Managing fatigue following spinal cord injury: A qualitative exploration

KAREN W. HAMMELL¹, WILLIAM C. MILLER¹,²,³,⁴, SUSAN J. FORWELL¹,²,³,⁵, BERT E. FORMAN⁶ & BRAD A. JACOBSEN⁶

¹Faculty of Medicine, Department of Occupational Science and Occupational Therapy, 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 Laboratory, Vancouver, British Columbia, Canada, ⁵Multiple Sclerosis Clinic, University of British Columbia, Vancouver, British Columbia, Canada, and ⁶British Columbia Paraplegic Association, Vancouver, British Columbia, Canada

Accepted November 2008

Abstract
Purpose. To identify, from the perspectives of people with spinal cord injury (SCI), (a) appropriate components of a fatigue management programme; and (b) important outcomes or indicators of success.

Method. Collaborative, qualitative methodology comprising four focus groups undertaken simultaneously in Kelowna, Prince George, and Victoria, British Columbia, Canada. Participants included a purposive sample of 21 men and women with complete and incomplete SCI of high and low tetraplegia and paraplegia. Two family members, two care-providing assistants and four occupational therapists provided additional information (total n=29). Interpretive data analysis identified common themes addressing each research question.

Results. Building on those strategies they perceived to facilitate coping with fatigue, the participants identified 10 components of a helpful fatigue management programme. Dimensions of 'successful' outcomes from such a programme reflected quality of life concerns: enabling people with SCI to do the things they value, enhancing their sense of control over their lives, reducing pain and helplessness, increasing motivation and enhancing relationships strained by fatigue.

Conclusions. This study identifies many of the necessary elements of a fatigue management programme to meet the specific needs of people with SCI; and ascertains important indicators of a successful programme from the perspectives of those who must live with the outcomes.

Keywords: Spinal cord injury, fatigue

Introduction
Fatigue is a common and debilitating problem for people with spinal cord injuries (SCI) [1–8]. In the context of SCI, fatigue has been described as an 'overwhelming sense of tiredness', 'full body sense of exhaustion', 'feeling completely worn out' and 'lacking energy' [3]; and is frequently associated with pain [8–11] and depression [12,13]. Although it has been reported in one study that fatigue is worst among young people and those with a recent SCI [7], most researchers have found fatigue to be associated with advancing age and with many years lived with an SCI [2,3,6,12,14,15].

Researchers in British Columbia (BC) [11] and California [4] have found that many people (57% [11] and 65% [4]) with SCI experience fatigue of sufficient severity to interfere with physical function. Fatigue magnifies the physical consequences of SCI by further compromising the ability to participate in life activities [3,7,8] and thus has serious adverse implications for quality of life [2,7,8,12,16].

People with SCI have identified fatigue as an issue of priority for research [17] and as an important topic...
about which they are in need of information and advice [9]. However, little is currently known about the nature or appropriate management of fatigue among people with SCI [8]. Moreover, it appears that interventions such as exercise and medications may serve to increase, rather than ameliorate, fatigue in this population [11,18]. Because fatigue following SCI is associated with poor quality of life, does not resolve over time and may become worse, focused attention is required on the development of appropriate interventions [8].

This study, undertaken collaboratively by researchers from the University of British Columbia and the British Columbia Paraplegic Association (BCPA) Peer Programme, was designed:

1. to explore (a) the experience of, and (b) contributors to fatigue following SCI;
2. to identify (a) desirable components of a fatigue management programme; and (b) important outcomes, or indicators of success.

Analysis of the data pertaining to the experience of, and contributors to fatigue among people with SCI is reported elsewhere [18]. In summary, these findings illustrate the profound impact of fatigue on the lives of people with SCI, their partners and families; demonstrate that fatigue in SCI has emotional, cognitive and physical dimensions; and suggest close inter-relationships between fatigue, pain, depression and feelings of hopelessness.

This article addresses the second aspects of the study: the identification of useful components of a fatigue management programme; and important outcomes or indicators of success.

