EVALUATING THE COMPREHENSIVE FATIGUE ASSESSMENT BATTERY FOR
ADULTS WITH SPINAL CORD INJURY

by

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Abstract

Background: Individuals living with spinal cord injuries (SCI) are faced with the increased likelihood of secondary health complications, affecting their physical and psychological functioning. Fatigue is among the most common of these problems and has been shown to profoundly affect the lives of people living with SCI. To develop effective fatigue management programs, clinicians first must be able to identify potential causes of fatigue. However, to our knowledge, there is currently no validated, comprehensive assessment battery of this kind.

Purpose: The purpose of this study is to test the convergent validity, and internal consistency of a novel Comprehensive Fatigue Assessment Battery for People with Spinal Cord Injury (CFAB-SCI) and to further our understanding of fatigue in SCI. Methods: Seventy community-dwelling adults with SCI were recruited. The participants completed the CFAB-SCI as well as six additional self-report measures to assess convergent validity with six matching sections of the battery. Convergent validity was assessed via Spearman’s ρ correlation, and internal consistency via Cronbach’s α. Open-ended survey data from the CFAB-SCI was analyzed to explore fatigue using a content analysis approach. Results: A total of 64 participants competed the study. Convergent validity and internal consistency values all exceeded the hypothesized values. Content analysis of text data revealed four major groupings when participants were asked to tell us more about their fatigue: 1) experience with fatigue; 2) impact of fatigue; 3) factors of fatigue; and 4) management of fatigue. Significance: Evidence reveals the complexity of fatigue and supports the validity and reliability of the self-report CFAB-SCI as a comprehensive, clinically useful tool to characterize fatigue in SCI. It will offer people with SCI an understanding of factors that may contribute to their fatigue experience and will direct the treatment decisions of clinicians who are intervening to mitigate the impact of fatigue.
Preface

One research study was conducted for this thesis. Identification and design of the research study was done in collaboration between the graduate student supervisor, the supervisory committee and myself. I was solely responsible for the data collection, data analysis, and writing of the thesis. The contributions from the supervisor and supervisory committee included guidance on the design of the research project and review of written work in preparation for thesis proposal, defence, and eventually journal submission. There were no other collaborators in this study.

Ethics approval was obtained from the UBC Behavioural Research Ethics Board.

Project title: Evaluating the Comprehensive Fatigue Assessment Battery for Adults with Spinal Cord Injury

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1 Introduction

Fatigue is a subjective feeling of exhaustion and sense of tiredness that is commonly experienced in the general population. For a person who is healthy, fatigue is usually triggered by mental or physical exertion that may alleviate with rest. For many people who experience chronic illness however, fatigue becomes a part of their every day life. It may appear without a trigger and could persist to hinder their day-to-day living. Fatigue is present across many neurological disorders such as multiple sclerosis (MS), Parkinson’s disease, stroke, traumatic brain injury (TBI), and spinal cord injury (SCI). Currently, the fatigue experience for people with SCI is poorly understood despite being highly prevalent in the population. What is known is that fatigue is a debilitating symptom that can dramatically affect a person’s functioning and quality of life. Thus, a focus is needed to understand, evaluate, and manage fatigue in the SCI population.

This thesis will work to address the understanding and evaluation of fatigue in SCI, which will in turn contribute to its management. The Comprehensive Fatigue Assessment Battery for Spinal Cord Injury (CFAB-SCI) is a tool in development to characterize fatigue and the factors of fatigue in SCI. This study collected data from community-dwelling adults with traumatic SCI through a Canada wide postal survey. The purpose of this study is to continue the evaluation of the CFAB-SCI by testing the validity and reliability of the battery. Secondly, the purpose is to further our understanding of fatigue in SCI by analyzing the open-ended survey data provided by participants who completed the CFAB-SCI. Chapter 1 will go in-depth into SCI and the fatigue experience, including a rationale for the research project. Chapter 2 will discuss the methods of this study and Chapter 3 will present the findings. These findings will be
discussed in Chapter 4, and the significance and impact of this study will be presented in Chapter 5.

1.1 Spinal Cord Injury

SCI is a chronic neurological disorder that occurs as a result of damage to the spinal cord and blocks or interrupts neural function between the brain and body. After SCI, the sensory, motor and reflex messages are affected. These messages may not be able to get past the damage in the spinal cord, or if they do, may be transmitted abnormally. SCI often results in profound and long-term disability and has tremendous social costs associated with expensive health care treatment, rehabilitation, and lost productivity. SCI is defined as either traumatic or non-traumatic. Traumatic spinal cord injury is a result of direct trauma to the spinal cord from events such as motor vehicle accidents, sports accidents, or violence. Non-traumatic spinal cord injury is a result of non-traumatic causes and includes etiologies such as spinal stenosis, spinal tumor, vascular ischemia, or congenital diseases (e.g., spina bifida). Injuries are referred to as complete or incomplete, based on whether any movement or sensation occurs at or below the level of injury. When all four limbs are impacted by the injury, this is called tetraplegia or quadriplegia, and when only the lower limbs are affected this is called paraplegia.

Pickett et al. described the epidemiology of traumatic SCI in a Canadian population. Age-adjusted incidence rates were 41.79 per million per annum among adults 15-64 years old, 50.87 per million per annum for adults above 65 years of age, and only 3.37 per million per annum for children. Male to female ratio in SCI was 3:1 and a bimodal age distribution was shown that peaks in the third and eight decades. Injuries in the cervical spinal cord were the most common, followed by thoracic injuries. Complete SCI and central cord syndrome were the most common types of injury presented in this sample. Overall, motor vehicle accidents and falls were
the most common causes of injury (35% and 31% respectively). Falls were the most common cause of injury in patients older than 65 years. Most falls occurred at the ground level as opposed to from a height. Motor vehicle accidents were the most frequent causes of SCI in young and middle-aged people.\textsuperscript{13} Accidents involving other types of vehicles were the third most common cause of injury, followed by sports-related injuries and violence. Eight percent of patients died during hospitalization, and increasing age was significantly associated with risk of death.

Mortality was 18% in patients above 60 years old compared to 5% in younger population. For patients with SCI, 71% chose surgical treatment. The mean length of stay in the hospital was 16.8 days for acute traumatic SCI, which was significantly associated with severity of injury.\textsuperscript{13}

These epidemiological values are similar to what is observed globally. According to a literature review by Wyndaele & Wyndaele,\textsuperscript{15} the global incidence rate of SCI lies between 10.4 and 83 per million per annum. One third of patients reported to have tetraplegia with two-thirds reporting paraplegia. Additionally 50% of people with SCI have a complete injury. The mean age at time of injury is 33 years old, and the male/female ratio is 3.8:1. The mean age at injury has increased from 28 years during the 1970s to 37 years between 2005 and 2008. This trend is representative of the increasing median age of the general population.\textsuperscript{16} Mortality rates immediately following SCI are high, with 20% of people with traumatic SCI dying before arrival to the hospital.\textsuperscript{17} These rates improve considerably after admission, but still remain around 13%.\textsuperscript{18}

In general, the higher on the spinal cord the injury occurs, the more dysfunction the person will experience. The most severe of the spinal cord injury levels is a high cervical injury located between vertebrae C1-C4. This causes paralysis in the arms, hands, trunk, and legs. A person with a high level cervical injury may not be able to breath on their own or control their
bowel or bladder movements. An injury on the lower half of the cervical spine (C5-C8) will still affect all four limbs, however the lower injury, the more control and independence they may have. People with cervical injuries will typically use power wheelchairs for mobility purposes.\textsuperscript{12}

The thoracic vertebrae are located in the mid-back. An injury to the upper thoracic area, between vertebrae T1-T5 will typically allow for normal arm and hand function and the use of a manual wheelchair. However, the trunk and legs are still affected. Injury to the T6-T12 vertebrae is typically associated with normal upper-body movement and trunk balance and control. Injuries to the lumbar or sacral spins (L1-L5; S1-S5) results in some loss of function in the hips and legs however there is potential to walk with or without an assistive device depending on the location of the injury. There is still little or no voluntary control of the bowel or bladder.\textsuperscript{12}

To describe the extent and severity of people with SCI and to determine their future care, a system of tests are administered to assign the patient a grade. This is referred to as the American Spinal Injury Association (ASIA) Impairment Scale (AIS). The patient is assigned one of five grades, depending on sensation and motor function. These tests are typically done within 72 hours of injury.\textsuperscript{12,19} Grade A is the most severe grade, representing complete lack of motor and sensory function below the level of injury. This is a complete injury. Grade B, sensory incomplete, has some sensory but no motor function preserved below the level of injury. Grade C, motor incomplete, has some motor function preserved below the level of injury, however 50 percent of key muscles below the neurological level of injury cannot be moved against gravity. Grade D, also motor incomplete, is similar to Grade C however there is more than 50 percent of key muscle function with full range of motion against gravity. Finally Grade E, normal, has all neurologic function returned to normal.\textsuperscript{12,19}
Acute SCI is comprised of both primary and secondary injury causing severe pathophysiological processes needing immediate medical and surgical management. A traumatic blow to the spinal cord causes the primary injury, resulting in compression forces on the spinal column and damage to the nervous system and blood vessels. This triggers the secondary injury, causing disruption of the microvasculature leading to haemorrhage and edema. Respiratory and cardiovascular dysfunction may exacerbate the effects of the SCI in the acute phase. If untreated, this could lead to systematic hypoxemia and hypotension causing irreversible damage.\textsuperscript{20}

The most essential aspect of acute medical treatment in SCI is the assessment and management of primary and secondary effects in the immediate period after injury. To counter the deleterious effect of the secondary injury cascade, the primary focus is to optimize tissue oxygenation and perfusion. Additionally, avoiding hypotension while inducing hypertension, monitoring for bradycardia and other arrhythmias, and promptly transferring patients to a specialized center are all fundamental in management of acute SCI.\textsuperscript{20} The administration of neuroprotective and neuroregenerative agents and decompression surgery are the next steps in the treatment of acute SCI. These are both at the center of research and debate. There is considerable controversy regarding the type of neuroprotective agents to administer in SCI.\textsuperscript{19, 20} Multi-phase clinical trials are currently ongoing to provide evidence of the efficacy and safety of multiple types of agents.\textsuperscript{20} Decompression surgery is crucial in removing the compressive forces on the spinal cord, restoring anatomical alignment and re-establishing spinal stability. The timing of spinal cord decompression is also a pervasive topic of debate.\textsuperscript{19, 20} There is evidence from a large-scale observational study that surgery performed within 24 hours improves motor neurological recovery and reduces length of stay in hospitals.\textsuperscript{21} However the optimal timing for decompression has yet to be established in clinical trials.\textsuperscript{19} The ability to accurately prognosticate
outcomes early on in the SCI is valuable for clinical, research, and patient perspectives. Typically, survival rates, neurological recovery, and functional recovery are regarded as the most important prognostic indicators.\(^{20}\)

Nearly all injuries to the spinal cord result in damage to both upper and lower motor neurons.\(^{22}\) The prognosis for regeneration differ between the two, therefore it is essential to establish the contributions of each type of neuron to loss of function. Lower motor neurons are damaged or lost in the central grey matter, and this can occur both at the injury site and in areas above and below the injury. This results in flaccid paralysis at the injury level.\(^{22}\) The clinical characteristics of lower motor neuron loss are presented in Table 1.1. Upper motor neuron damage is indicated by injury to the surrounding white matter below the level of injury.\(^{22}\) The clinical characteristic of upper motor neuron loss is also presented in Table 1.1.

**Table 1.1 – Clinical characteristics of upper and lower motor-neuron injury**

<table>
<thead>
<tr>
<th>Manifestation</th>
<th>Upper motor neuron</th>
<th>Lower motor neuron</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reflexes</td>
<td>Hyperactive</td>
<td>Diminished/absent</td>
</tr>
<tr>
<td>Atrophy</td>
<td>Less prominent</td>
<td>Present</td>
</tr>
<tr>
<td>Fasciculations</td>
<td>Absent</td>
<td>Present</td>
</tr>
<tr>
<td>Tone</td>
<td>Increased</td>
<td>Decreased</td>
</tr>
<tr>
<td>Pathological reflexes: Babinski</td>
<td>Dorsiflexion response</td>
<td>Absent or plantar flexion if L5 motor neurons damaged</td>
</tr>
</tbody>
</table>

*(McDonald & Sadowsky 2002; pg.418)*
Concurrent with the effects of acute SCI, individuals chronically living with this injury commonly face an increased likelihood of secondary health complications that affect their physical and psychological functioning. In Jensen and colleagues’ literature review, it was found that common secondary health problems associated with SCI include anxiety, muscle spasms, bowel and bladder regulation problems, pressure ulcers, cardiovascular problems, and issues with sexual activity.

Anxiety is a subjective feeling of worry, nervousness, or unease. Up to 40% of people with SCI are at risk for abnormal levels of anxiety or an anxiety disorder, and it has shown to be a major concern for people with SCI. Spasticity is a motor disorder characterized by an increase in muscle tone with exaggerated tendon jerks, caused by hyper-excitability of the stretch reflexes. Between 53-78% of individuals have reported spasticity in SCI, and 41% lists it as a major obstacle to community and workplace re-integration. The primary cause of bowel dysfunction in SCI is the lack of autonomic control of the gastrointestinal tract. This may lead to prolonged bowel transit time, constipation, fecal incontinence, and abdominal distension after eating a meal. An estimate of 49% of people with SCI experience occasional fecal incontinency, and 58% experience constipation. Disruption of sacral neural connectivity causes a loss of coordinated bladder filling and emptying. This causes complications such as urinary incontinence, urinary tract infections (UTI), bladder stones and bladder cancer. Approximately 46-48% of people with SCI experience UTIs, and 37-38% may experience urinary incontinence.

A pressure ulcer is a skin condition that is a result of externally applied pressure and/or friction for a prolonged period of time. More severe pressure ulcers can damage deep tissue. Prevalence has been reported between 10-38% of people with SCI, and pressure ulcers can have
a large impact on quality life and daily living. There is a large range of possible cardiovascular problems in SCI that includes autonomic dysreflexia (AD), orthostatic hypotension (OH), and cardiovascular disease (CVD). AD is a potentially fatal clinical emergency, which causes acute elevation of arterial blood pressure and is triggered by stimulation below the injury. OH is the reduction in systolic blood pressure caused by a change in position from supine to upright. It may lead to venous pooling and reduced cerebral blood flow triggering dizziness and fainting. CVD is the leading cause of mortality in both the able-bodied and SCI population, however it has been shown to be more prevalent in the SCI population. The prevalence of symptomatic CVD is between 30-50% in people with SCI, and between 60-70% are estimated to have asymptomatic CVD. SCI largely disrupts sexual health across many physiological, psychological and social dimensions. Physiological effects can alter sexual responses including genital sensation, arousal, ejaculation in males, and sensation of orgasm in females. These cause issues with sexual functioning, ability to engage in sexual activities, sexual intimacy and relationships, sexual self-view, and fertility and reproductive health.

Many symptoms in SCI are reported to either stay the same or worsen after initial onset of the symptom. The high level of symptom severity in the SCI population is closely linked to psychological function and social integration, and can have a large impact on people with SCI. Though individuals experiencing SCI encounter an array of problems that are indirectly associated with their disability; fatigue is among the most prevalent and appears to be closely linked to patient functioning. Self-reported fatigue has been shown to be present among 67-74% of the SCI population. Additionally, it is reported that 57% of outpatients with a SCI for longer than 1 year reported fatigue severe enough to interfere with function.
Though fatigue is one of the most common complications associated with SCI, treatment of fatigue receives limited attention in literature. This may be due to confusion surrounding the definition of the term fatigue, and the subsequent difficulty in assessing and managing fatigue. Fatigue is a word commonly used in colloquial language, which poses a problem differentiating scientific usage from everyday usage. Additionally, the experience of fatigue is subjective in nature, and is dependent upon an individual’s perception. This causes an overlap between the lay notion of tiredness and the clinically relevant symptom of fatigue. However, when present, patients with neurological disorders may describe their fatigue as one of the worst symptoms of their disorder or injury. Fatigue has been shown to profoundly affect the lives of people living with SCI, as it can interfere with work, social life, physical functioning, and other activities of daily living while markedly diminishing quality of life following injury. Therefore, it is crucial to determine effective ways to assess and manage fatigue in individuals with SCI.

1.2 Definition and Types of Fatigue

There are various definitions that are used in the literature to characterize the construct of fatigue. Fatigue can be seen as an “overwhelming sense of tiredness, lack of energy, and often a feeling of total exhaustion”. Fatigue can also be defined as “a mismatch between the energy required to perform routine tasks and the energy available to do the tasks”. Ream et al. revealed four defining attributes of fatigue in a concept analysis: “1) a total body feeling and experience, encompassing physical, cognitive and emotional dimensions; 2) an odious and unpleasant experience which causes distress; 3) a chronic and unrelenting phenomenon; 4) a subjective experience dependent upon an individual’s perceptions.”
Several types of fatigue have been described. The distinction between chronic and acute fatigue is defined for many people with long-term conditions. Chronic fatigue is defined as a state of excessive chronic tiredness and a pervasive feeling of exhaustion. Also known as “pathological fatigue”, the state of weariness in chronic fatigue is unrelated to previous exertion levels and likely has multiple or unknown causes. The severity of chronic fatigue should be distinguished from the transient and mild fatigue experienced by healthy adults. Chronic fatigue following SCI is also linked with aging, physiological and psychological deconditioning. Acute fatigue is generally the result of over exertion, acute infection or acute stressful events and can be ameliorated by rest. It is characterized by a rapid onset, a short duration and has an identifiable cause.

Fatigue may also be separated into peripheral and central fatigue. Peripheral fatigue, or neuromuscular fatigue, is attributable to a failure of a component of the motor unit in the peripheral nervous system, causing muscle fatigability. Central fatigue arises from the central nervous system (CNS), implicating the brain and spinal cord. During exercise or sustained muscle activity, central activation failure causes suboptimal CNS output to the motor unit, resulting in muscle fatigue. Central fatigue also may cause a feeling of total exhaustion.

