Title:

Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study

Short running title: Community integration following spinal cord injury

Authors:

Corresponding author –

Ms Libby Callaway

Lecturer

Occupational Therapy Department

Monash University

Frankston 3199

Victoria, Australia

Email: libby.callaway@monash.edu

Dr Joanne Enticott

Deputy Director and Coordinator of Health Services Research

Southern Synergy

Department of Psychiatry, Southern Clinical School, Monash University

Senior Research Fellow, Royal District Nursing Service, Victoria

Monash University

Clayton 3168

Victoria, Australia

Associate Professor Louise Farnworth

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/1440-1630.12350](https://doi.org/10.1111/1440-1630.12350)

This article is protected by copyright. All rights reserved

Occupational Therapy Department
Monash University
Frankston 3199
Victoria, Australia

Associate Professor Rachael McDonald
Department Chair
Department of Health and Medical Sciences
Swinburne University of Technology
Hawthorn 3122
Victoria
Australia

Dr Christine Migliorini
Research Fellow
Occupational Therapy Department
Monash University
Frankston 3199
Victoria, Australia

Professor Barry Willer
Professor of Psychology
Department of Psychiatry
State University of Buffalo
Buffalo
New York, USA

Received Date : 24-Aug-2016

Revised Date : 15-Oct-2016

Accepted Date : 26-Oct-2016

Article type : Feature Article

Abstract: Background/aims Australia's National Disability Insurance Scheme (NDIS) is designed to influence home, social and economic participation for Scheme participants. Given the major disability reform underway, this pilot study aimed to: 1) examine community integration outcomes of people with spinal cord injury (SCI); 2) compare findings with multiple matched controls; and 3) consider findings within the context of Australia's NDIS.

Method Setting: Victoria, Australia. Design: Matched analysis (people with and without SCI). Instrumentation: Community Integration Questionnaire (CIQ). Participants: n=40 adults with SCI (M age=52.8 years; 61% male; 77% traumatic SCI). Analyses: Matched analyses from each SCI subject aged <70 years (n=31) with four CIQ normative data subjects (from n=1,927) was undertaken, with key demographic variables matched (age range, gender, living location and living situation). Risk of low CIQ score as a function of SCI was also examined using conditional Poisson regression.

Results With key demographic variables held constant, small to medium effect sizes were found in favour of the normative sample, with statistically significant differences in home ($p=0.003$) and productivity integration ($p=0.02$). Relative risk of low home integration was significant in the SCI cohort (conditional RR (95% CI) =3.1(1.5 to 6.3), $p=0.001$). Relative risk of low CIQ total, social integration and productivity scores did not reach significance.

Conclusion This cohort of SCI participants was less integrated into home and productive occupations than matched norms, holding implications for planning and allocation of supports to influence outcomes within an NDIS. Further research is necessary to understand community integration outcomes in larger matched samples.

Australia's ten-year National Disability Strategy, endorsed by the Council of Australian Governments' in 2011, details priority areas for improving life for Australians with disability,

with a focus on community integration and inclusion (Department of Social Services, 2010). Aligned with the current Strategy, disability services in Australia are currently undergoing momentous reform with the introduction of a \$22B National Disability Insurance Scheme (NDIS), trialled from 2013 to 2016, and launched nationally from 1 July 2016. The NDIS has been designed and costed with a focus on influencing social and economic participation of people with significant disability (Productivity Commission, 2011). People with spinal cord injury (SCI) who experience permanent disability are one of the many participant groups who will be eligible for the NDIS (Callaway, Barclay, McDonald, Farnworth, & Casey, 2015). Approximately 9,000 Australians live with SCI (Cripps, 2008). Most recent estimates of the incidence of traumatic spinal cord injury in Australia indicate 21–32 cases per million population per year, with the prevalence highest in males, middle adulthood and those with tetraplegia (New, Baxter, Farry, & Noonan, 2015). However, this under-represents the total number of people living with spinal injury in Australia, with non-traumatic SCI found to be more common than traumatic SCI (Callaway, Barclay, et al., 2015; New & Sundararajan, 2008). Forecasting of SCI rates have indicated the annual number of cases will increase in the coming decades, particularly in young and elderly males (O'Connor, 2005). SCI may result in significant and permanent impairment, which can affect home, social and economic participation and necessitate use of assistive technologies, home modifications, and human supports (Callaway, Barclay, et al., 2015; Kratz, Chadd, Jensen, Kehn, & Kroll, 2015; Noreau & Fougereyrollas, 2000; Schopp et al., 2007). The permanent nature of these injuries mean that lifetime care costs are high and enduring (Access Economics, 2009).

