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# Nothing to lose: a phenomenological study of upper limb nerve transfer surgery for individuals with tetraplegia

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## ABSTRACT

**Purpose:** For individuals with tetraplegia, regaining upper limb function forms the highest priority for improving quality of life. Use of nerve transfers to reconstruct upper limb function is increasing, however little is known about individual's decision to have and experience of the surgery and associated rehabilitation outcomes. This qualitative study aimed to understand the experience of surgery on the lives of individuals with tetraplegia 18 months post-surgery.

**Method:** In-depth, semi-structured interviews were conducted with five purposively selected individuals who have undergone upper limb nerve transfers at a metropolitan health service, Melbourne, Australia, specializing in spinal cord injury rehabilitation. Collaizi's phenomenological framework guided data analysis, resulting in an essence statement describing the individuals' experience.

**Results:** An essence statement comprising three themes; Deciding on Surgery, Facing Challenges: Surgery to Recovery and Evaluating Surgical Outcomes, was developed.

**Conclusion:** The study suggests that for individuals with tetraplegia, hope to regain lost upper limb function forms a core consideration in the decision to have surgery. For clinicians supporting patient's decision, balancing hope with the realities of surgery is important. Even small changes in upper limb function had an important influence on participant's confidence in social situations through enhanced participation in a range of everyday activities.

## ARTICLE HISTORY

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## KEYWORDS

Spinal cord injury; tetraplegia; nerve transfers; upper limb; reconstructive surgery; qualitative research

## ► IMPLICATIONS FOR REHABILITATION

- In making a decision to have surgery, individuals with tetraplegia benefit from two way discussions with the healthcare team and others who have already undergone surgery.
- Healthcare teams need to help prepare individuals for the challenges of surgery including: expectations of pain, hospital stay, initial loss of independence and the time it may take to see re-innervation of target muscles and subsequent functional changes.
- Surgery should be routinely considered as individuals' report that even small changes in upper limb function positively increases participation in everyday tasks and confidence in social situations.
- When evaluating changes in upper limb function, patient-centered measures should be used.

## Introduction

Worldwide up to half million people sustain a spinal cord injury (SCI) annually [1,2]. Approximately half of all SCI are at the cervical spinal segments C5 and C6, resulting in tetraplegia [2]. Tetraplegia, describes the partial or total loss of sensation and motor control of the torso, and all four limbs [3].

Among those with tetraplegia, regaining upper limb (UL) function has been repeatedly identified as a primary priority for recovery, regardless of time since injury [4–6]. Improved UL function is rated a higher priority for recovery and more important to quality of life than the ability to walk, sexual function, bowel and bladder control, and considered more important than other key life areas such as leisure, employment and relationships [4–6]. Additionally, an American survey of 137 individuals with tetraplegia, found that activities of daily living (ADLs) requiring upper limb function, including dressing, feeding, transferring and writing, were the most important for improving quality of life [7]. Improving UL

function was of such importance to this sample, that four in five participants would be willing to experience up to three months of reduced independence following reconstructive surgery [7].

Current interventions available to enhance UL function for individuals with tetraplegia include surgical and non-surgical techniques. Systematic reviews examining the evidence for reconstructive surgery have supported the use of tendon transfers for improving key UL movements for individuals with tetraplegia. These movements include; pinch, grip, grasp, release and elbow extension, allowing increased independence and participation in ADLs [8,9]. More recently, nerve transfer surgery (NTS) has been increasingly used with this population, demonstrating promising improvements in hand and arm function [10].

Nerve transfers involve moving an active, expendable nerve, which is connected to the brain *via* the spinal cord (donor nerve) to the nerve of a paralysed muscle (recipient nerve). Following surgery axons of the donor nerve grow down the recipient nerve to the muscle motor endplate allowing active movement to be

regained [11]. Nerve transfers are performed earlier than tendon transfers. That is, commonly within 12 months of a SCI for nerve transfers compared with 12 months or more post injury for tendon transfers. Similar to results from tendon transfer surgery, a systematic review of 13 studies found nerve transfers effective for improving elbow extension, grasp, key pinch and release [12,13]. A recent study also found clinically and statistically significant improvements in performance and satisfaction of patient identified goals using the Canadian Occupation Performance Measure following nerve and, or combined nerve and tendon transfer surgery, the first study to utilize patient identified goals of surgery [13]. Some benefits of nerve transfers over tendon transfers have also been found. These include; reduced immobilisation time post-surgery, increased dexterity and the opportunity to re-innervate multiple muscle groups and functions from a single nerve transfer [12–15].

