

UTILIZATION AND ACCESS TO HEALTHCARE SERVICES AMONG PEOPLE  
LIVING WITH SPINAL CORD INJURIES IN THE COMMUNITY

Shayan Noorani, B.A.

APPROVED:

---

Major Professor

---

Committee Member

---

Committee Member

---

Committee Member

---

Department Chair

---

Dean, Graduate School of Biomedical Sciences

UTILIZATION AND ACCESS TO HEALTHCARE SERVICES AMONG PEOPLE  
LIVING WITH SPINAL CORD INJURIES IN THE COMMUNITY

INTERNSHIP PRACTICUM REPORT

Presented to the Graduate Council of the  
Graduate School of Biomedical Sciences

University of North Texas

Health Science Center at Fort Worth

In Partial Fulfillment of the Requirements

For the Degree of

MASTER OF SCIENCE IN CLINICAL RESEARCH MANAGEMENT

By

Shayan Noorani, B.A.

Fort Worth, Texas

November 2014

## ACKNOWLEDGMENTS

Dr. Simon Driver, PhD

Director of Research

Baylor Institute for Rehabilitation

Simon.Driver@BaylorHealth.edu

Data Analysis:

Monica Bennett, PhD

Biostatistician

Institute for Health Care Research and Improvement

Monica.bennett@baylorhealth.edu

Support Staff:

Cynthia Dunklin, CCRC

Certified Clinical Research Coordinator

Baylor Research Institute

Cynthia.Dunklin@baylorhealth.edu

Librada Callendar, CCRC

Certified Clinical Research Coordinator

Baylor Research Institute

Librada.Callendar@baylorhealth.edu

Samantha Cleveland, BS

Research Assistant

Baylor Research Institute

[Samantha.Cleveland@baylorhealth.edu](mailto:Samantha.Cleveland@baylorhealth.edu)

## TABLE OF CONTENTS

	Page
SIGNATURE PAGE.....	i
TITLE PAGE.....	ii
ACKNOWLEDGMENTS.....	iii
TABLE OF CONTENTS.....	v
LIST OF TABLES.....	vii
LIST OF ILLUSTRATIONS.....	ix
Chapter	
I. INTRODUCTION .....	1
II. INTERNSHIP SUBJECT.....	3
Background.....	3
Specific Aims.....	13
Significance of the problem.....	14
Research Design and Methodology.....	14
Results.....	18
Discussion.....	23
Conclusions.....	28
Limitations.....	30
II. INTERNSHIP EXPERIENCE.....	32
General Internship Experience.....	32
APPENDIX.....	34

A. Daily Journal.....	34
B. Figures and Tables.....	86
C. Survey.....	99
D. Table of Abbreviations.....	108
REFERENCES.....	109

## LIST OF TABLES

	PAGE
Table 1: Summary of Demographic Characteristics.....	10
Table 2: Summary of Spinal Cord Injury Information.....	11
Table 3: Doctor Visits in the Last 12 Months .....	87
Table 4: Accessibility of Doctor's Offices and/or Equipment.....	87
Table 5: Physician Knowledge and Communication.....	89
Table 6: Emergency Room Visits.....	92
Table 7: Preventative Care.....	92
Table 8: Summary of Demographic and Injury Related Characteristics for Patients with an SCI/Rehab Visit vs. Patients without SCI/Rehab Visits.....	93
Table 9: Healthcare Utilization and Preventative Care for Patients with a SCI/Rehab Visit vs. Patients without SCI/Rehab Visits.....	94

Table 10:	Summary of Demographic and Injury Related Characteristics for Patients with an ER Visit vs. Patients without ER Visit in the Past 12 Months.....	95
Table 11:	Healthcare Utilization and Preventative Care for Patients with an ER Visit vs. Patients without ER Visit in the Past 12 Months.....	95



## LIST OF ILLUSTRATIONS

	PAGE
Figure 1: Accessibility of Primary Care, SCI/Rehab, and Specialty Doctor's Office.....	89
Figure 2 (a-c): Physician Knowledge and Communication. ....	90

## ABSTRACT

Healthcare for individuals following spinal cord injury (SCI) plays a significant and necessary role in reducing an individual's risk of managing and preventing associated, secondary, or chronic conditions. Barriers alongside secondary, associated, and chronic issues prevent a viable access to healthcare. Some of these factors include age, income, race, medical insurance type, accessible resources, skill and knowledge of physicians, ER visits, and preventative health measures. This research project will use a cross sectional study design with a survey that utilizes the previously mentioned factors. The purpose of this study is to describe the utilization, accessibility, and satisfaction of primary and preventative health-care services of community-dwelling individuals with SCI. The population sampled was the former inpatient and current outpatient individuals with SCI at a rehabilitation hospital. There were 142 subjects in the study. Of these, 42 were administered the survey by phone and 100 were surveyed in person during a routine follow-up visit. Approximately 99% of individuals in the current sample reported that they had healthcare visits in the past 12 months. Results of the current project also indicated that PCP's (79%) were the most frequently visited physicians, followed by SCI/Rehab physicians (77%) and urologists (50%). Individuals with SCI also had a high number of ED visits (43% of sample within the past 12-months). The primary reasons for ED visits for the current sample were genital/urological (15%), wounds/skin problems (5%), and pneumonia (4%). Of note, individuals who visited the ER had a lower Geo Unit Quality Score and were less likely to have a post-secondary education. For preventative health services, patients with SCI also reported similar utilization to

previous SCI research and data from the general population. Accessibility did not present as a major issue with SCI physicians, and the majority of the study population was satisfied with their physicians. Consequently, further accessibility for individuals with disabilities should be implemented and other barriers should be ameliorated throughout the healthcare industry. Further research and analysis on socio-demographic factors such as transportation, work-related issues, quality of life, needs for better healthcare, and psychological factors can assist in learning more about the needs of individuals with SCI.