SCI most often occurs in early adulthood, at a time in the life course when development of independent living, long term social relationships, and career pathways is paramount (Wheeler, 2005). Given this, understanding factors that influence home, social and economic participation outcomes, and areas of focus for rehabilitation endeavour, is necessary. Current research demonstrates a complex interplay of demographic variables, neurological deficits, secondary health conditions, psychosocial adjustment, social and vocational opportunities, and environmental supports and barriers affect participation outcomes following SCI (Barclay, McDonald, & Lentin, 2015; Callaway, Barclay, et al., 2015; Callaway, Miller, & Migliorini, 2015; Kratz et al., 2015; Migliorini, Callaway, & New, 2013; Pershouse et al., 2012). This interplay may exacerbate the degree of disability following SCI and negatively impact community integration (Callaway, Barclay, et al., 2015; Gontovsky, Russum, & Stokie, 2009; Kratz et al., 2015).

Community Integration and SCI

The concept of community integration is multi-faceted. It includes access to relationships with others, independence in one's own living situation and meaningful activities in which to participate and is influenced by key demographic variables including age and gender, as well as culture (Gontovsky et al., 2009; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993). Community integration is a key goal of rehabilitation endeavours in SCI rehabilitation (Gontovsky et al., 2009; Kratz et al., 2015). SCI rehabilitation centres on assisting the person to re-establish previous, or develop new, roles in home, social and productivity pursuits, in turn establishing improvements in occupational performance and quality of life (Carpenter, Forwell, Jongbloed, & Backman, 2007; Kratz et al., 2015). Evaluation of rehabilitation outcomes following SCI should include examination of participation in social and community life (Barclay et al., 2015).

An individual's capacity to reintegrate into home and community life following SCI is a crucial aspect of establishing improvements in well-being and life satisfaction (Barclay et al., 2015; Boschen, Tonack, & Gargaro, 2003; Larsson Lund, 2005). Research to date has demonstrated that social and community participation for people with SCI continues to be an area of ongoing challenge (Barclay, McDonald, Lentin, & Bourke-Taylor, 2016; Carpenter et al., 2007; Lysack, Komanecky, Kabel, Cross, & Neufeld, 2007; Noreau & Fougereyrollas, 2000). In a study of 136 people with SCI who were on average 11.5 years post injury, Lysack and colleagues found a statistically significant relationship between perceived environmental barriers and community integration for adults with SCI (Lysack et al., 2007). Examining participation outcomes of 345 people with SCI, Noreau & Fougereyrollas (2005) identified the three most disrupted life habits following SCI as residence maintenance, participation in occupational roles (family life, domestic tasks, employment) and recreational activities. Improved life satisfaction following SCI has been associated with engagement in productive activities, such as work, leisure and education (Carpenter et al., 2007). Greater levels of social support and peer mentoring have also been identified as positively influencing long term outcomes (Barclay et al., 2015; Boschen et al., 2003). In the context of Australia's launch of an NDIS, and the forecast \$22 billion government investment in Scheme supports, it is imperative to continue to identify areas for redress to build home and community integration, and associated occupational participation, in the long term following SCI (Callaway, Barclay, et al., 2015; Russi, 2015).

Occupational Therapy and Community Integration

The re-building of meaningful occupational participation is an important focus of occupational therapy practice in SCI rehabilitation (Callaway, Barclay, et al., 2015; Stewart, Fischer, Hirji, & Davis, 2016, early online). Whilst participation is defined as involvement in a life situation (World Health Organisation, 2001), occupational therapy input may move beyond this participation focus to build re-integration and maximize independent living in the domains of home, social and productive life (Barclay et al., 2015). Therefore, within Australia's NDIS, occupational therapists will be one of the key professionals involved in assisting people with SCI, and other NDIS participants, to maintain their optimal level of functioning and occupational participation (National Disability Insurance Agency, 2015; Russi, 2015). Specific to home, social and productivity integration after SCI, occupational therapists provide a role in both inpatient and community rehabilitation programs, with a focus on a client-centred, problem solving approach, to help remove barriers to community participation (Price, Stephenson, Krantz, & Ward, 2011; Russi, 2015). In a critical review of research on social and community participation following SCI, Barclay and colleagues reported occupational therapy input as an important factor identified in facilitating participation following spinal injury (Barclay et al., 2014). Occupational therapy research in the field of neurotrauma has regularly included measurement of community integration outcomes (Boschen et al., 2003; Doig, Fleming, & Tooth, 2001; Lysack et al., 2007), with the Community Integration Questionnaire being one measure used in SCI research (Gontovsky et al., 2009; Kratz et al., 2015).

The Community Integration Questionnaire

Willer and colleagues were amongst the first to advocate the assessment of community integration, developing the Community Integration Questionnaire (CIQ) and defining community integration as 'effective role performance in community settings' (Willer et al., 1993). The CIQ is a 15-item scale providing a brief, reliable and objective assessment of home and social integration and productive (employment, education and volunteer) activities and has been used in occupational therapy and other research with a range of populations (Callaway et al., 2016). The CIQ home subscale examines participation in meal preparation, cleaning, grocery shopping, childcare (where applicable) and planning of social arrangements. The social integration subscale includes items on frequency of visiting family and friends, financial management, and participation rates in leisure, personal shopping and

community-based social activity. It also examines the most common social context of community activities completed (i.e. if the person usually does these activities alone, with family/friends or with other people with disability). The CIQ productivity subscale examines how frequently a person travels out of their home, as well as their level of participation in paid employment (with adjusted weighting for people who are retired due to age), study and/or volunteerism. Scores on the CIQ range from 0 to 29, with a high score indicating higher integration.