Previous studies have investigated the lived experience of people undergoing UL tendon reconstruction surgery following SCI [16,17]. In a qualitative study, Wangdell, Carlsson and Fridén [16] interviewed 11 people, aged 22–73, with SCI regarding their perceived gains post reconstructive hand surgery. Participants who had undergone tendon transfer surgery experienced enhanced independence in both practical and psychological aspects of everyday life. Participants reported functional improvements including reduced reliance on others for assistance, renewed participation in social activities, decreased environmental restrictions, and psychological enhancements relating to privacy, identity and relationships [16].

The current literature highlights the importance of improving UL function for individuals with tetraplegia, and the effectiveness of tendon transfer reconstruction surgeries in addressing this priority. Increasing quantitative evidence suggests that NTS is a promising addition to current procedures. With UL function crucial to participation in a range of everyday activities identified as important to individuals with tetraplegia, further research is needed to understand the experience and associated outcomes of NTS from patients' perspective. Thus, this phenomenological qualitative study aimed to examine the experience of NTS on the lives of individuals with tetraplegia 18 months post-surgery.

## Methods

Phenomenology focuses on describing individual perspectives and shared meanings of a particular phenomena [18]. This study focuses on the phenomena of NTS and associated recovery to improve UL function following a cervical SCI. Key aspects of phenomenology relevant to this study include; a shared experience among participants, description of subjective perspectives, and investigation of common meanings [18–20]. Thus, this study aimed to address the following research questions:

1. What is the experience of nerve transfer surgery for individuals with tetraplegia; including making the decision to have surgery, their expectations of the outcomes of surgery and the subsequent rehabilitation process?
2. How does the individual perceive their upper limb function to have changed since surgery?
3. How has a change in upper limb function influenced their ability to perform and their experiences of their daily occupations (self-care, productivity, leisure)?
4. What does a change in hand function mean to individuals with tetraplegia in relation to their quality of life?
5. How does nerve transfer surgery and resultant outcome influence the emotional wellbeing of an individual with a cervical SCI?

Human Research Ethics Committee approval from the Health Service (LNR/15/Austin/454) and University (2016-22 R) and informed consent from each participant, was obtained prior to commencing the study.

## Participants

A purposive sample of information rich participants with the necessary experience of NTS to answer the research questions were recruited from at a metropolitan health service specializing in spinal cord rehabilitation, Melbourne, Australia from March to June 2016. Of the twenty five individuals with tetraplegia who had undergone NTS at the health service since commencing in July 2012, 8 potential participants met the study inclusion criteria. Study inclusion criteria were:

1. Aged 18 years and over with tetraplegia.
2. Minimum one UL movement re-innervated solely by nerve transfer surgery, within 18 months of SCI.
3. Minimum 18 months post-surgery at time of interview.
4. Received pre and post-operative care through the health service and
5. Adequate English language skills and a willingness to reflect, in-depth on experience of surgery.

An advertisement was emailed to potential participants. Six responded and interviews were completed with five participants. The sixth participant was contacted however an interview time was unable to be arranged. With no set rules, sample size and saturation in qualitative research may be influenced by a range of factors, such as the study's aim, research design, sample characteristics, data collected, and analysis undertaken [21,22]. The study sample size is reflective of phenomenological qualitative studies and is supported by the narrow focus of the research aim, and the specific knowledge and experience held by participants [19,21]. Participant demographic characteristics are outlined in Table 1. A summary of participant surgical procedures and outcomes are provided in Table 2.

## Data collection

A single, 30 to 90-min audio-recorded, semi-structured interview was conducted *via* videoconference or telephone with each participant in May or July, 2016. Semi-structured interview guide comprised four sections; general information (e.g., interview date and time), study introduction, demographic questions and six interview questions. Interview questions were: (1) What were your goals of having nerve transfer surgery? (2) What was your experience of nerve transfer surgery? (3) Can you describe how your hand and arm function has changed since surgery? (4) What impact have these functional changes had on your daily activities? (5) What do these changes mean to you? (6) Is there any advice you would give to someone who is thinking about having nerve transfer surgery? Interview questions were developed based on existing NTS literature, consultation with an experienced SCI clinician and pilot testing with two individuals with a SCI who had undergone tendon transfer surgery to improve UL function. An additional question focused on exploring the emotional impact of NTS was added following pilot testing. Prior to conducting the interviews the primary author consulted with a SCI clinician to understand the specific movement targeted by the NTS

Table 1. Demographics of participants interviewed.

	Pete	John	Nick	Cam	Tom
Age at interview	30	37	27	23	20
SCI level & ASIA score <sup>a</sup>	C7 ASIA A	C6 ASIA A	C5 ASIA A (Motor sparing of left C6)	C4 ASIA A (Motor sparing of C5/C6)	C4 ASIA A (Motor sparing of C5)
Work/ study before SCI	Full-time work	Full-time work	Full-time university Part-time work	Full-time university Part-time work	Full-time high school
Current Work / Study	Nil formal	Nil formal	Part-time work	Full-time university (different course) Part-time work	Part-time high school
Living situation	Wife; infant son	Wife; school age daughter	Parents	Partner	Parents; 2 siblings
Paid care (hrs/wk)	0	42	30	13	33
Time between SCI and surgery	14 months	8 months	12 months	5 months	6 months
Time between surgery and interview	46 months	38 months	L - 38 months R - 36 months	22 months	21 months

<sup>a</sup>ASIA A Complete = No motor or sensory function is preserved in the sacral segments S3–S5.