## CHAPTER I

### INTRODUCTION

Healthcare for individuals following spinal cord injury (SCI) plays a significant and necessary role in reducing an individual's risk of managing and preventing associated, secondary, or chronic conditions<sup>13</sup>. Daily care with quality healthcare of the resulting health conditions is necessary for successful rehabilitation for the patient, and proper care of the SCI may be for the patient's entire life. The ability to see a qualified physician and having viable access to healthcare must be taken in account along with self-management. Lack of quality care of a physician and self-management may cause decreased quality of life and/or impairing psychological issues; resilience and a dedication to self-manage are needed for the patient to progressively improve on their health<sup>13</sup>. However, any combination of those previous conditions could prevent patients from receiving the care needed and is further impacted by environmental and personal factors. Barriers, alongside secondary, associated, and chronic issues, prevent a viable access to healthcare<sup>13</sup>. Some of these barriers include age, income, race, medical insurance type, accessible resources, skill and knowledge of primary care physician and spinal cord injury/rehab physician, ER visits, preventative health measures, community, and psychological issues<sup>13, 46</sup>. This research project used a cross sectional study design with a survey that utilizes the previously mentioned factors. The purpose of this study is to describe the utilization, accessibility, and satisfaction of primary and preventative health-care services of community-dwelling individuals with SCI. A secondary aim of

this study is to identify and examine barriers between individuals who completed outpatient visits with a SCI/Rehab physician in the past 12-months compared to individuals who did not.

## CHAPTER II

### INTERNSHIP SUBJECT

#### **Background**

Every year approximately 12,000 people sustain a SCI, and about 300,000 people currently live in United States with SCI <sup>1,2</sup>. SCI may result in significant changes in long-term functional status and quality of life for individuals and their families <sup>3,4</sup>. These impairments will ultimately lead to a multisystem dysfunction in different domains: physical, psychological, and social <sup>5-8</sup>. Furthermore, as a result of the injury individuals are at greater risk of experiencing different co-morbidities, which can further impact their ability to complete activities of daily living.

After SCI, individuals may experience a myriad of associated conditions that are a direct result of the original injury to the spinal cord. Damage to the spinal cord, roots, and attached nerves will lead to neurological impairments and dysfunction. Depending on the level and completeness of the damage, individuals may experience sensory, motor, or autonomic deficiencies <sup>3,9-11</sup>. For example, injury to the sensory nerves may affect the skin; injury to the motor neurons will correspondingly affect the limbs and may lead to incomplete or complete paralysis, and severed autonomic nerves can cause bladder and bowel issues <sup>12</sup>. Other common examples of associated conditions following SCI include, but are not limited to, spasticity, incontinence, emotional lability, gastrointestinal disorders, autonomic dysfunction, respiratory disorders <sup>13</sup>. Although these conditions are

rarely preventable, effective management will reduce the severity. Medications, medical devices, cognitive or behavioral therapy, and assistive technology are examples of effective methods to assist with management <sup>13</sup>.

Whereas associated conditions are a direct result of the injury, secondary disorders are indirectly related to the primary disability, and following SCI individuals are at greater risk of developing secondary conditions. This is emphasized by the fact that following an injury, patients will deal with around 8-14 secondary conditions per year <sup>5,14</sup>. Examples of secondary conditions are pain, obesity, fatigue, deconditioning, urinary tract infections (UTI's), and pressure sores <sup>13</sup>. Secondary medical conditions complicate and exacerbate living with SCI by impacting the long-term overall health, productivity/employment, dignity, mobility, and independence of the patient <sup>15</sup>. If not handled properly, these secondary conditions will lead to hospitalizations where patients are mostly treated (46%) for UTI's, decubitus ulcers, pneumonia, or septicemia. Approximately 14% of patients with SCI experienced more than one of these complications (these numbers change to 44% and 33% for re-hospitalizations, respectively.) <sup>16</sup>. UTI's are among the leading reason for re-hospitalizations, which is emphasized by Dryden et al. <sup>16</sup> who found that individuals with SCI have a 48% chance of being treated for a UTI, 34% for pneumonia, 28% for depression, and 20% for decubitus ulcers. In addition, the leading causes for hospital re-admissions following SCI are secondary complications related to respiratory (19%), urinary tract (14%), and dermatological conditions (7%) <sup>17</sup>, where re-hospitalizations were more likely (rate ratio = 2.6) for people with SCI <sup>16</sup>.

Furthermore, poor management of secondary conditions will also lead to

rehospitalization, and can be further exacerbated by the psychological issues faced. About 28% of individuals following SCI are treated for depression, and it is estimated that people are 2.5 times more likely (rate ratio = 2.5) to be diagnosed with depression when compared to non-injured matched controls <sup>16</sup>. Likewise, individuals who experience depression will have a higher chance of reporting symptoms such as anxiety (odds ratio (OR)=3.7), sleep disturbance (OR=3.5), and fatigue (OR =2.1) <sup>18</sup>. As a result, individuals who are depressed may avoid some social interactions and experience greater inactivity, which would compound secondary issues such as pressure ulcers, muscle wasting, and obesity <sup>19</sup>. Psychological problems can also include sadness, depression, irritability/anger, suicidal thoughts, and a lack of self-confidence <sup>20</sup>. Along with psychological issues, other issues can create further barriers for an individual, which can include: social isolation, lack of access to adequate medical care, financial hardship due to unemployment and the high cost of living, which are followed by difficulties with transportation, house modification, education, marriage, social communication, sports, and entertainment <sup>20</sup>. Improved self-management skills and proactive healthcare team is critical if secondary conditions are to be prevented <sup>13</sup>.