The CIQ is a recognised measure for examining community integration following SCI (Gontovsky et al., 2009) and is used in SCI research (Brown, Gordon, Spielman, & Haddad, 2002; Jensen, Hoffman, & Cardenas, 2005; Kratz et al., 2015; McVeigh, Hitzig, & Craven, 2009). The CIQ has been examined extensively, with demonstrated good criterion and construct validity, test-retest reliability, inter-rater reliability, and full-scale internal reliability, with some issues identified with distribution of subscale scores and factor structure (Callaway et al., 2016). Consideration of the influence of demographic variables on CIQ scores has previously been recommended (Sander et al., 1999). Suggestions for potential improvement of the CIQ for use in SCI research have been made, including the addition of items that reflect higher levels of productive functioning, such as career advancement (thus addressing potential Productivity subscale ceiling affects for SCI respondents), integration across the life span, and internet-based social functioning (Kratz et al., 2015). Addressing these issues and associated recommendations, the CIQ has recently been revised and extended to include measurement of the use of electronic social networking as a component of community integration, with recommendations for modification to scoring guidelines, forming the Community Integration Questionnaire-Revised (CIQ-R) (Callaway et al., 2016).

CIQ Normative Data and Normative Data Comparisons

As part of revision of the CIQ, large scale normative CIQ-R data has been gathered with Australian adults of working age, and converted to CIQ normative data for use with the original scale (Callaway, Winkler, et al., 2015; Callaway et al., 2016). The development of normative data provides opportunity for comparison of CIQ scores of people with disability to matched norms, allowing interpretation of an individual's score relative to the general population. It also provides greater opportunity to control for the influence key demographic variables may have on community integration, and for which the CIQ and other participation measures have been previously criticised. This CIQ normative data has recently been used in

the field of traumatic brain injury (TBI) to determine level of community integration in adults with TBI and high support needs compared with multiple matched controls (Migliorini, Enticott, Callaway, Moore, & Willer, 2016, early online). The ability to make comparisons of SCI outcomes with a matched normative sample of able-bodied Australians of working age, holding key demographic variables constant, will provide insights to necessary future directions for community integration interventions in SCI rehabilitation and research endeavours, including those of the occupational therapy profession (Barclay et al., 2015; Callaway et al., 2016).

There is currently very limited evidence on participation outcomes of people with SCI compared with normative cohorts living without SCI. A study by Brown and colleagues, applied a matching process through use of an analysis of covariance to specifically compare differences in community-based social-recreational activities of 62 individuals with SCI living in the community and 219 people with no reported disability (Brown et al., 2002). The relatively small between-group differences that were found became statistically insignificant when the groups were matched on key demographic variables (age, gender, ethnicity, marital status, education level and income). Age, ethnicity, and one environmental barrier – transportation – comprised the significant predictors of social-recreational activity for the SCI group, with 49% of the variance in activity accounted for.

Given this current limited evidence comparing SCI outcomes with matched normative samples, the aims of this research were to undertake a pilot study to: 1) examine integration outcomes of community-dwelling adults with spinal cord injury (SCI) using the CIQ; 2) compare findings with multiple matched controls using CIQ normative data; and 3) consider findings within the context of Australia's NDIS. The research group hypothesised that – based on other community integration research in the field – community living clients with SCI would show evidence of lower CIQ total and subscale scores relative to controls from the general population, even when matching of key demographic factors was undertaken to reduce influence expected from these variables.

METHOD

The setting for this research was Victoria, Australia. Inclusion criteria for recruitment were that the person was aged over 18 years and able to provide informed consent to participate in the study; had acquired an SCI after birth; and had returned to community living following

inpatient rehabilitation. People were excluded from participation if they experienced diagnosed intellectual or cognitive disability in addition to SCI, or where not able to provide their own consent to participate in the research. Human Research Ethics approval for all aspects of this study was gained from the Monash University Human Research Ethics Committee prior to project commencement. Forty adult participants with SCI living in the community were recruited through a number of sources. These included via advertisements in the newsletters of peak bodies representing people with SCI, outpatient clinics, and community-based allied health professionals working with people with SCI.

Of the 40 participants, 31 were aged under 70 years and thus able to be matched to and compared with the CIQ normative sample of adults of working age (Callaway, Winkler, et al., 2015). The general population sample had no subjects aged over 64 years; in contrast, two participants with SCI were aged 68 years. These two participants were matched to four normative cases from the 60-64 year age group, given the close proximity of the participants' age to the upper age of the normative sample. Each of the 31 participants with SCI was matched on four key characteristics, gender (male/female); age group; living location (metropolitan or regional/rural residence); and living situation (living alone or living with others), with data drawn from the entire data set of 1,973 participants from the general population sample. Random selection without replacement was established to identify matching sets consisting of four normative comparators per participant with SCI. Multiple normative comparators for each SCI participant are beneficial in increasing study precision; however, previously, more than four cases have not increased the precision of results (Rigby & Robinson, 2000).

