

Original Article

International differences in ageing and spinal cord injury

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Design: The present study is part of a programme of longitudinal research on ageing and spinal cord injury involving three populations – American, British and Canadian. The design was multivariate.

Objective: To identify international differences in outcomes associated with ageing and spinal cord injury.

Setting: A sample of 352 participants was assembled from five large, well-established databases. The Canadian sample was derived from the member database of the Canadian Paraplegic Association (Ontario and Manitoba divisions). The British sample was recruited from Southport Hospital's Northwest Regional Spinal Injuries Centre and Stoke-Mandeville Hospital's National Spinal Injuries Centre. The American sample has been recruited through Craig Hospital in Denver, Colorado.

Methods: The sample included individuals who had incurred a spinal cord injury at least 20 years previously; were admitted to rehabilitation within 1 year of injury; were between age 15 and 55 at the time of injury. Data were collected using a combination of self-completed questionnaires and interviews. Data included medical information, general health, hospitalisations, and changes in bladder and bowel management, equipment, pain, spasticity, the need for assistance, and other health issues.

Results: Clear international differences existed between the three samples in the three different countries. After controlling for sampling differences (ie, differences in age, level of lesion, duration of disability, etc.), the following differences were seen: (1) American participants had a better psychological profile and fewer health and disability-related problems; (2) British participants had less joint pain and less likelihood of perceiving they were ageing more quickly; (3) Canadians had more health and disability-related complications (particularly bowel, pain and fatigue problems).

Conclusion: These differences are discussed in terms of socio-political, health care system and cultural factors that might be used to explain them, and to generate hypotheses for future research.

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Keywords: spinal cord injury; ageing; complications; health care system; rehabilitation

Introduction

As recently as 10–20 years ago, rehabilitation professionals were still advising people that spinal cord injury was a relatively static condition. Once initial adjustment had occurred, they were led to believe they could expect to enjoy a stable level of function. However, a developing body of research on ageing and spinal cord injury has acknowledged that

a number of factors cause significant changes in the health experience of people with spinal cord injuries as they age. There are five types of age-related change that people with spinal cord injuries encounter: (1) the effects of living with a spinal cord injury for many years, such as shoulder deterioration, chronic bladder infections or postural problems; (2) secondary complications of the original lesion, such as post-traumatic syringomyelia; (3) pathological processes not related to the spinal cord injury, such as heart disease or other chronic disease; (4)

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degenerative changes associated with ageing, such as joint, sensory and connective tissue problems, and (5) environmental factors, such as societal, community and cultural issues that have the potential to further complicate the experience of ageing with a spinal cord injury.

This latter category of factors are of particular interest, because they inform the service sector about factors that may be within their purview to change. Given that differences in health-care delivery systems can affect quality of life and health outcomes, it may be informative to compare the ageing experiences of people with spinal cord injuries across international samples. One way of exploring these problems is to compare people living in different environments, to see how they differ in their experience of ageing.

The present study examined issues associated with ageing in a large international sample, and made comparisons among participants from three countries – Canada, UK and the United States. The three countries studied differ in a number of aspects of the provision of health and social services to people with spinal cord injuries. While all three have well-developed systems of emergency, health and social services, they differ in a number of important ways that could affect outcomes of long-term spinal cord injury. For example, both Canada and the UK are considered socialised medical systems, providing universal health-care coverage without time-of-service economic barriers to service. In the USA, on the other hand, service typically depends on private insurance coverage for most working-age people, and on government programmes that have moved away from providing much more than acute care. Most insurance plans for those with long-term SCI have very limited coverage for things such as personal assistance, durable medical equipment or outpatient therapy. When services are covered, the reimbursement rate tends to be quite low. Given the demographics of spinal cord injury, many people are eligible for Medicare, and in cases of financial indigence, can receive Medicaid. Insured services in the USA usually involve a system referred to as ‘managed care’, whereby services are offered based on the average needs within a population or diagnostic category. For inpatient services, this approach profoundly affects lengths of stay in rehabilitation, which differ dramatically between the three countries. For outpatient or community service, it results in difficulty finding providers who are willing to take on a high-risk patient, as people with disabilities have been shown to be.^{1–4}

A number of authors have shown ethnic and cultural differences within countries.^{5–9} However, international differences, while not conclusive in and of themselves, can lead to the generation of hypotheses about the effects of service delivery that can be tested in future research.

