

ORIGINAL ARTICLE

Fatigue and spinal cord injury: a qualitative analysis

KW Hammell¹, WC Miller^{1,2,3,4}, SJ Forwell^{1,2,3,5}, BE Forman⁶ and BA Jacobsen⁶

¹Department of Occupational Science and Occupational Therapy, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada; ²CanDo Research Unit, University of British Columbia, Vancouver, British Columbia, Canada; ³International Collaboration on Repair Discovery, University of British Columbia, Vancouver, British Columbia, Canada; ⁴G.F. Strong Rehabilitation Research Lab, Vancouver, British Columbia, Canada; ⁵Multiple Sclerosis Clinic, University of British Columbia, Vancouver, British Columbia, Canada and ⁶British Columbia Paraplegic Association, Vancouver, British Columbia, Canada

Objectives: To explore experiences of fatigue among people with spinal cord injuries (SCIs) and factors perceived to contribute to fatigue.

Setting: Kelowna, Prince George, Vancouver and Victoria, British Columbia, Canada.

Study design: Collaborative, qualitative methodology.

Methods: Four focus groups were undertaken simultaneously with a total of 29 participants, comprising a purposive sample of men and women: 21 people with complete and incomplete SCI of high and low tetraplegia and paraplegia, 2 family members, 2 assistants and 4 occupational therapists. Interpretive analysis was grounded in the themes identified in the data.

Results: Fatigue was perceived to have cognitive, emotional and physical dimensions and to exert a profound effect on the lives of many people with SCI, such that pleasurable activities were often eschewed to enable the accomplishment of more mundane tasks. Factors most consistently associated with fatigue were pain, depression and hopelessness, side effects of medications, poor quality sleep, spasticity, poor posture, diet, and the effort required to accomplish routine and self-care tasks.

Conclusions: Fatigue is a complex phenomenon, interlinked with pain, depression and hopelessness that significantly diminishes the quality of life following SCI. Further research is required to provide greater understanding of this issue and to determine appropriate and comprehensive forms of intervention.

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Introduction

Although fatigue affects many people with spinal cord injury (SCI),^{1–4} it is a poorly understood phenomenon. Some researchers report significantly worse fatigue among those with complete tetraplegia^{1,2,5} whereas others equate the greatest fatigue with incomplete lesions and paraplegia.^{6,7} Fatigue is often associated with advancing age and the length of time lived with SCI,^{1,2,5,8} yet fatigue has also been reported to be greatest among younger people and those with a short duration of disability.⁹

A recent literature review⁵ identified two kinds of fatigue following SCI: ‘muscular fatigue’, characterized as a physiological phenomenon of paralyzed muscles; and ‘chronic fatigue’, associated with ‘aging, physiological, and psychological deconditioning’ contributing to decreased quality of life. From

their clinical experience the review’s authors noted that cognitive complaints (attention, concentration and memory) accompany ‘chronic fatigue’ in SCI, yet contended that prevention depends on fighting physical deconditioning. This overlooks the identified linkages between overuse and fatigue^{1,4,8} and sidesteps the reality that fatigue is not activity-specific (and thus related to specific muscle weakness).¹⁰

Chart review at the GF Strong Rehabilitation Centre in Vancouver, British Columbia (BC) found that 57% of outpatients with SCI of greater than 1-year duration reported fatigue of sufficient severity to interfere with function.⁷ Fatigue is often characterized as a mismatch between the energy required to perform routine tasks and the energy available to do the tasks. Fatigue magnifies the physical consequences of SCI by further compromising the ability to participate in life activities,² yet little is known about the nature, course or treatment of fatigue among people with SCI, suggesting that research is ‘urgently needed’.⁴

The current study, undertaken collaboratively by researchers from the University of British Columbia and the British

Correspondence: Dr WC Miller, Department of Occupational Science and Occupational Therapy, University of British Columbia, T325-2211 Wesbrook Mall, Vancouver, British Columbia, Canada V6T 2B5.

