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Assessing Health-Related Quality of Life and Subjective Well-Being in Adults with Spinal Cord Injury

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Health Policy and Management

by

Alina Ionela Palimaru

2018

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ABSTRACT OF THE DISSERTATION

Assessing Health-Related Quality of Life and Subjective Well-Being in Adults with Spinal Cord Injury

by

Alina Ionela Palimaru

Doctor of Philosophy in Health Policy and Management

University of California, Los Angeles, 2018

Professor Ronald D. Hays, Chair

This dissertation contributes to the scholarship on health outcomes among individuals with spinal cord injury (SCI). SCI is a dramatic, life-changing trauma that requires long-term and evolving care. Life with SCI entails learning to self-care, acquiring the right wheelchair, home adaptations, and learning to move inside and outside the home. Improving health outcomes measurement of this subgroup may benefit them by making SCI care more patient-centered, i.e. reflective of patients' preferences and values. Three studies were conducted: (1) an assessment of associations between health-related quality of life (HRQOL) and evaluative well-being (EWB) measures collected in the United States (U.S.) Patient Reported Outcomes Measurement Information System (PROMIS®) project (Chapter 2); (2) a comparison of perceptions of quality of life (QOL) among adults with SCI in the U.S. versus the United Kingdom (UK) (Chapters 3 and 4); and (3) development and psychometric evaluation of a Fatigability Index for full-time wheelchair users with SCI (Chapter 5). The first study provides further evidence that there is an empirical overlap between HRQOL and EWB. The second study found that for adults living with SCI, good QOL is essential for successful rehabilitation. Differences between interviewees from the US and the UK in perceived medical care and functional adjustment suggest that factors affecting QOL may relate to broader health system characteristics. Also, understanding what HRQOL and subjective well-being (SWB) measures are valued by adults living with SCI can lead to selection of informative instruments, which could help clinicians to complement and tailor established care and rehabilitation protocols for individual needs. Specifically, measuring and managing fatigue in the context of SCI is important. The third study developed an instrument assessing physical and mental fatigability in adults with SCI. The instrument covers a comprehensive list of health problems and activities associated with fatigue. The psychometric evaluation shows high measurement precision in discriminating among individuals with a relatively wide range of fatigability. The resulting patient chart, the Fatigability Vector, highlights causes of fatigue and areas requiring immediate intervention.

The dissertation of Alina Ionela Palimaru is approved.

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2018

To my parents, my partner Marcus Dillistone, and my side-kick Tootsie

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CHAPTER 1

INTRODUCTION

1.1 Spinal Cord Injury

The spinal cord is a bundle of nerve fibers, like communication cables running from the brain to all parts of the body: a two-way message system carrying instructions from the brain to move muscles, for instance, and back to the brain, returning sensations such as touch or heat. The spinal cord runs inside the spinal column, protected by linked bones, known as vertebrae. If the spinal cord is damaged by injury or disease, the link between the brain and the body can be completely or partially damaged (Dillistone, 2012; Skriver Rose, 2012; Pope, 2007; Soopramanien, 1994).

A complete injury means there is no sensory or motor function below the level of spinal damage. An incomplete injury means there is partial sensory (hypesthesia) or motor (paresis) function. The level at which spinal cord injury occurs is important because it can determine the type or area of the resulting loss of sensory or motor function. A low-level injury (lumbar or back injury) is referred to as paraplegia. Typically, a paraplegic patient loses control over their lower body, but they retain varying degrees of control over their upper body and arms. Higher level injuries (cervical or neck injuries) are known as tetraplegia or quadriplegia. Tetraplegic patients usually lose control over more of their body –arms and hands, as well as lower body, and in extreme cases tetraplegia may affect vital functions such as breathing (Dillistone, 2012; Skriver Rose, 2012; Pope, 2007; Soopramanien, 1994).

1.2 Conceptual Model

If the main objectives of medicine and public health are to improve quality of care and quality of life, then we must ensure that the way we measure them is useful for clinicians and patients alike. It is useful to begin with a conceptual model that simultaneously captures the patients', the caregivers', and the medical care teams' perspectives.

A conceptual framework that encompasses clinical and patient-centered elements, and integrates health-related quality of life (HRQOL) and subjective well-being (SWB) in clinical practice is proposed (see Figure 1.1). The model draws from prior conceptualizations of HRQOL (Fung & Hays, 2008) and encodes assumptions about the SCI patient's journey through acute and post-acute care, based on prior knowledge and research.

The elements that contribute to quality of life go beyond medical care. Patients face problems in areas such as housing, gainful employment, and relationships. Because such people should be treated holistically by integrated health care teams, it is important that there be awareness of a patient's life circumstances. In the absence of key indicators such as HRQOL and SWB, the care team is less likely to be effective in maximizing the rehabilitation of the person. Standardized outcome measures of a patient's functioning and well-being could prove to be invaluable as the treatment and rehabilitation of people with lifelong conditions matures from a fix-and-stabilize approach to a more holistic process.

A typical care team for a patient with SCI may include a specialist physician, an SCI nurse, a physiotherapist, and occupational therapist, and a person charged with providing practical and logistical help with regard to home-adaptations, welfare claims, transportation arrangements, etc. This team may be based at a specialist SCI treatment center—that is, under one roof--but it will also have to liaise with community-based practitioners such as the patient's primary care doctor, local nursing support, a professional care-giver, and/or family members. Hence, the potential usefulness of health outcome measures is likely to extend beyond specialized care, into domestic care and even personal and family relationships. Assessing a patient's SWB and HRQOL may enable this extended support team to focus its efforts in areas of greatest need. Such measurements will be a significant strategic tool in using and targeting resources to best effect.

In creating a conceptual framework to convey the inter-relationship of factors in rehabilitation medicine, I began by using a traditional linear patient pathway approach. However, unlike areas of medicine where patients are repaired, such as gall-bladder surgery, patients with life-long conditions are involved in a constant cycle of rehabilitation. Sometimes this cycle is a virtuous cycle, where patients and their care teams set goals, which are then achieved, for example leading to increased function, which then inspires new goals in a new cycle of rehabilitation activity. Sometimes, however, especially with aging patients, rehabilitation medicine aims to slow the decline in a person's function, and to prolong their ability to care for themselves.

In the proposed framework, rehabilitation is an ongoing cycle of activity, with collectively agreed goals at its center. This process involves a cycle of assessment (physical function, emotional well-being, etc) and setting achievable goals (such as returning home, or even for some, going back to work). Whatever the goals, and whether they are achieved, the process is essentially an on-going cycle throughout a person's life. The degree of intervention undertaken by the care team may change in intensity, but by and large, the process does not end.

Having said that the process of rehabilitation is a cyclical process of assessment and review, there is a more conventional patient pathway that feeds into it.

The starting point of the framework (see Figure 1.1) is when a person acquires an SCI, whether that is a traumatic injury such as a road traffic accident or fall from a horse, or acquired through a diseased spinal cord (such as cancer). This process may involve, in the case of a traumatic injury, attendance by an emergency medical team, such as a paramedic at the road side, or in the case of a disease-based SCI, via the general practitioner referral route to a specialist. Either way, there will be a diagnosis using a combination of traditional physical examinations and technological support.

The framework diagram (Figure 1.1) simplifies the traumatic or disease-based starting point through the box labeled *SCI injury*, which delineates the point at which an injury is acquired. In best practice, traditional diagnosis will place the patient in the care of a medical team, which is typically led by the patient's specialist physician. That physician may spend less time with a patient than most of the other members of the care team, thereby further indicating the importance of outcome measurements to monitor a person's progress. The care team, should have a close relationship with the patient. SCI is a serious condition, often acquired suddenly, bringing with it a high degree of stress and anxiety, so the care team's communication with the patient is critically important. The patient's preferences for care are a very significant component in the cycle of rehabilitation.

In treating individual patients with differing needs, a care team will reference established protocols or national guidelines to help them to structure a package of care that best suits each individual. If the care team's relationship with the patient is functioning as it should, then it provides a platform for the highest level of positive behavior from the patient. This could be anything from compliance with a prescription regime, or a positive approach to physiotherapy and other rehabilitation activities. Patient behaviors, such as adherence to treatment, feed into their overall satisfaction with their care, and their overall satisfaction with their care feeds back into their behavior as progress is made (Fung & Hays, 2008). This is the virtuous cycle of health and enablement: the more people can do, the better they feel, and the better they feel, the more they can do.

The final elements in Figure 1.1 look at quality of care and satisfaction with care. Quality of care is the overall quality of all interventions carried out by the care team on behalf of the patient. In considering this, we can reference the same local or national protocols that were used to set the care program. We can also look at the technical quality of care in relation to practical and technical measures used in the process, such as scan results, testing, record-keeping, etc.

In addition to the technical aspects, quality of care also considers patient experience and the satisfaction that a patient feels with the care they are receiving on an on-going basis. It is therefore a combination of the quality of care that a patient receives, patient experience and a patient’s satisfaction with the care that they receive, that influence HRQOL and SWB.

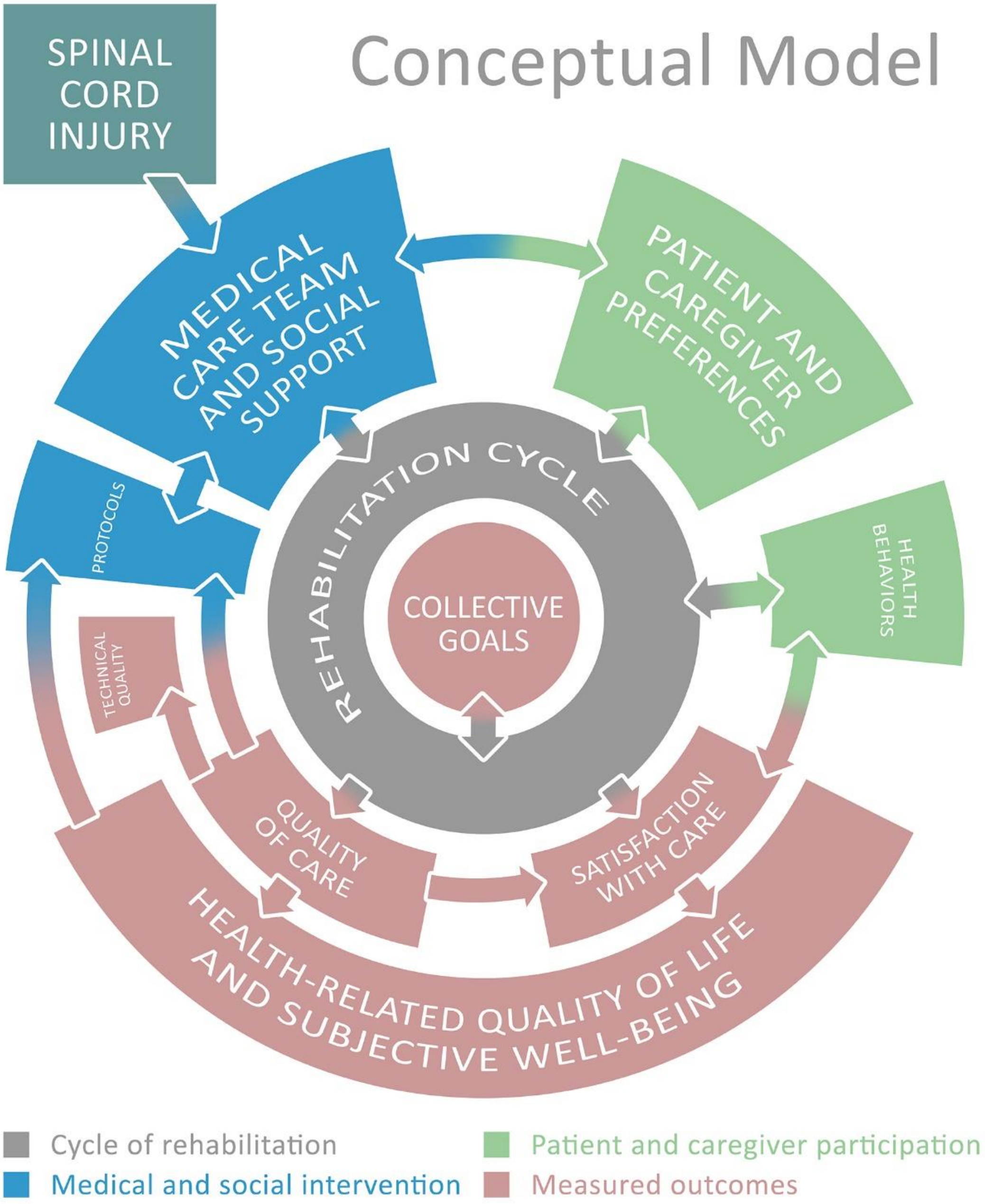
For SCI patients the process is on-going rather than linear, and the cycle of rehabilitation is punctuated by assessment review, goal-setting, and judging outcomes. So, in the same way that this core process is cyclical, the measurement of a patient’s behavior (compliance with the rehabilitation program), and their satisfaction with the process at any given point must also be measured periodically as part of their rehabilitation program.

The performance of the care team and its consistent delivery of high quality of care must also be measured as it is a major contributor to HRQOL and SWB (Van Der Eijk, et al., 2004; Lee, et al., 2013). The final element within the cycle of rehabilitation medicine is the patient's HRQOL and SWB information feeding back into the system. Figure 1.1 depicts a feedback loop showing how data from measurements such as HRQOL and SWB inform the care protocol, which is also the central record and reference point for those planning and reviewing individual care plans.

This conceptual model includes processes and protocols used by SCI specialty centers in the UK, and specifically The Duke of Cornwall Spinal Treatment Center at Odstock Hospital, Salisbury, England (Dillistone, 2008). It also references concepts proposed by Professor Scott Glickman, who in a discussion about the British Brain and Spine Foundation, talked about the virtuous cycle of health and enablement (Dillistone, 1996). He too advocated a care team approach to rehabilitation medicine, integrating practitioners with different skill sets into a group that best served the patients' rehabilitation care from medicine all the way through to personal well-being.

1.2.1. Figure 1.1 – Conceptual Model

Derived from Fung and Hays (2008), the care protocols utilized by The Duke of Cornwall Spinal Treatment Center (2008), and the model for health and enablement proposed by Dr. Scott Glickman (1996).


Conceptual Model
SPINAL CORD INJURY
MEDICAL CARE TEAM AND SOCIAL SUPPORT
PATIENT AND CAREGIVER PREFERENCES
PROTOCOLS
HEALTH BEHAVIORS
REHABILITATION CYCLE
COLLECTIVE GOALS
TECHNICAL QUALITY
QUALITY OF CARE
SATISFACTION WITH CARE
HEALTH-RELATED QUALITY OF LIFE AND SUBJECTIVE WELL-BEING
Cycle of rehabilitation
Patient and caregiver participation
Medical and social intervention
Measured outcomes

1.3. Health-Related Quality of Life

HRQOL is a patient-reported outcome (PRO). According to the Food and Drug Administration (2009), a patient-reported outcome is “any report coming from patients about a health condition and its treatment” (Food and Drug Administration, 2009, p. 2). HRQOL measures functioning and well-being in physical, mental and social domains of health. HRQOL includes physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions.

HRQOL measures are used for comparative performance evaluation, quality assurance and evaluation of healthcare interventions (Jenkinson, Gibbons, & Fitzpatrick, 2009). Use of HRQOL measures in clinical practice has been found to facilitate patient-physician communication and contribute to physicians’ holistic understanding of a patient’s health experience (Snyder, et al., 2012; Velikova, et al., 2004; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; Detmar & Aaronson, 1998).

1.4. Subjective Well-Being

Earlier definitions of SWB were predicated on two distinct views of human nature. First, the hedonic view, whereby the goal of life is to maximize the amount of pleasure and happiness of the body. On the other hand, the eudaimonic view transcends happiness, and rests on achieving meaning in life, and the realization of human potential. Under this philosophy, not all desires bring about well-being when achieved (Ryan & Deci, 2001).

Building on this early understanding of SWB, more recently, SWB has been described as having three components: (1) evaluative well-being (overall appraisal of one’s life); (2)

experienced or hedonic well-being (emotional status, mood, over short periods of time); and (3) eudemonic well-being (perceived purpose and fulfillment) (Dolan, Layard, & Metcalfe, 2011). While elements of well-being are broadly reflected in HRQOL, the body of work on subjective well-being is typically not integrated into HRQOL measures, especially with respect to specific patient populations.

1.5. Fatigue and Fatigability

Fatigue is commonly defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities” (National Institutes of Health, 2015, para. 4). It is unclear what the true prevalence of fatigue among SCI individuals is, but some researchers suggest that 25% of individuals with SCI report fatigue that is severe enough to impair daily activity function and well-being (Anton, Miller, & Townson, 2008; McColl, et al., 2003).

Adults with SCI may experience fatigue associated with their age, their full-time use of a wheelchair, daily activities, co-morbidities, and other consequences of SCI (e.g., poor posture, pressure management) (Pope, 2007; McColl, et al., 2003; Gerhart, et al., 1993; Charlifue, et al., 1999; Hirsch, et al., 1991; Elliott, 1996; Hughes, et al., 2001; Streeten and Anderson, 1998; Widerstrom-Noga, et al., 2001). Just like non-SCI adults, persons with SCI may try to avoid fatigue and exhaustion by decreasing or eliminating certain activities (cooking) or wheelchair maneuvers (wheelchair-to-car transfers).

There are more than 25 fatigue self-assessment instruments, including the Fatigue Severity Scale (FSS), and the Patient Reported Outcomes Measurement Information System (PROMIS®) Fatigue item-bank that assesses a broad range of fatigue states, from mild subjective feelings of tiredness, to an overwhelming, incapacitating, and relentless sense of physical/mental exhaustion (Cella, et al., 2010; Anton, et al., 2008).

Fatigability is “a characteristic describing an individual’s susceptibility to experiencing fatigue for a given quantifiable demand” (National Institutes of Health, 2015, para. 5). There are two ways of measuring fatigability. The first is performance-related fatigability, which is observed and measured by a clinician, and refers to erosion in force, power, speed or stamina related to performance of a given activity. The second type of fatigability is perceived (self-reported) fatigability, which is the focus of the third study: it refers to feelings of tiredness and wear related to duration and intensity of an activity (National Institutes of Health, 2015). Self-reported fatigability has been measured in contexts other than SCI, with instruments such as the Physical Energy Scale from the Motivation and Energy Inventory, the Dutch Exertion Fatigue Scale, the Situational Fatigue Scale, and the Pittsburgh Fatigability Scale (Glynn et al., 2015; Richardson, et al., 2015; Murphy, et al., 2013; Schnelle, et al., 2012; Yang and Wu, 2005; Tiesinga, et al., 1998). To date, no self-reported fatigability instrument specifically for SCI individuals has been developed and assessed psychometrically.

Development of such targeted instruments aligns with patient-centered care goals of being “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001, p. 6). This study from the dissertation presents the development and evaluation of an SCI fatigability measure that can complement clinical processes like rehabilitation, seating, pressure/posture management, or other interventions to ameliorate the symptoms.

1.6. References

Anton, H. A., Miller, W. C., & Townson, A. F. (2008). Measuring Fatigue in Persons with Spinal Cord Injury. *Arch Phys Med Rehabil*, 538-542.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., . . . Hays, R. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *Journal of Clinical Epidemiology, 63*(11), 1179-1194.

Charlifue, S., Weitzenkamp, D., & Whiteneck, G. (1999). Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. *Arch Phys Med Rehabil*, 1429-1434

Detmar, S. B., & Aaronson, N. K. (1998). Quality of Life Assessment in Daily Clinical Oncology Practice: a Feasbility Study. *European Journal of Cancer,* 1181-1186.

Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N. K. (2002). Health-Related Quality-of-Life Assessments and Patient-Physician Communication. *American Medical Journal*, 3027-3035.

Dillistone, M. (Director). (1996). *British Brain and Spine Foundation* [Motion Picture].

Dillistone, M. (Director). (2008). *Outreach* [Motion Picture].

Dillistone, M. (Director). (2012). *The Spinal Injury Patient Film* [Motion Picture].

Dillistone, M. (Director). (2013). *Choosing a Wheelchair* [Motion Picture].

Dolan, P., Layard, R., & Metcalfe, R. (2011). *Measuring Subjective Well Being for Public Policy: Recommendations on Measures.* London: Centre for Economic Performance, London School of Economics.

Elliott, T. (1996). Depression following spinal cord injury. *Arch Phys Med Rehabil*, 816-823.

Food and Drug Administration. (2009). *Guidance for Industry. Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims.* Silver Spring MD: US Food and Drug Administration.

Fung, C., & Hays, R. D. (2008). Prospects and challenges in using patient-reported outcomes in clinical practice. *Quality of Life Research, 17*(10), 1297-1302.

Gerhart, K., Bergstrom, E., Charlifue, S., Menter, R., & Whiteneck, G. (1993). Long-term spinal cord injury: functional changes over time . *Arch Phys Med Rehabil*, 1030-1034.

Glynn, N., Santanasto, A., Simonsick, E., Boudreau, R., Beach, S., Schulz, R., & Newman, A. (2015). The Pittsburgh Fatigability Scale for Older Adults: Development and Validation. *J Am Geriatr*, 130-135.

Hirsch, G., Menard, M., & Anton, H. (1991). Anemia in Spinal Cord Injury. *Arch Phys Med Rehabil*, 195-201.

Hughes, R., Swedlund, N., Petersen, N., & Nosek, M. (2001). Depression and Women with Spinal Cord Injury. *Topics in SCI Rehabilitation*, 16-24.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: Author.

Jenkinson, C., Gibbons, E., & Fitzpatrick, R. (2009). *A Structured Review of Patient Reported Outcome Measures in Relation to Stroke.* Oxford: University of Oxford.

Lee, H., Vlaev, I., King, D., Mayer, E., Darzi, A., & Dolan, P. (2013). Subjective well-being and the measurement of quality in healthcare. *Social Science and Medicine*, 27-34.

McColl, M., Arnold, R., Charlifue, S., Glass, C., Savic, G., & Frankel, H. (2003). Aging, spinal cord injury, and quality of life: structural relationships. *Arch Phys Med Rehabil*, 1137-1144.

Murphy, S. L., Alexander, N., Levoska, M., & Smith, D. (2013). The Relationship between Fatigue and Subsequent Physical Activity among Older Adults with Symptomatic Osteoarthritis. *Arthritis Care Res*, 1617–1624.

National Institutes of Health. (2015, September 16). *Development of Measures of Fatigability in Older Adults (R21)* . Retrieved from RFA Section I Funding: http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-16-013.html#_Section_I._Funding

Pope, P. M. (2007). *Severe and Complex Neurological Disability: Management of the Physical Condition.* London: Butterworth-Heinemann.

Richardson, C. A., Glynn, N. W., Ferrucci, L. G., & Mackey, D. C. (2015). Walking Energetics, Fatigability, and Fatigue in Older Adults: The Study of Energy and Aging Pilot. *J Gerontol A Biol Sci Med Sci*, 487-494.

Ryan, R. M., & Deci, E. L. (2001). On happiness and human potentials: A review of research on hedonic and eudaimonic well-being. *Annual Review of Psychology, 52*, 141-166.

Schnelle, J., Buchowski, M., Ikizler, T., Durkin, D., Beuscher, L., & Simmons, S. (2012). Evaluation of Two Fatigability Severity Measures in Elderly Adults. *Journal of the American Geriatrics Society*, 1527-1533.

Skriver Rose, L. (2012). *Impact of wheelchair type on reducing the risk of shoulder overuse injuries following spinal cord injury.* London: Institute of Orthopaedics and Musculoskeletal Sciences.

Snyder, C. F., Aaronson, N. K., Choucair, A. K., Elliott, T. E., Greenhalgh, J., Halyard, M. Y., . . . Santana, M. (2012). Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Quality of Life Research, 21*(8), 1305-1314.

Soopramanien, A. (1994). Epidemiology of Spinal Injuries in Romania. *Paraplegia*, 715-722.

Streeten, D., & Anderson, G. (1998). The role of delayed orthostatic hypotension in the pathogenesis of chronic fatigue. *Clin Autonomic Research*, 119-124.

Tiesinga, L., Dassen, T., & Halfens, R. (1998). DUFS and DEFS: Development, reliability and validity of the Dutch Fatigue Scale and the Dutch Exertion Fatigue Scale. *International Journal of Nursing Studies*, 115-123.

Van Der Eijk, I., Vlachonikolis, I. G., Munkholm, P., Nijman, J., Bernklev, T., Politi, P., . . . Russell, M. G. (2004). The role of quality of care in health-related quality of life in patients with IBD. *Inflammatory Bowel Diseases*, 392-398.

Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., & Selby, P. J. (2004). Measuring Quality of Life in Routine Oncology Practice Improves Communication and Patient Well-Being: A Randomized Controlled Trial. *Journal of Clinical Oncology*, 714-724.

Widerstrom-Noga, E., Felipe-Cuervo, E., & Yezierski, R. (2001). Chronic pain after spinal cord injury: Interference with sleep and daily activities. *Arch Phys Med Rehabil*, 1571-1577

Yang, C., & Wu, C. (2005). The Situational Fatigue Scale: A different approach to measuring fatigue. *Quality of Life Research*, 1357-1362.

CHAPTER 2

ASSOCIATIONS OF HEALTH-RELATED QUALITY OF LIFE WITH OVERALL QUALITY OF LIFE IN THE PATIENT REPORTED OUTCOMES MEASUREMENT INFORMATION SYSTEM (PROMIS®) PROJECT

2.1. Introduction

Health-related quality of life (HRQOL) is functioning and well-being in physical, mental and social health, and includes physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions (Ganz et al. 2014). HRQOL measures are used for comparative performance evaluation, quality assurance and evaluation of healthcare interventions (Jenkinson et al. 2009). Use of HRQOL measures in clinical practice has been shown to facilitate patient-physician communication and contribute to a holistic understanding of a patient's health (Snyder et al. 2012).

Subjective well-being (SWB) measures include global appraisals of life that include but go beyond health. There are three types of SWB measures: evaluative well-being (EWB)–overall appraisal of one's life; experienced well-being–emotional status over short periods of time; and eudaimonic well-being–perceived purpose in life (Dolan et al. 2011). Ravens-Sieberer et al. (2014) suggested that HRQOL measures could be enhanced with SWB measures that focus on "how well life is going for a person" (p. 208).

Prior research has noted substantial covariation among HRQOL and SWB measures, but the amount of shared variance varies by domain. For example, Spiro and Bossé (2000) found that SWB is “less related to physical and more to psychological aspects of health-related quality of life” (p. 313). Similarly, a study by the U.S. Centers for Disease Control noted that a measure of SWB correlated 0.70 with mental health and 0.46 with physical health (Barile et al. 2013). In addition, Oberjé et al. (2015) reported that SWB was strongly associated with the SF-12 v2 mental health summary score (r = .41) and environmental well-being (i.e. general satisfaction with and safety of one’s surroundings, r = 0.51), but weakly related to the SF-12 v.2 physical health summary score (r = 0.17) in a sample of people living with HIV in the Netherlands.

Wiest et al. (2011) reported that life satisfaction, an indicator of EWB, predicted mortality better than socio-demographic factors, but the effect was reduced after accounting for self-reported health and physical activity in a representative sample of 3124 persons living in Germany. Diener and Chan (2011) reviewed 26 studies of SWB predicting mortality and reported that 3 of the studies found support for mediation of the link by self-reported health (depression, chronic disease, physical activity).

Overall quality of life ratings are an indicator of EWB. A study of 231 individuals with multiple sclerosis documented significant associations of overall quality of life rated on a 0 (worst possible quality of life) to 10 (best possible quality of life) response scale with HRQOL domains of emotional well-being, social functioning, and health distress (Vickrey et al. 1997). The degree of overlap between HRQOL and overall quality of life in the U. S. general population is unknown. The National Institutes of Health (NIH) launched the Patient-Reported Outcomes Measurement Information System (PROMIS®) project in 2004 with the goal of developing, evaluating, and disseminating a comprehensive set of publicly available item banks assessing HRQOL (Cella et al. 2010). The PROMIS HRQOL measures are now widely used in the US.

PROMIS included an item assessing overall quality of life. We examine the extent to which overall quality of life is associated with HRQOL measures in data from the NIH PROMIS® project.

2.2. Methods

We conducted secondary analyses of data collected as part of the PROMIS® project, providing an opportunity for examining the overlap between HRQOL and EWB in the US population. PROMIS samples include individuals with a wide range of chronic diseases and conditions.

2.2.1. Samples

Sample 1 The data were collected from 2007 and 2008 and consisted of 21,133 individuals, of whom 19,601 were members of the YouGovPolimetrix's panel, while 1532 were recruited at medical sites (UNC, Stanford, Pittsburgh, and Duke) (Cella et al. 2010). Sample 1 was 52% female, had median age of 50 years, 9% Hispanic, 80% White (non-Hispanic), 9% Black (non-Hispanic), and 2% other (Table 2.1). Three percent of this sample had less than a high school education, 16% were high school graduates, and 82% had educational attainment beyond high school.