Methods

Because little prior research had been undertaken to probe the nature, course or management of fatigue following SCI [8], the present study was determined to be exploratory and thus required a qualitative approach. Moreover, in response to calls for rehabilitation researchers to enhance both the relevance and usefulness of their research by working in partnership with people living with impairments such as SCI [17,19–22], the research was planned, undertaken, analysed and reported by a collaborative team of academics and SCI professional and peer counsellors. Central to this approach was a commitment to translate findings into action, such that issues identified by the research would subsequently be addressed by appropriate interventions [19].

Focus groups are appropriate for exploring a relatively unknown field and for evaluating different research sites [23] and were deemed the most suitable method for the purposes of this study. Focus groups are a form of group interview that capitalise on communication and interaction between research participants to generate data, enabling participants to define their priorities, explore those issues they deem important, assert their own perspectives and develop their own analysis of a common experience [23,24]. By virtue of the number of research participants, focus groups have the potential to shift the balance of power away from the group leader, to challenge researchers’ opinions and to affect the direction and focus of the research [25]. The reality that focus groups are a relatively non-hierarchical research method [26] that enable a high level of participant involvement [23] aligned with the collaborative and non-hierarchical ethos underpinning this project.

To enable inclusion of perspectives from both rural and urban experiences of living with SCI, simultaneous focus groups were held at four sites across BC: Kelowna, Prince George (PG), Vancouver and Victoria. Each group followed a common, structured agenda. Using video-conferencing, the four groups met at pre-arranged times during the day to discuss their findings. This enabled issues of commonality and of difference to be identified and thereafter discussed by all the groups.

Participants

Potential participants were identified by the research team based on their knowledge and experience of, and interest in SCI and fatigue. Purposive sampling was undertaken to ensure the inclusion of a wide range of perspectives. This included community-dwelling men and women with traumatic SCI of various levels, durations (>1 year) and ages (>18 years), with complete and incomplete lesions, both employed and unemployed and with various domestic situations (single, married, partnered, with/without children). Individuals with other serious medical conditions that might impact fatigue (e.g. rheumatoid arthritis, Parkinson’s disease) were excluded, as were people with a head injury or dementia. Participants were required to be able to read, speak and understand English. In an effort to include some perspectives from those who live with people with SCI, close family members and personal assistants were also invited to participate, in addition to some occupational therapists known to have particular interest in, and knowledge of fatigue and its impact on every-day living.

Potential participants were sent a letter explaining the nature and purpose of the study and inviting them to contact either their regional BCPA representative or the research assistant if they were interested in becoming involved. Those who agreed...
to participate were sent a preparation package of information that included: background information defining and discussing fatigue, a copy of the questions to be discussed in the focus groups (to enable reflection), a copy of the Fatigue Severity Scale [27] and a demographic questionnaire. In addition, each participant was provided with an abbreviated summary of an energy conservation programme that has been used among people with multiple sclerosis (MS) [28]. During the focus groups the energy conservation information was evaluated and critiqued, and this provided a basis for subsequent discussion about appropriate interventions for people with fatigue related to SCI. In total, 29 people participated in one of the four focus groups: 21 people with SCI, two family members, two assistants and four occupational therapists. Table I presents the SCI participants’ demographics.

## Data collection

Each focus group was led by a member of the research team, with an assistant, and was guided by a series of questions. The questions of relevance to this article were:

- What would be the desirable components of a fatigue management programme for people with SCI?
- What would be important outcomes and indicators of success?

This latter question is important, because outcomes are usually evaluated according to the researchers’ priorities rather than according to the priorities of people with SCI, who must live with the outcomes [29,30].

The focus group discussions were audio-taped and the tapes were transcribed verbatim. Flip-charts were used during the discussions to document those issues identified by the study participants as important to the various questions. Field-notes 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. Every participant was provided an honorarium to acknowledge their time (~ 6 h) and any travel expenses.