If individuals with SCI experience secondary conditions, then they are at a greater risk for developing chronic conditions such as hypertension, cardiovascular disease, cancer, arthritis, diabetes, kidney disease and asthma <sup>13</sup>. This greater risk is associated with a variety of factors including pre-morbid health, age, greater physical inactivity, smoking, alcohol, obesity, high blood pressure (HBP) and cholesterol, lack of access to healthcare, and other numerous psychosocial issues <sup>13,21,22</sup>. For example, physiological changes associated with aging can make people more susceptible to chronic illnesses and



a weakened immune system can lead to a higher chance of infections<sup>23</sup>. In a study conducted with older men with SCI, the prevalence of diabetes, myocardial infarction, and stroke, were higher than the general population at 20%, 19%, and 10%, respectively<sup>22</sup>. In addition, literature suggests that individuals with SCI are 2.5 to 3 times greater to have HBP than able bodied individuals<sup>24</sup> and are at greater risk of developing type 2 diabetes (OR = 1.66); cardiovascular disease has a prevalence rate of 30-50% within this population (3-10 times more likely than age-matched individuals without the disability)<sup>25,26</sup>. Similarly, the prevalence of diabetes is 7% in the general population, yet individuals post-SCI will see a 17-22% prevalence<sup>27-30</sup>.

As a consequence of the increased risk of developing secondary and chronic conditions following injury, mortality rates are higher. Health factors are the most significant and immediate predictors of life expectancy.<sup>31</sup> As an example, chronic pressure ulcers lead to a 4.52 greater odds ratio (OR) of mortality and major depression results in a 1.6 greater mortality rate; also, 1 standard deviation of infectious symptoms is associated with 1.18 greater OR of mortality<sup>31</sup>. Greater neurologic impairment has been shown to correlate with a greater degree of mortality<sup>32</sup>. Thus, tetraplegics have a reduced life expectancy when compared to paraplegics. Moreover, examining the causes of death have shown that heart disease, external causes, urogenital diseases, and respiratory complications are among the leading causes of death within the first year post-injury<sup>33,34</sup>, but many other risk factors are present for higher mortality rates. For example, standardized mortality ratios (SMRs) for women and men in Norway were calculated to compare mortality rates between people with SCI and the general population. Results indicated individuals post SCI had an SMR of 6.9 for septicemia in men, 5.9 for

pulmonary cancers in women, 4.4 for urogenital cancers in men, 8.9 and 2.7 for respiratory disease in women and men, respectively, and 23.4 and 21.9 for diseases of the urogenital system in women and men, respectively <sup>34</sup>. Lastly, the suicide SMRs are staggeringly different between women (19.2) and men (4.7) <sup>34</sup>.

Due to the significant toll that SCI can cause to the health of the patient, it also creates a substantial financial burden for the patient and their families. People with disabilities make up approximately 20% of the U.S., but account for 47% of total medical expenditures <sup>35</sup>. The total annual cost attributed to SCI in the United States is \$21.5 billion including direct (\$14 billion to \$18.1 billion) and indirect costs (\$3.83 billion to \$7 billion) <sup>36,37</sup>. For individuals following an injury, significant costs are incurred throughout the lifespan for issues such as hospitalization and acute rehabilitation, home and vehicle modification, and recurring costs for durable medical equipment, medications, supplies, and personal assistance <sup>38</sup>. Specifically, hospital charges for initial hospitalization and acute rehab were an average of \$282,245 in 2003. After hospitalization, modifications to home and other lifestyle necessities (e.g., ramps, widening doors, remodeled bathroom) will incur costs as well, which average \$21,000 <sup>36,39</sup>. Vehicle modifications may also become necessary with costs ranging from \$1000 to \$65,000 depending on the severity of the injury <sup>39</sup>. Likewise, having an in-home caregiver following SCI costs an estimated \$21,000 per year <sup>39</sup>. Overall, individuals are estimated to spend from \$508,904 to \$1,044,197 yearly on healthcare utilization for their first year and \$67,415 to \$181,328 on each subsequent year <sup>40</sup>. The complexity of a SCI will influence the cost of healthcare, which accordingly leads to more physician contact. For example, individuals post SCI will have around a median of 22 (IQR 12.0-37.0)

contact points with the healthcare system in the year of injury compared to 3 (IQR 1.0-6.0) for the general population, and SCI patients are more likely to have more contact with their physicians (rate ratio = 2.7) <sup>16</sup>. Following the initial discharge, approximately 57.3% of SCI patients were re-hospitalized at least once during the follow-up period and 47% of patients were hospitalized once, 17% were hospitalized twice, 32% were admitted between three to nine times, and 4% were re-hospitalized on 10 to more occasions <sup>16</sup>. Moreover, these individuals will experience greater medication costs compared to the general population <sup>13</sup>.

A major contributing factor to the health of an individual following SCI are environmental factors<sup>13</sup>. The World Health Organization's (WHO) framework of International Classification of Functioning, Disability, and Health stresses the importance of environment (e.g., physical environment, attitudes of others, or policies) as either a barrier or facilitator in the daily activities of persons with disabilities <sup>41</sup>. Numerous different environmental factors inhibit people with disabilities including: structural or architectural, natural environments, transportation, a social support network, assistive aids, and other related intrapersonal factors (depression, motivation, anxiety, fatigue) <sup>13</sup>. Transport was the most cited need by at least 25% of people living with SCI <sup>6</sup>. People living with SCI often face restricted access to services from specialists, and only half of those who need rehabilitation services will receive it <sup>42</sup>. However, other factors have also been cited as obstacles to access or dissatisfaction with service including: cost, a belief that follow-up is not necessary, time, lack of a knowledgeable staff, and the number of organizations and professionals involved <sup>6</sup>. Also, patients who have severe sensory or physical disabilities will experience far more disabilities and environmental

barriers, and not to mention other factors that are in play, such as demographics, education level, household income, severity of disability<sup>43</sup>.

