons. Results of a cross-sectional and longitudinal study). University of Bern, Unpublished Dissertation. 2002.
- 66 Kreuter M, Sullivan M, Dahllöf AG, Siösteen A. Partner relationships, functioning, mood, & global quality of life in persons with spinal cord injury and traumatic brain injury. *Spinal Cord* 1998; **36**: 252–261.