The CIQ survey data collected for the SCI sample ($n=40$), as well as the subgroup of $n=31$ SCI participants who were aged under 70 years (and thus used in the matched analysis), were examined and the mean, median, standard deviation and ranges calculated. The matched analysis examined the continuous data CIQ scores using standard ANOVA with factors of SCI (yes/no) and another factor to account for the matched sets. Matching aimed to reduce variability expected from these demographics, thereby controlling for their potential influence on community integration outcomes reported. Estimates of the degree of association between the samples, eta squared effect sizes (η^2), were also calculated. A p -value of less than 0.05 was deemed significant. The overall frequency of CIQ scores at or below a cut-off indicating 'low' integration was also calculated (see Table 1). Low

integration in this study was defined as one standard deviation below the mean of the normative sample. One standard deviation below the mean represents the lowest 16% of all scores in the general population data set, being deemed as a meaningful cut off for a low score (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). This definition has been used in CIQ matched analysis with other neurotrauma populations, published by the research group previously (Migliorini et al., 2016, early online).

INSERT TABLE 1 HERE

The matched general population analysis was undertaken so prevalence of low CIQ scores could be compared with SCI participants by producing estimates of the risk ratio. The matched risk ratio (or relative risk) of having a low CIQ score as a function of SCI was calculated by comparing the proportions of SCI participants with low scores to the proportions in the matched comparators from the general population. In this matched analysis, we applied conditional Poisson regression (Cummings & McKnight, 2004).

For the matched set analysis, an alpha level of 0.05 was applied. Therefore, if a statistically significant relative risk was produced using conditional Poisson regression, there was less than a 5% probability of a type 1 error. The low number of matched sets in this initial pilot study (n=31) however corresponded to study power of between 60-70% (Pang, 1999). This meant that if a non-significant relative risk was produced, there was up to a 40% probability of a type II error (indicating that any non-significant results may arise due to low study power). In the case of non-significant relative risk being produced, the research group will examine effect sizes using the matched-set ANOVA and report the sample number needed to reach sufficient power (80%) in any future study.

RESULTS

Of the 40 participants with SCI, 61% were male, with a mean age of 58 years (SD=14.5, R=25-81). A majority experienced traumatic SCI (77.0%), with cervical (40.0%) and thoracic (37.0%) injuries most frequently report, and lived in metropolitan regions (90.0%) with others (85.0%). Given the matched design of the study, the demographic distribution of the normative comparators directly followed that of the 31 participants aged under 70 years in the matched SCI group. See Table 2.

INSERT TABLE 2 HERE

CIQ results for all SCI participants (n=40) and the subgroup aged less than 70 years (n=31) are reported in Table 3, demonstrating the CIQ total and subscale scores for the larger group were marginally lower than that of the sub-group with participants aged over 70 years removed. These differences were not found to be significant ($p>0.05$). Comparing the SCI and general population data in the matched analysis showed small to medium effect sizes favouring the general population, also reported in Table 3. The conditional one-way ANOVA suggested that, when key demographic variables were held constant, both home integration and productivity were significantly better in the general population than the SCI group. Medium effect size was seen in the home integration scores ($p=0.003$) and small-medium effect size in the productivity scores ($p=0.02$). In contrast, the CIQ social integration and CIQ total scores indicated a small effect size, which was not statistically significant (both $p=0.06$).

INSERT TABLE 3 HERE

Table 4 shows conditional risk ratios (95% Confidence intervals) produced by the matched analysis. The conditional Poisson regression indicated that only the home integration result was significant between the groups, with a relative risk of 3.1 (1.5 to 6.3), $p=0.001$. This indicated the SCI group were over three times (310%) more likely to report a low CIQ home integration scores compared to general population cases matched on gender, age group, living location, and living situation. Examination of the conditional risk ratio for SCI participants having low social integration and CIQ total scores was 0.7 (0.2 to 2.0) and 1.6 (0.8 to 3.3) respectively, and these results did not reach statistical significance. The conditional Poisson regression for productivity produced a non-significant relative risk of 1.5 (95% CI: 0.7-3.1) and it is possible that the study was under-powered to detect this small effect. To detect a significant relative risk of 1.5 with 80% power using a 1:4 matched design, the estimated matched-set sample would need to increase to over 150 subjects.

INSERT TABLE 4 HERE

DISCUSSION

This study has piloted use of the Community Integration Questionnaire and large-scale normative data to examine differences in community integration outcomes of a group of

people with SCI and matched normative comparators. The research has added further to the emerging evidence comparing community integration outcomes of adults with neurotrauma with Australian general population CIQ-based norms (Migliorini et al., 2016, early online). Previous research has identified individual priorities for each domain of community integration may vary by age and gender, and be influenced by living location and situation (Callaway et al., 2016; Sander, Clark, & Pappadis, 2010). The effects of such demographic variables on integration outcomes have traditionally been hard to unravel. Using normative data to match variables across SCI and normative samples is a useful way to control for these effects (Kratz et al., 2015; Migliorini et al., 2016, early online; Sander et al., 1999).

