

**FACTORS ASSOCIATED WITH WHEELCHAIR USE AND THE IMPACT
ON QUALITY OF LIFE AMONG INDIVIDUALS WITH SPINAL CORD
INJURY**

by

Peter Cody Hunt, MPH

BS, University of Binghamton, 1994

MPH, University of Boston School of Public Health, 1998

Submitted to the Graduate Faculty of
School of Health and Rehabilitation Sciences in partial fulfillment
of the requirements for the degree of
Doctoral of Philosophy

University of Pittsburgh

2005

UNIVERSITY OF PITTSBURGH
SCHOOL OF HEALTH AND REHABILITATION SCIENCES

This dissertation was presented

by

Peter Cody Hunt, MPH

It was defended on

April 6, 2005

and approved by

Dissertation Chair: Michael L. Boninger, MD
Professor, University of Pittsburgh School of Medicine
Professor, Department of Rehabilitation Science and Technology
Vice Chair for Research, Department of Physical Medicine and Rehabilitation
Executive Director, Center for Assistive Technology

Rory A. Cooper, PhD
FISA, PVA Chair and Distinguished Professor
Department of Rehabilitation Science and Technology
Director, Human Engineering Research Laboratories

Ross D. Zafonte, DO
Chair and Professor, Department of Physical Medicine and Rehabilitation
Vice President, Clinical Rehabilitation Services, UPMC Health System

Shirley G. Fitzgerald, PhD
Assistant Professor, Department of Rehabilitation Science and Technology

FACTORS ASSOCIATED WITH WHEELCHAIR USE AND THE IMPACT ON QUALITY OF LIFE AMONG INDIVIDUALS WITH TRAUMATIC SPINAL CORD INJURY

Peter Cody Hunt, PhD, MPH

University of Pittsburgh, 2005

ABSTRACT

We systematically examined the standard of care for wheelchair provision, factors associated with wheelchair choice, disparities in access to wheelchair technology, and the impact of wheelchair use on quality of life among individuals with spinal cord injury (SCI), participants of the National Model Spinal Cord Injury Systems (NMSCIS). We administered the Assistive Technology Survey developed by the consensus of the directors of the NMSCIS to a convenient sample of 635 adult full-time wheelchair users who met the eligibility criteria for the NMSCIS in 2 separate data collection periods. About 97% of manual and 54% power wheelchair users had customizable wheelchairs, lending evidence to show that ultralight weight customizable manual wheelchairs and customizable power wheelchairs with programmable controls are the standard of care for wheelchair users with SCI. Power wheelchair users were significantly older ($p=0.000$) than manual wheelchair users. However, regardless to the level of SCI, manual wheelchair users were able to use manual wheelchairs for an average of more than 10 years. Although the socioeconomic statuses (SES) of manual and power wheelchair users were similar, minorities with lower SES had less access to customizable wheelchairs and additional wheelchairs. We were not able to establish an association between the types and design features of wheelchair used on quality of life. Quality of life outcomes were measured in terms of physical/structural barriers, mobility,

physical independence, social integration, and life satisfaction; all of these measures are part of the Craig Hospital Inventory of Environmental Factors, the Craig Handicap Assessment and Reporting Technique, and the Satisfaction With Life Scale. However, we were able to conclude that having additional wheelchairs significantly enhanced mobility for wheelchair users. The results of our study generated new knowledge for the field of SCI rehabilitation by elucidating the standard of care for wheelchair provision, the characteristics of wheelchair users with SCI, and the impact of wheelchair use for this population. Furthermore, this study also provided policy makers with valuable data to address disparities in access to customizable wheelchairs and the lack of insurance coverage for additional wheelchairs.

Table of Contents

ABSTRACT	iii
ACKNOWLEDGEMENTS.....	ix
1.0 INTRODUCTION.....	1
1.1 BACKGROUND AND SIGNIFICANCE.....	5
1.1.1 Treatment and Rehabilitation of Spinal Cord Injury.....	6
1.1.2 Wheelchair Technology.....	7
1.1.3 Wheelchair Selection.....	11
1.1.4 Access to wheelchair Technology.....	13
1.1.5 Health and Function.....	16
1.1.6 Quality of Life.....	20
1.1.7 National Model Spinal Cord Injury Systems.....	25
1.2 PURPOSE.....	26
1.3 REFERENCES.....	28
1.4 APPENDIX.....	40
2.0 Demographic and Socioeconomic Factors Associated with Disparity in Wheelchair Customizability Among Individuals with Traumatic Spinal Cord Injury	42
2.2 METHODOLOGY.....	47
2.2.1 Subject Recruitment.....	47
2.2.2 Assistive Technology Survey (ATS).....	48
2.2.3 Data Management.....	48
2.2.4 Classification of Wheelchairs.....	49
2.2.5 Data Reduction.....	50
2.2.6 Statistical Analysis.....	50
2.3 RESULTS.....	51
2.3.1 Demographics.....	51
2.3.2 Socioeconomic Status.....	51
2.3.3 Wheelchair Distribution.....	52
2.3.4 Factors Associated with Customizable Manual Wheelchairs.....	52
2.3.5 Factors Associated with Customizable Power Wheelchairs.....	53
2.3.6 Additional Wheelchairs.....	53
2.4 DISCUSSION.....	54
2.5 CONCLUSION.....	58
2.6 REFERENCES.....	60
3.0 Association between age, post injury years, and wheelchair types and disparities in access to power wheelchairs among individuals with traumatic spinal cord injury	68
3.1 INTRODUCTION.....	71
3.2 METHODOLOGY.....	73
3.2.1 Population.....	73
3.2.2 Data Collection.....	74
3.2.3 Data Reduction.....	75

3.3 ANALYSIS.....	77
3.3.1 Study Sample	77
3.3.2 Characteristics of Study Sample	77
3.3.3 Post injury Years and Age	78
3.3.4 Access Disparities	78
3.4 RESULTS	78
3.4.1 Characteristics Profiles	78
3.4.2 Age and Post Injury Years	79
3.4.3 Access Disparities	79
3.5 DISCUSSION	79
3.6 CONCLUSION.....	82
3.7 REFERENCES	83
3.8 APPENDIX.....	90
4.0 The impact of wheelchair use on quality of life among individuals with traumatic spinal cord injury	91
4.1 INTRODUCTION	94
4.2 METHODOLOGY	96
4.2.1 Population	96
4.2.2 Survey Instruments	97
4.2.3 Data Collection	100
4.2.4 Power Wheelchair Classification	101
4.3 ANALYSIS.....	102
4.3.1 Study Sample	102
4.3.2 Statistical Procedures.....	103
4.4 RESULTS	103
4.4.1 Quality of Life Measures	103
4.4.2 Average Age, Post Injury Years, and FIM Scores.....	105
4.5 DISCUSSION.....	105
4.6 CONCLUSION.....	108
4.7 REFERENCES	110
4.8 APPENDIX.....	116
5.0 SUMMARY AND CONCLUSION.....	117
5.1 STANDARD OF CARE	117
5.2 FACTORS ASSOCIATED WITH WHEELCHAIR USED	118
5.3 DISPARITIES IN ACCESS TO WHEELCHAIR TECHNOLOGY	119
5.4 IMPACT OF WHEELCHAIR USE ON QUALITY OF LIFE	121
5.5 LIMITATIONS AND RECOMMENDATIONS FOR FUTURE STUDIES.....	123
5.5 REFERENCES	125

List of Tables

Table 1-1 Spinal cord injury treatments.....	33
Table 1-2 Average yearly expenses and estimated life time costs by age and injury....	34
Table 1-3 Examples of issues related to funding for a wheelchair	35
Table 1-4 Six indicators of lack of social participation for people with disabilities	36
Table 1-5 Top five reasons cited for not being involved with community.....	37
Table 2-1 Demographic and Socioeconomic Factors Associated with Manual Wheelchair Classification	63
Table 2-2 Demographic and socioeconomic factors associated with power wheelchair classification.....	64
Table 2-3 Socioeconomic factors associated with power wheelchair users with tetraplegia	65
Table 2-4 Demographic and Socioeconomic Factors Associated with Having Additional Wheelchairs	66
Table 3-1 Demographic and socioeconomic profiles of manual and power wheelchair users	87
Table 4-1 Distribution of wheelchair users	113
Table 4-2 Quality of life outcome measures among all comparison groups	114
Table 4-3 Age, post injury years, and FIM scores among all comparison groups	115

List of Figures

Figure 1-1 Leading etiologies of traumatic spinal cord injury.....	38
Figure 1-2 Relational model of wheelchair mobility	39
Figure 2-1 Level of education achieved among individuals who received standard and customizable wheelchairs	67
Figure 3-1 Differences in age and post injury years between manual and power wheelchair users with paraplegia	88
Figure 3-2 Differences in age and post injury years between manual and power wheelchair users with tetraplegia	89

ACKNOWLEDGEMENTS

This work was supported by funds from the National Institute on Disability and Rehabilitation Research in the Office of Special Education and Rehabilitation Services in the U.S. Department of Education (H133N000019).

1.0 INTRODUCTION

Spinal cord injury (SCI) is characterized by damage to the spinal cord that results from direct injury to the cord itself or from indirect injury to the bones, soft tissues, and blood vessels surrounding the spinal cord (1). In addition to the loss of sensation and motor function, individuals with spinal cord injury (ISCI) may experience a host of other medical complications such as decubitus ulcers, respiratory failure, autonomic dysreflexia, and loss of bladder and bowel control. Most of these medical complications, also known as secondary medical complications (2), are worsened by prolonged bed rest. Secondary medical complications can significantly shorten the life expectancy and lower the quality of life (QOL) of ISCI. Prior to World War II, ISCI died within weeks of their injury (3). Since then, advancement in medical and assistive technology (AT) have successfully managed or eliminated some of these secondary medical complications. As a result, the mortality rate of SCI is on the decline and life expectancy of ISCI is comparable to that of the general population (4).

Wheelchairs are a specific class of AT that serves to enhance mobility among ISCI. Wheelchairs differs in design, features, cost, performance, and durability (5,6,7,8). Wheelchairs that meet the needs of the user, based on clinical indicators and personal preferences, can maximize the user's function, independence, and productivity. Inappropriate wheelchairs will lead to misuse, abandonment, or worse yet, personal injuries (9,10). Unfortunately, current literature suggests that there are significant barriers in accessing adequate and appropriate wheelchair technology (11).

Under the current cost constraining health care system, U.S. health care providers, AT vendors, and insurance carriers are under tremendous pressure to provide the least cost alternative form of AT. The result is a significant number of people with disabilities (PWD) have unmet AT needs (12,13). Disparity in access to AT sharpens among PWD with low incomes and inadequate insurance coverage (14,15). Minorities who hold's cultural view that stigmatizes the use of AT and those do not participate in the AT decision-making process are at greater disadvantage in AT acquisition and rate of utilization (16).

Presently, there are no established standard of care for providing wheelchairs for ISCI. The National Model Spinal Cord Injury Systems (NMSCIS) maintain the world's largest database on individuals with traumatic spinal cord injury (ITSCI), which contains more than 31,000 data points and 25 years of longitudinal data (17). Notably absent from this database is information on AT. Therefore, the standard of care for providing wheelchairs to the NMSCIS population is unknown. Without the standard of care, it is not possible to assess the equity in access to wheelchair technology. Furthermore, because of the lack of data, little is known about the impact of wheelchair use on the QOL for this population. The goals of the current study are to determine the standard of care for providing wheelchairs to the NMSCIS population. Based on this standard of care, we will examine factors associated with manual and power wheelchair users among individuals with paraplegia and tetraplegia. Analyses will be conducted to determine if disparity exists in accessing type (manual or power), customizable, and additional wheelchairs among individuals from different demographic and socioeconomic backgrounds. Lastly, this study will assess the impact of wheelchair use

on QOL measures in terms of life satisfaction, social participation, and environmental barriers.

To our knowledge this is the first study to examine the standard of care for providing wheelchairs and the impact of wheelchair use among the NMSCIS population. The findings of this study will add new knowledge to the field of SCI rehabilitation. Health care providers, AT vendors, and rehabilitation professionals will be better informed about the standard of care within the NMSCIS to ensure equitable access to appropriate wheelchair technology. Policy makers, third-party payers, consumer advocates, and AT service agencies will be guided to develop policies to eliminate access barriers. Consumers will be benefited by the improved standard of care and equitable access to wheelchair technology.

Specific aims

The overarching goals of this study are to develop and implement the Assistive Technology Survey (ATS) to determine the standard of care for providing wheelchairs; disparity in access to wheelchair technology, and impact of wheelchair use on ITSCI received care at the NMSCIS. The methodology and results will be reported in three manuscripts and the aims and hypotheses for each of the manuscripts are as follow:

Manuscript One

Aims:

- 1) Determine the standard of care for providing customizable wheelchairs among the NMSCIS;
- 2) Investigate factors associated with wheelchair customizability and ownership of additional wheelchairs;
- 3) Determine if disparity exists in access to customizable and additional wheelchairs among individuals from different socioeconomic status.

We hypothesize that:

- 1) There exists a standard of care for providing customizable wheelchairs to the NMSCIS population.
- 2) Individuals with high socioeconomic status within the NMSCIS are likely to receive customized wheelchairs and have additional wheelchairs.

Manuscript Two

Aims:

- 1) Investigate factors associated with type (manual or power) of wheelchair use among individuals with paraplegia and tetraplegia; and
- 2) Determine if disparity exists in access to power wheelchairs among individuals from different socioeconomic status.

We hypothesize that:

- 1) Individuals with paraplegia who use a power wheelchair are likely to be older and have been injured for a longer period;
- 2) Individuals with tetraplegia who use a manual wheelchair are likely to be younger and injured more recently;
- 3) Individuals with high socioeconomic status will have greater access to power wheelchairs regardless of level of injury;

Manuscript Three

Aims:

- 1) Assess the impact of type (manual or power) of wheelchair use and having additional wheelchairs on QOL measures in terms of life satisfaction, social participation, and environmental barriers; and
- 2) Among power wheelchair users, Investigate the impact of customizable power wheelchair use on QOL measures in terms of life satisfaction, social participation, and environmental barriers.

We hypothesize that:

- 1) Individuals who use power wheelchairs achieve higher QOL;
- 2) Individuals who have additional wheelchairs attain higher QOL; and
- 3) Among power wheelchair users, individuals who use customizable power wheelchair with programmable controls have higher QOL.

1.1 BACKGROUND AND SIGNIFICANCE

Once described as “an ailment not to be treated” by an Egyptian physician about 5000 years ago (18), unfortunately, SCI remains an incurable condition today. Spinal cord injury is defined as “an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function” (19). Spinal cord injury can be sustained through different mechanisms, among the most common mechanisms are: destruction from direct trauma; compression by bone fragments, hematoma, or disk material; and ischemia from damage or impingement on the spinal arteries (20). Individuals who have sustained injuries to the cervical segments of the spinal cord are considered to be individuals with tetraplegia. Those with injuries sustained to the thoracic, lumbar or sacral regions of the spinal cord are classified as individuals with paraplegia (19). In addition to the loss of sensory, motor, and autonomic function, ISCI also experience many medical complications, known as secondary medical conditions, resulted from immobility and prolong bed rest (2). Some of these conditions are life threatening. Pneumonia remains the leading cause of death among individuals with high-level quadriplegia (21). Decubitus ulcers, autonomic dysreflexia, urinary track infections, and severe depression also pose significant risk to the survival of ISCI (2). Other conditions such as sexual dysfunctions may not be life threatening, but can significantly diminish QOL (22).

According to the Spinal Cord Injury Informational Network, in December 2003, the annual incidence of SCI, is approximately 40 cases per million population in the United States, or approximately 11,000 new cases per year. Although the estimated incidence has not been updated since the 1970's, the prevalence of SCI is estimated to

be approximately 243,000, with a range of 219,000 to 279,000 persons. The leading etiologies of traumatic SCI are attributed to motor vehicle crashes (40.9%), falls (22.4%), and acts of violence (21.6%) Figure 1.1 is a schematic presentation of these etiologies (4).

1.1.1 Treatment and Rehabilitation of Spinal Cord Injury

Prior to WWII, those who survived the initial SCI trauma died within few years of their injury due to medical complications and prolonged bed rest. With the introduction of categorical care for SCI during WWII and the advancement in medical technology and rehabilitative care in the past three decades, ISCI are living longer and enjoying higher QOL. Current treatments and rehabilitation of SCI focus on controlling secondary medical complications and maximizing functional recovery. The variety of medical, surgical, and rehabilitative interventions are summarized in Table 1.1.

The success of the current approach in treatment and rehabilitation of SCI has significantly reduced mortality and increased the life expectancy of ISCI. According to the National Spinal Cord Injury Statistical Center (NSCISC), the average life expectancy of the 20-year-old cohort with SCI is about 52.9 years compared to 57.8 years of their peers who have no SCI. For the 40-year-old cohort, ISCI have an average life expectancy of 34.4 years and 38.9 years for those without SCI. As ISCI are living longer, the accrued lifetime health cost and living expenses associated with SCI can be staggering (4). A 1996 report from the Agency for Health Care Policy and Research showed that SCI is the most expensive condition or diagnosis treated in U.S. hospitals (23). As shown in Table 1.2, the yearly expense in the first year of injury for a person

with high tetraplegia is averaged at U.S. \$626,588.00. While ongoing research and clinical activities are looking for cost-effective strategies to manage SCI, efforts are underway to develop novel approaches to treat and cure SCI.

1.1.2 Wheelchair Technology

In simple technical terms, a wheelchair is defined as “a chair with a backrest mounted on wheels, which allows people with mobility disabilities to move around” (24). In the past few decades, the development of wheelchair technology advanced with an accelerated pace. Several historical movements might have attributed to this revolution. The Disability Rights Movement of the 1960s demanded PWD be freed from institutionalization and have the rights to live independently in community settings (25). As more PWD integrated into mainstream society, there has been an increase in demand for wheelchairs that are suitable for community living, recreational activities, and sports participation. Legislation such as the Rehabilitation Act of 1973, the Individual with disabilities Educational Acts, and the Assistive Technology Act provided the necessary federal funding for wheelchair research and development. As a result, consumers have a vast array of options for selecting wheelchairs that meet the demands of their everyday living.

For the purpose of this study, wheelchairs are classified according to their means of propulsion, self/attendant propulsion or powered propulsion, and design characteristics. Wheelchairs can be self/attendant propelled or equipped with power propulsion. Within these two general types, wheelchairs differ by design and functional features, weight, and control interface. Based on these different characteristics,

wheelchairs can be further classified as standard or customizable wheelchairs. Under this classification scheme, wheelchairs are classified under two major and five subcategories. The two major categories are manual and power wheelchairs. The five subcategories are standard manual wheelchairs (SMW), customizable manual wheelchairs (CMW), standard power wheelchairs (SPW), standard power wheelchairs with programmable controls (SPWPC), and customizable power wheelchairs (CPW). Standard Manual wheelchairs include depot wheelchairs (DW) and lightweight wheelchairs (LW). These wheelchairs have few adjustable features such as back height and weigh more than 14 kg (30 lbs). Based on the Healthcare Common Procedure Coding System (HCPCS) of the Centers for Medicare and Medicaid Services (CMS) in the United States, these wheelchairs fall under the K0001-K0004 categories. Manual wheelchairs that weigh less than 14 kg (30 lbs), have a high degree of adjustability, and when equipped with an adjustable rear axle position are categorized as CMW. These wheelchairs are equivalent of K0005 category wheelchairs.

Power wheelchairs classification is based on characteristics of the frame or power base, programmable controls, and customizable features. CPW are power wheelchairs with programmable controls and have at least one of the following customizable features: 1) capable of accommodating an advanced seating systems such as tilt in space or standing; 2) a suspension system; or 3) a high torque motor and stronger frame. The SPWPC are standard power wheelchairs with just programmable controls. The remaining category is SPW. Using this classification system, CPW is equivalent of K0014, SPWPC corresponds to K0011, and SPW is the same as K0010 power wheelchairs as defined by CMS.

The different design characteristics between standard and customizable wheelchairs have a significant impact on performance, durability, and cost of the wheelchair. Numerous studies have compared the performance between CMW and SMW. The results of a study comparing functional mobility in SMW vs. CMW as measured by performance on a community obstacle course showed that individuals who used CMW had fewer number of contact errors, leading the authors to conclude that differences in wheelchair design can lead to differences in wheelchair performance (26). A study of energy costs for wheelchair propulsion among ISCI in an outdoor setting yielded similar results, CMW significantly improved the efficiency of propulsion. Test subjects were able to propel longer distance at a faster speed with less oxygen cost (27). Boninger and colleagues examining the effect of rear axle position relative to the shoulder on pushrim biomechanics concluded that wheelchairs with adjustable axle position can improve propulsion mechanics and likely reduce the risk of injury (28). In a focus group conducted among power wheelchair users and professionals working in the field, participants agreed that wheelchair durability and reliability are the most important criteria in developing the application of power mobility input devices and control concepts (29). A study on wheelchair injury reported about 25% of power wheelchairs users experienced physical injuries as a result of component failures (30). Fass et al compared durability of selected power wheelchairs using 2-drum and curb-drop machines in accordance with the American National Standards Institute/The Assistive Technology and Rehabilitation Engineering Society (ANSI/RESNA) standards and found CPW (K0014) has a longer life span than SPWPC (31). Differences in durability were also found in manual wheelchairs in laboratory testing. Fitzgerald et al

compared the fatigue life for 3 types of wheelchairs – CMW and high and low end SMW. The results showed the CMW was significantly more durable than the other 2 types of wheelchairs (7). In another study, Cooper et al reported similar results; CMW had a much higher fatigue life than those previously reported for SMW (32).

According to ABLEDATA, the price of a CMW can be 8 times or more than a low end SMW. A high end CMW is priced more than U.S. \$4,000.00 (1994 dollar figures) compared to \$500 for a low end SMW and \$1,800 for a high end SMW (33). However, in terms of cost effectiveness over the lifetime of a wheelchair, studies found the CMW to be more cost effective than other types of manual wheelchairs. In evaluating selected lightweight wheelchairs using the ANSI/RESNA standards, Cooper et al found CMW to be more cost effective over the life time of the wheelchair, costing 3.4 times less (dollars per life cycle) than low end SMW, and 2.3 times high end SMW (34). Subsequent study showed that CMW had a mean value of 673 cycles per dollar to compare to 210 cycles per dollar for the high end SMW (32). The study conducted by Fass et al also showed that CPW had a higher value compared to SPWPC (31). For individuals with mobility limitation who are full time wheelchair users, wheelchair comfort level and reliability are extremely important for the well-being and safety of the users. Customizable wheelchairs have been perceived to be more comfortable. A study conducted among community-dwelling manual wheelchair users, DiGiovine et al reported that a majority of test subjects perceived the CMW to be more comfortable and had better basic ergonomics than other manual wheelchairs (35). Differences in wheelchair design and features not only enhance wheelchair performance, durability, and cost, more

importantly customizable wheelchairs have been shown to greatly enhance the health, function, and QOL of wheelchair users.