Finally, fatigue may be classified as physical, mental (cognitive), or affective fatigue. Physical fatigue is viewed as the inability to initiate or maintain sustained voluntary activity. Mental fatigue is the failure to endure sustained mental tasks that may require attention, organization, sequencing, or problem solving. Affective fatigue is characterized by decreased motivation or interest. It is important to note that this paper will focus on chronic or pathological fatigue in SCI. Additionally; chronic fatigue in SCI must be distinguished from Chronic Fatigue Syndrome (CFS). Although CFS is characterized by a new onset of severe
fatigue, it is associated with flu-like symptoms and cannot be explained by other medical conditions such as SCI.\textsuperscript{3}

1.3 Theories of Fatigue

A way to understand a construct such as fatigue is to explore its conceptual frameworks. There were no conceptual frameworks found to characterize fatigue in SCI, however a few exist for other clinical populations. A theoretical model was proposed in the literature pertaining to fatigue in Chronic Fatigue Syndrome (CFS). It states that behavioural, cognitive and affective factors perpetuate fatigue.\textsuperscript{40} According to this model, patients with CFS avoid physical activity due to fear of it worsening symptoms. This avoidance behaviour in fact leads to more severe symptoms due to physical deconditioning. Attributing this behaviour to a somatic cause may lead to lowered sense of control over symptoms, possibly producing a mood disorder. Consequently, as depression is associated with low levels of physical activity, this may in turn contribute to further physical inactivity.\textsuperscript{41}

Vercoulen et al.\textsuperscript{41} tested the causal relationships of this model in CFS and MS patients. Attributing complaints to a somatic cause produced low levels of physical activity, creating a causal effect on the severity of fatigue. The patients’ sense of control over their symptoms, and focusing on these bodily symptoms, each had a direct causal effect on fatigue. Depression was eliminated from this model. This model demonstrated excellent fit with the CFS sample, however was rejected with the MS sample. Therefore a new model was developed for those with MS, where sense of control had a direct causal relationship with fatigue leading to impairment, however the physical state has no causal relationship with fatigue.\textsuperscript{41} This model demonstrates that cognitive and behavioural factors have an effect on the frequency and severity of fatigue.
Another theory proposed for fatigue in CFS is The Envelope Theory. The theory postulates: “those people with CFS who overexert themselves and push the limits of their energy resources might need to reduce their activity levels, whereas those who are not active enough might need to increase their activity levels.” Therefore keeping patients’ daily energy expenditure within the range of their available or perceived energy levels would in turn decrease fatigue. Findings show that when perceived energy levels were maintained closely with energy expenditure, participants experience decreased fatigue over time. This theory integrated into an intervention for fatigue may help to alleviate fatigue in CFS and possibly other clinical populations who experience fatigue.

Another clinical population who commonly experiences fatigue is cancer. Cancer-related fatigue (CRF) is reported to be the most common and troublesome symptom of cancer. Purcell et al. proposed a theoretical framework to further understanding and possible treatment of fatigue in the cancer population. The model presents predetermined factors of fatigue that cannot be controlled by the patient, such as disease-related factors, treatment-related factors, comorbidities, and underlying biomedical factors. However the experience with fatigue is modified by the patient’s own unique factors, such as physical/behavioural, psychological and socio-demographic factors. Fatigue in turn functionally impacts areas such as work, activities of daily living and overall health-related quality of life.

Although these conceptual frameworks are presented in non-SCI populations, there is reason to believe the fatigue experience may share similarities between clinical populations. These models reveal the complexity of both the fatigue experience and trying to manage fatigue. In most clinical populations, fatigue can be seen to have multiple contributing factors affecting
the frequency and severity of one’s symptoms. The factors associated with fatigue in SCI will be highlighted in a later section.

1.4 Pathophysiology of Fatigue

Although fatigue is a common symptom of SCI, very little is known about the pathophysiology of fatigue in SCI. Although understanding the pathophysiology would prove valuable towards treating fatigue, no studies having been found evaluating the biological factors of fatigue in SCI. Fatigue is a predominant symptom in MS, and therefore a greater amount of research is conducted on fatigue in the MS population. With SCI and MS both being chronic conditions involving pathology of the central nervous system, it is helpful to explore the literature pertaining to fatigue in MS and how it might relate to SCI. There is slightly more focus on the pathophysiology of fatigue in the MS population, however the research is non-conclusive. Studies have failed to develop an association between typical medical imaging markers in MS and fatigue. Additionally, there is contradictory evidence evaluating the relationship between MS-related fatigue and pathophysiological mechanisms, including autoimmune and neuroendocrine dysregulation, autonomic system dysfunction, and peripheral muscular mechanisms.\textsuperscript{44} For this reason, Bol et al.\textsuperscript{44} discusses the possibility of psychological mechanisms, such as mood, anxiety, cognition, personality, and cognitive-behavioral factors, to explain fatigue in MS. Nonetheless, further research is needed to explore the pathophysiological mechanisms of fatigue in neurological populations, especially SCI.

1.5 Factors Associated with Fatigue in SCI

Focus groups undertaken by Hammell et al.\textsuperscript{24} revealed three dimensions to fatigue: physical, cognitive, and emotional. The physical dimension was characterized by weakness, the need to change position, the need to relieve muscle tension, and coping with paralyzed limbs,
pain and unpleasant physical sensations. The cognitive dimension was characterized by being overwhelmed, the exhaustion of having to plan due to their injury, and having to use the body in a different way. Finally, the emotional dimension was explained as the frustration of not being able to do things due to their injury. Fatigue dictated that energy is only available for certain activities, which caused a reduction in the ability to engage in pleasurable activities. This caused a cycle of decreased motivation, increased depression, and increased fatigue. Together, physical, cognitive, and emotional fatigue suggest that it is a complex phenomenon in SCI. However it is important to note that there are distinctions between dimensions of fatigue and factors of fatigue. While dimensions help to characterize the construct of fatigue, factors are influences that may contribute to the outcome of fatigue. There are many potential factors that determine the presence and severity of fatigue in each individual.

One of the most common factors associated with fatigue is chronic pain. Chronic pain is associated with reduced personal functioning in people with severe illness and injury. It has been reported that more than 80% of adults with SCI are affected by chronic pain. Various types of pain were reported following SCI including neuropathic (central and peripheral nervous system), nociceptive (musculoskeletal), visceral (abdominal), or a combination of these. Pain was the factor most frequently cited in the study by Hammell et al. as an integral part of fatigue. In another study, fatigue experienced by people with SCI has shown to be significantly associated with bodily pain. Craig et al. demonstrated that patients with high levels of pain were 9 times more likely to have chronic fatigue. High co-occurrence between pain and fatigue was also reported by Craig et al., given that almost 70% of participants with high chronic pain also had high chronic fatigue, whereas 80% of participants who reported low chronic pain had low levels of chronic fatigue. Furthermore, another study reported that 27% of individuals with
SCI who experienced chronic pain also reported experiencing excessive fatigue within the past three months.48

SCI is also believed to place the individual at a high risk of psychological morbidity, which in turn is associated with fatigue.25 Psychological consequences associated with SCI include depression and/or depressive mood states, anxiety and distress, and post-traumatic stress disorder.25 Research has suggested a large overlap between fatigue and psychological morbidity 4 and depression may cause the symptoms of fatigue to be exacerbated.2 Depression is the most common psychological complication of SCI, with a prevalence between 20%-40%.25 Thirty percent of individuals with SCI are at risk of becoming depressed during rehabilitation, and 27% are at risk of raised levels of depressive symptoms when living in the community.25 In a cross-sectional survey, Alschuler et al.49 found a statistically significant correlation (P < 0.001) between fatigue and depressive symptoms among individuals with SCI. A study by Craig and colleagues 37 showed that participants with higher levels of depressive moods experienced higher levels of fatigue after participating in extended cognitive tasks. Qualitative studies have indicated that participants with SCI report pain and depression among the primary contributors to their fatigue.9,24 People with SCI may be caught in a cycle, where feelings of low energy, fatigue, low mood, and reduced motivation caused by depression may lead to a diminishment in personally meaningful activities. This in turn increases fatigue and depression, causing the cycle to be repeated.24

Medication may be another contributor to fatigue. People with SCI face many medical issues requiring or supporting the use of prescription medication, over the counter remedies, alternatives, and complementary substances. However, many of these may have side effects that magnify fatigue. Commonly prescribed categories of medications such as anti-spasticity
medications and analgesic medications were found to contribute to fatigue in the SCI population. Conventional antidepressants could also worsen fatigue and anxiety due to their side effects. Other common medications that may increase fatigue include β-blockers to treat cardiovascular issues, anxiolytics to treat anxiety, antiepileptic medication to manage epileptic seizures, anti-psychotics, dopaminergic medication used for a variety of conditions, proton pump inhibitors to reduce gastric acid production, and chemotherapeutic agents. In a study examining the effects of medication on fatigue, 28% of medications were determined by clinicians to be causing fatigue in SCI. Many people with SCI have identified the side effects of their medications as contributors to their feelings of lethargy, disengagement and detachment.

General sleep problems in SCI are emphasized by greater difficulty in falling asleep, poor subjective quality of sleep, more frequent use of sleep medication, sleeping more hours, snoring, and taking longer naps. Other sleep conditions recurring with SCI include sleep breathing disorders (e.g. obstructive sleep apnea) and sleep-related movement disorders (e.g. restless leg syndrome). People with SCI tend to experience far more sleep dysfunction than the general population, and are highly likely to self-report sleeping difficulty. Jensen et al. revealed that their SCI sample reported significantly greater sleep disturbance, more snoring, fewer hours of sleep per night, poorer sleep adequacy, and greater daytime somnolence than both chronically ill populations and the general population (p < 0.001). Participants with SCI also reported significantly more night-time respiratory difficulties than the general population (p < 0.001). In a sample of 822 participants with SCI, 49% had sleep dysfunction unrelated to sleep apnea. Research has also shown a significant association (p < 0.01) between fatigue and sleep problems in the SCI population. Furthermore, people with SCI identify sleep problems as being a significant contributor to their fatigue. Poor quality, disturbed sleep was attributed to pain,
spasticity, and the need to move and turn causing greater difficulty in getting comfortable and achieving adequate sleep. De Groot et al. proposed that working on improving sleep and minimizing sleep disturbances could prove beneficial in alleviating fatigue.

Stress related to the life-altering effects and chronic disability of SCI may be overwhelming and could be considered a contributor to fatigue. Participants interviewed by Hammell et al. observed that because the injury and fatigue are also wearing for partners, this added to the stress experienced by the person with SCI. Worrying about the burden being imposed on their caregiver and their well-being exacerbates the stress associated with SCI. Moreover, the large amount of effort required to perform routine self-care tasks and the considerable degree of planning needed while living with SCI can also add to the perceived stress and may contribute to fatigue.

Environmental factors are considered another contributor to fatigue. The prevalence of environmental barriers faced by the SCI population is extensive. In a study by Cao et al. participants reported at least one of the following barriers: policy related (22%), physical and structural barrier (46%), attitudinal and support barrier (22%), barrier to services and assistance (26%), and barrier at work or school (13%). Hammel et al. created a conceptual framework to describe how environmental factors influence the participation of people with neurological conditions, including SCI. They highlight 8 domains of environmental facilitators and barriers: 1) built environment; 2) natural environment; 3) transportation; 4) systems, services and policies; 5) economic factors; 6) social supports and societal attitudes; 7) information and technology access; and 8) assistive technology. Each of these domains has factors at the personal, community and societal level, which can influence participation either positively or negatively. Participation outcomes can be impacted in multiple areas, including home, community, work and
economic, and social areas.\textsuperscript{59} There is a significant relationship between perceived environmental barriers and community integration for people with SCI.\textsuperscript{60} Physical and structural barriers, and services and assistance barriers have been found to significantly predict subjective physical and mental health in chronic SCI.\textsuperscript{58} Fatigue may also be limiting, causing an increase in environmental barriers.\textsuperscript{24} With the expectations arising from a sociocultural environment that values independence, paid employment, and self-sufficiency, being limited by fatigue and their injury causes an increased burden.\textsuperscript{24}

Behavioural factors may also be associated with fatigue in SCI. Saunders et al.\textsuperscript{61} revealed that lack of exercise, poor diet, and daily use of prescription medication for pain are among dominant behavioural factors contributing to fatigue. Participants with less exercise were 2.74 times more likely of reporting disabling fatigue. Those who reported a poor diet were 3.13 times more likely of reporting disabling fatigue. And participants who reported daily use of prescription medication for pain were 3.46 times more likely to have disabling fatigue.\textsuperscript{61} Other behavioural factors associated with fatigue included prescription medication for stress, alcohol use, days out of bed, and days out of the house.\textsuperscript{61} Both nutrition and exercise, including the associated problem of weight gain were also cited by Hammell et al.\textsuperscript{7} as influencing behavioural factors of fatigue.

The association between fatigue and the factors presented above tend to be reciprocal. The exact causal relationships between fatigue and other secondary complications in SCI are undefined in the literature, yet it is understood that these symptoms are likely to co-occur. Hammell et al.\textsuperscript{24} identified close interrelationships between fatigue, depression, pain, and hopelessness, which some participants viewed as inseparable. They also perceived that pain and fatigue were both a cause and effect of depression.\textsuperscript{24} Studies have quantified the relationship
between fatigue, pain, and depression in SCI. Craig et al. developed a theoretical model towards this end. They proposed that 1) pain makes a direct causal contribution to depression that strengthens over time, and 2) pain and depression each contribute to fatigue. Forwell et al. further developed this relationship by evaluating it longitudinally during acute SCI rehabilitation. Fatigue, pain, and depression were inter-correlated at baseline, discharge, and at a 6-month follow-up into the community. They also found that these associations became increasingly strong at each of the three time points. Diab et al. examined these three conditions along with sleep problems, and found statistically significant correlations among them. With sleep problems as the dependent variable, a regression analysis revealed that fatigue, pain, and depression each made unique, statistically significant contributions to the model.

Fatigue is very complex in nature and affects the daily lives of those living with SCI. While it is important to develop effective management programs, clinicians report that fatigue, pain, and spasticity complicate treatment sessions. Researchers have argued that many factors may contribute to fatigue severity in chronic illnesses, and that a multidisciplinary approach to fatigue treatment is required.

1.6 Managing Fatigue

Hammell et al. conducted a qualitative analysis to identify the appropriate components of a fatigue management programme from the perspectives of people with SCI. The desirable components of a fatigue management programme were grouped into four areas: defining fatigue, identifying and managing factors associated with fatigue, enabling participation in valued occupations, and programme delivery. Participants stated the importance of defining fatigue, how it may be experienced, and how it may differ from the able-bodied populations. They also suggested it would be useful to understand the relationship between fatigue and other factors.
such as pain and depression. Participants also felt it was important to explore both their medical status and factors that may be associated with their fatigue with a knowledgeable professional in order to identify any co-existing physical or emotional problems. With this, they stressed the importance of developing strategies or interventions that target and mitigate these complications, which they called the “root of the problem”\(^9\) of fatigue. The participants also placed emphasis on the importance of participating in occupations that were experienced as being rewarding or personally important. 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. Participants also suggested a basic manual and a programme led by knowledgeable professionals as ways to enhance programme delivery. Quality of life, engaging in meaningful activities, and having more control over one’s life were identified as important outcomes or indicators of a successful fatigue management programme.\(^9\) In the end, the research team suggested, “to be relevant, a fatigue management programme would address the multidimensional nature of fatigue in SCI”.\(^9\) For clinicians to thus develop relevant fatigue management programs for individuals with SCI, they must first have the ability to assess the impact of fatigue in SCI and identify its contributing factors.

Although the findings by Hammell et al.\(^9\) prove valuable, there were no studies found evaluating fatigue interventions in the SCI population. Despite the lack of evidence-based interventions for SCI, plenty exist for managing fatigue in the MS population. A commonly cited fatigue management strategy in MS literature is the use of energy conservation.\(^64\) The Multiple Sclerosis Council for Clinical Practice Guidelines defines energy conservation as: “the identification and development of activity modifications to reduce fatigue through a systematic analysis of daily work, home, and leisure activities in all relevant environments.”\(^65\)
Common energy conservation strategies include: “analyzing and modifying activities to reduce energy expenditure, balancing work and rest, delegating some activities, examining and modifying standards and priorities, using the body efficiently, organizing workspaces, and using assistive technologies to conserve energy.” A community-based energy conservation course, an online self-management course, and the perceived effectiveness of energy conservation strategies have all been evaluated in the MS population.

A literature review conducted by Asano and colleagues explored rehabilitation interventions that reduce fatigue in MS. The two most common types of interventions were progressive resistance training (3 studies with significant data) and fatigue management programs (9 studies with significant data). The behaviour change interventions presenting significant intervention effect sizes were: energy conservation programs, mindfulness training, cognitive behavioural therapy, relaxation therapy, and inpatient rehabilitation. Although these studies were catered to the MS population, the success of these interventions might suggest that they can be used in the SCI population to also manage fatigue. Further research is needed to evaluate the efficacy of these behavioural change programs in the SCI population.

1.7 Measures of Fatigue

There are several fatigue measurements commonly used in the literature to assess fatigue in neurological populations. As mentioned fatigue is a symptom seen across many neurological disorders such as MS, Parkinson’s disease, stroke, and TBI. In 2014, Tyson and Brown conducted a systematic review to evaluate the psychometric properties and clinical utility of all measures found to evaluate fatigue in neurological populations. Seventeen measures were found, tested in populations ranging from MS, SCI, Parkinson’s disease, acquired brain injury, and motor neuron disease. All involved Likert-type scaling self-reported by the
participants and delivered by interview, post, or telephone. Tyson and Brown 69 evaluated all the measures based on pre-determined criteria for clinical utility and psychometric robustness. The criteria for clinical utility involved factors such as: time to administer, time to analyze, time to interpret, cost, special equipment needed, portability of tool, and accessibility of tool. The strength of psychometric properties was determined by pre-established framework regarding weak, moderate, good, and excellent validity, reliability, or internal consistency. All 17 tools were clinically feasible. Although they all generally presented good psychometric properties, none met all criteria for psychometric robustness set by the authors.69

The measures found by Tyson and Brown 69 include: Fatigue Assessment scale, Profile of Mood States, Multi-dimensional Assessment of Fatigue, Functional Assessment of Chronic Illness Therapy-Fatigue Scale, 4 versions of the Fatigue Severity Scale (5 item version, 7 item version, 9 item version, and MS specific version), 4 versions of the Fatigue Impact Scale (44 item version, 21 item version, 13 item version, and SCI specific version) and 3 versions of the Neurological Fatigue Index (MS specific version, motor neuron disease specific version, and stroke specific version). Among the 17 measures presented by Tyson and Brown, only 2 measures were psychometrically tested in the SCI population: The Fatigue Severity Scale (FSS) and the Modified Fatigue Impact Scale for SCI (MFIS-SCI).69 A search in two separate online databases for rehabilitation outcome measures did not find any further tools evaluating fatigue in SCI.70,71

The FSS 72 and MFIS-SCI 73 are both commonly used measurement tools designed to assess fatigue in the SCI population. Both of these measures presented strong psychometric properties. At the root, these measures share many similarities with only a few variations between the recall time, scoring method, and scoring interpretations. The FSS is a 9-item
measure with a likert-type scale and a recall time of 1 week. The score is calculated by averaging the items and a higher score indicated more severe fatigue. The FSS measures interferences of fatigue with daily life. The items ask participants questions regarding motivation, physical function, responsibilities, work, family or social life, exercise, how easily they are fatigued, frequency of problems, and priority of symptoms. The MFIS-SCI is a 21-item measure also with a likert-type scale and a 1-week recall time. Subscales are added for a total score and a higher score indicates greater fatigue. The MFIS-SCI measures the frequency with which fatigue has affected the participant in the last week. The three subscales include cognitive, physical, and psychosocial domains.