The YouGovPolimetrix internet panel consisted of over one million individuals: www.polimetrix.com (Cella et al. 2010). Their panelists were typically recruited using electronic newsletters, and other Internet advertisements (Hays et al. 2015). Liu et al. (2010) showed equivalence between U.S. national and general population norms.

Sample 2 The sample was recruited by Op4G (http://op4g.com/our-panel/). The sample consisted of 2996 individuals: 51% female, 17% Hispanic, 60% White (non-Hispanic), 14% Black (non-Hispanic), and 9% Asian (non-Hispanic). Fourteen percent of the sample had less than a high school education, 31% were high school graduates, and 55% had education beyond high school. Age was distributed as 30% 18–34, 18% 35–44, 19% 45–54, 16% 55–64, 9% 65–74, and 8% 75–88. Fifty-six percent of the sample were married or living with a partner (Hays et al. 2016).

2.2.2. Measures

Both samples included the PROMIS global health items (Hays et al. 2009). One of the items asks for a rating of overall quality of life: “In general, would you say your quality of life is: Excellent, Very Good, Good, Fair, Poor”? Sample 1 also included the EQ-5D-3L anxiety/depression, usual activities (e.g. work, study, housework, family or leisure activities), self-care, pain/discomfort, and mobility items (EuroQol Research Foundation 2015). Sample 2 included the Health Utilities Index Mark 3 (HUI-3) (Feeny et al. 2002). For the analyses reported here, we score all measures so that a higher score is better (i.e., better overall quality of life and health).

2.2.3. Analysis Plan

We report frequency distributions for the PROMIS Global Health, EQ-5D-3L and HUI-3 items. We then examine associations of the overall quality of life item with other PROMIS global health items and with the EQ-5D-3L items (Sample 1) and the HUI-3 (Sample 2). We report zero-order correlations and regress overall quality of life on the HRQOL items using ordinary least squares regression models. Because the multivariate analysis is conducted to estimate overlap of overall quality of life with HRQOL, we allow items with substantial correlations to be included in the same model. As a result, suppression effects are possible and we interpret regression coefficients in light of the zero-order correlations.

2.3. Results

2.3.1 Sample 1

Over 50% of respondents reported excellent or very good overall quality of life (Table 2.2). Likewise, more than half described themselves in excellent, very good or good health. Two thirds of participants reported excellent, very good, or good satisfaction with social activities and relationships. Nearly a half said they had no problems in walking about, and approximately one half reported no problems with performing usual activities. Also, a third were extremely anxious or depressed. Less than a third of those surveyed experienced no pain or discomfort, and about half reported not being anxious or depressed. More than half stated that they had no problems with self-care such as washing or dressing themselves. The percentage of missing item responses was below 5% for all items.

As seen in Table 2.3, all the zero-order correlations of the overall quality of life item with the other PROMIS global items and the EQ-5D-3L items were statistically significant ($p < 0.0001$) and ranged from 0.29 (EQ-5D-3L Self-care) to 0.70 (PROMIS® Physical Health). In addition to physical health, general health ($r = 0.69$), satisfaction with social activities and relationships ($r = 0.68$), and performance of social activities and roles ($r = 0.67$), were strongly associated with overall quality of life.

Nine of the fourteen items entered as independent variables in the regression model were significantly uniquely associated and accounted for 69% of the variance in the overall rating of quality of life. The largest unique associations were found for satisfaction with social activities and relationships (standardized beta =0.27), global rating of physical health (standardized beta =0.20), global rating of general health (standardized beta =0.18), and global rating of mental health (standardized beta =0.17).

The standardized beta for the PROMIS global health fatigue item was negative, indicating a suppression effect due to multicollinearity (Ludlow and Klein 2014). However, the beta coefficient was not statistically significant.

2.3.2. Sample 2

Less than half of the respondents reported excellent or very good overall quality of life. Similarly, less than half said they were in excellent or very good physical health. However, approximately one half reported excellent or very good mental health, and close to one half said their general health was excellent or very good.

Approximately two thirds reported experiencing no, mild, or moderate fatigue, but more than half said they could carry out physical activities mostly or completely. Compared to Sample 1 respondents, this sample was much sicker. In fact, Sample 2 reported worse health by about half a SD on PROMIS domains compared with Sample 1 (Hays et al. 2016).

As shown in Table 2.4, all correlations of the overall quality of life item with HRQOL measures were statistically significant ($p < 0.0001$) and ranged from 0.36 (PROMIS® Pain) to 0.82 (PROMIS® Physical Health). In addition to physical health, general health ($r = 0.79$), mental health ($r = 0.66$), satisfaction with social activities and relationships ($r = 0.64$), and physical functioning ($r = 0.56$) were strongly associated with overall quality of life.

Seven of the ten items entered as independent variables in this regression model were significantly uniquely associated with overall QOL, and accounted for 75% of the variance in the overall rating of quality of life. We found the largest unique associations for physical health (standardized beta =0.39), global rating of general health (standardized beta =0.27), and global rating of mental health (standardized beta =0.11).

2.4. Discussion

This paper provides further evidence of the empirical overlap between HRQOL and EWB measures. Specifically, our analyses of two PROMIS samples indicate that overall QOL was strongly associated with satisfaction with social activities and relationships, global rating of physical health, global rating of general health, and global rating of mental health. Overall quality of life was also correlated with the ability to carry out physical and usual activities, fatigue, emotional problems, anxiety/depression, pain/discomfort, overall pain, and mobility. The weakest zero-order association of overall quality of life was with the EQ-5D-3L self-care item in Sample 1 and with pain in Sample 2.

That overall quality of life is associated with satisfaction with social activities and relationships and mental health measures is not surprising given prior research (Christakopoulou et al. 2001; Vickrey et al. 1997; Yamaguchi 2015). In addition, the weak association of overall quality of life with the self-care item in Sample 1 is consistent with prior research. Quality of life may be determined more by well-being than physical functioning among those who have had physical disabilities for many years, and have come to terms with their condition. But overall quality of life also had noteworthy associations with physical health measures, consistent with prior research (Eller and Mahat 2007; Tsaousis et al. 2007).

There are several limitations of this study. First, we examined EWB only and did not have measures of experienced well-being or eudaimonic well-being. This is important because some have suggested that experienced well-being is best suited for outcomes research given its focus on narrow time intervals (Bradburn et al. 2013). Second, all the measures examined were self-reported. Third, observed associations may be due to "third" variables such as individual characteristics or recall capacity. Nonetheless, the findings of this study are useful in further understanding the overlap between HRQOL and EWB. This study provides evidence of substantial empirical overlap of HRQOL with EWB, particularly with mental and social health items, but also with physical health items.

Given the existing body of work, it is essential that SWB researchers and those focused on HRQOL approach future studies recognizing the overlap. For example, SWB has been shown to predict mortality in some studies, but the SWB associations with mortality are attenuated when self-reported physical health is controlled for in the analysis (Wiest et al. 2011).

Examination of the interplay between other aspects of SWB (e.g., experienced wellbeing) and HRQOL needs exploration in future research. In addition, it will be important to examine the extent to which overlap between HRQOL and SWB varies by patient subgroup (e.g., aging adults, those with spinal cord injury and wheelchair users). More research is also needed into how this intersection is moderated by individual characteristics (such as personality) and cultural traits. Previous findings suggest that both HRQOL and EWB are influenced by values and culture (Keith 2001; Diener and Suh 1997; Bradburn et al. 2013; Yamaguchi 2015; Tseng et al. 2003).

2.5. Tables

Table 2.1. Sample characteristics for the Patient Reported Outcomes Measurement Information System (PROMIS®) Datasets

Characteristic	Sample 1 (N=21,133)	Sample 2 (N=2,996)
Age (median)	50	52
Female Gender	52%	51%
Race		
Non-Hispanic White	82%	60%
Non-Hispanic Black	9%	14%
Multiracial	8%	N/A
Other	1%	N/A
Non-Hispanic Asian	N/A	9%
Hispanic	N/A	17%
Ethnicity		
Hispanic	9%	17%
Non-Hispanic	91%	83%
Education		
Less than high school	3%	14%
High school graduate	16%	31%
More than high school	82%	55%

Note: Percents may not add up to exactly 100% due to rounding.

Table 2.2. Frequencies for PROMIS® domains, Global Health, EQ-5D-3L, and HUI3 items

Item	**Sample 1 (N=21,133)**	**Sample 2 (N=2,996)**
	Frequency (Percent)	**Frequency (Percent)**
Global QOL	*Missing 98*	*Missing 3*
Excellent	4032 (19%)	346 (12%)
Very Good	7945 (38%)	922 (31%)
Good	6065 (29%)	992 (33%)
Fair	2414 (11%)	575 (19%)
Poor	579 (3%)	162 (5%)
Physical Health	*Missing 49*	*Missing 0*
Excellent	2270 (11%)	271 (9%)
Very Good	6478 (31%)	873 (29%)
Good	7390 (35%)	1025 (34%)
Fair	3893 (18.4%)	629 (21%)
Poor	1053 (5%)	202 (7%)
Mental Health	*Missing 36*	*Missing 0*
Excellent	5844 (28%)	506 (17%)
Very Good	7463 (35%)	927 (31%)
Good	5079 (24%)	883 (29%)
Fair	2242 (11%)	517 (17%)
Poor	469 (2%)	167 (6%)
General Health	*Missing 29*	*Missing 0*
Excellent	2541 (12%)	341 (11%)
Very good	7032 (33%)	921 (31%)
Good	7128 (34%)	988 (33%)
Fair	3491 (16%)	570 (19%)
Poor	912 (4%)	180 (6%)
Social activities and relationships satisfaction	*Missing 36*	*Missing 0*
Excellent	3737 (18%)	414 (14%)
Very Good	7030 (33%)	796 (27%)
Good	5752 (27%)	987 (33%)
Fair	3186 (15%)	556 (19%)
Poor	1392 (7%)	247 (8%)
Carry out physical activities	*Missing 27*	*Missing 1*
Completely	13544 (64%)	1071 (36%)
Mostly	3687 (17%)	746 (25%)
Moderately	2432 (12%)	648 (22%)
A little	1239 (6%)	408 (14%)
Not at all	204 (1%)	126 (4%)

Table 2.2. Continued. Frequencies for PROMIS® domains, Global Health, EQ-5D-3L, and HUI 3 items.

Pain	*Missing 33*	*Missing 1*
Worst pain (0)	109 (1%)	44 (1%)
1	183 (1%)	52 (2%)
2	684 (3%)	227 (8%)
3	1177 (6%)	283 (9%)
4	1296 (6%)	337 (11%)
5	1500 (7%)	349 (12%)
6	1555 (7%)	275 (9 %)
7	2580 (12%)	308 (10%)
8	3014 (14%)	350 (12%)
9	3900 (18%)	346 (12%)
No pain (10)	5102 (24%)	428 (14%)
Fatigue	*Missing 33*	*Missing 0*
None	4096 (19%)	394 (13%)
Mild	8753 (41%)	1056 (35%)
Moderate	6432 (30%)	1106 (37%)
Severe	1581 (7%)	346 (12%)
Very Severe	238 (1%)	98 (3%)
Carry out social activities	*Missing 32*	*Missing 1*
Excellent	4794 (23%)	463 (15%)
Very Good	7545 (36%)	922 (31%)
Good	5396 (26%)	897 (30%)
Fair	2695 (13%)	517 (17%)
Poor	671 (3%)	200 (7%)
Emotional problems	*Missing 44*	*Missing 0*
Never	4930 (23%)	507 (17%)
Rarely	7489 (36%)	866 (29%)
Sometimes	5901 (28%)	964 (32%)
Often	2267 (11%)	474 (16%)
Always	502 (2%)	189 (6%)
HUI 3		*Missing 0*
Average (range)	N/A	0.54 (-0.36, 1.00)
Mobility*	*Missing 18*	
No problems in walking about	9737 (69%)	N/A
Some problems in walking about	4341 (31%)	
Confined to bed	32 (0.2%)	

Self-Care*	*Missing 40*	
No problems with self-care	13230 (94%)	N/A
Some problems washing or dressing myself	824 (6%)	
Unable to wash or dress myself	34 (0.2%)	
Usual Activities*	*Missing 19*	
No problems with performing usual activities	9785 (69%)	N/A
Some problems with performing usual activities	4064 (29%)	
Unable to perform usual activities	260 (2%)	
Pain / Discomfort*	*Missing 3*	
No pain or discomfort	5928 (42%)	N/A
Some pain or discomfort	7208 (51%)	
Extreme pain or discomfort	969 (7%)	
Anxiety / Depression*	*Missing 24*	
Not anxious or depressed	9115 (65%)	N/A
Moderately anxious or depressed	4497 (32%)	
Extremely anxious or depressed	492 (3%)	

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* The respondents administered full banks in PROMIS Study 1 (n = 7,005) were not administered the EQ-5D-3L

Table 2.3. Regression of Overall Rating of Quality of Life on PROMIS global health and EQ-5D-3L items in Sample 1

	Standardized Beta	t-statistic	p-value	Zero-order correlation*
Satisfaction with social activities and relationships (global05)	0.27	36.34	<0.0001	0.68
Physical health (global03)	0.20	16.98	<0.0001	0.70
General health (global01)	0.18	15.07	<0.0001	0.69
Mental health (global04)	0.17	20.34	<0.0001	0.64
Perform social activities and roles (global09)	0.12	14.50	<0.0001	0.67
Usual activities (socio14)	0.04	5.36	<0.0001	0.50
Physical functioning (global06)	0.03	3.19	0.0014	0.50
Pain (global07)	0.02	2.69	0.0072	0.44
Emotional problems (global10)	0.01	0.90	0.3701	0.48
Self-care (socio13)	0.01	2.67	0.0077	0.29
Mobility (socio12)	0.01	0.84	0.3990	0.40
Pain/discomfort (socio15)	0.00	0.48	0.6298	0.42
Anxiety/depression (socio16)	0.00	0.19	0.8507	0.46
Fatigue (global08)	-0.01	-1.76	0.0789	0.50

* All p's < 0.0001

Note: Adjusted $R^2 = 0.69$ (n = 13,966). All items scored so that a higher score is better health.

Global03 (*In general, how would you rate your physical health?*); Global01 (*In general would you say your health is*); Global05 (*In general, how would you rate your satisfaction with your social activities and relationships?*); Global09 (*In the past 7 days, in general, please rate how well you carry out your usual social activities and roles.*); Global04 (*In general, how would you rate your mental health, including your mood and your ability to think?*); Global10 (*In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?*); Socio16 (EQ-5D-3L Anxiety/depression); Socio14 (EQ-5D-3L Usual activities); Global06 (*To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair*); Global07 (*In the past 7 days, how would you rate your pain on average?*); Socio13 (EQ-5D-3L Self-care); Socio15 (EQ-5D-3L Pain/discomfort); Socio12 (EQ-5D-3L Mobility); Global08 (*In the past 7 days, how would you rate your fatigue on average?*).

Table 2.4. Regression of Overall Rating of Quality of Life on PROMIS global health items and HUI-3 in Sample 2

	Standardized Beta	t-statistic	p-value	Zero-order correlation*
Physical health (global03)	0.39	22.04	<.0001	0.82
General health (global01)	0.27	16.45	<.0001	0.79
Mental health (global04)	0.11	7.94	<.0001	0.66
Satisfaction with social activities and relationships (global05)	0.09	6.01	<.0001	0.64
Perform social activities and roles (global09)	0.06	4.37	<.0001	0.62
Physical functioning (global06)	0.03	2.58	0.0101	0.56
HUI-3	0.03	2.19	0.0287	0.48
Pain (global07)	0.01	0.64	0.5235	0.36
Fatigue (global08)	0.01	0.93	0.3504	0.48
Emotional problems (global10)	0.00	-0.33	0.7437	0.39

* All p's < 0.0001

Note: Adjusted $R^2 = 0.75$. All measures scored so that a higher score is better health.

Global01 (*In general would you say your health is*); Global03 (*In general, how would you rate your physical health?*); Global04 (*In general, how would you rate your mental health, including your mood and your ability to think?*); Global05 (*In general, how would you rate your satisfaction with your social activities and relationships?*); Global06 (*To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair*); Global07 (*In the past 7 days, how would you rate your pain on average?*); Global08 (*In the past 7 days, how would you rate your fatigue on average?*); Global09 (*In the past 7 days, in general, please rate how well you carry out your usual social activities and roles.*); Global10 (*In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?*); HUI-3 (*Health Utility Index*).

2.6. References

Barile, J. P., Reeve, B. B., Wilder Smith, A., Zack, M. M., Mitchell, S. A., Kobau, R., . . . Thompson, W. W. (2013). Monitoring population health for Healthy People 2020: evaluation of the NIH PROMIS Global Health, CDC Healthy Days, and satisfaction with life instruments. *Quality of Life Research, 22*(6), 1201-1211.

Bradburn, N. M., Carstensen, L. L., Diener, E. F., Dolan, P. H., Graham, C. L., Hotz, V. J., . . . Card, D. (2013). *Subjective well-being: measuring happiness, suffering, and other dimensions of experience.* (A. A. Stone, C. Mackie, & Eds., Eds.) Washington, D.C.: The National Academies Press.

Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., . . . Hays, R. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *Journal of Clinical Epidemiology, 63*(11), 1179-1194.

Christakopoulou, S., Dawson, J., & Aikaterini, G. (2001). The Community Well-Being Questionnaire: Theoretical context and initial assessment of its reliability and validity. *Social Indicators Research, 56,* 321-351.

Diener, E., & Chan, M. Y. (2011). Happy people live longer: subjective well-being contributes to health and longevity. *Applied Psychology: Health and Well-Being, 3*(1), 1-43.

Diener, E., & Suh, E. (1997). Measuring quality of life: economic, social, and subjective indicators. *Social Indicators Research, 40,* 189-216.

Dolan, P., Layard, R., & Metcalfe, R. (2011). *Measuring Subjective Well Being for Public Policy: Recommendations on Measures.* London: Centre for Economic Performance, London School of Economics.

Eller, L. S., & Mahat, G. (2007). Predictors of life satisfaction in HIV-positive Nepali women. *The Journal of the Association of Nurses in AIDS Care, 18*(5), 17-26.

EuroQol Research Foundation. (2015, September 4). *EQ-5D-3L*. Retrieved from EuroQol.org: http://www.euroqol.org/eq-5d-products/eq-5d-3l.html

Feeny, D., Furlong, W., Torrance, G. W., Goldsmith, C. H., Zhu, Z., DePauw, S., . . . Boyle, M. (2002). Multiattribute and single-attribute utility functions for the health utilities index mark 3 system. *Medical Care, 40*(2), 113-128.

Ganz, P., Hays, R., Kaplan, R., & Litwin, M. (2014). Measuring Health-Related Quality of Life and Other Outcomes. In G. F.-E. Komiski, *Changing the U.S. Health Care System* (pp. 307-341). San Francisco: Jossey-Bass.

Hays, R. D., Bjorner, J., Revicki, D. A., Spritzer, K., & Cella, D. (2009). Development of physical and mental health summary scores from the patient-reported outcomes measurement information system (PROMIS) global items. *Quality of Life Research, 18*(7), 873-880.

Hays, R. D., Liu, H., & Kapteyn, A. (2015). Use of internet panels to conduct surveys. *Behavior Research Methods, 47*(3), 685-690.

Hays, R. D., Revicki, D. A., Feeny, D., Fayers, P., Spritzer, K. L., & Cella, D. (2016). Using Linear Equating to Map PROMIS Global Health Items and the PROMIS-29 V2.0 Profile Measure to the Health Utilities Index Mark 3. *PharmacoEconomics, 34*(10), 1015–1022.

Jenkinson, C., Gibbons, E., & Fitzpatrick, R. (2009). *A Structured Review of Patient Reported Outcome Measures in Relation to Stroke.* Oxford: University of Oxford.

Keith, K. D. (2001). International Quality of Life: Current Conceptual, Measurement, and Implementation Issues. In L. M. Glidden, *International Review of Research in Mental.* San Diego: Academic Press.

Liu, H. H., Cella, D., Gershon, R., Shen, J., Morales, L. S., Riley, W., & Hays, R. D. (2010). Representativeness of the PROMIS internet panel. *Journal of Clinical Epidemiology, 63*(11), 1169-1178.

Ludlow, L., & Klein, K. (2014). Suppressor variables: The difference between ‘is’ versus ‘acting as'. *The Journal of Statistics Education, 22*(2).

Oberjé, E. J., Dima, A., van Hulzen, A. G., Prins, J. M., & de Bruin, M. (2015). Looking beyond health-related quality of life: Predictors of subjective well-being among people living with HIV in the Netherlands. *AIDS and Behavior, 19*(8), 1398-1407.

Ravens-Sieberer, U., Devine, J., Bevans, K., Riley, A. W., Moon, J., Salsman, J. M., & Forrest, C. B. (2014). Subjective Well-Being (SWB) measures for children were developed within the PROMIS® project: presentation of first results. *Journal of Clinical Epidemiology, 67*(2), 207-218.

Snyder, C. F., Aaronson, N. K., Choucair, A. K., Elliott, T. E., Greenhalgh, J., Halyard, M. Y., . . . Santana, M. (2012). Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. *Quality of Life Research, 21*(8), 1305-1314.

Spiro, A., & Bossé, R. (2000). Relations between health-related quality of life and well-being: The gerontologist's new clothes? *International Journal of Aging and Human Development, 50*(4), 297-318.

Tsaousis, I., Nikolaou, I., Serdaris, N., & Judge, T. A. (2007). Do the core self-evaluations moderate the relationship between subjective well-being and physical and psychological health? *Personality and Individual Differences, 42*, 1441–1452.

Tseng, H. M., Lu, R. J., & Gandek, B. (2003). Cultural issues in using the SF-36 health survey in Asia: results from Taiwan. *Health and Quality of Life Outcomes, 1*(72), 1-9.

Vickrey, B. G., Hays, R. D., Genovese, B. J., Myers, L. W., & Ellison, G. W. (1997). Comparison of a generic to disease-targeted health-related quality-of-life measures for multiple sclerosis. *Journal of Clinical Epidemiology, 50*(5), 557-569.

Wiest, M., Schuz, B., Webster, N., & Wurm, S. (2011). Subjective well-being and mortality revisited: differential effects of cognitive and emotional facets of well-being on mortality. *Health Psychology, 30*(6), 728-735.

Yamaguchi, A. (2015). Influences of quality of life on health and well-being from a qualitative approach. *Social Indicators Research, 123*, 77-102.

CHAPTER 3

A COMPARISON OF PERCEPTIONS OF QUALITY OF LIFE AMONG ADULTS WITH SPINAL CORD INJURY IN THE UNITED STATES VERSUS THE UNITED KINGDOM

3.1. Introduction

Spinal cord injury (SCI) is a dramatic change in a person's life. There are approximately 300,000 (out of about 319 million) individuals living with spinal cord injury in the United States (NSCISC, 2016). A majority of these cases (91%) were acquired through trauma (vehicular 38%, falls 30%, violence 14%, sports and recreational activities 9%) while the rest were caused by diseases or surgical complications (5%) or other causes (4%) (NSCISC, 2016). In the United Kingdom, there are approximately 40,000 cases of SCI (out of about 64 million), and about 90% of these are caused by trauma (Werndle, et al., 2012; MASCIP, 2008). The impact of SCI on physical, mental, and social function varies by the level and extent of the injury.

Quality of Life (QOL) is an all-encompassing concept that refers to a person's physical, psychological, social, spiritual, and economic well-being (Fallowfield, 2009; Felce and Perry, 1995; Naess, 1999; Kahn and Juster, 2002; Christoph and Noll, 2003). Health-Related Quality of Life (HRQOL) is a subset of QOL and refers to physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions (Fung and Hays, 2008). However, conceptualization and measurement of QOL and HRQOL within the context of SCI have been largely atheoretical (Franceschini, et al., 2003; Westgren and Levi 1998; Vogel, et al., 1998; Glass, 1993; Siosteen, et al., 1990; Clayton and Chubon, 1994; Lin, et al., 1997; Dijkers, 2005). There is a dearth of information regarding perspectives about life and expectations of adults with SCI (Hammell, 2010; Hammell, 2004; Dijkers, 1999).

This paper examines QOL perspectives of adults in the United States (US) and in the United Kingdom (UK) because the SCI journey may differ in these countries. In the US, access to post-acute care is fragmented, and often hinges on individual insurance coverage or premorbid financial resources (Donovan, 2007; Halvorson, 2007). In the UK, services are integrated in the National Health Service, where emergency, post-acute care, rehabilitation, and even wheelchair provision are all free-at-the-point of need. As such, most UK SCI patients benefit from integrated long-term care and rehabilitation (Pollock, 204). There are also cultural differences that may influence QOL and HRQOL perceptions (Tseng, et al., 2003).

3.2. Methods

3.2.1. Data collection

Participants were eligible to be interviewed if they were 18 years or older, full-time (round-the-clock) wheelchair users, had a self-reported diagnosis of SCI, and could read and write in English. Exclusion criteria included inability to provide informed consent (including cognitive impairments such as dementia and Alzheimer’s disease).

Participants were recruited through (1) print advertisements distributed through patient advocacy organizations in the US (e.g. veterans’ support groups) and in the UK (e.g. Spinal Injuries Association); (2) online advertisements distributed through SCI fora, such as Apparelyzed (http://www.apparelyzed.com/) and Facebook wheelchair users’ groups. Upon expressing interest in being interviewed, participants were sent an email with information about the study.

A total of 33 individuals responded to the advertisements, 15 in the US, and 18 in the UK. Of these respondents, 4 did not meet the inclusion criteria (age and full-time wheelchair use) and 7 decided not to continue with the study after reviewing the information package. Twenty-two individuals were interviewed (N_{US}=11, N_{UK}=11).

Participants were offered $10/£7 remuneration for their participation, although only two of them accepted the offer. This study was approved (Certified Exempt) by the Institutional Review Board of the University of California Los Angeles (IRB#16-000229), and verbal consent was obtained from all participants.

3.2.2. Analysis

Semi-structured interviews were conducted to capture depth and perspective regarding QOL and HRQOL among adults with SCI. The sample varied by gender, age, etiology of SCI injury (trauma or disease), and type of SCI (paraplegia or quadriplegia).

Two people were selected for pilot interviews conducted by phone (N_{US}=1, N_{UK}=1) to test the interview questions. Because of the structural changes resulting from these pilot interviews (changes in the order of questions, phrasing of several questions, and addition of three questions) their data were excluded from the final analysis.

The main study included 20 participants (N_{US}=10, N_{UK}=10) interviewed between April and June 2016. In the UK, participants were interviewed in their homes in the following geographic areas: Merseyside, South Devon, Hampshire, West Kent, Northumberland, Staffordshire, Leicestershire, and Wales. In the US, participants were interviewed in their homes in the following geographic areas: Southern California (Los Angeles, San Diego), Southwest Pennsylvania, Southeast Pennsylvania, Wisconsin, Central Florida, North Texas, Maryland, Upstate New York, and Alabama. Of the 20 interviews considered for this analysis, 12 were conducted face-to-face (N_{US}=2, N_{UK}=10), and 8 via Skype/FaceTime (N_{US}=8). Each interview was conducted in a single session, lasting between 80 minutes to 4 hours. All interviews were audio recorded and transcribed verbatim.

The interviews focused on life with SCI including topics such as rehabilitation (Table 3.1). Interview guides were developed using literature on SCI, patient films, and informal conversations with SCI rehabilitation professionals.

Transcripts were uploaded to Atlas.ti (Atlas.ti, 1999) to facilitate management, coding, analysis and interpretation of the data. Based on grounded theory, i.e. inductive reasoning from the interview content, driven by a constant comparative analysis of themes emerging from the data, a codebook was developed and reconciled (by the author, AP, and a second trained coder, MD) (Charmaz, 2006).

The unit of analysis was the line of text (left to right margin on the Atlas.ti display), which allowed for a more detailed analysis than a paragraph approach, and open and in-vivo coding were used to establish categories and themes (Ryan and Bernard, 2003; Bernard and Ryan, 1998; MacQueen, et al., 1998). Open coding refers to labeling interview content based on dimensions emerging from it (Charmaz, 2006). In-vivo coding means assigning code labels using words or short phrases directly from the text (Charmaz, 2006). Coding was performed in two rounds, each consisting of two coders coding independently. Inter-coder reliability was estimated using Cohen’s Kappa (Cohen, 1960; Cohen, 1968; Benner and Kliebsch, 1996; McHugh, 2012) with software from the University of Pittsburgh’s Coding Analysis Toolkit (Schulman, 2011; Hruschka, et al. 2004). The first round of coding was done on a random sample of 5 transcripts. One person (AP) created code definitions and coded the transcripts. A total of 386 instances of coding resulted from the transcripts, using 58 codes. Then, the code list was provided to a second coder (MD) and he independently coded the transcripts. This coder added 18 new codes to the existing list, and provided a total of 400 instances of coding. Agreement between the two coders for the cumulative 786 instances of coding was 86%, with an unweighted kappa of .75. After reconciliation, coding was done on the remaining 15 transcripts, with kappa of .82.

