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Original Article

Perceived outcomes and utilization of upper extremity surgical reconstruction in individuals with tetraplegia at model spinal cord injury systems

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Study design: Survey.
Objective: To measure the utilization of upper extremity reconstructive surgery and the clinicians' perceptions of the outcomes provided for persons with tetraplegia across the Model Spinal Cord (SCI) Injury Systems.
Setting: Model SCI Systems.
Methods: *Participants*: A clinician from each of the Model Centers. *Main outcome measure*: A mailed survey eliciting responses with respect to: (1) utilization of upper extremity reconstructive procedures and (2) the clinicians' perceived outcomes of these procedures.
Results: In all, 76% responded positively about the availability and appropriateness of upper extremity surgical reconstruction at their center. Of the respondents, 75% felt that surgery recipients were generally satisfied with their surgeries, 80% felt that the surgery made a positive impact on recipients' lives, 81% felt that recipients showed increased independence, and 70% reported a positive impact on recipients' occupation. In all, 93% felt insurance companies should pay for the procedures. Compared to the satisfaction of surgery recipients using a similar instrument, clinicians anticipated slightly greater improvements in all areas except occupation.
Conclusions: There is a positive perception of the benefits of reconstructive surgery for tetraplegia; however, procedures are not routinely offered at all centers. The primary reasons reported for this include the misconception that insurance does not remit payment, that a surgeon is not available, and that surgical candidates are referred to another center.
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Keywords: reconstructive surgery; tendon transfers; tetraplegia; outcomes; upper extremity

Introduction

The effects of spinal cord injury (SCI) at the cervical spinal level are devastating to upper extremity function. Although there is currently no cure for SCI, there are medical, rehabilitative, and surgical interventions that can restore functional movement to the individuals who sustain this type of injury. One upper extremity reconstruction option for persons with tetraplegia is a tendon transfer procedure, where the attachment of a muscle that provides redundant function is transferred to provide a function that is absent. An example would be using the brachioradialis muscle, which provides elbow flexion in addition to the biceps brachii and brachialis, in someone with a C5 injury to provide wrist extension. Tendon transfer procedures are commonly used to improve upper extremity function by restoring movements such as elbow extension, wrist extension, and grasp/release.[1–15] In addition, there are procedures to reduce contractures such as the rotational radial osteotomy to correct a forearm supination contracture or a biceps tendon lengthening to reduce elbow flexion

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contractures.[16–21] Tendon transfer procedures have traditionally been most effective for individuals who have sustained injuries at the C5–C7 level, as persons at this level have strong but redundant donor muscles to be used for providing additional function. Tendon transfer options for persons injured at the C4 level are limited due to the lack of voluntary muscles. Table 1 provides examples of reconstructive procedures typically performed on persons with varying levels of tetraplegia.

Although much has been published about upper extremity reconstruction for individuals with tetraplegia, their utilization across SCI rehabilitation centers is not clear. Therefore, the utilization of upper extremity reconstruction and the clinicians' perception of their outcomes for recipients were examined in the Model Spinal Cord Injury Centers.[22] At the time of this study, there were 18 Model Center Spinal Cord Injury Systems designated by the United States Department of Education's National Institute on Disability Rehabilitation and Research (NIDRR). NIDRR has funded these centers to serve as a model for the treatment of spinal cord injury, to collect data for the national statistical data set, and to participate in collaborative research. The purpose of this study was to identify utilization patterns of upper extremity reconstruction in the National Model Spinal Cord Injury Systems and to examine clinicians' perceptions of these procedures. These results are compared to a study of participant satisfaction with upper extremity reconstruction.[23]

Methods

Respondents

Each Model Center was represented by a respondent, who was responsible for or directed the treatment of the persons with SCI in the rehabilitation setting and long-term follow-up. This person was a physiatrist at all centers but one where it was an occupational therapist.