The benefits of the FSS, the MFIS-SCI and the measures of fatigue for other neurological populations are that they act as an outcome measure for fatigue and are able to quantify a construct that is otherwise difficult to evaluate. They assess the frequency and severity of fatigue in a quick and reliable manner. Yet what is considered a benefit may also be considered a limitation. By just acting as an outcome measure, each measure only provides a part of the fatigue assessment picture and does not address the complexity of fatigue nor do they capture the multi-factorial nature of fatigue. In other words, these measures fail to assess the source or possible causes of fatigue and its impact on people with SCI. Most importantly, these measures do not direct treatment decisions for clinicians because in order for clinicians and patients to effectively manage fatigue, it is important to determine the specific factors associated with it. Therefore, a more clinically useful, evidence-based battery is required to evaluate the sources of fatigue, as well as the impact of fatigue on the patient.

69, 72

69, 73
1.8 Development of CFAB-SCI

In 2008, Grant et al.\textsuperscript{74} developed a comprehensive measure for fatigue in SCI called the Comprehensive Fatigue Assessment Battery - Spinal Cord Injury (CFAB-SCI). The CFAB-SCI is a tool to characterize fatigue and the factors of fatigue in SCI. The CFAB-SCI consists of 134 items divided in 11 sections. These sections include: participant information (7 items), medical history (5 items), general health (8 items), fatigue (34 items), environment (11 items), pain (7 items), sleep (14 items), stress (10 items), mood (11 items), nutrition (8 items), and fatigue management history (19 items). The content of the battery is further described in detail in Chapter 2, section 2.3.1. The purpose of the CFAB-SCI is to act as an assessment to help clinicians target and manage the modifiable factors of fatigue. It is important to distinguish this from an outcome measure. An outcome measure is used to quantify a construct in an objective manner. However an assessment, such as the CFAB-SCI, is meant to give clinicians a scope of the issues at hand, and can be interpreted subjectively on a case-by-case basis. Additionally, the CFAB-SCI is designed to be completed as a whole, and not in parts. If particular factors or areas require an evaluation, then it is suggested to use an outcome measure that is specialized in measuring that construct. For example, if it is believed that sleep apnea is a primary cause of fatigue in a patient, then a sleep apnea specific questionnaire could be administered to further explore the issue.

The subsequent ongoing development of this battery was undertaken then in three-phase study. The first phase was an in-depth literature search to identify factors contributing to fatigue in SCI, and measures to assess these factors. Consideration was also made to findings of the qualitative study conducted by Hammell et al.\textsuperscript{24} that explored factors contributing to fatigue in SCI. The factors chosen to be included in the CFAB-SCI were fatigue, pain, sleep, stress, mood,
environment, and nutrition. These were included because they have been shown to be significantly associated with fatigue in the literature. Once they were chosen, it was recognized that these factors are modifiable and that there is an urgency to deal with them. Constructs that have appeared in the SCI literature as common secondary health problems such as spasticity, anxiety, and hopelessness were not included in the CFAB-SCI. Although they appear to be anecdotally associated with fatigue, the in-depth literature review found little to no relationship between these symptoms and fatigue. Once the literature search revealed all of the important factors associated with fatigue, the research team conducted another in-depth literature review to explore measures used to evaluate these factors. Measures that had been used for populations with chronic neurological conditions (i.e. TBI, MS, SCI), had proven psychometrics, and demonstrated clinical utility were identified and considered for inclusion or informed items in the battery.

The development of the battery continued with a second phase. The objective of the second phase was to design a comprehensive fatigue assessment battery and to determine whether the battery represented the factors contributing to fatigue in SCI. Twenty-six measures were identified in phase 1 and congregated into a table. Selection of the most appropriate scales for use in the CFAB-SCI was based on careful consideration of the following criteria: 1) the scale has been used previously in one or more SCI study or with other rehabilitation populations; 2) the scale has good psychometric properties; 3) the scale has good clinical utility based on: administration time, ease of scoring, ease of administrator’s learning and format. Based on these criteria, scales were assigned ratings of ‘Excellent’, ‘Good’, ‘Average’ or ‘Poor’. If assigned an ‘Average’ or ‘Poor’ rating, the scales were not further considered for inclusion in the battery. If two or more scales for an individual construct appeared equal on the above criteria, an item analysis
of the individual scales was undertaken to identify the scale that provides the most useful information to support further clinical decision-making. The highest-rated measures for fatigue and each contributing factor were compiled to form a draft version of the battery. To maintain a consistent format, each measure that was included in the CFAB-SCI at this stage had to be modified. Some items may have been changed or deleted from its original version during the development process to enhance coherence and reduce redundancy. When applicable, Grant et al. set each item in the CFAB-SCI to a 5-point likert type scale and a recall time of 2 weeks. The following is a description of the measures that were included in the draft version of the CFAB-SCI:

1.8.1 Fatigue – Modified Fatigue Impact Scale for SCI (MFIS-SCI)

The MFIS-SCI is a 21-item measure with a 5-point scale assessing the impact of fatigue. Each statement determines how often fatigue has effected the participant in a certain way. A low value indicates that fatigue does not impact that aspect of their life often, while a high value indicates a high impact of fatigue. The measure has been psychometrically tested in the SCI population. Internal consistency was determined with Cronbach’s alpha and was 0.97. It had a correlation of $r = 0.68$ with the Fatigue Severity Scale and $r = 0.64$ with the Center for Epidemiological Depression Scale. The area under the ROC curve was 0.78 (95% confidence interval = 0.65-0.92). At the optimal cutoff score of 24.5, both the sensitivity and specificity were 0.67.

1.8.2 Pain – Brief Pain Inventory– 7 (BPI-7)

The BPI-7 is a 7-item measure evaluating pain interference with activities on a 10-point numerical rating scale. A higher score indicates a higher level of interference. The BPI-7 is a
modified version from the original, however all versions of the BPI have been psychometrically tested in the SCI population. The BPI-7 demonstrated excellent internal consistency, as Cronbach’s alpha was 0.92. The BPI-7 showed strong and significant association ($r = 0.62$) with average pain intensity within the past week (measured by a numerical rating scale), and showed significant and negative correlation with the SF-36 Mental Health Scale (-0.30 to -0.65). Finally, the measure showed clear associations with increasing levels of pain intensity.\textsuperscript{75}

1.8.3 Sleep – Medical Outcomes Study Sleep (MOS-S) Scale

The MOS-S scale is a 12-item measure with a variety of subscales. The most commonly used subscale to evaluate sleep problems is the sleep problems index-9. This includes a sum of 9 of the items evaluating the occurrence of: sleep disturbance, somnolence, sleep adequacy, and awakening short of breath or with headache. The MOS-S is on a 6-point scale ranging from all of the time (1) to none of the time (6). The measure has been psychometrically tested in the general US population\textsuperscript{76} and has been used in the SCI population.\textsuperscript{77} Internal consistency estimates for the MOS Sleep scales were 0.73 or higher, with the exception of daytime somnolence scale which was 0.63. Internal consistency on the 9-item sleep problems index, commonly viewed as a total score, was 0.78-0.83. The 9-item sleep problems index significantly correlated with the Restless Leg Syndrome Quality of Life Questionnaire total life impact score ($\rho = -0.59$).\textsuperscript{78} Significant differences were seen between neuropathic pain patients and general US population on MOS-S scale scores, and the scales were found to be responsive to change in the clinical trial.\textsuperscript{76}

1.8.4 Stress – Perceived Stress Scale (PSS)

The PSS is a 10-item measure evaluating the degree in which life situations make a person stressed. The 5-point scale ranges from never (0) to very often (4). The measure has only
been psychometrically tested in the general population, however it is the most widely used psychological instrument for measuring perceptions of stress and the questions are of a general nature. This avoids content specific to any subpopulation. Many methodological studies have reported a Cronbach’s alpha ranging from 0.74-0.91. A systematic review showed studies have also reported poor-moderate criterion validity with the following measures: College Student Life-Event Scale ($r = .35-.49$), Life Experience Scale ($r = .25-.36$), and Medical Outcomes Study-Short Form 36 ($r = -.21$ to -.70).  

1.8.5 Mood – Patient Health Questionnaire (PHQ-9)

The PHQ-9 is a 9-item measure of depression. The scale consists of 4-points evaluating how often a problem has been perceived as bothersome from not at all (0) to nearly every day (3). The PHQ-9 has been psychometrically tested in the SCI population. Internal consistency was reported as a Cronbach’s alpha value of 0.87. In terms of construct validity, greater depressive symptom severity as measured by the PHQ-9 correlated inversely with the Satisfaction with Life Scale (-0.51) and subjective health measured from the Short Form-36 (-0.50), and correlated positively with greater difficulty in daily role functioning (0.62). 

1.8.6 Additions

Measures in the areas of diet/nutrition and environment did not meet selection criteria. However, these contributory factors of fatigue were considered necessary for inclusion. Following a consultation with a SCI dietitian, the Canada Food Guideline was selected for inclusion in the battery as it was considered to be an appropriate diet/nutrition screen for the SCI population.
The participant information and medical history sections were chosen to be included to gather relevant demographic data concerning the personal details of those taking the assessment. The general health summary includes a series of visual analogue scales to provide clinicians an overview of possible contributing factors. These scales are not to be scored or quantified, they are only meant to give a quick scan of the problem. A section on fatigue management history was also added to provide clinicians a background on what strategies their patient had used in the past to manage fatigue, and whether it was helpful. These sections are further described in Chapter 2, section 2.3.1.

Item analyses of the draft battery were conducted in Grant et al.\textsuperscript{74} to determine the battery's representation of factors contributing to fatigue in SCI, to determine any areas of omission, and to assess the presence of items under each of the 3 domains of person, environment and occupation. The Person-Environment-Occupation model of occupational performance\textsuperscript{83} is a theoretical framework that drives occupational practice. It relies on the notion that the relationship between people, their occupations and roles, and the environments in which they interact, has an impact on occupational performance.\textsuperscript{83} An item analysis of the CFAB-SCI using the Person-Environment-Occupation model\textsuperscript{83} and the Canadian Model of Occupational Performance\textsuperscript{84} revealed that a low proportion of items fell under the domain of environment, and thus aspects of the physical environment had not been sufficiently addressed in the battery draft. Further items regarding the impact of the physical environment on fatigue were developed by the authors and were included in the battery. A second item analysis involving the same models of occupational performance\textsuperscript{83, 84} confirmed that the battery contained sufficient items to address the broad domains of person, environment and occupation.\textsuperscript{74}
Grant et al. concluded their development work with a third phase to assist in establishing the battery's face validity. This was done by conducting a focus group with four peer support workers from the British Columbia Paraplegic Association (BCPA), now known as SCI-British Columbia (SCI-BC). Participants had experienced their SCI for longer than five years. Three of the participants also completed written evaluations of the battery. Expert opinion from an occupational therapist working with people with SCI was also gathered. Overall, the battery's comprehensiveness was rated as ‘Good’, applicability ‘Excellent’, clarity of instructions ‘Good’, format ‘Excellent’, time to complete ranged from 20 – 40 minutes and length of time to complete was considered ‘Reasonable’. Minor formatting changes were made to CFAB-SCI based on feedback.

McFarlane et al. further modified the CFAB-SCI by conducting an updated literature review and item analysis. They also determined its clinical utility and content validity. The CFAB-SCI was further reviewed by two groups: four health care professionals and five individuals with SCI. Participants were asked to provide feedback and to rate the clarity, utility and relevance of each section of the CFAB-SCI on a scale of 1 (low) to 4 (high). These ratings are illustrated in Table 1.2 and suggested that the CFAB-SCI is clear, easy to use, and the content is relevant to the experience of fatigue in individuals with SCI. However there is a slight discrepancy between the perceived clarity and relevance of the CFAB-SCI from the health care professions and the individuals with SCI. The individuals with SCI on average had lower ratings, and four ratings had an average below 3 out of 4. This discrepancy may be caused by the difference in experiences between the two groups and thus their perception of what is clear and relevant. Therefore further changes were made to the structure and content of the CFAB-SCI based on the comments provided by the participants.
Based on this development work, there is confidence that the CFAB-SCI demonstrates strong clinical utility and content validity from the perspective of healthcare professionals and those with SCI. Further psychometric testing, however, is required to strengthen the validity of its inferences and to show internal consistency.

Table 1.2 – Participant feedback on CFAB-SCI

<table>
<thead>
<tr>
<th>CFAB-SCI Section</th>
<th>Mean scores of individuals with SCI (n=5) ¹</th>
<th>Mean scores of health care professionals (n=4) ¹</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Clarity</td>
<td>Ease of Use</td>
</tr>
<tr>
<td>1. Information about you</td>
<td>3.40</td>
<td>3.60</td>
</tr>
<tr>
<td>2. Medical History</td>
<td>3.60</td>
<td>3.20</td>
</tr>
<tr>
<td>3. General Health</td>
<td>3.40</td>
<td>3.20</td>
</tr>
<tr>
<td>4. Fatigue</td>
<td>3.00</td>
<td>3.00</td>
</tr>
<tr>
<td>5. Environment</td>
<td>2.80</td>
<td>3.00</td>
</tr>
<tr>
<td>6. Pain</td>
<td>3.40</td>
<td>3.40</td>
</tr>
<tr>
<td>7. Sleep</td>
<td>3.20</td>
<td>3.20</td>
</tr>
<tr>
<td>8. Stress</td>
<td>3.20</td>
<td>3.20</td>
</tr>
<tr>
<td>9. Mood</td>
<td>3.00</td>
<td>3.20</td>
</tr>
<tr>
<td>10. Nutrition</td>
<td>3.60</td>
<td>3.60</td>
</tr>
<tr>
<td>11. Fatigue History</td>
<td>2.80</td>
<td>2.80</td>
</tr>
<tr>
<td>Average of scores</td>
<td>3.22</td>
<td>3.22</td>
</tr>
</tbody>
</table>

(McFarlane et al., 2012)

¹Score range is from 1 (low) to 4 (high)
1.9 Psychometrics

Psychometrics is the science of psychological testing and how to maximize the quality of assessment. Despite the wide variety of applications between all types of assessments, they share common fundamental characteristics. Assessments must show strong validity, reliability, be standardized and free from bias. This is the basis of psychometric testing.\(^\text{86-88}\)

Validity is one of the most important aspects of psychometric testing. In the 1950s, a Trinitarian view of validity emerged. It argued for 3 types of validity: content validity, criterion-related validity (concurrent and predictive), and construct validity (convergent and discriminant). Validity was seen as a property of the test, and the content of the test was less important as long as it served its purpose.\(^\text{87}\) In our modern view of validity, validity testing is validating the inferences made from an observation or test score, and not the test itself. Validity is considered to be the degree to which an assessment is measuring what it intends to measure.\(^\text{87}\) ‘Validity’ and ‘construct validity’ are also synonymous in the modern validity theory. This unified view states that construct validity is the whole of validity, and any other types of validity simply add to the evidence of construct validity.\(^\text{87}\) There are many different types of validity: content validity, criterion validity (concurrent and predictive), and convergent/discriminant validity.\(^\text{86-88}\) Content-related evidence for validity involves the degree to which elements of a test (e.g. themes, wording, format, administration, scoring etc.) are appropriate and representative of the targeted construct of measure. A form of content validity is face validity, which is the estimate of whether a test appears to measure a particular construct. Criterion validity is the correlation between the test and a criterion variable, known as the gold standard in measuring the targeted construct of measure. The difference between concurrent and predictive validity depends on the timing of when the criterion measure is administered. If the measure being psychometrically tested and the
criterion are administered at the same time, then it is concurrent validity. However if the criterion is administered at a future date, it is considered predictive validity. Convergent validity is the degree of relation between two tests that theoretically should be measuring the same or similar construct. Discriminant validity is the degree of relation between two tests that theoretically should have no relation. The process of validation is always on going and the validity of our inferences may change over time.  

Reliability is another important property of psychometric testing. Reliability is the extent to which scores remain consistent over repeated administrations of the same or parallel tests. Reliability is also the degree to which test scores are free from random errors of measurement. There are three main types of reliability: reliability as equivalence (alternate-forms reliability), reliability as stability (test-retest reliability) and reliability as internal consistency (split-half reliability, Cronbach’s coefficient alpha, and Kuder-Richardson formula 20 or KR-20). Alternate-forms reliability is the idea that two versions of the same test are parallel, and therefore may be tested by correlating the variability. Test-retest reliability is the test of stability by measuring the correlation between the same tests administered at two separate time points. Without access to two formats or time points, one may split one test into two to measure reliability. This is split-half reliability. This theoretically falls under the definition of reliability, as splitting the test in two creates two parallel tests to compare. Cronbach’s alpha is a computerized method to combine all possible split-halves. Cronbach’s alpha conceives each item as a subtest, and the associations among the items can be used to estimate the reliability of the complete test. Cronbach’s alpha is thus a function of the number of items in a test, the average covariance between pairs of items and the variance of the total score. KR-20 is a historical method of this used before Cronbach’s alpha. Finally, if an observer or rater must administer a
test, inter-rater and intra-rater reliability testing is used to test the degree of agreement between (inter) or within (intra) raters. This tests the stability of the test over repeated administrations from multiple observers. This method of reliability is not appropriate for self-report measures.  

Testing psychometric properties of an assessment is essential in the development of a measurement tool, and must be done before presenting a tool for use in a clinical setting. Not all methods of psychometric testing are appropriate for each assessment, therefore careful consideration is needed to determine which methods of psychometric testing is needed for each individual assessment. Once this is determined, the psychometric properties can help guide the use of the measurement for both research and practical purposes.

1.10 Exploring the Experience of Fatigue

In addition to establishing the psychometric properties of the CFAB-SCI, this research also sought to understand additional elements of the fatigue experience that may not have been directly targeted in this assessment. This is deemed necessary as, previously mentioned, fatigue is a complex phenomenon that is determined by several varying factors and diverse experiences. This complicates treatment sessions for patients and clinicians, and thus researchers view it as essential to approach fatigue management in a multi-dimensional manner. However to be able to properly manage fatigue, it is critical to first understand its intricacies. An effective way to do so is to listen to the perspectives of the individuals with SCI affected by fatigue.

The CFAB-SCI contains items with closed-ended questions and likert-type scales in an effort to quantify fatigue. Although this is important, the CFAB-SCI also provides the responders an opportunity to tell the researchers more about their fatigue on the final item of the battery. While discussing critical issues in occupational therapy research, Hammell et al. notes that
there is a discrepancy between researchers’ understanding of SCI and the actual experiences of the SCI participants. Due to this discrepancy, many people with SCI responding to quantitative surveys tend to write comments in the margins in an attempt to provide context to their responses and to elaborate on areas the researcher may have missed. This demonstrates a gap in SCI research, and stresses the importance of including participant perspectives in the implementation of research and practice. This concept thus shows the value in analyzing open-ended responses or writing in the margins in self-report measures to further our understanding of the fatigue experience.

