ORIGINAL ARTICLE

Community participation for individuals with spinal cord injury living in Queensland, Australia

JJ Carr¹, MB Kendall^{2,3}, DI Amsters⁴, KJ Pershouse⁴, P Kuipers^{3,5}, P Buettner⁶ and RN Barker¹

Study design: Sequential mixed method design.

Objectives: Determine factors associated with community participation for individuals with spinal cord injury (SCI).

Setting: Queensland, Australia.

Methods: Phase I consisted of a quantitative telephone survey of 270 people who had sustained a SCI within the past 50 years. To verify and interpret survey findings, Phase II involved a qualitative investigation. One focus group, one dyadic and one in-depth interview were conducted with a separate sample of eight people who had sustained a SCI within the past 50 years.

Results: In Phase I, employment, paid or unpaid, was the strongest independent factor associated with community participation, whereas time since injury, completeness of injury, secondary conditions and functional independence were also independently associated. In Phase II, participants expressed that survey findings were consistent with their lived experiences. They explained that overall, they needed *a strong reason* to participate so that benefits outweigh the effort required to participate. Once out in the community, they recognised that other opportunities for participation arise.

Conclusion: Rehabilitation services need to support individuals with SCI to find meaningful employment and to engage in activities that provide them with a strong reason to participate.

Spinal Cord (2017) **55**, 192–197; doi:10.1038/sc.2016.169; published online 29 November 2016

INTRODUCTION

Quality of life for individuals with spinal cord injury (SCI) is lower than that for their able-bodied peers.¹ The extent to which individuals with SCI participate in the community is a key factor influencing quality of life.² Accordingly, there is pressure on rehabilitation services to focus attention on reintegration of individuals with SCI into the community.³ To guide resource allocation and service development, therefore, a greater understanding of why some individuals with SCI regularly participate in the community, whereas others do not, is required.

Previous studies that have explored community participation for individuals with SCI have identified a range of contributing factors that span all domains of the International Classification of Functioning, Disability and Health.^{4,5} Impairments of body functions and structures associated with community participation include level and severity of injury and the number of secondary conditions, whereas activity limitations include mobility and functional independence.⁶ Contextual factors associated with participation encompass personal factors including gender, age at injury, marital status, education and social support⁶ as well as environmental factors including natural and built environment, government and business policies, availability of assistance outside the home and societal attitudes.^{5,6}

Considerable variation exists between studies regarding factors associated with community participation.⁶ Differences between

communities investigated in terms of culture, climate, lifestyle and availability of rehabilitation services may explain this variation. For example, accessibility to the physical and structural environment is a major barrier to community reintegration for individuals with SCI in rural south India⁷ but not in metropolitan United States of America, where accessibility is typically good.⁸ Recognising that each community is unique, factors associated with participation need to be considered for each community.

Within the Australian SCI population, investigation of community participation has been limited.⁶ In Queensland, individuals with SCI face unique challenges associated with their lifestyle, particularly the tropical environment where rain and heat have a major effect on community participation for individuals with, and without, a disability.⁹ Therefore, the aim of the current study was to determine why some individuals with SCI, who live in Queensland, Australia, regularly participate in the community while others do not. The first objective was to identify factors associated with community participation, and the second objective was to explain how those identified factors affect community participation.

MATERIALS AND METHODS

A sequential mixed method design was chosen for this study. Phase I consisted of a quantitative telephone survey of people who had sustained a SCI within the past 50 years. To verify and interpret survey findings, Phase II involved a qualitative investigation that included one focus group interview, one dyadic