Table 2. Participant nerve transfer surgery procedures and outcomes.

	Pete	John	Nick	Cam	Tom
Surgical procedure (donor nerve transferred to recipient nerve) <sup>a,b</sup>	R: supinator-PIN	L: supinator-PIN, brachialis-AIN R: supinator- PIN, brachialis- AIN, teres minor- triceps	L: supinator-PIN, Brachialis-AIN, teres minor-triceps R: supinator- PIN, brachioradials-AIN, teres minor-triceps	L: supinator-PIN, Brachialis-AIN, teres minor & post div ax-triceps R: supinator-PIN, Brachialis-AIN, teres minor & post div ax-triceps	L: supinator -PIN, Brachialis- AIN, post div ax & teres minor- long head & medial head of triceps R: supinator -AIN; post div ax & teres minor- long head & medial head of triceps
Finger extension (MRC)	L: Movement not operated on R: pre 0, post 4	L: pre 0, post 4 R: pre 0, post 5	L: pre 0, post 3 R: pre 0, post 3	L: pre 0, post 4 R: pre 0, post 4	L: pre 0, post 3 R: Movement not operated on
Pinch (MRC)	Movement not operated on	L: pre 0, post 0 R: pre 0, post 3	L: pre 0, post 1 R: pre 0, post 3	L: pre 0, post 0 R: pre 0, post 4	L: pre 0, post 1 R: pre 0, post 3
Pinch strength	Movement not operated on	L: pre 0kg, post NA <sup>c</sup> R: pre 0kg, post NA <sup>c</sup>	L: pre 0kg, post 0kg R: pre 0kg, post 0.5kg	L: pre 0kg, post 0kg R: pre 0kg, post 3kg	L: pre 0kg, post 0kg R: pre 0kg, post 1kg
Grip (MRC)	Movement not operated on	L: pre 0, post 4 R: pre 0, post 0	L: pre 0, post 1 R: pre 0, post 3	L: pre 0, post 1 R: pre 0, post 4	L: pre 0, post 1 R: pre 0, post 3
Grip strength	Movement not operated on	L: pre 0kg, post NA <sup>c</sup> R: pre 0kg, post NA <sup>c</sup>	L: pre 0kg, post 0kg R: pre 0kg, post 0.6kg	L: pre 0kg, post 0kg R: pre 0kg, post 0.5kg	L: pre 0kg, post 0kg R: pre 0kg, post 2.3kg
Elbow extension (MRC)	Movement not operated on	L: Not operated R: pre 1, post 2	L: pre 0, post 3 R: pre 0, post 2	L: pre 0, post 3 R: pre 0, post 3	L: pre 0, post 0 R: pre 0, post 1

<sup>a</sup>Abbreviations: R: right; L: left; AIN: anterior interosseous nerve; PIN: posterior interosseous nerve; Post div ax: posterior division of axillary nerve. <sup>b</sup>Movements restored; supinator-PIN: finger/thumb extension; brachialis-AIN: finger/thumb flexion; teres minor & post div ax-triceps: elbow extension. <sup>c</sup>NA: results not available.

participants had undergone, supporting the researcher's knowledge on the topic to guide the in-depth interviews [23]. The primary author recorded researcher field notes following each interview and transcribed all interviews verbatim. Research field notes supported exploration of initial insights from participant's interviews with subsequent participants during the data collection process [24].

### Data analysis

Phenomenological data analysis draws on structured, analytical and reflective approaches to the data to explore individual experiences that captures the essence of the phenomena examined [18,25]. Guided by Colaizzi's phenomenological framework data analysis involved: (1) data familiarisation by reading and re-reading interview transcripts; (2) identifying and extracting significant statements pertinent to the phenomena from each transcript; (3) formulating meanings from the significant statements; (4) grouping similar significant statements into clusters of themes; (5) producing an essence statement describing the structure of the phenomena; and (6) essence statement was returned to all participants to confirm if their experience had been accurately described and interpreted [18,26]. All

participants affirmed the essence statement when contacted by the primary author, with no changes requested. All members of the research team, including a qualitative researcher and an experienced SCI clinician, independently coded each interview before discussing and agreeing on codes, and subsequent themes across the data. Prior to data analysis the primary author recorded a researcher statement reflecting on knowledge of and experiences relating to SCI, as a means of bracketing any preconceived ideas that may influence the analysis process [18]. Whilst new data collection and analysis may continue to yield new insights [27], ceasing sampling, data collection and analysis requires researchers to make an interpretive judgement [28]. Phenomenology aims to understand the essence of what participants experienced, and how it was experienced [19]. Saturation was considered reached when the core elements of NTS to improve UL function for individuals with tetraplegia and the experience and meaning of these had been captured and subsequently confirmed by participants through member checking.