Survey

A two-page survey consisting of 28 statements requiring Likert-style responses, and two open-ended statements were mailed to each of the Model Spinal Cord Injury Systems. The statements were designed to elicit information about the availability and appropriateness of the surgical procedures at each center, as well as the respondent's perception of the outcomes of the procedures. Statements from the Availability and Appropriateness section included: 'Surgery to improve hand and arm function should be part of the rehabilitation options available to individuals with tetraplegia' and 'Surgery to improve hand and arm function is part of our center's rehabilitation options available to patients'. Centers were also asked whether reconstructive surgery is routinely offered to individuals at each ASIA level C4–T1. Statements to measure the clinician's perceived outcomes of tendon transfers included: 'Patients benefit from surgery', 'Patients perform more activities', and 'Surgery makes a positive impact on the patient's ability to work or go to school'. Likert scale response options

Table 1 Reconstructive procedures

		Level			
Desired function	*Examples of procedures*	*C5*	*C6*	*C7*	*C8*
Reduced elbow contracture	Biceps Z-lengthening	X	X		
Elbow extension	PD to triceps	X	X		
	Biceps to triceps	X	X		
Forearm pronation	Radial rotational osteotomy	X	X		
(active or positioning)	Zancolli biceps rerouting	X	X		
Wrist extension	Br–ECRB	X			
Thumb flexion	FPL tenodesis to radius	X			
	Thumb IP joint stabilization	X	X	X	
	Br to FPL		X	X	
Finger flexion	ECRL to FDS/FDP		X	X	
	PT to FDS/FDP			X	
Thumb extension	EPL tenodesis		X		
	Br to EPL			X	
	PT to EPL		X	X	
Finger extension	EDC tenodesis		X	X	
	Br to EDC		X	X	
	ECRL to EDC and EPL		X	X	
Reduced claw hand	Intrinsic Zancolli Lasso		X	X	X
Thumb opposition	FCU or FCR to opponens with FTG of PL				X

Br = brachioradialis; ECRL = extensor carpi radialis longus; ECRB = extensor carpi radialis brevis; EDC = extensor digitorum communis; EPL = extensor pollicis longus; FCR = flexor carpi radialis; FCU = flexor carpi ulnaris; FDP = flexor digitorum profundus; FDS = flexor digitorum superficialis; FPL = flexor pollicis longus; FTG = free tendon graft; IP = interphalangeal; PL = palmaris longus; PD = posterior deltoid; PT = pronator teres

included: strongly agree, agree, neutral, disagree, and strongly disagree. A complete list of the survey statements is given in Appendix A. The results from this survey to clinicians were compared to the results from a patient satisfaction survey, similar in content and structure.[23]

Following the 28 Likert-style statements, respondents were asked to report the number of reconstructive surgery recipients followed at their center by choosing from the following categories: 0, 1–10, 11–20, 21–50, 51–100 and >100. The last question asked the respondents of centers that did not provide upper extremity surgical reconstructive procedures to report the reasons why this service was not available.

Data analysis

The statements were divided into three categories: (1) availability and appropriateness, (2) the level of tetraplegia surgery that is routinely offered to, and (3) clinician perception of outcomes. The category of perceived outcomes was further divided into the following domains: General Satisfaction, Life Impact, Activities of Daily Living (ADL), Independence and Occupation. Single statements concerning appearance, reliability, and insurance payment for surgical procedures were included. Clinician responses of 'Agree' and 'Strongly Agree' were interpreted as positive results. 'Don't Know' responses were removed from the analysis and examined separately. 'Neutral', 'Disagree', and 'Strongly Disagree' were nonpositive results.

The five perceived outcome domains were further examined for a relationship between the center's opinion on reconstructive surgery use and the number of surgery recipients followed by the center. The number of positive (strongly agree or agree) and nonpositive (neutral, disagree and strongly disagree) responses in each domain were determined for those centers following 10 or fewer individuals who have had reconstructive surgery and those following 11 or more individuals. A Mann–Whitney *U*-test was used to compare the two groups.

Results

Initial response to the survey was obtained from 12 of the 18 Model SCI Systems. A second contact was made to the centers that did not respond after approximately 6 months. The second contact yielded responses from an additional five centers showing an overall response rate of 94%. Of the 17 respondents, 16 were physical medicine and rehabilitation physicians. The remaining respondent was an occupational therapist.

Figure 1 shows the number of tetraplegic individuals who have had upper extremity surgical reconstruction followed by each center. Of the 17 individuals/centers who responded, two have followed no surgery recipients; seven have followed 1–10 recipients; five have followed 11–20 recipients; one has followed 21–50 recipients; and two have followed more than 100 recipients.

