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International Classification of Function, Disability and Health (ICF) Word Mapping to Determine the Human Functioning Associated with Upper Extremity Surgery for Tetraplegia

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Abstract

Understanding human functioning and disablement, the contributing factors and their interactions in individuals with tetraplegia is important since elective upper extremity (UE) reconstructive surgery is now offered earlier after injury prior to full recognition of what lies ahead. Qualitative and quantitative data were available from a prior series of mixed methods studies, including a case series design capturing the patients' lived-experience perspectives of nerve or tendon transfer surgery, or not as the case may be. The objective of this study was to perform secondary data analysis to determine whether the recommended outcome tools being used by clinicians reflect the all important domains of functioning identified by people with tetraplegia who were considering UE reconstructive procedures. The original 18 candidate themes derived from qualitative analysis were reviewed in retrospect, along with a content analysis of the tools' questions, undertaking word mapping links to the ICF taxonomy. The outcomes tools included in the content analysis were the Canadian Occupational Performance Measure, the Capabilities of Upper Extremity Questionnaire, The Personal Wellbeing Index, and the Grasp and Release Test. Comparison between clinical outcomes tools and the patient lived-experience data uniquely identified links to Chapter1 (b) Mental functions, which include consciousness, orientation, temperament/personality, energy/drive, and higher-level cognition.

Keywords

Tetraplegia, lived-experience, human functioning, ICF, cognitive demands

Introduction

Advanced reconstructive surgical interventions, including nerve transfer (NT) and/or tendon transfer (TT) procedures, can be used to increase upper extremity (UE) function for individuals with tetraplegia, specifically mid-cervical level spinal cord injury (SCI). This improves the individual's ability to perform activities of daily living without the need for adaptive equipment or orthoses.[1,2] Recent muscle reanimation procedures using NTs are offered far sooner than traditional TTs, requiring clinical assessment, selection, and decision-making to occur as early as 3 months postinjury.[3–6] It is important that health professionals provide expert knowledge to inform key decisions in a person's rehabilitation, determine areas of UE function requiring intervention, create the assessment tools, and even mediate to some extent what shapes "successful" outcomes.[1,7] However, the interface between clinicians' expert knowledge, assessment

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processes, and shared decision-making for vulnerable individuals with SCI requires careful reflection.[8]

With the advent of new and time-limited NT surgeries, significant procedural issues have been raised in terms of evaluation of suitability for UE surgery, shared decision-making processes, referral systems, determining outcomes of interest, approaches to person-centered goal setting and guidelines for best practice, whereby harm is minimized.[9] The justification for more research in this area is linked to an ethical dilemma of offering early elective surgery to people with tetraplegia before they can fully comprehend the daily impacts of living with their disability.[8,10]

Results of mixed methods, convergent design research exploring the unique intersection between arm/hand surgical reconstructions, intervention timing, physical assessment processes, and the life impacts described by individuals with tetraplegia have been reported previously.[8–10] These publications include the primary qualitative analysis using a data-driven inductive reflexive thematic analysis as per Braun and Clarke,[11] details about the utility, feasibility and psychometric properties of the 4 recommended outcome measures and the pre-post score changes following UE surgery,[10] as well as the transformative analysis when integration of the findings using the Stewart Model of Care, drawn from palliative health, enabled the interpretation of higher order messages.[8]

The purpose of this paper is to report the secondary analysis from this body of work to determine whether the suite of recommended patient-reported outcome tools capture fully the important aspects of lived-experience in individuals with tetraplegia undergoing UE reconstructive surgery. This involved performing a content analysis of each of the 4 outcome measures used by clinicians in New Zealand, alongside the content of the initial descriptive candidate themes from interview data, subsequent word mapping using the ICF taxonomy and final assessment of convergence between these different data for coverage of ICF domains.

Methods

We linked keywords and meaningful concepts of outcome measures used in UE surgery and candidate themes from qualitative interviews of people who did and did not have UE surgery to second or third level ICF classification categories. Inclusion criteria for this study are shown in Figure 1. In total there were 5 data sources linked, 4 were outcome measures and the final source was candidate themes from qualitative interviews.

