

ORIGINAL ARTICLE

Long-term patient satisfaction after reconstructive upper extremity surgery to improve arm–hand function in tetraplegia

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Study design: There is a paucity of literature about satisfaction after reconstructive surgery to improve upper limb function in persons with tetraplegia. The present literature describes mainly functional outcomes.

Objectives: To evaluate long-term satisfaction after reconstructive upper extremity surgery in persons with tetraplegia.

Setting: Two rehabilitation centers in the Netherlands.

Method: A three-part questionnaire consisting questions regarding satisfaction, activities, occupation, changes in functional ability and willingness to undergo the surgeries again was used. Internal reliability of the questionnaire was verified by factor analysis and calculation of Cronbach's alpha.

Results: In total, 39 out of 55 persons (70.9%) participated in the study. The participants' responses to questions about satisfaction, activities and occupation were positive in 73.5, 67.6 and 35.0%, respectively. Nearly 81% improved their functional ability. Approximately 65% of the participants were willing to undergo elbow extension surgery again and 77.1% expressed their willingness to undergo hand/wrist surgery again. Significant positive correlation was found between willingness to have surgery again and improvement in activities and occupation: Spearman's correlation coefficients: activities–elbow extension 0.63 ($P=0.003$), activities–hand/wrist 0.57 ($P<0.001$), occupation–elbow extension 0.53 ($P=0.025$), occupation–hand/wrist 0.57 ($P=0.001$). Differences between the subgroups who would have surgery again and those who would refrain were also significant; one-way analysis of variance for activities ($F=9.54$, $P<0.01$) and for occupation ($F=6.60$, $P<0.02$).

Conclusion: In the Netherlands, the majority of persons with tetraplegia who underwent reconstructive upper extremity surgery were satisfied with the results. This was related to improvement in activities and occupation.

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Introduction

Incidence of spinal cord injury (SCI) varies from 10.4 to 83 per million inhabitants per year worldwide. One-third of persons with SCI have tetraplegia.¹ In the Netherlands, the incidence of SCI is 12.1 per million inhabitants per year. The incidence of SCI surviving the acute phase is 10.4 per million inhabitants per year.²

Cervical SCI (CSCI) has greater impact on person's life. Limited arm function caused by CSCI increases dependence on caregivers in self-care and daily functioning. Studies in the past have concluded that regaining arm–hand function was one of the highest priorities for persons with CSCI.^{3,4}

The majority of persons with tetraplegia (77–92%) expected improvement in quality of life if their hand function could be improved.⁵ It is estimated that over 50% of persons with tetraplegia would benefit from some form of upper extremity reconstructive surgery.⁶ At the end of conventional rehabilitation treatment, a decision regarding the need and/or the type of procedure could be made. Aim of these procedures is to improve elbow extension and pinch and palmar grips by series of transfers, tenodeses or arthrodeses. For full description of available procedures, we refer to the literature.^{7,8}

However, in practice, use of reconstructive upper extremity surgery is limited and until now it is not considered as a standard procedure. Anderson *et al.*⁶ tried to find an answer to the question why persons with tetraplegia did not undergo reconstructive surgery more often. They found three main reasons. First, the majority of persons with CSCI had never been informed about the possibilities of

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reconstructive surgery to improve their arm–hand function. Second, clinicians working in non-specialized centers were unaware of the possibilities of reconstructive surgery and last, persons with CSCI simply did not want to undergo the invasive operative procedures associated with reconstructive surgery. There is only level 4 evidence that supports the use of reconstructive surgery of upper limb in persons with tetraplegia for the improvement of activities of daily life (ADL) and quality of life. Despite the level of evidence, the subjective acceptance among patients for reconstructive surgery is high.⁹