¹College of Healthcare Sciences, James Cook University, Cairns, Queensland, Australia; ²Transitional Rehabilitation Program, Queensland Spinal Cord Injuries Service, Princess Alexandra Hospital, Brisbane, Queensland, Australia; ³Menzies Health Institute Queensland, Griffith University, Brisbane, Queensland, Australia; ⁴Spinal Outreach Team, Queensland Spinal Cord Injuries Service, Princess Alexandra Hospital, Brisbane, Queensland, Australia; ⁵Centre for Functioning and Health Research, Metro South Health, Brisbane, Queensland, Australia and ⁶College of Public Health, Medical & Veterinary Sciences, James Cook University, Cairns, Queensland, Australia
Correspondence: JJ Carr, College of Healthcare Sciences, James Cook University, 14-88 McGregor Road, Smithfield, Cairns, Queensland 4878, Australia.
E-mail: jennifer.carr2@gmail.com

Received 17 June 2016; revised 19 October 2016; accepted 27 October 2016; published online 29 November 2016

interview (two individuals interacting in response to open-ended questions)¹⁰ and one individual in-depth interview with a separate sample of people who had sustained a SCI within the past 50 years. Ethical approval was granted by Princess Alexandra Hospital Human Research Ethics Committee, Brisbane, and James Cook University Ethics Committee, Townsville, Australia. All participants provided informed consent to be involved in the study.

Phase I

A secondary analysis of cross-sectional data from year 1 of a 5-year prospective longitudinal survey of individuals with traumatic SCI was undertaken. A pre-arranged and guided telephone interview format was utilised with a written survey questionnaire provided to participants in advance. This method of data collection was chosen to ensure that a large geographically dispersed sample of individuals with SCI could participate to minimise time, resource expenditure, incidence of missing data and for ease of administration.¹¹

Participants

A random sample of 270 individuals with traumatic SCI was selected from archival records of the Queensland Spinal Cord Injuries Service. Details regarding inclusion criteria and randomisation of the sample have been published in Barker *et al.* (2008).²

Measurement

A selection of measures of the International Classification of Functioning, Disability and Health components of function and disability were used in the survey questionnaire. Preference was given to measures shown to be valid and reliable when administered to a SCI population via telephone interview. The Community Integration Measure (CIM) was used to measure community participation. The CIM is a 10-item client-centred measure of community integration. Participants rate their agreement with statements about their personal attitudes, beliefs and perceptions regarding their connection with the community. The sum of scores of all 10 items provides a single summary score (between 10 and 50). The CIM is a valid and reliable measure when administered in a SCI population.¹² Impairments of body functions and structures were measured according to level and completeness of neurological injury in accordance with the American Spinal Injury Association classification system.¹³ Secondary conditions were measured using the Secondary Conditions Surveillance Instrument,¹⁴ in which a four-point scale is used to measure 40 different problems over 12 months. Overall severity is calculated by summing ratings across all conditions with a higher score indicating more secondary impairments. Activity limitations were measured using the motor subset of the Functional Independence Measure and the Clinical Outcome Variables Scale. The motor subset of the Functional Independence Measure consists of 13 items with higher scores indicating higher levels of functional independence. The Clinical Outcome Variables Scale consists of 13 items that are reported as a single composite score, a general mobility score and an ambulation score. Higher scores denote higher levels of function. The Functional Independence Measure and Clinical Outcome Variables Scale have demonstrated validity and reliability when used in a SCI population via telephone interview.^{15,16} Personal factors included gender, ethnicity, age and time since injury, education, marital status, living situation and employment status.

Procedure

Telephone interviews were conducted at pre-arranged times by one of three therapists who were experienced in the area of SCI. Participant consent forms, information sheets and the survey questionnaire were mailed to participants and returned in a reply-paid envelope prior to conduct of the telephone interview.