After analyzing all 20 interview transcripts, the codebook contained 108 content-grounded codes, all of which were tagged to at least one transcript (the codebook can be provided upon request). Of these codes, 76 (70%) were identified within the first 5 coded interviews. The rest of the codes were identified in the next 11 transcripts, indicating that saturation of the full range of content-grounded themes occurred within the first 16 interviews.

3.3. Results

Table 3.2 shows participant clinical characteristics and Table 3.3 shows their demographic characteristics. The two groups were similar in terms of levels of injury, but the median time since injury in the UK group was 32 years versus 8 in the US sample. Five overarching themes (QOL in the context of SCI; medical care; functional adjustment; financial resources; and socio-political context) and 20 subthemes emerged as factors that affect QOL. Tables 3.4 and 3.5 provide a summary of themes, subthemes and their influence on QOL domains. Below we review themes and subthemes, including illustrative quotes.

3.3.1. Quality of life in the context of SCI

More than half of interviewees (N_{US}=7, N_{UK}=8) explained how they perceived *their own* QOL. For example:

> *"What matters to me is that, since I don't have people living with me, that I am able to do things that I absolutely must do" (US-F4);*

> *"QOL for me as a para, I'd like to be able to do what I can that most people do, that's still within my ability. That's QOL" (US-M5).*

> *"My definition of quality of life revolves around care, almost completely around that most basic need – good quality care" (UK-M3);*

The following HRQOL dimensions emerged: physical health (including ability to conduct *Activities of Daily Living*, e.g. personal hygiene, dressing, eating, continence, mobility, and *Instrumental Activities of Daily Living*, e.g. communication, transportation, managing finances); mental health; social functioning; and intimate relationships (including sexual and reproductive functions). QOL dimensions mentioned were: material well-being (including housing security, acquisition of disability-specific items, services, and technology); rights (civil rights, government support); and religious beliefs. Most of these domains were expressed equally by the US and UK participants, apart from religious beliefs, which were offered exclusively by US participants.

Notably, for some interviewees the prioritized domains of QOL changed immediately after the injury, but also over the course of time with the injury.

> *"What matters to me varied a lot over the last 11 years. Actually, my first one was not being able to get up and do things. But eventually that passed on, and to tell you the truth, if I could only get one thing back without any issues, it would be my bowel care" (US-M1).*

> *"As I get older, my quality of life and the quality of health are becoming more of an issue. But at the moment it's more about keeping me socially active, and my relationship with my wife and family, and the quality of life in that respect" (UK-M4).*

3.3.2. Factors contributing to QOL: medical care

All participants discussed medical care as a key factor affecting their QOL, because *"with good quality care you can then build, you have got the foundation blocks to build the rest of your life" (UK-M3)*. Subthemes of medical care included rehabilitation experience (positive and negative comments), provision of wheelchairs (positive and negative), primary care (positive and negative), and care giving in the home (positive only).

3.3.2.1. Rehabilitation Experience

Negative rehabilitation experiences were mentioned by participants from both countries (N_{US}=10, N_{UK}=9). In the US group, two participants recalled experiences from the 1960s and 1970s, and eight from 2003 onwards, including one as recent as two years ago. Six UK participants recalled rehabilitation periods that took place in the 1970s and 1980s, two in the 1990s, and two after 2005.

Both groups talked to varying degrees about problems with quality of care during their specialist rehabilitation, particularly rude and impolite behavior by hospital staff; lack of patient education about treatment options, living with an SCI, self-care, sexual education, pressure sore prevention; hospital-acquired complications (e.g. pressure sores: US/UK, Clostridium difficile or C. diff: US only); lack of resources (range of physiotherapy in the US, and one-on-one specialist-patient time in the UK); lack of an holistic approach to rehabilitation (i.e., physical, mental, social, home environment, lifestyle); and institutional issues, such as privacy and strict routines.

> *"I came down with C diff, and I have had off-again on-again episodes for about probably 3 months. In one case, it was just lousy hygiene. The time that I spent sick in bed, they might well have taught me other things" (US-M1).*

> *"In 1983 they cut my sphincter to my bladder. I hadn't a clue what that meant, so they just did it when I was in hospital, it wasn't explained in terms of what might come further in life, that I might just drain all the time. Looking back on it I would go and slap them for doing that to me" (UK-M4).*

The US rehabilitation experience showed pronounced fragmentation of care, provision of care contingent on type of insurance and on insurers' judgements about medical necessity, little or no post-discharge follow-up, and insufficient length of rehabilitation.

> *"I was in a hospital for about a month, then I went to a rehabilitation center for three and a half months. Then I came home. The reason why they sent me home is because the insurance stopped paying. All that they care about is money" (US-M6, Incomplete Quadriplegia).*

Participants in both samples discussed positive rehabilitation experiences (N_{US}=6, N_{UK}=8). Of the six US participants with positive experiences, four obtained rehabilitation through the VA system, while the other two had private insurance. Aspects that both groups mentioned include good specialist care, physiotherapy/occupational therapy resources, regular follow-up post discharge, and access to on-demand advice/support. In addition, British participants talked about the importance of social activities and peer support received during rehabilitation, and adequate support in transitioning home (coordination with social services).

3.3.2.2. Wheelchair Provision

Both groups (N_{US}=7, N_{UK}=5) experienced negative wheelchair provision, however, the problems differed by country. US participants talked about receiving no assessment (such as pressure mapping, measurements, consideration of home environment, and post-discharge aspirations); no information about the range of wheelchairs, cushions and accessories available for their level of injury; no wheelchair training; and little wheelchair maintenance. More than half of the US group felt burdened by excessive bureaucracy when seeking wheelchairs and related accessories.

> *"They gave me a wheelchair that was absolutely unusable. I have rheumatoid arthritis, it was too wide and I did damage to my shoulders trying to get around in it. I had no pressure mapping, no evaluation, I did the research myself, it was an absolute nightmare" (US-F4).*

In the UK sample, there was only one mention of inadequate wheelchair training. Problems related mostly to lack of consideration for care-giver needs (e.g. wheelchair heavy to handle), limited availability of free outdoors/off-road wheelchairs through the National Wheelchair Service, and perceived exorbitant pricing by private wheelchair providers.

Positive wheelchair provision experiences (N_{US}=5, 3 of whom went to a VA hospital, and N_{UK}=8) also differed by country. In the US, it related to whether they were assessed in-hospital or at a mobility store when the wheelchair was selected, receipt of chair that the participant felt was adequate for their condition and needs, and to having the financial means to purchase the latest desired models. In the UK, it referred to having received assessment, such as pressure mapping (i.e. assessing the distribution of a body's downward pressure on a seating surface to determine the asymmetry of weight distribution and pressure points of concern) at rehabilitation center, at NHS Wheelchair Center, or in a mobility store; having received a free wheelchair through National Wheelchair Service; having received multiple wheelchairs to meet diverse needs (e.g. an outdoor chair, an indoor chair); having a spare wheelchair (in case of mechanical failure); and receiving assistance through the Access to Work scheme (such as chairs, accessories, or adapted cars).

3.3.2.3. Primary care experience

Both groups (N_{US}=7, N_{UK}=4) mentioned negative experiences with primary care provision, describing uncaring physicians, as well as general physician inexperience in dealing with SCI. Differences emerged regarding having no access to primary care because of lack of insurance (US only), perceived ineffective medical care (US only), refusal by a primary care doctor to keep a patient in the doctor's primary care panel after SCI occurred (US only), and difficulties with arranging home visits (UK only).

> *"I made a phone call, told him what had happened, told them that I was now a T10 complete, and asked him if he was OK to treat me, as a guy who was a paraplegic. And he told me No, he wasn't, he would much prefer it if I went and found someone else. So that attitude alone made me look for someone else" (US-M1).*

> *"I broke my leg once, and rather than go to the hospital here, I drove myself 40 miles down to the spinal injuries unit. I knew they would understand and would be able to treat me better. Whenever I broke my leg up here they insisted that they do a full-leg plaster cast on my leg. I have a huge mistrust of the GPs and the mainstream system" (UK-M4).*

Interviewees in both groups (N_{US}=4, N_{UK}=6) mentioned positive experiences with similar aspects of primary care: care coordination, proactive in facilitating access to specialists, follow-up with care and appointments, and involving them in medication management.

3.3.2.4. Caregiving at home

Half of the participants in both groups (N_{US}=5, N_{UK}=5) remark on the importance of receiving good quality care at home. Those who receive care from their spouse or other family members talk about the importance of specialist training for their care-givers:

> *"The VA trains your caregiver for things, bowel management programs, they make sure that you're not going home to somewhere that you are not going to be taken care of" (US-M3).*

> *"K. was very good at learning and asking the staff to teach her the best ways to do this sort of thing, so we have always kept that very much as the top priority. She took a number of caregiving courses while I was in hospital. She was always asking questions about what's best, how best to do this how best to do that. I think the staff were always willing to teach her as well" (UK-M2).*

3.3.3. Factors contributing to QOL: Functional Adjustment

All participants mentioned physical and mental function (including perceiving, thinking, memorizing, reasoning) as factors contributing to their QOL. The subthemes emerging were: mental adjustment post-discharge, impact of SCI on physical and mental function, SCI-related complications, consequences of aging with SCI, fatigue (physical and mental), SCI knowledge post-discharge, home adaptations, and public infrastructure.

3.3.3.1. Mental adjustment post-discharge

All participants (N_{US}=10, N_{UK}=10) talked about difficulties adjusting mentally to life with SCI immediately after their discharge from rehabilitation. Both samples mentioned feeling shocked, anxious, sorry, helpless, self-conscious, having doubts about self-worth, being in denial, accepting the injury, and expecting to improve.

Both groups also talked about a range of fears: fear of health complications, fear of institutionalization (i.e., going back to hospital, to rehabilitation, to a nursing home), fear of not being able to provide for oneself and the family, and fear of uncertainty (i.e., staying married, having children, housing).

Difficulties in adjustment were ameliorated by family support during transition from rehabilitation to home (e.g. managing logistics, moral support), an individual's pre-injury mindset (e.g. independence, optimism, not dwelling on negatives), and having the right home adaptations (e.g., having correct wheelchair ramps, showering facilities).

3.3.3.2. Impact of SCI on function (physical and mental)

The impact of the injury on daily function was another issue addressed by all study participants (N_{US}=10, N_{UK}=10). The most cited issues affecting physical and mental function were bladder and bowel (sphincter) management (N_{US}=7, N_{UK}=10), pain (N_{US}=7, N_{UK}=5), mobility (N_{US}=6, N_{UK}=4), spasticity (N_{US}=2, N_{UK}=4), sitting tolerance (N_{US}=2, N_{UK}=2), and lack of sensory ability (N_{US}=2, N_{UK}=1).

"Your life revolves around your bowels" (US-M5).

> *"I need help with my bowel care and bladder care. That is the absolute essence, that's the only thing that dictates my lifestyle now" (UK-M3).*

3.3.3.3. Fatigue (physical and mental)

Interviewees in both countries (N_{US}=6, N_{UK}=8) talked about fatigue, differentiating between physical and mental fatigue. Physical fatigue was defined as reduced physical function due to wear (joints, shoulder, back), disease, or SCI-related issue (pain, spasticity). Mental fatigue refers to reduced mental function resulting from perceived high-level of stress, worries about the future, perceived need for extensive logistical planning, and perceived bureaucratic burden (e.g., filling out applications to receive health care, social support, disability-specific services, etc.).

3.3.3.4. SCI knowledge post-discharge

Nearly all participants (N_{US}=9, N_{UK}=10) talked about how they acquired knowledge about SCI and life post-discharge. Although all study participants talked about learning from their lived experience, there were marked differences in knowledge acquisition. In the US group, nine participants described how they did not receive adequate information about SCI (what it is, levels of injury, types of care), basic self-care (such as managing bladder and bowels, skin management), wheelchair training (such as transferring) and wheelchair provision (understanding their own wheelchair needs), and sexual function and intimacy. Six individuals in this group indicated they had to resort to the internet and online peer support to find out about SCI, understand their own needs, and perform certain activities (particularly bowel management, wheelchair transfers, and dressing oneself).

> *"Your family tries to Google everything, but you get three different answers for the same question" (US-M3).*

> *"I learned to transfer and get my clothes on, through YouTube videos" (US-M5).*

Seven UK participants mentioned receiving sufficient information (during rehabilitation and post-discharge) about prevention of complications (e.g., skin management), wheelchair training, bladder and bowel management, and diet and nutrition advice. The other three talked about the lack of receiving specific information during rehabilitation (such as practical aspects of life with SCI, or intimate relationships).

3.3.3.5. Home adaptation

Both groups (N_{US}=8, N_{UK}=10) mentioned home adaptation—that is, layout and structural modifications made to a home to facilitate access (e.g., ramps), personal hygiene (e.g. showering, grooming, dressing), and activities such as transferring in/out of bed, using a wheelchair, cooking, working, etc. At the time of the interview, in the US group, four participants said their homes were still not adequately adapted for their needs: not having ramps, no access to basements or upper floors, inaccessible bathrooms, narrow doorways, not enough space to maneuver wheelchairs, not being able to get in and out of bed with ease.

> *"Where I am living now, the bathroom is on the second floor. That means I cannot really have guests in, because I use a potty chair which is in my kitchen, because that is the only way I can empty it, that's the only place to do it, in the kitchen" (US-F4, 7 years since injury).*

The entire UK group reported that their homes were adequately adapted to their needs, including ramps, wet rooms (bathrooms that facilitate open showering in a wheelchair, with central, sunken drainage, wall and floor tiling), and other assistive technologies. Three British interviewees added, however, that at the time of their injuries (in the 1970s and 1980s) they had to wait between one and five years to have their places adapted.

3.3.3.6. SCI-related complications

Both groups (N_{US}=10, N_{UK}=10) talked about complications related to their SCI because of poor management of skin care (pressure sores), blood pressure (persistent hypotension), bladder (chronic urinary tract infections), and bowel (bowel obstruction).

> *"My pressure sore was 9 cm long and 7 cm across and 3 1/2 cm deep. And this is on the tailbone, so you can imagine that part of my tail bone was sticking out. So 11 and 1/2 months later I finally pulled the thing off, and a month later it healed" (US-M1).*
>
> *"Does low blood pressure bring on fatigue or does fatigue bring on low blood pressure? I don't know but both of them happen simultaneously. It's just wanting to go I shut myself away a bit and recharge" (UK-M3).*

3.3.3.7. Consequences of aging with SCI

Participants in both groups (N_{US}=9, N_{UK}=9) talked about consequences of aging with SCI, and how it affects their function in terms of diminishing physical function (deterioration in upper-body strength, range of movement, wear and tear, weight gain), but also fear of loss of (care-giving) family and friends, fear of loss of housing, and fear of institutionalization.

> *"After 50 years of SCI, my arms or my shoulders are not a lot of fun. I literally don't sleep. At the moment I laid down on my arms or shoulders, I'm in a lot of pain. It is bad so I literally will sleep sitting up" (US-F1).*

> *"My muscle spasms have increased over the years as I got older, they've got worse. Also, getting tired really easily, and after a particularly busy day I do feel particularly tired the next day." (UK-M2).*

3.3.3.8. Public infrastructure

More than half of the sample (N_{US}=6, N_{UK}=6) discussed public infrastructure. The US group talked about positive aspects, such as wheelchair accessibility on public transit (bus), and having wheelchair-adapted cars and vans. They also mentioned such negative aspects as inaccessible car parks, cinemas, public transit, and even inaccessible hospital transportation.

> *"I think the environment disables me" (US-F1).*

> *"I can't get VA transportation here, because the VA system has vehicles for those who can ambulate but not the handicapped, so no lifts for chairs. So I am at a disadvantage" (US-M5).*

British participants mentioned positive aspects such as support when traveling by train and airplane, having access to wheelchair adapted cars and vans. They too talked about negative aspects, such as accessibility issues on streets, in supermarkets and smaller shops, primary care facilities, hotel rooms, pubs, and sports facilities.

> *"There's no facilities in the surgery for a paraplegic or somebody who's paralyzed from the chest down to be able to transfer from the chair onto like a consultancy table. It's too*

dangerous" (UK-M1).

3.3.4. Factors contributing to QOL: Financial Resources

Positive financial status consisted of having enough money to support oneself and/or family (housing, utility bills, including heat), and provide for one's health and rehabilitation needs (wheelchair provision, home adaptation, adapted transportation, and assistive technologies). This was typically associated with being independently wealthy before the injury (N_{US}=2, N_{UK}=1), receiving a settlement after the injury (N_{US}=1, N_{UK}=4), or continuing to work after the injury (N_{US}=4, N_{UK}=6). (There is overlap between these categories, that is, some who received settlement in the UK continued to work, and some who were independently wealthy in the US continued to work.)

In the US sample, participants emphasized negative financial status, that is, having insufficient money to support oneself and/or family, and provide for one's health and rehabilitation needs. This was typically associated with being disabled and unable to work, being retired, and receiving no settlement (N_{US}=5). Also notable is that outside the VA system, individual health insurance status determines out-of-pocket payment for care and rehabilitation, for receipt of assistive technology, support with housing adaptations, etc.

With universal provision of medical and social care, the UK stands out because health care and rehabilitation are free at the point of need, wheelchair provision is free at the point of need, and in most cases care coordination between specialist centers and social services ensured a standard level of provision regarding home adaptations and assistive technology. For instance, three UK participants were too disabled to work, two of them received settlements back in the 1980s, as well as continuous government support with care and rehabilitation, so they experienced a positive financial status. In the UK, negative financial comments were related to expensive disability products and services on the private market (N_{UK}=2), and generally financial concerns are on an altogether different level.

3.3.5. Factors contributing to QOL: Socio-political Context

Study participants talked about socio-political factors: issues regarding society at large were family attitudes to SCI, social relationships, other people's attitudes to disability, and government policy.

3.3.5.1. Family Attitudes

All participants talked positively about family attitudes to SCI post-injury. Family attitudes were positive for both groups and manifested themselves through moral, financial, and logistical support.

> *"When I became spinal cord injured I didn't go to rehab. My father went, and it was full of old people, and he said 'That's going to break her spirit, she cannot go there'. So we did it on our own" (US-F1).*
>
> *"My dad's a builder and he actually built me a self-contained sort-of flat that I could move into. So I had a place to go to" (UK-M8).*

3.3.5.2. Social Relationships

Most participants (N_{US}=9, N_{UK}=8) spoke of the role social relationships played in their lives. While some cited positive social experiences (N_{US}=4, N_{UK}=8), such as friends being inclusive, supportive, and accepting of the situation, participants also recalled negative experiences (N_{US}=5, N_{UK}=1). The most common negative experience was abandonment after injury.

3.3.5.3. Attitudes towards Disability

More than half of participants (N_{US}=7, N_{UK}=4) mentioned attitudes to disability as a factor affecting QOL, particularly lack of understanding of disability, failure to consider the needs of people with disabilities, infantilizing adults with disabilities, biased media representation of disabled people, disenfranchisement (e.g. being deprived of access to care or public spaces), and predatory behavior by commercial providers.

> *"Not many people know people with SCI, they don't! So it's got to be done on television. And how many times have you read an article where they talk about being wheelchair-bound? I am wheelchair enabled, I am not bound. The stereotypes are so ingrained, so part of the public psyche, that the language is all over the place." (US-F1).*

> *"I almost feel that a lot of companies prey on the vulnerable, which really frustrates me, with regards to disabled equipment, especially wheelchairs. I'd be able to buy a top of the range BMW with the price that I paid for my wheelchair. Which, for me, I just don't get really, which is why it's very frustrating, just unfair really" (UK-M8).*

3.3.5.4. Government Policy

A quarter of participants (N_{US}=3, N_{UK}=5) mentioned ways in which government policy affected QOL. In the US, three participants were highly critical of government policy towards people with disabilities.

> *"Anybody who does not fit, into the bell curve, those of us on the fringes of society, those of us with a disability, which is a big cauldron of worthlessness, because there's no distinction to it. What I need is not what somebody with autism needs. And the government made that determination. Nobody asked us. So it's gotten so diluted, that nothing gets done. Nothing" (US-F1).*

In the UK, three participants mentioned universal provision of medical and social care as a positive experience, while two recalled instances of discrimination during the 1980s in education provision and commercial services.

> *"I went to the cinema in my wheelchair and when I was told to get out of my wheelchair I refused, then they called the police and I was thrown out" (UK-M3).*

3.4. Discussion

The findings in this study are supported by previous studies on adults with SCI, especially the lifetime changes in priorities of QOL (Duggan and Dijkers, 2001; Boswell, et al., 1998). Domains of HRQOL (physical, mental, and social functioning) stand out in this study as key contributors to QOL in the context of SCI.

There were differences in the demographic and clinical characteristics of the two groups: 90% of the UK group were male versus 60% of the US group. The US sample had a higher median age at injury (38 years) than the UK sample (20 years), and a more recent time since injury (8 years versus 32 years). The etiology distribution is also different across groups: 40% of US sample acquired SCI through disease, compared with only 20% of the UK sample. Finally, the UK group did not include anyone with incomplete quadriplegia. Being injured when younger and having lived with the injury for longer could affect views on QOL and adjustment to life with an SCI. But changes in views about what mattered most in relation to QOL were mentioned both by those with relatively short time since injury (e.g., US male, 9 years) and those with longer lived experiences (e.g., UK male, 34 years). We also captured concerns about aging with an SCI, which were mentioned both by younger participants (e.g., US male, 32 years old, injured at 23) and aging participants (e.g., UK female, 60 years old, injured at 49). Half or more participants in each group discussed most themes and subthemes that emerged in the study, so it does not appear that clinical differences between the groups were a driving factor for differences of opinion or experience.

In both groups, the individuals who appeared to find it more difficult to adapt to SCI were those with very physically and socially active life-styles pre-injury. This suggests that perceived QOL and adjustment to life with SCI may rest in part on individual capacity and disposition to disregard the impact of the SCI on physical health and functional activities.

Factors affecting QOL also resemble to a degree those found in other studies, but this study is different because the findings emphasize the centrality of medical care as an influence on QOL to a much greater extent, both in the US (predominantly negative influence) and in the UK (predominantly positive influence). In the US sample, the negative influence appears to be linked to fragmented primary and specialist care, rehabilitation and wheelchair provision contingent on insurance, and an overwhelming bureaucratic burden on each person to secure basic care, rehabilitation, goods (such as wheelchairs) and services (e.g., home care). In the UK sample, the influence is predominantly positive, because of the advantages and benefits of universal provision, including free and continuous care, free provision of goods (wheelchairs) and services (home care), and length of rehabilitation in relation to level of injury.

This study produced several unexpected findinings. First, it was surprising to see how commonly problems with patient-physician communication regarding SCI and life with SCI were reported. UK patients appeared to be better informed upon discharge than their U.S. counterparts. The latter were poorly informed regarding SCI (what it is, levels of injury, types of care), basic self-care (such as managing bladder and bowels, skin management), wheelchair training (such as transferring), and wheelchair provision (understanding their own wheelchair needs). Lack of knowledge was consequential for daily functioning, particularly how to manage bladder and bowel, how to safely transfer to and from wheelchairs, and how to approach intimate relationships.

Second, the findings reiterate the importance of physical and mental fatigue as a functional impairment, and the absence of fatigue from discussions between medical providers and patients. This aligns with findings from previous studies, but further investigation into how to measure and manage fatigue is needed (Hammell, et al., 2009a; Hammell, et al., 2009b; Anton, et al., 2008). Third, the findings hint at the importance of home adaptations for QOL. The differences between the two groups point to the role of individual financial resources in the US to secure provision for basic adaptive needs such as ramps.

Furthermore, US participants' narratives about medical care that is constrained by insurance provision, the practice of discharging insufficiently rehabilitated persons to inaccessible homes, and insufficient knowledge and training about daily life with SCI, raise serious ethical and policy implications. However, given the small and likely unrepresentative sample in this study, more research on a national scale is needed to ascertain the extent of these issues in this population.

An important insight is gleaned from the use of newer communications technologies such as Skype/FaceTime to conduct in-depth interviews. This approach addresses one of the traditional shortcomings of in-depth qualitative research, which is limited in geographic scope, by enabling remote data collection and broadening the pool from which participants are recruited. Another advantage of remote interviewing is gaining access to participants who otherwise may not consent to having a stranger in their home, either out of fear, or embarrassment (particularly because of bladder/bowel accidents), or discomfort (e.g., having to transfer out of bed several times to accommodate the interviewer). Skype/FaceTime limits the content of field notes regarding an interviewee's home environment, but still enables eye contact and interpretation of upper-body language (attacks of spasticity, upper body strength and dexterity). Moreover, many video cameras are mobile, and several interviewees repositioned them to show issues with wheelchair cushions, or narrow doorframes for example. In the US sample, two participants were interviewed face-to-face and eight via Skype. We did not identify differences in the scope or depth of information provided by the two in-person interviewees versus those interviewed remotely. A disadvantage of not using remote interviewing in the UK is that we do not have a similar basis of comparison for the two interviewing methods in that sample. Considering the access to and wealth of information gained from individuals who may be otherwise difficult to reach, this trade-off is acceptable. Given the research questions and aims of the study, limited field notes about some participants' home environments do not undermine the validity of the findings. Other researchers have outlined the opportunities of harnessing modern communications technology, such as Skype, in conducting qualitative research (Saumure and Given, 2015; Sullivan, 2012).

A key limitation of the study is sample representativeness. Although use of newer communication technologies has broadened the scope of participant recruitment, the extent to which these participants represent those with SCI in their respective countries is unknown. Self-selection and access to a computer bias the sample against participants who do not have access to such technology. Another limitation is the low remuneration offered, which may have discouraged participation. Hence, the results reported here need to be examined further in future studies. Strengths of this study include the broad range of injury levels (especially two adults on ventilators), complete and incomplete injuries, the broad geographic scope (two countries, with broad geographic representation in each), and the diverse professional backgrounds of the participants: professionals with post-graduate degrees, musicians, athletes, artists, blue-collar workers, veterans, unemployed and retired individuals.

3.5. Tables

Table 3.1. Condensed Version of Interview Guide (excluding follow-up questions & probes)

1. How did you come to need a wheelchair?

2. How did you feel when you were told you were spinal cord injured?

3. What do you remember about your initial rehabilitation?

4. What do you remember about the days immediately after coming out of rehabilitation?

5. How would you define “quality of life”?

6. What matters to you most with regards to your quality of life?

7. What aspect of your injury makes you most unhappy?

8. Who is your primary source of medical advice when it comes to your injury?

9. Do you think your medical provider is interested in knowing about aspects of quality of life that matter to you? Why, why not?

10. When someone gives you medical advice, how important do you feel it is for them to know about other aspects of your life, such as those we have just discussed?