## Data analysis

Analysis occurred in two phases. The first phase was undertaken by four researchers and entailed amassing data from the transcripts, flip-charts and field-notes from each of the four locations. In the second phase, one of the UBC researchers combined the results of the four groups by identifying common themes arising from the pre-established questions, and listing these with supportive data. The resulting analysis was reviewed by each member of the research team to determine whether the identified themes fairly captured the information, perspectives and issues that had been raised during the focus groups in which each had participated. There was almost unanimous agreement that this interpretation of the data was both authentic and comprehensive, although one small difference of interpretation was raised by a BCPA peer counsellor. Because both the BCPA counsellor and the researcher undertaking the analysis had participated in the same focus group, this issue was discussed and the analysis was amended to incorporate both perspectives.

## Results

The focus groups addressed specific questions and the findings are presented as responses to these questions, with illustrative comments.

### What would be the desirable components of a fatigue management programme?

The responses to this question can be grouped into four areas: defining fatigue, identifying and managing factors associated with fatigue, enabling...
participation in valued occupations and programme delivery.

Defining fatigue

The participants felt that a fatigue management programme would first need to define fatigue, describe its various manifestations in the context of SCI (physical, cognitive, emotional), and then outline how fatigue may be experienced, depending upon the level and completeness of SCI lesion: ‘What is fatigue? . . . What does fatigue mean in spinal cord injury compared to the able-bodied population?’ (PG 1343). It was also suggested that it would be useful to understand the relationships between fatigue, depression, pain and feelings of hopelessness; between these four factors and motivation; and between fatigue and age. A fatigue management programme would first need to define fatigue, explaining what is fatigued and identifying what is fatigued, and from whom fatigued. The participants identified the importance of defining fatigue, allowing the participants to understand what is being fatigued. They wanted helpful ideas that would be useful to explore alternative methods of managing pain and spasticity that would not depend on those medications that include fatigue as a side-effect: ‘What are other ways of dealing with pain?’ (PG 1276); ‘I think it would be good to explore alternative approaches to pain management; to medications’ (Vancouver 609).

Identifying and managing factors associated with fatigue

The participants felt it was important to encourage each person to explore both their medical status and factors that may be associated with fatigue with a knowledgeable professional, to identify any co-existing physical or emotional conditions and problems, such as spasticity, hypotension or depression that might be amenable to intervention and to identify the ‘root of the problem’ of fatigue (PG 1376), if one existed. ‘Once you understand what’s leading you into this cycle of fatigue, then you can actually personalize it . . . and be able to build your strategies for that’ (Kelowna 864). Because depression was identified as being integral to the experience of fatigue, attention to emotional health was deemed an essential component of a fatigue-management programme: ‘Fatigue and depression become so tightly interwoven, you can’t separate them’ (Kelowna 62); ‘Fatigue is tied into depression quite heavily and it’s breaking that cycle, in order to get to the point where you want to go out and you want to do things’ (Vancouver 598); ‘I guess I would just put “emotional health” as part of one of your areas that you need to address in fatigue’ (Kelowna 70).

The importance of physical health, such as achieving optimal bladder and bowel function was also identified as being important to combating fatigue: ‘To what extent does the bladder and the slow bowel moving through your system and the lack of circulation . . . contribute to fatigue? Is there something that can be done at that level as opposed to strategies after you have fatigue? Put that in your research project there’ (PG 1192). In particular, the participants wished to explore alternative methods of managing pain and spasticity that would not depend on those medications that include fatigue as a side-effect: ‘What are other ways of dealing with pain?’ (PG 1276); ‘I think it would be good to explore alternative approaches to pain management; to medications’ (Vancouver 609).

The participants identified the importance of relieving muscle tension and counter-acting muscle imbalances and poor posture by using appropriate equipment and optimising their seating position by regularly reviewing and adjusting their wheelchairs: ‘A lot of it comes down to seating. If I am seated well in my chair, it is a good day’ (Vancouver 178); ‘This chair is tiring; it is a bad chair’ (Victoria 355). They suggested that regular opportunities to review their wheelchair set-up with a knowledgeable professional would be a beneficial component of a fatigue management programme.