Methodology

Design

The present study was part of a longitudinal programme of research on ageing and spinal cord injury involving three populations – American, British and Canadian. This paper presents results of a cross-sectional analysis of the data collected in 1999. Multivariate analysis was used to identify international differences in outcomes of interest associated with ageing.

Sample

A total sample size of 352 was assembled from five large, well-established databases:

- (1) the Canadian Paraplegic Association Ontario division;
- (2) the Canadian Paraplegic Association Manitoba division;
- (3) the Northwest Regional Spinal Injuries Centre (NRSIC) in Southport, UK;
- (4) the National Spinal Injuries Centre (NSIC) in Stoke-Mandeville, UK, and
- (5) the Craig Hospital in Englewood, Colorado, USA.

These five databases represent an exceptional international resource for the study of ageing with spinal cord injury. The sample includes individuals who:

- (1) had incurred a spinal cord injury at least 20 years previously;
- (2) were admitted to rehabilitation within 1 year of injury;
- (3) were between age 15 and 55 at the time of injury;
- (4) had survived for at least 1 year following injury.

The Canadian sample was derived from the member database of the Canadian Paraplegic Association (CPA) Ontario and Manitoba divisions. It offered 134 participants who met the above eligibility criteria, with an average age of 54.4 (± 10.5), and an average duration of disability was 29.4 years (± 8.2). The British sample consisted of 113 British SCI survivors recruited from Southport’s Northwest Regional Spinal Injuries Centre (NRSIC) and Stoke-Mandeville’s National Spinal Injuries Centre (NSIC). The average age of the British sample was 64.4 (± 8.3), and the average duration of disability was 40.4 years (± 5.1). The American sample was recruited through the Craig Hospital, and included 105 clients recruited since 1991, with an average age of 55.2 (± 9.7) and an average duration of disability of 32.1 years (± 6.2).

Details of the sample by country of origin are presented in Table 1. Significant differences between the three sub-samples existed on four important variables.

- (1) The British participants were significantly older than the Canadians or Americans, with an average age of 64, *versus* 54 and 55 respectively.

Table 1 Details of the three samples

	American sample (n = 105)		British sample (n = 113)		Canadian sample (n = 134)		P	Total sample (n = 352)		
	n	%	n	%	n	%		n	%	
Age										
40–49	35	33.33	1	0.90	53	39.85	0.000	89	25.36	
50–59	41	39.05	38	33.63	38	28.57		117	33.33	
60–69	20	19.05	44	38.94	26	19.55		90	25.64	
70–79	8	7.62	24	21.24	14	10.53		46	13.1	
80+	1	0.95	6	5.31	2	1.50		9	2.5	
Mean (s.d.)	55.29 (9.65)		64.43 (8.31)		54.43 (10.54)			57.89 (10.59)		
Gender										
Male	87	83.8	97	85.8	105	78.9		217	82.8	
Female	18	16.3	16	14.2	28	21.1		45	17.2	
Level of injury										
Cervical	51	48.6	31	31.0	61	51.3	0.000	143	44.1	
Thoracic	47	44.8	51	51.0	52	43.7		150	46.3	
Lumbo-sacral	7	6.7	18	18.0	6	5.0		31	9.6	
Duration										
20–29	44	41.9	0	0.0	79	59.4	0.000	123	35.0	
30–39	48	45.7	60	53.1	34	25.6		142	40.5	
40–49	12	11.4	45	39.8	17	12.8		74	21.1	
50+	1	0.95	8	7.08	3	2.3		12	3.4	
Mean (s.d.)	32.05 (6.16)		40.35 (5.14)		29.35 (8.20)			33.7 (8.20)		
Completeness										
ASIA-A (5)	70	67.3	72	72.0	54	72.0	0.007	196	58.1	
ASIA-B (4)	16	15.4	7	7.0	36	27.9		59	17.7	
ASIA-C (3)	5	4.8	4	4.0	22	17.1		31	9.3	
ASIA-D&E (2,1)	13	12.5	17	17.0	17	13.2		47	14.1	

- (2) The British participants also had more years of experience with their disabilities (average duration 41 *versus* 29 and 32).
- (3) Another significant difference between sub-samples related to the level and completeness of the spinal cord injury. While the Canadian and American samples looked similar to each other, the British sample had significantly more thoracic and lumbosacral lesions and fewer cervical lesions.
- (4) In terms of completeness of lesion, the Canadians had the most incomplete lesions.