Evaluation of results in literature is difficult mainly because of the diversity in operative procedures, neurological lesions and evaluation methods. However, in general, the results of reconstructive surgery to improve arm–hand function in persons with tetraplegia are favorable. The current literature describing clinical outcomes mainly consists of case reports.¹⁰ Results mainly describe functional outcomes such as muscle strength and ADL skills.¹¹ There are limited data about patient satisfaction, activities and participation after reconstructive surgery in persons with tetraplegia. Some studies report about satisfaction of participants as well, however, this is usually evaluated using only a few, untested questions.^{11–13} These studies report that the majority of the participants are satisfied with the results of the surgery. Lo *et al.*¹² described the outcome of tendon transfers for eight C6-spared quadriplegics (12 hands). They used the questionnaire of Lamb and Chan¹⁴ modified by Mohammed *et al.*¹⁵ Few questions were related to the level of satisfaction in this questionnaire. All of the operated persons with tetraplegia reported they would have surgery again, although two said that they would not consider surgery on the other side. Meiners *et al.*¹³ evaluated persons with tetraplegia before and after hand surgery (22 patients, 23 hands). Subjective satisfaction levels were determined by four questions. In total, 19 participants said that they would recommend the operation to others and 18 said they would have surgery again. Only two participants (out of seven working participants) stated the operation had a positive influence on their work. Forner-Cordero *et al.*¹¹ reviewed the results of upper extremity surgery in 15 persons with CSCI. They also used the questionnaire of Lamb and Chan,¹⁴ modified by Mohammed *et al.*¹⁵ The results of their study showed that 87.5% of their population were satisfied with the operation, 42.8% of the participants felt that the operation had fulfilled their expectations, however, 57.2% expected better results.

Aim of the present study was to evaluate long-term patient satisfaction after reconstructive upper extremity surgery. In addition, improvement in activities is evaluated and general comments regarding the treatment are assessed. In the Netherlands, this has not been evaluated before.

Materials and Methods

Questionnaire

Stroh Wuolle *et al.*¹⁶ used a questionnaire in their study on satisfaction with upper extremity surgery in persons with

tetraplegia in a selected American population (Appendix 1). They gave us permission to use the questionnaire for our study. The questionnaire was first translated into Dutch. Then the Dutch version was re-translated into English to make sure the Dutch translation conformed to the original questionnaire. The original questionnaire consisted of three parts. In part 1, the participants had to react to several statements on a five-point Likert scale (1 = strongly disagree, 5 = strongly agree). The questions were divided into eight areas: general satisfaction, life impact, ADL, independence, occupation, appearance, function over time and therapy. Part 2 consisted of questions about changes in the functional ability of participants after the surgery and their willingness to undergo the surgeries again. In part 3, participants had to list activities in which the surgeries were helpful and they were asked to give general comments on the surgery.

The local Medical Ethics Committees gave permission to use the questionnaire without further approval procedure, on condition that all data were stored anonymously in a database.

Participants

Persons with CSCI who underwent upper extremity surgery were identified in two rehabilitation centers in the Netherlands with an active ongoing upper extremity reconstruction surgery program for improvement of hand function in persons with tetraplegia. As a questionnaire was used for the study, participants had to be alive with a known current address. All of them were sent the questionnaire by mail and the answers were received by mail as well. In case persons did not respond, they were sent the questionnaire a second time. All participants gave written consent to investigate their medical records.

Data analysis

The internal reliability of the translated version was verified by factor analyses and calculation of Cronbach's alpha for different indices. All data were statistically analyzed by means of descriptive analysis, Spearman's correlation coefficients (two-tailed) and one-way analysis of variance. Results with *P*-value <0.05 were considered statistically significant.

Results

Participant characteristics

In total 55 persons with CSCI were considered suitable for the survey. Out of which, 39 (70.9%) returned the questionnaire, 15 did not respond and 1 questionnaire was returned because it could not be delivered.

Characteristics of the participant population, lesion level, the American Spinal Injury Association Impairment Scales¹⁷ and description of motor groups, according to the International Classification for Surgery of the Hand in Tetraplegia,¹⁸ of the participants are presented in Table 1a–c. Information of motor groups was available for 41 operated arms. In total 44 arms were operated. In total, 34 participants had surgery only on one extremity and five participants had surgery on both upper extremities. Most participants underwent hand/

Table 1a Participant characteristics

<i>N</i> , gender	31 male, 8 female
Year of injury (range)	1970–2006
Time between injury and first surgery (years)	4 (1–38) ^a
Age at first surgery (years)	37 (17–72) ^a
Follow-up (since last surgery, years)	9 (1–24) ^a

^aMean (range).**Table 1b** Participants according to AIS classification and lesion level

AIS	C3	C4	C5	C6	C7	C8
A	1	1	12	10	4	
B			1	3	1	
C	1	1		1		
D			1	1		1

Abbreviation: AIS, American Spinal Injury Association Impairment Scales.