The research group's hypothesis that the SCI cohort would show lower CIQ total and subscale scores relative to the matched normative sample was proven incorrect. When matched on key demographic variables, findings revealed small to medium effect size differences in CIQ scores favouring the general population. This pilot study finding is aligned with past SCI research examining social and community participation outcomes, finding relatively small between-group differences which became statistically insignificant when the SCI and normative groups were matched on key demographic variables (Brown et al., 2002). The finding is, however, in contrast to the large effects found to favor the general population when matched to a TBI group, using the same methodology (Migliorini et al., 2016, early online). The main limitation in the current pilot study – the small sample size – has likely affected study power and risk of type II error as discussed previously. Using this matching analysis in further research within larger neurotrauma samples, and increasing the matched variables (e.g. to include income or education level as did Brown et al.), holds merit and is possible now given the large Australian normative data set available (Callaway, Winkler, et al., 2015; Callaway et al., 2016). Whilst the current pilot work will be necessarily extended to include larger SCI samples, consideration of emerging findings in the context of individualised planning and resource allocation within Australia's NDIS will now be provided.

National Disability Insurance Scheme design has been informed by economic modeling assumptions that provision of timely, individualized supports and equipment will build social and economic participation, positively influencing both Scheme participant outcomes and social welfare costs (Productivity Commission, 2011). However, past SCI research has found extended periods of time spent in personal care tasks, and secondary health conditions

experienced following SCI, may negatively impact other participation opportunities (Callaway, Barclay, et al., 2015; Noreau & Fougereyrollas, 2000; Schopp et al., 2007). Research has also identified that return to economic participation (including work, study or volunteerism) may occur at the expense of home integration (Doig et al., 2001; Noreau & Fougereyrollas, 2000). Although limitations in the current pilot study restrict generalisation of findings, the low home integration rates of participants – with people with SCI 310% more likely to experience low home integration than matched norms – lends similar consideration.

Specific to larger studies, in a cohort of 345 community-dwelling participants with SCI, Noreau and Fougereyrollas (2000) found participation disruptions in home integration tasks, and the need for substantial human assistance in this domain. The authors pointed to the influence these disruptions may have on independent living in the long term, if resources are not available to carry out these basic home tasks. Based on findings from Noreau and colleagues, and participants in the current pilot study, it is reasonable to consider that, for some NDIS participants with SCI, assistance from others with everyday activities of daily living may be necessary. This assistance has potential to build efficiencies into daily routines, expedite these processes, and free up time for community participation (Callaway, Barclay, et al., 2015). Without access to financial resources, support for activities of daily living following SCI has traditionally fallen to family or other support networks. The NDIS also offers opportunity to shift the demand of this gratuitous care, potentially building not only the participation opportunities of the person with SCI, but also their informal support network. This potential broader Scheme impact warrants investigation.

The National Disability Insurance Agency approaches Scheme planning from the perspective of choice and control for the participant, within the lens of funding for equipment and supports deemed 'reasonable and necessary' by the Agency (National Disability Insurance Scheme, 2016). To build social and economic participation opportunities, it may be reasonable, and also necessary, to fund supports for home integration tasks (e.g. meal preparation; cleaning). Harnessing NDIS funding for specialized assistive technologies, such as a power-lift seat functions, sit-to-stand motorized wheelchairs or home modifications, may offer opportunity to build home participation opportunities, and time efficiencies, following SCI. When aligned with NDIS planning and goal setting, the option to secure such customised equipment, or direct support, is now available to eligible participants through Australia's NDIS where it may have been previously lacking (Callaway, Barclay, et al.,

2015). An important component of Scheme evaluation, including assessment of cost-benefit, will be exploration of the fiscal benefits of provision of home-based supports to build opportunities for economic participation, and the wellbeing benefits of growing autonomy and control in everyday living following SCI. The NDIS planning process, including goal setting, should also consider both of these potential benefits.

Goal setting for home and community integration may be determined in part by a person's specific demographic features and individual preferences (Sander et al., 2010). Further research, which includes larger SCI samples and makes use of matched CIQ or CIQ-R normative data, will be helpful to inform consideration in this area. This matching process moderates the effects key demographic variables have on home and community integration. Research utilising both this matched analysis and qualitative data collection to better understand aspects of participation deemed most important to individuals with SCI is also necessary. This will ensure rehabilitation endeavor and NDIS planning addresses individual priorities for home, social and community integration (Barclay et al., 2015; Callaway, Barclay, et al., 2015; Russi, 2015; Sander et al., 2010). Within an NDIS context, this mixed methods approach will provide more detailed information regarding how injury and personal factors impact daily life of the person with SCI. It will also provide insight to factors that direct decision making regarding productivity and inclusion following SCI. Such considerations are important for NDIS planners and health professionals, including occupational therapists, within Scheme implementation (Callaway, Barclay, et al., 2015).

