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ORIGINAL ARTICLE

The development of the NZ-based international upper limb surgery registry

KA Sinnott[1,2,3], JA Dunn[1,3], AG Rothwell[1,3], AS Hall[4] and MWM Post[5]

Study design: Implementation study.
Objectives: To describe the development and potential value of the New Zealand (NZ) upper limb surgery registry and report the demographic and spinal cord injury characteristics of individuals with tetraplegia collated to date.
Setting: Multi Center—coordinated from Burwood Spinal Unit, NZ.
Methods: Following discussions with eight international units, clinical information and outcomes measures were agreed upon for use in this specific population. To implement this consensus, a web-based upper limb surgery registry was developed in NZ. Inclusion criteria included referral to a hand clinic for clinical assessment for suitability for tendon transfer surgery. Clinical data were collected regardless of acceptance of surgery thereby creating a self-selected control group. Twenty-eight years of retrospective NZ data was entered into the registry, as well as 3 years of prospective data collected in NZ.
Results: From 1982 to 2013, a total of 357 persons with tetraplegia were assessed as suitable for surgery. Of those, 223 individuals underwent surgery and 134 declined the intervention(s). The prospective group currently comprises 55 assessments with 23 surgery individuals and 32 who have declined surgery to date.
Conclusion: Clinical information is now available within a web-based registry for all individuals reviewed in hand clinics from when upper limb surgery was first introduced. A broad range of outcomes of interest can easily be reported directly from the registry. The self-selected control group will allow comparative studies to be explicitly linked to the specific interventions of interest.
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INTRODUCTION

Upper limb reconstructive surgical procedures for individuals with tetraplegia were first described by Moberg[1] in the early 1970s and have since been adopted in many centers worldwide.[2,3] These procedures apply to a very specific group of persons with tetraplegia, usually with injuries at the spinal levels of C4 to C7, with explicit components of motor and sensory loss,[3] as assessed for suitability for surgery by clinician experts on the basis of available donor muscles.[4] Despite reports of positive results,[2,3] the effects of these interventions in comparison with more conventional rehabilitation have not yet been studied using comprehensive and comparative designs. Moreover, most studies were small and used a vast array of outcome measures, allowing little possibility for comparison between studies.[5] Consequently, knowledge about the effects of these interventions on levels of activities, participation and quality of life is largely lacking.

Clinical data routinely collected in hand surgery centers is also largely unavailable, because data collection was frequently incomplete, measures collected at variable time points and clinical examinations were largely subjective with poor reproducibility, and did not necessarily use internationally agreed upon classifications.[5] In addition, where measurements were collected, data were previously stored in multiple sources. For example, surgeons assessments are documented in medical notes, and functional assessments by therapists in their respective clinical records. Along with the lack of standardization in outcome measures, this issue of multiple storage systems had been identified as a barrier to coherent data analyses.[5]

There is a global need for comprehensive, robust, reliable and comparable data that can assist spinal cord injury (SCI) clinical care providers, policy makers and researchers and the benefits of central SCI registries are widely acknowledged.[6,7] At the 2007 Tetraplegia and Upper Limb Surgery meeting in Philadelphia, an international consensus therapist group was formed to address the issues of measurement of upper limb functional outcomes for persons referred to upper limb surgical teams around the world.[8] The target group includes persons with tetraplegia who undergo reconstructive surgery and those who meet the criteria for surgery, but for whatever reason, do not have surgery. The primary aim of this consensus effort was to establish a system by which more data could be collected and stored to compare changes in performance within this group, and then to determine the relative effectiveness of reconstructive hand surgery versus conventional rehabilitation. First, the International Classification of Functioning, Disability and Health (ICF)[9] was agreed as the conceptual framework. Second, it was agreed that all patients would be classified according to the International Classification of Hand Surgery for Tetraplegia (ICSHT) and the American Spinal Injury