### Results

*Having nothing to lose* was central to the participants' experience of nerve transfer surgery. When *deciding on surgery*, participants



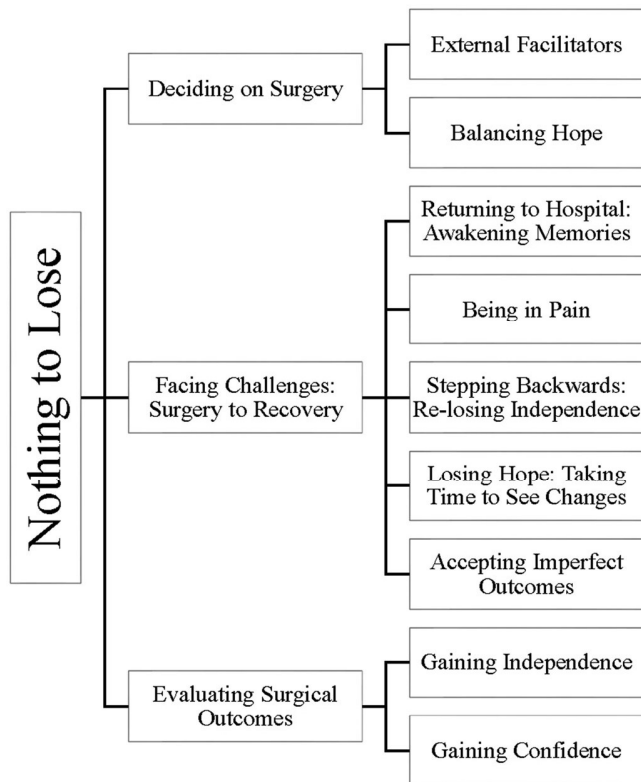


Figure 1. Essence statement themes and associated subthemes.

weighed the influence of external facilitators, reflecting on learning from the experience of others, meeting the treating team and potential costs of surgery. On a personal level, the participants' decision involved balancing their hope to regain UL function, no matter what it was, whilst acknowledging the risks of surgery. Having and recovering from surgery involved *facing challenges*. Returning to the hospital awakened memories from their SCI, whilst the recovery process involved being in pain, stepping backwards re-losing their independence and ultimately losing hope with the time taken to see regained UL movement post-surgery. Gaining independence across a range of everyday activities and confidence in social situations, formed the personal measure participants used when *evaluating their surgical outcomes*. Figure 1 provides an overview of the essence statement themes and associated subthemes identified in this study.

### Deciding on surgery

When deciding to have surgery, the participants reflected on the influence of *external facilitators* and the importance of *balancing hope* with realistic expectations of the potential to regain UL function following NTS.

#### External facilitators

The external facilitators influencing the participants' decision to have surgery included: learning from the experience of others who had previously had surgery, talking to the health care team and the costs of surgery. Cam and Tom reflected on the value of learning from others experiences of NTS in helping make their decision. Tom noted meeting "... a past patient who had the operation and saw how well it helped (him) out" while Cam having "heard really good things about it (the surgery)" stated: "... I didn't ended up meeting anyone that had had it yet,

but I'd seen some videos of people that had had it and it seemed ... like a good idea ... and it seemed pretty successful." Pete and John, the first patients to undergo NTS at the hospital, noted a lack of information available to them at the time. Reflecting on making his decision without other people to talk to, Pete remarked:

... personal experience from others ... would have been good ... there was no one to gage experience of ... to let people know that it is going to be hard work and you are going to lose your independence and it is going to be frustrating, but it is only a short amount of time and having the nerve transfer is for a lot longer ...

Beyond talking with individuals who had undergone NTS, meeting the treating team and physical assessments were important in Tom and John's decision making. Tom noted the value of talking with the treating hospital team and "all the meetings with the surgeons and things that helped (his) decision." Having progressed to a manual wheelchair six months post SCI, John felt his functional capacity was "as good as (he) was going to get." Reflecting on the assessments (physical examination, nerve conduction studies) completed to determine his suitability for surgery, John stated:

... when I had the testing and that done that I'd be able to have it done. ... if I was able to get some hand function back ... yeah it was certainly something that I wasn't going to knock back.

Whilst meeting the test requirements to be offered surgery, John also considered the financial costs of surgery. John stated: "... if it had of been something that we would have had to pay for ... we probably would have thought about it a bit more I guess." These findings highlight the value of learning from others experiences of NTS alongside guidance from the treating team and surgical costs on these participant's decisions.