Outcome Measures

The 4 outcome tools, Canadian Occupational Performance Measure (COPM), Grasp and Release Test (GRT), Capabilities of Upper Extremity Questionnaire (CUE-Q), and Personal Wellbeing Index (PWI), were those in use in New Zealand that were agreed upon by the International Therapist Consensus group in 2009.[12] All data analyzed in this study were derived from New Zealand. First, identified priorities from the COPM[13] were extracted from the International UE Surgery Registry for all people who had surgical reconstructions performed between 2009 and 2019. Secondly, the content of the questions of the CUE-Q,[14] PWI[15] were included in the ICF word-mapping. Finally, each of the 6 tasks of the GRT[16] was evaluated against the relevant ICF chapter content.

Sampling and Recruitment for Interviews

A cohort of individuals with C5-7 tetraplegia, assessed as suitable for reconstructive surgery at the Burwood Spinal Unit between August 2010 and August 2019, was extracted from the New Zealand portal of the International UE Surgery registry. Suitability for surgery was based on classification of the level and extent of SCI neurological impairment using the International Standards for Neurological Classification of SCI (ISNCSCI),[17] including the American Spinal Injury Association Impairment Scale[18] and the International Classification of Hand Surgery for Tetraplegia.[19] From this cohort, potential participants were identified for recruitment for the lived-experience interview study as shown in Figure 1 above. Recruitment was purposive to ensure broad representation in terms of the lived-experience response to the offer of elective UE surgery. Individuals who had elected to accept the offer of surgery many years following SCI, in addition to those who had consistently declined surgery were specifically targeted. All participants were provided with an information sheet and signed a consent form prior to interview. Interview questions were open-ended so that the conversations were ultimately guided by the needs and concerns of participants.

Interview Schedule

A semistructured schedule was used to guide the interview process. All the participants in both the late-to-surgery group and the group who declined surgery were explicitly asked about the selection and assessment process, their decision-making experience and what their advice about UE surgery would be based on current knowledge and life experience to: (a) A newly injured person in the spinal cord injuries unit today and (b) younger self with the benefit of hindsight.

Secondary Data Analysis

For all 5 data sources a word-by-word content analysis was performed and linked to the ICF taxonomy using specific linking rules.[20] This included retrospective linking of keywords and meaningful concepts to second or third level ICF classification from the previously completed qualitative data analysis, the preoperative COPM priorities related to