Analysis

Survey data were analysed using SPSS Version 22 (James Cook University, Townsville, QLD, Australia). Significance level was set at 0.05. Missing data were managed using mean substitution for computed variables and pair-wise deletion for single item variables.¹⁷ Frequency of missing item scores was less than 10 across the entire sample. Participant characteristics were described

Table 1 Descriptive characteristics and bivariate relationships between disability and community participation (270 participants with traumatic SCI)

Characteristics	Descriptive data	CIM	P-value
Age (years)	Mean 43 (range 20–76)	$r=0.174^{**}$	0.004
Age at injury (years)	Median 25, IQR 13	$r=0.013$	0.062
TSI (years)	Median 15, IQR 15	$r=0.169^{**}$	0.005
Gender ^a			
Male	218 (81%)	44 (38, 48)	0.882
Education ^a			
Tertiary	114 (42%)	44 (38, 48)	0.673
Employment ^a			
Working	142 (53%)	42 (35, 47)**	<0.001
Marital status ^a			
Partner	115 (43%)	43 (36, 38)	0.115
Level of injury ^a			
Paraplegic	127 (47%)	45 (39, 48)	0.091
Completeness ^a			
Incomplete	126 (46%)	43 (36, 48)*	0.015
SCSI overall	Median 15, IQR 12	$r=-0.173^{**}$	0.004
COVS composite	Median 57, IQR 29	$r=0.109$	0.074
FIM total	Median 76, IQR 40	$r=0.148^{*}$	0.015
Physical ^b	Mean 63 (range 7–97)	$r=0.335^{**}$	0.000
Psychological ^b	Mean 66 (range 4–100)	$r=0.394^{**}$	0.000
Social relationships ^b	Mean 62 (range 0–100)	$r=0.346^{**}$	0.000
Environment ^b	Mean 70 (range 22–100)	$r=0.402^{**}$	0.000
CIM	Median 44, IQR 10	—	—

Abbreviations: CIM, Community Integration Measure; COVS, Clinical Outcome Variables Scale; FIM, Functional Independence Measure; r , Spearman's rank correlation; SCSI, Secondary Conditions Screening Instrument; TSI, time since injury. *Correlation is significant at 0.05; **Correlation is significant at 0.01.

^aMED[IQR].

^bWHOQOLBref, World Health Organisation Quality of Life BREF Instrument.

using mean and standard deviation if symmetrical and using median and interquartile range if skewed.

To identify factors that were significantly associated with community participation, bivariate statistical tests of correlation were conducted. As CIM showed a skewed distribution, Spearman's rank correlation coefficients were used to correlate CIM with numerical variables, and non-parametric Mann–Whitney Wilcoxon tests or Kruskal–Wallis tests were used with categorical variables. To demonstrate the significant relationship between quality of life and community participation that led to this study,² the four domains of the World Health Organisation Quality of Life Assessment Instrument (WHOQOL)-Bref are described and included in the bivariate analyses (see Table 1), but not included in the multivariate analysis to avoid multicollinearity.

To determine independent factors associated with community participation, multiple linear regression analysis was conducted. Independent variables selected were those variables that could best represent the impact of SCI on each component of the International Classification of Functioning, Disability and Health—primary impairments (American Spinal Injury Association—level and completeness of injury), secondary impairments (Secondary Conditions Surveillance Instrument), activity limitations (motor subset of the Functional Independence Measure) and personal factors (age, age at injury, time since injury, education, marital status, employment status). All continuous variables were dummy-coded into quartiles. Stepwise forward and backward selection procedures were applied to identify variables that were independently associated with community participation. The dependent variable CIM was not normally distributed and therefore violated multiple linear regression assumptions. To overcome this, the CIM variable was logarithmically transformed and a further multiple regression analysis was executed using the same set of independent variables entered in the initial regression analysis to verify the results. All factors found not to be related to community participation were assessed, each

Table 2 Multiple regression analysis identifying independent associations with community participation (270 participants with traumatic SCI)

Predictors	Coefficient B	95% CI	P-value	Variance (%)
Employed	3.306	1.695–4.917	<0.001	5.8
Incomplete	2.185	0.566–3.803	0.008	2.8
FIM score 0–42	–2.424	–4.293 to –0.555	0.011	2.4
TSI 0–7.5 years	–2.232	–4.072 to –0.392	0.018	2.1
SCSI > 21	–2.105	–4.009 to –0.202	0.030	1.8
<i>Confounding^a</i>				
Age at injury	0.058	–0.026 to 0.143	0.176	—
Level of injury	0.393	–1.649 to 2.434	0.705	—

Abbreviations: 95% CI, 95% confidence interval; FIM, Functional Independence Measure; SCSI, Secondary Conditions Screening Instrument; TSI, Time Since Injury.

