

ORIGINAL ARTICLE

# Satisfaction with upper limb reconstructive surgery in individuals with tetraplegia: the development and reliability of a Swedish self-reported satisfaction questionnaire

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**Study design:** A questionnaire-based survey.

**Objectives:** To assess satisfaction after upper limb reconstructive surgery in individuals with tetraplegia and to determine the reliability of a Swedish satisfaction questionnaire.

**Setting:** A center for advanced reconstruction of extremities, Gothenburg, Sweden.

**Methods:** Seventy-eight individuals with tetraplegia were invited to participate in the survey assessing satisfaction with the result of surgery across various domains. Measures of reliability included stability and internal consistency of domains consisting questions regarding global satisfaction, activities and occupation/schooling.

**Results:** Fifty-eight individuals (76%) participated, among whom 47 (82%) completed the questionnaire twice for repeatability assessment. The responses in the domains relating to global satisfaction, activities and occupation/schooling were positive in 83%, 72% and 31% of participants, respectively. Ninety-five percent felt they had benefited from the surgery, and 86% felt that the surgery had made a positive impact on their life. The psychometric testing indicated that the questionnaire yields scores that are reliable by both test–retest and internal consistency, with the exception of the domain occupation/schooling that had a high prevalence of missing and neutral responses and seemingly represents separate and distinct entities.

**Conclusion:** Surgical rehabilitation of the upper limb in tetraplegia is highly beneficial and rewarding from a patient perspective, leading to satisfactory gains in activities of daily living as well as enhanced quality of life. The questionnaire is a reliable instrument for measuring satisfaction after surgery. However, occupationally and educationally related aspects of the surgical outcome should constitute separate domains, and further modifications of the questionnaire are thus recommended.

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## INTRODUCTION

Spinal cord injury (SCI) is considered one of the most devastating injuries to afflict the human body, and it is a significant global public health problem.<sup>1</sup> Full recovery from a complete SCI is exceedingly rare,<sup>2</sup> and the majority of injured people are disabled during the most productive periods of their lives. There are previous studies showing that restoration of arm and hand function is a high priority for individuals with tetraplegia,<sup>3–6</sup> judged to be most desirable to regain, before bowel, bladder, sexual function or walking ability.<sup>5,6</sup> Moreover, the majority of persons with tetraplegia expected enhanced quality of life, if their hand function could be improved.<sup>4</sup> Although a SCI remains incurable, reconstructive surgery is a powerful tool to restore upper-extremity functions and personal freedom, for example, the ability to groom, self-feed, self-catheterize, lift objects, write, swim, maneuver a wheelchair and drive a car.<sup>7</sup> Advanced reconstruction of grip in tetraplegic patients is shown to improve upper-extremity performance, as well as supplying an increased level of independence and control in life.<sup>8–12</sup> Significant

improvements in the basic activity of eating and more complex activities such as doing housework and taking part in leisure have also been shown.<sup>11</sup>

In tetraplegic patients, reconstructive surgery aims to restore elbow extension, pinch and/or palmar grips. The combination of triceps and grip reconstruction allows patients to effectively reach out to manipulate objects in space in front of them, as well as above their head. Tendon transfer is the most common traditional approach, in which the distal end of a functionally intact muscle is detached, rerouted and reattached to a nonworking muscle to replace its original function.<sup>7</sup> Recently, innovative concepts such as single-stage combined procedures have proven to offer considerable advantages over traditional approaches.<sup>7,13</sup>

The success or effectiveness of a surgical intervention must be judged by its ability to satisfy the patient in both the short and long term. Satisfaction is a broad concept that is measured in many different ways. Satisfaction can be defined as the extent of an individual's experience compared with his or her expectations.<sup>14</sup> It is

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an important but complex multidimensional concept measure of quality of care that contributes to a global evaluation of surgical and rehabilitative outcomes. It is a highly relevant outcome measure, especially as there is a well-documented discrepancy between clinician and patient ratings of health status.<sup>15</sup> Patients' expectations are shown to contribute to patient satisfaction, and there is evidence that the more satisfied the patients are, the more they tend to comply with treatment regimens.<sup>16</sup>

