



ARTICLE

Identifying barriers to upper extremity reconstruction in tetraplegia: a systematic scoping review

Celine Yeung¹ · Sabrin Salim² · Ida K. Fox³ · Christine B. Novak^{1,4} · Jana Dengler^{1,5}

Received: 27 August 2020 / Revised: 2 April 2021 / Accepted: 7 April 2021 / Published online: 28 April 2021
© The Author(s), under exclusive licence to International Spinal Cord Society 2021

Study design

Systematic scoping review

Objectives

The purpose of this study was to understand the barriers to accessing upper extremity (UE) reconstructive surgery among those living with tetraplegia, and to identify gaps in knowledge.

Methods

Using standardized scoping review methods, a literature search was conducted using four databases and 1069 articles were procured. Two independent reviewers systematically screened the articles in two phases. Retrieved articles underwent thematic analysis using a constructivist grounded theory methodology.

Results

The reviewed articles ($n = 25$) were published between 2002 and 2019, and study designs included: cross-sectional (64%), retrospective (16%), and review articles (8%). Common barriers to UE reconstruction were categorized into factors related to patients, providers, and systems. These general domains included lack of awareness of UE reconstruction and its benefits among people with tetraplegia and providers, poor interdisciplinary working relationships, and a lack of specialized centers that provide these reconstructive surgeries. Specific patient-related barriers related to intrinsic (coping skills, trust, fear) and extrinsic (support network, finances, postoperative course) factors that influenced decision-making.

Conclusions

There are many barriers that prevent individuals with tetraplegia from accessing surgery at different levels of the healthcare system. Establishing specialized centers with strong interdisciplinary working relationships and raising awareness about the advantages and disadvantages of UE reconstruction through peer networks may help to improve accessibility. Using a value-based, patient-centered approach by exploring how individuals with SCI weigh each decision factor when considering surgery may help providers develop treatment options that better align with their goals.

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41393-021-00631-7>.

✉ Jana Dengler
jana.dengler@mail.utoronto.ca

- ¹ Division of Plastic and Reconstructive Surgery, University of Toronto, Toronto, ON, Canada
- ² Translational Research Program, Faculty of Medicine, University of Toronto, Toronto, ON, Canada
- ³ Division of Plastic and Reconstructive Surgery, Washington University School of Medicine, St. Louis, MO, USA
- ⁴ Division of Plastic and Reconstructive Surgery, Hospital for Sick Children, Toronto, ON, Canada
- ⁵ Division of Plastic and Reconstructive Surgery, Sunnybrook Health Sciences Centre, Toronto, ON, Canada

Introduction

The loss of upper limb function in cervical spinal cord injury (SCI) contributes to substantial disability and loss of independence, and ultimately restricts participation and quality of life. People living with tetraplegia have identified improvement of upper limb function as a top priority [1]. Tremendous advances in upper extremity (UE) reconstruction, which include tendon transfer, joint-related procedures, and nerve transfer surgeries, have been made since its inception in 1948. Tendon transfer and joint-related procedures gained popularity in the 1960s to 1970s when techniques to reconstruct elbow extension, key pinch, and grasp were described [2]. More recently, nerve transfer procedures have emerged with unique advantages including less

downtime, minimal postoperative immobilization and non-weight bearing, and ability to restore more than one function using a single nerve donor [3]. Nerve transfer surgery involves adjoining a donor nerve with expendable function above the level of injury, to non-functioning but anatomically intact recipient nerve below. The donor action achieves the desired recipient action through guided rehabilitation. Nerve transfer expands candidacy for restorative UE reconstruction and may expand acceptability, but can be time-sensitive due to lower motor neuron injury that commonly coexist in SCI [4]. UE reconstruction may improve quality of life and independence and decrease cost-burden on the healthcare system and on those living with SCI [5].

Despite the recognized benefits of UE reconstruction, many studies have shown that these procedures are underutilized [6–8]. In the United States, <14% of people with tetraplegia who are eligible candidates have undergone tendon transfer surgery [6]. Reasons for underutilization are multifactorial and include gaps in knowledge and access for both people with SCI and their healthcare provider (e.g., surgeon, primary care physician, physiatrist, etc.) [6]. Underutilization may also be related to the variable, inconsistent outcomes following tendon transfer surgery. Most outcome studies to date are limited by study design (small case series) and inconsistent outcome measures that make it difficult to compare between studies and to assess the benefits of reconstruction [9]. This systematic scoping review was undertaken to map the literature on how people with SCI access UE reconstruction, in order to better understand and identify gaps in knowledge regarding the barriers to and facilitators of both novel nerve transfer and established tendon transfer surgery.

