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ORIGINAL ARTICLE

The relationship between fatigue and participation in spinal cord injury

EM Smith[1,2,3,4], B Imam[1,2,3,4], WC Miller[2,3,4,5,6], ND Silverberg[3,4,6,7], HA Anton[3,4,6,7], SJ Forwell[4,5] and AF Townson[3,4,6,7]

Study design: Cross-sectional national survey.
Objectives: To explore the association between fatigue and community participation frequency and provide an adjusted model of the relationship including important covariates.
Setting: Canada; Community.
Methods: Data were obtained from the Rick Hansen Spinal Cord Injury Registry Community Survey. We used multi-variable regression analyses with hierarchical backward elimination, including variable specification, interaction assessment and confounding assessment. Variables with statistically significant correlation with the primary-dependent variable (participation) were included for modeling.
Results: The crude model of association between fatigue and participation accounted for 7.2% of the variance in participation scores. The full model with all *a priori* selected variables accounted for 25.1% of variance in participation scores. The adjusted model, including the identified confounders (pain, depressive mood, comorbidities and level of injury), accounted for 21.1% of variance in participation scores. Depressive mood variables had the highest standardized beta coefficients, reflecting the largest contribution to this model.
Conclusion: Fatigue has a statistically significant negative association with participation for individuals with spinal cord injury, when controlling for pain, depressive mood, comorbidities and level of injury. Multifaceted clinical interventions and research addressing fatigue, pain and depressive symptoms are warranted.
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INTRODUCTION

Fatigue, characterized as ongoing and extreme tiredness, is commonly experienced following spinal cord injury (SCI).[1–3] This experience of fatigue can be distinguished from acute tiredness, which is commonly associated with mental or physical exertion.[3] Although there are few estimates of the prevalence of fatigue in SCI, there is evidence to suggest that this is a common concern.[1–6] In fact, a study of an outpatient sample of individuals with SCI reported that 57% experienced fatigue, which interfered with daily function.[7] The experience of fatigue was found to be exacerbated by other factors (for example, spasticity, completeness of injury, medication use).[7]

Despite the prevalence and importance of fatigue to individuals after SCI, there is little research exploring the consequences of fatigue. The link between fatigue and quality of life has been reported;[3] however, associations with other outcomes, such as participation,[8] have limited evidence. As research indicates that individuals with SCI are at risk of participation limitations,[9] participation is an important outcome for this population.

Fatigue is significantly associated with additional comorbidities following SCI, including pain and depression.[10] This pain-depression-fatigue triad is commonly reported clinically and in the literature as a complex multifactorial relationship that impacts function for individuals after SCI[11] and has been demonstrated to be associated with factors such as physical activity.[5] Pain[8] and depression[12] have each been shown to be associated with participation in community activities, an outcome recognized for its relationship to overall health[13] and quality of life.[14]

The relationships between factors are complex, and, it is clear it would be difficult to consider the association between participation and a single factor (that is, fatigue), without considering the influence of related factors. Therefore, the objective of our work is to explore the association between fatigue and community participation frequency controlling for important covariates such as pain and depressive mood. We hypothesize that a model including fatigue will account for significant variation in community participation, while controlling for important covariates. We also expect pain and depressive mood to have a significant association with both fatigue and community participation.

[1]Faculty of Medicine, Graduate Program in Rehabilitation Sciences, University of British Columbia, Vancouver, British Columbia, Canada; [2]GF Strong Rehabilitation Research Lab, Vancouver, British Columbia, Canada; [3]Rehabilitation Research Program, Vancouver Coastal Health Research Institute, Vancouver, British Columbia, Canada; [4]International Collaboration on Repair Discoveries, Vancouver, British Columbia, Canada; [5]Faculty of Medicine, Department of Occupational Sciences and Occupational Therapy, University of British Columbia, Vancouver, British Columbia, Canada; [6]GF Strong Rehabilitation Centre, Vancouver Coastal Health Authority, Vancouver, British Columbia, Canada and [7]Division of Physical Medicine and Rehabilitation, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada
Correspondence: Dr WC Miller, Faculty of Medicine, Department of Occupational Science and Occupational Therapy, University of British Columbia, T325-2211 Wesbrook Mall, Vancouver, British Columbia V6T 2B5, Canada.
E-mail: bill.miller@ubc.ca
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MATERIALS AND METHODS