### Balancing hope

Beyond external facilitators, the participants were balancing hope with realistic expectations; all deciding to proceed with surgery feeling they had nothing to lose. With a significant decrease in upper limb function following SCI, surgery appeared to offer the participants' hope for improved upper limb function. The hope for the surgery centered on enabling participant's "... to get more function out of (their) hands and arms" (Nick). Examples expressed by participants included: "increasing independence" with everyday activities, being able to "pick things up easier" (Cam), "... be(ing) able to open my hand, to be able to shake hands with people" (Pete), or "... hold a pen ... hold onto a bit of fruit or ... can of coke" (John).

The participants hope however was balanced with a sense of having no expectations, having been told that surgery "can be hit and miss" (Cam). Being one of the first to undergo surgery, Pete stated:

... I didn't really have anything to lose. ... I didn't really have any expectation I don't think because ... from what I knew I was one of the first ones to be having it done and they weren't really (sure) if it was going to affect what function I already had and if it was actually going to work out well or not ...

Despite no guarantees, participants accepted the risks of NTS. For instance, John commented: "... because I had nothing, no movement there, the opportunity to get something back ... no matter what it was ... it was still a risk ... worth taking ...". Thus, hope to regain some upper limb function following their SCI formed an important influence on the participants' decision to undergo surgery.

### ***Facing challenges: surgery to recovery***

Undergoing NTS involved participants *facing challenges* as they moved from *surgery to recovery*. During this time, participants faced challenges with *returning to hospital awakening memories* of being in hospital following SCI, *being in pain* and *stepping backwards: re-losing independence* with everyday tasks whilst recovering from surgery. Participants reflected on *losing hope* with it *taking time to see changes* in UL function and *accepting imperfect outcomes* of surgery.

#### ***Returning to hospital: awakening memories***

Undergoing and recovering from NTS, all participants reflected on emotional and/or physical challenges experienced, for example an extended hospital stay or returning to the same hospital participants were admitted to following their SCI. For Nick, having “...been back there (to the hospital) heaps of times” returning for surgery was “no drama.” John and Cam differed noting the challenges of returning to the hospital. John commented: it’s “...a pretty crap scenario ... it felt like we were back when we had our accident.” Undergoing surgery during his initial admission following his SCI, Tom reflected: “I think it would have been harder if I was at home and needed to go back to the hospital, but ... doing it while I was still in (the facility), definitely made it easier.” This highlights the importance of discussing the impact of the hospital admission on the individual and offering individuals control over timing of the surgery.

#### ***Being in pain***

Following surgery all participants reported experiencing UL pain or sensory changes. Describing his surgery as “painful” Nick acknowledged: “it was only sort of in the night for those first few days, maybe first week or so, ... just like any other surgery” and when “doing stuff during the day your mind goes off it.” Cam spoke of experiencing “some sensations changes ... with the nerve swaps” undertaken resulting in “a few sore ... and hypersensitive ... spots” post-surgery. Despite describing his surgery and recovery as “pretty good,” Pete reflected on being “in a sling ... 24/7” commenting: “I was the first person to do it (have the surgery), they weren’t really sure how much I could move my ... shoulder around, so it just got really stiff ... being stuck in the one spot.” These findings suggest the participants appeared to accept pain and sensation changes post-surgery as part of the natural recovery process, but also indicates an opportunity for staff to provide information to individuals early to allow them to normalize their experience.

#### ***Stepping backwards: re-losing independence***

Post-surgery most participants recalled the challenges of taking a “step back,” temporarily re-losing their independence with daily activities regained following their SCI (Tom). John reflected on taking six months “to regain and build back up to where (he) was” before surgery commenting: “...I mean you lose that initially, but once you get that back... and then to lose it again ... yeah, it’s certainly hard doing that.” Nick noted changes in his mobility and assistance needed post-surgery, recalling: “...just not being able to do much at all... so I had to use ... an electric wheelchair ... needed more help from carers and ... from my parents.... just help me do everything really.” Although Cam “struggled a bit just being back to square one” he felt “prepared in a way” having “had a fair few conversations with the Occupational Therapist around what was going to happen once (he) woke up afterwards,” he said:

... I sort of know it was going to be a real average sort of two weeks to a month, so ... just had to bite the bullet and do it because it was going to be better in the long run.

#### ***Losing hope: taking time to see changes***

With nerve regeneration occurring at approximately one millimeter a day, all participants spoke of doing the upper limb rehabilitation exercises “for a little bit and then there seemed to be nothing changing and ... just got tired of doing it and ... stopped” (Pete). Having lost motivation to continue with the exercises, and ultimately hope in the surgery, the participants were “quiet excited about ... movement coming back” (John) when they began noticing the first flicker of movement. Reflecting on noticing his first movements, John commented: “...when I first had that little bit of a flicker ... of movement and ... because ... you don’t know if it’s a bit of a spasm or ... movement or what so you’re a bit unsure.” Reflecting on having been “... told it might take 6–12 months ... for those muscles to kick in and start working, but for (him) it took a bit longer ... probably about 14 months,” Nick offered advice to future patients. He commented: “... So I was sort of just starting to lose hope in it when it started working, so yeah, just be persistent and keep doing the exercises as much as possible.”