1.11 Research Questions

As such, the purpose of this study is two-fold. First, the purpose is to complete the evaluation of the CFAB-SCI by testing the validity and reliability of the battery. The secondary purpose of this study is to characterize fatigue and further our understanding of fatigue in SCI by analyzing the open-ended survey data provided by the participants in the CFAB-SCI. Our research questions are as following:

Q1. Do the sections tested in the CFAB-SCI achieve the hypothesized convergent validity values?
Q2. Do the sections tested in the CFAB-SCI achieve the hypothesized internal consistency values?
Q3. What do people with SCI want to add about their fatigue when completing the CFAB-SCI?
2 Methods

This study was a methodological design, assessing the psychometric properties of the CFAB-SCI. Analyzing the open-ended survey data from the CFAB-SCI was a secondary purpose of the study.

2.1 Participants

This study recruited community-dwelling adults with traumatic SCI. A target sample of 70 was determined from sample size calculations. Because two analyses were being run, convergent validity and internal consistency, two separate sample size calculations were used. Bivariate correlations were used to analyze convergent validity; therefore, an online tool by the University of California, San Francisco Clinical and Translational Science Institute\(^9^0\) was used to determine the sample size required to achieve desired power. The online tool used a sample size calculation taken from Hulley et al.\(^9^1\) where total sample size = \(N = [(Z_\alpha + Z_\beta)/C]^2 + 3\). In the equation: \(Z_\alpha\) represents the standard normal deviate for \(\alpha\) (threshold probability for rejecting the null hypothesis); \(Z_\beta\) represents the standard normal deviate for \(\beta\) (probability of failing to reject the null hypothesis under the alternative hypothesis); and \(C = 0.5 \times \ln[(1+r)/(1-r)]\) where ‘\(r\)’ represents the expected correlation coefficient. Using an estimate of \(r = 0.5\), as that is our lowest hypothesized value for convergent validity, and a \(p < 0.05\), 38 subjects would give 90% power to detect a relationship if it exists.\(^9^0\) The sample size required to determine internal consistency however is inconclusive in the literature. There are no standard calculations or set guidelines, as recommended sample sizes range from 50 \(^9^2\) to 300.\(^9^3\) A formula proposed by Bonett\(^9^4\) was tested for its accuracy and was used to determine the sample size for this study. The sample size calculation used was \(n = \{2k/(k-1)}\{(Z_{\alpha/2} + Z_\beta )^2/\ln (\delta )\} + 2\) where \(k\) represents the number of
items in the measure, $Z_a$ and $Z_β$ represent the same variables as the previous equation, and $δ = (1 - c)/(1 - p_k)$. In the equation for $δ$, $c$ is the hypothesized value for Cronbach’s alpha, and $p_k$ the planning value obtained from expert opinion or prior research. The hypothesized value was set at 0.7, and the planning value was set at 0.8 as this is deemed good-excellent reliability in the literature. With a desired power of 90%, $p < 0.05$, and either a 25 item test (our largest section in the CFAB-SCI) or a 7 item test (our smallest section in the CFAB-SCI), the desired sample size ranges from 47-55. Due to the length of the questionnaires and the volume of materials, the research team included an additional 15 participants to account for subject attrition (a 25% drop out rate).

Prior to recruitment, criteria were established to determine study eligibility. Inclusion criteria were 1) sustaining a complete or incomplete traumatic SCI at least one year ago; 2) 19 years of age or older; 3) able to read and write in English; and 4) community dwelling. A one-year minimum since time of injury was chosen to allow the secondary complications of SCI to stabilize in the participants and to allow chronic fatigue to be distinguished from acute fatigue. Exclusion criteria included experiencing other medical conditions that might confound the results. Examples of conditions that might confound the results are conditions that are also associated with symptoms of fatigue such as multiple sclerosis, cancer, or arthritis. Demographic information and injury characteristics were reported in the CFAB-SCI as well as during the screening process. Research has revealed that cognitive deficits are commonly present for people with SCI, as approximately 40-50% of individuals with SCI have varying degrees of cognitive impairment. As such, cognitive status was included as a demographic characteristic to understand the level of cognition in this sample.
Participants were recruited using a convenience sampling approach. The target sample included individuals who have sustained a traumatic spinal cord injury and were chosen based on willingness to participate in the study. Participants were recruited using the Canada-wide SCI participant recruitment database at the Rick Hansen Institute. Recruitment resources available through the International Collaboration of Repair Discoveries were also used, and advertisements (Appendix A) were posted on bulletin boards commonly viewed by the target sample.

2.2 Study Protocol

Upon contacting the research team, potential participants were screened to ensure the eligibility criteria were met. This was mostly done over email. Those who met the criteria were given an electronic letter of information outlining the study’s process and how results will be used. The study design consisted of one data collection time point in which participants responded to questionnaires mailed to them in a package. For the study protocol, postal mail was chosen as the primary method of delivery. Electronic delivery was not used due to a history of difficulty in administering long questionnaires electronically. A review on different methods of questionnaire administration revealed that self-administered electronic surveys have a lower response rate than self-administered postal surveys. This might be due to a lack of motivation when the questionnaires are not physically present. Additionally, the electronic versions would be difficult to complete without a fillable PDF format or online format due to the type of questions administered. However, if a participant requested an electronic version because they had limited hand function and no caregiver to assist them in the completion of the questionnaires, an electronic copy was provided and the researcher took note. They were emailed the questionnaire in a Microsoft Word file, and were asked to type their answers or to make a mark,
such as an ‘x’, next to their desired responses. The package mailed to the participants included a covering letter (containing the same information as a consent form), a hard copy of the CFAB-SCI, and seven additional measures to determine convergent validity. The covering letter can be found in Appendix B. This package also included a stamped, addressed envelope to facilitate the return of the completed questionnaires. Participants provided consent by completing and returning the questionnaires. Follow-ups were conducted via email or phone 1-2 weeks after the package had been sent. This was done to ensure that the participants have received the package and that no contents were missing. It also gave the participants an opportunity to ask questions about any of the items. The researcher provided assistance as required. If the package was not returned, follow-ups were conducted again to ensure full completion of the study. Once the package was returned, data analysis was performed. If missing data appeared, the participants were contacted via phone or email to attempt to complete the information. Participants received a small honorarium for their time in the study.

2.3 Measures

2.3.1 CFAB-SCI

The CFAB-SCI has been developed in previous studies \textsuperscript{74, 85} and is included in Appendix C. The CFAB-SCI consists of 134 items divided in 11 sections. These sections include: participant information (7 items), medical history (5 items), general health (8 items), fatigue (34 items), environment (11 items), pain (7 items), sleep (14 items), stress (10 items), mood (11 items), nutrition (8 items), and fatigue management history (19 items).

The battery contains a mix of response formats including Likert-type scales, categorical responses, visual analogue scales, and open-ended questions. To maintain consistency, recall
times were all adjusted to 2 weeks and Likert-type scales were adjusted to a 5-point scale. Most scales range from never (0) to almost always (4). The pain section ranges from pain does not impact (0) to pain completely impacts (4). A part of the environment section also ranges from strongly disagree (0) to strongly agree (4). Scores from the CFAB-SCI are generated from the likert-type scales located in the fatigue, environment, pain, sleep, stress and mood sections of the battery. Scoring is done separately for each section, and involves averaging the responses of the items with likert-type scales to get a score for the section. There is no total score for the battery as it measures multiple different constructs. Participant information (section 1) and medical history (section 2) are composed of a series of demographic and injury characteristics collected for purposes of both the research study as well as for clinical use once the CFAB-SCI is used in a practical setting. It will also allow a relationship to be observed if certain demographic characteristics are associated with different level of severities among the factors. General health summary (section 3) is one page that contains visual analogue scales for fatigue and each of the subsequent factors in the CFAB-SCI. These visual analogue scales provide a quick scan for the clinician and directs their attention to problematic areas, while the rest of the battery elaborates on these issues with more detailed information. As the intended purpose of the visual analogue scales are to provide the clinician with an overview of the patient’s state, the visual analogue scales in the CFAB-SCI are not scored. Fatigue (section 4), is used to get a general sense of the participant’s fatigue while the following sections provide information on the factors associated with fatigue. These include environment (section 5), pain (section 6), sleep (section 7), stress (section 8), mood (section 9), and nutrition (section 10). The last section of the battery, fatigue management history (section 11), provides detail on strategies the participant has used in the past or is currently using to manage their fatigue and whether they are helpful. The last item is an
open-ended question that provides the participant opportunity to add any information that may not have been captured in any of the previous items, or to allow them to expand on previous points or ideas. It states “Would you like to tell us anything else about your fatigue?”

2.3.2 Cognitive Test - the Multiple Sclerosis Neuropsychological Screening Questionnaire (MS-NSQ)

As previously described, cognitive status, determined by the MS-NSQ (Appendix D), was used as a demographic variable. Due to a lack of cognitive status questionnaires in the SCI population, the MS-NSQ was chosen as the most appropriate screening tool for this study due to its psychometric properties, ease of use, and being catered to a population with a neurological condition.

The MS-NSQ contains 15 items. Each item asks how often and how severe a particular neuropsychological problem occurs. Responses on each item ranges from 0-4 (0=never, does not occur; 4= very often, very disruptive). A total score is summed, with higher score indicating larger cognitive impairment. Two versions of the MS-NSQ exist, a self-report format and an informant-report format (informant was defined as a significant other). The self-report MS-NSQ (used in this study) was psychometrically tested in the MS population. Validity was evaluated by correlating the MS-NSQ with the Cognitive Failures Questionnaire (CFQ), with a Pearson’s correlation of 0.81. The measure had a Cronbach’s α of 0.93, and sensitivity and specificity were 0.83 and 0.97 respectively. A cut off of 27 has been established as cognitively impaired for the informant-reported format, however no cut off has been determined for the self-report format. There is no information on whether the screening tool identifies people who need further testing.
2.3.3 Convergent Validity Measures

In addition to the CFAB-SCI and the MS-NSQ, the participants were also asked to complete six additional measures to evaluate convergent validity. These outcome measures match six sections of the CFAB-SCI: fatigue, environment, pain, sleep, stress, and mood. The measures were presented in the package in the same order as they appear in the CFAB-SCI. The convergent validity measures were chosen as parallel tests to those chosen during the development of the CFAB-SCI. Criteria for choosing convergent validity measures included: 1) measuring a similar construct as the matching section; 2) high psychometric quality; and 3) tested in the SCI population. The recall times and scale lengths were not adjusted for the convergent validity measures.

During development of the CFAB-SCI, “Environment” and “Nutrition” items were not derived by existing measures. However, for the purposes of psychometric testing, a measure evaluating environmental factors was found matching the above criteria and was included in this study. No psychometrically sound measure was found evaluating nutrition in SCI, however face validity and construct validity was still established for the nutrition section of the CFAB-SCI through the work of Grant et al.\(^74\) and McFarlane et al.\(^85\).

2.3.4 Fatigue – Fatigue Severity Scale (FSS)

The FSS (Appendix E) is a 9-item measure with a 7-point likert-type scale assessing the severity of fatigue. Participants recorded their agreement with 9 statements, ranging from strongly disagree (1) to strongly agree (7). The FSS asks to recall over the last week. Scorings are calculated with an arithmetic mean, with scores ranging from 1-7 and a cut score of 4 indicating severe fatigue. A low score indicates a low severity of fatigue, while a high score indicates a high severity of fatigue. The measure has been psychometrically tested in the SCI
population. Internal consistency of the FSS was excellent (Cronbach’s alpha = 0.89) and two-week test-retest reliability was adequate (intraclass coefficient = 0.84 with a 95% confidence interval of 0.74-0.90). The correlation between the FSS and the visual analog scale for fatigue (VAS-F), the vitality scale of the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36) and the Center for Epidemiologic Studies Depression Scale (CES-D) was $r = 0.67$, $r = -0.48$, and $r = 0.58$ respectively.\textsuperscript{72}

2.3.5 Environment – Craig Hospital Inventory of Environmental Factors – Short Form (CHIEF-SF)

The CHIEF-SF (Appendix F) is a 12-item measure evaluating barriers to participation in people with disabilities over the past 12 months. The participants answer how often the problem has occurred and the magnitude of said problem. The CHIEF-SF is scored by taking the product of the frequency score which indicated the frequency with which barriers were encountered (0 = never, 1 = less than monthly, 2 = monthly, 3 = weekly, and 4 = daily) and the magnitude score indicating the size of the problem which a barrier typically presented (0 = no problem, 1 = a little problem, and 2 = a big problem). The frequency-magnitude product score is on a scale of 0-8, indicating the overall impact of the barrier. The measure was shortened from the original 25-item questionnaire, however both have been psychometrically tested in several populations including SCI. The CHIEF-SF showed a test-retest reliability of ICC= 0.926. Scoring differentiation was seen between the SCI group and the group of people without disabilities. People with SCI reported an overall higher frequency and magnitude of environmental barriers (SCI group mean total CHIEF score = 1.25±1.08; group without disability mean total CHIEF score = 0.41±0.53).\textsuperscript{100}
2.3.6 Pain – Multidimensional Pain Inventory-SCI: Life Interference Subscale (MPI-SCI)

The original MPI-SCI (Appendix G) is a 60-item measure evaluating the impact of and adaptation to chronic pain on a 7-point Likert-type scale. It comprises of 3 sections: section 1 (pain impact), section 2 (responses by significant others), and section 3 (common activities). The subscales in section 1 include: life interference, support, life control, pain severity, and affective distress. For the purposes of this study only the life interference subscale on section 1 (pain impact) was used and comprises of 8 items. Only this subscale was used as the pain section on the CFAB-SCI only measures pain interference. A score is given my summing the items on a subscale and averaging them. A higher score indicates a higher level of pain impact. The original MPI has been modified to be used for people with SCI and has been psychometrically tested in the SCI population. Confirmatory and exploratory factor analyses were performed for each section of the MPI to determine how to modify the scale to make appropriate for the SCI population.\textsuperscript{101} The MPI-SCI showed adequate to excellent (Cronbach’s alpha = 0.60-0.94) internal consistency on the subscales, and a test-retest reliability ranging from ICC = 0.26-0.69. Life interference subscale showed an internal consistency of $\alpha = 0.90$ and test-retest reliability of ICC = 0.81. All MPI-SCI subscales were compared with an instrument evaluating the same constructs by using Pearson correlations and were significantly correlated with the related construct. Life interference subscale had a correlation of $r = 0.88$ with the Pain Disability Index.\textsuperscript{102}

2.3.7 Sleep – Pittsburgh Sleep Quality Index (PSQI)

The PSQI (Appendix H) consists of 19 self-rated questions with a recall time of 1 month, and 5 questions that are not tabulated in the scoring and therefore was not be used for this study. The items assess sleep quality, sleep duration and latency, and frequency and severity of specific
sleep-related problems. These 19 items are grouped into 7 component scores, each weighted equally on a 0-3 scale. They are summed to yield a global PSQI score (0-21), where higher scores indicate worse sleep quality. The measure was not tested in the SCI population; however was tested in healthy controls, “poor sleepers” with major depressive disorder, and “poor sleepers” with sleep disorders. The PSQI had an overall reliability coefficient (Cronbach’s alpha) of 0.83. It showed a significant difference between groups, and yielded a diagnostic sensitivity of 89.6% and specificity of 86.5% in distinguishing good and poor sleepers.¹⁰³

### 2.3.8 Stress – Depression Anxiety Stress Scale-21: Stress Subscale (DASS-21)

The DASS-21 (Appendix 1) is a 21-item measure of distress along the 3 axes of depression, anxiety and stress. DASS -21 is derived from DASS, a 42-item measure of the same three constructs. Each item is a statement, in which the participant indicates how much the statement applied to them over the past week. The 4-point likert-type scale ranges from never (0) to almost always (3). The scores are summed for each subscale (depression, anxiety, stress) and given a total. For the purposes of this study, only the stress subscale will be used, as depression and anxiety are assessed in the mood section of the CFAB-SCI. In this measure, stress is defined as the more cognitive, subjective symptoms of anxiety. The stress subscale consists of 7 items, with a score ranging from 0-21. Higher scores suggest higher severity of stress. Additionally, cut-off scores have been developed for defining mild/moderate/severe/extremely severe scores for each DASS scale. The DASS-21 has been psychometrically tested in the SCI population. The stress subscale correlated with 8 out of 9 subscales of the Brief Symptom Inventory to provide evidence of concurrent validity. DASS-21 Stress scale correctly identified all 3 patients with a diagnosis of generalized anxiety disorder (GAD) and identified 10 other participants as having
elevated levels of stress, but they did not have GAD diagnoses. No reliability tests were reported.\textsuperscript{104}

### 2.3.9 Mood – Center for Epidemiological Studies Short Depression Scale-10 (CESD-10)

The CESD-10 (\textit{Appendix J}) is a 10-item measure of depression. Responses capture the frequency of feelings and behaviors over the past 7 days and are rated on a 4-point scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Two items must be reversed scored (items 5 and 8). Scores are summed, and higher scores suggest greater levels of depressive symptoms. The CESD-10 was derived from the CESD-20, which was originally developed to screen for the frequency of symptoms of depression in the general population.\textsuperscript{105} Both the CESD-20 and the CESD-10 have been psychometrically tested in the SCI population. The CESD-10 reported a Cronbach’s alpha of 0.86, and test-retest reliability was ICC = 0.85 (95% CI 0.75-0.92). Using Pearson’s correlations, validity was assessed by comparing the CESD-10 with the Short Form-36 (SF-36) and visual analogue scale for fatigue (VAS-F). The strongest correlations were with outcomes representing mental health (r = -0.71), vitality (r = -0.60) and the VAS-F (r = 0.57). All correlations were significant and matched the hypothesized direction and magnitudes of the correlations.\textsuperscript{106}

### 2.4 Data Management

#### 2.4.1 Data Input

Demographic information at initial contact was inputted into a password-protected Microsoft Excel document, along with other information such as the date the package was sent, if the participant had been followed up with, whether they had received and returned the package, if there were any missing data, and any other special notes. Completed questionnaires,
along with gift card receipts signed by participants, were returned via mail to the department of Occupational Science and Occupational Therapy at the University of British Columbia. Once returned, the packages were opened and checked for missing data. If any missing data were found, the participant was contacted either by email or phone to attempt to complete the data. The participant was reminded that they do not need to answer any questions they do not feel comfortable answering.