^aConfounders: age at injury and level of injury confounded SCSI, TSI and FIM (i.e. changing the estimate by 10% or more).

separately, for confounding effects. If a factor changed the regression coefficient of one or more variables in the model by more than 10%, then this factor was considered a confounder and the model adjusted for its effects.

RESULTS

The final study sample of 270 individuals was comparable to the non-participant sample of the Queensland Spinal Cord Injuries Service population in terms of age at injury, gender, age and place of residence. The sample contained a larger percentage of those with tetraplegia and complete injuries than the non-participant sample. Participant characteristics are outlined in Table 1.

Factors associated with community participation

Factors associated with community participation are displayed in Table 1. Individuals with SCI were more likely to participate in the community if they were older ($P=0.004$), had a longer time since injury ($P=0.005$), were employed in paid or unpaid work ($P<0.001$) and if they had an incomplete injury ($P=0.015$), less secondary conditions ($P=0.004$) and a higher level of functional independence ($P=0.015$).

Factors independently associated with community participation

Being employed in paid or unpaid work was the strongest independent factor associated with community participation ($P<0.001$), accounting for the most variance (6%). Other significant independent factors included completeness of injury ($P=0.008$), time since injury ($P=0.018$), secondary impairments ($P=0.030$) and functional independence ($P=0.011$). The overall variance explained by the model was only 15%, associations between independent variables and CIM were weak and the magnitude of the differences between variables was small. Table 2 displays results of the multiple regression analysis.

Phase II

Phase II was conducted a year after the findings of Phase I had been reported. In order to verify and interpret those findings, Phase II involved one focus group interview in a metropolitan location ($n=5$), one dyadic interview in a regional location ($n=2$) and one in-depth interview in a rural location ($n=1$). The focus group interview was used to ensure various viewpoints were represented and to take advantage of the richness of group data. The dyadic interview was used to closely compare and contrast individual experiences. The in-depth interview was used to gain views of an individual who rarely participated in the community, to gain more personal responses and

Table 3 Descriptive characteristics of interview participants

Characteristics	Participants ($n=8$)							
Interview	FG	FG	FG	FG	FG	Dyad	Dyad	In-depth
Age (years)	35	56	57	47	34	62	41	31
TSI (years)	1	3	29	13	19	14	13	4
Gender	M	M	M	M	M	F	M	M
Location	Metro	Metro	Metro	Metro	Metro	Reg	Reg	Rural
Level	T4-C	C6-I	C4-C	C2-C	C5-I	C6-I	T7-I	C6-C
Lives alone	N	N	Y	N	N	Y	N	Y
Married	N	N	N	N	N	N	N	N
Tertiary edu	Y	N	N	Y	Y	N	Y	Y
Employed	N	Y	Y	Y	Y	Y	N	N

Abbreviations: C, complete injury; Dyad, dyadic interview; F, female; FG, focus group; I, incomplete injury; In-depth, in-depth interview; M, male; Metro, metropolitan; N, no; Reg, regional; Tertiary edu, tertiary education; TSI, time since injury; Y, yes.

to add greater depth. Practical difficulties of assembling multiple participants across large geographical distances of Queensland were also considered.¹⁰

