A nurse-coached exercise intervention to increase muscle strength, improve quality of life, and increase self-efficacy in people with tetraplegic spinal cord injuries: A single subject design study

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A NURSE-COACHED EXERCISE PROGRAM TO INCREASE MUSCLE STRENGTH, IMPROVE QUALITY OF LIFE, AND INCREASE SELF-EFFICACY IN PEOPLE WITH TETRAPLEGIC SPINAL CORD INJURIES

a dissertation

by

SUSAN B. SHEEHY

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for the degree of

Doctor of Philosophy

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ABSTRACT

A nurse-coached exercise intervention to increase muscle strength, improve quality of life, and increase self-efficacy in people with tetraplegic spinal cord injuries: A single subject design study

Dissertation by Susan Budassi Sheehy, Ph.D., R.N., F.A.E.N., F.A.A.N.
Chair: Mary E. Duffy, Ph.D., R.N., F.A.A.N.

A nurse-coached exercise intervention was conducted over a period of two years in a community-based YMCA, using specialized equipment adapted for people with tetraplegic spinal cord injuries. Ten people with tetraplegic spinal cord injuries participated in the study, each completing three three-hour nurse-coached exercise sessions a week over a period of six months.

The purpose of the study was to determine what effects a nurse-coached exercise intervention would have on muscle strength, self-reported self-efficacy, and quality of life. Results of the Manual Muscle Test (MMT), Moorong Self-Efficacy Scale (MSES), and Catz-Itzkovich Spinal Cord Independence Measures (CI-SCIM), the dependent variables, were collected at baseline (twice), and at three months into the intervention and at six months, which was the conclusion of the intervention.

The Sheehy Spinal Cord Injury Functional Improvement Via Exercise (SCI-FIVE) Model was constructed prior to the study and validated throughout the course of the study. Components of the SCI-FIVE Model include the spinal cord injured person, the nurse-coach, the exercise intervention in a community environment, and the presence of others with spinal cord injuries participating in the study who would provide encouragement and opportunities for vicarious learning. The expectations of the model
were that, as muscle strength increased, functional ability would improve, resulting in greater independence, a higher sense of self-efficacy, and a higher quality of life.

Research question #1, “What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on muscle strength?” was determined by visual analysis of participants’ MMT graphs and statistical analysis of the combined data of the ten study participants. Muscle strength improved in each participant. Of those muscles that demonstrated some strength at baseline, 75% experienced increased muscle strength at three months and/or six months into the intervention. Of those muscles that demonstrated no strength at baseline that were adjacent to muscles that had some strength, 66% were found to have increased strength at three months and/or six months. These results were consistent across ten participants regardless of the length of time since injury and validated that component of the Sheehy SCI-FIVE Model.

The answer to research question #2, “What effect does a nurse-coached program of exercise for people with tetraplegic SCI have on quality of life?” was determined using visual analysis of results from the CI-SCIM and it’s three subscales. Nine of ten study participants experienced upward trends in CI-SCIM scores overall. To determine whether CI-SCIM changes observed in each participant were statistically significant over all ten participants, Repeated Measures Analysis of Variance (R-ANOVA) was conducted with CI-SCIM Overall and the subscales of Self Care, Respiratory and Sphincter Management, and Mobility. CI-SCIM overall results support the efficacy of the intervention and validate this tenet of the Sheehy SCI-FIVE Model ((F (3,27), =16.5, p<.0001; Friedman’s = 2.67, p<.0001). The subscale Self Care was statistically significant (F(3.27=20.1, p<.0001; Friedman’s = 26.7, p<.0001).
The subscale Mobility results supports the efficacy of the intervention. R-ANOVA indicated significant changes over time (F(3,27) = 8.6, p<.0001; Friedman’s = 23.3, p<.0001). The subscale Respiratory and Sphincter Management results did not support the efficacy of the intervention. There were no statistically significant changes over time (p=.11).

The MSES was used to assess changes in self-reported self-efficacy in response to RQ #3, “What effect does a nurse-coached program of exercise for people with tetraplegic SCI have on self-efficacy?” Visual analysis of graphs revealed that all ten study participants experienced strong improvements in MSES scores from baseline to three months and from three months to six months. R-ANOVA confirmed statistical significance across ten subjects (F(3,27) = 24.6, p<.0001; Friedman’s = 30.0, p<.0001) and validated this tenet of the Sheehy SCI-FIVE Model.

The results of this study validated all components of the Sheehy SCI-FIVE Model and demonstrated increased muscle strength, increased self-efficacy, and improved quality of life for the ten study participants who participated in a nurse-coached program of exercise for people with tetraplegic SCI.
ACKNOWLEDGEMENTS

This research study was a scientific inquiry and a labor of love founded in deep gratitude. The Shepherd Center in Atlanta is where it all started. It is a place where the most catastrophically injured people in the world are taught that their lives are not over and that the human spirit can endure. It is a place where, “I can’t” is not allowed and a place that changed my life forever.

I will be eternally grateful to Alana Shepherd. Out of her personal tragedy came a vision to create the best spinal cord injury rehabilitation center in the world – and she did it. She has been a role model and guiding light for me. There are also so many others to thank at the Shepherd Center that I risk forgetting some of them. But I must acknowledge those who played such a key role in my knowledge development about spinal cord injuries – especially Erica Garafalo, Joannie Ventresca, Marcie Silver, Dr. Herndon Murray, Dr. Jill Koval, Cele Locke, Shelley Mitchell, and Minna Hong. Thanks, too, to Dr. Mike Jones for his support of this research project, and to Tammy King for taking it one step further and creating the “Beyond Therapy” program. And a very special thanks to all the amazing admissions evaluators who go above and beyond every day to assure that their patients receive every possible opportunity to reach their maximum potential and that their patients’ families are met with compassion and understanding.

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I want to pay tribute to every person who has sustained a spinal cord injury. No one can ever know what you and your families have been and are going through. Thank you for inspiring me to initiate and complete this research. I only hope that, in some small way, I have contributed to making your lives a little better. I pray that a cure will come soon so that spinal cord injuries will be something we only read about in history books.

To John O’Sullivan, your spirit will live within me always. I wish you could have been here to share this journey with me.

Saving the best for last, I want to thank my amazing, wonderful son, John, who showed me what a person can do when he doesn’t look back, but just keeps moving forward. After his spinal cord injury, when he was in outpatient rehabilitation and came to a stalemate, we looked for a different kind of therapy. We found Jamie, and John’s body responded to everything she asked it to do – she asked it all the right questions. When I asked John what was different about what Jamie was doing he said, “She treats me like an injured athlete and not like a disabled kid.” John, I have taken this message to heart and designed this exercise intervention with your words in mind – I treat people like injured athletes and not like disabled people. Thank you for believing in me when I didn’t believe in myself, for encouraging me at every step along this long and winding journey,
and for making me realize that if I finished this dissertation we would finally have our
dining room table back! ARRR!!! XO, M.

“Some choices will choose you. How you face these choices...
is what will define the context of your life” Dana Reeve
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CHAPTER 1

Purpose of the Study

The purpose of this analytic study was to determine the effects that participation in
this nurse-coached exercise program had on muscle strength, self-efficacy, and quality of
life in people with tetraplegic spinal cord injured (SCI) persons who participated in a
nurse-coached exercise program.

Background

Twelve thousand people who sustain spinal cord injuries (SCI) in the United States
each year survive to reach the hospital (NSCISC, 2008). It is estimated that an additional
5,000 people who sustain spinal cord injuries die before reaching a hospital (NIDDR,
2007). Between 250,000 – 400,000 people are living with spinal cord injuries in the
United States (Cleveland Clinic, 2007).

Fifty-five percent of people with SCI are between the ages of 16 and 30 years old.
(Spinal Cord Injury Information Network, 2008). However, because the incidence of
spinal cord injuries in people over 60 years of age has increased from 4.7% before 1980
to 11.5% since 2000, the average age of people with spinal cord injuries has risen to 38
years (NSCISC, 2008). The median age is 26 years and the highest incidence is in 19-
year-old males (Cleveland Clinic, 2007).

The etiology and extent of spinal cord injuries varies depending on the level of the
injury (Figure 1.1) and the severity of damage to the spinal cord (Pennsylvania State
University, 2009). Every person sustaining an SCI differs with respect to the level and
extent of paralysis, the level of pain and the amount of spasticity they experience, the
interventions required to sustain or achieve hemodynamic stability, and quality of life following the injury (Institute of Medicine, 2005).

Figure 1.1 The spinal nerves and levels of spinal cord injuries
Used with permission of www.sci-recovery.org

the injury (Institute of Medicine, 2005).

Most spinal cord injuries occur as a result of motor vehicle crashes (42%), falls (23%), acts of violence (15.3%), recreational sports (8% - 2/3 of which are from diving accidents), and 11.7% from other causes and unknown causes (NSCISC, 2008).
Injuries to the spinal cord in the cervical area of the spine (C1-C7) result in tetraplegia, where motor and sensory function of the arms, legs, chest (respiratory function), and abdomen (bowel, bladder, and sexual function) are affected. Injuries to the spinal cord at the level of the thoracic spine (T1-T12), lumbar spine (L1-L5), and sacral spine (S1-5) result in paraplegia, where motor and sensory function of the legs, chest, and abdomen may be affected and/or there is loss of a specific function, such as bowel or bladder function (McKinley, et al., 2008).

Neurologically, 51.6% of people with spinal cord injuries are tetraplegics and 46.3% are paraplegics. Of this total, 22.1% have complete tetraplegia, 34.3% have incomplete tetraplegia, 25.1% have complete paraplegia, and 17.5% have incomplete paraplegia. Only one percent of people who sustain spinal cord injuries have complete neurological recovery at the time of hospital discharge (Tchraloori, 2007).

People with spinal cord injuries are surviving and living longer than ever. Reasons reported include better initial stabilization at the scene of the accident and rapid transportation from accident scenes to acute hospital care (Williams, 2005; Washington University School of Medicine, 2005); new and improved pharmacological agents to prevent respiratory, urinary tract and other infections, to maintain hemodynamic stability, and to provide prophylaxis preventing pulmonary emboli. Greater expertise in emergency and critical nursing care, and refined equipment that assists in prevention of skin breakdown and improved ventilation are also factors in more favorable outcomes (Shepherd Center, 2008).

People with spinal cord injuries may experience numerous complications due to their injuries and the resulting immobility. These include muscle spasticity (Spinal Cord
Injury Info Net, 2009; Christopher Reeve Paralysis Foundation, 2005); neurogenic pain (NINDS, 2009); bladder dysfunction, urinary tract infections, autonomic dysreflexia (severe blood pressure elevation caused by some form of stimuli, such as a full bladder, ingrown toenail, or other irritant) (Christopher Reeve Paralysis Foundation, 2005); pressure sores, deep vein thrombosis and pulmonary emboli, osteoporosis, decreased cardiovascular function, muscle atrophy due to immobility, pneumonia due to decreased respiratory function, and depression due to loss of mobility and function (NINDS, 2009).

Spinal cord injured patients may survive the accidents that caused their injuries and hospitalization, only to die from complications that could have been prevented (University of Alabama, 2007).

Fourteen rehabilitation centers that treat spinal cord injured patients are currently designated as Model Spinal Cord Injury System Centers (Appendix A) and are provided research funding by the National Institute on Disability and Rehabilitation Research of the National Institutes of Health (NIDRR, 2008). These centers contribute data on spinal cord injured patients treated at their facilities to a central data repository known as the National Spinal Cord Injury Statistical Center (University of Alabama, 2007). Early causes of death as identified in this database include pneumonia, pulmonary embolism, and septicemia. Leading causes of death in the spinal cord injury population post hospitalization are respiratory disease (20.4%), heart disease (18.7%), septicemia (12.0%), and suicide (5.7%) (University of Alabama, 2007). Complications associated with a loss of motor and sensory function, and immobility profoundly affects all aspects of quality of life.
Of those patients admitted to Model Spinal Cord Injury Centers, 88.3% are discharged from the hospital to home, 5.1% are discharged to nursing homes, and 6.6% are discharged to other hospitals or group homes (NIDDR, 2008). The overall cost to the American economy is more than ten billion dollars a year (Spinal Cord Injury Information Network, 2008). Current practice in managing patients with catastrophic spinal cord injuries primarily focus on immediate acute outcomes of care with little focus on continuous functional improvements, prevention of complications, and wellness.

Spinal cord injuries place severe physical, social, emotional, and economic lifetime burdens on its victims and their family members. Because the majority of people suffering spinal cord injuries are under age 30, both quality of life and lifetime productivity are affected (Institute of Medicine, 2005). Ten years post injury only 32.4% of persons with paraplegic spinal cord injuries and 24.2% of persons with tetraplegic spinal cord injuries are employed either part time or full time (NSCISC, 2008).

People with SCIs spend short periods of time in acute care hospitals. They will receive interventions such as surgical or external stabilization of the cervical spine, hemodynamic stabilization (blood pressure, pulse, respirations, oxygen saturation), nutritional support, and interventions to prevent or treat complications such as infections, deep vein thrombosis (blood clots), pulmonary emboli (blood clots that break lose and become lodged in the lungs), pneumonia, and skin breakdown (Shepherd Center, 2008).

The average length of stay in acute care hospitals for people with SCIs has decreased from an average of 25 days in 1974 to an average of 18 days in 2004 (the latest statistics available), primarily due to insurance company limitations on length of stay (Spinal Cord Info Pages, 2009). Acute care hospitalization is typically followed by
inpatient rehabilitation, which has decreased from an average of 115 days in 1974 to an average of 39 days in 2004 (the latest available statistics), also primarily due to insurance company limitations on length of stay (NSCISC, 2008).

Following inpatient rehabilitation, patients are either discharged to home or to long-term care facilities. Seventy-five percent of persons with SCI receive outpatient rehabilitation services (University of Alabama, 2007). Only 24% receive more than 100 hours of outpatient services per year for a limited period of time – usually one year (University of Alabama, 2007). Again, insurance companies or public assistance plans determine the number of hours of outpatient rehabilitation that will be reimbursed.

Following exhaustion of outpatient benefits, individuals with SCI usually no longer have access to any form of accessible rehabilitation or exercise program designed to promote continued recovery and wellness, and to prevent complications. Leading causes of death since 1973 in persons with spinal cord injuries are pneumonia, pulmonary embolism, and septicemia (NSCISC, 2007). Average medical costs in the first year and subsequent years following a spinal cord injury are significant (Table 1.1) and estimated lifetime costs are staggering (Table 1.2). Functional gain expectations are usually limited (Table 1.3).

Since the time of Imhotep, an Egyptian physician from 2500 B.C. (Brested, 1993), to as recently as the mid-twentieth century, it was believed that once a person sustained a spinal cord injury there was no hope for recovery. In the late second half of the 20th Century, it was reported that patients with spinal cord injuries experienced most recovery in the first six months and no recovery after two years (Waters, Adkins, Yakura, et al, 1991) (Table 1.3).
Table 1.1

*Spinal Cord Injury – Average Medical Costs Per Year (NSCISC, 2007)*

<table>
<thead>
<tr>
<th>Level of Injury</th>
<th>Year One</th>
<th>Each Subsequent Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1-4</td>
<td>$741,425</td>
<td>$132,807</td>
</tr>
<tr>
<td>C5-C8</td>
<td>$478,782</td>
<td>$54,400</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>$270,913</td>
<td>$27,568</td>
</tr>
<tr>
<td>Incomplete motor function/partial motor deficit at any level</td>
<td>$218,504</td>
<td>$15,313</td>
</tr>
</tbody>
</table>

Table 1.2

*Estimated Lifetime Costs by Age at the Time of Spinal Cord Injury (NSCISC, 2007)*

<table>
<thead>
<tr>
<th>Level of Injury</th>
<th>25 year old</th>
<th>50 years old</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1-4</td>
<td>$2,924,513</td>
<td>$1,721,677</td>
</tr>
<tr>
<td>C5-8</td>
<td>$1,653,607</td>
<td>$1,047,189</td>
</tr>
<tr>
<td>Paraplegia</td>
<td>$977,142</td>
<td>$666,473</td>
</tr>
<tr>
<td>Incomplete motor function at any level</td>
<td>$651,827</td>
<td>$472,392</td>
</tr>
</tbody>
</table>

Note. Monetary amounts do not include lost wages, benefits, productivity (average $59,212 in 2006 dollars). Also does not include lost wages and benefits of family members.

1991 & 1993). More recently it was reported that most spontaneous recovery occurs within one year of injury (Kirshblum, et. al., 2004).
Table 1.3

Spinal Cord Injury Functional Expectations

<table>
<thead>
<tr>
<th>SCI Level</th>
<th>Muscles</th>
<th>Function</th>
<th>Possible Goals</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1-2</td>
<td>None below</td>
<td>None; ventilator-dependent; unable to clear secretions</td>
<td>Verbally direct care; may be able to propel wheelchair with head control or sip-and-puff device</td>
</tr>
<tr>
<td></td>
<td>the head</td>
<td></td>
<td></td>
</tr>
<tr>
<td>C3-4</td>
<td>Neck:</td>
<td>Fair neck control</td>
<td>Control power wheelchair with mouth or head control</td>
</tr>
<tr>
<td></td>
<td>Trapezius</td>
<td>Shoulder shrug</td>
<td>Verbalize care needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Use adaptive computer software</td>
</tr>
<tr>
<td>C-5</td>
<td>Above, plus:</td>
<td>Good neck control</td>
<td>Dress upper body</td>
</tr>
<tr>
<td></td>
<td>Deltoids</td>
<td>Fair shoulder control</td>
<td>Feed self with equipment</td>
</tr>
<tr>
<td></td>
<td>Biceps</td>
<td>Bend arm at elbow</td>
<td>Brush teeth, wash face with help</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Control power wheelchair with palm toggle</td>
</tr>
<tr>
<td>C6</td>
<td>Above, plus:</td>
<td>Flex wrist</td>
<td>Dress upper body</td>
</tr>
<tr>
<td></td>
<td>Wrist</td>
<td>Turn palm up</td>
<td>Dress lower body with help</td>
</tr>
<tr>
<td></td>
<td>extension</td>
<td></td>
<td>Groom self with equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Bowel/bladder program with help</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Transfer: bed/car/toilet with help</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Able to drive car with adaptations</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>May be able to push manual w/c</td>
</tr>
<tr>
<td>C7</td>
<td>Above, plus:</td>
<td>Straighten arm</td>
<td>Independent bed/car/toilet transfer</td>
</tr>
<tr>
<td></td>
<td>All arm</td>
<td>Grip using wrist extension (tenodesis)</td>
<td>Dress independent with equipment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Propel manual w/c</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Independent feeding, bathing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Bowel/bladder program with help</td>
</tr>
<tr>
<td>C8 to T4</td>
<td>Above, plus:</td>
<td>T1: All arm/hand</td>
<td>Independent transfers</td>
</tr>
<tr>
<td></td>
<td>Hands</td>
<td>Some trunk control</td>
<td>Push manual w/c</td>
</tr>
<tr>
<td></td>
<td>Some chest</td>
<td>Some chest</td>
<td>Independent self-care</td>
</tr>
<tr>
<td></td>
<td>Some trunk</td>
<td>Some trunk</td>
<td>Homemaking skills with help</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Independent bowel/bladder program</td>
</tr>
<tr>
<td>T5-T12</td>
<td>Above, plus:</td>
<td>All upper body</td>
<td>Independent self-care</td>
</tr>
<tr>
<td></td>
<td>All chest</td>
<td>Fair to good trunk control</td>
<td>T-12 walk with walker and long-leg braces (difficult, time consuming)</td>
</tr>
<tr>
<td></td>
<td>All trunk</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
To determine the effects that participants in this nurse-coached exercise program had on tetraplegic spinal cord injured persons, the following research questions were answered:

1. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on muscle strength?
2. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on quality of life measures?
3. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on self-reported self-efficacy?

**Operational Definitions**

**Functional Descriptors**

1. *Complete spinal cord injury*: A complete spinal cord injury is the term used when there is no sensory or motor function below the level of the spinal cord injury. Some participants in this study were diagnosed as having complete spinal cord injuries...
2. *Incomplete spinal cord injury.* Preservation of any sensory function in the sacral segment and/or motor function below the neurological level of injury is known as an incomplete spinal cord injury. There were participants in this study who were diagnosed as having incomplete spinal cord injuries.

3. *Paraplegia:* Paraplegia is a neurological deficit beginning at or below the level of T-1, resulting in loss of motor and/or sensory function of the lower extremities, possibly including bowel and bladder function.

4. *Tetraplegia:* Tetraplegia is a neurological deficit between the levels of C-1 and C-7, resulting in loss of motor and/or sensory function of upper and lower extremities, the chest, the abdomen, bowel and bladder. If the injury is at or between the levels of C1 and C-3, the patient will lose diaphragm function and thus, will be ventilator dependent.

5. **Level of Motor Function:** The level of motor function is the area identified by a healthcare professional trained in manual muscle examination using dermatome markers, in the cervical, thoracic, lumbar, or sacral vertebrae, where muscle movement is visible. Motor function level is tested independently on each side of the body, beginning at the C2 level and ending with the S4-5 level. Each motor level tested by a trained clinician is assigned a score, where 0 = total paralysis, 1 = a palpable or visible contraction, 2 = active movement with gravity eliminated, 3 = active movement against gravity, 4 = active movement against some resistance, and 5 = active movement against full resistance.

6. **Level of Sensory Function:** The area identified by a healthcare professional trained in manual muscle testing using dermatome markers, in the cervical, thoracic, lumbar, or sacral vertebrae, where sensation is identified. Sensory function level is tested independently on each side of the body, beginning at the C2 level and ending with the
S4-5 level. There are two types of sensory functions: response to light touch and response to a pin prick. Responses are given a score, where 0 = absent, 1 = impaired, and 2 = normal.

7. **ASIA Levels:** The international standard for neurological classification of spinal cord injuries, developed by the American Spinal Injury Association, is known as the ASIA Impairment Scale (Appendix E) (ASIA, 2002). It is used to determine the effect the injury has had on the motor and sensory systems by measuring sensation and muscle strength. Scores range from ASIA A, which is the most severe injury, to ASIA E, which is considered normal. ASIA levels were used to describe study participants at the start of the study.

**Dependent Variables**

8. **Muscle Strength:** Muscle strength is the measured strength of a specific muscle. The Manual Muscle Test (MMT) (Appendix B) is the standardized comprehensive measurement of muscle strength in specific muscles that was used in the study. Scores range from 0 = no strength, 1 = some slight movement, 2 = some movement without gravity, 3 = some movement against gravity, 4 = some movement against resistance, and 5 = normal movement. The MMT was used to measure changes over time in muscle strength in study participants. A detailed Manual Muscle Test is sometimes more informative than results of ASIA scoring because the MMT tests more muscles and is more sensitive to small, but perhaps significant, changes in motor function that may affect quality of life.

9. **Self-efficacy:** Self-efficacy is a person’s statement of his/her belief in his/her ability to reach a specific goal (Bandura, 1977) by witnessing others in similar circumstances being
successful (vicarious experience), observation (recognition of positive physiologic symptoms), and verbal persuasion (coaching/encouragement). The dependent variable of reported self-efficacy was measured using participants’ scores on the Moorong Self-Efficacy Scale (Middleton & Tate, 2003) (Appendix C).

10. Functional Gains: Following a spinal cord injury that results in paralysis, muscle activities that improve are known as functional gains. These functional gains may allow a person to perform additional activities of daily living, resulting in increased independence, and thus, a higher quality of life. In this study, functionality variables were measured by participants’ scores on the Catz-Itzkovich Spinal Cord Injury Quality of Life Index (Catz, Itzkovich, et. al, 2001) (Appendix D).

Other definitions

11. Learned Non-Use: Following a neurological injury where significant nerve groups have been damaged or affected by adjacent damaged nerves, some nerves may lie dormant, with the muscles controlled by these dormant nerves becoming non-functional. A pattern of “forgetfulness” occurs, where, because the affected extremity has not been used for a given period of time due to the dormancy of the nerves that control it, it becomes non-functional. This is known as “learned non-use.” The exercises used in this program were designed to evoke reversal of the learned non-use of specific muscle groups.

12. Coaching intervention: The coaching intervention in this research study was an exercise program designed to improve the performance of participants by mutually assessing the participant’s performance, reviewing the present situation, defining achievable goals, exploring exercises to achieve those goals, and supporting the
participant as s/he executes the exercise program to achieve those goals. The nurse-coach was the key to providing the environment, equipment, direction, encouragement, and support for each study participant to achieve his/her goal

Significance

The results of this study will provide evidence that a nurse-coached program of exercise for people with tetraplegic spinal cord injuries may result in increased muscle strength, increased self-efficacy, and a higher quality of life. Findings will provide a counter-opinion to the current belief that recovery following spinal cord injury occurs over a finite period of time.

In the past, major focus has been placed on adaptation to the spinal cord injury rather than on interventions to enhance recovery following spinal cord injury. Because of immobility due to spinal cord injury, many life-threatening complications may occur. As a result of a nurse-coached program of exercise, the issues that arise with immobility will be diminished.

Summary

This research was conducted to determine if the effects of a nurse-coached exercise program that occurred more than a year post injury resulted in increased muscle strength, increased reported self-efficacy, and improved quality of life for people with tetraplegic spinal cord injuries and if the intervention supported the Sheehy SCI-FIVE Model.
CHAPTER 2

Foundation for the Research

To review the foundation for this research, this chapter includes descriptions of the conceptual framework developed for this study and a review of the literature related to spinal cord injuries. Bodies of literature reviewed were: a.) demographics and statistics related to SCI; b.) health promotion in chronic disabling conditions; c.) self-efficacy; d.) personal attainment; e.) vicarious modeling; f.) verbal persuasion; g.) physiologic feedback; h.) physiologic effects of exercise on persons with SCI; i.) previous reports regarding recovery post SCI; j.) current reports regarding recovery post SCI; k.) spared motor tracts and learned non-use; l.) nurse-coaching; m.) manual muscle testing; n.) functional improvement measures; and o) measurement tools for persons with SCI.

The Conceptual Model

The conceptual model that guided this study was the Sheehy Spinal Cord Injury Functional Improvement Via Exercise (SCI-FIVE) Model (Figure 2.1). The Sheehy SCI-FIVE Model was constructed based results from a pilot study (Sheehy, 2004) (Appendix G), reports in the literature, and components of two other conceptual models, the Model of Health Promotion and Quality of Life in Chronic Disabling Conditions (MHPQOL) (Stuifbergen, 1995; Stuifbergen, Seraphine, & Roberts, 2000) and Bandura’s Self-Efficacy Model (Bandura, 1986).

The Sheehy SCI-FIVE Model integrates a nursing perspective with the perspective of a person with a tetraplegic spinal cord injury, with the goal of achieving a higher quality of life by strengthening muscles, and increasing self-efficacy and independence. The nursing perspective includes a nurse-coached exercise program, where barriers are
removed (the program is located in an accessible, safe community environment), resources are provided (nurse-coaching and specialized equipment), and self-efficacy is encouraged, leading to increased health promotion (exercise) behaviors that will affect well-being and quality of life.

A Nurse-Coached Intervention

A nurse-coach is an expert who guides a participant through a process, with a high degree of participation on the part of the participant. The expert nurse provides guidance to a participant after having insight into the scope and meaning of the participant’s injury and the specific characteristics of the participant (Benner, et al., 1985). Nurse-coaching should be specific to a research study and tailored to the unique needs of each participant (Lewis & Zaklis, 1997). Nurse-coaching has been used in many models in a number of different settings such as patients dealing with stress, recovering from an acute illness, self-care programs, and applying comfort measures (Fox, Bruer, & Wright, 1997; Jaarsma, et al., 1998).

This nurse-coached exercise intervention incorporates the assessment of the participant’s beliefs, promotes participation in the exercise program, encourages wellness and self-efficacy, and assures adherence to the exercise plan. The nurse-coach designs a validated exercise program to facilitate a program of exercise designed specifically for people with tetraplegic spinal cord injuries. Reliable tools and techniques are integrated into the program. Decisions about the program are founded in current research findings that result in a practice framework that incorporates encouragement, teaching, and supportive therapy.
The goal of nurse coaching is to change behaviors by promoting an exercise program of wellness that will increase function, self-efficacy, and quality of life while also preventing complications that result from immobility. The nurse-coach will use strategies that are participant-directed rather than injury-directed (Schenk & Hartley, 2002).

Most people have faith and confidence in nurses and value their skills, clinical expertise, and nurse/patient connection abilities. Clinical expertise includes knowledge of spinal cord injuries, dermatome levels of injury, results of injuries, functional expectations, psychosocial impacts on the injured person and family members, and the prevention of complications and adverse events. The nurse-coach is ideal for this type of wellness program because of the nurse’s holistic and integrative health perspective. Nurses have an inherent ability to understand the interconnectivity of mind, body, and spirit.