Data source, survey design and participants

We obtained data from the Rick Hansen Spinal Cord Injury Registry (RHSCIR) Community Survey, obtained between May 2011 and August 2012. This cross-sectional survey was a follow-up survey with participants who were included in the RHSCIR and collected data on the needs, service utilization and outcomes of 1549 Canadians with SCI. Survey respondents had a SCI caused by trauma or disease, had lived in the community for at least 1 year after discharge from hospital and were $\geqslant 18$ years of age. The survey was developed by a Canadian collaboration of researchers, clinicians, service providers and individuals with SCI.[15] Methodology of the survey is described in detail in a previous publication by Noreau *et al.*[16]

Measures

We selected the following RHSCIR survey variables to address the research objective.

Community participation. Community participation is defined in the survey as 'any level of involvement in regular daily activities at home and in the community' with individual items linked to participation concepts in the ICF.[15] Participation was measured by asking respondents to rate their interest and degree of participation in 26 items, such as preparing meals, maintaining physical health by exercising and carrying out family responsibilities. The response options were as follows: 'No, and I don't want to do it (not applicable)' 'No, but I would like to do it (0)' 'Yes, but less than I want (1)' 'Yes, as much as I want to (2)'. The sum of response scores for applicable items (those the individual was interested in) for each individual was calculated and divided by the maximum score the participant could have for the applicable items. This score was multiplied by 100 to derive a percent total participation score for each individual and varied from 0 to 100%, with higher percentages indicating higher participation. Total participation score reflects the degree to which individuals were able to participate in the activities that were of interest to them. A score of 100% would indicate that the individual was able to participate in all activities that they were interested in to the level that they desired.

Fatigue. Fatigue was defined in the survey as 'constantly feeling tired, having low energy, and feeling listless'. It was measured using a single question that asked individuals to indicate the frequency with which they had experienced fatigue over the past 12 months. The ordinal response options varied from 0 to 3: never/once or a few times a year (0), a few times a month (1), a few times a week (2) and every day (3).

Potential covariates. Covariates refer to secondary variables that affect the relationship between the dependent and the independent variables, including both confounders and effect modifiers. On the basis of evidence in the literature, theory and our *a priori* hypotheses, the following demographic and clinical variables were explored in the initial data analysis: age,[17] sex,[17] relationship status,[12] education,[18] level (cervical versus thoracic and lumbosacral)[17] and completeness of injury,[18] years since injury,[18] comorbidities (a list of 9 chronic conditions based on mapping self-reported health conditions from the RHISCIR Survey to the items of the Functional Comorbidity Index:[19] arthritis, osteoporosis, lung disease, stroke, diabetes, upper gastrointestinal disease, cancer, liver disease and kidney disease),[20] employment status,[21] household income,[21] ongoing and intense pain,[22] and depressive mood[12] lasting more than 2 weeks and interfering with daily life. Pain and depressive mood were measured by single questions that asked 'in the past 6 months, have you experienced this problem?' The ordinal response options for pain were as follows: never/once or a few times a year (0), a few times a month (1), a few times a week (2) and every day (3). The response options for depressive mood were as follows: none or a little of the time (0), some of the time (1) and most or all of the time (2).