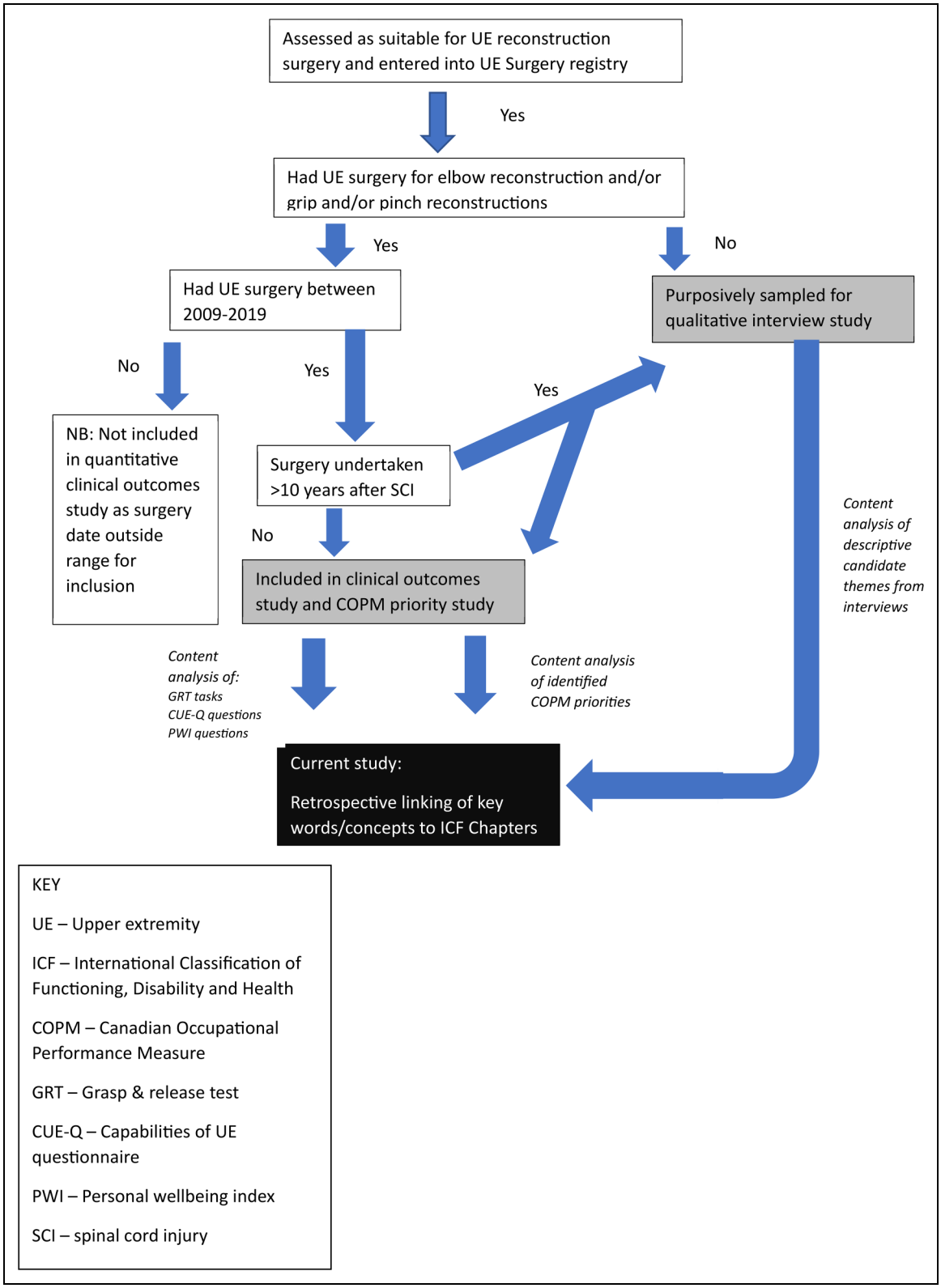


Figure 1. Cohort sampling system.

each individual surgical procedure, each question within the CUE-Q and the PWI, and each GRT task. This standardized linking procedure is widely used to qualitatively link content within and between outcome measures and is well known to 1 member of the research team (KASJ), as has been used in previous ICF linking projects.[21–24] The ICF linking software

was used to map the keywords or phrases to create meaningful concepts.[25] Given the volume of data across ICF domains of Body Structures (s), Body Functions (b), Activity and Participation (d) and Environmental Factors (e) and the 1064 possible ICF categories, the first level links to domain chapters for each category was performed for the outcome tools. Specifically, this data integration step was undertaken to represent the content in terms of human functioning by visually representing the ICF chapter coverage across the 5 data sources.

Both the primary and secondary analysis of narrative data were completed by 2 of the team. These were KASJ as the PhD candidate, a physiotherapist and qualitative researcher in SCI, and RPS 1 of 3 academic supervisors, a psychologist with 40 + years of lived experience of SCI and a recipient of UE surgery. This was overseen by academic supervisor (JAD), who is a clinical expert in the topic-field, and primary supervisor (JWM), who is a rehabilitation physician and professor of rehabilitation medicine.

Results

Word Mapping of the Outcome Measures

COPM Priorities. A total of 885 priorities were identified across all UE reconstructions within the COPM categories of (i) self-care (ii) leisure and (iii) productivity.[26] At a macro word-for-word recognition level, 1213 possible meaningful concepts were identified using the ICF search browser. Irrespective of the context in terms of personal experience, all chapters of the ICF components for Body Structures and Functions, Activities and Participation and Environmental Factors were represented by the ICF categories identified by the participants. Thirty-six priorities were not able to be readily classified using the ICF because they were personal factors. Examples include: *To be able to help my baby climb onto my lap*, *To be able to spend time alone without caregivers.*

Capabilities of Upper Extremity Questionnaire. The ICF linking suggests that the CUE-Q predominantly covers the Body Function and Body Structures domains of the ICF.[27] Specifically, the Body Function domain of Chapter 7 Neuromusculoskeletal and movement-related functions, and in terms of Body Structures to Chapter 7 Structures related to movement of the upper limb and/or trunk control, head and neck and the scapula. The CUE-Q also covers, but to a lesser extent the Activity domain including Chapter 4 Mobility-related with reference to Chapter 5 Self-care, Chapter 6 Domestic Life, and Chapter 3 Communication.