A nurse-coach experienced in care of the spinal cord injured person is essential to this model, as the nurse will be able to assess participants for clinical restrictions, unusual physical and emotional situations, and special requirements, while gaining the participant’s trust and confidence as a person knowledgeable about spinal cord injuries. Participants will know that the nurse-coach understands their specific limitations and needs based on the participant’s level and extent of injury. The nurse-coach will define the specific components of the exercise program (the equipment used, the adaptive devices required, the amount of weight and resistance for the specific exercises, the length of time on each piece of equipment, and any special precautions).
The nurse-coach will introduce venues and activities that eliminate barriers to exercise and s/he will identify and enhance available resources. The nurse-coach will orient each participant to the program, design a program of exercise specified for each participant, coach the participant in the defined exercises, and monitor the participant before, during, and after the exercises for any unexpected or adverse effects.

It must be noted that a nurse-participant relationship that develops over the period of the coached exercise program may positively influence the participant’s performance due to the level of trust that will have developed between the nurse and the participant. Much like a parent-child relationship, in the nurse-participant relationship the participant may work harder to please the nurse-coach. The participant will know that the nurse-coach is closely monitoring their activities, carefully recommending increased efforts or added resistance, weights, or time in a given exercise activity.

The nurse-coach will know what exercises need to be changed during the course of the intervention (the length of time and amount of resistance) and when that change must take place. The nurse-coach’s efforts will be focused on the goals of increased function, increased endurance, increased independence, and increased self-efficacy while decreasing isolation and medical and psychological complications inherent with spinal cord injuries.

Because there will be others with tetraplegic spinal cord injuries participating in the exercise program, the nurse-coach will facilitate group encouragement and vicarious learning. S/he will provide guidance, support, and motivation. Motivational interviewing techniques inherent to the practice of nursing will be used to explore the participant’s beliefs about attitudinal barriers and physiologic responses to the intervention. Nurse
coaching has been successfully used to address patient’s attitudes and behaviors (Fahey, et al., 2008). S/he will support activities to enhance the participant’s attaining personal objectives (Bandura, 1997).

The nurse-coach will direct the participant through the exercise activities in an effort to improve outcomes. S/he will provide structure (a defined program of exercise) and encouragement to move participants toward their envisioned goals. During the course of the exercise program, a nurse-coach/participant partnership will form that is bonded in trust and respect. As this phenomenon occurs, the nurse-coach can explore the participant’s beliefs that help or hinder his/her behavior.

The nurse-coach will provide education, guides, and prompts (Wilkie, et al., 1990). S/he will help the participant to make informed choices and take ownership of their own progress by helping them to set goals. S/he will provide information and constant communication about spinal cord injuries and the body’s responses to the exercises as well as provide answers to questions that arise during the course of the exercise program.

The perspective of the person with a spinal cord injury includes being directed in an exercise program by a nurse-coach and receiving encouragement and exemplars from others with spinal cord injuries in an accessible and safe environment with equipment adapted for people with spinal cord injuries. These concepts are integrated in the Sheehy SCI-FIVE Model. Key concepts of the model are a defined environment and a defined period of time, nurse coaching, group encouragement, vicarious learning, and a program of exercise.
Theoretical models reviewed to develop the Sheehy SCI-FIVE Model

The Model of Health Promotion and Quality of Life (MHPQOL) in Chronic Disabling Conditions

The MHPQOL model combines concepts of severity of illness and barriers from the Health Belief Model (Glanz, Rimmer, & Lewis, 2002) with Bandura’s Self Efficacy Theory (Bandura, 1997), relating health and health promotion concepts to quality of life concepts. The model is based on the premise that quality of life perceptions occur as a result of personal attitudes, contextual factors, and behaviors (Stuifbergen, et al., 2000). The model was constructed based on both qualitative (Stuifbergen & Rogers, 1997) and quantitative (Stuifbergen & Becker, 1994; Stuifbergen, 1995) studies and a thorough review of the literature. Key concepts of the MHPQOL model are barriers, resources, and self-efficacy that lead to health promotion behaviors that affect perceived health and well being and quality of life.

Bandura’s Self-Efficacy Theory

Bandura’s Self-Efficacy Theory (Bandura, 1986) is a social cognitive theory that addresses factors that govern how a person’s acquired competencies play a part in his/her self-regulation of health habits and the affect of those acquired competencies on physical and emotional outcomes. Self-efficacy is defined by Bandura (1977) as a person’s capabilities to organize and execute the sources of action required to manage prospective situations. Self-efficacy beliefs determine how people feel, think, motivate themselves, and behave (Bandura, 1994). Discussion of the theory is organized around four major premises: personal attainment, modeling, verbal persuasion, and physiological feedback (Bandura, 1994).
Three components from Bandura’s Self-Efficacy Model were incorporated into the Sheehy SCI-FIVE Model – the participant’s actual experience with the activity, vicarious learning (observing another person performing the activity), and verbal persuasion (coaching by a nurse). The literature (Bandura, 1977) suggests that combining efficacy-enhancing components is more effective that using one component alone.

**Pilot Study Influence on the Model**

The pilot study (Sheehy, 2004), a descriptive phenomenologic study, revealed that people with spinal cord injuries prefer to exercise with other spinal cord injured people in a community setting along with able-bodied people rather than at home alone. All participants in the pilot study reported functional gains and improved quality of life. Participants felt that the encouragement they received from others with similar injuries and the ability to learn from each other was essential to their success, as was the presence of a nurse-coach.

Verbal coaching and vicarious learning were identified as essential to the Sheehy SCI-FIVE model as reported by pilot study participants, as were self-attainment and the physical feeling of improvement, as tested in Bandera’s Self-Efficacy Model (Bandura, 1977). These were identified as essential components in the Sheehy SCI-FIVE Model.

One of the major barriers to exercise cited by people with spinal cord injuries (Sheehy, 2004) is the lack of a safe, easily accessible (by both public and private transportation), community environment for such a program. Therefore, this model was designed to be used in a community setting that offers accessibility and allows the spinal cord injured person to integrate, as an athlete with special needs, into an environment that has been designed for all persons as a place to stay fit and to socialize with others.
The SCI-FIVE Model imbeds the program of exercise into an easily accessible, affordable community environment, such as a YMCA, where there are other participants with similar conditions also participating in the exercise program. This promotes an environment of group encouragement and vicarious learning with opportunities for celebration of accomplishments/gains. Study participants will be able to observe other people with tetraplegic spinal cord injuries exercising, and will encourage them to “try a little harder” or encourage them with words like “I know you can do it!” or “If I can do this, you can do this.” In addition, when one participant achieves something, a new movement or functional gain, other study participants can learn from that participant and be encouraged that they may also be able to achieve the same gain.

Over time, as participants regularly exercise under the guidance of the nurse-coach, it is anticipated that they will develop increased muscle strength and endurance by increasing exercise repetitions and/or time and increasing resistance and/or weights. The increased muscle strength and endurance will result in functional improvements. These will be measured using tools specifically designed for the spinal cord injured population.

When functional abilities improve, the participant’s self-reported self-efficacy increases, which enhances the desire to continue exercising to achieve increased muscle strength, endurance, and functionality. An outcome of increased functionality is increased independence, which may result in such things as a person being able to groom themselves, or go out into the community to find employment, or to attend school.
Increased self-efficacy and independence combine to produce a higher quality of life, which is the ultimate goal of such a program and the core of the Sheehy SCI-FIVE Model (figure 2.1).

The components of the Sheehy SCI-FIVE model underpin the research questions:

1. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on muscle strength?
2. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on quality of life measures?
3. What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on self-reported self-efficacy?

It will demonstrate how a person with tetraplegic spinal cord injury who participates in an exercise program in a community environment over a defined period of time, coached by a nurse, and in the presence of others with similar injuries participating in the same program, will experience increased muscle strength and endurance, leading to increased functionality, increased self-efficacy, and increased independence – all significant contributors to a higher quality of life.

Literature Review

Current Beliefs Regarding Recovery Following Spinal Cord Injury

Current thinking is that it is not a matter of “if” but a matter of “when” therapies will be available to restore neurological function caused by injuries to the spinal cord (Young, 2005a). Neurological recovery is generally a very slow process. Results of a
Figure 2.1 The Sheehy Spinal Cord Injury Functional Improvement Via Exercise Model
A non-scientific poll conducted on the website CareCure Community (Young, 2005a) found that 61% of people with spinal cord injuries who responded to the poll stated that they recovered function after more than a year following their injuries.

Young (2005b) stated that most people recover some function after a spinal cord injury and that those with complete injuries recover between 8 to 21% of function and those with incomplete injuries recover between 59 and 75% of function. He went on to say that some functional recovery might take place over two or more years after the injury.

Understanding the cellular and molecular mechanisms involved in both the functional and damaged spinal cord could lead to therapies that might prevent secondary damage, identify interventions that enhance axon growth around injured areas, and reconnect vital neural circuits within the spinal cord and the central nervous system (Medicine Net, 2009). Blakslee (2002) hypothesized that as little as 10% of spinal neuronal tracts that remain intact may be able to support significant function, including ambulation. One theory is that a small number of nerves around the site of the injury survive the injury but somehow become dormant. He believes that exercise may reactivate these nerves, allowing signals to pass between the body and the brain, or that exercise induces new neurological connections that bypass the site of injury.

McDonald (2005) explained that immobility causes decreased neural activity because neural cells are activity-dependent. When a spinal cord injury happens, inactivity occurs in a number of neural cells including many cells that have not been primarily injured. These cells need to be forced to reorganize and become functional again. Scar tissue begins to form around the spinal cord injury site and neural inhibitory
substances are secreted. Activity/exercise helps to break through the scar tissue to activate intact circuits that have not been in use since the injury (McDonald, 2005). The central nervous system generates 100,000 new cells each day. McDonald’s hypothesis is that optimization of patterned activity will result in increased cell regeneration.

**Anecdotal Exemplars**

Several anecdotal reports of spinal cord injured patients’ significant recoveries have appeared in the literature. On November 17, 1991, a twenty six year old professional football player sustained a C6-7 vertebral fracture during a game. He was rendered tetraplegic and was paralyzed from his shoulders to his feet. For almost seven years he remained totally dependent. In April of 1998, he began a program of exercise at a local gym under the guidance of an athletic trainer and a physical therapist (McHaney, 2002). He exercised four times a week and focused on both functional and non-functional muscles, balancing, using a standing frame, and doing exercises while upright. Four years later he was receiving a normal signal in his paraspinal muscles to the T-10 level. He also had voluntary movements in his lower legs and feet. In February 1999 he took his first steps. By 2002 he was participating in a gait training program and walking with the use of leg braces and crutches (McHaney, 2002).

In June of 1995, a psychologist/bicycle racer was injured and sustained a spinal cord injury while on a bike ride. He was paralyzed from the mid-chest down. This young gentleman also worked out intensively under the guidance of the same athletic trainer and physical therapist as the previous patient. Four years after his injury, he took his first unaided steps (Maher, 1999). These two cases were reported on a non-scientific website (McHaney, 2005). Perhaps it is a coincidence that both men experienced
significant neurological recovery so many years after their injuries. However, the work of the athletic trainer and physical therapist merits further investigation.

In May of 1999, the mother of a 13 year-old C4 level incomplete spinal cord injured child was not satisfied with progress being made at the local outpatient rehabilitation center following acute rehabilitation center discharge. An athletic trainer was hired to work with her son. Over a period of two years, this young man made significant neurological progress which no clinician predicted would be possible, including walking unassisted and without appliances, running long distances, and competing in athletics at the Division I college level (Sheehy, 2005). The work of these athletic trainers suggests that additional scientific investigation into exercise post spinal cord injury should become a research priority.

*Spinal Cord Injury and Exercise*

There is a growing body of evidence that supports the health benefits of regular participation in a program of exercise for spinal cord injured individuals (McDonald, et al., 2002; McDonald, 2005; IOM, 2005; Sheehy, 2005; Young, 2005a; Shepherd Center, 2009). There is much evidence that supports the reduction in morbidity and mortality due to cardiac disease, diabetes, hypertension, stroke, cancer, obesity, and osteoporosis through participation in physical activities (USDHHS, 1999).

Programs for the spinal cord injured population are difficult to locate and to access. Major barriers are lack of available programs, the cost of those programs if they do exist, a feeling by the person with a spinal cord injury that pre-existing physical impairment will hinder progress, and that such a program may not be located in a safe, accessible place (Becker, Stuifbergen, & Sands, 1991).
Cardiovascular effects

Cardiovascular disease is a leading cause of death in spinal cord injured persons. A review of the literature was conducted (DeVillard, et al., 2007) on the effectiveness of training programs for people with spinal cord injuries. Sixty-five articles were reviewed. It was found that training programs after spinal cord injuries resulted in reconditioning the cardiovascular system and improved quality of life. Exercise increased VO2 maximum, reversed leg vascular resistance and cardiac adaptation, and modified lipid profiles resulting in a decreased risk of cardiovascular disease and improved mechanical efficiency (wheelchair propulsion abilities).

People with tetraplegia have decreased compensatory vasoconstriction due to secondary changes in sympathetic nervous system response, causing lower extremity venous pooling, decreased venous blood return to the heart, and reduced stroke volume and blood pressure (Mathias & Frankel, 1983).

The autonomic nervous system regulates the electrophysiology of the heart. Ventricular dysrhythmias and reflex bradycardia can occur from autonomic dysfunction, which is common in persons with tetraplegia. Because autonomic nervous system control is affected in persons with tetraplegia, circulation to the lower extremities is decreased. The resulting venous stasis increases the risk of deep vein thrombosis and pulmonary emboli.

Congestive heart disease is more common in tetraplegic spinal cord injured people due to associated factors of obesity, hypotension, increased pro-thrombotic and pro-
inflammatory states, and dislipidemia (high cholesterol) (Myers & Kiratli, 2007; Marujama, et al., 2008).

In the non-disabled population, the effects of exercise have proven beneficial in reference to heart disease. Traditionally the belief has been that there were obvious limitations to exercise in people with tetraplegic spinal cord injuries due to paralysis, limited muscle function, and adrenergic nervous system dysfunction (Myers, et. al., 2007).

**Pulmonary effects**

Mixed results of the effects of exercise on pulmonary function have been reported. It was reported that pulmonary function decreases when a person with a spinal cord injury does not exercise, but that no improvement was evidenced in those who exercised (Taylor, et al, 1986; Yim, et al., 1993, Noreau & Shephard, 1995). In another study comparing twelve paraplegic males with thoracic spinal cord injuries with twelve able-bodied males, Silva and colleagues (1998) reported that pulmonary functions of the spinal cord injured participants were substantially lower than the able-bodied males. Following an arm crank exercise program that took place three times a week for six weeks for the paraplegic subjects, their pulmonary functions were found to be similar to those of the able-bodied subjects (Silva, et. al., 1998).

**Metabolic and immune response effects**

If activity level is increased to a moderate intensity in persons with spinal cord injuries, lipid profile (increased HDL-C, known as “good cholesterol”) improves (Hooker & Wells, 1989; Washburn & Figoni, 1999). It has been hypothesized that immune function is suppressed when a spinal cord injury occurs due to lack of exercise that leads
to de-conditioning. LaPierre, et al. (1994) reported that immune function improved when people with spinal cord injuries exercised. A program of exercise in spinal cord injured persons demonstrated that an improvement in oral glucose tolerance tests was observed (Jean, et al., 2002) and that free fatty acid levels decreased during exercise in spinal cord injured persons, but not as much as the non-spinal cord injured controls (Kjaer, 2001).

Bone and muscle response effects

Increased bone density was reported in persons with spinal cord injuries who exercised (Mohr, et al., 1997) as was a decreased rate of bone loss (Hangartner, et al., 1994). Increased muscle strength was noted after a program of exercise by persons with spinal cord injuries (Noreau & Shephard, 1995; Heath & Fentem, 1997).

Exercise Theories

Spared motor tracts and learned non-use

There has been detection of preserved innervations in persons with spinal cord injuries using transcranial magnetic stimulation of the motor cortex to elicit motor-evoked potentials (MEPS) in muscles innervated below the level of the spinal cord lesion (Wolfe, 1996). Results of the study support the theory that patients with spinal cord injuries may have intact, but latent, innervations, in the absence of useful sensory and/or motor function. Several other researchers have reported that distal disconnected segments of the spinal cord may be able to “learn” the role of damaged neuronal circuits via neuroplasticity. It was theorized that one could tap into spinal circuitry to restore motor function (Barbeau, et al., 1999). Behrman & Harkema (2000) used locomotor body-weight supported treadmill training after spinal cord injury and Field-Fote (2001)
combined use of body-weight supported functional electrical stimulation with treadmill training to improve walking in persons with incomplete spinal cord injuries.

Taub and colleagues (1993) from the Department of Psychology at the University of Alabama, Birmingham, studied people who had sustained one-sided paralysis following a stroke. Half of the subjects had their non-affected upper extremity restrained for fourteen days while they were awake. Ten out of the fourteen days they were exposed to six hours a day of focused exercises on their impaired upper extremity. This procedure is known as constraint-induced movement.

A second (comparison) group had exercises on their impaired upper extremity without restraint of the unimpaired extremity. The participants who had their non-impaired extremities restrained made significant improvements in each of the several motor function measurements. Each of these subjects also made significant functional gains in activities of daily living that were sustained during a two-year follow up period. In contrast, subjects in the comparison group demonstrated slight to moderate improvements in only one of the motor function measures and improvement was not sustained in the two-year follow up period. The authors concluded that restraint of an unaffected upper extremity combined with a program of exercise to improve functional movement of the impaired extremity resulted in return of significant long-term motor improvement (Taub, et al., 1993).

A study by Kunkle et al. (1999) reported preliminary data suggesting that exercise of the affected extremity, plus verbal feedback and coaching enhances motor recovery even more than the results reported in the 1993 Taub study. The Kunkel study showed
large effects in five subjects and comparable effects to the studies by Taub, et al. (1993) and Miltner, et al. (1999) in other study participants.

In addition to improvements in motor function, participants with chronic central nervous system disabilities demonstrated an increase in motor output area size and motor evoked potential (MEP) amplitudes on spatial mapping using focal transcranial magnetic stimulation (TMS) after fourteen days of interventions (Liepert, et al., 1998). These results indicate that there is enhanced neuronal excitability in the damaged hemisphere of the brain. In addition, the mean center of gravity of the motor output maps shifted significantly after the intervention period, suggesting that motor areas near the original damaged areas were being recruited.

These studies have led to the theory that therapy-induced recovery of function can occur following a central nervous system injury. A meta-analysis of studies on the effect of exercise therapy on stroke rehabilitation (Ottawa Panel, 2006) concluded that more intense exercise training will improve function and that it is a matter of intensity and duration of the exercise that correlates with functional motor improvement.

A significant demonstration of reversed learned non-use was reported with body weight supported locomotion (BWSL) on a treadmill (Wernig & Mueller, 1992). Eight people with incomplete spinal cord injuries regained the ability to walk more than 100 meters, unsupported, on a flat surface. The study participants were trained in BWSL from one and a half to seven months, five days a week for 30 to 60 minutes each day. Participants were five to twenty months post injury. Over time in all study participants, weight support was reduced from 40% to 0%, unsupported walking distance was
increased from 0 to 104 meters by the end of the last week of training, and treadmill speed was increased from 0 to 10 meters per minute to 13 to 23 meters per minute.

There is significant evidence to suggest that intense, repetitive motor activity can reverse learned non-use. This has produced a new class of therapy called “forced-use” therapy that entices motor activities in previously paralyzed limbs. “Intense training and exercise may enhance motor recovery or even restore motor function in people who have been long paralyzed due to spinal cord injury or stroke” (Young, 2005a).

*The effects of exercise on persons with spinal cord injuries*

Most studies in spinal cord injury and exercise have focused on laboratory and animal studies and the physiologic benefits such as cardiovascular, pulmonary, and metabolic. The first case of a person with a C1-2, ASIA A spinal cord injury who improved two ASIA levels more than two years after his injury (during which time no initial recovery had occurred) was reported in 2002 (McDonald, et al., 2002). The patient was seven and a half years post initial injury and it had been five years since he participated in a planned exercise program. A program of functional electrical stimulation, weight bearing in a standing frame, range of motion, and aquatic exercises was initiated.

After two-years, the subject recovered more than 70% of sensory function to the S4-5 level, and 20% of normal motor function. The subject had recovery of 50% of normal pain (pin prick) sensation and 66% of normal light touch (cotton wisp). He was also able to differentiate between hot and cold. He had motor recovery in his left fingers and left hand. He was able to move most muscles in his upper arms and had some slight movement, without gravity, in his legs. His infection rate dropped from twenty-three
infections in 1996 to eight in 1999. During that same time period, his antibiotic use decreased from 169 days to 99 days annually. He sustained two pathological fractures that resulted from osteoporosis, which was corrected by 2002.

He was reclassified from an ASIA A spinal cord injury to an ASIA C, as he went from having no motor or sensory function at and below the level of his C-1/2 injury to having some motor function preserved below the level of his injury and more than half of the key muscles below the neurological level of his injury demonstrating a muscle strength grade of less than 3 on a scale of 0 to 5. It was inferred, from this single-subject case study, that a program of exercise may reduce infections, skin sores, spasticity, pathological fractures, deep vein thrombosis, and autonomic dysreflexia and improve motor and sensory function in persons with spinal cord injuries.

Published reports of the effects of an exercise program on people with spinal cord injuries are sparse. The studies referenced in previous paragraphs reported on benefits of functional electrical stimulation and BWST. Only one study (McDonald, et al., 2002) addressed increased functionality and improved quality of life, indicating a need for additional research.

A study of an aerobic exercise program on people with physical disabilities (stroke, spinal cord injury, polio, and amputations) was conducted by Santiago (1993). Using a pre-test/post-test design, eight subjects, three in one exercise group and five in a home-based exercise program, participated in a twelve-week aerobic exercise program. A control group of thirteen people was made up of those who did not wish to participate in an exercise program. Cases demonstrated a 23.7% improvement in cardiovascular function while the control group demonstrated a 17.1% decrease in cardiovascular function.
function. There was a high dropout rate (five subjects of the original twenty one) and the methodology of the study was poor - there were a small number of subjects, there were mixed diagnoses among the subjects, the subjects’ levels of disability were not described, and there was no randomization.

A prospective non-randomized controlled observational study (Harness, et al., 2008) was conducted comparing twenty-one participants receiving a multi-modal exercise intervention with a control group performing self-regulated exercises over a six month period of time. After six months, participants who underwent the multi-modal exercise intervention showed significantly greater motor gains than the control group, as measured by ASIA score. The conclusion was that a program of multi-modal exercise in patients with chronic spinal cord injuries may provide greater motor benefits that those doing a self-regulated program of exercise.

**Barriers to Fitness**

People with spinal cord injuries must exercise to maintain good health. But, barriers to fitness programs for spinal cord injured people exist. One study from the Wellness and Spinal Cord Injury Project (Tate, et al., 2002) reported that 73.6% of spinal cord injured persons surveyed said they wanted to exercise, 45.8% do exercise, 47.2% say their physicians encourage them to exercise, and 60% report lack of motivation to exercise. Fifty percent worried that fitness staff would not know how to work with someone with a spinal cord injury and many believed that their spinal cord injuries prevented them from exercising or that exercise might make their conditions worse.
In a 1996 survey (Hart, Rintala, & Fuhner), 53% of spinal cord injured persons (N=590) ranked exercise programs as their number one educational topic of interest. Special concerns of people with spinal cord injuries related to exercise were that fitness center staff would not know how to develop a program for their special needs and that they would not know how to work with someone with a spinal cord injury (University of Michigan, 2002).

Most public and private fitness centers do not have specialized equipment that people with tetraplegic spinal cord injuries can access and use. They also usually don’t employ coaches/trainers who are knowledgeable about the limitations, special needs, and possible complications of this specific population. In addition, accessibility (lack of public transportation, inadequate parking, and/or ease of entry into the facility) is often a barrier to an exercise program for people in wheelchairs – especially power chairs that are large and extremely heavy.

Improvement in the physical health status of paraplegic spinal cord injured persons participating in wheelchair athletics resulted from participation in exercise and fitness activities (ATRA, 2004). Participants experienced significant improvements in cardiovascular and respiratory function, increased strength, endurance, and coordination as compared to spinal cord injured non-athletes. Complication rates secondary to their disabilities (pressure sores, urinary tract infections) were one-third that of the matched group of non-athletes.
Theoretical Models

The Model of Health Promotion and Quality of Life (MHPQOL)

The MHPQOL model (Stuifbergen, et al., 2000) was tested on a group of 786 people who were diagnosed with multiple sclerosis. The authors found that the variables (barriers, resources, reported self-efficacy, and reported acceptance) accounted for 58% of the variance in health promotion behaviors and accounted for 66% of the variance in perceived well-being and perceived quality of life (Stuifbergen, et al., 2000).

Barriers were identified as perceptions regarding unavailability, inconvenience, or difficulty of a health-promoting option (Stuifbergen & Rogers, 1997). Resources were identified as “personal environmental characteristics that positively influence quality of life directly and indirectly through their encouragement of the selection and/or use of health promoting behaviors” (Stuifbergen, et al., 2000, p.123).

Self-efficacy was defined as a person’s reported belief about his/her ability to be successful at performing a specific health promoting behavior. Health promoting behaviors were identified as behavioral, cognitive, and emotional efforts that sustained and/or improved health and well-being. Acceptance was defined as a person’s reported acknowledgement of the existence of his/her disease/injury (Stuifbergen, et al., 2000).

In the above study, barriers were addressed, education was provided regarding chronic health issues in females with multiple sclerosis, and performance accomplishments were celebrated, resulting in reported increased self-efficacy and health promotion behaviors. It was reported that initial outcomes demonstrated significant increases in health promoting behaviors such as exercise, better nutrition, and stress management interventions (Stuifbergen et al., 2000).
Integration of concepts from the MHPQOL model into the Sheehy SCI-FIVE Model required introducing activities that decreased or eliminated barriers, provided resources (information, location, equipment, coaching), and increased self-efficacy that resulted in health promoting behaviors. If health-promoting behaviors occurred, the participant’s perception of his/her improved health and well being occurred, and resulted in an improved quality of life.

Bandura’s Self-Efficacy Model

Self-efficacy is a person’s reported self-confidence level or belief in his/her own successful future performance of a particular task or behavior (Bandura, 1977). Strong self-efficacy will effect the choices a person makes, the action a person takes, the person’s level of motivation, how that person functions, how resilient the person is when something goes wrong, and how vulnerable the person is to stress and depression (Maddux & Stanley, 1996).

People who lack self-efficacy have a weak commitment and low aspirations. They do not take on difficult tasks because they focus on their personal deficiencies and the formidable obstacles, and they worry about adverse outcomes, and give up very quickly. The more the feeling of success, the more the person will believe that there will be additional successes (Schwartzer, 1992). Most people are okay with some setbacks and look at them as “lessons learned” – they rebound quickly (Bandura, Adams, Hardy, & Howells, 1980; Bandura, 1995).

A vicarious experience is “modeled attainment” through the accomplishments of others (Bandura, 1986). Seeing others in similar situations and in similar circumstances attain goals causes a person to believe, “I can do this, too!” This is especially true when
the person lacks prior experience or is uncertain of his own capabilities (Bandura, Adams, Hardy, & Howells, 1980).

Verbal persuasion is encouragement from a knowledgeable and credible person. It is telling someone they are capable of succeeding – promoting their self-efficacy (Bandura, Adams, & Beyers, 1977). It is important that the person who is doing the persuading has confidence in the outcome.

Physiological and emotional feedback is the person’s intrinsic mechanism telling them how they are doing. Stressors may be evidenced by increased blood pressure and pulse, increased respiratory rate, fatigue, diaphoresis, or pain (Bandura, Adams, & Beyers, 1977; Bandura, 1995). Control of physiological responses results in increased self-efficacy. Perception and interpretation of emotional and physical responses is important. “A performance is not an outcome… it is an accomplishment” (Valiente, 2003). Much of human behavior can be controlled by the person thinking about the goals they value (Bandura, 1977).

Antecedent determinants of behavior, knowledge, skills, and previous accomplishments may predict a person’s subsequent behaviors. These, along with his/her beliefs about his/her own abilities, will affect the outcomes of his/her efforts. If someone believes that something can happen, he/she will carry out behaviors to make that event happen. He/she will evaluate his/her accomplishments, and then adapt his/her beliefs to be used in subsequent situations. Using self-efficacy theory as a framework, caregivers can work to improve their patients’ emotional states, improve their self-beliefs, enhance their self-regulatory practices, and alter the environments to enhance goal-attainment.
Self-efficacy has been studied in many clinical areas. For example, self-efficacy has been studied in recovery following myocardial infarction (Ewart, et al., 1986; Taylor, et al., 1985; Schroder, et al., 1997); coronary artery bypass surgery recovery (Allen, et al., 1990; Jensen et al., 1993; Bastone & Kerns, 1995; Oka et al., 1996; Mahler & Kulik, 1998); physical activity levels and heart failure (Borsody, et al., 1999); and living with cancer (Cunningham, Lockwood, & Cunningham, 1991; Beckham et al., 1997; Merluzzi & Martinez-Sanchez, 1997). Self-efficacy has also been the focus of studies in childbirth (Manning & Wright, 1983; Dilles & Beal, 1997); diabetes (Hurley & Shea, 1992; Plotnikoff, Brez, & Holz, 2000); long term care (Resnick, 2003a); end-stage renal disease (Devins, et al., 1982); maternal depression (Gross, et al., 1994); exercise (Fletcher & Banasik, 1998); pregnancy (Sinclair & O'Boyle, 1999); breast cancer (Adderly-Kelly & Rabin, 1997); substance abuse (Washington, 2001); and risks for osteoporosis (Harahan, et al., 1998; Resnick, et al., 2003b).