Similarly, Cam encouraged future patients to “... not get ... frustrated with how long it takes to get back to where you were ... before you had the surgery” despite continuing to experience “... a bit of pain sensation” from his scars at times. When contemplating whether he would go through with the surgery knowing what he now knows, John remarked: “... without a doubt at all, as I say it was a bit of a hard slog and probably harder than what I thought it would have been,” even with the challenges experienced.

#### ***Accepting imperfect outcomes***

Having known the risks of surgery, participants reflected on *accepting imperfect outcomes*, with the UL and, or hand movements regained post-surgery. For example, although UL function in terms of “... triceps, ... didn’t really work out as much,” Tom observed improvements with finger movement, commenting: “... it’s a big difference, I couldn’t move my fingers or anything before, and now I can ... grasp on the right hand and the left hand, same thing ...”. Similarly, Cam noted differences in his UL and hand function regained on both sides of his body. He said:

... at triceps I can lower down to my [hip]. with my left arm slowly and sometimes I can get it back up against gravity ... with my right arm I can get it down slowly but I can’t get (it) ... back up. ... on my right hand I can open fully, ... quite strongly and then can ... semi (close it) but it fatigues quite easily, and ... the left (fingers) don’t open up as well as the right ...

Despite improved “finger flexion and extension,” Nick was conscious of his poor hand strength and spoke of “still using palmer pockets afterwards” and “hold(ing) things with two hands.” He commented:

... it worked on both sides ... so I can ... open up my hand and close it but it’s pretty weak, so ... it made a few things ... easier but I don’t (know) if it really ... let me do something new that I could(n’t) do before.

Although “a bit disappointed” with his triceps strength and a “bit of an annoyance” with his right fingers opening but not closing, John appeared to accept his imperfect hand outcome acknowledging: “... you know, I got told about the risks,” he commented:

... ... to have a little bit less strength in your (elbow flexion) to have finger function to be able to hold and grab things ... ... you’re going

to prefer to have finger movement over a little bit of (elbow flexion) strength lacking

Weighing the value of UL versus hand function in his life appeared to help John accept an imperfect outcome.

### **Evaluating surgical outcomes**

Following recovery from surgery, participants reflected on *gaining independence* across a range of everyday tasks and *gaining confidence* in social situations.

#### **Gaining independence**

With changes UL and hand function post-surgery, participants spoke about gaining independence in a range of everyday tasks; performing them with greater ease, and less reliance on adaptive aids, carers or family members. For instance, reflecting on being "able to open (his non-dominant) hand and get it around things to grasp things" Pete identified a range of everyday tasks he could now perform, such as: "... making lunch, getting stuff out of the fridge, grabbing a water bottle ... picking up my phone ...". Cam, Tom and John reflected on being able to carry out community based tasks such as "... go out to a bar ... and buy a beer and carry it yourself, or go to the grocery store and ... use the eftpos machine ... get stuff off the shelves, and pick things up you drop" with greater independence. For most participants, this also extended to increased ease in using technology, such as mobile phones and computers, supporting their engagement in study, work and socialising. Cam reflected: "... I'm definitely a lot better on my laptop than I used to be, and being able to write ... at uni, is a pretty big deal."

For John, Tom and Nick increased independence across a range of self-care tasks was also noted. Having had "close to full support" before surgery and despite still needing assistance with aspects of dressing such as putting on socks, John reflected on how "... being able to hook (his) fingers into the top of (his) pants or shirts or ... reaching and being able to grab a shirt" had assisted with getting dressed. With a permanent catheter that requires emptying a leg bag, Tom also observed changes in bladder management having gained "a bit more independence," particularly in social situations. Tom commented: "... when I go out with friends and things like (that) it's good to be able to do ... my own leg bag ... instead of needing to worry about carers being there all the time." For Nick, holding equipment, such as cutlery, shaver or toothbrush, changed post-surgery, he commented:

... before, for eating, for example I used to ... put the fork ... feed it through my fingers have it sitting on top of my thumb ... but ... now ... I use ... built up cutlery. Same with ... brushing my teeth or shaving ... used to have ... palmer pockets ... whereas now I can ... just hold it normally.

Most participants also observed improvements in wheelchair use and transferring between their wheelchair, a chair, car or bed post-surgery. Reflecting on his improved wheelchair control, in particular breaking, Tom said: "... before I wasn't able to ... brake ... if I was going downhill, I'd need someone to give me a hand, ... especially going down ramps, it helps now that I can grip the wheel a bit more." Beyond pushing his wheelchair, Nick noted an increase ease "repositioning (him)self, ... getting comfortable ... in the chair, just sort of wriggling a little bit left to right with moving my hips" with his improved triceps strength post-surgery.

