ORIGINAL ARTICLE

Issues influencing the decision to have upper limb surgery for people with tetraplegia

JA Dunn^{1,2}, EJC Hay-Smith¹, LC Whitehead³ and S Keeling⁴

Study design: Grounded theory.

Objectives: To explore to better understand the decision-making process of people with tetraplegia regarding reconstructive upper limb (UL) surgery.

Setting: New Zealand.

Methods: In-depth interviews with 22 people with tetraplegia, 10 of whom had UL surgery and 12 had not. Verbatim transcripts were analysed using constructivist grounded theory.

Results: The primary reason for having reconstructive UL surgery was to improve independence and return to previous pastimes. Reasons not to have surgery were hope for further recovery or cure, and inadequate physical environment or social supports while rehabilitating. In addition, women identified the temporary loss of independence and need for increased care while rehabilitating as issues. Importantly, these issues were not static, often changing in importance or relevance over time.

Conclusions: The moment of making the decision for reconstructive UL surgery is elusive; therefore, multiple offers of surgery at different timeframes in an individual's life are required. In addition, flexibility in timing for surgery would allow for surgery to better coordinate with an individual's goals and priorities.

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Keywords: tetraplegia; upper limb surgery; decision making; rehabilitation

INTRODUCTION

Following cervical spinal cord injury (SCI), upper limb (UL) impairments of movement, strength and sensation are commonplace and can limit performance of activities and community participation. The return of arm and hand function is reported as the highest priority by people with tetraplegia.^{1,2} Surgical procedures to improve elbow extension, pinch grip and finger grasp in people with tetraplegia are performed worldwide. Experts in this field estimate that over half of the tetraplegic population could benefit from some form of UL surgical procedure.^{3,4} The benefit is acknowledged by surgeons and people with tetraplegia as being improved function and independence with activities of daily living.⁵ A previous NZ study found that the uptake of reconstructive UL surgery was close to half (44%) the eligible population.⁶ Uptake in the New Zealand is substantively higher than the reported uptake in the United States,^{7–9} although in the New Zealand, women and those who identified as NZ Maori were underrepresented in the surgery group.⁶

Low uptake of reconstructive UL surgery is an important issue worldwide. One of the most commonly cited reasons for low utilisation in the United States is the lack of clarity in the existing literature about the value of the procedures performed.^{5,8–11} This makes it difficult for physicians and health professionals to summarise useful information from the literature for patients and even more difficult for people with tetraplegia to find this information for

themselves.^{5,9} In addition, physician preconceptions about reconstructive UL surgery appear to be a leading contributor to the low referral rate to surgeons in the United States.¹²

Aside from this, clinicians have suggested a number of reasons why people with tetraplegia do not pursue the option of reconstructive UL surgery such as disinterest, lack of education about the procedure and benefits, funding perceptions, interference with recreational pursuits, lack of resources for follow-up, post-operative encumbrance, fear of surgery and fear that surgery may be a disadvantage in case of a cure for SCI.^{7,13} Absent from the literature is any study exploring the reasons for and influences on the decision about reconstructive UL surgery from the perspective of the person with tetraplegia. Therefore, our qualitative study aimed to address this gap in knowledge.

METHODS

This constructivist grounded theory¹⁴ study used semi-structured, in-depth interviews to explore the decision-making process for reconstructive UL surgery in 22 people with tetraplegia. Grounded theory is a suitable approach to studying actions and processes in the social context.¹⁵ Constructivist grounded theory sees the researcher as part of the world being studied with the data and analysis created through the shared experience and relationship formed in the research process. Thus, constructivist grounded theory was congruent both with the question and principal researcher's (JD) positioning as a physiotherapist in post-UL reconstructive surgery rehabilitation.