Self-efficacy studies involving patient education began to appear in the literature. Diabetes education and self-efficacy was studied by Hurley and Shea (1992). Hanson’s study of parental self-efficacy and asthma self-management skills was published in 1998 (Hanson, 1998). Boehm and colleagues (1995) conducted an intervention study where they increased the knowledge base of African American men with prostate cancer and found that the participant’s self-efficacy was increased when their knowledge level was increased.

Summary

The conceptual model that guided this study was the Sheehy Spinal Cord Injury Functional Improvement Via Exercise (SCI-FIVE) Model. People with spinal cord
injuries are living longer than ever due to expert clinical care and therapeutic interventions. However, they also experience numerous complications due to prolonged immobilization. There is a growing body of evidence that supports the health benefits (cardiovascular, pulmonary, metabolic, bone and muscle, psychological) of regular participation in exercise programs.

A number of exemplar reports have been published regarding increased muscle strength and quality of life improvements following programs of intense coached exercise that occurred more than one-year post injury. These exemplars have sparked interest in conducting larger studies that are currently in progress. It is hypothesized that physical improvements may be due to activation of spared motor tracts and the concept of learned non-use and re-education of motor tracts. No studies could be found that reported increased self-efficacy, group encouragement, and vicarious learning in people with spinal cord injuries participating in a coached exercise program. There is growing belief that therapies will soon be available that will restore neurological function. “Pessimism has given way to optimism” (Lammertse, 2003).
CHAPTER 3

Research Design

Introduction

The purpose of this study was to evaluate the effectiveness of a six-month nurse-coached exercise program for people with tetraplegic spinal cord injuries on muscle strength, self-reported self-efficacy, and quality of life. A single-subject research design (SSD) with a multiple baseline, multiple probe, across subjects technique was used.

Overview of Single-Subject Design

Single-subject design (SSD) was first used by psychologists to evaluate the effects of their therapies on individual subjects (Bithell, 1994). It is the measurement of variables from baseline, during, and at the completion of an intervention to determine if the intervention had a direct effect on the dependent variables. The purpose of SSD is to evaluate the effectiveness of an intervention on a specific study participant. The study participant’s evaluation data are compared from time interval to time interval. This helps to determine a specific course of action for the individual (Guyatt, et al., 1986). When the intervention is found to be beneficial, it is continued and may be intensified. Because a relatively small number of study participants are needed in order to evaluate the intervention, the methodology may be applied in a variety of clinical settings (Gannella, 1989).

Single subject design requires a formal evaluation design, specific measurement rules, specified analytical procedures, and a defined intervention program that includes when the intervention starts and stops (Bloom, et al., 2003). It is theory-free, as any given
intervention may be evaluated within the process of the design. This process helps to enhance the intervention based on information collected on each participant.

A randomized case/control research design was not desirable for this study population because each participant’s neurosensory and muscle response was very unique and could not be compared to other participants’ responses. Reporting means would not provide useful information on which to make individual intervention modifications. Every spinal cord injury is completely unique from any other because of the millions of neural fibers that may or may not be affected by the injury, producing a myriad of different motor and sensory deficits. By using SSD, each participant is measured against his/her own baseline data, providing specific information required to modify the exercise intervention based on that individual’s unique response to the intervention.

Single-subject design is a good-fit research method for nursing because it focuses on the unique needs of an individual in a clinical practice setting. Real-time understanding of the intervention and response allows the researcher to gain a greater understanding of the intervention/response and to tailor the intervention to the response of the individual.

*Multiple Baseline/Across Subjects Design*

A multiple baseline across subjects design (Barlow & Herzen, 1984; Kratchowill & Levin, 1992; Kazdin, 1998; Bailey, Riddoch, & Crowne, 2002; Bloom, Fischer, & Orme, 2003) was used in the original study (Shepherd, 2006) to evaluate the effects of the exercise intervention on ASIA Examination Scores. Data on manual muscle testing, reported self-efficacy, and quality of life were collected but had not yet been analyzed.
This multiple baseline across subjects design is a type of A-B design that combines baseline (non-intervention phase) observations (A) and intervention period (B) observations (Figure 3.1). The assumption in A-B designs is that, if not for the intervention, observations made in the baseline phase will most likely continue in the same pattern. The intervention is designed to affect change in the baseline findings. Data on variables collected in the intervention (B) phase must be the same as those collected in the baseline (A) phase. The A-B design is thought to be the foundation of single-subject design (Kratchovil, & Levin, 1992). A-B design is known as “the work horse” for practice evaluation in the course of clinical work (Bloom, et. al., 2003) as it allows time for the researcher to evaluate problems in the course of the study and to intervene to solve them.

Baseline data are essential for program evaluation. In this study, pre-intervention (baseline) measurements were compared to measurements obtained at specified times during the intervention and at the conclusion of the intervention. The assumption is that if the nurse-coached exercise intervention had not occurred, there would be no observable changes in muscle strength, self-efficacy beliefs, and quality of life measurements. The
results of ten A-B single-subject design interventions were examined for the potential need for further investigation into a program of exercise for people with tetraplegic spinal cord injuries post rehabilitation phase of care.

The length of the phases in this study was designed in order to collect a sufficient number of data points to identify a clear, stable description of the target events (Barlow & Hensen, 1984). Given that muscle strength, self-efficacy, and quality of life issues in spinal cord injured persons are not likely to change rapidly over time, and considering the amount of time and intensity of the testing, and the fatigue factors for the participants to obtain these data points it was decided that there would be two data point collections in the baseline phase in order to establish a stable baseline. Provided that there were no changes in the data at the two baseline collection points, we moved to the intervention phase.

**Strengths and Limitations of Single Subject Design**

**Strengths.** Single-subject design is widely applicable to many types of problems and settings. There is intense analysis of the dependent variables in all phases of SSD. The repeated measures clearly reveal if there has been a change in the dependent variables. Graphic/visual inspection of the data allowed for strong study conclusions. As a result, visual inspection of the intervention effectiveness makes it easier to compare results across subjects (Gannella, 1989). Single-subject design can be useful as a clinical decision-making tool to continue, modify (increase, decrease, or eliminate) a specific intervention. With SSD, the change of health plan is data-driven and client-centered (Gannella, 1989). It provides outcome information to both the researcher and the participant.
Limitations. If the intervention is complex, as in this study using several different exercises as the independent variable, it does not permit the researcher to know which one component or combination of components were more influential (Bloom, et. al., 2003). Results of SSD may not be generalized to a larger population. There is always the possibility of homogeneous sampling and experimental bias. Using an independent evaluator to collect data can eliminate experimental bias and confounding of results.

Validity, Generalizability, Replicability, and Causality

External Validity. External validity is the extent to which the effect of an intervention can be generalized (Campbell, D.T. & Stanley, J.C., 1963). Threats to external validity are the practitioner effect and the reactive effect to evaluation. A practitioner’s personal style of practice and interaction can influence outcomes. Different practitioners applying the same interventions may have different effects on participants based not only on the intervention itself, but also on interpersonal relationships formed during the course of the study. Participant’s awareness of the fact that they are in a study may lead them to work harder and change their performance in order to achieve more (Bloom, et al., 2003).

Generalizability and Replicability. The study is said to be generalizable when one case, in depth, clearly represents many and/or when the research focuses on a problem by defining the questions and variables that may lead to a more refined research study (Thomas, 1975). Successful repetition of results from one case to another done by the same researcher in the same setting with similar problems across participants is known as direct replication.
Causality. Causality is said to have occurred when changes in the target have occurred between the baseline and the intervention. The inference is that the intervention produced the observed outcome. It is possible to develop clues to causality by comparing results of several A-B single-subject designs (Levin, R.L. & Bavendam, T.G., 1995). In this study, the results of ten single-subject designs were compared to demonstrate causality that the major components of the intervention are the probable causes of the results.

Inclusion Criteria

People with tetraplegic spinal cord injuries were deemed potential study participants, by self-referral, peer-referral, or professional referral. Inclusion as a participant required command of the English language, a traumatic tetraplegic spinal cord injury of at least one year’s duration, level of the SCI between C-4 and C-7, between 16 and 65 years of age, and not ventilator-dependent. In addition, participants were asked to assure that they had transportation to/from the study site, could access the study site, and could commit to the study schedule (three hours, three evenings a week) for six months. Participants provided letters from their primary care physicians attesting to their relative good health, without serious ongoing medical complications, and written prescriptions for use of the standing frame and functional electrical stimulation bike during the research study.

The Setting

The study took place in two different publically accessible locations. The first two study participants exercised in a gym at a state school for children with disabilities. When that option was no longer available, the subsequent eight study participants participated at
an urban, easily accessible (by public and private transportation) YMCA where both able-bodied and people with disabilities work out. This proved to be a much more desirable location for participants.

**Dependent and Independent Variables**

Data were collected using the Manual Muscle Test (MMT) (Kendall, et al., 2000), the Moorong Self-Efficacy Scale (MSES) (Middleton, et al., 2003), and the Catz-Itzkovitch Spinal Cord Injury Quality of Life Scale (CI-SCIM) (Catz, et al., 2001). Two sets of baseline data (MMT, MSES, and CI-SCIM) were collected prior to beginning the exercise program to assure baseline stability. Additional data were collected at three months and six months into the intervention. Independent variables were the components of the exercise program – use of the Vita Glide®, the Nu-Step®, the Easy Stand®, and the RT 300 FES Bike®

**Instruments**

Instruments used for data collection were the Manual Muscle Test (MMT) (Kendall, et al., 2005), the Catz-Itzkovich Spinal Cord Independence Measure (CI-SCIM) (Catz, et al., 2001), and the Moorong Self-Efficacy Scale (MSES) (Middleton, et al., 2003) (Table 3.1).

**Manual Muscle Testing**

The Manual Muscle Test (MMT) was first presented in the 1950’s (Kendall, Kendall, Creary, & Provance, 2005). Since that time, this standardized test has been integrated into routine evaluations by clinicians around the world. MMT is an extensive diagnostic procedure where the evaluator must have significant knowledge of human anatomy and physiology and extensive education and training in order to perform the test accurately.
Table 3.1

*Data Collection Tools* and Measurements

<table>
<thead>
<tr>
<th>Tool</th>
<th>Observation Times</th>
<th>What is Measured</th>
<th>How it is Reported</th>
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<tbody>
<tr>
<td>Manual Muscle Test</td>
<td>Baseline</td>
<td>Strength of a specific muscle</td>
<td>Value 0 – 5</td>
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<td>3 months</td>
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<td>6 months</td>
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<tr>
<td>Moorong Self-Efficacy Scale</td>
<td>Baseline</td>
<td>Reported</td>
<td>Total Score</td>
</tr>
<tr>
<td></td>
<td>3 months</td>
<td>self-efficacy</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 months</td>
<td>beliefs</td>
<td></td>
</tr>
<tr>
<td>Catz-Itzkovich SCI Quality of Life Measurements</td>
<td>Baseline</td>
<td>Activities of daily living/ functionality</td>
<td>Sub-scale and Total Score</td>
</tr>
<tr>
<td></td>
<td>3 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*All tools were used as screening tools at baseline and as time interval measures to assess gains/losses in muscle strength, self-efficacy, and quality of life measurements.*

MMT is based on the theory that a given muscle or muscle group will be less able to resist an outside force, such as gravity, when there is an alteration in the nervous system, such as occurs in spinal cord injury. When performing an MMT, a particular muscle or muscle group is isolated and then an external force is applied to take the muscle from an isometric to an eccentric contraction. Muscle test scores range from zero to five, with zero indicating no active movement and five indicating movement against full resistance in relation to the ability to resist an applied force. Any muscle or muscle group can be tested and is rated as follows:

0 = no active movement

1 = muscle contraction alone/no movement

2 = movement through range of motion without gravity
3 = movement through range of motion against gravity

4 = movement against some resistance

5 = movement against full resistance (considered normal)

A study was conducted to determine the reliability of the MMT. With the hand-held piece of equipment known as the Dynametric Muscle Test (DMT) (Wadsworth, Krisnan, Sean, Harrold, & Nielson, 1987), a physical therapist was asked to perform a MMT and DMT on five muscle groups in eleven different patients and then repeat the tests two days later. Correlation coefficients were high and significantly different from zero for four muscle groups tested dynamically and for two muscle groups tested manually. Test-retest reliability coefficients for two muscle groups tested manually were identical. The authors concluded that MMT and DMT are both reliable testing methods to measure muscle strength.

Although motor scores are obtained in the motor sub-scale of the ASIA Score, the ASIA exam is limited to ten specific muscle groups. Using MMT, any muscle or muscle group may be tested and this information may add to the body of information that is gathered about a specific spinal cord injured patient’s level of injury and impairment and subsequent regression or progress.

The Catz-Itzkovich Spinal Cord Independence Measure (CI-SCIM).

Catz and colleagues (Catz, et al., 1997) developed the Spinal Cord Independence Measure (SCIM) in 1997 because they were not satisfied with existing tools that measured disability in spinal cord injured persons. The SCIM was developed specifically for the measurement of functionality in persons with spinal cord injuries. The original SCIM had reproducible results and was found to be more sensitive than the Functional
Improvement Measures (FIM) tool in regards to changes in functional abilities of spinal cord injured patients at various points along the rehabilitation continuum. The authors weighted scores in those areas that were determined to be important to the function being evaluated. The SCIM was found to be very user friendly because of the availability of a checklist for the evaluator.

Even though the SCIM was found to be user-friendly, reproducibility in the categories of bathing, dressing, bed mobility, and bowel management were found to be unsatisfactory at less than 80%, with a Kappa coefficient of 0.66 to 0.73. Evaluation of the scoring system determined that the scoring for dressing and bathing was inaccurate and the description of the scoring criteria for several functions, most specifically bed mobility and bowel management, needed significant clarification.

Twenty-eight newly admitted patients with spinal cord injuries participated in the Catz study, 18 men and 10 women (Catz, et al., 2001). Patients with co-existing disabilities were excluded. Six patients were tetraplegic and twenty-two were paraplegic. Seven subjects had complete injuries and twenty-one had incomplete injuries. Both the CI-SCIM and FIM were used to evaluate each subject one week after admission and once a month following initial evaluation throughout their hospitalization time (2 to 7 months). Time to administer both the FIM and the CI-SCIM was approximately the same – 30-45 minutes. Each of the four categories of the CI-SCIM were scored by two clinical staff members who were relevant to the category being evaluated – occupational therapists evaluated self-care; nurses evaluated respiratory, sphincter function, mobility in the room, and toileting; physical therapists evaluated indoor and outdoor mobility. The
evaluators were not aware of the other evaluators’ scores. One nurse did all of the FIM scoring.

Inter-rater reliability of the CI-SCIM was determined by analysis of frequency of identical scores for a given function and patient (total agreement), chance-corrected measure of agreement (Kappa coefficient), paired t-test, and correlation measures (linear regression, Pearson, and Spearman correlation coefficients). Pearson and Spearman correlation coefficients were used to determine correlation between the CI-SCIM and the FIM (Keith, et al., 1987).

Frequency of identical scores for each individual function ranged from 64% to 100%. Frequency was 80% or more in 13 of the 18 functions that make up the total CI-SCIM. The Kappa coefficient was 0.70 to 0.95. When bathing and dressing were evaluated together, the frequency was 80-91%. The original SCIM frequency was 75-79% and the Kappa coefficient were 0.70 to 0.87. There was high correlation between each of the sub-scores assigned by the two evaluators (r = 0.90 – 0.97, p<0.0001) in each of the four sub-categories, considered separately. There was also a high correlation between the total scores of the two-evaluator teams (r = 0.99, p<0.0001). There was significant difference between the mean scores of the two evaluators (nurses) in the mobility-in-the-room and toileting categories (p<0.01).

There was a high positive correlation between the scores for individual functions of the CI-SCIM and the FIM (Spearman’s r = 0.84, p<0.001). The evaluators were unanimous in their belief that the CI-SCIM is a better tool for use with spinal cord injured patients. The precursors to the CI-SCIM, primarily the FIM and Quadriplegic Index of Function (QIF) (Gresham, et al., 1980), do not satisfactorily capture the functional gains
(such as sphincter management and mobility) made as a result of interventions with the spinal cord injured population. The consensus was that the CI-SCIM is a better functional measurement tool to use with spinal cord injured patients, given their limitations and potential gains.

As problems were identified with the SCIM, a revision process was undertaken and several key changes were made. The scores assigned to dressing and bathing were weighted based on the location of the disability (upper or lower body), clarification was made to the descriptions of bed mobility and bowel management, additional scoring criteria were added to the category of bladder management, and to the categories in ambulation/mobility. A revised SCIM, known as the Catz-Itzkovich SCIM (CI-SCIM) was produced. A study was conducted to examine the advantages of the CI-SCIM over the SCIM and the FIM (Catz et al., 2001).

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Self-Efficacy Measurement Instruments

Numerous instruments have been developed, validated, and used to evaluate the level of self-efficacy reported by people with specific clinical conditions. The following are examples of some of the clinical conditions for which self-efficacy instruments have been developed: Perceived Self-Efficacy in People with Arthritis (Lorig, et al., 1989; Barlow, et al., 1984); self-efficacy in asthma (Tobin, et al., 1987); self-efficacy in heart disease (Sullivan, et al., 1998); self-efficacy in people with headaches (Martin, Holroyd & Rokicki, 1993); self-efficacy in people with fibromyalgia (Lomi, et al., 1995); self-efficacy in chronic pain (Anderson, et al., 1995); self-efficacy in people with multiple sclerosis (Schwartz, et al., 1996); self-efficacy in substance abuse (Burling, et al., 1989; DiClemente, et al., 1994); self-efficacy in osteoporosis (Horan, et al., 1998); self-efficacy in people with Parkinson’s Disease (Fujii, et al., 1997); and self-efficacy in people with spinal cord injuries (Shnek et al., 1997; Lou, Dai, and Catanzaro, 1997; Horn et al., 1998; Hampton, 2000; and Middleton, et al., 2003).

There is a vast and growing body of evidence that demonstrates that a person’s self-reports about their efficacy to control health behaviors appear to be related to their health status and clinical outcomes. Resnick’s research (Resnick, 1994, 1996, 1998a, 1998b, 2001, 2002) on exercise in an older population demonstrated that outcomes and self-reported self-efficacy play an important role in health behaviors. The greater the self-
reported self-efficacy, the more likely one is to activate and maintain efforts towards a health goal.

The Mooring Self Efficacy Scale (MSES) (Appendix E) was selected for use in this study. It is a sixteen-item rating scale that rates spinal cord injured patients’ self-reported confidence in performance of every day activities on a 7-point Likert scale, ranging from 1 (very uncertain) to 7 (very certain) (Middleton et al., 2003). It does not break down the items into subscales. The higher the total score, the higher the person’s self-reported self-efficacy beliefs. Because psychological variables are found to be influential in health outcomes following spinal cord injury, the construct of self-efficacy, and a person’s self-reported confidence in his/her own ability to perform a specific task, data was collected and evaluated prior to the start and during the course of this study.

A descriptive correlational study was conducted to determine the psychometric properties of the Moorong Self-Efficacy Scale (Middleton et al., 2003). The MSES was administered to 175 spinal cord injured patients – 31 newly injured inpatients, 36 outpatients a few months from their initial spinal cord injury, and 108 patients living in the community with spinal cord injury. Two spinal cord injury clinicians generated items of the MSES, along with the clinical staff of a spinal cord injury unit, a psychologist, and two spinal cord injured persons (a tetraplegic and a paraplegic) who represented consumer organizations.

Reliability was examined in two samples of spinal cord injury study participants. Factor structure of the scale was examined in a third sample of spinal cord injured patients. Validity of the scale was examined by administering questionnaires related to self-concept, locus of control, and emotional distress, to the first sample. Because of a
significant range of lifestyles, varied attendant care, availability of adapted equipment, and an accessible environment, it was hypothesized that there would be no significant association between the MSES and the level of physical disability. It was expected, however, that there would be significant correlations with measures of psychological disability and handicap. The expectation of the researchers was that the patterns of results would provide evidence for the discriminant and convergent construct validity of the tool.

The initial review of the data in each of the sample groups demonstrated that there was not normal distribution of the data. Therefore, nonparametric statistics were used. Spearman correlations and Wilcoxon signed-ranks test were used to examine stability and responsiveness and Mann-Whitney $U$ tests were used to compare groups. Item total correlations were statistically significant for all but two of the items (bowel accidents and family relationships). Therefore, the general scale had good internal consistency and was found to be reliable. There were no statistically significant differences on the total scores for any test between sub-groups with different levels of spinal cord injuries (paraplegic versus tetraplegia and complete injury versus incomplete injury).

In the sample of 36 outpatients, the MSES was compared with other measurement tools. Significant correlations were found between the MSES and the Tennessee Self Concept Scale (TSCS-2) (Fitts & Warren, 1996) and the Locus of Control of Behavior (LCB) (Craig, Franklin, & Andrews, 1984) self-concept measures (.70 to .44). There was significant negative correlation ($r_s = -.61$ for depression) with emotional distress, measured by the Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1994). Convergent and discriminant provisional support for construct validity of the MSES was found with the Functional Improvements Measures tool (Keith, et al., 1987),
the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck, et al., 1992), and the Sickness Impact Profile (SIP) (Bergner, et al., 1981) tools. The psychosocial domains showed significant correlations with MSES ($r_s = -.80$). All physical domains, as hypothesized, demonstrated low/non-significant correlations ($r_s = .15$ to .04). Factor structure was also conducted in order to determine the underlying structure of the MSES.

The results of the psychometric evaluation of the MSES have demonstrated that the MSES is an internally consistent, stable, sensitive, valid instrument. Statistical significance and high correlation coefficients between the MSES and several other psychological instruments used in the spinal cord injury population proved validity of the MSES. The scale proved to be sensitive and the individual items responsive to changes that occurred over time (between the three time intervals – acute, outpatient, and community) and was therefore deemed suitable for use at all phases of spinal cord injury hospitalization and post-hospitalization.

*Exercise Equipment*

The exercise program included use of equipment designed specifically for people with neurologic dysfunctions. Study participants used four basic pieces of equipment: the Vita Glide®, the Nu-Step®, the Easy Stand®, and the RT 300 FES Bike®. The duration and intensity of the exercises and the resistance applied were adjusted during the course of participation depending upon the participant’s capabilities and the decision of the nurse-coach based on physiological findings.

*The Vita Glide®* (Figure 3.2) is a wheelchair-seated exercise apparatus that uses push/pull technology generated by the participant to provide a natural arm and shoulder
motion. Working muscles on the front and back of the shoulder and in the torso improves range of motion. In addition, it was anticipated that as muscle strength increased, trunk muscles would be conditioned to improve stability, muscle capacity, and endurance. Study participants increased time and resistance on the Vita Glide over the course of the study and exercised both upper body and torso muscles simultaneously.

Figure 3.2 Vita Glide ® (RTM Fitness)

The Nu-Step® TRS 4000 Recumbent Cross Trainer (Figure 3.3) is a low impact exercise apparatus that allows for a variable work rate depending upon the user’s ability. There is no electronic or motor assistance on this apparatus. Participants without lower body function are able to range all major muscle groups by activating the machine using hand and arm motions. Participants with some lower extremity function may use both upper and lower extremities to work all major muscle groups. Anticipated benefits of using the NuStep® are increased muscle strength, increased endurance, and improved cardiovascular fitness. It is an accessible piece of equipment as the seat swivels to allow for transfer by people in wheelchairs. Special gloves can be used to secure hands to hand
grips and footplates are fitted with Velcro® straps to secure feet. Leg guides are available to provide stability for those people without intrinsic leg control.

The NuStep TRS 4000 Recumbent Cross Trainer® (NuStep) is a sit-to-stand apparatus that supports a person who does not have the ability to stand independently, resulting in active standing. Use improves upper body strength and lower body range of motion. It also provides the psychological benefit of being able to stand tall and talk with able-bodied people “face to face,” something that is very meaningful to people in wheelchairs. The glider handles allow for a person to either “range” their lower body themselves if they have upper body strength or for another person to assist with the gliders to provide lower body range of motion.

The Easy Stand Evolv Glider® (Figure 3.4) is a sit-to-stand apparatus that supports a person who does not have the ability to stand independently, resulting in active standing. Use improves upper body strength and lower body range of motion. It also provides the psychological benefit of being able to stand tall and talk with able-bodied people “face to face,” something that is very meaningful to people in wheelchairs. The glider handles allow for a person to either “range” their lower body themselves if they have upper body strength or for another person to assist with the gliders to provide lower body range of motion.

The RT300-S FES Bike® (Figure 3.5) provides repetitive neural activity to induce stimulation of the central nervous system. The RTS 300-S bike delivers a consistent,
reliable therapy using electrical stimulation via electrodes that are placed on the gluteus maximi, the hamstrings, and the quadriceps muscles to maximize muscle contractions in a coordinated pattern that results in “bike peddling” that is either active or passive. It has been shown to improve overall health, improve cardiovascular fitness, increase circulation, improve range of motion and flexibility, increase energy, decrease spasticity, prevent the formation of deep vein thrombosis, and prevent muscle atrophy. It requires no wheelchair transfer, as the wheelchair is used in conjunction with the apparatus.

Figure 3.4  Easy Stand Evolv Glider® (Altimate Corporation)
Data Collection

Data were collected for the original study using the ASIA Exam (ASIA, 2002), MMT (Kendall, et al., 2005), the MSES (Middleton, et al., 2003), and the CI-SCIM (Catz, et al., 2001). Data for the MMT were collected by an independently contracted certified ASIA evaluator who tested each study participant individually. The MMT evaluator was not otherwise involved in the research study. Data for the MSES were collected via study participant self-reports during interviews by the researcher. Data for the CI-SCIM were collected by the researcher using direct observations of attempts at physical tasks identified on the CI-SCIM. Data were collected at baseline and at three months and six months (the conclusion of the study).
The Nurse-Coached Exercise Program

The nurse-coached exercise program occurred over a two-year period of time with a six-month exercise intervention occurring for each participant. This allowed the researcher to evaluate changes in the dependent variables from baseline and then, following introduction of the intervention, at midpoint and endpoint of the study (Kazdin, 1998). In subsequent months of program participation, the interventions were intensified (time and resistance) as tolerated by the study participants. This enabled the researcher to evaluate changes in the dependent variables and closely monitor any complications or unexpected events.

Intervention Integrity

Each study participant was assigned a study number. All data were recorded, stored, and reported using that number, protecting participant confidentiality. The integrity of the intervention was maintained through a defined plan of exercise (the independent variables) for each study participant (Sunderland, 1990). The occurrence, duration, and intensity of each exercise were recorded on a “workout log.” Logs were reviewed after each session for accuracy and consistency. If an exercise component was skipped, a notation was made in the log stating the reason for the omission. At the conclusion of the study, logs were reviewed to determine if any aspect of the exercise intervention had not been completed sufficiently – there were no insufficiencies found in the ten participants who completed the study.

Human Subjects Protection

The Shepherd Center (Atlanta) Research Review Board approved the original study for a twelve-month period of time and for an additional twelve-month continuation
(Appendix I). Each study participant provided informed consent (Appendix J).

Permission was granted by the Shepherd Center to mine data from the original study for this study (Appendix K). The Boston College Institutional Review Board granted an IRB exemption for this study. (Appendix L).

**Data Analysis**

Data that were analyzed for this study were from a database of ten single-subject spinal cord injured tetraplegic participants who each participated in a six-month coached exercise program (Shepherd, 2006). A secondary data analysis was performed to determine the effect of a nurse-coached exercise program on muscle strength, reported self-efficacy, and quality of life measures in persons with tetraplegic spinal cord injuries. In this study, changes in individuals were monitored over time to evaluate whether positive or negative events occurred as a result of the intervention and whether the nurse-coached intervention was causally linked to the changes in the individuals (Bloom, et al., 2003).

All comparison data was collected at baseline, and at three month and six months. To determine if muscle strength increased as a result of the nurse-coached study, MMT (Kendall, et al., 2005) baseline and probe results were compared using visual analysis. Visual analysis is the analytic method of single-subject design. It consists of examining the data to find patterns, beginning with baseline (A), where stability is determined and moving on to the intervention phase (B) where the magnitude of the effect (trend) is determined. (Figure 3.6 a,b,c). The end of the intervention is known as the final magnitude (Bloom, et. al., 2003). Discontinuity is the term used where there is a change
from baseline to intervention. Trend is the term used to describe the directionality of the data – increased, decreased, or no change.

