ORIGINAL ARTICLE

Acceptable benefits and risks associated with surgically improving arm function in individuals living with cervical spinal cord injury

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Study Design: Secure, web-based survey.

Objectives: To determine how quadriplegics in the US view tendon transfer surgeries (TTS) and what activities of daily living (ADL) involving arm/hand function are important in improving quality of life (QoL).

Setting: World wide web.

Methods: Individuals ≥ 18 years of age living with a cervical spinal cord injury (SCI). Participants obtained a pass code to enter a secure website and answered survey questions. A total of 137 participants completed the survey.

Results: Two-thirds of participants had injury levels between C4/5 and C5/6. Over 90% felt that improving their arm/hand function would improve their QoL. ADL that were ranked most important to regain were dressing, feeding, transferring in/out of bed, and handwriting. Less than half of the participants had never been told about TTS and only 9% had ever had TTS. Nearly 80% reported that they would be willing to spend 2–3 months being less independent, while recovering from surgery, to ultimately become more independent. Over 75% reported that the ideal time preferred to have TTS, if chosen, would be within 5 years post-injury.

Conclusion: Regaining arm and hand function is of primary importance to individuals with cervical SCI, in particular, to increase independence in multiple ADL. There is a critical need in the US to improve awareness of TTS as a viable option for improving arm/hand function in some people. This information needs to be provided early after injury so that informed choices can be made within the first 5 years.

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Introduction

Sustaining a spinal cord injury (SCI) is a life-changing event. There is a physical loss of function as well as psychological, social and economic losses. Having an injury in the cervical spinal cord is even more significant because arm and hand impairments greatly reduce one's ability to care for oneself, which forces one to rely on attendants for daily, life-sustaining needs. Relying on attendants is financially overwhelming, unpredictable, and extremely stressful.

Regaining arm/hand function has been documented as the highest priority for people with cervical SCI.^{1–3} One

intervention that exists and has been well-documented to enhance the function is reconstructive surgery of the upper limb through tendon transfers.^{4–9} The primary outcomes targeted with these interventions are elbow extension, key pinch, and hook grip. All these are the movements vital for the independent performance of multiple activities of daily living (ADL). Despite the fact that these surgeries have been available and continuously improved upon for over 40 years, relatively few people with cervical SCI have had them, especially in the US. It is estimated by expert opinion that approximately 50% of the people with cervical SCI would benefit from some sort of upper limb reconstructive surgery.^{5,10–13} One recent epidemiologic study reported that only 14% of qualified candidates actually received reconstructive surgery in the US.¹³

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The goal of this study was to identify underlying reasons as to why the majority of people with cervical SCI in the US do not undergo tendon transfer surgery (TTS) to improve upper limb function.

Materials and methods

Survey design

A questionnaire was developed to acquire information about TTS from people with cervical SCI living in the US. The questionnaire was divided into six sections: (1) demographics and current health, (2) independence level, (3) arm/hand function, (4) TTS, (5) risk-benefit, and (6) quality of life (QoL). Wherever possible, lists of answers were provided for each question. This was done to standardize responses. To obtain a portable document format (PDF) version of the complete survey questions and answer choices, contact the corresponding author.

The study was approved by the University of California, Irvine Institutional Review Board (IRB). We certify that all applicable institutional and governmental regulations concerning the ethical use of human participants were followed during the course of this research. Attached to the survey was an introductory statement explaining the purpose of the survey, directions for participating, the right to privacy, what the results were to be used for, and informing that one of the investigators conducting the survey also had a cervical SCI. This information served as the informed consent statement, as required by the IRB.

Participant recruitment

The eligibility requirements for the survey were simply that an individual must be ≥ 18 years of age and must be living in the US with a permanent cervical SCI. Advertisements were placed on multiple SCI websites, online support groups, SCI bulletin boards, and so on. Print advertisements were also placed in *Paraplegia News*, *New Mobility*, Reeve-Irvine Research Center's *Spinal Connections* newsletter, and the California Paralyzed Veterans Association's monthly newsletter.