E-mail: bcmiller@telus.net

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Columbia Paraplegic Association (BCPA) Peer Program, was designed to explore the experience of, and contributors to fatigue following SCI and identify successful management strategies and appropriate interventions. This paper addresses the first aspect of the study: an analysis of the experience of, and contributors to fatigue among people with SCI.

Methodology

The exploratory nature of the study required a qualitative approach. Moreover, in response to appeals for researchers to enhance the usefulness and relevance of their work by collaborating more closely with people living with disabilities, for example see White,¹¹ the research was planned, undertaken, analyzed and reported by a collaborative team of academics and SCI peer counselors.

Method

Focus groups were deemed the most appropriate and efficient method to explore the research topic. Focus groups are a form of group interview that capitalize on communication between research participants to generate data, enabling participants to identify their priorities, explore those issues they deem important and develop their own analysis of a common experience.¹² To enable a diversity of rural and urban experiences, simultaneous focus groups were held at four sites across BC: Kelowna, Prince George, Vancouver and Victoria. Linked by audiovisual connections, the combined groups discussed their findings at prearranged times during the day.

Participants

The researchers identified potential participants based on their knowledge and experience of, and interest in SCI and fatigue. Purposive sampling was undertaken to include a broad range of perspectives: community-dwelling men and women with traumatic SCI of various levels and durations (>1 year), of a range of ages (>18 years), with complete and incomplete lesions, both employed and unemployed and with various domestic situations (single, married, partnered and with/without children). Individuals with other serious medical conditions (for example rheumatoid arthritis, Parkinson's disease) that might impact fatigue were excluded, as were people with a head injury or dementia. Participants were required to be able to read, speak and understand English. Close family members and assistants were also invited to participate, in addition to some occupational therapists identified as having particular knowledge of fatigue.

Potential participants were sent a letter explaining the nature and purpose of the study and inviting interested people to contact either their regional BCPA representative or the research assistant. People who agreed to participate were sent a package of information that included background information defining and discussing fatigue, an abbreviated summary of an energy conservation programme¹³ (to provide a basis for discussion about

appropriate interventions), a copy of the questions to be discussed in the focus groups, a demographic questionnaire and a copy of the Fatigue Severity Scale (FSS).¹⁴ The FSS is a widely used measure of fatigue in neurologic disorders that has been shown to have acceptable reliability and validity for use in studies of SCI.¹⁵ The range of possible scores on the FSS is 0–7, with a cutoff score >4 indicating severe fatigue.

Data collection

Table 1 summarizes the participants' demographic information. The focus groups were guided by a series of questions that had been provided to the participants in advance (to enable reflection and considered responses). Those questions of relevance to this paper were:

- What is your experience with fatigue in SCI?
- What contributes to fatigue in SCI?

The sessions were audiotaped and the tapes transcribed verbatim. Flip charts were used during the sessions to document the issues deemed important by the study participants. Fieldnotes were also compiled at each location by the focus group facilitator and an assistant.

Ethics

Ethical approval was granted by the university ethics review board. All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research. Every participant was given an honorarium of \$100 to acknowledge their time (approximately 6 h) and any travel expenses.

Data analysis

The initial phase of analysis involved four researchers amassing data from the transcripts, flip charts and fieldnotes from each of the four locations. The second phase, undertaken by one researcher, entailed combining the results of the four groups by identifying common themes, and listing these with supportive data. This analysis was reviewed by the research team.

Findings

A total of 29 people participated in the study: 21 people with SCI, 2 family members, 2 assistants and 4 occupational therapists.

Fatigue Severity Scale

Valid FSS scores were obtained from 16 SCI participants. The mean = 4.65 (s.d. = 1.42), range = 2.22–7 and median = 4.6.

Qualitative results

The focus groups addressed specific questions and the findings are presented as responses to these questions, with representative comments. To conserve time, participants were encouraged to 'ditto' those experiences that reflected their own.

Table 1 SCI participants ($n = 21$)

<i>Age</i>	
Range	26–69 years
Mean (s.d.)	50 (11.80)
<i>Gender</i>	
Men	12
Women	9
<i>Level of SCI</i>	
C3–5	$n = 4$
C6–7	$n = 4$
T1–5	$n = 3$
T6–12	$n = 9$
L1	$n = 1$
<i>ASIA scores</i>	
ASIA A	9
ASIA B	2
ASIA D	2
Do not know	6
Missing data	2

Abbreviations: ASIA, American Spinal Injury Association; SCI, spinal cord injury.

