

WELL ON WHEELS: A HOLISTIC WELLNESS INTERVENTION FOR INDIVIDUALS
WITH SPINAL CORD INJURIES: RISK PROFILE, LONGITUDINAL OUTCOMES, AND
SUCCESS

A Dissertation

Presented to

The Faculty of the Department of Health and Human Performance

University of Houston

In Partial Fulfillment

Of the Requirements for the Degree of

Doctor of Philosophy

By

Stephanie L. Silveira

March, 2018

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ABSTRACT

Individuals with spinal cord injuries (SCI) report significantly lower satisfaction with life (SWL) than the general population. One ultimate goal of rehabilitation is to increase SWL. The Well on Wheels intervention was a pilot intervention aimed at increasing SWL in individuals with SCI. Seventy-two participants were randomized to either a seven-month intervention group or a no treatment control group and followed longitudinally with measurements at baseline, 3 months, 7 months, 1 year, and 2 years.

This study is a secondary data analysis of this intervention with three primary aims. First, a decision tree regression model examined the relationship between SWL at baseline and demographics and injury characteristics that were associated with high and low SWL. Those with low SWL were more likely to be less than 4.5 years post injury or between 4.5 and 17.5 years post injury and single/divorced. Those with high SWL were more likely to be married and less than 49 years old.

Next, linear mixed model analyses were used to examine changes over time by SWL group in primary, secondary, and exploratory variables of interest. Significant improvements in SWL occurred in individuals with low baseline SWL. Individuals with high baseline SWL also showed significant increases in total cholesterol 2 years following intervention. There were no other significant interaction effects.

Finally, successful individuals in the Well on Wheels intervention were identified. A decision tree regression analysis for demographic and injury characteristics associated with success in the intervention. Successful individuals were more likely to be married and not successful individuals were more likely to be single/divorced and less than 50 years old.

These aims help researchers and clinicians: 1) identify individuals at risk for secondary conditions and poor psychological wellbeing associated with low SWL who may benefit from interventions, 2) help researchers understand how participants in this intervention fared longitudinally who differed in baseline SWL, and 3) guide future research and program development as some individuals did not benefit from this intervention and may need different interventions. Findings from this research further delve into the role of social support in adjustment following SCI.

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CHAPTER 1

1. INTRODUCTION

1.1 STUDY RATIONALE

Spinal cord injury (SCI) is a life altering event in which an individual experiences damage to a portion of the spinal cord or nerves of the spinal canal. This damage may be acute or chronic, but often results in permanent changes in bodily sensations, strength, and body functioning at and below the site of injury. Individuals with SCI often experience changes in psychological status including satisfaction with life. Individuals presenting with certain demographic and injury related factors may be more susceptible to low satisfaction with life and would benefit from interventions to improve satisfaction with life following injury. The Well on Wheels intervention is a wellness intervention designed specifically for individuals with SCI. The longitudinal impact of this intervention and qualities of those who were successful were explored to determine the intervention's effectiveness and guide recommendations for future research and program implementation.

1.2 PROBLEM STATEMENT

Individuals with disabilities generally experience significant health disparities. In populations with disabilities obesity and other secondary health conditions are far more prevalent in individuals without disabilities.¹ For example, women with disabilities disproportionately experience obesity, secondary health conditions, and poverty.² Additionally, secondary data analysis show common secondary conditions among people with physical disabilities include: fatigue, depression, chronic pain, anxiety, bowel

dysfunction, urinary tract infections, pressure sores, respiratory infections, contractures, autonomic dysreflexia, and seizures.³ The traditional medical models of disability separate good health and disability, positing that by definition an individual with a disability is not healthy. However, progress in the field has helped guide understanding that individuals with disabilities can live long, fulfilling, and healthy lives. The goal of health promotion and wellness research is to reduce health disparities and help all individuals live to their full potential.

Approximately 300,000 people in the U.S. today are living with SCI.⁴ Men represent a disproportionate percentage of the population with SCI (~81%). Individuals with SCI often struggle to learn how to complete daily tasks of living in a whole new way.⁵ High rates of unemployment, low income, and rehospitalizations following injury all negatively impact independence.^{6,7} Satisfaction with life generally decreases immediately after SCI.⁸ In the years following injury increases typically occur, but overall individuals with SCI on average report lower levels of satisfaction with life than the general population.^{9,10} Factors associated with low satisfaction with life have been explored in the literature. However, results are mixed and work is needed to identify demographic variables and injury characteristics that are shared by individuals with SCI reporting low satisfaction with life. In all populations, individuals who report lower satisfaction with life generally experience more secondary conditions, specifically negative health behaviors and psychological distress. A better understanding of qualities shared by individuals reporting low satisfaction with life can aid researchers and practitioners seeking individuals who would benefit from effective interventions.

One of the ultimate goals of rehabilitation following a SCI is to increase satisfaction with life. Longitudinal research from the Spinal Cord Injury Model Systems study shows that satisfaction with life changes over time and interventions are being developed targeting important antecedents to satisfaction with life that are amenable to change such as self-efficacy and health promoting behaviors.⁹ Little is known about who these interventions are reaching and if they are effective for diverse populations. Therefore, we must further examine which interventions are effective and if there are specific subpopulations of individuals that benefit most from interventions. In addition, there is a general call for researchers to utilize existing datasets in innovative ways to further knowledge in the field and aid in choosing interventions to fund and disseminate in the community.

Holistic wellness interventions target modifiable behaviors associated with overall health that impact global quality of life. Wellness interventions provide an avenue for helping individuals with SCI improve their satisfaction with life by reducing barriers and increasing resources that can help to empower individuals and promote self-confidence. Analyses of currently developed wellness interventions are necessary in order to guide recommendations for rehabilitation practitioners in choosing and providing services to help individuals with SCI following injury. This research aims to better understand both who is enrolling in interventions designed to improve satisfaction with life and who is successful in these interventions.

1.3 RESEARCH QUESTIONS AND HYPOTHESES

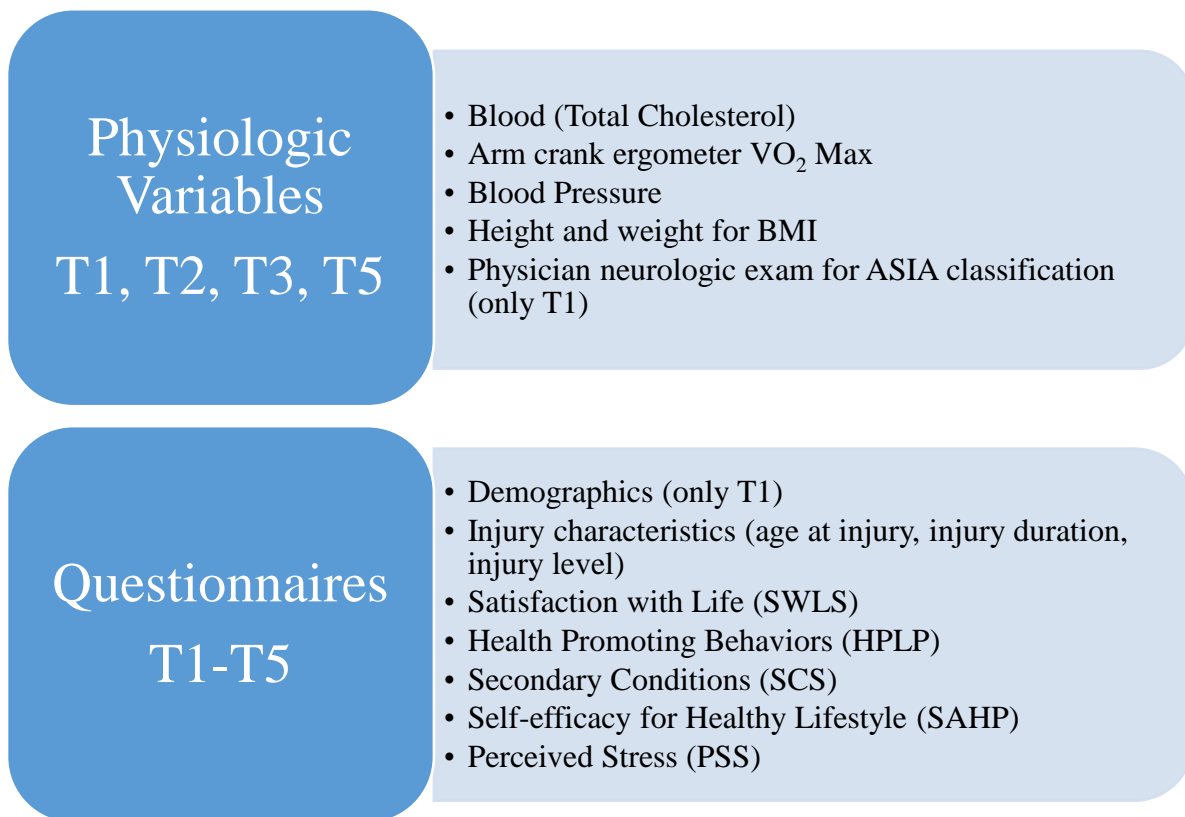
Dr. Denise Tate and colleagues at the University of Michigan developed the Well on Wheels intervention aimed at improving satisfaction with life in individuals with SCI.

The intervention consisted of an intensive period with 6 workshops over a 3-month period and a more individualized 4-month tapering period. The curriculum was created and facilitated by experts in the area of SCI using Social Cognitive Theory to change important antecedents to satisfaction with life (i.e. self-efficacy and health promoting behaviors). This study was a secondary analysis of the Well on Wheels intervention aimed at identifying qualities of individuals low on satisfaction with life enrolling in the intervention, examining longitudinal outcomes of participants, and identifying qualities of successful individuals in this specific program. Initial post-intervention analyses showed that the program positively impacted individuals in the intervention group, however a better understanding of those who benefit most from this program is needed to guide rehabilitation practitioners providing resources to individuals recovering from injuries.

Figure 1. Study timeline and flow diagram for the Well on Wheels pilot study examining the feasibility of holistic wellness intervention for individuals with spinal cord injuries.



Figure 2. Psychological and physiological variables of interest



This study involved 3 general research questions, each with 1-3 related hypotheses.

Research question 1: What are demographic and injury characteristics of individuals with spinal cord injuries with low satisfaction with life at baseline?

Hypothesis 1.1: Demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) will accurately identify >75% of individuals with low satisfaction at baseline.

Research question 2: What is the differential effect of the Well on Wheels intervention on participants with SCI among those with high versus low satisfaction with life at baseline?

Hypothesis 2.1: Individuals in the low satisfaction with life group at baseline will show significant positive change in primary outcomes (i.e. satisfaction with life and self-efficacy for health practices) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Hypothesis 2.2: Individuals in the low satisfaction with life group at baseline will show significant positive change in secondary outcomes (i.e. health promoting behaviors and secondary conditions) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Hypothesis 2.3: Individuals in the low satisfaction with life group at baseline will show significant positive change in exploratory outcomes associated with secondary health conditions (i.e. total cholesterol, peak VO₂ max, diastolic blood pressure, systolic

blood pressure, and BMI) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Research question 3: Which demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) are associated with success in the Well on Wheels intervention?

Hypothesis 3.1: Demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) will accurately identify >75% of individuals at baseline who go on to not be successful in Well on Wheels intervention. Success is categorized by improvement from baseline in satisfaction with life, self-efficacy for health practices, secondary condition severity, and perceived stress greater than mean control change in outcomes following the intensive phase of the intervention (3 months).

The purpose of this study was to assess the effects of Well on Wheels, a holistic wellness intervention on individuals with SCI. The primary aim of the intervention was to improve satisfaction with life following SCI. Therefore, we identified differences at baseline that may be vital to our understanding of the usefulness of intervention and effective strategies in “at risk” individuals who report low satisfaction with life at baseline. To address this aim individuals high or low self-reported satisfaction with life were identified (RQ1). Those reporting low satisfaction with life were considered individuals at risk most likely to benefit from a wellness intervention created to help individuals with SCI by providing tools to modify behaviors including: lifestyle management, nutrition, physical activity, and secondary condition management that

directly and indirectly impact satisfaction with life. A decision tree regression analysis was used to explore the relationship between satisfaction with life at baseline and demographic variables and injury characteristics that can be used to help clinicians and practitioners identify individuals who would benefit from interventions (RQ1).

Next, longitudinal changes in the primary, secondary, and exploratory variables were examined (RQ2). Changes in variables of interest over the intervention period were assessed by comparing outcomes in groups reporting high versus low satisfaction with life at baseline. All individuals are presumed to benefit from wellness intervention, but we expected the potential benefit to be greatest for those who initially report low satisfaction with life. It is also important to examine those with a low satisfaction with life because they are at highest risk of engaging in poor health behaviors and experiencing secondary health conditions that can negatively impact overall quality of life following SCI. Effects of intervention were explored longitudinally at five time points in order to better understand if there are different trajectories of change in the Well on Wheels intervention for individuals with high versus low satisfaction with life at baseline.

Successful individuals in the Well on Wheels intervention were identified by calculating each participant's change scores on primary (satisfaction with life and self-efficacy) and secondary variables (health promoting behaviors, perceived stress, and secondary conditions). Intervention participant change scores were compared to control group mean change score following the 3 month group intervention. Those who score higher than control on three out of five variables are classified as successful intervention participants. A decision tree regression analysis was then conducted to identify

demographic variables and injury characteristics unique to the individuals who are successful in the Well on Wheels intervention (RQ3). This strategy has real-world implications in providing variables that clinicians can use to identify individuals who arrive in their practice that may benefit from behavioral intervention strategies and principles used in the Well on Wheels intervention. Additionally, many interventions are currently conducted and investigators only assess effectiveness of the intervention by comparing mean scores on outcomes between groups. Knowledge of characteristics shared by individuals for whom interventions are working for is vital. The ultimate goal of intervention development is to widely disseminate effective programs to benefit the community. As such, there is a great need to assess whether interventions work for diverse groups or only individuals with certain characteristics.

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

This literature review presents a detailed overview of current understanding of satisfaction with life and wellness interventions for individuals with spinal cord injuries (SCI). Individuals with SCI experience a trauma that has a multifactorial impact on life following injury. Further, individuals with SCI are different from the general population and other populations with disabilities requiring appropriate and tailored intervention to promote longitudinal health and wellbeing. The focus of this literature review is providing an overview of our current knowledge of factors that may be associated with satisfaction with life following SCI. Factors associated with satisfaction with life among patients with SCI may also be associated with intervention success. Further, this section outlines current knowledge of interventions in all the domains of Well on Wheels intervention that guided formation of the evidence-based research questions and hypotheses. Specifically, this chapter reviews literature on: 1) satisfaction with life following SCI, 2) potential mediators and moderators of satisfaction with life following SCI, 3) previous wellness interventions conducted in individuals with SCI, and 4) the theoretical basis of the Well on Wheels intervention. This literature review focuses on the unique area of individuals with SCI, drawing on literature on other populations with disabilities to fill any large gaps.

2.2 SATISFACTION WITH LIFE FOLLOWING SCI

2.2.1 SPINAL CORD INJURY

SCI is a traumatic event with about 17,000 new cases occurring each year.⁴ Age at injury on average is 42 years old and injuries occur most often in men. The most common etiology of injury is a trauma such as a fall or vehicle accident, but can also occur from surgery or cancer.⁴ Additionally, an injury is considered either complete or incomplete on the basis of function below level of injury. Regardless of etiology, age, and other factors a significant change in life circumstances occurs in individuals with SCI.

Individuals with SCI show higher rates of cardiovascular disease, obesity, and other secondary conditions.¹ Each year approximately 30% of the overall population with SCI is rehospitalized for some reason.⁴ Rehospitalization and secondary conditions result in significant expenses and disruptions in daily living.⁷ Additionally, the majority of individuals with SCI experience changes in mobility, functional status, and independence that may impact overall satisfaction with current life situation.⁶

Prior to advances in medicine and assistive device technology survival rates for individuals with SCI were poor.¹¹ Individuals with SCI are living to older ages; though life expectancy is closely related to level of injury and age at injury.⁴ There is a great need to understand changes following injury and the trajectory of psychological and physiological factors as individuals' age. Of interest in this study were consistently low levels of satisfaction with life reported following SCI. In other words, individuals with SCI are living to older ages and though they experience low satisfaction with life; we have the opportunity to improve satisfaction with life as individuals adapt and continue their lives.