Following SCI, individuals also face barriers when visiting their physicians. Individuals with SCI will see a variety of physicians and specialists throughout their rehabilitation including family physicians, physiatrists, internists, neurologists, neurosurgeons, orthopedic surgeons, urologists, and other physicians that specialize in SCI<sup>44</sup>. In total, 93% of individuals reported having a family doctor, 63% had a spinal injuries specialist, and 56% had both<sup>45</sup>. All specialties of physicians (and other members of the healthcare team) must work together to better the health condition of the many people living with SCI. A physician has numerous roles in the health of patient. This includes empowering individuals to self-manage their own health while promoting enabling environments that support good health promotion practices in the home, work, and community settings<sup>13</sup>. This framework also consists of reducing secondary conditions, improving functional health to allow optimum independence and participation in the community, and increasing access to built, natural, and social environments<sup>13</sup>. For example, Donnelly et al. reported that 27% of people with SCI could not use all the equipment in their family physicians' offices<sup>45</sup>. These barriers are usually structural; hence, most barriers are clustered in the examination room. Inaccessible exterior doorways were frequently reported, as well as a lack of transfer aids. However, physician knowledge can present as a barrier, as family physicians may have limited knowledge of how to meet the unique and complex needs of SCI patients. While physicians focus on issues pertaining to the injury, they may forget to schedule regular preventative health measures such as flu shots, colonoscopy, mammograms, or Pap smears. This is

emphasized by the fact that 40% of women with SCI reported that they had not have a pelvic examination or Pap smear within the previous 3 years, and only 40% of women 50 years of age or older had received a mammogram the previous year<sup>46</sup>. In addition, less than half of respondents received bone density testing, with 73% of individuals not receiving a physician recommendation<sup>46</sup>. As a result, patients with SCI often become frustrated with their primary care physician's knowledge of the conditions that result from SCI. When asked how well they felt their PCP understood medical concerns specific to their disability, 33% of participants responded "not at all" or "a little," 31% responded "moderately well," and 36% responded "well" or "very well."<sup>46</sup>

Along with the support of a dedicated physician are the informational needs of the patient. Perceived information needs of persons with SCI are occasionally not met after the transition to the community, as facilitating the transition of individuals with SCI from inpatient rehab to the community is one of the more difficult challenge for healthcare professionals<sup>47</sup>. The percentage of participants with SCI in a study who needed information was higher than those who did not need it.<sup>48</sup> Better overall education of the impact of SCI on the individual is needed for patients to become better managers, educators, and researchers for their chronic disability<sup>49</sup>.

The WHO also stresses other contextual factors that work alongside environmental factors: personal factors, or also known as internal factors<sup>50</sup>. These are the background of an individual's life and living, and subsequently are not a part of the health condition or state. However, they will still positively or negatively affect the person's function, health, and the experience of their disability<sup>41</sup>. These are categorized into 6 different levels: general personal characteristics (age, sex, and genetic factors),

physical factors (weight, height, and body composition), mental stability (personality and cognitive factors), lifestyle (attitudes, basic skills, and behavior patterns), life situation (socioeconomic/sociocultural), and lastly, health factors that involves health conditions that are not a part of the “overall health condition” such as prior diseases and impairments or prior interventions.

Consequently, following SCI individuals are faced with a myriad of health conditions, which can be exacerbated by environmental and personal barriers. Thus, health professionals are challenged to improve the health and healthcare for individuals following SCI. People with chronic and disabling conditions must have access to appropriate, timely, and high-quality healthcare, which presents as one of the most challenging health care policy issues in the United States <sup>42</sup>. Unfortunately, people with disabilities or chronic conditions (such as SCI) who have the poorest health and income are least likely to receive a wide variety of services <sup>42</sup>. If individuals with SCI do not have these services, they are at risk of a lower health status and independence, more depression, and a higher frequency and severity of secondary complications of SCI <sup>51</sup>. Furthermore, results indicate that people with chronic or disabling conditions often require a comprehensive array of health services and more information on their injury and how to care for it. <sup>42</sup>. Consequently, a better healthcare system can include a multidisciplinary outreach scheme <sup>47</sup> that provides skills from a variety of disciplines to meet these needs <sup>6</sup>. This team includes doctors of numerous specialties, nurses of different backgrounds, physical therapists, occupational therapists, dieticians, speech therapists, social workers, and of course, family and friends <sup>52</sup>. Along with the support of a healthcare team are the informational needs of the patient. The healthcare team will

need to change their approached care and provide for the needs and concerns of a chronically ill population<sup>53</sup>; multiple areas that need to be addressed are person-centered care, lifelong access to specialist care, rehabilitation, adjustment and social reintegration, supported independent living, and pulling these services together<sup>19</sup>. This may require planned, regular interactions with their caregivers with a focus on function and prevention of exacerbations and complications. This interaction includes systematic assessments, attention to treatment guidelines, and behaviorally sophisticated support for the patient's role as self-manager<sup>53</sup>.

Wagner et al. discuss a chronic care model that creates specific aims in hopes of improving the self-management of patients. These aims include: (1) increase patient activation through education, greater motivation, and improved skill-set, (2) redesign of the healthcare system and continuum of care to enable proactive and productive patient-provider interactions, (3) support providers to maximize patient adherence to evidence-based practice, and (4) implement information systems that provide timely data<sup>53</sup>. Those who have greater activation are able to better manage their health and healthcare, and can increase their QOL and overall health. Thus, self-management becomes a priority when dealing with secondary conditions following SCI. Successful self-management involves the patient actively taking care of their secondary conditions through communication with physicians, and the healthcare system, being knowledgeable of the injury and comprehending how to take care of it, the skill to effectively care for their conditions, and the motivation or perseverance to do manage<sup>54</sup>. This can lead to the patient self-managing their skin care, medication compliance, physical activity, bowel management, and other conditions<sup>55</sup>.

## Specific Aims

1. The purpose of this study is to describe the utilization, accessibility, and satisfaction of primary and preventative health-care services of community-dwelling individuals with spinal cord injury (SCI).

Hypothesis: Individuals with SCI will report high utilization of the healthcare system, report accessibility issues to healthcare in all forms, and report low satisfaction with healthcare.

2. A secondary aim of this study is to describe any differences between individuals who completed outpatient visits with a SCI/Rehab physician in the past 12-months compared to individuals who did not.

Hypothesis: Individuals who follow up will report greater satisfaction of primary health-care services than those who do not. Those who follow up will also report higher usage of preventative healthcare services such as mammograms, flu shots, colonoscopies, pap smears, etc. Furthermore, those, who do not follow-up, are not being told to use these preventative healthcare services. Patients who return to outpatient services have found greater accessibility within the healthcare system, and those who have not returned have found less. Those who follow up will report higher satisfaction than those who have decided to not come back to outpatient services.