[1]Department of Orthopaedic Surgery and Musculoskeletal Medicine, University of Otago, Christchurch, New Zealand; [2]Burwood Academy of Independent Living (BAIL), Christchurch, New Zealand; [3]Burwood Spinal Unit, Canterbury District Health Board, Christchurch, New Zealand; [4]New Zealand Spinal Trust, Christchurch, New Zealand and [5]Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and Rehabilitation Center De Hoogstraat, Utrecht, The Netherlands
Correspondence: KA Sinnott, Allan Bean Centre, Burwood Hospital, Private Bag 4708, Christchurch 8083, New Zealand.
E-mail: anne.sinnott@otago.ac.nz
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Association (ASIA) Impairment Scale (AIS) to allow for comparison across and between sites. These two classification systems, although imperfect, are routinely used by surgeons and therapists worldwide and are recognized as useful clinical classification tools to determine the availability of muscles for transfer.[4] Next, it was agreed that the Canadian Occupational Performance Measure[10] would be used universally. Two further measures were recommended for feasibility testing. These were the Capabilities of Upper Extremity Questionnaire v 2.1,[11] to capture capability of upper limb function, and the Personal Wellbeing Index.[12,13] Next, it was agreed that all grip and pinch strength measurements would be reported in Newtons, the presence of pain and spasticity would be reported, and two-point discrimination used for sensibility. Finally, it was established that a single hand function measure could not be agreed upon and a variety of measures already in use around the world be considered acceptable. Such measures included the Grasp Release Test,[14] the Action Research Arm Test,[5] the Graded Redefined Assessment of Strength, Sensibility and Prehension (GRASSP),[15] the Motor Capabilities Scale[16] and the Van Lieshout Test.[17]

After outcome measures consensus was reached, the next challenge was to incorporate these measures into the usual hand clinic assessments. It was evident for the relevant health services that extra clinician time would be required for the measurements to be completed. By the 2010 International Tetraplegia and Upper Limb Surgery meeting in Paris, it became apparent that practical problems of data collection and storage would likely inhibit progress towards a joint registry. There were issues raised around intellectual property, data ownership, governance, political interests, privacy, data heterogeneity, language heterogeneity and analysis. The New Zealand (NZ) research group therefore offered to develop a simple web-based registry for data storage. This coincided with other registry developments for SCI as well as drawing on the experiences of other clinical registry development for small sample diagnostic groups.

The aim of the current paper is firstly, to describe the development and potential value of the NZ upper limb surgery registry and secondly, to use this registry to describe the demographic and SCI characteristics of individuals with tetraplegia collected and collated in NZ since 1982.

MATERIALS AND METHODS

Our web-based patient registry was designed by AH in 2009. Its features are: (i) each contributing site will have access to its own data entry portal only, (ii) online data is protected with 128 BIT encryption and (iii) offline data are only accessible to the authorized independent administrator. The registry allows for the following data entry at specific and defined time points (Figure 1): (i) basic information including mechanism of injury, age, AIS and ICSHT classifications. Mechanism of injury was entered in accordance with the ISCOS core data set,[18] which classifies into the following categories: sport, transport, fall, assault, non-trauma, other trauma and unknown. Sports were further specified as rugby union, rugby league, diving, fall from a horse, cycling, skiing and others, (ii) reason for decline of surgery based on previous work in NZ,[19] (iii) grip and pinch strength data reported in Newtons, and presence of pain and/or spasticity, (iv) the scores from the standardized assessments that the consensus group had previously agreed to use (Canadian Occupational Performance Measure, Capabilities of Upper Extremity Questionnaire and Personal Wellbeing Index), (v) the scores from any hand function measure used by specific sites and finally (vi) each surgical procedure performed.

Specific time points for measurement were agreed upon to best reflect the clinical systems to allow for variability with referral patterns around the world. Measurements are taken at the initial assessment (B) and/or preoperatively (A1), 6–12 months postoperatively (A2), at 2–3 years (A3) and onward (R) for review.

The clinical characteristics of a retrospective cohort and a prospective cohort of NZ patients have been entered since August 2010. First, the retrospective full cohort from historical data from 1982 when tendon transfer surgery commenced in NZ. Second, prospective data has been entered according to the agreement reached in 2007 and described above. The clinical assessments were undertaken in two centers in NZ, by one surgical team comprising between 2–4 surgeons. One hand surgeon (AR) has been performing the surgery throughout the entire time period. Ethical approval for this project was received from the Upper South A Regional Ethics Committee, Ministry of Health, NZ. Data entry and clinical interpretation is ongoing with the retrospective cohort requiring cross referencing of information from multiple clinical notes.

RESULTS

From 1982 to 2013, a total of 357 persons with tetraplegia were assessed as suitable for surgery and their data have been entered in the registry. Of those, 223 individuals underwent surgery (or surgeries) and 134 declined the intervention(s). The full cohort characteristics and classifications are described in Table 1 (left columns). In the prospective group, 55 individuals were reviewed and tested using the full battery of measures introduced in August 2010. To date, 23 individuals have commenced surgery interventions and 32 eligible individuals have declined. The prospective group characteristics and classifications are described in Table 1 (right columns).