2.2.2 QUALITY OF LIFE

Quality of life is a general term used to describe objective and subjective components in a person's life that contribute to feelings of joy and fulfillment and is often used synonymously with happiness.¹² Cohen, Mount, MacDonald¹³ describe the general construct of quality of life as having three parts: objective life conditions, subjective wellbeing, and personal values or aspirations. These factors work dynamically within the domains of physical wellbeing, material wellbeing, social wellbeing, productive wellbeing, emotional wellbeing, and civic wellbeing.¹⁴ In the literature, quality of life and satisfaction with life are often used interchangeably, but there are distinct differences theoretically that merit an interest in satisfaction with life specifically.

2.2.3 SATISFACTION WITH LIFE

Satisfaction with life is a unique domain of overall subjective wellbeing. More specifically, subjective wellbeing includes three separate constructs: positive affect, negative affect, and satisfaction with life.¹² Positive and negative affect include the emotional portion of subjective wellbeing. Individuals use current and previous emotional states experienced to assess their current feelings of wellbeing.¹²

Satisfaction with life is the portion of subjective wellbeing that requires a cognitive judgment or perception.¹⁵ Satisfaction with life is a global assessment of quality of life that focuses on the individual's opinion of their current state. It is an evaluative judgment based on either individually chosen or domain-specific components, that come together to form a general judgment of satisfaction.¹⁶ Domain specific measures of both satisfaction with life and quality of life exist, but these measures assume that individuals' priorities in domains such as health or employment are equal across the board. Several

factors that are universally connected to global judgments of satisfaction with life including: marital satisfaction, social relationships, academic success, reduced suicide risk, and physical health.^{17,18} Global satisfaction with life judgments allow individuals to choose information that is most important to their overall satisfaction; utilizing information that is most salient to them as opposed to imposing specific domains. Individuals are also able to assess their general wellbeing, value of experiences and attainment of important goals such as life goals.

The focus of this study was the subjective evaluation of global satisfaction with life. Pragmatically quality of life and satisfaction with life are often used synonymously. Due to the limited literature specifically measuring satisfaction with life following SCI, studies utilizing measures of quality of life are included in outlining literature in this area to help illuminate factors that may be associated with satisfaction with life following SCI or that may help in improving satisfaction with life.

2.3 MEDIATING AND MODERATING FACTORS OF WELLNESS

FOLLOWING SCI

One focus of this study is factors associated with satisfaction with life following SCI. The Well on Wheels study participants include diverse individuals including a large age range (20-80 years) and from different backgrounds (11% minority). In order to formulate evidence-based hypotheses about individuals who report low satisfaction with life, a comprehensive understanding of the current knowledge of factors associated with satisfaction with life following SCI was needed including: trajectory, correlates, and previous wellness intervention outcomes. This portion of the literature review was vital to understanding mediators and moderators of satisfaction with life.

2.3.1 TRAJECTORY OF SATISFACTION WITH LIFE FOLLOWING SCI

Patient satisfaction is a top priority in rehabilitation and management of chronic diseases, including SCI. Following SCI, individuals typically experience a decrease in quality of life and satisfaction with life, but the majority of individuals show great improvements in the first year of rehabilitation.⁸ Less is known about the trajectory following the first year after injury and most studies find that individuals with SCI report lower levels of satisfaction with life than the general population even decades post-injury.^{19,20}

Literature on the trajectory of satisfaction with life following SCI shows that satisfaction with life is not stable in this population and changes over time. Age of SCI does not seem to be related to higher satisfaction with life. General population literature posits that satisfaction with life is generally high and stable as an individual ages, which seems to be consistent in populations with SCI.²¹ Relatedly, qualitative data suggests that after an adjustment period, individuals with SCI no longer perceive themselves as different from the general population and they have a new “normal” in their life perception that subsequently shifts quality of life to be similar to the general population.²² A synthesis of what is known in the literature on this trajectory is necessary to better understand how interventions can impact satisfaction with life over time.

In some studies, individuals with SCI report high levels of satisfaction with life and quality of life. One early study found quality of life in veterans with SCI is actually higher than able bodied male counterparts and relatively good overall.²³ However, veteran status may have a differential effect on ratings of quality of life. With limited literature on individuals with SCI, knowledge gained from individuals with other

disabilities may be more appropriate in helping guide initial inferences about satisfaction with life following SCI. In a study of individuals with various disability types those between 16 and 24 years old individuals reported the greatest satisfaction, whereas those between 45 and 54 reported the least.²⁴ Additionally, those who acquired disabling conditions before the age of 20 reported highest satisfaction with life. Dijkers⁶ found satisfaction with life was lower in populations with SCI based on SCI Model Systems data, but not drastically so. A gap in the literature exists as to whether aging is the primary factor influencing satisfaction with life or disability status.

Satisfaction with life ratings in individuals with SCI have been obtained cross-sectionally ranging from immediately following injury to 5, 10, 15, or 20 years post-injury. Studies of individuals who were 10 and 15 years post injury report their life as comparable or somewhat better than that of same age peers without SCI.²⁵ Twenty years following injury approximately three quarters of individuals rate their current quality of life as either good or excellent, providing evidence for the “new normal” hypothesis.²⁶ In a retrospective study individuals with SCI reported on the previous 10 year period and a similarly favorable response occurred, but only 56% reported a favorable score 20 years ago around the time of their SCI.²⁶ Therefore, in individuals with SCI satisfaction with life ratings seem to be higher when reporting on their current status as opposed to periods closer to their injury.

In an early study, seventeen individuals with SCI were followed from 6 months-5 years following injury showing different trajectories of coping.²⁷ Individuals who reported initial low levels of quality of life that later increased in coping were young, had returned to work and reported fewer secondary conditions. Individuals with SCI who

were initially unstable, but show fairly good coping over time attribute pain as a large factor that shifts quality of life as well as unemployment and dependence on others for activities of daily living. Unsatisfactory coping occurred in individuals who were older, with only 20% working 5 years post-injury, 2 had severe pain below injury level and 2 had moderate pain. The sample size is not adequate in this study to make definitive decisions, but is a first step in understanding coping trajectories following SCI that may be related to overall satisfaction with life and identifies age, pain, and secondary conditions as factors of interest.

Many studies include “one year post-injury” as inclusion criteria due to the fact that satisfaction with life begins to stabilize. Satisfaction with life is generally relatively stable 1 year post-injury and 4 years following.²⁸ Additionally, when following people during inpatient rehabilitation in the 3 months after start of active rehabilitation, discharge from rehabilitation, and 1 year after discharge individuals considered unsatisfied with life decreased from 74.6% at beginning of active rehabilitation to 49.3% at 1 year post-discharge and remained stable over time.²⁹ Overall, researchers measuring time variables find a significant increase in mean satisfaction with life total score between the start of active rehabilitation and discharge and a stable score between discharge and 1 year after discharge.

The trajectory of satisfaction with life following SCI has been explored showing initial declines with significant increases following active rehabilitation. Therefore, satisfaction with life may be more flexible and dynamic in individuals with SCI than the general population; if satisfaction with life is amenable to change in individuals with SCI they may benefit from interventions aimed at improving satisfaction with life. Some

individuals report higher satisfaction with life earlier in the rehabilitation process, but little is known about the factors that are reliably associated with positive psychological or physiological outcomes. Most notably there is a need for a better understanding of factors associated with higher rated satisfaction with life that may be modifiable via evidence-based interventions (e.g. health behaviors or self-efficacy).

2.3.2 CORRELATES OF SATISFACTION WITH LIFE FOLLOWING SCI

The literature on factors associated with satisfaction with life following SCI are mixed. Therefore, an overview of current knowledge of the relationship between demographic variables and injury characteristics with satisfaction with life is necessary. These factors are highlighted as potential mediators of interest that may be modifiable using an intervention. Because there is much overlap between satisfaction with life and quality of life, studies of quality of life are included.

Research shows some factors are associated with higher or lower satisfaction with life. Employment following SCI is an indicator of positive adjustment, independence, and generally a significant predictor of higher satisfaction with life.^{9,30-33} Closely related to employment status is income, which is also a significant predictor of level of satisfaction with life with higher income being related to more satisfaction.^{9,25,30-33} Rural community status is a significant factor of interest that is associated with higher levels of satisfaction with life.³⁰ Another factor related to level of satisfaction with life, income and employment is education in which those with a higher education report higher satisfaction with life.^{9,31,32} Therefore, literature shows that employment, income, community, and education are modifiable demographic factors related to satisfaction with life following SCI.

Some non-modifiable factors related to satisfaction with life following SCI include age, race and gender.^{9,20,30,33,34} Satisfaction with life is generally a stable construct, but known to change as individuals age and as a result of life events in the positive or negative direction. These circumstances play a role in individuals with SCI however they are outside of the individuals' control. Similarly, people can identify with a certain race or gender, but generally these factors that remain unchanged. Minority individuals and men generally report lower levels of satisfaction with life; these non-modifiable variables can have a significant impact on ratings of satisfaction with life due to personality and learned culture. Other factors may change as a result of stressors or lifestyle changes following SCI such as marital status, sexual functioning, and family life.^{20,30,35} Social support may also play a large role in ratings of satisfaction with life following SCI.^{34,36} Non-modifiable factors associated with satisfaction with life are an area of interest for interventions to tailor to specific needs of sub-populations such as gender-specific groups or age-specific groups. Individuals sharing these factors that are beyond their control may require different resources and approaches to improving their current life situation.

Injury related variables also contribute to ratings of satisfaction with life. Better self-rated health status is related to satisfaction with life.^{6,9,36} Secondary complications, hospitalizations, and medical complications are universal contributors to lower reported levels of satisfaction with life.^{9,31,34} More specifically, pain is a secondary condition that is significantly associated with satisfaction with life and of great interest in rehabilitation literature.^{29,36} Injury duration is also associated with this construct, but difficult to separate from aging related changes that may occur in satisfaction with life.^{9,32} Use of

assistive devices such as manual or power wheelchair is also associated with lower levels of satisfaction with life³⁴ and related to functioning, which is shown to impact satisfaction with life in examining scores on measures of self-care,²⁰ mobility,⁶ impairment,⁹ Functional Independence Measure (FIM),^{29,34} and severity of disability.^{31,36} Less studied factors such as insurance status and cause of injury were examined by Putzke, Richards, Hicken, DeVivo⁹ showing lower satisfaction with life score in those with injuries of a violent nature and Medicaid insurance. Therefore, injury related characteristics might be important factors to consider in creating interventions to improve satisfaction with life following SCI. Different groups such as individuals with para- vs. tetraplegia may require different resources, information, and support.

Psychological status has been studied in individuals with SCI following injury and similar to satisfaction with life, there are stark changes in the year following injury that level off to generally lower levels than the general population. For example, depression scores are associated with low satisfaction with life in adults with SCI onset in childhood.³⁷ Additionally, satisfaction with life is lower in those reporting any suicidal ideation. Bussing, Fischer, Haller, Heusser, Ostermann, Matthiessen³⁶ posited that some populations with chronic disease experience stressors as a result of their condition, but also a special appreciation for life as a product of disabling conditions. Many psychological factors are studied following SCI that are beyond the scope of this literature review and available for studies specific to this area of interest.

Further, different trajectories in satisfaction with life are mentioned, but a gap exists as to significant and consistent trends in factors, such as demographic variables. Examination of non-modifiable and modifiable factors associated with satisfaction with

life might be of interest in dissemination of lifestyle interventions that would be most effective for subpopulations. For example, one study used questions about current and before SCI quality of life to examine longitudinal changes in individuals with SCI.⁸ Several groups were identified: the first group showed low levels at all time points, the second group had high levels with slight increases over time, the third group showed low rates at baseline then small increases over time to high satisfaction, the fourth group had high rates at baseline then steep declines over time, and the final trajectory fluctuated over time. Members of the second group, which had consistently high levels of satisfaction with life, were most likely to be younger, paraplegic, higher functioning, report less pain, and more social support at rehabilitation than members of the other groups. Those in the third group, who had greatest recovery of initially low scores included more females and individuals with higher reported functional status. Across all groups, functional status, female gender, and less pain were associated with higher satisfaction with life over time.

Additionally, other studies highlight the importance of asking individuals which factors they believe would improve their overall satisfaction. When subjects are asked about factors that they think would improve their quality of life, common factors include: driving a car, walking or moving around better, improved bladder function, improved arm function, improved defecation, less pain, and lower body weight. Furthermore, having a partner and/or children, work, and better living conditions are self-reported factors that individuals with SCI believe would improve their self-perceived life quality.²⁷ Overall, there is a gap in the literature on the trajectory of satisfaction with life following SCI and factors associated with positive adjustment over time. Further, there is cross-

sectional research available to help guide our understanding of factors associated with satisfaction with life following SCI that may be modifiable through intervention.

However, we also know that there isn't consensus in the literature on the most significant factors contributing to satisfaction with life ratings. Earlier sections outlined consistent associations between variables of interest and satisfaction with life, but some research suggests demographic variables and injury characteristics mentioned are not significantly associated with satisfaction with life. Early work by Whiteneck, Charlifue, Frankel, Fraser, Gardner, Gerhart, Krishnan, Menter, Nuseibeh, Short, et al.²⁶ showed little promise for identification of non-modifiable demographic covariates of interest with no effects of injury level or completeness, age, or years post injury on the psychological wellbeing variables of interest. Another study found quality of life ratings did not differ by injury level, completeness of injury, time since injury, or employment status at 10 and 15 years post-injury.²⁵ Some effects of exercise exist in which fewer problems with weight gain and need for additional assistance are reported and those who exercise regularly report having to make fewer changes in daily routine due to fatigue. Other studies find little evidence for an association between level of injury or completeness and satisfaction with life ratings.^{29,30} Additionally, some studies find that gender, social integration, and employment are not significant predictors of satisfaction with life, identifying factors with mixed evidence in the literature.^{6,25}

Relatedly, one study of longitudinal levels of satisfaction with life showed a positive correlation with adjustment and activity as well as a negative correlation with health problems and dependency. General ratings of satisfaction with life predicted longitudinal satisfaction with life ratings better than any other subscale including factors

such as economic satisfaction. Based on results they concluded that demographic variables were relatively unimportant predictors of satisfaction with life and overall self-perceptions of adjustment may be the best predictor.³³

Overall, there is some evidence in the literature that demographic and injury characteristics are associated with satisfaction with life following SCI, but further studies examining these associations are needed due to mixed evidence and lack of consensus. Additionally, a risk profile of individuals with SCI who experience low satisfaction with life does not currently exist. These characteristics may be crucial screening criteria for determining which patients with SCI may benefit from a wellness intervention. Evidence-based lifestyle interventions would benefit individuals with SCI by potentially reducing healthcare costs, but the field has only progressed to small pilot studies and cross-sectional research funded by the federal government. There is a need to analyze currently existing interventions to create and disseminate a widely available wellness intervention for individuals with SCI that reaches diverse groups. One of the aims of this study was to identify factors associated with satisfaction with life among treatment seeking individuals with SCI that could help guide practitioners working with this population.

2.4 SOCIAL COGNITIVE THEORY

Modifiable and non-modifiable factors are highlighted as the promising mechanisms for identification and intervention to improve satisfaction with life following SCI. Interventions are developed to target modifiable factors with the ultimate goal of behavior change and positive outcomes. In order to initiate change researchers must use theory to better understand the associations among constructs and mechanisms underlying behaviors. For the Well on Wheels intervention Social Cognitive Theory

(SCT) is the driving conceptual model used to target modifiable factors of individuals with SCI that may subsequently improve satisfaction with life.

SCT is an evidence-based theory often used in creating interventions aimed at behavior change in diverse populations. Bandura³⁸ posited that learning is a dynamic process that involves interaction between individual processes, the environment, and behavior. Principles from SCT not only focus on predicting behavior, but provide mechanisms for behavior change.