Quantitative data from questionnaires were also inputted into a password-protected Microsoft Excel document. Shortened variable names were created for each item of the CFAB-SCI and the additional questionnaires. A codebook was created to accompany the data sheet, detailing the variable, a description of the item, the source of the item (which questionnaire and section), and the format of the inputted values. For likert-type scale questionnaires, the assigned numerical values for the corresponding response were inputted into the data sheet and were reversed if necessary. If responses were a numerical value (e.g. age), then that value was inputted as it is. If the participants were given options to choose from in which they had to only check one, a numerical value was assigned to each option. If similar response options re-appeared, these numerical values were kept consistent (e.g. yes or no options). If the item asked the participant to check all that applies, then each possible response was separated into its own variable. If the response was checked, then a “1” was assigned, and if it was not checked, a “0” was assigned. Codes were also assigned for missing, declined, and non-applicable responses. If data were missing, it was assigned “.99”; if the participant refused or declined to respond, it was assigned “.88”, and if the question was not applicable to the participant, it was assigned “.77”. Examples of questions that would not be applicable are items that are referring to work while the participant is unemployed. If the response required short text, it was inputted into the Excel data
Responses to two items required long text, and thus were inputted separately into a Microsoft Word file. In “Medical History”, participants were asked to list their medication and usage, and this was inputted into Word. Additionally, the response to the final item of the battery, which was an open-ended question, was inputted into a separate Word document as well. Any text that was written in the margins or anywhere outside of the designated responses were congregated and inputted into a Word file.

2.4.2 Missing Data

If contacting the participants could not complete the missing data, then steps were taken to account for missing data. As mentioned, scores on each section of the CFAB-SCI were calculated by averaging the items. If items were missing (including if it were non-applicable to the participant), then individual mean imputation was used. Individual mean imputation is the process of only calculating the mean of the items in which data is present. Therefore a score could still be calculated. The scoring methods of the convergent validity measures however, did not allow for individual mean imputation to be done. Therefore if missing data appeared in those scores, then the data was excluded pairwise. There are both pros and cons to mean imputation. The benefit of mean imputation is that it does not change the sample size for that variable. The shortcoming with mean imputation is that it may attenuate any correlations involving the imputed variables and may underestimate the standard error of the variables. However, with a very low rate of missing data, it can be argued that the choice for managing missing data would have minimal effect on the results of the study.
2.5 Data Analysis

2.5.1 Descriptive Statistics

Means, standard deviations, and frequencies were used for descriptive statistics of the responses on the CFAB-SCI. The frequency distribution of age and time since injury were described, as spinal cord injury is expected to have a bimodal age distribution due to the increased likelihood of older and younger adults being injured. Age was divided into 6 intervals (20-29, 30-39, 40-49, 50-59, 60-69, 70+) and time since injury was divided into 5 intervals (1-9, 10-19, 20-29, 30-39, 40+). The frequency of scores appearing above the cut-off of 27 on the MS-NSQ was presented, as scores greater than 27 indicate cognitive impairment. Scores on the CFAB-SCI were represented as means, standard deviations, and frequency distributions. These scores were taken as the average of the likert-type scale responses on each separate section. The frequency distribution of these scores were also presented in 4 intervals (0.00-0.99, 1.00-1.99, 2.00-2.99, 3.00-4.00)

2.5.2 Research Question 1

Data analysis was performed separately on each section of the CFAB-SCI. To answer Q1, we assessed convergent validity. Evaluating the correlation between the CFAB-SCI sections and a parallel measure of a similar construct provides evidence of convergent validity. The following sections were tested: fatigue, environment, pain, sleep, stress, and mood. The analysis plan to address convergent validity was to calculate a Spearman’s ρ correlation with each section of the CFAB-SCI and the corresponding outcome measure as outlined above. The data were tested for normality by using the Shapiro-Wilk test. The optimal values for convergent validity testing are typically kept in the moderate range. If the correlation between the new measure and
the old measure were too high, then one may argue that there is no need to develop another measure if they assess the same information. During the development of this tool, existing measures were combined into a battery, and formatted accordingly for easy use by clinicians and patients. Considering each section is derived from a pre-existing measure, it is likely that these will differ from the measures chosen to assess convergent validity. Therefore, by understanding that the constructs being measured are complex, and that no two measures can assess these constructs the same way, the following values have been hypothesized:

1) Fatigue: \( \rho \geq 0.6 \)
2) Environment: \( \rho \geq 0.5 \)
3) Pain: \( \rho \geq 0.6 \)
4) Sleep: \( \rho \geq 0.6 \)
5) Stress: \( \rho \geq 0.5 \)
6) Mood: \( \rho \geq 0.6 \)

Values of \( \rho \geq 0.6 \) were hypothesized for 4 of the 6 measures because this is deemed as a good value for convergent validity in statistical literature. It is expected that similarities still exist between these convergent validity measures and the CFAB-SCI since they are measuring similar constructs. Therefore we anticipated moderate to strong relationships between the measures. In general, “for absolute values of r, 0-0.19 is regarded as very weak, 0.2-0.39 as weak, 0.40-0.59 as moderate, 0.6-0.79 as strong and 0.8-1 as very strong correlation” Lower values were hypothesized for the Environment and Stress sections. This is because their sections on the CFAB-SCI are considerably different from their convergent validity measure. The Environment section on the CFAB-SCI was not derived from existing measures. Therefore, it is likely that it does not correlate highly with any pre-existing assessment of environmental
barriers to disability as they are measuring similar, yet different constructs. The convergent validity measure chosen for stress is the DASS-21. Although the DASS-21 contains a stress subscale, the measure is assessing depression and anxiety as well. From their definition of stress, it is evident that there is overlap among the constructs and that they consider stress as a construct that is a part of anxiety. This assumption is not made in the PSS, which is the measure used for stress in the development phase of the CFAB-SCI. Convergent validity values above $\rho = 0.5$ are deemed adequate by statistical literature.\(^{86-88}\)

2.5.3 Research Question 2

To answer Q2, internal consistency was measured using Cronbach’s Alpha and a hypothesized value of $\alpha \geq 0.7$. A value of 0.7 was hypothesized as it is considered the minimal acceptable value to present adequate reliability. The following ranges of Cronbach’s Alpha are presented in the literature: “$> .9$ – Excellent, $> .8$ – Good, $> .7$ – Acceptable, $> .6$ – Questionable, $> .5$ – Poor, and $< .5$ – Unacceptable.”\(^{109}\) The following sections of the CFAB-SCI will be tested for internal consistency: fatigue, environment, pain, sleep, stress, and mood.

2.5.4 Research Question 3

All comments on fatigue from the last open-ended item in the CFAB-SCI as well as any writing that appeared in the margins of the questionnaires were inputted into an electronic document. The last item states: “Would you like to tell us anything else about your fatigue?” The responses were then analyzed using conventional content analysis. Content analysis is a research method used to analyze text data. Although content analysis has been used in the past to convert text into quantitative data, qualitative content analysis was used for the purposes of this study.
Conventional content analysis is typically used to describe a phenomenon; in this case fatigue in SCI.\textsuperscript{110} Data analysis began by reading all of the data repeatedly, to get a sense of the text. Specific phrases were then highlighted from the text to capture thoughts or concepts. Initial thoughts and analysis were written out, and labels for codes emerged. This became the initial coding scheme. Codes were then sorted into groupings based on how the data was related. The data was organized into four major groupings, and these were then further divided into sub-groups to better reflect the text-data. Definitions for each grouping and sub-grouping were developed, which will be elaborated in the following chapter.
3 Findings

3.1 Descriptive Statistics

A total of 70 participants were screened for eligibility and sent a research package through the mail. Two participants stated they were being assisted by a caregiver to complete the questionnaires, and one participant had to complete the survey online due to very limited upper limb function and no access to assistance. Of those questionnaires, 64 were returned and included in analysis. This represents a 91.4% response rate. Six participants had missing data (9.4%) and there were 8 missing items on the CFAB-SCI out of a possible 5568 items (0.14%). These 8 missing data points were from separate items. There was a greater amount of missing data in the convergent validity measures however. Forty-one total items were missing on the convergent validity measures out of a possible 5376 items (0.76%). The majority of these missing items (36) occurred on the CHIEF-SF.

Participant information is presented in Table 3.1. Participants are, as a group, slightly older, predominately men, and close in the expected proportion for quadriplegia to paraplegia and complete to incomplete injuries. Demographic characteristics in this sample are in line with the epidemiology of traumatic SCI in a Canadian population. MS-NSQ scores are provided in Table 3.1 to indicate the level of cognitive impairment in this population. Scores range from 0-60, with a cut off of 27 established as cognitively impaired. The means (SD) scores on the CFAB-SCI are presented in Table 3.2. These scores represent the average of the responses on the Likert-type scales of each corresponding section. Fatigue, pain, and sleep problems have the highest scores in this sample.
Table 3.1 - Participant characteristics

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<td>Time with SCI (years)</td>
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</tr>
<tr>
<td>Completeness of injury</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>34 (53.1%)</td>
</tr>
<tr>
<td>Incomplete</td>
<td>28 (43.8%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>2 (3.1%)</td>
</tr>
<tr>
<td>MS-NSQ scores</td>
<td></td>
</tr>
<tr>
<td>Mean ± SD</td>
<td>18.5 ± 8.9</td>
</tr>
<tr>
<td>Possible range</td>
<td>0-60</td>
</tr>
<tr>
<td>Scores ≥ 27</td>
<td>10</td>
</tr>
</tbody>
</table>
Table 3.2 - Mean scores and frequency distribution of scores in the CFAB-SCI (n=64)

<table>
<thead>
<tr>
<th>Section of CFAB-SCI(^1)</th>
<th>Mean ± SD Scores(^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>1.82 ± 0.74</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>9</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>23</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>30</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>2</td>
</tr>
<tr>
<td>Environment</td>
<td>1.42 ± 0.71</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>17</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>33</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>11</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>3</td>
</tr>
<tr>
<td>Pain</td>
<td>2.00 ± 1.08</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>16</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>14</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>21</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>13</td>
</tr>
<tr>
<td>Sleep</td>
<td>1.93 ± 0.69</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>7</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>22</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>31</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>4</td>
</tr>
<tr>
<td>Stress</td>
<td>1.69 ± 0.81</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>13</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>25</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>22</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>4</td>
</tr>
<tr>
<td>Mood</td>
<td>1.48 ± 0.77</td>
</tr>
<tr>
<td>0.00-0.99</td>
<td>17</td>
</tr>
<tr>
<td>1.00-1.99</td>
<td>30</td>
</tr>
<tr>
<td>2.00-2.99</td>
<td>14</td>
</tr>
<tr>
<td>3.00-4.00</td>
<td>3</td>
</tr>
</tbody>
</table>

\(^1\)No mean score is available for Nutrition due to the format of the section

\(^2\)Possible scores on each section range from 0-4, with higher scores indicating greater severity.
3.2 Psychometric Data

Upon analysis of the data set using the Shapiro-Wilk test, some of the scores were not normally distributed. This means the data was non-parametric. Thus, Spearman’s ρ was used to determine correlation between scores. The results of the convergent validity analysis are presented in Table 3.3. All correlations exceeded the hypothesized values for each respective comparison, and all the values were significant at the p<0.01. The values for internal consistency are also presented in Table 3.3. All alpha values were above the hypothesized values; as well all sections but sleep exceeded values of 0.8, which represents good-excellent internal consistency. Since the items on the CFAB-SCI were derived from previously existing self-report measures, we compared the psychometric results from this study with previous psychometric testing done on the original questionnaires. The psychometric properties of the original measures are presented in Table 3.4.
### Table 3.3 - Psychometric results of CFAB-SCI

<table>
<thead>
<tr>
<th>Section of CFAB-SCI</th>
<th>Convergent validity (p)</th>
<th>Internal consistency (α)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>.719*</td>
<td>.950</td>
</tr>
<tr>
<td>Environment</td>
<td>.635*</td>
<td>.809</td>
</tr>
<tr>
<td>Pain</td>
<td>.897*</td>
<td>.945</td>
</tr>
<tr>
<td>Sleep</td>
<td>.659*</td>
<td>.782</td>
</tr>
<tr>
<td>Stress</td>
<td>.571*</td>
<td>.924</td>
</tr>
<tr>
<td>Mood</td>
<td>.821*</td>
<td>.897</td>
</tr>
</tbody>
</table>

*Correlation significant at p<0.01*
Table 3.4 - Psychometric properties of original measures

<table>
<thead>
<tr>
<th>Original Measure</th>
<th>Convergent validity</th>
<th>Internal consistency (α)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MFIS-SCI (Fatigue)</td>
<td>0.68 (Fatigue Severity Scale)</td>
<td>0.97</td>
</tr>
<tr>
<td>BPI-7 (Pain)</td>
<td>0.62 (Numerical Pain Scale)</td>
<td>0.92</td>
</tr>
<tr>
<td>MOS-S (Sleep)</td>
<td>-0.59 (Restless Leg Syndrome Quality of Life Questionnaire)</td>
<td>0.78-0.83</td>
</tr>
<tr>
<td>PSS (Stress)</td>
<td>0.25-0.36 (Life Experience Scale)</td>
<td>0.74-0.91</td>
</tr>
<tr>
<td>PHQ-9 (Mood)</td>
<td>-0.51 (Satisfaction with Life Scale)</td>
<td>0.87</td>
</tr>
</tbody>
</table>

*Environment section was not derived from any previous measure*

### 3.3 Content Analysis Data

Forty-three participants had responded to the final item in the CFAB-SCI and 36 participants had written in the margins of the questionnaires. Of the 36 participants who wrote in the margins, only 6 participants provided comments (13 comments total) substantive enough to be included in the analysis. Other comments included clarification of their responses or minor information to provide context to their response, such as: “Have had, but not this year”, “Not
serious”, or “Varies week to week”. Five of the 6 participants who wrote substantive comments in the margins also responded to the final item of the CFAB-SCI. From the data, four major theme groupings were identified: experience with fatigue, impact of fatigue, factors of fatigue, and management of fatigue. Among these, sub-groups were also identified.

3.3.1 Experience with Fatigue

Twenty-one respondents took the opportunity to elaborate on the experience of having fatigue. Twelve did so by describing the frequency and intensity of their fatigue, which differed between respondents. Five cited fatigue as being constant and part of everyday life, as described by one respondent: “Fatigue is with me all the time. I have learned to work through it because if I did not I would do nothing. It is a constant companion.” (848; 72 years old, incomplete tetraplegia) Despite fatigue being constant for many, the intensity of the fatigue was not always consistent. Seven respondents described fatigue as having high’s and low’s, with fluctuating intensity: “Fatigue and pain seem to be part of my everyday life. The only thing that changes is the intensity of the fatigue and pain. There are better days but more worse days.” (844; 54 years old, incomplete paraplegia) When describing their fatigue experience, six respondents also elaborated on the type of fatigue. This included mental fatigue, physical fatigue, and sometimes both: “I waste so much time being tired both mentally & physically.” (811; 55 years old, incomplete tetraplegia) Alternatively, not everyone from this sample experienced fatigue.

Three participants stated not experiencing fatigue at all. One participant wrote: “I cannot remember being fatigued for a long time unless being tired by evening and ready for sleep by 10 p.m. is considered to be fatigue. I consider it to be ageing. I am very fortunate that I am healthy, pain free and reasonably able to lead a normal life.” (827; 76 years old, complete paraplegia) Another participant wrote: “I do not consider fatigue much of an issue in my life… Actually I am
a healthy person who functions at a high level for my degree of injury.” (814; 71 years old, incomplete tetraplegia) For those that did experience fatigue, its impact was evident.

### 3.3.2 Impact of Fatigue

Twelve respondents described the impact fatigue has on both their day-to-day life and on social participation. Daily life may be impacted by fatigue in a variety of ways. Activities of daily living were generally more difficult for 9 respondents due to their fatigue and their disability: “I believe that all activities are exercise. Housework, reaching, cooking – all these things use up so much energy.” (820; 54 years old, incomplete tetraplegia) Activities of daily living also take longer for people with SCI due to the need to rest or manage their fatigue: “I feel like I waste so much time resting or being too tired to do things. I feel like I am always so far behind in house keeping, chores, errands, etc. because I am not efficient.” (811; 55 years old, incomplete tetraplegia) Dealing with an injury and the fatigue associated with it also has a perceived impact on the health of one respondent: “Taking care of my body is constant. Bowel and bladder management. Temperature considerations. The minutiae of navigating life in an able-bodied world. I have been living this way for 33 years and find I am aging early.” (848; 72 years old, incomplete tetraplegia) Along with daily activities, fatigue can impact other facets of people’s lives.

Fatigue also has an impact on social activities. Three respondents appeared to give up on discretionary activities to deal with fatigue: “I can keep on top of the core elements of my job – barely – but after a long day of dealing with random obstacles on top of everything else, I have no energy or desire to go out to social functions & deal with it all over again.” (818; 42 years old, complete paraplegia) Fatigue also impacts the amount of effort one respondent can put into their social relationships: “Everyone wishes for my time and attention and joyful involvement in
their lives and activities. I should be grateful. But often I resent being included because it takes so much effort to be present and appear happy.” (862; 56 years old, complete paraplegia) The frequency, severity, and impact of fatigue can all be affected by a variety of factors as highlighted in the next section.

3.3.3 Factors of Fatigue

Participants described several factors that may be contributing to their fatigue. Pain was most commonly cited (10 respondents) as a factor of fatigue: “Pain, and the impact it has on everything (sleep, appetite, mood, etc.) is my biggest determinant of fatigue.” (838; 46 years old, complete paraplegia) Another participant wrote: “I am in 24/7 pain from my injury down to my toes and no medication I’ve tried helps to ease or stop it. The pain causes me to feel fatigued every waking minute.” (817; 65 years old, incomplete paraplegia) The types of pain noted in the responses include chronic pain (2), neuropathic pain (3), and phantom pain (1).

Sleep is another major factor of fatigue (6 respondents) as one respondent noted: “My fatigue is mostly drowsiness secondary to poor sleep quality and amount.” (810; 58 years old, incomplete tetraplegia) The causes of sleep problems are mostly interference from pain (3), spasticity (2), external disturbances (2), and periodic limb movement (1). Many medications that manage a variety of secondary complications of SCI have side effects that include fatigue. Six respondents mentioned medications. For one, the benefits of the medication outweighed the side effect of fatigue: “I really think a lot of my fatigue is a side effect of the Baclofen & Amitriptyline, but is a small pay off for relief from spasms and nerve pain.” (858; 56 years old, incomplete paraplegia) But for two respondents, it was the opposite: “Tried painkillers but the side effects were causing far more problem than the pain. Better to be coherent and be able to
think clearly.” (815; 58 years old, complete paraplegia) Three other respondents were aware of the side effects of their medication and acknowledged its impact on fatigue.

Other factors of fatigue were also cited in this study. The environment appeared to have an impact on the fatigue levels of 6 respondents. Temperature has a large impact on pain, which in turn may impact fatigue: “My fatigue depends on factors involving what was talked about in this study, as well as the weather. If it is a nice sunny day, my pain is much better as opposed to an overcast, cold, rainy day.” (805; 33 years old, complete paraplegia) Environmental barriers may also cause fatigue, such as the lack of road and sidewalk maintenance during snowy conditions. Stress may also impact fatigue, as described by one respondent: “I think its related to my stress level. Lately I’ve been more stressed both due to work + personal life.” (809; 44 years old, complete paraplegia) A total of two respondents cited stress as a factor of fatigue.