A total of 1411 surgical procedures have been undertaken on these 223 individuals. The majority of procedures were directed towards restoration of key pinch grip, elbow extension and grasp.[1] The 1411 surgical procedures are described in Table 2. In the prospective group, 163 surgical procedures have been undertaken to date on the 23 individuals, predominantly bilateral simultaneous surgeries. There

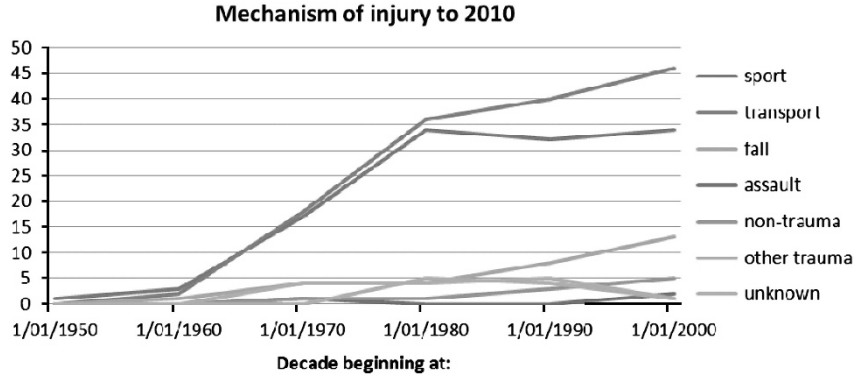

Figure 1 ISCOS classifications for mechanism of injury per decade of onset of SCI 1982–2010. A full color version of this figure is available at the *Spinal Cord* journal online.

Table 1 Surgery versus no surgery details: full cohort 1982–2013 and prospective cohort 2010–13

Full cohort	*Surgery (N = 223)*	*No surgery (N = 134)*	*Prospective cohort*	*Surgery (N = 23)*	*No surgery (N = 32)*
Sex			*Sex*		
Male	192	112	Male	21	29
Female	31	22	Female	2	3
Age at SCI			*Age at SCI*		
<30	145	82	<30	11	18
30–49	50	29	30–49	9	8
⩾50	23	13	⩾50	3	6
Unknown	5	10	Unknown	0	0
Current age			*Current age*		
<30	13	18	<30	8	10
30–49	81	65	30–49	10	13
⩾50	126	42	⩾50	5	9
Unknown	3	9			
Level of SCI			*Level of SCI*		
C4	19	8	C4	1	4
C5	51	33	C5	4	10
C6	76	39	C6	11	11
C7	37	21	C7	7	2
C8	0	1	C8	0	1
Other	3	2	Unknown	0	3
Unknown	40	30	Other	0	1
AIS			*AIS*		
A	126	66	A	16	15
B	24	10	B	4	7
C	11	9	C	2	2
D	25	20	D	1	4
Unknown	37	29	Unknown	0	4
ICSHT			*ICSHT*		
O0	4	3	O0	0	0
O1/Ocu1	35	17	O1/Ocu1	6	8
O2/Ocu2	17	13	O2/Ocu2	1	2
Ocu3	27	16	Ocu3	3	6
Ocu4	54	18	Ocu4	5	3
Ocu5	21	12	Ocu5	4	7
Ocu6	7	2	Ocu6	4	2
Ocu7	3	1	Ocu7	0	1
Ocu8	2	1	Ocu8	0	0
Ocu9	1	0	Ocu9	0	0
X	12	15	X	0	1
Unknown	40	36	Unknown	0	2
Deaths since assessment	19	18	Deaths since assessment	0	0

Abbreviations: AIS, ASIA impairment scale; ICSHT, International classification of hand surgery for tetraplegia; SCI, spinal cord injury.

are a large number of 'one off' procedures, which are common with this very individualized surgery. For example, in more recent times, surgery is offered for spasticity. Two surgical and a single rehabilitation complication(s) were reported to date.

Mechanism of injury data are shown in Figures 1 and 2. Although difficult to extrapolate per decade, the trends suggest a decrease in sports as a cause of tetraplegia, and a rapid increase in falls.

Table 2 NZ upper limb surgery surgical procedures 1982–2013

	n
Surgeries	
Total	1411
Surgical complications (includes not returning for rehabilitation)	67
Procedures	
Elbow extension	
Post deltoid to triceps	150
Biceps to triceps	2
Other	45
Hook grip	
ECRL to FDP	149
BR to ECRB	37
BR to FDP	36
FDP tenodesis	34
Key pinch	
BR to FPL	209
EPL tenodesis	97
FPL tenodesis	54
PT to FPL	21
Split FPL tenodesis	242
Other	
CMC joint fusion	57
Lassos	41
Other finger procedures	33
Intrinsic tenodesis	15
APL tenodesis	14
ED tenodesis	7
MCP joint release	6

Abbreviations: APL, abductor pollicus longus; BR, brachioradialis; CMC, carpometacarpal; ECRB, extensor carpi radialis brevis; ECRL, extensor carpi radialis longus; ED, extensor digitorum; FDP, flexor digitorum profundus; FPL, flexor pollicis longus; MCP, metacarpophalangeal; NZ, New Zealand; PT, pronator teres.

