

Original Article

Survey of the needs of patients with spinal cord injury: impact and priority for improvement in hand function in tetraplegics

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Objective: To investigate the impact of upper extremity deficit in subjects with tetraplegia.

Setting: The United Kingdom and The Netherlands.

Study design: Survey among the members of the Dutch and UK Spinal Cord Injury (SCI) Associations.

Main outcome parameter: Indication of expected improvement in quality of life (QOL) on a 5-point scale in relation to improvement in hand function and seven other SCI-related impairments.

Results: In all, 565 subjects with tetraplegia returned the questionnaire (overall response of 42%). Results in the Dutch and the UK group were comparable. A total of 77% of the tetraplegics expected an important or very important improvement in QOL if their hand function improved. This is comparable to their expectations with regard to improvement in bladder and bowel function. All other items were scored lower.

Conclusion: This is the first study in which the impact of upper extremity impairment has been assessed in a large sample of tetraplegic subjects and compared to other SCI-related impairments that have a major impact on the life of subjects with SCI. The present study indicates a high impact as well as a high priority for improvement in hand function in tetraplegics.

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Keywords: tetraplegia; hand function; quality of life; need assessment

Introduction

Patients with spinal cord injury (SCI) above level Th1 suffer from impairments of the upper extremities.

The level and the extent of the lesion have great impact on the level of independence of the patient.^{1,2} In this respect, therapy of the upper extremities in tetraplegics is of paramount importance. According to Murphy and Chuinard,³ this therapy can be divided into three phases: the acute, the subacute and the reconstructive phase. The aim in the first two phases (together referred to as the initial phase) is to prevent complications, to achieve optimal functioning within the limits of the neurological deficit and to create optimal conditions for the reconstructive phase.^{4–7} In the latter phase, various options for surgical and functional electrical stimulation (FES) are available to improve positioning and stabilisation of the arm as well as key and palmar

grasp function.^{8–12} Implanted FES devices are usually combined with augmentative and substitutional reconstructive surgery.¹³

According to Moberg,¹⁴ over 60% of the tetraplegic population could benefit from reconstructive surgery. Gorman *et al*¹⁵ deduced that 11% of the tetraplegic population could be candidates for an implanted FES device (Freehand system). Reconstructive surgery is widely advocated, and a number of papers that have been published describe its technical aspects and functional benefits. However, the benefits have not been clarified with good-quality randomised clinical trials.¹⁶ In a recent paper, Peckham *et al*¹² described the results of the Freehand system in a study of 51 subjects with C5 and C6 lesions with a follow-up of at least 3 years. Compared to nonuse of the system by these subjects pinch force, grasp abilities and independence increased significantly and user satisfaction was high. Although the number of treatment options has increased in recent decades, clinical practice has shown that suitable

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candidates for reconstructive surgery or FES interventions often do not accept the treatment that is offered.

This led to debate about the importance of improvement in arm and hand function for the tetraplegic patient, compared to the other needs that they experience. Need assessment is gaining increasing interest as an important instrument in the development of treatment modalities and services. With regard to health care, needs are defined as the ability to benefit in some way from health care.¹⁷ This depends on the number of people affected and the effectiveness of the available services. In addition to health-care needs, other categories of needs can be distinguished and could be taken into account in the assessment of needs, such as personal and social care, accommodation, finance, education, employment and leisure.

Two studies were identified in which impairment of the upper extremities in patients with tetraplegia was assessed in terms of the importance of treatment or needs to be addressed. In 1976, Hanson and Franklin¹⁸ studied the importance of loss of sexual function, compared to three other impairments in patients with SCI. They included 74 tetraplegic men from two Veteran Administration SCI centres with functional complete injuries (distribution of SCI levels was not described). Their mean age was 37 years, and the time since injury varied from less than 1 month to over 20 years. The subjects were shown cards on which was written: normal use of legs, normal control of bladder and bowel, normal feeling and use of sexual organs, and normal use of hands. The subjects were asked to rank the items in terms of importance on a scale ranging from 1 to 4. Of these subjects, 75.7% gave the highest priority to upper extremity function. The mean scores were 1.31 for improvement in hand function improvement, 2.50 for improvement in bladder and bowel function, 2.65 for use of legs and 3.54 for improvement in sexual function. This study is cited when the importance of hand function and reconstructive surgery for tetraplegics is discussed.^{19,20} Ranking is a valuable method of assessment, but it does not provide information about the relative importance of improvement in hand function, compared to improvement in the other items. In contrast to other studies, in which upper extremity function was not included, reported high ratings for these impairments (eg bladder and bowel function, inability to walk and sexual dysfunction) in relation to the perceived difficulty of dealing with the consequences of SCI.²¹ Unfortunately, their study population was relatively small, the subjects were recruited from two centres, and their needs were not assessed per level of lesion.