Methods

A systematic scoping review of barriers to accessing UER in tetraplegia was performed. The scoping review

framework, described by Arksey and O'Malley [10], and modifications outlined by Levac et al. [11] were used. The framework consists of five stages: (1) identifying the research question; (2) identifying relevant studies; (3) selecting the studies; (4) charting the data; (5) collating, summarizing, and reporting the results. There is an optional sixth stage where stakeholders may be consulted if additional insights could be offered and this stage was not included in this study.

To identify relevant studies, the search strategy used four databases (MEDLINE/PubMed, 1946–February 15, 2021; SciVerse Scopus, 2004–February 15, 2021; Embase, 1947–February 15, 2021; and Web of Science Core Collection, 1900–February 15, 2021), which were chosen to provide a comprehensive search of a wide range of disciplines and select search terms. The search terms (Supplementary Appendix 1) and inclusion and exclusion criteria (Table 1) were established by the research team. Covidence (Veritas Health Innovation, Melbourne, Australia; www.covidence.org) was used for the title and abstract relevance screening and the full article review phases.

Two reviewers (SS and CY) performed the title and abstract relevance screening ($n = 865$ articles) and selected articles for full-text review ($n = 134$) using a self-developed standard data extraction form that was approved by the senior author (JD). Additional articles were identified from a review of relevant references ($n = 10$). An initial review of 25 articles was performed by the two reviewers (SS and CY), and an inter-rater agreement was calculated to determine whether the reviewers were consistent on the articles that were included or excluded. The reviewers then performed a full-text screening of the remaining articles ($n = 25$). The two reviewers met throughout the review process and ensured consistency by assessing inter-rater agreement. No major adjustments were made to the data extraction form. Any disagreements that arose from the review process were resolved by a third author (JD).

Table 1 Scoping review: inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> •Any clinical, patient-outcome, review, systematic review, meta-analysis study •English language articles •Any location •Any publication date •All ages •Cervical spinal cord injury OR quadriplegia OR tetraplegia •Healthcare providers (e.g., upper extremity hand surgeons, physiatrists, urologists, therapists) •Upper extremity reconstruction procedures only (e.g., nerve and tendon transfers, tenolysis, arthrodesis, joint-related procedures) 	<ul style="list-style-type: none"> •Anatomic, biomechanical, basic science articles •Patients with brachial plexus injuries, cerebral palsy, sarcoma, paraplegia, or hemiplegia, requiring cervical decompression •Interventions other than upper extremity reconstruction (e.g., neuroprostheses, neuromodulators, vertebral arthrodeses, spinal column instrumentation, rehabilitation programs, stem cell therapy, etc.) •Studies on surgical outcomes of function (e.g., activities of daily living, instrumental activities of daily living, satisfaction, etc.)

The study characteristics extracted included: author(s), title; journal, publication year, publication type, study location, study population, study aims or purpose, intervention (if applicable), comparators (if applicable), duration of intervention, and key findings (Supplementary Appendix 2). NVivo qualitative data analysis software (QRS International Pty Ltd. Version 12, 2018) was used for thematic analysis. Using inductive and deductive approaches, the included articles were reviewed to understand the content, and were coded by a research team member (CY). Common recurring themes related to patient, provider, and system barriers and facilitators and strategies to improve access, were identified. The themes were reviewed regularly by the research team (SS, JD, and CBN) to ensure consensus was reached and to ensure accuracy of the data.

Results

The search strategy identified 1069 articles (Fig. 1). After duplicated articles were removed, 865 articles underwent title and abstract screening and relevant articles were identified (Table 2). These articles were reviewed using the selected inclusion and exclusion criteria. Excellent interrater agreement during the full-text screening was found ($r = 0.7$, $p < 0.001$). After two screening phases, 25 articles were included for thematic analysis (Fig. 1). The articles were published between 2002 and 2020; most papers were published in the United States (60%) and in journals targeting either UE surgeons or physiatrists (Table 2). Studies categorized tendon transfers, joint-related surgeries, and nerve transfers broadly under UE procedures, rather than examining specific barriers unique to each surgical

procedure. Thematic analysis was used to identify and categorize the barriers to and facilitators of UE reconstruction into three broad themes related to: (1) individuals with SCI, (2) providers, and (3) the healthcare system (Fig. 2).