DISCUSSION

A web-based registry has been developed for clinical data and outcome assessment in persons with tetraplegia clinically eligible for hand surgery. Although based in NZ, the registry is available for use by hand surgery centers in other countries although not yet utilized.

Three crucial factors facilitated the development of the NZ registry. First, professional credibility; the NZ-based upper limb surgery team led the efforts to create a standardized suite of clinical assessment 'measures' for upper limb surgery for individuals with tetraplegia that were approved by the international consensus group established in 2007. Second, the use of the ICF which was previously recommended by this group as the basis of interpretation of measurement, which had enhanced the surgeons' interest in participation outcomes.[20] Finally, as there was no national SCI database in NZ or epidemiological data relevant to tetraplegia, local support for this initiative was readily forthcoming.

Although it is not the primary goal of the registry, we used it to reveal the first etiology figures in NZ. This data suggest change in etiology of tetraplegia over time, including the peak of rugby injuries in the 1980s, and their subsequent decline and the increase in water sport injuries, cycling accidents and falls. Such information is important to focus preventive action.[16]

The registry creates a recall system to ensure those patients who decline surgery are followed and offered clinical review. Interestingly,

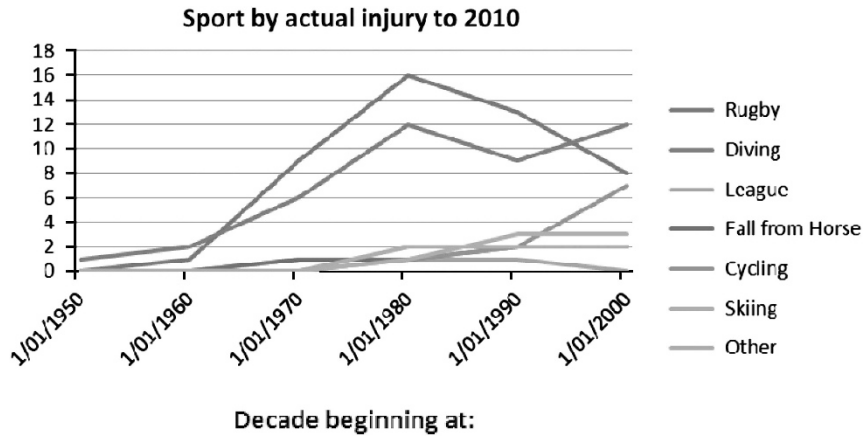

Figure 2 NZ actual sports injuries per decade of onset of SCI 1982–2010. A full color version of this figure is available at the *Spinal Cord* journal online.

in the group assessed for surgery since 2010, the date of injury spans four decades (1977–2012), which supports the influence of repeat invitations for further review as recommended by Dunn *et al.*[19] This final attribute creates a self-selected 'control group' over time. This is of particular interest in NZ where extensive work has been undertaken around factors involved in surgical or non-surgical decision making.[19,21] Although other groups have looked at uptake for surgery in this population,[22] this control group, to our knowledge, will be the first such well-defined and monitored group in the hand surgery and tetraplegia field. We believe that it will broaden the scope for future comparative studies and provide answers to the critics of hand surgery.[3] As a result of this consensus work, there is available Canadian Occupational Performance Measure data in Melbourne and Goteborg, and Capabilities of Upper Extremity Questionnaire and Personal Wellbeing Index data in Palo Alto, USA for future repeat analysis. Although outcomes for individuals with SCI including employment prospects, sport and recreation activities, relationship pursuit, social interaction, intimacy and the pursuit of dreams within this population of SCI individuals are increasingly reported following hand surgery,[23,24] more explicit linking to hand function outcomes in larger samples are needed for such associations to be made. As more innovative technologies are developed, such associations are likely to become more critical. The NZ registry might serve as an example for other registries particularly as the ISCOS data sets[18] are incorporated into clinical practice. The ultimate goal is to connect registries or merge data from existing registries for research purposes.

CONCLUSION

A registry for upper limb surgery after SCI has been created including outcomes relevant to the clinician and the individual with SCI. Future utilization of this registry ensures that when a person with tetraplegia faces the prospect of elective upper limb surgery, accurate information is readily available regarding all aspects of surgical options, rehabilitation requirements including time frames, and expected functional outcomes. Such availability of detail provides a more evidence-based approach that is client-centred orientated. We acknowledge that this is preliminary work. Since 2010, the NZ upper limb surgery team are successfully collecting data on all individuals referred for assessment for hand surgery regardless of whether surgery is performed or not, and we aim to report on the measures currently being used.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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