Participants

Purposive sampling was used to reflect the range of individuals with SCI in Queensland, and hence to achieve maximum variation in the perspectives explored. Participant characteristics are summarised in Table 3. Participants were recruited via Spinal Life Australia, an independent not-for-profit, membership-based organisation that represents individuals with SCI in Queensland. The Spinal Life Australia Brisbane branch recruited metropolitan participants and the Townsville branch, located over 1200 km away in the state's far north, recruited regional and rural participants. Each participant was invited to participate by a Spinal Life Australia staff member and offered financial assistance with transport to attend the meeting. This method of recruitment and venue were chosen to maximise participation by providing a familiar and supportive environment. Of 13 individuals who initially agreed to participate, 8 attended and 5 did not, due to illness, 'problems' or gave no reason.

Data collection

Individuals with SCI who agreed to participate were mailed information and consent forms and asked to return the signed consent form in a reply-paid envelope prior to the interview. The focus group interview was held at the Brisbane Spinal Life Australia office, the dyadic interview at the Townsville Spinal Life Australia office and in-depth interview in the participant's home. Semistructured interviews with open-ended questions derived from Phase I were as follows: (1) What do you think influences community participation following SCI? (2) How does each factor influence community participation (employment status, completeness of injury, secondary conditions, functional independence)? (3) What do you think makes some people participate more than others?

Procedure

Interviews were conducted by one researcher who acted as a group leader (RB). A second researcher (JC) acted as a scribe, taking notes of non-verbal communication such as body language and group dynamics. At the beginning of each interview, the aim of the study and the process for conduct of the interview were explained. Participants were encouraged to share their story and reason for attendance, in order to build rapport between researchers and participants. The group leader then presented the results of Phase I,

asked participants the prepared questions, then encouraged them to share their views and respond to other participants' views. Additional probes were used to broaden discussion. At interview end, the group leader summarised the discussion and invited participants to support, modify or refute points made. Following participant consent, audio-tapes of all interviews were recorded.

Analysis

Analysis of qualitative data was undertaken according to predetermined themes, that is, independent factors identified in Phase I. Once data collection was finalised and audiotapes transcribed verbatim, analysis involved reading each transcription and hand coding data according to the predetermined themes. Data under each theme were grouped and then, through a process of reading and re-reading, analysed to determine the specific properties of each theme. Member checking with one representative from each interview occurred to confirm accuracy of the findings and to enable participants to comment on the findings. This led to small additions and modifications to the content.¹⁸

RESULTS

Participants felt that the survey findings were consistent with their lived experience. Their perspectives on the survey findings and on community participation are outlined below.

Completeness of injury

A person with an incomplete injury was considered to be more likely to participate regularly because they 'stood a chance' of being able to stand and walk. In contrast, a person with a complete injury was considered more likely to have secondary conditions, require more equipment and be more dependent on others, all of which could make participation difficult.

Time since injury

Participants believed that soon after leaving hospital, community participation was difficult because function was poor. They recognised that this steadily improved, then plateaued. Over time, however, function gradually declined, mostly because of the secondary conditions that developed as a result of ageing and from years in a wheelchair.

Secondary conditions

The impact of secondary conditions on participation was consistently discussed, particularly spasm, fatigue, pain, urinary tract infections, pressure areas and issues with bladder and bowel. Interview participants felt secondary conditions were a major barrier to participation, with one participant highlighting the embarrassment and frustration they cause.

It's embarrassing for me, but for the people around as well...more so with bowel accidents...but it's the frustration ... got your clothes on, you've got into town, your just about to get into the chair and..... you've got to go home.

Functional independence

Participants acknowledged that the more functionally independent a person was the more easily they could participate. They recognised that wheelchairs, equipment and assistance from carers helped to achieve functional independence, yet felt these 'aids' could also be a burden. Being in a wheelchair meant physical access to community

facilities was a major problem, especially in extreme weather. They expressed frustration with inaccessible doors, toilets and stairs, poor access to parking due to insufficient or misuse of disabled parking as well as poor availability, reliability and high cost of wheelchair accessible public transport. In tropical north Queensland, going out when it was wet or hot was a challenge. One participant in a manual chair reported that by the time he transferred and dismantled his chair, he was 'soaked' or 'overheated'. Being caught in the rain in a power chair brought its own problems.