Many physical factors of fatigue were noted as well, which included: spasticity (2), muscle weakness (1), posture (1), discomfort (1), and weight (1). “The more weight we put on the harder it is to do transfers and this will cause fatigue and is hard on the shoulders.” (828; 55 years old, complete paraplegia) Another respondent wrote: “I’m sure discomfort adds to my fatigue. I have to monitor how much I stand and how much I sit and change position to avoid discomfort.” (848; 72 years old, incomplete tetraplegia) Cardiovascular factors, mostly blood pressure (2), can be a determinant of fatigue as well: “My blood pressure fluctuates for various reasons and when it is higher I have more energy.” (855; 60 years old, incomplete paraplegia) Another respondent also noted a common issue in SCI, autonomic dysreflexia: “Biggest influence on fatigue for me is autonomic dysreflexia. During the day being in pain is tiring. During the night it interrupts my sleep.” (830; 41 years old, complete tetraplegia) Only one
respondent cited depression as a factor of their fatigue. Unique circumstances, such as the sudden death of a family member, were also a cause of increased fatigue.

### 3.3.4 Management of Fatigue

Although there is a section in the CFAB-SCI on management of fatigue, participants wanted to elaborate on strategies that have helped them manage their fatigue. Four respondents mentioned a healthy lifestyle as a strategy to manage fatigue. “Earlier on in my life as a quad I experienced more fatigue. I find exercise and a healthy diet has been very beneficial in reducing fatigue.” (806; 31 years old, incomplete tetraplegia) Furthermore, all three participants who reported no fatigue had active lifestyles, and noted this as a reason for their low fatigue levels. However, the ability to exercise was limited for two respondents due to physical constraints: “Because of my incapacitated bodily function/movements, my muscle cannot be exercised properly.” (826; 54 years old, complete tetraplegia) Another management technique used by three respondents was rest. This may include sleeping longer, or taking naps throughout the day: “I will sometimes sleep longer, increase my normal 8 to 10 hours to 12 hours. This works very well.” (814; 71 years old, incomplete tetraplegia) Finally, technology is a resource that may help manage fatigue. One respondent suggested assistive technology as means to reduce fatigue:

“...Regarding previous section on fatigue management history. Right after I was injured I looked at these as an indication of dependence/incapacity. Now I see them as facilitators/guarantors of independence/self-reliance/full enjoyment of life (partly by decreasing fatigue).” (803; 62 years old, incomplete paraplegia)
For those experiencing sleep apnea, three respondents used either Bilevel Positive Airway Pressure (BiPAP) or Continuous Positive Airway Pressure (CPAP) machines to manage their sleep quality, and subsequently their fatigue.
4 Discussion

4.1 Psychometric Findings

The results of this study present the psychometric properties of the self-response CFAB-SCI. The data presented exceed the hypothesized values for convergent validity and internal consistency. Convergent validity is the relationship between two measures that theoretically should be testing the same constructs. This provides evidence that the tool in development is measuring what it intends to measure. Convergent validity was evaluated for 6 constructs in the CFAB-SCI: fatigue, environment, pain, sleep, stress, and mood. Each individual section was compared to a pre-existing measure that has been psychometrically tested to evaluate a similar construct. As a result, all 6 correlations exceeded their hypothesized values and showed statistically significant (p<.01) moderate to strong correlations with their matching measure.

Internal consistency is a form of reliability and item homogeneity. Internal consistency conceives each item as a subtest, and the associations among the items can be used to estimate the reliability of the complete test. Internal consistency was measured in 6 sections: fatigue, environment, pain, sleep, stress, and mood. All sections exceeded their hypothesized values of 0.7, which indicates acceptable internal consistency. Additionally, all but the sleep section had Cronbach’s alpha values in the good-excellent range (> 0.8). This provides strong evidence for the internal consistency of the six testable sections of the CFAB-SCI.

During the development of the CFAB-SCI, previously existing measures were used to drive the content of the battery. For the constructs of fatigue, pain, sleep, stress and mood, their sections in the CFAB-SCI were derived from the MFIS-SCI, BPI-7, MOS-S Scale, PSS, and PHQ-9 respectively. Slight changes were made to the items, the recall time, and the response
scale. As such, it is worthy to compare the psychometric results of this study with previous psychometric testing to see the effects of these changes. For convergent validity, the only questionnaire that used that same convergent validity measure as this study was the MFIS-SCI. Both the MFIS-SCI and the fatigue section of the CFAB-SCI were correlated with the FSS; and as expected both values were similar (within 0.05 of each other). The BPI-7, MOS-S Scale, PSS, and PHQ-9 were all compared with convergent validity measures that were drastically different than the ones used for this study. Therefore it is difficult to draw any meaningful comparisons from their values. For internal consistency, it was expected that the Cronbach’s alpha values on the original measures would be comparable with those on the CFAB-SCI. Alpha values on the original measures were within 0.05 of their CFAB-SCI counterparts. This suggests that the changes made to the measures when developing the CFAB-SCI had little effect on the internal consistency.

Along with the psychometric quality of the CFAB-SCI, this study presents descriptive findings that help further our understanding of SCI, fatigue, and factors of fatigue. The participant characteristics showed a typical ratio of male to female in SCI, and an expected proportion of paraplegia to quadriplegia, and complete to incomplete injuries.13 Pickett et al.13 described the SCI population to be bimodal, with peaks for age at time of injury coming in the third and eight decades. The age distribution of this sample is not bimodal, as only 2 participants were between 20 and 29 years old, and only 6 participants were over the age of 70. The majority of this sample was middle-aged, as over half were between 40 and 59 years old. However, this may be explained by the sample’s rather large mean time with SCI. Although the time with SCI was more evenly distributed than their age, over half of the participants have been with their SCI for longer than 20 years. This might suggest that many middle-aged participants may have been
with their injury since their early adulthood, which is when it is more likely to sustain an injury. This observation might limit the generalizability of the study, as the sample might not be adequately representative of the older SCI population who sustain an injury in their late adulthood.

Cognitive status was another descriptive variable that was presented in this study. Cognitive status was determined by the MS-NSQ, where there is a possible scoring range of 0-60 and a cut-off score of 27 indicating cognitive impairment. The mean of the scores on the MS-NSQ was below the cut-off at 18.5. However 10 participants scored above the cut-off of 27. This indicates approximately 16% of the sample is cognitively impaired. As previously mentioned, cognitive impairment is commonly associated with people with SCI, and it is believed that between 40-50% of people with SCI are cognitively impaired. This is a much higher prevalence rate than seen in this study, suggesting that this sample has a low level of cognitive impairment as compared to the SCI population as a whole.

Mean scores on the CFAB-SCI were presented along with their frequency distributions. The constructs with the highest mean scores from the CFAB-SCI were fatigue, pain, and sleep problems. Fatigue being present in this sample, along with pain and sleep problems being among the more severe factors of fatigue in SCI, are both consistent with the literature. The frequency distribution of the scores may suggest at what levels these constructs are present. For fatigue, 53 participants had a score between 1.00 and 2.99 (out of a possible 4.00), suggesting the majority of participants experience moderate fatigue and few experience either extreme. Environment had the lowest mean score out of all the sections on the CFAB-SCI, and 50 participants had a score below 2.00. Although environmental factors are still present, their severity may be minor in this sample. Pain had the highest mean score, and has a more even
distribution of scores. Pain levels appear to be variable in this sample, and can range from little to extreme pain. The pain section also has the largest number of participants who scored above 3.00. Sleep had a similar frequency distribution to fatigue, and thus the same conclusions can be made. Stress and mood also have similar distributions to fatigue, however a larger number of participants had scores between 0.00 and 0.99 on the stress and mood scales, suggesting a slightly larger skew towards that extreme. Nonetheless, these findings suggest fatigue and its possible factors are both present and impactful in this SCI sample. These findings also support the inclusion of these factors in the CFAB-SCI, as they are persistent problems that may affect fatigue levels and lower quality of life in people with SCI.

As previously mentioned, there are several self-report fatigue measures commonly used in neurological populations and there are two measures tested in the SCI population. On the other hand, these measures are limited by addressing only one part of the fatigue assessment picture. They only evaluate fatigue as an outcome, and do not explore possible factors associated with fatigue. This presents a research and practice gap, in which a comprehensive tool is needed for both clinicians and individuals with SCI to gain a better understanding of fatigue. A major component of an effective fatigue management programme, as described in Hammell et al., is to identify and manage factors associated with fatigue. The CFAB-SCI is a valuable tool in identifying those factors and thus helping clinicians and patients develop management strategies.

There are multiple benefits to administering the CFAB-SCI as a whole, as opposed to individually administering multiple outcome measures from various constructs. Firstly, it is consistent in its scale lengths and recall times, which would avoid possible confusion, caused by multiple scales with varied response formats. Additionally, the CFAB-SCI provides information beyond the closed likert-type scales. There are many items with categorical responses, short
answer responses, and open-ended responses, which supplements the quantifiable information. The CFAB-SCI is able to provide the clinician the whole picture, and assesses fatigue beyond a cut score. This would facilitate the planning of successful fatigue management programs.

Although not part of the study’s objectives, evaluating the participant response rate and missing data rate presents interesting findings in regards to the length of the CFAB-SCI. With the battery containing 134 items, concerns for response burden in the participants are reasonable. However, upon completion of the study, 91.4% of participants who were sent the research package returned completed questionnaires. Of the data inputted in the analysis, only 0.14% of items were missing data. With high response burden, one would expect a lower response rate and higher rate of missing data from the participants. Therefore these findings suggest that the length of the CFAB-SCI may be suitable for people with SCI.

In two previous development studies of the CFAB-SCI, item analysis, face validity, content validity, and clinical utility were evaluated.\textsuperscript{74, 85} The current study presented the convergent validity and internal consistency of the measure. Therefore, in conjunction with previous work,\textsuperscript{74, 85} evidence supports the strong psychometric properties of the CFAB-SCI, presenting it as a clinically useful tool to characterize fatigue in SCI. Although further research may be needed to test the stability of the CFAB-SCI over time, we expect it to be an assessment tool that can direct treatment decisions for clinicians and can be readily used in practice to explore the multiple factors associated with fatigue in SCI. Additionally, the CFAB-SCI can be used for people with SCI to gain a better understanding of their fatigue experience, and to assist them in managing their symptom profile.
4.2 Content Analysis Findings

The results of this study highlight the complex nature of the fatigue experience. When provided the opportunity to tell researchers more about their fatigue, comments written by participants on the CFAB-SCI emerged into four major groupings: experience with fatigue, impact of fatigue, factors of fatigue, and management of fatigue. These findings are in accordance with the limited qualitative data on fatigue in SCI. One of the few SCI studies to obtain qualitative data about people’s experience with fatigue was by Hammell et al.\(^{24}\) Hammell et al. explored participants’ experiences with fatigue, its impact, and factors that may relate to them. The study revealed cognitive, emotional, and physical dimensions of fatigue, which are in line with our study’s findings. Hammell et al.\(^{9}\) conducted another qualitative study that also evaluated the management of fatigue in SCI.

4.2.1 Experience with Fatigue

When responding to the CFAB-SCI, participants wanted to further describe the experience of having fatigue with a SCI. Many people with SCI experience fatigue on a regular basis, however the intensity of the fatigue may vary daily. Despite the variations in frequency and intensity, participants described fatigue as a debilitating symptom of their injury, which has also been reported in the literature.\(^2\) Participants also made distinctions between mental and physical fatigue, two dimensions of fatigue that have been established.\(^4,24\) That only three people reported experiencing no fatigue is not surprising given a high prevalence of fatigue in SCI,\(^8-10\) however it does not take into account participants who do not experience fatigue yet did not explicitly state it in writing. Reasons that were stated by these participants for not feeling fatigued included having supportive family members and a healthy, active lifestyle. Intuitively, a supportive family and healthy lifestyle should alleviate fatigue in SCI. These factors could affect
the emotional and physical dimensions of fatigue, as described by Hammell et al.\textsuperscript{24}, and help reduce the impact on daily life.

4.2.2 Impact of Fatigue

Fatigue has a large impact on the daily lives of many people with SCI. Many studies have reported that fatigue can interfere with work, social life and other activities of daily living while diminishing quality of life.\textsuperscript{3,24,36} This was reinforced by this study’s results, as many participants found it difficult to balance work, social life, and activities of daily living with fatigue acting as such a large limiting factor. As described by Hammell and colleagues,\textsuperscript{24} fatigue dictates energy that is only available for certain activities. Fatigue increases the time and difficulty to do simple daily tasks, and this may prevent people with SCI from participating in other activities that may in turn benefit their well-being, such as social participation. This may lead to decreased motivation, increased depression and increased fatigue, creating a vicious cycle that has an impact on the quality of life of people with SCI.\textsuperscript{24}

4.2.3 Factors of Fatigue

Many participants took the opportunity to cite factors that contributed to their fatigue, reinforcing the idea that fatigue is a multi-factorial construct. The majority of the factors described by this sample were consistent with both the literature on SCI, including the Hammell et al.\textsuperscript{24} qualitative study, as well as with the factors that were chosen to be included in the CFAB-SCI. The factor of fatigue mentioned most frequently was pain. The association between fatigue and pain is evident in the literature,\textsuperscript{24,45,48} and has a large impact on functioning and quality of life. Fatigue was also impacted by sleep problems in this group. People with SCI tend to experience far more sleep dysfunction than the general population,\textsuperscript{51,52} and it has shown to be significantly associated with fatigue.\textsuperscript{24,57} Medication was another determinant of fatigue
appearing in this data, as many conventional medications prescribed to people with SCI such as anti-spasticity or analgesic medications are found to contribute to fatigue.\textsuperscript{24, 50} Environmental factors were another sub-group, and can range from physical barriers to weather and extreme temperatures.\textsuperscript{24} These factors may also be exacerbated in areas with extreme meteorological conditions, such as heavy snow fall. Stress, whether it may be from work, personal life, or managing the injury, can contribute to fatigue in SCI evident in both this study and previous literature.\textsuperscript{2, 24}

Only one person cited depression as a factor of fatigue, despite being highly prevalent in the SCI population and shown to be associated with fatigue.\textsuperscript{2, 4, 9, 24, 25, 49} The low report of depression might be due the stigma associated with depression or the high sensitivity of the topic. As such, participants may be less likely to describe their depression in a self-report questionnaire delivered to them through the mail. Another possible reason for the low report of depression on the open-ended question may be that participants have not made the connection between their depression and fatigue. Although depression is known to be associated with fatigue, it may not be intuitive for a person experiencing depression to relate it to their fatigue when thinking about it affectually.

The final two factors of fatigue mentioned by participants were physical factors (i.e. spasticity, muscle weakness, posture, etc.) and cardiovascular factors. These two factors are not covered in the CFAB-SCI as in-depth as the other factors listed. However, clinicians may already be assessing physical and cardiovascular factors as they are more traditional symptoms of SCI, and can be combined with the CFAB-SCI to form a more comprehensive assessment of secondary complications in SCI. The inclusion of these factors into the CFAB-SCI will not be
considered, as it has been previously determined that there are no significant relationships between these factors and fatigue in the SCI literature.\textsuperscript{74}

### 4.2.4 Management of Fatigue

Lastly, participants with SCI shared strategies used to manage their fatigue. This varied between living a healthy lifestyle through diet and exercise, rest, and technology. According to Hammell et al.\textsuperscript{9}, an important component of an effective fatigue management programme would be both the identification and management of factors of fatigue. They stressed the importance of developing strategies or interventions to alleviate the impact of fatigue. The results of this study imply there are successful strategies that can be suggested by clinicians for people experiencing fatigue. The CFAB-SCI contains a section on fatigue management history, which can guide the clinician on what the participant has attempted in the past to manage their fatigue and if it was successful. This can help guide the implementation of fatigue management strategies catered for each individual with SCI.

This study is important in furthering our understanding of fatigue. The construct of fatigue is complex in nature, and truly unique to each individual. It is evident that the experiences, impact, factors and management of fatigue vary drastically between each individual with SCI. This highlights the need for a comprehensive assessment to evaluate fatigue in SCI. The CFAB-SCI is developed to assist clinicians in understanding fatigue as it pertains to each individual experience and the intricate factors involved. While collecting quantitative data is important, telling the story of one’s fatigue must expand beyond quantitative analysis. Each fatigue experience is unique, and can be affected by a variety of factors. There is value in including an open-ended question, providing participants the opportunity to write about their fatigue. It allows clinicians and researchers to explore beyond the closed, Likert-type scales.
present in most fatigue assessments. Thus, clinicians must interpret the results of the CFAB-SCI as it pertains to each individual who completed it. Only when one analyzes the CFAB-SCI in the context of the respondent will you be able to understand their individual experience. This is crucial in developing effective fatigue management programs that address the multi-factorial nature of fatigue in SCI, and that are individualized for each fatigue experience.
5 Conclusion

The study findings suggest that the CFAB-SCI has good convergent validity and internal consistency, exceeding the hypothesized values, and can be implemented in a clinical setting. Although many fatigue measures exist, this study contributes to the literature by presenting a tool that assesses fatigue in a multi-factorial manner, which is currently a gap in research and practice. This study also explores the concept of fatigue, and identified four major groupings to characterize what participants want to say about their fatigue: experience with fatigue, impact of fatigue, factors of fatigue, and management of fatigue. This furthers our understanding of fatigue beyond what is currently known in the literature. It reiterates the notion that fatigue is a complex, multi-factorial construct. It also suggests that researchers and clinicians alike should examine fatigue on an individual level, as it is truly unique to each personal experience.

