JSM Orthopedics and Rheumatology

Study Protocol

Using Mixed Methods to Better Appreciate the Life Impact of Upper Limb Reconstruction Surgeries for Tetraplegia in New Zealand – A Study Protocol

K. Anne Sinnott Jerram[1,2]*, Jennifer Ann Dunn[3], Richard Peter Smaill[2], James Walter Middleton[1,4]

[1]John Walsh Centre for Rehabilitation Research, Sydney Medical School, Faculty of Medicine and Health, The University of Sydney, Australia

[2]Burwood Academy of Independent Living, Christchurch, New Zealand

[3]Department of Orthopaedic Surgery & Musculoskeletal Medicine, University of Otago, Christchurch, New Zealand

[4]Kolling Institute of Medical Research, Level 12, Royal North Shore Hospital, St Leonards, NSW 2065, Australia

Abstract

Background: Until the recent advent of innovative nerve transfer (NT) procedures, upper limb reconstructive surgeries for people with tetraplegia have traditionally involved tendon transfers being performed at a time when neurological recovery had plateaued and the person had returned to live, adapt and acquire new life skills prior to having surgery. This study aims to provide a greater understanding of the process of decision-making for upper limb reconstructive surgical procedures at an early stage prior to full knowledge of life with tetraplegia, as well as the life impacts of surgical arm/hand reconstruction procedures.

Methods: A mixed methods convergent design is utilized to allow for the concurrent exploration of narrative data from a case series; and qualitative content analysis of one and quantitative analysis of the two patient-reported outcome measures (PROMs) collected in New Zealand Upper Limb Surgery Registry since 2010. Concurrently, the international classification of functioning, disability and health (ICF) taxonomy is used as the analytical lens to guide data interpretation.

Discussion: This study series challenges the conduit role of research and lived experience collaborations for embracing both rehabilitation and disability philosophies to generate and translate knowledge in the SCI field. The designed studies will inform identification of the most relevant therapeutic targets and their measurement, with increased integrity around the 'person-centred assessment process' and elaboration of PROMs that reflect that integrity, and are less clinician-directed in terms of content.

Keywords: Mixed methods; Tetraplegia; Upper limb surgery; Research integrity; Patient-reported outcome measures

Abbreviations

ICF: International Classification of Function Disability and Health; NT: Nerve Transfer; PROMs: Patient Reported Outcome Measures; SCI: Spinal Cord Injury

Introduction

The level and extent (severity) of neurological impairment following spinal cord injury (SCI) determines the residual functional capacity and muscles under voluntary control, with complete tetraplegia having the greatest degree of severity [1], and therefore being the most disabling [2,3]. Yet there is little reference to 'disablement' in the field of arm/hand surgery research in the SCI [4]. Typically, comprehensive rehabilitation by an interdisciplinary specialist team focuses on physical retraining and exercise, learning new procedural skills along with compensatory strategies and use of adaptive equipment for independent living and self-management, as well as psychosocial support to assist adjustment and coping [5]. Research and innovation of new therapies, surgical approaches and advanced technologies have an important role to play in enablement, however, the various stakeholders involved in SCI research have valued functional outcomes differently with research often not being well aligned with the priorities of people with SCI [6,7]. It has even been said that 'current rehabilitation research does our clients or patients a disservice as it assumes that all we need is evidence about which interventions are effective - without a comprehensive understanding of how an intervention works for an individual client with a particular set of problems in a unique psychosocial context' [8] pg.22.

With advances in research and technology over the latter part of the 20th century, more options and innovative interventions aimed at restoring upper extremity function for people with tetraplegia have evolved throughout the world for improving hand function and quality of life [9]. The hierarchy for surgical restoration of function begins with maximizing ability as much

Submitted: 31 May 2019 | **Accepted:** 18 July 2019 | **Published:** 20 July 2019

***Corresponding author:** K. Anne Sinnott Jerram, John Walsh Centre for Rehabilitation Research, Sydney Medical School, Faculty of Medicine and Health, The University of Sydney, Australia, Burwood Academy of Independent Living, Private Bag 4708, Christchurch, New Zealand, Tel: M: +6421994878; Email: anne.sinnott@burwood.org.nz

Citation: Sinnott Jerram KA, Dunn JA, Smaill RP, Middleton JW (2019) Using Mixed Methods to Better Appreciate the Life Impact of Upper Limb Reconstruction Surgeries for Tetraplegia in New Zealand – A Study Protocol. JSM Orthoped Rheumatol 5: 7.