Table 3.2. Clinical Characteristics of the Sample

Characteristic	**US (N=10)**		**UK (N=10)**	
Level of Injury (%)				
Incomplete Paraplegia	4	(40)	3	(30)
Complete Paraplegia	2	(20)	3	(30)
Incomplete Quadriplegia	2	(20)	-	-
Complete Quadriplegia	2	(20)	4	(40)
Etiology (%)				
RTA (car, motorcycle, pedestrian, off-road)	3	(30)	5	(50)
Disease (e.g. Spinal infarct, Myelitis)	4	(40)	2	(20)
Leisure (Riding all, swimming, diving)	2	(20)	2	(20)
Sport/Rugby	0	(0)	1	(10)
Work (Fall from height)	1	(10)	-	-
Rehabilitation (Median / Range)				
Post-acute SCI Rehabilitation (Weeks)	14	(2-34)	40	(12-72)

Table 3.3. Demographic Characteristics of the Sample

Characteristic	US (N=10)		UK (N=10)	
Age (Median / Range)				
Chronological Age	57	(23-69)	51	(31-62)
Age at Injury	38	(9-64)	20	(0-49)
Time since Injury	8	(2-50)	32	(11-47)
Gender (%)				
Male	6	(60)	9	(90)
Race/Ethnicity (%)				
White	8	(80)	9	(90)
Black/African-American	1	(10)	1	(10)
Pacific Islander	1	(10)	0	(0)
Education (%)				
Highschool or GED	2	(20)	5	(50)
Some college or 2-year degree	2	(20)	1	(10)
Four-year college	3	(30)	3	(30)
More than 4-year college	3	(30)	1	(10)
Employment (%)				
Full-time (30 hrs/week or more) for pay	2	(20)	5	(50)
Part-time (less than 30 hrs/week) for pay	1	(10)	1	(10)
Volunteer (no pay)	0	(0)	1	(10)
Disabled (not working)	3	(30)	2	(20)
Retired	4	(40)	1	(10)
Living Circumstances (%)				
Alone with no caregiver support	2	(20)	2	(20)
With family live-in caregiver	4	(40)	4	(40)
With non-family live-in caregiver	0	(0)	1	(10)
With someone who is not a caregiver	3	(30)	3	(30)
In a residential home	1	(10)	0	(0)
Living with Partner at time of interview (%)				
Yes	6	(60)	6	(60)

Table 3.4. Summary of Positive Themes, Subthemes and Influence on Quality of Life Domains

Themes and Subthemes	Participants	Quality of Life Domains				
	US(N=10) / UK(N=10)	Physical Health	Mental Health	Social Functioning	Intimacy	Material Well-being
MEDICAL CARE						
Positive Rehabilitation	$N_{US}=6$ / $N_{UK}=8$	x	x	x	x	
Positive Wheelchair Provision	$N_{US}=5$ / $N_{UK}=8$	x	x	x		x
Positive Primary Care	$N_{US}=4$ / $N_{UK}=6$	x	x			
Care-giving at home	$N_{US}=5$ / $N_{UK}=5$	x	x			
FUNCTIONAL ADJUSTMENT						
Mental adjustment post-discharge	$N_{US}=0$ / $N_{UK}=0$					
Impact of SCI on function	$N_{US}=0$ / $N_{UK}=0$					
Complications	$N_{US}=0$ / $N_{UK}=0$					
Aging with SCI	$N_{US}=0$ / $N_{UK}=0$					
Fatigue (physical and mental)	$N_{US}=0$ / $N_{UK}=0$					
SCI Knowledge	$N_{US}=0$ / $N_{UK}=8$	x	x	x		
Home adaptation	$N_{US}=4$ / $N_{UK}=7$	x	x	x		
Public Infrastructure	$N_{US}=6$ / $N_{UK}=6$	x	x	x		x
FINANCIAL RESOURCES						
Financial resources	$N_{US}=4$ / $N_{UK}=9$	x	x			x
SOCIO-POLITICAL CONTEXT						
Family attitudes	$N_{US}=10$ / $N_{UK}=10$	x	x	x	x	
Social relationships	$N_{US}=4$ / $N_{UK}=8$	x	x	x		
Attitudes towards disability	$N_{US}=0$ / $N_{UK}=2$	x	x			x
Government policy	$N_{US}=2$ / $N_{UK}=3$	x	x			x

Table 3.5. Summary of Negative Themes, Subthemes and Influence on Quality of Life Domains

Themes and Subthemes	Participants	Quality of Life Domains				
	US(N=10) / UK(N=10)	Physical Health	Mental Health	Social Functioning	Intimacy	Material Well-being
MEDICAL CARE						
Negative Rehabilitation	$N_{US}=10$ / $N_{UK}=9$	x	x		x	
Negative Wheelchair Provision	$N_{US}=7$ / $N_{UK}=5$	x	x	x		x
Negative Primary Care	$N_{US}=7$ / $N_{UK}=4$	x	x			
Care-giving at home	$N_{US}=0$ / $N_{UK}=0$					
FUNCTIONAL ADJUSTMENT						
Mental adjustment post-discharge	$N_{US}=10$ / $N_{UK}=10$	x	x	x		
Impact of SCI on function	$N_{US}=10$ / $N_{UK}=10$	x	x	x	x	
Complications	$N_{US}=10$ / $N_{UK}=10$	x	x	x	x	
Aging with SCI	$N_{US}=9$ / $N_{UK}=9$	x	x	x	x	x
Fatigue (physical and mental)	$N_{US}=6$ / $N_{UK}=8$	x	x	x		
SCI Knowledge	$N_{US}=9$ / $N_{UK}=2$	x	x	x		
Home adaptation	$N_{US}=6$ / $N_{UK}=3$	x	x	x		
Public Infrastructure	$N_{US}=6$ / $N_{UK}=6$	x	x	x		x
FINANCIAL RESOURCES						
Financial resources	$N_{US}=6$ / $N_{UK}=1$	x	x			x
SOCIO-POLITICAL CONTEXT						
Family attitudes	$N_{US}=0$ / $N_{UK}=0$					
Social relationships	$N_{US}=5$ / $N_{UK}=1$	x	x	x		
Attitudes towards disability	$N_{US}=7$ / $N_{UK}=4$	x	x			x
Government policy	$N_{US}=3$ / $N_{UK}=0$	x	x			x

3.6. References

Anton, H. A., Miller, W. C., & Townson, A. F. (2008). Measuring fatigue in persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 538-542.

Atlas.ti. Version 7.5.12 [Computer software]. (1999). Berlin, Scientific Software Development.

Benner, H., & Kliebsch, U. (1996). Dependence of Weighted Kappa Coefficients on the Number of Categories. *Epidemiology*, 199-202.

Bernard, R. H., & Ryan, G. W. (1998). Text Analysis Qualitative and Quantitative Methods. In R. H. Bernard, *Handbook of Methods in Cultural Anthrolopolgy* (pp. 595-646). Walnut Creek: AltaMira Press.

Boswell, B., Dawson, M., & Heininger, E. (1998). Quality of life as defined by adults with spinal cord injuries. *Journal of Rehabilitation*, 27-32.

Cohen, J. (1960). A coefficient of agreement for nominal scales. *Educ Psychol Meas*, 37-46.

Cohen, J. (1968). Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. *Psychological Bulletin*, 213-220.

Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis.* London: Sage.

Christoph, B., & Noll, H.-H. (2003). Subjective well-being in the European Union during the 90s. *Social Indicators Research, 64*, 521-546.

Clayton, K. S., & Chubon, R. A. (1994). Factors Associated With the Quality of Life of Long-Term Spinal Cord Injured Persons. *Archives of Physical Rehabilitation and Medicine*, 633-638.

Dijkers, M. P. (1999). Correlates of Life Satisfaction Among Persons With Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*, 867-876.

Dijkers, M. P. (2005). Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *Journal of Rehabilitation Research & Development, 42*(3), 87-110.

Donovan, W. H. (2007). Spinal Cord Injury—Past, Present, and Future. *Journal of Spinal Cord Medicine*, 85-100.

Duggan, C. H., & Dijkers, M. (2001). Quality of Life After Spinal Cord Injury: A Qualitative Study. *Rehabilitation Psychology*, 3-27.

Fallowfield, L. (2009). What is quality of life? *Oxford Medicine What is ...? Series Second Edition*, 1-8. Retrieved from http://www.medicine.ox.ac.uk/bandolier/painres/download/whatis/WhatisQOL.pdf

Felce, D., & Perry, J. (1995). Quality of life: its definition and measurement. *Research in Developmental Disabilities, 16*(1), 51-74.

Franceschini, M., Di Clemente, B., Rampello, A., Nora, M., & Spizzichino, L. (2003). Longitudinal outcome 6 years after spinal cord injury. *Spinal Cord*, 280-285.

Fung, C., & Hays, R. D. (2008). Prospects and challenges in using patient-reported outcomes in clinical practice. *Quality of Life Research, 17*(10), 1297-1302.

Glass, C. A. (1993). The impact of home based ventilator dependence on family life. *Paraplegia*, 93-101.

Halvorson, G. C. (2007). *Healthcare Reform Now! A prescription for Change.* Los Angeles: Jossey-Bass.

Hammell, K. R. (2004). Exploring quality of life following high spinal cord injury: a review and critique. *Spinal Cord*, 491-502.

Hammell, K. W., Miller, W. C., Forwell, S. J., Forman, B. E., & Jacobsen, B. A. (2009). Managing fatigue following spinal cord injury: A qualitative exploration. *Disability and Rehabilitation, 31*(17), 1437-1445.

Hammell, K. W., Miller, W. C., Forwell, S. J., Forman, B. E., & Jacobsen, B. A. (2009). Fatigue and spinal cord injury: a qualitative analysis. *Spinal cord*, 47, 44-49.

Hammell, K. R. (2010). Spinal cord injury rehabilitation research: patient priorities, current deficiencies and potential directions. *Disability and Rehabilitation*, 1209-1218.

Hruschka, D. J., Schwartz, D., Cobb St. John, D., Picone-Decaro, E., Jenkins, R. A., & Carey, J. W. (2004). Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. *Field Methods*, 307-331.

Kahn, R. L., & Juster, F. T. (2002). Well-being: Concepts and measures. *Journal of Social Issues*, *58*(4), 627-644.

Lin, K.-H., Chuang, C.-C., Kao, M.-J., I-Nan, L., & Tsauo, J.-Y. (1997). Quality of life of spinal cord injured patients in Taiwan: a subgroup study. *Spinal Cord*, 841-849.

MacQueen, K. M., McLellan, E., Kay, K., & Milstein, B. (1998). Codebook Development for Team-Based Qualitative Analysis. *Cultural Anthropology Methods*, 31-36.

MASCIP, BASCIS, British Society of Rehabilitation Medicine, & Royal College of Physicians (2008). *Chronic spinal cord injury: management of patients in acute hospital settings.* Retrieved from http://www.bsrm.org.uk/downloads/sciwebversion.pdf

McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochimia Medica*, 276-282.

Naess, S. (1999). Subjective approach to quality of life. *Feminist Economics*, *5*(2), 115-118.

NSCISC. (2016, May 27). *SCI Facts and Figures at a Glance*. Retrieved from The National Spinal Cord Injury Statistical Center: https://www.nscisc.uab.edu/Public/Facts%202016.pdf

Pollock, A. M. (2004). *NHS plc.* Bath: The Bath Press.

Ryan, G. W., & Bernard, H. R. (2003). Techniques to identify themes. *Field Methods*, 85-109.

Saumure, K., & Given, L. M. (2015). Using Skype as a Research Tool: Lessons Learned from Qualitative Interviews with Distance Students in a Teacher-Librarianship Program.

Shulman, S. W. (2011, November 30). *Measure Inter-Rater Reliability and Adjudicate Coder Choices for Measures of Accuracy*. Retrieved from Coding Analysis Toolkit: http://cat.ucsur.pitt.edu

Siosteen, A., Lundqvist, C., Blomstrand, C., Sullivan, L., & Sullivan, M. (1990). The Quality of Life of Three Functional Spinal Cord Injury Subgroups in a Swedish Community. *Paraplegia*, 476-488.

Sullivan, J.R. (2012). Skype: An Appropriate Method of Data Collection for Qualitative Interviews? *The Hilltop Review*, 54-60.

Tseng, H. M., Lu, R. J., & Gandek, B. (2003). Cultural issues in using the SF-36 health survey in Asia: results from Taiwan. *Health and Quality of Life Outcomes*, *1*(72), 1-9.

Vogel, L. C., Klaas, S. J., Lubicky, J. P., & Anderson, C. J. (1998). Long-Term Outcomes and Life Satisfaction of Adults Who Had Pediatric Spinal Cord Injuries. *Archives of Physical Medicine and Rehabilitation*, 1496-1503.

Werndle, M. C., Zoumprouli, A., Sedgwick, P., & Papadopoulos, M. C. (2012). Variability in the Treatment of Acute Spinal Cord Injury in the United Kingdom: Results of a National Survey. *Journal of Neurotrauma*, 880-888.

Westgren, N., & Levi, R. (1998). Quality of Life and Traumatic Spinal Cord Injury. *Archives of Physical Medicine and Rehabilitation*, 1433-1439.

CHAPTER 4

PREFERENCES OF ADULTS WITH SPINAL CORD INJURY FOR WIDELY USED HEALTH-RELATED QUALITY OF LIFE AND SUBJECTIVE WELL-BEING MEASURES

4.1. Introduction

Spinal cord injury (SCI) is a life-changing event. In the United States, there are approximately 300,000 (out of about 319 million) individuals living with SCI, whereas the UK has approximately 40,000 cases of SCI (out of about 64 million) (NSCISC, 2016; Werndle, et al., 2012; Aung, et al., 1997). In both countries, SCI is predominantly acquired through traumatic events (approximately 90%) such as vehicular accidents, falls, and violence (NSCISC, 2016; Werndle, et al., 2012; Aung, et al., 1997). Long-term care for SCI should align with the goals advanced by the Institute of Medicine (2001) for patient-centered care that is “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (p. 6). One way to make care more patient-centered is to include patient-reported measures in clinical practice. Patient-reported measures include perceptions about quality of care, health behaviors, and health outcomes (Fung and Hays, 2008). They can facilitate patient-physician communication, thereby helping clinicians target interventions that will improve outcomes (Fung and Hays, 2008).

Quality of Life (QOL) is an all-encompassing concept that refers to a person’s physical, psychological, social, spiritual, and economic well-being (Martin, et al., 2010; Felce and Perry, 1995; Naess, 1999; Kahn and Juster, 2002; Christoph and Noll, 2003). Health-Related Quality of Life (HRQOL) is a subset of QOL and refers to perceived health. HRQOL domains include physical functioning, role functioning, social functioning, emotional well-being (depressive symptoms, anxiety, anger, positive affect), pain, energy, and general health perceptions (Fung and Hays, 2008).

Subjective well-being (SWB) refers to global appraisals of life that include but go beyond health. There are three types of SWB measures: evaluative well-being --overall appraisal of one's life; experienced well-being--emotional status over short periods of time; and eudaimonic well-being (EWB) --perceived purpose in life (Dolan, et al., 2011). Ravens-Sieberer *et al.* (2014) suggested that HRQOL measures could be enhanced with SWB measures that focus on "how well life is going for a person" (p. 208).

Many studies on adults with SCI use outcome measures developed for the general population and may not reflect the needs of those with SCI (Martin, et al., 2010). We examine which HRQOL and SWB measures are most valued by a sample of adults living with SCI in the United States and in the United Kingdom. We compare adults in the two countries to highlight potential cultural differences in valuing these measures.

4.2. Methods

4.2.1. Participants

Participants were eligible to be interviewed if they were 18 years or older, full-time wheelchair users, had a self-reported diagnosis of SCI, and could read and write in English. Exclusion criteria included inability to provide informed consent (including cognitive impairments such as dementia).

Recruitment occurred through (1) print advertisements through patient advocacy organizations in the UK (e.g. Spinal Injuries Association) and the US (e.g. veterans' support groups); (2) online advertisements through SCI fora, such as Apparelyzed (http://www.apparelyzed.com/) and Facebook wheelchair users' groups. Upon expressing interest in being interviewed, participants were sent an email with information about the study.

A total of 33 individuals responded to the advertisements, 15 in the US, and 18 in the UK. Of these respondents, 4 did not meet the inclusion criteria (age and full-time wheelchair use) and 7 decided not to continue with the study after reviewing the information package. Twenty-two individuals were interviewed (N_{US}=11, N_{UK}=11).

Participants were offered $10 / £7 remuneration for their participation, but only two accepted the offer. The Institutional Review Board of the University of California Los Angeles approved this study (Certified Exempt) (IRB#16-000229), and verbal informed consent was obtained from all participants.

4.2.2. Interview protocol

Semi-structured interviews were conducted by the first author (AP) to elicit in-depth views regarding HRQOL and SWB measurement among adults with SCI. We also collected demographic data from the sample.

The interview guide was developed using literature on SCI, and informal conversations with SCI rehabilitation professionals. We included six well-established self-report survey instruments [Short Form 36 (SF-36), Spinal Cord Independence Measure III (SCIM-III), Satisfaction with Life Scale (SWLS), Fatigue Severity Scale (FSS), Eudaimonic Subjective Well-Being (ESWB), and Hedonic Well-Being-12 (HWB-12)] and administered all of them to all participants (Kreuter, et al., 2005; Andersen, et al., 1999; Dijkers, 1999; Ravenek, et al., 2012; ONS, 2012; Fekete, et al., 2013; Catz, et al., 2002; Anton, et al., 2008; Garratt, et al., 1993; Bradburn, et al., 2013). The first half of the interview (approximately 1 hour) focused on

QOL in the context of SCI, whilst the second half (approximately 1 hour) focused on reviewing the instruments (Table 4.1). Methods and findings from the first half of the interviews are discussed elsewhere (Palimaru, et al., 2017). The sequence in which the surveys were presented and discussed was varied randomly for each interviewee to control for order effects (Whitehurst, et al., 2014; Perreault, 1975). The interview prompt for the review of the surveys was: "We are going to look at 6 surveys that have been used to assess health-related quality of life, and well-being in adults with SCI. Please answer each survey question as it applies to you, then please tell me how important it is for your medical provider to know your answer to each question, by choosing: vital, important, not important, or don't know." After completing each survey, participants were also asked to rate the overall importance of each survey using the same answer categories.

4.2.3 Survey instruments

The surveys we reviewed with the participants were not selected following a systematic review of the literature, but with the exception of Hedonic Well-Being (HWB-12) and the Eudaimonic SWB question, these instruments are widely used in studies of adults with SCI (Kreuter, et al., 2005; Andersen, et al., 1999; Dijkers, 1999; Ravenek, et al., 2012; ONS, 2012; Fekete, et al., 2013; Catz, et al., 2002; Anton, et al., 2008). We included the HWB-12 and the EWB instruments to assess their potential utility to SCI (Bradburn, et al., 2013). Four of the instruments (SF-36, SCIM III, FSS, EWB) have been assessed psychometrically in both the US and the UK (Andersen, et al., 1999; ONS, 2012; Fekete, et al., 2013; Anton, et al., 2008; Garratt, et al., 1993; Bradburn, et al., 2013). The psychometric properties of the Satisfaction with Life Scale (SWLS) and the HWB-12 instruments have been evaluated in the US only (Kapteyn, et al., 2015; Dijkers, 1999). Table 4.2 summarizes the key properties of the instruments discussed with the participants, including how they are scored.

4.2.4. Data Collection

The first two people who were eligible and agreed to be interviewed were selected for pilot interviews conducted by phone (N_{US}=1, N_{UK}=1) to test the interview guide, ensuring the questions were understandable and the length of the interview was reasonable. Because of the structural changes resulting from these pilot interviews (changes in the order of questions, phrasing of several questions, and addition of three questions) these were not included in the final analysis. In total, 20 participants were interviewed (N_{US}=10, N_{UK}=10) between April and June 2016. In both countries participants resided in a mix of urban, suburban, and rural areas. In the UK, participants were interviewed in their homes in the following geographic areas: Merseyside, South Devon, Hampshire, West Kent, Northumberland, Staffordshire, Leicestershire, and Wales. In the US, participants were interviewed in their homes in the following geographic areas: Southern California (Los Angeles, San Diego), Southwest Pennsylvania, Southeast Pennsylvania, Wisconsin, Central Florida, North Texas, Maryland, Upstate New York, and Alabama. Of the 20 interviews considered for this analysis, 12 were conducted face-to-face (N_{US}=2, N_{UK}=10), and 8 via Skype/FaceTime (N_{US}=8). To minimize travel costs and represent geographic distribution of US participants, most of the US interviews were conducted via Skype. Interview length ranged between approximately 80 minutes to 4 hours (median time was 103.5 minutes). None of the participants decided to end the interview early. All interviews were audio recorded, and transcribed verbatim.

4.2.5. Analysis

Transcripts were uploaded to Atlas.ti (Atlas.ti, 1999) to facilitate management, coding, analysis and interpretation of complex qualitative data, using grounded theory. These transcripts included both the first half of the interview, regarding QOL in the context of SCI (Palimaru, et al., 2017), and the second half, regarding survey preferences. Coding was performed in two rounds, each consisting of two coders coding independently. The process was driven by inductive reasoning based on the interview content, and included both open coding (codes identify dimensions emerging from the data) and in-vivo coding (codes are assigned directly from the text, when interviewees' own words are compelling). Inter-coder reliability was estimated using Cohen's kappa (Cohen, 1960; Cohen, 1968; Benner and Kliebsch, 1995; McHugh, 2012), with software from the University of Pittsburgh's Coding Analysis Toolkit (Shulman, 2011; Hruschka, et al., 2014). The initial kappa on a random sample of 5 transcripts was 0.75. After reconciliation, coding was done on the remaining 15 transcripts, with kappa of 0.82. The codebook is available upon request. The survey results and group comparisons were analyzed using STATA version 14 for Windows (StataCorp, 2014).

To further understand the motivation behind the respondents' ratings of each survey, we conducted a Keyword in Context (KWIC) analysis. Using freely available Web-based text processing software, *Voyant Tools* (Sinclair, 2016), we analyzed the verbatim transcripts of the comments that all participants made in relation to each of the 6 surveys; the comments were divided into six different text files, one for each survey. *Voyant Tools* produced a raw frequency of distinctive words (i.e. it excluded prepositions, conjunctions, etc) used by each participant to explain their survey rating. Through the KWIC function, the most frequently used distinctive words were selected and analyzed in context—that is, 15 words preceding and 15 words following each frequently used word.

4.3. Results

Table 4.3 shows participant demographic and clinical characteristics. The two groups were similar in terms of levels of injury, but they differed significantly at $P < 0.05$ based on independent group t-tests on median age at injury (38 versus 20 years for US and UK, respectively), time since injury (8 versus 32 years for US and UK, respectively), and post-acute rehabilitation weeks (14 versus 40 weeks for US and UK, respectively).

For each participant, we collected answers to all 6 instruments (82 questions in total), ratings of importance for each survey question (82 in total), as well as overall ratings of the importance of each of the 6 instruments. Table 4.4 summarizes results of participant reviews of the six surveys with illustrative quotes. The findings are presented in the order of survey importance, starting with the least important. Table 4.5 summarizes participant ratings of how important they felt it was for their medical provider to know their answers to each of the 6 survey instruments overall and the individual survey items. Of the 6 surveys, the only scores that differed significantly between the two country groups were those for the FSS. FSS scores are summary scores, ranging from 9 to 63, where higher scores indicate higher fatigue. The mean scores were 37.8 in the US group (SD=5.43), and 42.1 in the UK group (SD=4.95), t statistic = 2.29, $P < 0.05$. Table 4.6 provides a summary of themes relating to identified survey problems, and suggested improvements. The improvements in Table 4.6 are a summary of participant feedback.

Figure 4.1 displays the most frequently used words by survey importance rating (vital/important/not important) for each of the 6 surveys. For the FSS, the most distinctive words used were “fatigue” and “pain.” Pain was described as bodily pain in relation to wrists, elbows, shoulders, and bones. Of the 32 occurrences of the word “pain” in 12% of instances pain was described as causing physical and mental fatigue.

For the SCIM III, in 16% of 25 occurrences “know” was used to refer to knowledge by the respondent about their own needs, deficiencies, problems, etc. The rest referred to the importance that doctors know a patient, their lifestyle, and medical and non-medical needs. In 41% of occurrences of the word ‘wheelchair’ participants talked about problems with wheelchair use: armrest being broken, inability to do push-ups in the chair, risk of falling out of the chair, and sitting tolerance.

For EWB, overall, “family” was mentioned in 33% of the occurrences of the “worthwhile,” while the rest related to work, contributions to society, and pursuit of pleasures. When “doing” was used, 25% of the mentions related to work, 13% related to self-care activities, and the rest were about doing things in general. In the context of the SWLS, more than half (64%) of the occurrences of “health” relate to mental health. In the comments about SF-36, occurrences of “health” were related to physical and mental health, both for those who rated the survey “important” and those who thought it was “not important.”

4.4. Discussion

This study examined preferences of adults with spinal cord injury for widely used HRQOL and SWB instruments in two small samples in the US (N=10) and the UK (N=10). The respondents’ scores for SF-36, SWLS, SCIM-III, EWB and FSS were similar to those found in other studies, including SF-36 mental component scores being higher than physical component scores (Kreuter, et al., 2005; Andersen, et al., 1999; Dijkers, 1999; Ravenek, et al., 2012; ONS, 2012; Fekete, et al., 2013; Catz, et al., 2002; Anton, et al., 2008). However, only for the Fatigue Severity Scale scores is there a statistically significant difference between the two groups. Because the HWB-12 has not been used on SCI adults, comparisons were unavailable.

Of the total number of 82 items from the six surveys, only 15 (18%) were rated as vital or important, suggesting that overall these surveys do not capture well what matters to them, or what they think their medical provider should know about them.

The findings in this study highlight differences among adults with SCI in their preferences for HRQOL and SWB measures. The participants who rated surveys as vital were primarily those with incomplete injuries. This may be explained by the fact that the persons with incomplete spinal injuries tended to experience higher levels of pain and fatigue. The participants who rated any of the surveys as important tended to be those with higher level injuries. This may be explained by the fact that higher-level cervical-spine injuries often result in loss of control over more of the body (arms and hands, as well as lower body), and in extreme cases tetraplegia may affect vital functions such as breathing. So the importance of communicating survey results to their medical providers could be driven in part by higher levels of pain and physical impairment.

An unexpected finding was the particiants' top rating of the FSS as a vital or important survey for medical providers to know about. They talked about the importance of physical and mental fatigue as a functional impairment, and its implications for self-care, mobility and activities of daily living. Yet both groups reported the absence of fatigue from discussions with their medical providers. This could be explained by the short duration of the appointments, and by the fact that much of the patient-physician communication regarding SCI and life with SCI occurs in an unstructured, inconsistent manner. A key advantage of the FSS seemed to be its potential to instigate a discussion about fatigue and its underlying issues. However, there were suggestions for improvement of survey scope, especially language and content to better address fatigue in the context of SCI. This finding invites further investigation into measurement, management and prevention of fatigue for adults with SCI. A survey that captures causes of fatigue would seem particularly useful.

Another finding was the low rating for the importance of the SF-36 survey. Some of the issues relating to this survey, such as items immaterial to life with SCI, or the offence caused to some respondents, were known from previous studies (Mallinson, 2002; Andersen and Meyers, 2000; Mattson-Prince, 1997; Hays, et al., 2002). Another issue is the potential for response error. Andersen *et al.* (1999) used the question about lifting and carrying things to mark individuals as having an upper-body impairment. But in this study, those who said that they were “limited a lot” in lifting and carrying things, did so out of an awareness of danger of activity, fear of bags breaking in someone’s lap, or awareness of poor pressure support. Their answer was not necessarily an indication that they couldn’t complete the activity.

An important insight is gleaned from the use of newer communications technologies such as Skype/FaceTime to conduct in-depth interviews. This addresses one of the traditional shortcomings of in-depth qualitative research, which is limited in geographic scope, by enabling remote data collection. Another advantage is access to participants who otherwise may not consent to having a stranger in their home, either out of fear, discomfort, or embarrassment (particularly because of bladder/bowel accidents). With Skype, they are in control of how much they show of themselves and their surroundings, so they can easily highlight for the interviewer issues with their wheelchair, posture or home adaptations. Although the use of Skype was not primarily driven by participant preference, these advantages were noted by several participants following the interview. This method increased participant comfort, as some accessed Skype from mobile devices, not just a desktop computer, and could change locations during the interview. They could easily discontinue the session if they felt uncomfortable. A disadvantage is that this limits field notes, but considering the access to and wealth of information garnered from individuals who otherwise may not participate, this trade-off is reasonable. Other researchers have outlined the opportunities of harnessing modern communications technology in qualitative research (Sullivan, 2012; Saumure, 2015). In the US sample, we did not observe differences in the scope or depth of information provided by the two in-person interviewees compared to those interviewed via Skype.

A key limitation of the study is small sample size and unknown representativeness, thus, we cannot generalize these findings to SCI in the US or the UK. That there were statistically significant differences between countries on age at injury, time since injury, and post-acute rehabilitation time is another limitation. Being injured when younger, having lived with the injury for longer, and having received inadequately short rehabilitation could affect survey responses as well as views on how these surveys reflect one’s needs. Self-selection and access to a computer or mobile device (tablet/smartphone) may bias the sample against participants who do not or cannot use such technology. We recruited using both print ads and online posts, but only one US participant referenced a print ad when they contacted the interviewer. So adults with SCI who do not use the internet may have been left out. A disadvantage was not using remote interviewing in the UK sample, to provide a basis for comparison for in-person vs Skype interviewing methods. Finally, the low remuneration offered may have discouraged participation.

4.5. Conclusions

In this study, we found that participants in both samples identified the FSS as “vital” in terms of importance of informing medical providers about what it measures. The most frequently used distinctive words to discuss FSS were “fatigue” and “pain.” The FSS was followed by the SCIM III, and a stand-alone EWB question. Knowing what HRQOL and SWB measures are valued by adults living with SCI can help clinicians select informative population-specific instruments, thus helping them to complement and tailor established care and rehabilitation protocols for individual needs. The results reported here need to be examined in further studies, ideally with nationally representative samples in both countries. Future studies should also continue to investigate the potential of new communications technologies in conducting one-on-one interviews, preferably by offering respondents a choice between in-person and Skype interviews. Finally, further research should investigate survey length and respondent burden of surveys for adults with SCI.

4.6. Tables

Table 4.1. Condensed Version of Interview Guide (excluding follow-up questions & probes)

1. How did you come to need a wheelchair?

2. How did you feel when you were told you were spinal cord injured?

3. What do you remember about your initial rehabilitation?

4. What do you remember about the days immediately after coming out of rehabilitation?

5. How would you define “quality of life”?

6. Who is your primary source of medical advice when it comes to your injury?

7. Do you think your medical provider is interested in knowing about aspects of quality of life that matter to you? Why, why not?

8. When someone gives you medical advice, how important do you feel it is for them to know about other aspects of your life, such as those we have just discussed?

9. We are going to look at 6 surveys that have been used to assess health-related quality of life, and well-being in adults with SCI.
Please answer each survey question as it applies to you, then please tell me how important it is for your medical provider to know your answer to that question, by choosing: vital, important, not important, don’t know.

10. The first question of SF-36 is “In general, would you say your health is: Excellent, Very good, Good, Fair, or Poor”. How would you answer this question?

11. Having answered this question, how important do you feel it is for [*use their previous answer regarding their primary source of medical advice*] to know your answer to this question?

12. How important do you feel it is for [*use their previous answer regarding their primary source of medical advice*] to know your answers to this [*insert survey name*] survey overall?