The experience of fatigue following spinal cord injury

It was apparent that not everyone with a SCI experiences fatigue, prompting the following suggestion: ‘Maybe a research project for another time could be: If 60% of people with spinal cord injury experience this fatigue (and) 40% don’t: Why? What’s going on here?’ (Prince George, 987).

For many, however, fatigue was debilitating: ‘it is just too tiring. How can I face this day?’ (Vancouver, 296) and was perceived to have cognitive, emotional and physical dimensions.

The cognitive dimension was characterized by a sense of being overwhelmed, and of being exhausted due to the need to plan everything and use the body in a different way. ‘I don’t think I’m depressed, but there’s real fatigue and it’s not physiological fatigue...it’s a general being overwhelmed, being just worn out’ (Kelowna, 3102); ‘every time I go to do something I have to...map out in my head what I have to do, and I am so mentally exhausted from 8 years of doing this’ (Vancouver, 58).

The emotional dimension of fatigue was explained as follows: ‘I get frustrated because I can’t do things...but it is not because I am tired and I can’t do—it is because I physically can’t do. That leads me to depression, which may then enter into fatigue’ (Victoria, 762). Several participants observed that because both the SCI and fatigue are also wearing for partners, this adds to the stress experienced by the person with SCI: ‘It takes me forever to get going, and she has to wait, and all these things cause me fatigue—worrying and thinking about her’ (Vancouver, 346).

Fatigue was also described as having a physical dimension, identified by weakness, the need to change position, relieve muscle tension and cope with paralyzed limbs, pain and unpleasant physical sensations. ‘I experience fatigue. I have pins and needles in my legs, and I am sitting on pins and needles all day long...the sensation fatigues me to a point where I have to lie down’ (Victoria, 54); ‘The body cannot

complete what you want to do’ (Kelowna, 635). Physical fatigue might demand immediate relief: ‘with my husband, it’s instant...if he doesn’t sit down right then wherever we are, he’ll collapse’ (Kelowna, 842).

Fatigue dictates that energy is only available for certain activities: ‘Once you start experiencing fatigue, you are spending all your energy on things that you have to do...so you don’t get to enjoy anything, so then motivation goes down...and it is just a vicious cycle’ (Victoria, 631). ‘The first thing that goes are the recreation or the fun things...it only helps to add to the negative feelings because that is the stuff that you want to do’ (Vancouver, 165). Reduction in the ability to engage in pleasurable activities was described as leading to a cycle of decreased motivation, increased depression and increased fatigue. Particularly troubling, was the revelation that in striving to minimize the impact of their impairment on other family members, people with SCI may encourage their partner and children to go out without them and even to plan holidays without them: ‘We are trying to plan a holiday right now and (my husband) says “No, you guys go—it’ll be so much better”’ (Vancouver, 356).

Contributors to fatigue in SCI

Many factors were perceived as contributing to fatigue (listed in Table 2 in priority order). The assumption that pain, fatigue and depression can be separated and assessed in isolation from each other underpins much research, yet many study participants insisted that this was not their experience: ‘Is there a line between fatigue and depression?’ (Kelowna, 203); ‘fatigue and the depression become so tightly interwoven, you can’t separate them’ (Kelowna, 2809).