Personal Wellbeing Index. The ICF linking suggests Part 1 Q1.1 and Part 2 Q2.3 are designated personal factors and therefore not included in the current ICF taxonomy. Part 2 provides more scope within the taxonomy with coverage of the ICF domain chapters of Activity and Participation, and Environmental Factors.

Grasp and Release Test. From our ICF linking the activities in the GRT shows the most specific coverage in terms of ICF Body Structures and Functions.

Qualitative Interview Data

Semistructured in-depth interviews were undertaken with 18 individuals with tetraplegia, including 6 individuals who had accepted early NT surgery, 5 individuals with over 10 years duration who had arm/hand TT surgery, and 7 individuals who consistently declined surgery. The mean current age of participants was 42 years (range: 22-61 years), with a median time since SCI of 18 years (range: 0.5-36 years). The median time from SCI to surgery for the NT group, who had undergone surgery was 7 months (range 5-9 months), in contrast to duration for the TT group of 18 years postinjury (range 11-26 years). Refer to Tables 1a and 1b for participant characteristics.

While final themes were created and reported elsewhere,[9] the language of the initial themes was more descriptive and illustrative. The initial candidate theme NVIVO mind map is shown in the Supplemental Material and the ICF chapter links are shown in Table 2 along with the ICF chapter links from the 4 outcome measures. The interview data ICF chapter linkages from the NVIVO mind map included 1 from Body Structures relating to movement (Chapter 7), 3 from Body Functions including seven references to Chapter 1 Mental Functions, 6 out of the possible 8 chapters from Activity & Participation (Chapters 1, 3, 4, 5, 7, 8) and 3 from Environmental Factors where Chapter 3 Relationships and Chapter 4 Attitudes, dominated.

Secondary Data Convergence

The qualitative interview data was the only source of linkages to Body Functions (b) Chapter 1 Mental Functions (n = 8). In terms of total scores per domain across the 5 data sources Chapter 4 (b) Mobility showed the greatest frequency of ICF chapter links (n = 27) from the 5 data sources. Following this, from the Environmental domain's Chapter 5 (e) Services, systems and policies were next highest with 21 chapter links from three data sources. This was followed by Body Structure's (s) Chapter 7 Structures related to movement (n = 19) and an equal number of links to Body Function's (b) Chapter 7 Neuromuscular and movement (n = 18), Activity and Participation's (d) Chapter 5 Self-care (n = 18) and Environmental domain's (e) Chapter 4 Attitudes (n = 18). All these ICF domain chapters had links to 3 or 4 of the 5 data sources, with the COPM data source making up the majority of the links in these chapters. Both the COPM and qualitative interview data sources provided similar numbers of linkages to the Environmental chapters. The PWI and the interview data shared the majority of activity and participation (d) Chapter 7 Interpersonal and

Table 1a. Participant Demographics, SCI Characteristics, and Surgery Details.

Interview sequence	Sex	Age at interview	ISNCSCI	Cause of SCI	Work/employment pre SCI	Current employment	Time SCI to first surgery	Ethnicity
NT 1	M	21	C5 A	Fall	Study	Student	8 months	NZ European
NT 2	M	28	C5 B	Fall	Employed	Unemployed	6 months	NZ European
DS 1	M	51	C6 B	Transport	Study	Employed	N/A	NZ European
TT 1	M	42	C7 A	Transport	Study	Employed	16 years	NZ European
DS 2	M	35	C5 A	Sports	Employed	Employed	N/A	Māori/NZ Euro
NT 3	M	52	C5 B	Assault	Employed	Unemployed	6 months**	NZ European
DS 3	M	40	C5 A	Sports	Employed	Student	N/A	NZ European
DS 4	M	45	C7 A	Transport	Employed	Employed	N/A	Māori
NT 4	M	27	C5 A	Sports	Study	Unemployed	6 months**	Māori
TT 2	M	55	C7 A	Sports	Employed	Retired	27 years	Māori
NT 5	F	37	C5 A	Sports	Unemployed	Unemployed	5 months	Māori
DS 5	M	60	C5 A	Sports	Employed	Employed	N/A	NZ European
DS 6	M	39	C6 A	Transport	Employed	Unemployed	N/A	NZ European
DS 7	M	37	C7 A	Transport	Employed	Unemployed	N/A	NZ European
TT 3	F	47	C7 B	Sports	Employed	Employed	12 years	NZ European
NT 6	M	22	C5 A	Transport	Employed	Employed	9 months	Māori
TT4	M	40	C6 A	Sports	Study	Employed	11 years	NZ European
TT 5	M	52	C7 A	Transport	Employed	Employed	23 years	Māori

Abbreviations: ISNCSCI, International Standards for Neurological Classification of SCI; SCI, spinal cord injury; NT, nerve transfer; TT, tendon transfer.
[a]Individuals consented for surgery but had not yet undergone first procedure which in both cases to date was subsequently limited to NT.