13. Overall, do you think that your medical provider’s awareness of your answers to this survey might improve the overall quality of your rehabilitation care? If yes, how, if no, why not?

Table 4.2. Key properties of the six HRQOL and SWB instruments discussed with participants

Instrument	Target	Dimensions/domains	Scoring	Evaluated in SCI
Short Form 36 (SF-36)	General population	8 scale scores (physical functioning, role functioning, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, mental health); 2 summary scores (Physical Component Summary (PCS) score, Mental Component Summary (MCS) score); 1 preference-based score, SF-6D. Multiple types of answer ranges.	T scores, where mean is 50 and standard deviation is 10.	Yes
Hedonic Well-Being 12	General population	12 questions about well-being experiences the previous day. Answers range from 1 (Not at all) to 5 (Very).	Factor analysis.	No
Satisfaction with Life Scale	General population	5 questions assessing overall satisfaction with life (evaluative subjective well-being). Answers range from 1 (Strongly disagree) to 7 (Strongly agree).	Range 5-35. Benchmarks: 31-35 extremely satisfied; 26-30 satisfied; 21-25 slightly satisfied; 20 neutral; 15-19 slightly dissatisfied; 10-14 dissatisfied; and 5-9 extremely dissatisfied.	Yes
Eudaimonic Well-Being	General population	1 question about overall worth of life. Answer ranges from 0 (not at all worthwhile) to 10 (extremely worthwhile).	Overall score from 0 to 10.	No
Spinal Cord Independence Measure III	Adults with SCI	19 questions about overall level of independence. 1 self-care scale; 1 respiration and sphincter management scale; 1 mobility scale. Multiple types of answer ranges.	Overall independence score from 0 to 100. Self-care scale from 0 to 20. Respiration and sphincter management from 0 to 40. Mobility scale from 0 to 40.	Yes
Fatigue Severity Scale	General population	9 questions about overall fatigue severity. Answers range from strongly disagree (1) to strongly agree (7).	Overall score of fatigue severity, ranging from 9-63, higher score means higher fatigue severity.	Yes

Table 4.3. Demographic and Clinical Characteristics of the Sample

Characteristic	US (N=10)		UK (N=10)		Sample Total (N=20)	
Sex (%)						
Male	6	(60)	9	(90)	15	(75)
Race/Ethnicity (%)						
White	8	(80)	9	(90)	17	(85)
Black/African-American	1	(10)	1	(10)	2	(10)
Pacific Islander	1	(10)	-	-	1	(5)
Education (%)						
High school or GED	2	(20)	5	(50)	7	(35)
Some college or 2-year degree	2	(20)	1	(10)	3	(15)
Four-year college	3	(30)	3	(30)	6	(30)
More than 4-year college	3	(30)	1	(10)	4	(20)
Employment (%)						
Full-time (30 hrs/week or more) for pay	2	(20)	5	(50)	7	(35)
Part-time (less than 30 hrs/week) for pay	1	(10)	1	(10)	2	(10)
Volunteer (no pay)	-	-	1	(10)	1	(5)
Disabled (not working)	3	(30)	2	(20)	5	(25)
Retired	4	(40)	1	(10)	5	(25)
Living with Partner at time of interview (%)						
Yes	6	(60)	6	(60)	12	(60)
Age (Median / Range)						
Chronological Age	57	(23-69)	51	(31-62)	53	(23-69)
Age at Injury*	38	(9-64)	20	(0-49)	21	(0-64)
Time since Injury*	8	(2-50)	32	(11-47)	18	(2-50)
Level of Injury (%)						
Incomplete Paraplegia	4	(40)	3	(30)	7	(35)
Complete Paraplegia	2	(20)	3	(30)	5	(25)
Incomplete Tetraplegia	2	(20)	-	-	2	(10)
Complete Tetraplegia	2	(20)	4	(40)	6	(30)
Etiology (%)						
RTA (car, motorcycle, pedestrian, off-road)	3	(30)	5	(50)	8	(40)
Disease (e.g. Spinal infarct, Myelitis)	4	(40)	2	(20)	6	(30)
Leisure (Riding, swimming, diving)	2	(20)	2	(20)	4	(20)
Sport/Rugby	-	-	1	(10)	1	(5)
Work (Fall from height)	1	(10)	-	-	1	(5)
Rehabilitation (Median / Range)						
Post-acute Rehabilitation (Weeks)*	14	(2-34)	40	(12-72)	27	(2-72)

*Abbreviations: GED (general education diploma); RTA (road traffic accident). *Statistically significant differences between the two groups ($P < 0.05$) based on two-sample t-tests.*

Table 4.4. Summary of participant reviews of the six surveys with illustrative quotations

Survey Instrument	Summary of reviews	Illustrative quotations
Short Form 36 (SF-36)	In answer to the first question *"In general, would you say your health is…"*, more than half of all participants (N_{UK}=7; N_{US}=4) said their health was linked to their injury, especially as they aged with the injury. In the US group, participants said their SCI and their health were connected.	*"In terms of treatment or diagnosis, they tend to be separate, but my general state of health is very connected to my spinal cord injury. The older I get it is very connected" (UK-M4).*
	When they thought about their overall health, nearly half said they considered physical and mental health to be equally important. There was no mention of social functioning. Physical health was more important than mental health for seven US and three UK interviewees.	*"I would say that majority of my life is about mental health, obviously because physically I can't do things. To be mentally sound and to be in a good place, it's so, so important" (UK-M8).*
	More than half of all interviewees (N_{UK}=7, N_{US}=8) said they interpreted the questions about limitations of activities literally, while a quarter (N_{UK}=3, N_{US}=2) said they adapted the questions to suit their context: they replaced "running" and "walking" with "wheeling"	*"Walking and wheeling are the same to me" (US-M1).*
	Five participants (N_{UK}=4, N_{US}=1) considered skipping items (3a through 3i) that cover daily activities such as running, lifting heavy objects, climbing several flights of stairs, bending, kneeling, stooping, walking more than a mile. They felt these didn't consider the level of danger, duration, and intensity of activity, type of surface for wheeling, weights of objects to be lifted, and the broader context of living with SCI (having the right adaptations and wheelchair, having assistance, etc).	*"I could do it. But I'd then have to weigh up the danger in doing that. Because if I can't see my feet, it's gonna sound stupid this, but when you're sitting in a wheelchair, especially power chair, if you can't see your feet, and you can't feel your feet, you don't know whether you're catching them on something" (UK-M1).*
	Two respondents took offense to the items regarding climbing stairs.	*"What a bloody stupid question. It's insulting in a way. I'm C4-5" (UK-M5)* *"It's stupid, why are you going to ask me if I can walk when I can't? I kind of was offended" (US-M5).*
	Regarding questions inviting comparisons with other people, two participants mentioned they could compare themselves to either able-bodied people or other persons with SCI	*"If you put me up against spinal cord injured people, I'd say I have very good health. But if you put me up against the general population then I'm going to say fair to good" (UK-M6)*
	Some measurement error was revealed when participants explained the rationale for answers. For instance, those who said that they were "limited a lot" in lifting and carrying things, did so out of an awareness of the danger of the activity, fear of bags breaking in someone's lap, or awareness that extra weight	*"To turn around in the kitchen, if I can't see my feet where they're up against the bottom of the cupboard, as the chair is turning, and I have a bulky load sitting on my knees, like clothes ready for the dryer, and I do like a complete U-turn in the kitchen, there's a*

	increases pressure on already vulnerable soft tissue. Their answer was not necessarily an indication that they couldn't complete the activity.	*possibility that I actually break my foot on the bottom of the cupboard" (UK-M1).*
Hedonic Well-Being 12	Those who recognized this survey as important talked about its potential contribution to holistic care, but added that it should be administered frequently to bring up a pattern. Others described it as too abstract, context-dependent, and too broad.	*"To me, this survey doesn't really tell you anything about the person or the circumstances. It doesn't reveal anything meaningful" (US-F4).*
Satisfaction with life scale	Several commented that the survey was too vague, confusing and broad to be helpful.	*"Does conditions of my life refer to my health or life separate from health" (US-F1).*
	Half of British respondents thought the survey would inform their medical provider about their psychological well-being in a comprehensive and nuanced manner.	*"Important in the general mental health assessment, make sure you're not feeling down about your life" (UK-M2).* *"This deals with a very specialist area of psychological well-being, which is important to know, and I think should be important for health consultants to know (UK-M3).*
	Some participants in both samples doubted its utility because of prior negative experiences with their medical providers: doctors seen as not caring, concerned with physical health only, and lacking a holistic approach to care. While this negative perception of doctors was seen across the two groups, there was a difference: in the US mistrust was directed at both primary care and specialist doctors; in the UK it was mostly directed at lack of SCI specialist training among primary care and emergency room physicians and nurses.	*"I just had such bad experiences with doctors that don't care about their patients that I can't imagine them caring about the answers to the survey." (US-F2).* *"I think it would be very important, because most patients and most doctors, are not overly concerned about this information that you are bringing up, and I think they should be" (US-M1).*
	Those who regarded this survey as useful, commented on its potential to trigger further probing about psychological well-being.	*"Pretty important because these may lead to questions that help your doctor understand what you need at home. I do believe it's useful. Most of the satisfaction issue, especially with an injury like mine, is because something isn't accommodating you" (US-M3).*
Eudaimonic Well-Being	Half of the respondents in both groups noted its importance as part of holistic care, and its potential to instigate more clinical probing on issues of mental health and lifestyle.	*"I think it's quite important, it could tell the GP if somebody was depressed or didn't like their life" (UK-M6).*
	When talking about things that were worthwhile to them, both UK and US participants talked about family, work, contributions to society, and pursuit of pleasures and creative interests.	*"I think worthwhile to me are things that benefit my family, things that, from a selfish point of view, nourish my intellect" (UK-M3).* *"I think your primary care physician should know this stuff. I think they should know how you feel about your life. How can they*

		possibly make a diagnosis, or even make any assumptions unless they know what's going on psychologically, physically, emotionally. I just think physicians know so little" (US-F1).
Spinal Cord Independence Measure III	Participants were positive about this survey, because they felt it was relevant to their life circumstances and their needs. A few stressed the efficiency with which this survey communicates a lot of important information to their medical provider, thus leaving more time to discuss issues during the visit.	*"I think this was good. I think it's important to know what a person is capable of doing. Because that factors into the quality of life, the potential for experiencing different problems. This is basically practical, this is basically objective almost, these are the things I can and can't do, versus something more subjective like happiness. I think they need to know that" (US-F1).*
	Several suggested improvements in the scope of the survey.	*"This seems to be differentiating between when you are out of the home, and in the home. I don't think that's a meaningful distinction. I am assuming that they are asking it that way, because in the home you have control over what devices you have. Out of the home, you don't necessarily. I want my doctor to understand what I need to function, particularly as it relates to the wheelchair, whether I am at home or not. They are not asking any questions about how long you sit in the wheelchair, do you need to move to a different space to get pressure relief? I need to be some place where I can move to a seat I can actually sit on for a bit, to get different pressure than what's in my wheelchair. That's an important distinction to make" (US-F4).*
Fatigue Severity Scale	Most respondents described fatigue as something exacerbated by aging, but also as a symptom of more serious problems such as bowel cancer, thus highlighting the potential of the survey to trigger more probing	*"It's important and I wouldn't have even thought to bring it up" (US-F2)*
	About half of interviewees noted that it was unclear if the survey referred to mental or physical fatigue, or both. Regarding question 2 about exercise, about half also noted that the answer it elicited was not informative, because exercise means different things to different people.	*"Regarding exercise, there are two sides. If I have to wheel myself to the village that will tire me out. But if I do a work out, let's say, just on my arms, it might make my wrists a bit sore, but I actually come out of that and I feel boosted and stronger, because I have pumped my arms. But some people call exercise just sitting up unaided" (UK-M4).*
	A few respondents offered suggestions to improve the relevance and scope of this survey, including differentiating between physical and mental (emotional) fatigue.	*"I think of physical fatigue, but when I do get really physically fatigued, then I am more mentally fatigued as well, I won't be able to concentrate as well, if I am really, really tired physically. What makes you vulnerable to fatigue includes sitting tolerance, and the environment in which a wheelchair is used. If you've got a manual wheelchair and you're pushing it in an area where the surfaces aren't great, that can tire you out. But you also get fatigued just*

		from sitting in your wheelchair. You can get fatigued from pain" (UK-M9). *"Physical fatigue is if you can't lift one more thing, or can't push that vacuum one more time. Emotional fatigue means you don't think you can do it, but in fact you can physically do it. These things have to be asked very specifically. Because the emotional affects the physical so much, and in fatigue that is more evident than in other things" (US-F4).*

Table 4.5. Participants' ratings of instruments and items by importance of sharing information with medical providers

Instruments* and Items**	Vital	Important	Not important	Don't know
Fatigue Severity Scale	**5**	**10**	**2**	**3**
9. Fatigue interferes with my work, family, or social life.	5	12	1	2
1. My motivation is lower when I am fatigued.	6	10	1	3
2. Exercise brings on my fatigue.	7	8	2	3
6. My fatigue prevents sustained physical functioning.	4	7	4	5
3. I am easily fatigued.	5	5	6	4
Spinal Cord Independence Measure III	**6**	**7**	**3**	**4**
6. Bladder management.	8	10	1	1
7. Bowel management.	8	10	1	1
3(b). Dressing your lower body.	5	11	1	3
1. Eating and drinking.	4	8	3	5
Eudaimonic Well-Being	**4**	**7**	**2**	**7**
Overall, to what extent do you feel that the things you do in your life are worthwhile?	4	7	2	7
Satisfaction with Life Scale	**1**	**8**	**7**	**4**
No items deemed vital or important				
Hedonic Well Being-12	**0**	**9**	**4**	**7**
12. Yesterday, did you feel pain?	2	8	5	5
Short Form-36	**0**	**6**	**11**	**3**
29. Do you feel worn out?	0	12	4	4
1. In general, would you say your health is.	4	7	3	6
21. How much bodily pain have you had during the past 4 weeks?	2	9	2	7
22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	2	9	8	1

**We report overall instrument ratings of importance of sharing information in each with medical providers, listed in order of perceived importance, from most to least important. These are numbers of respondents who described each instrument as either vital, important, not important, or don't know.*

***We report items rated as "vital" or "important" by more than half of participants. Some participants who rated a survey overall as "not important" or "don't know" rated some of its individual items as "vital" or "important". Some who rated a survey as "vital" or "important" rated some of its individual items as "not important" or "don't know".*

Table 4.6. Summary of identified survey problems and suggested improvements

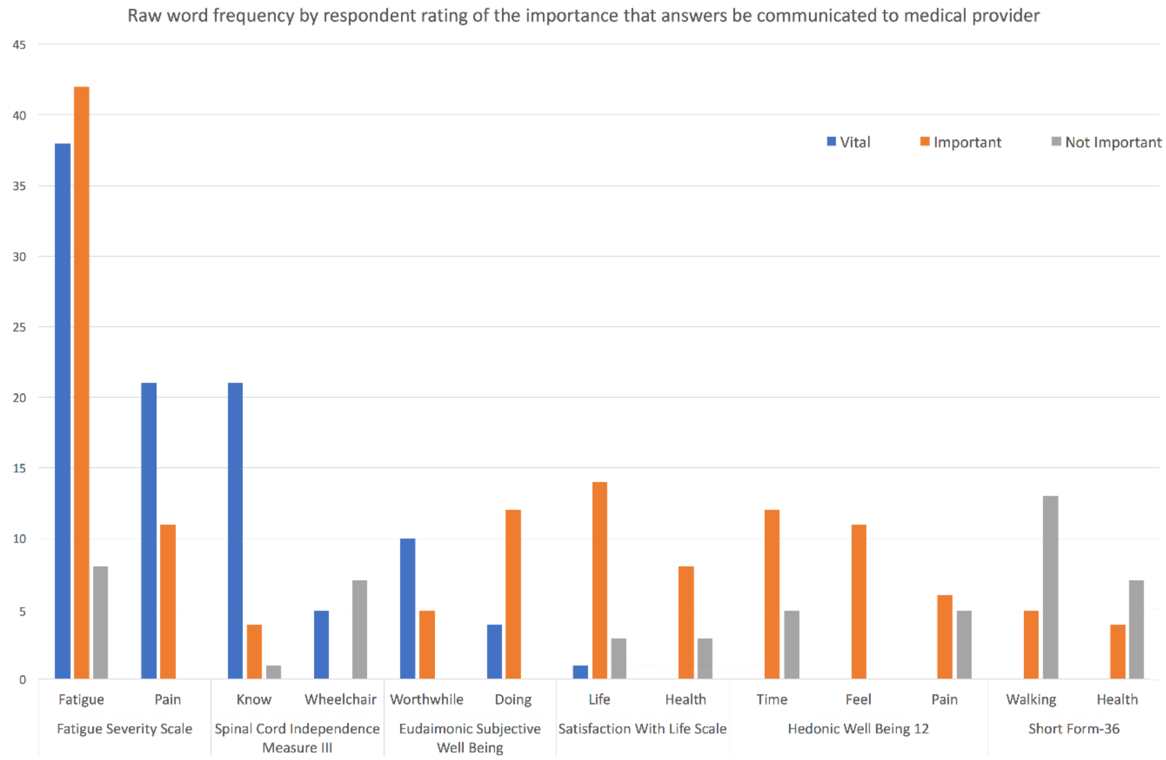
Survey instrument	Identified problems	Suggested improvements
Short Form 36	• Questions irrelevant to life with SCI, especially about ability to walk or run • Offensive phrasing in questions about ability to walk or run	Adapt content to SCI context Re-write questions to consider SCI target population
Hedonic Well-Being 12	• Items not informative of true daily experience • Requires frequent administration to provide a picture of quality of life	Administer just selected items that are relevant to SCI, such as pain
Satisfaction with Life Scale	• Items are vague, confusing and too broad	Re-write items to make them more focused and relevant to SCI
Eudaimonic Well-Being	• The item is too broad	Provide an open-ended option so that respondents can explain what they mean
Spinal Cord Independence Measure III	• Items focus on in-home function as opposed to outside the home	Improve scope by adding more questions on wheelchair use and function outside the home
Fatigue Severity Scale	• Several items were too vague, particularly about exercise and disabling symptoms • Scope was unclear, no distinction between physical and mental fatigue	Focus on causes of fatigue based on a broader range of activities Improve scope to include mental fatigue

Note: After completing each survey, participants were asked to discuss the surveys overall in terms of utility to providers, including identifying problems and suggesting improvements.

Here we provide a summary of participants' feedback.

4.7. Figure 4.1

Raw word frequency by respondent rating of the importance that answers be communicated to medical provider. For each of the six surveys, these are the top two most frequently used words when respondents discussed their utility. Word frequency is also displayed by the overall importance rating that answers be communicated to a medical provider: vital, important, not important.



4.8. References

Andersen EM, Fouts BS, Romeis JC, Brownson CA. Performance of health-related quality-of-life instruments in a spinal cord injured population. Arch Phys Med Rehabil 1999;80(8):877-84.

Andersen, E. M., & Meyers, A. R. Health-related quality of life outcomes measures. Arch Phys Med Rehabil 2000;81(12 Suppl 2):S30-45.

Anton HA, Miller WC, Townson AF. Measuring Fatigue in Persons with Spinal Cord Injury. Arch Phys Med Rehabil 2008;89(3):538-42.

Atlas.ti. Version 7.5.12 [Computer software]. 1999. Berlin, Scientific Software Development.

Aung TS, El Masry WS. Audit of a British Centre for spinal injury. Spinal Cord 1997;35(3):147-50.

Institute of Medicine. Crossing the quality chasm: A new health system for the 21st century. 2001. Washington, D.C.: Author.

Benner H, Kliebsch U. Dependence of Weighted Kappa Coefficients on the Number of Categories. Epidemiol 1996;7(2):199-202.

Bradburn NM, Carstensen LL, Diener EF, Dolan PH, Graham CL, Hotz VJ, et al. Subjective well-being: measuring happiness, suffering, and other dimensions of experience. (A A Stone, C Mackie, Eds). 2013. Washington, D.C.: The National Academies Press.

Catz A, Itzkovich M, Steinberg F, Philo O, Ring H, Ronen J, et al. Disability Assessment by a single rater or a team: a comparative study with the Catz-Itzkovich Spinal Cord Independence Measure. J Rehabil Med 2002;34:226-30.

Christoph B, Noll H-H. Subjective well-being in the European Union during the 90s. Soc Indic Res 2003;64:521-46.

Cohen J. A coefficient of agreement for nominal scales. Educ Psychol Meas 1960;20:37-46.

Cohen J. Weighted kappa: nominal scale agreement with provision for scaled disagreement or partial credit. Psychol Bull 1968;70(4):213-20.

Dijkers MP. Correlates of Life Satisfaction Among Persons With Spinal Cord Injury. Arch Phys Med Rehabil 1999;80(8):867-76.

Dolan P, Layard R, Metcalfe R. Measuring Subjective Well Being for Public Policy: Recommendations on Measures. London: Centre for Economic Performance, London School of Economics. 2011.

Fekete C, Eriks-Hoogland I, Baumberger M, Catz A, Itzkovich M, Lüthi H, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). Spinal Cord 2013;51(1):40-7.

Felce D, Perry J. Quality of life: its definition and measurement. Res Dev Disabil 1995;16(1):51-74.

Fung C, Hays RD. (2008) Prospects and challenges in using patient-reported outcomes in clinical practice. Qual Life Res;17(10):1297-1302.

Garratt AM, Ruta DA, Abdalla MI, Buckingham JK, Russell IT. The SF-36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? BMJ 1993;306(6890):1440-4.

Hays RD, Hahn H, Marshall G. Use of the SF-36 and other health-related quality of life measures to assess persons with disabilities. Arch Phys Med Rehabil 2002;83(12 Suppl 2):S4-9.

Hruschka DJ, Schwartz D, Cobb St. John D, Picone-Decaro E, Jenkins RA, Carey JW. Reliability in Coding Open-Ended Data: Lessons Learned from HIV Behavioral Research. Field Methods 2014;16(3):307-31.

Kahn RL, Juster FT. Well-being: Concepts and measures. J Soc Issues 2002;58(4):627-44.

Kapteyn A, Jinkook L, Tassot C, Vonkova H, Zamarro G. Dimensions of subjective well-being. Soc Indic Res. 2015;123(3):625-60.

Kreuter M, Siosteen A, Erkholm B, Bystrom U, Brown DJ. Health and quality of life of persons with spinal cord lesion in Australia and Sweden. Spinal Cord 2005;43(2):123-9.

Mallinson, S. Listening to respondents: a qualitative assessment of the Short-Form 36 Health Status Questionnaire. Soc Sci Med 2002;54:11-21.

Martin Ginis KA, Jetha A, Mack DE, Hetz S. Physical activity and subjective well-being among people with spinal cord injury: a meta-analysis. Spinal Cord 2010;48(1):65-72.

Mattson-Prince, J. A rational approach to long-term care: comparing the independent living model with agency-based care for persons with high spinal cord injuries. Spinal Cord 1997;35:326-31.

McHugh ML. Interrater reliability: the kappa statistic. Biochimia Medica 2012;22(3):276-82.

Naess S. Subjective approach to quality of life. Fem Econ 1999;5(2):115-8.

National Spinal Cord Injury Stastical Center. Spinal Cord Injury Facts and Figures at a Glance [document on the internet]. 2016 [updated 2016, cited 2016 June 30th]. Available from https://www.nscisc.uab.edu/Public/Facts%202016.pdf

Office of National Statistics. First annual ONS experimental subjective well-being results. London: Office for National Statistics. 2012 [updated 2012, cited 2016 June 30th]. Available from http://www.ons.gov.uk/ons/dcp171766_272294.pdf

Palimaru A, Cunningham W E, Dillistone M, Vargas-Bustamante A, Liu H, Hays R D. A comparison of perceptions of quality of life among adults with spinal cord injury in the United States versus the United Kingdom. Qual Life Res 2017;26(11):3143-55.

Perreault WJ. Controlling order-effect bias. Public Opin Q 1975;39(4):544-51.

Ravenek KE, Ravenek MJ, Hitzig SL, Wolfe DL. Assessing quality of life in relation to physical activity participation in persons with spinal cord injury: A systematic review. Disabil Health J 2012;5(4):213-23.

Ravens-Sieberer U, Devine J, Bevans K, Riley AW, Moon J, Salsman JM, Forrest CB.

Subjective Well-Being (SWB) measures for children were developed within the PROMIS® project: presentation of first results. J Clin Epidemiol 2014;67(2):207-18.

Saumure K, Given LM. Using Skype as a Research Tool: Lessons Learned from Qualitative Interviews with Distance Students in a Teacher-Librarianship Program. 2015.

Shulman SW. Measure Inter-Rater Reliability and Adjudicate Coder Choices for Measures of Accuracy. 2011 [updated 2011, cited 2016 June 30th]. Available from http://cat.ucsur.pitt.edu

Sinclair S. Voyant Tools: See through your texts. Available at http://voyant-tools.org/

StataCorp. Stata Statistical Software. [Computer software]. 2014. Release 14. College Station, TX: StataCorp LLC

Sullivan JR. Skype: An Appropriate Method of Data Collection for Qualitative Interviews? The Hilltop Review 2012;6(1):54-60.

Werndle MC, Zoumprouli A, Sedgwick P, Papadopoulos MC. Variability in the Treatment of Acute Spinal Cord Injury in the United Kingdom: Results of a National Survey. J Neurotrauma 2012;29(5):880-8.

Whitehurst DG, Suryaprakash N, Engel L, Mittmann N, Noonan VK, Dvorak MF, Bryan S. Perceptions of individuals living with spinal cord injury toward preference-based quality of life instruments: a qualitative exploration. Health Qual Life Outcomes 2014;12(1):646-54.

CHAPTER 5

DEVELOPMENT AND PSYCHOMETRIC EVALUATION OF A FATIGABILITY INDEX FOR FULL-TIME WHEELCHAIR USERS WITH SPINAL CORD INJURY

5.1. Introduction

Spinal cord injury (SCI) affects approximately 300,000 individuals in the US (NSCISC, 2016). A prevalent symptom associated with SCI is fatigue: “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities” (NIH, 2015). About 25% of individuals with SCI report fatigue that is severe enough to impact upon daily functioning and well-being (Anton, et al., 2008; McColl, et al., 2003). Adults with SCI may experience fatigue associated with their age, their full-time use of a wheelchair, daily activities, co-morbidities, and other consequences of SCI (e.g., poor posture, pressure management) (McColl, et al., 2003; Elliott, 1996; Hirsch, et al. 1991; Hughes, et al., 2001; Streeten and Anderson, 1998; Widerstrom-Noga, et al., 2001; Gerhart, et al., 1993; Charlifue, et al., 1999). Just like non-SCI adults, persons with SCI may try to avoid fatigue and exhaustion by decreasing or completely eliminating certain activities (cooking) or wheelchair maneuvers (wheelchair-to-car transfers).

Fatigability is “a characteristic describing an individual’s susceptibility to experiencing fatigue for a given quantifiable demand” (NIH, 2015). There are two forms of fatigability. The first is performance-related fatigability, which is observed and could be measured by a clinician, and refers to erosion in force, power, speed or stamina related to performance of a given activity (NIH, 2015). The second type of fatigability is perceived (self-reported) fatigability, which is the focus of this study: it refers to feelings of tiredness and wear related to duration and intensity of an activity (NIH, 2015). Self-reported fatigability has been measured in contexts other than SCI, with instruments such as the Physical Energy Scale from the Motivation and Energy Inventory, the Dutch Exertion Fatigue Scale, the Situational Fatigue Scale, and the Pittsburgh Fatigability Scale (Glynn, et al., 2015; Richardson, et al., 2015; Murphy, et al., 2013; Schnelle, et al., 2012; Yang and Wu, 2005; Tiesinga, et al., 1998). To date, no self-reported fatigability instrument specifically for SCI individuals has been developed and assessed psychometrically.

Development of such targeted instruments aligns with patient-centered care goals of being "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" (Institute of Medicine, 2001). In this study we aimed to develop and evaluate a SCI fatigability measure that could complement clinical processes like rehabilitation, seating, pressure/posture management, or other interventions to ameliorate the symptoms.

5.2. Methods

We developed the measures following the International Society for Quality of Life Research (ISOQOL) minimum standards and recommendations for patient-reported outcome measures (Figure 5.1) (Reeve, et al., 2013).