¹Rehabilitation Teaching and Research Unit, University of Otago, Wellington, New Zealand; ²Department of Physiotherapy, Burwood Spinal Unit, Burwood Hospital, Christchurch, New Zealand; ³Centre for Postgraduate Nursing Studies, University of Otago, Christchurch, New Zealand and ⁴Department of Medicine, University of Otago, Christchurch, New Zealand

Correspondence: Dr JA Dunn, Department of Physiotherapy, Burwood Spinal Unit, Burwood Hospital, Mairehau Road, Private Bag 4708, Christchurch 8000, New Zealand. E-mail: jennifer.dunn@cdhb.health.nz

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Participants

From the population identified in an earlier study,⁶ after ethical and locality approvals were obtained, 22 participants were recruited from the two spinal units in the New Zealand. The first eight participants were selected to embody a range of demographic characteristics, and thereafter theoretical sampling was used to choose participants who had demographic or other characteristics not already represented. Theoretical sampling involves selection of participants with the aim of exploring, challenging or expanding the evolving theory from the data already collected.¹⁶ In total, 10 participants had reconstructive UL surgery performed, and 12 had not. Participants were 4–9 years post-SCI at the time of interview, and 21 participants had been offered assessment for reconstructive surgery between 12 and 18 months following SCI. One participant had not been offered assessment for surgery, although the participant knew about the procedures. Table 1 summarises the demographic information for the participants; the characteristics are not presented by participant to help maintain anonymity in the small population of people with SCI in the New Zealand.

Data collection

Interviews of 30–90-min duration, comprising broad open-ended questions, facilitated detailed descriptions of the individual's experiences and views about reconstructive UL surgery. All interviews were performed by the principal researcher. The iterative process of analysis alongside data collection allowed consecutive interviews to clarify and extend new questions and concepts from the emerging theory. Data collection continued to saturation, which is the point where no new concepts were generated by participants. Interviews were audio recorded then transcribed verbatim.

Table 1

Participant demographics	Surgery group n = 10	No surgery group n = 12	Declined to participate n = 5
Male	8	7	1
Female	2	5	4
NZ European	8	10	4
Maori	2	2	1
Partner	5	4	0
No partner	5	8	5
Motor complete SCI (AIS A and B)	8	8	3
Motor incomplete SCI (AIS C and D)	2	4	2
Average age at the time of injury (years)	39.4	28.9	16.6
BSU	5	5	3
ASRU	5	7	2
SCI level			
C4	1	0	0
C5	3	4	0
C6	4	6	5
C7	2	2	0
Year of injury			
2001	1	4	1
2002	2	2	1
2003	2	4	1
2004	3	1	1
2005	2	1	1

Abbreviations: AIS, ASIA Impairment Scale; ASRU, Auckland Spinal Rehabilitation Unit, Auckland; BSU, Burwood Spinal Unit, Christchurch; SCI, spinal cord injury.

Analysis

Transcripts were analysed sentence by sentence and the text coded to denote the content (open coding) by the principal researcher. Codes were grouped into larger categories by examining the data within each code and finding other codes with similar or related meaning. Then categories were merged into more abstract concepts and a framework that described the decision-making process for reconstructive UL surgery. Throughout this process other members of the research group cross-checked coding and categorisation of the data. Data were managed using the software package NVivo (Version 8.0, QSR International Pty Ltd).

A number of steps were taken to optimise the rigour of findings. The four components of trustworthiness, credibility, transferability, dependability and confirmability¹⁷ were addressed. Techniques to support credibility used in this study were as follows: collection of data over a prolonged period and from a range of participants showing prolonged engagement; triangulation using a reflective journal, memos and discussion within the research team about themes and ongoing development of the interview schedules and member checking (that is, a progress report on the emerging themes from the first 14 interviews was sent to all participants for their perusal and comment). With regard to transferability, participants and the setting are described in enough detail to allow for comparisons with other SCI populations. Dependability (relates to the consistency between the data and the findings) was supported by an audit trail of memos, journal entries and minutes of debriefing discussions within the research team. Finally, confirmability was demonstrated through an audit trail of peer review and decision points throughout the process. Specifically, checking with participants, expert colleagues and other members of the research team about the interview schedules, transcripts, coding and drafts of data analysis and conceptual framework.

RESULTS

All participants were aware of the possibility of reconstructive UL surgery, and 21 were offered assessment for the procedure within the first 18 months following their injury. The participants' decision-making process for reconstructive UL surgery was underpinned by six core influences: outcomes of surgery, goals and priorities, hope, environmental factors, social supports and information.

Outcomes of surgery

Participants who did not have surgery knew they could improve their hand function with surgery, but felt the net benefits were not worth the inconvenience. They did not want to put their lives on hold for what they perceived as small functional gains.

The major setback is that I do not want to be having my hands in (plaster) casts for 6 weeks. Not being able to push your chair, or transfer or do anything. Participant 17.