Barriers related to individuals with SCI

Among individuals with SCI, the common barriers were related to intrinsic patient-related factors like coping skills [12], physical complications [13], access to and interpretation of information on UE reconstruction [7, 12, 14, 15], personal decision-making factors (e.g., previous hospital experiences [13], trust in providers [13], and fear of surgery [12]). Further, extrinsic factors like postoperative rehabilitation requirements [16, 17], social supports [12, 13, 18, 19], logistic [13, 14], and financial barriers [20, 21] were also identified.

Table 2 Summary analysis of included articles ($n = 25$).

Study location	Frequency n (%)
United States	15 (60)
New Zealand	5 (20)
Netherlands	3 (12)
Sweden	1 (4)
Hungary	1 (4)
Journal	
Spinal Cord	8 (32)
Journal of Hand Surgery	4 (16)
Archives of Physical Medicine and Rehabilitation	4 (16)
Hand Clinics	2 (8)
Disability and Rehabilitation	2 (8)
Journal of Rehabilitation Medicine	1 (4)
Surgery	1 (4)
Hand	1 (4)
Journal of Rehabilitation Research and Development	1 (4)
Journal of Spinal Cord Medicine	1 (4)
Study type	
Cross-sectional	16 (64)
Retrospective	4 (16)
Review	2 (8)
Prospective	1 (4)
Implementation	1 (4)
Perspective	1 (4)
Population	
Patients	666 (44)
Physical medicine and rehabilitation physicians	410 (27)
Surgeons	406 (27)
Therapists	12 (1)
Caregivers	6 (0)
Types of surgery	
Tendon and/or nerve transfer surgery	11 (38)
Tendon transfer only	4 (14)
Nerve transfer only	1 (3)
Repeated patient population	4 (14)
N/A	5 (17)

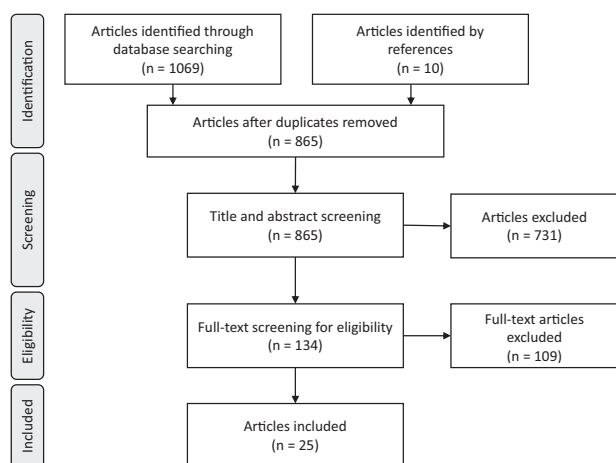
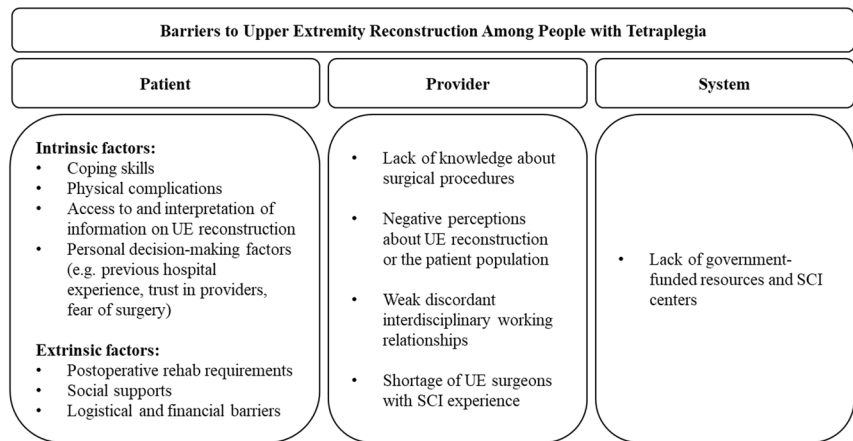


Fig. 1 Flowchart depicting the article review process. The search strategy identified 1069 articles; 10 additional articles identified by review of references. After duplicate articles were removed, 865 underwent title and abstract screening; 134 underwent full-text screening, and 25 articles met inclusion criteria.

Fig. 2 Summary of common barriers of upper extremity reconstruction in SCI.

Thematic analysis categorized barriers into three broad categories related to individuals with SCI (“patient”), providers (“provider”), and the healthcare system (“system”). Individual (“patient”) factors are further categorized into intrinsic and extrinsic factors.