as possible based on the person's voluntary function, and then augmenting that function by implementing technology or advanced reconstructive surgical interventions [1,10,11]. Until recently, surgical reconstructions were limited to the availability of innervated muscles for tendon transfer (TT) and/or functional electrical stimulation (FES), however, the use of innovative nerve transfer (NT) surgeries has become more widespread [12-14]. The time-limited nature of these new innovations, with need for surgery ideally within the first 6-9 months post-injury, raises new challenges for clinicians in terms of accurate early prognostication, as well as for the potential surgery candidates, who may not yet have come to terms with the permanence of their disability [12-20]. In view of this requirement, it is interesting to note that a review by Fox et al (2018) reports "both nerve and tendon transfer surgeries produce gains in function and are valuable techniques that may be used alone or in combination. Augmenting the armamentarium of available treatment options provides individuals with choices that can be tailored to their goals and preferences" [21] pg.285. Notably, the recent Melbourne prospective NT/TT study is encouraging in terms of pre-post change over time scores for all measures used [12].

As innovations like NT surgeries become readily available treatment options for SCI, there is a concomitant increase in the difficulties in developing and validating the most suitable outcome measures, with competing interests of different research groups favoring certain tools and a predominance of expert clinician-driven consensus in both design of measures [22] and the development of data sets [23,24]. While the various measures being used are considered to be the best available at the time, limitations may exist due to relatively little use of some in practice, and where the data available for comparison is restricted to results from psychometric evaluation only [1,22,25-27]. The clinical utility, feasibility and sensitivity to detect functional changes must be reported in studies from independent sites to allow future improvement and/or development of new outcome measures to progress. Regardless of the type of innovation, and there will certainly be more coming in the future for SCI, PROMs are now being used more widely in research, clinical practice and management to assess how SCI services and interventions have impacted over time on attributes, which only individuals with SCI can know, such as symptom severity, daily functioning, quality of life and other dimensions of health and wellbeing. Crucially, it is essential that the development phase for PROMs is well described and the fundamental differences between clinician-directed and patient-centered origins are declared. This is important in the field of SCI rehabilitation, since the ultimate goal of treatment is not simply for individuals to survive and be able to function, but to thrive and enable full active participation, promoting high quality of life with adjustment to disability.

The efforts and challenges regarding the measurement of outcomes for arm/hand reconstructions are well reported [9,22]. Differing levels of impairment and disability, as well as the heterogeneity of the population with tetraplegia, affect what types of measurements are possible [26]. The small and heterogeneous patient population makes it difficult to recruit sufficiently large numbers of participants for outcome studies.

This is even more difficult if the outcome tools used are too variable. Another challenge is to find broad acceptance of both performance and capacity measures that are capable of detecting small changes in multiple domains. Thus, multi-center data sets can be compiled and used for the evaluation of a range of novel treatment approaches, including robotics and passive work stations, FES and NT procedures. In reality, however, collaboration among centers is complex, not least because of the extensive choice of measurement tools, which limits uniformity [4]. Within the field of SCI research there are a variety of organizations with comprehensive websites to better inform clinicians [28]. However, an issue of considerable concern for the field is that there are almost as many measures used for assessment of outcomes as there are studies reported, mirroring concerns previously raised more generally in SCI research [4], and one that is evident in the upper limb function reviews [25-27]. Figure 1 highlights the large range and variability of instruments being used by ICF domain across international centers. Additionally there is little published on the lived-experience of people with SCI following arm/hand surgery interventions that is considerate of the broader disability perspective. The justifications for which are wide-ranging, but in the first instance include the ethics of offering early elective surgery to people with tetraplegia before they can fully comprehend the life impacts of their disability, the validity of informed consent under such circumstances, the influence of clinician confidence on this process of decision-making and the longstanding voice of experience of life with tetraplegia.

Clinician-researchers in New Zealand have shown longstanding commitment in this field, contributing to advances in knowledge and practice. The contributions have included developing new surgical procedures, [15] examining the decision-making processes faced by this small and vulnerable group of individuals with tetraplegia [17,18,29] use of the International Classification of Functioning, Disability and Health (ICF)(WHO) [30] to interpret outcomes data [31] and the development of an international upper limb surgery registry for future data sharing and collaboration, given the world-wide challenges of small sample size for empirical research [32]. These efforts contributed to a therapist consensus meeting [22] which succeeded in reaching agreement to use certain standard classifications and systems and at least one outcome measure in common. Specifically, the group agreed on the collective use of the Canadian Occupational Performance Measure (COPM) [33] in all upper limb surgery centers in an effort to capture and document patients' self-identification of problems which are formulated as functional tasks of interest. Subsequent studies have reported on COPM-based 'achievements' following staged arm/hand reconstructions [34]. However, there has been nothing reported that relates COPM content to ICF categories that are linked for language identity against lived experience narrative data. This is of interest as it captures amongst other factors, goals that are derived from a broader dialogue. The overall objective of this multi-phased study is to determine convergence between clinician-directed PROMs and the voice from the lived-experience on the topic of complex elective arm/hand surgery interventions for individuals with tetraplegia. In particular, we emphasize the