In contrast, the 10 people who had reconstructive UL surgery performed did so because the expected gains were perceived to be highly valuable.

They said if I could get (upper limb surgery) then I had the possibility of driving (a car), and driving was probably one of my major things that I hated not being able to do. Participant 10.

Goals and priorities

The participant's goals and priorities influenced the decision to undergo surgery. Many non-operated participants were studying or training, and the time needed for surgery and rehabilitation was considered disruptive to achievement of current goals, impractical or a lower priority.

I am quite sort of focussed on my future at the moment. I am quite keen to further my education and get a job, become financially independent, travel, things like that. Participant 1.

The decision not to have surgery was described by some as a temporal one. Priorities changed over time, and if the offer of surgery was made again, some took or would take the opportunity. This extract of a participant who did not have surgery at time of initial offer demonstrates how his priorities have changed and how he would be more receptive to the offer of reconstructive UL surgery now.

I guess the 4 or 5 years ago when I last had the assessment (for surgery), I was not quite as independent as I am now. So I had a lot more people around me, a lot more carers around me to do things for me and now I am trying to get into the cooking and dressing myself and ... I am just trying to be a lot more independent. Participant 17.

Therefore, multiple offers for reconstructive UL surgery over time may be needed to accommodate changes in life goals and plans.

Hope

The role of hope varied. For participants who did not have surgery hope for further recovery from their SCI or for the cure of SCI were prominent and strongly influenced their decision not to have surgery.

Definitely the cure is a big part of my life. You have to give people hope. Participant 20.

In contrast, those who chose surgery believed that the cure for SCI was a remote possibility and they were not willing to put their lives on hold waiting.

My thoughts on hand surgery were that I would not wait for (the cure) to happen. I would go ahead with hand surgery ... I do not hold out any great hope that some miracle cure is going to come along. Participant 9.

Environmental factors and social supports

A stable home environment was a prerequisite for having surgery.

I think this is the right time in my life, I am in the right head space and my house is all modified, everything has settled down—2 years ago we had just moved in. Participant 3.

Social support for the increased burden of care while the hands were in plaster casts was also essential. The increased burden of care while in plaster casts appeared to be more of an issue for those who were single, although women (irrespective of their relationship status) said that having to rely on others was a disincentive.

My husband was worried if I got two (hands) done at once it would be 6 weeks of not being able to (do anything). I mean he gets annoyed trying to put my hair up, so the impact on (husband) was a big part of it. Participant 20.

For women, a compounding factor was the need for a caregiver to be available 24 h a day. All women interviewed identified they would want a close friend or family member to be available to assist them if they were to have surgery. None of the men interviewed identified the need for increased care by either a family member or paid caregiver as being an issue.

Information

Most of the participants had seen others who had reconstructive UL surgery. The opinions and thoughts of these credible others supported the decision to have surgery. In fact, other people with tetraplegia appeared to have a greater role in the decision-making process than the inner circle of social contacts, such as family or friends.

I think talking to them—they are the best people to talk to, they have had the surgery and they live with it (tetraplegia) day in and day out. Participant 4.

As well as the source, the timing of information about reconstructive UL surgery had a role in the decision. Some people described receiving information about surgery very early, during their acute rehabilitation. Others did not receive any information until ~12 months following injury while being reviewed by a spinal unit physician. Irrespective of the timing of the information, readiness to explore the option of reconstructive UL surgery was linked to the participant's focus of hope. If the participant held hope for continued recovery or cure, then surgery was discounted. In contrast, for those who hoped for increased independence and improved quality of life, the option of improved hand function through surgery was invited.

Knowing what the movements can be and know what you can achieve from surgery just gave me a big boost of what I wanted and how I wanted it done. Participant 8.

Unexpected functional gains of surgery

There were unexpected functional gains following surgery. For participants with an incomplete SCI, the ability to hold walking aids such as crutches or walking sticks following surgery improved their overall functioning.

I feel that gaining the function I did (from hand surgery) probably assisted me with my recovery. Mentally becoming more independent actually fed that process. By becoming more independent, I became even more independent ... I found I did not need to get around with crutches, I could actually balance and get around with a walking stick. Before the hand surgery, I never had the strength to be able to hold the stick and I think using the crutches I was pretty tenuous because I did not have a very good grip of them. Participant 9.