I have been caught out in the chair in the rain... that night watching TV...all of a sudden my power chair just took off and went straight through the wall with me in it....

Participants expressed exasperation with limited carer hours and the lack of flexibility they experienced as a result.

A Christmas party I would have liked to go to...but I spilt coffee all down myself... at 11 o'clock in the morning and had no-one to help me change myself, I couldn't go....

Employment status

Participants agreed that being employed, whether paid or unpaid, was a critical factor that influenced community participation. Those who were employed had their own reasons for doing so that included making some extra money, a young family to raise, strong support from a former employer or strong work experience pre-injury that was maintained after injury.

Having worked before injury, one participant felt his experience and expectations to return to work gave him an advantage over adolescents who had never worked. In contrast, another participant who ran his own business and had been injured when at school believed he simply followed life's expected path, from school to university and the workplace.

When considering why an individual with SCI might not return to work, participants acknowledged that those with 'white collar' jobs pre-injury had an easier transition back to work compared with those in 'blue collar' jobs who were unable to return to their pre-injury work. When considering another job, participants emphasised that it could not simply be 'any old job', but rather, it had to be an interesting job.

...The only job that the competitive employment agency...told me I could do was be a telemarketer...and I know what I thought about telemarketers.

In contrast to most, one participant, who was reasonably happy with his level of participation in the community, stated that his only motivation for work before his injury was to fund his hobbies and sporting interests. Since his injury, he had sufficient funds to participate and, therefore, saw no reason to work.

Paradoxically, most interview participants considered they participated regularly in the community, despite experiencing most factors found to impede participation. When asked why they felt they participated regularly in the community while others did not, interview participants felt it was because they had a strong reason to participate such as for work, both paid and voluntary, managing a family business, playing sport or bringing up their children. One participant who rarely participated in the community felt that an accumulation of factors made it hard for him to participate, and reached a point where it was not 'worth the effort'.

Normally I'd be keen to go out and have a drink with my mates...or get some kind of job... bladder and bowel stuff and pressure areas are the biggest things...and then parking is an issue...and I've got problems with transferring because of these spasms...then I need someone to help me set the chair up....

Overall, participants acknowledged that to make the effort to participate in the community, they must be doing something that they see as worthwhile so that the benefits outweigh the effort required to participate. In addition, they felt strongly that being out in the community meant that other opportunities for participation would arise. Hence, to regularly participate in the community throughout the lifespan, participants suggested that the individual with SCI would need to maintain the dynamic balance between what an activity is worth to them and the effort that is required to participate in it.

I have been thinking about finding some sort of job to start off... hopefully that might lead me to something else somewhere else...

DISCUSSION

The purpose of this study was to identify factors associated with community participation for individuals with SCI living in Queensland, Australia. A survey of 270 individuals with SCI identified that employment status was the strongest independent factor, followed by completeness of injury, time since injury, secondary conditions and functional independence. Subsequent interviews with eight individuals with SCI from metropolitan, regional and rural Queensland highlighted that for each individual, community participation is influenced by the extent to which benefits outweigh the effort required to participate.

There are a number of study limitations that must be acknowledged. Participation in the survey was restricted to individuals who were contactable via telephone, and participation in the interviews was limited to members of Spinal Life Australia. Findings of the interview, in particular, are likely to reflect the views of individuals who felt that to participate was 'worth the effort' and not of those who find it more difficult to participate in the community. The method of recruitment utilised, however, offered significant support to participants to attend, and so may have included individuals who would have been otherwise reluctant to volunteer. Response bias may also have occurred as self-report measures, and interviews rely on memory and may reflect desirable responses rather than accurate ones.¹⁹ Overall, therefore, these study findings cannot be generalised to the SCI population, particularly as there was a relatively small number of participants, with a particularly diverse range of lifestyles and because the experience of SCI may have altered more recently amid the rapid medical and technological advances of the current decade. Methods of administration used, however, were deemed to have the least bias for capturing the lived experience of the geographically dispersed population of individuals with SCI in Queensland.