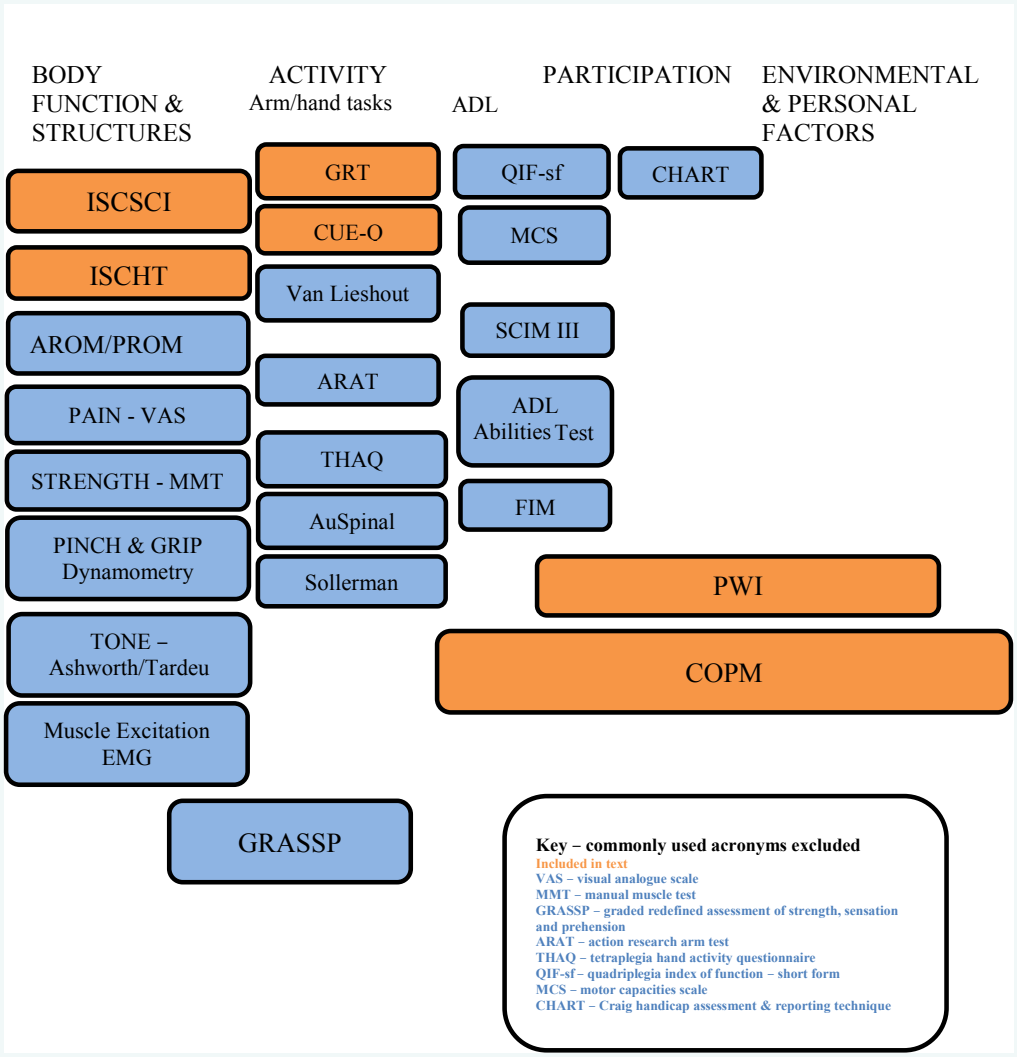

Figure 1 Variability of tools used in international centers in 2009.

requirement for a pragmatic focus on the issues of study design, data collection and analysis. We believe that the flexibility provided by the mixed methods design provides greater scope to achieve these ends.