Data collection

Participants from all three countries were contacted by mail to request their participation in the study. For those who agreed, a set of measures was mailed for self-completion, along with a stamped return envelope. Those measures included the following:

The Current Problem Questionnaire (CPQ¹⁰) The CPQ includes 18 Likert-type items, on which subjects

are asked to rate, on a scale of 1 to 5, the degree to which they have had problems with various aspects of their lives. Three subscales were created for these analyses, using principal components factor analysis and reliability analysis,¹¹ all with acceptable values of internal consistency reliability (Disability-related problems: Cronbach's alpha = 0.727; Psychosocial problems: 0.772; Health problems: 0.721).

The Life Satisfaction Index (LSI-adapted¹²) The LSI includes 13 statements about whether individuals perceive they are better or worse off than they once were or than they perceive others are. The LSI has been shown to correlate well with life satisfaction ratings obtained by trained judges.¹³ Scores ranged from 0–26, with higher scores reflecting greater life satisfaction.

The Centre for Epidemiological Studies Depression Scale (CES-D¹⁴) The CES-D is a 20-item self-report measure, widely used with non-psychiatric populations. The items ask subjects about the weekly frequency of a

range of depressive symptoms. Reliability estimates are 0.84–0.90 for internal consistency and 0.45–0.70 for test–retest at a variety of intervals. Concurrent and construct validity are supported by correlations with other depression measures. Noh and Posthuma¹⁵ have shown that disabled individuals who were depressed showed high rates of both psychological and somatic symptoms, thus dispelling the concern about over-diagnosing depression on the basis of somatic symptomatology.¹⁶

The Craig Handicap Assessment and Reporting Technique (CHART¹⁷) CHART is a measure of community integration. The version used in this study includes five domains: Physical Independence; Mobility; Occupation; Social Integration; and Economic Self-Sufficiency. Each of the subscales of CHART has a maximum score of 100 points, indicating a level of community integration equivalent to that of most able-bodied persons. The original CHART scoring system was specifically calibrated for use with people with SCI. CHART showed high test–retest reliability – 0.93 for the total score and from 0.80 to 0.95 for the subscales. Rasch analysis established that CHART is a linear scale, with a good fit of both items and persons to its data.¹⁷

Once the completed set of measures was received, a telephone interview was scheduled in most cases. In some instances in the British sample, clinic appointments were scheduled to permit face-to-face interviews, however all of the American and Canadian and about half of the British participants were interviewed by telephone. The interview took between 30 and 60 min. It included: *The demographic form*, including age, gender, education, employment, marital status, injury level, ASIA injury classification, duration of disability, age at injury, era of rehabilitation. *The current status interview* – an extensive clinical interview, from which the following variables were derived: (a) Effects of fatigue and effects of pain – four 7-item rating scales asking participants to rate the effects of fatigue and pain on daily activities (0–28); (b) Number of joints affected by pain (0–25); (c) Changes in the need for equipment or physical assistance; (d) The presence of a number of common secondary complications, such as urinary tract infections, chronic pain, bowel irregularities, autonomic dysreflexia; (e) Perceptions of ageing more rapidly or more severely than able-bodied contemporaries.

Upon completion of the data collection, the data were entered, cleaned and analyzed, using Microsoft Access database management system and SPSS statistical package. Missing data were accounted for in the following ways: (1) In analyses involving original variables, missing cases were deleted pairwise where possible; (2) In analyses involving computed variables, such as scales and subscales, if fewer than 15% of variables were missing from a particular computation, the mean of missing items was imputed, and the scale total was subsequently computed; (3) If

more than 15% of items were missing from a computed score, the entire score was treated as missing.

Identification and resolution of ethical issues

Ethical issues were resolved through approval of the Research Ethics Board at Queen's University, the Institutional Review Board at the Craig Hospital and the Ethics Committee of the two British hospitals.