Specifically, people with SCI on either extreme of the coping spectrum and those who hoped for recovery or a cure, were less likely to seek additional treatment such as UE reconstruction [12, 19]. Those who accepted the need for assistance as part of their new identity, and those who were dissatisfied with their current physical state, sought information on treatments to improve function and were more likely to undergo surgery [12]. Individuals who made a decision to undergo UE surgery shortly after injury were not willing to wait for advances in SCI treatment (e.g., stem cell treatments) and had a linear, definitive decision-making pattern; these individuals did not ruminate on their decision for a long period of time. Those who deferred surgery had a more cyclical decision-making pattern, which was dynamic or temporal in nature [19]. Those who had a negative experience with their care also held poor perceptions of subsequent treatment options and were more likely to decline surgery [13].

Lacking awareness of UE reconstruction was frequently cited as a patient-related barrier [3, 7, 15]. Healthcare providers and the internet are common sources of information for people with tetraplegia [7, 16, 22]. Physicians who hold a negative perception or are skeptical of the benefits of UE reconstruction may not offer these treatment options when counseling patients [23], thus presenting a barrier to patients receiving relevant information. Zhong et al. [15] found minimal online information regarding the surgical management options for people with tetraplegia, and described potential challenges associated with accessing online content. Communication barriers included: lack of health literacy [15], difficulty in operating communication devices or physically turning pages of printed material, and not having access to adaptive devices like voice-recognition software [12].

The information source is an important factor. Individuals who were informed about surgery from primary care providers or physiatrists were more likely to have a negative impression of reconstruction and less likely to believe that these surgeries would improve their quality of life [20]. In

contrast, receiving information from peers who had undergone surgery had a more positive influence. First-hand accounts of postoperative function created a positive impression, provided insight into the individual’s potential for improvement, and encouraged them to seek surgical management [16, 24, 25].

After learning about surgery, individuals with tetraplegia balance many influencing intrinsic and extrinsic factors. Intrinsic factors that prevented people from choosing reconstruction included fear of surgery [12] and re-entering the medical system where they may have previously had negative experiences [13]. Extrinsic factors included the postoperative period of immobilization or rehabilitation [12, 17], and the impact of surgery on employment/academic status, caregivers, their support network, or on other life commitments [12]. Surgery was commonly declined if individuals thought that they would lose independence postoperatively, add burden on caregivers [12, 18, 26], or lacked social support [12, 13, 18, 19] such as a stable home environment [18]. Travel barriers (e.g., traveling to and from appointments, accessing hospital parking, etc. [14, 24]) and financial barriers (e.g., taking time off work, costs related to surgery, etc.) were additional factors considered. In the United States, financial constraints and lack of medical insurance coverage were influential barriers to surgery [20, 21, 24].

Barriers related to providers

Provider level barriers were related to lack of knowledge about surgical procedures [7, 27], negative perceptions about treatment options or the patient population [23], weak discordant interdisciplinary working relationships [25, 28], and an overall shortage of UE surgeons with experience in SCI [8, 27, 28].

Negative perceptions of surgery held by providers and poor interdisciplinary connections were frequently cited as factors that precluded physicians from referring patients to a

UE surgeon [8, 20, 25]. Compared to surgeons, physiatrists were more likely to have concerns about patient compliance following surgical management [23, 27], more comfortable offering nonoperative options [27], and less likely to recognize the benefits of reconstruction [23].

In some regions, there are shortages of surgeons trained to perform UE reconstruction in SCI [8, 27]. Perceptions regarding reimbursement [8] and patient candidacy contributed to lack of access [23, 27]. Wangdell et al. [29, 30] found that surgeons were less likely to offer reconstruction in patients with neuropathic pain, although their study demonstrated that individuals with pain had similar postoperative outcomes compared to those without neuropathic pain. Furthermore, surgeons frequently felt their practices were too busy to add an additional patient population but were more likely to perform UE reconstruction if they were connected with interested physiatrists [27].

Barriers related to the system

System barriers included lack of funding and resources for UE reconstruction [25, 28]. There is variation in resource allocation and in existing healthcare models that manage people with SCI. In Sweden and New Zealand, people with SCI were found to be well supported by government-funded SCI care centers [9, 30], and investigators in these countries have frequently reported on UE reconstruction after tetraplegia injury [9]. In Hungary, providers had difficulty obtaining funding and experienced challenges with implementing a new UE reconstruction service without the presence of a strong advisory group consisting of experts and patients [31]. Similarly, most Asian countries do not have government-funded resources for rehabilitation, and individuals rely heavily upon their families for therapy [25]. In the United States, the shortage of coordinated SCI centers limits access to surgery [25]. People without private insurance rely on personal funds or state assistance [28]. Lacking social support to complete the postoperative rehabilitation or the financial resources to afford surgery or perioperative care influenced individuals with tetraplegia to opt for alternative and more affordable treatment options [12, 21].