Factors associated with community participation in this study were consistent with the findings in the literature for other localities.⁶ Challenges relating to the Queensland context (e.g. heat and rain) were voiced but were not the focus of any discussion. Many participants interviewed reported regular participation despite experiencing factors known to be associated with low levels of participation (e.g. more severe injuries). This perhaps reinforces the view expressed by interview participants that rather than individual factors, it is the accumulation of factors, both psychological and physical, which influences participation. It would seem that despite embarrassment,

burden, frustration and hardship, if they have a strong reason to participate in the community, the benefit outweighs the effort required to participate. Given the limited variance explained by the variables included in the regression model, the views expressed by individuals with SCI would suggest that further research is required to identify factors such as 'motivation' and 'effort' that could be contributing to participation but were not included in this survey.

Employment status was the factor that demonstrated the strongest independent association with community participation. Interview participants explained that being employed was important not only because it offered something interesting and meaningful to do, but also because it meant the individual with SCI was regularly out in the community where opportunities for further participation could arise. This is consistent with the view that employment is a foundation for social inclusion for both able-bodied and disabled individuals.²⁰ This is an important consideration for those individuals with SCI who are at 'risk' of not returning to employment, such as those who were manual workers before injury who are unable to return to their previous job.²¹ Given their previous work experience and the significant resources involved in retraining for sedentary occupations, employment in sedentary or clerical jobs could be perceived by these individuals as having insufficient benefit to outweigh the effort required to return to employment.²² The challenge is to assist each individual with SCI to find a strong area of interest and to provide the education and support required, given that post- as well as pre-injury education is a predictor of employment.²³ In addition, with rates of employment previously shown to be lower in Australia than other countries such as Sweden,²⁴ continued investigation of strategies to promote employment post-injury is warranted.

Overall, the findings of this study indicate that services for individuals with SCI need to focus on exploring meaningful employment opportunities and everyday activities that are meaningful to each individual. In essence, this means supporting people with SCI to establish their goals and priorities and then supporting them to achieve their goals and priorities. In parallel, services must emphasise reducing the effort required to participate, by minimising secondary impairments and optimising functional independence. Furthermore, with the emergence of community rehabilitation and lifespan services, support for individuals with SCI needs to continue in the long term, to help maintain this dynamic balance as changes occur in goals, priorities and the effort required to participate.

CONCLUSION

Individuals with SCI living in Queensland, Australia, report that employment status is the strongest factor contributing to community participation, similar to findings elsewhere in the world. From their perspective, however, an individual with SCI is more likely to participate regularly if they have a good reason to participate, so that benefits gained outweigh the effort required. Then once out in the community, further opportunities for participation will arise.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

We thank the participants for sharing their stories. Financial support for this project was provided by Queensland Health and the Centre of National Research on Disability and Rehabilitation Medicine (CONROD).