1.1.3 Wheelchair Selection

Having the “right” wheelchair is the key to independence and better QOL for wheelchair users (36). According to Routhier et al, the right wheelchair is one that allows users to best carry out their daily activities and social roles, and operate the wheelchair and its accessories such as the brakes and control interface with ease and efficiency. Therefore, wheelchair provision must take in account personal, environmental, and technology factors (24). While there is effort underway to develop the standard of care for wheelchair provision for individuals with degenerative disorders such as multiple sclerosis (37), currently there is no standard of care for providing wheelchairs for ITSCI.

Selecting an appropriate wheelchair can be a complex process and requires the collaboration of a multi-disciplinary team of professionals and the wheelchair user. The multi-disciplinary team of professionals consists of physicians, physical or occupational therapists, rehabilitation engineers, certified AT providers, AT vendors, and third party payers. Physicians are responsible for writing the wheelchair prescription. Together, the physicians and therapists assess the functional capacity of the user. The rehabilitation engineers, certified assistive technology providers, and therapists interview the user to determine his/her needs. Based on this interview, the team can select the wheelchair that is capable of meeting the demands of the user. Often times, reimbursement policy of the third-party payer may limit the choices of wheelchairs. In

such cases, the team of professionals may file an appeal to obtain the appropriate wheelchair (5).

Routhier et al contends that the ultimate end goal of wheelchair provision is to enhance the function of the user. Therefore, Routhier et al proposed a performance assessment framework for wheelchair provision based on wheelchair mobility. The authors believed that the success of wheelchair mobility assessment would lead to better occupational and social participation outcomes. The relational model of wheelchair mobility proposed by Routhier has five components: 1) the user's profile, 2) the wheelchair, 3) the environment, 4) the daily activities and social roles, and 5) the assessment and training received. Details of these components are shown in Figure 1.2 (24).

Scherer however argued that taking into account the user's personality and temperament was vital to the success of matching users with appropriate wheelchair technology. She proposed the Matching Person Technology (MPT) model for assessing AT for individuals. The MPT emphasizes the importance of environmental and psychological factors, as well as the individual's personality and temperament (38). Aside from personality, environment, and technology factors, the assessment team must also take into account the funding factor. Navigating through the maze of complex funding mechanisms is not a simple task for the consumers; therefore, a knowledgeable assessment team is important. In the U.S., most wheelchairs are purchased by third-party payers. Third-party payers consist of private, state, and federal insurance or assistance programs. Funding eligibility and percentage of coverage depends on funding sources, reimbursement policies, and the individuals' status and wheelchair

characteristics. In many instances, consumers are required to make a co-payment. The success of obtaining funding for the appropriate wheelchair also relies on the quality and detail of the medical necessity documentation provided by clinicians and AT vendors. This documentation is used to justify that the requested wheelchair is necessary for the individual to perform daily activities and it is not merely a device for convenience. Unfortunately, often times, third-party payers will use medical necessity documentation to deny requested items citing insufficient causes for medical necessity. When this occurs, the assessment team can submit additional justification for an appeal. Not all appeal processes, unfortunately, are successful; third-party payers may deny the request completely or opt for the least costly alternative. Examples of the complex issues related to wheelchair funding are detailed in Table 1.3 (5).

1.1.4 Access to wheelchair Technology

The ability of ISCI to successfully integrate into society and regain independence depends much on access to appropriate and adequate AT such as wheelchairs. Unfortunately, the current budgetary constraints of the U.S. health care system and the often-rapid changes in public health care policies created disparities in access to AT for many PWD. In 1990, the National Health Interview Survey showed that 2.5 million people said they needed AT that they did not have (12). A more recent study showed that disparity in access to AT might have increased over the years. In 2002, Bingham and Beatty found that about 28% the 500 working-age respondents indicated that they needed AT in the last 12 months and did not receive the technology every time it was

needed (13). Both of these studies cited financial barrier as the main reason for the unmet need.

According to the Healthy People 2010, financial barriers that limit access to health care include, not having health insurance, not having enough health insurance to cover needed services, or not having the financial capacity to cover services outside a health plan or insurance program (12). In the US, most health insurance plans cover wheelchair purchases. Unfortunately most insurance plans have co-payments and high deductibles (5). For example, Medicare covers 80% of the cost of a wheelchair, and the beneficiary is responsible for paying the 20% co-payment. Consider the fact that wheelchairs are expensive equipments; the 20% out-of-pocket co-payment can impose a significant financial barrier for PWD, especially those with lower socioeconomic backgrounds.

In the US, disability has shown to be strongly associated with individuals from lower socioeconomic backgrounds. In 1993, the Bureau of Census reported that individuals with low incomes are more likely to have disabilities than persons with high incomes. This study compared family income to a threshold of poverty for a family of specified size and composition and found a consistent relationship between low-income status and severe disability across a range of income levels (39). In the same year, LaPlante reported “some 4.1 million Americans with disabilities have no health insurance, public or private, out of a total uninsured population of 35.3 million adults and children” (40). Among those with health care insurance, PWD often exceed caps on coverage for AT and medical rehabilitation services (13). As a result, “cost and

coverage limitations of health plans have been identified as the most prominent [financial] barriers for people with disabilities seeking [assistive] equipment” (15).

Studies on acquisition of AT revealed that personal and cultural factors could be barriers of access to appropriate AT. Assistive technology provides the means for PWD to overcome barriers and thus, enhancing their capability to perform everyday activities and fulfill social roles. However, personal meanings attributed to AT play a decisive role in whether AT will be successfully integrated into a person’s life. Pape et al conducted a literature review on the influence of personal factors on AT found that psychological, cultural and adaptation factors have significant influence on individualized meanings attributed to AT (16). Failure to take in account these factors would result technology abandonment and disparity in access and usage of appropriate AT.

High rate of technology abandonment has been documented and could have serious repercussions for PWD and for society. Phillips and Zhao surveyed a sample of 277 adults with various disabilities and found that 29.3% of all devices were completely abandoned. Mobility aids were more frequently abandoned than other types of devices. Factors that were significantly related to technology abandonment included lack of user opinion in selection and change in user need or priorities (41). The involvement of the AT users and their family in the AT decision-making process is vital. The family-centered approach suggested that involving families in AT decision making requires careful gathering of information needed to address the family strengths, needs, and priorities, and to match the AT decision making process with the family’s culture (42,43).

Studies on acquisition of AT showed that minority AT users and their family do not participate in the AT decision making process. Parette et al revealed that low

income African American family often experienced a great of economic pressures, which prevent them from participation. These families felt that the urgent need for “putting food on the table” is more of a priority (14,42). For other minority groups, such as Chinese-Canadian associated the use of AT to be “dishonor, disgrace, and embarrassment” (44). The lack of participation in AT decision-making among these groups resulted in a disparity in ownership and usage of AT. In assessing the needs for AT devices, Carrasquillo found that African American and Hispanic elderly were more likely to report functional limitations and therefore a greater need for AT when compared to their Caucasian counterparts (45). However, when examining the rate of ownership and utilization of AT among similar populations, African American elders were found to have owned and used fewer devices than Caucasian elders (46).

1.1.5 Health and Function

Surviving a traumatic SCI can have a devastating impact on the lives of survivors. In addition to emotional adjustment, individuals have to cope with the loss of sensory and motor function (47). The loss of functional mobility has been identified as the most problematic issue for ISCI. A retrospective analysis of health records at the GF Strong Rehab Centre of Vancouver revealed that the top three problems identified by ISCI were functional mobility (including transfer and wheelchair use), dressing, and grooming (48).

Wheelchair use, according to Cooper, has the potential to maximize the user’s functional abilities in many aspects of everyday life: development and socialization, recreation and play, learning and working, and living independent lives (5). Several

studies reported the beneficial intervention of providing wheelchairs to individuals with mobility impairments. In a study conducted to determine the effect of early provision of power wheelchairs in children with tetraplegia, Bottos et al found that the level of independence improved significantly after power wheelchair provision. A majority of the participants, children and parents alike expressed positive feelings about the intervention (49). Similar results were achieved with providing power wheelchairs to a cohort of 111 Danish wheelchair users over age 65. Nearly all users regarded the intervention to be important and significantly increased their level of independence. The use of power wheelchairs made activity and participation, such as “going for a ride in the summer and shopping in the winter”, possible for all users (50). Another study investigated the effect of providing electric indoor/outdoor power wheelchairs to a group of severely disabled wheelchair users. In a 3-month follow up, recipients of power wheelchairs reported a significant improvement in mobility and reduction in pain and discomfort (51).

While wheelchair use provides an unprecedented level of mobility freedom and independence for individuals with mobility impairment (11); unfortunately, it also poses a significant risk for upper extremity impairment and pain. There is ample literature documenting the epidemiology of neck, shoulder, and wrist impairment and pain associated with wheelchair use. In 1976, The Spinal Cord Injury Association surveyed its 708 members and found that 51.4% suffered from shoulder pain related to wheelchair use (52). However, more recent studies found that the prevalence of shoulder pain related to wheelchair use is substantially higher than previously indicated. A study conducted at the Edward Hines Jr. Veterans Affairs Hospital showed that 72.7%

of the 800 patients with SCI surveyed reported some degree of chronic pain in one or both shoulders resulting from wheelchair propulsion and transfer (53). The Northwestern study reported that 72% of 53 patients with SCI from the onset of injury until 15 years duration demonstrated radiological evidence of degenerative changes, but only 11% complained of pain in the shoulders (54). The University of Washington reported among its 130 respondents, 71% had shoulder pain, 53% wrist pain, 43% hand pain, and 35% elbow pain (55). The most recent meta-analysis study conducted at Kessler Medical Rehabilitation Research and Education Corporation found that shoulder pain is more common in individuals with tetraplegia and complete injuries, and may occur more frequently in women (56). Upper extremity pain not only hampers wheelchair propulsion and transfer, thus further limiting mobility function, it also takes on an emotional toll and severely impacts the individual's ability to perform daily activities.

Though there are various treatments available for shoulder pain, such as physical therapy, pharmacological treatment, and surgical procedures, these treatments are not the permanent solution (55). Since wheelchair propulsion and transfer are the main causes of shoulder pain, one logical solution would be to improve wheelchair propulsion technique and design. Numerous studies investigated wheelchair propulsion technique and found that stroke pattern is related to mechanical efficiency. Boninger et al investigated the relationship between stroke pattern and biomechanics among manual wheelchair users. The results of the study showed the semicircular motion of propulsion displayed characteristics consistent with reduced repetition and more efficient propulsion (57). In a more recent study, Boninger et al found that subjects using a greater range of motion showed better nerve function than subjects propelling

with a smaller range of motion, leading the authors to conclude long and smooth strokes may benefit median and ulnar nerve health in manual wheelchair users (58). Testing wheelchair propulsion technique with able bodied subjects, DeGroot et al found pumping to be the most energetically efficient stroke pattern compared to semicircular and single-looping over propulsion patterns (59).

In addition to stroke pattern, the direction of force applied during wheelchair propulsion also contributes to upper extremity impairment and pain. Investigating the relationship between pushrim forces and the progression of shoulder injuries in manual wheelchair users, Boninger et al observed individuals who propel with a greater percentage of force directed toward the axle were at increased risk of progressive shoulder injuries over time (60). Similar results were found in a study examining the effects of SCI level on shoulder kinetics during manual wheelchair propulsion among male wheelchair users. The results showed that increased vertical force at the shoulder joint, coupled with reduced shoulder depressor strength, might contribute to shoulder problems in subjects with tetraplegia. The authors recommended wheelchair design modifications, combined with strength and endurance retention, should be considered to prevent shoulder pain development (61). Therefore, while improved wheelchair propulsion techniques may prevent or reduce the risk for upper extremity impairment and pain among manual wheelchairs, improving wheelchair design and ergonomics may be other viable solutions.

Customizable manual wheelchairs that are equipped with adjustable rear axles make it possible to adjust the center of gravity of the wheelchair and the ergonomics of the user. Such an adjustment can have an impact on wheelchair propulsion. A study

conducted by Boninger et al to determine the effect of rear axle position relative to the shoulder on pushrim biomechanics found that biomechanical parameters such as frequency of propulsion, rate of rise of the resultant force, and push angle at multiple speeds were related to axle position relative to the shoulder. The results lead the authors to recommend that fitting users to wheelchairs with adjustable axle position will likely reduce the risk of injury (39). Power wheelchairs equipped with customizable features such as tilt-in-space and recline systems have shown to be effective in reducing discomfort and pain associated with prolonged static sitting among power wheelchair users, overwhelmingly 97.5% of 40 participants reported high satisfaction (62). In terms of wheelchair ergonomics, Wei et al investigated wrist kinematics characterization at various wheelchair seat positions and found that during wheelchair propulsion, seat height was found to be a critical factor affecting the temporal parameters of movement and wrist kinematics. Wrist joint angles and wrist flexion-extension range of motion all varied according to seat height. While no ideal seat position was determined, seat position may be a factor in reducing arm/wrist pain (63). Similarly, various push handle heights had a differential impact on the external forces and biomechanical loading on the shoulder. Adjusting the push handle to a proper height might be a means to reducing shoulder impairments (64).

1.1.6 Quality of Life

Quality of life in general is considered to be a multidimensional construct, based on a person's subjective appraisal of their physical, functional, emotion, and social well-being (65). Tate et al. conducted a literature review of studies on QOL of ISCI and

noted, “Very few of these studies addressed the specific needs of ISCI”. According to Tate, the problem lies within the intrinsic definition of QOL measurement. The dynamic nature and multidimensionality of QOL and its inherent subjectivity as self-report seems to lack sensitivity to the subtleties or complexity inherent in human behavior. As such, clinical research on QOL “often yielded findings that do not make sense, are paradoxical, cannot help clinical and social sciences researchers identify which treatments are better or even clinically equivalent, and cannot help us understand how people perceive their QOL over time and/or after disability onset (e.g. SCI, TBI). Despite these limitations, QOL studies have flourished (66). According to the American Academy of Physical Medicine and Rehabilitation, one of the most important contributors to QOL is the ability to function (11). Loss of mobility function not only limits independence, it also contributes to the lack of social participation. Dijkers et al compared factors associated with social participation among ISCI in the U.S. and Turkey and found that mobility is the major predictor of social participation (67). Study of activity restriction among wheelchair users also found mobility limitation to be associated with restricted participation. Furthermore, the lack of social participation also leads to a great rate of home confinement (68).

Home confinement can have adverse personal and social consequences. The personal adverse effects associated with being homebound include reduced social and leisure activities, lower life satisfaction, malnutrition, experience of dysthymia, and greater use of home health care services. Adverse effect on the social level is the healthcare cost associated with home confinement. Since home confinement is the major qualifier for receipt of paid home health services, the health costs for home

confinement can be measured against the estimated national expenditures for home health care. In 1999, the total U.S. expenditures for home health care services amounted to more than \$33 billion and is expected to nearly triple by 2010 (69).

The rate of social participation among PWD is significantly less than their peers without disabilities. A Harris Survey conducted in 2000 assessed the differences in degree of social participation between people with and people without disabilities. A nationwide sample of 535 PWD and 614 people without disabilities surveyed. The results showed that a higher percentage of PWD are “not involved with their community”, “less satisfied with community involvement”, “did not feel a valuable or contributing member of their community”, “more isolated from others”, “left out of things”, and “not regularly invited to give opinion on community issues”. The findings also showed that the degree of disability is related to lack of community involvement, the more severe the disability the lesser degree of social participation. The findings of this study are summarized in Table 1.4 (70).

Besides mobility limitation, there are other factors associated with lack of social participation. Environmental barriers were found to be significantly associated with the lack of social participation. Hoenig et al investigated factors associated with activity restriction among U.S. veterans who use wheelchairs and found that mobility limitations and environmental barriers were associated with restricted participation in diverse activities outside the home. Studies on activity restriction among wheelchair users in community dwellings yielded similar conclusions. Environmental barriers posed significant limitations for social participation (68). Schopp et al explored the barriers encountered by women with disabilities seeking gynecologic services and found that

women with disabilities encountered a variety of obstacles: attitudinal, environmental, economic, and informational barriers (71). In a qualitative study, Levin et al. identified two major themes that account for lack of social participation among ISCI: individual influences – mourning the loss of an “able identity and adjusting to the living with an SCI, and societal influences, which included environmental and attitudinal barriers (72).

Whiteneck et al. concurred that environmental barriers encompass more than just architectural barriers, environmental barriers encountered by PWD included: attitudes and support, services and assistance, physical and structural, policy, and work and school environmental barriers (73). As indicated in the Harris Poll survey, PWD encountered a great deal of attitudinal barriers when it comes to community involvement. When asked “Why are you not as involved in your community as you would like?” The top five reasons given by PWD were: do not feel encouraged by community organizations to participate (54%), do not have the necessary income (53%), not aware of the activities (46%). don’t have the time, and no accessible transportation. A lower percentage of people without disabilities gave the same reasons. The results of the survey are summarized in Table 1.5 (70).

Lack of social participation has the potential to lower satisfaction of life. Studies on the association of lack of social participation and life satisfaction yielded mixed results. Life satisfaction is a measurement to assess QOL based on the subjective appraisal of the individual’s current life situation. Life satisfaction can be assessed specific to a particular domain of life (e.g. social participation, work, family) or globally (74). A study examining longitudinal changes in community reintegration among people aging with SCI found there was a general decline in mobility, occupation, and social integration

among the participants. The authors concluded there was a significant relationship between life satisfaction and community integration (75). Another study assessed the effects of age across a variety of outcome domains following SCI found similar results; there was a significant linear decline with age for overall life satisfaction in the area of social integration (76). Studies among adults with pediatric onset SCI provided supportive findings. A study investigating domain-specific satisfaction in adults with pediatric-onset SCI found the primary predictive factors of life satisfaction were in the area of participation. The authors also reported social, recreational, job, and dating opportunities were moderately associated with life satisfaction (77). Another study with similar population, adults who had pediatric SCI, also found life satisfaction to be associated with social/recreational opportunities (78). However, a study analyzing the correlates of life satisfaction for ISCI from 1 to 20 years post injury concluded the effects of life satisfaction on social participation, health, and other aspects of life need further study (79).

So far, only a few studies examined the impact of wheelchair use on QOL among ISCI. However, none of these studies measured the impact of wheelchair use on QOL outcomes such as social participation, environmental barriers, and life satisfaction. Furthermore, these studies only measured the impact of wheelchair intervention and use only one kind of wheelchair as intervention. For example, a study conducted by Davies et al investigated the effect of providing power indoor/outdoor wheelchair to a cohort of individuals with severe disability; the authors found that provision of power indoor/outdoor wheelchairs significantly increased mobility and QOL among participants (51). Another study examining wheelchair use among non-ambulatory nursing home

residents concluded that improving wheelchair skills and making wheelchairs more “user friendly” could result in higher degree of independence, freedom of movement, and QOL (80). Boninger et al found providing wheelchairs with adjustable axle position can result in better median nerve function (39). None of these studies, however, take into account the impact of the differences in wheelchair design or the use of different wheelchair type on QOL.

1.1.7 National Model Spinal Cord Injury Systems

Categorical care of SCI was introduced concurrently in the United Kingdom and the United States during World War II. Based on this concept, ISCI were treated at special medical care units, which provided extensive medical and rehabilitative services. In the late 1960s, Dr. John S. Young took the concept of categorical care one step further and developed the visionary concept of comprehensive coordinated centers of care for ISCI. Dr. Young successfully advocated the Rehabilitation Services Administration (RSA) to fund a national demonstration project at the Good Samaritan Hospital in Phoenix to carry out his visionary concept. The success of this first demonstration project convinced the RSA to provide additional funding to develop what is known today as the NMSCIS (18).

Today, the NMSCIS is a consortium of 16 (funding cycle 2000-2005) nationally renowned centers of excellence specializing in the treatment of spinal cord injury. The NMSCIS is funded by the National Institute of Disability and Rehabilitation Research (NIDRR) of the Department of Education and is part of NIDRR’s statutory programs. The function of each model center comprises four critical components: to provide

comprehensive continuum of care, to conduct research development, to make contributions to a national database, and to disseminate findings and educate professionals in spinal cord injury medicine.

Collectively, the NMSCIS contributes to the largest database on traumatic spinal cord injury in the world, and captures information on approximately 13% of new traumatic spinal cord injury cases in the U.S. Since its inception in 1973, 25 model centers have made contributions to this database. Currently, the database contains longitudinal information on approximately 31,000 ITSCI; information includes demographic, injury severity, medical complications, surgical procedures, types and amounts of therapy, length of stay, charges, and both short-term and long-term treatment outcomes. The NMSCIS database is maintained by the NSCISC at the University of Alabama at Birmingham (17). Notably absent from the NMSCIS database is information on AT such as wheelchair use.

1.2 PURPOSE

To our knowledge, this is the first study examining the standard of care for providing wheelchair to ISC, factors associated with wheelchair use, and the impact on QOL among ISCI. One of the devastating impacts of traumatic SCI is the loss of function. Wheelchair use has the potential to increase function and improve QOL for individuals with mobility impairments. However, the use of wheelchairs also poses significant risk for the users. Long-term wheelchair use has been associated with a high prevalence of upper extremity impairment and pain. Improving wheelchair propulsion technique and wheelchair design have been shown to be potential remedies for

mitigating or reducing pain associated with wheelchair use, thus increasing QOL.

Because of the lack of data, currently, there is no comprehensive or systemic study on the impact of wheelchair use on the NMSCIS population.

The current study proposes to develop and administer the Assistive Technology Survey (Appendix) to examine the standard of care for wheelchair provision within the NMSCIS. Based on this standard of care, the profile and characteristics of wheelchair users will be explored. Analyses will be conducted to determine if disparity exists among NMSCIS wheelchair users from different socioeconomic backgrounds. Lastly, this study will examine the impact of wheelchair use on QOL in terms of social participation, environmental barriers, and life satisfaction.

We believe the findings of this study will add new knowledge to the field of spinal cord injury rehabilitation. Health care providers, AT vendors, and rehabilitation professionals will be better informed about the standard of care within the NMSCIS to ensure equitable access to appropriate wheelchair technology. Policy makers, third-party payers, consumer advocates, and AT service agencies will be guided to develop policies to eliminate access barriers. Consumers will benefit by the improved standard of care and equitable access to wheelchair technology.