Attaining restful sleep and having strategies of rest during the day, especially for times of low energy, were felt to be helpful: ‘[sleep] turns the brain off. You are no longer thinking about all the things you are doing. And until you actually fall asleep you don’t get the muscular release’ (Victoria 150); ‘Since I have been taking my afternoon rests, I find I can participate more in my day to day kind of life and enjoy my evenings . . . whereas when I was working, I would go to work in the morning and come home at 4.30 and go to bed, sometimes for the rest of the day’ (Victoria 74). However, for some people, napping during the day led to grogginess: ‘I can’t rest in the middle of the day, because if I do, that is it, the day is over’ (Victoria 2193); while other people are unable to change their position during the day because of a lack of assistance: ‘I sleep at my table. I’ll put a pillow down and I’ll put my head on my table ‘cause I can’t get out of my chair and I don’t have twenty-four hour care’ (Kelowna 1960). As part of a fatigue management programme, the participants wished to explore strategies that might enhance the quality of their sleep. They wanted helpful ideas that would be relevant to the context of their SCI (including spasticity, the need to turn to prevent skin breakdown and relieve muscle tension); and they wanted practical ideas about how they might incorporate helpful forms of rest and relaxation into their everyday lives. These ideas would need to be tailored to the level and completeness of their SCI and to the
context of their lives (for example, their access to assistance and their employment status).

A variety of approaches to managing physical, cognitive and emotional stresses were also viewed as important. Successful strategies that enable the management of stressors were felt to include: music (both relaxing and energising), yoga, breathing and relaxation techniques: ‘I use yoga techniques and thinking, and breathing techniques to try and release. And if I don’t get the mental release, the fatigue just builds and builds’ (Victoria 163). Strategies that specifically target potential cognitive stressors were also articulated, such as developing positive financial strategies that generate a sense of control. Budgeting was experienced as fatiguing, with limited finances providing limited options for assistance or access to equipment that might reduce fatigue: ‘Money is a huge issue’ (Victoria 1521); ‘instead of always asking family and friends for help] if you could just hire someone and pay them; it just gives you a little sense of independence, that you are doing it yourself’ (Victoria 1574); ‘I need money to get myself a vehicle that will take an electric wheelchair. And that will – we are talking about money, money, money’ (Victoria 1864).

The participants felt that a fatigue management programme could also address emotional and cognitive aspects of fatigue by fostering an enhanced understanding of one’s SCI. This might include both modifying one’s self-expectations – ‘You have to accept your limitations too. There is a bit of acceptance’ (Victoria 2624) – and acknowledging one’s capabilities: ‘You have to take hold of that disability and realize what you can and cannot do’ (Victoria 2659). This incorporated the idea of self-acceptance and rejection of the role of ‘victim’ and also of eschewing attempts to live as if SCI had not occurred: ‘Stop thinking like an able-bodied person’ (Victoria 2575).

Several people spoke of the importance of re-establishing a positive sense of self-worth. This was achieved, in part, by engaging in positive self-talk that affirmed their abilities and positive qualities: ‘We all know people that are very negative . . . no wonder you are depressed because of the way you talk about yourself and your life’ (PG 1289). Integral to the process of reflection about one’s capabilities would be a commitment to taking control of one’s life by identifying one’s priorities and goals: ‘First you have to sit down and say “What’s important to me? What can I drop off?”’ (PG 894). This relates to the importance of being able to spend time engaged in valued occupations.