Cox *et al*²² described the need for an outreach service for people with SCI living in the community in Queensland, Australia. In this study, 54 subjects who were representative of the SCI population in Queensland were asked to rate the current level of need for 29 different items on a 5-point scale (no need, minimal need, some need, high need and very high need). Their results showed that only 17% indicated some need, high

need or very high need for hand function/splinting therapy. In all, 16 items had higher scores, four of which addressed physical impairments (physical changes, spasm, pain and sexuality). This study addressed a large number of topics, covering all the categories of needs mentioned by Kersten *et al*.¹⁷ The results indicate, in contrast to those reported by Hanson and Franklin,¹⁸ a lower importance or less need for improvement of hand function. However, only 54 subjects were included in the study, 30 were tetraplegics whose data were not analysed separately. Although a number of studies have reported on the impact of SCI on the lives of individuals (see references 1–12 of the study carried out by Cox *et al*²²), information about the impact of hand function deficit in individuals with tetraplegia is sparse. For this reason, the present study was carried out, and the aim was to include a large sample of tetraplegic subjects for a nation-wide survey in two countries. The importance of improvement in hand function, compared to seven other SCI-related impairments was investigated for the entire sample, as well as for separate levels of lesion.

Method

Survey design

In the present study, use was made of the database of a survey that was carried out as a part of the EU project Clinical Rehabilitation Using Electrical Stimulation Via Telematics (CREST).²³

The aim of the CREST project was to develop an FES system for incomplete paraplegics with marginal walking abilities. As part of the CREST project, a questionnaire was developed to assess the mobility needs in the target population for the CREST system. In addition to providing data on the mobility needs of SCI subjects with marginal walking abilities, the results of the survey also provided valuable information about other SCI-related problems, and these were used in the present study.

The CREST questionnaire was comprised of four sections, two of which were used in the present study (sections A and D). Section A contained questions about the respondent (eg age, gender, time since injury) and questions directed at classification of the level of lesion (eg paraplegia or tetraplegia, involvement of upper extremities, level of lesion, movement and/or sensation below the level of lesion). Section D addressed the needs and expectations of the subjects with regard to various aspects of SCI. The first question in this section focussed on coping with various impairments. The subjects were asked to indicate how well they felt they could cope with six impairments on a 5-point Likert scale. In the second question, the subjects were asked to indicate the importance of a variety of impairments and disabilities in terms of improvement in quality of life (QOL) on a 5-point scale. See Table 1 for detailed information about section D.

Table 1 Topics addressed in section D of the questionnaire

<i>Section D question 1</i>	<i>Section D question 2</i>
How well do you think you are able to cope with the items listed below:	In terms of QOL, how important would improvement of the following items be for you:
Very well – well – adequately – poorly – very poorly	Very important – important – moderately important – not very important – unnecessary
Bowel management	Bowel management
Bladder management	Bladder management
Sexual function	Sexual function
Management of spasm	Management of spasm
Prevention of pressure sores	Prevention of pressure sores
Management of pain	Management of pain
	Hand function
	Standing time

Question 2 contained 13 other items concerning standing and walking related to the objectives of the project: Clinical Rehabilitation Using Electrical Stimulation via Telematics (CREST). These topics are not specified, as they are not of interest in the present study

Sample and execution of survey

The questionnaire was distributed among the SCI populations in the Netherlands and the United Kingdom via the SCI associations. All registered members were contacted by means of a letter explaining the purpose of the study, and enclosing the questionnaire and a prepaid reply envelope to maximise response rate. No reminders were sent.

Data analysis

The percentages of paraplegic and tetraplegic subjects in the Dutch and UK groups were calculated by combining the answers to the questions in section A about a paraplegia or tetraplegia, level of lesion and the involvement of the upper extremities. The subjects were defined as paraplegic if they stated that they were paraplegic and also gave a negative reply to the question about impairment of the upper extremities. The subjects were defined as tetraplegic if their answers concerning two or three of the following items were positive: tetraplegia, a cervical level of lesion and impairment of the upper extremities.