Results

A two-step process was undertaken to explore international differences in the outcomes of interest:

- (1) First, univariate analyses were performed, to identify outcomes that were significantly associated with the country of origin. Descriptive analyses of the three study groups were performed using Chi square and one-way analysis of variance.
- (2) Where significant differences were identified, other variables known to differ between the three samples (age, duration of disability, level and completeness of lesion) were explored for relationships to the outcome of interest, to ascertain whether these accounted for international differences. Linear and logistic regression were used for these multivariate analyses.

Univariate analysis

Tables 2 and 3 show the outcomes of interest where significant differences between countries were found in univariate analyses. Table 2 shows the results of analyses of variance (ANOVA's), where the outcomes of interest were measured on a continuous scale, and Table 3 shows the results of Chi-square analyses, where the outcomes of interest were dichotomous.

According to Table 2, where significant differences existed between countries, the Canadian sample reported the most unfavourable results on all outcomes, with the exceptions of the CHART total score and the CHART Economic self-sufficiency subscore, where the USA participants reported the worst outcomes. The table shows the two-way comparisons that were significant ($P < 0.05$). Significant differences were detected on: effects of fatigue; effects of pain; number of joints affected by pain; depression (CES-D); physical independence (CHART); mobility (CHART); life satisfaction (LSI); disability-related problems (PPQ); psychosocial problems (PPQ); and health problems (PPQ). There were no significant differences among the three samples on urinary tract infections, occupational functioning (CHART) or social integration (CHART).

Table 3 shows the results of the Chi-square analysis for dichotomous outcomes. Again, the Canadians reported the highest levels of bowel problems;

Table 2 International comparisons (ANOVA's) – Mean values for each sub-sample

	<i>A</i> <i>American sample</i> (n = 105)	P <i>A/B</i>	<i>B</i> <i>British sample</i> (n = 113)	P <i>B/C</i>	<i>C</i> <i>Canadian sample</i> (n = 134)	P <i>A/C</i>
Interview						
Fatigue effects	2.4		1.4	*	6.9	*
Pain effects	2.4		3.2	*	4.5	*
# joints affected by pain	3.8	*	2.6	*	5.1	*
Chart						
Physical independence	90.4		90.7	*	83.2	
Mobility	85.5	*	76.0		74.5	*
Economic self-sufficiency	70.5	*	90.8		90.9	
Total score	377.9		407.0		471.7	*
Perceived problems						
Disability-related	12.7		13.5		15.0	*
Psychosocial	10.8	*	12.6		12.9	*
Health	9.7	*	11.4	*	12.8	*
CES-D	8.7	*	12.5		14.2	*
LSI	11.9		10.3		10.2	*

Highest value for each indicator shown in bold. $P < 0.05$

Table 3 International comparisons (Chi-squares) – Proportion of the sample responding positively

	<i>American sample</i> (n = 105)	<i>British sample</i> (n = 113)	<i>Canadian sample</i> (n = 134)	P
Interview				
Bowel accidents	29.4	36.8	55.0	0.000
Bowel constipation	33.3	42.1	63.4	0.000
Change in equipment	27.7	47.4	49.6	0.002
Chronic pain	28.1	37.9	60.6	0.000
Ageing more quickly	35.7	17.4	44.2	0.000
Ageing worse	50.0	76.3	62.3	0.015

Highest frequency among the three subsamples in bold

equipment changes; chronic pain; and, the sense that they were ageing more quickly than able-bodied counterparts. The British participants were most likely to report the sense that ageing was more severe or more complicated for them. There were no differences among the three samples on general health; cardiovascular disease; diabetes; pressure sores or needing more assistance.

Multivariate analysis

For those variables where significant country effects were seen on univariate analyses, multivariate analyses were undertaken in an attempt to isolate country effects from other possible effects on outcomes. Linear regression was used to model outcomes that were

measured continuously, and logistic regression was used for dichotomous outcomes.