CONCLUSION

This pilot study has provided some directions for future research to investigate community integration outcomes of people with SCI compared to the general population, and work to close the participation gap between this group and other Australians. Replication and extension of this methodology, using large-scale normative data, will provide further evidence regarding both injury-related and demographic factors that moderate or contribute to low community integration. This knowledge can further inform SCI rehabilitation endeavours. Occupational therapists, with a core focus on the relationship between meaningful occupational, health and wellbeing, are well placed to contribute to this work (Stewart et al., 2016, early online).

In the context of Australia's new NDIS, the current pilot study provides some insights into

areas of home, social and economic participation that may benefit from assistive technology, modifications or human supports following SCI. Provision of these supports may address or compensate for participation restrictions experienced, or allow time for pursuit of other areas of participation deemed important to an individual with SCI. Given Australia's NDIS is designed to build independence, choice and control, and has been structured to respond to Australia's National Disability Strategy, research to inform interventions to improve life participation following SCI is now imperative.

REFERENCES

- Access Economics. (2009). The economic cost of spinal cord injury and traumatic brain injury in Australia. Retrieved from <https://http://www.tac.vic.gov.au/about-the-tac/our-organisation/research/tac-neurotrauma-research/vni/the20economic20cost20of20spinal20cord20injury20and20traumatic20brain20injury20in20australia.pdf>
- Barclay, L., McDonald, R., & Lentin, P. (2015). Social and community participation following spinal cord injury: A critical review. *International Journal of Rehabilitation Research*, 38(1), 1-19. doi: 10.1097/MRR.0000000000000085
- Barclay, L., McDonald, R., Lentin, P., & Bourke-Taylor, H. (2016). Facilitators and barriers to social and community participation following spinal cord injury. *Australian Occupational Therapy Journal*, 63(1), 19-28. doi: 10.1111/1440-1630.12241
- Boschen, K., Tonack, M., & Gargaro, J. (2003). Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research*, 26(3), 157-164. doi: 10.1097/01.mrr.0000088440.78481.1f
- Brown, M., Gordon, W., Spielman, L., & Haddad, L. (2002). Participation by Individuals with Spinal Cord Injury in social and recreational activity outside the home. *Topics in Spinal Cord Injury Rehabilitation*, 7(3), 83-100. doi: 10.1310/7U35-GDQ4-FDV3-GVYV
- Callaway, L., Barclay, McDonald, Farnworth, L., & Casey, J. (2015). Secondary health conditions experienced by people with spinal cord injury within community living: implications for a National Disability Insurance Scheme. *Australian Occupational Therapy Journal*, 62, 246–254. doi: 10.1111/1440-1630.12206

- Callaway, L., Miller, R., & Migliorini, C. (2015). Transition to supported community living: An environmental scan and qualitative experiences of TAC clients. Retrieved from http://www.iscrr.com.au/_data/assets/pdf_file/0007/479032/311181334-061-Transition-to-supported-community-living.pdf
- Callaway, L., Winkler, D., Tippet, A., Migliorini, C., Herd, N., & Willer, B. (2015). The Community Integration Questionnaire: Australian normative data for adults of working age. Melbourne, Australia: Summer Foundation Ltd.
- Callaway, L., Winkler, D., Tippet, A., Migliorini, C., Herd, N., & Willer, B. (2016). The Community Integration Questionnaire – Revised: Australian normative data and measurement of electronic social networking. *Australian Occupational Therapy Journal*, 63(3), 143-153. doi: 10.1111/1440-1630.12284
- Carpenter, C., Forwell, S., Jongbloed, L., & Backman, C. (2007). Community participation after spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 88(4), 427-433. doi: 10.1016/j.apmr.2006.12.043
- Cripps, R. A. (2008). Spinal Cord Injury, Australia, 2006–07: Injury research and statistics series number 48. Adelaide, SA: Australian Institute of Health and Welfare.
- Cummings, P., & McKnight, B. (2004). Analysis of matched cohort data. *Stata Journal*, 4, 274-281.
- Department of Social Services. (2010). National Disability Strategy 2010–2020. Retrieved from <http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy>
- Doig, E., Fleming, J., & Tooth, L. (2001). Patterns of community integration 2-5 years post-discharge from brain injury rehabilitation. *Brain Injury*, 15, 747-762. doi: 10.1016/j.apmr.2003.12.002
- Gontovsky, S., Russum, P., & Stokie, D. (2009). Comparison of the CIQ and CHART short form in assessing community integration in individuals with chronic spinal cord injury: a pilot study. *NeuroRehabilitation*, 24, 185-192. doi: 10.3233/NRE-2009-0467
- Jensen, M., Hoffman, A., & Cardenas, D. (2005). Chronic pain in individuals with spinal cord injury: a survey and longitudinal study. *Spinal Cord*, 43(12), 704-712. doi: 10.1038/sj.sc.3101777