To determine if muscle strength changed, results from baseline, three month, and six month (probe times) Manual Muscle Test measurements were evaluated. To determine if self-reported self-efficacy increased, MSES (Middleton, et al., 2003) scores from baseline and probe timelines were compared. To determine if quality of life improved, scores on the CI-SCIM tool (Catz, et al., 2001) from baseline were compared to probe timeline data.

Figure 3.6a  Example of Trends
Each study subject served as his/her own baseline. Participants in this study and the researcher did not compare the MMT baseline or three-month measurements until the conclusion of the study so as not to influence exercise participation, effort, duration, or intensity. Data obtained from the MMT, MSES, and CI-SCIM had not been previously analyzed. A secondary analysis of the MMT, MSES, and CI-SCIM data were completed to answer the research questions presented in Chapter 1.
Summary

The research methodology for the SCI-FIVE study has been reviewed. The data obtained using the research methodology outlined in this chapter will be analyzed in Chapter 4 to answer the study’s three research questions.
CHAPTER 4

Findings

Introduction

The purpose of this chapter is a report of the analysis of data. The first part of the chapter will focus on a description, demographics, and spinal cord injury information about the participants enrolled in the study.

Establishment of baseline stability, a key component of SSD, was reviewed in Chapter 3. Baseline stability results of each study participant will be presented as defined by SSD. The dependent variables responses to the exercise intervention will also be presented for each individual study participant. In addition, an aggregate presentation of participant’s responses to the exercise intervention and statistical analysis will be presented. Reliability data for the measurement instruments used in this study are reported in this chapter. The chapter will conclude with a response to the research questions posed in Chapter 1.

Description of the sample

Initially thirteen tetraplegic spinal cord injured people referred by self, peers, or health care professionals, were identified by the researcher as meeting the criteria for inclusion in the study (Table 4.1). These thirteen potential participants met with the researcher to learn about the study and the requirements for participation. Potential participants met at the exercise intervention site. Each met the cognitive inclusion criteria, provided informed consent, and letters and prescriptions from their primary care physicians granting permission for study participation. attesting to ongoing good health,
and providing written prescriptions for use of the functional electrical stimulation (FES) bike and standing frame.

Table 4.1

Profile of Study Participants

<table>
<thead>
<tr>
<th>Subject</th>
<th>Age</th>
<th>Sex</th>
<th>Years from Injury</th>
<th>Level</th>
<th>SCI</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>20</td>
<td>F</td>
<td>2</td>
<td>C-5</td>
<td>Complete</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
<td>F</td>
<td>2</td>
<td>C-5</td>
<td>Complete</td>
</tr>
<tr>
<td>3</td>
<td>27</td>
<td>M</td>
<td>2.5</td>
<td>C-4</td>
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</tr>
<tr>
<td>4</td>
<td>23</td>
<td>F</td>
<td>3</td>
<td>C-6</td>
<td>Complete</td>
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<tr>
<td>5</td>
<td>27</td>
<td>M</td>
<td>1.5</td>
<td>C-6</td>
<td>Incomplete</td>
</tr>
<tr>
<td>6</td>
<td>20</td>
<td>M</td>
<td>1.5</td>
<td>C-5</td>
<td>Complete</td>
</tr>
<tr>
<td>7</td>
<td>26</td>
<td>M</td>
<td>3</td>
<td>C-6</td>
<td>Incomplete</td>
</tr>
<tr>
<td>8</td>
<td>39</td>
<td>M</td>
<td>18</td>
<td>C-4/5</td>
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</tr>
<tr>
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<td>29</td>
<td>M</td>
<td>1</td>
<td>C-6</td>
<td>Complete</td>
</tr>
<tr>
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<td>41</td>
<td>F</td>
<td>22</td>
<td>C-7</td>
<td>Complete</td>
</tr>
<tr>
<td>11</td>
<td>42</td>
<td>F</td>
<td>1.5</td>
<td>C-6</td>
<td>Incomplete</td>
</tr>
<tr>
<td>12</td>
<td>49</td>
<td>M</td>
<td>4</td>
<td>C-4</td>
<td>Complete</td>
</tr>
<tr>
<td>13</td>
<td>42</td>
<td>F</td>
<td>1.5</td>
<td>C-6</td>
<td>Incomplete</td>
</tr>
</tbody>
</table>

* Dropped out due to chronic unresolved health issues
** Dropped out due to unfavorable family issues

Three participants withdrew early in the intervention phase – two due to ongoing unresolved medical issues that were not articulated at the start of the study, and one due to family issues that resulted in inability to provide transportation to and from the study site. A total of six men and four women completed the study. No adverse events or
complications as a result of the exercise intervention were experienced during the study phases. Thus, the final sample size reported in this study was ten (n = 10) participants.

The mean age of the study participants was 27.2 years +/- 13.8, median age was 27 (range 20 to 41 years). One participant was married, one was engaged to be married, and eight were single. Eight participants lived with relatives/spouses: one with a spouse, six with parents, one with siblings, and two lived independently. Family members provided support by performing or assisting with activities of daily living and transporting participants to the study site. One participant relied on a hired care giver for assistance and took public transportation to the study site. Two participants could perform their own activities of daily living and were able to drive themselves to the study site. One of the study participants was able to self-drive to the study site half way through the study when he became able to transfer from his wheelchair to his vehicle unassisted.

None of the participants lived in extended/long term care environments or subsidized public housing. Eight of the participants lived at home or in an addition of the family home. Two participants lived independently in their own homes.

The mean educational level of the sample was 13.7 years, +/- 3.3 years (range 12 to 17 years). Participants were able to read all of the documents related to the study. Three participants reported working part time and three reported attending college (part time). By the conclusion of the study one participant reported working full time, one participant reported working full time and attending college classes part time, two reported working part time and attending college classes part time, one reported working part time, and five reported attending college classes – two full time and three part time.

It should be noted that the national average for tetraplegic spinal cord injured persons to
either attend school (at any grade or college level) or work (part time or full time) is less than 30% (Krause, et al., 1999).

The mean length of time since the spinal cord injury initial event was 5.7 years, +/- 16.5 years (range of 1 to 22 years). The median length of time since injury was 2.25 years. Regardless of the variability of the length of time since the initial injury, all participants were in relatively good health and anxious to begin the exercise intervention.

Baseline stability

A key component of single subject design methodology is to establish baseline stability prior to the intervention phase of the study. Because of the high intensity and length of time to complete data collection for the dependent variables that resulted in participant fatigue and because the dependent variables in tetraplegic spinal cord injured persons do not usually fluctuate, it was determined that if two sessions of data collection, with MMT data being collected by an independent evaluator and MSES and CI-SCIM data being collected by the researcher, demonstrated similar findings, the baseline of each participant would be considered stable and the intervention phase could commence.

Stability was determined by the researcher when 90% of the data points for a specific variable were within 10% of the mean score for that variable. Stability was determined by the researcher and confirmed by an independent evaluator prior to initiation of the intervention phase to minimize potential researcher bias and to solidify the design rigor.

Measurement of Dependent Variables

To answer the research questions, a visual analysis of baseline and intervention
probe times was completed to determine intervention magnitude effects on the variables of muscle strength, self-efficacy, and quality of life measures. The visual analyses completed for this study are presented in this chapter, and include both baseline and intervention phase data. Additionally, to supplement single subject analysis presentation, ANOVA results from the CI-SCIM (Quality of Life Measures) and the MSES (Self Efficacy) are presented to determine whether changes from baseline were statistically significant overall across the group of ten participants.

**Manual Muscle Test Results**

Research Question 1 asked, *What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on muscle strength?*

In accordance with single subject design methodology, each participant’s manual muscle scores are displayed individually. Muscles strength was scored from 0 to 5, where 0 = no activity, 1 = some slight movement, 2 = some movement without gravity, 3 = some movement against gravity, 4 = some movement against resistance, and 5 = normal movement. To avoid researcher bias, an independent evaluator not involved with the research intervention and who had not worked with the participants previously, gathered the data using the Manual Muscle Test (MMT) standard format and methodology. Because of the intensity and time involved in gathering data for the Manual Muscle Test and the high fatigue factor for participants, participants were tested twice to establish a stable baseline, and then again at three months after the intervention had started and at six months, which was the conclusion of the study intervention period. Each of the ten study participants demonstrated a stable baseline. There are usually not significant improvements observed in muscle strength in persons with spinal cord injuries
more than a year post injury without the benefit of interventions. All muscle strength measurements reported for this study began at the lowest level of the spinal cord innervation where “normal” (defined as strength measured as 5) function of a muscle was observed and continued caudally to the level where there was no muscle strength (measured as 0) on each individual participant. Evidence that increased muscle strength enhances one’s ability to perform activities that improve quality of life will be demonstrated in the reported data analysis from the Catz-Itzkovich Spinal Cord Independence Measures.

Visual analyses were used to compare data from baseline to the intervention phases. Single subject design draws its strength from the pictorial/visual nature of the data as it is applied to a single person. When a dependent variable’s value is increasing over time (a positive trend) neither the mean nor the median will provide an accurate summary for that individual. Strong visual evidence is confirmed when the dependent variable’s value changes significantly from baseline.

*Manual Muscle Test Results for Participant #1*

Study participant #1 was a 20 year old female who sustained a C-5 complete spinal cord injury two years prior to the research study. Figures 4.1a – 4.14 b and Table 4.2 display her MMT scores at baseline, and at three months and six months after the intervention had been initiated. The muscles of her neck were all scored “5” at baseline and are, therefore, not displayed in graphs. Scores of muscles of her scapula, shoulder, elbow, wrist, and fingers are displayed. Muscles of her back, legs, and feet (below the level of her injury) were all scored at “0” (no strength) at baseline and are, therefore, not displayed.
There were upward trends in muscle strength in twenty of thirty muscles at three months. Eight of these muscles continued trending upward at six months and an additional five muscles that demonstrated no upward trends between baseline and three months demonstrated upward trends at six months. Four muscles demonstrated normal strength at three months and three additional muscles improved to normal strength at six months. Her deltoid and biceps muscles of her arms demonstrated the greatest magnitude of upward trends. Generally, when her muscles increased in strength, they improved bilaterally.

In addition to increased muscle strength in her shoulders, arms, elbows, and fingers that resulted in improved quality of life measures, she was able to return to her passion for horses and riding. Because of the newly acquired increase in muscle strength in her upper body, this accomplished equestrian was able to drive and handle an adapted horse-drawn buggy.

*Manual Muscle Test Results – Participant #1 (Figures 4.1a – 4.14b)*

![Graphs showing MMT Score over time for Middle Trapezius - Left and Middle Trapezius - Right muscles.](https://example.com/graphs.png)

Figure 4.1a *Middle Trapezius – Left*  
Figure 4.1b *Middle Trapezius - Right*
Figure 4.2a. Lower Triceps - Left

Figure 4.2b. Lower Trapezius - Right

Figure 4.3a. Anterior Serratus - Left

Figure 4.3b. Anterior Serratus - Right

Figure 4.4a. Rhomboid - Left

Figure 4.4b. Rhomboid - Right

Figure 4.5a. Shoulder Medial Rotator

Figure 4.5b. Shoulder Medial Rotator - Right
Figure 4.10a  Biceps - Left

Figure 10b. Biceps - Right

Figure 4.11a  Triceps - Left

Figure 4.11b  Triceps - Right

Figure 4.12a  Extensor Carpi Radialis - Left

Figure 4.12b  Extensor Carpi Radialis - Right

Figure 4.13a  Flexor Digitorum Profundus - Left

Figure 4.13b  Flexor Digitorum Profundus - Right
Figure 4.14a  *Flexor Pollicus Longus - Left*

Figure 4.14b  *Flexor Pollicus Longus - Right*
Table 4.2

**Summary of Study Participant # 1’s Muscle Strength Trends**

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↑↑ increase in muscle strength (two levels)

↑↑↑ increase in muscle strength (three levels)

↑↑↑↑ increase in muscle strength (four levels)
Manual Muscle Test Results for Participant #2

Participant #2 was also a twenty year-old female who sustained a C-5 complete injury two years prior to the exercise intervention. Figures 4.15a – 4.28b and Table 4.3 display her MMT scores at baseline, and at three months and six months after the intervention had been initiated. The muscles of her neck were all scored “5” at baseline, and are, therefore, not displayed in graphs. Muscles of her fingers, thumb, back, legs, and feet (below the level of her injury) were all scored at “0” at baseline and throughout the study and are, therefore, not displayed in graphs.

Of the twenty muscles tested and reported on Participant #2, four muscles tested normal at baseline. Seven muscles trended upward at three months and, of those seven muscles, five increased to normal strength. At six months, five of the muscles that trended upward at three months continued to trend upward, plus four additional muscles increased strength at six months. One muscle that tested normal at baseline experienced a downward trend at three months, possibly due to fatigue, as this muscle returned to normal strength at six months.

Muscles that improved in strength were located in her shoulders, chest, arms, and wrists. Because of these muscle strength changes, in addition to her increased quality of life measurements, her voice quality improved significantly. At the start of the study, her voice volume was barely audible, causing her embarrassment and frustration. By the completion of the exercise program, her voice volume had increased significantly and she
could be heard at moderate distances. Her self-confidence increased and she enrolled in college courses.

**Manual Muscle Test Results – Participant #1 (Figures 4.15a – 4.28b)**

Figure 4.15a  *Upper Trapezius - Left*

Figure 4.15b  *Upper Trapezius - Right*

Figure 4.16a  *Lower Trapezius - Left*

Figure 4.16b  *Lower Trapezius - Right*

Figure 4.17a  *Serratus Anterior - Left*

Figure 4.17b  *Serratus Anterior - Right*
Figure 4.18a *Rhomboid - Left*

Figure 4.18b *Rhomboid - Right*

Figure 4.19a *Pectoralis Clavicular - Left*

Figure 4.19b *Pectoralis Clavicular - Right*

Figure 4.20a *Shoulder Medial Rotator - Left*

Figure 4.20b *Shoulder Medial Rotator - Right*

Figure 4.21a *Shoulder Lateral Rotator - Left*

Figure 4.21b *Shoulder Lateral Rotator Right*
Figure 4.22a *Anterior Deltoid - Left*

Figure 4.22b *Anterior Deltoid - Right*

Figure 4.23a *Middle Deltoid - Left*

Figure 4.23b *Middle Deltoid - Right*

Figure 4.24a *Posterior Deltoid - Left*

Figure 4.24b *Posterior Deltoid - Right*

Figure 4.25a *Biceps - Left*

Figure 4.25b *Biceps - Right*
Table 4.3

Summary of Study Participant #2’s Muscle Strength Trends

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↑↑ increase in muscle strength (two levels)
↓ decrease in muscle strength (one level)
M maintained level from previous measurement
N normal (5) muscle strength

Manual Muscle Test Results for Participant #3

Participant #3 was a 27 year-old male who had sustained a C-4 incomplete spinal cord injury two and a half years prior to the intervention. He demonstrated normal strength in the muscles of his neck and variable strength in the muscles of his scapulae, shoulders, elbows, wrists, fingers thumb, legs, feet, and toes at baseline. He was not
ambulatory at baseline. Figures 4.29a – 4.48b and Table 4.4 display his muscle strength results.

Thirty-eight muscles were tested because this participant had an incomplete spinal cord injury and there was evidence of some muscle strength below the level of his injury. Seventeen muscles experienced an upward trend at three months, with seven muscles returning to normal strength. Of those muscles that experienced an upward trend at three months, eleven muscles continued an upward trend at six months. In addition, five muscles not experiencing changes at three months, experienced muscle strength improvements at six months. Two muscles that demonstrated a downward trend from baseline to three months returned to baseline at six months. This may be attributed to muscle fatigue.

The muscles of his scapulae, shoulders, wrists, hands/fingers, thumbs, hips, upper legs, and toes demonstrated upward strength trends. As a result of these muscle strength improvements, his quality of life measures increased including his ability to stand independently for extended periods of time, take several steps unassisted, walk fifty yards with bilateral assistance, and navigate a flight of stairs.

Manual Muscle Test Results – Participant #3 (Figures 4.29a,b – 4.48b)

![Figure 4.29a Lower Trapezius - Left](image)

![Figure 4.29b Lower Trapezius - Right](image)
Figure 4.34a  Triceps - Left

Figure 4.34b  Triceps - Right

Figure 4.35a  Supinators - Left

Figure 4.35b  Supinators - Right

Figure 4.36a  Flexor Carpi Radialis - Left

Figure 4.36b  Flexor Carpi Radialis - Right

Figure 4.37a  Extensor Digiti - Left

Figure 4.37b  Extensor Digiti - Right
Figure 4.38a  *Lumbricales - Left*

Figure 4.38b  *Lumbricales - Right*

Figure 4.39a  *Flexor Policus Longus - Left*

Figure 4.39b  *Flexor Policus Longus - Right*

Figure 4.40a  *Extensor Policus Longus - Left*

Figure 4.40b  *Extensor Policus Longus - Right*

Figure 4.41a  *Abductor Policus Longus - Left*

Figure 4.41b  *Abductor Policus Longus - Right*
Table 4.4

Summary of Study Participant #3’s Muscle Strength Trends

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Manual Muscle Test Results for Participant #4

Participant #4 was a 23 year-old female, who sustained a C-6 complete spinal cord injury three years prior to the start of the intervention. Neck and shoulder muscles all demonstrated normal strength at baseline and throughout the intervention. She had no movement or sensation in her thumb, back, legs, feet, and toes. Figures 4.49a – 4.54b and Table 4.5 display her MMT results. She had strong shoulder and arm strength at baseline. Eight additional muscles were tested. All eight muscles demonstrated no strength at baseline and seven of those muscles demonstrated an upward trend at three months. Most impressive was the magnitude of the upward trend (five levels) in her bilateral external carpi radii (wrist) muscles that enable wheelchair transfers. Muscles that demonstrated increased strength were located in her elbows, wrists, and fingers, resulting in improved quality of life measures.

A total of sixteen muscles were tested and results reported. Four of the muscles tested at baseline demonstrated normal strength. Five muscles demonstrated increased muscle strength at three months that were maintained at six months. In addition, one muscle experienced a positive trend at six months.
Manual Muscle Test Results – Participant #4 (Figures 4.49a – 4.54b)

Figure 4.49a  Biceps - Left

Figure 4.49b  Biceps - Right

Figure 4.50a  Triceps - Left

Figure 4.50b  Triceps - Right

Figure 4.51a  Extensor Carpi Radialis - Left

Figure 4.51b  Extensor Carpi Radialis - Right

Figure 4.52a  Flexor Carpi Radialis - Left

Figure 4.52b  Flexor Carpi Radialis - Right
Table 4.5

Summary of Study Participant #4’s Muscle Strength Trends

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↑↑↑ increase in muscle strength (three levels)
↑↑↑↑↑ increase in muscle strength (five levels)
M maintained level from previous measurement
N normal (5) muscle strength
Manual Muscle Test Results for Participant #5

Participant #5 was a 27 year old male who sustained a C-6 incomplete spinal cord injury one and a half years prior to the exercise intervention. His baseline, three, and six-month MMT scores for muscles in his neck and shoulders all demonstrated normal strength. Muscles of his elbows, wrists, fingers thumbs, and legs demonstrated variable strength at baseline. A display of his MMT scores can be found in Figures 4.55a – 4.62b and Table 4.6.

As a result of these muscle strength improvements in his elbows, fingers, and legs, he was able to accomplish transfers from his wheelchair to his truck, enabling him to drive independently, transport himself, and allow him to volunteer as a service dog trainer.

Manual Muscle Test Results – Participant #5 (Figures 4.55ab – 4.62ab)
Figure 4.61a *Hamstring - Left*

Figure 4.61b *Hamstring - Right*

Figure 4.62a *Gastrocnemius Soleus - Left*

Figure 62.b *Gastrocnemius Soleus - Right*
Table 4.6

Summary of Study Participant #5’s Muscle Strength Trends

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<tr>
<td>Gastroc Soleus</td>
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</tr>
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</table>

-- no change from previous measurement
↑ increase in muscle strength (one level)
M maintained level from previous measurement
N normal (5) muscle strength

Muscle Test Results for Participant #6

Participant #6 was a 20 year old male who sustained a C-5 complete injury one and a half years prior to the exercise intervention. Neck, scapula, and shoulder muscles demonstrated normal strength. Muscles of the thumb, lower torso, legs, and feet demonstrated no strength from baseline to completion of the intervention. Ten other muscles, located in his elbows, wrists, and fingers were tested. His results are displayed in Figures 4.63a – 4.72b and Table 4.7.
Of the eighteen muscles that were tested and results reported, two tested normal at baseline. Eleven demonstrated an upward trend at three months, with seven continuing to trend upward at six months. An additional three muscles trended upward at six months. Four muscles increased to normal strength.

Muscles in his shoulders, arms, and wrists increased in strength, which resulted in increased quality of life measures. Anecdotally, his vital capacity increased, which helped him to project his singing voice. He was able to return to college out-of-state as a fulltime theater major, participating in several productions and singing in his university chorale and other singing groups. After college graduation, he moved to California where he is pursuing a career in theater/film as an actor.

*Manual Muscle Test Results – Participant #6 (Figures 4.63a – 4.72b)*
Figure 4.69a  Biceps - Left

Figure 4.69b  Biceps - Right

Figure 4.70a  Triceps - Left

Figure 4.70b  Triceps - Right

Figure 4.71a  Extensor Carpi Radialis - Left

Figure 4.71b  Extensor Carpi Radialis - Right

Figure 4.72a  Flexor Digiti Profundus - Left

Figure 4.72b  Flexor Digiti Profundus - Right
Table 4.7

*Summary of Study Participant #6’s Muscle Strength Trends*

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-- no change from previous measurement  
↑ increase in muscle strength (one level)  
↑↑ increase in muscle strength (two levels)  
M maintained level from previous measurement  
N normal (5) muscle strength

*Muscle Test Results for Participant #7*

Participant #7 was a 26 year-old male who sustained a C-6 incomplete spinal cord injury three years prior to the exercise intervention. All the muscles of his neck, scapulae, and shoulders demonstrated normal strength at baseline. Muscles of his arms, elbows,
wrist, fingers, thumbs, legs, and feet demonstrated variable strength at baseline. Results of his MMT are displayed in Figures 4.73a -4.85b and Table 4.8.

Because this study participant had an incomplete injury and some “spotty” muscle strength in some muscles below the level of his injury, twenty muscles were tested. Eight muscles demonstrated increased muscle strength (to normal) at three months. Four muscles tested normal at baseline. Three other muscles demonstrated increased trends at three months. Two additional muscles demonstrated an upward trend at six months. Because he had an incomplete injury, it is believed that the response to normal for many muscles was due to the evoked potential the exercise program elicited, especially on the right side of is body.

Muscles that demonstrated increased strength were located in his arms, wrists, right thumb, back, right lower leg, and perineum. These increases in muscle strength resulted in higher quality of life measures. After the study he completed an MBA, married, and became a father. He works full time in finance.

*Manual Muscle Test Results – Participant #7 (Figures 4.73a – 4.85b)*

![Figure 4.74a Triceps - Left](image)

![Figure 4.74b Triceps - Right](image)
Figure 4.75a  *Anterior Deltoid - Left*

Figure 4.75b  *Anterior Deltoid - Right*

Figure 4.77a  *Medial Deltoid - Left*

Figure 4.76b  *Medial Deltoid - Right*

Figure 4.78a  *Posterior Deltoid - Left*

Figure 4.78b  *Posterior Deltoid - Right*

Figure 4.73a  *Biceps - Left*

Figure 4.73b  *Biceps - Right*
Table 4.8

Summary of Study Participant #7 Muscle Strength Trends

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<td>6 mo</td>
<td>BL 2</td>
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</tr>
</tbody>
</table>

-- no change from previous measurement
↑ increase in muscle strength (one level)
↑↑ increase in muscle strength (two levels)
M maintained level from previous measurement
N normal (5) muscle strength
Muscle Test Results for Participant #8

Participant #8 was a 39 year old male who sustained a C-4/5 complete injury eighteen years prior to the exercise intervention. He was the most severely injured of the study participants. He had normal muscle strength in his neck and shoulder muscles, but other muscle responses were limited to his elbows, wrists, and one finger. He had no strength in his other fingers, thumbs, back, legs, feet, or toes. Results of his MMT are displayed in Figures 4.86a – 4.88b and Table 4.9.

This participant demonstrated that, despite his very high level of injury and two decades since his original injury, he was able to experience some limited gains in muscle strength in those muscles with no strength at baseline. This limited improvement provided a significant psychological boost for this study participant and increases his self-reported self-efficacy beliefs. He enrolled in online college courses with the intention of attending courses on a college campus once he was assured he could complete all required course work. His goal is to become a high school history teacher.

Manual Muscle Test Results – Participant #8 (Figures 4.86a – 4.88b)

Figure 4.86a  Biceps - Left

Figure 4.86b  Right
Summary of Study Participant #8’s Muscle Strength Trends

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<td>Triceps</td>
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<tr>
<td>Ext Carp Rad</td>
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<td>Ext Digiti</td>
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</tr>
</tbody>
</table>

-- no change from previous measurement
↑ increase in muscle strength (one level)
M maintained level from previous measurement
N normal (5) muscle strength
Muscle Test Results for Participant # 9

Participant #9 was a 29 year-old male who sustained a C-6 complete injury one year prior to the exercise intervention. His neck, scapula, and shoulder muscles demonstrated normal strength at baseline. There was no demonstrated strength in muscles of his back, legs, feet, and toes at baseline. His MMT results are displayed in Figures 4.89a – 4.99b and Table 4.10.

Besides those muscles that were determined to be normal at baseline and those that demonstrated no strength at baseline, six additional muscles were tested and reported. All six of the muscles demonstrated increased strength at three months. Two muscles experienced additional strength increases at six months. Two of these muscles demonstrated normal strength. Muscles that demonstrated improvements were located in the upper arms, elbows, and wrists.

Eighteen muscles were tested for strength. Three muscles tested normal at baseline. No muscles demonstrated increased strength at three months. Nine muscles demonstrated increased strength at six months, including three that increased to normal. Muscles that demonstrated increased strength were located in his the upper arms, elbows, wrist, fingers, and thumbs. The effects of muscle strength increases improved his quality of life measures. This study participant was a manual laborer up to the time of his injury. With the recommendation of a study volunteer, he procured a job in a college admissions department and enrolled in college courses, hoping to become a high school teacher. The participant’s “delayed” strength improvement results raise the issue of non-predictability in the time it takes for a muscle to improve its strength when it is being exercised.
Manual Muscle Test Results – Participant #9 (Figures 4.89a – 4.99b)

Figure 4.89a  Biceps - Left

Figure 4.89b  Biceps - Right

Figure 4.90a  Triceps - Left

Figure 4.90b  Triceps - Right

Figure 4.90a  Extensor Carpi Radialis

Figure 4.90b  Extensor Carpi Radialis - Right
Figure 4.98a  *Extensor Policus Longus - Left*

Figure 4.98b  *Extensor Policus Longus - Right*

Figure 4.99a  *Abductor Policus Longus - Left*

Figure 4.99b  *Abductor Policus Longus - Right*
Table 4.10

*Summary of Study Participant #9’s Muscle Strength Trends*

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<td>Ext Carp Rad</td>
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<td>Flexor Dig Prof</td>
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<tr>
<td>Flexor Pol Long</td>
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<tr>
<td>Flexor Pol Brev</td>
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</tr>
</tbody>
</table>

-- no change from previous measurement  
↑ increase in muscle strength (one level)  
M maintained level from previous measurement  
N normal (5) muscle strength

*Manual Muscle Test Results for Participant #10*

Participant #10 was a 41 year old female who sustained a C-7 complete spinal cord injury twenty-two years prior to the exercise intervention. Her neck, scapulae, shoulder and elbow muscles demonstrated normal strength at baseline. Her leg, feet, and toes muscles demonstrated no strength at baseline. Her MMT results are displayed in Figures 4.100a – 4.114b and Table 4.11.
This participant was the most independent of all study participants. Thirty muscles were tested. Neurological deficits were greater on her right side than her left side. One muscle tested normal at baseline, fourteen muscles exhibited positive trends at three months, with one muscle achieving normal strength, and two muscles in her right wrist achieved three levels of improvement. Eight muscles demonstrated increased strength at six months. One of those muscles increased strength at three months, then decreased to baseline level at six month.

Muscles that demonstrated increased strength were in her wrists, fingers, thumb, back and chest. Although her quality of life measures did not increase (because she was already very independent), her self-efficacy beliefs increased. Increased muscle strength in her back and chest allowed her to bend over while sitting in her wheelchair to retrieve objects off of the floor – not something that is measured in the CI-SCIM.