Table 1c Motor groups according to the International Classification for Surgery of the Hand in Tetraplegia (41 operated arms)

Motor group	No. of patients' arms
0	2
1	5
2	10
3	13
4	4
5	5
6	1
8	1

wrist surgery, 20 participants underwent elbow extension surgery. Details of these surgeries are shown in Table 2.

Questionnaire

Part 1 of the questionnaire in this study was divided into three factors, namely, satisfaction, activities and occupation, by implementation of a factor analysis. Cronbach's alpha was calculated for each factor. Cronbach's alpha for satisfaction was 0.95, for activities 0.93 and for occupation 0.91. On the basis of factor analysis, the following five questions were excluded from further analysis because of their unreliability:

- (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.
- (4) The appearance of my hand has improved since my hand/arm surgery.
- (5) I perform activities more like I used to before I was injured after my hand/arm surgery.

The results of part 1 of the questionnaire used in this study are presented in Table 3. The five unreliable questions are not shown. The participants' reactions to questions in part 1 were generally positive except to those relating to occupation. The participants' response to questions about satisfaction was in 73.5% positive, 14.8% neutral and 11.7% negative. The responses to questions about activities

Table 2 Operative procedures (44 operated arms)

Procedure	Number of patients
Active elbow extension	14
PD to triceps transfer	14
Correction flexion deformity elbow	6
Lengthening biceps	6
Split brachialis	1
Correction supination deformity forearm	6
Rerouting biceps	5
Rotation osteotomy	1
Active wrist extension	6
BR to ECRB transfer	5
BR to ECRL transfer	1
Passive lateral grip	13
FPL tenodesis to radius	13
Thumb IP stabilisation	13
EPB tenodesis	3
EPB/EPL tenodesis	2
EPL tenodesis	3
CMC 1 arthrodesis	3
Active lateral grip	22
BR to FPL transfer	19
PT to FPL transfer	3
FPL split transfer	6
EPL tenodesis	10
Thumb IP arthrodesis	5
Active cylinder grip	21
ECRL to FDP transfer	13
PT to FDP transfer	4
BR to FDP transfer	4
Correction intrinsic minus	22
Zancolli lasso	22

Abbreviations: BR, brachioradialis; ECRB, extensor carpi radialis brevis; ECRL, extensor carpi radialis longus; EPB, extensor pollicis brevis; EPL, extensor pollicis longus; FDP, flexor digitorum profundus; FPL, flexor pollicis longus; IP, interphalangeal; PD, posterior deltoid; PT, pronator teres.

were 67.6% positive, 18.5% neutral and 13.9% negative. Responses to questions relating to occupation or schooling were positive in 35.0% of the participants, 43.5% neutral and 21.5% negative.

The participants' reactions to questions in part 2 were generally positive as well. Among the 20 participants who underwent elbow extension surgery, 30% stated that their ability to function was much better and 45% stated that their function was better. In total 36 participants underwent hand/wrist surgery and 47.2% of those said that their ability to function was much better and in 38.9% it was better post-operatively. In summary, 80.6% of the responses were positive. Participants were asked whether they would choose to undergo the surgery again; 65% of them who underwent elbow extension surgery answered positive and 77.1% of the participants who underwent hand/wrist surgery answered positive.

Spearman's correlation coefficients between participants' readiness to have surgery again and their mean scores regarding the factors activities and occupation were: activities–elbow extension 0.63 ($P=0.003$), activities–hand/wrist 0.57 ($P<0.001$), occupation–elbow extension 0.53

Table 3 Results of the questionnaire, part 1 (questions are classified by one of the three factors)