The underpinnings of SCT are that individuals learn and behave in a way that is socially constructed. Driving forces of behavior come from both internal and external factors. This process occurs when the individual, environment, and behavior all influence each other. For example, to improve anxiety status a psychiatrist may prescribe medication or identify triggers in the individual (individual processes), help the individual to seek positive outside support in their network (environment), and teach coping strategies (behavior) all aimed to work together to help improve the underlying problem of anxiety. SCT has shown to be an effective behavior change strategy when used in different health settings such as wellness, weight loss, and psychological interventions.³⁹

The driving force of SCT is self-efficacy.³⁸ Self-efficacy is the confidence an individual has that they can perform a task or behavior. Further, self-efficacy is the foundation of motivation, accomplishments, and emotional wellbeing.³⁹ Many different forms of self-efficacy have emerged in the literature as a result of research on SCT including general self-efficacy and self-efficacy for specific behaviors. Self-efficacy to engage in health practices is of interest in health-promotion research.⁴⁰ Interventions aim

to increase self-efficacy and therefore impact subsequent behavior. Strategies to increase self-efficacy include modeling, goal setting, reinforcements, and knowledge.⁴⁰ The aim of increasing self-efficacy is to arm the individual with tools to make lasting changes to their confidence and behavior.

Self-efficacy is also a strong determinant of self-regulation, which is crucial to health behaviors such as nutrition and physical activity.⁴¹ For individuals with chronic diseases, self-efficacy becomes vital to self-management of health conditions. Therefore, increasing self-efficacy can play a large role in promoting independence in individuals with chronic diseases.

In this study SCT is used in several ways. SCT was the basis for behavior modification in the curriculum for the Well on Wheels program. Self-efficacy comes from both vicarious learning and knowledge from trusted sources. This intervention includes peer support through other group members and peer facilitators as well as experts in their field leading curriculum aimed at increasing knowledge in specific domains. SCT was also used to identify factors of interest in creating a profile of individuals who are successful in the Well on Wheels intervention group. A better understanding of factors associated with success in the intervention can aid practitioners in intervening in the community as some individuals may benefit most from an SCT-based intervention.

2.5 WELLNESS INTERVENTIONS IN SCI

Wellness interventions for individuals with SCI and other disabilities have been developed aimed at improving health promoting behaviors and satisfaction with life over time. Generally, these programs seem to be effective in improving health-related quality

of life, mobility, depression, self-rated health, self-efficacy, well-being, and general quality of life.⁴²⁻⁴⁶ However, results from these interventions often show non-significant results; reporting positive trends or means in the intervention group. There is currently no validated, widely available wellness program available for individuals with SCI who would benefit from an intervention following injury and rehabilitation.

Health and lifestyle interventions often target specific factors such as exercise, nutrition, and self-esteem. Some literature shows little association between satisfaction with life and these factors. SCI Model Systems data shows satisfaction with life may not be associated with BMI.⁴⁷ However, other studies have found that obesity status is related to lower satisfaction with life following SCI.³⁶ Exercise is also associated with higher satisfaction with life following SCI and in other populations with chronic diseases.^{25,48} Therefore, further analyses of existing studies is needed in order to understand how lifestyle interventions impact satisfaction with life and its associated modifiable behaviors.

This secondary data analysis used data from the Well on Wheels intervention for individuals with SCI. Zemper, Tate, Roller, Forchheimer, Chiodo, Nelson, Scelza⁴⁹ published preliminary analysis of Well on Wheels outcomes. The Well on Wheels intervention was created using SCT concepts aimed at improving satisfaction with life in individuals with SCI using evidence-based behavior change strategies. Targeted behaviors for change by the intervention were derived from Stuijbergen's model of quality of life in individuals with chronic disabling conditions. This model explains a large portion in variance in quality of life in individuals with disabling conditions (66%), providing strong evidence for targeting chosen factors associated with wellness following

SCI.⁵⁰ The intervention curriculum is further described in the methods as the basis of this secondary data analysis.

Zemper, Tate, Roller, Forchheimer, Chiodo, Nelson, Scelza⁴⁹ conducted analyses on the first and third data points of the intervention. Paired t-tests were conducted on intervention participants on changes from baseline to following 7-month intervention period. The focus of their preliminary analysis was the treatment group due to assumed changes following intervention as opposed to the no treatment control. Multiple regression analyses for between group differences were then conducted accounting for baseline differences.

There were no significant differences between groups on measures from baseline to 7 months, though the intervention group showed positive improvements in self-efficacy for health practices, health promoting behaviors, nutrition awareness, nutrition behaviors, stress management, physical activity behaviors, and secondary conditions. However, significant changes were not found in perceived stress, BMI, serum blood indicators such as cholesterol, physical fitness, and blood pressure. Further, multivariate analyses were conducted to account for baseline differences between groups and to re-examine potential outcome differences. Results showed partial support for improvement in health promoting behaviors (nutrition and physical activity), but no evidence for significant changes in any other outcomes of interest. Therefore, the Well on Wheels may have had some impact on intervention individuals on important antecedents of improved satisfaction with life including self-efficacy, health promoting behaviors, and secondary conditions, but knowledge of the longitudinal impact of this intervention and factors associated with success in Well on Wheels Intervention remained unknown.

Feasibility of this intervention was investigated showing promise; participants overall rated the program highly on a 1-7 scale with mean usefulness score of 6.5, understandability score of 6.5 and likelihood to recommend program to others score of 6.7. However, the lack of results in the multivariate analyses and additional longitudinal data collection led to this study. The goal of wellness intervention development is lasting impact on participant health promoting behavior and in turn satisfaction with life.⁵¹

Research questions in this study focused on a comprehensive understanding of individuals who benefitted from or were successful in this intervention. Identification of successful group participants can improve knowledge to tailor interventions for diverse communities and meet the needs of diverse populations. There is a general call in the field to better understand whom interventions are reaching and this study utilized existing intervention data to help fill this gap in the literature. This study also highlights non-modifiable factors that may be vital in identification target populations who will benefit from an intervention based on SCT. There is currently no widely available wellness intervention for individuals with SCI and an understanding of who the Well on Wheels intervention worked for could help guide clinicians looking for options for their patients.

2.5.1 THEORETICAL BASIS OF THE WELL ON WHEELS

CURRICULUM

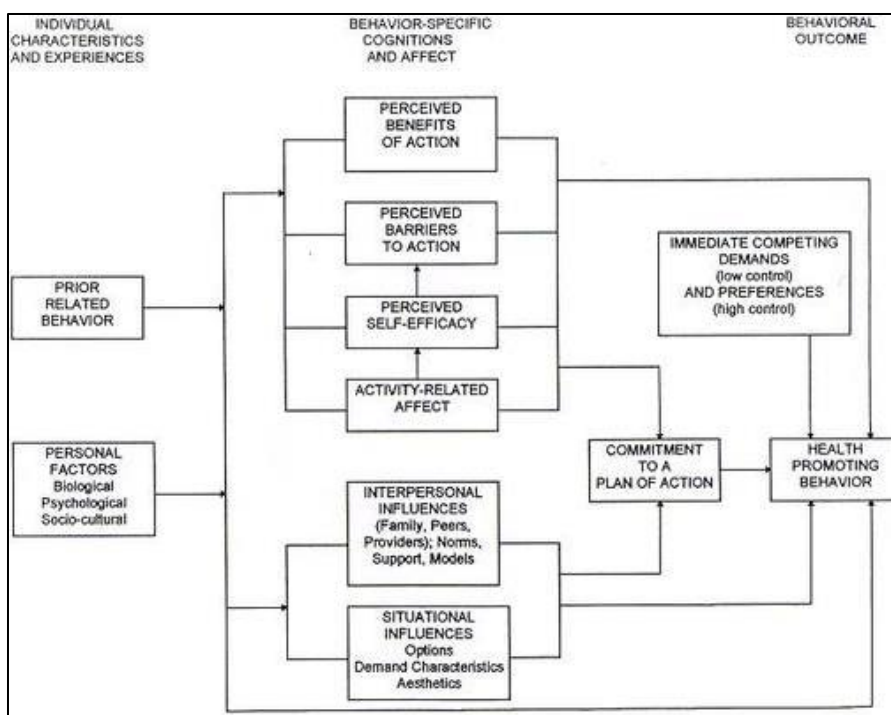
The Well on Wheels intervention draws on SCT basis for behavior change by providing individuals with SCI resources to change themselves and their environment with the expectation that this will result in lasting positive behavior change. However, the intervention development also drew on another theoretical model to identify evidence-based modifiable factors associated with improvements in satisfaction with life.

According to the Stuijbergen model of quality of life in persons with chronic disabling conditions like SCI, improvements in severity of condition, health promoting behaviors and self-efficacy will improve overall quality of life. Therefore, the intervention aimed to improve satisfaction with life by providing knowledge for secondary condition management as well as increasing health promoting behaviors and self-efficacy. These two theories work together in guiding curriculum development and intervention strategies.

2.5.2 STUIJBERGEN'S MODEL OF QUALITY OF LIFE IN PERSONS WITH CHRONIC DISABILING CONDITIONS

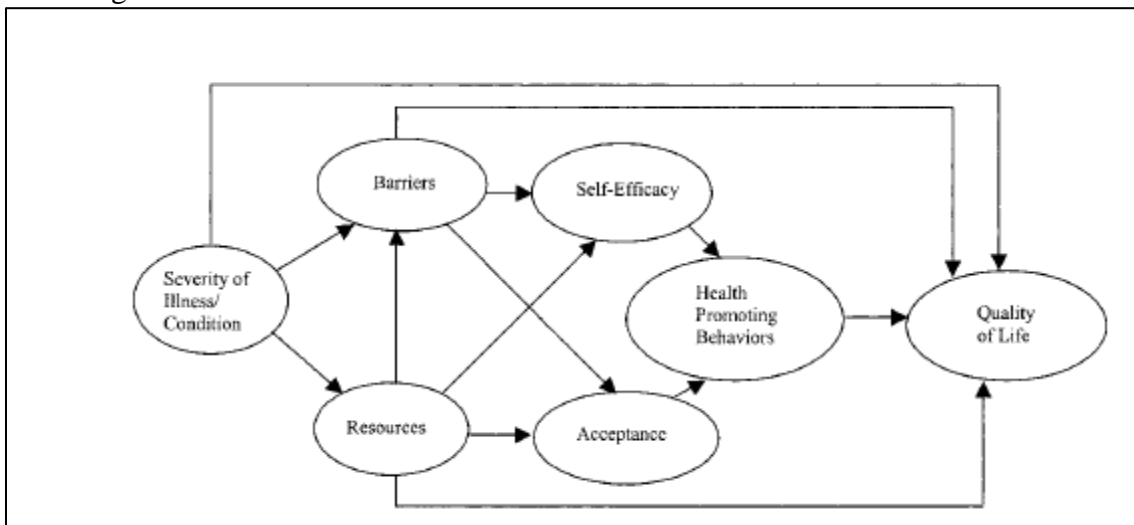
Pender, Walker, Sechrist, Stromborg⁵² presented a model of health promoting behaviors to explain individual engagement in health promoting behaviors that helped guide the Stuijbergen model of quality of life. Pender and colleagues posited cognitive-perceptual factors as the primary motivational mechanism driving engagement in health promoting behaviors. Factors of interest in this model include perceived self-efficacy, perceived health, perceived barriers and benefits. Non-modifiable factors such as demographics, biologic characteristics, and interpersonal influences are proposed mediators through cognitive-perceptual processes that exert an indirect influence on health promoting behaviors (Figure 3). Internal or external cues to action are considered transient that serve to promote behavioral actions. Experience of illness plays a role in the continuum of health, in which we no longer define health as absence of illness or disability, but rather a host of factors along the continuum that culminate in an overarching construct.

Figure 3. Pender's Model of Health Promotion



Stuifbergen, Becker⁵⁰ adapted the Pender model of health promoting behavior in the model of quality of life in individuals with chronic disabling conditions. The factors associated with health-promoting behaviors and quality of life identified in this model are: severity of illness/condition, barriers, resources, acceptance, self-efficacy, and health-promoting behaviors. These factors impact each other directly and indirectly as shown in Figure 4 in individuals with disabling conditions.

Figure 4. Stuijbergen's Model of Quality of Life in Individuals with Chronic Disabling Condition



More specifically, these factors are applicable to individuals with SCI; a chronic disabling condition. Severity of illness in this population is applicable to injury level, completeness, function (FIM scores), and presence of secondary conditions. These factors have a direct impact on quality of life as well as an indirect impact through barriers and resources. According to Stuijbergen et al.⁵⁰ severity of illness is considered the dominant contextual factor in this model impacting quality of life. Barriers can encompass a whole host of factors faced by individuals with SCI including environmental barriers such as accessibility in the physical environment that directly have a negative impact on self-efficacy and quality of life. Resources highlighted in this population are often financial and emotional (e.g. social support) that positively impact barriers, self-efficacy, and acceptance directly. Acceptance of condition positively impacts health promoting behaviors. Further, self-efficacy is the primary modifiable variable of interest impacting health-promoting behavior. These factors of interest culminate in health

promoting behaviors, which directly impact quality of life and serves as the mediators of the effects of the antecedent variables in the model.

Previous analyses show that up to 66% of the variance in quality of life in individuals with disabling conditions can be explained by this model.⁵⁰ Outcomes of interest in this study were based on the causal pathways identified in Stuijbergen's model. Research using this model highlights the importance of physical activity, nutrition, and stress management to prevent secondary conditions, promote community integration and maintain quality of life.⁵¹ Acceptance is considered the weakest link in the antecedent variables in this model and therefore was not included in this study. However, secondary condition severity was examined for moderating and mediating effect on satisfaction with life. Self-efficacy for health practices was identified for its mediating effect on satisfaction with life through self-report health-promoting behaviors, which was also examined due to their direct impact on satisfaction with life in this model. Self-efficacy is also an important variable of interest as the driving force of behavior change in SCT and presumably associated with success in the Well on Wheel intervention. These modifiable factors were identified as the primary and secondary variables of interest driving positive behavior change in individuals with SCI at baseline and longitudinally.

Research utilizing the Stuijbergen model of quality of life in chronic disabling conditions (Figure 4) has further highlighted the importance of health promoting behaviors including lifestyle management, physical activity, nutrition, and secondary condition prevention and management.⁵¹ Emerging research shows that individuals with SCI benefit from specific adaptations and interventions in these areas.^{49,53,54} Current work

in the context of individuals with SCI is outlined to provide current knowledge of these domains as the focus areas of interventions to improve quality of life and satisfaction with life following injury. Based on Stuijbergen's model a positive impact on self-efficacy that increases health-promoting behaviors may significantly impact and improve satisfaction with life.

2.5.3 HEALTH PROMOTING BEHAVIORS

Theory was used to identify the specific determinants that were targeted for change in the intervention. Specifically, the Well on Wheels intervention targets four domains of behavior including: lifestyle management, nutrition, physical activity, and secondary conditions. These domains were chosen based on the Stuijbergen model of quality of life in persons with chronic disabling conditions. Information on each domain is presented to provide proper background on the behaviors the intervention targeted.

2.5.3.1 LIFESTYLE MANAGEMENT

Lifestyle management programs aim to improve factors that decrease stress and increase confidence in executing daily activities. Literature shows that a traumatic event such as an SCI increases individual's perceived stress and higher rates of depression and anxiety are reported directly after injury and in the years following.⁵⁵ Interventions focused on lifestyle management aim to reduce stress by teaching techniques for coping and stress management as well as other skills such as self-efficacy and self-esteem. This portion of the Well on Wheels Intervention curriculum was focused on improving psychological status.

Cognitive behavioral therapy (CBT) is often used in the psychological literature in interventions to help improve psychological wellbeing and decrease psychological

distress. An internet-based CBT intervention for psychological health following SCI was effective in improving depression, anxiety, stress, and satisfaction with life following SCI.⁵⁶ However, another study found that a CBT intervention did not show large differences in intervention versus control group longitudinally on measures of anxiety, depressive mood, and self-esteem, but those who were more depressed at baseline showed greater improvements.⁵⁷ This study shines a light on the importance of identification of populations most at risk for poor outcomes who would benefit most from interventions. Overall, CBT may be effective in improving psychological status following SCI, but other intervention strategies are also effective.