Pain was the factor most frequently cited, in all the four groups, as integral to the experience of fatigue: ‘Pain is number one’ (Vancouver, 247), ‘Fatigue...varies mainly because of pain’ (Kelowna, 9). Moreover, fatigue and pain were perceived to be both a cause and effect of depression: ‘Pain causes fatigue, fatigue causes depression and anxiety’ (Kelowna, 20). Depression was closely associated with motivation: ‘Depression removes the motivation’ (Victoria, 611), although some people observed: ‘I’m motivated to do things but I don’t have the energy to do them’ (Prince George, 60). Affiliated with the concept of motivation was boredom, and the accompanying urge to nap: ‘Boredom is a killer’ (Kelowna, 126); ‘I think a lot of (fatigue) could be boredom...lack of activity’ (Kelowna, 106). For some, fatigue was inseparable from a sense of hopelessness, such that fatigue was perceived to be a symptom rather than a cause of suffering: ‘I have the distinct feeling that once you rule out the medical issue, that most of the fatigue, if not all of the fatigue, is generated by a feeling of hopelessness of ever obtaining a meaningful existence’ (Kelowna, 2796); ‘I think fatigue is a coping mechanism, actually’ (Kelowna, 3313).

Many people, in all the groups, identified the side effects of medications as contributing to their feelings of lethargy, disengagement and detachment: ‘I’m easily fatigued but...I’m sure it’s drug related’ (Prince George, 378); ‘I found

Table 2 Factors contributing to fatigue in spinal cord injury*Major contributors*

- Pain
- Depression, hopelessness, reduced motivation and anxiety
- Side effects of medications
- Sleep problems (poor quality, disturbed sleep)
- Secondary sequelae (notably spasticity and urinary tract infections)
- Posture—muscle imbalance and pain (often attributed to inappropriate equipment)
- Diet and nutrition
- The effort required to accomplish routine and self-care tasks (which increased with time since injury)

Additional contributors

- The degree of planning required to live with SCI
- The effort of coping with SCI
- Problems arising from environmental circumstances—physical barriers/lack of access, weather/temperature, high social expectations leading to high self-expectations
- Cumulative injuries, decrease in muscle mass, over-activity and exercise

Abbreviation: SCI, spinal cord injury.

that my energy levels were so marginal that Baclofen took the edge off it' (Victoria, 305).

Sleep problems were identified as being a significant contributor to fatigue. Poor quality, disturbed sleep was attributed to pain, spasticity and the need to move and turn: 'I deal with a fair bit of muscle pain, muscle imbalance, which makes it very difficult to get comfortable...it causes fatigue and creates problems at night when I am trying to sleep' (Vancouver, 17); 'You don't feel like getting up because you haven't had a good sleep' (Vancouver, 33).

Secondary sequelae of SCI were perceived to contribute to the experience of fatigue, especially spasticity (which contributed both to pain and problems sleeping) 'Spasming in my left arm...creates stress on the shoulder, which creates pain' (Kelowna, 15); 'For me (fatigue results from) pain and spasms. I get leg spasms, and...when I am lying in bed my legs tense up' (Vancouver, 476). Urinary tract infections (UTIs) were also identified as contributing to fatigue, as were low blood pressure, orthostatic hypotension, sleep apnoea, and pressure sores and their management. In addition, reduced respiratory capacity contributed to fatigue among those with higher lesions: 'Just breathing and talking can exhaust you' (Kelowna, 382).

Muscle imbalance and pain, often attributed to inappropriate equipment, were identified as contributing to fatigue as a result of poor posture: 'Posture is my biggest fatigue thing because of the discomfort that comes out of my posture' (Victoria, 1283); 'having to struggle just to maintain your position is very fatiguing' (Kelowna, 412). Postural problems and pain were perceived to be associated with poorly designed, inadequately adjusted wheelchairs 'This chair...is tiring. It is a bad chair', 'Bad chair. Let's go 'ditto' on that one' (Victoria, 355, 360).

Diet and nutrition were repeatedly cited as factors influencing fatigue: 'Incredibly important, nutrition is, and how you eat, when you eat and what you eat' (Kelowna, 789). The associated problem of weight gain was also identified: 'two things affect me the most, is the weight

and the lack of sleep', 'Ditto', 'Ditto', 'Ditto' (Victoria, 211, 214, 215, 216).