Methods

Overall Design

In order to answer the research questions posed above, this project will implement a multistage mixed methods convergent design. Phase One is in two parts and involves two qualitative components and Phase Two involves a quantitative study. The final Phase Three is the data transformation phase (Figure 2).

Data stored in the New Zealand International Upper Limb Surgery Registry [4] provides baseline data for SCI level and severity characteristics (including the ICSHT and ISNCSCI referred to previously), as well as demographics and hand function using the gold standard Grasp and Release Test (GRT) [35]. All participants are over the age of 16 years at the time of clinical assessment and provide consent by an opt-out process for data inclusion in the registry. All data is collected routinely in the Burwood Spinal Unit Hand Clinic.

Outcome Measures

Canadian Occupational Performance Measure: The COPM, employs a client-centered approach with a focus on activities that are important to an individual in terms of personally meaningful goals and contextually relevant circumstances [33]. When completing the COPM, the patient identifies his/her problems in partnership with a therapist through a semi-structured interview, and then subjectively evaluates his or her performance and satisfaction regarding each problem. For example, in the setting of arm/hand surgery the individual identifies 'limitations' in areas of 'occupational performance' as for all COPM assessments in the domains of self-care, leisure and productivity to establish achievable desirable tasks/activities of interest. Once five limitations are identified, the patient is asked to rate the importance of being able to perform a specified activity