Enabling participation in valued occupations

The study participants placed particular emphasis on the importance to their lives, and to the management of their fatigue, of participating in occupations that were experienced as being rewarding, absorbing or personally important. (‘Occupations’ are defined in this article as being ‘purposeful or meaningful activities or tasks in which humans engage as part of their normal daily lives’[31, p.4]). Engagement in meaningful occupations was perceived to help counter fatigue while supporting a balanced lifestyle, and was felt to combine both enjoyable and essential occupations: ‘When I’m working, I’m concentrating on what I’m doing, I just don’t have the pain then . . . soon as you stop, the pain starts. Other than that I have no fatigue at all’ (Kelowna 166). Reflecting the literature, ‘meaningful occupations’ were identified as being those that provide a reason to get up in the morning, a way to keep busy and counteract boredom, and that provides a sense of fulfilment or accomplishment – ‘I have to have a personal accomplishment’ (PG 1059) – and enable someone with an SCI to contribute to others: ‘becoming useful to someone else’ (Victoria 2253); ‘I think that helping others – whether its volunteering – I feel good when I do things like that, so when I’m feeling good I am less fatigued’ (PG 1048).

Having identified those rewarding, meaningful and important activities that they wished to accomplish, the study participants felt it would be appropriate to explore strategies that would conserve energy and enable them to participate in these valued occupations. Suggested strategies included evaluating energy expenditure, planning and pacing activities such that both routine and pleasurable occupations would be included, streamlining activities for maximum achievement with minimal effort, identifying appropriate lifting and carrying techniques (for people with low and incomplete SCI), incorporating rest into daily schedules and modifying the use of equipment to include, for example, power wheelchairs and transfer boards. The participants provided many examples of strategies they found helpful: ‘If I can go somewhere and take the bus, it is going to save me 2,4 or 6 transfers, I will do that because I won’t have to transfer’ (Vancouver 47); ‘Every time I go to do something I have to . . . map out in my head what I have to do’ (Vancouver 58); ‘strategies that work for me is planning my day so that I am not going 4 different places in one afternoon [so] that I have got in and out of the car 4 separate times’ (Victoria 2027).

Another strategy for managing low energy levels was recruiting, accepting and valuing assistance from others, recognising that people often like to be able to help. For some it was possible to pay for assistance: ‘I have somebody come in once a week for two hours to do cleaning that, okay, I could do, but it would take me all day . . . so, for the two hours that the person comes in, they could do my floors and my tub and those things, and I can then focus my energy on where it should be, which is
playing with my kids, visiting other people, working on having a life' (Vancouver 85).

The study participants felt that, to be effective, a fatigue management programme would need to explore issues of nutrition: ‘Incredibly important, nutrition is, and how you eat, when you eat and what you eat’ (Kelowna 789). This would need to include the logistics of shopping for, and preparing nutritious meals in the contexts of both significant physical impairment and environmental constraints such as transportation difficulties and low incomes: ‘[if I had more money] I would be able to eat better’ (Vancouver 296); ‘I would pay for pre-prepared food. I would pay for lots of stuff. Pay for someone to come and do some of the chores that I do myself, if I had the money’ (Victoria 1533).

The issue of exercise was complex, being perceived as both a remedy for, and contributor to, fatigue: ‘When I don’t exercise I feel lousy. When I do exercise everything works better’ (PG 247); ‘If I do too much exercising, using my muscles, I get a lot of pain, back pain, shoulder pain, wrist pain, neck pain’ (PG 276); ‘A lot of times you are too tired to exercise’ (Victoria 523); ‘Exercise could be just wheeling around the garden looking at flowers’ (PG 1048). Many people felt it would be helpful to explore various forms of appropriate exercise, relevant to different levels and completeness of SCI, such as yoga.

Programme delivery

The study participants suggested that an appropriate fatigue management programme would require a basic manual that could be used both as a basis for discussion within groups, and also be used by those who would be unable to meet in a group setting: ‘If I’ve got it in writing I can go back and really examine it or put it more into my situation’ (Kelowna 2422). They felt that the programme needed to be led by knowledgeable professionals: ‘You’d like to see some credibility – an OT [occupational therapist] or somebody’ (PG 1490). However, they placed the greatest emphasis on the benefits of learning with and from other people with SCI: ‘Hearing what other people are dealing with . . . makes you feel more part of a normal population. It is a different normal population. It is inclusion’ (Victoria 1228); ‘I have already learned so much in the last 15 minutes [in the focus group]. I have learned that I am not alone’ (Vancouver 310); ‘You cannot believe how much I have learned today [in the focus group], in the last two hours. It is just phenomenal’ (Vancouver 1257).