Although in Sweden, the functional gains after tendon transfer procedures have been clearly demonstrated, the knowledge about patient satisfaction after upper limb reconstructive surgery is insufficient. Patient satisfaction surveys are widely used in rehabilitative care, but there is a lack of a standard approach to measure satisfaction and there is a limited number of studies investigating satisfaction after reconstructive surgery in individuals with tetraplegia. There are only three previous studies that address this question. These studies conducted in the United States, the Netherlands and Denmark, examine the degree of satisfaction after reconstructive surgery in individuals with tetraplegia.<sup>17-19</sup> The studies show that between 70 and 76% of patients were satisfied with the outcome of surgery. However, the degree of satisfaction regarding the appearance and cosmesis of the hand after surgery was surprisingly low.<sup>17,19</sup> Nevertheless, the heterogeneity of subjects and the diversity in surgical procedures, the time elapsed since surgical intervention, as well as the routine protocol and evaluation methods used, make it difficult to draw overall conclusions about the degree of satisfaction. Thus, work remains to be done to ascertain whether surgical restoration of upper-extremity function can produce robust and satisfactory functional gains in individuals with tetraplegia. Investigating patient satisfaction would make an important contribution to determine whether reconstructive surgery in tetraplegic patients is successful in meeting its goals. Moreover, demonstrating the success in terms of patient satisfaction may potentially increase the number of patients referred for surgery both nationally and internationally.

Assessment of the psychometric properties is essential in the evaluation of complex psychological phenomena such as patient satisfaction. When there is no satisfactory standard against which to assess the validity of a measurement, as for the present satisfaction questionnaire, assessment of repeatability (test-retest) is said to be helpful.<sup>20</sup> Poor repeatability of a measure would indicate that the characteristic measured varies over time, or has poor validity.<sup>20</sup> As no translated version of the satisfaction questionnaire for surgical intervention in tetraplegia was available in Swedish, the translation process and cultural adaptation is described in the present study. As no formal assessment of the psychometric properties of the questionnaire has yet been described, an expert panel review and a reliability assessment was also included in order to ascertain face validity and test-retest reliability.

### Study aim

The aim of the present study was twofold. First, we aimed to describe the development and reliability of the Swedish tetraplegia surgery satisfaction measure to be used for patients after upper limb reconstructive surgery. Second, we aimed to evaluate satisfaction after upper limb reconstructive surgery in individuals with tetraplegia in a Swedish cohort. More specifically, we sought to determine the following: (1) overall satisfaction with the outcome of surgery; (2) subjective improvements in participants' abilities to carry out activities of daily living after surgery; (3) the general impact of surgery on occupational performance and education; (4) the appearance and cosmesis of the hand after surgery; and (5) possible differences in patient satisfaction after triceps- and hand/wrist surgery. Moreover, we

aimed to identify other perceived advantages as well as disadvantages regarding the intervention.

## MATERIALS AND METHODS

### Development of the Swedish tetraplegia surgery satisfaction questionnaire

A modified and translated version of the questionnaire developed by Wuolle *et al.*<sup>17</sup> was used in the present study. The questionnaire was reviewed and modified by a group of experts in the area of reconstructive surgery and tetraplegia. Based on the study by Focks-Feenstra *et al.*<sup>18</sup> showing that five items in the original version developed by Wuolle *et al.*<sup>17</sup> were unreliable, the following four questions were excluded from the Swedish version: (1) the surgery has made a negative impact on my life; (2) I use less adaptive equipment after my hand/arm surgery; (3) I spend more time out in the community alone after my hand/arm surgery; and (4) I perform activities more 'normally' after my hand/arm surgery. The statement regarding appearance and cosmesis of the hand was, however, retained as empirically, this aspect of the surgery has been shown to be of importance for patients. In order to adjust to Swedish conditions, the question regarding whether patients would pay for the surgery was also excluded.

In order to validate the accuracy of the translation, back translation was used. The original questionnaire was first translated into Swedish by a bilingual (English/Swedish) professional medical translator. As a result of disparities between certain languages such as equivalent terms that do not exist in both languages, a group of experts in the area of reconstructive surgery and tetraplegia discussed which disparities were merely a different way of expressing things in different languages, or whether any disagreement could be considered a translation error. A synthesis was formed, and the translation was slightly modified because of these circumstances. The questionnaire was then translated back into the source language by a second independent translator, without reference to the original document. The two source language versions were finally compared. After another careful review of the questionnaire, it was tested on five patients in order to assess the comprehensibility of the Swedish version. All tetraplegic patients correctly understood the questionnaire, and the final version was established.

Similar to the original version of the questionnaire, participants are asked to respond to statements on a five-point Likert scale ranging from 1 to 5 (that is, strongly disagree, disagree, neutral, agree and strongly agree).<sup>17</sup> Based on findings in the study by Fock-Feenstra *et al.*,<sup>18</sup> the first section of the questionnaire was divided into the following categories: (1) satisfaction, (2) activities and (3) occupation/schooling. The second section consists of one question about the appearance and cosmesis of the hand after the surgery, together with two questions about changes in the functional ability of participants after triceps- and hand/wrist surgery, respectively. In order to obtain an insight into activity gains, a third section contains questions where participants are asked to list activities in which function was improved after surgery. Similarly, a question was added where individuals are asked to report whether the surgery has complicated certain tasks. Two final questions were added where participants were asked to mention any other disadvantages with the surgery and to give general comments, if any.