First, the Dutch and the UK paraplegic and tetraplegic subgroups were analysed. An impairment was considered to be important with regard to QOL if the subjects rating was either important or very important for the specific impairment in question 2 (Table 1). The percentages of subjects with these ratings was calculated for the Dutch and the UK paraplegic and tetraplegic subgroup separately. Subsequently, the scores per level

of lesion were analysed for the items that were also investigated earlier by Hanson and Franklin,¹⁸ that is, hand function, management of bladder and bowel function, feeling and function of sexual organs, and use of legs. In the CREST survey, 14 different standing and walking qualities were assessed. In the present study, the standing and walking item with the highest score in the tetraplegic group was included, that is, improvement in standing. The percentage of subjects per level of lesion who indicated a (very) important improvement in QOL in relation to improvement in the impairments was calculated.

For all percentages, 95% confidence intervals were determined.

Results

The overall response was 42%; 426 of the 700 Dutch questionnaires (response of 61%) and 1122 of the 4800 UK questionnaires (response of 23%) were returned.

In 23 subjects in the Dutch group and in 50 subjects in the UK group, it was not possible to determine the level of the lesion, and the data from these questionnaires were therefore not included in the analysis.

The demographic data for this sample of the SCI population are presented in Table 2.

Figure 1 shows for the Dutch and UK paraplegic and tetraplegic groups the percentage of subjects who expected an important or very important improvement in QOL related to a possible improvement in different SCI-related impairments and disabilities. In addition

Table 2 Population of CREST survey, divided into Dutch and UK populations

	<i>Number</i>	<i>Female</i>	<i>Male</i>	<i>Mean time since injury (years)</i>	<i>Mean age (years)</i>
Dutch paraplegics	269	98 (36%)	171 (64%)	12.2 (SD 9.9)	45 (SD14)
Dutch tetraplegics	134	42 (31%)	92 (69%)	13.9 (SD10.4)	43 (SD 13)
UK paraplegics	641	206 (32%)	435 (68%)	15.9 (SD 12.2)	42.1 (SD 14)
UK tetraplegics	431	109 (25%)	322 (75%)	15.8 (SD 11)	43.1 (SD 11)

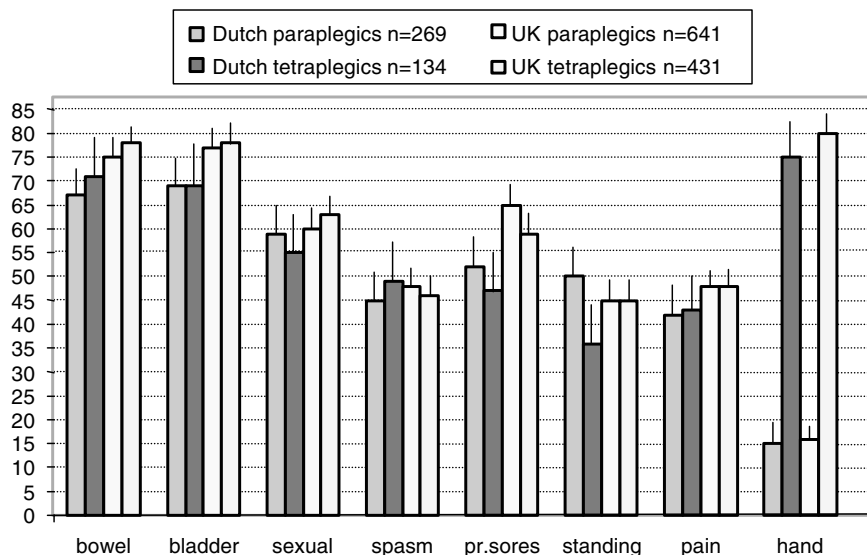


Figure 1 Y-axis shows the percentage and 95% confidence intervals of subjects in the Dutch and UK paraplegic and tetraplegic subgroups who expected an important or very important improvement in QOL if the impairments on the X-axis improved. (eg 80% of the UK tetraplegics expected an important or very important improvement in QOL if hand function improved)

to a high rating for improvement in bowel and bladder management, the tetraplegic population also indicated that the improvement in hand function was equally important.

The results per level of lesion are shown in Figure 2. Especially in the C4, C5 and C6 groups and the C7 UK group, the improvement in hand function is important for the subjects, and comparable to improvement in bladder and bowel function. In the other groups, the number of subjects was too small to draw statistically valid conclusions (wide range of 95% confidence intervals).

Discussion

One of the most devastating aspects of an SCI at cervical level is the impairment of arm and hand function, and this has great impact on the level of independence. So far, only two studies on the impact of SCI-related impairments and the needs of SCI patients have included upper extremity dysfunction.^{18,22} Limitations of these studies are the relatively small size of the study population, a small number of other impairments or disabilities that were assessed, and the absence of either separate analysis of tetraplegics or analysis per level of lesion. As treatment modalities have been developed in order to restore some function of the upper extremities, it is important that the impact of upper extremity deficit on the lives of tetraplegic subjects is quantified, and that an awareness of the needs of these patients is generated. This was therefore the objective of the present study.