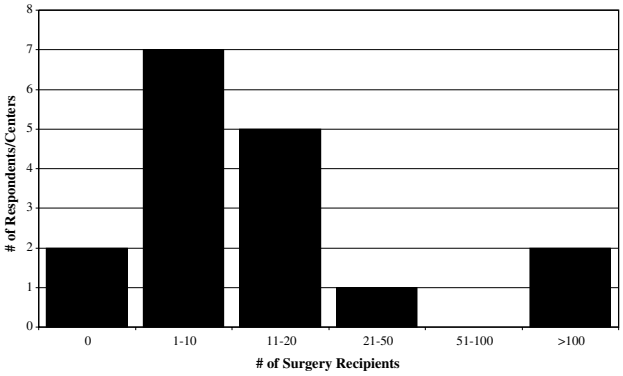

Figure 1 Number of tetraplegic participants who have had tendon transfers followed by each respondent

In general, responses to the 28 Likert-style statements were positive (Figure 2). Many positive statements were noted in the perceived outcomes category. Fewer positive responses resulted from the statements concerning availability and appropriateness of the procedures at the various centers.

Availability and appropriateness

Overall, 76% of the respondents reported positively about the availability of upper extremity reconstructive procedures at their center. Of the respondents, 94% felt that reconstructive procedures should be a rehabilitation option and 69% reported that these procedures are a part of their center's rehabilitation options. Of these centers, only 45% report that persons with tetraplegia who are appropriate actually receive surgery. The centers that offer surgical reconstruction report that such services are offered to individuals with C5 tetraplegia (73%), C6 (91%), C7 (73%), C8 (45%) and T1 (36%). No center reported use of reconstructive surgery in persons with C4 tetraplegia. In all, 94% of all of the respondents said they were familiar with the surgical procedures for individuals with tetraplegia, and 88% felt that surgery should not be performed prior to 1-year postinjury.

Perceived outcomes

General satisfaction Of the respondents, 75% felt that surgery recipients were generally satisfied with their results. When asked to estimate recipients' satisfaction, 87% of the respondents felt that recipients were satisfied with their surgeries, 67% felt that the surgeries met recipients' expectations, and 79% felt that if surgery recipients had to do it over, they would have the surgeries again. Of the respondents, 69% said that they recommend surgery to persons with tetraplegia.

Life impact Of the responses, 80% were positive with respect to the impact reconstructive surgery had on surgery recipients' lives. Of the respondents, 80% felt