Hughes, Robinson-Whelen, Taylor, Hall⁵⁸ have extensively studied women with mobility limitations including SCI and found that their stress management intervention enhances self-efficacy and social connectedness, which leads to reduced stress, in turn contributing to improved mental health in diverse populations. Coping effectiveness training also helped to reduce anxiety and depression following 6-week intervention in individuals with SCI.⁵⁹ Peer mentoring interventions are gaining interest in clinical practice and currently implemented in many rehabilitation hospitals for individuals following SCI. The mechanism for effectiveness of peer interventions fits well in the SCT framework through observational learning and modeling. Peer interventions specifically have an impact by improving self-efficacy following inpatient rehabilitation and fewer hospitalizations.⁶⁰

Sexuality is another tenet of interest in the lifestyle management literature in individuals with SCI. People are often unaware of their sexual capabilities following injury and physicians often do not effectively convey information to help improve their

confidence in engaging in sexual activity and knowledge of how to engage in activities safely. Qualitative interviews with women with SCI show that sexual adjustment happens in phases and women benefit from peer support and communication from a professional who is educated on sexuality in this population.⁶¹ The six months following SCI is a sensitive period for sexual education and inclusion of partners may aid in sexual adjustment.⁶² Overall, research in the area of sexual adjustment following SCI has shown the effectiveness of interventions, but there is an emphasis on the importance of resources and education in the rehabilitation period and longitudinally.⁶³

Therefore, lifestyle management programs may be effective for improving outcomes following SCI including: anxiety, depression, stress, self-esteem, sexual education and self-efficacy. Different intervention strategies help to improve these outcomes, but few studies have investigated subgroups in their interventions that benefit most from specific intervention strategies. Identification of these subgroups is important for improving clinical practice for those exhibiting negative psychological status following SCI and providing appropriate interventions that will have a lasting impact.

2.5.3.2 PHYSICAL ACTIVITY

Engagement in regular physical activity has many benefits physically and psychologically. Emerging research has focused on the potential benefits of exercise and physical activity for individuals with SCI. Interventions and programs to promote physical activity exist with aims to improve psychological status, physical health, and increase strength.

Due to physiological changes following SCI in the distribution of fat mass, changes in body composition are the focus of many physical activity interventions. Some

interventions have shown improvements in body composition following interventions including rowing, rugby, and general exercise protocols.⁶⁴⁻⁶⁶ Other interventions find that physical activity alone does not significantly improve body composition following SCI.⁶⁷ Similar findings exist for improvements in cardiovascular health with some studies showing significant improvements⁶⁸ and others finding no significant changes.^{69,70} However, research in this area often does not follow individuals longitudinally and changes in these physiologic variables may require longer interventions to show clinically significant changes. These factors also show significant changes as part of the nature of injury and disability.⁷¹

Positive findings exist for strength improvements following exercise interventions for individuals with SCI^{66,72} as well as functional capabilities.⁷³⁻⁷⁶ Functional capability improvement is vital to this population to help in increasing independence in activities of daily living. Exercise interventions are also effective in decreasing in secondary conditions such as pain^{74,77} and improving bowel programs.⁷⁸ These factors contribute to improvement in overall satisfaction with life and self-management.

Psychological changes are often noted in the literature as a results of exercise, but findings on the impact of exercise interventions on psychosocial variables are mixed. Some interventions show that following exercise program individuals show significant increases in self-efficacy, quality of life, and self-esteem.^{72,75,79-82} However, other interventions find no significant differences in psychosocial variables following intervention, most notably quality of life in adults with SCI.^{83,84} Most interventions show improvements in psychosocial variables and decreases have not been reported, therefore

exercise is a vital and beneficial part of a wellness intervention included in the Well on Wheels curriculum.

2.5.3.3 NUTRITION

Nutrition interventions for individuals with SCI are emerging, but little is known about the specific needs of individuals with different levels of SCI. Generally, researchers and clinicians assert that individuals with SCI have reduced metabolic rate following injury due to changes in mobility such as use of wheelchair, but some individuals who are ambulatory may expend more energy following injury due to increased effort in walking. Guidelines for nutrition following SCI are currently being researched and a recent book called Live Well Eat Well with Spinal Cord Injury was published by Smith and James that focuses on the specific needs of this population. Much of the focus of this book is on how to eat for secondary conditions such as pain, neurogenic bowel and bladder, and depression. This book is a step in the right direction, but few interventions address nutrition specifically for individuals with SCI outside the context of weight loss or general wellness.

A study of behavioral intervention plus nutrition education program for individuals with SCI found no significant impact of classes conducted in 5 sessions over 7 months on weight or lipid profile.⁸⁵ It is possible that this intervention was not frequent enough to have a real impact on behavior and habits of participants with only 5 sessions over an extended time period. However, other researchers have conducted weight management interventions for individuals with mobility limitations, including individuals with SCI, and their samples significantly decreased weight and show feasibility of a weight management intervention in this population.^{53,86} Chen, Henson, Jackson,

Richards⁸⁷ conducted a weight loss intervention specifically for individuals with tetraplegia finding significant decreases in weight, BMI, waist circumference, neck circumference, skin fold thickness, body fat percentage, and no decrease in lean mass or bone density. More specifically, this intervention showed promising behavior modification results for nutrition related variables by decreasing cholesterol and saturated fat intake and increasing fiber.

Therefore, much of our understanding of nutrition and interventions in this area currently focus on weight loss, but nutrition is a pressing factor in other aspects of individual's lives including psychological and physical functioning. Another area of nutrition that is not well understood in populations with SCI is the environmental barriers at the micro and macro level. According to SCT the environment is a pivotal aspect of behavior that could be adapted and modified for this population. Research in this area is starting to take shape, but the emphasis on improving caregiver relationships and support is a consideration for promoting independence and improvement in nutrition for individuals with SCI. Inclusion of nutrition in the Well on Wheels intervention was vital to help improve health promoting behaviors and increase self-efficacy for health practices.

2.5.3.4 SECONDARY CONDITIONS

Secondary conditions are common in individuals with SCI, but no longer a common cause of death.⁸⁸ However, secondary conditions can be life threatening and significantly impact activities of daily living and satisfaction with life following SCI. Common secondary conditions include: bowel and bladder management, urinary tract infections (UTI), deep vein thrombosis, spasticity, osteoporosis, pressure ulcers, chronic

pain, cardiovascular disease, sexual dysfunction, and respiratory problems.⁸⁹ Prevention and management of these conditions plays a large role in ratings of overall satisfaction with life in individuals with SCI.

Stuifbergen's model of quality of life in individuals with chronic disabling conditions shows a direct impact of secondary conditions on quality of life, barriers, and resources.⁹⁰ Secondary conditions directly impact barriers due to their connection with independence and functional capabilities. Additionally, individuals often require resources such as a caregiver to help with bowel and bladder programs, showing the direct impact of these conditions on independence and down the road self-efficacy for managing their condition and health behaviors. Overall, secondary conditions play a large role in living with a SCI and are a vital educational portion of initial rehabilitation and continued wellness.

Interventions have been developed to aid in management of a range of secondary conditions. UTIs are one of the primary reasons for rehospitalizations following SCI. Nurse education interventions for treatment of recurrent UTIs show positive results in utilizing resources within the rehabilitation team, but the goal is to avoid incidence of UTIs and rehospitalizations through educational programs.⁹¹ Cardenas, Hoffman, Kelly, Mayo⁹² developed a promising UTI education program specifically for individuals with SCI that showed increases in self-efficacy and fewer UTI symptoms reported by participants. Pressure ulcer incidence is another major area of concern. Positive outcomes in individuals with SCI in a pilot educational program to prevent pressure ulcers helped identify another area where educational materials will benefit individuals in this

population.⁹³ Therefore, education about UTIs and pressure ulcer prevention is feasible and should be incorporated in wellness interventions.

Another major area of concern for individuals with SCI is chronic pain. Most individuals experience some form of chronic pain whether physical or neuropathic below the level of injury. CBT is a promising strategy for helping with pain management in individuals with SCI by modifying pain coping strategies and cognitions about pain.⁹⁴ Additionally, interventions developed to help with pain management following SCI with some positive results,⁹⁵ but findings from Norrbrink Budh, Kowalski, Lundeberg⁹⁶ showed no impact on satisfaction with life or health related quality of life (HRQOL). However, this study did show significant results for the intervention impact on depression and sleep quality, which may be agents to change in satisfaction with life longitudinally. A better understanding of pain development and management is needed. Generally, pain is an important component to address in interventions with individuals with SCI because they will experience pain in their lifetime that may cause fatigue or impact daily living in other ways.

Houlihan, Jette, Friedman, Paasche-Orlow, Ni, Wierbicky, Williams, Ducharme, Zazula, Cuevas, Rosenblum, Williams⁹⁷ created a general peer-led telephone-based intervention aimed at helping in health self-management that led to improvement in secondary conditions, but not quality of life. This study shows that changes in secondary conditions during interventions are possible, but the impact on quality of life may not manifest if appropriate longitudinal designs are not utilized. Therefore, more work is needed to better understand the impact of educational programs on secondary conditions on ratings of satisfaction with or quality of life in individuals with SCI. Educational

materials on secondary conditions were included in Well on Wheels due to potential benefit in providing general knowledge and helping improve health outcomes, self-management and satisfaction with life longitudinally.

The aim of the Well on Wheels intervention was to improve satisfaction with life by increasing health promoting behaviors and self-efficacy for these behaviors. Based on SCT principles, behavior change strategies used to increase self-efficacy and health promoting behaviors in Well on Wheels were goal setting, experiential exercises, observational learning, and self-monitoring. The intervention addressed factors within the individuals such as biological changes following SCI and stress as well as environmental factors such as their food environment and relationships with caregivers. The intervention also arms participants with knowledge in several health-promoting behavior domains previously outlined that theoretically have a positive impact on overall quality of life.

2.6 SUMMARY AND SYNTHESIS

This secondary analysis aimed to determine if there are identifiable qualities or characteristics of individuals with SCI who report low levels of satisfaction with life since these are the individuals most in need of intervention. Identifying such characteristics may be a first step in formulating screening criteria for determining which patients with SCI would benefit from a wellness intervention. This study worked to identify this group and based on strong theoretical background to investigate changes in self-efficacy and health-promoting behavior following the Well on Wheels intervention. Additionally, change in different individuals included in the “at risk” group of individuals with low satisfaction with life at baseline were examined. Lastly, success in the

intervention was examined to help guide the creation of future interventions for subpopulations of individuals with SCI.

The Well on Wheels intervention curriculum is based on strong theoretical background showing individuals with chronic diseases benefit from improvements in secondary conditions, resources, self-efficacy, and decreases in barriers. Based on SCT, individuals were given experiential instruction from peers and experts as well as resources to increase their confidence to engage in behavior change outside of the workshops. The longitudinal impact of the intervention is vital to our understanding of the efficacy of the Well on Wheels program curriculum and principles. We also identified variables associated with success in the program. Individuals with SCI may experience different benefits from peer-supported and expert-led group interventions. Therefore, we identified those who benefited most to help guide future dissemination of this curriculum and development of innovative programs for those who do not benefit from this format.

CHAPTER 3

3. METHODOLOGY

3.1 DESIGN

Well on Wheels was a randomized controlled pilot trial of a holistic wellness intervention for individuals with SCI. Participants were randomized to either the intervention group or no treatment control group. *Figure 1* depicts the timeline for this pilot study with the number of participants completing data and *Figure 2* depicts measures of interest for this study. These measures included physiological data collected at clinic appointments at 4 timepoints (i.e. total cholesterol, arm crank ergometer VO₂ max, blood pressure, and BMI) and self-report questionnaire data collected at 5 timepoints (i.e. demographics, injury characteristics, satisfaction with life, self-efficacy for health practices, health promoting behaviors, perceived stress, and secondary conditions).

This study is a secondary analysis of data from the Well on Wheels intervention. Three primary research questions were examined utilizing the Well on Wheels participant dataset. Primary variables of interest are the focus of each research question; these are hypothesized as the primary agents associated with change or differences between the groups. Other variables included in analysis are called secondary and exploratory variables of interest that may be associated with changes following the Well on Wheels intervention. Secondary and exploratory variables are included due to their association with overall wellness, but not the primary focus of this study. The primary variable of interest for research question 1 was satisfaction with life; used to classify individuals into

groups at baseline. The primary variables of interest for research question 2 were satisfaction with life as the aim of wellness intervention and self-efficacy for health practices based on SCT as the driver of changes in health promoting behaviors. Research question 2 included secondary variables of interest (i.e. secondary conditions and health-promoting behaviors) and exploratory physiologic variables of interest (i.e. total cholesterol, arm crank ergometer VO_2 max, blood pressure, and BMI). Research question 3 included primary and secondary variables of interest from research question 2 to assess success in the Well on Wheels intervention. Lastly, covariates of interest included demographic variables and SCI characteristics. All measures were collected at baseline (T1), post-intervention (T2, 3 months), 4 months post-intervention (T3, 7 months), 1 year post-intervention (T4, 1.5 years), and 2 years post intervention (T5, 2.5 years) in both intervention and control group except exploratory outcomes (not collected at T4).

Intervention participants attended a series of six 4-hour workshop sessions over a 3-month period. A tapering phase was included for intervention participants with two personalized phone calls on attainment of individual goals in 4-month period following intervention, thus ending the intervention period at approximately 7 months. Preliminary analyses from this dataset at T1 and T3 were conducted and published.⁴⁹ Results from that study are described in the introduction. The purpose of this study was to identify characteristics associated high versus low on satisfaction with life in individuals with SCI, examine the longitudinal effect of the intervention on primary, secondary, and exploratory variables of interest in high and low satisfaction with life groups and identify variables related to success in the Well on Wheels intervention. Further, the unique aim of this study was to determine factors related to low satisfaction with life and Well on

Wheels intervention success to identify individuals who could benefit from this intervention and the strategies used in the future. This secondary data analysis study was approved by the University of Michigan Medical Center Institutional Review Board and a data use agreement was obtained between the investigators at University of Michigan and University of Houston.

3.2 SETTING

Participants were recruited from several locations including: an outpatient SCI clinic in the Department of Physical Medicine and Rehabilitation at the University of Michigan Health System, the University of Michigan SCI Model Care System database (SCIMS), and the mailing list for the Center for Independent Living in Ann Arbor. Clinic assessments at all time points were conducted on Saturdays for convenience at the university. Workshops were conducted at the University of Michigan Health System.

3.3 PARTICIPANTS

3.3.1 ELIGIBILITY

Eligibility was determined via telephone screening with a trained research assistant. Inclusion criteria for participation in the intervention included: SCI of C5 and below, American Spinal Injury Association (ASIA) Impairment Classification Scale A-D, 18-80 years of age, and at least 1 year post-injury. Exclusion criteria included diagnosis of cognitive deficits preventing learning and carryover such as traumatic brain injury or dementia, medical problems that could impose a health risk such as recent myocardial infarction, and primary disability not due to SCI. All participants with booklet data available at each time point were included; the focus of the research questions are these self-report measures.

3.3.2 PARTICIPANT CHARACTERISTICS

Ninety-eight individuals expressed interest in participating in the study after screening and completed a brief survey about their interest in the study and a survey of barriers to participation in physical activity. Interest and barriers to participation surveys were returned to the study team and reviewed by the PI and study physician to confirm eligibility. Fifteen individuals were deemed ineligible for the study, and 83 individuals were enrolled. After providing informed consent and completing an initial in-person assessment, participants (N = 72) were randomly assigned to either intervention or control condition (Appendix A). Total sample at T2 included 58 participants, 47 at T3, 44 at T4, and 36 at T5 based on individuals who completed a minimum of booklet data. Participants received a \$45 incentive for attending clinic visits.

3.4 INTERVENTION

The Well on Wheels intervention included six 4-hour workshops over a 3-month period. Following the six workshop sessions, all intervention participants were provided an individual coaching session with facilitators to outline individualized goals for the four-month tapering period. Two follow-up phone calls by research assistants during 4-month tapering period of the intervention were conducted to discuss goal attainment and barriers; the focus of the telephone calls was individualized and solution focused. Control participants completed all assessment visits, but received no treatment.