What would be important outcomes/indicators of success?

‘Quality of life, I guess’ (Victoria 3205). The sort of outcomes to which the participants with SCI aspired, and which they believed would constitute important measures of success following a fatigue management programme, were centrally concerned with enhancing the quality of their lives: ‘Well, I think for me the indicator of success would be a global thing . . . are they satisfied with their life, with how they’re coping – quality of life basically . . . if you were to ask them ‘On a scale of 1 to 10 how do you feel? Is there a balance? Are you happy with that?’” (PG 1663). ‘Quality of life’ was strongly associated with the ability to ‘do’: to engage in chosen and valued occupations: ‘Do you have enough in your life that you are happy, or that you are satisfied with whatever activities that you have chosen are a priority?’ (PG 1674).

The importance of being able to engage in meaningful activities – to do things that were personally important – recurred, and was associated with a sense of pleasure, accomplishment and enhanced self-worth: ‘I think being able to do the things you want to do’ (Victoria 3229); ‘I do what I want to do and need to do’ (PG 1603); ‘[a satisfactory outcome would be] If my motivational levels were higher. If I felt motivated to go out and be in the world’ (PG 1635). Indeed, as one participant noted: ‘Boredom is a killer’ (Kelowna 126). Reflecting the close association the participants had identified between pain, helplessness, depression and fatigue, several people felt that an appropriate measure of success following a fatigue management programme would be decreases in both pain and depression and enhanced motivation such that they would feel more able to participate in valued occupations: ‘I made a list. I just think you [would] have more energy, less muscle pain, your motivation would increase, you would be doing more activity, which means you would have a better social life, better body image’ (PG 1594).

The sense of ‘coping with life’ (PG 1653) and having more control over one’s life was another important outcome that related to the ability to ‘do’ things: ‘Even for those that maybe their fatigue is the same, I would still think [the programme] was successful if you feel like you have more control – you know, that fatigue doesn’t control your life anymore – at least now I have some strategies that now I can deal with this, it’s kind of like self-competency, right? You know you may still be tired but, hey! now at least I can cope with it better and do some things I want to do’ (PG 1678).

Two further outcomes were identified as being desirable after a fatigue management programme. These pertained to enhanced and less stressful relationships – ‘Your relationship with your partner or relationship with your husband’ (PG 1656) – and to gaining the knowledge that fatigue is not an inevitable component of SCI, but something that can potentially be alleviated or controlled – ‘Awareness of the issue is probably a huge, huge outcome’
Exploring strategies to ensure excellent nutritional intake

Taking control of physical strategies to enhance efficiency and

Focussing on those meaningful, valuable and rewarding activities

Identifying priorities and goals

Fostering an understanding and acceptance of one’s capabilities

Exploring strategies to enhance sleep and maximise rest

Enhancing stability and function, and reducing muscle imbalance

Investigating any underlying causes of fatigue and exploring

Table II. Desirable components of a fatigue management programme for people with SCI.

Understanding fatigue in the context of SCI and its relationship to
depression, pain and hopelessness; and ‘naming’ fatigue in the
context of one’s own life
Investigating any underlying causes of fatigue and exploring
alternatives to medications
Enhancing stability and function, and reducing muscle imbalance
through appropriate wheelchair adjustment
Exploring strategies to enhance sleep and maximise rest
Fostering an understanding and acceptance of one’s capabilities
and limitations
Identifying priorities and goals
Focussing on those meaningful, valuable and rewarding activities
that enhance the quality of one’s life
Taking control of physical strategies to enhance efficiency and
decrease energy expenditure, such as pacing and planning,
recruiting assistance, modifying daily activities, incorporating
rest and increasing the use of equipment
Exploring strategies to ensure excellent nutritional intake
Exploring forms of exercise appropriate to the individual

Discussion

Although fatigue is known to be a significant problem for people with SCI, little research has been undertaken to identify useful strategies for managing fatigue in this population. This exploratory study contributed to this objective by identifying the desirable components of a fatigue management programme that people with SCI feel would be helpful; and ascertaining the nature of the outcomes to which they aspire and which would, for them, constitute a successful fatigue management programme.