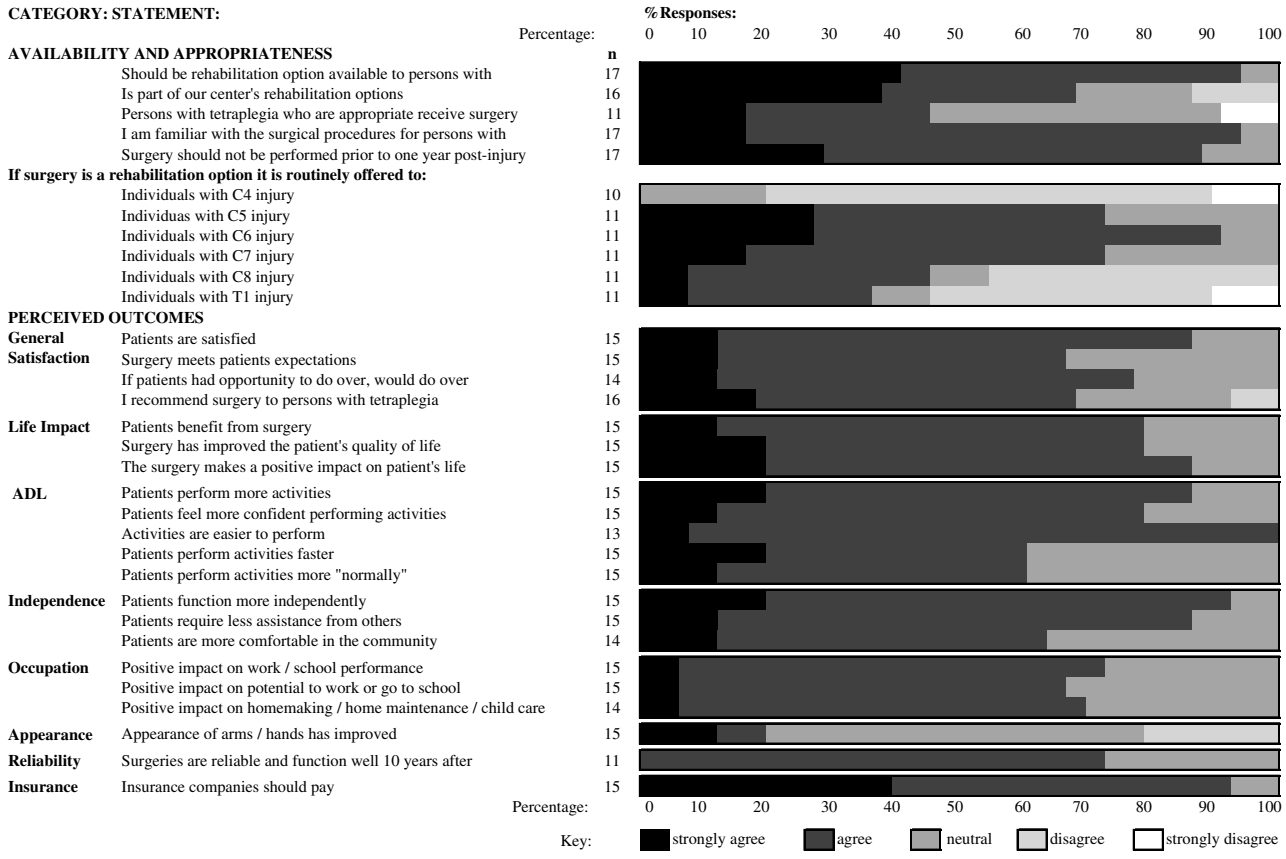

Figure 2 Responses to the Likert-style statements are shown above. 'Don't know' responses were removed from the analysis and the number of respondents for each question was adjusted accordingly

that recipients benefited from surgery, 80% felt that surgery improved the recipients' quality of life, and 87% felt that surgery makes a positive impact on the recipients' life.

ADL In all, 77% of the responses with respect to ADL performance after reconstructive surgery were positive. Of the respondents, 87% felt that surgery recipients performed more activities after surgery, 80% reported that recipients felt more confident performing activities, 100% felt that activities were easier for the recipient to perform, 60% said recipients perform activities faster, and 60% felt that recipients performed activities more 'normally'.

Independence Overall, 81% of the responses related to independence were positive. Of the respondents, 93% felt that surgery recipients function more independently, 87% felt that they required less assistance from others, and 64% believed that recipients were more comfortable in the community.

Occupation In all, 70% of the responses for the statement related to occupation were positive. Of the respondents, 73% felt that surgery had a positive impact on recipients' work or school performance and 67% felt that it had a positive impact on their potential to work or attend school. In all, 71% percent felt that the surgery had a positive impact on homemaking, home maintenance, and child care activities.

Appearance Of the respondents, 20% felt that surgery improved the appearance of recipients' arms/hands. In all, 60% were neutral about the appearance after surgery.

Reliability Of the respondents, 73% reported that the surgeries are reliable and function well for recipients 10 years later. The remaining 27% were neutral. No one felt that the function diminished for surgery recipients over time.

Insurance In all, 73% of respondents felt that insurance companies should pay for upper extremity reconstructive surgery for persons with tetraplegia and 7% were neutral.

Figure 3 represents the percentages of positive responses in relation to the number of surgery recipients

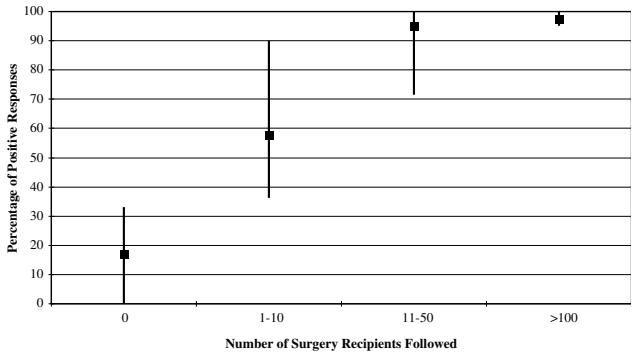

Figure 3 Percentage of positive, neutral, and negative responses in relation to the number of participants followed as reported by each respondent/center is shown. The median percentage and range of percentages are shown