## **Significance**

Those individuals with SCI's will subsequently need greater utilization of the healthcare system for all the associated, secondary, and chronic conditions that they may experience. However, there are numerous potential barriers that may inhibit the patient from receiving the care necessary. These barriers can be personal, environmental, or healthcare-related. Additionally, these different factors will also determine the extent of the utilization and accessibility patients can receive through the healthcare system; these can include income, insurance, and level of education. Considering that limited research exists on the healthcare utilization of individuals with SCI, discovering these factors can assist healthcare professionals with knowledge on any potential disparities that should be eliminated.

## **Research Design and Methodology**

This study was conducted at the outpatient rehabilitation facility and under the Institutional Review Board to ensure that all procedures were ethical. The research design is cross sectional, utilizes a convenience sample, and includes a survey.

## **Participants**

The population sampled was the former inpatient and current outpatient individuals with SCI at a rehabilitation hospital. Inclusion criteria were: Male or female

patients between 18 and 64 years old, traumatic- or non-traumatic spinal cord injury, and living in the community for at least 12 months post inpatient rehabilitation discharge. Exclusion criteria were severe cognitive impairment, pre-morbid mental illness, pre-morbid developmental disability, and prisoners.

### Procedures

Individuals who meet the inclusion criteria were contacted regarding participation in the study by phone if they do not follow up to outpatient, or during a routine follow-up visit if they do return for outpatient. Individuals who were contacted completed a series of questionnaires. Participation in the study was voluntary; participants were able to withdraw from the study at any time without penalty, and no incentives were provided.

Upon obtaining written or informed consent, participants were asked to complete the questionnaires via paper and pencil at the outpatient facility if they were patients at the outpatient facility or answer the survey questions over the telephone if they were not. Members of the study performed the telephone calls in the research office at the rehabilitation hospital. If patients were physically unable to read independently, study personnel endorsed their responses and completed the questionnaire on their behalf. It was estimated that participants should have been able complete the questionnaires in approximately 30 minutes. Each participant was asked a series of questions regarding their health care utilization and perceived access to care over the past 12 months, along with demographic and injury related information (see Appendix C).

## Measures

Demographic information was obtained from a questionnaire and also from the patient's electronic medical record and included: age, gender, ethnic/racial identification, socioeconomic indicators (pre-injury income, current income, occupation, living situation, education level), and insurance status. Injury related information was obtained from a questionnaire and also gathered from the patient's electronic medical record and included: etiology of injury, traumatic or non-traumatic injury, level of injury, age at time of injury, and length of rehabilitation stay. Health care related information was obtained from a questionnaire which consists of 34 questions assessing health care utilization (e.g., Have you been to the emergency room in the last 12 months?), health care access (e.g., Indicate whether or not the following doctors' offices and/or equipment were accessible.), preventative health information provided (e.g., If you are a female aged 12 or over, do you get a PAP smear at least every 3 years?), and satisfaction with current health care delivery (e.g., My primary care physician is knowledgeable about my spinal cord injury needs?).

## Analysis

Demographic and clinical data were summarized using appropriate descriptive statistics. Means and standard deviations were used for continuous variables or medians and interquartile ranges if skewed, and counts and percentages were used for categorical data. Survey questions regarding health care utilization and accessibility were summarized with counts and percentages. Additionally, each patient received a

compliance score defined as the number of preventative health activities performed within the recommended time divided by the total number of preventative health activities for which the patient is required. The individual compliance scores were summarized across the entire population and were stratified across multiple subgroups defined by characteristics such as injury severity, geographic location, and follow-up location.

These patients' data were compared and analyzed to find the similarities and differences between the two groups: one group that follows up with outpatient rehabilitation and one that does not follow up. This data was compiled into an online database using Survey Monkey.

### Statistical Methods

Data were summarized with means and standard deviations for continuous variables and counts and percentages for categorical variables. Analysis to compare between groups was performed using t-tests for continuous variables and chi-square tests for categorical variables. For categorical variables with low counts, Fisher exact tests were used instead. Statistical significance was set at the 0.05 level. All analyses were performed using SAS 9.3 (Cary, NC).

## Results

There were 142 subjects in the study. Of these, 42 subjects were administered the survey by phone and 100 subjects were surveyed in person during a routine follow-up visit.

### Demographic Data Summary

Table 1 summarizes the demographic characteristics of the study participants. Summary statistics are provided for all subjects combined, and are also divided into phone and visit groups. Subjects in both groups were around equal age (41 years) at the time of survey, and most subjects were male (65%). Moreover, an overwhelming majority of subjects was white (84%), followed by black/African-American (11%). Socioeconomic status was established by using the zip code provided to create a Geo Unit Quality Score, which is a function of the value and type of homes in that zip code, the education of those over the age of 25, and the occupations of the labor force. The score for the national average in the US is 100, so a good score would be above 100 while a bad score would be below 100. Our population's average was 100.1, while scores were above average for those who visited in person (103) and below for those completed by phone (98). Around 72% of the study population lives in the DFW Metroplex, and the majority (66%) live in areas with a population of 10,000 to 49,999 people. Education level is mostly at the post-secondary level (54% vs. 44% for high school diploma or equivalent). Relationship status is similar for all categories (87% single or married, and 12% divorced) in both phone and visit groups. Similarly, yearly household incomes prior

to injury are similar, yet current household incomes show that individuals typically make less after SCI injury. Of note, there was a considerable difference in subjects who had a decrease in income from pre-to-post injury between phone (61%) and visit (32%) groups. Subjects' health insurance shows variability between the two groups, where the visit group is more likely to have private insurance (50%) compared to the phone group (33%), and vice versa for public insurance (24% for the visit group vs. 45% for the phone group).

Table 1: Summary of demographic characteristics.