### Study design, participants and procedure

A questionnaire-based survey was designed to assess satisfaction after upper limb reconstructive surgery in individuals with tetraplegia. The eligibility criterion was having undergone reconstructive surgery including at least one tendon transfer between the years 2005 and 2014. This timeframe was chosen to include similar standardized surgical interventions and rehabilitation protocols. A total of 78 individuals with tetraplegia who underwent surgery at Sahlgrenska University Hospital, Gothenburg, Sweden were identified and invited to participate. Selected individuals were sent a letter by mail containing information about the study, with the questionnaire and an informed consent form enclosed. They were asked to give written consent and to return the consent form by mail together with the completed questionnaire in self-addressed envelopes. Persons who did not respond were sent the questionnaire a second time. In order to assess the test-retest reliability of the satisfaction measure, study participants who returned the first questionnaire were sent the

questionnaire by mail a second time between 7 and 10 days after the first one had been received by mail. Participants' responses to the first questionnaire were used for the satisfaction survey. Ethics approval was granted by the Regional Ethical Review Board in Gothenburg, Sweden (ref number: 991-15), and the study was conducted in accordance with relevant ethical guidelines.

### Data analysis

Test-retest reliability was assessed using Spearman correlation coefficient. An often quoted rule of thumb for interpreting the size of a correlation coefficient is the following: 0.90–1.00—very high correlation; 0.70–0.90—high correlation; 0.50–0.70—moderate correlation; 0.30–0.50—low correlation; and 0.00–0.30—little if any correlation. In order to assess the hypothesis of zero bias, paired-samples *T*-test was used to calculate the mean difference in the scores between the two administrations, that is, any systematic bias in the test-retest assessments. The internal consistency among items in the categories, 'satisfaction', 'activity' and 'occupation/schooling' was calculated using Cronbach's alpha.<sup>21</sup> A commonly accepted rule of thumb for describing internal consistency is as follows:  $\alpha \geq 0.9$  = excellent;  $0.8 \leq \alpha < 0.9$  = good;  $0.7 \leq \alpha < 0.8$  = acceptable;  $0.6 \leq \alpha < 0.7$  = questionable;  $0.5 \leq \alpha < 0.6$  = poor; and  $\alpha < 0.5$  = unacceptable.<sup>22</sup>

Satisfaction data were analyzed by means of descriptive statistics. In order to enable calculations of the proportion of participants with positive responses in each of the categories, results were grouped into the following categories: 'positive' and 'negative' by merging the response alternatives 'strongly agree' with 'agree' and 'strongly disagree' with 'disagree'. The neutral response was analyzed as a separate category. Analyses were done using SPSS v.22.0 (IBM Corp., Armonk, NY, USA), and the confidence intervals (CIs) were calculated with the 'cronbach.alpha:CI' command of the R package 'cocron', R version 3.1.1 (R Foundation for Statistical Computing, Vienna, Austria). All tests were two-sided and with  $P < 0.05$  as a level of significance.

## RESULTS

### Study participants

Out of the 78 individuals selected for the study, one person had died. One questionnaire was returned because it could not be delivered. In total, 58 individuals (76%) with a mean age of 47 years (range = 23–78) chose to participate in the study. Of these, 15 were women (26%), with a mean age of 49 years (range 24–77) and 43 were men (74%), with a mean age of 46 years (range 23–78). The mean number of years elapsed since the surgery, the mean age at the time of surgery, as well as the cause of injury are presented in Table 1. The description of motor groups according to The International Classification for Surgery of the Hand in Tetraplegia<sup>23</sup> of the participants and information relating to the neurological level of the SCI was available for 49 and 46 participants, respectively, and is also presented in Table 1. A summary of all surgical procedures is presented in Table 2. Only frequent standard surgical procedures are included in this summary, and other miscellaneous procedures are not reported.

### Reliability assessment

Among the 58 participants, 47 (82%) completed the questionnaire twice for repeatability assessment. The average response time between survey 1 and 2 was 18.5 days (range 9–59 days). Table 3 presents the results of the Spearman correlation coefficients for the test-retest reliability assessments. Excellent correlation was found in the categories, satisfaction and activities, as well as for the question regarding functional improvement after hand or wrist surgery. Slightly lower test-retest correlations were found for the question regarding appearance/cosmesis and functional improvement after triceps reconstruction. The occupation/schooling test-retest scores had the lowest, albeit acceptable correlation. In order to assess the hypothesis that there was no systematic bias between the test-retest assessments, the mean difference in the category scores between the two administrations was