Living with a SCI requires a huge effort just to accomplish routine and self-care tasks, and this was identified as being profoundly fatiguing: 'You have to rearrange your whole life around...your bladder and bowels' (Prince George, 1176); 'Just the time it takes to do things. It is not just a five minute thing, it is a two hour thing. And by the time you are done that, you are like, okay, gotta go out and do something (now) and I think, 'I will just go sit over here'' (Vancouver, 266). With increasing time since injury these problems worsened, such that routine tasks required increased effort: 'I am just about out of wind by the time I finish getting into my vehicle' (Victoria, 1317); 'it is even stressful to think about things like transferring to a chair that I can feel more rested in because of the difficulty in doing that, whereas before I could do it much easier' (Vancouver, 431).

Moreover, living with SCI demands a considerable degree of planning—trying to anticipate any difficulties, such as wheelchair access—and this was perceived as contributing to fatigue: 'It's planning, it's thinking, it's not just living' (Kelowna, 739); 'You constantly have to think ahead of what that day is going to bring to you so that you then can take the appropriate measures to actually make it through the day' (Kelowna, 719). Indeed, fatigue was perceived as resulting from simply trying to cope with life with a SCI. 'We are constantly trying to cope' 'Yeah, exactly. That is what it is. We are always coping' (Victoria, 1090, 1092).

Additional problems, cited less frequently, included the environmental context: physical barriers and a lack of wheelchair access; the weather and extreme temperatures; and the expectations arising from a sociocultural environment that values independence, paid employment, self-sufficiency and productivity: 'When you have a spinal cord injury you feel that you have to prove something, that you are still able, and you can still go through your day and be efficient, and a good family member...but fatigue is limiting' (Prince George, 1318).

In addition, exercise was identified as being potentially positive and negative following SCI: 'exercise for me is like a saving grace' (Prince George, 262); 'Exercise does bring on fatigue for me' (Prince George, 194).

Discussion

The mean FSS score for this SCI participant group (4.65, *s.d.* = 1.42) is similar to previous SCI studies that have reported mean FSS scores of 4.4 (*s.d.* = 1.4)¹⁵ and of 4.1 (*s.d.* = 1.8).⁷ These FSS scores are slightly lower than those reported in studies of multiple sclerosis (mean = 5.16, *s.d.* = 1.47;¹⁶ mean = 4.8, *s.d.* = 1.3¹⁴) and postpolio syndrome (mean = 5.06, *s.d.* = 1.66),¹⁶ but significantly higher than FSS scores reported among people with no known pathology (mean = 2.17, *s.d.* = 1.09;¹⁶ mean = 2.3, *s.d.* = 0.7¹⁴).

Qualitative data from this study illustrate the impact of fatigue on the lives of people with SCI, and the lives of their partners and families, and suggest that fatigue in SCI has

physical, emotional and cognitive dimensions. This is a more complex phenomenon than the commonly posited, linear equation in which fatigue is viewed as a purely physical phenomenon leading to diminished physical independence and resulting from reduced energy, disuse or overuse.⁴

The results of this study identified close interrelationships between fatigue, depression, pain and hopelessness, which some participants viewed as inseparable. However, during the dynamic interchanges that often occur within focus groups, other participants challenged this viewpoint and raised the possibility that once fatigue was 'named', specific strategies could be enacted to enable some control over this dimension of their lives. This appeared to engender a sense of empowerment and hope.

Researchers who study depression among the general (that is non-SCI) population observe a cycle in which feelings of low energy, fatigue, low mood and reduced motivation lead to reduced levels of activity, such that only essential tasks are undertaken and pleasurable, fun and social activities are eschewed.¹⁷ Diminished engagement in personally meaningful activities leads, in turn, to a sense of hopelessness, increased pain, increased fatigue and decreased motivation, and the whole cycle repeats itself.¹⁷ The physical sequelae of SCI dictate that an enormous degree of effort is expended to accomplish daily activities, even in the absence of depression, pain and fatigue and in the presence of motivation. High levels of fatigue,^{4,7} depression¹⁸ and pain^{4,19,20} among people with SCI, and the observed interconnections between these factors, suggest that sustained engagement in activities that are personally meaningful and rewarding may be inordinately difficult following SCI.