Table 1b. Participant's Surgery Procedures Details in Order of Study Group.

	Reason for delay or decline	Time SCI to first surgery	First surgery	Second surgery	Third surgery	Bilateral/unilateral/ simultaneous or staged	Complications
NT 1	N/A	8 months	SPIN[a]	TROIDS[b]	Hands[c]	Bilateral simultaneous	No
NT 2	N/A	6 months	SPIN	TROIDS	Hands	Bilateral simultaneous	No
NT 3	N/A	6 months	SPIN			Bilateral simultaneous	No
NT 4	N/A	6 months	SPIN			Bilateral simultaneous	No
NT 5	N/A	5 months	SPIN	TROIDS	Hands	Bilateral simultaneous	No
NT 6	N/A	9 months	SPIN	TROIDS		Bilateral simultaneous	No
TT 1	Sports	16 years	Hand	Hand		Bilateral staged	No
TT 2	Failed previous procedure	27 years	Hands			Bilateral simultaneous	Previous not current
TT 3	Sports	12 years	Hands			Bilateral simultaneous	No
TT4	Poor impression of assessment	11 years	TROIDS	Hands		Bilateral simultaneous	No
TT 5	Sports	23 years	Hands			Unilateral simultaneous	No
DS 1	Logistics	N/A	N/A	N/A	N/A	N/A	
DS 2	Alternative priorities	N/A	N/A	N/A	N/A	N/A	
DS 3	Logistics	N/A	N/A	N/A	N/A	N/A	
DS 4	Logistics	N/A	N/A	N/A	N/A	N/A	
DS 5	Alternative priorities	N/A	N/A	N/A	N/A	N/A	
DS 6	Recovery	N/A	N/A	N/A	N/A	N/A	
DS 7	Alternative priorities	N/A	N/A	N/A	N/A	N/A	

[a]SPIN refers to supinator to posterior interosseous nerve transfer.
[b]TROIDS is an abbreviation for Posterior deltoid to triceps tendon transfer.
[c]Thumb and/or finger TTs ± distal split flexor pollicis longus (FPL) tenodesis.

relationships linkages (n = 6). Table 3 represents these ICF chapter links in a color-coded display.

There was 1 significant feature drawn from the 18 interviews of the participants' collective experience of their own SCI and diagnosis of tetraplegia. Each participant referred back in some detail to their experience of being a patient assessed as suitable for UE surgery. Furthemore each participant was readily able to provide definite feedback about this process in light of the necessity now with newer NT procedures for assessment performed far earlier, and how this would change the decision-making process following SCI. The demands of the decision-making process in terms of higher

Table 2. Data Source and ICF Linking to Second (or Third Level Coding if Provided Clarity).