- 1 Pershouse KJ, Barker RN, Kendall MB, Buettner PG, Kuipers P, Schuurs SB *et al*. Investigating changes in quality of life and function along the lifespan for people with spinal cord injury. *Arch Phys Med Rehabil* 2012; **93**: 413–419.
- 2 Barker RN, Kendall MD, Amsters DI, Pershouse KJ, Haines TP, Kuipers P. The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord* 2008; **47**: 149–155.
- 3 Gomara-Toldra N, Sliwinski M, Dijkers MP. Physical therapy after spinal cord injury: a systematic review of treatments focused on participation. *J Spinal Cord Med* 2014; **37**: 371–379.
- 4 Barclay L, McDonald R, Lentin P, Bourke-Taylor H. Facilitators and barriers to social and community participation following spinal cord injury. *Aust Occup Ther J* 2016; **63**: 19–28.
- 5 Reinhardt JD, Ballert C, Brinkhof MW, Post MW. Perceived impact of environmental barriers on participation among people living with spinal cord injury in Switzerland. *J Rehabil Med* 2016; **48**: 210–218.
- 6 Barclay L, McDonald R, Lentin P. Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res* 2015; **38**: 1–19.
- 7 Sekaran P, Vijayakumari F, Hariharan R, Zachariah K, Joseph SE, Kumar RK. Community reintegration of spinal cord-injured patients in rural south India. *Spinal Cord* 2010; **48**: 628–632.
- 8 Whiteneck G, Meade MA, Dijkers M, Tate DG, Bushnik T, Forchheimer MB. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Arch Phys Med Rehabil* 2004; **85**: 1793–1803.
- 9 Woodruff RE, McMichael T, Butler C. Action on climate change: the health risks of procrastinating. *Aust NZ J Public Health* 2007; **30**: 567–571.
- 10 Morgan D, Ataie J, Carder P, Hoffman K. Introducing dyadic interviews as a method for collecting qualitative data. *Qual Health Res* 2013; **23**: 1276–1284.
- 11 Addington-Hall J, Walker L, Jones C, Karlsen S, McCarthy M. A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. *J Epidemiol Community Health* 1998; **52**: 802–807.
- 12 McColl MA, Davies D, Carlson P, Johnston J, Minnes P. The community integration measure: development and preliminary validation. *Arch Phys Med Rehabil* 2001; **82**: 429–434.
- 13 Weitzenkamp DA, Jones RH, Whiteneck GG, Young DA. Ageing with spinal cord injury: cross sectional and longitudinal effects. *Spinal Cord* 2001; **39**: 301–309.
- 14 Seekins T, Clay J, Raveslout C. A descriptive study of secondary conditions reported by a population of adults with physical disabilities served by three independent living centres in a rural state. *J Rehabil Med* 1994; **60**: 47–51.
- 15 Campbell J, Kendall M. Investigating the sustainability of the clinical outcome variables scale (COVS) as a mobility outcome measure in spinal cord injury rehabilitation. *Physiother Canada* 2003; **55**: 135–144.
- 16 Masedo A, Hanley M, Jensen M, Ehde D, Cardenas D. Reliability and validity of a self-report FIM (FIM-SR) in persons with amputation or spinal cord injury and chronic pain. *Am J Phys Med Rehabil* 2005; **84**: 167–176.
- 17 Pigott T. A review of methods for missing data. *Educ Res Eval* 2001; **7**: 353–383.
- 18 Creswell J. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, 3rd edn (Los Angeles: Sage Publications, 2009).
- 19 Song HY. Modeling social reintegration in persons with spinal cord injury. *Disabil Rehabil* 2005; **27**: 131–141.
- 20 Leach LS, Butterworth P, Strazdins L, Rodgers B, Broom DH, Olesen SC. The limitations of employment as a tool for social inclusion. *BMC Public Health* 2010; **10**: 621.
- 21 Tomassen P, Post MvA F. Return to work after spinal cord injury. *Spinal Cord* 2000; **38**: 51–55.
- 22 Hu X, Kaplan S, Dalal R. An examination of blue- versus white-collar workers' conceptualizations of job satisfaction facets. *J Voc Behav* 2010; **76**: 317–325.
- 23 Krause J, Terza J, Dismuke C. Earnings among people with spinal cord injury. *Arch Phys Med Rehabil* 2008; **89**: 1474–1481.
- 24 Ottomaneli L, Lind L. Review of critical factors related to employment after spinal cord injury: implications for research and vocational services. *J Spinal Cord Med* 2009; **32**: 503–531.