Intervention workshops included four modules: lifestyle management (sexual health and stress management), physical activity, nutrition, and preventing secondary conditions. *Table 1* provides an overview of topics covered in each module at each of the six workshops. Social Cognitive Theory was used in creating intervention materials

aimed at promoting behavior change through empowering individuals with knowledge (e.g. experiential education) and confidence (e.g. self-efficacy) to improve their overall wellness.³⁸ The curriculum materials were modeled off of a previous wellness program created by the research team for women with polio. Modifications were completed by the study PI Dr. Denise Tate in conjunction with faculty, investigators, and outside consultants with expertise in individuals with SCI. Generally, didactic and experiential components were utilized to keep participants involved and engaged including: experiential exercises, observational learning, self-monitoring, and goal setting were the primary behavior change strategies utilized in the intervention. The aim of the intervention was to increase self-efficacy and in turn increase engagement in health-promoting behaviors related to increased satisfaction with life (Figure 4).⁵⁰ Peer facilitators were two individuals with SCI from local centers for independent living who were there primarily for support and guidance. These individuals were given an informational session on the program goals and their role in peer support. All specific course areas were taught by professionals involved in curriculum modifications (e.g. exercise modules taught by a physical therapist). All intervention participants received the Well on Wheels bound manual written by facilitators at the first workshop.

Table 1. Workshop topics covered by module

Number	Secondary Conditions	Lifestyle Management	Nutrition	Physical Activity (PA)
1	-Long-term conditions e.g. Cardiovascular Disease (CVD), pulmonary problems, obesity	-General principles of wellness -Self-efficacy and wellness -Long-term effects of stress on body -Identify causes of stress	-Food guide pyramid -Cholesterol -Fats -Importance of moderation and variety	-Benefits of PA on CVD and pulmonary system -Long-term effects of deconditioning -Preparing a PA

		<ul style="list-style-type: none"> -Body's reaction to stress -Introduction to sexuality -Changes in sexuality with SCI and aging 		<ul style="list-style-type: none"> program -Environmental barriers -Community resources
2	<ul style="list-style-type: none"> -Cause of pain -Pain management -Skin problems -Improving physical functioning, strength, and endurance to offset pain -Pressure sores 	<ul style="list-style-type: none"> -Cognitive and personality factors -Coping and pain -Individual consequences of stress -Developing a stress management program -Individual differences in sexual attitudes, behavior, and skills before and after SCI 	<ul style="list-style-type: none"> -Identifying hunger signals -All foods are legal (no bad foods) -Importance of balance, variety, and moderation 	<ul style="list-style-type: none"> -Safety precautions for exercise -Importance of warming up and cooling down -Self-monitoring
3	<ul style="list-style-type: none"> -Neurogenic bowel and bladder 	<ul style="list-style-type: none"> -Coping with bowel and bladder accidents -Sexual functioning -Preventing urinary tract infections and constipation -Spectrum of sexual activities and preferences for persons with SCI 	<ul style="list-style-type: none"> -Fiber -Water -Vitamins -Minerals -Herbal supplements -All with a focus on bowel and bladder management 	<ul style="list-style-type: none"> -Effect on bowel and bladder management -Improve circulation to reduce skin problems
4	<ul style="list-style-type: none"> -Respiratory -Spasticity -Depressed mood -Anxiety 	<ul style="list-style-type: none"> -Emotional health promotion -Addressing grief and loss -Stress and adaptation -Anxiety -Coping styles and strategies -Medical concerns in sexuality and sexual functioning 	<ul style="list-style-type: none"> -Healthy eating in restaurants -Social occasions -Selecting snacks 	<ul style="list-style-type: none"> -Social benefits of PA -Integrating PA into leisure -Maintaining an active lifestyle
5	<ul style="list-style-type: none"> -Sexual dysfunction 	<ul style="list-style-type: none"> -Interpersonal communication 	<ul style="list-style-type: none"> -Weight management to 	<ul style="list-style-type: none"> -Sexual dysfunction in

		with focus on stress and support -Stress with spouse or caregivers -Benefits of social support -Enhancing sexual health by addressing concerns with partner or family	improve body image	physiologic terms -Medical issues -Body image -Physical wellness
6	-Medical aspects -Prevention of conditions	-Personal stress management plan -Implementing stress plan -Various roles in life and impact on sexuality for persons with SCI	-Personal nutritious eating plan	-Maintaining wellness program -Community options for exercise -Designing and implementing exercise program

3.5 MEASURES

3.5.1 PRIMARY VARIABLES OF INTEREST

Satisfaction with Life Scale (SWLS), is a 5-item instrument to measure global cognitive judgments of satisfaction with one's life.¹² The SWLS has been used in various studies across populations to assess global satisfaction with life. It is a 5-item scale, rated on a 7-point Likert scale with a minimum score of 5 and maximum score of 35. A score of 20 represents the neutral point on the scale based on previous validation studies.¹⁷ Low scores between 5 and 9 indicate the respondent is extremely dissatisfied with life and high scores between 31 and 35 indicate the respondent is extremely satisfied with life. Examples of test-retest reliability include coefficients of 0.84⁹⁸ and 0.80⁹⁹ for a 1-month interval, and 0.54 over a 4-year span.¹⁰⁰ These studies provide evidence of the temporal stability of scores on SWLS, but is also changes over time potentially due to domain specific changes posited by Fujita and Diener.¹⁰¹ Based on previous literature using this

measure scores range between samples: the average score in a college student population is 23-25,¹⁵ older adults 23-28,¹⁰² prisoners 12.3,¹⁰³ and sex workers 10.3.¹⁰⁴ Scores were used to categorize individuals by satisfaction with life status in research question 1.

Research question 2 focused on satisfaction with life (SWLS) and self-efficacy for health practices. Self-rated Abilities for Health Practice Scale (SAHP) was used to assess healthy lifestyle self-efficacy or self-perceived ability to implement health-promoting behaviors.¹⁰⁵ The scale includes 28-items rated on a 5-point scale from 0 (not at all) to 4 (completely). Subscales include 7 items measuring exercise, nutrition, responsible health practice, and psychological wellbeing. For example, “I am able to: find ways to exercise that I enjoy.” Total scores range from 0-112 with higher scores indicating greater self-efficacy for health practices. Reliability for this scale in adults with disabilities is 0.91 for total score and 0.76-0.90 for subscales.

3.5.2 SECONDARY VARIABLES OF INTEREST

Health Promoting Lifestyle Profile II (HPLP) was used to assess personal health promoting habits.¹⁰⁶ The HPLP includes a total score and subscale scores (i.e. health responsibility, nutrition, physical activity, stress management). There are 52 items rated on 4-point Likert scales ranging from never (1) to routinely (4). For example, “eat 2-4 servings of fruit per day.” Total scores range from 52 to 108 with higher scores indicated greater health promotion behaviors. Reliability for this scale is 0.922 overall and 0.702-0.904 for subscales.

Secondary Conditions Scale (SCS) is used to report new problems related to SCI.¹⁰⁷ This scale was modified from reporting secondary conditions experienced over the past year to conditions over a 3-month period in order to be appropriate for the data

collection time points. Sixteen common secondary conditions related to SCI are rated on 4 point Likert scales ranging from 0, not a problem to 3, significant or chronic problem. Examples of secondary conditions include pressure ulcers and bladder dysfunction. Scores are summed for a total score, ranging from 0 to 48 with higher scores indicating greater severity of secondary conditions.

The Perceived stress scale (PSS) measures the degree to which situations in one's life are appraised as stressful.¹⁰⁸ Items were designed to tap how unpredictable, uncontrollable, and overloaded respondents find their lives. Ten items are rated on 5-point Likert scale ranging from never (0) to very often (4). For example, "In the last month, how often have you felt nervous and 'stressed.'" The total score is obtained by reversing responses to the four positively stated items and then summing across all scale items, so high scores indicate higher stress levels.

3.5.3 EXPLORATORY VARIABLES OF INTEREST

Clinical assessments for physiologic variables were conducted at Saturday clinics at the university hospital. As noted in *Figure 2* physiologic data was conducted at 4 timepoints (T1-T3, T5). These visits included a blood draw for total fasted cholesterol. A VO₂ max test was completed on the arm crank ergometer to assess endurance. A Borg perceived exertion scale rating of 13-14 protocol was used to identify maximal exertion. Additionally, blood pressure was measured prior to completing exercise testing to ensure participant capability and safety for inclusion. The ACSM suggests a resting blood pressure <160/100 mmHg in order to engage in exercise testing.¹⁰⁹ Blood pressure and heart rate were also monitored during and after testing. Additionally, physicians measured height and weight in order to calculate body mass index (BMI). Physiologic

variables are exploratory due to the short timeframe of the intervention. Research question 2 was an appropriate place to examine these measures with longitudinal data available that may be sufficient to assess these changes. However, changes in physiologic variables often occur over longer timespans and intervention periods therefore changes in these variables favorably would be a benefit of the study, but were not expected.

3.5.4 COVARIATES

Demographic variables of interest included: age, gender, race, education, employment, and marital status. Injury characteristics were also examined including: years since injury, injury level, and ASIA score. Physician's completed a neurologic exam for ASIA classification at T1. Demographic variables and injury characteristics were collected at T1. These covariate variables of interest were used to identify characteristics of individuals who are high versus low on satisfaction with life at baseline (T1) and individuals who are successful following the Well on Wheels intervention. These variables were used to classify individuals into groups that can help clinicians and researchers identify at risk individuals in the community.

3.6 DATA MANAGEMENT

The Well on Wheels database is housed at the University of Michigan. Any data distributed for analyses at the University of Houston was completely de-identified per data use agreement (#17818). Paper logs and forms are kept in a secure, locked cabinet in an office in the University of Michigan. Data sharing occurred via the secure REDCap application. All de-identified data downloaded from REDCap for analysis was stored on a secure server on a password protected computer at the University of Houston. Only the

Principal Investigator and approved study staff had access to data. Data was checked for entry errors or values that are extreme or unrealistic.

3.7 ANALYSIS

3.7.1 STATISTICAL ANALYSES

Descriptive analyses were conducted to examine distributional characteristics of data for all demographic variables, injury related characteristics, physiologic and psychosocial outcome variables. Last observation carried forward was utilized for missing cases.

Research question 1: What are demographic and injury characteristics of individuals with spinal cord injuries with low satisfaction with life at baseline?

Descriptive analyses were used to identify high and low satisfaction with life groups based on bimodal distribution of the data, where two latent groups manifested. The Classification and Regression Tree (CR&T) method was then used to split data into segments that are as homogenous as possible with respect to satisfaction with life high vs low group status (dependent variable/primary variable of interest). Based on previous literature, demographic and injury characteristics associated with satisfaction with life were included as the predictor variables of interest. The tree was formed using criteria for splitting until terminal nodes were identified. The Gini index was used as the criteria for identifying the target group (low satisfaction with life); this method splits the nodes to find two groups as homogenous as possible with respect to the child nodes. Criteria were also needed for minimum cases per node; this method aids in not over fitting the data. Minimum cases in the parent nodes $n=21$ equal to 30% or more of the sample, which splits the groups by reasonable proportions for the sample size and child node $n=10$ cases

to avoid a group that was less than 15% of the sample that may not be representative of a significant subgroup in this data. Cross validation with 10 sample folds was also used to avoid overfitting the model. Cross validation tests the CR&T tree by sampling the data 10 times to investigate if the factors in the tree are stable. These criteria were all used to reduce inaccuracy in splitting the tree to small nodes with very few cases that will not generalize to other datasets. The CR&T method allowed the research team to create a profile to predict the group individuals would fall in on a specific target variable based on shared characteristics or input variables. In this study the goal was to predict which satisfaction with life group individuals would belong to on the basis of shared demographic variables and injury related characteristics.

Research question 2: What is the differential effect of the Well on Wheels intervention on participants with SCI among those with high versus low satisfaction with life at baseline?

Linear mixed model analysis was used to address research question 2 analyzing the relationship between satisfaction with life group and time on primary, secondary, and exploratory outcomes. Fixed factors included satisfaction with life group, time, and the interaction of satisfaction with life group x time. Individuals were grouped by the identified high and low satisfaction with life groups from research question 1 for these analyses. Time included all 5 timepoints with baseline (T1) as the reference. Dependent variables of interest included the primary (i.e. satisfaction with life and self-efficacy for health practices), secondary (i.e. health promotion behaviors and secondary conditions) and exploratory variables of interest (i.e. BMI, systolic BP, diastolic BP, VO₂, and total cholesterol). Significant covariates of interest (i.e. demographic variables and injury

characteristics) for each outcome were included for each outcome based on theoretical associations. Significant covariates were then included in the model as an interaction term by satisfaction with life group by time to identify any significant associations related to the research question. None of the covariate interaction terms were significant and therefore unadjusted models are presented. Autoregressive modeling was utilized due to assumed correlation among the series of data for each participant and maximum likelihood estimation as only fixed effects were included in the models. *P*-values were obtained by likelihood ratio tests for main effects and interaction effect.

Research question 3: Which demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) are associated with success in the Well on Wheels intervention?

Descriptive statistics of the mean control group change scores on primary and secondary outcome variables from research question 2 were utilized to address research question 3. The control group was used to provide a model of how individuals with SCI without intervention would track over time. This provided a unique opportunity to compare scores between individuals who experience a wellness intervention and those who did not. Mean control group change scores following intensive intervention period at T2 were used to classify intervention individuals as successful or not successful. More specifically, intervention individuals who showed positive changes higher than the control mean at T2 are considered successful because individuals are theoretically reporting more positive outcomes than they would without intervention. Intervention participants were then split into groups based on the number of variables on which they score higher than the control mean. Success was defined as positive change in at least 3

out of 5 variables of interest (satisfaction with life, self-efficacy, health promoting behaviors, perceived stress, and secondary conditions). CR&T method was used to split data into segments that are as homogenous as possible with respect to successful vs not-successful group status. Predictor variables were the same demographic and injury characteristics from RQ1 until identification of terminal nodes. Consistent with RQ1 criteria to avoid overfitting the CR&T tree was used: Gini index, parent nodes of 30% of the sample (n=9), 15% for child nodes (n=4), and cross validation with 10 sample folds. This statistical method allowed the research team to enter characteristics into the analysis and factors significantly associated to success vs non-success group that automatically branched off in a manner that is easily interpretable.

CHAPTER 4

4. RESULTS

4.1 STUDY SAMPLE

Table 2 provides sociodemographic and injury characteristics of the 72 individuals who enrolled in the Well on Wheels intervention. Mean age at baseline was 44.1 (SD=13.0) and year injured 13.1 (SD=10.6). Sixty nine percent were male, 52.8% identified as having paraplegia and 45.8% had complete injuries (ASIA A). The majority of the participants were white (88.9%) and had at least some college education (69.4%). Participants ranged in their employment status with the largest portion being unemployed (45.8%). Marital status also varied with 47.2% of participants being married, 37.5% single, never married, and 15.3% divorced. See Appendix A for specific sociodemographic information comparing the intervention and control groups in the Well on Wheels study. The only significant difference between intervention and control groups was employment status, with more unemployed individuals in the intervention group.