#### **Gaining confidence**

Being able to participate in a range of everyday tasks, all of the participants spoke of gaining confidence as they appeared "a bit more normal" (John) in social situations. Conscious of other people's reactions to their functional limitations prior to NTS, most participants found it "frustrating" and "embarrassing" when unable to do certain tasks, such as shaking hands, while out socially. Described as a "guy sort of thing" (Pete), difficulty shaking hands was a shared experience for most participants. Feeling "uncomfortable ... meeting new people," particularly being wheelchair bound, Cam commented:

... my hands used to ... be all closed over, ... so when (I) went to shake someone's hand (I) always got a funny look ... I can't squeeze their hand still, but ... I suppose it's just nice to be able to put (my) hand out and if (I'm) meeting someone new, even if it's to do a wet fish handshake, ... (it) probably gives (me) a bit more confidence out and about.

John, Nick and Cam, conscious of others' perceptions of their functional limitations, shared their experiences. Nick, describing the impact of being able to hold a drink in one rather than two hands on others' perceptions, stated: "... for other people ... looking at me, they might see me as pretty high level disability, whereas if I'm drinking it normally, yeah I might look a bit more ... independent." Having previously used a splint for writing, Cam also reflected on feeling "less self-conscious being able to ... sit in class and write my own notes" post-surgery. He noted:

... ... I feel like it's probably made me a bit more confident out in (uni), ... I don't ... care what I look like when I'm at home but it's always nice to look like you're capable when you've out and about ... ... sometimes you still need a hand and that, it's nice for people to think that you can do some stuff for yourself.

John also highlighted a link between his improved UL movements, others' reactions when interacting with people and his own well-being, noting: "... when you can do those things a bit more normally, you don't get as many of those kind of reactions ... which ... makes you happy." Reflecting on needing assistance to "pick up and open the tablets" when out for dinner due to his limited hand strength, Cam stated:

... I'd have to pull the bag of tablets out and get someone to pop them all out from the container for me and then ... as I did that people would stare cause they're curious, but it is still pretty awkward.

Through being able to do simple tasks such as; shake hands, hold a drink, write independently and manage medications, participants reflected on regaining their confidence in social situations.

In all, when *evaluating surgical outcomes* there was a general sense that, despite participants perceived imperfect outcomes and still needing assistance, the UL and hand function regained "... helps that little bit with everything" (Nick).

Cam captured the true value of nerve transfers whilst preparing to complete his final tests to measure his UL strength, grip strength and range of movement post-surgery. He commented:

... ... it's not really what the measurements say, it's about what feel you can do yourself and how independent you feel you can be, so ... my personal experience is I've had a very successful outcome from what's happened, even if the results might not ... say too much.

### **Discussion**

Nerve transfer surgery is a more recent surgical intervention to enhance UL function for individuals with tetraplegia. Existing research on NTS has focused on surgical outcomes such as grip



strength, grasp and pinch [12,13]. This qualitative study aimed to extend the existing research by exploring the lived experience of nerve transfer surgery for individuals with tetraplegia. The study highlighted that a participant's decision to have surgery was guided by both external factors and a sense of hope for improved UL function. External facilitators centered on learning from others experiences of surgery and talking with the healthcare team. Despite NTS occurring earlier than tendon transfers, these findings are consistent with Dunn et al. [29] mixed methods study on decision making for tendon transfers. This previous study described how a participants' decision to have UL surgery was supported by seeing others with a similar injury regain function and the impact it had on everyday tasks. Participants in the current study also noted the value of having multiple opportunities to discuss the nerve transfers with multidisciplinary treating team to make a decision to have surgery. This finding supports the idea that shared decision making needs to be a two way conversation between a client and clinical team. Beyond providing information, clinicians needs to create a safe space for clients to "think, talk and feel their way through" (p.628) the available treatment options [30]. Although noted, financial costs of surgery were not a core consideration in participants' decision to have NTS in this study, with surgery funded by the public health care system in Australia. Where a health care system does not publically fund NTS, the influence of patients needing to meet these costs on their decision to have surgery would warrant further investigation.

Hope has been identified as an important facilitator of adjustment following a SCI [31]. Individuals in this study sought treatment options, which offered hope for improved UL outcomes, with UL function identified as a key recovery priority for individuals with tetraplegia [4–6]. Importantly, whilst participants in this study hoped for improved function, all acknowledged nerve transfers were not without risks and that a perfect outcome was not guaranteed. This is an important acknowledgement given nerve transfers are offered in the first year after spinal cord injury where an individual is still absorbing the reality of their condition. As NTS becomes more common these current findings highlight an important role for healthcare professionals in supporting individuals with tetraplegia to maintain a balanced view of surgery by acknowledging both the hopes, potential risks and associated outcomes of surgery.