In all, 18 models were tested, all with the same five parameters. For all of the models, the dependent variable was the outcome of interest. Country was treated as a categorical variable and coded as dummy variables, with the British as the reference group. The other independent variables in each model were:

- age in years;
- years post injury (YPI), expressed in years;
- level of lesion (a 13-point scale, with high numbers reflecting high lesions (cervical), and low numbers reflecting lower-level lesions (sacral));
- completeness of lesion (ASIA scale, with A coded as 5 and E coded as 1).

These four variables were chosen because they were shown in Table 1 to differ significantly between the three countries, and therefore could potentially account for the differences seen between countries.

A backwards stepwise procedure was used to arrive at a final model for each outcome. All five predictors were initially entered in the model, and variables were excluded if $P > 0.10$. The final model for each outcome contains only variables for which $P < 0.05$.

Table 4 shows the results of the multiple linear regression for continuous outcomes. The last column shows that relatively little variance was accounted for by these rather limited models (r^2 between 0.031 and 0.231), however they do help to explain the effects of country and other important variables. The table shows that international differences persisted, even

Table 4 Multiple regression models of international differences for continuous outcomes

	Country ^a		YPI	Age	Level	Asia	r ²
	Canada	USA					
Physical independence (CHART)					-2.14 (0.000)		0.144
Health problems (CPQ)	1.35 (0.022)	-1.74 (0.004)					0.102
Life satisfaction (LSI)		1.76 (0.003)					0.031
Depression (CES-D)		-8.95 (0.000)					0.049
Economic (CHART)		-15.12 (0.008)		0.50 (0.054)			0.139
CHART total		-49.39 (0.009)		-1.77 (0.027)			0.145
Effects of pain		-1.63 (0.009)		-0.13 (0.000)			0.061
Effects of fatigue	4.44 (0.000)			-0.08 (0.001)			0.231
Psych problems (CPQ)		-2.12 (0.000)		-0.06 (0.031)			0.056
Disability problems (CPQ)		-1.75 (0.006)			0.50 (0.000)		0.123
Joint pain	2.42 (0.000)	1.25 (0.007)			-0.11 (0.046)		0.094
Mobility (CHART)	-6.17 (0.037)	7.04 (0.016)		-0.52 (0.000)	-1.41 (0.000)	-3.72 (0.000)	0.184

^aBritain used as reference population

when other factors known to differ between countries were controlled. The only exception was the Physical Independence score on the CHART, on which level of lesion alone accounted for the difference seen in the univariate analysis.

Country effects alone continued to explain the differences on three outcomes: the Canadians were more likely to experience health problems (CPQ-Health) than the British participants, and the Americans were less likely; the Americans were more likely than non-Americans to report higher life satisfaction (LSI) and less depression (CES-D).

Although years-post-injury did not appear to significantly affect any of the outcomes of interest, age had significant effects on six outcomes. However, even after controlling for the effects of age, country differences were still seen on the following variables: The Americans experienced fewer psychological problems (CPQ-Psych), less economic dependency (CHART-Econ), greater community integration generally (CHART Total), and fewer effects of pain than the non-Americans. The Canadians experienced more effects of fatigue than the other two samples, in addition to the significant negative effects of age.

After controlling for the significant effects of level of lesion, two significant international differences persisted: The Americans had fewer disability-related problems (CPQ-Dis) than the non-Americans; and both the Canadians and Americans had more joints affected by pain than the British reference sample.

After controlling for age, level and completeness of lesion, the Americans had more mobility difficulties than the British and the Canadians had less.

Table 5 shows the results of the logistic regression analysis. With regard to the dichotomous outcomes studied, the international effects shown in the univariate analyses all held in the presence of the other four variables. In fact, country effects remained the only significant effects for four of the outcomes of interest: Being American was protective against

equipment changes and against the perception that individuals were ageing with greater difficulty than able-bodied contemporaries; being Canadian was a risk factor for bowel accidents; and both the Canadians and the Americans were more likely than the British to report that they were ageing more quickly than others without disabilities.

After controlling for the significant effects of age, Canadians reported more chronic pain than non-Canadians. After controlling for duration of disability and level of lesion, Canadians still reported more constipation than the other two groups.