Manual Muscle Test Results – Participant #10 (Figures 4.100a – 4.114b)

Figure 4.100a  *Extensor Carpi Radialis - Left*

Figure 4.100b  *Extensor Carpi Radialis - Right*
Figure 4.101a  Flexor Carpi Radialis - Left

Figure 4.101b  Flexor Carpi Radialis - Right

Figure 4.102a  Flexor Digitorum Profundus - Left

Figure 4.102b  Flexor Digitorum Profundus - Right

Figure 4.103a  Extensor Digitorum - Left

Figure 4.103b  Extensor Digitorum - Right

Figure 4.104a  Lumbricales - Left

Figure 4.104b  Lumbricales - Right
Figure 4.113a  *External Obliques - Left*

Figure 4.113b  *External Obliques - Right*

Figure 4.114a  *Internal Obliques - Left*

Figure 4.114b  *Internal Obliques - Right*
Table 4.11

*Study Participant #10 Muscle Strength Trends*

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<tr>
<td>Flex Carpi Rad</td>
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-- no change from previous measurement  
↑ increase in muscle strength (one level)  
↑↑↑ increase in muscle strength (three levels)  
↓ decreased in muscle strength (one level)  
M maintained level from previous measurement  
N normal (5) muscle strength
Combined results of manual muscle testing of all participants (Table 4.12)

The answer to research question number one, “What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on muscle strength?” was found by visual analysis of individual participant’s Manual Muscle Test score graphs and analysis of the combined data of the ten study participants (Table 4.12). Muscle strength improved in each of the ten study participants as a result of participation in this nurse-coached exercise program (Table 4.13).

Table 4.12

Combined Data of Manual Muscle Test Scores

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<th>Improved</th>
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<th>2 levels</th>
<th>3 levels</th>
<th>4 levels</th>
<th>5 levels</th>
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A total of two hundred twenty four muscles were tested and reported at four
different probe times. Of the total, thirty (30) tested normal at baseline, fifty (50) had no strength at baseline, and one hundred forty four (144) demonstrated some strength at baseline. Of those muscles that demonstrated some strength (but not normal) at baseline, 108 (75%) experienced increased muscle strength during or at the conclusion of the intervention. More than half (66%) of the muscles tested that demonstrated no strength at baseline that were adjacent to muscles demonstrating some strength at baseline, demonstrated some improvement during or at the conclusion of the study. These results were consistent in each participant, regardless of the number of the time lapse since the original injury.

Table 4.13

Changes in Muscles Strength

<table>
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<tr>
<th>Participant #</th>
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<th># Decreased Strength</th>
<th># Increased Strength</th>
<th>% Improved</th>
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<td>16</td>
<td>80%</td>
</tr>
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<td>6</td>
<td>38%</td>
</tr>
<tr>
<td>6</td>
<td>18</td>
<td>0</td>
<td>13</td>
<td>72%</td>
</tr>
<tr>
<td>7</td>
<td>26</td>
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<td>54%</td>
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<td>0</td>
<td>6</td>
<td>33%</td>
</tr>
<tr>
<td>9</td>
<td>18</td>
<td>0</td>
<td>9</td>
<td>50%</td>
</tr>
<tr>
<td>10</td>
<td>30</td>
<td>0</td>
<td>16</td>
<td>53%</td>
</tr>
</tbody>
</table>
Catz-Itzkovich Spinal Cord Independence Measures (CI-SCIM)

Research Question 2 asked, *What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on quality of life measures?*

The current CI-SCIM (Appendix C) consists of eighteen measurements (Catz, et al, 2001). The measures are divided into three sub-scales: self-care, respiratory and sphincter management, and mobility. Self-care consists of six items that address feeding, bathing (upper and lower body), dressing (upper and lower body), and grooming. Respiration and sphincter management has four items addressing breathing, bladder management, bowel management, and use of toilet. Mobility has eight items addressing mobility in bed, bed-to-wheelchair transfers, wheelchair-to-tub/toilet transfers, indoor mobility, moderate distance mobility, outdoor mobility, stairs management, and wheelchair-to-car transfers. The response in each item is scored based on degree of difficulty. Scores in self-care items range from 0 to 20. Scores in breathing/sphincter management items range from 0 to 40. Scores in mobility items range from 0 to 40. Total scores can range from 0 to 100 (Catz, et al., 2001).

The following are scores for the ten participants in each of the three categories. Complete scores for all items can be found in Appendix K. Cronbach’s alpha (Table 4.14) were high for self-care and mobility. As anticipated, Cronbach’s alpha were low for respiratory because all ten participants were not on ventilators nor did they require ventilatory assistance. All were able to breathe on their own, which was a requirement for inclusion in the study. There were similar low Cronbach’s alphas for sphincter (bowel,
bladder, and toilet) as individual scores on these items were very similar (most did not have bowel and bladder function or toileting abilities).

Table 4.14

*Cronbach’s Alpha for CI-SCIM Combined scores*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Baseline 1</th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-care</td>
<td>0.97</td>
<td>0.97</td>
<td>0.95</td>
<td>0.95</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>0.42</td>
<td>0.53</td>
<td>0.53</td>
<td>0.51</td>
</tr>
<tr>
<td>Mobility</td>
<td>0.87</td>
<td>0.87</td>
<td>0.90</td>
<td>0.90</td>
</tr>
<tr>
<td>Total CI-SCIM</td>
<td>0.92</td>
<td>0.93</td>
<td>0.92</td>
<td>0.92</td>
</tr>
</tbody>
</table>

The following are results of the sub-categories on the Catz-Itzkovich Spinal Cord Independence Measures for each study participant. Individual item scores can be found in Appendix D.

*Participant #1 CI-SCIM results.* Participant #1’s (Figures 4.115-4.117 and Table 4.14) results are displayed below. The self care sub-scale was stable at baseline and improved by one point at three months. There were additional three point improvements noted at six months. Respiratory and sphincter scores remained unchanged throughout baseline and the intervention phases. There was a slight improvement in mobility at three months that remained the same at six months. These changes were reflected in the participant becoming more independent with feeding, grooming, and bathing and dressing her upper body with assistance. In addition she was able to participate slightly in moving in bed to prevent pressure sores.
CI-SCIM Results by Subscale – Participant #1 (Figures 4.115-4-117)

Figure 4.115 Self-Care - Participant #1

Figure 4.116 Respiratory and Sphincter - Participant #1

Figure 4.117 Mobility – Participant #1
Table 4.15

*Participant #1 CI-SCIM Trends*

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑</td>
<td>↑↑↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑</td>
<td>M</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑ Increase in level (one level)
↑↑↑ Increase in level (three levels)

*Participant #2 CI-SCIM Results.* Participant #2 (Figures 4.118-4.120, Table 4.16)) demonstrated a four point increase in self-care from baseline to three months and a one-point increase from three months to six months allowing her to groom herself with a little help, feed herself with adaptive equipment, bathe her upper body, and dress her upper body with assistance. There was no change in her respiratory and sphincter function. There was a one-point increase from baseline to three months and from three months to six months in mobility. This resulted because she became able to roll side to side in bed to prevent pressure sores.
CI-SCIM Results by Subscale – Participant #2 (Figures 4.118-4.120, Table 4.16)

Figure 4.118  Self-Care – Participant #2

Figure 4.119  Respiratory and Sphincter-Mobility – Participant #2

Figure 4.120  Mobility – Participant #2
Table 4.16

Participant #2 CI-SCIM Trends

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 Months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑↑↑↑</td>
<td>↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑</td>
<td>↑</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑ Increase in level (one level)
↑↑↑↑ Increase in level (four levels)

Participant #3 CI-SCIM Results. Participant #3 (Figures 4.12 – 4.13, Table 4.17) was a high functioning tetraplegic at the start of the study. At baseline he scored high in all self-care areas except dressing his lower body. At three months he achieved maximum independent function in dressing his lower body. His respiratory and sphincter scores remained high and stable from baseline to three and six months. His greatest gains were in the subcategory of mobility.

As the muscle strength in his back and legs increased, he was able to begin to ambulate at three months with maximum assistance, and at six months with minimal assistance. He also achieved climbing stairs, first with assistance at three months and then with minimal assistance at six months.
CI-SCIM Results by Subscale – Participant #3 (Figures 4.124-4-126, Table 4.17)

Figure 4.121 Self-Care – Participant #3

Figure 4.122 Respiratory and Sphincter - Participant #3

Figure 4.123 Mobility – Participant #3
Table 4.1  *Participant #3 CI-SCIM Trends*

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑</td>
<td>M</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑↑</td>
<td>↑↑↑↑↑↑↑↑↑↑</td>
</tr>
</tbody>
</table>

-- No change from previous measurement  
M Maintained level from previous measure  
↑ Increase in level (one level)  
↑↑↑ Increase in level (three levels)  
↑↑↑↑↑↑↑↑↑↑ Increase in level (ten levels)

*Participant #4 CI-SCIM Results* (Figures 4.124 – 4.126). Participant #4 demonstrated trend improvements in two sub-scales of the CI-SCIM. In self-care her scores improved by four points from baseline to three months and another three points from three months to six months. This was evidenced by her new abilities to feed herself and bathe her lower body with minimal assistance. She was also able to bathe her upper body with some assistance and to dress her upper body and groom herself with the assistance of adaptive devices, all of which improved from baseline measures that demonstrated that she was totally dependent for these activities.

This participant experienced increased independence in mobility as a result of improved muscle strength, allowing her to increase her bed mobility to prevent pressure sores, transfer independently from bed to wheelchair, transfer with some assistance from wheelchair to shower chair, and wheelchair to car, increase her outdoor mobility distance. After completing the study, she decided, after confirming with another study
participant, to undergo a surgical procedure that enabled her to self-catherize.

**CI-SCIM Results by Subscale – Participant #4 (Figures 4.127-4-129, Table 4.18)**

![Graph for Self-Care – Participant #4](image1)

**Figure 4.124  Self-Care – Participant #4**

![Graph for Respiratory and Sphincter - Mobility – Participant #4](image2)

**Figure 4.125 Respiratory and Sphincter - Participant #4**  **Figure 4.126 Mobility – Participant #4**
Table 4.18

**Participant #4 CI-SCIM Trends**

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td></td>
<td>↑↑↑↑</td>
<td>↑↑↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mobility</td>
<td></td>
<td>↑↑↑↑</td>
<td>M</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑↑↑ Increase in level (three levels)
↑↑↑↑↑ Increase in level (four levels)

**Participant #5 CI-SCIM Results** (Figures 4.127-129, Table 4.19). Participant #5 was a high-functioning tetraplegic at the start of the study. He increased his self-care skills slightly – as he became totally independent with feeding himself and grooming himself, and was able to improve from requiring total assistance with dressing his lower body to being able to dress his lower body with some assistance. His respiratory and sphincter scores remained the same from baseline to three months to six months. His transfers from wheelchair to shower chair, bed to wheelchair, and wheelchair to car became independent functions and he greatly improved his mobility in bed to prevent pressure sores.
CI-SCIM Results by Subscale – Participant #5 (Figures 4.127-4.129, Table 4.19)

Figure 4.127  Self-Care – Participant #5

Figure 4.128  Respiratory and Sphincter - Participant #5

Figure 4.129  Mobility – Participant #5
Table 4.19

*Participant #5 CI-SCIM Trends*

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>--</td>
<td>↑↑↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑↑↑↑</td>
<td>M</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑↑↑ Increase in level (three levels)
↑↑↑↑↑ Increase in level (four levels)

*Participant #6 CI-SCIM Results* (Figures 4.130-4.132). Participant #6 demonstrated increased independence in self-care measures in upper body dressing, feeding, and grooming. He was able to advance from using an indwelling catheter to intermittent catheterizations and his mobility indoors, at moderate distances, and outdoors improved slightly.

*CI-SCIM Results by Subscale – Participant #6* (Figures 4.130-4.132, Table 4.20)
Figure 4.131  
*Respiratory and Sphincter - Mobility – Participant #6*

**Participant #6 CI-SCIM Trends**

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑↑↑</td>
<td>↑↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>↑↑↑↑</td>
<td>M</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑</td>
<td>M</td>
</tr>
</tbody>
</table>

--  No change from previous measurement  
M  Maintained level from previous measure  
↑  Increase in level (one level)  
↑↑  Increase in level (two levels)  
↑↑↑  Increase in level (three levels)  
↑↑↑↑  Increase in level (four levels)

*Participant #7 CI-SCIM Scores* (Figures 4.133 – 4.135). Participant #7 was a
high functioning incomplete tetraplegic. Although his baseline scores in three sub-scales were high, he was able to demonstrate improvements in self-care feeding and dressing his lower body. His use of the toilet became independent, and his wheelchair to car transfers improved slightly.

*CI-SCIM Results by Subscale – Participant #7 (Figures 4.133-4-135, Table 4.21)*

**Figure 4.133**  *Self-Care – Participant #7* 

**Figure 4.134**  *Respiratory and Sphincter – Participant #7* 

**Figure 4.135**  *Mobility – Participant #7*
Table 4.21

Participant #7 CI-SCIM Trends

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑</td>
<td>↑↑↑</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measurement
↑ Increase in level (one level)
↑↑↑ Increase in level (three levels)

Participant #8’s CI-SCIM Results (Figures 4.136-4.138). Participant #8 had the least amount of change as the level of his spinal cord injury was high and complete. He experienced some slight improvements self-care in self-feeding and self-grooming where he was able to use adaptive devices to accomplish these two tasks. Because he was in a power chair and was unable to push his own wheelchair, his mobility scores remained the same from baseline through three months and six months.

CI-SCIM Results by Subscale – Participant #8 (Figures 4.136-4.138, Table 4.22)

![Figure 4.136 Self-Care – Participant #8](chart.png)
Table 4.22

*Participant #8 CI-SCIM Trends*

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑↑↑</td>
<td>M</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑↑↑ Increase in level (two levels)

*Participant #9’s CI-SCIM Results* (Figures 4.139-4.141). Participant #9 experienced changes in all items of the self-care sub-score. His overall self-care score improved by five points at three months and an additional point at six months. As anticipated, there was no change in his respiratory-sphincter sub-scale score. In the
mobility sub-scale, his mobility in bed to prevent pressure sores improved slightly.

CI-SCIM Results by Subscale – Participant #9 (Figures 4.139-4.141, Table 4.23)

Figure 4.139 Self-Care – Participant #9

Figure 4.140 Respiratory and Sphincter – Participant #9

Figure 4.141 Mobility – Participant #9
Table 4.23

Participant #9 CI-SCIM Trends

<table>
<thead>
<tr>
<th></th>
<th>Baseline 2</th>
<th>3 Months</th>
<th>6 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>--</td>
<td>↑↑↑↑</td>
<td>↑↑</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>↑</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>↑</td>
<td>↑↑↑↑↑</td>
</tr>
</tbody>
</table>

-- No change from previous measurement
M Maintained level from previous measure
↑ Increase in level (one levels)
↑↑ Increase in level (two levels)
↑↑↑ Increase in level (four levels)
↑↑↑↑↑ Increase in level (five levels)

Participant #10's CI-SCIM Scores (Figures 4.142–144, Table 4.24). Participant #10 was a high functioning tetraplegic at the start of the study. She was functioning at normal levels in half of the sub-category items at baseline. None of her scores in all subcategories of the CI-SCIM changed from baseline through the two other probe phases of the study.

CI-SCIM Results by Subscale – Participant #10 (Figures 4.142-4.144, Table 4.24)
Table 4.24

*Participant #10  CI-SCIM Trends*

<table>
<thead>
<tr>
<th></th>
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<th>3 Months</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Self-Care</td>
<td>N</td>
<td>M</td>
<td>M</td>
</tr>
<tr>
<td>Respiratory/Sphincter</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Mobility</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
</tbody>
</table>

--  No change from previous measurement
M  Maintained level from previous measure
↑  Increase in level (one level)
↑↑  Increase in level (two levels)
↑↑↑ Increase in level (three levels)

Figure 4.143  *Respiratory and Sphincter - Participant #10*

Figure 4.144  *Mobility – Participant #10*
CI-SCIM across participants: Analysis of Variance (ANOVA)

Justification. To determine whether CI-SCIM quality of life changes seen in individual single subjects (Table 4.25) were statistically significant overall across ten (10) participants, Repeated Measures Analysis of Variance (ANOVA) was conducted, with CI-SCIM and CI-SCIM Scales (Self Care, Respiratory and Sphincter Management, and Mobility) serving as the dependent variable in parallel analyses. Repeated Measures ANOVA was chosen because the goal was to determine directionality (improvement or decline) and magnitude of changes over time, without regard for the initial quality of life level of individual participants. With Repeated Measures ANOVA, individual differences in initial ability are accounted-for because the statistic is focused on determining change.

For this study, the two baseline points were measured prior to initiation of the intervention, along with a three-month assessment during the intervention and a six-month assessment at the conclusion of the intervention.

Repeated Measured ANOVA analysis provides both an overall F-value, with associated p-value, to assess whether any changes occurred over time overall, without regard for individual time points, which is important to the present study, Repeated Measured ANOVA analysis also provides the localizing pairwise comparisons crucial to assessing the efficacy of treatment. For example, if treatment resulted in a statistically significant benefit in CI-SCIM across the 10 participants, ANOVA results should indicate that (a) the two baseline measures were not significantly different from each other, and (b) the 6 month assessment at the conclusion of the intervention should be significantly higher than baseline. If baselines vary significantly, then it would not be possible to credit
Table 4.25

_Catz-Itzkovich Spinal Cord Independence Measures – All_

<table>
<thead>
<tr>
<th>Participant Number</th>
<th>Categories improved</th>
<th>Normal at baseline</th>
<th>Baseline Scores</th>
<th>Month 3</th>
<th>Month 6</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>5</td>
<td>1</td>
<td>26</td>
<td>28</td>
<td>31</td>
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<td>3</td>
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<td>70</td>
<td>73</td>
<td>83</td>
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<td>4</td>
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<td>25</td>
<td>33</td>
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<tr>
<td>10</td>
<td>0</td>
<td>7</td>
<td>70</td>
<td>70</td>
<td>70</td>
</tr>
</tbody>
</table>

or blame treatment for changes because no stability of measurement was established at baseline.

Therefore, both baseline 1 and baseline 2 must be similar before proceeding to further exploration of the effects of the intervention. Further, if the six-month measurements are not significantly improved compared to baseline, a strong statement cannot be made regarding the efficacy of intervention in significantly improving CI-SCIM scores.
Assumptions of ANOVA. The crucial assumption of ANOVA is independence. This crucial independence assumption is only met if scores from one participant are not influenced by the scores from another participant. The minor assumptions of ANOVA are related to the shape of the raw data: skew (tilt) kurtosis (peaked or flat), and equality of variance between groups. These assumptions are considered minor assumptions because ANOVA is robust against violations of the minor assumptions. In this context, robust means that the ANOVA false alarm rate stays near p < .05 regardless of the shape of the raw data. However, the power of ANOVA to objectively detect significant differences is fostered when the assumptions of ANOVA are met.

Fostering the Assumptions of ANOVA. The crucial ANOVA assumption of independence was fostered in the present study by testing participants individually, so that the scores from one participant would not be influenced by the scores from other participants. With few exceptions, data from the present one-group study did not demonstrate significant kurtosis or significant skew. Some data were significantly skewed. Linear transformations (Tukey, 1977) to re-express these skewed data as square root or log transformed variables failed to reduce skew below the threshold for statistical significance. Therefore, because significant skew could not be adequately ameliorated, and to foster interpretability of findings, data and analyses in the results chapter reflect untransformed raw values in tables, figures, and in text. Additionally, to provide convergent validity to the statistical conclusions regarding the efficacy of treatment, each ANOVA finding was confirmed by a non-parametric test, which is insensitive to skew violations.
Confirming ANOVA Findings: Non-Parametric Statistical Tests. Because minor assumptions of ANOVA were violated, each ANOVA result was confirmed by a non-parametric statistical test. Non-parametric test are parameter free, meaning that the statistic is based on rankings of data and not values on a measurement scale. Because non-parametric tests are based on rankings and not on scale values, non-parametric tests are insensitive to skew. Each overall repeated-measures ANOVA result was confirmed by the non-parametric Freidman’s test. Each ANOVA localizing pairwise comparison was confirmed by the non-parametric Wilcoxon sign-rank test.

Potential Confounds. Because of the possibility that ANOVA findings could be an artifact of confounding variables, each ANOVA finding for the MSES, CI-SCIM, and the CI-SCIM scales (Self-Care, Respiratory and Sphincter Management, Mobility) was replicated with participant age, sex, years since injury, level of spinal damage, and whether the injury was complete or incomplete included as covariates (ANCOVA). Because no potentially confounding variable or combination of potentially confounding variables changed the substantive findings regarding the efficacy of treatment, ANOVA results are presented without covariates.

Presentation. For each ANOVA comparison, the overall F-value and associated p-value are provided. The presentation of localizing pairwise comparisons are focused on determining whether (a) the two baseline measures were not significantly different from each other, and (b) the 6 month assessment at the conclusion of the intervention is significantly higher than baseline. Additionally, the 3-month outcomes are provided.

Findings are presented in text, tables, and graphical figures to foster appreciation of the effects of the intervention on CI-SCIM over time. Findings are expressed as means
and standard deviations (SD). ANOVA findings are presented as the F-values and the associated p-values for the overall analysis of four time points (baseline 1, baseline 2, 3 months, 6 months), in addition to the p-value associated with the key comparison of interest: 6 months versus baseline. For the non-parametric tests, p-values are provided for the Friedman test, the non-parametric Wilcoxon sign-rank test results are expressed as the p-value of the z-score. All comparisons were made at a statistical significance threshold of p < .05, indicating that the findings were rare enough to only occur less than one chance in twenty, if only chance was operating.

**CI-SCIM Results.** CI-SCIM results support the efficacy of the intervention. Repeated measures ANOVA indicated significant changes over time (F (3,27) = 16.5, p < .0001; Friedman = 26.7, p < .0001). Localizing pairwise comparisons revealed that baseline 1 and baseline 2 were identical (M = 42.2, SD = 21.6). At 3 months, scores rose 3.9 points from baseline, to 46.1 (SD = 20.3), a statistically significant improvement (p < .01, ANOVA and Wilcoxon). At 6 months, the average score of 51.1 was 8.9 points above baseline, (p < .01, ANOVA and Wilcoxon) and 5.0 points above the 3 month assessment (p < .02, ANOVA and Wilcoxon). Combined, these findings indicate that CI-SCIM values were stable at baseline, improved significantly by the 3-month assessment, then significantly increased from 3 months to 6 months (Figure 4.145; Table 4.25).

Because the CI-SCIM was statistically significant overall, locating effects within the three CI-SCIM scales was important. Each of the three CI-SCIM scales (Self Care, Respiratory and Sphincter Management, Mobility) were evaluated in parallel, using the identical Repeated Measures ANOVA statistics used to evaluate the overall CI-SCIM.
Self Care, Respiratory and Sphincter Management, and Mobility are each presented with text and a figure to foster appreciation of the effects of the intervention on quality of life.

*Self-Care CI-SCIM Results.* CI-SCIM Self-Care results support the efficacy of the intervention. Repeated measures ANOVA indicated significant changes over time ($F(3,27)$).

![CI-SCIM over Time](image)

Figure 4.145. CI-SCIM changes over time. Values indicate mean scores ($n = 10$). Error bars indicate standard error of the mean (SEM).
Table 4.26

CI-SCIM over Time

<table>
<thead>
<tr>
<th>CI-SCIM</th>
<th>Bl 1</th>
<th>Bl 2</th>
<th>3 mo</th>
<th>6 mo</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCIM</td>
<td>42.2</td>
<td>21.6</td>
<td>42.2</td>
<td>21.6</td>
<td>46.1</td>
</tr>
<tr>
<td>Scales</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCIM-SC</td>
<td>8.9</td>
<td>7.9</td>
<td>8.9</td>
<td>7.9</td>
<td>10.9</td>
</tr>
<tr>
<td>SCIM-RSM</td>
<td>24.4</td>
<td>7.8</td>
<td>24.4</td>
<td>7.8</td>
<td>24.8</td>
</tr>
<tr>
<td>SCIM-MO</td>
<td>8.9</td>
<td>6.5</td>
<td>8.9</td>
<td>6.5</td>
<td>10.4</td>
</tr>
</tbody>
</table>

Note. SC = Self Care, RSM = respiratory and spincter management, MO = mobility, M = mean. SD = standard deviation. BL 1 = baseline 1, BL 2 = baseline 2, F = p-value from ANOVA (6 months compared to baseline), Z = p-value from Wilcoxon z-score (6 months compared to baseline).

Self-Care CI-SCIM Results. CI-SCIM Self-Care results support the efficacy of the intervention. Repeated measures ANOVA indicated significant changes over time (F (3,27) = 20.1, p < .0001; Friedman = 26.7, p < .0001). Localizing pairwise comparisons revealed that baseline 1 and baseline 2 were identical (M = 8.9, SD = 7.9). At 3 months, scores rose 2.0 points from baseline, to 10.9 (SD = 6.8), a statistically significant improvement (p < .02, ANOVA and Wilcoxon). At 6 months, the average score of 12.4 was 3.5 points above baseline, (p < .01, ANOVA and Wilcoxon) and 1.5 points above the 3 month assessment (p < .02, ANOVA and Wilcoxon). Combined, these findings indicate that CI-SCIM Self-Care values were stable at baseline, improved significantly by the 3-month assessment, and then significantly increased from 3 months to 6 months (Figure 4.146; Table 4.27 & 4.28).
Figure 4.146. CI-SCIM Self-Care changes over time. Values indicate mean scores (n = 10). Error bars indicate standard error of the mean (SEM).

Self-Care Item Results. Because the CI-SCIM Self-Care scale was statistically significant overall, locating effects within individual CI-SCIM Self-Care items was important. Each of the six CI-SCIM items were evaluated in parallel, including feeding, bathing (upper and lower body), dressing (upper and lower body), and grooming. All Self-Care feeding, grooming, and dressing items demonstrated significant improvement ($p < .05$) by 6 months of the intervention. Lower body bathing failed to show significant improvement, while upper body bathing trended (ANOVA: $p = .052$; Wilcoxon: $p = .059$) towards improvement. These findings demonstrate significant intervention effects in Self-Care areas of feeding, grooming, dressing, but not lower body bathing (Table 4.27 & 4.28).
### Table 4.27

**Self-Care Items over Time**

<table>
<thead>
<tr>
<th>Self-Care</th>
<th>Bl 1 M</th>
<th>Bl 1 SD</th>
<th>Bl 2 M</th>
<th>Bl 2 SD</th>
<th>3 mo M</th>
<th>3 mo SD</th>
<th>6 mo M</th>
<th>6 mo SD</th>
<th>F</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeding</td>
<td>2.1</td>
<td>1.2</td>
<td>2.1</td>
<td>1.2</td>
<td>2.7</td>
<td>0.9</td>
<td>3.0</td>
<td>0.9</td>
<td>.001</td>
<td>.01</td>
</tr>
<tr>
<td>Grooming</td>
<td>1.9</td>
<td>1.7</td>
<td>1.9</td>
<td>1.7</td>
<td>2.2</td>
<td>1.5</td>
<td>2.8</td>
<td>1.2</td>
<td>.01</td>
<td>.01</td>
</tr>
<tr>
<td>Bathing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper</td>
<td>1.6</td>
<td>1.3</td>
<td>1.6</td>
<td>1.3</td>
<td>1.9</td>
<td>1.3</td>
<td>2.1</td>
<td>1.2</td>
<td>.052</td>
<td>.059</td>
</tr>
<tr>
<td>Lower</td>
<td>1.3</td>
<td>1.5</td>
<td>1.3</td>
<td>1.5</td>
<td>1.4</td>
<td>1.4</td>
<td>1.6</td>
<td>1.3</td>
<td>.19</td>
<td>.18</td>
</tr>
<tr>
<td>Dressing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upper</td>
<td>1.3</td>
<td>1.5</td>
<td>1.3</td>
<td>1.5</td>
<td>1.8</td>
<td>1.1</td>
<td>1.8</td>
<td>1.1</td>
<td>.01</td>
<td>.03</td>
</tr>
<tr>
<td>Lower</td>
<td>0.7</td>
<td>1.1</td>
<td>0.7</td>
<td>1.1</td>
<td>0.9</td>
<td>1.2</td>
<td>1.1</td>
<td>1.3</td>
<td>.04</td>
<td>.046</td>
</tr>
</tbody>
</table>

**Note.** M = mean. SD = standard deviation. BL 1 = baseline 1, BL 2 = baseline 2, F = p-value from ANOVA (6 months compared to baseline), Z = p-value from Wilcoxon z-score (6 months compared to baseline).

### Table 4.28

**Subscale - Self Care Score Improvements**

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Bl Score</th>
<th>Bl to 3mo</th>
<th>3mo to 6mo</th>
<th>Bl to 6mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>+2</td>
<td>+4</td>
<td>+10</td>
</tr>
<tr>
<td>2</td>
<td>6</td>
<td>+5</td>
<td>2</td>
<td>+13</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>+2</td>
<td>-</td>
<td>+2</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>+3</td>
<td>+5</td>
<td>+10</td>
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<tr>
<td>5</td>
<td>16</td>
<td>-</td>
<td>+3</td>
<td>+3</td>
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<tr>
<td>6</td>
<td>2</td>
<td>+1</td>
<td>+4</td>
<td>+5</td>
</tr>
<tr>
<td>7</td>
<td>17</td>
<td>+1</td>
<td>+2</td>
<td>+3</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>+3</td>
<td>-</td>
<td>+3</td>
</tr>
<tr>
<td>9</td>
<td>6</td>
<td>+3</td>
<td>+2</td>
<td>+5</td>
</tr>
<tr>
<td>10</td>
<td>20</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Respiration and Sphincter Management CI-SCIM Results. CI-SCIM Respiration and Sphincter Management results did not support the efficacy of the intervention. Repeated measures ANOVA indicated no significant changes over time (F (3,27) = 2.3, p = .11; Friedman = 9.9, p < .02). Localizing pairwise comparisons revealed no significant differences between baseline 1 (M = 24.4, SD = 7.8), baseline 2 (M = 24.4, SD = 7.8), 3 month (M = 24.4, SD = 7.8) and 6 month (M = 24.4, SD = 7.8) assessments (each p > .05, ANOVA and Wilcoxon). These findings provide no evidence that CI-SCIM Respiration and Sphincter Management values were significantly improved by the intervention (Figure 4.147; Table 4.26).