Satisfaction	Strongly agree (%)	Agree (%)	Neutral (%)	Disagree (%)	Strongly disagree (%)
1. I would recommend hand/arm surgery to persons with SCI	41.0	46.2	7.7	2.6	2.6
2. I would have the surgery again	46.2	28.2	12.8	5.1	7.7
3. I am satisfied with hand/arm surgery	36.8	34.2	18.4	5.3	5.3
4. I would be willing to pay for surgery if I had the money	21.1	28.9	31.6	13.2	5.3
5. The hand/arm surgery has met my expectations	20.5	41.0	20.5	10.3	7.7
6. I have benefited from the surgery	51.3	35.9	5.1	0.0	7.7
7. The surgery has made a positive impact of my life	30.8	53.8	7.7	5.1	2.6
8. The surgery has improved the quality of my life	28.9	44.7	18.4	2.6	5.3
9. I feel more confident performing activities	28.2	51.3	10.3	5.1	5.1
10. My surgeries are working as well now as when I first had the surgery	11.1	50.0	19.4	13.9	5.6
11. The therapy I received after my surgery helped me functionally	18.4	60.5	10.5	7.9	2.6
<i>Activities</i>					
12. I can perform more activities	47.4	36.8	5.3	0.0	10.5
13. Activities are easier to perform	30.8	48.7	10.3	2.6	7.7
14. I perform activities faster	25.6	33.3	33.3	2.6	5.1
15. I am able to function more independently	28.2	30.8	23.1	12.8	5.1
16. I require less assistance from others	7.7	48.7	20.5	17.9	5.1
<i>Occupation</i>					
17. My hand/arm surgery has made a positive impact in my actual work performance	8.6	48.6	28.6	2.9	11.4
18. My hand/arm surgery has made a positive impact in my potential to return to work	5.6	27.8	41.7	13.9	11.1
19. My hand/arm surgery has made a positive impact in my actual school performance	3.4	10.3	65.5	13.8	6.9
20. My hand/arm surgery has made a positive impact in my potential to return to school	3.4	17.2	62.1	10.3	6.9
21. My hand/arm surgery has made a positive impact in my actual homemaking of home maintenance performance	8.3	41.7	19.4	19.4	11.1

($P=0.025$), occupation–hand/wrist 0.57 ($P=0.001$). The correlations were all positive and significant, meaning that participants' readiness to have surgery again correlated with a positive score on questions about activities and occupation. Differences in scores between the group who were willing to have surgery again and the group who would refrain were also significant; one-way analysis of variance for activities $F=9.54$, $P<0.01$ and for occupation $F=6.60$, $P<0.02$.

In part 3, the participants were asked to list the activities in which surgery was helpful. Most mentioned activities were: holding the cutlery, picking up objects, writing, using the computer and using the wheelchair. Participants were also asked to give general comments. Most participants reacted positively and mentioned the activities in which the surgery had helped. Seven participants gave negative comments including: lack of monitoring after the surgery, deterioration in independence or no improvement, increase of paresis after surgery and stagnation of the rehabilitation process due to the waiting period before the surgery. None of the participants reported postsurgical complications. Suggestions to improve the surgery and rehabilitation process were given by three participants. They were: evaluation of the results after surgery, starting surgery on the arm with the worse function and perform surgery on one hand only.

Discussion

The purpose of this study was to evaluate the level of satisfaction after upper extremity surgery in persons with tetraplegia in the Netherlands and to obtain positive and/or

negative comments on the surgical and rehabilitation process regarding upper extremity surgery. It was found that 73.5% of the participants were satisfied with the results of surgery and 65–77% of the participants would choose to undergo surgery again. An important finding of this study is the significant positive correlation between the willingness to have surgery again and improvement in activities and occupation. Dissatisfaction was mainly due to absence or lack of improvement post surgery. It appears to be essential to evaluate outcomes of the surgeries on the level of activities and/or participation. The results obtained in this study are considered to be relevant because the group participated in this study is a significant part of persons with tetraplegia who underwent upper extremity surgery in the Netherlands. Furthermore, the response rate is high.

The only previous study with primary aim to evaluate patient satisfaction was carried out by Stroh Wuolle *et al.*¹⁶ They sent a questionnaire to 67 persons with CSCI in the United States (107 arms) to evaluate satisfaction after upper extremity surgery in detail. Approximately 70% among their study population were satisfied; 77% reported positive life impact, 66–68% reported improvement in ADL and independence and 69% reported improvement in occupation. Results of this study are similar except regarding the occupation. Only 35% of the participants from our population were positive about questions related to occupation and school. As the questionnaire used in both studies is the same, the results are comparable.