Table 2. Baseline sociodemographic and injury characteristics of Well on Wheels full study sample, High vs. Low Satisfaction with Life Groups, Intervention Group, and Successful vs Not Successful Intervention Groups

Variable	Full Sample N= 72	High N=40	Low N=32	Intervention N=29	Successful N=18	Not Successful N=11
	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)
Age at enrollment (years)	44.1 (13.0)	44.3 (13.3)	43.9 (12.9)	43.2 (11.2)	44.8 (11.4)	40.6 (11.1)
Injury years	13.1 (10.6)	15.2 (11.6)	10.6 (8.8)	12.0 (9.8)	11.5 (10.1)	12.9 (9.6)
Sex						
Female	22 (30.6)	15 (68.2)	7 (31.8)	10 (34.5)	7 (70.0)	3 (30.0)
Male	50 (69.4)	25 (50.0)	25 (50.0)	19 (65.5)	11(61.1)	8 (72.7)
Level of Injury†						
Paraplegia	38 (52.8)	18 (47.4)	20 (52.6)	16 (55.2)	10 (62.5)	6 (37.5)
Tetraplegia	30 (41.7)	20 (66.6)	10 (33.3)	13 (44.8)	8 (61.5)	5 (38.5)
ASIA Completeness‡						
Complete (A)	33 (45.8)	21 (63.6)	12 (36.4)	18 (62.1)	11 (61.1)	7 (38.9)
Incomplete (B-D)	34 (47.2)	17 (50.0)	17 (50.0)	11 (37.9)	7 (63.6)	4 (36.4)
Normal (E)	1 (1.4)	0	1 (100.0)	0	0	0
Race						
White	64 (88.9)	37 (57.8)	27 (42.2)	25 (86.2)	16 (64.0)	9 (36.0)
Minority	8 (11.1)	3 (37.5)	5 (62.5)	4 (13.8)	2 (50.0)	2 (50.0)
Education†						
High School	21 (29.2)	9 (42.9)	12 (57.1)	5 (17.2)	3 (60.0)	2 (40.0)
Some college	25 (34.7)	14 (56.0)	11 (44.0)	11 (37.9)	6 (54.5)	5 (45.5)
College degree or more	25 (34.7)	16 (64.0)	9 (36.0)	13 (44.8)	9 (69.2)	4 (30.8)
Employment						
Unemployed	33 (45.8)	19 (57.6)	14 (42.4)	16 (55.2)	10 (62.5)	6 (37.5)
Employed	23 (31.9)	13 (56.5)	10 (43.5)	9 (31.0)	6 (66.7)	3 (33.3)
Retired	16 (22.2)	8 (50.0)	8 (50.0)	4 (13.8)	2 (50.0)	2 (50.0)

Marital Status			*	*			
	Single	27 (37.5)	12 (44.4)	15 (55.6)	10 (34.5)	4 (40.0)	6 (60.0)
	Married	34 (47.2)	24 (70.6)	10 (29.4)	12 (41.4)	10 (83.3)	2 (16.7)
	Divorced	11 (15.3)	4 (36.4)	7 (63.6)	7 (24.1)	4 (57.1)	3 (42.9)
Primary Outcomes							
	SWLS	20.7 (8.0)	26.9 (4.2)*	12.9 (3.7)*	19.9 (7.3)	19.3 (7.4)	20.8 (7.3)
	SAHP	89.5 (16.6)	87.4 (18.5)	92.2 (13.6)	90.1 (18.0)	86.3 (18.2)	96.4 (16.7)
Secondary Outcomes							
	SCS Severity	22.7 (15.7)	24.0 (15.3)	21.1 (16.25)	23.9 (15.7)	28.7 (16.1)*	16.1 (11.8)*
	HPLP	129.9 (23.3)	128.5 (23.1)	131.5 (23.8)	130.4 (24.6)	122.4 (17.2)*	143.5 (29.8)*
	PSS	32.5 (5.3)	32.7 (5.1)	32.2 (5.6)	30.0 (4.7)	33.8 (4.7)	31.7 (4.4)
Exploratory Outcomes†							
	BMI	26.8 (7.2)	26.6 (8.2)	27.0 (6.0)	26.1 (8.2)	28.0 (8.9)	22.7 (5.6)
	Systolic BP	119.6 (23.3)	116.3 (22.2)	122.3 (24.6)	118.3 (22.4)	119.2 (24.7)	116.9 (18.9)
	Diastolic BP	70.2 (13.5)	70.2 (13.8)	70.2 (13.3)	70.5 (14.1)	67.9 (13.1)	74.6 (15.5)
	VO ₂ Max	12.8 (6.4)	11.9 (6.9)	13.8 (6.2)	12.2 (6.1)	12.6 (7.3)	11.9 (5.9)
	Total Cholesterol	189.3 (37.1)	189.2 (38.6)	189.4 (35.9)	191.5 (40.1)	195.1 (41.8)	185.6 (38.4)

*= Significant differences $P < 0.05$

† Missing Baseline Values: Level of injury=2, ASIA=2, Education=1, BMI=8, BP= 5, VO₂=8, Cholesterol=6

4.2 FACTORS ASSOCIATED WITH LOW BASELINE SATISFACTION WITH LIFE

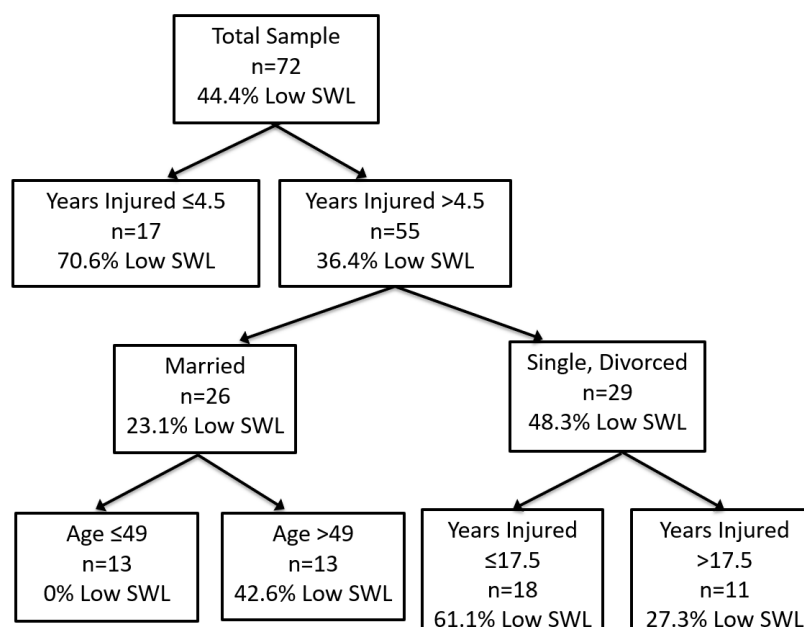
Hypothesis 1.1: Demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) will accurately identify >75% of individuals with low satisfaction at baseline.

Baseline satisfaction with life scores were examined. Participants were categorized as high or low satisfaction with life on the basis of baseline SWLS scores. Two groups were determined by inspection of the histogram of baseline SWLS scores; a bimodal distribution in the data split participants at 20. The low satisfaction with life group includes all individuals below the midpoint score of 20 (5-19) and the high satisfaction with life group includes all individuals with a score from 20-35. Mean SWLS score at baseline was 20.7 (SD=8.0) for the total sample, 26.9 (SD=4.2) for high group and 12.9 (SD=3.7) for low group.

Based on previous literature, demographic and injury related variables that are associated with satisfaction with life included: age, years since injury, ASIA completeness, level of injury, sex, education, marital status, race, and employment (Table 2). At baseline, there were significantly more individuals who were married in the high satisfaction with life group.

Figure 5 shows the results of the C&RT decision tree with 5 terminal nodes predicting satisfaction with life group status for baseline individuals in the Well on Wheels study. Low reported satisfaction with life was most likely in individuals less than or equal to 4.5 years since injury (70%). Among those who greater than 4.5 years post-injury, those who were single or divorced and less than or equal to 17.5 years post injury

were most likely to report low satisfaction with life (61% vs 27%). Among those > 4.5 years post injury individuals who were married, those who were greater than 49 years old were more likely to report low satisfaction with life (46.2% vs 0%). Within these two groups it is notable that those married and ≤ 49 years old all reported high satisfaction with life. Calculated risk estimates for the tree were .29 (SD=.05) indicating that the satisfaction with life group status predicted by the tree was wrong for 29% of the cases. Overall, based on sociodemographic and injury characteristics this decision tree model correctly predicted 71.9% of individuals with low satisfaction and 70.0% of participants with high satisfaction. Hypothesis 1.1 was not confirmed because less than 75% of the sample was identified by the decision tree. However, this method yielded promising results showing both demographic (i.e. marital status and age) and injury characteristics (i.e. years since injury) can be used to identify a large portion of individuals at risk for low satisfaction with life. Low satisfaction with life individuals with SCI were most likely to be less than 4.5 years post injury. Among those who were more than 4.5 years post-injury 2 groups at risk for low satisfaction with life emerged: 1) single or divorced marital status and less than 17.5 years post injury and 2) married and age greater than 49.

Figure 5. CR&T Decision Tree High and Low Baseline Satisfaction with Life

4.3 LONGITUDINAL OUTCOMES IN WELL ON WHEELS BY SATISFACTION WITH LIFE GROUP

Baseline demographic and injury characteristics for all intervention group participants who are classified as high or low satisfaction with life are reported in Appendix B. Significant differences between groups were identified using chi-square and t-tests and were different from the full sample reported in Table 2. Intervention group individuals with low satisfaction with life were on average fewer years post injury and a higher proportion of individuals with incomplete injuries were in the low satisfaction with life group.

Hypothesis 2.1: Individuals in the low satisfaction with life group at baseline will show significant positive change in primary outcomes (i.e. satisfaction with life and self-efficacy for health practices) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Linear mixed model analyses were used to assess longitudinal change in primary, secondary, and exploratory outcomes. Analyses include only individuals randomized to the intervention group in the Well on Wheels study. The first primary outcome of interest was satisfaction with life score (SWLS). There was a significant satisfaction with life group x time interaction ($P = .02$). Individuals with low satisfaction with life at baseline showed greater improvement in satisfaction with life over time than those high at baseline (Table 3). There were also significant main effects of both satisfaction with life group ($P = .001$) and time ($P = .01$) with high satisfaction with life group scoring significantly higher and SWLS scores increasing over time. Additionally, estimates of covariance parameters were examined to identify correlation between SWLS scores over time. Results for covariance parameters showed that there is significant correlation between SWLS scores over time (AR1 rho = .68, SE = .06).

The other primary outcome of interest was self-efficacy for health practices (SAHP) based on SCT behavior change theory. There was no significant satisfaction with life group x time interaction or main effect for satisfaction with life group. There was a significant main effect of time ($P = .04$), but post-hoc analyses showed no significant differences between specific timepoints (Table 3). The lack of significant post-hoc test significance is likely due to small sample size and large standard error. Estimates of

covariance parameters show that there was no significant correlation between SAHP scores over time (AR1 rho= 0.05, SE= 0.12).

Hypothesis 2.2: Individuals in the low satisfaction with life group at baseline will show significant positive change in secondary outcomes (i.e. health promoting behaviors and secondary conditions) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Secondary conditions severity (SCS) was included as a secondary outcome. There was no significant satisfaction with life group x time interaction or main effects for satisfaction with life group or time (Table 4). Estimates of covariance parameters show that there is a weak correlation between SCS severity scores over time (AR1 rho= 0.15, SE= 0.11).

Health promoting behavior (HPLP) was included as a secondary outcome. There was no significant satisfaction with life group x time interaction or main effect for satisfaction with life group. However, there was a significant main effect of time where health promoting behavior scores decreased over time ($P = .04$) but post-hoc analyses showed no significant differences between specific timepoints (Table 4). Again, the lack of significant post-hoc test significance is likely due to small sample size and large standard error. Additionally, estimates of covariance parameters show that there is a correlation between HPLP scores over time (AR1 rho= -0.20, SE= 0.12).

Perceived stress (PSS) was included as a secondary outcome. There was no significant satisfaction with life group x time interaction or main effects for satisfaction with life group or time (Table 4). Additionally, estimates of covariance parameters show

that there was no significant correlation between PSS scores over time (AR1 rho= 0.01, SE= 0.10). Hypothesis 2.2 was not confirmed, with no significant interactions for satisfaction with life group x time among secondary outcomes.

Hypothesis 2.3: Individuals in the low satisfaction with life group at baseline will show significant positive change in exploratory outcomes associated with secondary health conditions (i.e. total cholesterol, VO₂ max, diastolic blood pressure, systolic blood pressure, and BMI) compared to those with high satisfaction with life following 3 month intervention, 7 month tapered intervention, at 1 year post-intervention, and 2 years post-intervention.

Exploratory outcomes of interest included BMI, total cholesterol, systolic BP, diastolic BP, and VO₂. Appendix C shows the results of these models. There was a significant interaction effect for satisfaction with life group x time for total cholesterol ($P= 0.04$). Individuals in the high satisfaction with life group had significantly higher total cholesterol at T5. The only other main effect was for time in systolic BP ($P= 0.001$) with a significant increase in systolic BP at T5.

Hypothesis 2.3 was confirmed for total cholesterol with individuals in the high satisfaction with life group showing significantly greater increase total cholesterol over time. There with no significant interactions for any other cardiovascular health indicators including: blood pressure, BMI, and VO₂ max.

Table 3. Satisfaction with Life Group Primary Outcomes T1-T5 (N=39)
SWLS **SAHP**

	Estimate (SE)	<u>95% CI</u>		Estimate (SE)	<u>95% CI</u>	
		LB	UB		LB	UB
Intercept	12.06 (1.22)***	9.64	14.49	91.31 (4.16)***	83.08	99.55
SWL Group	13.68 (1.59)***	10.52	16.83	-4.70 (5.42)	-15.43	6.02
Time 2	3.64 (1.72)*	0.24	7.04	3.23 (6.52)	-9.67	16.14
Time 3	4.71 (1.73)**	1.29	8.12	-1.45 (7.21)	-15.71	12.81
Time 4	5.38 (1.74)**	1.93	8.83	12.95 (7.96)	-2.81	28.70
Time 5	6.24 (1.56)***	3.14	9.34	-10.37 (8.42)	-27.07	6.33
SWL Group x Time						
High Time 2	-4.21 (2.20)	-8.56	0.13	8.77 (8.37)	-7.78	25.32
High Time 3	-5.16 (2.16)*	-9.44	-0.88	0.04 (9.02)	-17.80	17.89
High Time 4	-6.21 (2.11)**	-10.40	-2.03	-8.39 (9.69)	-27.56	10.78
High Time 5	-5.75 (1.89)**	-9.50	-1.99	10.21 (10.34)	-10.31	30.72

Referent Low Satisfaction with Life Group and Baseline Time 1

Satisfaction with life= SWL

* $P < .05$, ** $P < .01$, *** $P < .001$

Table 4. Satisfaction with Life Group Secondary Outcomes T1-T5 (N=39)

	SCS Severity			HPLP			PSS		
	Estimate (SE)	95% CI		Estimate (SE)	95% CI		Estimate (SE)	95% CI	
		LB	UB		LB	UB		LB	UB
Intercept	19.63 (3.66)***	12.39	26.86	132.75 (5.58)***	121.71	143.79	31.06 (1.37)***	28.35	33.78
SWL Group	4.85 (4.76)	-4.57	14.28	-3.31 (7.26)	-17.69	11.06	1.98 (1.79)	-1.56	5.52
Time 2	-1.90 (5.73)	-13.24	9.24	0.98 (8.73)	-16.31	18.26	-0.70 (2.15)	-4.95	3.56
Time 3	-4.31 (6.31)	-16.79	8.17	-5.72 (9.64)	-24.80	13.36	0.81 (2.38)	-3.89	5.51
Time 4	-8.38 (6.94)	-22.11	5.35	9.10 (10.51)	-11.69	29.89	0.44 (2.63)	-4.76	5.64
Time 5	-5.43 (7.15)	-19.62	8.75	-16.88 (11.82)	-40.32	6.55	-6.24 (2.81)*	-11.80	-0.68
SWL Group x Time									
High Time 2	-6.17 (7.35)	-20.72	8.37	17.90 (11.02)	-4.27	40.08	-0.01 (2.76)	-5.47	5.45
High Time 3	2.89 (7.90)	-12.73	18.52	3.78 (12.07)	-20.11	27.68	-4.48 (2.97)	-10.37	1.40
High Time 4	2.23 (8.44)	-14.46	18.93	-0.46 (12.77)	-25.73	24.81	-1.49 (3.20)	-7.82	4.84
High Time 5	2.76 (8.76)	-14.61	20.14	11.43 (14.63)	-17.58	40.44	3.93 (3.45)	-2.91	10.77

Referent Low Satisfaction with Life Group and Baseline Time 1

Satisfaction with life= SWL

* $P < .05$, ** $P < .01$, *** $P < .001$

4.4 FACTORS ASSOCIATED WITH SUCCESS IN WELL ON WHEELS INTERVENTION

Intervention participants were categorized as successful versus not successful if they had a positive change on 3/5 outcome variables compared to control group. Control group mean change at T2 was first calculated for primary and secondary outcomes: SWLS total, SAHP total, PSS total, SCS severity, and HPLP total. Then, intervention group was classified as successful or not successful for each outcome if their change at T2 was more positive than the control mean (i.e. higher for positive SWLS, SAHP, and HPLP or lower for SCS and PSS). Intervention participants showing positive change above the control mean on 3/5 outcomes were classified as successful. Eighteen intervention participants were classified as successful and 11 participants were classified as not successful at T2 appointment after the intensive intervention phase.