<b>Characteristic</b>	<b>Overall (N=142)</b>	<b>Phone (N=42)</b>	<b>Visit (N=100)</b>
<b>Age at time of survey (years)</b>	40.8±13.0	42.0±13.5	40.3±12.8
<b>Male Gender</b>	92 (65%)	29 (69%)	63 (63%)
<b>Hispanic Ethnicity</b>	16 (11%)	6 (14%)	10 (10%)
<b>Race</b>			
Asian	4 (3%)	3 (7%)	1 (1%)
Black/African American	16 (11%)	6 (14%)	10 (10%)
White	119 (84%)	33 (79%)	86 (86%)
More than one race	3 (2%)	0 (0%)	3 (3%)
<b>Geo Unit Quality Score</b>	101.±1.7	97.9±11.7	102.5±14.3
<b>Lives in DFW Metroplex (% of subjects)</b>	102 (72%)	22 (52%)	80 (80%)
<b>Zipcode population (2012) (% of subjects)</b>			
<2500	3 (2%)	2 (5%)	1 (1%)
2,500-9,999	15 (11%)	4 (10%)	11 (11%)
10,000-49,999	94 (66%)	32 (76%)	62 (62%)
≥50,000	30 (32%)	4 (10%)	26 (16%)
<b>Education Level (number (#) of subjects)</b>			
Elementary school	2 (1%)	1 (2%)	1 (1%)
High school Diploma or Equivalent	63 (44%)	18 (43%)	45 (45%)
Associate's/ Vocational/Technical Degree	27 (19%)	9 (21%)	18 (18%)
Bachelor's Degree	29 (20%)	10 (24%)	19 (19%)
Postgraduate Degree	21 (15%)	4 (10%)	17 (17%)
<b>Relationship status (# of subjects)</b>			
Single	65 (46%)	20 (48%)	45 (45%)
Married	58 (41%)	16 (38%)	42 (42%)
Divorced	17 (12%)	5 (12%)	12 (12%)
Widowed	2 (1%)	1 (2%)	1 (1%)
<b>Yearly household Income prior to injury</b>			
Less than \$25,000	29 (20%)	7 (17%)	22 (22%)
\$25,000 - \$49,000	31 (22%)	7 (17%)	24 (24%)

\$50,000 - \$74,000	26 (18%)	9 (21%)	17 (17%)
\$75,000 - \$99,000	21 (15%)	5 (12%)	16 (16%)
≥\$100,000	19 (13%)	7 (17%)	12 (12%)
Not reported/Unknown	16 (11%)	7 (17%)	9 (9%)
<b>Current Yearly household Income</b>			
Less than \$25,000	42 (30%)	14 (34%)	28 (28%)
\$25,000 - \$49,000	35 (25%)	9 (22%)	26 (26%)
\$50,000 - \$74,000	18 (13%)	5 (12%)	13 (13%)
\$75,000 - \$99,000	13 (9%)	2 (5%)	11 (11%)
≥\$100,000	19 (13%)	2 (5%)	17 (17%)
Not reported/Unknown	14 (10%)	9 (22%)	5 (5%)
<b>Drop in income category* (# of subjects)</b>	48 (39%)	19 (61%)	29 (32%)
<b>Type of Insurance (# of subjects)</b>			
Self Pay/Uninsured	4 (3%)	3 (7%)	1 (1%)
Public	43 (30%)	19 (45%)	24 (24%)
Private	64 (45%)	14 (33%)	50 (50%)
Combination	31 (22%)	6 (14%)	25 (25%)

\*Only includes those subjects who reported both current and prior to injury income

Table 2 summarizes injury-related information for the different groups. Of note, age of injury is significantly different between those in the visit vs. the phone group. The subject population was approximately equal based on type of injury (paraplegia vs. tetraplegia).

Table 2: Summary of spinal cord injury information.

<b>Characteristic</b>	<b>Overall (N=142)</b>	<b>Phone (N=42)</b>	<b>Visit (N=100)</b>
<b>Age at injury* (years)</b>	33.0±13.2	38.0±13.8	30.6±12.4
<b>Years since injury*</b>	8.1±4.6	4.8±5.9	9.6±5.7
<b>Paraplegic or Tetraplegic (# of subjects)</b>			
Paraplegic	70 (49%)	22 (52%)	48 (48%)
Tetraplegic	67 (47%)	17 (40%)	50 (50%)
Unknown	5 (4%)	3 (7%)	2 (2%)
<b>Level of injury (# of subjects)</b>			
Cervical	67 (47%)	19 (45%)	48 (48%)
Thoracic	60 (42%)	17 (40%)	43 (43%)
Lumbar	10 (7%)	5 (12%)	5 (5%)

Unknown	5 (4%)	1 (2%)	4 (4%)
<b>ASIA Impairment Scale (# of subjects)</b>			
A=Complete	73 (51%)	18 (43%)	55 (55%)
B=Sensory Incomplete	14 (10%)	5 (12%)	9 (9%)
C=Motor Incomplete	21 (15%)	8 (19%)	13 (13%)
D=Motor incomplete	22 (15%)	3 (7%)	19 (19%)
Unknown	12 (8%)	8 (19%)	4 (4%)

\*Only includes patients whose condition was the result of trauma

### Results for Research Question 1

Tables 3-7 and Figures 1-2 (Appendix) summarize the utilization, accessibility, and satisfaction of the study participants.

Based on participants reported doctor's visits in the past 12-months (Table 3 - Appendix B) PCP's are the physicians most seen by subjects with SCI (79%), followed by SCI physicians (77%) and urologists (50%). For accessibility to medical offices and equipment (Figure 1/Table 4) participants reported that for every category except parking, SCI/Rehab physicians had the most accessible resources. Similarly, specialty physicians had the second most accessibility with PCP the least accessible.

Overall, patients were satisfied with their PCP (66% somewhat agreed/agreed/strongly agreed that their PCP was knowledgeable). (See Table 5 and Figure 2a,b,c). Notably, none of the subjects in the study population viewed their SCI physician as not knowledgeable about their health (0% for strongly disagree/disagree/somewhat disagree). Furthermore, 90% of the visit group strongly agreed that their SCI physician was knowledgeable, compared to 19% of the phone group. Finally, more than half of subjects agreed that their physicians communicated well (55%), while only 17% disagreed.