Facilitators of UE reconstruction

Patient-, provider-, and system-related facilitators of accessing UE reconstruction and strategies to improve access have been described. Facilitators of surgical management included having strong patient support networks during the decision-making process [12, 16, 18], strong interdisciplinary connections [27, 32, 33], and awareness of UE procedures [7]. Recommended strategies to improve access to surgery and facilitate UE reconstruction included creating accessible educational tools [15] and establishing

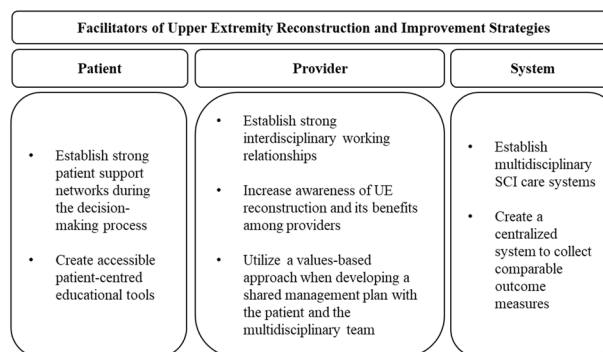


Fig. 3 Facilitators of upper extremity reconstruction in SCI and improvement strategies to increase access to surgery. Thematic analysis categorized facilitators into three broad categories related to individuals with SCI (“patient”), providers (“provider”), and the healthcare system (“system”).

multidisciplinary care centres or centralized patient registries [9, 25] (Fig. 3).

In the optimal setting, the treating surgeon, physiatrist, SCI team, and person with SCI work closely together, to develop the best treatment solution. Establishing trust between patients and providers is essential [13]. Individuals were more likely to trust providers if they demonstrated an understanding of the individual’s specific needs when developing a patient-centered treatment plan [18]. For example, women with tetraplegia were more interested in surgery when offered unilateral procedures instead of simultaneous bilateral procedures. Being a burden on their support network postoperatively was a disincentive when deciding to undergo surgery [18]. Furthermore, people with tetraplegia were more likely to trust individuals who had undergone UE surgery, had a positive impression on potential postoperative function and were more likely to seek surgical intervention [16]. Moreover, people with tetraplegia who accepted their condition as part of their new identity, or those who were not willing to wait for advances in SCI treatment, were more likely to have surgery [12].

Facilitators of UE reconstruction among healthcare workers included increasing awareness among providers about the benefits of reconstruction [22], and establishing strong working relationships between providers may increase referrals to UE surgeons [25]. Investigators found that physicians who were aware of surgeons that performed these procedures were more likely to refer patients. Similarly, surgeons were more likely to perform UE reconstruction if they were connected with interested physiatrists [27].

Discussion

Patient-, provider-, and system-level barriers and facilitators to UE reconstruction were identified. Most studies

examined the perceptions of people living with tetraplegia, physiatrists, and surgeons, while few studies considered the perspectives of caregivers and other SCI healthcare providers (e.g., physical and occupational therapists, social workers etc).

Following SCI, maintaining good health is a continuous process for individuals with tetraplegia. Healthcare providers are faced with the challenge of managing high complication rates (e.g., pressure injuries, recurrent urinary tract infections, etc.) that may preclude individuals with tetraplegia from being candidates for surgery. Numerous interactions with different healthcare providers throughout their care continuum may not be of equal value and negative exchanges can erode an individual's trust in healthcare providers long before consulting with a hand surgeon [13].

Given the time-sensitive nature of nerve transfer surgery, UE surgeons are in a unique position where they must decide when to discuss surgical intervention and be mindful that individuals with tetraplegia are adjusting to significant life changes. Providers are also faced with the challenge of balancing hope while making accurate, realistic prediction of future disability. For individuals with tetraplegia to benefit from nerve transfer surgery, these discussions are ideally initiated within the first 6–9 months of the SCI, which may be challenging for those who have not accepted their new disability [34].

Furthermore, individuals with tetraplegia have different coping strategies that influence their decision-making process. These differences may be shaped by differences in personal life priorities, cultural or religious values, and/or by individual social contexts. In addition to presenting treatment options at various time points [18], providers should initially seek to understand the priorities, goals, and values of individuals with tetraplegia, involving them in the decision-making process [34, 35]. Using a value-based approach early in the management plan may help providers establish a trusting relationship with their patients to help individuals with tetraplegia better understand UE reconstruction and the associated benefits and risks.

