

ORIGINAL ARTICLE

A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months

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Study design: Multi-centre, single cohort.

Objectives: To assess the needs, perceived environmental barriers, level of participation and psychological function of spinal cord injured patients living in the community 3–18 months after discharge.

Setting: The National Spinal Injuries Centre, Stoke Mandeville, UK.; Princess Royal Spinal Injuries Centre, Sheffield UK.; Midlands Centre for Spinal Injuries, Oswestry, UK.

Method: Participants sustaining injury aged 18 or above were recruited from one of three spinal cord injuries units 3–18 months after discharge. Postal packs containing questionnaires, consent forms and information were distributed and a 2-week reminder was sent.

Results: Main findings showed community needs to be generally well addressed however psychosocial needs were rated significantly lower than physical. Responses suggested no environmental impact on participation levels, however, qualitative data highlighted delays in accommodation, adaptations and availability of equipment to interfere with transition to community living. A substantial amount of respondents reported significant impact on independence and activity from secondary conditions and pain. Nearly all the sample reported dissatisfaction with their sexual life and these needs were not well addressed.

Conclusions: Societal participation continues to be affected by secondary conditions and pain, whereas delays in equipment and structural adaptations impact on the transition to community living. Sexual needs and problems remain an issue for the spinal cord injured population and a need which is left unaddressed in the community.

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Introduction

Kennedy *et al.*¹ recognize the fundamental goal of rehabilitation as being one of societal participation; however, the literature suggests that unaddressed needs in the community continue to impact on this aim. If community reintegration is considered to be the major aim of outpatient rehabilitation, the extent to which individuals with disabilities lack integration into important aspects of life can be considered to constitute a need. Therefore, measuring peoples' level of community integration and the barriers that prevent integration can be used to identify community needs.

Wheelchairs have been reported as being the most frequently stated barrier to participation, preceding the actual physical impairment,² highlighting the need for high-quality wheelchairs to provide as little restriction as possible to facilitate participation.

Other environmental barriers such as transport may prevent community participation³ although Richards *et al.*⁴ report environmental access to be positively associated with satisfaction.

Secondary complications are found to negatively impact quality of life.⁵ Chronic pain is also widely experienced among the population with spinal cord injury (SCI). Kennedy *et al.*⁶ found that 25–45% of people with SCI experience persistent pain. In one study 27% of the 86% of participants who reported pain found it to negatively impact on activity participation^{7,8} and have a negative impact on psychological affect and activities in daily living.

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This indicates a need to target pain in early rehabilitation and again after discharge when residing in the community.

It is essential to reduce secondary complications where possible because they have been found to pose serious physical and psychological barriers to community participation.⁹

Sexual function has also been recognized as an area that has not been sufficiently addressed¹ and most likely due to the sensitive nature of the subject.

Bowel and bladder accidents, altered body image, concerns about autonomic dysreflexia, pain and spasms have been identified as factors that may prevent patients from pursuing a physical relationship.

A further area of need has been found to be employment and leisure participation. In Tasiemski *et al.*¹⁰ sport participation and employment declined after injury due to reduced access to facilities, whereas in a separate study work and leisure time was found to reduce by 40% compared to pre-injury status.¹¹

Access to employment has been recognized as particularly weak within the community for people with SCI. Furthermore, outpatients report a lack of informational support for them to pursue a specific job they had re-trained for and were provided with information for a more 'suitable' placement. This information highlights a discrepancy between what the individual wishes and service objectives.

Suicide within the SCI population is 2–6 times more prevalent than the general population¹² with high levels of depression.¹³ The importance of assessing psychological well-being within the community is essential to minimizing clinical disorder.

The literature indicates there are needs that still require attention. The purpose of the proposed study is to investigate the community needs of people with SCIs in the first 18 months after discharge.

The study aims to identify key areas in which needs are not being met, to highlight disparities in rehabilitation service provision and environmental barriers impacting on the individual's community participation.

Methods

Participants were recruited 3–18 months following discharge from one of three centres (National Spinal Injuries Centre, Princess Royal Spinal Injuries Centre and Midlands Centre for Spinal Injuries). Inclusion criteria were that their injury had been sustained aged 18 or above and medical clearance had been obtained from their consultant.

Postal packages containing questionnaire booklets, consent forms and information letters were sent; a reminder letter was sent after 2 weeks.