Data analyses

Demographic information is presented as frequency, percentage or mean and standard deviation. Ordinal responses were re-categorized using dummy variables with the lowest level (0) as the reference category. For variables that were potentially confounding, we calculated the association between participation scores and potential covariates to determine significance ($P<0.05$). Multiple linear regression analyses with hierarchical backward elimination were used to determine the magnitude of association between fatigue and participation while controlling for confounding variables. The results obtained from backward elimination were verified through forward selection. All assumptions for multiple linear regression were met.

Participation regression on fatigue. We used Kleinbaum's three-stage modeling to provide an adjusted estimate of the relationship between fatigue and participation while controlling for covariates.[23]

Stage 1 (variable specification). Fatigue variables (fatigue a few times a month, fatigue a few times a week, fatigue every day) were entered into the model as dummy variables, representing the independent variable of interest. From the list of 12 covariates, only continuous variables with a minimum correlation of $r=|0.10|$ with participation or categorical variables that showed a statistically significant difference ($P<0.05$) in the participation scores for each of the fatigue response options were included.[23] We tested all included variables for collinearity, defined as a bivariate relationship of a magnitude of $\geqslant 0.70$ between the independent variables and with variation inflation factor values $\geqslant 10$.[23] Unstandardized coefficients (b) and 95% confidence intervals, standardized coefficients (β), standard errors of mean (s.e.m.) and percentage of variance explained (r^2) were calculated for the regression model.

Stage 2 (interaction assessment). Six interaction terms were considered: fatigue a few times a month × depressive mood some of the time; fatigue a few times a week × depressive mood most or all of the time; fatigue every day × depressive mood most or all of the time; fatigue a few times a month × pain a few times a month; fatigue a few times a week × pain a few times a week; fatigue every day × pain every day. All interaction terms were entered into the full model, and we retained interaction terms that were statistically significant ($P\leqslant 0.05$).[23]

Stage 3 (confounding assessment). We investigated potential confounders to determine whether the association between fatigue and participation remained statistically significant in the presence of those variables. If the estimate of the unstandardized beta coefficient of each of the fatigue variables changed by $\geqslant 10\%$ when the variable was present compared with when it was absent, the variable was considered a confounder and was kept in the adjusted model. All assumptions of multiple linear regression were tested for the adjusted model.[23]

RESULTS

A total of 1549 participants completed the survey, and all data were included (no missing data). Survey respondents represented all provincial regions in Canada (Atlantic, Quebec, Ontario, Prairies and British Columbia). Relevant demographic variables are provided in Table 1, and further information regarding the sample may be found in results published by Noreau *et al.*[16] Mean total participation score was 75.7% (19.0). More than half the sample (53.8%) experienced fatigue at least a few times a month for the past 12 months, and 18.6% of those experienced it every day. Table 1 provides descriptive statistics for analysed variables (mean and s.d.).

Stage 1 (variable specification) and stage 2 (interaction assessment)

On the basis of the correlation coefficients and *P*-values of the association between covariates and the dependent variables (Table 1), the following variables were included in the analyses: independent variable of interest (fatigue) and potential confounders (relationship status, education level, level of injury, years since injury, comorbidities, vocational status, household income, pain and depressive mood). Estimates of the crude model of the association between fatigue and participation are found in Table 2.

Table 1 Descriptive summary and correlations with/mean difference in participation ($n = 1549$)