Eligible participants contacted the principal investigator to receive a randomly generated pass code for entry into the secure website. Upon completion of the survey, the pass code used by an individual to enter the website was unlinked from his/her answers, thereby preserving anonymity. Individuals who did not have access to the internet and were interested in participating could receive a paper version of the questionnaire through mail to complete and send it back to the principal investigator. Participants were enrolled over a 5-month period.

Statistical analyses

Statistical assessments were carried out using the JMP 7.0 Statistical Discovery software package from SAS. Descriptive analyses of the data were first carried out, followed by a series of bivariate analyses. The resulting contingency tables were reviewed and none of the factors accounted for $>9\%$ of the

variability of responses; therefore those data are not presented here.

Results

Demographics

There were a total of 137 participants, out of which 90 were males (66%). The mean age of the study population was 44 ± 14 years. The mean number of years post-injury was 13 ± 11 years. Approximately 19% of all participants had a SCI in the C1–C4 region, 61% had a lesion in the C4/5–C5/6 region and 20% had injuries in the C6–C8 region. The same cause-of-injury classification groupings used by the Model SCI Systems (National SCI Statistical Center) were used in this study (vehicular incidents, fall, violence, sports, and so on). The most common cause of injury was related to vehicular incidents (53%), followed by sports (23%), falls (12%) and violence (7%). Table 1 contains data regarding multiple components of neurological intactness, current health, and functional ability of all the participants.

Tendon transfer surgery

The first questions were regarding knowledge about TTS. When asked about it, 61% of the participants had at least heard of the phrase. However, only 39% had ever been told that TTS may have been an option for enhancing their arm

Table 1 Neurologic intactness, current health, and functional ability of all participants

Characteristic	Yes (%)
<i>Neurologic intactness</i>	
Feel touch below level of lesion	63
Feel touch in anal area	55
Tell difference between sharp and dull	37
Voluntarily tighten anal sphincter	26
Lift legs against gravity	28
Walk without assistance	12
<i>Current health</i>	
Reported chronic pain	28
Reported severe spasticity	48
Reported depression	19
Use bladder maintenance medication	53
Use pain management medication	39
Use spasticity medication	61
<i>Functional ability</i>	
Require help getting in/out of bed	70
Require help with bladder/bowel/pelvic hygiene	73
Require a person to help with other personal hygiene	48
Require equipment to help with other personal hygiene	27
Require help cooking food	78
Drive adapted vehicle	39
Require help with laundry and house cleaning	86
Biceps movement	87
Triceps movement	41.5
Thumb-index finger pinch	22.5
Extend wrists	52.5
Rotate forearms inwards	53.5
Flex wrists	44
Sensation in thumb-index finger	62.5

Figure 1 Source from which information was received regarding TTS. Categories from which information was received from included: doctor, therapist, friend, media, and other. The majority of people who received information about TTS received it from a doctor or therapist.

Figure 2 Ideal time frame post-injury to undergo TTS. The time periods were separated into the following groups: less than 1 year post-injury, between 1 and 5 years post-injury, between 6 and 10 years post-injury, greater than 10 years post-injury, and never.

Table 2 Types of tendon transfer surgery undertaken

Type/combination	Number
Elbow extension	1
Key pinch	4
Finger flexion	1
Finger and thumb extension (opening hand)	1
Elbow extension+key pinch	1
Elbow extension+key pinch+finger flexion	1
Elbow extension+key pinch+finger flexion+finger and thumb extension	1
Key pinch+finger flexion+finger and thumb extension	1
Finger flexion+finger and thumb extension	1

or hand function. Among the people who had been told about TTS, 50% were told within 1 year post-injury and 32% were told within 1–5 years post-injury. Figure 1 shows that the majority of participants who had been informed that TTS may have been a viable option, received the information from either doctors or therapists.