Measures

In addition to demographics questions and open-ended questions regarding rehabilitation, the following measures were included within the questionnaire booklet:

*Functional Independence Measure:*¹⁴ a self-administered scale to examine level of independence in activities of daily living. Each domain is scored on a Likert-type scale ranging from 1

(total assistance) to 7 (total independence). It has been validated for use within the SCI population.¹

*Hospital Anxiety and Depression Scale:*¹⁵ a self-administered, 14-item scale to assess depression and anxiety state levels. It has widely been used within the SCI population.

*Craig Hospital Inventory of Environmental Factors (CHIEF-SF):*¹⁶ 25 environmental barriers measured on a Likert-type scale according to frequency (0 = daily, 4 = never) and size of problem. Overall impact is measured by the sum of these measures.

*Craig Handicap and Assessment Reporting Technique (CHART):*¹⁷ used as an objective measure of participation for people with physical disabilities in six areas: physical independence, cognitive independence, social integration, mobility, occupation and economic self-sufficiency. The highest score is 100, which suggests a level of participation similar to that of a non-disabled person (used within the SCI population).

Pain Numerical Rating Scale: ratings of pain 'in the last 24 hours', 'at its worst this week', 'at its least this week' on a 10-point scale. Total impact of pain expressed as sum of three subscales.

*Life Satisfaction Questionnaire:*¹⁸ a scale examining satisfaction in nine life domains. Responses range from dissatisfying (1) to very satisfying (6).

Current Needs Assessment: the needs were extracted from the current needs checklist in Kennedy *et al.*¹ Items scored according to whether need is considered to be addressed (1 = fully, 5 = not at all). Scores were recoded in reverse order before analysis.

*Secondary Complication Screening Instrument:*¹⁹ frequency and impact of secondary problems on independent activity is measured on a Likert-type scale ranging from 0 to 3, items were selected as those that were most relevant to the SCI population.

*Female Sexual Function Index:*²⁰ a self-administered scale used to assess female sexual function. The subscale of 'satisfaction' will be used for the purpose of this study, and has been validated for use in male samples.

Open questions (researcher developed): These questions were compiled based on certain areas highlighted in the literature and designed for the purpose of identifying more specific problems with service delivery that may impact community reintegration. For example, questions were asked about availability of resources, delays in receiving resources, what makes a difference to quality of life and what services would the individual like more access to. Responses to open-ended questions were categorized in to commonly occurring themes. Percentages for each theme were calculated from the total number of responses to each question.

All three centres were involved in data collection, and analysis was conducted at the NSIC, Stoke Mandeville Hospital using SPSS (SPSS Inc., Chicago, IL, USA) for Windows. Data were dealt with in accordance to ethical guidelines and data protection laws.

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Results

Mean age was 50.37 years, a range of 18–81 and a ratio of 2:1 men/women. A total of 32% (26) of the respondents were employed at time of study with a further 7.6% actively seeking employment. Injury characteristics were as follows: 8 participants (10%) had complete tetraplegia, 23 (29%) had incomplete tetraplegia, 17 (21%) had complete paraplegia, 23 (29%) had incomplete paraplegia and 9 (11%) did not know their injury type.

Functional Independence Measure

Participants rated their level of independence on a seven-point Likert scale ranging from 1 (total assistance) to 7 (total independence). As 13 items corresponded to motor function and 5 to cognitive, total scores for each subsection were recoded to remain on a seven-point scale. Mean motor independence was 67.16 (recoded to 5 'modified dependence') whereas mean cognitive independence was 33.14 (recoded to 7 'completely independent'). Non-parametric analysis found a significantly higher level of independence in the cognitive ($M=6.74$, $s.d.=0.96$) domain than motor ($M=5.54$, $s.d.=1.92$), $Z=-4.392$, $P<0.00$.

Hospital anxiety and depression scores

Mean anxiety score was 6.12 ($s.d.=4.43$), mean depression score was 6.30 ($s.d.=4.14$), meaning the majority of the sample were classified under 'non-clinical' levels.

The researchers were interested in whether there would be a gender difference in this area. A Mann-Whitney U-test revealed women to have significantly higher anxiety scores than men ($U=491$, $N_1=54$, $N_2=27$, $P=0.017$). No significant gender difference was found on depression scores.