![CI-SCIM RSM Respiration and Sphincter Management over Time](image)

Figure 4.147. CI-SCIM Respiration and Sphincter Management changes over time. Values indicate mean scores (n = 10). Error bars indicate standard error of the mean (SEM).
Mobility CI-SCIM Results. CI-SCIM Mobility results support the efficacy of the intervention. Repeated measures ANOVA indicated significant changes over time (F(3,27) = 8.6, p < .0001; Friedman = 23.3, p < .0001). Localizing pairwise comparisons revealed that baseline 1 and baseline 2 were identical (M = 8.9, SD = 6.5). At 3 months, scores rose 1.5 points from baseline, to 10.4 (SD = 6.7), a statistically significant improvement (p < .01, ANOVA and Wilcoxon). At 6 months, the average score of 12.9 was 4.0 points above baseline, (p < .01, ANOVA and Wilcoxon) and 2.5 points above the 3 month assessment (p < .05, ANOVA and Wilcoxon). Combined, these findings indicate that CI-SCIM Mobility values were stable at baseline, improved significantly by the 3-month assessment, and then significantly increased from 3 months to 6 months (Figure 4.148; Tables 4.29 & 4.30).

Figure 4.148. CI-SCIM Mobility changes over time. Values indicate mean scores (n = 10). Error bars indicate standard error of the mean (SEM).
*Mobility CI-SCIM Item Results.* Of eight (8) CI-SCIM Mobility Items, two supported the efficacy of treatment. Mobility in Bed and Action to Prevent Pressure Sores and Mobility for Outdoors Distances (100+ meters) scores were significantly higher at 6 months than at baseline (p < .05, ANOVA and Wilcoxon). Transfers: Wheelchair-Car trended towards improvement at 6 months, but did not achieve statistical significance (ANOVA: p = .07; Wilcoxon: p < .04). No other mobility items were statistically significant. Mobility CI-SCIM Item results are summarized in Tables 4.28 and 4.29.

Table 4.29

*Mobility Items over Time*

<table>
<thead>
<tr>
<th>Mobility</th>
<th>Bl 1 M</th>
<th>SD</th>
<th>Bl 2 M</th>
<th>SD</th>
<th>3 mo M</th>
<th>SD</th>
<th>6 mo M</th>
<th>SD</th>
<th>p-value</th>
<th>F</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed Action</td>
<td>2.1</td>
<td>2.4</td>
<td>2.1</td>
<td>2.4</td>
<td>2.8</td>
<td>2.3</td>
<td>3.4</td>
<td>2.5</td>
<td>.01</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>Outdoors</td>
<td>1.3</td>
<td>0.8</td>
<td>1.3</td>
<td>0.8</td>
<td>1.5</td>
<td>0.7</td>
<td>1.7</td>
<td>0.9</td>
<td>.04</td>
<td>.046</td>
<td></td>
</tr>
<tr>
<td>Moderate Distance</td>
<td>1.7</td>
<td>0.7</td>
<td>1.7</td>
<td>0.7</td>
<td>1.7</td>
<td>0.7</td>
<td>2.0</td>
<td>1.5</td>
<td>.34</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Stairs</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.1</td>
<td>0.3</td>
<td>0.2</td>
<td>0.6</td>
<td>.34</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Indoors</td>
<td>1.6</td>
<td>0.7</td>
<td>1.6</td>
<td>0.7</td>
<td>1.6</td>
<td>0.7</td>
<td>1.9</td>
<td>1.5</td>
<td>.34</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Transfer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bed-Wheelchair</td>
<td>0.8</td>
<td>0.9</td>
<td>0.8</td>
<td>0.9</td>
<td>1.0</td>
<td>0.9</td>
<td>1.1</td>
<td>1.0</td>
<td>.34</td>
<td>.18</td>
<td></td>
</tr>
<tr>
<td>Wheelchair-Toilet-Tub</td>
<td>0.6</td>
<td>1.3</td>
<td>0.3</td>
<td>0.9</td>
<td>0.6</td>
<td>1.3</td>
<td>0.7</td>
<td>1.5</td>
<td>.34</td>
<td>.18</td>
<td></td>
</tr>
<tr>
<td>Wheelchair-Car</td>
<td>0.6</td>
<td>0.8</td>
<td>0.6</td>
<td>0.8</td>
<td>0.8</td>
<td>0.9</td>
<td>1.6</td>
<td>1.9</td>
<td>.07</td>
<td>.04</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* M = mean. SD = standard deviation. BL 1 = baseline 1, BL 2 = baseline 2, F = p-value from ANOVA (6 months compared to baseline), Z = p-value from Wilcoxon z-score (6 months compared to baseline).
Table 4.30

Subscale – Mobility Improvements

<table>
<thead>
<tr>
<th>Participant #</th>
<th>Bl Score</th>
<th>Bl → 3mo</th>
<th>3mo → 6mo</th>
<th>Bl → 6mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>+1</td>
<td>-</td>
<td>+1</td>
</tr>
<tr>
<td>2</td>
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<tr>
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<td>+7</td>
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<td>-</td>
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<tr>
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<td>+1</td>
<td>-1</td>
<td>-</td>
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<tr>
<td>10</td>
<td>17</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Summary of CI-SCIM ANOVA Results

In response to research question two, What effects does a nurse-coached exercise program with people with tetraplegic spinal cord injuries have on quality of life measures?: CI-SCIM results indicate that quality of life improved for participants on average, with the largest gains in Self-Care and in Mobility. No significant improvement was evident for Respiration and Sphincter Management.

Moorong Self-Efficacy Scale Scores

Research Question 3 asked, What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on self efficacy?
The Mooring Self Efficacy Scale (MSES) (Appendix E) was used in this study to assess changes in self-reported self-efficacy as they relate to participation in an exercise program designed specifically for people with tetraplegic spinal cord injuries. It remains to be determined if functional improvement is concurrent with increased self-reported self-efficacy. The sixteen items in the MSES are not divided into sub-categories but are reported as a total score.

The calculated internal consistency reliabilities (Cronbach’s alpha coefficients) for the study result’s total MSES scale were 0.925 for baseline 1, 0.927 for baseline 2, 0.927 at three months into the intervention, and 0.931 at six months into the intervention. All were greater than 0.80, which is desirable. It was concluded that the MSES might provide information regarding the multidimensional aspects of self-efficacy measures as experienced by people with tetraplegic spinal cord injuries. Graphs for each item in the MSES for each study participant can be found in Appendix F.

Participant #1’s MSES Results. Participant #1’s overall MSES (Figure 4.149) demonstrated strong improvement at three months that continued at six months. By the conclusion of the study, she was designing an adaptive horse buggy and wanted to resume her equestrian activities. She also began attending college on a full time basis and as studying to become a social worker, specializing in people with disabilities.

Participant #2’s MSES Results. Participant #2 (Figure 4.150) experienced strong improvement in her MSES score at three months that continued to trend upwards at six months. At midpoint into the intervention, she was able to switch from a power wheelchair to a manual chair and she enrolled in college courses.
Participant #3’s MSES Results. Participant #3 (Figure 4.150) experienced a strong improvement in his self-efficacy scores at three months that continued through six months. He was living independently and working part time prior to the start of the intervention. During the intervention he increased his work to full time and he became politically active in disability rights issues.

Participant #4’s MSES Results. Participant #4 (Figure 4.152) had the greatest improvement in self-efficacy scores of the ten study participants. Initially quiet and shy, during the intervention she enrolled, for the first time, in college courses and became quite socially active with the other study participants and volunteers. During the intervention she made the decision to have a surgical procedure that would allow her to self-catheterize, allowing her a great deal of independence.
At the conclusion of the intervention she moved into her own apartment, living independently, with the assistance of a personal care attendant a few hours each day for the first time since her accident. She frequently sought the advice of others in the study who lived independently, as this was one of her long-term goals.

![Figure 4.151 Participant #3’s MSES](image1)

![Figure 4.152 Participant #4’s MSES](image2)

**Participant #5’s MSES Results.** Participant #5 (Figure 4.153) demonstrated strong improvement in self-efficacy scores at three months and six months. During the study when he achieved the ability to transfer independently, he was able to transfer from his wheelchair to his truck and began to drive again, giving him great independence. He is currently training service dogs for people with disabilities.

**Participant #6’s MSES Results.** Participant #6 (Figure 4.154) experienced a strong increase in self-efficacy scores at three months and six months. Following completion of the study he returned to college out of state as a full time student where he participated in choir and theater.
Participant #7’s MSES Results. Participant #7 (Figure 4.155) had a high self-efficacy score prior to the start of the intervention. He experienced a small increase in trend from baseline to three months to six months.

Participant #8’s MSES Results. Participant #8 (Figure 4.156) was the most severely injured of the study participants. He experienced a strong improvement in his self-efficacy scores from baseline to three months to six months. At the conclusion of the intervention he enrolled in online college courses.

Participant #9’s MSES Results. Participant #9 (Figure 4.157) experienced a significant increase in self-efficacy from baseline to three months to six months. At the conclusion of the study he secured a full time position in a college admissions office.

Participant #10’s MSES Results. Participant #10 (Figure 4.158) experienced a strong improvement from baseline to three months to six months in her self-efficacy
scores. She was independent prior to the start of the study. She was unsure what she would accomplish by participating in the study and was very pleased with her results.

Figure 4.155 Participant #7’s MSES  
Figure 4.156 Participant #8’s MSES

Figure 4.157 Participant #9’s MSES  
Figure 4.158 Participant #10’s MSES
**MSES across participants: Analysis of Variance (ANOVA)**

To determine whether MSES self efficacy changes seen in individual single subjects were statistically significant overall across ten (10) participants (Table 4.31), Repeated Measures Analysis of Variance (ANOVA) was conducted, confirmed by the Freidman and Wilcoxon non-parametric tests, with MSES serving as the dependent variable across baseline 1, baseline 2, and assessments at 3 months and at 6 months of treatment.

Table 4.31

*Moorong Self-Efficacy Score Improvements*

<table>
<thead>
<tr>
<th>Participant #</th>
<th>BL Score</th>
<th>Bl → 3mo</th>
<th>3mo → 6mo</th>
<th>Bl → 6mo</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
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<td>+3</td>
<td>+12</td>
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<td>+17</td>
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MSES ANOVA Results. MSES results support the efficacy of treatment Figure 4.159). Repeated measures ANOVA indicated significant changes over time, $F(3,27) = 24.6, p < .0001$; Friedman $= 30.0, p < .0001$).

![MSES over Time](image)

Figure 4.159. MSES self-efficacy changes over time. Values indicate mean scores ($n = 10$). Error bars indicate standard error of the mean (SEM).

Localizing pairwise comparisons revealed that baseline 1 and baseline 2 were identical ($M = 71.1, SD = 7.3$). At 3 months, scores rose 8.1 points from baseline, to 79.2 (SD = 6.0), a statistically significant improvement ($p < .005$, ANOVA and Wilcoxon). At 6 months, the average score of 86.9 was 15.8 points above baseline, ($p < .005$, ANOVA and Wilcoxon) and 7.7 points above the 3 month assessment ($p < .005$, ANOVA and Wilcoxon). Combined, these findings indicate that MSES values were stable at baseline, improved significantly by the 3 month assessment, then significantly increased from 3 months to 6 months (Figure 4.159).
In response to Research Question 3: *What effect does a nurse-coached exercise program for people with tetraplegic spinal cord injuries have on self efficacy?* These findings support the efficacy of the exercise intervention in improving self efficacy.

**Summary of Findings**

All study participants experienced increased muscle strength in some muscles, regardless of the number of years that had passed since their initial spinal cord injury. A total of 224 muscles were tested on four different occasions. Of the 144 muscles that demonstrated some strength at baseline, 75% demonstrated an increase at three and/or six months into the intervention. Of the 50 muscles that had no strength at baseline that were adjacent to muscles that demonstrated some strength, 66% demonstrated increased strength by the conclusion of the study.

Catz-Itzkovich Spinal Cord Independence Measures Scores (Quality of Life) increased in all participants except one, who was functioning at a high level at the start of the study. The overall CI-SCIM changes over time were significant (p<.0001). The subscale scores of self care and mobility were statistically significant (p<.001). The subscale scores for respiratory and sphincter was not statistically significant (p>.05). In addition, all study participants experienced gains in their Moorong Self Efficacy Scores. The across participants ANOVA was statistically significant (p<.0001).

This nurse-coached exercise program resulted in increased muscle strength, improved quality of life, and increased self-efficacy in the ten study participants with tetraplegic spinal cord injuries. The findings demonstrate that the ten participants in this study were able recover some function.
CHAPTER 5

Discussion

Introduction

The purpose of this study was to demonstrate how a nurse-coached program of focused exercise for people with tetraplegic spinal cord injuries improves muscles strength quality of life independence measures, and self-efficacy. The exercise intervention focused on a nurse-coached exercise program for each of ten study participants. The nurse-coach and the study participant worked together to carry out a program of exercise specific to the person’s level of injury and ability. A discussion of how the study findings confirm or refute the tenets of the Sheehy SCI-FIVE Model (the Model) and reports in the literature follow.

Findings

The Conceptual Model

The exercise intervention flowed from the Model, beginning with the establishment of an accessible, safe public location in which the exercise intervention occurred. A YMCA was found to be an ideal location, as it was accessible by public and private transportation and access to the facility met with the Americans With Disabilities Act Standards for Access (ADA, 2002). It is a place where a group of people with tetraplegic spinal cord injuries could come together to exercise.

Nurse-Coach. The nurse-coach, a key tenet of the Model provided the core relationship between the study participants and the nurse-coach. Successful nurse-coaching interventions have been described in the literature, but have been limited to health behaviors, educational topics, counseling, psychological support, and clinical
monitoring (Naylor, et al., 1994). The Model included all of those areas plus the added
dimension of the person with a tetraplegic spinal cord injury in a nurse-coached exercise
program.

During the pre-study work and the course of the intervention, the nurse-coach and
the study participants developed relationships. These first started with a face-to-face
home visit, followed by two group orientation meetings at the study site, individual
meetings with potential participants to discuss the program in detail and to obtain
informed consent, and continued with the actual exercise program.

The nurse-coach provided direction, encouragement, feedback, and answered
questions (face-to-face, email, telephone conversations) about progress, participants
reporting improvements, physiologic changes, and new physical findings. Discussions
also involved requests for information about experimental procedures, employment
opportunities, career advice, educational opportunities, family issues, and requests for
letters of reference.

The role for the nurse-coach was to define the exercise program, activate and
guide the exercise program, collect data, listen and observe, and watch for non-verbal
cues and possible precursors to adverse events. The nurse-coach always provided
feedback, took the time to praise when appropriate, celebrate gains, and provide
corrective direction when needed.

The nurse-coach built relationships, inspired creativity, motivated and encouraged
improved performance, and increased participant empowerment. The nurse-coach worked
with participants to find creative ways to accomplish a task. She inspired participation by
helping to release the participant’s potential by raising awareness and nurturing new ideas.

The nurse-coach directed the participants in ways that increased their enthusiasm and energy levels. Participants were assisted in reaching their goals through knowledge development, insights, and encouragement. The intention to increase self-efficacy and quality of life drove everything the nurse-coach said and did. The participants learned by reaching beyond their immediate objectives and developed when their self-awareness occurred as muscle strength increased and quality of life improved.

The nurse-coach was knowledgeable about spinal cord injuries, developed the exercise plan, schedule the sessions, worked with participants’ strengths and weaknesses, made adjustments during the course of the program, gave pep talks, and provided frequent feedback. This was accomplished by the nurse-coach’s inherent ability to be attentive to details, observe from a holistic perspective, be convincing and encouraging, and by balancing clinical expertise and guidance with allowing the participant to maintain ownership and responsibility for their exercise program.

The role of the relationship between the nurse-coach and the participant is a topic of great interest, yet it is difficult to quantify. Nurses have always professed the need to know their patient well (Radwin, 1995). The questions remains – did the study participants work harder in response to the nurse coach and why?

Group support and vicarious learning. Group support and vicarious learning are also major tenets of the Model. By exercising with other people with like injuries, a phenomenon occurs where they offered each other support and encouragement. They learned from each other and tried things that others were doing or had accomplished.
Group support and vicarious learning were powerful supports of the Model. It is believed that the relationships that form between and among study participant play a large role in individual participant motivation, attendance, and accomplishments.

The literature supports this model’s findings that actual participation in the exercise program, along with verbal persuasion by the nurse-coach and other study participants, along with vicarious learning, are effective in increasing self-efficacy beliefs. The participants in this study reported that participating in this exercise program in the presence of other participants with similar injuries was most beneficial and enhanced their efforts in the program and their self-efficacy beliefs. One subject stated, “I really appreciate being able to exercise with people with the same condition as me. I learn so much from them and they make me work harder. I think I do the same for them.”

*The dependent variables of the model.* The dependent variables of the Model are muscle strength, self-efficacy, and quality of life (and, indirectly, endurance and independence).

*Muscle strength.* In this study, the level and trend of muscle strength increased consistently, sometimes as early as three months into the intervention. When muscle strength improved by three months, it either remained stable or increased at six months. Muscles with some measurable strength at baseline increased in strength over the course of the intervention 75% of the time. In muscles that showed no strength at baseline that were adjacent neurologically to muscles with some strength at baseline, those muscles with no strength improved in strength 66% of the time.
These findings validate the tenet of the Model that an exercise program in an environment that includes nurse coaching along with group encouragement and vicarious learning, results in increased muscle strength.

*Self-efficacy.* The self-efficacy data demonstrated similar increases both individually and in the aggregate, as muscle strength and quality of life improved. Increases in self-reported self-efficacy were evidenced at both three months and six months into the intervention. It is difficult to determine if self-efficacy increased solely due to increased muscle strength and/or quality of life or if it was affected by group encouragement and vicarious learning that occurred throughout the intervention.

*Quality of life.* The level and trend of quality of life measures increased consistently over the time of the intervention in two sub-categories, self-care and mobility as muscle strength increased and self-efficacy increased.

*Conceptual Assumptions*

The findings of this study support all components of the Sheehy SCI-FIVE Model. As proposed in the Model, muscle strength, self-efficacy, and quality of life were amenable to change during the exercise intervention held in a community environment, lead by a nurse-coach, in the presence of others with similar injuries. The tenets of a nurse-coach, group encouragement, and vicarious learning were found to be strong components of the Sheehy SCI-FIVE Model.

During and at the conclusion of the exercise program, statistically significant increases were evidenced in muscle strength, two of the three subscales of the CI-SCIM (quality of life), and the MSES (self-efficacy). In addition, participants reported improved health, no complications (UTI, pneumonia, pressure sores, deep vein thrombosis),
improved sleep patterns, reduced spasticity, improved social skills, increased social activities, and decreased isolation – all which increase self-efficacy and lead to a higher quality of life.

*How the Study Findings Inform the Literature*

Blakslee (2002) hypothesized that a small number of nerves around the site of the injury survive the injury but somehow became dormant and that exercise may reactivate those nerves. This study’s results lend credence to his theory. McDonald’s theory (2005) that a program of guided exercise forced reorganization of some neural cells that became inactive due to a spinal cord injury, was also supported by the findings of this study. All three studies’ results support the theory that activity/exercise helps to activate intact but dormant circuits that have not been used since the injury.

The results of this study also support the findings of Noreau and Shepard (1995) and Heath and Fentem (1997) - research that demonstrated increased muscle strength after a program of exercise in people with spinal cord injuries. Their studies, although limited in scope and time, involved people with paraplegic spinal cord injuries. This study took place with people with tetraplegic spinal cord injuries, a very challenging population.

Kunkle, et al. (1999) conducted research with stroke patients. Their research found that exercising the affected extremity along with coaching and verbal feedback enhanced motor recovery. This was found to be true in the spinal cord injured population in this study as well.

The Ottawa Panel (2006) compiled a meta-analysis on the effects of exercise on people undergoing rehabilitation post stroke. The finding was that the more intense the
exercise, the greater the functional improvement and that it is a matter of intensity and duration that correlates with functional motor improvement. This study’s results demonstrate that motor strength increased from baseline to three months into the intervention and improved significantly yet again at six months with intense exercise of increasing duration.

The body weight-supported treadmill work done by Wernig and Mueller (1992) demonstrated significant evidence that suggested that intense repetitive motor activity can reverse learned non-use. Those findings were validated in this study. Young (2005a) calls this “forced use.” This study demonstrated that with intense exercise, over time, motor recovery was enhanced in some muscles.

Published studies of the effects of a coached exercise program in the spinal cord injured population are sparse. Only one was found. Harness, et al., (2008) found that people with spinal cord injuries who participated in a multi-modal coached exercise program showed significantly greater motor gains than the control group that practiced self-regulated (at home) exercises. In keeping with these findings, this study was conducted in an environment where multi-modal exercises under the guidance of a nurse-coach occurred.

Other concerns of people with spinal cord injuries reported in the literature were addressed in this study. Barriers to access to a program of exercise for people with spinal cord injuries were removed by offering the intervention at a community YMCA, easily assessed by public and private transportation and with accessible entry and adapted equipment.
Results of a survey by the University of Michigan (2002) found that people with spinal cord injuries were concerned that fitness center staff would not know how to develop a program for their special needs and would not know how to work with someone with a spinal cord injury. This intervention was developed by a nurse knowledgeable about the special needs of people with spinal cord injuries. Specially adapted equipment was procured and select fitness center staff was trained in use of the equipment by this special population so that the program could continue after the intervention phase was completed.

ATRA (2004) reported that complications secondary to spinal cord injuries (pressure sores and urinary tract infections) occurred one third of the time in people with spinal cord injuries who participated in a program of exercise as compared to a matched group of non-exercising people with spinal cord injuries. Although this information on complications was not scientifically collected during the course of this intervention, it was reported anecdotally by all ten study participants that during the course of the intervention, no complications (pressure sores, urinary tract infections, pneumonia, and deep vein thromboses) occurred.

This study offered unique contributions to the literature in terms of the effects of a nurse-coached exercise program for people with tetraplegic spinal cord injuries on self-efficacy and quality of life. It extends the limited previous research by describing patterns of change in muscle strength, self-efficacy, and quality of life in a small sample of people with tetraplegic spinal cord injuries. The combined data demonstrate statistically significant increases in the levels and trends of the dependent variables and the visual data provide convincing evidence of these trends and the timing of the changes.
Strengths and Limitations of the Study

Strengths. The greatest strength of this study was its ability to provide information so that interventions could be refined/adjusted during the course of the intervention. It is in this setting that improvements took place, self-efficacy beliefs were formed, and quality of life improved. By evaluating the data points along the spectrum of the intervention, the researcher began to witness patterns of change that were occurring. The intervention was evaluated based on the visual display and evaluation of the individual’s response to the intervention. If data demonstrated an adverse effect, which it did not, the intervention would have been changed or stopped. When there was a positive effect, the intervention was enhanced or increased for a specific participant in a timely manner.

Intervention effectiveness/analysis occurred during the data collection phases. Visual/graphical displays allowed for easy data analysis for trends. In this the multiple baseline design, the replication of positive intervention effects across multiple participants strengthened the study findings (Gannella, 1989).

Muscle strength data were collected by independent evaluators. They were not shown previous test results prior to completing their testing to avoid testing bias. Testing occurred at the same time of day at each of the four testing periods. To assure rigor of the testing methodology.

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Limitations. This single-subject design was time-intensive and may limit the ability to replicate the study. The greatest limitation of this SSD was the risk of researcher bias (Polit & Hungler, 1999). This was avoided by using independent evaluators to collect the muscle strength data. There may have also been an effect because of the nurse-participant relationship. Results may not be able to be replicated when a different researcher conducts the intervention. This can be seen as both strength and a limitation of single-subject design.

Intensive multiple data point collection enhances SSD studies. In this study, however, due to the intensity of the data collection (an all-day undertaking), the fatigue factor on the participants, and the expected stable baseline measurements due to slow changes, both positive and negative, in the SCI population, data collection points were
limited to two in the baseline phase and one each at three months and six months in the intervention phase.

The participants in this study were enthusiastic and anxious to participate in the study. Each was in good health relative to their injury, was able to travel to the study site, and commit to the six-month program requirements. This may not be possible in others who do not have transportation to a study site or who are not willing or able to commit to the rigorous study schedule.

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**Recommendations**

**Implications for Nursing**

Nurses have important roles to play in developing wellness and continuous improvement interventions for tetraplegic spinal cord injured persons - a population that has basically been forgotten in the healthcare continuum after a brief period of outpatient rehabilitation. A nurse-coached exercise program for this population involves motivation skills and individual goal setting, skills that are inherent to nursing practice. Nurses are ideally suited to be coaches in goal-focused exercise programs because of the holistic focus of nursing practice, dealing not only with physiologic responses to the exercises, but also to the psychosocial implications of self-efficacy and quality of life. Knowing that tetraplegic spinal cord injured persons can continue to gain strength, sensation, and function to improve quality of life well beyond the initial injury, acute hospitalization and rehabilitation phases, should drive the development of plans for exercise intervention programs. The skills of the nurse to plan opportunities for exercise interventions, to obtain physiologic measurements, and to plan individual programs of exercise in an accessible, affordable community environment are essential.

Quantitative studies should be complemented by qualitative studies that explore beliefs about how self-efficacy is nurtured in the tetraplegic spinal cord injured population, how they activate self-efficacy beliefs, and how these beliefs affect clinical outcomes. We must identify ways to determine how to use self-efficacy to achieve goals
in programs of care, and ways to identify gender, race, and ethnic differences as they relate to self-efficacy beliefs.

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Advanced practice nurses should consider incorporating a discussion about the benefits of exercise and the value of such a program with patients who have tetraplegic spinal cord injuries.

**Implications for Practice**

The current healthcare environment is forcing focused-attention on cost containment and cost effective interventions. An exercise program for tetraplegic spinal cord injured persons is timely, as persons with this diagnosis are high-cost consumers of health care due to their significant assistance needs, expensive durable medical equipment, and frequent medical complications. Increased muscle strength and sensory levels, an increased quality of life and improved self-efficacy that may reduce assistance needs or medical complications as a result of such a program, evidence the argument in favor of nurse-coached exercise programs. This study also demonstrated that these gains occurred in some participants many years after the initial spinal cord injury occurred. The results of this study have shown that a nurse-coached program of exercise in this population will lead to continued improvements beyond the traditional (limited) rehabilitation phase of care. The evidence is convincing that wellness programs for this population will enhance quality of life and self-efficacy. This evidence should be used to guide practice and enhance/inform policy creation (Brooten & Naylor, 1995; Maas, Johnson, & Morehead, 1996).

In spinal cord injury rehabilitation care, time in therapy is limited by resources and cost (as approved by insurance companies and other third party payers). By providing community-based locations that are accessible and affordable to the tetraplegic spinal cord injured population, the cost of a continued exercise program outside of the
hospital/rehabilitation environment proves to be not only cost-effective, a positive alternative to costly hospitalizations due to complications. It would behoove healthcare insurance companies and public assistance programs to fully investigate the cost/benefit of funding such community-based programs.

**Implications for Knowledge Development, Theory Development, and Future Research**

Much is to be learned about the effects of a continued program of exercise for people with tetraplegic spinal cord injuries. It is unknown how long the neural network will respond to activity-based interventions or if muscle strength and quality of life measures will continue to improve if the program of exercise continues over a longer period of time.

We must determine the effects of exercise in people with tetraplegic spinal cord injuries on the prevention of complications (UTI, pneumonia, pressure sores, deep vein thrombosis, pulmonary embolism, sepsis, pathologic fractures, cardiovascular disease, depression, suicide). We must explore the benefits of such a program on psychosocial issues – relationships, family, marriage, work, education, social interaction, spirituality.

There is much to learn about nurse coaching. We must define the characteristics of a nurse-coach and understand how the nurse-coach and participant relationship affects outcomes. What motivates participants? What information do they need? We should investigate the evaluation process, the outcomes, and the implications of the nurse as a coach when working with people with spinal cord injuries. Nurses are in a unique position to be among the leaders in our evolving integrative healthcare system.

Reports of theoretically grounded research involving tetraplegic spinal cord injured persons and the effects of exercise were not found in the literature. The most promising
interventions have come from anecdotal reports or individual case studies. Current recommendations for exercise programs for tetraplegic spinal cord injured persons are largely non-existent and, if they do exist, are based on small clinical trials that lack research rigor or expert opinion that lacks theoretical grounding and has limited theoretical support. As a result, the sparse amount of knowledge development in this area is generally fragmented and lacks direction.