- Kratz, A., Chadd, E., Jensen, M., Kehn, M., & Kroll, T. (2015). An examination of the psychometric properties of the Community Integration Questionnaire (CIQ) in spinal cord injury. *Journal of Spinal Cord Injury*, 38(4), 446-455. doi: 10.1179/2045772313Y.00000000182
- Larsson Lund, M. (2005). Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury. *Journal of Rehabilitation Medicine*, 37(1), 3-8. doi: 10.1080/16501970410031246
- Lezak, M., Howieson, D., Loring, D., Hannay, H., & Fischer, J. (2004). *Neuropsychological assessment*. United Kingdom: Oxford University Press.
- Lysack, C., Komanecky, M., Kabel, A., Cross, K., & Neufeld, S. (2007). Environmental factors and their role in community integration after spinal cord injury. *Canadian Journal of Occupational Therapy*, 74, 243-254. doi: 10.1177/00084174070740S304
- McVeigh, S., Hitzig, S., & Craven, C. (2009). Influence of sport participation on community integration and quality of life: a comparison between sport participants and non-sport participants with spinal cord injury. *Journal of Spinal Cord Medicine*, 32(2), 115-124.
- Migliorini, C., Callaway, L., & New, P. (2013). Preliminary investigation into subjective well-being, mental health, resilience, and spinal cord injury. *Journal of Spinal Cord Medicine*, 36(6), 660-665. doi: 10.1179/2045772313Y.00000000100
- Migliorini, C., Enticott, J., Callaway, L., Moore, S., & Willer, B. (2016, early online). Community integration questionnaire: Outcomes of people with traumatic brain injury and high support needs compared with multiple matched controls. *Brain Injury*. doi: 10.1080/02699052.2016.1175666
- National Disability Insurance Agency. (2015). *Mainstream interface: Health supports the NDIS will fund in relation to healthcare*. Canberra, Australia: Retrieved from https://myplace.ndis.gov.au/ndisstorefront/html/sites/default/files/documents/fact_sheet_supports_ndis_fund_healthcare.docx.
- National Disability Insurance Scheme. (2016). *Reasonable and necessary supports*. Canberra, Australia: Author Retrieved from <http://www.ndis.gov.au/participants/reasonable-and-necessary-supports>

- New, P., Baxter, D., Farry, A., & Noonan, V. (2015). Estimating the incidence and prevalence of traumatic spinal cord injury in Australia. *Archives of Physical Medicine and Rehabilitation*, 96(1), 76-83. doi: 10.1016/j.apmr.2014.08.013
- New, P., & Sundararajan, V. (2008). Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review. *Spinal Cord*, 46(6), 406-411. doi: 10.1038/sj.sc.3102152
- Noreau, L., & Fougereyrollas, P. (2000). Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disability and Rehabilitation*, 22(4), 170-180. doi: 10.1080/096382800296863
- O'Connor, P. (2005). Prevalence of spinal cord injury in Australia. *Spinal Cord*, 43(1), 42-46. doi: 10.1038/sj.sc.3101666
- Pershhouse, K., Barker, R., Kendall, M., Buettner, P., Kuipers, P., Schuurs, S., & al, e. (2012). Investigating changes in quality of life and function along the lifespan of people with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 93, 413-419. doi: 10.1016/j.apmr.2011.10.014
- Price, P., Stephenson, S., Krantz, L., & Ward, K. (2011). Beyond my front door: The occupational and social participation of adults with spinal cord injury. *Occupational Therapy Journal of Research*, 31, 55-63. doi: 10.3928/15394492-20100521-01
- Productivity Commission. (2011). Disability Care and Support, Report no. 54. Canberra, Australia: Commonwealth of Australia.
- Rigby, A., & Robinson, M. (2000). Statistical methods in epidemiology. IV. Confounding and the matched pairs odds ratio. *Disability and Rehabilitation*, 22, 259-265. doi: 10.1080/096382800296719
- Russi, M. (2015). NDIS and occupational therapy: Compatible in intention and purpose from the consumer perspective. *Australian Occupational Therapy Journal*(61), 364-370. doi: 10.1111/1440-1630.12138

- Sander, A., Clark, A., & Pappadis, M. (2010). What is community integration anyway?: Defining meaning following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 25, 121-127. doi: 10.1097/HTR.0b013e3181cd1635
- Sander, A., Fuchs, K., High, J., Hall, K., Kreutzer, J., & Rosenthal, M. (1999). The Community Integration Questionnaire revisited: an assessment of factor structure and validity. *Archives of Physical Medicine and Rehabilitation*, 80, 1303-1308.
- Schopp, L., Clark, M., Hagglund, K., Sherman, A., Stout, B., Gray, D., & Boninger, M. (2007). Life activities among individuals with spinal cord injury living in the community: Perceived choice and perceived barriers. *Rehabilitation Psychology*, 52(1), 82-88. doi: 10.1037/0090-5550.52.1.82
- Stewart, K., Fischer, T., Hirji, R., & Davis, J. (2016, early online). Toward the reconceptualization of the relationship between occupational and health and well-being. *Canadian Journal of Occupational Therapy*. doi: 10.1177/0008417415625425
- Wheeler, S. (2005). Transitions to adult life. In A. Cronin & M. Mandich (Eds.), *Human development and performance throughout the lifespan* (pp. 264-284). Clifton Park NJ: Thomson Delmar Learning.
- Willer, B., Rosenthal, M., Kreutzer, J., Gordon, W., & Rempel, R. (1993). Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*, 8, 75-87.
- World Health Organisation. (2001). *International classification of functioning, disability, and health (ICF)*. Geneva, Switzerland: Author.