The participants identified physical, cognitive and emotional dimensions to their fatigue following SCI [18] and also identified physical (e.g. optimising posture and sleep), cognitive (e.g. engaging in absorbing activities, budgeting) and emotional (e.g. positive self-talk, ‘naming’ and acknowledging fatigue) strategies that helped them cope with fatigue. Their data suggest that to be relevant, a fatigue management programme would address the multi-dimensional nature of fatigue in SCI. This study has identified several components of such a programme (Table II).

Researchers exploring the experience and management of fatigue in MS have identified the importance of similar physical strategies (incorporating rest, planning activities, recruiting assistance, balancing daily activities and using equipment) [32,33]; emotional strategies (challenging negative self-talk [33], developing an awareness and understanding of fatigue and its impact on the performance of, and participation in, daily activities [32]; attaining realistic self-expectations and a realistic acknowledgment and acceptance of one’s limitations – making ‘peace with the diagnosis’ [33]); and cognitive strategies (refocussing one’s priorities, becoming pro-active in soliciting assistance, cognitively restructuring one’s attitude towards impairment and seeking to regain control over one’s life) [33,34].

The premise that a relevant fatigue management programme for people with SCI would be one in which cognitive and emotional elements would be considered alongside the physical dimensions of fatigue is supported by research findings indicating that those people with MS who perceive their impairment as being the most disruptive to their lives also report the highest levels of fatigue, even in the presence of minimal disease severity [35]; and that quality of life is a product of cognitive appraisal and not simply of physical contingencies [36]. Moreover, perceptions of helplessness and hopelessness among people with MS (characterised by feelings of uselessness, of having little control over one’s life and of being unable to do the things one wishes to do) [37] are associated with higher levels of both fatigue and depression; and have been found to mediate the relationship between physical impairment and fatigue severity [37].

Being engrossed in an absorbing activity was frequently cited as being an antidote to both pain and fatigue. However, the participants with SCI in this study aspired, not simply to reduced levels of fatigue, but to increased participation in rewarding, fulfilling and personally meaningful occupations. Frustrated by the additional limitations that fatigue placed on daily activities already severely constrained by physical impairments [3,7,8,38], the participants wanted a fatigue management programme that would enable them to maximise their residual abilities and achieve greater participation in the everyday lives of their families and communities. The ability to ‘do’ more was perceived to be a central determinant of ‘quality of life’ and a key indicator of a successful programme outcome.

The participants in this study identified the need to incorporate the involvement of peers in the delivery of a fatigue management programme, such that people with SCI have the opportunity to learn from others with SCI as well as from knowledgeable professionals. This is congruent with the findings of studies among people with MS [34].

It is apparent that relevant appraisal of outcomes following a fatigue management programme for people with SCI would need to consider issues pertaining to quality of life, and not simply to improvements of physical endurance gauged by such measures as the Fatigue Severity Scale [27] Fatigue is a multi-dimensional experience which negatively
impacts upon multiple dimensions of life and of quality of life following SCI and a successful management programme is perceived to be one that would enable people with SCI to do the things that are important to them, to give them a sense of enhanced control over their lives, to reduce pain and helplessness, increase motivation and enhance relationships strained by fatigue.

Acknowledgements

The authors greatly appreciate the time and input of the study participants; as well as the following people who made valuable contributions to research planning and data collection: Dr. Andrea Townsend, Tracy Henderson, Dr. Joanna Mereu and Cordelle Neufeld. They also acknowledge the Canadian Institutes of Health Research Institute of Aging who provided a New Investigator salary award for Dr. Miller. This research was funded by a Michael Smith Foundation for Health Research, Disability Health Research Network grant.

References


Copyright of Disability & Rehabilitation is the property of Taylor & Francis Ltd and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.