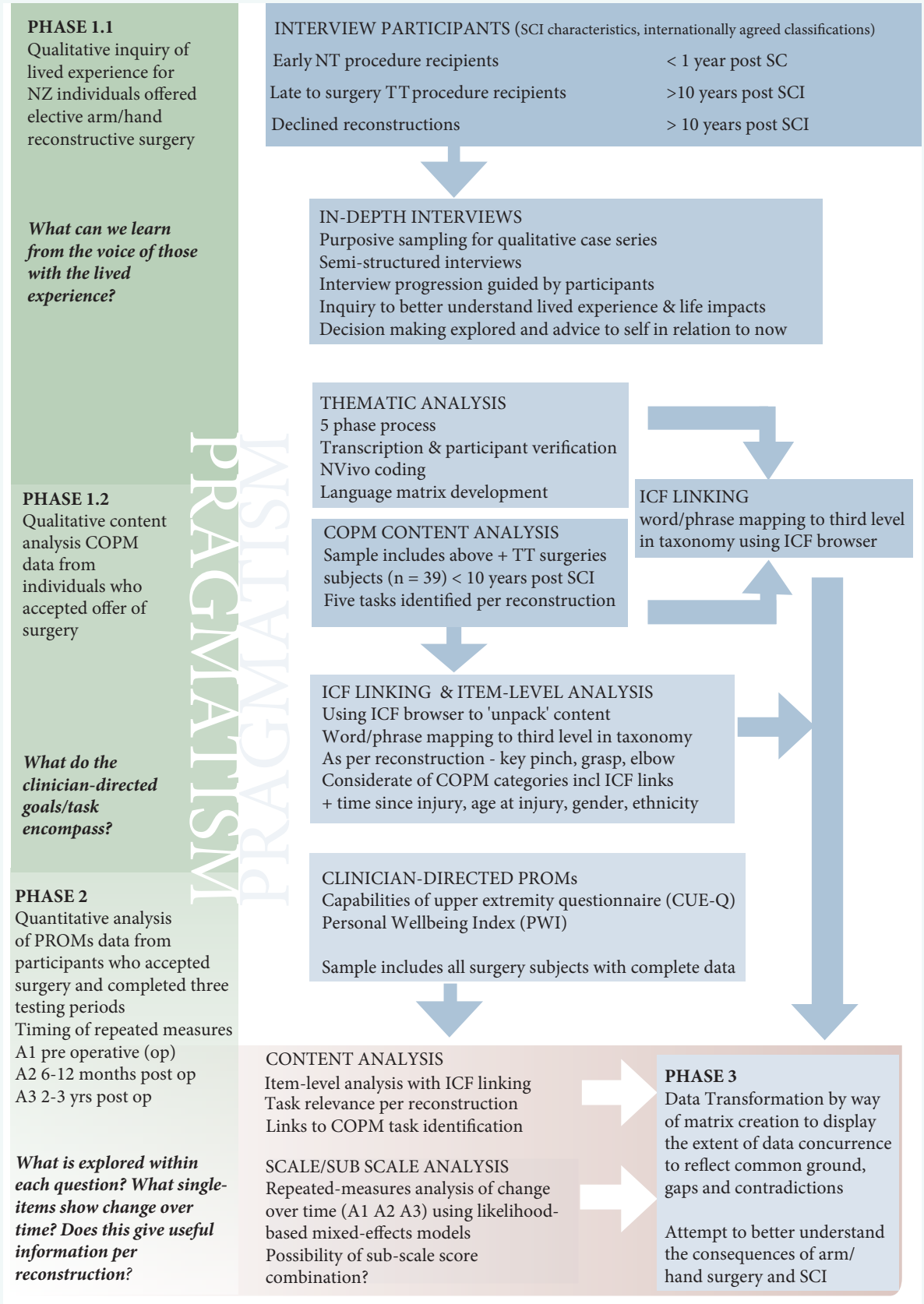

Figure 2 Overall design devised for this convergent mixed methods inquiry.

using a 1-10 scale, which helps to prioritize tasks/activities. The patient is then asked to rate their current performance and their satisfaction with each task/activity using the same scale. The process is repeated after each arm/hand reconstruction and subsequent follow up review.

Capabilities of the upper extremity instrument: The CUE-Q is a 32-item questionnaire assessing a total of 17 tasks, with inclusion of testing of two bi-manual maneuvers. This self-report questionnaire requires the individual to rate the difficulty they have completing a number of everyday activities relevant to people with tetraplegia (such as raising blankets above head, lifting buttocks to release pressure, or inserting a key into a lock) on a four-point scale (ranging from complete difficulty/inability to no difficulty). The CUE-Q contains definitions of the activities in the questionnaire for clarification if required. Execution of this procedure can take place in the clinical setting or be sent to the individual for self-completion. It takes between 10-15 minutes to complete. In 2007, the CUE-Q was reported to evaluate improvements following reconstructive arm/hand surgery [36] and later considered appropriate for inclusion in the New Zealand Upper Limb Registry given its use of ICF positive terminology and assessment in the activity domain.

Personal Wellbeing Index: Although there are better known measures for perceived life satisfaction reported for use in SCI research, the construct of personal wellbeing was topical at the time of the 2007 therapist consensus meeting [37,38]. The Personal Wellbeing Index (PWI) was developed in Australia for use in national surveys and subsequently adapted for international use, being available in 24 languages. The PWI consists of seven items gauging satisfaction with specific life domains (living standard, health, achievement, relationships, safety, community, future security) and one optional item about overall life satisfaction. Responses are provided on a 0-10 numeric rating scale with the anchor points of being 'completely dissatisfied' to 'completely satisfied'. All responses are self-reported. This self-administered questionnaire can be performed in either a clinical setting or as a postal follow-up, with time for completion taking less than 10 minutes.

Phase 1.1: Identification of life impacts of Arm/Hand surgery from the 'Lived Experience' perspective: The objective of the two-part qualitative phase is to hear the voice of individuals living with tetraplegia who are clinically assessed as suitable for and subsequently offered elective arm/hand reconstructive surgery. First, semi-structured interviews using a guide with questions and prompts will be conducted face-to-face or via telephone, audio-recorded and transcribed verbatim, along with any field notes. Transcripts will be returned to participants for verification. To ensure representation purposive recruitment will create three participant groups: (i) individuals offered early NT procedures as part of the arm/hand reconstruction surgeries; (ii) Tendon Transfer (TT) reconstruction recipients at greater than 10 years post SCI; and (iii) individuals who have Declined Surgery (DS). Thematic analysis of data will be performed identifying codes and themes using NVivo [39], and matrix development based on a five-stage process. Sample size will be determined by reaching data saturation.

Phase 1.2: Qualitative content analysis of COPM data from individuals who accepted offer of surgery: Next, a content analysis of each goal narrative will be performed and linked to the ICF comprehensive core sets taxonomy using specific linking rules [40]. This standardized linking procedure is widely used to qualitatively link content within and between outcome measures. Each participant completed the COPM prior to each surgical reconstruction and on each occasion was instructed by their therapist to identify and prioritize everyday issues that restrict or impact their performance in all areas of life, including (i) self-care, (ii) leisure and (iii) productivity.

Phase 2: Quantitative analysis of clinician-directed PROMs: Concurrently, the quantitative scores will be analyzed for strength of association with SCI impairment characteristics, surgery details including bilateral/unilateral procedures, time since SCI and age at SCI, first assessment and initial surgery. Additionally, score changes over time using linear mixed effects models will be exploited and mapped to the content analysis of the questions themselves.