Hypothesis 3.1: Demographic variables (i.e. age, sex, marital status, employment, and education) and injury characteristics (i.e. ASIA, injury years, and injury level) will accurately identify >75% of individuals at baseline who go on to not be successful in Well on Wheels intervention. Success is categorized by improvement from baseline in satisfaction with life, self-efficacy for health practices, secondary condition severity, and perceived stress greater than mean control change in outcomes following the intensive phase of the intervention (3 months).

Demographic and injury related variables included in the C&RT tree are reported in Table 2, including: age, years since injury, ASIA completeness, level of injury, sex, education, marital status, race, and employment. There were no significant differences in demographic variables between successful vs. not successful individuals at baseline.

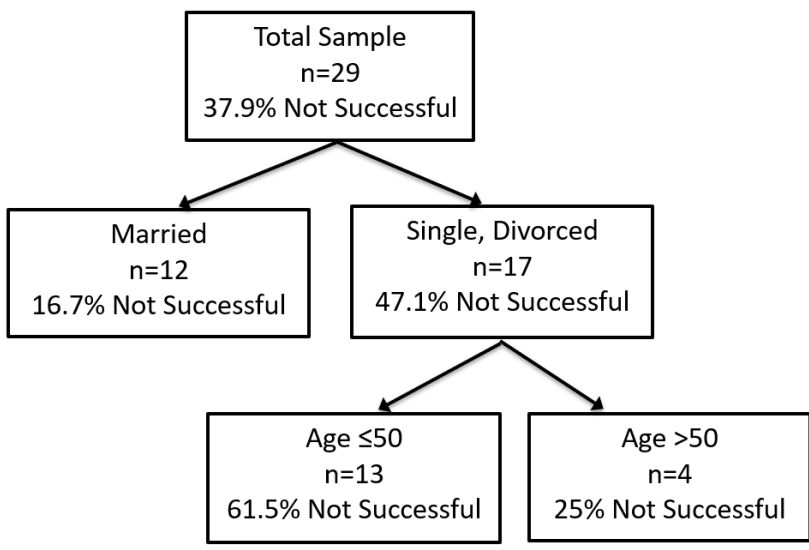
However, successful individuals reported significantly greater secondary condition severity ($P= 0.03$) and fewer health promoting behaviors ($P= 0.02$).

Figure 6 shows the results of the C&RT decision tree with 3 terminal nodes predicting successful versus not successful individuals in the Well on Wheels study. Individuals who were single or divorced were more likely to not be successful in the intervention (47% vs 16%). Among those who were single or divorced, individuals who were less than or equal to 50 years old were most likely to not be successful (62% vs 25%). Calculated risk estimates for the tree were .28 (SD=.08) indicating that the successful group predicted by the tree was wrong for 28% of the cases. Overall, based on sociodemographic and injury characteristics this decision tree model predicted 72.7% of individuals who were not successful and 72.2% of participants who were successful.

Hypothesis 3.1 was not confirmed because less than 75% of the sample was identified by the decision tree. The small sample size in this analysis provides instability in the decision tree technique. Each participant included had a large impact on the outcome and therefore different trees were yielded depending on factors included and ordering. The research team worked to choose the tree that best fit the data without overfitting. However, this method showed demographic characteristics (i.e. marital status and age) can be used to identify a large portion of individuals at risk for low satisfaction with life in Hypothesis 1.1. More work is needed to investigate if injury characteristics can be used to identify individuals who will be successful in interventions like Well on Wheels. Individuals who were not successful in the Well on Wheels intervention were single or divorced and less than 50 years old. Individuals who were successful in the Well

on Wheels intervention were more likely to be either 1) >50 years of age and single/divorced or 2) married.

Figure 6. CR&T Decision Tree Predicting Success in the Well on Wheels Intervention



CHAPTER 5

5. DISCUSSION

This study identified years post-injury, marital status, and age as significant factors associated with satisfaction with life following SCI. Results from longitudinal analysis of the Well on Wheels intervention showed different change in satisfaction with life over 2 years between those with low and high satisfaction with life at baseline. Successful and not successful individuals in the intervention were then identified; marital status and age were significantly associated with success in this program. The results of this study provide useful information for clinicians in identifying individuals most at risk and in need of an intervention, and determine who is most likely to benefit from the specific strategies and curriculum used in Well on Wheels.

Those who were recently injured (<4.5 years) were more likely to have low satisfaction with life at baseline. Those who have been injured longer (>4.5 years) and married were most likely to report high satisfaction with life. Among married individuals, participants who were younger (<49 years) all reported high satisfaction with life and appear to be a protected group of individuals with SCI. In individuals who were single/divorced, those who had been injured a substantial amount of time (>17.5 years) were more likely to report high satisfaction with life. Further, those injured a moderate amount of time (4.5-17.5 years) and single/divorced were more likely to report low satisfaction with life. Overall, individuals with SCI who have been injured less time are more likely to report low satisfaction with life whereas those who are married and younger report high satisfaction with life.

This research is important because individuals with SCI report lower levels of satisfaction with life than the general population.¹¹⁰ The first year post-injury is well documented as a sensitive period during the rehabilitation process in which physiological and psychological factors shift in both positive and negative directions.⁸ Previous studies report good or excellent quality of life in the majority (75%) of individuals 20 years or more post injury and similar satisfaction with life compared to same aged peers 10 and 15 years post-injury.^{25,26} Further, this study's findings highlight time as an important piece to consider. On the surface the strong association between years injured and satisfaction with life fit well into stage theory. Stage theory posits that adjustment to SCI occurs sequentially in 3-5 stages.¹¹¹ However, we know that adjustment following SCI is not simple or the same for any two individuals; making stage theory a weak model for adjustment across individuals.¹¹¹ This study identified other factors that are associated with adjustment outside of years post injury that should be considered and utilized to accelerate and promote positive adjustment.

The demographic and injury factors identified fit well within the Moss-Morris working model of adjustment to chronic illness.¹¹² The working model of adjustment theory posits that personal background factors, illness specific factors, and background social and environmental factors are the base of adjustment. Personal background (e.g. demographics) and illness-specific factors (e.g. degree of disability) impact key critical events (e.g. SCI) and illness-specific and background social and environmental factors (e.g. social support) impact possible ongoing illness stressors (e.g. uncertain future) which disrupts the person's emotional equilibrium and quality of life.¹¹² Cognitive and behavioral factors then dictate whether the person will experience good or bad

psychological, physical and social adjustment. Years post injury is an illness-specific factor identified in this study. Findings specifically highlight the importance of further examining individuals not just 1 year post-injury, but up to 4.5 years as they are at risk for low satisfaction with life. Individuals seem to report higher satisfaction with life after this period, leaving the question as to which factors may improve satisfaction with life sooner. The other critical pieces in this model can be utilized to encourage positive adjustment as years post injury is outside of anyone's control.

Marital status fits within the working model of adjustment as a social and environmental factor that can impact ongoing illness stressors. Married individuals on average report greater satisfaction with life than those who are single or divorced.³² Having a partner provides significant opportunities for social support and more available support is associated with better coping.^{113,114} Social support is focused on the process by which individuals interact related to altruism, a sense of obligation, or perception of reciprocity.¹¹⁴ The process by which individuals perceive provided or received social support is multidimensional and complicated. However, it is well understood is that social support has a positive effect on wellbeing as it may buffer the negative impact of stress as long as there isn't stark asymmetry between each person's perception of the exchange of resources.¹¹⁴ For example, a caregiver for an individual with SCI may think they are assisting them when they perform all instrumental tasks for them, but the individuals may feel a loss of independence and want to learn how to start doing some of these tasks. On the other end the caregiver may start to resent their relationship because they feel like they're obligated to do everything. Overall, the positive support from being married seems to outweigh the potential stressors that lead to negative adjustment.

Further, individuals with SCI identify having a partner as a significant factor that would improve their overall quality of life.²⁷ Partners play an important role as they often serve as caregivers for individuals with SCI and regularly provide tangible and emotional support. A caretaker such as an attendant primarily provides tangible support. We believe multilevel support is the driving factor associated with marital status that leads to higher satisfaction with life. It is possible that people with higher satisfaction with life are more likely to attract a partner or have good marital relationships as opposed to marital status being associated with higher satisfaction with life. Additionally, marital status is not a factor that clinicians can directly modify, but perceived social support is a factor that we can work to identify and improve.

Social support for individuals who are single or divorced can come from other sources. One study found that satisfaction with life following SCI was associated with having a peer mentor and not associated with having a live in partner.¹¹⁵ Peer support is a great avenue for individuals with SCI as shared lived experiences can provide educational resources (e.g. teaching how to get dressed more efficiently) as well as emotional benefits (e.g. emotional support).¹¹⁵ Therefore, a peer is able to provide elements of both tangible and emotional support that can benefit individuals with SCI and promote independence. Additionally, peer relationships often come with fewer obligations that may foster more symmetry in perception of resources exchanged, which based on social support theory would foster coping and reduce stress.¹¹⁴ Family may also be important to consider, particularly in younger individuals with SCI as they often depend on parental support following injury. The benefits of social support for individuals with SCI are clear,

however further studies are needed exploring the effect of perceived satisfaction in these relationships and most beneficial types of social support.

Younger individuals, more than 4.5 years post injury, who were married are identified as a protected group of individuals with SCI who universally reported high satisfaction with life. Age is an important personal background factor to consider in the adjustment process as younger individuals with SCI may vary greatly from older individuals with SCI. Younger individuals are more likely to experience an injury (i.e. key critical event) from an accident whereas older individuals are more likely to have experienced injury from a fall.⁴ Etiology of SCI may have a significant impact on psychological wellbeing following injury as individuals who experience trauma such as a car accident may face significant psychological distress that modifies their rehabilitation plan and necessary resources to improve satisfaction with life.¹¹⁶ Age is also associated with social participation; younger individuals generally reporting more social participation and ease in community reintegration.¹¹⁷ Therefore, in the working model of adjustment, age may be confounded with background social and environmental factors (i.e. social support and relationships with others) that must be considered in conceptualizing the association between age and satisfaction with life. Further, age and injury years can be highly correlated as individuals with SCI are living to older ages. It is difficult to separate effects from these two variables in predicting satisfaction with life in this population. However, our findings provide a more comprehensive picture of how marital status, age, and years following injury interact. These interactions provide valuable information to clinicians helping them better identify individuals with SCI most at risk for low satisfaction with life in different periods of rehabilitation.^{9,32,35}

This study found no associations between satisfaction with life and race, gender, employment status, education, level of injury, and completeness of injury though these have been related in other studies.^{6,9,19,20} The sample size and homogeneity in demographics such as race within these groups precludes us from determining if there is a lack of association or if a larger sample was needed. One of the most striking and consistent trends reported in the literature is the association between employment status and satisfaction with life.^{9,30-32} The overall employment rate in the Well on Wheels sample was 31.9%. Current national statistics show a similar employment rate with 27.6% of individuals with SCI employed 10 years following injury.⁴ However, this study lacks information on income, which may be an important factor to consider in satisfaction with life that is not always associated with employment in individuals with SCI.¹¹⁸ Some individuals with SCI have a settlement or other source of income outside of employment, therefore they may be unemployed, but not low income. More research is needed to investigate the intricate relationship between employment status, income, and satisfaction with life following SCI as these are modifiable factors that interventions and social support could significantly impact.

Individuals in this study volunteered for a wellness intervention and therefore wanted to improve their life situation in some way. This sample may be different from other samples of individuals with SCI but provide an important picture of individuals who on average started the intervention with lower satisfaction with life than the general population. Because of this, our model should be tested in larger and more diverse samples. Practitioners need to consider these factors when working with patients during rehabilitation and collect updated demographic information continuously. Individuals

who are more recently injured are at high risk for low satisfaction with life and practitioners have the chance to provide them with important resources such as wellness interventions to aid this process. Clinicians should also track individuals over time and assist them during significant life changes such as divorce where satisfaction with life is amenable to negative change. Further, individuals who lack a strong support system should be identified as they are most likely to feel isolated and report psychological distress. Our results indicate that social support is a key background social and environmental factor in adjustment that may help improve satisfaction with life earlier in individuals with SCI.

Social support provided by peers and experts in the Well on Wheels intervention may have impacted participants in different ways. We examined longitudinal outcomes in the intervention group based on baseline satisfaction with life group status (high vs low). Over the course of the intervention participants with low satisfaction with life at baseline showed significant improvement. The performance of individuals who started the intervention with low satisfaction with life were of particular interest in this study as they are most at risk for anxiety, depression, and report more secondary health conditions.^{119,120}

At baseline in this sample, mean satisfaction with life was lower than the general population mean.¹² Therefore, many individuals in the Well on Wheels intervention were part of a significant at risk group that may benefit from wellness intervention. Generally, global satisfaction with life is considered a stable construct when measured longitudinally,^{21,29} however our study shows that the Well on Wheels intervention individuals in the low satisfaction with life group significantly improved over time.

Individuals in the high satisfaction with life group on average maintained above average satisfaction. Strategies from this intervention may provide resources to help improve satisfaction with life in individuals with low baseline satisfaction.

SCT and the working model of adjustment both posit that support from others is a strong environmental factor that can positively influence cognitions and behavior change. Expert facilitators and peer support were core components of the Well on Wheels intervention. Modeling, goal setting, and experiential learning exercises may have positively impacted participants in the intervention. More specifically, these factors interact as social support may facilitate self-regulation by increasing self-efficacy that can help individuals handle stress and overcome adversity. The behavior change strategy in the Well on Wheels intervention is based on evidence-based theory however, participants only significantly increased satisfaction with life, not any other outcomes.

This study showed no significant improvements in self-efficacy for health practices, secondary conditions, or health promoting behaviors by baseline satisfaction with life group status. Previous findings from the Well on Wheels study report that individuals in the intervention group experienced significant improvements in their self-efficacy for health practices, secondary conditions, and health promoting behaviors at seven months compared with a no treatment control group. However, multivariate statistics comparing the intervention and control group did not show any significant difference between groups. Lack of between group differences indicates that these outcomes likely just change over time.⁴⁹ This conclusion is consistent with findings from this study as the only significant predictor for secondary outcomes was time.

These findings are concerning as curriculum for this program was chosen from the Stuijbergen model of quality of life in individuals with chronic disabling conditions.⁵⁰ This model identifies self-efficacy, secondary conditions, and health promoting behaviors as the antecedents to improvements in quality of life in individuals with chronic disabling conditions. This model identifies many variables that intuitively are associated with quality of life in individuals with SCI, but the underlying mechanisms and direction of changes may be different in individuals with SCI as they experience a unique trauma. For example, individuals with higher satisfaction with life following injury may have more resources to take care of themselves and therefore experience fewer secondary conditions and barriers as opposed to fewer secondary conditions and barriers being antecedents to satisfaction with life. It is also possible that changes in satisfaction with life in this study were primarily due to time or other variables that were not measured such as intervention engagement. Therefore, we do not discount this model, but the direction of the association among secondary conditions, self-efficacy, barriers, resources, acceptance, and health promoting behaviors needs to be examined in individuals with SCI. More effective interventions to aid adjustment can be created once the direction of these relationships are better understood.