**Table 1 Demographics and clinical characteristics of the study population**

Demographics	Mean (s.d.)
Age at the time of surgery (years)	40.9 (13.8)
Time elapsed since surgery (years)	6.2 (2.9)
<i>Cause of injury</i>	N (%)
Transport activities	23 (40)
Sports and leisure activities	17 (29)
Falls	9 (16)
Other traumatic causes	6 (10)
Nontraumatic causes	3 (5)
<i>Level of injury (N = 46)</i>	N (%)
C5	9 (20)
C6	20 (43)
C7	14 (30)
C8	3 (7)

Group	Muscles, grade 4 or more (N = 49)	N (%)
0	No muscle below the elbow	
1	Brachioradialis	8 (16)
2	Extensor carpi radialis longus	13 (27)
3	Extensor carpi radialis brevis	4 (8)
4	Pronator teres	17 (35)
5	Flexor carpi radialis	3 (6)
6	Finger extensors	1 (2)
7	Thumb extensors	1 (2)
8	Partial finger flexors	2 (4)
9	Lack only of intrinsics	
	Exceptions	

Descriptions of motor groups according to the International Classification for Surgery (ICSHT) of the Hand in Tetraplegia. N = 58 unless otherwise noted.

calculated using paired-samples *T*-test. The test-retest comparisons showed excellent agreement in the categories, satisfaction, activities and occupation/schooling (Table 3). The questions regarding appearance/cosmesis, functional improvements after triceps reconstruction and hand or wrist surgery had perfect agreement.

The categories, satisfaction and activities showed excellent internal consistency; Cronbach's alpha = 0.95 (95% CI = 0.93–0.97) and 0.96 (95% CI = 0.94–0.97). Taken into account that the prevalence of missing data seriously complicates the estimation of internal consistency forms of reliability,<sup>24</sup> Cronbach's alpha for the category occupation/schooling was not calculated.

### Satisfaction survey

The participants' responses to the statements in the first part of the questionnaire are grouped into the three categories—satisfaction, activities and occupation/schooling (Figure 1). Overall, the participants agreed with most of the statements in the categories, satisfaction and activities. However, for occupation/schooling, the number of participants with positive responses was fewer and a larger proportion was neutral. The average of positive, neutral and negative responses for each category is presented in Figure 2. Out of the 58 participants, 55 (95%) responded as having benefited from surgery. Fifty participants (86%) responded that the surgery has made a positive impact of their life, and 46 participants (79%) agreed with the statement that the surgery has improved the quality of their life. Three participants (5%) gave a negative response to these two questions regarding life impact. The majority of participants (71%) felt more confident performing activities and believed their restored functions are working as well now

**Table 2** A summary of 402 surgical procedures performed during 103 surgical interventions in the study population

Surgical procedures	N (%)
<i>Triceps reconstruction including the below procedure:</i>	30
PD-Tri with tibialis anterior graft	30 (7)
<i>Hand/wrist surgery including one or several of the below procedures<sup>a</sup></i>	73
Brachioradialis to FPL	50 (12)
Extensor carpi radialis longus to flexor digitorum profundus	42 (10)
Brachioradialis to extensor carpi radialis brevis	14 (3)
Brachioradialis to flexor digitorum profundus	11 (3)
Intrinsic reconstruction	56 (13)
ELK	45 (10)
Split FPL—EPL tenodesis	58 (13)
CMC I arthrodeses	51 (12)
FPL tenodesis to the distal radius	13 (3)
Extensor carpi ulnaris tenodesis	24 (6)
Thumb abduction	6 (1)

Abbreviations: CMC, carpometacarpal; ELK, extensor pollicis longus-loop-knot; EPL, extensor pollicis longus; FPL, flexor pollicis longus; PD-Tri, posterior deltoid-to-triceps transfer.  
<sup>a</sup>Termed the alphabet procedure when the combination of surgical procedures provide simultaneous active key pinch and global finger grasp, together with passive hand opening and intrinsic function.<sup>8</sup> Several procedures may have been performed on the same individual.

as when they first had the surgery (81%). Forty-eight participants (83%) answered that they could perform more activities, and 49 (85%) answered that activities were easier to perform after surgery. Thirty-eight participants (66%) believed that they function more independently and 33 (57%) responded that they require less assistance from others after surgery.

Fifty-six participants (97%) answered the two questions regarding work performance/return to work among whom 50% responded that the hand/arm surgery positively impacted on the actual work performance, and 36% agreed that the surgery had made a positive impact on their potential to return to work. The rate of missing responses to the two questions regarding schooling was 19%, and neutral answers were given by approximately 60% of participants. Only eight participants (17%) answered that the surgery had made a potential impact on the actual school performance and seven (15%) responded that the surgery had positively impacted on the potential to return to school. To the question regarding home maintenance performance, 24 participants (41%) responded positively, 14 participants (24%) responded negatively and 20 participants (35%) responded neutrally.