Only 9% of all participants had actually ever had TTS and 75% of those were performed within the first five years post-injury. Table 2 lists the types and combinations of TTS that those participants received. The majority of participants (78%), however, expressed interest in learning more about TTS.

The next questions pertained to how people weighed the risks versus benefits of TTS. Regarding triceps function, 44% of participants stated that they would be willing to undergo surgery to regain a 30% increase in elbow-extension strength (36% already had triceps function). Regarding finger-thumb pinch, 66% of participants stated that they would be willing to undergo surgery to obtain a 50% increase in pinch function (18% already had finger-thumb gripping ability). Furthermore, the majority of participants stated that they would be willing to spend 2–3 months being less independent, while recovering from TTS to become more independent after healing fully and undergoing rehabilitation (79%). In addition, Figure 2 shows that the ideal time to have TTS would be within 1 year post-injury. Finally, 76% of

participants stated that if the costs associated with TTS, recovery, and rehabilitation were covered by their health insurance, they would choose to have TTS.

Quality of life and activities of daily living

The final group of questions focused on how impairments in arm/hand function impact QoL and which ADL were deemed as high priorities to regain arm/hand function in people with cervical SCI. Sixty-eight percent of participants expressed that their SCI had altered their sense of self and 92% indicated that improving arm/hand function was important to improve their QoL. Participants were asked to rate several ADL as to whether they were very important, somewhat important, or not important to regain arm/hand function. These activities were chosen arbitrarily to provide a general representation of ADL influencing independence to a variety of cervical injury levels. Many other specific activities could have been included, but were not done in an effort to limit the burden of the survey. Figure 3 shows that the activities that $\geq 50\%$ of the participants rated as very important to regain were dressing, feeding, transferring in/out of bed, writing, and propelling a manual wheelchair (asterisks, Figure 3). The ranking of a task as important or not was independent of having biceps, triceps, and/or pinch function (data not shown).

Discussion

This study shows that the majority of participants believe that their SCIs altered their sense of self and that improving their arm/hand function would improve their QoL. The data also show that the subject population views the benefits of regaining elbow extension and/or finger-pinch ability as outweighing the risks associated with the TTS surgical procedures and recovery period.

Figure 3 Daily activities important to regain. Individuals rated the following categories as very important, somewhat important, or not important: transfer yourself in/out of bed, transfer yourself in/out of car, propel a manual wheelchair, better maneuver an electric wheelchair, feed yourself, dress yourself, catheterize yourself, sexually satisfy yourself, and perform handwriting.

Why are people not utilizing upper limb reconstructive options?

The most obvious factor influencing this situation is that the majority of participants in this study had never been informed about the option of undergoing TTS to enhance their potential level of functional independence. It stands to reason that this is the predominant situation in the SCI community throughout the US. Among the participants who had actually been told about TTS, the majority received the information from a doctor or a therapist. A survey of clinicians at the Model SCI Systems sites showed that TTS was usually available at their centers and that these surgeries are appropriate and beneficial for the intended population.¹⁴ Unfortunately, the majority of people in the US who sustain a SCI do not end up at a Model SCI Systems center. It is estimated that the National SCI Statistical Center database, which is fed by the Model SCI Systems, represents only 13% of all the people with SCI in the US.¹⁵ It is a reality, then, that most people who sustain a SCI are not cared for by clinicians who specialize in SCI and treat patients with SCI on a daily basis. It is a reasonable assumption that such clinicians may not be aware of TTS availability, efficacy, or reimbursability. Hence, this may be one of the reasons why the majority of people with cervical SCI are not aware of TTS options.