1.3 REFERENCES

1. National Library of Medicine and the National Institute of Health. Medical Encyclopedia: spinal cord trauma. [cited June 22, 2004]. Available from URL: <http://www.nlm.nih.gov/medlineplus/ency/article/001066.htm>
2. Jackson AB. Secondary conditions of Spinal Cord Injury; 2000. [Cited August 1, 2004]. Available from: <http://www.spinalcord.uab.edu/show.asp?durki=32106&site=1021&return=21611>
3. Paralyzed Veterans of America Michigan Chapter. About MPVA; nd. [Cited August 1, 2004]. Available from: <http://comnet.org/mpva/InformationPVA.html>
4. Spinal Cord Injury Information Network. Facts and figures at a glance; December 2003. [Cited August 1, 2004]. Available from: <http://www.spinalcord.uab.edu/show.asp?durki=21446>
5. Cooper RA. Wheelchair selection and configuration. New York: Demos Medical Publishing, Inc.;1998.
6. Cooper RA, Cooper R. Trends and Issues in Wheeled Mobility Technologies. Nd. [Cited August 1, 2004]. Available from: [http://www.ap.buffalo.edu/idea/space%20workshop/Papers/WEB%20-%20Trends_Iss_WC%20\(Cooper\).htm](http://www.ap.buffalo.edu/idea/space%20workshop/Papers/WEB%20-%20Trends_Iss_WC%20(Cooper).htm)
7. Fitzgerald SG, Cooper RA, Boninger ML, Rentschler AJ. Comparison of fatigue life for 3 types of manual wheelchairs. Arch Phys Med Rehabil 2001;82:148-8.
8. Rogers H, Berman S, Falls D, Jaser J.A comparison of functional mobility in standard vs. ultralight wheelchairs as measured by performance on a community obstacle course. Disabil Rehabil. 2003 Oct 7;25(19):1083-8.
9. Scherer MJ. The change in emphasis from people to person: introduction to the special issue on assistive technology. Disability and Rehabilitation 2002;24:1-4.
10. Kirby RL, Ackroyd-Stolarz SA, Brown MG, Kirkland SA, MacLeod DA. Wheelchair-related accidents caused by tips and falls among noninstitutionalized users of manually propelled wheelchairs in Nova Scotia. Am J Phys Med Rehabil. 1994 Sep-Oct;73(5):319-30.
11. The American Academy of Physical Medicine and Rehabilitation and The Foundation for Physical Medicine and Rehabilitation. Access to assistive technologies: improving health and well-being for people with disabilities. Chicago: AAPM&R and Foundation for PM&R; 2003.
12. Healthy People 2010. Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed. Chapter 6.11. Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services.
13. Bingham SC, Beatty PW. Rates of access to assistive equipment and medical rehabilitation services among people with disabilities. Disabil Rehabil. 2003 May 6;25(9):487-90.
14. Parette HP, VanBiervliet A, Hourcade JJ. Family-centered decision making in assistive technology. Journal of Special Education Technology 2000;15(1):45-55.

15. O'Day BL, Corcoran PJ. Assistive technology: problems and policy alternatives. *Arch Phys Med Rehabil* 1994;75:1165-9.
16. Pape TL, Kim J, Weiner B. The shaping of individual meanings assigned to assistive technology: a review of personal factors.
17. DeVivo MJ, Go BA, Jackson AB. Overview of the national spinal cord injury statistical center database. *J Spinal Cord Med* 2002;25(4):335-8.
18. Thomas PJ. The model spinal cord injury concept: development and implementation. In, Stover SL, DeLisa JA, Whiteneck GG. *Spinal cord injury: clinical outcomes from the model systems*. Maryland: Aspen Publishers, Inc.;1995.
19. Dawodu ST. Spinal cord injury: Definition, epidemiology, pathophysiology; August 24, 2001. [Cited August 1, 2004]. Available from URL: <http://www.emedicine.com/pmr/topic182.htm>
20. McDonald JW, Sadowsky C. Spinal cord injury. *Lancet*. 2002 Feb 2;359(9304):417-25.
21. Burns SP, Weaver FM, Parada JP, Evans CT, Chang H, Hampton RY, Kapur V. Management of community-acquired pneumonia in persons with spinal cord injury. *Spinal Cord*. 2004 Mar 23
22. Reitz A, Tobe V, Knapp PA, Schurch B. Impact of spinal cord injury on sexual health and quality of life. *Int J Impot Res*. 2004 Apr;16(2):167-74
23. Federal Register. Vol. 68, No. 26, February 7, 2003, pp. 6456-6458.
24. Routhier F, Vincent C, Desrosiers J, Nadeau S. Mobility of wheelchair users: a proposed performance assessment framework. *Disabil Rehabil*. 2003 Jan 7;25(1):19-34.
25. Shapiro JP. *No pity: people with disabilities forging a new civil rights movement*. New York: Times Books;1993.
26. Rogers H, Berman S, Falls D, Jaser J. A comparison of functional mobility in standard vs. ultralight wheelchairs as measured by performance on a community obstacle course. *Disabil Rehabil*. 2003 Oct 7;25(19):1083-8.
27. Beekman CE, Miller-Porter L, Schoneberger M. Energy cost of propulsion in standard and ultralight wheelchairs in people with spinal cord injuries. *Phys Ther*. 1999 Feb;79(2):146-58.
28. Boninger ML, Baldwin M, Cooper RA, Koontz A, Chan L. Manual wheelchair pushrim biomechanics and axle position. *Arch Phys Med Rehabil*. 2000 May;81(5):608-13.
29. Brienza D, Angelo J, Henry K. Consumer participation in identifying research and development priorities for power wheelchair input devices and controllers. *Assist Technol*. 1995;7(1):55-62.
30. Gaal RP, Rebholtz N, Hotchkiss RD, Pfaelzer PF. Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *J Rehabil Res Dev*. 1997 Jan;34(1):58-71.
31. Fass MV, Cooper RA, Fitzgerald SG, Schmeler M, Boninger ML, Algood SD, Ammer WA, Rentschler AJ, Duncan J. Durability, value, and reliability of selected electric powered wheelchairs. *Arch Phys Med Rehabil*. 2004 May;85(5):805-14.

32. Cooper RA, Boninger ML, Rentschler A. Evaluation of selected ultralight manual wheelchairs using ANSI/RESNA standards. *Arch Phys Med Rehabil.* 1999 Apr;80(4):462-7.
33. ABLEDATA. Fact Sheet #23-Manual Wheelchairs; July 1994. [August 1, 2004]. Available from: <http://www.abledata.com/text2/manwhch.htm>
34. Cooper RA, Gonzalez J, Lawrence B, Renschler A, Boninger ML, VanSickle DP. Performance of selected lightweight wheelchairs on ANSI/RESNA tests. American National Standards Institute-Rehabilitation Engineering and Assistive Technology Society of North America. *Arch Phys Med Rehabil.* 1997 Oct;78(10):1138-44.
35. DiGiovine MM, Cooper RA, Boninger ML, Lawrence BM, VanSickle DP, Rentschler AJ. User assessment of manual wheelchair ride comfort and ergonomics. *Arch Phys Med Rehabil.* 2000 Apr;81(4):490-4.
36. Karp G. *Life on wheels for the active wheelchair user.* Sebastopol, CA: O'Reilly & Associates, Inc.; 1999.
37. Fay BT, Boninger ML. The science behind mobility devices for individuals with multiple sclerosis. *Med Eng Phys.* 2002 Jul;24(6):375-83.
38. Scherer MJ. The change in emphasis from people to person: introduction to the special issue on assistive technology. *Disability and Rehabilitation* 2002;24:1-4.
39. McNeil, J. M. (1993). *Americans with disabilities: 1991-92.* Washington, DC: U.S. Department of Commerce, Bureau of the Census.
40. LaPlante, M. P. (1993). *Disability, health insurance coverage, and utilization of acute health services in the United States.* Washington, DC: U.S. Department of Health and Human Services.
41. Phillips B, Zhao H. Predictors of assistive technology abandonment. *Assist Technol.* 1993;5(1):36-45.
42. Parette HP, Brotherson MJ. Family-centered and culturally responsive assistive technology decision making. *Infants and Young Children.* 2004;17(4):355-367.
43. Judge S. Family-centered assistive technology assessment and intervention practices for early intervention. *Infants and Young Children.* 2002;15(1):60-68.
44. Anderson JM. Ethnicity and illness experience: Ideological structures and the health care delivery system. *Social Science and Medicine* 1986;22:1277-1283.
45. Carrasquillo O, Lantigua R, Shea S. Differences in functional status of Hispanic versus non-Hispanic White elders: data from the medical expenditure panel survey. *Journal of Aging and Health.* 2000;12:342-361.
46. Tomita M, Mann W, Fraas F, Burns L. Racial differences of frail elders in assistive technology. *Assistive Technology.* 1997;9:140-151.
47. Ray C, West J. Coping with spinal cord injury. *Paraplegia.* 1984 Aug;22(4):249-59.
48. Donnelly C, Eng JJ, Hall J, Alford L, Giachino R, Norton K, Kerr DS. Client-centred assessment and the identification of meaningful treatment goals for individuals with a spinal cord injury. *Spinal Cord.* 2004 May;42(5):302-7.
49. Bottos M, Bolcati C, Sciuto L, Ruggeri C, Feliciangeli A. Powered wheelchairs and independence in young children with tetraplegia. *Dev Med Child Neurol.* 2001 Nov;43(11):769-77.

50. Brandt A, Iwarsson S, Stahle A. Older people's use of powered wheelchairs for activity and participation. *J Rehabil Med.* 2004 Mar;36(2):70-7.
51. Davies A, De Souza LH, Frank AO. Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs. *Disabil Rehabil.* 2003 Mar 18;25(6):286-90.
52. Nichols PJ, Norman PA, Ennis JR. Wheelchair user's shoulder? Shoulder pain in patients with spinal cord lesions. *Scand J Rehabil Med.* 1979;11(1):29-32.
53. Subbarao JV, Klopstein J, Turpin R. Prevalence and impact of wrist and shoulder pain in patients with spinal cord injury. *J Spinal Cord Med.* 1995 Jan;18(1):9-13.
54. Lal S. Premature degenerative shoulder changes in spinal cord injury patients. *Spinal Cord.* 1998 Mar;36(3):186-9.
55. Dalyan M, Cardenas DD, Gerard B. Upper extremity pain after spinal cord injury. *Spinal Cord.* 1999 Mar;37(3):191-5.
56. Dyson-Hudson TA, Kirshblum SC. Shoulder pain in chronic spinal cord injury, Part I: Epidemiology, etiology, and pathomechanics. *J Spinal Cord Med.* 2004;27(1):4-17.
57. Boninger ML, Souza AL, Cooper RA, Fitzgerald SG, Koontz AM, Fay BT. Propulsion patterns and pushrim biomechanics in manual wheelchair propulsion. *Arch Phys Med Rehabil.* 2002 May;83(5):718-23.
58. Boninger ML, Impink BG, Cooper RA, Koontz AM. Relation between median and ulnar nerve function and wrist kinematics during wheelchair propulsion. *Arch Phys Med Rehabil.* 2004 Jul;85(7):1141-5.
59. de Groot S, Veeger HE, Hollander AP, van der Woude LH. Effect of wheelchair stroke pattern on mechanical efficiency. *Am J Phys Med Rehabil.* 2004 Aug;83(8):640-9.
60. Boninger ML, Dicianno BE, Cooper RA, Towers JD, Koontz AM, Souza AL. Shoulder magnetic resonance imaging abnormalities, wheelchair propulsion, and gender. *Arch Phys Med Rehabil.* 2003 Nov;84(11):1615-20.
61. Kulig K, Newsam CJ, Mulroy SJ, Rao S, Gronley JK, Bontrager EL, Perry J. The effect of level of spinal cord injury on shoulder joint kinetics during manual wheelchair propulsion. *Clin Biomech (Bristol, Avon).* 2001 Nov;16(9):744-51.
62. Lacoste M, Weiss-Lambrou R, Allard M, Dansereau J. Powered tilt/recline systems: why and how are they used? *Assist Technol.* 2003 Summer;15(1):58-68.
63. Wei SH, Huang S, Jiang CJ, Chiu JC. Wrist kinematic characterization of wheelchair propulsion in various seating positions: implication to wrist pain. *Clin Biomech (Bristol, Avon).* 2003 Jul;18(6):S46-52.
64. Van Der Woude LH, Van Koningsbruggen CM, Kroes AL, Kingma I. Effect of push handle height on net moments and forces on the musculoskeletal system during standardized wheelchair pushing tasks. *Prosthet Orthot Int.* 1995 Dec;19(3):188-201.
65. Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Predictors of life satisfaction: a spinal cord injury cohort study. *Arch Phys Med Rehabil.* 2002 Apr;83(4):555-61.

66. Tate DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. *Arch Phys Med Rehabil.* 2002 Dec;83(12 Suppl 2):S18-25.
67. Dijkers MP, Yavuzer G, Ergin S, Weitzenkamp D, Whiteneck GG. A tale of two countries: environmental impacts on social participation after spinal cord injury. *Spinal Cord.* 2002 Jul;40(7):351-62.
68. Hoenig H, Landerman LR, Shipp KM, George L. Activity restriction among wheelchair users. *J Am Geriatr Soc.* 2003 Sep;51(9):1244-51.
69. Centers for Medicare and Medicaid Services. Table 5: Personal Health Care Expenditures by Type of Service, by Region and State: United States, 1998. [Cited August 1, 2004]. Available from URL: <http://www.cms.hhs.gov/statistics/nhe/state-trends/t5.asp>
70. Humphrey Taylor. Many people with disabilities feel isolated, left out of their communities and would like to participate more. *The Harris Poll: #34*, July 05, 2000.
71. Schopp LH, Sanford TC, Hagglund KJ, Gay JW, Coatney MA. Removing service barriers for women with physical disabilities: promoting accessibility in the gynecologic care setting. *J Midwifery Womens Health.* 2002 Mar-Apr;47(2):74-9.
72. Levins SM, Redenbach DM, Dyck I. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study. *Phys Ther.* 2004 Jun;84(6):496-509.
73. Whiteneck GG, Harrison-Felix CL, Mellick DC, Brooks Ca C, Charlifue SB, Gerhart KA. Quantifying environmental factors: A measure of physical, attitudinal, service, productivity, and policy barriers. *Arch Phys Med Rehabil.* 2004 Aug;85(8):1324-35.
74. Cusick CP, Gerhart KA, Mellick D, Breese P, Towle V, Whiteneck GG. Evaluation of the home and community-based services brain injury Medicaid Waiver Programme in Colorado. *Brain Inj.* 2003 Nov;17(11):931-45.
75. Charlifue S, Gerhart K. Changing psychosocial morbidity in people aging with spinal cord injury. *NeuroRehabilitation.* 2004;19(1):15-23.
76. Charlifue S, Gerhart K. Community integration in spinal cord injury of long duration. *NeuroRehabilitation.* 2004;19(2):91-101.
77. Anderson CJ, Vogel LC. Domain-specific satisfaction in adults with pediatric-onset spinal cord injuries. *Spinal Cord.* 2003 Dec;41(12):684-91.
78. Vogel LC, Klaas SJ, Lubicky JP, Anderson CJ. Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Arch Phys Med Rehabil.* 1998 Dec;79(12):1496-503.
79. Dijkers MP. Correlates of life satisfaction among persons with spinal cord injury. *Arch Phys Med Rehabil.* 1999 Aug;80(8):867-76.
80. Simmons SF, Schnelle JF, MacRae PG, Ouslander JG. Wheelchairs as mobility restraints: predictors of wheelchair activity in nonambulatory nursing home residents. *J Am Geriatr Soc.* 1995 Apr;43(4):384-8.
81. National Model Spinal Cord Injury Model System. Data collection syllabus 2000-2005. Alabama: National Spinal Cord Injury Statistics Center; 2004.

Table 1-1 Spinal cord injury treatments

Medical	Surgical	Rehabilitative
Spinal stabilisation: spine immobilisation during transport and resuscitation	Internal fusion/instrumentation; external orthoses	
Cardiovascular: haemodynamic instability; autonomic dysfunction; thromboembolism		Management of chronic haemodynamic issues; autonomic dysreflexia
Respiratory system: respiratory failure; atelectasis; pneumonia; vent-dependent care	Tracheostomy	Preventive respiratory care; respiratory conditioning programme
Gastrointestinal system: ileus; impaction, constipation; gastric and duodenal ulcers; GORD, cholelithiasis		Establish predictable bowel continence programme; preventive gastrointestinal care
Genitourinary system: urinary-tract infection; hydronephrosis; cycto/nephroethiasis	Urinary system augmentation; diversion procedures; penile implants; lithotripsy; sphincterotomy	Programme to establish bladder continence; preventive genitourinary care; sexual dysfunction programme
Dermatological: pressure ulcers	Pressure ulcer repair	Establish skin integrity programme; prevent and manage pressure ulcers
Musculoskeletal system: osteoporosis; heterotopic ossification; fractures; overuse syndromes; acute and chronic pain	Treatment of delayed neurological and spine complications: syringomyelia; focal nerve entrapments; central pain, spasticity; spinal instability; implantation of intrathecal drug-delivery systems	Prevent/manage musculoskeletal complications: contractures; spasticity; postural abnormalities; skeletal deformities; long-term intrathecal drug treatment
		Functional retraining in self-care; mobility; psychosocial adaptation; vocational and recreational skills; adaptive equipment and orthotic devices
GORD=gastro-oesophageal reflux disease.		

Source: McDonald JW, Sadowsky C. Spinal-cord Injury. Lancet. 2002 Feb 2;359(9304):417-25

Table 1-2 Average yearly expenses and estimated life time costs by age and injury

Average Yearly Expenses (in 2000 dollars)		
Severity of Injury	First Year	Each Subsequent Year
High Tetraplegia (C1-C4)	\$626,588	\$112,237
Low Tetraplegia (C5-C8)	\$404,653	\$45,975
Paraplegia	\$228,955	\$23,297
Incomplete Motor Functional at any Level	\$184,662	\$12,941

*These figures do not include any indirect costs such as losses in wages, fringe benefits and productivity which average \$52,915 per year but vary substantially based on education, severity of injury and pre-injury employment history

Table 1-3 Examples of issues related to funding for a wheelchair

Individual's Status	Wheelchair Characteristics	Payment Options
Is the wheelchair medically necessary?	How much does the wheelchair cost?	Preferred Provider Insurance
How old is the current wheelchair?	How long should the wheelchair be usable?	Health Maintenance Organization
What is the condition of the current wheelchair?	How much will maintenance cost?	Education assistance Program
Is the person of employment age?	What is availability?	Vocational Rehabilitation Program
Is the person of school age?	Will use of the wheelchair precipitate other expenses?	U.S. Department of Veterans Affairs
Is the person of retirement age?	Do other assistive devices exist that will better meet mobility needs?	Medicare
Is the person a military veteran?	Will use of the wheelchair meet criteria specified by third-party payer?	Self-pay
Is the person currently employed?	Will use of the wheelchair meet the user's mobility needs?	Medicaid
Does the person's employer provide medical insurance?	Is there a trade-in market for the wheelchair?	Financing
Can the person afford to purchase the wheelchair?		Personal or Employer Tax Incentives
Can the person afford to maintain the wheelchair?		Employer ADA Accommodation Program
Are there tax incentives for the employer or individual?		
How convenient is the payment plan for the wheelchair?		

Table 1-4 Six indicators of lack of social participation for people with disabilities

	All adults (%)		Degree of Disability (%)	
	With Disabilities	Without Disabilities	Slight and Moderate	Very and Somewhat
Not at all involved in the community	35	21	29	40
Not at all satisfied with community involvement	23	11	19	27
Not a valuable or contributing member of the community	31	21	26	35
Isolated from others	46	23	41	51
Left out of things	48	32	50	46
Not regularly invited to give opinion on community issues	65	54	59	72

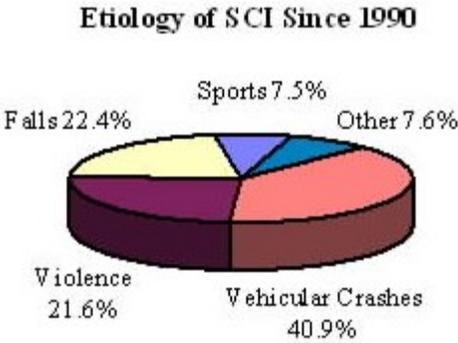
Source: Humphrey Taylor. Many people with disabilities feel isolated, left out of their communities and would like to participate more. The Harris Poll: #34, July 05, 2000.

Table 1-5 Top five reasons cited for not being involved with community

	All Adults		Degree of Disability	
	With Disabilities	Without Disabilities	Slight and Moderate	Very and Somewhat
Community Organizations have not encouraged or invited me	54	35	44	64
I don't have the income needed to participate	53	36	56	50
I am not aware of what activities exist	46	39	52	41
I don't have the time	34	76	55	15
No available or accessible transportation	18	14	11	24

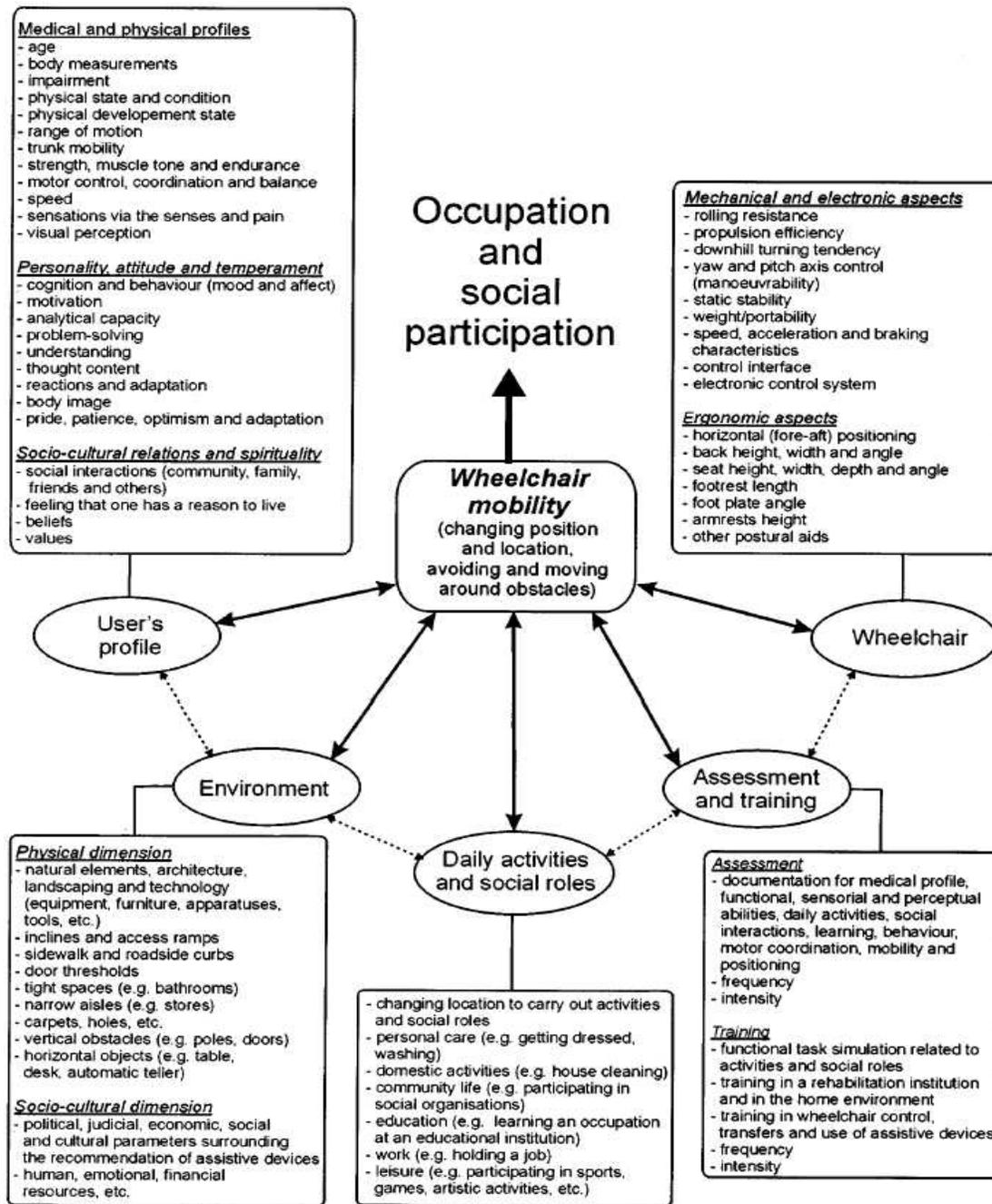
Source: Humphrey Taylor. Many people with disabilities feel isolated, left out of their communities and would like to participate more. The Harris Poll: #34, July 05, 2000.