Beyond the decision for surgery, participants shared their experience of returning to the hospital along with the physical and emotional challenges associated with recovery. Challenges included: pain, a temporary increased dependence on others, and the time it takes to see changes in UL function, contributing to the participants losing motivation to continue with their post-surgical exercises. Despite the challenges experienced and a sense of losing hope with the surgery, in hindsight the participants considered these experiences worthwhile for the functional gains made. Prior research on tendon transfer surgery found similar results, with participants willing to experience reduced independence following surgery to regain UL function [7]. Understanding the challenges of recovering from NTS provides valuable insights to help medical and allied health professionals to work with individuals' at different stages of the surgery process. For instance, for those contemplating surgery understanding the challenges others experienced returning to hospital and post-surgery may help them mentally prepare for and validate their own experiences, supporting them to maintain hope during the recovery process.

Consistent with previous literature on outcomes of tendon transfer surgery, participants in this current study reported increased ease and independence across a range of everyday

activities [16,17]. The increased independence expressed by participants was similar to the practical aspects of 'enhanced independence' described by Wangdell, Carlsson and Friden [16] following tendon transfers. Practical aspects of enhanced independence centered on individuals with tetraplegia being able to perform a broader range of everyday activities with less assistance from others and restrictions within the physical environment. These changes underpinned participants sense of everyday life occurring more smoothly and renewed participation in social activities. Increased participation in activities also connected to participants regaining their previous identity, a psychological aspect of independence identified by Wangdell et al. [16]. Other psychological aspects include the privacy regained through increased independence with daily activities such as self-care or using technology and increased confidence with managing and sense of control over their own life. Ultimately, participants experienced a sense of pride recapturing use of the UL and sharing these positive experiences with close family and friends. The current study lends support to these findings with participants expressing a sense of appearing normal when participating in a range of everyday activities, enhancing their confidence in social situations following their SCI.

A limitation of this study was the small sample size of five participants. Participants in this study formed approximately a fifth of Australians with tetraplegia who had undergone NTS at the time. Focused on collecting rich data to adequately explore the phenomena, saturation was considered reached when the core elements of NTS (e.g., decision, recovery process, and surgical outcomes) and associated experiences of these had been captured. The potential for recall bias in this study is also acknowledged. With the time it takes for transferred nerves to reinnervate targeted muscles, all participants were required to be at least 18 months post-surgery. Thus, participant interviews were conducted 21–46 months post-surgery. While reflecting on earlier aspects of their experience, such as prior to surgery and early stages of recovery was challenging for some participants, the surgical experiences recalled may be considered the most meaningful to participants.

Purposive sampling, a non-probability sampling approach commonly used in qualitative research, was used in this study. With pre-determined inclusion and exclusion criteria guiding recruitment, participants were not selected based on surgical outcomes. Participants described both positive and challenging experiences of nerve transfer surgery, which suggests participants were comfortable to reflect on all aspects of NTS.

With NTS a more recent UL intervention for individuals living with tetraplegia, findings from this study provide a basis for future research. This study focused on individuals with tetraplegia who underwent surgery and associated reviews at the same health care service, publically funded by the Australian health care system. Future research may examine patient's experiences of different models of care following NTS, such as those undergoing inpatient rehabilitation or regional rehabilitation such as via telehealth. The influence of surgical costs on people with tetraplegia's decision to have surgery also warrants further attention in health care systems where patients bear the costs of surgery. This study also drew on the experiences of five men with tetraplegia who underwent NTS. Whilst statistically men form the majority of individuals living with a SCI, gender differences are evident in relation to daily activities. Thus, future research would benefit from examining women's experience of NTS to identify any potential gender differences in the experience and outcomes of surgery.



## Conclusion

With evidence based practice a central component of healthcare, evaluating the effectiveness of interventions such as NTS is of central importance. This study extends existing quantitative outcome studies by exploring the lived experience of NTS. The study highlights factors used to make a decision to have surgery, the challenges of the surgery and the impact changes in UL function have on independence and sense of self when participating in the community. The reported importance of even small changes in hand or UL function highlights the need for clinicians and researchers to evaluate quality of life, self-efficacy, and subjective measures of daily activities in addition to standard outcome measures. Ultimately, multidisciplinary healthcare teams can use these findings to guide practice when working with individuals with tetraplegia who are contemplating NTS and throughout the recovery process. Thus, assisting individuals approaching surgery to potentially feel better prepared for the ensuing rehabilitation process, and have a better understanding of how changes in UL movement may translate into daily activities and functional independence.

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## Disclosure statement

Jodie Hahn, a member of the research team, is an Occupational Therapist from Austin Health where participants were recruited.

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