Table 2 Reasons reported for not providing upper extremity reconstructive procedures

Reasons	*# Centers that reported*
Insurance does not cover	4
No surgeon	3
Refer to another center	2
No therapy	1
Not benefit	1
Costs too high	1
Few pts interested, hard to justify need	1
Program under development	1

Eight centers reported not providing the option of reconstructive surgery to persons with tetraplegia. The reasons for not providing this service and the number of centers reporting each reason are given above. Some of the centers reported more than one reason

followed as reported by each respondent/center. Respondents who had followed fewer recipients (10 or fewer) had lower median percentages of positive responses and higher median percentages of neutral and negative responses. Respondents who had followed a greater number of individuals who have had reconstructive surgery (11 or more) had higher median percentages of positive responses. The respondents who reported following more than 100 surgery recipients had no negative responses. There was more variability in response among the respondents with less experience in following persons who received reconstructive surgery. A Mann–Whitney *U*-test comparing the two groups yielded a *W*-value of 32.00, $P = 0.004$.

Eight centers reported that they do not provide the option of upper extremity surgical reconstruction to persons with tetraplegia. The reasons for not providing this service and the number of centers reporting each reason are given in Table 2. The most common reasons reported were that insurance would not provide coverage for the service, a surgeon was not available, or potential candidates were referred to another center.

Figure 4 shows the differences in the perceived outcomes by clinicians to the levels of satisfaction reported by individuals who received reconstructive surgery.[23] For all domains where a comparison was possible (General Satisfaction, Life Impact, ADL, Independence, Occupation, Appearance and Reliability), the persons who had undergone tendon transfer procedures ($n = 67$) reported slightly lower levels of satisfaction than the levels of satisfaction perceived by the clinician respondents to this survey. The only exception is to the statements with respect to occupation, where surgery recipients responded more positively than the clinicians.

Discussion

This study explored the utilization of upper extremity reconstructive procedures for individuals with tetraplegia at the Model Spinal Cord Injury Centers. Most of the clinician respondents (88%) reported having followed some individuals who have had reconstructive surgery. Within this group of clinicians, most (80%) reported following 20 surgery recipients or fewer, while only two clinicians (13%) reported following more than 100. Only one clinician respondent reported having followed 21–50 surgery recipients and no respondents reported following 51–100 recipients. Therefore, although most of the clinician respondents have had direct experience in working with recipients of reconstructive procedures, only two have had extensive experience in this area. The fact that only two respondents reported having had extensive experience in following recipients of reconstructive surgery may be a reflection of: (1) upper extremity reconstructive procedures is a newly established program at a center or (2) the clinician respondent is early in his or her career or experience with this population.

The statements of the survey reflect three main themes or categories: the level of tetraplegia to which surgery is routinely offered, the clinician's perception of outcomes for recipients of reconstructive surgery, and the availability of the procedures at a center. No center reported offering the surgery to persons with C4 level of injury, due to the lack of surgical options available to assist individuals at that high level. Surgery was most often reported as being offered to individuals with C5–C7 tetraplegia. This corresponds to present clinical practice as these individuals have a significant need for improved hand function and the availability of muscles strong enough to be transferred for function. Reconstructive procedures at the C8 and T1 levels were less frequently reported, likely related to minimal deficits in hand function at this level.

Responses to the survey items where clinician respondents were asked to estimate the satisfaction of surgery recipients were generally positive. At least 70% of the responses overall were positive in the categories of General Satisfaction, Life Impact, ADL, Independence and Occupation. The categories of Appearance and Reliability of the procedures over time showed