Figure 1-1 Leading etiologies of traumatic spinal cord injury



Source: National Spinal Cord Injury Statistic Center, December 2003.

Figure 1-2 Relational model of wheelchair mobility



Source: Routhier F, Vincent C, Desrosiers J, Nadeau S. Mobility of wheelchair users: a proposed performance assessment framework. Disability and Rehabilitation, 2003; 25(1),19-34.

1.4 APPENDIX

Assistive Technology Survey

Identifiers

V100 (center code): _____

V101 (subject ID#): _____

V200 (year follow up): _____

Wheelchair Related Variables

1) Do you use a wheelchair or scooter over 40 hours/week?

Yes No – if no skip to question 2

Please answer the follow question for the wheelchair or scooter you use the most

1a) Type of Wheelchair Manual Power
 Scooter Power Assist
 Other: _____

1b) Make of Wheelchair _____

1c) Model of Wheelchair _____

1d) What funding source paid for the chair? (check all that apply)

Medicare Medicaid Self-pay VA
State Vocational Office Private Insurance Worker's
Comp Other _____

1e) Does the wheelchair have (check all that apply)

Tilt-in-space Recline Standing Seat
elevation Leg elevation

1f) Make of cushion _____

1g) Model of cushion _____

1h) Aside from the wheelchair listed above, do you own any other wheelchair you currently use?

(Put a number representing the number of working devices you have next to each one)

___ Manual ___ Power ___ Scooter ___ Other: _____

Internet Access and Computer Information

2) How often do you access the Internet?

Daily Weekly Monthly Never

2a) Rank the items you most use the Internet for (1 = most, do not rank items that you don't use)

___ Employment/vocation information
___ Disability/ Health information ___ Email
___ Chat rooms ___ Games ___ Shopping ___
Other (specify) _____

3) Do you own a computer? Yes No

4) Do you have Internet access at home? Yes No

4a) If yes, what type? phone (modem) high speed

5) Do you own a computer access device? Yes No

5a) if yes, list _____

Other Technology

6) Do you own a modified vehicle? Yes No

6a) If yes, do you drive the vehicle? Yes No

6b) If yes do you drive from your wheelchair? Yes No

7) Do you own a cell phone? (Yes (No

8) What exercise technology do you use for at least 15 minutes once a week?

(None (Electrical stimulation
(Standing device (Other: _____

2.0 Demographic and Socioeconomic Factors Associated with Disparity in Wheelchair Customizability Among Individuals with Traumatic Spinal Cord Injury

Peter Cody Hunt, M.P.H.^{1,2}, Michael L. Boninger, M.D.^{1,2,3,4,5}, Rory A. Cooper, Ph.D.^{1,2,3,4}, Ross D. Zafonte, D.O.^{1,2}, Shirley G. Fitzgerald, Ph.D.^{1,2,3}, Mark R. Schmeler, MS, OTR/L, ATP^{2,5}

¹Human Engineering Research Laboratories of the Department of Physical Medicine and Rehabilitation, School of Medicine, University of Pittsburgh, Pittsburgh, PA;

²Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, PA;

³VA Pittsburgh Healthcare Systems, Pittsburgh, PA;

⁴Department of Bioengineering, School of Engineering, University of Pittsburgh, Pittsburgh, PA.

⁵The Center for Assistive Technology, UPMC Health System, Pittsburgh, PA

ADDRESS CORRESPONDENCE TO:
Michael L. Boninger, M.D.
Professor and Vice Chair for Research
Department of Physical Medicine and Rehabilitation
3471 Fifth Avenue, Suite 201
Pittsburgh, PA 15213
TEL: 412-648-6654
FAX: 412-692-4110
Email: boninger@pitt.edu

Acknowledgements: This work was supported by funds from the National Institute on Disability and Rehabilitation Research in the Office of Special Education and Rehabilitation Services in the U.S. Department of Education (H133N000019).

ABSTRACT

Objectives: To determine if a standard of care for wheelchair provision exists within the participating centers and if there is disparity in wheelchair customizability amongst the study sample.

Design: Convenience Sample Survey

Settings: 13 National Spinal Cord Injury Model Systems that provide comprehensive rehabilitation for individuals with traumatic spinal cord injury (ITSCI) and are part of the national database funded through the Department of Education.

Participants: 412 ISCI who use wheelchair over 40 hours per week.

Method: Survey information was obtained from subjects via telephone and in person interviews and from the national database. Collected information included age, race, education, level of injury, and wheelchair funding source.

Main Outcome Measures: Number and type (manual or power) of wheelchairs.

Wheelchair customizability as defined by design features (e.g. adjustable axle position, programmable controls).

Results: 97% of manual wheelchair users and 54% of power wheelchair users had customizable wheelchairs. No power wheelchair user received a wheelchair without programmable controls. Minorities with low socioeconomic backgrounds (low income, Medicaid/Medicare recipients, less educated) were more likely to have standard manual and standard programmable power wheelchairs. Older individuals were also more likely to have standard programmable power wheelchairs.

Conclusion: The standard of care for manual wheelchair users with spinal cord injury is lightweight and customizable. The standard of care for power wheelchairs users has

programmable controls. Unfortunately socioeconomically disadvantaged individuals were less likely to receive customizable wheelchairs.

Key Words: Wheelchair, spinal cord injury, demographic, socioeconomic.

2.1 INTRODUCTION

Wheelchairs are an integral part of the lives of individuals with spinal cord injury (ISCI). The ability of ISCI to successfully reintegrate into society and regain independence depends much on access to appropriate and adequate assistive technology, such as wheelchairs (1,2). Therefore, providing appropriate wheelchairs with design features that are customized to the users' environment, needs, and preference is an important part of successful rehabilitation (3). However, not all wheelchairs are alike. Wheelchairs differ in design, features, weight, durability, and cost. The traditional depot manual wheelchairs are found to be inappropriate for personal use in community settings (4). Boninger et al. argued that manual wheelchair users should only use customizable, very lightweight wheelchairs because of the risk for upper limb injuries (5,7). Other studies also found customizable manual wheelchairs to be more durable (5), cost-effective over the life of the chair (8), and comfortable for the users (9).

Power wheelchair users are also at risk of having similar deleterious conditions such as upper limb (10) and neck pain (11). Individuals with tetraplegia have been found to rapidly develop scoliosis and kyphosis (12) leading the authors to recommend customizable seating for this group. Durability of power wheelchairs also varies considerably (13). Furthermore, wheelchair failures can lead to injuries (14). Improved and alternative design and customizable wheelchairs can provide reasonable preventive measures against deleterious conditions while improving function (1,15,16).

There are potential socioeconomic barriers that prevent individuals from obtaining more appropriate and customizable wheelchairs. In its 1993 landmark study,

the National Council on Disability (NCD) concluded “There are significant groups of individuals with disabilities who remain un-served or underserved by existing public and private programs that have financing available for assistive technology.”(2) These findings are supported by subsequent studies that found extrinsic factors such as racism, prejudice, equity of resources, and professional bias (17) as well as intrinsic barriers, such as different cultural view and lack of knowledge of assistive technology (18) can negatively impact the ability to obtain appropriate technology such as wheelchairs.

Furthermore, rising health care costs and the lack of funding led to pressures to provide low cost interventions. In some instances, this also led to fraud and abuse by providers and denials of needed equipment by third-party payers (19). This in turn resulted in policies and practice trends that can impact the users’ ability to obtain appropriate wheelchairs (20). In the face of these pressures it is important to establish if a standard of care exists, as this can be used to argue on behalf of better technology. Standard of care is technically a legal definition and is define as “that (care) which a reasonable and prudent practitioner would do under the same or similar circumstances” (21).

The goal of the current study is to determine if there is a standard of care for providing wheelchairs to individuals with traumatic spinal cord injury (ITSCI) across a multi-site sample. Although no clear definition of standard of care existed, we posited that if over 90% of wheelchair users received wheelchairs with customizable features it could be considered a standard of care. In addition, we wanted to investigate if disparity exists in wheelchair customizability amongst our sample. We hypothesized

that individuals from minority backgrounds and with low socioeconomic status would more likely to receive standard wheelchairs and would be less likely to have an additional wheelchair.

2.2 METHODOLOGY

2.2.1 Subject Recruitment

All subjects were recruited from The National Spinal Cord Injury Model Systems (NSCIMS). The NSCIMS consists of 16 centers providing acute and rehabilitative care for ITSCI. The NSCIMS are funded by the Department of Education and maintain the world's largest database on the demographic, socioeconomic, and treatment outcomes for ITSCI. To date, the NSCIMS database contains longitudinal data on approximately 31,000 individuals and captures an estimated 13% of new SCI cases in the United States (22). In order to be included in the database subjects must receive rehabilitative care within designated NSCIMS facilities within one year of injury, must have a clinically discernible degree of neurologic (spinal cord) impairment following a traumatic event, must sign informed consent, and must be a citizen of the United States (23). To qualify for this study, subjects had to report using a wheelchair at least 40 hours per week and be at least one year post SCI. Thirteen of the 16 centers volunteered to collect data related to wheelchairs and assistive technology. Data collectors from the 13 centers contacted and administered the survey to eligible subjects from January 2003 to June 2003 as part of annual follow up.

2.2.2 Assistive Technology Survey (ATS)

The ATS is a one-page questionnaire, developed by consensus of center directors at a NSCIMS meeting. The survey includes questions on wheelchairs and on other assistive technology such as cushions and computers. Our study focuses only on wheelchair variables. The wheelchair variables collected included manufacturer and model of primary wheelchair. Information on wheelchair funding sources (i.e. Medicare, Medicaid, private health insurance, worker's compensation) and wheelchair features (tilt-in-space, recline, standing, seat elevation, and leg elevation) were also recorded. Aside from their primary wheelchair, subjects were asked whether they owned any additional wheelchairs.

2.2.3 Data Management

Data were submitted via FTP, e-mail, fax, or postal mail. The University of Pittsburgh Model Center on Spinal Cord Injury and the National Spinal Cord Injury Statistical Center at the University of Birmingham served as central data collection sites. No personal identification information of subjects was transmitted. Demographic, socioeconomic, and post injury status of wheelchair users were culled from the NSCIMS database. Race, gender, date of birth, and date and level of spinal cord injury were determined from data collected during the initial phase of rehabilitation. Employment status, income, and level of education were obtained from the most recent follow up data.

2.2.4 Classification of Wheelchairs

We reviewed manual wheelchair manufacturer and model, and classified wheelchairs as customizable or standard. Customizable wheelchairs weighed less than 14 kg (30lbs) and had an adjustable axle position. These wheelchairs also had better components such as bearings and additional adjustability (6), more durable (7) and more cost-effective over the lifetime of the wheelchair (8). Wheelchairs did not have these features were classified as standard wheelchairs. In general, the customizable wheelchairs are equivalent to K0005 wheelchairs based on the Health Care Common Procedure Coding System of the Centers for Medicare and Medicaid Services (CMS) in the United States (24). Standard wheelchairs are in the K0001 and K0004 category.

Power wheelchairs were classified based on characteristics of the frame or power base, programmable controls, and customizable features. Wheelchair manufacturer and model were reviewed and power wheelchairs were classified into three categories. The customizable power wheelchair were power wheelchairs with programmable controls and had at least one of the following customizable features: 1) capable of accommodate an advanced seating systems such as tilt in space or standing; 2) a suspension system; or 3) a high torque motor and stronger frame. The second category was standard power wheelchairs with programmable controls. The remainder category was standard power wheelchairs. Using this classification system the majority of customizable wheelchairs with programmable controls corresponded to K0014 as defined by CMS, where as standard power wheelchairs with programmable controls corresponded to K0011, and standard power wheelchairs corresponded to K0010.

2.2.5 Data Reduction

To increase the power of this study, we recoded variables so that our sample was not divided into too many smaller groups. In terms of employment, we were most interested in individuals who were in the competitive labor market. Thus, the analysis included only the employed and unemployed categories. Students and homemakers were not included in the analysis. The race variable was compressed into two general categories, Caucasian and Minority (African American, Native American, Eskimo, Aleut, Asian, Pacific Islander, and unclassified group). The original 9 categories of level of education were reorganized into 3 groups: less than high school (8th grade or less, 9th through 11th grade); completed high school; and college graduates (Associate, Bachelor, Master, Doctorate degrees). The insurance variable was divided into 2 major categories, private and public sector health insurance. The private sector health insurance included, private health insurance companies, self-insure, and worker's compensation. The public sector insurance encompassed, Medicare, Medicaid, VA, and state vocational rehabilitation programs. Lastly, the Income variable was recoded into three categories: low income (<\$10,000), moderate income ($\$75,000 \leq X \leq \$10,000$), and high income (>\$75,000). Low income is equivalent to the U.S. national average poverty level (25).

2.2.6 Statistical Analysis

Descriptive analyses of demographic and socioeconomic factors associated with customizable wheelchair were conducted with SAS (version 8.2)^b statistical software. Chi-square tests were performed to analyze ordinal data. Fisher's Exact tests were

used for variables that had small expected cell value (less than 5 or less than 20%). Student t-tests were used to compare group means of continuous variables. The level of significance was set a priori at $p=0.05$ for all the statistical analyses.

2.3 RESULTS

2.3.1 Demographics

A total of 521 NSCIMS subjects were surveyed. Among these, 412 were classified as individuals who use wheelchair more than 40 hours per week. The average age of this cohort was 41.98 years (± 13.74). The distribution of gender was predominately male (79%). The group was comprised of 81% Caucasian and 19% Minority. Post injury-years averaged at 8.90 years (± 7.39) among all wheelchair users. The distribution of individuals with paraplegia and tetraplegia were 51% and 49% respectively. Data on manufacturer and model were incomplete and could not be included in the analysis for 134 (33 %) of wheelchair users completing the survey. Individuals with incomplete data were compared to those with complete data and found to be significantly older (44.44 [± 15.0] years versus 40.44 [± 12.8] years, $p=0.008$) and more likely to have public versus private health insurance ($p = 0.019$).

2.3.2 Socioeconomic Status

About 18% of the wheelchair users earned a combined annual income less than \$10,000, 52% earned \$10,000-\$75,000, and 29% earned \$75,000 or more. The levels of education among the group were as follow: 17% completed less than high school,

54% graduated from high school, and 29% had college and graduate degrees. A high number of individuals, 69%, were unemployed and only 31% were employed. About 59% had private sector health insurance and 41% had health insurance from the public sector. The demographic and socioeconomic characteristics of the study sample were nearly identical to that of the NMSCIS population as a whole.

2.3.3 Wheelchair Distribution

Among the 412 wheelchair users, 61% used manual wheelchairs, 38% used power wheelchairs, and 1% used scooters or power assisted wheelchairs. The majority of the manual wheelchair users, 97%, had customizable wheelchairs. Three percent used standard wheelchairs. Among the 155 power wheelchair users, the percentage of standard programmable and customizable wheelchair was similar, 46% and 54% respectively. No subject received standard power wheelchairs without programmable controls.

2.3.4 Factors Associated with Customizable Manual Wheelchairs

Comparative analyses revealed several factors that were significantly associated with standard versus customizable manual wheelchairs. The results presented in Table 2.1 indicate there was a significant difference in the demographic variable of race ($p=0.006$) and socioeconomic variables of education ($p=0.003$), health insurance ($p=0.032$), and income ($p=0.033$) between groups receiving customizable versus standard manual wheelchairs. Standard wheelchair users were more likely to be

minority, less educated, had public sector insurance, and annual combined family income below poverty level (<\$10,000). Figure 2.1 provided a graphical representation of level of education and wheelchair type.

2.3.5 Factors Associated with Customizable Power Wheelchairs

Table 2.2 depicts factors associated with the standard and customizable power wheelchairs. The two groups of power wheelchair users differed significantly in level of injury ($p=0.021$), age ($p=0.028$), education ($p=0.020$) [see figure 1], health insurance ($p=0.003$), and income ($p=0.039$). Users with standard power wheelchair were more likely to be older less educated, had paraplegia, and had public sector health insurance. Because one may expect that individuals with tetraplegia would require the functions available on customizable wheelchair, we did a secondary analysis to see if differences exist when looking only at the power wheelchair group with tetraplegia. Table 2.3 shows that individuals with tetraplegia who used customizable power wheelchairs were more likely to have achieved a higher level of education ($p=0.003$), have private health insurance ($p=0.018$), and have higher income ($p=0.001$).

2.3.6 Additional Wheelchairs

In addition to their primary wheelchair, 40% of manual wheelchair users had at least one additional wheelchair. Within this cohort, 73% had additional manual wheelchairs and 27% had additional power wheelchairs. Among power wheelchair users, 57% participants had at least one additional wheelchair. About 84% and 16%

had additional manual and power chairs respectively. Approximately 5% of all those who had additional wheelchairs had both additional manual and power wheelchairs. As seen in Table 2.4, individuals who had at least one additional wheelchair were more likely to be Caucasian ($p=0.001$), had higher income ($p < 0.001$) and private health insurance ($p=0.045$).

2.4 DISCUSSION

To our knowledge this is the first study to systematically collect information on the characteristics of wheelchairs provided to ITSCI. This study shows that there is a standard of care for wheelchair customizability across the NSCIMS. The standard of care found in this study supports previous studies that recommend manual wheelchair users with SCI be provided with lightweight customizable wheelchairs. In addition, this study indicates that power wheelchair users with SCI be provided with programmable controls and customizable features.

The standard of care found in this study is not codified in Medicare regulations that dictates wheelchair users be prescribe with standard non-customizable manual and power wheelchairs. Although this study indicates that customizable wheelchairs are being provided despite these regulations, recent efforts by the CMS to crack down on fraud have threatened the ability of Rehabilitation Technology Suppliers and Rehabilitation Professionals to obtain these customizable equipments (26). It is possible that by establishing this standard of care will help assistive technology suppliers and rehabilitation professionals better advocate for their patients.

This study also found disparity in wheelchair customizability among participants of the NSCIMS. Individuals from minority backgrounds with low socioeconomic status were more likely to receive standard wheelchairs instead of the more appropriate customizable wheelchairs. The results of this study are supported by studies on access barriers to assistive technology among socioeconomically disadvantaged population. Family of individuals from low socioeconomic backgrounds often have other pressing concerns such as food, clothing, transportation, and shelter, which make it difficult for the family to participate in the decision process of obtaining assistive technology or advocate for the need of high quality assistive technology (17,18). The lack of participation in decision-making may result in limiting the user's access to the appropriate and adequate assistive technology (3).

Furthermore, individuals with public sector insurance (Medicare/Medicaid) and low income were associated with standard wheelchairs. This finding is supported by the National Council on Disability study, which concluded federal policy barriers are responsible for the disparity in acquisition of appropriate assistive technology (20). The gap in Medicare reimbursement poses a significant financial burden on Medicare recipients with low income. Customizable wheelchairs are considerably more expensive than standard wheelchairs. Medicare reimburses only 80% of the total cost of wheelchairs, the other 20% of the cost must be assumed by the users. Individuals who cannot afford this 20% co-payment may force to choose a less expensive wheelchair in order to minimize their out-of-pocket expenses.

Among individuals who used power wheelchairs, age was also found to be associated with standard wheelchairs. One may expect older individuals to be suited

with customizable wheelchairs with programmable controls with in order to accommodate the limitation in functional ability among this population. Contrary to this expectation, the results showed that older individuals were more likely to receive standard wheelchairs with programmable controls. This may be a result of professional bias, which assumes that older individuals may not be as active as younger people; therefore, they may not need a more powerful wheelchair for daily living activities or outdoor use.

When comparing power wheelchair users with paraplegia and tetraplegia, there was a significant difference in wheelchair customizability between these two populations. Individuals with paraplegia have higher functional capacity compare to individuals with tetraplegia; thus, it is intuitive that they may not need customizable power wheelchairs. The results of the current study confirmed this assumption. On the hand, individuals with tetraplegia who have lower functional capacity may expect to use customizable power wheelchairs. The results of the study showed that higher percentage of individuals with tetraplegia indeed received customizable power wheelchairs. Further analysis also indicated that individuals with tetraplegia who used standard power wheelchairs with programmable controls were associated with low socioeconomic status. Therefore, overall, level of injury might not have impacted the disparity in wheelchair customizability among power wheelchair users.

The results also showed that individuals in the higher socioeconomic stratum (Caucasian, higher income, and private health insurance) were more likely to own additional wheelchairs. Possession of additional wheelchairs is a potential solution to the occasional malfunction of wheelchairs. Martin et al showed that wheelchairs require

frequent repair (27). This is particularly problematic for older and more frequently used wheelchairs. For individuals without back up wheelchairs, their daily life can be severely hampered when their only wheelchair breaks down.

With regard to the results of the current study, a note worth mentioning is the fact that the current study included only a convenient sample of subject who was eligible for follow up interview during the six-month study period. These subjects were exclusively NSCIMS patients. The NSCIMS are centers of excellent designated by the Department of Education responsible for providing the highest quality of care. There are reasons to believe that ITSCI received care in other institutions may not benefited by the same standard of care. Therefore, the disparity in wheelchair customizability observed in this study is expected to be much greater within the TSCI population as a whole.

There are several limitations to the current study. There are inherited limitations in the data collection. A notable percentage of individuals did not report the manufacturer and model of their primary wheelchairs; therefore, the quality of their wheelchair could not be determined. However, besides age and insurance coverage, the demographic and socioeconomic status of this sample was similar to that of the study sample. The average age of this sample was significantly higher than the study sample. This age difference might be a result of recall-bias; older individuals had difficulty remembering the manufacturer and model of their wheelchairs.