In common with other researchers,¹⁸ this study found that people with SCI often curtail recreational and social activities as they strive to maintain self-care activities and work. This is of concern because positive perceptions of quality of life following SCI are associated with satisfying engagement in social, recreational and productive occupations.²¹

The interrelationships between fatigue, pain, depression and hopelessness among people with SCI, identified within this study have been noted by previous researchers, with pain closely associated with fatigue^{4,18,19} and centrally implicated in the development of depression, anxiety, sleep disturbance, reduced motivation and feelings of hopelessness.²² Pain is reportedly increased by fatigue and spasticity as well as by factors perceived in the present study to contribute to fatigue: UTIs, prolonged sitting, environmental temperature, anxiety, helplessness and depression.^{19,20} Moreover, the work of living with pain is compounded by sleep disturbances that result in fatigue,²⁰ and fatigue is associated with sleep disturbance, depression and pain.^{5,8} More research is required before directions of causality can be stated with any confidence.

Pain, fatigue and the effects of some medications result in a reduced capacity to engage in educational, work, leisure or social activities.²⁰ Researchers commonly note relationships between pain and fatigue following SCI yet rarely acknowledge that although pharmacological attempts to relieve pain

after SCI are not demonstrably effective,²³ they may significantly increase fatigue.⁷ Moreover, by considering the impact of fatigue solely on self-care activities, for example^{3,24} researchers have often overlooked its impact on those activities most closely associated with quality of life: engagement in family, social, recreational and productive activities.¹⁸ It is evident that fatigue can have serious adverse implications for quality of life following SCI,^{1,4,5,9} especially when combined with pain and depression;²⁵ a situation frequently shared by the partners and families of people with SCI.

Several of the factors identified in this study that were perceived to contribute to fatigue appear readily amenable to intervention, such as a review of diet, medications (especially for pain and spasticity) and equipment (particularly wheelchairs). A literature review of the nature and treatment of pain following SCI noted the striking deficiency of knowledge about effective treatments for addressing pain,²³ despite considerable research interest in this area. The claim that fatigue in SCI may be prevented by fighting physical deconditioning⁵ fails to address the multifactorial influences on fatigue in SCI (Table 2). Moreover, because physical exercise is experienced by some as contributing to both fatigue and pain, it appears unlikely that physical conditioning is a panacea for fatigue in SCI.

Although this paper reports the findings of a small study, from which generalizations are not possible, the findings suggest that fatigue following SCI is a problem of considerable complexity that merits further research to enhance understanding and to determine appropriate and comprehensive responses. Because symptoms of depression and fatigue overlap, further research is needed to determine whether the FSS can distinguish fatigue from depression.¹⁵ Well-designed longitudinal studies are also required to tease out the relationships between associated variables (notably depression and fatigue).

Conclusions

This small, exploratory study provides qualitative evidence indicating the complex nature of fatigue following SCI. Rather than constituting a simple, physical phenomenon, fatigue following SCI was perceived to have cognitive, emotional and physical dimensions that require a broad range of responses.

Further, participants in this study contended that fatigue is closely connected to hopelessness, pain and depression and is affected by sleep problems, spasticity and reduced motivation, which fatigue also effects. The impact of fatigue upon the everyday lives and quality of lives of people with SCI—who already struggle with severe physical impairments—is significant and constitutes a problem deserving significant research attention.