5.2.1. Initial Fatigability 82-Item Pool

First, we conducted a literature review to identify areas of interest relating to fatigue, that is, causes of fatigue in adults with SCI, and the relationship between fatigue and health-related quality of life in this subgroup of the population (Anton, et al., 2008; McColl, et al., 2003; Elliott, 1996; Hirsch, et al., 1991; Hughes, et al., 2001; Streeten & Anderson, 1998; Widerstrom-Noga, et al., 2001; Gerhart, et al., 1993; Charlifue, et al., 1999; Glynn, et al., 2015; Richardson, et al., 2015; Murphy, et al., 2013; Schnelle, et al. 2012; Yang & Wu, 2005; Tiesinga et al., 1998). We also identified existing fatigue instruments that were evaluated psychometrically among persons with SCI (Anton, et al., 2008; McColl, et al., 2003; Elliott, 1996; Hirsch, et al., 1991; Hughes, et al., 2001; Streeten & Anderson, 1998; Widerstrom-Noga, et al., 2001; Gerhart, et al., 1993; Charlifue, et al., 1999; Glynn, et al., 2015; Richardson, et al., 2015; Murphy, et al., 2013; Schnelle, et al. 2012; Yang & Wu, 2005; Tiesinga et al., 1998). We conducted 20 in-depth interviews with adults with SCI who are full-time wheelchair users, exploring quality of life in the context of SCI, and preferences for different health outcome measures, with findings reported elsewhere (Palimaru, et al., 2017). The need for two separate scales emerged from these in-depth interviews. Physical fatigue was defined as reduced physical function due to wear or disease (tiredness and weakness are symptoms of fatigue). Physical fatigue was also described as progressive, increasing in severity over time. Interviewees defined mental fatigue as reduced mental function due to perceived high level of stress, worries about the future, perceived need for extensive logistical planning, and perceived bureaucratic burden (such as filling out forms for health or welfare benefits). Participants discussed that for many activities, physical and mental fatigue can compete and conspire to frustrate and reduce what a disabled person can do in their life. With input from experts in wheelchair and seating assessment, rehabilitation, wheelchair sports coaching, survey development and psychometric evaluation, we drafted a large pool of Physical Fatigability (PF) and Mental Fatigability (MF) items (Table 5.1). The items represent four areas of fatigability: health problems, problems in the home environment, activities in the home, and activities away from home (which may be more demanding, with varying degrees of logistical challenges and physical exertion). For example, going to a doctor's appointment differs from taking an overnight trip away from home.

We asked, separately, about the level of physical and mental fatigue associated with 41 activities using the following response scale: 0 (no fatigue), 1 (Mild fatigue), 2 (Moderate fatigue) and 3 (Extreme fatigue), and Did not have this/Did not do this. In addition, we assessed the importance of each item to the respondent. For health, they were asked *"How important is it that each of the following is treated?"*; regarding activities they were asked *"How important is it that you can perform each of these activities?"* The importance questions were not used in the analyses reported here.

5.2.2. Field Test Data Collection and Sampling

Eligibility included being 18 years or older, U.S. residents, with a self-reported diagnosis of SCI, at least 1-year post hospital discharge, full-time wheelchair users, and could read and write in English. Excluded were individuals unable to provide informed consent (including cognitive impairments such as dementia or Alzheimer's disease), and those who were part-time wheelchair users.

This was a non-probability (convenience) sample recruited nationally through (1) print advertisements distributed through peer support groups in the United States (US), and veterans' support groups (local chapters of Paralyzed Veterans of America); (2) online advertisements distributed through organizations such as The Dana and Christopher Reeve Foundation (Members' Board: http://www.spinalcordinjury-paralysis.org/) and the United Spinal Association (http://www.spinalcord.org/resource-center/askus/index.php). In addition, 4 separate paid ad campaigns were conducted via Facebook Ads at 2-week intervals, with target specifications including US as a location, "SCI" and "wheelchairs" as user interests, and a population target of 12,000 for each campaign. Upon expressing interest in being interviewed, participants were sent an email with information about the study, and were given the option to take the survey online or via the phone. All respondents in this study, including several with high neck injuries who were on ventilators, chose to take the survey online between January and May 2017. No remuneration was provided for survey participation. A total of 491 individuals expressed interest in the study; 478 completed the survey. Fourteen respondents were eliminated because they resided in Australia, New Zealand, Canada, England and Scotland. The final sample was 464. This study was approved (Certified Exempt) by the Institutional Review Board of the University of California Los Angeles (IRB#16-000231).

5.2.3. Missing Data

Inappropriately missing data was 6% and was similar across all diagnosis levels. This degree of missing data is considered small in magnitude, and acceptable by traditional standards (Marshall, et al., 2001). In contrast, appropriately missing data due to items not being applicable was 21%. The number of *"did not have"* or *"did not do this"* responses per item varied from 2% to 85%.

The high proportion of the not-applicable answers resulted in some response options rarely being chosen – that is, a data sparsity problem. We further investigated the position of the not applicable responses in relation to the other response options. Average PF and MF scores were used as dependent variables in one-way ANOVAs with response options for each item as the independent variables. Duncan multiple range tests were used to compare mean scores by each response option (SAS Institute, 2013). Means for both PF and MF for those picking the not applicable response to items were closer to the Mild Fatigue score than any other answer option. Therefore, we collapsed the not applicable response with the "Mild fatigue" responses so that no cell had less than 5% of data (23 participants). We retained items with the high levels of not applicable responses because the majority of them were considered by at least half of the respondents to be “Vital” or “Important” for them to be able to do. For example, the high not applicable rate for an item such as *“Taking a vacation away from home”* may reflect inadequate transport and leisure infrastructure for people in wheelchairs, but it is possible that such services will improve in future.

5.2.4. Categorical Confirmatory Factor Analysis (CFA)

We investigated the factor structure of the 41 PF items and the 41 MF items using Mplus v. 7.4 (Muthen, 2015). The hypothesized structure was based on theories proposed by previous studies (Palimaru, et al., 2017; Hammell, et al., 2009). For the PF scale, we hypothesized five multi-item domains: “Health challenges,” “Daily living challenges,” “Mental tasks,” “Access challenges,” and “Seating challenges.” The hypothesized structure for the MF scale included four multi-item domains: “Daily living challenges,” “Access challenges,” “Concentration challenges,” and “Health challenges.”

A five-factor categorical confirmatory analysis model, a modified four-factor model, and a bifactor model were fit for the PF items. For the MF scale, a four-factor categorical confirmatory analysis model, a modified four-factor model, and a bifactor model were fit. All models used weighted least squares means and variances adjusted (WLSMV) estimation (Brown, 2006). The multi-factor models specified correlations among the domains (factors), but not among item error variances. We also estimated item means, standard deviations, item-total correlation (corrected for overlap), and coefficient alpha for each multi-item scale using Stata 15 (StataCorp, 2015).

The following commonly used model fit indices and thresholds were used: Root Mean Square Error of Approximation (RMSEA) < 0.08; Comparative Fit Index (CFI) > 0.95; and the Tucker-Lewis Index (TLI) > 0.95 (Tulsky, et al., 2015; Jette, et al., 2015; Jackson, et al., 2009; Reeve, et al., 2007). Factor loadings (i.e. the relation of an item to the hypothesized scale) were also inspected, looking for standardized loadings lower than 0.30, and R^2 lower than 10% as indicators of potential problematic items. For the bi-factor model, an instrument is considered primarily unidimensional if the percent uncontaminated correlations (PUC) < 0.80 (this is the percentage of covariance that reflects only variance from the general dimension), the explained common variance on the general dimension (ECV_{GEN}) > 60%, and omega hierarchical, the variance in raw total scores that can be attributed to individual differences on the general factor (Omega H) > 0.70 (Reise, et al., 2007; Reise, et al., 2013).

5.2.5. Item Response Theory (IRT) - Graded Response Model Analysis

Unidimenional IRT has several underlying assumptions. Unidimensionality was evaluated using CFA. Local independence means that after accounting for the underlying factor, items are uncorrelated (Embretson and Reise, 2000). To assess this we evaluated the residual correlation matrix for any values higher than 0.20. Monotonicity was evaluated by graphing item characteristic curves depicting the relationships between IRT estimated fatigability scores and responses to each item (Reeve, et al., 2013; Wellman, et al., 2015). Reliability (analogous to IRT information) of at least 0.70 was considered adequate for group comparisons (Hays and Revicki, 2005).

Differential Item Functioning (DIF) analyses evaluated whether the items were free of measurement bias—that is, conditional on estimated fatigability, the probability of selecting each response option was not associated with other factors such as age, time since injury, level of injury (paraplegia or quadriplegia) or gender (Embretson and Reise, 2000; Edelen et al., 2015; Hays, et al., 2000). For this study we used the Wald chi-square procedure which evaluates the equality of parameter estimates across groups. The approach obviates the need to identify DIF-free anchor items, and estimates the mean difference between the groups based on all the items in the scale (Edelen et al., 2015). To avoid false positives due to multiple hypotheses testing we applied the Benjamini-Hochberg adjustment ($P < 0.01$) (Reeve, et al., 2007; Wellman, et al., 2015; Edelen et al., 2015; Hays, et al., 2000; Benjamini and Hochberg, 1995). The magnitude of DIF was assessed using the weighted area between the curves (wABC) method, which measures the DIF effect size whilst accounting for the underlying distribution: for measurement items with four response categories, a wABC of 0.24 is considered non-negligible (Wellman, et al., 2015; Edelen et al., 2015).

5.2.6. Construct Validity

We assessed construct validity for the PF/MF scales, with F statistics evaluating the significance of difference between means among the four diagnosis groups (Hays and Reeve, 2010). We hypothesized that means would be higher for those with paraplegia and for those with incomplete paraplegia than for those with complete paraplegia. Finally, we examined the magnitude of correlations between responses to the PF and MF measures. We expected these two measures to be highly correlated, but we also expected to have higher correlations between the PF and MF Access Challenges scales, PF and MF Health Challenges scales, and PF and MF Daily Living Challenges scales. The rationale for these hypotheses is that individuals with comparatively higher mobility might exert themselves more in order to perform otherwise “normal” daily activities, and would thus be more susceptible to feeling exhausted. A wider range of activities also requires more cognitive and logistical planning and worry, for example anticipating access to parking (or lack thereof) and ramps in public spaces, resulting in higher physical and mental fatigability.

5.3. Results

5.3.1. Sample Characteristics

The 82-item fatigability survey was administered to a sample of individuals with SCI in 27 states in the US (Table 5.2). Supplemental Table 1 and Supplemental Figure 1 show readability scores for the item pool.

5.3.2. CFA Analyses

The hypothesized PF five-factor model was a poor fit to the data (RMSEA=0.095; CFI=0.812; and TLI=0.830). After removing two items with loadings below 0.30, and R^2 below 10% (*PFAway8 – Receiving a session of physiotherapy,* and *PFAway11 – Going out to a restaurant*), we moved the “Mental tasks” items under the “Daily living challenges” items. This four-factor model had a better, but still less than optimal fit: RMSEA = 0.081; CFI=0.922; and TLI = 0.940 (Supplemental Table 2).

For the MF scale, the initial and modified four-factor models were a poor fit to the data: (RMSEA=0.098, CFI=0.846, TFI=0.851; and RMSEA = 0.088, CFI=0.888, TLI = 0.901) (Supplemental Table 3). Supplemental Tables 4 and 5 show PF and MF item means, item-total correlations, and coefficient alphas.

Correlations among the PF factors and among the MF factors ranged from 0.575 to 0.772 and 0.565 to 0.856, respectively, suggesting the potential for a single general factor that may underlie the items in each scale (Stucky, et al., 2014; Brown, 2006). In addition, an exploratory factor analysis showed that the first factor explained 30% of the PF variability, and 35% of the MF variability (at least 20% is desirable), and the eigenvalue ratio (first to second) was 4.11 for the PF scale and 4.33 for the MF scale (ratios in excess of 4 provide support for unidimensionality) (Reeve, et al., 2013).

The bifactor models yielded RMSEA=0.076, CFI=0.931, TLI=0.956 for PF, and RMSEA=0.073, CFI=0.923, TLI=0.911 for MF (Reise, et al., 2007; Stucky, et al., 2014). Tables 5.3 and 5.4 show PF and MF bifactor loadings and the I-ECV values (each item's explained common variance). On both scales certain items suggested some multidimensionality. However, 32 PF items and 28 MF items had stronger loadings on the general factor than on the specific factors, suggesting unidimensionality of the PF and MF scales respectively. The loadings on the general factor of each scale were close to those of the 1-factor model, although slightly lower. Across both PF and MF items, ECV_{GEN} was 0.70, PUC was 0.71, while Omega H was 0.882 (PF) and 0.869 (MF). So, both scales were primarily unidimensional.

We assessed local dependence by fitting a one factor CFA model for each scale separately, and evaluating residual correlations. On both scales we found several problematic correlations: 0.201 and 0.203 (PF) and 0.207, 0.211, -0.216, -0.223 (MF). We further examined the effect of including the few locally dependent (LD) items on the IRT item discrimination parameters. For both scales, we first ran a base graded response model with the 39 (PF) and 36 (MF) items respectively. Then we ran alternative models excluding one LD item at a time and compared the item slopes across all models. We found that the effect of the LD items was minimal, so we decided to keep the base model for both scales.

5.3.3. IRT Parameters

Parameter estimates from the base IRT graded response model, fit in STATA15, are given in Tables 5.5 and 5.6. The measurement precision in the theta range between -2.0 and 2.5 is the equivalent of 0.94 reliability for PF and 0.91 for MF (Figure 5.2). Sixty-eight of the total 75 items showed well-differentiated category characteristic curves (CCC), indicating that each answer choice is the most likely answer at some point along the fatigability trait. In seven of the items the CCCs showed minor problems: in some the “extreme fatigue” option was subsumed under “moderate fatigue,” in others the “mild fatigue” choice was subsumed under “moderate fatigue.”

5.3.4. Differential Item Functioning

After Benjamini-Hochberg adjustment, there was no significant DIF by age or time since injury. Tables 5.7 and 5.8 show chi-square and wABC values with significant DIF by gender and diagnoses for the two measures. Only two items exceeded the 0.24 threshold for non-ignorable DIF in the diagnosis comparison: *“Taking an overnight trip away from home”* (PF scale) (wABC = 0.28), and *“Posture problems”* (MF scale) (wABC = 0.31). Given the same level of fatigability, uniformly across the continuum respondents with paraplegia (n=288) were more likely than those with quadriplegia (n=176) to report physical fatigue when taking an overnight trip away from home. For mental fatigue relating to posture problems, at the lower end of the theta range those with paraplegia were less likely than those with quadriplegia to report mental fatigue, but more likely to report it as fatigability increased. Figure 5.3 shows graphical representations of the effect size for both items. The impact of DIF on the overall mean scores for the two diagnosis groups was small. When DIF was accounted for by estimating item parameters separately for paraplegia and quadriplegia, the mean score difference between the groups was 0.49 SD (PF), and 0.74 SD (MF). When DIF was ignored by constraining all items to have equal parameters across diagnosis groups, the mean differences were 0.42 SD and 0.64 SD for the PF and MF scores, respectively. So adjusting for DIF makes only 0.07 SD (PF) and 0.10 SD (MF) change in the difference between diagnosis groups.

5.3.5. Construct Validity

For both scales, F-statistics p-values for paraplegia and incomplete paraplegia groups were significant at $p < .01$, and means were higher for those who reported having a paraplegia vs quadriplegia, and for those with an incomplete paraplegia vs complete paraplegia, incomplete and complete quadriplegia (Supplemental Tables 6 and 7). The correlation between the two scales was 0.92. The largest significant correlations were found between the PF and MF Access scales (0.86), PF and MF Health scales (0.75), and PF and MF Daily living scales (0.81).

5.3.6. Visualizing Fatigue

To ensure ease of application in clinical settings, patient answers need to be presented in a simple and meaningful way, that delivers an instant picture of a person’s physical and/or mental fatigability footprint, and in doing so, immediately highlights areas for possible intervention.

To visualize a patient’s vulnerability to fatigue, we propose a Fatigability Vector that includes all items retained after the psychometric assessment (Figure 5.4). To our knowledge, this visualization approach has not been proposed before. In this vector, each survey item has its own spoke with the four answer options. Taken together, they capture the full response plot for both physical and mental fatigue, showing the respondent’s physical and mental fatigability footprint. A clinician can thus identify areas that require immediate intervention, to address extreme fatigability, as well as preemptive intervention in the case of mild and moderate fatigue. The diagram can also help compare physical and mental fatigability, and a patient’s footprint over time, showing the result of the intervention over time.

5.4. Discussion

We developed and evaluated the psychometric properties of two measures: physical and mental fatigability. The need for two separate scales emerged from our in-depth interviews. During the cognitive interviews conducted prior to the field test (see Figure 5.1) we found that participants had no trouble differentiating between the two scales, which aligned with our findings from the in-depth interviews. A specific index of susceptibility to fatigue in SCI—that is, fatigability-- can help clinicians establish the level of vulnerability of an individual. It can also highlight issues that might cause fatigue and require further probing, such as correct techniques to self-propel in manual wheelchairs, moving up and down ramps, or doing wheelchair transfers. Adding this index to other SCI-specific instruments, such as the self-reported Spinal Cord Independence Measure III, can increase the focus on patient-centered care in SCI. More broadly, the index could be incorporated into wheelchair assessment and prescription protocols by mobility vendors.

The test information curves for the fatigability measures reported here show that the questions work best for individuals with mild and moderate fatigability, where interventions could ameliorate symptoms. But they are also informative for those with limited fatigability and extreme fatigability, where the need for interventions is more immediate.

This study also found that 18 PF items and 26 MF items had high or very high discrimination power (slopes > 1.35). In addition, the item category characteristics are generally well-differentiated for 68 of the 75 items. For the few items where that is not the case, it might be helpful to collapse one or more of the answer categories into an adjacent response option and offer fewer response options in the future.

5.5. Limitations

Socially desirable response bias is a concern with this type of self-reported data, even though the survey was not administered in person or via telephone (McHorney, et al., 1994; Hays, et al., 2009). Another limitation is selection bias. Certain types of individuals may be more likely to respond because they are computer-literate, or have access to a peer-group based at a rehabilitation center, while other types of individuals may be more inclined to offer their time to complete the surveys for no remuneration. Non-representative sampling makes the generalizability of findings problematic especially because we did not formally explore the extent to which the measurement process is similar across different measurement situations, for example community vs clinical settings, and modes of administration. A larger and more-representative sample would allow more definitive evaluation of DIF (Reeve, et al., 2007). Finally, because the denominator is unknown for this convenience sample, the response rate is unknown.

5.6. Conclusions

These findings should be confirmed with larger, representative datasets, which would improve the precision of the estimates. Future research needs to be done to evaluate whether the not applicable response category should be treated differently. Future research should focus on the development of short forms for the two measures, and exploring computer-adaptive test administration of the existing item banks.

5.7. Tables

Table 5.1. Physical and Mental Fatigability (PF/MF) Item Pool

ItemID		Item Stem and Item Content
Health		During the past 4 weeks did you experience each of the following? If so, how much physical & mental fatigue did each cause you?
PF&MF	Hlth1	Sleep problems
PF&MF	Hlth2	Pain
PF&MF	Hlth3	Indigestion problems
PF&MF	Hlth4	Dehydration problems
PF&MF	Hlth5	Poor posture
PF&MF	Hlth6	Spasticity
PF&MF	Hlth7	Stress
PF&MF	Hlth8	Medication side-effects
Home environment		During the past 4 weeks did you experience each of the following? If so, how much physical & mental fatigue did each cause you?
PF&MF	Envr1	Lack of peace and quiet
PF&MF	Envr2	Inadequately adapted home
PF&MF	Envr3	Inadequate medical care when at home
PF&MF	Envr4	Inadequate non-medical care when at home
Activities at home		During the past 4 weeks did you experience each of the following? If so, how much physical & mental fatigue did each cause you?
PF&MF	Home1	Wheelchair transfer to and from bed

PF&MF	Home2	Sitting in a wheelchair for an hour or more
PF&MF	Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)
PF&MF	Home4	Using a computer for an hour or more
PF&MF	Home5	Wheelchair use around the home
PF&MF	Home6	Spending all day in your wheelchair
PF&MF	Home7	Pressure management (preventing pressure sores)
PF&MF	Home8	Posture management
PF&MF	Home9	Household chores, such as cleaning and tidying
PF&MF	Home10	Preparing and clearing away a meal
PF&MF	Home11	Eating a meal
PF&MF	Home12	Letter-writing, form filling or paying bills
Activities away from home	During the past 4 weeks did you experience each of the following? If so, how much physical & mental fatigue did each cause you?	
PF&MF	Away1	Wheelchair use over a smooth surface
PF&MF	Away2	Wheelchair use over an uneven surface
PF&MF	Away3	Wheelchair transfer to and from car
PF&MF	Away4	Traveling in your vehicle for an hour or more
PF&MF	Away5	Using an adapted taxi
PF&MF	Away6	Using a bus
PF&MF	Away7	Using a train
PF&MF	Away8	Receiving a session of physiotherapy
PF&MF	Away9	Going to a doctor's appointment

PF&MF	Away10	Shopping, such as having access and reaching merchandise
PF&MF	Away11	Going out to a restaurant
PF&MF	Away12	Attending an event, such as cinema, theater, or a show
PF&MF	Away13	Visiting friends
PF&MF	Away14	Attending a sporting event
PF&MF	Away15	Taking a day trip away from home
PF&MF	Away16	Taking an overnight trip away from home
PF&MF	Away17	Taking a vacation away from home

Abbreviations: Physical Fatigue (PF); Mental Fatigue (MF). These 41 items were presented separately for the physical fatigue and the mental fatigue scales, hence 82 total item count. The answer range was: No Fatigue (0), Mild Fatigue (1); Moderate Fatigue (2), Extreme Fatigue (3); Did not have or Did not do this (99). However, due to sparse distributions, the "Did not have or Did not do this" category was collapsed into "Mild fatigue" (based on Duncan Multiple Range Test results) in order to have no cell with <5% of the data (23 participants). For all these items, higher scores mean higher vulnerability to physical and mental fatigue respectively.

Table 5.2. Sample participant characteristics (N=464)

Age (Mean years, SD)		45	(12)
Time Since Injury (Mean, SD)		13	(12)
Sex (%)			
	Male	222	(48)
	Female	242	(52)
Ethnicity (%)			
	Hispanic	16	(3)
	Non-Hispanic	446	(96)
Race (%)			
	White	424	(91)
	Black or African American	14	(3)
	Asian	6	(1)
	Native Hawaiian or Other Pacific Islander	-	-
	American Indian or Alaska Native	5	(1)
	Other	14	(3)
Living Arrangements (%)			
	Alone with no caregiver support	70	(15)
	Alone but with visiting caregiver support	62	(13)
	With a live-in caregiver who is a family member	213	(46)
	With a live-in caregiver who is not a family member	7	(2)
	With someone who is not your caregiver	111	(24)
	In a nursing home	-	-
	In some other living arrangement	1	(0.2)
Education (%)			
	8th grade or less	44	(9)
	Some high school, but did not graduate	10	(2)
	High school graduate or GED	60	(13)
	Some college or 2-year degree	162	(35)
	4-year college graduate	104	(22)
	More than 4-year college degree	84	(18)

Employment Status (%)		
Full-time paid work (30 or more hours a week)	61	(13)
Full-time voluntary work (less than 30 hours a week)	-	-
Part-time paid work (30 or more hours a week)	48	(10)
Part-time voluntary work (less than 30 hours a week)	51	(11)
Not working, but seeking work	14	(3)
Not working due to disability	210	(45)
Student	33	(7)
Retired	46	(10)
Worries about financial situation (%)		
All the time	187	(40)
Occasionally	162	(35)
Rarely	90	(20)
Never	23	(5)
Spinal Cord Diagnosis (%)		
Complete paraplegia	139	(30)
Incomplete paraplegia	149	(32)
Complete quadriplegia	70	(15)
Incomplete quadriplegia	106	(23)
Type of Wheelchair Used (%)		
Manual (I self-propel)	321	(69)
Manual (I am pushed)	39	(8)
Power chair	160	(34)

Note: The numbers for "Type of Wheelchair Used" do not add up to 100 because participants could select a combination of wheelchair options.

Table 5.3. Physical Fatigability Bifactor Loadings and I-ECV Values

Item Content	General Factor	Health Challenges	Daily Living Challenges	Seating Challenges	Access Challenges	I-ECV
Sleep problems	0.377	0.725				0.213
Pain	0.730	0.218				0.918
Indigestion problems	0.385	0.906				0.153
Dehydration problems	0.560	0.092				0.974
Spasticity	0.419	0.284				0.685
Stress	0.323	0.458				0.332
Medication side-effects	0.420	0.126				0.917
Wheelchair transfer to and from bed	0.477		0.320			0.690
Wheelchair use around the home	0.700		0.496			0.666
Household chores, such as cleaning and tidying	0.551		0.830			0.306
Preparing and clearing away a meal	0.478		0.206			0.843
Eating a meal	0.555		0.278			0.799
Lack of peace and quiet	0.476		0.276			0.748
Inadequately adapted home	0.583		0.143			0.943
Inadequate medical care when at home	0.374		0.083			0.953
Inadequate non-medical care when at home	0.380		0.107			0.927
Concentrating for an hour or more (such as reading, writing, or holding a conversation)	0.604		0.108			0.969
Using a computer for an hour or more	0.566		0.024			0.998
Letter-writing, form filling or paying bills	0.678		0.038			0.997

Sitting in a wheelchair for an hour or more	0.512	0.672		0.367
Poor posture	0.615	0.244		0.864
Spending all day in your wheelchair	0.935	0.263		0.927
Pressure management (preventing pressure sores)	0.496	0.335		0.687
Posture management	0.745	0.078		0.989
Wheelchair use over a smooth surface	0.773		0.251	0.905
Wheelchair use over an uneven surface	0.811		0.126	0.976
Wheelchair transfer to and from car	0.608		0.063	0.989
Traveling in your vehicle for an hour or more	0.510		0.679	0.361
Using an adapted taxi	0.543		0.597	0.453
Using a bus	0.653		0.172	0.935
Using a train	0.621		0.199	0.907
Going to a doctor's appointment	0.968		0.210	0.955
Shopping, such as having access and reaching merchandise	0.962		0.167	0.970
Attending an event, such as cinema, theater, or a show	0.518		0.435	0.586
Visiting friends	0.582		0.555	0.524
Attending a sporting event	0.702		0.530	0.637
Taking a day trip away from home	0.643		0.570	0.560
Taking an overnight trip away from home	0.648		0.465	0.660
Taking a vacation away from home	0.495		0.462	0.534

Abbreviations: Physical Fatigue (PF); Item explained common variance (I-ECV); Items stem was: During the past 4 weeks did you experience each of the following? If so, how much physical fatigue did each cause you? Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Table 5.4. Mental Fatigability Bifactor Loadings and I-ECV Values

Item Content	General Factor	Health Challenges	Daily Living Challenges	Concentration Challenges	Access Challenges	I-ECV
Sleep problems	0.434	0.467				0.463
Pain	0.573	0.341				0.738
Poor posture	0.493	0.721				0.319
Stress	0.476	0.197				0.854
Medication side-effects	0.482	0.298				0.723
Wheelchair transfer to and from bed	0.759		0.041			0.997
Sitting in a wheelchair for an hour or more	0.704		0.316			0.832
Wheelchair use around the home	0.778		0.360			0.824
Spending all day in your wheelchair	0.832		0.319			0.872
Pressure management (preventing pressure sores)	0.787		0.348			0.836
Posture management	0.836		0.248			0.919
Household chores, such as cleaning and tidying	0.723		0.365			0.797
Preparing and clearing away a meal	0.683		0.364			0.779
Eating a meal	0.735		0.378			0.791
Lack of peace and quiet	0.505		0.320			0.714
Inadequately adapted home	0.526		0.574			0.456
Inadequate medical care when at home	0.470		0.476			0.494
Concentrating for an hour or more (such as reading, writing, or holding a conversation)	0.590			0.195		0.902
Using a computer for an hour or more	0.737			0.530		0.659

Letter-writing, form filling or paying bills	0.794			0.225		0.926
Wheelchair use over a smooth surface	0.567				0.589	0.481
Wheelchair use over an uneven surface	0.468				0.782	0.264
Wheelchair transfer to and from car	0.303				0.785	0.130
Traveling in your vehicle for an hour or more	0.774				0.065	0.993
Using an adapted taxi	0.723				0.254	0.890
Using a bus	0.736				0.075	0.990
Using a train	0.761				0.272	0.887
Going to a doctor's appointment	0.741				0.501	0.625
Shopping, such as having access and reaching merchandise	0.871				0.142	0.974
Going out to a restaurant	0.513				0.273	0.779
Attending an event, such as cinema, theater, or a show	0.648				0.419	0.705
Visiting friends	0.761				0.448	0.743
Attending a sporting event	0.806				0.413	0.792
Taking a day trip away from home	0.697				0.563	0.605
Taking an overnight trip away from home	0.702				0.424	0.733
Taking a vacation away from home	0.502				0.615	0.400

Abbreviations: Mental Fatigue (MF); Item explained common variance (I-ECV); Items stem was: During the past 4 weeks did you experience each of the following? If so, how much mental fatigue did each cause you? Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Table 5.5. Physical Fatigability Item Response Theory Parameters

Scale	Item Content	Slope	Threshold 1	Threshold 2	Threshold 3
Health Challenges					
PF Hlth1	Sleep problems	1.07	-2.83	-0.31	1.43
PF Hlth2	Pain	1.27	-2.47	-0.46	0.8
PF Hlth3	Indigestion problems	0.89	-1.98	1.56	2.94
PF Hlth4	Dehydration problems	0.54	-2.01	1.94	2.56
PF Hlth6	Spasticity	0.99	-1.60	0.48	2.34
PF Hlth7	Stress	1.13	-2.01	0.27	1.71
PF Hlth8	Medication side-effects	0.82	-2.77	0.85	2.84
Daily Living Challenges					
PF Home1	Wheelchair transfer to and from bed	1.02	-1.27	1.13	3.02
PF Home5	Wheelchair use around the home	1.68	-0.32	1.17	2.44
PF Home9	Household chores, such as cleaning and tidying	1.70	-1.94	0.38	1.53
PF Home10	Preparing and clearing away a meal	2.13	-1.14	0.73	2.01
PF Home11	Eating a meal	1.50	0.62	2.03	3.98
PF Envr1	Lack of peace and quiet	0.77	-1.94	2.29	3.88
PF Envr2	Inadequately adapted home	1.00	-2.04	1.15	2.43
PF Envr3	Inadequate medical care when at home	1.04	-1.46	2.15	3.61
PF Envr4	Inadequate non-medical care when at home	0.95	-2.08	2.03	2.89
PF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	1.51	-0.64	0.68	2.28
PF Home4	Using a computer for an hour or more	1.15	-1.02	0.63	3.06

PF Home12	Letter-writing, form filling or paying bills	1.13	-0.53	2.36	3.41
Seating Challenges					
PF Home2	Sitting in a wheelchair for an hour or more	1.68	-0.81	0.69	2.21
PF_Hlth5	Poor posture	0.55	-2.25	1.73	3.09
PF Home6	Spending all day in your wheelchair	1.24	-2.27	-0.47	1.07
PF Home7	Pressure management (preventing pressure sores)	0.91	-0.53	2.22	3.44
PF Home8	Posture management	1.10	-1.03	1.50	3.16
Access Challenges					
PF Away1	Wheelchair use over a smooth surface	1.35	-0.08	1.66	3.18
PF Away2	Wheelchair use over an uneven surface	1.36	-1.57	0.04	1.28
PF Away3	Wheelchair transfer to and from car	1.56	-1.11	0.92	1.97
PF Away4	Traveling in your vehicle for an hour or more	1.42	-1.35	0.38	1.85
PF Away5	Using an adapted taxi	2.26	-2.94	1.83	2.45
PF Away6	Using a bus	1.96	-2.69	2.23	2.69
PF Away7	Using a train	2.39	-2.71	2.03	2.47
PF Away9	Going to a doctor's appointment	1.15	-1.61	1.28	3.06
PF Away10	Shopping, such as having access and reaching merchandise	1.69	-1.01	0.56	1.77
PF Away12	Attending an event, such as cinema, theater, or a show	2.05	-1.12	0.99	2.28
PF Away13	Visiting friends	2.03	-1.16	1.09	1.82
PF Away14	Attending a sporting event	1.71	-1.81	1.40	2.25
PF Away15	Taking a day trip away from home	2.11	-1.75	0.48	1.45
PF Away16	Taking an overnight trip away from home	1.86	-2.48	0.17	1.15

PF Away17	Taking a vacation away from home	1.17	-3.13	0.88	2.85

Abbreviations: Physical Fatigue (PF). Items stem was: During the past 4 weeks did you experience each of the following? If so, how much physical fatigue did each cause you?