The results of this study should provide the impetus for additional large-scale studies measuring the effectiveness of coached exercise programs for tetraplegic spinal cord injured persons. The collective findings of studies at multiple sites will provide critical information that may move interventions in a direction that will enhance the quality of life for spinal cord injured persons everywhere.

There is a great need for replication of this study using a larger sample size conducted over a longer period of time. This study is the only one known to date that evaluates the effectiveness of an affordable, community-based exercise program on the tetraplegic spinal cord injured population. The effects of exercise on additional dependent variables, such as medical complications, pain, spasticity, sleep patterns, and work and school activities should be investigated. It is worthwhile to note that decreased complications, decreased pain and spasticity, and improved sleep patterns, although not measured in this study, were reported anecdotally by study participants.

Larger quantitative studies that address the effectiveness of specific exercise interventions should be conducted to answer such research questions as which exercises and equipment are most effective in producing desired outcomes, how long the interventions should last, when the exercise intensities should be increased (and by how
much), and the cost effectiveness of such intervention programs. We have just begun to
skim the surface of the effects of exercise programs on SCI persons post rehabilitation
phase.

There is a need to develop more precise measurements of changes in health-related
quality of life measures as they relate specifically to the level and severity of the spinal
cord injury. We must find ways to increase generalizability and applicability of results in
order to design programs that can reach more spinal cord injured persons. We must
validate the benefits of extending exercise interventions well beyond the time of the
initial injury acute hospitalization, and inpatient and outpatient rehabilitation phases. We
must also examine the role that patient preferences play in programs of exercise.

Implications for Policy

This study was in keeping with the National Institute for Nursing Research
Agenda for the Future (NINR, 2003). Of the five themes in this research agenda, two
were directly supported by this research. Changing lifestyle behaviors (theme number
one) was addressed by introducing a program of exercise (healthy behaviors) to people
with tetraplegic spinal cord injuries. The health promotion intervention focused on a
population that is very high risk for disease and complications.

Managing the effects of chronic illnesses to improve health and quality of life
(theme number two) was addressed by initiating a life activity of exercise that would lead
to improved physical conditioning and the possible reduction of complications inherent in
this population.

The National Institute of Neurological Disorders and Stroke has declared that
“spinal cord injury research has come of age” and has called for research that will address
rehabilitation strategies in the management of spinal cord injuries (NINDS, 2005). Specifically, they have asked for rehabilitation strategies that are crucial for maintaining flexibility and muscle strength and reorganizing the nervous system. This research study addresses those specific criteria.

The Institute of Medicine issued a lengthy report (IOM, 2005) that listed the priorities for spinal cord injury research. Of the six priorities, two priorities, #5 and #6, were addressed in this research study. Priority #5: Prevention of acute and chronic complications, directs the researcher to develop interventions that prevent and reverse the evolution of events that lead to a wide range of outcomes that result from chronic injury and disability after spinal cord injury. Priority #6: Maintain maximum potential for recovery, includes expanding the understanding of requirements for proper post injury care and rehabilitation that are needed to maintain maximal potential for full recovery.

The Paralyzed Veterans of America issued,” Guidelines for Outcomes Following Spinal Cord Injuries (PVA, 1999). Guideline #12: Assess quality of life for individuals with spinal cord injuries using direct perceptions of the individual involved, was addressed in this study using self-efficacy scores and quality of life changes to assess quality of life. Guideline #13, “Facilitate opportunities for optimal quality of life with full continuum of healthcare rehabilitation programs,” was addressed in this community-based exercise intervention study.

In today’s healthcare environment, policy makers are focused on quality and cost effectiveness. There are ongoing efforts to improve healthcare while maintaining quality in a cost-effective manner. As more spinal cord injured persons survive to be integrated back into society, we must identify ways to encourage the development of the resources
they require to maintain good health and reduce complications that lead to hospitalizations. One key way is to develop policies that provide guidelines, mandates, and funding for programs that have proven to be effective in promoting wellness, reducing complications, and improving quality of life for people with chronic spinal cord injuries. Research studies that address improving quality of life for this population will do much to encourage the creation of policies to support such programs that can be made accessible to every tetraplegic spinal cord injured person who chooses to participate.

In light of the recent passage of federal healthcare legislation that prohibits insurance companies from dropping a person with a chronic condition or capping their lifetime healthcare expense payments, it would behoove insurance companies to fund research and programs that promote wellness and independence in spinal cord injured populations.

Conclusions

A six-month intervention of a nurse-coached exercise program for tetraplegic spinal cord injured individuals resulted in increased muscle strength, increased self-reported self-efficacy scores, and an improved quality of life. The findings validated all components of the Sheehy SCI-FIVE conceptual model.

The findings of this study have provided a counter-opinion to the long-held belief that motor function recovery usually occurs during a finite period of time and is limited following SCI. The impact of the Sheehy SCI-FIVE Model may result in evolving middle-range theory development. Nurses can serve as leaders in the effort to improve the lives of persons with these catastrophic life-altering disabilities by effecting post-
rehabilitation exercise program research and healthcare policies that support such efforts
until the time when there is finally a cure for spinal cord injuries.
References


Schroder, K.E E., Schwartzer, R., & Endler, N.S., (1997). Predicting cardiac patients' quality of life from the characteristics of their spouses. *Journal of Health Psychology, 2*, 231-244.


### STANDARD NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY

#### MOTOR

| C2  | C3  | C4  | C5  | C6  | C7  | C8  | T1  | T2  | T3  | T4  | T5  | T6  | T7  | T8  | T9  | T10 | T11 | T12 | L1  | L2  | L3  | L4  | L5  | L6  | S1  | S2  | S3  | S4-5 |
|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
|     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |

- **KEY MUSCLES**
  - Elbow flexors
  - Wrist extensors
  - Elbow extensors
  - Finger flexors (distal phalanx of middle finger)
  - Finger abductors (little finger)
  - Hip flexors
  - Knee extensors
  - Ankle dorsiflexors
  - Long toe extensors
  - Ankle plantar flexors
  - Voluntary anal contraction (Yes/No)

#### SENSORY

- **KEY SENSORY POINTS**
  - 0 = absent
  - 1 = impaired
  - 2 = normal
  - NT = not testable
  - Any anal sensation (Yes/No)

#### Neurological Level

- **NEUROLOGICAL LEVEL**
  - The most caudal segment with normal function

- **SENSORY**
  - Incomplete = Any sensory or motor function in S4-S5

- **COMPLETE OR INCOMPLETE?**
  - 

- **ZONE OF PARTIAL PRESERVATION**
  - Caudal extent of partially innervated segments

- **ASIA IMPAIRMENT SCALE**

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<td>C9-14</td>
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</table>

**Notes & comments**
- Comments: palpation: description of firm, semi-flex or soft.
- Sensation: paresthesia, anesthesia, mild, semi-flex or soft.
- Movements: range of motion, active, passive.
- Tenderness: alignment, stability.
# SHEPHERD CENTER
## LOWER EXTREMITY MUSCLE TEST

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<td>T   T1-T9 Back Extensors T</td>
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<tr>
<td>L   T10-L5 Back Extensors L</td>
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<tr>
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<td>T7-T10 External Obliques</td>
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<td>T19-L1 Internal Obliques</td>
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<td>L5-S1 Gluteus Maximus Inf. Glutaeal</td>
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<td>L4-S1 Gluteus Medius Sup. Glutaeal</td>
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<tr>
<td>L4-S1 Tensor Fascia Lata Sup. Glutaeal</td>
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<td>L1-4 Iliopsoas</td>
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<td>L2-4 Sartorius Femoral</td>
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<td>L2-S1 Hip Adductors Obturator</td>
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<td>Ex. L3-S2 Hip Rotators Ex.</td>
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<td>In. L4-S2 Hip Rottors In.</td>
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<td>L2-L4 Quadriceps Femoral</td>
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<td>In. L4-S2 Hamstrings Sacro</td>
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<td>Out. L5-S3 Hamstrings Sacro Out</td>
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<td>Ly. S1-2 Gastrosoleus Tibial Ly.</td>
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<tr>
<td>Stand S1-2 Gastrosoleus Tibial Stand</td>
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<td>L4-5 Anterior Tibialis Peroneal</td>
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<td>L5-S2 Posterior Tibialis Tibial</td>
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<td>L4-5 Peroneus Peroneal</td>
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<td>L4-S2 Toe Extensors Peroneal</td>
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<td>L4-S2 Extensor Hallucis Longus Peroneal</td>
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<td>L5-S2 Toe Flexors Tibial</td>
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**COMMENTS:**

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**NOTE:** See KEY on back.

**Signature**

**Lic. #**

**MUSCLE EXAMINATION**
Catz-Itzkovich Spinal Cord Independence Measure (C-I SCIM)

Subject: ________________________________

**Self-Care**

1. **Feeding** (cut, open containers, bring food to mouth, hold cup with fluid)
   0. Needs parenteral, gastrostomy, or fully assisted oral feeding
   1. Eats cut food using several adaptive devices for hand/dishes; unable to hold cup
   2. Eats cut food using only one adaptive device for hand; holds adaptive cup
   3. Eats cut food without device; hold regular cup; needs assistance opening containers
   4. Independent in all tasks without any adaptive devices

2. **Bathing** (soaping, manipulating water tap, washing) **A- upper body; B – lower body**
   A. 0. Requires total assistance
      1. Requires partial assistance
      2. Washes independently with adaptive devices or specific setting
      3. Washes independently; does not require adaptive devices or a specific setting
   B. 0. Requires total assistance
      1. Requires partial assistance
      2. Washes independently with adaptive devices or specific setting
      3. Washes independently; does not require adaptive devices or a specific setting

3. **Dressing** (preparing clothes, dressing, undressing) **A – upper body; B – lower body**
   A. 0. Requires total assistance
      1. Requires partial assistance
      2. Dresses independently with adaptive devices or specific setting
      3. Dresses independently; does not require adaptive devices or a specific setting
   B. 0. Requires total assistance
      1. Requires partial assistance
      2. Dresses independently with adaptive devices or specific setting
      3. Dresses independently; does not require adaptive devices or a specific setting

4. **Grooming** (wash hands/face, brush teeth, comb hair, shave, apply makeup)
   0. Requires total assistance
   1. Performs only one task (e.g., washing hands or face)
   2. Performs some tasks using adaptive devices; needs help to put on/take off devices
   3. Independent without adaptive devices)

**SUBTOTAL (0- 20)**

**Respiration and Sphincter Management**

5. **Respiration**
   0. Requires assisted ventilation
   1. Requires a tracheal tube and partially assisted ventilation
   2. Breaths independently but requires much assistance in tracheal tube management
   3. Breaths independently and requires little assistance in tracheal tube management
   4. Breaths w/o tracheal tube; sometimes requires mechanical assistance w breathing
   5. Breaths independently without any device

6. **Sphincter Management – Bladder**
   0. Indwelling catheter
   4. Residual urine volume >100 cc; no caths or assisted intermittent caths
   8. Residual urine volume <100 cc; needs assistance to apply drainage device
   12. Intermittent self-cath
15. Residual urine volume <100 cc; no cath or assistance required for urine drainage

7. Sphincter Management – Bowel
   0. Improper/irregular timing or very low frequency (<1x/3 days)
   5. Proper/regular timing; requires assistance (e.g., suppository); rare accidents (<1/mo)
   10. Regular bowel movements/proper timing, w/o assistance; rare accidents (<1/mo)

8. Use of Toilet
   0. Requires total assistance
   1. Partially undresses lower body, needs assistance in all other areas
   2. Partially undresses lower body; partially cleans self; needs assistance adjusting clothes
   3. Undresses/cleans self; needs assistance adjusting clothes
   4. Independent in all tasks but needs adaptive devices or special setting (e.g., bars)
   5. Independent without adaptive devices or special setting

Mobility – Room and Toilet
9. Mobility in Bed and Action to Prevent Pressure Sores
   0. Requires total assistance
   1. Turns in bed to one side only
   2. Turns in bed both sides but does not fully release pressure
   3. Releases pressure when lying down
   4. Turns in bed and sits up without assistance
   5. Independent in-bed mobility; push-ups in sitting position w/o full body elevation
   6. Independent in-bed mobility; push-ups in sitting position with full body elevation

10. Transfers: Bed-Wheelchair
    0. Requires total assistance
    1. Needs partial assistance and/or supervision
    2. Independent

11. Transfers: Wheelchair-Toilet-Tub
    0. Requires total assistance
    1. Needs partial assistance and/or supervision, or adaptive device (e.g., grab bars)
    2. Independent

Mobility (Indoors and Outdoors)
12. Mobility Indoors
    0. Requires total assistance
    1. Needs electric wheelchair or partial assistance to operate manual wheelchair
    3. Requires supervision while walking (with or without device)
    4. Walks with walker or crutches (swing gate)
    5. Walks with crutches or two canes (reciprocal gate)
    6. Walks with one cane
    7. Needs leg orthosis only
    8. Walks without aids

13. Mobility for Moderate Distances (10-100 meters)
    0. Requires total assistance
    1. Needs electric wheelchair or partial assistance to operate wheelchair
    2. Moves independently in manual wheelchair
    3. Requires supervision while walking (with or without device)
    4. Walks with a walker or crutches (swing)
    5. Walks with a crutches or two canes (reciprocal walking
    6. Walks with one cane
    7. Needs leg orthosis only
8. Walks without aids

14. **Mobility Outdoors** (more than 100 meters)
   0. Requires total assistance
   1. Needs electric wheelchair or partial assistance to operate manual chair
   2. Moves independently in a manual wheelchair
   3. Requires supervision while walking (with or without device)
   4. Walks with a walker or crutches (swing)
   5. Walks with crutches or two canes (reciprocal walking)
   6. Needs leg orthosis
   7. Walks without aids

15. **Stairs Management**
   0. Unable to climb or descend stairs
   1. Climbs/descends ≥ 3 steps with support or supervision of another person
   2. Climbs/descends ≥ 3 steps with support of handrail and/or crutch or cane
   3. Climbs/descends ≥ 3 steps without support or supervision

16. **Transfers: Wheelchair-Car** (approaches car, locks wheelchair, removes Arm-footrests; transfers to/from car, brings wheelchair into/out of car)
   0. Needs total assistance
   1. Needs partial assistance
   2. Independent with adaptive devices
   3. Independent without adaptive devices

   **SUBTOTAL (0-40)**

   **TOTAL C-I SCIM SCORE (0-100)**
Appendix D

Participant #1 Catz-Itzkovich Spinal Cord Independence Measures

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<tr>
<td>Breathing – Upper Body</td>
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Score variability over time is illustrated in the diagrams, showing changes from Baseline to Intervention at various time points (A1 to A6) and months (0 to 6).
**Mobility Moderate Distances (10-100 meters)**

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**Mobility Outdoors (>100 meters)**

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**Transfers: Wheelchair to Car**

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Participant #2 Catz-Itzkovich Spinal Cord Independence Measures

**Feeding**

**Bathing – Upper Body**

**Bathing – Lower Body**

**Dressing – Upper Body**

**Dressing – Lower Body**

**Grooming**

**Breathing**

**Sphincter Management - Bladder**
Sphincter Management - Bowel

Use of Toilet

Mobility in Bed and Action to Prevent Pressure Sores

Transfers: Bed to Wheelchair

Transfers: Wheelchair - Toilet - Tub

Mobility Indoors
Participant #3 Catz-Itzkovich Spinal Cord Independence Measures

**Feeding**

Baseline vs Intervention

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**Bathing – Lower Body**

Baseline vs Intervention

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**Dressing – Lower Body**

Baseline vs Intervention

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**Dressing – Upper Body**

Baseline vs Intervention

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**Breathing**

Baseline vs Intervention

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**Sphincter Management - Bladder**

Baseline vs Intervention

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<td>Mobility Outdoors (&gt;100 meters)</td>
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218
Participant #4 Catz-Itzkovich Spinal Cord Independence Measures

Feeding

Bathing – Upper Body

Bathing – Lower Body

Dressing – Upper Body

Dressing – Lower Body

Grooming

Breathing

Sphincter Management - Bladder
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**Mobility Moderate Distances (10-100 meters)**

- Baseline: 3
- Intervention: 2

**Mobility Outdoors (>100 meters)**

- Baseline: 8
- Intervention: 7

**Stairs Management**

- Baseline: 1
- Intervention: 2

**Transfers: Wheelchair to Car**

- Baseline: 0
- Intervention: 2
# Participant #5 Catz-Itzkovich Spinal Cord Independence Measures

## Feeding
![Graph showing baseline and intervention scores for feeding over 6 months.]

## Bathing – Upper Body
![Graph showing baseline and intervention scores for bathing – upper body over 6 months.]

## Bathing – Lower Body
![Graph showing baseline and intervention scores for bathing – lower body over 6 months.]

## Dressing – Upper Body
![Graph showing baseline and intervention scores for dressing – upper body over 6 months.]

## Dressing – Lower Body
![Graph showing baseline and intervention scores for dressing – lower body over 6 months.]

## Grooming
![Graph showing baseline and intervention scores for grooming over 6 months.]

## Breathing
![Graph showing baseline and intervention scores for breathing over 6 months.]

## Sphincter Management - Bladder
![Graph showing baseline and intervention scores for sphincter management - bladder over 6 months.]

### Table of Scores

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- A1: Baseline
- A2: Intervention
Participant #6 Catz-Itzkovich Spinal Cord Independence Measures

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**Bathing – Lower Body**

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**Dressing – Lower Body**

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**Dressing – Upper Body**

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**Grooming**

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**Sphincter Management - Bladder**

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Participant #7 Catz-Itzkovich Spinal Cord Independence Measures

Feeding

Bathing – Upper Body

Bathing – Lower Body

Dressing – Upper Body

Dressing – Lower Body

Grooming

Breathing

Sphincter Management - Bladder
Participant#8 Catz-Itzkovich Spinal Cord Independence Measures

Feeding

Bathing – Upper Body

Bathing – Lower Body

Dressing – Upper Body

Dressing – Lower Body

Grooming

Breathing

Sphincter Management - Bladder
Sphincter Management - Bowel

Use of Toilet

Transfers: Bed to Wheelchair

Transfers: Wheelchair - Toilet - Tub

Mobility in Bed and Action to Prevent Pressure Sores

Mobility Indoors
Participant #9 Catz-Itzkovich Spinal Cord Independence Measures

Feeding

Bathing – Lower Body

Dressing – Lower Body

Grooming

Breathing

Sphincter Management - Bladder
Participant #10 Catz-Itzkovich Spinal Cord Independence Measures

Feeding

Bathing – Upper Body

Bathing – Lower Body

Dressing – Upper Body

Dressing – Lower Body

Grooming

Breathing

Sphincter Management - Bladder
Mobility Moderate Distances (10-100 meters)

Mobility Outdoors (>100 meters)

Stairs Management

Transfers: Wheelchair to Car
Appendix E

MOORONG SELF-EFFICACY SCALE

Subject_______________________________________ ___ baseline ___ 3 month ___ 6 mo

To indicate your answer, please circle one of the numbers on the scale under each item, where 1 = “very uncertain” and 7 = “very certain.” It is important to remember that this questionnaire is NOT asking whether or not you have been doing these things, but rather how certain you are that you will be able to do them.

1. I can maintain my personal hygiene with or without help.
   Very uncertain 1 2 3 4 5 6 7 Very certain

2. I can avoid having bowel accidents
   Very uncertain 1 2 3 4 5 6 7 Very certain

3. I can participate as an active member of the household
   Very uncertain 1 2 3 4 5 6 7 Very certain

4. I can maintain relationships in my family
   Very uncertain 1 2 3 4 5 6 7 Very certain

5. I can get out of my house whenever I need to
   Very uncertain 1 2 3 4 5 6 7 Very certain

6. I can have a satisfying sexual relationship
   Very uncertain 1 2 3 4 5 6 7 Very certain

7. I can enjoy spending time with friends
   Very uncertain 1 2 3 4 5 6 7 Very certain

8. I can find hobbies and leisure pursuits that interest me
   Very uncertain 1 2 3 4 5 6 7 Very certain

9. I can maintain contact with people who are important to me
   Very uncertain 1 2 3 4 5 6 7 Very certain

10. I can deal with unexpected problems that come up in my life
    Very uncertain 1 2 3 4 5 6 7 Very certain

11. I can imagine being able to work at some time in the future
    Very uncertain 1 2 3 4 5 6 7 Very certain

12. I can accomplish most things I set out to do
    Very uncertain 1 2 3 4 5 6 7 Very certain

13. When trying to learn something new, I will persist until I am successful
    Very uncertain 1 2 3 4 5 6 7 Very certain

14. When I see someone I would like to meet, I am able to make first contact
    Very uncertain 1 2 3 4 5 6 7 Very certain
15. I can maintain good health and well-being

Very uncertain 1 2 3 4 5 6 7 Very certain

16. I can imagine having a fulfilling lifestyle in the future

Very uncertain 1 2 3 4 5 6 7 Very certain
Appendix F

Participant #1 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

Baseline Intervention

I can participate as an active member of the household

Baseline Intervention

I can get out of my house whenever I need to

Baseline Intervention

I can enjoy spending time with friends

Baseline Intervention

I can maintain contact with people who are important to me

Baseline Intervention

I can have a satisfying sexual relationship

Baseline Intervention

I can find hobbies and leisure pursuits that interest me

Baseline Intervention

I can maintain relationships in my family

Baseline Intervention

I can participate as an active member of the household

Baseline Intervention

I can deal with unexpected problems that come up in my life

Baseline Intervention
I can imagine having a fulfilling lifestyle in the future

I can maintain good health and well-being

When trying something new, I will persist until I am successful

When I see someone I would like to meet, I am able to make first contact

I can accomplish most things I set out to do

I can imagine being able to work at some time in the future

I can accomplish most things I set out to do

I can imagine having a fulfilling lifestyle in the future

I can imagine being able to work at some time in the future
Participant #2 Moorong Self Efficacy Scores

1. I can maintain my personal hygiene without help

2. I can avoid having bowel accidents

3. I can participate as an active member of the household

4. I can maintain relationships in my family

5. I can get out of my house whenever I need to

6. I can have a satisfying sexual relationship

7. I can enjoy spending time with friends

8. I can find hobbies and leisure pursuits that interest me

9. I can maintain contact with people who are important to me

10. I can deal with unexpected problems that come up in my life
When I see someone I would like to meet, I am able to make first contact

I can imagine having a fulfilling lifestyle in the future

I can maintain good health and well-being

When trying something new, I will persist until I am successful

I can accomplish most things I set out to do

When I see someone I would like to meet, I am able to make first contact
### Participant #3 Moorong Self Efficacy Scores

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<td>I can enjoy spending time with friends</td>
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<td>I can have a satisfying sexual relationship</td>
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**Graphs:**
- **Chart 1:** I can maintain my personal hygiene without help
- **Chart 2:** I can participate as an active member of the household
- **Chart 3:** I can get out of my house whenever I need to
- **Chart 4:** I can enjoy spending time with friends
- **Chart 5:** I can maintain contact with people who are important to me
- **Chart 6:** I can deal with unexpected problems that come up in my life
- **Chart 7:** I can have a satisfying sexual relationship
- **Chart 8:** I can find hobbies and leisure pursuits that interest me
- **Chart 9:** I can maintain relationships in my family
- **Chart 10:** I can avoid having bowel accidents
When I see someone I would like to meet, I am able to make first contact

I can imagine having a fulfilling lifestyle in the future

When trying something new, I will persist until I am successful

I can maintain good health and well-being

I can accomplish most things I set out to do

I can imagine being able to work at some time in the future

When I see someone I would like to meet, I am able to make first contact

I can maintain good health and well-being

I can accomplish most things I set out to do

I can imagine having a fulfilling lifestyle in the future

I can imagine being able to work at some time in the future
Participant #4 Moorong Self Efficacy Scores

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<tr>
<td>I can maintain contact with people who are important to me</td>
<td>7</td>
<td>6</td>
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<tr>
<td>I can deal with unexpected problems that come up in my life</td>
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<tr>
<td>I can maintain relationships in my family</td>
<td>7</td>
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<tr>
<td>I can avoid having bowel accidents</td>
<td>7</td>
<td>6</td>
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<tr>
<td>I can have a satisfying sexual relationship</td>
<td>7</td>
<td>6</td>
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<tr>
<td>I can find hobbies and leisure pursuits that interest me</td>
<td>7</td>
<td>6</td>
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</tbody>
</table>
I can imagine being able to work at some time in the future
When trying something new, I will persist until I am successful
I can maintain good health and well-being
I can imagine having a fulfilling lifestyle in the future

When I see someone I would like to meet, I am able to make first contact
I can accomplish most things I set out to do
When I can imagine being able to work at some time in the future
Participant #5 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

I can avoid having bowel accidents

I can participate as an active member of the household

I can maintain relationships in my family

I can get out of my house whenever I need to

I can have a satisfying sexual relationship

I can enjoy spending time with friends

I can find hobbies and leisure pursuits that interest me

I can maintain contact with people who are important to me

I can deal with unexpected problems that come up in my life

I can avoid having bowel accidents
I can imagine being able to work at some time in the future

When trying something new, I will persist until I am successful

I can maintain good health and well-being

When I see someone I would like to meet, I am able to make first contact

I can accomplish most things I set out to do

When I try something new, I will persist until I am successful

I can imagine having a fulfilling lifestyle in the future

When I see someone I would like to meet, I am able to make first contact
Participant #6 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

Baseline | Intervention
---|---
Uncertain | Certain

I can maintain contact with people who are important to me

Baseline | Intervention
---|---
Uncertain | Certain

I can find hobbies and leisure pursuits that interest me

Baseline | Intervention
---|---
Uncertain | Certain

I can enjoy spending time with friends

Baseline | Intervention
---|---
Uncertain | Certain

I can participate as an active member of the household

Baseline | Intervention
---|---
Uncertain | Certain

I can get out of my house whenever I need to

Baseline | Intervention
---|---
Uncertain | Certain

I can avoid having bowel accidents

Baseline | Intervention
---|---
Uncertain | Certain

I can have a satisfying sexual relationship

Baseline | Intervention
---|---
Uncertain | Certain

I can maintain relationships in my family

Baseline | Intervention
---|---
Uncertain | Certain

I can participate as an active member of the household

Baseline | Intervention
---|---
Uncertain | Certain

I can deal with unexpected problems that come up in my life

Baseline | Intervention
---|---
Uncertain | Certain
I can imagine being able to work at some time in the future

Baseline | Intervention
Uncertain | Certain

I can maintain good health and well-being

Baseline | Intervention
Uncertain | Certain

When trying something new, I will persist until I am successful

Baseline | Intervention
Uncertain | Certain

When I see someone I would like to meet, I am able to make first contact

Baseline | Intervention
Uncertain | Certain

I can imagine having a fulfilling lifestyle in the future

Baseline | Intervention
Uncertain | Certain

I can accomplish most things I set out to do

Baseline | Intervention
Uncertain | Certain
Participant #7 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

I can avoid having bowel accidents

I can participate as an active member of the household

I can maintain relationships in my family

I can get out of my house whenever I need to

I can have a satisfying sexual relationship

I can enjoy spending time with friends

I can find hobbies and leisure pursuits that interest me

I can maintain contact with people who are important to me

I can deal with unexpected problems that come up in my life
I can imagine being able to work at some time in the future

When trying something new, I will persist until I am successful

I can maintain good health and well-being

I can accomplish most things I set out to do

When I see someone I would like to meet, I am able to make first contact

I can imagine having a fulfilling lifestyle in the future

When I try something new, I will persist until I am successful

I can accomplish most things I set out to do

When I see someone I would like to meet, I am able to make first contact

I can imagine having a fulfilling lifestyle in the future
Participant #8 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

Baseline Intervention

I can avoid having bowel accidents

Baseline Intervention

I can participate as an active member of the household

Baseline Intervention

I can maintain relationships in my family

Baseline Intervention

I can get out of my house whenever I need to

Baseline Intervention

I can have a satisfying sexual relationship

Baseline Intervention

I can enjoy spending time with friends

Baseline Intervention

I can find hobbies and leisure pursuits that interest me

Baseline Intervention

I can maintain contact with people who are important to me

Baseline Intervention

I can deal with unexpected problems that come up in my life

Baseline Intervention
When I see someone I would like to meet, I am able to make first contact

When trying something new, I will persist until I am successful

I can accomplish most things I set out to do

I can maintain good health and well-being

I can imagine being able to work at some time in the future

I can imagine having a fulfilling lifestyle in the future
Participant #9 Moorong Self Efficacy Scores

I can maintain my personal hygiene without help

Baseline Intervention

I can avoid having bowel accidents

Baseline Intervention

I can participate as an active member of the household

Baseline Intervention

I can maintain relationships in my family

Baseline Intervention

I can get out of my house whenever I need to

Baseline Intervention

I can maintain my personal hygiene without help

Baseline Intervention

I can have a satisfying sexual relationship

Baseline Intervention

I can enjoy spending time with friends

Baseline Intervention

I can find hobbies and leisure pursuits that interest me

Baseline Intervention

I can maintain contact with people who are important to me

Baseline Intervention

I can deal with unexpected problems that come up in my life
I can imagine being able to work at some time in the future

When trying something new, I will persist until I am successful

I can maintain good health and well-being

I can accomplish most things I set out to do

When I see someone I would like to meet, I am able to make first contact

I can imagine having a fulfilling lifestyle in the future
Participant #10 Moorong Self Efficacy Scores

I can deal with unexpected problems that come up in my life

I can maintain my personal hygiene without help

I can avoid having bowel accidents

I can maintain contact with people who are important to me

I can participate as an active member of the household

I can have a satisfying sexual relationship

I can find hobbies and leisure pursuits that interest me

I can get out of my house whenever I need to

I can maintain relationships in my family

I can enjoy spending time with friends

I can participate as an active member of the household

I can maintain my personal hygiene without help
I can imagine being able to work at some time in the future
When trying something new, I will persist until I am successful
I can maintain good health and well-being
I can accomplish most things I set out to do
When I see someone I would like to meet, I am able to make first contact
I can imagine having a fulfilling lifestyle in the future
Spinal Cord Injury Exercise Program Pilot Project

Descriptive phenomenology was used to better understand the experience of a coached exercise program on tetraplegic spinal cord injured individuals and to determine what components should be included in future studies and what measurements should be obtained. Descriptive phenomenology was selected to allow for study participants to describe what it was like “in the moment” (Husserl, 1964). This approach allowed the researcher to develop insight into the experience in order to refine future studies.