Variable	*Statistics*		*Correlation with/mean difference in participation*	
	Mean (s.d.)	*Frequency (%)*	r *(Continuous vars.)*	*Eta squared for ANOVA*[b]
Dependent variable				
Total participation score (0–100%)	75.7 (19.0)		1.00	
Main independent variable				
Fatigue (0–3)				
Never/once or few times a year (0)		693 (44.7)		0.08**,[a]
A few times a month (1)		289 (18.7)		
A few times a week (2)		256 (16.5)		
Every day (3)		288 (18.6)		
Potential covariates:				
Age (years)	49.6 (13.9)		0.03	
Sex (males)		1041 (67.2)		0.0007
Relationship status				
Married/common law		797 (51.5)		0.01**,[a]
Single/separated/divorced/widowed		737 (47.6)		
Education level				
Less than HS		216 (13.9)		0.01**,[a]
HS/some college/certificate		818 (52.8)		
Bachelor's and higher		403 (26.0)		
Level of injury				
Cervical		656 (42.3)		0.06**,[a]
Thoracic/lumbosacral		892 (57.6)		
Completeness of injury				
Incomplete		1033 (66.7)		0.001
Complete		516 (33.3)		
Years since injury	18.5 (14.3)		0.12*,[a]	
Comorbidities (0–9)	1.0 (1.1)		−0.14*,[a]	
Vocational status				
Unemployed/retired		703 (45.4)		0.04**,[a]
Unpaid/volunteer/student		416 (26.9)		
Paid work		429 (27.7)		
Household income				
<30 000		400 (25.8)		0.05**,[a]
30 000–49 999		253 (16.3)		
50 000–79 999		276 (17.8)		
80 000+		318 (20.5)		
Pain (0–3)				
Never/once or few times a year (0)		434 (28.0)		0.03**,[a]
A few times a month (1)		108 (7.0)		
A few times a week (2)		144 (9.3)		
Every day (3)		834 (53.8)		
Depressive mood (0–2)				
None or little of the time (0)		998 (64.4)		0.11**,[a]
Some of the time (1)		361 (23.3)		
Most or all of the time (2)		177 (11.4)		

Abbreviations: ANOVA, analysis of variance; HS, higher secondary.
[a]Included for modeling.
[b]Eta squared: between group sum of squares/total sum of squares. Eta squared effect sizes with magnitudes of ⩽0.01 were considered small, between 0.06 and 0.137 were medium and ⩾0.138 were large.
*$P<0.05$; **$P<0.01$.

Table 2 Regression models to establish the adjusted estimate of the relationship between fatigue and participation ($n=1549$)

Variables	*Crude model*				*Full model*				*Final adjusted model with confounders*			
	b	*s.e.m.*	*95% CI*	*β*	*b*	*s.e.m.*	*95% CI*	*β*	*b*	*s.e.m.*	*95% CI*	*β*
Fatigue[a]												
A few times per month	−5.45*	1.28	−8.0, −2.9	−0.11	−3.20**	1.19	−5.5, −0.9	−0.07	−2.92***	1.21	−5.3, −0.5	−0.06
A few times per week	−9.06*	1.34	−11.7, −6.4	−0.18	−3.78**	1.29	−6.3, −1.3	−0.07	−3.93**	1.31	−6.5, −1.3	−0.08
Every day	−13.22*	1.28	−15.7, −10.7	−0.27	−5.23*	1.32	−7.8, −2.6	−0.11	−5.78*	1.34	−8.4, −3.2	−0.12
Relationship[b]												
Single/separated/divorced/widowed					1.63	0.92	−0.2, 3.4	0.04				
Education[c]												
HS/some college/certificate					2.31***	1.11	0.1, 4.5	0.06				
Bachelor's and higher					1.97	1.3	−0.6, 4.5	0.05				
Level of injury[d]												
Thoracic/lumbosacral					10.32*	0.86	8.6, 12.0	0.27	10.56*	0.88	8.8, 12.3	0.28
Years since injury					0.12*	0.03	0.06, 0.2	0.09				
Comorbidities					−1.92*	0.42	−2.7, −1.1	−0.11	−1.52*	0.4	−2.3, −0.7	−0.09
Vocational status[e]												
Unpaid/volunteer/student					2.23***	1.05	0.2, 4.3	0.05				
Paid work					4.74*	1.1	2.6, 6.9	0.11				
Income[f]												
30 000–49 999					1.93	1.24	−0.5, 4.4	0.04				
50 000–79 000					3.58*	1.24	1.2, 6.0	0.07				
80 000+					5.42*	1.3	2.9, 8.0	0.12				
Pain[g]												
A few times a month					−1.12	1.8	−4.7, 2.4	−0.02	−2.88**	0.9	−4.6, −1.1	−0.08
A few times a week					1.02	1.61	−2.1, 4.2	0.02				
Every day					−2.02***	1.02	−4.0, −0.02	−0.05				
Depressive mood[h]												
Some of the time					−7.76*	1.07	−9.9, −5.7	−0.2	−8.33*	1.09	−10.5, −6.2	−0.19
Most or all of the time					−12.13*	1.51	−15.1, −9.2	−0.2	−14.19*	1.52	−17.2, −11.2	−0.24
Adjusted r^2	7.20%				25.10%				21.10%			