Exact comparison of our data with epidemiological data on SCI is difficult, because there are great methodological differences between the various epidemiological studies. Furthermore, because patients do not always know the exact level of lesion or confuse the

level of lesion with the level of the fractured vertebra, the results per level of lesion must be interpreted with this in mind. In general, the demographic data of the present study population and the distribution of the levels of lesion are comparable to those reported in various epidemiological studies.^{24,25} Given the large sample size, response rate and apparently representative percentage of tetraplegics in the present study, it is arguable that the sample covers the spectrum of cervical SCI. Cox *et al*²² claim that their study population is representative of the SCI population in Queensland. However, they studied only 30 tetraplegic patients who were not analysed separately. Hanson and Franklin¹⁸ do not report on the representativeness of their sample, and they only recruited subjects from two centres.

The first impression is that our results are remarkably comparable to the results reported by Hanson and Franklin.¹⁸ In their study, 75% of the tetraplegic subjects ranked improvement in hand function as most important out of four possibilities. In the present study, 75% of the Dutch tetraplegic population and 80% of the UK population of the CREST survey indicated that an important to very important improvement in the quality of their lives was related to an improvement in hand function.

Cox *et al*²² reported lower scores for hand function in relation to the scores for other physical impairments, compared to the present findings. However, exact comparison is compromised by the fact that the size of their study population was substantially smaller, and only 30 subjects were tetraplegic. Moreover, they did not analyse the tetraplegic subjects separately.

Cox *et al*²² also described the issues most commonly reported in the literature as having an impact on the QOL of SCI patients: pain, spasticity, pressure sores, mobility impairments, bladder management, finances,

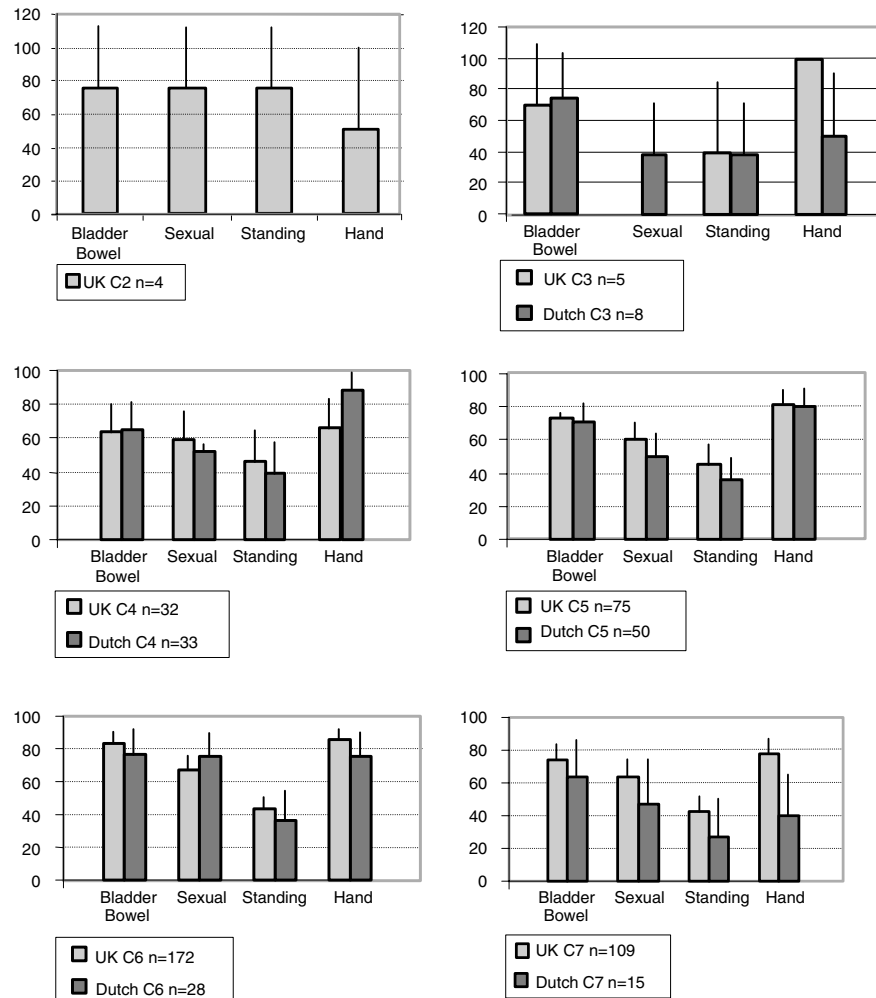


Figure 2 Y-axis shows the percentage and 95% confidence intervals of subjects indicating a (very) important improvement in QOL if the impairment on the X-axis improved

transportation, equipment, accessible housing, sexual function and employment. All the physical aspects were also included in the present study and compared to hand function deficit.