The answers to the question regarding satisfaction with the appearance and cosmesis of the arm/hand satisfaction were relatively evenly distributed between the response categories (positive/neutral/negative) with a somewhat higher proportion of dissatisfied individuals.

The responses to the questions in the second section concerning functional improvements after each surgical intervention are presented in Figure 3. A clear majority responded positively to both questions regarding how the function had changed following the triceps and hand/wrist surgery. Two participants were highly dissatisfied with the outcome of their hand/wrist surgery. Both experienced post-operative complications; one was operated once again due to hematoma and the other developed a long-term post-operative infection.

The responses to the open questions regarding advantages and disadvantages after the upper-extremity surgery are summarized in Table 4. In total, 50 participants (86%) responded positively and mentioned activities in which their function was improved after surgery. Six participants reported that the surgery had complicated

certain tasks, most commonly, the picking up of larger objects ( $n = 4$ ). There were 18 comments regarding negative experiences from surgery. The most common negative aspects were scarring (reported by three women and three men) and long rehabilitation (Table 3).

Some of the general comments given by the participants were: 'Having the surgery is the best thing I have ever done', 'My hand appears more natural after the surgery', 'There is a long rehabilitation time, but given the improvements that I have experienced, it is really worth it', 'I am grateful that I had the surgery' and 'I recommend the surgery to others, it enhances the quality of life', 'I don't think I could undertake as many activities if I did not have the surgery' and 'There are only advantages with having the surgery, I am very satisfied and have not regretted the surgery for one second'.

## DISCUSSION

The results of the present study are encouraging and show that the degree of satisfaction after upper limb reconstructive surgery in Swedish individuals with tetraplegia is high, with most individuals reporting positive results with regard to global satisfaction and activity. The survey clearly indicates that restored grip functions have expanded participants' capacity in daily life activities, which most likely influenced their perception of a quality of life in a positive way. The proportion of participants responding that the surgery had been beneficial (95%) was similar but slightly higher as compared with previous studies conducted in the United States, Netherlands and Denmark, ranging between 80 and 90%.<sup>17–19</sup> The average of positive responses in the category occupation/schooling was lower in the present survey compared with the other two categories. The somewhat divergent results in this category are similar to the results from the survey in the Netherlands in which only 35% of the participants were positive. Yet, half of the Swedish study cohort responded that the surgery had positively impacted on actual work performance. Taking into account that most individuals suffering from impairment due to cervical SCI are of working age, upper limb reconstructive surgery potentially also has a socioeconomic impact. However, the high rate of neutral and missing responses in the occupation/schooling category may indicate that for retired individuals and adults, these questions are irrelevant. But most of all, questions relating to occupation and schooling appear to be more complex as compared with questions relating to global satisfaction and activity in terms of a multitude of factors that may mediate the outcome in these terms. Apart from regained independency, there are supposedly economic, social and psychological factors, as well as laws that guide eligibility for disability financial benefits that can impact on individuals' motivation to return to work or education.

Participants' answers regarding the appearance and cosmesis of the arm or hand are also similar to the findings in the Dutch study in which approximately one-third of the individuals were satisfied. This is an important drawback of the surgery that should be appropriately addressed by surgeons and nursing staff. However, in order for patients to achieve the highest level of hand function, several surgical procedures are required and scarring is inevitable. Patient characteristics have a large factor in scarring, and some patients have a predisposition to keloid formation. Patients often mention scarring at clinical follow-ups but most commonly claim that it is well worth it, given the improvements they have experienced. Surgeons should, however, strive toward making the patient more comfortable with his or her appearance. Although the troublesome scars will never be completely alleviated, there are non-invasive options such as topical silicone therapy available.

**Table 3** Reported advantages and disadvantages after upper-extremity surgery in individuals with tetraplegia

Activities in which participants' function was improved after surgery	N = 50
To grasp/pick up objects	28
Maneuver the wheelchair	21
Eating	17
Practice personal hygiene	13
Writing	10
Dressing	10
Drive the car	10
Using the phone, computer and remote control	9
Reach wider and higher	7
Drinking	6
Exercise	6
Open and closing doors	5
Making transfers	5
Leisure activities	5
Housework	5
Hold the cutlery	4
Cooking	3
Using tools	3
Open bottles	3
Shake hands	2
Handle a pair of scissors	2
Doing make-up	2
Catheterize	1
Give a hug	1
Activities in which participants' function was impoverished after surgery	N = 6
Picking up larger objects	4
Using the computer	2
Playing wheelchair rugby	1
Negative comments	N = 18
Scars after surgery	6
Long rehabilitation	3
Increased pain after surgery	2
Negatively affected opening of the hand	1
I expected an even higher independence after surgery	1
Tough to have the arm immobilized such a long time after surgery	1
Stiff fingers	1
Worsened pinch grip	1
Shoulder pain due to overstrain	1

Forty-nine out of 57 participants (86%) gave their comments. Multiple answers were sometimes given.