Tables 6 and 7 (Appendix B) summarize emergency room visits and preventative care data, respectively. Note that for preventative care, the denominator for all calculations only included subjects for which the measure was applicable. Approximately 43% of the study population had ER visits, and 21% visited the ER on multiple occasions. The most common reason for ER visits was “Genital/Urological” (15% overall) for our study subjects, which is consistent with the SCI literature as UTI’s are in fact the most common secondary condition following SCI. The second most cited reason for an ER visit was “Other”, which includes infections, reactions to medications, bleeding, back pain, and fatigue. Following those are wound/skin problems and pneumonia. Preventative care measures completed (e.g., PAP smear, mammogram, flu shot) or presented to both groups (e.g., do you exercise 5 days a week, do you use tobacco products) was approximately equal.

#### Comparisons for Research Question 2

Tables 8-11 in Appendix B report findings comparing subjects who had visited an SCI/Rehab doctor in the past 12 months compared to those who had not. Demographic and injury related factors are presented in Table 8. There were significant differences between groups for several variables including whether individuals lived in the DFW Metroplex (77% who had visit; 53% no visit;  $p=0.0075$ ), and drop in income following injury (34% who had visit; 64% no visit;  $p=0.0100$ ). Further, significant differences also existed for whether individuals had private insurance (75% who had visit; 38% no visit;  $p<0.0001$ ), age at injury (31.6 years who had visit; 37.2 years no visit;  $p=0.0377$ ), and years since injury (9.0 years who had visit; 5.3 years no visit;  $p=0.0176$ ).

Table 9 summarizes healthcare utilization and preventative care for patients who had seen a SCI/Rehab physician vs. those who had not. The only healthcare utilization factor that was significantly different was whether or not the patient saw a specialist in the past 12 months with the SCI/Rehab physician group seeing a greater number of specialists (85% compared to 53%,  $p=0.0002$ ). No other comparisons were significantly different.

Finally, Table 10 summarizes the differences in demographics and injury related characteristics between individuals who visited the ER compared to those who did not. Significant differences were found in Geo Unit Quality Score (104 for ER visit; 98 for no visit;  $p=0.0170$ ), post-secondary education (44% for ER visit; 62% for no ER visit;  $p=0.0386$ ), and a household income greater than \$50,000 (22% for ER visit; 53% for no ER visit;  $p=0.0004$ ). No significant differences were found in utilization or preventative care steps taken between those who went to the ER and those who did not (Table 11).

## **Discussion**

Overall, the purpose of this study was to describe the utilization, accessibility, and satisfaction of primary and preventative health-care services of community-dwelling individuals with SCI. Results indicated that utilization, accessibility, and satisfaction was higher in some areas, yet similar for others when compared to previous SCI research and population level data<sup>56</sup>. For example, 99% of individuals in the current sample reported that they had healthcare visits in the past 12 months, which is consistent with previous SCI research<sup>16,46,57</sup>. Specifically, Stillman et al. (2014) reported that approximately 99%

of their sample visited a PCP within the previous 12 months, and Dryden et al. (2004) found that 99% of their participants saw a PCP at least once over a six-year follow-up (median 52 physician contacts) <sup>16,46</sup>. This level of utilization is significantly higher than population data reported in the 2013 National Health and Nutrition Examination Survey (NHANES) which indicated that 25% of the population aged 18-44 years and 15% aged 45-64 years reported no healthcare visits in the previous 12 months <sup>56</sup>. As patients with SCI will see a variety of secondary, associated, and chronic conditions, a greater amount of healthcare utilization becomes necessary to reduce the severity of the conditions.

Results of the current project also indicated that PCP's (79%) were the most frequently visited physicians, followed by SCI/rehab physicians (77%) and urologists (50%). This pattern of usage following SCI is consistent with previous research which has shown high utilization of physicians (i.e., PCP, physiatrist) and specialists (e.g., urologist) <sup>16,45,58</sup>. The high utilization of PCP's and specialists by individuals with SCI emphasizes another disparity with the general population who visit a PCP (63% for ages 18-44 years and 47% for ages 45-64 years) or specialist (45%) less frequently <sup>56</sup>

In addition to increased utilization of primary care and specialist physicians, individuals with SCI also had a high number of ED visits (43% of subjects within the past 12-months), which is lower than previous SCI research findings (57%) <sup>59</sup>, but higher than that reported by the general population (19% for ages 18-44 years; 18% for ages 45-64 years).

The primary reasons for ED visits for the current sample were genital/urological (15%), wounds/skin problems (5%), and pneumonia (4%). While the reason for ER visit is consistent with previous findings, the number of visits is considerably less.

Specifically, Dryden et al. (2004) reported that 48% of patients with SCI were treated for urinary tract infections, 34% for pneumonia, 20% for decubitus ulcers, and 16% for septicemia <sup>16</sup>. According to the same study, these complications were also reported to have been higher than the control group, or general population <sup>16</sup>. In addition, Skelton et al. (2014) indicated that genitourinary and musculoskeletal issues (e.g., pain, fatigue) were the most common reasons for ED visits <sup>59</sup>. Overall, the increased usage of healthcare is believed to be a result of the fact that individuals with SCI face considerably more health conditions relative the general population <sup>16,18,58</sup>.

Of note, individuals who visited the ER had a lower Geo Unit Quality Score and were less likely to have a post-secondary education. A likely explanation is that this group had a lower socioeconomic status, lived in a rural area and had lower education <sup>60</sup>. Specifically, a significant predictor of ED visits is rurality as those individuals with SCI in more rural locations may have limited access to physicians and specialists, especially ones with SCI knowledge <sup>58</sup>. Thus, this accessibility issue may lead to their only option of receiving care in the ED <sup>58</sup>.