Table 5.6. Mental Fatigability Item Response Theory Parameters

ItemID	Item Content	Slope	Threshold 1	Threshold 2	Threshold 3
Health Challenges					
MF Hlth1	Sleep problems	0.86	-3.24	-0.11	1.57
MF Hlth2	Pain	0.89	-3.34	-0.22	1.34
MF Hlth5	Poor posture	0.38	-3.75	2.12	3.47
MF Hlth7	Stress	1.01	-2.34	-0.28	1.52
MF Hlth8	Medication side-effects	0.48	-3.35	1.71	3.81
Daily Living Challenges					
MF Home1	Wheelchair transfer to and from bed	1.52	-0.32	1.29	2.45
MF Home2	Sitting in a wheelchair for an hour or more	1.65	-0.25	1.31	1.93
MF Home5	Wheelchair use around the home	2.07	-0.01	1.08	1.94
MF Home6	Spending all day in your wheelchair	1.35	-1.19	0.61	1.57
MF Home7	Pressure management (preventing pressure sores)	1.32	-0.41	1.92	3.32
MF Home8	Posture management	1.53	-0.19	1.56	2.81
MF Home9	Household chores, such as cleaning and tidying	2.22	-0.78	0.72	1.67
MF Home10	Preparing and clearing away a meal	2.25	-0.41	0.94	1.99
MF Home11	Eating a meal	2.53	0.52	1.77	2.71
MF Envr1	Lack of peace and quiet	0.42	-2.72	2.56	3.74
MF Envr2	Inadequately adapted home	0.85	-2.06	1.42	2.63
MF Envr3	Inadequate medical care when at home	0.62	-1.95	2.48	3.81
Concentration Challenges					

MF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	1.85	-0.70	0.57	1.93
MF Home4	Using a computer for an hour or more	1.62	-0.46	0.66	2.66
MF Home12	Letter-writing, form filling or paying bills	1.24	-0.44	1.51	2.81
Access Challenges					
MF Away1	Wheelchair use over a smooth surface	1.70	0.72	1.95	3.92
MF Away2	Wheelchair use over an uneven surface	2.02	-0.44	0.86	1.95
MF Away3	Wheelchair transfer to and from car	1.78	-0.66	1.32	1.96
MF Away4	Traveling in your vehicle for an hour or more	2.44	-0.56	0.68	1.53
MF Away5	Using an adapted taxi	1.49	-2.47	2.60	3.01
MF Away6	Using a bus	2.11	-2.46	2.40	2.61
MF Away7	Using a train	2.66	-2.85	2.17	2.40
MF Away9	Going to a doctor's appointment	1.87	-1.01	1.16	2.07
MF Away10	Shopping, such as having access and reaching merchandise	3.10	-0.54	0.60	1.41
MFAway11	Going out to a restaurant	3.36	-0.12	1.16	1.61
MF Away12	Attending an event, such as cinema, theater, or a show	2.51	-0.69	1.14	1.59
MF Away13	Visiting friends	2.59	-0.64	1.21	2.13
MF Away14	Attending a sporting event	1.80	-1.57	1.52	2.31
MF Away15	Taking a day trip away from home	3.08	-1.03	0.69	1.35
MF Away16	Taking an overnight trip away from home	2.59	-1.44	0.72	1.18
MF Away17	Taking a vacation away from home	1.48	-2.64	1.37	2.02

Abbreviations: Mental Fatigue (MF). Items stem was: During the past 4 weeks did you experience each of the following? If so, how much mental fatigue did each cause you?

Table 5.7. Chi-square and wABC values for physical fatigability items with significant DIF by sex and diagnosis

Comparison	Item	wABC	Chi-square	p-value
Sex	PFHome1	0.10	24.2	0.0001
Sex	PFHome9	0.14	22.1	0.0002
Sex	PFHome10	0.08	17.5	0.0015
Sex	PFHome3	0.05	14	0.0012
Sex	PFHome6	0.10	17.8	0.0013
Sex	PFaway1	0.22	25.7	0.0001
Sex	PFAway3	0.13	15.2	0.0043
Sex	PFAway10	0.08	13.3	0.0100
Sex	PFAway15	0.08	21.8	0.0002
Diagnosis	PFHlth6	0.16	24.1	0.0001
Diagnosis	PFEnvr2	0.19	29.3	0.0001
Diagnosis	PFHome2	0.13	16.9	0.0021
Diagnosis	PFHome3	0.21	32.7	0.0001
Diagnosis	PFHome8	0.15	27	0.0019
Diagnosis	PFAway3	0.10	16.3	0.0027
Diagnosis	PFAway4	0.09	23	0.0001
Diagnosis	PFAway6	0.17	18.6	0.0009
Diagnosis	PFAway13	0.07	18.9	0.0033
Diagnosis	PFAway16	**0.28**	20.5	0.0004

Abbreviations: Weighted area between the curves (wABC).

Table 5.8. Chi-square and wABC values for mental fatigability items with significant DIF by sex and diagnosis

Comparison	**Item**	**wABC**	**Chi-square**	**p-value**
Sex	MFHlth1	0.09	15.1	0.0062
Sex	MFHome8	0.06	14.4	0.0011
Sex	MFEnvr2	0.07	18.3	0.0092
Sex	MFAway14	0.07	15	0.0047
Sex	MFAway15	0.06	15.1	0.0045
Diagnosis	MFHlth1	0.12	16.1	0.0029
Diagnosis	MFHlth5	**0.31**	39.1	0.0001
Diagnosis	MFHlth7	0.10	13.8	0.0079
Diagnosis	MFHome8	0.14	21.6	0.0002
Diagnosis	MFEnvr3	0.10	17	0.0001
Diagnosis	MFAway16	0.10	24.4	0.0001

Abbreviations: Weighted area between the curves (wABC).

Supplemental Table 1.

Mean, median, standard deviation, and range of item readability scores

Scale	Score	Mean	(95% CI)	SD	Median	Range
Physical Fatigability						
	F-K without answers	6.11	(5.9-6.4)	0.83	6.17	4.84-8.02
	FRE without answers	67.38	(65.6-69.1)	5.71	67.44	52.86-76.27
Mental Fatigability						
	F-K without answers	5.67	(5.4-5.9)	0.84	5.75	4.33-7.59
	FRE without answers	70.5	(68.8-72.3)	5.72	70.46	56.25-79

Abbreviations: F-K (Flesch-Kincaid grade level score); FRE (Flesch Reading Ease score); CI (Confidence interval); SD (standard deviation). Reading difficulty: Very easy (FRE 90-100; F-K 5th grade); Easy (FRE 80-90; F-K 6th grade); Fairly easy (FRE 70-80; F-K 7th grade); Standard (FRE 60-70; F-K 8th-9th grade); Fairly difficult (FRE 50-60; F-K 10th-12th grade); Difficult (FRE 30-50; F-K 13th-16th grade); Very difficult (FRE 0-30; F-K > College graduate).

Supplemental Table 2. Physical Fatigability Four Factor Categorical Analysis Standardized Factor Loadings

Scale	Item Content	Standardized factor loadings* (SE)		R^2
Health Challenges				
PF Hlth1	Sleep problems	0.635	(0.046)	0.404
PF Hlth2	Pain	0.392	(0.033)	0.213
PF Hlth3	Indigestion problems	0.638	(0.047)	0.406
PF Hlth4	Dehydration problems	0.701	(0.044)	0.491
PF Hlth6	Spasticity	0.569	(0.046)	0.323
PF Hlth7	Stress	0.422	(0.053)	0.178
PF Hlth8	Medication side-effects	0.504	(0.046)	0.254
Daily Living Challenges				
PF Home1	Wheelchair transfer to and from bed	0.493	(0.036)	0.243
PF Home5	Wheelchair use around the home	0.819	(0.021)	0.671
PF Home9	Household chores, such as cleaning and tidying	0.693	(0.026)	0.480
PF Home10	Preparing and clearing away a meal	0.530	(0.038)	0.281
PF Home11	Eating a meal	0.598	(0.032)	0.358
PF Envr1	Lack of peace and quiet	0.453	(0.039)	0.205
PF Envr2	Inadequately adapted home	0.603	(0.035)	0.363
PF Envr3	Inadequate medical care when at home	0.385	(0.039)	0.148
PF Envr4	Inadequate non-medical care when at home	0.378	(0.043)	0.143
PF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	0.608	(0.032)	0.369
PF Home4	Using a computer for an hour or more	0.585	(0.032)	0.342

PF Home12	Letter-writing, form filling or paying bills	0.706	(0.031)	0.498
Seating Challenges				
PF Home2	Sitting in a wheelchair for an hour or more	0.570	(0.042)	0.325
PF_Hlth5	Poor posture	0.709	(0.039)	0.503
PF Home6	Spending all day in your wheelchair	0.948	(0.015)	0.898
PF Home7	Pressure management (preventing pressure sores)	0.881	(0.017)	0.776
PF Home8	Posture management	0.887	(0.033)	0.787
Access Challenges				
PF Away1	Wheelchair use over a smooth surface	0.818	(0.018)	0.669
PF Away2	Wheelchair use over an uneven surface	0.827	(0.027)	0.684
PF Away3	Wheelchair transfer to and from car	0.642	(0.031)	0.412
PF Away4	Traveling in your vehicle for an hour or more	0.723	(0.025)	0.523
PF Away5	Using an adapted taxi	0.726	(0.024)	0.527
PF Away6	Using a bus	0.671	(0.025)	0.451
PF Away7	Using a train	0.676	(0.027)	0.457
PF Away9	Going to a doctor's appointment	0.959	(0.017)	0.920
PF Away10	Shopping, such as having access and reaching merchandise	0.958	(0.015)	0.918
PF Away12	Attending an event, such as cinema, theater, or a show	0.640	(0.027)	0.410
PF Away13	Visiting friends	0.767	(0.021)	0.588
PF Away14	Attending a sporting event	0.866	(0.020)	0.749
PF Away15	Taking a day trip away from home	0.821	(0.017)	0.674
PF Away16	Taking an overnight trip away from home	0.794	(0.022)	0.631

PF Away17	Taking a vacation away from home	0.653	(0.034)	0.427

RMSEA = 0.081

RMSEA CI = [0.079 - 0.090]

CFI = 0.922

TFI = 0.940

* Statistically significant P < 0.0001

Abbreviations: Physical Fatigue (PF); Standard Error (SE); Root Mean Square Error of Approximation (RMSEA); Confidence Interval (CI); Comparative Fit Index (CFI); Tucker-Lewis Index (TLI). Note: For adequate model fit, RMSEA < 0.08; CFI > 0.95; TLI > 0.95.

Items stem was: During the past 4 weeks did you experience each of the following? If so, how much physical fatigue did each cause you?

Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Supplemental Table 3. Mental Fatigability Four Factor Categorical Analysis Standardized Factor Loadings

Scale	Item Content	Standardized factor loadings* (SE)		R^2
Health Challenges				
MF Hlth1	Sleep problems	0.627	0.041	0.393
MF Hlth2	Pain	0.787	0.036	0.619
MF Hlth5	Poor posture	0.744	0.036	0.554
MF Hlth7	Stress	0.347	0.066	0.135
MF Hlth8	Medication side-effects	0.383	0.049	0.147
Daily Living Challenges				
MF Home1	Wheelchair transfer to and from bed	0.786	0.020	0.617
MF Home2	Sitting in a wheelchair for an hour or more	0.771	0.031	0.594
MF Home5	Wheelchair use around the home	0.841	0.018	0.707
MF Home6	Spending all day in your wheelchair	0.832	0.019	0.693
MF Home7	Pressure management (preventing pressure sores)	0.794	0.020	0.631
MF Home8	Posture management	0.886	0.015	0.784
MF Home9	Household chores, such as cleaning and tidying	0.789	0.021	0.623
MF Home10	Preparing and clearing away a meal	0.753	0.021	0.567
MF Home11	Eating a meal	0.806	0.020	0.649
MF Envr1	Lack of peace and quiet	0.549	0.037	0.302
MF Envr2	Inadequately adapted home	0.644	0.032	0.415
MF Envr3	Inadequate medical care when at home	0.568	0.034	0.322
Concentration Challenges				

MF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	0.573	0.036	0.328
MF Home4	Using a computer for an hour or more	0.719	0.026	0.517
MF Home12	Letter-writing, form filling or paying bills	0.775	0.024	0.600
Access Challenges				
MF Away1	Wheelchair use over a smooth surface	0.769	0.021	0.591
MF Away2	Wheelchair use over an uneven surface	0.794	0.020	0.630
MF Away3	Wheelchair transfer to and from car	0.680	0.021	0.462
MF Away4	Traveling in your vehicle for an hour or more	0.803	0.027	0.645
MF Away5	Using an adapted taxi	0.787	0.02	0.619
MF Away6	Using a bus	0.739	0.025	0.546
MF Away7	Using a train	0.823	0.02	0.677
MF Away9	Going to a doctor's appointment	0.819	0.037	0.671
MF Away10	Shopping, such as having access and reaching merchandise	0.941	0.043	0.886
MFAway11	Going out to a restaurant	0.581	0.042	0.337
MF Away12	Attending an event, such as cinema, theater, or a show	0.767	0.020	0.588
MF Away13	Visiting friends	0.888	0.013	0.788
MF Away14	Attending a sporting event	0.920	0.016	0.847
MF Away15	Taking a day trip away from home	0.861	0.013	0.741
MF Away16	Taking an overnight trip away from home	0.816	0.018	0.665
MF Away17	Taking a vacation away from home	0.724	0.024	0.524

RMSEA = 0.088

RMSEA CI = [0.085 - 0.091]

CFI = 0.888

TFI = 0.901

* Statistically significant P < 0.0001

Abbreviations: Mental Fatigue (MF); Standard Error (SE); Root Mean Square Error of Approximation (RMSEA); Confidence Interval (CI); Comparative Fit Index (CFI); Tucker-Lewis Index (TLI). Note: For good model fit, RMSEA < 0.08; CFI > 0.95; TLI > 0.95.

Items stem was: During the past 4 weeks did you experience each of the following? If so, how much mental fatigue did each cause you?

Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Supplemental Table 4. Physical Fatigability Item means (SD), item-total correlations, and coefficient alphas, by subscale

Scale	Item Content	Mean	(SD)	Item-total correlation	Coefficient alpha
Health Challenges					
PF Hlth1	Sleep problems	1.72	(0.885)	0.385	0.743
PF Hlth2	Pain	1.85	(0.905)	0.652	
PF Hlth3	Indigestion problems	1.14	(0.815)	0.392	
PF Hlth4	Dehydration problems	0.87	(0.474)	0.377	
PF Hlth6	Spasticity	1.32	(0.937)	0.528	
PF Hlth7	Stress	1.46	(0.926)	0.500	
PF Hlth8	Medication side-effects	1.34	(0.825)	0.462	
Daily Living Challenges					
PF Home1	Wheelchair transfer to and from bed	1.11	(0.852)	0.536	0.846
PF Home5	Wheelchair use around the home	0.84	(0.851)	0.635	
PF Home9	Household chores, such as cleaning and tidying	1.45	(0.835)	0.474	
PF Home10	Preparing and clearing away a meal	1.15	(0.796)	0.628	
PF Home11	Eating a meal	0.43	(0.669)	0.572	
PF Envr1	Lack of peace and quiet	0.99	(0.686)	0.381	
PF Envr2	Inadequately adapted home	1.24	(0.841)	0.502	
PF Envr3	Inadequate medical care when at home	0.94	(0.679)	0.546	
PF Envr4	Inadequate non-medical care when at home	1.08	(0.742)	0.479	

PF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	1.03	(0.916)	0.539	
PF Home4	Using a computer for an hour or more	1.12	(0.869)	0.493	
PF Home12	Letter-writing, form filling or paying bills	0.75	(0.720)	0.466	
Seating Challenges					
PF Home2	Sitting in a wheelchair for an hour or more	1.1	(0.896)	0.634	0.758
PF_Hlth5	Poor posture	1.08	(0.798)	0.398	
PF Home6	Spending all day in your wheelchair	1.77	(0.936)	0.615	
PF Home7	Pressure management (preventing pressure sores)	0.75	(0.703)	0.441	
PF Home8	Posture management	0.98	(0.799)	0.548	
Access Challenges					
PF Away1	Wheelchair use over a smooth surface	0.69	(0.804)	0.658	0.907
PF Away2	Wheelchair use over an uneven surface	1.52	(1.003)	0.678	
PF Away3	Wheelchair transfer to and from car	1.12	(0.867)	0.569	
PF Away4	Traveling in your vehicle for an hour or more	1.34	(0.910)	0.542	
PF Away5	Using an adapted taxi	1.09	(0.400)	0.457	
PF Away6	Using a bus	1.05	(0.385)	0.445	
PF Away7	Using a train	1.06	(0.375)	0.457	
PF Away9	Going to a doctor's appointment	1.09	(0.745)	0.534	
PF Away10	Shopping, such as having access and reaching merchandise	1.21	(0.945)	0.669	
PF Away12	Attending an event, such as cinema, theater, or a show	1.07	(0.745)	0.713	

PF Away13	Visiting friends	1.11	(0.807)	0.672
PF Away14	Attending a sporting event	1.12	(0.650)	0.569
PF Away15	Taking a day trip away from home	1.39	(0.819)	0.709
PF Away16	Taking an overnight trip away from home	1.57	(0.823)	0.661
PF Away17	Taking a vacation away from home	1.38	(0.769)	0.437

Abbreviations: Physical Fatigue (PF); Standard Error (SE). Note: Item-total correlations were corrected for item overlap. Item names indicate the initial four categories in which they were grouped when the survey was administered (Hlth, for health issues; Home, for activities at home;

Envr, environmental issues, and Away, for activities away from home). Items stem was: During the past 4 weeks did you experience each of the following? If so, how much physical fatigue did each cause you? Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Supplemental Table 5. Mental Fatigability Item means (SD), item-total correlations, and coefficient alphas, by subscale

Scale	Item Content	Mean	(SD)	Item-total correlation	Coefficient alpha
Health Challenges					
MF Hlth1	Sleep problems	1.68	(0.916)	0.438	0.788
MF Hlth2	Pain	1.75	(0.921)	0.698	
MF Hlth5	Poor posture	0.98	(0.632)	0.363	
MF Hlth7	Stress	1.65	(0.946)	0.580	
MF Hlth8	Medication side-effects	1.27	(0.920)	0.409	
Daily Living Challenges					
MF Home1	Wheelchair transfer to and from bed	0.82	(0.861)	0.621	0.895
MF Home2	Sitting in a wheelchair for an hour or more	0.85	(0.949)	0.736	
MF Home5	Wheelchair use around the home	0.74	(0.914)	0.797	
MF Home6	Spending all day in your wheelchair	1.28	(0.995)	0.644	
MF Home7	Pressure management (preventing pressure sores)	0.73	(0.735)	0.613	
MF Home8	Posture management	0.72	(0.794)	0.740	
MF Home9	Household chores, such as cleaning and tidying	1.10	(0.898)	0.631	
MF Home10	Preparing and clearing away a meal	0.89	(0.877)	0.667	
MF Home11	Eating a meal	0.41	(0.668)	0.685	
MF Envr1	Lack of peace and quiet	1.00	(0.790)	0.389	
MF Envr2	Inadequately adapted home	1.20	(0.876)	0.498	

MF Envr3	Inadequate medical care when at home	0.98	(0.772)	0.494	
Concentration Challenges					
MF Home3	Concentrating for an hour or more (such as reading, writing, or holding a conversation)	1.14	(0.938)	0.785	0.814
MF Home4	Using a computer for an hour or more	0.99	(0.902)	0.685	
MF Home12	Letter-writing, form filling or paying bills	0.84	(0.836)	0.542	
Access Challenges					
MF Away1	Wheelchair use over a smooth surface	0.38	(0.640)	0.544	0.931
MF Away2	Wheelchair use over an uneven surface	0.96	(0.915)	0.712	
MF Away3	Wheelchair transfer to and from car	0.92	(0.852)	0.627	
MF Away4	Traveling in your vehicle for an hour or more	1.07	(0.961)	0.729	
MF Away5	Using an adapted taxi	1.02	(0.440)	0.500	
MF Away6	Using a bus	1.03	(0.387)	0.501	
MF Away7	Using a train	1.06	(0.358)	0.506	
MF Away9	Going to a doctor's appointment	1.02	(0.792)	0.698	
MF Away10	Shopping, such as having access and reaching merchandise	1.08	(0.967)	0.808	
MFAway11	Going out to a restaurant	0.75	(0.879)	0.778	
MF Away12	Attending an event, such as cinema, theater, or a show	0.97	(0.860)	0.788	
MF Away13	Visiting friends	0.90	(0.760)	0.711	
MF Away14	Attending a sporting event	1.05	(0.625)	0.558	
MF Away15	Taking a day trip away from home	1.21	(0.878)	0.784	

MF Away16	Taking an overnight trip away from home	1.30	(0.862)	0.766
MF Away17	Taking a vacation away from home	1.22	(0.660)	0.439

Abbreviations: Mental Fatigue (MF); Standard Error (SE). Note: Item-total correlations were corrected for item overlap. Item names indicate the initial four categories in which they were grouped when the survey was administered (Hlth, for health issues; Home, for activities at home; Envr, environmental issues, and Away, for activities away from home). Items stem was: During the past 4 weeks did you experience each of the following? If so, how much mental fatigue did each cause you? Answer options: No fatigue (0); Mild fatigue (1); Moderate fatigue (2); Extreme fatigue (4).

Supplemental Table 6. Physical Fatigability scale means (SD) by validity variables: F statistic (p value)

Scale		Complete Paraplegia	Incomplete Paraplegia	Complete Quadriplegia	Incomplete Quadriplegia	Paraplegia	Quadriplegia
Health challenges	Means (SD)	9.37 (4.13)	11.18 (3.34)	7.91 (3.40)	9.22 (3.01)	10.31 (3.85)	8.70 (3.23)
	F (p)	1.56 (0.212)	38.03 (0.0001)	19.96 (0.0001)	2.27 (0.1325)	21.45 (0.0001)	
Seating challenges	Means (SD)	5.85 (2.76)	6.35 (3.60)	5.25 (1.55)	4.83 (2.77)	6.10 (3.19)	5.01 (2.37)
	F (p)	0.76 (0.3850)	10.52 (0.0013)	1.73 (0.1892)	11.48 (0.0008)	15.43 (0.0001)	
Daily living challenges	Means (SD)	12.10 (5.92)	14.57 (5.78)	10.04 (4.16)	10.06 (5.26)	13.38 (5.97)	10.05 (4.84)
	F (p)	0.17 (0.673)	43.01 (0.0001)	10.82 (0.0011)	17.90 (0.0001)	38.90 (0.0001)	
Access challenges	Means (SD)	16.90 (7.89)	21.37 (7.76)	16.07 (4.24)	15.14 (5.49)	19.21 (8.12)	15.51 (5.04)
	F (p)	3.04 (0.0817)	58.24 (0.0001)	4.68 (0.0309)	18.94 (0.0001)	29.66 (0.0001)	

Note: We hypothesized that means were higher for those who reported having paraplegia vs quadriplegia, and for those with incomplete paraplegia.

Supplemental Table 7. Mental Fatigability scale means (SD) by validity variables: F statistic (p value)

Scale		Complete Paraplegia	Incomplete Paraplegia	Complete Quadriplegia	Incomplete Quadriplegia	Paraplegia	Quadriplegia
Health challenges	Means (SD)	7.51 (3.07)	8.67 (3.08)	5.7 (2.38)	6.30 (2.49)	8.11 (3.12)	6.06 (2.46)
	F (p)	0.66 (0.4162)	46.02 (0.0001)	24.74 (0.0001)	16.16 (0.0001)	54.69 (0.0001)	
Concentration challenges	Means (SD)	2.73 (2.21)	3.69 (2.48)	2.92 (1.83)	2.26 (2.09)	3.22 (2.40)	2.52 (2.01)
	F (p)	2.00 (0.1577)	23.30 (0.0001)	0.02 (0.8903)	13.18 (0.0003)	10.46 (0.0013)	
Daily living challenges	Means (SD)	11.02 (7.55)	12.80 (7.79)	9.15 (3.44)	8.46 (5.51)	11.94 (7.71)	8.73 (4.80)
	F (p)	0.35 (0.5519)	20.54 (0.0001)	4.27 (0.0394)	15.13 (0.0001)	24.56 (0.0001)	
Access challenges	Means (SD)	13.78 (7.79)	21.30 (9.70)	14.27 (5.77)	12.39 (5.35)	17.67 (9.58)	13.14 (5.58)
	F (p)	13.03 (0.0003)	64.27 (0.0001)	3.19 (0.0748)	24.85 (0.0001)	32.55 (0.0001)	

Note: We hypothesized that means were higher for those who reported having paraplegia vs quadriplegia, and for those with incomplete paraplegia.

5.8. Figures

Figure 5.1. Overview of survey development and testing approach.

1. Conducted Literature Review

We identified areas of interest to fatigue in the context of SCI (e.g., causes, risk factors, impact on quality of life).

2. Identified Existing Fatigue and Fatigability Measures

We ascertained their strengths, weaknesses, and relevance to spinal cord injury (SCI).

3. Conducted In-depth Interviews

We identified activities (of different duration and intensity) and risk factors that make adults with SCI vulnerable to fatigue. We also consulted rehabilitation and seating experts, and a wheelchair tennis coach.

4. Drafted Instrument Items

We drafted items to assess Physical Fatigability and Mental Fatigability.

5. Conducted Cognitive Interviews

We conducted 8 cognitive interviews between December 2016 and January 2017 by phone. Interviewees represented all 4 injury types (complete and incomplete, paraplegia and quadriplegia). After 3 interviews and expert review the order and phrasing of several items were changed, 2 new items were written and added (one to the health symptom list and one to the demographic survey). After 2 more interviews and expert review we added a *"Did not have this"* or *"Did not do this"* response option for all questions. The last 3 interviews resulted in no changes.