Also this study is a survey by design. It was not possible to establish the causality for the differences in factors associated with disparity in wheelchair quality, the results only accounted for association. Furthermore, given the small sample size and the many missing and unknown variables in both the study and national database, it

was not feasible to conduct any multivariate analysis to assess the interactive effects of the outcome variables. In addition, because of the small sample size we did not correct our p value for multiple comparisons. This fact should be taken into account when interpreting the results. To address these limitations, future studies should increase sample size by including ITSCI outside of the NSCIMS. As wheelchair technology, health insurance policy, and practice trend continue to advance; longitudinal studies assessing wheelchair use among the TSCI population are needed to examine the impact of these changes.

Based on the findings of the current survey, solutions must be created to address the inequity of access to high quality wheelchairs among the socioeconomically disadvantaged population. A solution would be to reform the current Medicare reimbursement policy to address the inequity of coverage for economically disadvantaged minorities. Alternative funding schemes such as governmental subsidy and low interest-rate loan programs would this population to obtain the appropriate wheelchairs. Wheelchair users also need to be educated consumers and actively participating in the decision making process. Rehabilitation Professionals and Rehabilitation Technology Suppliers may help by being strong advocates for socioeconomically disadvantaged individuals in acquiring better wheelchair technology.

2.5 CONCLUSION

The current study reveals that the standard of care for prescribing wheelchairs to individuals with TSCI is consistent across the NSCIMS. According to this study the standard of care for manual wheelchair users is a lightweight customizable manual

wheelchair and the standard of care for power wheelchair users is a power wheelchair with programmable controls and customizable features. The customizable wheelchair with adjustable axle position is the most often prescribed manual wheelchair and power wheelchair with programmable controls is the most frequently prescribed power wheelchair. However, the results showed there is disparity in wheelchair customizability and number of wheelchair own among the study population. Low socioeconomic status was associated with standard wheelchair and not having additional wheelchair. Based on these findings, effective solutions such as health care policy reform are needed to address the lack of equity in access to customizable wheelchairs among socioeconomically disadvantaged individuals.

2.6 REFERENCES

1. Scherer MJ, Cushman L. Measuring subjective quality of life following spinal cord injury: a validation study of assistive technology device predisposition assessment. *Disability and Rehabilitation* 2001;23:387-393.
2. National Council on Disability. Study on the financing of assistive technology devices and services for individuals with disabilities: a report to the President and Congress of the United States. March 4, 1993 [cited March 15, 2004]. Available from: URL: <http://www.ncd.gov/newsroom/publications/assistive.html>
3. Scherer MJ, editor. Assistive technology: matching device and consumer for successful rehabilitation. Washington (DC): American Psychological Association; 2002.
4. Cooper RA, Robertson RN, Lawrence B, Heil T, Albright SJ, VanSickle DP, Gonzalez J. Life-cycle analysis of depot versus rehabilitation manual wheelchairs. *J Rehabil Res Dev* 1996;33(1):45-55.
5. Boninger ML, Cooper RA, Baldwin MA, Shimada SD, Koontz A. Wheelchair pushrim kinetics: body weight and median nerve function. *Arch Phys Med Rehabil* 1999; 80: 910-5.
6. Boninger ML, Baldwin M, Cooper RA, Koontz A, Chan L. Manual wheelchair pushrim biomechanics and axle position. *Arch Phys Med Rehabil* 2000;81:608-13.
7. Fitzgerald SG, Cooper RA, Boninger ML, Rentschler AJ. Comparison of fatigue life for 3 types of manual wheelchairs. *Arch Phys Med Rehabil* 2001;82:148-8.
8. Cooper RA, Boninger ML, Rentschler A. Evaluation of selected ultralight manual wheelchairs using ANSI/RESNA standards. *Arch Phys Med Rehabil* 1999;80:462-7.
9. DiGiovine MM, Cooper RA, Boninger ML, Lawrence BM, VanSickle DP, Rentschler AJ. User assessment of manual wheelchair ride comfort and ergonomics. *Arch Phys Med Rehabil* 2000;81:490-4.
10. Sie IH, Waters RL, Adkins RH, Gellman H. Upper extremity pain in the post rehabilitation spinal cord injured patient. *Arch Phys Med Rehabil* 1992;73:44-48.
11. Boninger ML, Cooper RA, Fitzgerald SG, Lin J, Cooper R, Dicianno B, Liu B. Investigating neck pain in wheelchair users. *Am J Phys Med Rehabil* 2003;82:197-202.
12. Boninger ML, Saur T, Treffler E, Hobson DA, Burdette R, and Cooper RA: Postural Changes with Aging in Tetraplegia. *Arch Phys Med Rehabil* 1998;79:1577-1581.
13. Fass MV, Cooper RA, Fitzgerald SG, Schmeler M, Boninger ML, Algood SD, Ammer WA, Rentschler AJ, Duncan J. Durability, Value, and Reliability of Selected Electric Powered Wheelchairs. *Arch Phys Med Rehabil* in press, 2004.
14. Gaal RP, Rebholtz N, Hotchkiss RD, Pfaelzer PF. Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *J Rehabil Res Dev*. 1997;34(1):58-71.

15. Cooper RA. Advances in wheelchair and related technologies. *Med Eng Phys* 2001;23(4),iii-iv.
16. Karp G. Life on wheels for the active wheelchair user. Sebastopol (CA): O'Reilly; 1999.
17. Kemp, Crystal E, Parrette, Howard P. Barriers to Minority Family Involvement in Assistive Technology Decision-Making Processes. *Education and Training in Mental Retardation and Development Disabilities* 2000;35 (4):384-92.
18. Parrette HP, VanBiervliet A, Hourcade JJ. Family-centered decision making in assistive technology. *Journal of Special Education Technology* 2000;15(1):45-55.
19. O'Day BL, Corcoran PJ. Assistive technology: problems and policy alternatives. *Arch Phys Med Rehabil* 1994;75:1165-9.
20. National Council on Disability. Federal policy barriers to assistive technology: a report to the President of the United States. May 31, 2000 [cited March 15, 2004]. Available from URL:
<http://www.ndc.gov/newsroom/publications/assistivetechology.html>
21. Selbst, AG. Standard of care: so who decides? *Oral Surgery, Oral Medicine, Oral Pathology, Oral Radiology, & Endodontics*. 1997;83:637.
22. Stover SL, DeVivo MJ, Go BK. History, implementation, and current status of the national spinal cord injury database. *Arch Phys Med Rehabil* 1999;80:1365-1371.
23. Model Spinal Cord Injury Systems' Data Collection Syllabus for the National Spinal Cord Injury Database: 2000-2005 Project Period. National Spinal Cord injury Statistical Center, Birmingham, AL.
24. CIGNA HealthCare Durable Medical Equipment Regional Carrier (DMERC) Region D Supplier Manual; 2003. Ch 16, HCPCS-K, p 1-14. [cited March 15, 2004]. Available from:
<http://www.cignamedicare.com/dmerc/dmsm/C16/sm1612.html>.
25. Federal Register. Vol. 68, No. 26, February 7, 2003, pp. 6456-6458.
26. Centers for Medicare and Medicaid Services. New efforts aimed at stopping abuse of the power wheelchair benefit in the Medicare program. [cited March 15, 2004]. Available from URL:
<http://www.cms.hhs.gov/media/press/release.asp?Counter=843>
27. Martin SG, Fitzgerald SG, Cooper RA, Collins DM, Impink BG, Characteristics of ultralight wheelchairs: maintenance and repairs, proceedings of the 26th annual RESNA Conference, Atlanta, Ga, CD-Rom, 2003.

Suppliers

- a. Microsoft Corporation, One Microsoft Way, Redmond, Washington 98052
- b. SAS Institute Inc., SAS Campus Drive, Cary, North Carolina 27513, USA.

Table 2-1 Demographic and Socioeconomic Factors Associated with Manual Wheelchair Classification

Manual Wheelchairs Users, n=171*		Standard Wheelchair	Customizable Wheelchair
Percentage (%)		3	97
Age P=0.534	Mean (Std Dev)	45.00 (21.07) yrs.	38.58 (11.55) yrs.
Race P=0.006	Caucasian	20	82
	Minority	80	18
Employment P=0.551	Employed	0	35
	Unemployed	100	65
Education P=0.003	Less than HS	80	14
	High School	20	55
	College & Graduate	0	31
Health Insurance P=0.032	Public	100	31
	Private	0	69
Income P=0.033	Low	75	19
	Moderate	25	50
	High	0	31
Level of Injury P=0.633	Paraplegia	60	70
	Tetraplegia	40	30
Post injury years P=0.528	Mean (Std Dev)	13.20 (11.23) yrs.	9.72 (7.20) yrs.

* 81 chairs were unclassifiable because of unknown manufacturer and/or model

+ Unknowns and Others were excluded from the statistical analysis

Table 2-2 Demographic and socioeconomic factors associated with power wheelchair classification

Power Wheelchairs Users, n=106*		Standard Wheelchair	Customizable Wheelchair
Percentage (%)		46	54
Age P=0.028	Mean (Std Dev)	46.43 (13.64) yrs.	40.51 (13.51) yrs.
Race P=0.212	Caucasian	84	91
	Minority	16	9
Employment P=0.087	Employed	13	30
	Unemployed	87	70
Education P=0.020	Less than HS	26	17
	High School	62	46
	College & Graduate	12	37
Health Insurance P=0.003	Public	61	31
	Private	39	69
Income P=0.039	Low	24	10
	Moderate	62	51
	High	14	39
Level of Injury P=0.021	Paraplegia	20	5
	Tetraplegia	80	95
Post injury years P=0.512	Mean (Std Dev)	8.29 (6.79) yrs.	9.23 (7.95) yrs.

- * 49 chairs were unclassifiable because of unknown manufacturer and/or model
- + Unknown and Other were excluded from the statistical analysis

Table 2-3 Socioeconomic factors associated with power wheelchair users with tetraplegia

Power Wheelchairs Users, n=91*		Standard Wheelchair	Customizable Wheelchair
Percentage (%)		41	59
Employment P=0.078	Employed	12	32
	Unemployed	88	68
Education P=0.003	Less than HS	14	17
	High School	17	48
	College & Graduate	69	35
Health Insurance P=0.018	Public	60	34
	Private	40	66
Income P=0.001	Low	26	12
	Moderate	70	64
	High	4	24

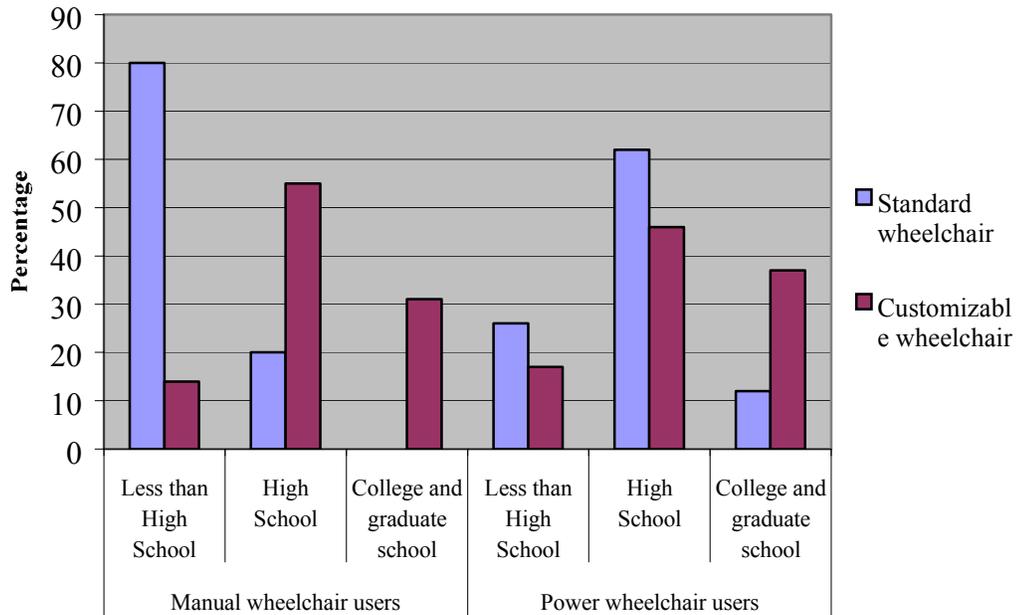
* Unknown and Other were excluded from the statistical analysis

Table 2-4 Demographic and Socioeconomic Factors Associated with Having Additional Wheelchairs

Additional Wheelchairs, n=412		Yes	No
Percentage (%)		46	54
Age P=0.623	Mean (Std Dev)	41.10 (13.33) yrs.	41.44 (13.96) yrs.
Race P=0.001	Caucasian	88	75
	Minority	12	25
Employment P=0.192	Employed	35	28
	Unemployed	65	72
Education P=0.857	Less than HS	17	17
	High School	52	54
	College & Graduate	31	29
Health Insurance P=0.045	Public	35	49
	Private	65	51
Income P=0.000	Low	9	24
	Moderate	53	55
	High	38	21
Level of Injury P=0.217	Paraplegia	47	53
	Tetraplegia	53	47
Post injury years P=0.689	Mean (Std Dev)	9.66 (7.26) yrs.	9.36 (7.56) yrs.

* Unknowns and Others were excluded from the statistical analysis

Figure 2-1 Level of education achieved among individuals who received standard and customizable wheelchairs



3.0 Association between age, post injury years, and wheelchair types and disparities in access to power wheelchairs among individuals with traumatic spinal cord injury

Peter Cody Hunt, M.P.H.^{1,2}, Michael L. Boninger, M.D.^{1,2,3,4,5}, Rory A. Cooper, Ph.D.^{1,2,3,4}, Ross D. Zafonte, D.O.^{1,2}, Shirley G. Fitzgerald, Ph.D.^{1,2,3}, Mark R. Schmeler, MS, OTR/L, ATP^{2,5}

¹Human Engineering Research Laboratories of the Department of Physical Medicine and Rehabilitation, School of Medicine, University of Pittsburgh, Pittsburgh, PA;

²Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, PA;

³VA Pittsburgh Healthcare Systems, Pittsburgh, PA;

⁴Department of Bioengineering, School of Engineering, University of Pittsburgh, Pittsburgh, PA.

⁵The Center for Assistive Technology, UPMC Health System, Pittsburgh, PA

ADDRESS CORRESPONDENCE TO:

Michael L. Boninger, M.D.
Professor and Vice Chair for Research
Department of Physical Medicine and Rehabilitation
3471 Fifth Avenue, Suite 201
Pittsburgh, PA 15213
TEL: 412-648-6654
FAX: 412-692-4110
Email: boninger@pitt.edu

Acknowledgements: This work was supported by funds from the National Institute on Disability and Rehabilitation Research in the Office of Special Education and Rehabilitation Services in the U.S. Department of Education (H133N000019).

ABSTRACT

Objectives: To determine if differences in age and post injury years are associated with the types (manual or power) of wheelchairs used among people with paraplegia and tetraplegia and if a disparity in access to power wheelchairs exists among wheelchair users with lower socioeconomic status.

Design: Convenience Sample Survey

Settings: Sixteen National Model Spinal Cord Injury Systems (NMSCIS) that provide comprehensive rehabilitation for people with traumatic spinal cord injury and that are part of the national database funded through the National Institute on Disability and Rehabilitation Research.

Participants: A sample of 462 NMSCIS participants who used a wheelchair over 40 hours per week.

Method: Survey information was obtained from participants via telephone, in-person interviews, and from the national database. Collected information included age, race, post injury years, income, employment status, insurance, education, and wheelchair types (manual or power).

Main Outcome Measures: Type of wheelchair used, post injury years, age, and socioeconomic status of wheelchair users.

Results: Power wheelchair users with paraplegia were significantly older (55.96 ± 12.81 yrs vs. 39.61 ± 12.58 yrs, $p=0.000$) than manual wheelchair users. No differences in average age ($p=0.449$) were found between manual (41.06 ± 12.95 yrs) and power (39.75 ± 11.38 yrs) wheelchair users with tetraplegia. There were also no differences in

socioeconomic status between manual and power wheelchair users regardless of the level of injury..

Conclusion: Age was found to be strongly associated with wheelchair type for users with paraplegia; older wheelchair users were more likely to use power wheelchairs.

Regardless of the level of injury, manual wheelchair users were able to use manual wheelchairs for a long period of time. Although no disparities in access to power wheelchairs were found among minorities with lower socioeconomic status, disparities in access to customizable wheelchairs remains a great concern for this population.

Key Words: Wheelchair, spinal cord injury, demographic, socioeconomic, disparity, access.

3.1 INTRODUCTION

The loss of function that results from a spinal cord injury (SCI) can severely hamper the ability to carry on daily life activities. With the aid of wheelchair use, individuals with spinal cord injury (ISCI) can achieve unprecedented levels of function (1,2). Wheelchairs can be classified into two general types, manual and power operated wheelchairs. Manual wheelchairs are often prescribed for users with good upper body strength and trunk control, attributes that are necessary for propelling a manual wheelchair. Those with limited upper body function and trunk control are often prescribed with power operated wheelchairs (3). Upper body strength and trunk control are determined by the level of SCI (4). However, these clinical indicators are not absolute determinant factors for wheelchair prescription. There are many other factors that may influence wheelchair choice (3,5,6).

There are many risks and benefits associated with the different types of wheelchair use. Simplicity of design and portability are two advantages of manual wheelchairs. Without the complex electronic components of power wheelchairs, manual wheelchairs are less likely to breakdown. Wheelchair failures can cause death and injuries (7). With removable wheels, folding frame, and lightweight material construction; manual wheelchairs are more portable (3,8,9). However, propelling a manual wheelchair requires tremendous upper body strength and repetitive motion, especial traveling through challenging terrains such as uphill slopes and rough surfaces. For those with declining physical strength due to aging, the physical demand for propelling a manual wheelchair may pose significant challenges (10). Overtime, the repetitive motion of propelling a manual wheelchair may increase the risk for upper

extremity pain and impairments (UEPI) (11,12,13,14,15). Therefore, the transition to a power wheelchair may be an option for these wheelchair users (16).

Power wheelchair use, however, also has advantages and disadvantages. Long lasting batteries allow power wheelchairs to go considerable distances and through challenging terrains without depleting the strength and energy of the user. Modern power wheelchairs are equipped with design features such as tilt-in-space, reclining function, and leg elevation; which are important for pressure relief and user's comfort (3,17,18). But, the greater the number and more sophisticated the electronic components a power wheelchair has also means greater chances for wheelchair failures (7,19). In terms of portability, power wheelchairs are bulky and require a modified van equipped with a wheelchair lift for transport (20).

In addition to the advantages and disadvantages of power wheelchair use, there are other socioeconomic factors that may also influence power wheelchair choice. Compared to manual wheelchairs, a fully equipped power wheelchair can cost three times as much (21). In the U.S., healthcare insurance is the primary funding source for wheelchairs. However, most insurance plans require consumers to pay a percentage of the wheelchair cost (22). This required co-payment may be a substantial financial burden for those with lower socioeconomic status (23,24). Furthermore, wheelchair selection requires a team effort among healthcare providers, wheelchair vendors, the consumer, and family members. But, low income minority families often do not participate in the assistive technology decision making process because they have more urgent priorities such as making provisions for the family (25,26). In some traditional societies, using technology to assist people with disabilities instead of

providing direct human care is culturally unacceptable (27). These financial and cultural barriers may have an impact on access to power wheelchairs for minorities with lower socioeconomic status.

Because of the lack of data, little is known about the factors that influence wheelchair choice among ISCI. In order to gain a better understanding of these factors; first we will explore the differences in demographic and socioeconomic characteristics of wheelchair users with SCI. In light of the clinical evidence associating long-term manual wheelchair use with the risk for developing UEPI; we will then examine the association between post injury years, age, and the types of wheelchairs used. To do so, the following hypotheses will be tested:

1. Older wheelchair users who had been injured longer were more likely to use power wheelchairs;
2. Younger wheelchair users who had been injured more recently were more likely to use manual wheelchairs.

Lastly, to take into account the financial and cultural barriers; we will determine if minorities with lower socioeconomic status experienced disparities in access to power wheelchairs with the following hypothesis:

1. Minorities with lower socioeconomic status had less access to power wheelchairs.

3.2 METHODOLOGY

3.2.1 Population

A convenient sample of the NMSCIS was surveyed for this study. The NMSCIS, funded by the National Institute on Disability and Rehabilitation Research, is comprised

of 16 centers providing comprehensive acute and rehabilitation care for ISCI. Together, the NMSCIS maintains the world's largest database on SCI (28). Participants for this study must be 18 years old, be at least 6-months post injury, and be eligible for annual follow up interview as of January 2003. The inclusion criteria for the NMSCIS dictate that participants must be U.S. citizens who sustained a discernable degree of neurological impairment as a result of SCI, received treatment at 1 of the 16 NMSCIS within 1-year of injury, did not receive care at another NMSCIS, lived within the catchment area of the respective NMSCIS, and signed an informed consent. All participants are to be followed from the time of system admission up to 25 years post injury. Annual follow up interviews are conducted at years 1, 5, and 10 post injury and every 5 years thereafter (29).

3.2.2 Data Collection

The Assistive Technology Survey (ATS) is a 1-page questionnaire developed by the consensus of the center directors at the NMSCIS Directors' meeting in Washington D.C. The ATS includes questions on wheelchairs and other assistive technologies such as modified vehicles and computers. The initial phase of data collection began in January 2003 and ended in June 2003 with the participation of 13 NMSCIS centers. After which, the ATS was revised by adding more variables on other mobility devices. Data collection resumed in April 2004 with all 16 NMSCIS centers (see Appendix) participating in the data collection. For the purpose of this study, we included data collected in the first phase and only data collected from April to August of 2004 during the subsequent phase.

Data collectors from each participating center were responsible for administering the ATS, which is part of the annual follow up interview. The follow up interview included questions on demographics, socioeconomics, and wheelchair technology. Participants completed the follow up interview by phone, in person interview, or postal mail. Data collected at the participating centers were submitted via FTP, e-mail, fax, or postal mail to the central data collection sites: the University of Pittsburgh Model Center on Spinal Cord Injury and the National Spinal Cord Injury Statistical Center at the University of Birmingham. No personal identification of the participants was transmitted to ensure confidentiality of the data.

3.2.3 Data Reduction

To increase the power of this study, we collapsed across some variables so that our sample was not divided into too many smaller groups. Race was compressed into two main categories: Caucasian and Minority (African American, Native American, Eskimo, Aleut, Asian, Pacific Islander, and unclassified group). This was based on the fact that the NMSCIS population was comprised of 80% Caucasian (30). Individuals with incomplete and complete paraplegia were grouped as individuals with paraplegia. Similarly, those with incomplete and complete tetraplegia were classified as individuals with tetraplegia. Individuals with minimal neurological impairment and those with normal neurological function were excluded. The highest level of education achieved was reorganized into 2 categories: those who completed less than or equivalent to a high school level education and those who completed a post secondary education (Associate, Bachelor, Master, Doctorate degrees). In terms of employment, we were

most interested in individuals who were in the competitive labor market. Therefore, we regrouped the answers to the employment variable into three separate groups: employed, unemployed, and other (students, homemakers, retirees, and shelter workshop training). For the insurance variable, we regrouped the answer choices into 2 general categories: private and public sector health insurance. The private sector health insurance included, private insurance companies, self-insured, and worker's compensation. The public sector insurance encompassed Medicare, Medicaid, VA, and state vocational rehabilitation programs. Lastly, income status was based on the United States Department of Health and Human Services 2004 Poverty Guidelines of the 48 contiguous states within the U.S. (31). To determine poverty levels, we divided the combined annual family income by the number of people living in the family. The resulting figure determines whether or not the family income was below or above the national poverty level.