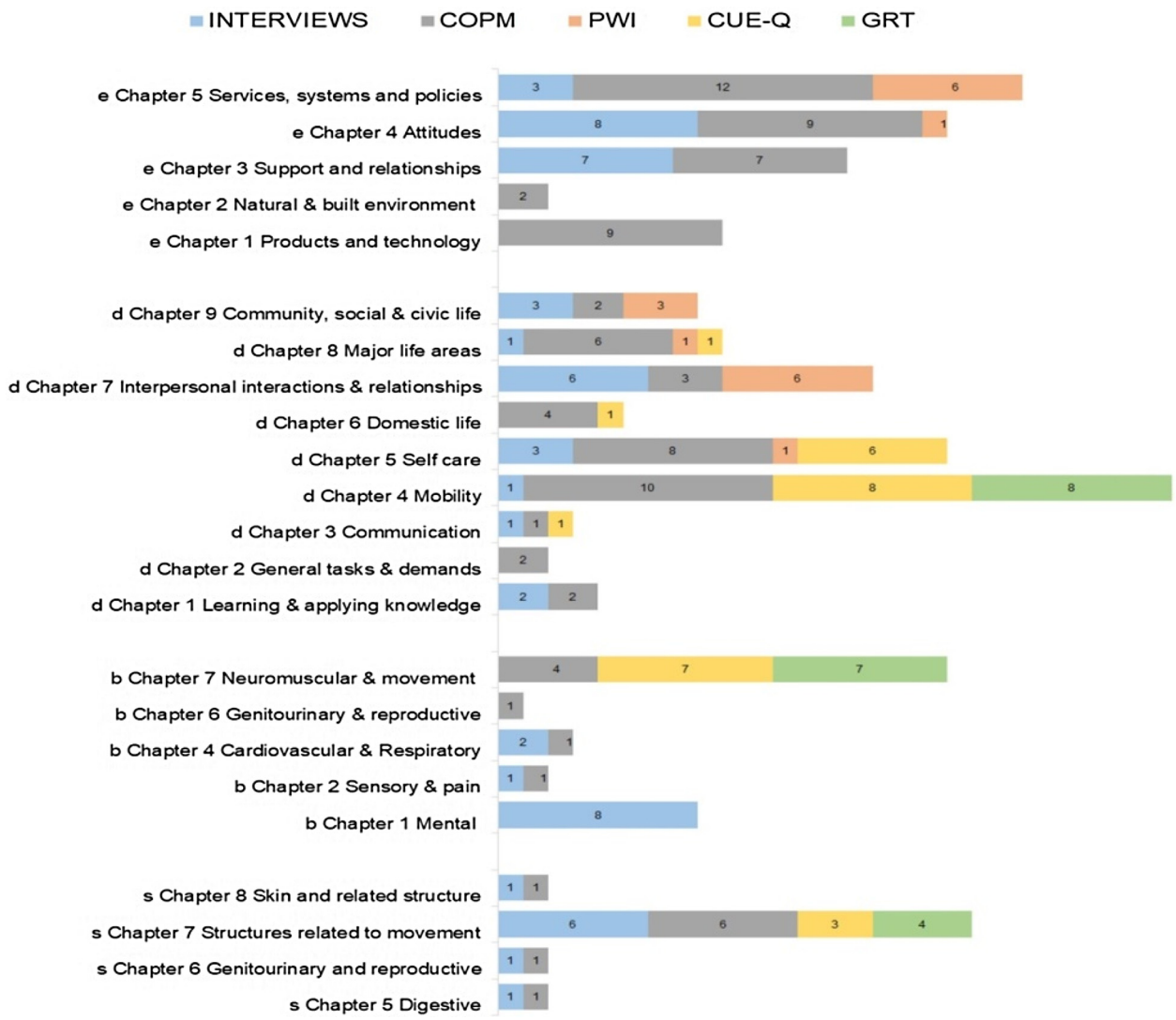
Data source	Body structures (s)	Body functions (b)	Activity and participation (d)	Environmental factors (e)
Candidate themes				
Triumphs of hope over inexperience of SCI		Chapter 1: Mental functions	Chapter 1: Learning and applying knowledge Chapter 5 Self-care Chapter 7: Community, social, and civic life Chapter 8 Major life areas	Chapter 4: Attitudes
Deal breakers including driving	Chapter 7: Structures related to movement	Chapter 1: Mental functions Chapter 4: Functions of the cardiovascular system	Chapter 1: Learning and applying knowledge Chapter 4 Mobility Chapter 5 Self-care Chapter 8 Major life areas	Chapter 4: Attitudes Chapter 5: Services, systems & policies
Don't underthink the future Nothing to lose Don't be rushed		Chapter 1: Mental functions	Chapter 1: Learning and applying knowledge Chapter 5 Self-care	Chapter 3 Relationships Chapter 4: Attitudes
SCI peers do know Yet we are all different Not ready to see self in peers Clinicians know but don't know		Chapter 1: Mental functions	Chapter 7 Interpersonal interactions and relationships	Chapter 3 Relationships Chapter 4: Attitudes
Always hoping for better Hope for recovery Regret retiming		Chapter 1: Mental functions	Chapter 5 Self-care	Chapter 3 Relationships Chapter 4: Attitudes
Funding discrepancies Social geography Power of case managers		Chapter 1: Mental functions	Chapter 7 Interpersonal interactions and relationships Chapter 7: Community, social and civic life	Chapter 4: Attitudes Chapter 5: Services, systems & policies
Acceptance versus adjustment		Chapter 1: Mental functions		Chapter 3 Relationships Chapter 4: Attitudes Chapter 5: Services, systems & policies
COPM priorities				
	Chapter 5: Structures related to the digestive, metabolic and endocrine systems	Chapter 2: Sensory functions and pain	Chapter 1: Learning and applying knowledge	Chapter 5: Services, systems & policies
	Chapter 6: Structure related to genitourinary and reproductive systems	Chapter 4: Functions of the cardiovascular system	Chapter 1: Learning and applying knowledge	Chapter 2: Natural environment and human-made changes
	Chapter 7: Structure related to movement	Chapter 6: Function related to genitourinary and reproductive systems	Chapter 2: General tasks and demands	Chapter 3: Support and relationships
		Chapter 7: Function related to movement	Chapter 3: Communication	Chapter 4: Attitudes