The research questions being addressed by this six month pilot study, known as The First Five Project were: 1) What effect(s) does an accessible, coached exercise program have on quadriplegic spinal cord injured patients? 2) Is such a program meaningful and valuable to participants?

Four quadriplegic, spinal cord injured participants were interviewed at the conclusion of a six-month coached exercise program. The participants, all males, were 11, 15, 24, and 19 years old. Time of injury until entry onto the study ranged from 1.5 to 8 years. Prior to the study, all participants had been told by their clinicians not to expect any further motor or sensory neurological improvements due to the elapsed time since the onset of their injuries. The personal experiences of study participants were the focus of this study (Wimpeny & Gass, 2000). The researcher was a witness to this phenomenological interchange.

Data Source

The data for this study were obtained from interviews of the four participants in the pilot project. Participants were asked several questions about their experience
participating in the First Five Project. The initial study design was a descriptive phenomenological design and two questions were asked. The first question was, “What were the most important aspects of the First Five Project?” The second question was, “What affects did the First Five Project have on you?” Interviews were audio taped and later transcribed. Each interview lasted approximately thirty minutes and took place in the gym immediately proceeding or following an exercise session. Transcripts were reviewed by the participants to give them the opportunity to clarify or add information.

**Data Analysis**

The Gorgi Method (Omery, 1983) was used to analyze the data. The entire transcript was read twice through to get a sense of the whole. VanManen (1990) describes this as one way of approaching the data – a holistic first read. The researcher then listened to the tapes a second time. The transcript was read very slowly a third time and full sentences or paragraphs were transcribed onto index cards. The index cards were sorted into individual meaning units. Twelve units were initially identified. A second reader reviewed the cards and identified meaning units to check for inter rater reliability and to further refine the units.

The twelve units were sorted into four major themes that crossed from person to person – participants experienced physical improvements; positive psychosocial effects occurred; participants found the program valuable, and family members were enthusiastic about the project. Each major theme except one, had sub-themes (Table 2). The researcher reflected on the subjects’ comments in each of these themes in order to describe the meaning of their experience in the project.
Findings

Participants are Experiencing Physical Improvements

All four participants commented on improved activities of daily living and increased independence - “It’s given me more ability to do things on my own and more ability to do more things on my own at home, such as reaching things, using my balance to be able to reach things, to be able to pick things up, um, I can cath myself independently now, which I have been working on. I’m…today I catheterized myself by myself. I did it yesterday. Um, so it’s really helping me in my day-to-day daily functions.” They also commented on how the project has given them the ability to do things they didn’t think they could do and how it has increased their independence – “I don’t need to bother my family with simple things, you know, reaching for X or ‘can you pick up Y?’ I can do these on my own.”

Negative symptom reductions were reported by all participants. Pain reduction in the shoulders and upper back appears to be significant – “My upper back has been feeling a lot better, especially sleeping – I sleep on my side. Um, a lot of the pain has gone away that normally occurs after sleeping, six hours of sleeping on my side.” Sleep has improved – “I’ve been sleeping through the nights more than I had before, and, uh, it’s a good thing…it’s good to get a good night’s sleep… I’ll take it – extra sleep!” The participants also report that spasms are reduced – “The FES cycle actually calms down my spasms, and after I work out on the bike, I don’t spasm as much – my legs don’t and that’s a good side effect.”
Physiologic Improvements Reported by Each Participant

“Every time I see somebody I haven’t seen I a while, they compliment me on how much better I am moving and how they think I have more function. It has increased mobility and strength and range of motion, and, you know, I haven’t received…being injured for almost eight years now, I haven’t had any return, to the point that I can, you know, with the increased range of motion and strength, ability to do more things on my own, it almost looks like I have more return” and “Since I’ve started the program, I have noticed that signals are getting down into my arms, lifting my arm. Like nerve signals have been traveling and bypassing my, my uh, injury and one going down into my arm and I can lift it up and now push a skateboard back and forth, bring, like increasingly go, like forwards and backwards.”

Positive Psychosocial Effects are Occurring

A recurring theme was the project’s ability to keep participants focused – “It’s a good program to keep my body physically fit and keep me focused on starting to do more.” Optimism was expressed by all participants. “I think possibly because you start to see you achieve things you didn’t think you could and that kind of sparks a light in your head saying that if this is possible, maybe that’s possible” and “You know, some of the younger, newer quads are even seeing return. And that’s definitely grounds for optimism and I think it’s a wonderful program.”

Increased confidence is evident. “It’s given me more confidence to do things on my own” and “I am confident!” “When you achieve those goals, it’s, you know, it makes you feel like you have done something… and you have!”
Participants Find the Program Valuable

There was overwhelming praise for the program. “I’ve always had hope. I think you would be pretty depressed if you went through life without hope, without optimism. But the First Five helps, any time you see good results and you see yourself getting better over all, getting healthier, getting stronger … it gives you more self esteem, makes you proud of yourself – gives optimism. My overall rating of the First Five from 1 to 10 – I give it an 11! It’s a great program. The people are excellent.” All participants liked the fact that the program was not in a hospital setting – “It’s something that I love, going to the gym. I love working out with others. I look forward to it.”

Time commitment was not an issue. Because the program requires a significant time commitment, it was interesting to learn that the participants felt it is time well spent “This is a chance to get me out of the chair. I’ll give up my leisure time for it, definitely. And, it’s fun!” “It’s actually been better than free time. I don’t mind coming here at all. Give up that time! What are they gonna do besides … what’s more important than this?”

Interaction with Other Participants is Important

“I’m not the only one at the gym. I get to work out and socialize with other quads, monitor my progress along with theirs, compare notes. I think we have a special bond as quadriplegics because we’ve been through the same hardships and we can learn from each other and how each one of us has progressed with our injury. Some people can do some things that others can’t and some people have never tried this, a certain technique or a certain skill. But after seeing another quad perform the skill, you know, they try it and are able to do it. It’s a wonderful experience being around other quads.”

Not Traditional Therapy
All four of the participants highlighted that this exercise program was different from anything else they have done. “The FES bike is a highlight of the project. It’s not traditional therapy … we didn’t do the FES bike. I’ve never done that before in any of my other therapies.” “There are so many things I do here that I haven’t done before. I am treated like an injured athlete and not a disabled person.”

Pleased that Family Members are Enthusiastic

It was important to participants that their family members were pleased with the program. Each of them mentioned their family members’ response regarding the program. “[My family is} definitely glad that I am doing this and I think it does help with keeping hope alive that I’ll improve drastically” and “Every time we have a family get together they tell me how much better I am doing.”

Discussion

A coached exercise program for tetraplegic spinal cord injured patients has been very well received by this study population. They have unanimously discussed physical improvements, positive psychosocial effects, family member enthusiasm, the benefits of working out with other tetraplegics, and the overall value of the program. It appears that this type of program would be valuable to other spinal cord injured people.

Information gathered from the pilot study along with concepts from the two conceptual frameworks, the MHPQOL and Bandura’s Self–Efficacy Model were combined to create the new model – The Sheehy SCI-Five Model. This model requires an accessible community environment where spinal cord injured persons participate in a coached exercise program over a defined period of time. The accessible environment includes ample handicapped parking, easy access to the center, exercise equipment
designed especially for persons with spinal cord injuries, and assistance using this equipment. A coach guides the participant through a program of exercise. Several spinal cord injured persons participate in the program concurrently, which provides for encouragement of each other by the group participants and vicarious learning, where one spinal cord person may observe another spinal cord injured person doing and exercise or function they have not yet tried.

Table 2. Major Themes and Sub-Themes

- Participants are experiencing physical improvements
  - Increased activities of daily living
  - Decreased negative symptoms
  - Specific improvements

- Positive psychosocial effects are occurring
  - Improved focus
  - Increased optimism
  - Increased confidence

- Participants find the program valuable
  - Overall value of the program
  - Not an imposition on time
  - Enjoy interacting with other tetraplegics
  - Appreciate the FES bike

- Family members are enthusiastic
Information gathered from the pilot study along with concepts from the two conceptual frameworks, the MHPQOL and Bandura’s Self–Efficacy Model were combined to create the new model – The Sheehy SCI-Five Model. This model requires an accessible community environment where spinal cord injured persons participate in a coached exercise program over a defined period of time. The accessible environment includes ample handicapped parking, easy access to the center, exercise equipment designed especially for persons with spinal cord injuries, and assistance using this equipment. A coach guides the participant through a program of exercise. Several spinal cord injured persons participate in the program concurrently, which provides for encouragement of each other by the group participants and vicarious learning, where one spinal cord person may observe another spinal cord injured person doing and exercise or function they have not yet tried.

In this environment, a person’s muscle strength and endurance should improve, leading to increased function. When function increases, a person’s level of independence becomes greater and self-efficacy increases. All of these components lead to a higher quality of life.
Appendix H

The Model Spinal Cord Injury System program, sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR)

UAB Model Spinal Cord Injury Care System
University of Alabama at Birmingham
Dept. of Physical Medicine & Rehabilitation
619 19th Street South, SRC 529
Birmingham, AL 35249-7330

California Model Spinal Cord Injury System
Santa Clara Valley Medical Center
Rehabilitation Research Center
751 S. Bascom Avenue
San Jose, CA 95128

Regional Spinal Cord Injury Care System of Southern California
Los Amigos Research and Education Institute, Inc. (LAREI)
Rancho Los Amigos National Rehabilitation Center
7601 East Imperial Highway, HB 117
Downey, CA 90242-4155

Rocky Mountain Regional Spinal Injury System (RMRSIS)
Craig Hospital
3425 South Clarkson Street
Englewood, CO 80113

South Florida Regional Spinal Cord Injury Model System
University of Miami
School of Medicine
P.O. Box 016960 (D-461)
Miami, FL 33101

Georgia Regional Spinal Cord Injury Care System
Shepherd Center
2020 Peachtree Road, NW
Atlanta, GA 30309-1402

New England Regional Spinal Cord Injury Center
NE Regional SCI Center
Boston Medical Center, Preston F511
732 Harrison Avenue
Boston, MA 02118-2393
University of Michigan Model Spinal Cord Injury Care System
University of Michigan
Dept. of Physical Medicine and Rehabilitation
300 North Ingalls, Room NI2A09
Ann Arbor, MI 48109-0491

Missouri Model Spinal Cord Injury (MOMSCIS)
University of Missouri-Columbia
One Hospital Drive, DC046.46
Columbia, MO 65212

Northern New Jersey Spinal Cord Injury System
Kessler Medical Rehabilitation Research and Education Corp. (KMRREC)
1199 Pleasant Valley Way
West Orange, NJ 07052-1499

Mount Sinai Spinal Cord Injury Model System
Mount Sinai School of Medicine
Department of Rehabilitation Medicine
One Gustave L. Levy Place, Box 1240
New York, NY 10029-6574

Regional Spinal Cord Injury Center of the Delaware Valley (RSCICDV)
Thomas Jefferson University Hospital
132 S. 10th Street, 375 Main Bldg.
Philadelphia, PA 19107-5244

University of Pittsburgh Model Center on Spinal Cord Injury (UPMC-SCI)
University of Pittsburgh
Human Engineering Research Laboratories
7180 Highland Dr., 151R-1
Pittsburgh, PA 15206

Texas Model Spinal Cord Injury System
The Institute for Rehabilitation and Research (TIRR)
1333 Moursund St.
Houston, TX 77030-3405

VCU Model Spinal Cord Injury System
Virginia Commonwealth University
School of Medicine
PO Box 980661
Dept. of Physical Medicine and Rehabilitation
Richmond, VA 23298-0661
Northwest Regional Spinal Cord Injury System
University of Washington
Box 356490
Seattle, WA 98105-6613
December 18, 2007

Susan B Sheehy, PhIXc, RN, FAAN, FAEN
17 Mill Street
Dorchester, MA 02122

Dear Ms. Sheehy,

Permission is granted to you to utilize data collected under Shepherd Center's Research Review Board Project #323 "The First Five Project: Effects of a Goal-Directed Exercise Program on Functional Improvement, Self-Efficacy, ASIA, and Manual Muscle Scores on Patients with Spinal Cord Injury Quadriplegia" for your doctoral dissertation, which is being completed at the William F. Connell School of Nursing at Boston College.

The research project was approved by the Shepherd Center Research Review Board (Project #323) and data were collected between the dates of September 9, 2004 and September 8, 2006.

Sincerely,

Michael L. Jones, PhD
Vice President, Research & Technology
Shepherd Center
Appendix J

Project: #323
Event: #1758

DATE:  September 24, 2004

TO:  Susan Sheehy, RN, FAAN
      Principal Investigator

FROM:  Michael L. Jones, Ph.D.
        Chair, Shepherd Center Research Review Committee

RE:  Project #323 - Revised Application with new title:
      Effects of a goal-directed exercise program on functional
      improvement, self-efficacy, and ASIA scores in spinal cord injured
      quadriplegics

      Request for Approval of The Use of Human Subjects in
      Research

On behalf of the Research Review Committee, I thank you for meeting with the
Committee, presenting your revised study and answering member’s questions.
We have changed the original title from: Continuing Functional Recovery
Following Outpatient Rehabilitation in Spinal Cord Injured Patients to the above
referenced title. The Project number remains the same.

Approval for this research is granted effective for one year as of September 9, 2004.
One month before expiration, you will be reminded to inform the Research Review
Committee of the status of this project. Re-approval must be granted before the
expiration date or the project will automatically be “suspended”. Failure to receive
a notification that it is time to renew does not relieve you of your
responsibility to provide the RRC with a request for “Continuation Approval”
in time for the request to be processed and approved before your expiration
date.

Enclosed is the stamped/approved/dated Informed Consent form for use in
recruitment. This will also be reviewed in one year. Changes in the research
may not be initiated without RRC review and approval except where necessary to
eliminate hazards to human subjects. Any changes, which have been necessary
for the above reasons, must be promptly reported to the RRC.

The Principal Investigator must report to this office, in writing, within 5 days, any
unanticipated problems involving risks to the subjects or others, such as serious
adverse reactions to biological drugs, radio-isotopes or to medical devices.
Records pertaining to research must be retained for at least three years after
completion of the research.

You are responsible for notifying all parties about the approval of this project,
including your Co-PI’s and department head. If you have any questions, please
feel free to call me at 404-350-7595.
Project: #323
Event: #2206

DATE: August 26, 2005

TO: Susan Sheehy, RN. FAAN
Principal Investigator

FROM: Michael L. Jones, Ph.D.
Chair, Shepherd Center Research Review Committee


Request for Project Continuation Approval with submission of Annual Status Report

On behalf of the Shepherd Center Research Review Committee, this is to acknowledge receipt of a copy of your Annual Status Report dated August 24, 2005, submitted under cover of your email dated August 25, 2005, which has been reviewed and approved, extending approval for the project through September 9, 2006.

Enclosed is the dated/stamped Informed Consent Form, approved for one additional year until September 9, 2006, which must be used for enrolling subjects into this protocol. One month before expiration you will be reminded to inform the RRC of the status of this project. Re-approval must be granted before the expiration date or the project will automatically be “suspended”. Failure to receive a notification that it is time to renew does not relieve you of your responsibility to provide the RRC with a request for “Continuation Approval” in time for the request to be processed and approved before your expiration date.

Changes in the research may not be initiated without RRC review and approval except where necessary to eliminate hazards to human subjects. Any changes, which have been necessary for the above reasons, must be promptly reported to the RRC.

The Principal Investigator must report to this office, in writing, within 5 days, any unanticipated problems involving risks to the subjects or others. Records pertaining to research must be retained for at least three years after completion of the research.
Appendix K

SHEPHERD CENTER
INFORMED CONSENT

Subject's Name:

Title of Research Protocol: Effects of a goal-directed exercise program on functional improvement, self-efficacy, and ASIA scores in spinal cord injured quadriplegics

Principle Investigator's Name: Susan Sheehy RN, FAAN

Protocol #:

INTRODUCTION
In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This process is known as “informed consent.”

This consent form describes the purpose, procedures, benefits, risks, discomforts and precautions of the study.

You have the right to withdraw from the study at any time.

No guarantees or assurances can be made as to the results of the study.

Once you understand the study and if you decide to participate, you will be asked to sign this informed consent.

You will receive a copy of the signed informed consent to keep for your files.

THE PURPOSE OF THE STUDY
You are being asked to participate in a study to evaluate a type of exercise program for people with quadriplegic spinal cord injuries. The purpose of the study is to determine if this exercise program will reduce the number of medical complications you usually experience (such as skin breakdowns, urinary tract infections, and spasms), improve your functional abilities, and increase your self-efficacy (your belief that you can achieve reasonable goals).

SUBJECT SELECTION
A total of 5 to 6 people with quadriplegic spinal cord injuries will participate in this study, which will take place at the Massachusetts Hospital School. In order to determine your eligibility for this study, you will be asked a series of questions before being asked to sign this consent form.

#323, Version September 2004
The decision to participate in this study is solely your own and is totally voluntary.

PROCEDURES
To participate in this study, you will need to have a letter of permission from your primary care physician, a copy of your original emergency department record, and a copy of your first and latest motor and sensory testing results. In addition, you will be asked to compile a list of all of the complications, such as urinary tract infections, pain, pneumonia, blood clots, and pressure ulcers, that you have had the six months prior to the study.

STUDY PROTOCOL
At the beginning of the study, we will obtain your current motor and sensory values, and you will be asked to complete a questionnaire regarding your feelings about setting goals.

We will also ask you about your short-term goals (ones that you would like to achieve in the first part of the study). We will then begin a program of exercises that will be aimed at improving your balance, your upper extremity strength and function, and improving your over all conditioning. This will include functional electrical stimulation.

Your exercise sessions will be video taped. These videotapes will be used to analyze your progress.

You will be asked questions about your functional activities approximately every two weeks. In addition, at the end of the third month of the study and the sixth month of the study, you will again be tested for motor and sensory function and your feelings about your short-term goals and being able to achieve them.

At the end of the third month and the sixth month, you will be interviewed and asked questions about how you feel about participating in the study. The interviews will be audio taped so that accurate transcripts of your interview can be produced.

Throughout the study, you will be asked to keep a journal of any positive or negative things that have happened that you feel are the results of your participation in the study.

TIME COMMITMENT
If you agree to participate in this study, you will be expected to attend three two-hour exercise sessions each week for a period of approximately six months. It is understood that there will be occasions when you will not be able to attend.
RISKS AND DISCOMFORTS
Because this study will require an intensive exercise program, you may find that you will experience some muscle soreness the day following an exercise session. This is normal and to be expected.

BENEFITS
If you agree to participate in this study, there may or may not be a direct benefit to you. There is no guarantee that your motor or sensory function will improve or that your medical complications will be reduced.

STUDY PARTICIPATION AND WITHDRAWAL
Participation in this study is voluntary. You have the right to refuse to take part in this study. If you do choose to participate in this study, you have the right to withdraw at any time. You may also be withdrawn from this study without your permission if, in the opinion of the researchers or your physician, further participation will be harmful to your health or if you are unable to meet the time commitments of the study. In addition, the sponsors of the study may stop the study at any time.

COST/PAYMENT
There will be no cost to participate in the study. There will be no payment or reimbursement to you for your participation in this study, with the exception of reimbursement for use of public transportation provided receipts are presented.

CONFIDENTIALITY
Every effort will be made to keep your personal information confidential. Any information that identifies you will be available only to the study investigators. We cannot guarantee absolute confidentiality. Your name will be removed from any data that is reported from the study.

Data from your participation in the study will be permanently kept in a database at the Shepherd Center and may be used for future research. Your personal information may be disclosed only if law requires it.

AUTHORIZATION FOR USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION
As part of this study, we will be collecting and sharing information about you with others. Please review this section carefully as it contains information about federal privacy rules and the use of your information.

Protected Health Information (PHI)
By signing this informed consent document, you are allowing the researchers and other authorized personnel to use (internally at the Shepherd Center) and disclose (to people and
organizations outside of the Shepherd Center) health information about you that we have obtained through questionnaires and tests that we will ask you to undergo. This is your protected health information.

**People/Groups at the Shepherd Center Who Will Use Your Protected Health Information**

Your protected health information may be shared between the researcher and the supporting research team, such as the director of research, research assistants, statisticians, data managers, and administrative assistants. Your protected health information data may also be shared with the Research Review Committee, as it is responsible for reviewing studies for the protection of the research participants.

**People/Groups Outside of the Shepherd Center With Whom Your Protected Health Information May Be Shared**

We will take care to maintain your confidentiality and privacy. WE may share your protected health information with the following groups so that they may carry out their duties related to this study:

- Statisticians and other data monitors not affiliated with the Shepherd Center
- The Department of Health and Human Services
- Hospital and Clinical Research Accrediting Agencies
- Data and Safety Monitoring Boards that oversee this study

**No Expiration Date – Right to Withdraw Authorization**

Your authorization for the use and disclosure of your protected health information in this study shall never expire. However, you may withdraw your authorization for use and disclosure of your protected health information at any time, provided you notify the Principal Investigator in writing at the following address:

The Shepherd Center
2020 Peachtree Rd, NW
Atlanta, GA 30309

Please be aware that the investigators in this study will not be required to destroy or retrieve any of your protected health information that has already been used or disclosed before the principal investigator receives your letter.

**CONTACT**

If you have any questions about this research or experience any problems related to the study, you should contact Susan Sheehy at (617) 416-5128. If you have any questions concerning your rights as a research subject, you may contact Michael L. Jones, Ph.D., Chair, Shepherd Center Research Review Committee at (404) 350-7395.
CONSENT FORM FOR CLINICAL RESEARCH
I have read the above information of this consent form and the investigator has explained the
details of the study. I understand that I am free to ask additional questions.

If I wish additional information regarding this research and my rights as a research subject, or if I
believe that I have been harmed by this study, I may contact the Chairperson of the Shepherd
Center’s Research Review Committee at (404) 350-7595.

I understand that this is a research project and that unforeseen side effects may occur.

I understand that the Shepherd Center has no formal program for compensating patients for
medical injuries arising from this research.
I understand that the Shepherd Center’s Research Review Committee may contact me during or
after my participation in this study as part of its efforts to monitor the experience of participants
in clinical investigations.

I understand that participation in this study is voluntary and I may refuse to participate, or I may
discontinue participation at any time.

I acknowledge that no guarantees have been made to me regarding the results of the treatment
involved in this study. I consent to participate in the study and have been given a copy of this
form.

WITNESS            DATE            STUDY SUBJECT        DATE

The subject has been given the opportunity to read this consent form, to ask questions before
signing, and has been given a copy.

Principle Investigator’s Name

Signature of Investigator   (or designee)

Shepherd Center
Research Review Committee
(Approved) /Acknowledgment

Date       9/24/04
Expires    9/7/05

#323, Version September 2004
Appendix L

BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

Protocol IRB: 09.172.01exe
TO: Susan Sheehy
FROM: Institutional Review Board – Office for Research Protections
DATE: March 20, 2009
RE: Effects Of A Coached Exercise Program In People With Tetraplegic Spinal Cord Injuries

Notice of Evaluation- [EXEMPT 45 CFR 46.101(b) (4)]

The Office for Research Protections (ORP) has evaluated the project named above. According to the information provided, you intend to determine if people with tetraplegic spinal cord injuries who participated in this study experienced increased muscle strength, improved quality of life, and improved self-efficacy as a result of participation. This is a minimal risk study.

This study has been granted an exemption from Boston College IRB review in accordance with 45 CFR 46.101 (b) (4), which provides exemption for research with pre-existing data sources in which the information will not be recorded in such a manner that subjects can be identified, directly or through identifiers linked to the subjects. This designation is based on the assumption that the materials that you submitted to the ORP contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This exemption is given with the following conditions:

1. You will conduct the project according to the plans and protocol you submitted;
2. No further contact with the ORP is necessary unless you make changes to your project or adverse events or injuries to subjects occur;
3. If you propose to make any changes in the project, you must submit the changes to the ORP for IRB review; you will not initiate any changes until they have been reviewed and approved by the IRB;
4. If any adverse events or injuries to subjects occur, you will report these immediately to the ORP.

The University appreciates your efforts to conduct research in compliance with the federal regulations that have been established to ensure the protection of human subjects in research.

Date of Exemption: March 20, 2009

Boston College OHRPP
Sincerely,

Stephen Erickson
Interim Director
Office for Research Protections

jac

Boston College OHRPP
Appendix M

Moorong Self-Efficacy Scale

From: James Middleton <jmid2576@usyd.edu.au>
To: Susan Sheehy sheehyboston@gmail.com
Date: Wed., April 14, 2010
Subject: Permission to Use MSES

Dear Susan,

I would be delighted for you to use the MSES in your doctoral work. I would be most interested in results of your research and any other feedback about tool when you have had a chance to use it. We are planning to further develop it over the next 12 months.

Please let me know if I can be of any other assistance.

Cheers,

James.

Associate Professor James W Middleton MBBS, PhD, GradDipExSpSci, FAFRM(RACP), FACRM
Director, NSW Statewide Spinal Cord Injury Service,
Royal Rehabilitation Centre, PO Box 6, Ryde, NSW 1680
Ph: 61 2 9808 9666 Fax: 61 2 9808 9658
E-mail: j.middleton@usyd.edu.au
Dear Dr. Susan Sheehy,

SCIM can be used free for clinical and academic purposes. Its use for any for-profit purpose, including a clinical trial sponsored by a commercial firm, requires an agreement with Loewenstein Hospital and a $35 fee for each examined subject. I recommend using the 3rd SCIM version, which is attached.

Best wishes,

Amiram Catz

Prof. Amiram Catz

Medical Director, the Spinal department

Loewenstein rehabilitation Hospital, Raanana

Head of the Rehabilitation Department, Tel-Aviv University

Tel-Aviv, Israel
Hi Sue.

Congratulations on completion of your dissertation – I know that is a monumental amount of work! Yes, you have permission to use Shepherd Center’s Manual Muscle Test and ASIA forms in your dissertation. Let me know if you need anything more formal in the way of permission.

Best wishes!

Mike

Michael L. Jones, Ph.D.
Vice President, Research and Technology
Director, Virginia C. Crawford Research Institute
Shepherd Center
2020 Peachtree Rd, NW
Atlanta, GA 30309
RT300-S FES Bike

From: Judy Klein/Restorative Therapies
To: Susan Sheehy
Date: Wed., April 14, 2010
Subject: Permission to use photo of RTS Bike

Dear Sue,

Great to hear from you.

We have shared your story with many people around the globe as we believe the SSYMCA program shows what can and should be available in communities everywhere.

And Sheryl Rosa's enthusiasm never wanes.

Do you know that our cycle now does trunk stimulation while one is either leg or arm cycling? We have to make workouts as efficient as possible!

We would be delighted for you to include a photo of the RT300 in your doctoral dissertation.

Kind regards,

Judy

Judy Kline
Sales and Marketing
Restorative Therapies
Ph 800 609 9166 ext 301
Hi Sue,

Yes you can use a picture of the EasyStand Evolv Glider in your presentation. Would it be possible to see a copy of the presentation? It sounds very interesting.

Thanks

Jackie Kaufenberg  Marketing Manager
jackie@easystand.com

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Vita Glide®

From: John Caden <johnjcaden@gmail.com>
Date: Wed, Apr 14, 2010 at 4:41 PM
Subject: VitaGlide Photo
To: sheehyboston@gmail.com

Hi Sue,

Thanks for your email regarding your research project.

By all means, please use any photo of the VitaGlide for your paper. If you post it online, please send me a link.

Thanks again and best of luck.

Best regards,

John Caden

SR Smith, LLC
800-577-4424
503-266-2231
305-586-7779 C
SKYPE: jjcaden