3.3 ANALYSIS

3.3.1 Study Sample

It is not uncommon for wheelchair users to have multiple wheelchairs. These additional wheelchairs may not be the same type as the primary wheelchair. For example, users who are capable of using a manual wheelchair as their primary wheelchair may have a power wheelchair as their additional wheelchair. In order to obtain a pure sample of manual and power wheelchair users, wheelchair users who had additional wheelchairs that were different from their primary wheelchair and non-wheelchair users were excluded. Our final study sample included only wheelchair users who used a single type of wheelchair more than 40 hours per week.

3.3.2 Characteristics of Study Sample

All statistical analyses for this study were conducted using SPSS version 12 software^a. To explore the demographic and socioeconomic characteristics of our study sample, we divided our study sample into 2 groups based on the type of wheelchair used. Using descriptive analysis, we determined the frequency of the demographic and socioeconomic variables (sex, race, level of injury, education, employment, insurance, poverty level, post injury years, age) of the total sample, manual and power wheelchair users, as well as non-wheelchair users.

3.3.3 Post injury Years and Age

Wheelchair prescription is based primarily on the level of SCI. To control the potential confounding effect of the level of injury, we divided our total sample into 2 groups based on the level of injury in order to determine the association of post injury years and age with wheelchair types. Preliminary analysis indicated that data on post injury years and age were not normally distributed among our comparison groups. Therefore, Kruskal-Wallis tests were used to analyze the differences in mean age and post injury years between manual and power wheelchair users within each group.

3.3.4 Access Disparities

To determine disparities in access to power wheelchairs, using Chi-Square analysis we compared the distribution of the following socioeconomic variables: race, education, employment, insurance, and poverty status, between manual and power wheelchair users with paraplegia and those with tetraplegia. Disparities will be determined based on the differences in socioeconomic status.

3.4 RESULTS

3.4.1 Characteristics Profiles

A total of 807 eligible NMSCIS participants were surveyed. The demographic and socioeconomic characteristics of our sample were similar to those of the NMSCIS population as a whole (30). Among our sample, 172 non-wheelchair users and 173

wheelchair users who used both types of wheelchairs were excluded. Participants who were excluded from the study had similar demographic and socioeconomic characteristics as those in the study sample. The demographic and socioeconomic profiles of our study sample, manual and power wheelchair users are shown in Table 3.1.

3.4.2 Age and Post Injury Years

The average age of power wheelchair users with paraplegia (55.96 ± 12.81 yrs) was significantly greater ($p=0.000$) than that of manual wheelchair users (39.61 ± 12.58 yrs) [Figure 3.1]. The average post injury years between these two groups was not statistically significant (9.68 ± 7.73 yrs for manual, 10.65 ± 7.87 yrs for power, $p=0.609$). Among wheelchair users with tetraplegia, there were no statistical differences found in average age (41.06 ± 12.95 yrs for manual, 39.75 ± 11.38 yrs for power, $p=0.449$) and post injury years (11.85 ± 7.48 yrs for manual, 11.39 ± 7.49 yrs for power, $p=0.398$) [Figure 3.2].

3.4.3 Access Disparities

There were no statistical differences found in socioeconomic status between manual and power wheelchair users with paraplegia and those with tetraplegia.

3.5 DISCUSSION

The type of wheelchair prescribed to ISCI is primarily determined by their level of SCI, upper body function, and trunk control (3). However, declining in physical strength

associated with aging and post injury years are also potential factors in determining the suitable wheelchair type. As our results showed, older wheelchair users with paraplegia were more likely to use power wheelchairs. However, age differences were not found between manual and power wheelchair users with tetraplegia. Wheelchair transition might have been a confounder for this observation. If there was a large number of young manual wheelchair users who already transitioned to power wheelchair use at the time of the survey, this would have lowered the average age of power wheelchair users. Without any information on wheelchair transition among our sample, it is difficult to eliminate this potential confounder.

With regard to post injury years, there were also no differences found among all comparison groups. However, the post injury years for manual wheelchair users with paraplegia and tetraplegia averaged around 10 years, meaning the manual wheelchair users in our study sample were able to use manual wheelchairs for a long period of time. The results of our previous study might provide a plausible explanation for this observation. Our previous study found 97% of manual wheelchair users in our study sample used customizable ultralight weight manual wheelchairs (32). These wheelchairs are constructed with lighter materials and are customized with features such as an adjustable axle position, making wheelchair propulsion more energy efficient, and thus lessen the risk for developing UEPI (33,34,35). The advantages of using customizable ultralight weight wheelchairs among the majority of our sample might account for the results observed in the current study that many wheelchair users were able to use manual wheelchairs for a long period of time.

Our results found no differences among all the socioeconomic indicators among our comparison groups, indicating that regardless of socioeconomic status, there were no disparities in access to power wheelchairs among our study sample. However, disparities in access to customizable power wheelchairs among minorities with lower socioeconomic status found in our previous study remain a great concern (32). Thus, the results of our previous and current studies provided a synergistic finding that even though minorities with lower socioeconomic status had equal access to power wheelchairs, the power wheelchairs provided might not be customizable power wheelchairs equipped with programmable controls.

There were several limitations with the current study that need to be addressed in future studies. This was a cross sectional study by design. We were not able to determine how many long-term manual wheelchair users have already transitioned to power wheelchair use since their time of injury. Also, among those who have transitioned to power wheelchairs, there was no information on when the transition occurred and what factors influenced the decision for wheelchair transition. Future studies need to consider taking a prospective approach in studying wheelchair transition. Furthermore, about 25% of our study sample had missing information on income. Even though subsequent analysis showed that the missing information was evenly distributed among the comparison groups, this high percentage of missing values might account for the null results in analysis of access to power wheelchairs. Also wheelchair users who used both manual and power wheelchairs were excluded from the study sample in order to get a pure sample of manual and power wheelchair users. Among this excluded sample, some manual wheelchair users might have

already transitioned to a power wheelchair, thus having an additional power wheelchair. By excluding this sample, we might have compromised the power of our study. Therefore, future studies need to over sample to get a larger pure sample in order to achieve meaningful results.

3.6 CONCLUSION

Age was found to be strongly associated with wheelchair type for users with paraplegia; older wheelchair users were more likely to use power wheelchairs. Regardless of the level of injury, manual wheelchair users were able to use manual wheelchairs for a long period of time. Although no disparities in access to power wheelchairs were found among minorities with lower socioeconomic status, disparities in access to customizable wheelchairs remain a great concern for this population.

3.7 REFERENCES

1. Chaves ES, Boninger ML, Cooper R, Fitzgerald SG, Gray DB, Cooper RA. Assessing the influence of wheelchair technology on perception of participation in spinal cord injury. *Arch Phys Med Rehabil*. 2004 Nov;85(11):1854-8.
2. The American Academy of Physical Medicine and Rehabilitation and the Foundation for Physical Medicine and Rehabilitation. *Access to assistive technologies: improving health and well-being for people with disabilities*. Chicago: AAPM&R and Foundation for PM&R; 2003.
3. Cooper RA. *Wheelchair selection and configuration*. New York: Demos Medical Publishing, Inc.;1998.
4. Young W. Spinal Cord Injury Levels and Classification; June 24, 2003. [Cited November 1, 2004]. Available from URL: <http://carecure.rutgers.edu/spinewire/Articles/SpinalLevels/SpinalLevels.html>
5. Routhier F, Vincent C, Desrosiers J, Nadeau S. Mobility of wheelchair users: a proposed performance assessment framework. *Disabil Rehabil*. 2003 Jan 7;25(1):19-34.
6. Scherer MJ. The change in emphasis from people to person: introduction to the special issue on assistive technology. *Disability and Rehabilitation* 2002;24:1-4.
7. Gaal RP, Rebholtz N, Hotchkiss RD, Pfaelzer PF. Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *J Rehabil Res Dev*. 1997 Jan;34(1):58-71.
8. Karp G. Cutting edge manual wheelchairs. *New Mobility*. July 2001.
9. Benson, G. Spinal Cord Injury – InfoSheet “Selecting a Wheelchair” #7. Alabama: UAB-Spain Rehabilitation Center; 1995. Grant (#H133B30025). Sponsored by the National Institute on Disability and Rehabilitation Research, Dept of Education.
10. Lal S. Premature degenerative shoulder changes in spinal cord injury patients. *Spinal Cord*. 1998 Mar;36(3):186-9.
11. Boninger ML, Towers JD, Cooper RA, Dicianno BE, Munin MC. Shoulder imaging abnormalities in individuals with paraplegia. *J Rehabil Res Dev*. 2001 Jul-Aug;38(4):401-8.
12. Nichols PJ, Norman PA, Ennis JR. Wheelchair user's shoulder? Shoulder pain in patients with spinal cord lesions. *Scand J Rehabil Med*. 1979;11(1):29-32.
13. Subbarao JV, Klopstein J, Turpin R. Prevalence and impact of wrist and shoulder pain in patients with spinal cord injury. *J Spinal Cord Med*. 1995 Jan;18(1):9-13.
14. Dyson-Hudson TA, Kirshblum SC. Shoulder pain in chronic spinal cord injury, Part I: Epidemiology, etiology, and pathomechanics. *J Spinal Cord Med*. 2004;27(1):4-17.
15. Dalyan M, Cardenas DD, Gerard B. Upper extremity pain after spinal cord injury. *Spinal Cord*. 1999 Mar;37(3):191-5.
16. Cooper RA, Boninger ML, *Walking on Your Hands*, Paraplegia News. 1999;53(3).

17. Cooper RA. Engineering manual and electric powered wheelchairs. *Crit Rev Biomed Eng.* 1999;27(1-2):27-73.
18. Edlich RF, Nelson KP, Foley ML, Buschbacher RM, Long WB, Ma EK. Technological advances in powered wheelchairs. *J Long Term Eff Med Implants.* 2004;14(2):107-30.
19. Martin SG, Fitzgerald SG, Cooper RA, Collins DM, Impink BG, Characteristics of ultralight wheelchairs: maintenance and repairs, proceedings of the 26th annual RESNA Conference, Atlanta, Ga, CD-Rom, 2003.
20. Holiche C. Transitions: from manual to power. *New Mobility.* February, 1999.
21. Benson, G. Spinal Cord Injury – InfoSheet “Selecting a Wheelchair” #7. Alabama: UAB-Spain Rehabilitation Center; 1995. Grant (#H133B30025). Sponsored by the National Institute on Disability and Rehabilitation Research, Dept of Education.
22. Center for Medicare and Medicaid Services. Power wheelchair coverage overview. February 2004. [Cited November 1, 2004]. Available from URL: <http://www.cms.hhs.gov/medlearn/PowerWheelchair.pdf>
23. LaPlante, M. P. (1993). Disability, health insurance coverage, and utilization of acute health services in the United States. Washington, DC: U.S. Department of Health and Human Services.
24. Healthy People 2010. Reduce the proportion of people with disabilities who report not having the assistive devices and technology needed. Chapter 6.11. Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services.
25. Parette HP, VanBiervliet A, Hourcade JJ. Family-centered decision making in assistive technology. *Journal of Special Education Technology* 2000;15(1):45-55.
26. Parette HP, Brotherson MJ. Family-centered and culturally responsive assistive technology decision making. *Infants and Young Children.* 2004;17(4):355-367.
27. Anderson JM. Ethnicity and illness experience: Ideological structures and the health care delivery system. *Social Science and Medicine* 1986;22:1277-1283.
28. Stover SL, DeVivo MJ, Go BK. History, implementation, and current status of the National Spinal Cord Injury Database. *Arch Phys Med Rehabil.* 1999 Nov;80(11):1365-71.
29. National Model Spinal Cord Injury Model System. Data collection syllabus 2000-2005. Alabama: National Spinal Cord Injury Statistics Center; 2004.
30. Spinal cord injury information network. Facts and figures at a glance; August 2004. [Cited November 1, 2004]. Available from URL: <http://www.spinalcord.uab.edu/show.asp?durki=21446>
31. Federal Register, Feb 12, 2004;69(30): 7336-7338, in United States Department of Health and Human Services. 2004 Federal Poverty Guidelines. nd. [Cited November 1, 2004]. Available from URL: <http://aspe.hhs.gov/poverty/04poverty.shtml>
32. Hunt PC, Boninger ML, Cooper RA, Zafonte RD, Fitzgerald SG, Schmeler MR. Demographic and socioeconomic factors associated with disparity in wheelchair customizability among people with traumatic spinal cord injury. *Arch Phys Med Rehabil.* 2004 Nov;85(11):1859-64.

33. Boninger ML, Baldwin M, Cooper RA, Koontz A, Chan L. Manual wheelchair pushrim biomechanics and axle position. *Arch Phys Med Rehabil.* 2000 May;81(5):608-13.
34. Beekman CE, Miller-Porter L, Schoneberger M. Energy cost of propulsion in standard and ultralight wheelchairs in people with spinal cord injuries. *Phys Ther.* 1999 Feb;79(2):146-58.
35. Boninger ML, Impink BG, Cooper RA, Koontz AM. Relation between median and ulnar nerve function and wrist kinematics during wheelchair propulsion. *Arch Phys Med Rehabil.* 2004 Jul;85(7):1141-5.

SUPPLIER

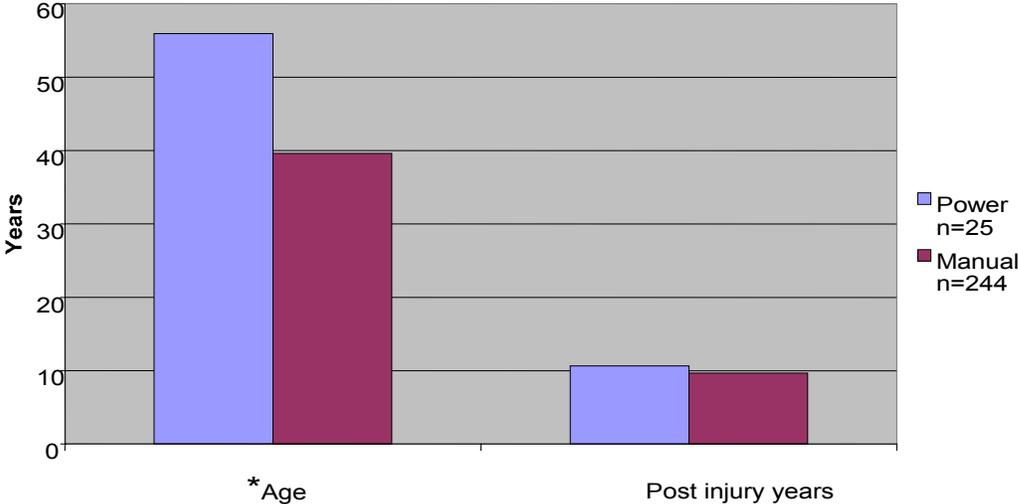
^aSPSS Inc. Headquarters, 233 S. Wacker Drive, 11th floor, Chicago, Illinois 60606

Table 3-1 Demographic and socioeconomic profiles of manual and power wheelchair users

		Total	Manual	Power
n		462	331 (71.6%)	131 (28.4%)
Sex	Male	82.3%	83.1%	80.2%
	Female	17.7%	16.9%	19.8%
Race	Caucasian	82.5%	82.0%	84.0%
	Minority	17.55	18.0%	16.0%
*Level of injury	Para	58.2%	73.7%	19.1%
	Tetra	41.8%	26.3%	80.9%
Education	HS	68.1%	66.2%	72.6%
	Col	31.9%	33.8%	27.4%
Employment	Employed	27.9%	30.3%	21.8%
	Unemployed	46.1%	43.5%	52.4%
	Other	26.0%	26.1%	25.8%
Insurance	Public	52.4	50.7%	56.7%
	Private	47.6	49.3%	43.3%
Poverty	Above	76.6%	77.7%	73.7%
	Below	23.4%	22.3%	26.3%
Post injury years		10.90 (<u>+7.70</u>)	10.96 (<u>+7.78</u>)	10.76 (<u>+7.55</u>)
*Age		40.80 (<u>+12.89</u>)	39.99 (<u>+12.67</u>)	42.85 (<u>+13.26</u>)

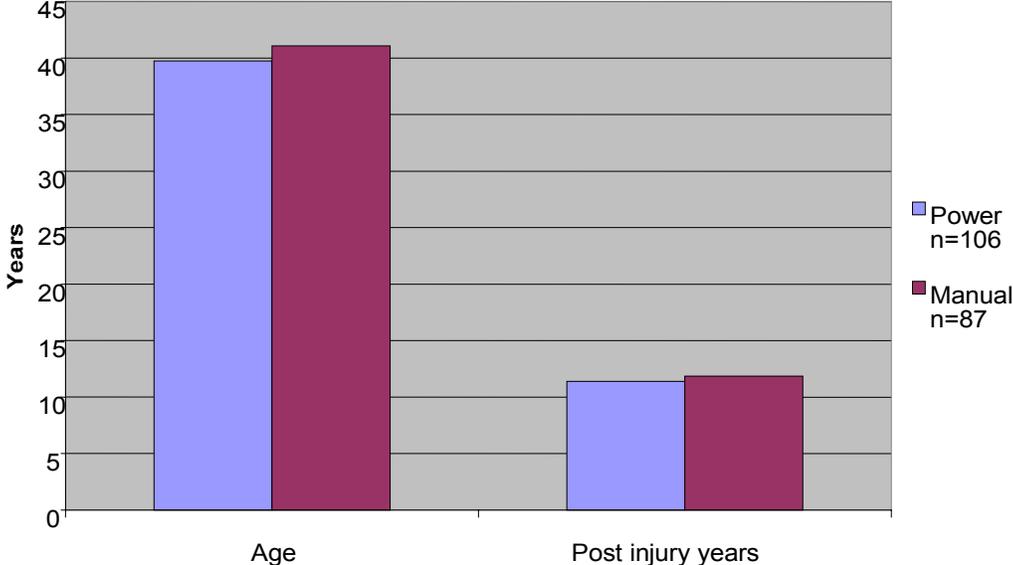
*p<0.050, differences between manual and power wheelchair users

Figure 3-1 Differences in age and post injury years between manual and power wheelchair users with paraplegia



Note: * p<0.050

Figure 3-2 Differences in age and post injury years between manual and power wheelchair users with tetraplegia



3.8 APPENDIX

NMSCIS centers participated in the data collection for this study

1. University of Alabama at Birmingham SCI Care System^a
2. Regional SCI Care System of Southern California^a
3. Northern California SCI System^{ab}
4. Rocky Mountain Regional SCI System^{ab}
5. Georgia Regional SCI System^{ab}
6. New England Regional SCI Center^a
7. University of Michigan Model SCI System^{ab}
8. Missouri Model SCI System^{ab}
9. Mount Sinai SCI Model System^a
10. Regional SCI System of Delaware Valley^{ab}
11. University of Pittsburgh Model System on SCI^{ab}
12. Texas Regional SCI System^{ab}
13. Virginia Commonwealth Regional SCI System^{ab}
14. Northern New Jersey Spinal Cord Injury System^b
15. South Florida Regional Spinal Cord Injury Model System^b
16. Northwest Regional Spinal Cord Injury System^b

Key: ^a Centers participated in only the initial phase of data collection
^b Centers participated in only the subsequent phase of data collection
^{ab} Centers participated in the initial and subsequent phase of data collection

4.0 The impact of wheelchair use on quality of life among individuals with traumatic spinal cord injury

Peter Cody Hunt, M.P.H.^{1,2}, Michael L. Boninger, M.D.^{1,2,3,4,5}, Rory A. Cooper, Ph.D.^{1,2,3,4}, Ross D. Zafonte, D.O.^{1,2}, Shirley G. Fitzgerald, Ph.D.^{1,2,3}, Mark R. Schmeler, MS, OTR/L, ATP^{2,5}

¹Human Engineering Research Laboratories of the Department of Physical Medicine and Rehabilitation, School of Medicine, University of Pittsburgh, Pittsburgh, PA;

²Department of Rehabilitation Science and Technology, School of Health and Rehabilitation Sciences, University of Pittsburgh, Pittsburgh, PA;

³VA Pittsburgh Healthcare Systems, Pittsburgh, PA;

⁴Department of Bioengineering, School of Engineering, University of Pittsburgh, Pittsburgh, PA.

⁵The Center for Assistive Technology, UPMC Health System, Pittsburgh, PA

ADDRESS CORRESPONDENCE TO:

Michael L. Boninger, M.D.
Professor and Vice Chair for Research
Department of Physical Medicine and Rehabilitation
3471 Fifth Avenue, Suite 201
Pittsburgh, PA 15213
TEL: 412-648-6654
FAX: 412-692-4110
Email: boninger@pitt.edu

Acknowledgements: This work was supported by funds from the National Institute on Disability and Rehabilitation Research in the Office of Special Education and Rehabilitation Services in the U.S. Department of Education (H133N000019).

ABSTRACT

Objectives: To determine the impact of wheelchair types, design features, and ownership of additional wheelchairs on quality of life measures in terms of degree of environmental barriers encountered, mobility, physical independence, social integration, and life satisfaction.

Design: Convenience Sample Survey

Settings: Sixteen National Model Spinal Cord Injury Systems (NMSCIS) that provide comprehensive rehabilitation for individuals with traumatic spinal cord injury and that are part of the national database funded through the National Institute on Disability and Rehabilitation Research.

Participants: A sample of 462 NMSCIS participants who used a wheelchair over 40 hours per week.

Method: Survey information was obtained from participants via telephone, in-person interviews, and from the national database. Collected information included demographic; socioeconomic status; rehabilitation outcomes; wheelchair manufacturer, model, and type (manual or power); and ownership of additional wheelchairs.

Main Outcome Measures: Age, post injury years, Satisfaction with Life Scale, Craig Handicap Assessment Reporting Technique (physical independence, mobility, and social integration), and Craig Hospital Inventory of Environmental Factors (physical/structural barriers), and Functional Independence Measures.