5.1 Limitations

There are a number of limitations to this study. The primary limitation to this study is the inability to test the sequencing effects of the CFAB-SCI on its psychometric quality. Due to the length of the CFAB-SCI, it is possible that response fatigue may cause items near the end of the battery to be compromised. Therefore, members of the research team suggested changing the sequencing of the sections in the CFAB-SCI in order to determine if answers from the participants would be significantly different depending on what order they answered the measure. In other words, testing a reversed-order form of the CFAB-SCI as alternate form reliability. However, a problem with this arises as statistical literature states that alternate forms must be parallel tests with different content. Therefore, reversing the order and testing sections with the same content, yet taken at different points in the battery, would not hold as an
alternate form and would be psychometrically invalid. This is where tension arises between clinical and statistical perspectives. It is important for clinicians to know whether the sequencing of the battery and response fatigue associated with lengthy measures have an effect on the responses from their patients. This type of error would be problematic for clinicians as they attempt to assess fatigue and its associated factors in people with SCI. Statisticians on the other hand, are more concerned with statistical integrity and ensuring the battery is tested in a valid manner. After consultation with an expert in the statistical field at the University of British Columbia, no solution was found regarding this matter. The research team has yet to determine a way to psychometrically test the sequencing effect of a lengthy battery such as the CFAB-SCI. Consulting the literature to find ways this problem has been addressed also yielded no result. Therefore, the research team came to the conclusion that they were unable to add a test of the sequencing effect of the battery to the study protocol and thus must be listed as a limitation of the study. \[86-88\]

Internal consistency was chosen as the only method of testing reliability. Cronbach’s Alpha is a practical method of measuring the test’s homogeneity between items, meaning their ability to test the same construct. \[87\] Furr and Bacharach \[87\] indicate that due to the limitations associated with other forms of reliability testing, internal consistency is considered the most practical and most widely used form of reliability testing. Internal consistency is a convenient method of reliability testing, as the test only needs to be administered once. Due to the length of the CFAB-SCI, asking participants to complete the measure more than once within a short period of time in addition to the added convergent validity measures may have caused extra response burden and an increased attrition rate. Therefore, internal consistency was an appropriate choice for reliability testing in this study. The limitations however, are that internal consistency cannot
measure the CFAB-SCI’s stability over time, which is of practical importance in a clinical setting. Therefore future testing of the test-retest reliability of the CFAB-SCI would be beneficial.

A convenience sampling approach may be susceptible to selection bias. Those who agree to volunteer for the study or who are already on the recruitment mail-out list might have certain characteristics that may not be found in people unwilling to partake in the study. This affects the generalizability of the study. Another limitation would be a social desirability bias. This term describes the idea that respondents may answer questions in a manner that would be viewed as “desirable” by others. It can include over-reporting “good” behaviour, or under-reporting “bad” behaviour.

The design of this study only allowed for in-text data to be collected and analyzed, which may be less effective than interview-based data collection. This limited the researchers from being able to clarify or elaborate on topics mentioned by participants, and therefore may limit the ability to make conclusions based on the data of this study. Because participants filled out multiple surveys at the same time, there may be a reactive or interaction effect, as one survey may influence how subsequent ones are completed. This may be considered as another limitation to the study. One might also suggest that participants may experience response burden due to the length and number of questionnaires involved. However, the overall commitment of the study was not more than a total of 1.5 hours. This burden is deemed reasonable for research purposes.

Lastly, the inability to control for administrator bias may arise as a minor limitation. If a participant has a high level SCI injury and limited function in the upper extremities, a caregiver might need to complete the questionnaire on behalf of the subject. This information was
recorded in the screening process of the study protocol, and only two participants noted the assistance of a caregiver.

5.2 Implications

The purpose of the CFAB-SCI is to act as a tool for clinicians intervening to mitigate the impact of fatigue in SCI. It will help direct treatment decisions, and facilitate planning and prioritization fatigue management that focuses on areas based on individual issues and results. The CFAB-SCI is an assessment tool, designed to provide clinicians a scope of the issues related to fatigue and to intervene in the factors that are most problematic. The CFAB-SCI differentiates from outcome measures, as its primary purpose is not to quantify the construct of fatigue, but to characterize it. Furthermore, the intent of the CFAB-SCI is to be completed as a whole and not in parts. This will give an overview of the whole fatigue experience. If clinicians are interested in any particular constructs individually, then it is recommended they use outcome measures that are specialized to measuring that specific construct. For example, if a clinician believes that sleep apnea is the main factor of fatigue in a patient, then the clinician may use an outcome measure specific to sleep apnea. In doing so, the integrity and purpose of the CFAB-SCI remains intact.

The study suggests that the CFAB-SCI is approaching readiness to be implemented into a practical setting. However, due to the length of the questionnaire, certain practical considerations need to be taken into account. The CFAB-SCI may take up to 45 minutes to complete, and it may not be feasible for clinicians to sit down with their patients for this long. Because it is so time-intensive, clinicians can work around it to fit the needs of both the patients and themselves. To do so, the CFAB-SCI could be administered outside of the therapy sessions (e.g., patients could complete it at home or in the rehabilitation center for example, and bring the completed tool to their therapist). This also relieves some burden for the respondent, as they are allowed to
complete the measure at their own pace, taking breaks if needed. Administration outside of the session is valuable in allowing the clinician to still be able to assess fatigue in a comprehensive manner without having to sacrifice critical time in a therapy session. The CFAB-SCI can have a large impact on both the research and clinical field, as it will allow fatigue to be better understood, and will provide the necessary information to appropriately guide treatment sessions and manage fatigue.

The next step in the development of the CFAB-SCI would be to evaluate the test-retest reliability of the battery. This would allow us to make inferences on the battery’s stability over time, and would further enforce its readiness for clinical use. Another future research direction could be to use the data obtained in this study to build a theoretical framework of fatigue in SCI. As mentioned in Chapter 1, there is currently no conceptual framework in place to explain fatigue in SCI. Using our understanding of fatigue and the factors associated with fatigue, in addition to the information provided by the CFAB-SCI, a framework could be created to facilitate the understanding of fatigue in research and practice.

The exclusion criteria of this study made participants ineligible if they had conditions that may have confounded the results. This included conditions that may also be associated with fatigue such as cancer, MS, or arthritis. Therefore the results of this study can only be generalized to people with SCI and no other co-morbidities that can affect fatigue. In reality, it is possible that somebody with SCI has co-morbidities such as MS or cancer that may increase fatigue. Therefore future research would need to conduct additional testing of the CFAB-SCI with this population to increase the generalizability of the battery.

The implementation of the CFAB-SCI in a clinical setting would also need to be evaluated to ensure the proper use by clinicians and to determine the efficacy of the battery in
helping direct treatment decisions for clinicians. A possible method of testing the implementation of the CFAB-SCI in clinical practice would be to conduct a pre-post study, or randomized controlled trial where the CFAB-SCI would act as an intervention. Although it may be counter-intuitive to think of an assessment as an intervention, the clinical use of the CFAB-SCI should theoretically improve the outcome of fatigue. With access to the CFAB-SCI, the clinician would have a better understanding of their patients’ fatigue experiences, which would inform their treatment decisions. The study would examine whether clinicians with access to the CFAB-SCI could better develop successful fatigue management strategies compared to clinicians with no access to the battery. We could also evaluate which particular strategies were successful in that study, and use it to inform practice.

Practically, future directions of the CFAB-SCI include creating an electronic version of the battery. This will allow ease of administration for the clinician as well as reduce response burden. With upper extremity impairment being common in SCI, having an option to answer the questionnaire electronically would be efficient and inclusive for all individuals with SCI. It would also dismiss the need for the clinician or caregiver to fill out the questionnaire on behalf of a respondent who does not have the upper extremity function to complete a hard copy of the CFAB-SCI. An electronic version would also create ease for the clinician, and allow them to use their time more efficiently elsewhere. This version would include a fillable PDF format or tablet format, which allows the responders to tick boxes and select responses that otherwise would not be possible electronically. It will also facilitate the distribution of the battery as we intend to make it openly available to the public. It may also prove helpful to apply item response theory in order to use computer adaptive testing. This would be able to adapt to the responses of the participant and possibly reduce the number of items to in turn reduce response burden. Thus,
creating an electronic version of the CFAB-SCI would be a valuable future project. In the meantime, the next step would be to make the CFAB-SCI publicly available, once it is ready, for clinicians to use in their practice while they work towards mitigating the impact of fatigue in SCI.

5.3 Significance

This study provides evidence of the psychometric quality of the CFAB-SCI. Psychometric testing is essential in determining whether the assessment is measuring what it is intended to measure, and that the results are reproducible and consistent. This study also provides further understanding of fatigue and what participants want researchers to know about their fatigue. Evaluating the validity and internal consistency related to the CFAB-SCI will eventually lead to the practical use of the battery in a clinical setting. It is evident that fatigue is a complex and multi-factorial construct in SCI, and thus a comprehensive fatigue assessment is necessary in this population. The CFAB-SCI is a current need for clinicians intervening to mitigate the impact of fatigue in the SCI population. This battery will direct the treatment decisions of these clinicians, facilitate planning and prioritizing, and allow them to develop a comprehensive fatigue management program aimed to address the modifiable factors contributing to the fatigue of the patient. Additionally, it will offer people with SCI a thorough understanding of factors that may contribute to their own fatigue experience and in turn may aid them with the management of their symptom profile. In all, we hope the CFAB-SCI will contribute to the improved management of fatigue in SCI and in turn an increase in quality of life and functioning of people with SCI.
References


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Appendices

Appendix A: Recruitment Poster

Do You Experience Fatigue With Your SCI?

- If so, you are invited to participate in a research study: Evaluating the Comprehensive Fatigue Assessment Battery for Adults with Spinal Cord Injury (CFAB-SCI).
- The CFAB-SCI is a self-report tool developed to assess factors related to fatigue in SCI.

AM I ELIGIBLE?

You are eligible if you are:
- An adult who sustained a complete or incomplete SCI at least 1 year ago
- Willing and able to provide informed consent
- Able to read and write in English

But you CANNOT:
- Have a diagnosis of multiple sclerosis, cancer, arthritis or another condition that may be worsening your fatigue

WHAT DO I HAVE TO DO?

- Complete the CFAB-SCI along with 7 additional questionnaires mailed to you
- The study will take no longer than 1.5 hours
- You will receive a $20 gift certificate as an appreciation for your involvement.

This study is being conducted by researchers from the Rehabilitation Sciences program and the Department of Occupational Science and Occupational Therapy at the University of British Columbia. It is part of a Masters of Science graduate thesis project.

CONTACT US

If you would like to participate please contact:

Kyle Diab, MSc Graduate Student
[Contact Information]

For more information please contact:

Susan Forwell, Principal Investigator
[Contact Information]
Appendix B: Covering Letter

Dear Participant,

This letter is to invite you to participate in a study that aims to develop a new way of assessing fatigue in spinal cord injury (SCI). The collected information will serve as evidence for a clinically useful tool that characterizes fatigue in SCI. It will offer you an understanding of factors that may contribute to your fatigue experience and will direct the treatment decisions of clinicians who are intervening to lower the impact of fatigue on daily activities.

We invite you to take no more than 1.5 hours total to complete the questionnaires contained in this package. This includes the Comprehensive Fatigue Assessment Battery-SCI (CFAB-SCI) and 7 other measures. We do not think there is anything in this study that could harm you or be bad for you. Some of the questions we ask might upset you, however you do not need to answer questions that you are not comfortable answering. Once complete, please return the questionnaires via the stamped, addressed envelope provided in the package.

This study is voluntary and you may withdraw at any time without penalty. All information received will be kept confidential. You will be identified by a research code on all data collection forms and personal information will only be used to track the completion of the questionnaires and to follow up with you during the study. Once the data collection is complete your personal information will be deleted. All materials will be kept safe in a locked cabinet inside the principal investigator’s office or on a password protected computer. Only the graduate student, the principal investigator, and two members of the graduate supervisory committee will have access to the data.

This project will be conducted for a graduate thesis. The results of this study will be reported in a graduate thesis and may also be published in academic journal articles. By completing the surveys, you will be consenting to participate in the study. You will receive a $20 gift certificate as an appreciation for your involvement.

If you have any questions or concerns about this project or if you do not wish to participate, please contact Kyle Diab at Kyle.Diab@alumni.ubc.ca. You may also contact the principal investigator, Dr. Susan Forwell, at Susan.Forwell@ubc.ca.

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Thank you in advance for your participation.
Appendix C: Comprehensive Fatigue Assessment Battery – SCI (CFAB-SCI)

Comprehensive Fatigue Assessment Battery For Person’s with Spinal Cord Injury (CFAB-SCI)

This assessment is a thorough review of your fatigue as related to your spinal cord injury and your daily activities.

To help you think about fatigue, the following definition is provided:

“Fatigue is a lack of physical and/or mental energy that interferes with usual and desired activities”

Please complete the CFAB-SCI if fatigue makes daily activities difficult or impossible. Results of this assessment will guide your healthcare team in making recommendations to manage your fatigue and help you get on with the things you need and want to do.

SECTION 1: INFORMATION ABOUT YOU

Please check the box matching your response and fill in the blanks to answer the following questions.

1. Year of birth: ___________________

2. Sex:
   □ Female
   □ Male

3. Marital status:
   □ Single
   □ Married of living common law
   □ Divorced or separated
   □ Widowed

4. Living situation:
   □ Number of adults you live with: ______________
   □ Number of children you live with: ______________
   □ Other (please specify): ____________________________________________

5. Please indicate the type(s) of home support you receive (select all that apply):
   □ None
   □ Meal preparation
   □ Transportation
   □ Housekeeping
   □ Laundry
   □ Financial management
   □ Shopping
   □ Medication management
   □ Other (please specify): ____________________________________________

6. Employment status (select all that apply):
   □ Paid work (hours per week: ___________)
   □ Volunteer work (hours per week: ___________)
   □ Student (□ Part time □ Full time)
   □ Unemployed (□ Looking for work □ Not looking for work)
   □ Caring for a household or a family member
   □ Retired
   □ Other (please specify): ____________________________________________

7. Job title (if employed): ____________________________________________
SECTION 2: MEDICAL HISTORY
Please check the appropriate box or fill in the blank that best matches your response.

8. Level of spinal cord injury: _____________________
   □ Incomplete
   □ Complete

9. Year of spinal cord injury: _____________________

10. What do you use as your primary mobility aid?
    □ Power wheelchair
    □ Manual wheelchair
    □ Crutch(es)
    □ Cane
    □ I do not use a mobility aid
    □ Other (please specify): ____________________________________________

11. Please indicate if you have any of the following illnesses or conditions (select all that apply):
    □ No other illnesses
    □ Stroke
    □ Cancer
    □ Diabetes
    □ Breathing difficulties (shortness of breath, asthma, bronchitis, etc.)
    □ Arthritis
    □ Migraine or frequent headache
    □ Low iron (anemia)
    □ Decreased thinking/cognitive function
    □ Stomach problems
    □ Heart disease
    □ Thyroid problems
    □ Urinary Tract Infections (UTI)
    □ Chronic infection
    □ Other (please specify): _____________________________________________
SECTION 2: MEDICAL HISTORY (continued)
Please check the appropriate box or fill in the blank that best matches your response.

12. Please list all regular prescription and non-prescription medications, vitamins, and other substances you use for therapeutic effects:

□ Not taking any medications

<table>
<thead>
<tr>
<th>Medication</th>
<th>Amount/Dose</th>
<th>When do you take it?</th>
</tr>
</thead>
<tbody>
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</tbody>
</table>
SECTION 3: GENERAL HEALTH SUMMARY

Please strike through each of the lines below in a place that represents your ratings on various health-related scales, during the last 2 weeks.

For example, if the question asked about whether you like watching TV, the following response would indicate that you like watching TV very much:

Love watching TV  Love watching TV  Hate watching TV

13. No fatigue  Extreme fatigue
14. No pain  Extreme pain
15. Not depressed  Very depressed
16. Not stressed  Very stressed
17. No sleep problems  Constant sleep problems
18. Excellent nutrition  Poor nutrition

If you use a wheelchair:

19. Using my wheelchair is not fatiguing  Using my wheelchair is completely fatiguing

If you walk:

20. Walking is not fatiguing  Walking is completely fatiguing
SECTION 4: FATIGUE

Please check the appropriate box to answer the following questions.

21. How long have you experienced fatigue?
   - □ Less than 6 weeks
   - □ Between 6 weeks and 3 months
   - □ Between 3 months and 6 months
   - □ Greater than 6 months
   - □ I don’t know

The questions in this section ask you about the characteristics of your fatigue during the last 2 weeks.

22. How often have you experienced fatigue?
   - □ Daily
   - □ Most days (more than half of the days)
   - □ Occasionally (less than half of the days)
   - □ Rarely (less than weekly)
   - □ I don’t know

23. When does your fatigue usually begin?
   - □ When I get up
   - □ Late morning
   - □ Early afternoon
   - □ Late afternoon
   - □ Early evening
   - □ I don’t know

24. When is your fatigue usually at its worst?
   - □ When I get up
   - □ Late morning
   - □ Early afternoon
   - □ Late afternoon
   - □ Early evening
   - □ I don’t know
SECTION 4: FATIGUE (continued)

25. Does your fatigue go up and down throughout the day?
   □ Yes
   □ No
   □ I don’t know

26. How long do you feel fatigued during a usual day?
   □ Less than 3 hours
   □ 3 – 6 hours
   □ 6 – 12 hours
   □ 12 – 24 hours
   □ I don’t know

27. Fatigue significantly impacts your activities (select all that apply):
   □ At home
   □ At work
   □ At school
   □ In leisure
   □ Other: _______________________________________________________

28. How often have you exercised?
   □ Not at all
   □ Less than once per week
   □ 1- 2 times per week
   □ More than 3 times per week

29. What factors influence your fatigue (select all that apply)?
   □ Anxiety
   □ Autonomic dysreflexia
   □ Bowel problems
   □ Bladder problems
   □ Spasticity
   □ Posture
   □ Other (please specify): ___________________________________________
SECTION 4: FATIGUE (continued)

The questions* in this section ask you about your social, mental and physical fatigue during the last 2 weeks. Please circle the number that best describes your experience.

<table>
<thead>
<tr>
<th>Because of my fatigue...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>30. I have been less alert.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>31. I have had difficulty paying attention for long periods of time.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>32. I have been unable to think clearly.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>33. I have been forgetful.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>34. I have had difficulty paying attention for short periods of time</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>35. I have had to pace myself in my physical activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
<td></td>
</tr>
<tr>
<td>36. I have been less motivated to do anything that requires physical effort.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>37. I have been less motivated to participate in social activities.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>38. I have been limited in my ability to do things.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>39. I have trouble maintaining physical effort for long periods.</td>
<td>0</td>
<td>1</td>
<td>2</td>
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<td>4</td>
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<tr>
<td>40. I have had difficulty making decisions.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>41. I have been less motivated to do anything that requires thinking.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>42. I have trouble maintaining physical effort for short periods</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>43. I have been physically uncomfortable.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Because of my fatigue...</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Often</td>
<td>Almost Always</td>
<td></td>
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<tr>
<td>44. I have had <strong>trouble finishing tasks that require thinking.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
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<tr>
<td>45. I have had <strong>difficulty organizing my thoughts when doing things.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>46. I have been <strong>less able to complete tasks that require physical effort.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>47. My <strong>thinking has been slowed down.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>48. I have <strong>had trouble concentrating.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
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<tr>
<td>49. I have needed to <strong>rest more often or for longer periods.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>50. I have <strong>avoided/ eliminated certain tasks, activities and lifestyles.</strong></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How often is your fatigue increased by a...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>51. lack of <strong>understanding from friends and family?</strong> (i.e. not understanding the nature of challenges you may face)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>52. lack of <strong>support from friends and family?</strong> (i.e. not helping in supporting any challenges you may face)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>53. lack of <strong>understanding from the professionals you interact with?</strong> (e.g. health care professionals, government personnel etc.)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>54. a lack of <strong>understanding of legislation, rules and regulations?</strong> (e.g. policies related to housing, disability supports, the legal system)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

SECTION 5: ENVIRONMENT

The questions in this section* ask you about your environment during the last 2 weeks. Please circle the number matching your response to the following questions.