Discussion

In summary, international comparisons showed that:

- (1) Being American was related to:
 - (a) More favourable psychological outcomes: fewer psychological problems, less depression, less fatigue, more life satisfaction, and a decreased perception that ageing is worse for them than for their able-bodied contemporaries;
 - (b) Fewer effects of pain on day-to-day life;
 - (c) Fewer equipment changes;
 - (d) Fewer disability-related problems and greater community integration.
- (2) Being British was related to:
 - (a) Fewer joints affected by pain;
 - (b) A decreased perception that ageing is happening more quickly for them than for able-bodied contemporaries.
- (3) Being Canadian was related to:
 - (a) More specific health complaints;
 - (b) More bowel problems, including both accidents and constipation;
 - (c) More pain and fatigue.

There are a number of possible factors that may help to explain the differences seen between countries.

Table 5 Logistic regression models of international differences for dichotomous outcomes

	Country ^a e^B (P) ^b		Age	YPI	Level	Asia	P ^c
	USA	Canada					
Change equipment	0.37 (0.000)						0.000
Age worse	0.28 (0.007)						0.008
Bowel accident		3.56 (0.000)					0.000
Age more quickly	2.78 (0.036)	3.96 (0.000)					0.000
Chronic pain		2.04 (0.027)	0.96 (0.003)				0.000
Constipation		4.20 (0.000)		1.05 (0.003)	1.09 (0.027)		0.000

^aBritain used as reference group; ^bInterpret as odds ratio; ^cChi-square on 5 d.f. of $-2 \log$ likelihood

We will consider socio-political factors, health system factors and cultural factors. One of the most significant differences between the socio-political environments of the three countries in relation to people with disabilities is the legislative frameworks that govern the provision of services. In the United States, since 1990, the rights of people with disabilities have been ensured by the wide-ranging provisions of the Americans with Disabilities Act.¹⁸ This omnibus legislation covers everything from employment equity to public washrooms, and is accompanied by an extensive bureaucracy charged with upholding the regulations. Our study found that American participants reported fewer disability-related problems and greater community integration. There is room to speculate that the socio-political environment of the USA creates a climate where people with spinal cord injuries are better able to access opportunities in the community and to experience equity in a number of areas.

In Canada, many of the same rights are protected, albeit in numerous different pieces of legislation. The rights of disabled people are specifically ensured in the Canadian Charter of Rights and Freedoms, however the only way to address a particular infraction is to lodge an individual complaint, and embark on a process that will inevitably be time-consuming, and may also be costly. In the UK, the Disability Discrimination Act of 1995 was set up to help secure rights for people with disabilities, particularly with regard to employment and access to goods, services and facilities.¹⁹ Similar to the Canadian situation, the only means of enforcement is to bring forward a complaint, requiring personal initiative and often expense.²⁰ The results of this study suggest that the perception that one belongs in society is greatest among the American participants. One might speculate that this is related to a legislative and regulatory framework that looks out for the rights of disabled citizens, rather than simply providing them with an avenue for looking out for their own rights.

Holcomb²¹ contends that community integration has deteriorated in the USA in the past 10 years (1989–1999). She points to trends in institutionalisation, mortality and unemployment to make the case that cost containment strategies have led to greater

inequities for people with spinal cord injuries. If this is so, then our data would suggest that these cuts have either not affected people with long-standing injuries, or else they still have not eroded the lead that American participants have over British and Canadian.

With regard to health system differences between the three countries, we have already mentioned the impact of managed care in America *versus* universal health care in Canada and the UK, particularly as it affects initial care and rehabilitation. In the long-term, however, there is greater concern for access to primary care and preventive services. Teasell and Allatt²² underlined the need for informed primary care, and numerous authors have outlined a long list of particular complications of long-term spinal cord injury that require not just medical attention, but attentiveness.^{23–25}

The Canadians had the highest levels of three important complications of spinal cord injury, bowel problems, pain and fatigue. This troubling result is difficult to explain without resorting to speculation. More so than the other two countries, older Canadians with spinal cord injuries experience greater restrictions of their mobility for at least 6 months of the year, due to weather. Inactivity and social isolation carry with them the potential for a number of other complications, of which these might be a few examples. It may also be that these problems are related to one another. For example, the problems with bowel function may be the result of medications taken for pain. Codeine in particular has devastating effects on bowel regularity when taken in sufficiently high doses for extended periods of time. Fatigue may also be a function of medications taken for pain or of sleeplessness associated with other symptoms.