Results: Manual wheelchair users with paraplegia scored significantly higher on physical independence (91.25 ± 22.43 vs. 56.73 ± 42.33 , $p=0.000$) and mobility (83.68 ± 22.51 vs. 64.00 ± 32.73 , $p=0.001$) than power wheelchair users. Among those

with tetraplegia, compared to power wheelchair users, manual wheelchair users achieved a higher level of physical independence (84.27 ± 29.73 vs. 60.34 ± 36.78 , $p=0.000$). Wheelchair users with paraplegia who had additional wheelchairs scored significantly higher on mobility (89.52 ± 18.03 vs. 78.47 ± 25.85 , $p=0.001$) than those who did not have additional wheelchairs. There were no differences in other quality of life measures between all the comparison groups. In terms of age differences, power wheelchair users with paraplegia were older (55.96 ± 12.81 vs. 39.61 ± 12.58 , $p=0.000$) than manual wheelchair users. No differences in post injury years were detected among all comparison groups. However, the FIM scores were significantly different among all comparison groups: manual and power wheelchair users with paraplegia (77.61 ± 8.95 vs. 57.45 ± 20.16 , $p=0.000$); manual wheelchair users with tetraplegia, (64.11 ± 21.73 vs. 32.43 ± 16.40 , $p=0.000$); and K0011 and K0014 power wheelchair users (57.85 ± 30.95 vs. 38.27 ± 24.23 , $p=0.005$).

Conclusion: We were not able establish an association between the types and design features of wheelchair used on quality of life. However, based on the results, we were able to conclude that having additional wheelchairs was associated with enhanced mobility for wheelchair users. Also power wheelchair users with advanced age and lower functional capacity were able to achieve comparable quality of life outcome measures compared to their counterparts, younger manual wheelchair users who had higher level of functional capacity. This finding may provide important evidence for advocating for the benefit of providing additional wheelchairs to ISCI and addressing the problem of lack of insurance coverage for additional wheelchairs.

Key Words: Wheelchair, spinal cord injury, quality of life, CHART, CHIEF, FIM.

4.1 INTRODUCTION

Wheelchair users with a spinal cord injury (SCI) encounter a significant amount of architectural barriers in their daily life activities within the community (1). Wheelchairs are designed to increase mobility of the users by assisting the users to overcome physical and structural barriers (2). Increased mobility has been found to be associated with higher levels of independence and social integration (3,4,5). All of these may contribute to a higher level of life satisfaction (6,7,8). However, because of the lack of data, little is known about the impact of wheelchair types, design features, and ownership of additional wheelchairs on these quality of life outcome measures.

Wheelchairs can be classified under two general categories, manual and power operated wheelchairs. Manual wheelchairs are often prescribed for users with good upper body strength and trunk control, attributes that are necessary for propelling a manual wheelchair. Those with limited upper body function and trunk control are often prescribed power operated wheelchairs (2). For some wheelchair users, manual wheelchairs are considered to have more advantages over power wheelchairs for handling environmental barriers. With advanced wheelchair training skills, obstacles such as curbs, single steps, and tight-turn corners can be easily overcome with manual wheelchairs. Power wheelchairs, however, offer the advantage of energy conservation. With a larger capacity battery, power wheelchair users can go considerable distances without depleting strength and energy. Moreover, power wheelchairs enable users to travel through extreme climate and challenging terrain such as steep uphill slopes without risking the strength and health of the users (9,10).

The different design features of wheelchairs also have a significant impact on the performance and durability of the wheelchairs, factors that are important for overcoming architectural barriers. Power wheelchair technology has advanced with an accelerated pace in the past four decades. The level of sophistication in power wheelchair design ranges from simple electrical powered wheelchairs to completely customizable power wheelchairs equipped with smart electronic controls and standing, reclining, and tilt in space functions. Today's customizable power wheelchairs with programmable controls have greater weight capacity, motor with higher torque, longer life span, and are more durable when compared with standard wheelchairs with programmable controls (11,12,13). The advantages of these design features may better equip the users to conquer more challenging environmental obstacles. However, as the results of our previous study indicated, a significant portion of power wheelchair users were not using these customizable power wheelchairs (14). It is not known how these design features impact the ability to overcome environmental barriers.

Wheelchairs experience frequent breakdowns and require repairs (15). Wheelchair breakdown is not only an inconvenience, physical injuries have been found to be caused by wheelchair "component failures" (16). When wheelchair breakdown occurs, the user may be left stranded in a public place or confined inside the home. Wheelchair repair requires time. Most often, approval from insurance companies is needed in order to reimburse wheelchair vendors for the necessary repair work. This causes further delay. Without additional wheelchairs, the user's daily life activities, mobility function, and independence can be severely affected.

The goal of the current study is to determine the impact of wheelchair types, design features, and ownership of additional wheelchairs on quality of life. For the purpose of this study, quality of life is measured in terms of environmental barriers, mobility, physical independence, social integration, and life satisfaction based on the following logic. The ability to overcome environmental barriers results in a higher level of mobility, physical independence, and social integration. All these will result in greater satisfaction of life. Our study will test the following hypotheses:

1. We believed that power wheelchairs were better suited for challenging terrains and long distances, therefore, we hypothesized that among wheelchair users with paraplegia and tetraplegia, power wheelchair users achieved a higher level of mobility, physical independence, social integration, and life satisfaction;
2. Similarly, we hypothesized that those with additional wheelchairs achieved a higher level of mobility, physical independence, social integration, and life satisfaction;
3. We also hypothesized that those with customizable power wheelchairs with programmable controls achieved a higher level of mobility, physical independence, social integration, and life satisfaction.

4.2 METHODOLOGY

4.2.1 Population

We surveyed a convenient sample of the National Model Spinal Cord Injury Systems (NMSCIS) participants for this study. The NMSCIS, funded by the National Institute on Disability and Rehabilitation Research, is comprised of 16 centers providing comprehensive acute and rehabilitation care for ISCI. Together, the NMSCIS maintains the world's largest database on SCI (17). Participants for this study must be 18 years or

older, be at least 6-months post injury, and be eligible for annual follow up interview as of January 2003. The inclusion criteria for the NMSCIS dictates that participants must be U.S. citizens who sustained a discernable degree of neurological impairment as a result of SCI, received treatment at 1 of the 16 NMSCIS within 1-year of injury, did not receive care at another NMSCIS, lived within the catchment area of the respective NMSCIS, and signed an informed consents. All participants are to be followed from the time of system admission up to 25 years post injury. Annual follow up interviews are conducted at years 1, 5, and 10 post injury and every 5 years thereafter (18).

4.2.2 Survey Instruments

Five different surveys were used as data collection tools for this study. The central focus of this study is the implementation and administering of the Assistive Technology Survey (ATS), which documents information on wheelchair use. The second survey is Satisfaction With Life Scale (SWLS), which measures the subjective well-being of the participants (19). The third survey is the Craig Handicap Assessment and Reporting Technique (CHART), which assesses the degree of social participation (20). The fourth survey is the Craig Hospital Inventory of Environmental Factors (CHIEF), which quantifies environmental barriers (21). The fifth survey is the Functional Independence Measure (FIM), which measures functional capacity based on severity of disability (22,23). The SWLS, CHART, CHIEF, and FIM are the standard components of the NMSCIS follow up questionnaire.

4.2.2.1 Assistive Technology Survey (ATS)

The ATS is a one-page questionnaire, developed by the consensus of the center directors at a NMSCIS meeting. The survey included questions on wheelchairs and other assistive technologies such as modified vehicles and computers. This study focuses only on wheelchair variables. The wheelchair variables include manufacturer and model of the primary wheelchair. Information on wheelchair funding sources (i.e. Medicare, Medicaid, private health insurance, worker's compensation) and wheelchair features (tilt-in-space, recline, standing, seat elevation, and leg elevation) will also be recorded. Aside from their primary wheelchair, subjects were asked whether they owned any additional wheelchair.

4.2.2.2 Satisfaction With Life Scale (SWLS)

The Satisfaction With Life Scale (SWLS) measures the subjective well being of an individual. The SWLS consists of 5-items determining the level of satisfaction based on the individuals' self-appraisal of the current status of their lives in comparison with self-defined expectations of what they would like their lives to be. This comparison is based on a self-defined ideal, to other people, or to one's own past. The SWLS has only five questions about satisfaction of current life status. The degree of life satisfaction is measured in a 7-point Likert scale, with a higher score indicating a higher satisfaction rate. The internal consistency of the SWLS and the alpha coefficients was reported to be 0.80. The two month test-retest yielded a higher correlation coefficient of 0.82 (19).

4.2.2.3 Craig Handicap Assessment and Reporting Technique (CHART)

The CHART-SF (short form) has 19 items, which measures the degree of active social participation for individuals with disabilities. The items in CHART are designed based on objectively observable criteria to minimize subjective interpretation. These items include five of the six dimensions of the WHO conceptualization of handicap: 1) physical independence, 2) mobility, 3) occupation, 4) social integration, and 5) economic self-sufficiency. For the purpose of this study, our analyses included only 3 of the 5 domains: physical independence, mobility, and social integration. Scores for each domain ranges between 0 and 100, with the higher score indicating the absence of disability and active social participation. Analysis of CHART-SF has been conducted on various disability populations including individuals with SCI. The results showed CHART-SF yielded reasonable estimates of all domains. The CHART's one week test-retest reliability was reported to be 0.93 (20).

4.2.2.4 Craig Hospital Inventory of Environmental Factors (CHIEF)

The CHIEF-SF (short form) is designed to quantify the degree of environmental barriers that either impede or facilitate social integration for individuals with disabilities. Environmental barriers are characterized by five domains: 1) policies; 2) physical and structural; 3) work and school; 4) attitudes and support; 5) services and assistance. For the purpose of this study, our analyses included only 1 of the 5 domain, physical and structural. Respondents rate the frequency with which they encounter barriers (daily, weekly, monthly, less than monthly, or never) on the 25 items of the CHIEF-SF. When respondents indicate that they encounter environmental barriers at any frequency other

than never, a follow-up question is asked about whether they consider the barrier to be a big or a little problem. Scoring of each CHIEF-SF item is the product of the frequency score (from never=0 to daily=4) and the magnitude of impact score (little problem=1 and big problem=2) to produce an item score that ranges from 0-8. Therefore, higher scores indicate a greater frequency and/or magnitude of environmental barriers. The two week test-retest reliability was found to be 0.93 (21)

4.2.2.5 Functional Independence Measure (FIM)

The FIM instrument measures functional capacity based severity of disabilities. It has 18 items covering 6 different domains: self care, sphincter control, mobility, locomotion, communication, and social cognition. This study included only 13 items of the four domains: self care, sphincter control, mobility, and locomotion. The item of each domain is scored on a scale of 1 to 7. A score of 7 means the individual is able to perform the specific task independently without the aid of a person or equipment. An individual who is fully dependent receives a score of 1. The highest total score is 91 and the lowest total score is 13. The reliability coefficient of 0.83 for total FIM scores was obtained from a study among individuals with a spinal cord injury (22,23).

4.2.3 Data Collection

The initial phase of data collection began in January 2003 and ended in June 2003 with the participation of 13 NMSCIS centers. Thereafter, the ATS was revised by adding more variables on other mobility devices. Data collection resumed in April 2004

with all 16 NMSCIS centers (listed in the Appendix) participating in the data collection. For the purpose of this study, we included data collected in the first phase and only data collected from April 2004 to August 2004 during the subsequent phase.

Data collectors from each participating center were responsible for administering the ATS, which is part of the annual follow up interview. The follow up interview included questions on demographics, medical complications, functional capabilities, quality of life measures, and wheelchair technology. Participants completed the follow up interview by phone, in person interview, or postal mail. Data collected at the participating centers were submitted via FTP, e-mail, fax, or postal mail to the central data collection sites: the University of Pittsburgh Model Center on Spinal Cord Injury and the National Spinal Cord Injury Statistical Center at the University of Birmingham. No personal identification of the participants was transmitted to ensure confidentiality of the data.

4.2.4 Power Wheelchair Classification

Power wheelchairs were classified based on the characteristics of the frame or power base, programmable controls, and customizable features. Wheelchair manufacturer and model were reviewed and power wheelchairs were classified into three categories. Customizable power wheelchairs were power wheelchairs with programmable controls that had at least one of the following customizable features: 1) capable of accommodating advanced seating systems such as tilt-in-space or standing; 2) a suspension system; or 3) a high torque motor and stronger frame. The second category was standard power wheelchairs with programmable controls. The remaining

category was standard power wheelchairs. Using this classification system the majority of customizable wheelchairs with programmable controls corresponded to K0014 as defined by Centers for Medicare and Medicaid Services' Healthcare Common Procedure Coding System, where as standard power wheelchairs with programmable controls corresponded to K0011, and standard power wheelchairs corresponded to K0010 (24).

4.3 ANALYSIS

4.3.1 Study Sample

The goal of this study focused on the impact of wheelchair use; therefore, non-wheelchair users were excluded from the study sample. With regard to the types of wheelchair used, we were interested in getting a pure sample of manual and power wheelchair users. Since it is not uncommon for wheelchair users to have multiple wheelchairs and these additional wheelchairs may not be the same type as the primary wheelchairs. Those who used more than one type of wheelchair are potential confounders when assessing the impact of a specific type of wheelchair. Therefore, for the analyzing the impact of manual and power wheelchairs, we included only individuals who used one type of wheelchair. For analyzing the impact of ownership of additional wheelchairs, we divided the study sample into three subgroups: those who did have any additional wheelchairs, those who had more than one wheelchair but of the same type, and those who had more than one wheelchair but of different types. The distribution of these comparison groups are detailed in Table 4.1.

4.3.2 Statistical Procedures

All analyses for this study were conducted with SPSS^a Software version 12. Preliminary analyses showed that data on quality of life measures, age, post injury years, and FIM were not distributed normally. Therefore, Kruskal-Wallis tests were used to compare the mean scores of all the quality of life measures: physical/structural barriers, mobility, physical independence, social integration, and life satisfaction as well as average age, post injury years, and FIM scores, for all the comparison groups. Mann-Whitney U tests were used to detect interaction effect between wheelchair users with and without additional wheelchairs.

4.4 RESULTS

4.4.1 Quality of Life Measures

The results of all the quality of life outcome measures among all the comparison groups are shown in Table 4.2. The following sections highlighted the significant findings of the comparison groups.

4.4.1.1 Wheelchair Types

Among wheelchair users with paraplegia, manual wheelchair users scored significantly higher on physical independence (91.25 ± 22.43 vs. 56.73 ± 42.33 , $p=0.000$) and mobility (83.68 ± 22.51 vs. 64.00 ± 32.73 , $p=0.001$) than power wheelchair users. Among those with tetraplegia, manual wheelchair users also scored higher on physical

independence (84.27 ± 29.73 vs. 60.34 ± 36.78 , $p=0.000$) compared to power wheelchair users. All other outcome measures were not statistically different between these comparison groups.

4.4.1.2 Additional Wheelchairs

Among wheelchair users with paraplegia, single type wheelchair users scored significantly higher on mobility than those who did not have additional wheelchairs (89.52 ± 18.03 vs. 78.47 ± 25.85 , $p=0.002$) and those who used 2 types of wheelchairs (89.52 ± 18.03 vs. 76.72 ± 23.19 , $p=0.001$). Those who did not have additional wheelchairs attained a higher level of physical independence when compared to those who used two types of wheelchairs (88.51 ± 26.46 vs. 77.11 ± 34.59 , $p=0.011$). Among wheelchair users with tetraplegia, all three comparison groups achieved different level of physical independence. Single type wheelchair users had the highest level of physical independence (78.86 ± 35.13 , $p=0.020$), followed by those who did not have any additional wheelchairs (71.79 ± 34.88 , $p=0.000$), and those who used two types of wheelchairs had the lowest scores (58.69 ± 36.71 , $p=0.009$). All other outcome measures between these groups were not statistically different.

4.4.1.3 Customization

The differences in all the quality of life outcome measures between those who used K0011 and K0014 power wheelchairs were found not to be statistically significant.

4.4.2 Average Age, Post Injury Years, and FIM Scores

Among wheelchair users with paraplegia, power wheelchair users were significantly older (55.96 ± 12.81 vs. 39.61 ± 12.58 , $p=0.000$) than manual wheelchair users. Those who used 2 types of wheelchairs were also older (49.46 ± 14.56) when compared to the single type wheelchair users (40.20 ± 13.09 , $p=0.002$) and those who had no additional wheelchairs (41.52 ± 13.63 , $p=0.003$). The differences in average age among all wheelchair users with tetraplegia and those who used K0011 and K0014 wheelchairs were not statistically significant.

The differences in average FIM scores were statistically significant between all comparison groups except between single type wheelchair users with paraplegia and those who had no additional wheelchairs (77.59 ± 8.77 vs. 74.66 ± 13.36 , $p=0.361$) as well as wheelchair users with paraplegia who used two types of wheelchairs and those who had no additional wheelchairs (74.66 ± 13.36 vs. 69.13 ± 16.82 , $p=0.095$). There were no statistical differences found in post injury years between all comparison groups. The results of these analyses are shown in Table 4.3.

4.5 DISCUSSION

Contrary to our hypotheses, power wheelchair users did not perform better across all the quality of life outcome measures. In fact, power wheelchairs with paraplegia attained lower mobility scores and power wheelchair users with tetraplegia achieved lower level of physical independence when compared to their counterparts who used manual wheelchairs. However, the observed differences may be confounded by the age and functional capacity of the wheelchair users as indicated in the

subsequent analyses. Our results indicated that power wheelchair users with paraplegia were significantly older than manual wheelchair users. Also the functional capacity of power wheelchair users, regardless of the level of injury, was significantly lower when compared to manual wheelchair user. Declining physical strength due to aging and a decreased in functional capacity resulting from severity of disability can significantly impact mobility as well as physical independence (25). Therefore, the observed differences in mobility and physical independence may be attributed to diminished functional capacity, advanced age, and wheelchair types. However, it is worth noting that even though the power wheelchair users in our study sample were older and had lower functional capacity, they were able to overcome similar levels of physical and structural barriers, achieve comparable levels of social integration and life satisfaction. Similarly, K0014 power wheelchair users with lower level of functional capacity achieved comparable scores on all outcome measures compared to those who used K0011 power wheelchairs. The customizable features such as higher torque motor, suspension system, and stronger power base might account for the enhanced performance of those who used K0014 wheelchairs.

However, when comparing wheelchairs users with paraplegia who had no additional wheelchairs and those who used single type wheelchairs; single type wheelchair users scored the highest on mobility. Subsequent analysis showed that there were no differences in age, post injury years, and FIM scores between these two groups. This lead us to conclude that observed results were not confounded by age, post injury years, or functional capacity, and that having additional wheelchairs enabled wheelchair users to achieve higher level of mobility.

Our results make intuitive sense in that having additional wheelchairs is a great benefit to wheelchair users when their primary wheelchair experiences problems. With additional wheelchairs, the risk of stranded in a public place or confined to the home would be mitigated. Furthermore, daily life activities such as work and school would not have to be disrupted. Thus, allowing wheelchair users to have a higher level of mobility function.

The results of this study also showed that higher levels of mobility and physical independence among manual wheelchair users did not lead to higher levels of social integration and life satisfaction. A plausible explanation might be the multidimensional nature of the social integration and life satisfaction constructs. There are indeed a host of other factors that may influence the levels of social integration and life satisfaction. For example, as reported in a 2000 Harris Polls survey, the lack of social participation among PWD can also be attributed to attitudinal barriers of the community (26). In a qualitative study, Levin et al associated the lack of social participation to psychological adjustment living with an SCI (27). Therefore, the multidimensional nature of these constructs might have been too broad to address the specific queries of the mobility and physical independence domains as they are related to mobility function.

Several limitations of this study need to be addressed in future studies. Besides age and functional capacity, there may be other factors that confound the measure of mobility and physical independence. In terms of the impact of wheelchair use on these factors, besides physical and structural barriers, other factors such as terrain and weather can severely impact mobility and physical independence. For example, manual wheelchair users who have to navigate through challenging terrains like uphill slopes

and gravel surfaces on a daily basis might have limited mobility and physical independence compared to those who travel through paved level streets. Likewise, manual wheelchair users living in cold climates may have mobility restriction in the winter months when frigid icy weather makes it difficult if not impossible to use manual wheelchair in an outdoor setting. To address these shortcomings, future studies should include other factors that may impact mobility and physical independence related to wheelchair use. With regard to the multidimensional nature of the social integration and life satisfaction constructs, future studies should include questions that are more specific and narrow in scope to capture the impact of wheelchair use on these constructs.

While our study results could not establish a direct association between the types and design features of wheelchair used and the level of social participation and life satisfaction; it showed that a strong association existed between having additional wheelchairs and high levels of mobility among wheelchair users with paraplegia. This leads us to conclude that having additional wheelchairs can greatly enhance the mobility function of wheelchair users. The results of this study may provide important evidence for advocating the benefit of providing additional wheelchairs to ISCI and addressing the problem of lack of insurance coverage for additional wheelchairs.

4.6 CONCLUSION

We were not able to establish an association between the types and design features of wheelchair used on quality of life. However, based on the results, we were able to conclude that having additional wheelchairs was associated with enhanced

mobility for wheelchair users. Also power wheelchair users with advanced age and lower functional capacity were able to achieve comparable quality of life outcome measures compared to their counterparts, younger manual wheelchair users who had higher level of functional capacity. This finding may provide important evidence for advocating for the benefit of providing additional wheelchairs to ISCI and addressing the lack of insurance coverage for additional wheelchairs.

4.7 REFERENCES

1. Meyers AR, Anderson JJ, Miller DR, Shipp K, Hoenig H. Barriers, facilitators, and access for wheelchair users: substantive and methodologic lessons from a pilot study of environmental effects. *Soc Sci Med*. 2002 Oct;55(8):1435-46.
2. Cooper RA. *Wheelchair selection and configuration*. New York: Demos Medical Publishing, Inc.;1998.
3. Davies A, De Souza LH, Frank AO. Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs. *Disabil Rehabil*. 2003 Mar 18;25(6):286-90.
4. Brandt A, Iwarsson S, Stahle A. Older people's use of powered wheelchairs for activity and participation. *J Rehabil Med*. 2004 Mar;36(2):70-7.
5. Routhier F, Vincent C, Desrosiers J, Nadeau S. Mobility of wheelchair users: a proposed performance assessment framework. *Disabil Rehabil*. 2003 Jan 7;25(1):19-34.
6. Vogel LC, Klaas SJ, Lubicky JP, Anderson CJ. Long-term outcomes and life satisfaction of adults who had pediatric spinal cord injuries. *Arch Phys Med Rehabil*. 1998 Dec;79(12):1496-503.
7. Anderson CJ, Vogel LC. Domain-specific satisfaction in adults with pediatric-onset spinal cord injuries. *Spinal Cord*. 2003 Dec;41(12):684-91.
8. Dijkers MP. Correlates of life satisfaction among persons with spinal cord injury. *Arch Phys Med Rehabil*. 1999 Aug;80(8):867-76.
9. Karp G. Cutting edge manual wheelchairs. *New Mobility*. July 2001.
10. Benson, G. Spinal Cord Injury – InfoSheet “Selecting a Wheelchair” #7. Alabama: UAB-Spain Rehabilitation Center; 1995. Grant (#H133B30025). Sponsored by the National Institute on Disability and Rehabilitation Research, Dept of Education.
11. Edlich RF, Nelson KP, Foley ML, Buschbacher RM, Long WB, Ma EK. Technological advances in powered wheelchairs. *J Long Term Eff Med Implants*. 2004;14(2):107-30.
12. Cooper RA. Engineering manual and electric powered wheelchairs. *Crit Rev Biomed Eng*. 1999;27(1-2):27-73.
13. Attali X, Pelisse F. Looking back on the evolution of electric wheelchairs. *Med Eng Phys*. 2001 Dec;23(10):735-43.
14. Hunt PC, Boninger ML, Cooper RA, Zafonte RD, Fitzgerald SG, Schmeler MR. Demographic and socioeconomic factors associated with disparity in wheelchair customizability among people with traumatic spinal cord injury. *Arch Phys Med Rehabil*. 2004 Nov;85(11):1859-64.
15. Martin SG, Fitzgerald SG, Cooper RA, Collins DM, Impink BG. Characteristics of ultralight wheelchairs: maintenance and repairs, proceedings of the 26th annual RESNA Conference, Atlanta, Ga, CD-Rom, 2003.
16. Gaal RP, Rebholtz N, Hotchkiss RD, Pfaelzer PF. Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *J Rehabil Res Dev*. 1997;34(1):58-71.