The similar responses to the two questions regarding functional improvement after triceps- and hand/wrist surgery indicate that an improved elbow extension increases individuals with tetraplegia' ability to use their hands despite paralysis below the wrist. Improved elbow extension increases the individual's capability to reach out in space, stabilizes the elbow in various angles, improves the ability to push away items and affects the usability of the tenodesis grasp and release mechanism. Similarly, a well-functioning triceps muscle is required for the individual to maximize the usability of a restored grip function.

Answers to the open questions in the third section of the questionnaire were mainly positive, with only a few participants reporting that the surgery has complicated certain tasks. The activities in which participants' function was improved after surgery were similar to the activities mentioned in the Danish study by Gregersen *et al.*<sup>19</sup>

To the question whether the surgery had complicated certain tasks, the activities mentioned by respondents were mostly related to a

restricted opening of the hand. In combined surgical procedures, such as grip reconstructions (restoring key pinch and palmar grip), fusion of the carpometacarpal thumb joint is often included with the aim to optimize the positioning of the thumb while activating the key pinch. As a result, the ability to open the hand becomes somewhat restricted, which in turn, may affect the patient's grasp ability. New innovative techniques, such as nerve transfer in tetraplegia hand surgery, show promising results in restoring finger and thumb extension for opening of the hand.<sup>25</sup> Combining traditional tendon transfer techniques with these new approaches has the potential to restore hand function to a level as close to normal as possible in tetraplegia. Disappointment with respect to a restricted opening of the hand will most likely be less frequent in the future through combined procedures. Other negative comments included scarring and long rehabilitation. Scarring was mentioned as a negative aspect by 10% of the study population. Considering the large amount of surgical procedures included in an advanced grip reconstruction, 10% is relatively low. Still, it is the most frequent negative aspect of the surgery and goes in line with the high rate of negative responses to the question regarding appearance and cosmesis of the hand, which surgeons should bear in mind. The second most common negative aspect mentioned by participants relates to the length of the rehabilitation. It has previously been acknowledged that persons with tetraplegia hesitate, and even decline surgery because of the long immobilization and rehabilitation time.<sup>26</sup> Further research is needed with the aim to reduce the post-operative restriction time with maintained surgical success.

As surgical restorative techniques continue to be refined and vary between countries, it is important that the impact of upper-extremity surgery on the lives of tetraplegic subjects is quantified, and that the knowledge of patient satisfaction is generated. This is the first report of a translation, adaptation and evaluation of the Swedish version of the tetraplegia surgery satisfaction questionnaire in terms of reliability. As the questionnaire was reviewed and modified by a group of experts in the area of reconstructive surgery and tetraplegia, the measure is subjectively viewed as covering the concept it purports to measure, that is, having good face validity. A response rate exceeding 80% in the test-retest assessments is considered high. Lack of previous formal assessment of the psychometric properties of the questionnaire necessitates the current study, which demonstrates that this version of the questionnaire is highly consistent over time, and thus could be considered reliable. Moreover, the domains overall satisfaction and activity were shown to have excellent internal consistency, which is in accordance with the survey undertaken in the Netherlands and Denmark.<sup>18,19</sup> The fact that the internal consistency of the domain occupation/schooling was not calculated because of the high level of missing data should, however, not be dismissed. The relevance of combining occupation and schooling that seemingly represent two separate constructs into one category could be questioned. The large amount of neutral responses indicates that these questions may have been irrelevant for some participants. As reconstructive surgery is offered to individuals with tetraplegia of varying ages, one should consider modifying the occupation/schooling aspects into separate domains.

Surgical reconstruction of grip function in tetraplegia has been performed since the early 1970s and has constantly been developed since then. It was chosen, however, to only include subjects who had surgery from 2005 onward in order to get a more homogenous sample in terms of surgery techniques and rehabilitation. Each surgery had to include at least one active tendon transfer, and participants were to complete only one questionnaire independent of the number of surgeries performed. Thus, in some cases participants' responses