For other participants, the performance of everyday tasks led to improvements in other areas such as mobility, driving and also improvements in confidence.

I hated going out, would not go out for dinner, being in public to eat was a no-no for me because someone would feed me or I would have this spoon tied to my hand that I could not put down ... whereas now, I can go out to a restaurant and ... you are sitting there eating alongside everybody else, being able to pick up a wine glass, a beer mug whatever and it is amazing. Someone not feeding you with a straw or a spoon. So that is a huge psychological improvement. Participant 10.

Thus, the functional gains of surgery led to improvements in psychological constructs such as self-esteem.

DISCUSSION

The timing of data collection for this study meant all participants at least 4 years from the time of their SCI to be assessed and make a decision about reconstructive UL surgery. This was thought to be an adequate length of time for the person with tetraplegia to have completed their rehabilitation, return to their home and community, and commence their new life. However, the results showed that while the majority of participants had been assessed or offered assessment for surgery within the first 18 months following SCI, many deferred the decision about reconstructive UL surgery beyond this period and were waiting to make the decision at an ill-defined time in the future.¹⁸

Although all of the participants maintained some form of hope for the cure following SCI, the degree to which this impacted their lives and their decision to have reconstructive UL surgery varied greatly. The focus of an individual's hope following SCI appeared to change with time, with many participants initially deferring the decision about reconstructive UL surgery as they continued to hope for further recovery from their SCI. This is similar to the findings of Dorsett¹⁹ who found that the focus of hope following SCI changed over time, with immediate hopes for recovery from SCI moving to hope for the cure or quality of life as time from SCI progressed. In our study, the timing of the information received and offer for surgery, when combined with the focus of hope, strongly influenced the decision about reconstructive UL surgery. Those participants who were hoping for improved quality of life by increasing their independence or functioning were more likely to consider reconstructive UL surgery as an option.

Clinical implications

With regard to decision making for reconstructive UL surgery, our study demonstrated that even if an individual did not choose to have reconstructive UL surgery at the time of initial offer, this did not mean it had been discounted as a future option. Therefore, it behoves clinicians to continue to offer the option of reconstructive UL surgery at follow-up appointments throughout an individual's lifetime. This not only takes into account the changing thoughts on hope following SCI, but also changes in goals and priorities and environmental and social supports. Influences that increase the likelihood of an individual having reconstructive UL surgery include interaction with others who have had reconstructive UL surgery performed and were satisfied with the results, education about the availability of the procedures and the impact on functioning. Flexibility with regard to timing of surgery and the option of either unilateral or bilateral procedures may increase the attractiveness of the procedures to some individuals, especially women with tetraplegia.

The outcomes of surgery theme suggest there are things to measure beyond the performance of tasks and strength but also psychological functioning and quality of life as surgical outcomes. This will assist in clinicians providing meaningful information to those with tetraplegia.

CONCLUSION

This study showed that the decision-making process for reconstructive UL surgery is individual and dependent upon a number of issues. These issues are temporal, and influence not only if the person has reconstructive UL surgery, but when issues such as the stability of the home environment, caregiver support and hope, change with time. Thus, multiple offers for surgery are recommended throughout an individual's lifetime to take into account the temporality of the issues that influence the decision.

STUDY LIMITATIONS

One of the limitations of this study is the application of findings; it was performed in the New Zealand and was therefore strongly influenced by the clinical culture and funding systems here. The differences between funding systems and clinical settings throughout the world make it more difficult to generalise some of the findings. The NZ funding system currently has no limit on the funding period for reconstructive UL surgery following SCI. Thus, the participants in this study were not pressured by a time constraint and indeed time was a major component within the decision-making process. In addition, reconstructive UL surgery is a fully funded procedure in the New Zealand. Therefore, fiscal considerations of the surgery, its

associated rehabilitation, and possible loss of wages were not issues identified by any of the participants in this study while this may be a important consideration for people in other contexts.

A second potential limitation (or equally a potential strength) of this study is the dual role the principal researcher as researcher and physiotherapist involved in the assessment of people with tetraplegia for reconstructive UL surgery. For example, the pre-existing relationship between the researcher and participants may have limited a frank and open discussion by participants, and conversely, this may have assisted in building rapport with participants and allowed for greater information sharing.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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