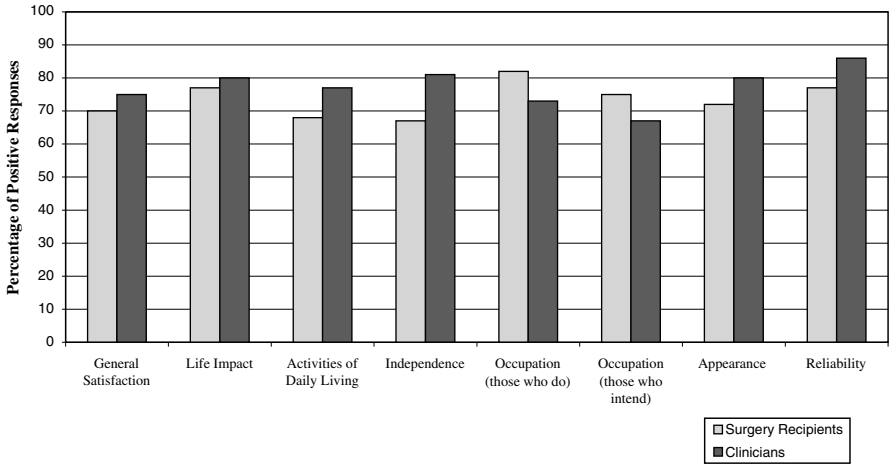

Figure 4 Comparison of the participants' and clinicians' positive responses to the statements in the perceived outcomes category. The persons who had undergone reconstructive surgery generally reported lower levels of satisfaction than what was perceived by clinicians. For the statement with respect to appearance of the hand following surgery, positive and neutral responses are represented to show that very few respondents thought that surgery had a negative effect on appearance

variability in the responses. The authors did not anticipate that respondents would report improved appearance of the arm or hand. However, 20% of the respondents reported this to be true, whereas 60% were neutral and 20% responded negatively. The negative responses could have resulted from the consideration of the scars caused by surgery. Conversely, the positive responses could have resulted from the impression of improved hand posture postsurgery. There was a low number of respondents to the question of whether reconstructive procedures function reliably after 10 years. This is not surprising, considering the large number of respondents who reported following 10 or fewer surgery recipients. Increasing time and the number of recipients followed is likely to change the response to this question.

It is interesting that 93% of the respondents felt that insurance companies should pay for tetraplegic individuals to have reconstructive surgery, considering that only 10 of the centers offer this service and out of those centers, the number of individuals followed is relatively low. However, in considering the high number of positive responses shown in the category of perceived outcomes, it is not surprising that most of the clinician respondents feel that insurance companies should pay for procedures. No respondent felt that insurance should not pay for reconstructive surgery and rehabilitation. Therefore, procedures are not offered for reasons unrelated to their value.

Although the general impression is that clinician respondents feel that this population benefits from reconstructive surgery, the utilization of these procedures is surprisingly low. In fact, most of the negative responses to the survey were from items related to the availability of procedures at a center. A very high number of respondents agreed that reconstructive surgery should be a rehabilitation option available to individuals with tetraplegia. However, a smaller percentage of respondents reported that reconstructive surgery was an option at their center. An even smaller percentage of respondents reported positively that persons who are appropriate actually receive surgery. This raises the question of why these persons do not actually receive the surgery. Various reasons could include: (1) the individual's disinterest, (2) lack of education about the procedures and benefits, (3) perception of insurance refusing to pay, (4) interference with the person's vocational/avocational pursuits, (5) lack of resources such as transportation to follow-up visits, (6) postoperative encumberance, (7) fear of surgery or change, or (8) the perception that surgery now would later be a disadvantage in case of a cure for SCI.

Unfortunately, one of the primary reasons that centers reported for not providing surgical reconstruction to tetraplegic individuals is based on the misconception that insurance companies will not reimburse for these procedures. In fact, the centers that provide this service have established a set of billing procedures that have become mainstream to recover costs for surgery and subsequent rehabilitation. These centers would not likely be able to continue to offer this service if insurance companies did not provide reimbursement. Education in the process of obtaining reimbursement is key to the success of upper extremity reconstructive surgery programs for persons with tetraplegia. Centers with programs that are well established serve as informational resources.

Another reported limitation to the provision of upper extremity reconstructive procedures is the lack of a surgeon to perform the service. The act of performing reconstructive procedures on persons with tetraplegia is becoming more and more common. Surgeons who already perform this service have a network with other surgeons who provide this service. If a center was interested in establishing an upper extremity reconstruction program, a surgeon could be sought via this

network, or the center could refer their patients to another center as two of our responding centers have reported.