Results of the current study showed that 35% of the persons who underwent elbow extension surgery and 23% of the persons who underwent hand/wrist surgery would not

choose to have surgery again. These persons did answer negatively to questions about activity and occupation. We can only presume why they do not want to have surgery again. A possible explanation could be that the information given to them before the surgery was not precise, resulting in higher expectations. Forner-Cordero *et al.*¹¹ found in their study that 57.2% of the persons expected better results of the surgery. Another possibility could be that there was really no improvement after surgery. This could be due to insufficient strength of the muscle used for transfer that had borderline strength before surgery.

Former studies have already identified treatment characteristics contributing to the decision to undergo upper extremity surgery. The duration of in-patient rehabilitation, type of intervention, number of operations, duration of immobilization and the risk of complications were, to the patients, either equally or more important considerations as functional outcome for decision-making. Outpatient treatment was considered to be relatively unimportant by the patients if it lasted up to 12 weeks.⁵ Anderson *et al.*⁶ stated that 80% of their population would be willing to spend 2–3 months being less independent during recovery from surgery in order to become more independent afterward. Roach *et al.*¹⁹ found in their study that Dutch persons with tetraplegia would trade less time than those from the United States for return to normal arm-hand function. Contrary to that, none of the participants in the present study made a negative comment about the number of operations or the duration of the rehabilitation process.

This study has some limitations. First, the questionnaire was not standardized, therefore generalization of the results is limited. Second, and maybe more important, because this survey had to be anonymous, as a consequence, it is not possible to find out to what extent treatment and patient characteristics have a role in satisfaction and the decision to have reconstructive surgery again. Further research is needed to clarify this relation. However, an advantage of this anonymous questionnaire might be that there is no positive answer bias. Participants were free to give negative comments.

Conclusion

In the Dutch study population, the majority of the persons with tetraplegia who underwent reconstructive upper extremity surgery were satisfied with the results. Few patients gave negative comments. Generally, satisfied participants were able to perform more activities (like ADL) and they were more independent.

Conflict of interest

The authors declare no conflict of interest.

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Appendix 1

Original questionnaire, used by Stroh Wuolle *et al.*¹²

Part 1

(Answers: 5-level Likert scale: strongly agree- agree- neutral-disagree- strongly disagree)

General satisfaction

1. I would recommend hand/arm surgery to other people with SCI
2. If I had the opportunity to do it over again, I would still have hand/arm surgery
3. I am satisfied with hand/arm surgery
4. If I had the money, I would be willing to pay for the surgery
5. The hand/arm surgery has met my expectations

Life impact

6. I have benefited from the surgery
7. The surgery has made a negative impact on my life
8. The surgery has made a positive impact of my life
9. The surgery has improved the quality of my life

ADL

10. I can perform more activities after my hand/arm surgery
11. I feel more confident performing activities after my hand/arm surgery
12. Activities are easier to perform after my hand/arm surgery
13. I perform activities faster after my hand/arm surgery
14. I perform activities more like I used to before I was injured after my hand/arm surgery

Independence

15. I am able to function more independently after my hand/arm surgery
16. I use less adaptive equipment after my hand/arm surgery
17. I need less help from others after my hand/arm surgery

18. I spend more time out in the community alone after my hand/arm surgery

Occupation

19. My hand/arm surgery has made a positive impact in my actual work performance
20. My hand/arm surgery has made a positive impact in my potential to return to work
21. My hand/arm surgery has made a positive impact in my actual school performance
22. My hand/arm surgery has made a positive impact in my potential to return to school
23. My hand/arm surgery has made a positive impact in my actual homemaking or home maintenance performance

Appearance

24. The appearance of my hand has improved since my hand/arm surgery

Reliability

25. My surgeries are working as well now as when I first had the surgery

Therapy

26. The therapy I received after my surgery helped me functionally

Part 2

How did (each surgery) change your ability to function? (answers: much better- better- no change- worse- much worse)

- Elbow extension surgery
- Hand/wrist surgery

Would you have surgery again? (answers: yes-no)

- Elbow extension surgery
- Hand/wrist surgery

Part 3

List of activities for which upper-extremity surgery has helped

General comments or criticisms