Regarding the evidence on UE reconstruction, the current literature consists of studies with small sample sizes, varied interventions, and inconsistent outcome measures [9, 34]. The paucity of evidence makes it challenging for providers to compare the risks and benefits of surgery when counseling individuals with tetraplegia, and may reinforce the negative perceptions some providers hold on the patient population or the benefits of UE surgery. Without adequate evidence, it may also be difficult for policymakers to justify allocating resources toward SCI care.

Strategies to improve access to UE reconstruction have been described and warrant future investigation to address local hospital barriers (e.g., creating accessible, patient-

centered educational materials tailored to meet physical limitations, or establishing travel reimbursements). Connecting individuals with those who have had reconstruction through online forums or support groups should be integrated into the care pathway. Specifically, having patient advocates discuss their experiences prior to surgical consultation or during the acute rehabilitation period may help improve access. Online networks or scheduled e-mails with information about these support groups could also be established. On the provider level, introducing new referral contact points (e.g., through urologists) may also help increase access to UE surgical care [13]. Counseling on postoperative needs, managing expectations, and setting up homecare resources can reduce caregiver burden and help individuals to assess UE surgical options. There is emerging evidence describing lived experiences of five individuals who have undergone nerve transfer surgery, which may help providers counsel patients on expected postoperative courses (e.g., around experiencing pain, sensory changes, and transient loss of independence) [24].

At a system level, regions with comprehensive SCI care programs demonstrated lower case-mortality rates, fewer medical complications (e.g., pressure sores and urinary tract infections), improved functional outcomes, and shorter lengths of stay in hospital [30]. These findings can be extrapolated to UE reconstruction [31]. Creating similar models of care may help improve access to surgery on a systems level in other countries.

Future directions

Our scoping review on barriers to UE reconstruction for people with tetraplegia found that the majority of studies related specifically to tendon transfer surgery. Only two of the 25 studies described barriers related to nerve transfer surgeries. As these innovative procedures gain more attention and become more widespread, future efforts should focus on developing a better understanding of the barriers to and the facilitators of accessing care as these procedures. Nerve transfer procedures have unique advantages, disadvantages, and postoperative rehabilitation programs that individuals with tetraplegia may consider differently and may help providers target-specific barriers.

Decision-making may be influenced by the individual's personal context, life priorities, values system, clinical culture, and overall healthcare funding system. The experience of a person with tetraplegia in countries, where fully funded UE reconstruction and postoperative supports are offered to all patients, may be drastically different compared to countries with less funding or lack of coordinated care. The majority of qualitative studies examining barriers come from New Zealand where this is the case, and thus may not apply to North America.

This study focused on barriers and facilitators to UE reconstructive surgery and has some study limitations. By including only English language articles, perspectives from other non-English language countries were not explored ($n = 3$; excluded at the title and abstract screening phase). There have been few publications investigating the caregivers' perspective and the influence on decision-making of individuals living with tetraplegia, or on the perspectives of other SCI healthcare team members (social workers, therapists, psychologists etc). Fox et al. [14] examined the caregiver perspective in the context of nerve transfer surgery but did not include caregivers of individuals with SCI who declined surgery. Future research exploring the relationship between people with tetraplegia and their caregivers will provide insights on how UE reconstruction is accessed and the influences of intrinsic or extrinsic decision factors and support networks. Expanding the literature search through the inclusion of databases like the Cumulative Index to Nursing & Allied Health database may capture the perspective of other SCI healthcare team members. Individuals with tetraplegia who decline surgical intervention would be another perspective worth exploring as understanding the rationale behind the decision-making process may shed light on additional barriers that may not have been reported. Many of the published studies are qualitative designs and inherently subject to recall bias. Specific thoughts and emotions experienced by these individuals may be impacted by subsequent events in their overall care. To better understand the nuances related to decision-making, future investigations should capture patient experiences through the healthcare system. In doing so, a value-based approach to care may be cultivated and ultimately improve access to UE reconstruction as well as the overall care of this patient population. Recently, investigators have used a mixed methods approach, such as Sinnott et al. [34] who combined clinician-directed patient-reported outcome measures with qualitative lived-experiences of individuals with tetraplegia undergoing either nerve or tendon transfer surgery. A mixed methods approach may better inform clinical practice and decision-making around current and emerging therapies. Finally, no study has examined the interrelation of individual, provider, and system-level factors. Elucidating the complex relationship between these factors may help promote consideration of UE surgery.