Francisco, Chae and DeLisa²⁶ surveyed American physiatrists and found that most considered themselves the primary care provider of choice for people with spinal cord injuries, and yet it is clear in the three countries studied that access to physiatry on a primary care basis is highly restricted. Anecdotal observations of the interviewers for the present study suggest that the British participants had the strongest links with physiatrists at the centre where they received their initial rehabilitation and Canadians had the weakest.

However this could be a function of the manner in which participants were recruited – American and British participants were enlisted through rehab centres, and Canadians through a community-based organisation. This may also have affected the willingness of British and American participants to report problems, for fear of reflecting badly on service providers in the three centres (Craig, Stoke-Mandeville and Southport).

The Americans also reported that they had fewer equipment changes than the other two countries. It is doubtful that American participants had less access to new and improved technology. Instead, it may be that more Americans would have had to pay out-of-pocket for the full cost of new equipment, whereas Canadian and British subjects could claim against publicly funded programs for equipment updates.

Finally, there are a number of psychosocial differences in the results that suggest that Americans have the most favourable overall adjustment to long-term spinal cord injury – they are generally less depressed and more satisfied with life than their counterparts in either of the other two countries. Although all English-speaking and of substantially Anglo-Saxon heritage, the cultural differences between the three countries are legion. For example, the North American ideal of independence may be a factor in some of these findings. This ideal probably has its roots in the pioneering origins of North American society. In the United States in particular, there is an extremely high value placed on individualism and independence. Although the Independent Living movement and ideology have firmly taken hold in Europe and the UK, they originated in the USA.

An anecdote about independence helps to illustrate this point. In the interviews for this study, one of the questions asked was the extent to which people could use their transportation ‘independently’. In North America, this meant transferring in and out of the car and loading and unloading the wheelchair without assistance. In the UK, when respondents referred to independent use of transportation, they allowed for someone else to load and unload the chair in the trunk (or boot) of the car. Given the relatively high cost of motoring in the UK, there is a preference for smaller cars, many of which would not accommodate even the most compact folded wheelchair. However, of greater interest was the fact that the definition of ‘independence’ may have differed from country to country: in the USA and Canada, it meant without any form of human assistance, while in the UK it allowed for assistance with peripheral functions, such as loading and unloading the chair. Is it true to say that British people are more tolerant of some degree of *interdependence*? These discussions are better left to the sociologists and cultural anthropologists, however it would be interesting to better understand this notion of independence that is so pervasive in the rehabilitation and disability communities.

The current study also found that the British participants were less likely to report that they felt they were ageing more quickly than their non-disabled contemporaries. There are at least three ways of looking at this finding. First, it could be that people with spinal cord injuries are ageing more slowly in the UK than in either the USA or Canada. Second, it could be that non-disabled people in the UK are ageing more quickly than those in Canada or the USA. Third, and most likely, it could be that comparisons of this type are less meaningful in the UK than they are in North America. This latter option suggests that there may be a different view of ageing in the UK than there is in North America. Are Britons less enamoured of all things young and beautiful than North Americans? Or is it simply the famous British stoicism that resists this sort of comparison of the troubles of one relative to another? It should be noted that the British participants were significantly older and had lived with their disabilities longer than the other two nationalities. Also, the British sample had significantly fewer people with quadriplegia.

Conclusion

The study has shown that there are significant international differences in the ageing experiences of people with spinal cord injuries, even between three countries with well-developed and advanced systems of rehabilitation and follow-up. What this study does not allow us to do is to provide definitive information about the relationships between patterns of care and these outcomes of interest. For example, we are aware that there are distinct preferences for particular methods of bladder management in the three centres studied, and yet no differences in urinary tract infections was found. Results such as these warrant further consideration and research to assist practitioners to anticipate long-term results of treatment and lifestyle decisions.