6. Evaluated Readability

None of the items fell in the "fairly difficult", "difficult", or "very difficult" categories of the Flesch-Kincaid scale. Supplemental Table 1 shows mean, median, standard deviation, and range of item readability scores. Supplemental Figure 1 shows the F-K scores by item.

7. Conducted Field Test and Completed Psychometric Analyses

The final sample size was 464, recruited from across the United States.

Figure 5.2. **Physical and Mental Fatigability Test Information and Standard Error**

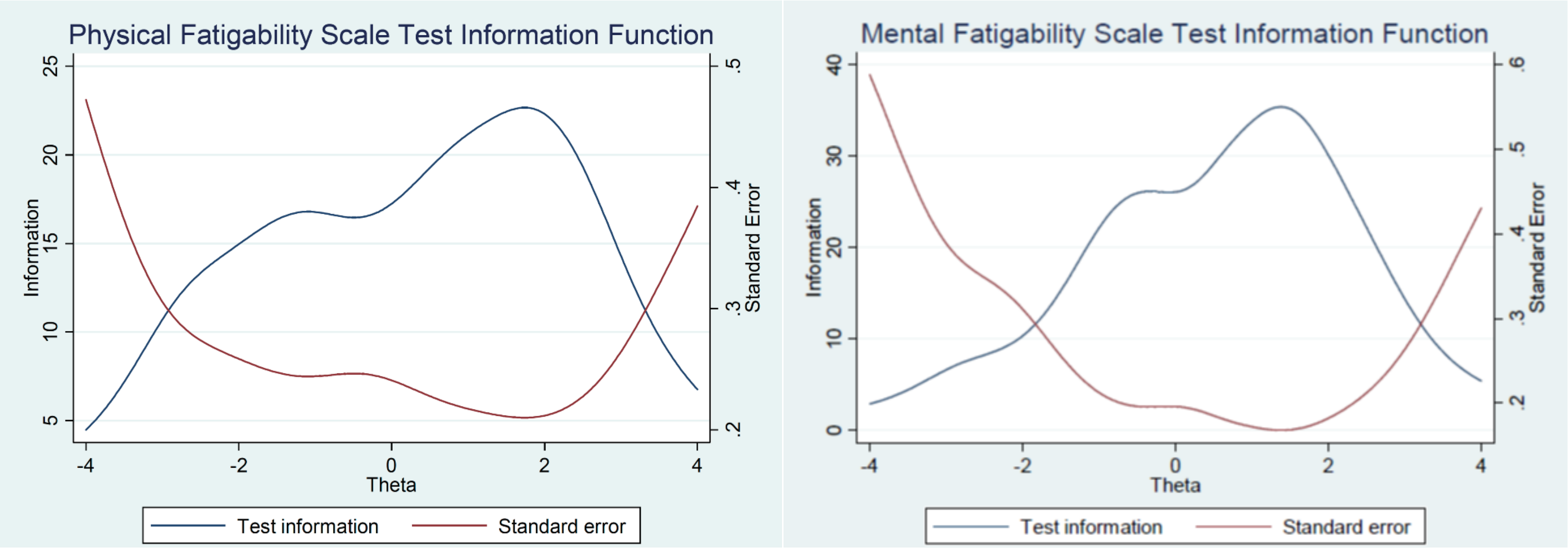
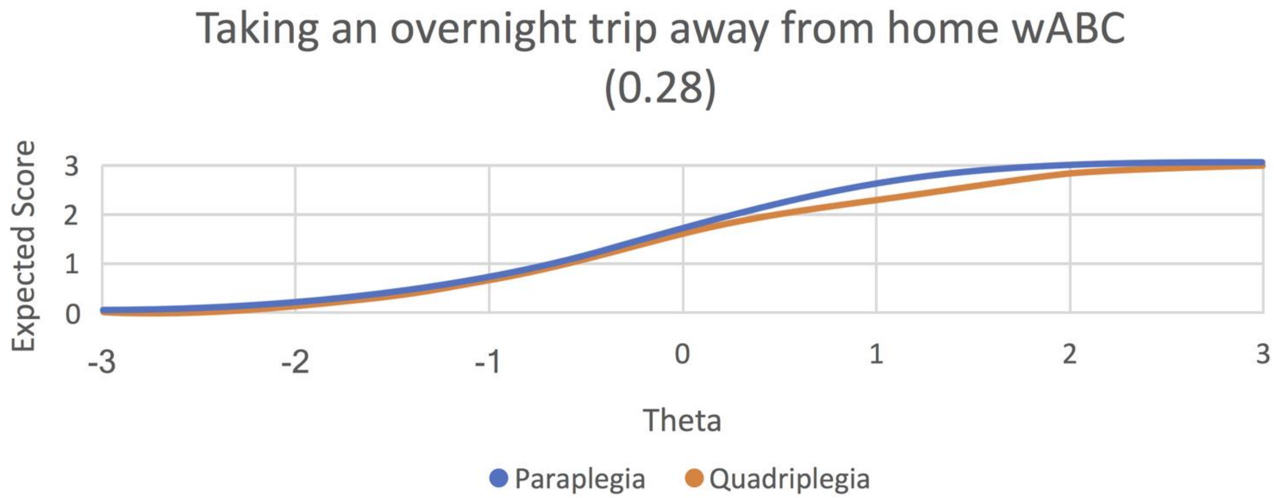


Figure 5.3. Graphical Representation of Differential Item Functioning Effect Size


Taking an overnight trip away from home wABC (0.28)

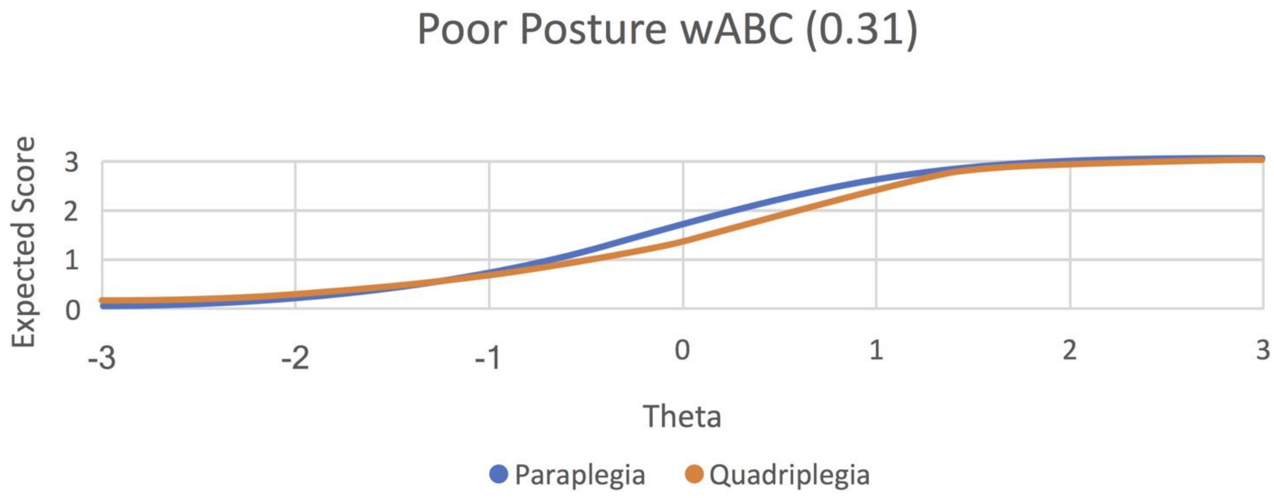
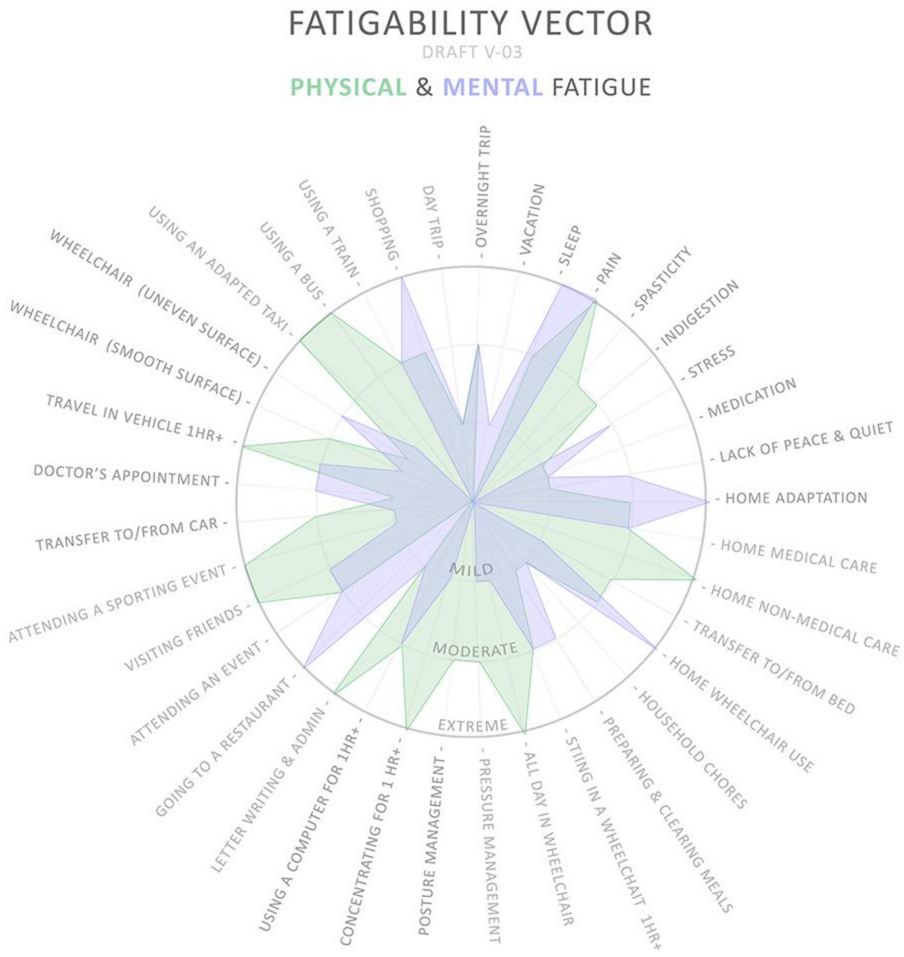
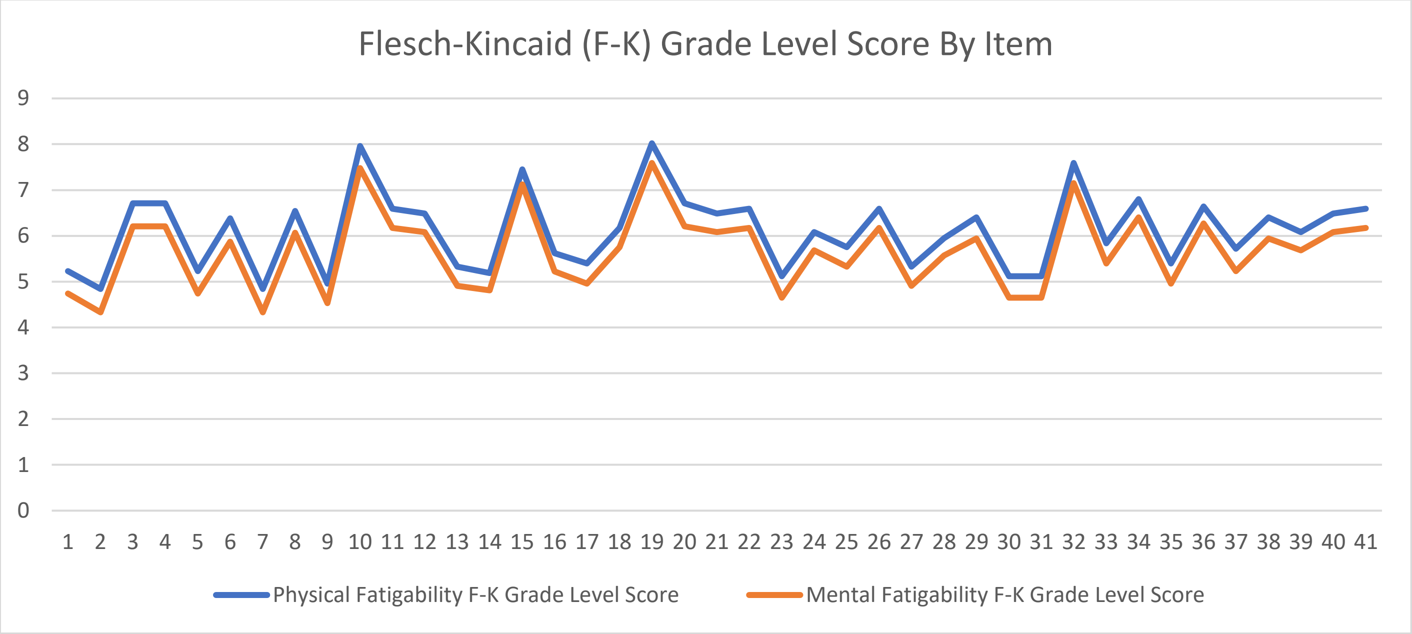

Poor Posture wABC (0.31)

Figure 5.4. Combined Physical and Mental Fatigability Vector



Supplemental Figure 1. Flesch-Kincaid (F-K) Grade Level Score By Item, Physical and Mental Fatigability Scales.



5.9. References

Anton, H. A., Miller, W. C., & Townson, A. F. (2008). Measuring Fatigue in Persons with Spinal Cord Injury. *Arch Phys Med Rehabil*, 538-542.

Benjamini, Y., & Hochberg, Y. (1995). Controlling the false discovery rate: a practical and powerful approach to multiple testing. *Journal of the Royal Statistical Society, 57*(1), 289-300.

Brown, T. A. (2006). *Confirmatory Factor Analysis for Applied Research.* New York, New York: The Guilford Press.

Charlifue, S., Weitzenkamp, D., & Whiteneck, G. (1999). Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. *Arch Phys Med Rehabil*, 1429-1434.

Edelen, M. O., Stucky, B. D., & Chandra, A. (2015). Quantifying 'problematic' DIF within an IRT framework: application to a cancer stigma index. *Quality of Life Research, 24*, 95-103.

Elliott, T. (1996). Depression following spinal cord injury. *Arch Phys Med Rehabil*, 816-823.

Embretson, S. E., & Reise, S. P. (2000). *Item Response Theory for Psychologists.* Mahwah, New Jersey: Lawrence Erlbaum Associates.

Gerhart, K., Bergstrom, E., Charlifue, S., Menter, R., & Whiteneck, G. (1993). Long-term spinal cord injury: functional changes over time . *Arch Phys Med Rehabil*, 1030-1034.

Glynn, N., Santanasto, A., Simonsick, E., Boudreau, R., Beach, S., Schulz, R., & Newman, A. (2015). The Pittsburgh Fatigability Scale for Older Adults: Development and Validation. *J Am Geriatr*, 130-135.

Hammell, K. W., Miller, W. C., Forwell, S. J., Forman, B. E., & Jacobsen, B. A. (2009).

Managing fatigue following spinal cord injury: A qualitative exploration. *Disability and Rehabilitation*, *31*(17), 1437-1445.

Hays, R. D., Morales, L. S., & Reise, S. P. (2000). Item Response Theory and health outcomes measurement in the 21st century. *Medical Care, 9 Suppl*, II28 - II42.

Hays, R. D., & Revicki, D. (2005). Reliability and Validity (Including Responsiveness). In P. Fayers, & R. D. Hays, *Assessing Quality of Life in Clinical Trials 2nd Edition* (pp. 25-39). Oxford: Oxford University Press.

Hays, R. D., Kim, S., Spritzer, K. L., Kaplan, R. M., Tally, S., Feeny, D., . . . Fryback, D. G. (2009). Effects of mode and order of administration on generic health-related quality of life scores. *Value in Health*, 1035-1039.

Hays, R. D., & Reeve, B. B. (2010). Measurement and modeling of health-related quality of life. In J. Killewo, H. K. Heggenhougen, & S. R. Quah, *Epidemiology and demography in public health* (pp. 195-205). San Diego: Elsevier.

Hirsch, G., Menard, M., & Anton, H. (1991). Anemia in Spinal Cord Injury. *Arch Phys Med Rehabil*, 195-201.

Hughes, R., Swedlund, N., Petersen, N., & Nosek, M. (2001). Depression and Women with Spinal Cord Injury. *Topics in SCI Rehabilitation*, 16-24.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, D.C.: Author.

Jackson, D. L., Gillaspy, J. A., & Purc-Stephenson, R. (2009). Reporting practices in confirmatory factor analysis: an overview and some recommendations. *Psychological Methods, 14*(1), 6-23.

Jette, A. M., Slavin, M. D., Ni, P., Kisala, P. A., Tulsky, D. S., Heinemann, A. W., . . . Williams,

S. (2015). Development and initial evaluation of the SCI-FI/AT. *The Journal of Spinal Cord Medicine, 38*(3), 409-418.

Lara, M., Edelen, M. O., Eberhart, N. K., Stucky, B. D., & Sherbourne, C. D. (2014). Development and validation of the RAND Asthma Control Measure. *European Respiratory Journal*, *44*, 1243-1252.

Marshall, G. N., Morales, L. S., Elliott, M., Spritzer, K., & Hays, R. D. (2001). Confirmatory factor analysis of the Consumer Assessment of Health Plans Study (CAHPS) 1.0 Core Survey. *Psychological Assessment*, *13*(2), 216-229.

McColl, M., Arnold, R., Charlifue, S., Glass, C., Savic, G., & Frankel, H. (2003). Aging, spinal cord injury, and quality of life: structural relationships. *Arch Phys Med Rehabil*, 1137-1144.

McHorney, C. A., Kosinski, M., & Ware, J. E. (1994). Comparisons of the costs and quality of norms for the SF-36 health survey collected by mail versus telephone interview: results from a national survey. *Medical Care*, 551-567.

Murphy, S. L., Alexander, N., Levoska, M., & Smith, D. (2013). The Relationship between Fatigue and Subsequent Physical Activity among Older Adults with Symptomatic Osteoarthritis. *Arthritis Care Res*, 1617–1624.

Muthén, L. a. (2015). *Mplus User’s Guide* (Vol. Seventh Edition). Los Angeles, CA: Muthén & Muthén.

NSCISC. (2016, May 27). SCI facts and figures at a glance. Retrieved from https://www.nscisc.uab.edu/Public/Facts%202016.pdf

National Institutes of Health. (2015, September 16). *Development of Measures of Fatigability in*

Older Adults (R21) . Retrieved from RFA Section I Funding: http://grants.nih.gov/grants/guide/rfa-files/RFA-AG-16-013.html#_Section_I._Funding

Palimaru, A., Cunningham, W. E., Dillistone, M., Vargas-Bustamante, A., Liu, H., & Hays, R. D. (2017). A comparison of perceptions of quality of life among adults with spinal cord injury in the United States versus the United Kingdom. *Quality of Life Research, 26*(11), 3143–3155.

Reeve, B. B., Hays, R. D., Bjorner, J. B., Cook, K. F., Crane, P. K., Teresi, J. A., . . . Cella, D. (2007). Psychometric evaluation and calibration of health-related quality of life item banks: plans for the patient-reported outcome measurement information system (PROMIS). *Medical Care, 45,* S22-31.

Reeve, B. B., Wyrwich, K. W., Wu, A. W., Velikova, G., Terwee, C. B., Synder, C. F., . . . Butt, Z. (2013). ISOQOL recommends minimum standards for patient-reported outcome measures used in patient-centered outcomes and comparative effectiveness research. *Quality of Life Research, 22,* 1889-1905.

Reise, S. P., Morizot, J., & Hays, R. D. (2007). The role of the bifactor model in resolving dimensionality issues in health outcomes measures. *Quality of Life Research, 16,* 19-31. Reise, S. P., Scheines, R., Widaman, K., & Haviland, M. (2013). Multidimensionality and structural coefficient bias in structural equation modeling: a bifactor perspective. *Educational and Psychological Measurement, 73*(1), 5-26.

Richardson, C. A., Glynn, N. W., Ferrucci, L. G., & Mackey, D. C. (2015). Walking Energetics, Fatigability, and Fatigue in Older Adults: The Study of Energy and Aging Pilot. *J Gerontol A Biol Sci Med Sci,* 487-494.

SAS Institute Inc (2013). SAS/ACCESS® 9.4 Interface to ADABAS: Reference. Cary, NC: SAS

Institute Inc.

Schnelle, J., Buchowski, M., Ikizler, T., Durkin, D., Beuscher, L., & Simmons, S. (2012). Evaluation of Two Fatigability Severity Measures in Elderly Adults. *Journal of the American Geriatrics Society*, 1527-1533.

StataCorp. (2015). Stata Statistical Software: Release 14. College Station, TX: StataCorp LP.

Streeten, D., & Anderson, G. (1998). The role of delayed orthostatic hypotension in the pathogenesis of chronic fatigue. *Clin Autonomic Research*, 119-124.

Stucky, B. D., Edelen, M. O., Vaughan, C. A., Tucker, J. S., & Butler, J. (2014). The psychometric development and initial validation of the DCI-A short form for adolescent therapeutic community treatment process. *Journal of Substance Abuse Treatment, 46*, 516-521.

Tiesinga, L., Dassen, T., & Halfens, R. (1998). DUFS and DEFS: Development, reliability and validity of the Dutch Fatigue Scale and the Dutch Exertion Fatigue Scale. *International Journal of Nursing Studies*, 115-123.

Tulsky, D. S., Kisala, P. A., Tate, D. G., Spungen, A. M., & Kirshblum, S. C. (2015). Development and psychometric characteristics of the SCI-QOL Bladder Management Difficulties and Bowel Management Difficulties item banks and short forms and the SCI-QOL Bladder Complications scale. *The Journal of Spinal Cord Medicine, 38*(3), 288-302.

Wellman, R. J., Edelen, M. O., & DiFranza, J. R. (2015). Item Response Theory analysis of the Autonomy over Tobacco Scale (AUTOS). *Addictive Behaviors, 45*, 195-200.

Widerstrom-Noga, E., Felipe-Cuervo, E., & Yezierski, R. (2001). Chronic pain after spinal cord injury: Interference with sleep and daily activities. *Arch Phys Med Rehabil*, 1571-1577.

Yang, C., & Wu, C. (2005). The Situational Fatigue Scale: A different approach to measuring fatigue. *Quality of Life Research*, 1357-1362.

CHAPTER 6

CONCLUSIONS

6.1. Conclusions

This dissertation contributes to the scholarship on health outcomes among individuals with spinal cord injury (SCI). Three studies were conducted: (1) an assessment of associations between health-related quality of life (HRQOL) and evaluative well-being (EWB) measures collected in the U.S. Patient Reported Outcomes Measurement Information System (PROMIS®) project; (2) a comparison of perceptions of quality of life (QOL) among adults with SCI in the U.S. versus the U.K.; and (3) development and psychometric evaluation of a Fatigability Index for full-time wheelchair users with SCI.

6.2. Study findings

In the first study, we estimated associations between a quality of life item and HRQOL items in two datasets (N=21,133 and N=2,996) collected as part of the U.S. PROMIS® Project. HRQOL measures accounted for 69% to 75% of variance in overall quality of life. This study provides further evidence that there is an empirical overlap between HRQOL and EWB.

In the second study, we conducted 20 in-depth interviews with adults with SCI (ten in the US and ten in the UK). Five overarching themes emerged describing: QOL in the context of SCI; functional adjustment; medical care; financial resources; and socio-political issues. Twenty subthemes emerged on factors that affect QOL. Participants in both samples identified medical care as a key influence on QOL. The US group talked about a predominantly negative influence (e.g., fragmented primary and specialist care, insurance constraints, bureaucracy), whereas UK interviewees mentioned a predominantly positive influence (e.g., universal provision, including free and continuous care, free wheelchairs and home care, and length of rehabilitation commensurate with level of injury). Functional adjustment, such as physical and mental adjustment post-discharge and aging with SCI, was another important contributor to QOL, and varied by country. Most US interviewees reported poor knowledge about self-care post-discharge and poor quality of home adaptations compared to the UK group.

Another set of findings from this second study relate to preferences of adults with SCI for widely used HRQOL and subjective well-being (SWB) measures. Interviewees reviewed six survey instruments and rated how important it was for their medical providers to know answers to each survey. Keyword-in-context (KWIC) analysis identified the most frequently used words by interviewees to discuss the merits of each survey. Participants in both samples identified the Fatigue Severity Scale (FSS) as vital that their medical provider know about it. This was followed by the Spinal Cord Independence Measure III, and a eudaimonic SWB question. The KWIC analysis showed that the most distinctive words used to discuss FSS were “fatigue” and “pain.”

This second study provides evidence that for adults living with SCI, good QOL is essential for successful rehabilitation. Differences between interviewees from the US and the UK in perceived medical care and functional adjustment suggest that factors affecting QOL may relate to broader health system characteristics. Also, understanding what HRQOL and SWB measures are valued by adults living with SCI can lead to selection of informative instruments, which could help clinicians to complement and tailor established care and rehabilitation protocols for individual needs. Specifically, measuring and managing fatigue in the context of SCI is important.

The third study developed an instrument assessing physical and mental fatigability in adults with SCI. The instrument covers a comprehensive list of health problems and activities associated with fatigue. Using a non-probability convenience U.S. sample, the dimensional structure was assessed by confirmatory factory analysis. The relationship between item responses and fatigability was estimated with item response theory (graded response model). Reliability was measured with test information functions. Differential item functioning was evaluated with Wald chi-square tests and the weighted area between the curves (wABC) (Edelen, et al., 2015). Construct validity was assessed using the known groups method (Hays and Reeve, 2010). The psychometric evaluation shows high measurement precision in discriminating among individuals with a relatively wide range of fatigability.

An 82-item pool was developed from prior qualitative research and consultation with rehabilitation experts. The item pool was reduced to 75 items based on factor loadings and R^2. Both scales are primarily unidimensional. There was good discrimination overall: more than half of the items have high or very high discrimination (slopes > 1.35). The measurement precision in the theta range -2.0 to 2.5 is the equivalent of 0.94 reliability for the physical fatigability scale and 0.91 for mental fatigability. The resulting patient chart, the Fatigability Vector, provides an instant overview of a person’s vulnerability to fatigue, and highlights areas requiring immediate intervention.

6.3. Contributions, limitations, and implications for future research

These three studies make an important contribution to the field of health outcomes in the context of SCI. This dissertation is unique in comparing QOL of life perspectives and preferences for health outcomes measures among adults with SCI in the U.S. versus the U.K., as well as in developing an index to measure vulnerability to fatigue in this sub-group.

Despite these contributions, these three studies have limitations that are worth noting. In the first study, we examined overall quality of life only and did not have measures of experienced well-being or eudaimonic well-being. This is important because some have suggested that experienced well-being is best suited for outcomes research given its focus on narrow time intervals (Bradburn et al., 2013). Second, all the measures examined were self-reported. Third, in our models we did not account for individual characteristics.

A key limitation in the second study is sample representativeness. Although use of newer communication technologies has broadened the scope of participant recruitment, the extent to which these participants represent those with SCI in their respective countries is unknown. Self-selection and access to a computer may bias the sample against participants who do not have access to such technology. Hence, the results reported here need to be examined in future studies.

In the third study, non-representative sampling makes generalizability problematic. Self-selection is also an issue, as certain types of individuals may be more likely to respond because they are computer-literate, while other types of individuals may be more inclined to offer their time to complete the surveys for no remuneration. Socially desirable response bias remains a concern with this type of self-reported data, even though the survey was not administered in person or via telephone. Finally, because the denominator is unknown we do not know the response rate.

With regards to implications for further research, the findings in this dissertation should be confirmed with larger samples of participants both for qualitative (in-depth interviews) and quantitative (psychometric evaluation) approaches. There are several specific opportunities for future research in relation to the Fatigablity Index, such as test items on a U.K. sample, examine responsiveness over time using longitudinal datasets, create a short-form of the measure to reduce response burden, and explore computer adaptive administration (CAT) which would reduce the number of items a person must answer and ensure that the items are appropriate for their level of fatigability. More importantly, the Fatigability Index should be tested in clinical settings to evaluate its utility, feasibility, effectiveness, and sustainability. It should also be explored for self-management purposes in the context of telehealth/telemedicine. Finally, we ought to investigate fatigability in other populations, such as older adults, partial and temporary wheelchair users, and sub-groups with other disabling pathologies.

6.4. References

Bradburn, N. M., Carstensen, L. L., Diener, E. F., Dolan, P. H., Graham, C. L., Hotz, V. J., . . . Card, D. (2013). *Subjective well-being: measuring happiness, suffering, and other dimensions of experience.* (A. A. Stone, C. Mackie, & Eds., Eds.) Washington, D.C.: The National Academies Press.

Edelen, M. O., Stucky, B. D., & Chandra, A. (2015). Quantifying 'problematic' DIF within an IRT framework: application to a cancer stigma index. *Quality of Life Research*, *24*, 95-103.

Hays, R. D., & Reeve, B. B. (2010). Measurement and modeling of health-related quality of life. In J. Killewo, H. K. Heggenhougen, & S. R. Quah, *Epidemiology and demography in public health* (pp. 195-205). San Diego: Elsevier.