Abbreviations: β, standardized coefficients; b, unstandardized coefficients; CI, confidence interval; HS, higher secondary; s.e.m., standard error of mean.
*$P<0.0001$; **$P<0.005$; ***$P<0.05$ level.
Reference categories:
[a]Fatigue never/once or a few times a year.
[b]Married/common law.
[c]Less than HS.
[d]Cervical levels of injury.
[e]unemployed/retired.
[f]<30 000.
[g]Pain never/once or few times a year.
[h]Depressive mood none or little of the time.

Stage 3 (confounding assessment)

The full model with all variables selected *a priori* accounted for 25.1% of participation scores. The backward elimination showed that exclusion of depressive mood some of the time and depressive mood most/all of the time, pain every day, thoracic/lumbosacral level of injury and comorbidities variables changed the estimates of fatigue variables by more than 10%; therefore, these were considered confounding. The adjusted model reduced the Beta estimates of fatigue dummy variables: by 46% for 'fatigue a few times a month' ($\beta=-0.06$; $P<0.05$); by 57% for 'fatigue a few times a week' ($\beta=-0.08$; $P<0.005$); and by 56% for 'fatigue every day' ($\beta=-0.12$; $P<0.0001$) (Table 2). The adjusted model explained 21.1% of the variance in participation. Among the confounders, the largest influences on participation scores were as follows: 'having depressive mood most or all of the time' ($\beta=-0.24$; $P<0.0001$) compared with having depressive mood none or little of the time; and having thoracic/lumbosacral levels of injury ($\beta=0.28$; $P<0.0001$) compared with having cervical injuries.

DISCUSSION

In the crude model, fatigue accounted for 7.2% of variance in participation scores, making fatigue an important variable in the

model. When including additional variables, notably depressive mood, pain, level of injury and comorbidities, the adjusted model accounted for 21.1% of the variance in participation scores. The influence of these confounding variables suggests that the relationship between fatigue and participation may be altered by the presence of additional conditions. Regardless, fatigue remains an important predictor of participation scores.

Consistent with published literature and our hypotheses, fatigue, years since injury, comorbidities, level of education, vocational status, household income, relationship status, level of injury, pain and depressive mood all had a statistically significant relationship with participation. However, age and sex did not reach significance in this sample, despite significant association in other studies.[17]

The mean participation score of 75.7% suggests that the survey respondents are largely able to engage in activities that are important to them. The high participation scores may reflect the method used to calculate participation, as the survey only measures the extent to which individuals participate in activities that they are interested in. As a result, this does not provide an indication of participation in all areas of life, as individuals were not scored on those areas of participation in which they had no interest. Fatigue, pain and depression may all have a role in the interest an individual has for participation. For individuals with depressive mood, the high scores may be reflective of symptomatic amotivation, which could minimize the desired areas of participation. Within our sample, 11.4% of respondents indicated that they experienced depressive mood most or all of the time, within the range of prevalence of depression in SCI research.[24]

Depression has been associated with fatigue in SCI,[10] and therefore it is not surprising that depressive mood is an important covariate. In fact, fatigue is listed as one of the 9 potential symptoms considered in the diagnosis of major depressive disorder.[25] Although prevalence estimates for depression in SCI vary, it is a common concern that has the potential to be significantly associated with participation. It is unclear whether depression has a unidirectional effect on fatigue (that is, depression causes fatigue) or whether the relationship is more complex. For example, a recent study on the relationship between mobility device usage and depressive symptomology in SCI found pain and fatigue to mediate the relationship,[26] supporting the concept of a more complex relationship between these factors. Regardless of direction of the effect, the associations of both depression and fatigue with participation are notable and speak to the need for research focused on treatment for depression and fatigue and the resultant effect on participation.