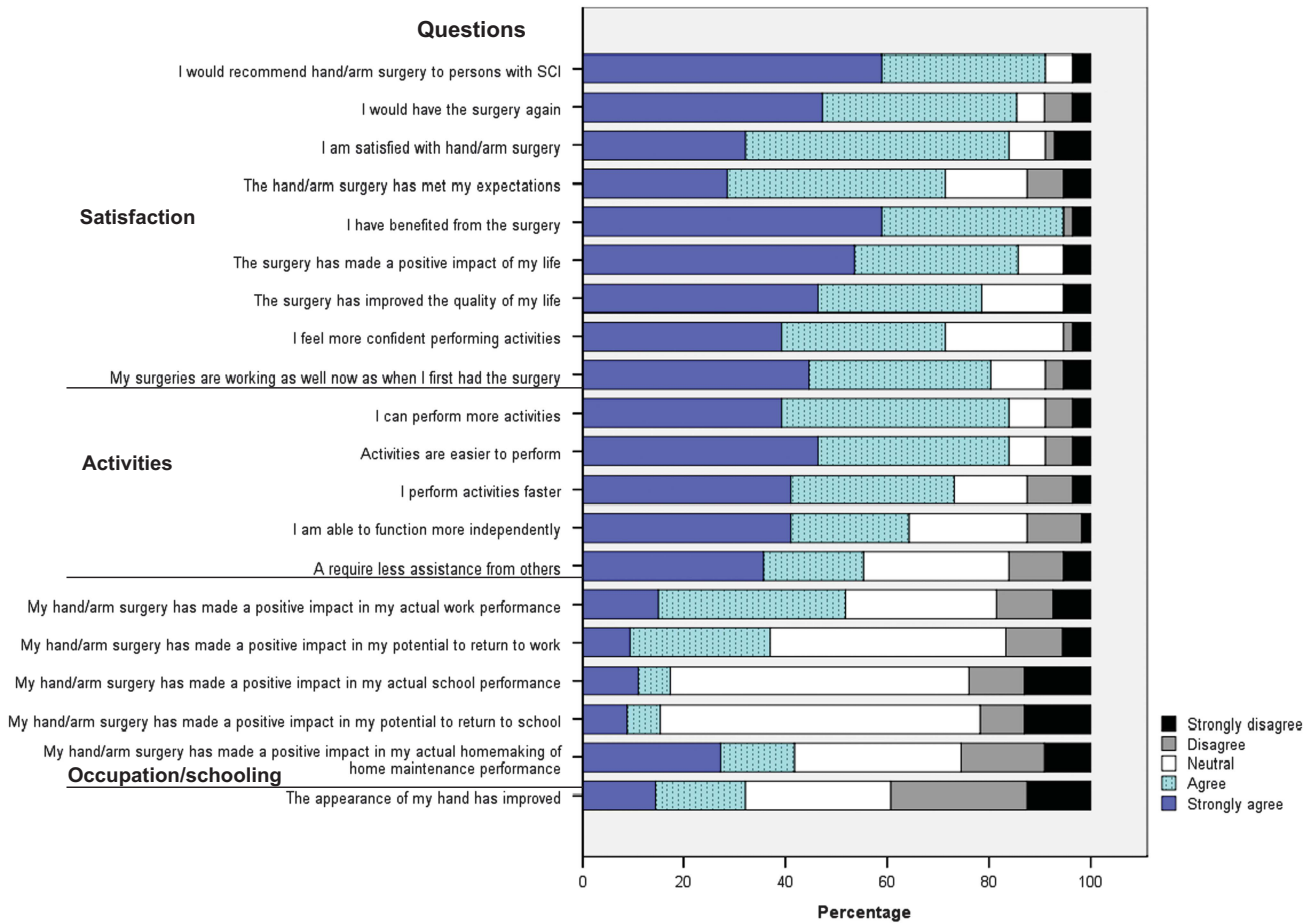


Figure 1 The proportion of participants responding at each of the five levels ('strongly agree' to 'strongly disagree') to questions in the satisfaction survey.

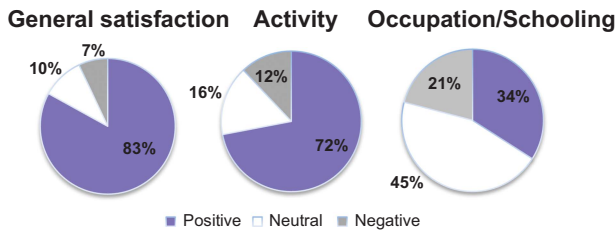


Figure 2 The average of positive, neutral and negative responses for the domains satisfaction, activities and occupation/schooling.

may be more of an overall appraisal of satisfaction after upper limb surgery.

In the present survey, there were some individuals who were less satisfied with the outcome of surgery. Two participants were highly dissatisfied, presumably due to post-operative complications, one reporting a severe infection and another reporting a major post-operative bleeding. Dissatisfaction may also be due to overuse or nonadherence to the rehabilitation protocol. This has the result that tenodesis may stretch over time.<sup>7</sup> Follow-up visits in this cohort were scheduled 1, 3, 6 and 12 months after surgery, when patients meet the team for evaluation. These follow-up visits are critical for the team to identify signs that indicate stretch of the transfer and/or whether either the post-operative treatment or the orthosis need to be modified.<sup>7</sup> Another reason for dissatisfaction may be unrealistic expectations.