17. Stover SL, DeVivo MJ, Go BK. History, implementation, and current status of the National Spinal Cord Injury Database. *Arch Phys Med Rehabil.* 1999 Nov;80(11):1365-71.
18. National Model Spinal Cord Injury Model System. Data collection syllabus 2000-2005. Alabama: National Spinal Cord Injury Statistics Center; 2004.
19. Pavot, W., Diener, E. (1993). Review of the Satisfaction With Life Scale. *Psychological Assessment*, 5(2), 164-172.
20. Whiteneck, GG, Charlifue, SW, Gerhart, KA, Overholser, JD, Richardson, GN. Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation* 1992, 73:519-526.
21. The center for outcome measurement in brain injury. CHIEF properties. Nd. [Cited March 1, 2005]. Available from: <http://www.tbims.org/combi/chief/chiefprop.html>
22. Granger CV, Hamilton BB, Linacre JM, Heinemann AW, Wright BD. Performance profiles of the functional independence measure. *Am J Phys Med Rehabil.* 1993 Apr;72(2):84-9.
23. Segal ME, Ditunno JF, Staas WE. Interinstitutional agreement of individual functional independence measure (FIM) items measured at two sites on one sample of SCI patients. *Paraplegia.* 1993 Oct;31(10):622-31.
24. Centers for Medicare and Medicaid Services. Healthcare Common Procedure Coding System (HCPCS). [Cited March 1, 2005]. Available from URL: <http://www.cms.hhs.gov/medicare/hcpcs/default.asp?>
25. Charlifue S, Gerhart K. Community integration in spinal cord injury of long duration. *NeuroRehabilitation.* 2004;19(2):91-101.
26. Humphrey Taylor. Many people with disabilities feel isolated, left out of their communities and would like to participate more. *The Harris Poll: #34*, July 05, 2000.
27. Levins SM, Redenbach DM, Dyck I. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study. *Phys Ther.* 2004 Jun;84(6):496-509.

SUPPLIER

^aSPSS Inc. Headquarters, 233 S. Wacker Drive, 11th floor, Chicago, Illinois 60606

Table 4-1 Distribution of wheelchair users

Comparison Groups	
Pure Sample	Wheelchair users who used only one type of wheelchair (n=462)
Paraplegia	Power (n=25) vs. Manual (n=244) WC users
Tetraplegia	Power (n=106) vs. Manual (n=87) WC users
Customization	K0011 (n=49) vs. K0014 power (n=36) WC users
Study Sample	
	All wheelchair users with and without additional wheelchairs (n=635)
	Users with no additional (n=189) vs. users with 1 type of (n=80) WC
Paraplegia	Users with 1 type (n=80) vs. users with 2 types (n=55) of WC
	Users with no additional (n=189) vs. users with 2 types of (n=55) WC
	Users with no additional (n=153) vs. users with 1 type of (n=40) WC
Tetraplegia	Users with 1 type (n=40) vs. users with 2 types (n=118) of WC
	Users with no additional (n=153) vs. users with 2 types of (n=118) WC

Table 4-2 Quality of life outcome measures among all comparison groups

		Life Satisfaction	Physical Independence	Mobility	Social Integration	Physical Barriers
Paraplegia	Power WC	18.32±8.64	56.73±42.33	64.00±32.73	84.91±28.48	0.79±1.28
	Manual WC	21.39±8.00	91.25±22.43	83.68±22.51	90.14±19.67	0.84±1.13
		p=0.149	p=0.000	p=0.001	p=0.609	p=0.212
Paraplegia with add WC	No add WC	20.53±7.92	88.51±26.46	78.47±25.85	88.60±21.44	0.87±1.24
	1 type WC	22.40±8.37	87.14±27.43	89.52±18.03	92.09±18.59	0.74±0.842
	2 types WC	21.47±7.24	77.11±34.59	76.72±23.19	89.43±22.48	1.11±1.27
		*p=0.089 +p=0.374 ‡p=0.677	*p=0.787 +p=0.048 ‡p=0.011	*p=0.002 +p=0.001 ‡p=0.304	*p=0.191 +p=0.544 ‡p=0.766	*p=0.841 +p=0.320 ‡p=0.244
Tetraplegia	Power WC	20.29±7.44	60.34±36.78	72.71±23.37	87.71±23.57	1.35±1.77
	Manual WC	22.56±7.35	84.27±29.73	79.73±24.93	91.08±22.37	1.13±1.39
		p=0.152	p=0.000	p=0.113	p=0.608	p=0.870
Tetraplegia with add WC	No add WC	21.04±7.66	71.79±34.88	74.67±25.08	88.92±23.27	1.23±1.59
	1 type WC	21.89±7.09	78.86±35.13	84.38±19.72	92.14±19.61	0.93±1.40
	2 types WC	19.54±8.34	58.69±36.71	77.56±21.59	89.81±20.87	1.15±1.44
		*p=0.433 +p=0.256 ‡p=0.437	*p=0.020 +p=0.023 ‡p=0.009	*p=0.058 +p=0.184 ‡p=0.198	*p=0.206 +p=0.342 ‡p=0.573	*p=0.532 +p=0.632 ‡p=0.702
Customization	K0011 WC	19.09±7.44	68.45±35.25	73.98±23.36	84.58±26.55	1.29±1.70
	K0014 WC	20.40±7.78	55.35±36.81	72.16±27.05	90.78±19.64	1.48±2.03
		p=0.484	p=0.063	p=0.782	p=0.109	p=0.984

Note: * Differences between those who had no additional wheelchairs and those who used a single type of wheelchairs
+ Differences between those who used a single type of wheelchair and those who used two types of wheelchairs
‡ Differences between those who had no additional wheelchairs and those who used two types of wheelchairs
|| Those who used a single type of wheelchairs mean both their primary and additional wheelchairs were of the same types of wheelchairs
¶ Those who used two types of wheelchairs mean their primary and additional wheelchairs were of different types of wheelchairs

Table 4-3 Age, post injury years, and FIM scores among all comparison groups

		Age		PIY		FIM	
Paraplegia	Power WC	55.96±12.81	p=0.000	9.68±7.73	p=0.204	57.45±20.16	p=0.000
	Manual WC	39.61±12.58		10.65±7.87		77.61±8.95	
Additional WC	No add WC	41.52±13.63	*p=0.540 +p=0.002 ‡p=0.003	10.21±7.64	*p=0.385 +p=0.091 ‡p=0.201	74.66±13.36	*p=0.361 +p=0.033 ‡p=0.095
	1 type WC	40.20±13.09		11.38±8.31		77.59±8.77	
	2 types WC	49.46±14.56		8.36±7.01		69.13±16.82	
Tetraplegia	Power WC	39.75±11.38	p=0.925	11.01±7.52	p=0.721	32.43±16.40	p=0.000
	Manual WC	41.06±12.95		11.85±7.48		64.11±21.73	
Additional WC	No add WC	41.06±13.10	*p=0.709 +p=0.595 ‡p=0.822	10.34±7.54	*p=0.306 +p=0.224 ‡p=0.751	42.69±24.97	*p=0.003 +p=0.000 ‡p=0.043
	1 type WC	39.12±10.74		12.00±7.54		62.95±22.96	
	2 types WC	40.24±10.67		10.23±8.07		36.56±17.63	
Customization	K0011 WC	43.82±13.42	p=0.178	9.88±7.96	p=0.516	57.85±30.95	p=0.005
	K0014 WC	39.83±11.80		11.11±7.91		38.27±24.23	

Note: * Differences between those who had no additional wheelchairs and those who used a single type of wheelchairs

+ Differences between those who used a single type of wheelchair and those who used two types of wheelchairs

‡ Differences between those who had no additional wheelchairs and those who used two types of wheelchairs

|| Those who used a single type of wheelchairs mean both their primary and additional wheelchairs were of the same types of wheelchairs

¶ Those who used two types of wheelchairs mean their primary and additional wheelchairs were of different types of wheelchairs

4.8 APPENDIX

NMSCIS centers participated in ATS data collection

17. University of Alabama at Birmingham SCI Care System^a
18. Regional SCI Care System of Southern California^a
19. Northern California SCI System^{ab}
20. Rocky Mountain Regional SCI System^{ab}
21. Georgia Regional SCI System^{ab}
22. New England Regional SCI Center^a
23. University of Michigan Model SCI System^{ab}
24. Missouri Model SCI System^{ab}
25. Mount Sinai SCI Model System^a
26. Regional SCI System of Delaware Valley^{ab}
27. University of Pittsburgh Model System on SCI^{ab}
28. Texas Regional SCI System^{ab}
29. Virginia Commonwealth Regional SCI System^{ab}
30. Northern New Jersey Spinal Cord Injury System^b
31. South Florida Regional Spinal Cord Injury Model System^b
32. Northwest Regional Spinal Cord Injury System^b

Key: ^a Centers participated in only the initial phase of data collection
^b Centers participated in only the subsequent phase of data collection
^{ab} Centers participated in the initial and subsequent phase of data collection

5.0 SUMMARY AND CONCLUSION

5.1 STANDARD OF CARE

The results of our study showed that there is a standard of care for wheelchair customizability across the National Model Spinal Cord Injury Systems (NMSCIS). The standard of care found in this study supports previous studies that recommend manual wheelchair users with SCI be provided with lightweight customizable wheelchairs (1,2). In addition, this study indicated that power wheelchair users with SCI be provided with programmable controls and customizable features.

The standard of care found in this study, however, is not reflected in the current Medicare regulations that dictates wheelchair users be prescribe with standard non-customizable manual and power wheelchairs. Although this study indicates that customizable wheelchairs are being provided despite these regulations, recent efforts by the Centers of Medicare and Medicaid Services to crack down on fraud have threatened the ability of Rehabilitation Technology Suppliers and Rehabilitation Professionals to obtain these customizable equipments (3).

Furthermore, this standard of care may not be generalizable to ISCI receiving treatments in other healthcare systems. In a recent study, Hubbard and colleagues found that the standard of care for providing wheelchairs within the U.S. Veterans Health Administration to be quite different, about 38% of veterans with SCI received standard manual wheelchairs and 40% of veterans received standard power wheelchairs. The differences in standard of care might attribute to how services are being delivered in different healthcare systems (4).

It is possible that by establishing this standard of care will help assistive technology suppliers and rehabilitation professionals within the NMSCIS to better advocate for their patients..

5.2 FACTORS ASSOCIATED WITH WHEELCHAIR USED

The type, manual or power, of wheelchair prescribed to ISCI is primarily determined by the level of SCI, upper body function, and trunk control (5). However, these clinical indicators are not absolute determinant factors for wheelchair prescription, factors such as age and the duration of wheelchair used may also be potential factors in wheelchair choice (6,7). As indicated by the results of this study, older wheelchair users with paraplegia were more likely to use power wheelchairs. However, age differences were not found between manual and power wheelchair users with tetraplegia. Wheelchair transition might have been a confounder for this observation. If there was a large number of young manual wheelchair users already transitioned to power wheelchair use at the time of the survey, this would have lowered the average age of power wheelchair users. Because this study was a survey by design, we were not able to gather any information on when wheelchair transition occurred and the factors that influenced wheelchair transitions. Without such information, it was not possible to eliminate this potential confounder for the current study.

With regard to the duration of wheelchair use as measured by post injury years, there were also no differences found between manual and power wheelchair users with paraplegia and tetraplegia. However, a positive correlation was found between age and post injury. Such observation indicated that, regardless of the level of SCI, many

manual wheelchair users were able to use manual wheelchairs for a long period of time. The average post injury years for manual wheelchair users with paraplegia and tetraplegia averaged more than 10 years. The fact that 97% of our study sample used customizable ultralight weight manual wheelchairs might provide a plausible explanation for this observation. Ultralight weight manual wheelchairs are constructed with lighter materials and are customized with features such as an adjustable axle position, making wheelchair propulsion more energy efficient. Use of ultralight weight customizable manual wheelchairs might lessen the risk for developing upper extremity pain and impairments (1,2) and enabled users to continue manual wheelchair use for an extended period of time.

5.3 DISPARITIES IN ACCESS TO WHEELCHAIR TECHNOLOGY

Although our study did not find any differences in the socioeconomic statuses (SES) between manual and power wheelchairs users, minorities with lower SES had less access to customizable wheelchairs and less likely to own any additional wheelchairs. Having access to additional wheelchairs is important for the mobility and safety of the wheelchair users. Wheelchair breakdown is not only an inconvenience, physical injuries have been found to be caused by wheelchair “component failures” (8). Our results showed that individuals in the higher socioeconomic stratum were more likely to own additional wheelchairs. Possession of additional wheelchairs is a potential solution to the occasional malfunction of wheelchairs. This is particularly problematic for older and more frequently used wheelchairs. For individuals without back up

wheelchairs, their daily life can be severely hampered when their only wheelchair breaks down.

The results of this study are supported by studies on access barriers to assistive technology among socioeconomically disadvantaged population. Family of individuals from low socioeconomic backgrounds often have other pressing concerns such as food, clothing, transportation, and shelter, which make it difficult for the family to participate in the decision process of obtaining assistive technology or advocate for the need of high quality assistive technology (9,10). In some traditional cultures, replacing human care for people with disabilities with assistive technology is culturally unacceptable (11). The lack of participation in decision-making and cultural tradition may result in limiting the user's access to the appropriate and adequate assistive technology.

Furthermore, individuals with public sector insurance (Medicare/Medicaid) and low income were associated with standard wheelchairs. This finding is supported by the National Council on Disability study, which concluded federal policy barriers are responsible for the disparity in acquisition of appropriate assistive technology (12). The gap in Medicare reimbursement poses a significant financial burden on Medicare recipients with low income. Customizable wheelchairs are more expensive than standard wheelchairs. Medicare reimburses only 80% of the total cost of wheelchairs, the other 20% of the cost must be assumed by the users. Individuals who cannot afford this 20% co-payment may force to choose a less expensive wheelchair in order to minimize their out-of-pocket expenses.

Based on the findings of the current survey, solutions must be created to address the inequity of access to high quality and additional wheelchairs among the

socioeconomically disadvantaged population. A solution would be to reform the current Medicare reimbursement policy to address the inequity of coverage for economically disadvantaged minorities. Alternative funding schemes such as governmental subsidy and low interest-rate loan programs would this population to obtain the appropriate wheelchairs. Wheelchair users also need to be educated consumers and actively participating in the decision making process. Rehabilitation Professionals and Rehabilitation Technology Suppliers may help by being strong advocates for socioeconomically disadvantaged individuals in acquiring better wheelchair technology.

5.4 IMPACT OF WHEELCHAIR USE ON QUALITY OF LIFE

In determining the impact of wheelchair types on quality of life measures, we found significant differences in mobility and physical independence among manual and power wheelchair users. However, subsequent analysis showed that age and function were potential confounders for the observed differences. Therefore, we could not establish an association between wheelchair types and its impact on quality life. However, it is worth noting that even though the power wheelchair users in our study sample were older and had lower functional capacity, they were able to overcome similar level of physical and structural barriers, achieve comparable levels of social integration and life satisfaction. Similarly, K0014 power wheelchair users with lower level of functional capacity achieved comparable scores on all outcome measures compared to those who used K0011 power wheelchairs.

In determining the impact of having additional wheelchairs, our results also showed that manual wheelchair users with paraplegia who had additional wheelchairs attained higher mobility scores. Since there were no differences in age, post injury

years, and FIM scores between those who had and those who did not have additional wheelchairs, the observed results indicated that having additional wheelchairs was strongly associated with a higher level of mobility function. Our results make intuitive sense in that having additional wheelchairs is a great benefit to wheelchair users when their primary wheelchair experiences failures. With additional wheelchairs, the risk of stranded in a public place or confined to the home would be mitigated. Furthermore, daily life activities such as work and school would not have to be disrupted. Thus, allowing wheelchair users to have a higher level of mobility function. This finding may provide important evidence for advocating for the benefit of providing additional wheelchairs to ISCI and addressing the problem of lack of insurance coverage for additional wheelchairs.

The results of this study also showed that higher levels of mobility and physical independence among manual wheelchair users did not lead to higher levels of social integration and life satisfaction. A plausible explanation might be the multidimensional nature of the social integration and life satisfaction constructs. There are indeed a host of other factors that may influence the levels of social integration and life satisfaction. For example, as reported in a 2000 Harris Polls survey, the lack of social participation among PWD can also be attributed to attitudinal barriers of the community (13). In a qualitative study, Levin et al associated the lack of social participation to psychological adjustment living with an SCI (14). Therefore, the multidimensional nature of these constructs might have been too broad to address the specific queries of the mobility and physical independence domains as they are related to mobility function. To address

this problem, future studies should include questions that are more specific and narrow in scope to capture the impact of wheelchair use on these constructs.

Besides age and functional capacity, there may be other factors that confound the measure of mobility and physical independence. In terms of the impact of wheelchair use on these factors, besides physical and structural barriers, other factors such as terrain and weather can severely impact mobility and physical independence. For example, manual wheelchair users who have to navigate through challenging terrains like uphill slopes and gravel surfaces on a daily basis might have limited mobility and physical independence compared to those who travel through paved level streets. Likewise, manual wheelchair users living in cold climates may have mobility restriction in the winter months when frigid icy weather makes it difficult if not impossible to use manual wheelchair in an outdoor setting. To address these shortcomings, future studies should include other factors that may impact mobility, physical independence, and quality of life as they are related to wheelchair use.

5.5 LIMITATIONS AND RECOMMENDATIONS FOR FUTURE STUDIES

The current study has several limitations that need to be addressed in future studies. First, this was a cross sectional study by design. We could only establish association but not causality with our findings. Because it was a survey, we had no knowledge about the type of wheelchair use since the time of injury and whether or not the participants had transitioned to a different type of wheelchair prior the time of this study. Such information was vital to fully understand the factors that influenced wheelchair choice for this population. Also, the questionnaires used to assess quality of

life measures might not have been designed specifically for assessing the impact of wheelchair use. Lacking such specificity might account for our inability to establish any association between wheelchair use, social integration, and life satisfaction. Future studies need to adapt a prospective approach with questionnaires that are specifically designed to evaluate wheelchair use.

Secondly, our study sample was comprised of more than 80% Caucasians. The remaining 20% of Non-Caucasians were representative of many different cultural and ethnic groups. In order to conduct some meaningful analysis, we had to group all these Non-Caucasians together as "minorities". By doing so, we were not able to fully investigate the socioeconomic and cultural influence of each of these minority groups on disparities in access to wheelchair technology. Future studies need to take a more diligent approach to over-sample the minority population.

Lastly, a significant number of our participants did not report information on the manufacturer and model of their wheelchairs, quality of life outcome measures, and their annual income. These missing values in turn greatly diminished our sample size, which prevented us from using parametric analyses to assess quality of life outcome measures. The lack of sample size also impeded our ability to conduct multivariate analysis of variance to eliminate many of the potential confounders on mobility and physical independence. We suggest future studies include a much larger study sample to account for the missing values.

5.5 REFERENCES

1. Boninger ML, Cooper RA, Baldwin MA, Shimada SD, Koontz A. Wheelchair pushrim kinetics: body weight and median nerve function. *Arch Phys Med Rehabil* 1999; 80: 910-5.
2. Boninger ML, Baldwin M, Cooper RA, Koontz A, Chan L. Manual wheelchair pushrim biomechanics and axle position. *Arch Phys Med Rehabil* 2000;81:608-13.
3. Centers for Medicare and Medicaid Services. New efforts aimed at stopping abuse of the power wheelchair benefit in the Medicare program. [cited March 15, 2004]. Available from URL: <http://www.cms.hhs.gov/media/press/release.asp?Counter=843>
4. Hubbard SL, Fitzgerald SG, Reker DM, Boninger ML, Cooper RA, Kazis LE. Wheelchairs and demographic characteristics: Demographic characteristics of veterans receiving wheelchairs and scooters from the veteran health administration [Dissertation]. Pittsburgh (PA): University of Pittsburgh; 2005.
5. Cooper RA. Wheelchair selection and configuration. New York: Demos Medical Publishing, Inc.;1998.
6. Charlifue S, Gerhart K. Community integration in spinal cord injury of long duration. *NeuroRehabilitation*. 2004;19(2):91-101.
7. Benson, G. Spinal Cord Injury – InfoSheet “Selecting a Wheelchair” #7. Alabama: UAB-Spain Rehabilitation Center; 1995. Grant (#H133B30025). Sponsored by the National Institute on Disability and Rehabilitation Research, Dept of Education.
8. Gaal RP, Rebholtz N, Hotchkiss RD, Pfaelzer PF. Wheelchair rider injuries: causes and consequences for wheelchair design and selection. *J Rehabil Res Dev*. 1997;34(1):58-71.
9. Kemp, Crystal E, Parrette, Howard P. Barriers to Minority Family Involvement in Assistive Technology Decision-Making Processes. *Education and Training in Mental Retardation and Development Disabilities* 2000;35 (4):384-92.
10. Parrette HP, VanBiervliet A, Hourcade JJ. Family-centered decision making in assistive technology. *Journal of Special Education Technology* 2000;15(1):45-55.
11. Anderson JM. Ethnicity and illness experience: Ideological structures and the health care delivery system. *Social Science and Medicine* 1986;22:1277-1283.
12. National Council on Disability. Federal policy barriers to assistive technology: a report to the President of the United States. May 31, 2000 [cited March 15, 2004]. Available from URL: <http://www.ndc.gov/newsroom/publications/assistivetechonology.html>
13. Humphrey Taylor. Many people with disabilities feel isolated, left out of their communities and would like to participate more. *The Harris Poll: #34*, July 05, 2000.

14. Levins SM, Redenbach DM, Dyck I. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study. *Phys Ther.* 2004 Jun;84(6):496-509.