Craig Hospital Inventory of Environmental Factors

The overall impact of environmental barrier is calculated by the product of occurrence frequency and degree of problem. With a maximum impact of 8, mean score in Attitudes and Support was 0.51 ($s.d.=1.14$), Services and Assistance 1.44 ($s.d.=1.85$), Physical and Structural 2.24 ($s.d.=2.27$), Policies 0.86 ($s.d.=1.76$), and Work and School 0.18 ($s.d.=0.56$). The results would suggest that in this sample environmental barriers do not appear to have a large impact on activities.

Craig Handicap and Assessment Reporting Technique

The CHART can be divided into six subsections each with an optimum score of 100.

Mean score for Physical Independence was 91.05 ($s.d.=10.69$), Mobility 78.12 ($s.d.=24.34$), Occupation 56.05 ($s.d.=36.57$), Social Integration 86.82 ($s.d.=25.42$), Economic Self-Sufficiency 77.66 ($s.d.=31.48$) and Cognitive Independence 65.97 ($s.d.=31.10$).

Notably, 51.9% of participants were found to score the maximum score of 100 in the Social Integration domain, and on removing retired aged adults from analysis, mean scores for Occupation were taken to 64.17 ($s.d.=35.58$).

The research team were interested to look at whether injury type had an impact on participation levels. Kruskal-Wallis analysis revealed a significant effect of level of injury

on Physical Independence ($\chi^2=8.37$, $d.f.=3$, $P=0.039$). The CHART total mean scores were 336.89 for participants with a cervical level of injury, 411.29 for those injured at the thoracic region and 429.29 for those injured at the lumbar region. A Kruskal-Wallis test revealed a significant main effect of level of injury for CHART total scores ($\chi^2=8.54$, $d.f.=2$, $P=0.01$).

Pain

On a scale of 0–10, mean pain in the last 24 h was 3.28 ($s.d.=2.78$), pain at its worst in the last week 3.83 ($s.d.=3.06$), and 3.53 ($s.d.=2.76$) for average pain unpleasantness in the past 24 h. 48 participants (59.3%) scored below 10 on total pain scores, 19 participants (23.4%) scored between 11 and 20, and 14 (17.3%) scored in the higher end of the scale. Responses are shown in Figure 1.

Life Satisfaction Questionnaire

Ratings of satisfaction in nine areas of life on a five-point scale were recoded into 'Satisfied' or 'Dissatisfied' as indicated in Fugl-Meyer *et al.*¹⁸ As Figure 2 shows, in the

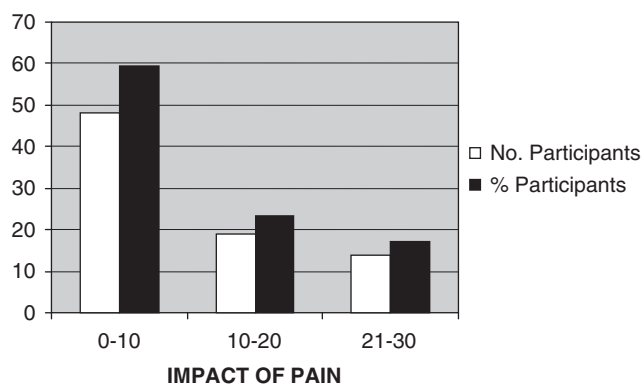


Figure 1 Responses to a measure of overall impact of pain on a scale of 0–30 expressed as number of respondents and percentages in groups.

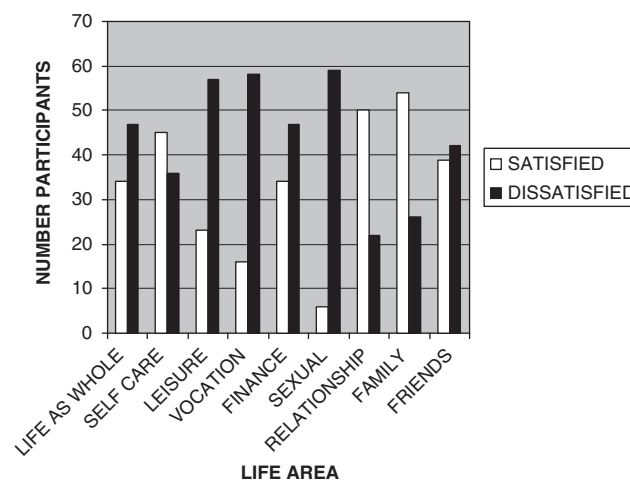


Figure 2 Number of participants expressing satisfaction/dissatisfaction in nine life domains.