Phase 3: Data transformation with interpretation for translation into clinical recommendations for SCI services: The overall objective of the final phase of this study series is to translate knowledge gained from the previous qualitative and quantitative phases. This is essential as there is little point measuring clinician-directed outcomes if/when the content of the PROMs questions have not been scrutinized from a 'lived experience' perspective. Theoretically, this integration process brings the QUANT numbers dataset and QUAL word datasets together for comparison in terms of content. This will be done by creating a data mapping system as previously reported in mixed methods designs of this nature [41], to ascertain the presence or absence of correlations between data sources where explicitly agreement, gaps and contradictions are identified.

Discussion

The findings of this study will contribute to a deeper appreciation of the life impacts of elective arm/hand surgery procedures for individuals with tetraplegia. This is necessary to better inform processes for referral, assessment and evaluation, to identify the potential range of measurement of outcomes and to facilitate international replication with more standardization, greater consistency and clinical process through improved knowledge of the active component(s) and potential barriers to implementation. We believe clinicians will welcome and benefit both from the outcomes of this work, as well as its conceptualization. There are teams of surgeons, physicians and therapists involved with early assessment, determining suitability for surgery, consideration of best practice recommendations in terms of upper limb reconstructions including timing, sequencing and logistics, not to mention goal setting [34]. These clinicians now carry even greater responsibility with the addition of early NT procedures to incorporate a person-centerd approach to assessment and treatment planning with shared decision-making processes.

A mixed methods approach helps to answer whether an intervention works, why it works, and also its fidelity. Mixed

methods have good potential in SCI research, since the majority of interventions are complex, whether surgical or non-surgical, and the process of evaluation and identification of suitable outcomes is particularly challenging [3,27,42]. We have adopted a pragmatic approach [43] with the design being driven by the nature and context of our research questions. For example, our sampling decisions relate to both the quantitative and qualitative components. For the quantitative component, we will be utilizing existing agreed PROMs data. This is the first time the PROMs data has been reported since the recommendations in 2007 and the first time it has been analyzed to determine its congruence with the lived experience perspective. However, our choice of method has been driven not only by the research question/s, but also by the respondents targeted. For example, we were interested not only in the impact for newly injured individuals offered earlier NT surgeries within a time-limited therapeutic window, but also the perspectives of those who have declined surgical reconstructions over time and individuals who made the decision to accept the offer of surgery at a much later stage after onset of tetraplegia. The lived-experience perspectives of these community-based groups were also sought on the time limitations now imposed on decision-making to undergo NT procedures in newly injured individuals, given their obvious lack of experience of life with tetraplegia beyond the hospital doors. The challenge of data collection in this mixed methods design relates to the unique skills required for each method, and the need for flexibility within the mixed method framework. To this end, narrative data, identification of emerging themes and data fidelity will involve advice and input from the point of view of one of the current authors (RS), an academic with a health psychology background, who also has 44 years lived experience of tetraplegia, as well as being a recipient of hand surgery.

Ethical Approval and Consent to Participate

For the purpose of data collection an amendment to the existing 2014 New Zealand Health and Disability Ethics Committee (HDEC) data registry approval has been made to allow for the qualitative case series to be undertaken in New Zealand (14/NTB/46). This was approved in November 2016 for the purpose of this enquiry by Canterbury District Health Board Ethics Committee (RO 14063-A1). An extension to this time frame will be sought. Study information for participants has been provided to date, however, variations to the protocol are acceptable to the ethics committee based on peer review.

Funding

University of Sydney fees are covered by the Australian Clinical Training program. The data collection time-costs are not supported by salary, however travel costs are provided by the Upper Limb Surgery Endowment Fund administered by the NZ Spinal Trust (Charitable Foundation). The NZ Spinal Trust has no commercial interest in the data, but do have an interest in the 'lived experience' contribution to SCI research. Their charitable trust status is external to the academic process of both the University of Sydney, Australia, and the Upper Limb Surgery research group, New Zealand.

Availability of Data and Material

This is not a clinical trial. The New Zealand based International Upper Limb Surgery registry access was approved by the Canterbury District Health Board Ethics Committee. This registry is administered by the NZ Spinal Trust and is available for use with secure international web-based access. However, this is carefully controlled in New Zealand due to the small population and concerns regarding participant identification. De-identified data in SPSS format will be available from the corresponding author who has clinical-researcher access to all routinely collected measurement data entered as part of Hand Clinic assessments at Burwood Hospital, Christchurch, New Zealand.

