

ORIGINAL RESEARCH

Decision-Making About Upper Limb Tendon Transfer Surgery by People With Tetraplegia for More Than 10 Years



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Abstract

Objectives: To quantify time from spinal cord injury to upper limb reconstructive surgery for individuals with tetraplegia; to explore influences on decision-making about surgery for persons with long-standing (>10y) tetraplegia; and to determine the applicability of our previously developed conceptual framework that described the decision-making processes for people with tetraplegia of <5 years.

Design: Quantitative-qualitative mixed-methods study.

Setting: Community based in New Zealand.

Participants: People (N=9) living with tetraplegia for >10 years.

Interventions: Not applicable.

Main Outcome Measures: An audit of time frames between injury, assessment, and surgery for people with tetraplegia was undertaken. Interviews of people with tetraplegia were analyzed using constructivist grounded theory.

Results: Sixty-two percent of people with tetraplegia assessed for surgery had upper limb reconstructive surgery. Most were assessed within the first 3 years of spinal cord injury. Over half had surgery within 4 years after injury; however, 20% waited >10 years. Changes in prioritized activities, and the identification of tasks possible with surgery, were influential in the decision-making process. Participants were aware of surgery, but required a reoffer from health professionals before proceeding. The influence of peers was prominent in reinforcing the improvement in prioritized activities possible after surgery.

Conclusions: Findings confirmed that the previously developed conceptual framework for decision-making about upper limb reconstructive surgery was applicable for people with tetraplegia of >10 years. Similarities were seen in the influence of goals and priorities (although the nature of these might change) and information from peers (although this influence was greater for those injured longer). Repeat offers for surgery were required to allow for changes in circumstances over time.

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Regaining arm and hand function is documented as the highest priority for people with tetraplegia.^{1,2} One intervention that exists and demonstrates improvement in arm and hand function is reconstructive surgery of the upper limb through tendon transfers.³⁻⁹ These surgical techniques can provide elbow extension,

key pinch, and gross grasp. All of these movements are important for performing activities of daily living (ADL). Despite the wide availability of these procedures, the uptake of surgery by people with tetraplegia is relatively low.^{10,11} In the United States, the uptake is reported to be as low as 10%.¹⁰ Possible reasons for low uptake have been explored and include the following: lack of knowledge of the procedures in both clinicians and people with tetraplegia,¹² postoperative burden, perceptions that surgery may be a disadvantage in case of a cure for spinal cord injury (SCI),

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interference with recreational pursuits, fear of surgery, and lack of resources for follow-up.^{10,13} The uptake of surgery in countries other than the United States has not been reported, but a 5-year case review in New Zealand found uptake for surgery to be higher than the United States at 44%.¹¹ Issues influencing the decision to have upper limb surgery in New Zealand in the first 5 years after injury¹⁴ were similar to those reported by Curtin,¹⁰ Bryden,¹³ and colleagues.

A conceptual framework of the decision-making process for upper limb surgery in the first 5 years after SCI has been developed.¹⁵ This framework described 3 distinct groups of people: those who actively pursued the option of surgery (let me have it), those who were waiting for further recovery/cure and did not see surgery as an option (no thanks), and those who felt they may want surgery at a later date (maybe later).¹⁵ For this last group, the conceptual framework demonstrated that deciding about upper limb surgery was ongoing rather than a single decision. A number of issues influenced the decision, but these issues appeared to change over time. Therefore, it was recommended that clinicians offer the option of upper limb surgery at different time points postinjury to take into account changing thoughts and priorities. However, the optimal time for this offer and reoffer for surgery has yet to be quantified, and the reasons for the changes in the decision about surgery have not been explored.

The present study had 3 aims. The first is to quantify the time it takes for individuals with tetraplegia in New Zealand to have upper limb surgery. The second is to explore, from the perspective of the person with longstanding (>10y) tetraplegia, the issues that influenced their decision-making about upper limb reconstructive surgery. The third is to determine the applicability of the previously developed conceptual framework¹⁵ describing the decision-making process.

Methods

A mixed-methods approach in a sequential quantitative-qualitative enquiry was used. First, an audit of registry data aimed to quantify uptake of upper limb surgery in New Zealand and the time taken from injury to assessment, assessment to surgery, and injury to surgery. Second, interviews were performed on people identified from the audit as having taken >10 years from their initial SCI to make the decision to have upper limb surgery.

Audit of registry data

Participants

Participants were identified from the International Upper Limb Surgery Registry in New Zealand.¹⁶ This registry contains data with comprehensive information regarding demographics, clinical reports, and surgical history for individuals with SCI since upper limb surgery commenced in New Zealand in 1982. The audit included a review of all individual cases with assessments to determine eligibility for upper limb reconstructive surgery. Cases were included if the records showed the person had a cervical SCI in C4-7 and had been offered surgery. Cases with brachial plexus or nerve injuries or those solely requiring orthopedic procedures (eg,

joint fusions) were excluded. Cases were also excluded if no tendon transfer procedure was performed; however, alternative surgery (eg, lengthening procedures for spasticity) might have been conducted.

Data extraction

Demographic information was collected from the International Upper Limb Surgery Registry¹⁶ and entered into an Excel spreadsheet^a for analysis.

Data analysis

The population was described using medians and interquartile ranges (IQRs) because of the spread of the data. Of interest to this study were the time points: injury to initial assessment, initial assessment to surgery, and injury to surgery. Differences between the surgery and no surgery groups were tabulated and investigated using chi-square tests for nonparametric data. The level of significance was set at .05.

Interviews

Participants

Ethical approval from the University of Otago (Health) Ethics Committee was obtained prior to recruitment of participants to the interview phase. Participants were identified from the audit of registry data. Nine participants were recruited from around New Zealand. Participants were included if they had sustained an SCI at least 10 years previously, were currently living in New Zealand, and were able to speak and understand English. Initial sampling was purposive with the first 4 participants chosen because they had been assessed for upper limb surgery within 3 years of their injury but had elected to have upper limb surgery at least 10 years later. For the remaining interviews, theoretical sampling was used, whereby the selection of participants was directed by the emerging analysis and included participants in different geographic locations, different insurance funding for their injury, long lengths of time to first assessment, and different ethnicities.

Interview

Semistructured face-to-face interviews using the same schedule as our previous study (lasting 20–40min) were used to explore the decision-making process about upper limb surgery. All interviews were performed by one researcher (J.A.D.) and took place at a mutually agreed location; for most participants this was at their own home. Each interview began with broad questions concerning the participant's experiences, issues, and attitudes about SCI and upper limb surgery, followed by more focused questions to explore their decision-making process about upper limb surgery. New issues in the collected data and concepts from the emerging theory were clarified by using increasingly focused and detailed questioning in interviews of subsequent participants. Data collection occurred over a period of 6 months and continued to a point where no new concepts were identified by participants. Additional detailed field notes were written that recorded nonverbal content (eg, when a participant demonstrated use of their hands) and captured the interviewer's immediate impressions of the interview and a general overview of the participant's decision-making process.

Analysis

Interviews were digitally recorded and later transcribed verbatim. Data (both interviews and field notes) were analyzed in

List of abbreviations:

ADL activities of daily living
IQR interquartile range
SCI spinal cord injury

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