<table>
<thead>
<tr>
<th>How often is your fatigue increased by</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>55. The design and layout of your home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>56. The effort required accessing your local community? (e.g. buildings, navigating within your community)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>57. Using your regular transportation method? (e.g. driving, taxi, public transit)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>58. The equipment you use for mobility?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>59. Your regular seating and positioning?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Neutral</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>60. I can manage well in my work environment.</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>61. I can get what I need at the grocery store.</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>62. I manage well in my home/living environment.</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>63. I have all the help in my home that I need.</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>64. I can get around my neighbourhood.</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

65. What is your primary method of transportation?

- [ ] Automobile (car, truck, van)
- [ ] Taxi
- [ ] Bus
- [ ] Scooter or electric wheelchair
- [ ] Other (please specify): ____________________________________________

**SECTION 6: PAIN**

The questions in this section* ask you about the impact of pain on activity during the last 2 weeks.

<table>
<thead>
<tr>
<th>Question</th>
<th>Pain does not impact</th>
<th>Pain has a little impact</th>
<th>Pain has a moderate impact</th>
<th>Pain has a great impact</th>
<th>Pain completely impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>66. General activity</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>67. Sleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>68. Mobility (ability to get around)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>69. Normal work (includes work outside the home and housework)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>70. Relations with other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>71. Mood</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>72. Enjoyment of life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

SECTION 7: SLEEP

The questions in this section* ask you about your sleep during the last 2 weeks. Please circle the response that best applies and fill in the blanks to answer the following questions.

73. How long did it usually take for you to fall asleep during the last 2 weeks?
   - □ 0 - 15 minutes
   - □ 16 - 30 minutes
   - □ 31 - 45 minutes
   - □ 46 - 60 minutes
   - □ Over 60 minutes

74. On average, how many hours did you sleep each night during the last 2 weeks?
   Number of hours per night: _________________

75. Select all that apply:
   - □ I have a routine prior to night time sleep
   - □ I experience restless legs when in bed
   - □ I drink alcohol or caffeinated beverages in the evening
   - □ I experience sleep apnea (stop breathing in your sleep momentarily)

76. Why do you awaken at night? (Select all that apply)
   - □ I don’t wake up at night
   - □ I’m worried about something
   - □ Other people wake me up
   - □ I need to urinate
   - □ I have muscle spasms
   - □ I experience pain (other than spasms)
   - □ Other (please specify)

77. Do you wake up earlier than you intend?
   - □ I don’t know
   - □ It changes night to night
   - □ No
   - □ Yes

**SECTION 7: SLEEP (continued)**

The questions in this section* ask you about your sleep during the last 2 weeks. Please circle the response that best applies to the following questions.

<table>
<thead>
<tr>
<th>During the last 2 weeks ...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>78. How often did you feel that your sleep was restless (moving restlessly, feeling tense, speaking, etc., while sleeping)?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>79. How often did you get enough sleep to feel rested upon waking in the morning?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>80. How often did you awaken short of breath or with a headache?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>81. How often did you feel drowsy or sleepy during the day?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>82. How often did you have trouble falling asleep?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>83. How often did you awaken during your sleep time and have trouble falling asleep again?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>84. How often did you have trouble staying awake during the day?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>85. How often did you snore during your sleep?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>86. How often did you get the amount of sleep you needed?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

SECTION 8: STRESS
The questions in this section* ask you about your feelings and thoughts during the last 2 weeks. Please circle the number that best describes how often you felt or thought a certain way.

<table>
<thead>
<tr>
<th>How often have you...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>87. Been upset because of something that happened unexpectedly?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>88. Felt that you were unable to control the important things in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>89. Felt nervous and “stressed”?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>90. Lacked confidence about your ability to handle your personal problems?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>91. Felt that things were not going your way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>92. Found that you could not cope with all the things that you had to do?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>93. Been unable to control the irritations in your life?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>94. Felt that you were not on top of things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>95. Been angered or upset because of things that happened that were outside of your control?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>96. Felt difficulties were piling up so that you could not overcome them?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### SECTION 9: MOOD

The questions in this section* ask you about your mood during the last 2 weeks. Please circle the number that best describes the way you have been feeling.

<table>
<thead>
<tr>
<th>How often have you...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>97. Had little interest or pleasure in doing things?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>98. Been feeling down, depressed or hopeless?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>99. Been feeling tired or having little energy?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>100. Had a poor appetite or overeating?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>101. Been feeling bad about yourself - that you have let yourself or your family down?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>102. Had trouble concentrating on things such as reading the newspaper or watching television?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>103. Been moving/ speaking so slowly that other people might have noticed OR, been so fidgety/ restless that you have been moving around a lot more than usual?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>104. Had thoughts that you would be better off dead or thoughts of hurting yourself in some way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

If you have experience any of the above points:

<table>
<thead>
<tr>
<th>How often have they made it difficult for you...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>105. To do your work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>106. Take care of things at home?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>107. Get along with others</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

SECTION 10: NUTRITION

The questions in this section* ask you about your nutrition during the last 2 weeks. Please check the response that best applies and fill in the blanks to answer the following questions.

108. Is your appetite usually:

- □ Very good
- □ Good
- □ Fair
- □ Poor
- □ Very poor

109. How long does it take you to eat an average meal?

- □ 0 – 10 minutes
- □ 10 – 20 minutes
- □ 20 – 30 minutes
- □ Greater than 30 minutes

110. Do you usually:

- □ Eat three meals per day
- □ Eat smaller meals/snacks more frequently throughout the day
- □ Other (please specify): _____________________________

111. Are you eating food or following a specialized diet with the specific intent to:

- □ Maintain skin health
- □ Protect yourself from or reduce the occurrence of urinary tract infections
- □ Optimize efficient digestion and bowel management
- □ Promote good vascular function
- □ Lose weight
- □ None of the above

112. Have you changed or started a new diet in the past 2 weeks?

- □ Yes (please specify):
  _____________________________

- □ No

* Adapted from: Spitzer, R., Kroenke, K., Williams, J. (1999). Validation and utility of a self-report version of the PRIME-MD: the PHQ primary care
SECTION 10: NUTRITION (continued)

113. Have you noticed any significant weight changes (increase or decrease) in the past 2 weeks?

  □ No
  □ Yes

114. Please indicate if you have any of the following (select all that apply):

  □ Constipation
  □ Diarrhea
  □ Nausea
  □ Heart burn
  □ Abdominal pain
  □ Indigestion
  □ Irregular bowel movements
  □ Other (please specify): ____________________________________________

115. Do any of the following disrupt your ability to eat good meals regularly? (Select all that apply):

  □ Inadequate financial resource
  □ Lack of energy to prepare meals
  □ Decreased/increased appetite
  □ Busy schedule/ lack of time
  □ Other (please specify): ____________________________________________

**SECTION 11: FATIGUE MANAGEMENT HISTORY**

The questions in this section ask you about different ways you have tried to manage your fatigue in the past. Please check the box or fill in the blanks to answer the following questions.

### Environmental Strategies

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Tried?</th>
<th>Helpful?</th>
<th>Still Using?</th>
</tr>
</thead>
<tbody>
<tr>
<td>116. Taking a cool shower/bath</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>117. Drinking a cold beverage</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>118. Drinking a caffeinated beverage</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>119. Taking medications</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>120. What is your confidence level in using the above strategies?</td>
<td><strong>Not Confident</strong></td>
<td><strong>Very Confident</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activity-based Strategies</th>
<th>Tried?</th>
<th>Helpful?</th>
<th>Still Using?</th>
</tr>
</thead>
<tbody>
<tr>
<td>121. Changing your diet</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>122. Napping or resting during the day</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>123. Using relaxation techniques</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>124. Changing activity at home or at work</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>125. Planning and pacing your day</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>126. Exercise (specify type):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>127. What is your confidence level in using the above strategies?</td>
<td><strong>Not Confident</strong></td>
<td><strong>Very Confident</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Assistive Devices / Tools

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Tried?</th>
<th>Helpful?</th>
<th>Still Using?</th>
</tr>
</thead>
<tbody>
<tr>
<td>128. Using a scooter or electric wheelchair to conserve energy</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>129. Using a persons with disability parking sticker to decrease distances</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>130. Using a cooling vest</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>131. What is your confidence level in using the above strategies?</td>
<td><strong>Not Confident</strong></td>
<td><strong>Very Confident</strong></td>
<td></td>
</tr>
</tbody>
</table>


**SECTION 11: FATIGUE MANAGEMENT HISTORY (cont.)**
132. **Other Strategies (specify):**

<table>
<thead>
<tr>
<th>Tried?</th>
<th>Helpful?</th>
<th>Still Using?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

- 
- 
- 
- 

133. What is your confidence level in using the above strategies?

<table>
<thead>
<tr>
<th>Not Confident</th>
<th>Very Confident</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

134. Would you like to tell us anything else about your fatigue?

________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

111
Appendix D: MS Neuropsychological Screening Questionnaire

**Instructions:** The following questions ask about problems that you may experience. Rate how often these problems occur AND how severe they are. Base your ratings on how you have been over the last three months.

Please check the appropriate box.

<table>
<thead>
<tr>
<th></th>
<th>Very often, very disruptive</th>
<th>Quite often, interferes w/ life</th>
<th>Occasionally, seldom a problem</th>
<th>Very rarely, no problem</th>
<th>Never, does not occur</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Are you easily distracted?</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>2. Do you lose your thoughts while listening to somebody speak?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Are you slow when trying to solve problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Do you forget appointments?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Do you forget what you read?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Do you have trouble describing shows or programs recently watched?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
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<td>7. Do you need to have instructions repeated?</td>
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<td>8. Do you have to be reminded to do tasks?</td>
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<tr>
<td>9. Do you forget errands that were planned?</td>
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<tr>
<td>10. Do you have difficulty answering questions?</td>
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<tr>
<td>11. Do you have difficulty keeping track of two things at once?</td>
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<tr>
<td>12. Do you miss the point of what someone is trying to say?</td>
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<tr>
<td>13. Do you have difficulty controlling impulses?</td>
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<tr>
<td>14. Do you laugh or cry with little cause?</td>
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<td>15. Do you talk excessively or focus too much on your own interests?</td>
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</table>

Appendix E: Fatigue Severity Scale (FSS)

Please read each statement and circle a number from 1 to 7, depending on how appropriate you feel the statement applies to you over the past week.

A low value indicates that the statement is not very appropriate whereas a high value indicates agreement:

1 2 3 4 5 6 7

Strongly Disagree Strongly Agree

<table>
<thead>
<tr>
<th>During the past week, I have found that:</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My motivation is lower when I am fatigued.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>2. Exercise brings on my fatigue.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>3. I am easily fatigued.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>4. Fatigue interferes with my physical functioning.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>5. Fatigue causes frequent problems for me.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>6. My fatigue prevents sustained physical functioning.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>7. Fatigue interferes with carrying out certain duties and responsibilities.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>8. Fatigue is among my three most disabling symptoms.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
<tr>
<td>9. Fatigue interferes with my work, family, or social life.</td>
<td>1 2 3 4 5 6 7</td>
</tr>
</tbody>
</table>

Appendix F: Craig Hospital Inventory of Environmental Factors Short Form (CHIEF-SF)

Being an active, productive member of society includes participating in such things as working, going to school, taking care of your home, and being involved with family and friends in social, recreational and civic activities in the community. Many factors can help or improve a person’s participation in these activities while other factors can act as barriers and limit participation.

First, please tell me how often each of the following has been a barrier to your own participation in the activities that matter to you. Think about the past year, and tell me whether each item on the list belowe has been a problem daily, weekly, monthly, less than monthly, or never. If the item occurs, then answer the question as to how big a problem the item is with regard to your participation in the activities that matter to you.

(Note: if a question asks specifically about school or work and you neither work nor attend school, check not applicable)

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>Weekly</th>
<th>Monthly</th>
<th>Less than monthly</th>
<th>Never</th>
<th>Not applicable</th>
<th>Big problem</th>
<th>Little problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In the past 12 months, how often has the availability of transportation been a problem for you? When this problem occurs has it been a big problem or a little problem?</td>
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<td>2. In the past 12 months, how often has the natural environment – temperature, terrain, climate – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?</td>
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<td>3. In the past 12 months, how often have other aspects of your surroundings – lighting, noise, crowds, etc. – made it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>4. In the past 12 months, how often has the information you wanted or needed not been available in a format you can use or understand? When this problem occurs has it been a big problem or a little problem?</td>
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<td>5. In the past 12 months, how often has the availability of health care services and medical care been a problem for you? When this problem occurs has it been a</td>
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<td>big problem or a little problem?</td>
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<tr>
<td>Daily</td>
<td>Weekly</td>
<td>Monthly</td>
<td>Less than monthly</td>
<td>Never</td>
<td>Not applicable</td>
<td>Big problem</td>
<td>Little problem</td>
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<tr>
<td>6. In the past 12 months, how often did you need someone else’s help in your home and could not get it easily? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>7. In the past 12 months, how often did you need someone else’s help at school or work and could not get it easily? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>8. In the past 12 months, how often have other people’s attitudes toward you been a problem at home? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>9. In the past 12 months, how often have other people’s attitudes toward you been a problem at school or work? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>10. In the past 12 months, how often did you experience prejudice or discrimination? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>11. In the past 12 months, how often did the policies and rules of businesses and organizations make problems for you? When this problem occurs has it been a big problem or a little problem?</td>
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<tr>
<td>12. In the past 12 months, how often did government programs and policies make it difficult to do what you want or need to do? When this problem occurs has it been a big problem or a little problem?</td>
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</table>
**Appendix G: Multidimensional Pain Inventory-SCI: Life Interference Subscale (MPI-SCI)**

**Instructions**

An important part of our evaluation includes examination of pain from your perspective because you know your pain better than anyone else. The following questions are designed to help us learn more about your pain and how it affects your life. The questionnaire has three sections. Under each question is a scale to mark your answer. Read each question carefully and then *circle a number* on the scale under that question to indicate how that specific question applies to you. If there is a question that you think does not apply to you, please circle the number of that question. After you have completed the questionnaire, check your responses to make sure that you have answered each question.

The following example may help you to better understand how you should answer these questions.

**Example**

How nervous are you when you ride in a car when the traffic is heavy?

Not at all nervous 0 1 2 3 4 5 6 Extremely nervous

If you are not at all nervous when riding in a car in heavy traffic, you would want to *circle* the number 0. If you are very nervous when riding in a car in heavy traffic, you would then circle the number 6. Lower numbers would be used for less nervousness, and higher numbers for more nervousness.

<p>| | | | | | | | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>How much has your pain changed recreational activities?</td>
<td>No change</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>How much has your pain changed your ability to take part in recreational and other social activities?</td>
<td>No change</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>How much do you limit your activities in order to keep your pain from getting worse?</td>
<td>No at all</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?</td>
<td>No change</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>How much has your pain changed your relationship with your spouse, family, or significant other?</td>
<td>No change</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tbody>
</table>
6. How much has your pain changed your ability to do household chores?
No change 0 1 2 3 4 5 6 Extreme change

7. How much has your pain interfered with your ability to plan activities?
No change 0 1 2 3 4 5 6 Extreme change

8. How much has your pain interfered with your friendships with people other than your family?
No change 0 1 2 3 4 5 6 Extreme change

Appendix H: The Pittsburgh Sleep Quality Index (PSQI)

Instructions: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. Please answer all questions. During the past month,

1. When have you usually gone to bed? ______________

2. How long (in minutes) has it taken you to fall asleep each night? ______________

3. When have you usually gotten up in the morning? ______________

4. How many hours of actual sleep do you get at night? (This may be different than the number of hours you spend in bed) ______________

5. During the past month, how often have you had trouble sleeping because you...

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not during the past month (0)</th>
<th>Less than once a week (1)</th>
<th>Once or twice a week (2)</th>
<th>Three or more times a week (3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Cannot get to sleep within 30 minutes</td>
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<tr>
<td>b. Wake up in the middle of the night or early morning</td>
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<td>c. Have to get up to use the bathroom</td>
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<tr>
<td>d. Cannot breathe comfortably</td>
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<tr>
<td>e. Cough or snore loudly</td>
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<tr>
<td>f. Feel too cold</td>
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<tr>
<td>g. Feel too hot</td>
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<tr>
<td>h. Have bad dreams</td>
<td></td>
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<tr>
<td>i. Have pain</td>
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<tr>
<td>j. Other reason(s), please describe, including how often you have had trouble sleeping because of this reason(s):</td>
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</tbody>
</table>

6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help you sleep?

7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?

8. During the past month, how much of a problem has it been for you to keep up enthusiasm to get things done?

<table>
<thead>
<tr>
<th>Rating</th>
<th>Very good (0)</th>
<th>Fairly good (1)</th>
<th>Fairly bad (2)</th>
<th>Very bad (3)</th>
</tr>
</thead>
<tbody>
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</table>

9. During the past month, how would you rate your sleep quality overall?

Appendix I: Depression Anxiety Stress Scale-21 (DASS-21)

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

0 Did not apply to me at all  
1 Applied to me to some degree, or some of the time  
2 Applied to me to a considerable degree, or a good part of time  
3 Applied to me very much, or most of the time

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rating Scale</th>
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</thead>
<tbody>
<tr>
<td>1 I found it hard to wind down</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>2 I tended to over-react to situations</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>3 I felt that I was using a lot of nervous energy</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>4 I found myself getting agitated</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>5 I found it difficult to relax</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>6 I was intolerant of anything that kept me from getting on with what I was doing</td>
<td>0 1 2 3</td>
</tr>
<tr>
<td>7 I felt that I was rather touchy</td>
<td>0 1 2 3</td>
</tr>
</tbody>
</table>

Appendix J: Center for Epidemiologic Studies Short Depression Scale (CES-D 10)

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the **past week** by checking the appropriate box for each question.

<table>
<thead>
<tr>
<th>Items:</th>
<th>Rarely or non of the time (less than 1 day)</th>
<th>Some or a little of the time (1-2 days)</th>
<th>Occasionally or a moderate amount of time (3-4 days)</th>
<th>All of the time (5-7 days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I was bothered by things that usually don't bother me.</td>
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<tr>
<td>2. I had trouble keeping my mind on what I was doing.</td>
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<tr>
<td>3. I felt depressed.</td>
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<td>4. I felt that everything I did was an effort.</td>
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<td>5. I felt hopeful about the future</td>
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<tr>
<td>6. I felt fearful.</td>
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<tr>
<td>7. My sleep was restless.</td>
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<tr>
<td>8. I was happy.</td>
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<tr>
<td>9. I felt lonely.</td>
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</tbody>
</table>
| 10. I could not "get going."