References

1. Friden J, Gohritz A. Tetraplegia Management Update. J Hand Surg Am. 2015; 40: 2489-2500.
2. Bourke JA, Hay-Smith EJ, Snell DL, DeJong G. Attending to Biographical Disruption: The Experience of Rehabilitation Following Tetraplegia Due to Spinal Cord Injury. Disabil Rehabil. 2015; 37: 296-303.
3. Hammell KR. Spinal Cord Injury Rehabilitation Research: Patient Priorities, Current Deficiencies and Potential Directions. Disabil Rehabil. 2010; 32: 1209-1218.
4. Sinnott KA, Dunn JA, Wangdell J, Johanson ME, Hall AS, Post MW. Measurement of Outcomes of Upper Limb Reconstructive Surgery for Tetraplegia. Arch Phys Med. 2016; 97: 169-181.
5. Kennedy P, Evans M, Sandhu N. Psychological Adjustment to Spinal Cord Injury: The Contribution of Coping, Hope and Cognitive Appraisals. Psychol Health Med. 2009; 14: 17-33.
6. Anderson KD. Targeting Recovery: Priorities of the Spinal Cord-Injured Population. J Neurotrauma. 2004; 10: 1371-1383.
7. Lo C, Tran Y, Anderson K, Craig A, Middleton J. Functional Priorities in Persons with Spinal Cord Injury: Using Discrete Choice Experiments to Determine Preferences. J Neurotrauma. 2016; 33: 1958-1968.
8. Siegert RJ, C O'Connell, WMM Levack. Psychology, Goals and Rehabilitation: Providing a Theoretical Foundation. Rehabilitation Goal Setting Theory, Practice and Evidence. (edsitord). 1st edn. Boca Raton CRC Press. 2014; 22.
9. Bryden AM, Peljovich AE, Hoyen HA, Nemunaitis G, Kilgore KL, Keith MW. Surgical Restoration of Arm and Hand Function in People with Tetraplegia. Top spinal cord inj rehabil. 2012; 18: 43-49.
10. Freehafer AA. Tendon Transfers in Patients with Cervical Spinal Cord Injury. J Hand Surg AM. 1991; 16: 804-809.
11. Moberg E. Surgical Treatment for Absent Single-Hand Grip and Elbow Extension in Quadriplegia.Principles and Preliminary Experience. JBone Joint Surg Am. 1975; 57: 196-206.
12. Van Zyl N, Hill B, Cooper C, Hahn J, Galea MP. Expanding traditional tendon-based techniques with nerve transfers for the restoration of upper limb function in tetraplegia: a prospective case series. The Lancet. 2019; 394: 565-575.
13. Van Zyl N, Hahn JB, Cooper CA, Weymouth MD, Flood SJ, Galea MP. Upper Limb Reinnervation in C6 Tetraplegia Using a Triple Nerve Transfer: Case Report. J Hand Surg Am. 2014; 39: 1779-1783.
14. Cain SA, Gohritz A, Fridén J, van Zyl N. Review of Upper Extremity Nerve Transfer in Cervical Spinal Cord Injury. Journal of Brachial Plexus and Peripheral Nerve Injury. 2015; 10: 34-42.

15. Mohammed KD, Rothwell AG, Sinclair SW, Willems SM, Bean AR. Upper Limb Surgery in Tetraplegia. J Bone Joint Surg Am. 1992; 74: 873-879.

16. Rothwell AG, Sinnott KA, Mohammed KD, Dunn JA, Sinclair SW. Upper Limb Surgery for Tetraplegia: a 10-Year Re-Review of Hand Function. J Hand Surg Am. 2003; 28: 489-497.

17. Dunn JA, Hay-Smith EJ, Whitehead LC, Keeling S. Liminality and Decision Making for Upper Limb Surgery in Tetraplegia: A Grounded Theory.Disability & Rehabilitation. 2013; 35: 1293-1301.

18. Dunn JA, Hay-Smith EJ, Whitehead LC, Keeling S. Issues Influencing the Decision to Have Upper Limb Surgery for People with Tetraplegia. Spinal Cord. 2012; 50: 844-847.

19. Dunn JA, Rothwell AG, Mohammed KD, Sinnott KA. The Effects of Aging on Upper Limb Tendon Transfers in Patients with Tetraplegia. J Hand Surg Am. 2014; 39: 317-323.

20. Dunn JA, Sinnott KA, Rothwell AG, Mohammed KD, Simcock JW. Tendon Transfer Surgery for People with Tetraplegia: An Overview. Arch Phys Med Rehabil. 2016; 97: 75-80.