This inquiry also revealed a relationship between the amount of positive responses and the amount of surgery recipients the respondent has followed. This finding is not surprising as clinicians who believe in the merits of reconstructive procedures would be more likely to recommend these procedures to potential candidates. Respondents who have followed fewer recipients (10 or fewer) had lower median perceived outcome scores and greater ranges, indicating more varied responses. This may be the result of limited experience with surgery recipients by some of the respondents. Centers/respondents who followed more recipients showed less variability in their responses, most likely due to having had greater experience with persons who have had the surgery.

The comparison of the respondents' perception of outcomes to those reported by surgery recipients[23] is intriguing. There is a small but clear difference between 'clinicians' perception' and 'recipients' perception' of the outcome. The clinicians reported their perception of surgical benefits to recipients to be higher than what the recipients themselves reported. In most cases, the difference was small, approximately 10% or less; however, the difference was slightly larger for the subcategories in ADL and Independence. Occupation was the only category in which surgery recipients responded more positively than the clinician respondents.

There are many questions that emerge from this information. Is satisfaction lower than what the clinicians anticipate because the recipients' answers are reflecting their experiences with the process of surgery and rehabilitation (for example, pain, discomfort, length of time for rehabilitation)? Does this difference reflect the need for clinicians to become better aware of recipient outcomes through better and more frequent outcome measurements? Although the difference in what the clinicians and the surgery recipient think is generally small, it deserves more exploration. Although there are differences, the magnitude of the differences is not alarming, considering that it is a comparison between what doctors think and what surgery recipients think. Overall, these results are promising, because having doctor and client agreement is very important in the success of this type of intervention, which has the potential to impact a person's functional abilities profoundly.

In examining the reasons why reconstructive surgeries were not provided, a small discrepancy in how two of the centers responded was found. Six centers did not respond positively to providing reconstructive procedures as a rehabilitation option at their center (three centers neutral, two disagree, and one 'don't know'). Eight centers reported reasons why reconstructive procedures were not provided at their center. Of the two centers that seemed to have given contradictory responses to the two questions, one reported that reconstructive procedures are an option at their center but that they refer potential candidates to another center to have them performed. The other center indicated that insurance did not pay for the procedures, even though it is known that this service is a rehabilitation option at that center. Perhaps, the respondent misinterpreted the question, or the response reflected that candidates are provided with services at this center despite insurance issues.

The survey contains statements that are worded positively. The Likert scale provided for response is balanced between negative and positive responses, allowing respondents the opportunity to express opinions that are not positive. In general, the 'neutral' and 'I don't know' responses to the survey were fairly evenly distributed across the statements rather than concentrated in one area. Many of the 'I don't know' responses came specifically from one respondent, but the rest of those responses came from varying respondents/centers.

The authors believe that the reported low utilization could reflect a misinterpretation of the question eliciting this information. The intent of the question was to determine, without a specified time frame, approximately how many individuals with reconstructive procedures are followed at each particular center. In hindsight, however, it was seen that the question may have encouraged the respondent to report their own personal experience in the number of surgery recipients followed rather than the experience of the center as a whole. To explore fully the reasons for the wide disparity between the centers that perform these surgeries on a routine basis and the centers that perform few or no surgeries would require additional in-depth study. The authors feel that the information provided by this survey accurately reflects modern impressions and challenges in employing upper extremity reconstructive procedures in individuals with tetraplegia.

Conclusion

The purposes of this study were many: (1) to determine the utilization of reconstructive procedures for persons with tetraplegia at model center SCI systems; (2) to measure the perceived outcomes of these procedures by the clinicians at these centers; (3) to compare the utilization and perceived outcomes of these procedures with the number of surgery recipients the clinician has reported to have followed; and (4) to compare the clinicians' perceived outcomes of the procedures with an actual measure of participant satisfaction with reconstructive surgery. The survey responses have indicated that almost all of the clinicians are aware of the procedures available to improve function for tetraplegic individuals; however, their utilization could be higher at many of the centers. The respondents who reported following larger numbers of participants were generally more positive about the outcomes of these procedures. The responses of surgery recipients in a similar study were not radically different from those of the clinicians;

however, the clinicians generally reported the recipients to be more satisfied.

Although the results of this survey are positive toward reconstructive procedures for persons with tetraplegia, they also show the need for more frequent and more specific outcome measures to be taken to reflect the effects of the procedures. This would enable better education of the surgery recipients and clinicians in what to expect from surgery and provide more information to third-party payers to support education about reimbursement for these procedures.

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