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References

- 1 Charlifue SW, Gerhart KA, Whiteneck GG. Conceptualizing and quantifying functional change: an examination of aging with spinal cord injury. *Top Geriatr Rehabil* 1998; **13**: 35–48.
- 2 Thompson L. Functional changes in persons aging with spinal cord injury. *Assist Technol* 1999; **11**: 123–129.
- 3 Prysak GM, Andresen EM, Meyers AR. Prevalence of secondary conditions in veterans with spinal cord injury and their interference with life activities. *Top Spinal Cord Inj Rehabil* 2000; **6**: 34–42.
- 4 Jensen MP, Kuehn CM, Amtmann D, Cardenas DD. Symptom burden in persons with spinal cord injury. *Arch Phys Med Rehabil* 2007; **88**: 638–645.
- 5 Barat M, Dehail P, de Souza M. Fatigue after spinal cord injury. *Ann Readapt Med Phys* 2006; **49**: 365–369.
- 6 Gerhart KA, Charlifue SW, Weitzenkamp DA. Mild and incomplete spinal cord injuries: a walk in the park? *SCI Life* 2000; **Winter**: 24–25.
- 7 Fawkes-Kirby TM, Wheeler MA, Anton HA, Miller WC, Townson AF, Weeks CAO. Clinical correlates of fatigue in spinal cord injury. *Spinal Cord* 2008; **46**: 21–25.
- 8 Pentland W, Walker J, Tremblay M, Brouwer B, Gould M. Women with spinal cord injury and the impact of aging. *Spinal Cord* 2002; **40**: 374–387.
- 9 McColl MA, Arnold R, Charlifue S, Glass C, Savic G, Frankel H. Aging, spinal cord injury, and quality of life: Structural relationships. *Arch Phys Med Rehabil* 2003; **84**: 1137–1144.
- 10 Thompson L, Yakura J. Aging related functional changes in persons with spinal cord injury. *Top Spinal Cord Inj Rehabil* 2001; **6**: 69–82.
- 11 White GW. Consumer participation in disability research: the golden rule as a guide for ethical practice. *Rehabil Psychol* 2002; **47**: 438–446.
- 12 Kitzinger J. Focus groups with users and providers of health care. In: Pope C, Mays N (eds). *Qualitative Research In Health Care*, 2nd edn. BMJ: London, 2000, pp 20–29.
- 13 Packer TL, Brink N, Sauriol A. *Managing Fatigue: A Six-Week Course for Energy Conservation*. Therapy Skill Builders: Tucson, AZ, USA, 1995.
- 14 Krupp L, LaRocca N, Muir-Nash J, Steinberg AD. The Fatigue Severity Scale: application to patients with multiple sclerosis and systemic lupus erythematosus. *Arch Neurol* 1989; **46**: 1121–1123.
- 15 Anton HA, Miller WC, Townson AF. Measuring fatigue in persons with spinal cord injury. *Arch Phys Med Rehabil* 2008; **89**: 538–542.
- 16 Packer TL, Sauriol A, Brower B. Fatigue secondary to chronic illness: postpolio syndrome, chronic fatigue syndrome, and multiple sclerosis. *Arch Phys Med Rehabil* 1994; **75**: 1122–1126.
- 17 Williams C. *Overcoming Depression and Low Mood. A Five Areas Approach*. 2nd edn. Hodder Arnold: London, 2006.
- 18 Kemp BJ, Adkins RH, Thompson L. Aging with a spinal cord injury: what recent research shows. *Top Spinal Cord Inj Rehabil* 2004; **10**: 175–197.
- 19 Roth EJ. Pain in spinal cord injury. In: Yarkony GM (ed). *Spinal Cord Injury: Medical Management and Rehabilitation*. Aspen: Gaithersburg, MD, USA, 1994, pp 141–158.
- 20 Henwood P, Ellis JA. Chronic neuropathic pain in spinal cord injury: the patient's perspective. *Pain Res Manage* 2004; **9**: 39–45.
- 21 Hammell KW. Exploring quality of life following high spinal cord injury: a review and critique. *Spinal Cord* 2004; **42**: 491–502.
- 22 Britell CW, Umlauf R, Loehr JT, deLisa JA. Survey of health issues in spinal cord injured out-patients: a case for specialised, multifaceted ongoing care. *Arch Phys Med Rehabil* 1986; **67**: 654.
- 23 Ehde DM, Jensen MP, Engel J, Turner JA, Hoffman AJ, Cardenas DD. Chronic pain secondary to disability: a review. *Clin J Pain* 2003; **19**: 3–17.
- 24 Gerhart KA, Bergstrom E, Charlifue SW, Menter RR, Whiteneck GG. Long-term spinal cord injury: functional changes over time. *Arch Phys Med Rehabil* 1993; **74**: 1030–1034.
- 25 Widerstrom-Noga EG, Felipe-Cuervo E, Yezierski RP. Chronic pain after spinal cord injury: interference with sleep and daily activities. *Arch Phys Med Rehabil* 2001; **82**: 1571–1577.