(continued)

Table 2. (continued)

Data source	Body structures (s)	Body functions (b)	Activity and participation (d)	Environmental factors (e)
			Chapter 4: Mobility	
			Chapter 5: Self-care	Chapter 5: Services, systems and policies
			Chapter 6: Domestic life	
			Chapter 7: Interpersonal interactions and relationships	
			Chapter 8: Major life events	
			Chapter 9: Community, social and civic life	
CUE-Q tasks				
	Chapter 7: Structure related to movement	Chapter 7: Function related to movement	Chapter 3: Communication	
			Chapter 4: Mobility	
			Chapter 5: Self-care	
			Chapter 6: Domestic life	
			Chapter 8: Major life events	
PWI question content				
			Chapter 5: Self-care	Chapter 4: Attitudes
			Chapter 7: Interpersonal interactions and relationships	Chapter 5: Services, systems and policies
			Chapter 8: Major life events	
			Chapter 9: Community, social and civic life	
GRT tasks				
	Chapter 7: Structure related to movement	Chapter 7: Function related to movement	Chapter 4: Mobility	

Table 3. Color-Coded ICF Chapters.



level cognitive and emotional functions were most evident in the individuals who declined surgery. Examples are provided in Table 4.

Discussion

The purpose of this paper is to report the secondary analysis which comprised ICF linking to represent human functioning in the context of UE surgery for individuals with tetraplegia. We have attempted to determine whether the domains of human functioning portrayed through in-depth interviews are reflected in the question coverage of the outcome tools in use in New Zealand (the COPM, CUE-Q, PWI, and the GRT). From this study, we have shown that the questions/activities of the CUE-Q and GRT mostly cover the ICF's Body Functions and Body Structures domains, the questions of the PWI that can be categorized cover the ICF's Activity & Participation, and Environmental domains. The self-identified priorities of the COPM cover all domains of the ICF. While individual outcome measures are obviously limited in terms of the dimension of human functioning that is measured,[28] once the lived-experience ICF-linked data was superimposed the picture changed. Without the interview data, the complexity of the patients' experiences of UE surgery that deals with cognitive and executive functions of the brain would have been omitted. The ICF refers to Mental Function as global mental functions, such as consciousness, as well as the functions of psychic energy and drive, and the specific mental functions, including memory, cognitive-linguistic, and numeracy capabilities.[25]

Not surprisingly, the greatest number of links to the ICF from all 5 data sources was Chapter 4 Mobility. These were associated with fine hand use including grasping,

Table 4. Interview Data with ICF Linkages to Mental Functions.