21. 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. Summer; 24: 275–287.

22. Dunn JA, Sinnott KA, Bryden AM, Connolly SJ, Rothwell AG. Measurement Issues Related to Upper Limb Interventions in Persons Who Have Tetraplegia. Hand Clin. 2008; 24: 161-168.

23. Biering-Sorensen F, Bryden A, Curt A, Friden J, Harvey LA, Mulcahey MJ, et al. International Spinal Cord Injury Upper Extremity Basic Data Set. Spinal Cord. 2014; 52: 652-657.

24. Biering-Sørensen F, Noonan VK. Standardization of Data for Clinical Use and Research in Spinal Cord Injury. Brain Sciences. 2016; 6: 29.

25. Connolly SJ, Aubut, Teasell, Jarus. Enhancing Upper Extremity Function with Reconstructive Surgery in Persons with Tetraplegia: A Review of the Literature. Top Spinal Cord Inj Rehabil. 2007; 13: 58-80.

26. Kalsi-Ryan S, Verrier MC. A Synthesis of Best Evidence for the Restoration of Upper-Extremity Function in People with Tetraplegia. Physiother Can. 2011; 63: 474-489.

27. Velstra IM, BallertCS, Cieza A. A Systematic Literature Review of Outcome Measures for Upper Extremity Function Using the International Classification of Functioning, Disability, and Health as Reference. PM R. 2011; 3: 846-860.

28. Post MWM. Outcome measurement in Spinal Cord Injury Research and Clinical Practice. ISCoS textbook on comprehensive management of spinal cord injuries. Chhabra, H. (ed.). New Delhi: Wolters Kluwer.2015; 918-928.

29. 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: 88-96.

30. WHO. International Classification of Functioning, Disability and Health: Icf. Geneva. 2001.

31. Sinnott KA, JA Dunn, AG Rothwell. Use of the ICF Conceptual Framework to Interpret Hand Function Outcomes Following Tendon Transfer Surgery for Tetraplegia. Spinal Cord. 2004; 42: 396-400.

32. Sinnott KA, Dunn JA, Rothwell AG, Hall AS, Post MW. The Development of the NZ Upper Limb Surgery Registry for Tetraplegia. Spinal Cord. 2014; 52: 611-615.

33. Law M, Baptiste S, McColl M, Opzoomer A, Polatajko H, Pollock N. The Canadian Occupational Performance Measure: An Outcome Measure for Occupational Therapy. Can J Occup Ther. 1990; 57: 82-87.

34. Wangdell J, Carlsson G, Friden J. From Regained Function to Daily Use: Experiences of Surgical Reconstruction of Grip in People with Tetraplegia. Disabil Rehabil. 2014; 36: 678-684.

35. Woulle K, Van Doren CL, Thrope GB, Keith MW, Peckham PH. Development of a Quantitative Hand Grasp and Release Test for Patients with Tetraplegia Using a Hand Neuroprosthesis. J Hand Surg Am. 1994; 19: 209-218.

36. Mulcahey MJ, Hutchinson D, Kozin SH. Assessment of the Upper Limb in Tetraplegia: Considerations in Evaluation and Outcomes Research. Journal of Rehabil Res Dev. 2007; 44: 91-102.

37. Robert AC, Eckersley R, Pallant J, Vugt JV, Misajon AR. Developing a National Index of Subjective Wellbeing: The Australian Unity Wellbeing Index. Social Indicators Research. 2003; 64: 159-190.

38. Lau LD, Cummins AR, McPherson W. An Investigation into the Cross-Cultural Equivalence of the Personal Wellbeing Index. Social Indicators Research. 2005; 72: 403-430.

39. Richards L. (2005). Handling Qualitative Data: A Practical Guide. London: Sage Publications.

40. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF Linking Rules: An Update Based on Lessons Learned. J Rehabil Med. 2005; 37: 212-218.

41. Bourke JA, Nunnerley JL, Sullivan M, Derrett S. Relationships and the Transition from Spinal Units to Community for People with a First Spinal Cord Injury: A New Zealand Qualitative Study. Disabil Health J. 2018; 12: 257-262.

42. Elf M, Flink M, Nilsson M, Tistad M, von Koch L, Ytterberg C. The Case of Value-Based Healthcare for People Living with Complex Long-Term Conditions. BMC Health Serv Res. 2017; 17: 24.

43. Greene CJ, Hall NJ. Dialectics and Pragmatism: Being of Consequence. SAGE Handbook of Mixed Methods in Social and Behavioral Research 2010.