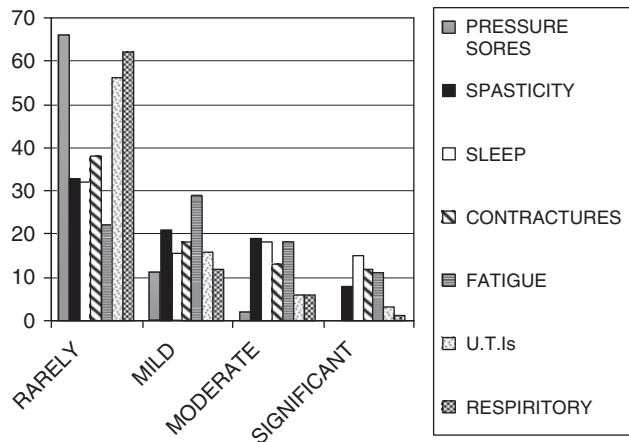


Figure 3 Frequency of impact on an individual's ability to carry out tasks independently as a result of secondary conditions.

areas of vocation, leisure and sexual life there is a large discrepancy between ratings of satisfaction, with the majority of respondents feeling dissatisfied with these areas of life.

Current needs

The mean recoded score for the current needs questionnaire was 4 'quite well addressed'. The individual needs questions were grouped according to 'physical' or 'psychosocial' domains. Wilcoxon analysis found a significantly lower level of addressed needs within the psychosocial areas than physical ($Z = -5.978$, $P < 0.00$).

Secondary conditions

Participants rated on a three-point scale the amount each of seven secondary conditions. As seen in Figure 3, the majority of participants had rare/mild impact of secondary conditions however there were a substantial proportion ($n = 50$) stating significant disruption due to the effects of secondary conditions.

Sexual satisfaction

On a scale ranging 0–6, sexual satisfaction was frequently rated as very low, the mean total sexual satisfaction score was 1.98. Analysis found no significant difference in rated sexual satisfaction between genders.

Qualitative findings

The majority of participants (67.9%) felt there were issues after discharge that made transition difficult, mostly due to accommodation and adaptations (29%), example responses included 'family home was not appropriate, I spent fourteen months in a care home before moving into a bungalow', Psychological/Social/Adjustment issues such as feeling 'abandoned and scared', 'anxiety and problems integrating' were experienced by 25% of respondents and Rehabilitation Services proved problematic for 22%, comments such as 'after six months of transition, services forget about you' and 'preparation for life at home was almost non existent' were included within this theme. Forty-nine per cent of respondents experienced a delay in acquiring the necessary

adaptations. The lack of resources making transition most difficult were, in order, adaptations (35%), equipment, (27%) and poor access (19%). In a question focusing on quality of life, the majority of participants felt independence to be a main factor (16%), some of the responses gathered were 'being able to live independently, in my own home and manage my own affairs', and 'being able to get out and about'. This was followed by relationships (14%), with 'family', 'wife', 'partner' and 'friends' frequently observed. Issues of participation were felt as being important in 13% of the responses, with 'Sport/Exercise' frequently mentioned alongside 'Employment', 'Outdoor opportunities' and 'Activities'. Results are summarized in Table 1.

Discussion

The main findings from this study show that within the current sample community needs were generally well addressed. However, there was a discrepancy between the number of psychosocial needs being met and those of physical. Answers given to open-ended questions highlighted delays in accommodation, adaptations and availability of equipment. A substantial amount of respondents reported significant impact on independence and activity from secondary conditions and pain, and nearly all the sample reported that they were dissatisfied with their sexual life and these needs were not well addressed. Clearly, there remain issues within the SCI population that may be targeted to improve the transition to community living and improve quality of life.

Results found that the majority of participants were generally psychologically well adjusted with non-clinical levels of anxiety and depression. The percentage of respondents exhibited clinical levels of anxiety were similar to a previous study however slightly elevated levels of depression in comparison. The higher levels of anxiety reported by women in this study and previous research suggest a susceptibility that should be regularly assessed through outpatient services to prevent clinical levels of anxiety impacting on rehabilitation in the community.