Table 1. Mean CIQ normative sample scores (n=1,973, Callaway et al., 2016) and cut-off scores indicating low integration.

	Mean	Standard deviation	Cut off score indicating low integration
Home integration	6.2	2.4	<3.8
Social integration	8.2	2.1	<6.1
Productivity	4.7	1.8	<3.0
CIQ total	19.1	4.0	<15.1

Note. Low integration was defined as one standard deviation below the mean of the normative sample.

Table 2. Characteristics of the sample with SCI (n=40) and sub-sample used for matching (n=31).

	n (%)	n (%)
Gender		
Male	25 (62)	19 (61)
Female	15 (38)	12 (39)
Age (years)		
Minimum	25	25
Maximum	81	68
Mean	58	52.8
Standard Deviation	14.5	12.1
Injury type		
Traumatic	31 (77)	24 (77)
Non-traumatic	9 (23)	7 (23)
Injury level		
Cervical	16 (40)	13 (42)
Thoracic	15 (37)	12 (39)
Lumbar	9 (23)	6 (19)
Living location		
Metro	36 (90)	27 (87)
Rural/regional	4 (10)	4 (13)
Living situation		
Living alone	6 (15)	5 (16)
Living with others	34 (85)	26 (84)

Table 3. Total CIQ score for the SCI sample (n=40) and the matched samples (n=31 matched sets)

		Mean	Stand Dev	Min	Max	n	Comparison analyses
SCI (all ages N=40)	Home integration	4.5	3.3	0	10	40	
	Social integration	8.5	2.3	3	12	40	
	Productivity	3.4	1.9	0	6	40	
	CIQ total	16.4	6.1	4	26	40	
SCI (<70 years old N=31)	Home integration	4.9	3.2	0	10	31	
	Social integration	8.8	2.3	3	12	31	
	Productivity	3.6	1.9	0	6	31	
	CIQ total	17.4	5.7	4	26	31	

**Comparing SCI (<70 years old) and
general population groups**

**Effect size
(partial eta**

							(Matched ANOVA analysis)		
General population	Home integration	6.5	2.4	0	10	124	Home integration	F(1, 153)=9.1, ρ =0.003	0.09 (medium)
	Social integration	8.1	1.9	13	12	124	Social integration	F(1, 153)=3.6, ρ =0.06	0.01 (small)
	Productivity	4.5	1.8	1	7	124	Productivity	F(1, 153)=5.7, ρ =0.02	0.04 (small-medium)

Table 4. Relative Risk (RR) estimates comparing ‘low’ CIQ sub-scale and total scores in the SCI group with the general population

				Relative Risk (RR)	ρ -value
Home integration		Poor score (<15.1)	Not poor score (>=15.1)		
	SCI sample (n=31)	14 (45.2%)	17 (54.8%)	Crude RR (95% CI) = 3.1 (1.7 to 5.5)	
	General Population matched sample (n=124)	18 (14.5%)	106 (85.5%)	Conditional RR (95% CI) = 3.1 (1.5 to 6.3)	0.001*
Social integration		Poor score (<15.1)	Not poor score (>=15.1)		
	SCI sample (n=31)	4 (12.9%)	27 (87.1%)	Crude RR (95% CI) = 0.7 (0.3 to 1.9)	
	General Population matched sample (n=124)	23 (18.6%)	101 (81.5%)	Conditional RR (95% CI) = 0.7 (0.2 to 2.0)	0.503
Productivity		Poor score (<15.1)	Not poor score (>=15.1)		
	SCI sample (n=31)	10 (32.3%)	21 (67.7%)	Crude RR (95% CI) = 1.5 (0.8 to 2.7)	
	General Population matched sample (n=124)	27 (21.8%)	97 (78.2%)	Conditional RR (95% CI) = 1.5 (0.7 to 3.1)	0.288

Total CIQ score		(<15.1)	(>=15.1)	Crude RR (95% CI) = 1.6 (0.9 to 2.9)	
	SCI sample (n=31)	10 (32.3%)	21 (67.7%)		
	General Population matched sample (n=124)	25 (20.2%)	99 (79.8%)	Conditional RR (95% CI) = 1.6 (0.8 to 3.3)	0.209

Note. * = risk ratio results significant, indicating the SCI group were more likely to have sub/scores ($p < 0.05$).

Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Callaway, L;Enticott, J;Farnworth, L;McDonald, R;Migliorini, C;Willer, B

Title:

Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study

Date:

2017-06-01

Citation:

Callaway, L., Enticott, J., Farnworth, L., McDonald, R., Migliorini, C. & Willer, B. (2017). Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study. AUSTRALIAN OCCUPATIONAL THERAPY JOURNAL, 64 (3), pp.226-234. <https://doi.org/10.1111/1440-1630.12350>.

Persistent Link:

<http://hdl.handle.net/11343/292264>