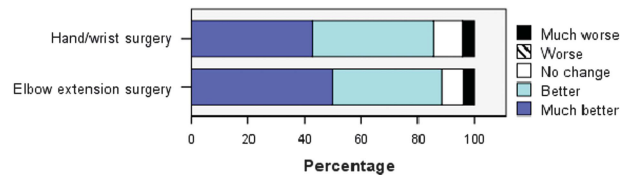


Figure 3 The proportion of participants responding at each of the five levels ('strongly agree' to 'strongly disagree') to the two questions about functional improvement after hand/wrist and elbow extension surgery, respectively.

This should be minimized by carefully informing the patient both through face-to-face communication and supplying detailed written information. All patients with tetraplegia should be offered assessment and information about possible reconstructive options. The offer should be repeated over time since the moment of making the decision for upper limb reconstructive surgery is elusive.<sup>27</sup> One advantage with traditional tendon transfer is that there is no 'time-window' in the sense that patients can undergo surgery irrespective of the time passed since the cervical spinal cord paralysis.

The response rate in the study was 75%. In the literature, the response rate varies according to the subjects studied and the technique used, and the mean response rate among mail surveys published in medical journals is shown to be approximately 60%.<sup>28</sup> Given the relatively high response rate, the rather large sample size and the representative sample of individuals with tetraplegia in the present

**Table 4** Test–retest reliability scores in each domain of the satisfaction questionnaire and differences in mean values for the test–retest domain scores

	N	$R_s$	P-value	Mean diff.	s.e.	P-value	95% CI
Satisfaction (9–45)	44	0.82	<0.001	0.68	0.41	0.10	–0.13 to 1.50
Activities (5–25)	44	0.85	<0.001	0.21	0.32	0.51	–0.43 to 0.85
Occupation/schooling (5–25)	43	0.52	<0.001	0.15	0.71	0.83	–1.27 to 1.58
Appearance/cosmesis (1–5)	44	0.71	<0.001	0.00	0.14	1.00	–0.20 to 0.27
Functional improvement triceps surgery (1–5)	27	0.59	<0.01	0.00	0.09	1.00	–0.19 to 0.19
Functional improvement hand/wrist surgery (1–5)	38	0.80	<0.001	0.00	0.08	1.00	–0.15 to 0.15

Abbreviations: CI, confidence intervals; Mean diff., differences in mean values for the test and retest domain scores;  $R_s$ , Spearman rank-order coefficient.

study, the study cohort could be considered a representative Swedish sample of individuals with cervical SCI. An exact comparison of our data with similar studies on satisfaction after upper-extremity surgery in tetraplegia is difficult, because of methodological differences between the studies, as well as differences in study designs and patient cohorts. Another difference is the time span in which study participants are recruited.

Taking into account the number of people who sustain a SCI worldwide, restorative surgery is an underutilized procedure, although widely advocated.<sup>7</sup> The reason for this is suggested to be skepticism among patients, therapists and rehabilitation physicians because of inadequate information, as well as inadequate referral networks.<sup>29</sup> A number of papers have been published that describe technical aspects of safe surgical procedures, functional benefits and the importance of rehabilitation including early mobilization.<sup>7–10,13</sup> This study confirms previous results from patient-reported satisfaction surveys<sup>17–19</sup> indicating that surgery and rehabilitation is beneficial to the individual. Taking these findings into account, surgical restoration of upper limb function should be offered to all suitable candidates living with tetraplegia. Greater knowledge of patient benefits, as well as improved communication among healthcare providers, patients and their family/spouses will hopefully contribute to increasing the number of patients referred for surgery both nationally and internationally. In conclusion, the present study shows that surgical rehabilitation of arm and hand function in individuals with tetraplegia is rewarding from a patient perspective, leading to satisfactory and sustainable gains in activities of daily living, as well as enhanced quality of life. Since questions referring to occupation and schooling seemingly represent separate and distinct entities that may be of less relevance for certain age groups, further modifications of the questionnaire are recommended.

#### DISCLAIMER

The authors affirm that the manuscript is an honest, accurate and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

#### DATA ARCHIVING

There were no data to deposit.

#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

#### AUTHOR CONTRIBUTIONS

All authors contributed to the rationale and conceptualization of the study. LBK coordinated the study and contributed to data collection and analyses. LBK, JW, CR and JF contributed to the interpretation of the results. All authors

wrote the manuscript and approved its final version and had final responsibility for the decision to submit for publication.

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