In addition, a recent study assessed the perceptions of individuals with cervical SCI who had been informed about upper limb reconstructive surgery. It was found that people who received information about these procedures from physicians were most likely to have a negative first impression compared with the individuals who received information from other sources.¹⁶ Another potential factor could be that people simply do not want to undergo the invasive procedures associated with TTS. Wuolle *et al.*,¹⁷ however, examined satisfaction levels in a group of 66 individuals who had undergone upper extremity surgery. When asked if they were satisfied with their overall surgery, ~65% of them were satisfied, ~17% were neutral and ~18% were not satisfied. The reasons for dissatisfaction were not

identified. When asked if they would have the surgery again, 77% of them said yes. Our data further suggest that people are willing to undergo surgical risks and temporary loss of independence to eventually gain more function.

Potential sample bias

As with any study involving humans, only those individuals who are interested will volunteer to participate. Thus, it is possible that the data obtained from the study participants may not be a representative sample of the entire population with the disease of interest. Nevertheless, important information can be gained from such studies.

Using an internet-based survey is a recent innovation that offers many advantages in accessing potential research participants. The Internet has become a prominent means of gathering resource information and has removed multiple barriers for many people with SCI, who in the past may have had limited access to information and who may have experienced social isolation. Precautions must be taken, however, as there are good and bad things about the Internet. For that reason, the security measures described in the Materials and methods section were employed. However, earlier studies show that people with SCI prefer to receive research information through the Internet¹⁸ and important scientific information can be gained from Internet-based research surveys.^{2,19} In an effort to not exclude individuals who did not have access to the Internet, we placed recruitment advertisements in multiple disability magazines providing the option of completing the survey through the postal mail. It must be pointed out, however, that there is an unknown proportion of people living with SCI, who are either isolated and have no means of learning about research studies, or who have no interest in hearing about or participating in research. Therefore, the data presented here may even be an over-representation of how much knowledge and access to information the SCI population actually has about TTS.

Limitations of the study

Ideally in a research survey one would like to obtain as many answers as possible to prospectively asked questions. At least two factors influence this, however, in the practical setting. First, the survey must not be too long, otherwise it could become burdensome to the participants. Second, the data usually generate more questions that one would wish to have queried originally. Using a secured, de-identified database is prohibitive of asking the participants questions retrospectively. In relation to the data presented here, it would have been enlightening to find out how much detailed knowledge participants already had about the risks associated with TTS, as well as how long they would be willing to be less functional after any intervention with the hope of becoming more functional later. It would have been informative to identify how much rehabilitation/retraining people would be willing to undergo after a surgical intervention and for how long.

The data regarding general ADLs that are important to regain may be a representation of many factors. As the

activities were general, to represent a range of cervical injury levels, people with lower level injuries may have already been able to carry out some of the tasks, thus rated those as 'not important'. However, the majority of people included comments regarding the tasks and less than 25% stated that they could already carry out some of them. The majority of people stated that any degree of improvement in arm/hand function would allow them to carry out an activity that they currently could not perform or it would allow them to carry out an activity in an easier manner.

Toward the future

The findings presented here indicate that improving arm/hand function remains a priority for people living with SCI and that the current means of enhancing function are not being offered to many individuals living with cervical SCI in the US. Expanding knowledge and potential use of procedures that are already known to improve arm/hand function is not only warranted, but is also a moral obligation. Furthermore, the data indicate that one cannot predict what is important to people living with SCI simply by knowing what muscle function is intact.

In light of the fact that most people sustaining a SCI in the US are not treated in SCI-specialized centers, it is imperative that a clinical educational initiative be developed, targeted at raising awareness among non-SCI specialized physicians about the efficacy, safety, and availability of upper limb reconstructive options as well as other highly relevant options, such as emerging advances in the development of neuroprostheses. It may be most effective to develop a handful of highly-specialized centers scattered across the country to which people can be referred. This could optimize outcomes and provide more information about efficacy, satisfaction, re-training strategies, and so on. The success of restricting where procedures are performed, however, does depend on a nationwide awareness campaign for all physicians who may come in contact with a person having a SCI so that they are informed about referral options. Ultimately, providing people with the opportunity to undergo therapeutic treatments that can lead to greater functional independence will significantly impact multiple factors influencing the lives of individuals living with SCI.

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