In general, the outcomes in the Dutch and UK tetraplegic populations were comparable. In the scores per level of lesion there was a difference in the C3, C4 and C7 groups. The C4 group had a higher score for improvement in hand function in the Dutch group, compared with the UK group. The scores on the other items in the C4 group were comparable.

The scores in the Dutch C3 and C7 groups indicated a lower priority for improvement in hand function. Scope for improvement in hand function is limited by poor upper limb control in the very-high-level tetraplegics (C3 and higher). Lower-level tetraplegics (C7 and below) can be fully ADL independent with limited hand function. However, this finding is not reflected in the UK data. The small number of subjects in the C3 group and the Dutch C7 group makes it impossible to draw statistically valid inferences from these data.

In summary, the present study indicates a high priority for improvement in hand function, compared to other impairments in tetraplegic subjects.

Reconstructive interventions may be of benefit to patients who fulfil specific criteria. However, it is clear that eligible patients do not always wish to have this treatment. The apparent poor uptake of reconstructive options for restoring upper limb function is beyond the scope of this study. In this respect, some remarks can be made about the method used to assess preference, as well as the multidimensional aspects of the evaluation of health states and the utilisation of health-care services.

Preferences for health outcomes can be established in several ways. In nonchoice-based methods that are not based on choice, that is, those used in the present study as well as in the studies carried out by Hanson and Franklin¹⁸ and Cox *et al*,²² use is made of rating, ranking or visual analogue scales. The advantage of these methods is that they are relatively easy to use. However, there are some theoretical drawbacks. Ranking makes it difficult to compare the weight of preference

for the various items, because there may be a very small, in fact clinically unimportant, difference between the items, which is not revealed. This is illustrated by the fact that in contrast to the findings of Hanson and Franklin,¹⁸ other studies have indicated that bowel and bladder dysfunction is one of the most disabling factors of SCI. In the present study, as well as in the study carried out by Cox *et al*,²² the items were separately scored on a 5-point scale. By offering the subjects a list containing all the items, there may have been some implicit ranking, but this remains uncertain. More importantly, a positive response has no negative consequences, which may result in positive answer bias. In methods to assess preference that involve no actual choice, no trade-off can be observed and exact comparison between the preferences assessed in this way is not possible. Therefore, choice-based methods to assess preference valuation are more appropriate to obtain a theory-based preference weight, because these methods actually involve a choice in terms of a trade-off between various possibilities.^{26–29} The valuation of health outcomes is complex because physical, psychological and social factors are involved, and the actual utilisation of health care depends on a great variety of factors.³⁰ Andersen³¹ describes a model that was used to assess the utilisation of health-care services, in which environmental factors, population characteristics, health behaviour and outcomes all play a role. In this respect, multicriteria decision analysis, taking all these factors into account, is needed to provide information about actual willingness to receive reconstructive interventions.^{26,28}

Finally, the main outcome parameter in the present study was the concept in improvement of QOL related to improvement in impairments. Although QOL is the primary aim of rehabilitative treatment, it is a very complex concept. The definition of QOL is multi-dimensional and in addition to health, many other aspects contribute to the QOL experienced by an individual, and should be taken into account in QOL assessment. Impairments are only one attribute of QOL, and are correlated less with QOL than level of activity and participation.^{32–34} These aspects must be kept in mind when interpreting the results of the present study. A high percentage of subjects indicating improvement in QOL if a certain impairment could be improved is an indication of the burden imposed by that specific impairment. However, actual improvement or cure of the impairment does not necessarily result an improvement in QOL.

Conclusion

The present study is the first study in which the impact of impairment in hand function has been assessed in a large sample of tetraplegic subjects. In addition, analysis was performed at the level of lesion and compared to other SCI-related impairments. This study is unique in its explicit assessment of the issues that are involved in living with consequences of SCI.

The results of the present study indicate a high impact and a high priority for improvement in hand function in tetraplegics, comparable to that for bladder and bowel dysfunction, which is known to have great impact on the lives of SCI patients.

This study is a first step in investigating the patient's perspective with regard to the potential for reconstructive interventions. Further research is needed to illuminate the decision-making process in patients who are contemplating participation in such reconstructive interventions.

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