Additional variables of interest included exploratory physiological outcomes. We hypothesized that if changes occurred in these variables, the longitudinal nature of this study would allow time to identify them. High satisfaction with life group individuals showed significant increases in total cholesterol 2 years following the intervention, whereas low satisfaction with life group individuals did not show significant change. Physiological data was not collected at 1 year post intervention, which would help

identify if there was a trajectory of change or a distinct difference between the baseline, immediately post-intervention and 2 years post-intervention. In other words, it is unknown if participants changed incrementally or suddenly 2 years following intervention. Other health behaviors not examined in this study such as increased consumption of unhealthy fat could contribute to change in cholesterol over 2 years. Systolic BP also increased from baseline to 2 years following intervention in all individuals. This finding is consistent with general population trends, but more work is needed to understand the effects of injury on cardiometabolic outcomes in individuals with SCI. Overall, exploratory variables of interest are important to include when conducting longitudinal wellness interventions targeting secondary health conditions. Physiological changes can have a significant impact on satisfaction with life and provide valuable information outside of self-report. Interventions should aim to collect data continuously to provide better context for the trajectory of change.

As previously stated, change in satisfaction with life in the low satisfaction with life group could be due to time effects. Adjustment theory would support this notion that as individuals spend more time learning to cope with their circumstances, global life satisfaction will likely improve.¹²¹ Growing literature focused on resilience provides important insights on potential mediators of satisfaction with life over time. Much like global satisfaction with life, resilience focuses on the individual's perspective and factors they believe will improve their adjustment following trauma.¹¹⁶ Trajectories of resilience following trauma show that some individuals stay positive through the whole rehabilitation process (resilience), some start with low affect and improve over time (recovery), and some individuals consistently report significant negative affect over time

(distress).¹¹⁶ Interventions focused on resilience have the potential to positively impact adjustment following SCI because they normalize negative emotions that are typical following trauma and use positive psychology techniques to improve wellbeing.

Individuals in the distress trajectory of resilience also report significantly less social support and more feelings of loneliness and isolation over time. Peer support is a great avenue currently put into practice in many rehabilitation hospitals that may help individuals in the sensitive period of adjustment of the intensive rehabilitation phase. The Well on Wheels intervention and another more recent intervention utilize experienced peers aiming to improve social support following SCI.^{122,123} A family-based intervention targeting a different system of social support showed promising results, increasing wellbeing in both individuals with SCI and caregivers.¹²⁴ Interventions with more individualized components focused on medical management of SCI show improvements in self-management of secondary health conditions and reducing costs; however, based on our results we posit that social support is an integral mediator of adjustment that should be established prior to individualized intervention.^{43,125}

The Well on Wheels intervention showed some promising results in satisfaction with life improvement over time in those with low satisfaction with life at baseline, but it was necessary to further examine individual changes. Therefore, we identified those who were not successful and successful in order to better understand who this intervention did and did not benefit. Results showed that those who did not succeed in the Well on Wheels intervention were more likely to be single or divorced and less than 50 years old. Those who were successful in the intervention were more likely to be married OR single or divorced and greater than 50 years old. This is consistent with our previous findings

that marital status and age are important factors to consider in working with individuals with SCI.

The connection between marital status and social support is further emphasized in these findings. Partners provide significant aid in the adjustment process as long as marital satisfaction is also high; strain in marital relationships is associated with negative outcomes following SCI.¹²⁶ Patterns of marital status following SCI must also be considered as early literature showed that marital status following injury was more dynamic in this group than the general population, with much higher divorce rates.¹²⁷ However, recent literature shows that marital status and potential for meaningful social support may not be as different in individuals with SCI as previously believed.¹²⁸ We believe this social support for behavior change from partners through tangible support such as helping with medical needs and meal preparation, transportation, and aid in other activities of daily living as well as emotional support contributed to higher success rates among married individuals.

Therefore, clinicians should consider marital status and opportunities for support that may be present for individuals they see in practice. If someone is not married it may be pivotal to help them identify individuals in their network that may provide support that can positively impact their satisfaction with life such as emotional support from a peer or an attendant helping with medical care. Further research is needed to better understand the driving aspects of support that having a spouse or partner provides, but we posit that all individuals with SCI can benefit from tangible and/or emotional support that they feel positively contributes to their self-management.

Additional analyses showed that younger individuals, less than 50 years old, were not likely to be successful in the Well on Wheels intervention. This association could be confounded by other variables such as years since injury or the large range in age in this small sample (20-80 years). However, it is also important to consider that individuals who were successful in the intervention started with more secondary conditions and fewer health promoting behaviors. Individuals who begin with more secondary conditions and fewer health promoting behaviors may be more motivated to change. Motivation has been identified as a mediator of self-efficacy and health behavior change that may be vital in identifying individuals most likely to succeed in interventions.¹²⁹ This finding is striking as more secondary conditions are associated with older age, whereas older individuals may engage in more health promoting behaviors.^{130,131} Therefore, we would potentially expect younger individuals to benefit more from the intervention, but older individuals were more likely to succeed; if they are single or divorced. It is possible that older individuals who are single or divorced are more likely to have established social support in their lives that aided in positive behavior change. These associations must be tested in more datasets in order to better understand the relationship between age and success in SCT-based interventions.

Marital status, age, and years post-injury are highlighted as important factors to consider when aiming to improve adjustment and wellbeing following SCI. There subgroups require tailored interventions suited to the specific needs of individuals. Precision health is a recent push in medicine and public health to provide each patient with a treatment appropriate to their needs; this approach challenges the status quo that programs are not one-size-fits-all.¹³² The goal of intervention research is to identify

programs that are effective by making a lasting positive impact on the lives of patients. More specifically, in the rehabilitation realm the goal is to improve self-efficacy and independence so that individuals can take skills with them to enhance their quality of life and self-management. Programs are not one-size-fits-all and we posit that there needs to be a shift in the field to spend more time and resources to understand not only which interventions are efficacious and effective, but also who these programs benefit most and who may require altered intervention strategies. In this study we found that the Well on Wheels did not benefit most individuals who were single or divorced. Therefore, an intervention should be adapted with resources more focused on identifying appropriate social support specific to their current needs.

Researchers rarely identify individuals who are successful and not successful in intervention studies; this is a major innovative and impactful portion of this study. Individuals with SCI may not all benefit from the strategies used in existing interventions and special attention to qualities that can be used to help identify those who would benefit most is necessary. Clinicians working with individuals with SCI should involve the patient in their treatment plan and understand not only their available social supports, but their perceptions of those relationships and potential need for avenues that would provide new meaningful support. The trajectory of satisfaction with life in individuals with SCI is not well understood beside the fact that generally they increase over time, but we have the opportunity to intervene and help individuals improve sooner. Individuals with SCI as a whole are living to older ages and experiencing many negative health conditions that appropriate wellness interventions can help address. Future research is needed focused on identifying who is benefitting from interventions and for whom we

need to create new interventions. We have all the resources to improve the lives of thousands of individuals, we must now work together to provide individuals with programs that will set them up for success.

CHAPTER 6

6. LIMITATIONS, STRENGTHS, AND FUTURE DIRECTIONS

This study includes several limitations. The sample size in this study is average for interventions in individuals with SCI, but power is not strong. A major interest and push in all fields at this time is secondary data analysis as much can be learned from existing evidence. Secondary data analysis provides answers to important and interesting questions that can help drive the field without using significant resources.

The Well on Wheels study included individuals from only one Midwestern state and primarily included participants who identified as Caucasian. This sample is not representative of all individuals with SCI at the time of study or now. Individuals were randomly assigned to the intervention, but randomization was compromised in this study as individuals were grouped based on satisfaction with life status. Therefore, this is not a randomized study as we only examine the longitudinal impact of the intervention on the intervention group. Further, retention rates in this study were low with only 50% of individuals completing the 2 year assessment, however similar retention rates occurred between intervention and control groups. There were also no differences at baseline in demographics between those who came back for 1 or 2 year follow-up and those who dropped out. The intervention was short, consisting of 6 workshops and an individualized tapering phase; observed changes may be due to time as opposed to the intervention's impact. However, we do identify important factors associated with change over time that clinicians can use in surveillance and interventions in this population. Lastly, the Well on Wheels intervention was conducted in person and individuals with SCI often experience

significant barriers in transportation. The field has generally moved towards telehealth interventions that may be of interest in adapting this program.

Another factor to consider in this study is the timing of the intervention. This study was conducted in the late 1990s when the Americans with Disabilities Act (ADA) regulations had just been established. The ADA prohibits discrimination based on disability, provides clear laws for accommodating individuals with disabilities in the work place and access in the community. For example, the ADA set standards for the number of accessible spaces necessary depending on a parking lot size and mandated a width for all doors in order to accommodate most assistive devices. This program is based on SCT and a driving force within this framework is the environment. Individuals at this time dealt with a much less accessible environment and often much more isolated than they are today. There is still much work to be done to make the environment more accessible, but this is a factor that cannot be underestimated. Timing may significantly impact outcomes when analyzing interventions that occurred prior to full ADA implementation. However, we assert that a program that showed promise improving health promoting behaviors for many individuals when it was much harder to navigate the environment, should be tested further with updated content in today's environment. More research is needed in this realm, but it is important to highlight and consider comparison of classical vs new-age interventions as the field moves forward in precision health as much can be learned from previous work.

Strengths of this study include the longitudinal nature of the dataset. Few studies follow individuals in underserved populations over 2 years, providing an opportunity to better understand the trajectory of changes. Additionally, previous research on correlates

of satisfaction with life in individuals with SCI show mixed results. Our findings provide a profile of individuals at risk for low satisfaction with life by grouping these vulnerable individuals based on shared demographic and injury variables. This study is also innovative and aligned with current goals in public health utilizing a precision health philosophy to identify individuals with SCI who benefited most from the Well on Wheels intervention strategies.

Future directions are focused on creating innovative telehealth interventions to improve satisfaction with life for individuals with SCI. The theoretical basis of the Well on Wheels study must be revisited in creating and disseminating programs as the curriculum subject areas may require modifications; many important antecedents to change in quality of life did not significantly improve in most intervention group participants. However, findings from this study show positive outcomes for satisfaction with life following SCI and highlight important factors that can drive future research questions such as: “what kind of support does a partner provide that is most beneficial in adjustment following SCI: tangible or emotional support?” Once these mechanisms are better understood more effective interventions for subpopulations of individuals with SCI may be possible.

New technology and accessibility provide ways to improve outcomes and disseminate a widely available wellness intervention for individuals with SCI that could be delivered anywhere. Qualitative data collection such as focus groups should be used to identify variables and program modifications that would benefit individuals who have been injured longer and who are single or divorced. The Well on Wheels intervention curriculum has the potential to be easily modified and disseminated to rehabilitation

practitioners as an expert- or peer-led group health promotion intervention that can help those recently injured. The top rehabilitation hospitals are currently utilizing peer support in the early stages of rehabilitation highlighting the benefit of providing newly injured individuals with avenues for significant social support that must be further studied. Based on theories of adjustment we believe peer support in a wellness intervention would also benefit individuals who have been injured longer that report low satisfaction with life.

Additionally, several decision tree models were used in this study that need to be tested in other datasets. Often individuals use decision trees without retesting the factors of interest in future studies. The small sample size in this study led to some instability and variation in decision trees that requires further examination. We plan to test these factors in a randomized pilot weight management intervention for individuals with SCI in progress that includes similar outcomes of interest. Our methodology for defining success will also be tested in other datasets as a feasible and intuitive method that can be used in precision health.

The Well on Wheels study is an existing wellness intervention for individuals with SCI. An ultimate goal of rehabilitation for individuals with SCI is improvements of satisfaction with life, especially those with significantly low satisfaction with life at baseline. The evidence-based materials for this study should be updated, adapted, and expanded in future research studies.

CHAPTER 7

7. APPENDICES

Appendix A. Intervention and control sociodemographic and injury characteristics of Well on Wheels study sample (N=72)

Variable		Intervention n=39	Control n=33
		<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)
Age at enrollment (years)		43.1 (11.3)	45.3 (14.9)
Injury years		11.6 (10.2)	14.9 (11.0)
Sex			
	Female	12 (30.8)	10 (30.3)
	Male	27 (69.2)	23 (69.7)
Level of Injury			
	Paraplegia	20 (51.3)	18 (54.5)
	Tetraplegia	16 (41.0)	14 (42.4)
ASIA Completeness			
	Complete (A)	21 (53.8)	12 (36.4)
	Incomplete (B-D)	15 (38.5)	19 (57.6)
	Normal (E)	0	1 (3.0)
Race			
	White	34 (87.2)	30 (90.9)
	Minority	5 (12.8)	3 (9.1)
Education			
	High School	11 (28.2)	10 (30.3)
	Some college	13 (33.3)	12 (36.4)
	College degree or more	15 (38.5)	10 (30.3)
Employment*			
	Unemployed	23 (59.0)	10 (30.3)
	Employed	10 (25.6)	13 (39.4)
	Retired	6 (15.4)	10 (30.3)
Marital Status			
	Single	14 (35.9)	13 (39.4)
	Married	17 (43.6)	17 (51.5)
	Divorced	8 (20.5)	3 (9.1)

Appendix B. Satisfaction with Life Group sociodemographic and injury characteristics of Well on Wheels intervention participants (N=39)

Variable	High n=23	Low n=16
	<i>n</i> (%) or Mean(SD)	<i>n</i> (%) or Mean(SD)
Age at enrollment (years)	42.3 (9.7)	44.1 (13.4)
Injury years*	14.9 (11.4)	6.8 (5.6)
Sex		
Female	9 (39.1)	3 (18.8)
Male	14 (60.9)	13 (81.3)
Level of Injury		
Paraplegia	11 (47.8)	9 (56.3)
Tetraplegia	10 (43.5)	6 (37.5)
ASIA Completeness*		
Complete (A)	16 (69.6)	5 (31.3)
Incomplete (B-D)	5 (21.7)	10 (62.5)
Normal (E)	0	0
Race		
White	22 (95.7)	12 (75.0)
Minority	1 (4.3)	4 (25.0)
Education		
High School	4 (17.4)	7 (43.8)
Some college	8 (34.8)	5 (31.3)
College degree or more	11 (47.8)	4 (25.0)
Employment		
Unemployed	13 (56.5)	10 (62.5)
Employed	8 (34.8)	2 (12.5)
Retired	2 (8.7)	4 (25.0)
Marital Status		
Single	8 (34.8)	6 (37.5)
Married	12 (52.2)	5 (31.3)
Divorced	3 (13.0)	5 (31.3)

Appendix C. Satisfaction with Life Group Exploratory Outcomes T1-T3, T5 (N=39)

	BMI Estimate (SE)	Cholesterol Estimate (SE)	VO_s Max Estimate (SE)	BP Systolic Estimate (SE)	BP Diastolic Estimate (SE)
Intercept	25.47 (2.00)***	184.73 (10.45)***	12.18 (1.54)***	118.13 (5.68)***	70.40 (3.25)***
SWL Group	2.16 (2.66)	7.60 (13.68)	.09 (2.06)	-1.37 (7.43)	-.30 (4.25)
Time 2	-.13 (1.11)	16.47 (11.97)	.41 (1.79)	-2.02 (7.56)	-2.44 (4.28)
Time 3	-.17 (.98)	3.97 (11.15)	.46 (1.67)	-5.68 (4.15)	-6.98 (4.04)
Time 4	-	-	-	-	-
Time 5	-.91 (.85)	-16.38 (10.39)	2.22 (1.57)	19.85 (6.91)**	5.64 (3.89)
SWL Group x Time					
High Time 2	.07 (1.45)	-7.35 (15.43)	-1.29 (2.34)	-1.22 (9.70)	-1.70 (1.49)
High Time 3	.61 (1.24)	1.83 (14.07)	.55 (2.13)	1.43 (9.02)	-5.37 (5.10)
High Time 4	-	-	-	-	-
High Time 5	1.97 (1.09)	-33.64 (13.22)*	-2.00 (2.00)	-10.22 (8.80)	-6.59 (4.95)

Referent Low Satisfaction with Life Group and Baseline Time 1

Satisfaction with life= SWL

* $P < .05$, ** $P < .01$, *** $P < .001$

CHAPTER 8

8. REFERENCES

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