Consistent with literature on fatigue and participation, pain is a confounding variable. This is consistent with research demonstrating that pain is common in SCI[27] and is associated with fatigue[11] and participation.[7] Although pain is an important predictor of participation, the relationship between pain and fatigue has not been fully explored. Further research to investigate the relationship between pain, fatigue and participation in community activities for individuals with SCI is warranted. Given previous attention paid to the pain-fatigue-depression symptom cluster in other populations, notably individuals with cancer[28] or post-stroke,[29] it is not surprising to see a relationship between these factors in this study. The directional nature of this cluster remains unclear and presents an opportunity for further interventional research to determine the nature of this phenomenon.

Level of injury was a confounding variable, consistent with evidence that the level of injury is associated with both participation[17] and fatigue.[30] Research to determine the impact of the level of injury would help further understand the factors related to fatigue in SCI. This knowledge could be used clinically to identify those at risk of increased fatigue and reduced participation.

Overall, our model demonstrates that fatigue has a statistically significant negative association with participation, even in the presence of other variables. The model including fatigue, pain, comorbidities, depressive mood and level of injury accounts for 21.1% of the variance in participation. Among these variables, level of injury accounted for the largest percentage of variation in participation, followed by depressive mood and fatigue every day.

These results have relevance to rehabilitation and community care in SCI, particularly the need for clinicians to be aware that fatigue is associated with engagement in participation. Future clinical research should focus on how to improve participation among individuals living with SCI, through multifaceted intervention to reduce depressive symptoms, fatigue and pain.

LIMITATIONS

Although the RHSCIR Community Survey has a large sample and was advertised through a variety of means, we are unable to assume that this sample is representative of all Canadians residing in the community with SCI. A detailed description of the recruitment methodology and sample demographics has been published elsewhere,[16] and we have provided basic demographic information in this paper. It does not capture those living in residential care. Study measures were theoretically linked to ICF constructs but have unknown psychometric properties. Although there are validated measures for fatigue, pain and depression, which would provide greater strength to this analysis, none of these were used in the RHSCIR Community Survey. We have provided an explanation of how scores were reached for each of the variables. As many variables were measured by a single question, they may not capture the complexity of the construct (for example, depressive mood, fatigue). These variables would be better measured with established outcome measures that offer a more nuanced understanding of each of the concepts. As this study reports cross-sectional correlations, it is impossible to determine the directional effect of fatigue on participation. As a result, we are unable to identify whether fatigue and other covariates are responsible for reductions in participation or whether this is a more complex relationship. Further experimental research addressing conditions such as fatigue, pain and depressive mood would provide additional information to determine the impact of these conditions. In addition, participation was measured based on an individual's interest in particular activities and may therefore not reflect participation in all areas of daily life, as identified by the ICF. Because indicating non-participation in an activity due to low interest did not count toward the total participation score, we may also be underestimating the magnitude of the association of depressive mood with participation.

CONCLUSION

In the model that controls for pain, depressive mood, level of injury and comorbidities, fatigue continues to have a statistically negative association with participation for individuals with SCI. Future research should focus on establishing a relationship between fatigue and participation using validated tools to strengthen the preliminary results found in this cross-sectional survey. In addition, interventional studies will help determine whether participation can be improved by a multifaceted intervention including management of depressive mood, fatigue and pain.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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