The overall impact of environmental barriers was found to be relatively low. Highest levels were aspects of the physical environment and transportation and support previous research.²¹ Of concern is the range of responses in this area, with some participants indicating the largest scores in some domains. This is clearly an area that requires close observation due to its relationship with life satisfaction, and the results obtained from open-ended questions showed that transition to community living had been made difficult due to problems with environmental issues. It is important to acknowledge these problems and establish why they continue to occur. It may be that clearer communication is required between services, departments and funding bodies, and equipment ordered at an earlier time point. Patients should be in receipt of comprehensive information regarding equipment and supplies before they are discharged, and where possible given details of timescales for any adaptations that take place. Not only will this communication aid the

Table 1 Percentages of qualitative response themes to open-ended questions concerning transition to the community and quality of life

<i>Response theme</i>	<i>Q1. What problems were experienced that made transition to difficult?</i>	<i>Q2. What could be a focus of rehab in order to make transition easier?</i>	<i>Q3. What resources were you lacking that made transition difficult?</i>	<i>Q4. What makes a difference to your quality of life?</i>
Community and rehabilitation	22%	46%	13%	6%
Psychological and social	31%	13%		37%
Accommodation and access	29%	8%	54%	19%
Secondary complications	10%			6%
Equipment	5%	2%	33%	10%
Employment	3%			
Physiotherapy		31%		6%
Relationships				14%

discharge process but also give the individual a sense of empowerment and improve psychological well-being. Clearly, such changes would be advantageous to community transition and prevent problems impacting on levels of participation and rehabilitation.

As identified in the results of the CHART measurement, this sample of spinal cord injured people was found to be participating well, with 51.9% of respondents achieving the same level of Social Integration as one without a disability, and with 43% of respondents scoring the maximum on measures of Economic Self-Sufficiency.

Low levels of CHART Cognitive Independence and Occupation were found, with Occupation also being identified as an area with low satisfaction. However, the sample contained a large proportion of retired participants (31%), which may have impacted on these results. The high levels of economic self-sufficiency found may be an explanation for low occupational participation—if an individual is in receipt of sufficient funds this may discourage them from seeking alternate income.

The mean rating of current needs was that they were 'Quite Well Addressed'; however the research identified a significant difference between the degrees of need addressed in physical areas and psychosocial areas. Areas that reported most dissatisfaction were Sexual Issues, Community Services, Employment and Recreation, which support previous findings finding employment and sexual activity to be rated as 'least well addressed' across four European countries.¹ As such, although SCI patients are entering the community with physical needs addressed and with the skills to adjust to their injury, psychosocial issues remain lacking. A large amount of evidence suggests that employment and social interaction are important to successful adjustment. Ongoing employment clinics and links to voluntary organizations may be potential services offered to the SCI population in the community, alongside giving patients more information on where to get accessible recreation activities after discharge.

Low scores were generally reported for secondary complications, which was unexpected due to a high prevalence of complications reported in the SCI literature. The above findings may be attributable to the relatively early stages of discharge and the more regular follow-up appointments during this stage. Sleep problems, spasticity and contractures were reported by many to be impacting on their ability to carry out activities independently and may be a focus of

attention for outpatient services, for example regular medication reviews.

Similarly, low average pain scores were reported, which is contrary to the SCI literature. However, despite the average score being relatively low, frequencies revealed that 17% of participants were experiencing pain 'as bad as one can imagine'. Due to the relationship between pain and quality of life and the negative impact on participation,^{7,10} it is essential that pain is addressed for people living in the community and that they should have regular reviews of pain management and medication.

The majority of participants reported the lowest sexual satisfaction score possible. It has been previously highlighted as an area of need in this population and the results from this scale relate to the dissatisfaction expressed in the current needs domain. This scale also reflected responses when measuring secondary complications and Functional Independence, supporting the view that physical barriers present problems for people with SCI to engage in sexual activity. Many patients would not feel comfortable seeking advice or openly discussing sexual dysfunction, despite it impacting on psychological well-being. Education and information on this matter may be better translated through booklets. Alternatively, approved Internet accessible pages and peer group support may be more favoured than addressing issues with clinical team members.

The results of this study are promising, and have clear clinical implications in the focus of community rehabilitation. Although in this study needs were found to be generally well addressed, the results reiterate the importance of sexuality in overall levels of satisfaction and the necessity in addressing such issues during rehabilitation. The current study investigated a large number of factors potentially impacting on participation levels and as such necessitated the use of many measures. Although this may have resulted in respondent fatigue studies such as this, wider research into the quality and patient satisfaction in community residence would be beneficial to the process of reintegration and participation.

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