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References

- 1 DeJong G. Primary care for people with disabilities: An overview of the problem. *Arch Phys Med Rehabil* 1997; **76** (Suppl): S2–S8.
- 2 McKinley WO, Jackson AB, Cardenas DD, DeVivo MJ. Long-term medical complications after traumatic spinal cord injury: a regional model systems analysis. *Arch Phys Med Rehabil* 1999; **80**: 1402–1410.
- 3 Meyers AR, Bisbee A, Winter M. The 'Boston model' of managed care and spinal cord injury: A cross-sectional study of outcomes of risk-based, prepaid managed care. *Arch Phys Med Rehabil* 1999; **80**: 1450–1456.
- 4 Stineman M. The story of function-related groups – Please first do no harm. *Arch Phys Med Rehabil* 2001; **82**: 553–557.
- 5 Jacob KS, Zachariah K, Bhattacharji S. Depression in individuals with spinal cord injury: methodological issues. *Paraplegia* 1995; **33**: 377–380.
- 6 Kemp BJ, Krause JS, Adkins RA. Depressive symptomatology among African-American, latino, and Caucasian participants with SCI. *Rehabil Psychol* 1999; **44**: 235–247.
- 7 Krause JS. Aging after spinal cord injury: an exploratory study. *Spinal Cord* 2000; **38**: 77–83.
- 8 Krause JS, Coker J, Charlifue S, Whiteneck GG. Health behaviors among American Indians with spinal cord injury: Comparison with data from the 1996 behavioral risk factor surveillance system. *Arch Phys Med Rehabil* 1999; **80**: 1435–1440.
- 9 Krause JS. Aging and life adjustment after spinal cord injury. *Spinal Cord* 1998; **36**: 320–328.
- 10 Krause JS, Crewe NM. Concurrent and long-term prediction of self-reported problems following spinal cord injury. *Paraplegia* 1990; **28**: 186–202.
- 11 McColl MA, Arnold C, Charlifu S, Gerhart K. Social support and aging with a spinal cord injury: Canadian and British experiences. *Top Spinal Cord Inj Rehabil* 2001; **63**: 83–101.
- 12 Neugarten BL, Havighurst RJ, Tobin SS. The measurement of life satisfaction. *J Gerontol* 1961; **16**: 134–143.
- 13 Wood V, Wylie ML, Sheafor B. An analysis of a short self-report measure of life satisfaction: Correlation with rater judgments. *J Gerontol* 1969; **244**: 465–469.
- 14 Radloff LS. The CESD scale: A selfreport depression scale for research in the general population. *Appl Psychol Measure* 1977; **1**: 385–401.
- 15 Noh S, Posthuma B. Physical disability and depression: A methodological consideration. *Can J Occupat Ther* 1990; **87**: 9–15.
- 16 Rodin G, Voshart K. Depression in the medically ill: An overview. *Am J Psych* 1986; **143**: 696–705.
- 17 Whiteneck GG, Charlifue SW, Gerhart KA, Overholser JA, Richardson GN. Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Phys Med Rehabil* 1992; **73**: 519–526.
- 18 Batavia AI, DeJong G. Disability, chronic illness and risk selection. *Arch Phys Med Rehabil* 2001; **82**: 546–552.
- 19 Glass CA. Spinal cord injury: Impact and coping. Leicester, UK: *British Psychological Society* 1999: 142–143.
- 20 Lawson J. Disability discrimination: The Disability Discrimination Act 1995. *Personal Injury* 1996; **3**: 140–155.
- 21 Holcomb LO. Community reintegration and chronic spinal cord injury. *SCI Nursing* 2000; **17**: 52–58.
- 22 Teasell R, Allatt D. Managing the growing number of spinal cord-injured elderly. *Geriatrics* 1991; **466**: 83–85, 89.
- 23 Tepperman P. Primary care after spinal cord injury. *Postgrad Med* 1989; **86**: 211–218.
- 24 Pruitt SD, Wahlgren DR, Epping-Jordan JE, Rossi AL. Health behaviour in persons with spinal cord injury: Development and initial validation of an outcome measure. *Spinal Cord* 1998; **36**: 724–731.
- 25 Bernardez SJ, Brown LT, Nora JT, Steverman D. Primary care for the spinal cord injured patient. *Am Acad Phys Assist* 1994; **7**: 526–531.
- 26 Francisco GE, Chae JC, DeLisa JA. Physiatry as a primary care specialty. *Am J Phys Med Rehabil* 1995; **74**: 186–192.