UE reconstruction is a useful treatment option that can improve upper limb function in individuals with tetraplegia but remains underutilized secondary to many patient-, provider-, and system-level barriers. Strategies to target factors such as the lack of knowledge on UE reconstruction, weak interdisciplinary relationships, and logistic and financial barriers may help better inform individuals with tetraplegia and providers. Addressing barriers that lead to

low utilization of UE reconstruction will ultimately improve upper limb function in this population.

Data availability

The dataset analyzed during the current study is available from the corresponding author on reasonable request.

Acknowledgements The authors would like to thank the support of the Sunnybrook Health Sciences Centre librarians, who provided us with their expertise during the literature search process.

Author contributions CY acquired the data, interpreted the results, drafted and revised the manuscript, and approved the final version. SS acquired the data and edited and approved the final manuscript. CBN is an expert within the field of spinal cord and peripheral nerve surgery; she provided the team with extensive expertise in the area of research design and conduct, edited the manuscript thoroughly, provided feedback on the report, and approved the final version. IKF is an expert in the field of peripheral nerve surgery and provided the team with her expertise, assisted with interpreting the results, and editing the manuscript. JD was the principal investigator, conceived and designed the study, and oversaw every phase of the study from its conception through its completion.

Compliance with ethical standards

Conflict of interest The authors declare no competing interests.

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

References

1. Snoek GJ, IJzerman MJ, Hermens HJ, Maxwell D, Biering-Sorensen F. Survey of the needs of patients with spinal cord injury: impact and priority for improvement in hand function in tetraplegics. *Spinal Cord*. 2004;42:526–32.
2. Zancolli EG. History of surgery in the rehabilitation of the tetraplegic upper limb. *Hand Clin*. 2002;18:369–76.
3. Fox IK, Miller AK, Curtin CM. Nerve and tendon transfer surgery in cervical spinal cord injury: individualized choices to optimize function. *Top Spinal Cord Inj Rehabil*. 2018;24:275–87.
4. Coulet B, Allieu Y, Chammas M. Injured metamere and functional surgery of the tetraplegic upper limb. *Hand Clin*. 2002;18:399–412.
5. Ram AN, Curtin CM, Chung KC. Population-based utilities for upper extremity functions in the setting of tetraplegia. *J Hand Surg*. 2009;34:1674–81. <https://doi.org/10.1016/j.jhsa.2009.07.003>.
6. Curtin CM, Gater DR, Chung KC. Upper extremity reconstruction in the tetraplegic population, a national epidemiologic study. *J Hand Surg*. 2005;30A:94–9.
7. Fox PM, Suarez P, Hentz VR, Curtin CM. Access to surgical upper extremity care for people with tetraplegia: an international perspective. *Spinal Cord*. 2015;53:302–5.
8. Bryden AM, Wuolle KS, Murray PK, Peckham PH. Perceived outcomes and utilization of upper extremity surgical reconstruction in individuals with tetraplegia at model spinal cord injury systems. *Spinal Cord*. 2004;42:169–76.
9. Sinnott KA, Dunn JA, Rothwell AG, Hall AS, Post MWM. The development of the NZ-based international upper limb surgery registry. *Spinal Cord*. 2014;52:611–5.

10. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005;8:19–32.
11. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010;5:1–9.
12. Harris CA, Muller JM, Shauver MJ, Chung KC. Checkpoints to progression: qualitative analysis of the personal and contextual factors that influence selection of upper extremity reconstruction among patients with tetraplegia. *J Hand Surg*. 2017;42:495–505. <https://doi.org/10.1016/j.jhsa.2017.04.003>.
13. Harris CA, Muller JM, Shauver MJ, Chung KC. Leveraging the medical context to increase upper extremity reconstruction among patients with tetraplegia: a qualitative analysis. *Arch Phys Med Rehabil*. 2018;99:459–67. <https://doi.org/10.1016/j.apmr.2017.06.028>.
14. Fox I, Hoben G, Komaie G, Novak C, Hamm R, Kahn L, et al. Nerve transfer surgery in cervical spinal cord injury: a qualitative study exploring surgical and caregiver participant experiences. *Disabil Rehabil*. 2019;0:1–8. <https://doi.org/10.1080/09638288.2019.1669225>.
15. Zhong S, Reed GE, Kalliainen LK. Upper extremity surgery in tetraplegia and the online information void. *Hand*. 2019:1–4.
16. Dunn JA, Hay-Smith EJ, Keeling S, Sinnott KA. Decision-making about upper limb tendon transfer surgery by people with tetraplegia for more than 10 years. *Arch Phys Med Rehabil*. 2016;97: S88–96. <https://doi.org/10.1016/j.apmr.2015.09.026>.
17. Snoek GJ, van Til JA, Krabbe PFM, Ijzerman MJ. Decision for reconstructive interventions of the upper limb in individuals with tetraplegia: the effect of treatment characteristics. *Spinal Cord*. 2008;46:228–33.
18. Dunn JA, Hay-Smith EJC, Whitehead C, Keeling S. Issues influencing the decision to have upper limb surgery for people with tetraplegia. *Spinal Cord*. 2012;50:844–7.
19. Dunn JA, Hay-Smith EJC, Whitehead C, Keeling S. Liminality and decision making for upper limb surgery in tetraplegia: a grounded theory. *Disabil Rehabil*. 2013;35:1293–301.
20. Wagner JP, Curtin CM, Gater DR, Chung KC. Perceptions of people with tetraplegia regarding surgery to upper-extremity function. *J Hand Surg*. 2007;32:483–90.
21. Harris CA, Shauver MJ, Nasser JS, Chung KC. The golden year: how functional recovery sets the stage for tendon transfer surgery among patients with tetraplegia—a qualitative analysis. *Surgery*. 2019;165:365–72. <https://doi.org/10.1016/j.surg.2018.07.009>.
22. Anderson KD, Friden J, Lieber RL. Acceptable benefits and risks associated with surgically improving arm function in individuals living with cervical spinal cord injury. *Spinal Cord*. 2009;47: 334–8.
23. Curtin CM, Wagner JP, Gater DR, Chung KC. Opinions on the treatment of people with tetraplegia: contrasting perceptions of physiatrists and hand surgeons. *J Spinal Cord Med*. 2007;30:256–62.
24. Mooney A, Hewitt AE, Hahn J. Nothing to lose: a phenomenological study of upper limb nerve transfer surgery for individuals with tetraplegia. *Disabil Rehabil*. 2020;0:1–9. <https://doi.org/10.1080/09638288.2020.1750716>.
25. Punj V, Curtin C. Understanding and overcoming barriers to upper limb surgical reconstruction after tetraplegia: the need for interdisciplinary collaboration. *Arch Phys Med Rehabil*. 2016;97: S81–7. <https://doi.org/10.1016/j.apmr.2015.11.022>.
26. Hummel JMM, Snoek GJ, van Til JA, van Rossum W, Ijzerman MJ. A multicriteria decision analysis of augmentative treatment of upper limbs in persons with tetraplegia. *J Rehabil Res Dev*. 2005;42:635–43.
27. Curtin CM, Hayward RA, Kim M, Gater DR, Chung KC. Physician perceptions of upper extremity reconstruction for the person with tetraplegia. *J Hand Surg*. 2005;30A:87–93.
28. Weiss AA. Contemporary trends in management of the upper limb in tetraplegia: a multinational perspective. *Hand Clin*. 2008;24: 157–60.
29. Wangdell J, Friden J. Outcomes of reconstructive hand surgery in patients with tetraplegia and neuropathic pain. *Spinal Cord*. 2018;56:1194–8.
30. Divanoglou A, Westgren N, Bjelak S, Levi R. Medical conditions and outcomes at 1 year after acute traumatic spinal cord injury in a Greek and a Swedish region: a prospective, population-based study. *Spinal Cord*. 2010;48:470–6.
31. Turcsanyi I, Gohritz A, Friden J. Launching a new national tetraplegia upper extremity surgery service. *J Rehabil Med*. 2016;48: 571–5.
32. Squitieri L, Chung KC. Current utilization of reconstructive upper limb surgery in tetraplegia. *Hand Clin*. 2008;24:169–73.
33. Dunn JA, Hay-Smith EJC, Whitehead LC, Keeling S, Rothwell AG. Upper limb reconstructive surgery uptake for persons with tetraplegia in New Zealand: a retrospective case review 2001–2005. *Spinal Cord*. 2010;48:832–7.
34. Sinnott KA, Dunn JA, Smaill RP, Middleton JW. Using mixed methods to better appreciate the life impact of upper limb reconstruction surgeries for tetraplegia in New Zealand—a study protocol. *JSM Orthop Rheumatol*. 2019;5:1–7.
35. Snoek GJ, Ijzerman MJ, Post MW, Stiggelbout AM, Roach MJ, Zilvold G. Choice-based evaluation for the improvement of upper-extremity function compared with other impairments in tetraplegia. *Arch Phys Med Rehabil*. 2005;86:1623–30.