b110 Consciousness	b114 Orientation Functions	b126 Temperament and personality	b130 Energy and drive	b152 Emotional responses	b164 Higher-level cognitive functions
I was definitely in an altered state in my head. And I felt he [the surgeon] had a real vested interest in going through with it, or that he was offering me something that was going to make my life better and I thought, 'You don't know me from a bar of soap, you can't say whether or not this is going to make my life better'. **DS Male 35 years**	*I mean, for myself, I mean I knew immediately that the severity of my injury in terms of the damage I did was, you know, I was classed as ASIA A complete. I was pretty content that I knew that I wasn't going to get any big gains post sort of six months injury. And anything I'd gain from that point would be quite minor, if anything at all.* **NT Male 21 years**	*It's positive, you know, like when you have a severe injury like I did, I guess, any sort of improvement's got to be a pretty positive thing. It is kind of all about my future now.* **NT Male 21 years**	*Like driving was my big motivation, maybe for the new surgery that would help you know, like make a focus for them early and maybe help with the decision [re the surgery] early while they are still there at the spinal unit since they gotta make the decision in a rush.* **DS Male 39 years**	*Because everyone else [the staff] just gets to walk home. At the end of the day it's just an 8-hour job. It's not a 24-h life.* **DS Male 37 years**	*I don't think [in the early days] anyone is in a space to make the decision of that magnitude and I think a hand surgeon would probably think it's not a big deal. It's a massive deal.* **TT Female 47 years**
Well, to speak honestly, I was still overwhelmed. But I regret saying no to the surgery—I planned to tell you that today —really regret it. **DS Male 37 years**	*I think that your brain is important, having so many years to work out, "OK, this is how I do things," if you get it early enough, you've actually, you get rid of all the bad habits, and you get rid of all the p*ssed-offness.* **TT Male 55 years**	*"Hey, how would, how would you like to improve your life? We can give you hand surgery or give this back." Quite honestly, I'd say "Sod off, unless you can give me my legs back and everything else back."* **TT Male 52 years**	*Yeah, I would say maybe [I would] be a bit less stubborn about the goal to walk again. And maybe think about improvements with some independent things like transfers that would make life easier for others—like X [wife] and her sore back.* **DS Male 40 years**	*I hope to be happy but the hope to walk again never crossed my mind, just never crossed my mind* **NT Male 22 years**	*I was coping with what I'd got you know. I wasn't interested in spending a whole lot of time having a whole lot of surgery cos actually doing the little things for myself weren't the important things for me; the important things were the big things, the really big things.* **DS Male 60 years**

manipulating (objects), reaching, and turning or twisting the hands or arms and broader mobility activities include changing basic body position, maintaining a body position, transferring oneself, lifting and carrying objects, moving around in different locations, moving around using equipment and driving. There are clear limitations to the ICF in the context of measurement, not least the absence of personal factors from the taxonomy.[29–31] However, the ICF does explore the extent to which human functioning is considered within outcome measures , and as such provides a repeatable systematic evaluation. Given what we know about psychosocial consequences and demands of living with SCI,[32,33] the coverage of human functioning excluded Chapter 1 (d) Mental functions unless the patient lived-experience data was viewed. This is particularly important given recent work from our broader research group on SCI in relation to cognition and psychosocial adjustment.[34,35] While there are several valid measures to assess cognition and psychosocial adjustment, one straightforward approach for development of future outcome measures might be the creation of an item bank of UE surgery priorities. The clinician-lead interview used with the COPM for priority identification might be an opportunity to address higher executive cognitive demands at play. With the advent of early NT procedures following SCI this is more urgent. This would allow for an individual to be better targeted in terms of what it is they desire for themselves from the surgical reconstructions. This would allow for specific capabilities to be clarified, thereby making the process more acceptable to the individual considering surgery. This is not meant to sound like a "pick and mix" process, rather that functional priorities identified by others before them and "banked" for future identification would at least ensure better integrity in terms of the identification of priorities that extend beyond what might be considered by well-meaning clinicians.

Conclusion

The results of this secondary content analysis showed clearly how the ICF domains of human functioning were largely represented across the different outcome tools, where there was common coverage, where gaps existed and how representative the data sources were in terms of the patients' lived experience contribution. We know that evidence is stronger for the value of lived-experience research in SCI particularly to ensure that the experience of living with severe disablement is considered. We are not saying that qualitative interviews ought to replace the use of standardized tools. Rather, the clinicians' evaluation for UE surgery suitability might include careful consideration of an individual's emotional well-being, psychological readiness, and the cogntive demands of the decision-making process. These are important implications for the validity of informed consent under such circumstances, where the influence of clinician confidence on decision-making may dominate.

Acknowledgement

We dedicate this body of work to the late Dr Richard Smaill, who died on 30 May 2023 during the review phase of this final manuscript. Richard's contribution to this academic body of work, and many more in the SCI lived-experience research field, is unprecedented, given his professional background in organizational psychology. Aroha nui - kia kaha.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

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Informed Consent Declaration

Informed consent was obtained via the opt-out option for data collection as per the Canterbury District Health Board Ethics Committee

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Supplemental Material

Supplemental material for this article is available online.

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