For preventative health services, patients with SCI also reported similar utilization to previous SCI research and data from the general population. For example, for patients in the current sample that qualified, 71% received mammograms, 63% received pap smears, 54% received colonoscopies, and 55% received flu vaccines, which is consistent with other SCI data (Stillman et al.) and similar to population level data (73% had mammograms, 64% had pap smears, 56% had colonoscopies, and 58% had flu vaccines <sup>46,56</sup>. Healthy People 2020, which is a program of nationwide health promotion and disease-prevention goals and objectives set by the US Department of Health and Human

Services, specifically has an objective to reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventative care due to specific barriers <sup>61</sup>. Thus, regarding this similarity, physicians may be bringing more of an effort to create an environment where there are patients who report no delays in preventative care. However, their ultimate goal should be 100%.

In addition to no differences in preventative services, individuals reported that accessibility was not an issue at medical offices or with equipment at PCP's, SCI/Rehab physicians, and other specialties. Of note, examination tables were reported as being the least accessible for PCP's and specialty physicians, while parking was the least accessible for SCI/Rehab doctors (but this is only indicative of one facility). Stillman et al., reported that examination tables were also the least accessible aspect of physician offices and suggested that this was a result of non-SCI physicians not having height adjustable exam tables or the proper staff to accommodate individuals in wheelchairs <sup>46</sup>. Interestingly, Donnelly et al. (2006) found that while SCI physician offices were more accessible, PCPs themselves were more accessible to the patient when needed <sup>45</sup>. Another objective of Health People 2020 is to reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs <sup>61</sup>. Likewise, study subjects with SCI finding accessibility within medical offices is another example of physicians working towards accessibility for people with disability. Furthermore, the principle of "universal design", which ensures that accessibility to buildings and public spaces is fully accessible for people with disabilities, is an important consideration when building new and retro-fitting existing medical facilities <sup>62</sup>. If the principle of universal

design is implemented, this would ensure that all aspects of physicians offices and medical facilities are fully accessible by anyone.

Finally, the majority of participants were satisfied with their physician's knowledge of SCI (66% satisfied with PCP; 100% with SCI physician) and that their physicians communicated well with each other. However, this finding is relatively inconsistent with other authors who reported that their participants were dissatisfied with their physicians' knowledge of SCI. For example, Stillman et al. reported that 66% were provided incomplete care by a PCP or specialty physician and only 54% were satisfied with their PCP <sup>46</sup>. A potential reason for this low satisfaction is provided by results from Cox et al. (2001) who reported that the greatest perceived barrier for needs being met (81% of sample) was the limited knowledge of SCI by their local specialist <sup>6</sup>.

The secondary aim of this study was to describe any differences between individuals who completed outpatient visits with an SCI/Rehab physician in the past 12-months compared to individuals who did not. Data on the significant differences between these groups indicated that individuals with SCI who visited an SCI/Rehab physician were more likely to live in the DFW Metroplex (77% for those who visited; 53% for those who did not;  $p=0.0075$ ), experience a greater drop in income after their SCI (34% for those who visited; 64% for those who did not;  $p=0.0100$ ), and have private insurance (75% for those who visited; 38% for those who did not;  $p<0.0001$ ). However, characteristics that were thought to have been also significant such as Geo Unit Quality Score, post-secondary education, and current yearly household income in fact showed no great statistical difference. This is consistent with Beatty et al. (2003), who acknowledges that insurance coverage limitations can lead to poor access to rehabilitative services

resulting in those with chronic or disabling conditions having issues receiving their care (e.g., visiting an SCI specialist)<sup>42</sup>. Likewise, Beatty et al. suggests that income level was significantly correlated with difficulty receiving care and that those with incomes lower than \$20,000 were least likely to receive care when needed<sup>42</sup>. For individuals living in more rural areas, the literature suggests that individuals have lower healthcare utilization (e.g., physician, specialist visits) due to issues with access and availability of healthcare resources<sup>58,60</sup>.

## **Conclusion**

Physician and hospital utilization (including the Emergency Department (ED)) is greater for individuals with SCI than the general population. However, preventative healthcare utilization was actually similar to the general public. Frequent contact with SCI physicians should be encouraged for patients to better manage health conditions, avoid worsening of those health conditions, and reduce use of the ED. In addition, technology can be utilized to provide information needs and services to patients and allow more immediate contact with physicians. Another method of providing adequate information to patients can be through the Health Literate Care Model: a system wide approach to delivering basic health information and services to patients, and it can be further utilized to help patients understand more about their conditions<sup>63</sup>. This model aims to aid in various aspects of care such as organization and planning of health care, providing self-management and decision-making support, as well as delivery system design<sup>63</sup>.

Likewise, the accessibility of medical offices and equipment was not a major issue as hypothesized, and most subjects were satisfied with their physicians' knowledge of SCI and communication skills. The study group found the most accessibility and satisfaction with their SCI physicians; yet accessibility with other physicians' offices and equipment should be addressed. Consequently, further accessibility for individuals with disabilities should be implemented and other barriers should be ameliorated throughout the healthcare industry. Clinical staff should become better prepared to treat those with disabilities to improve accessibility; this includes making offices and exam rooms better suited to accommodate individuals in wheelchairs. Similarly, physicians should ensure that their local referral and diagnostic centers are accessible for patients with disabilities.

Outpatient visits to an SCI physician were prevalent with those who reported a smaller drop in income post-injury, having private insurance, and living in the DFW Metroplex (Geo Unit Quality Score). As the high cost of healthcare and coverage are major reasons for preventing patients from receiving healthcare, the service delivery model for people with SCI may need to adapt to include those who are currently not getting adequate care. For example, multi-disciplinary outreach services can eliminate costs and travel for people with SCI. Further research and analysis on socio-demographic factors such as transportation, work-related issues, quality of life, needs for better healthcare, and psychological factors can assist in learning more about the needs of individuals with SCI.



## **Limitations**

It is important to note several certain limitations with this study. First, the sample size consisted of patients only in the DFW Metroplex, and conclusions can only be made to this population and geographic region. Second, as age limitations were set at 18-64 years, results do not reflect the healthcare usage and accessibility issues faced by older individuals where health care needs are recognized to change <sup>6</sup>. Third, considering the survey in its entirety is all self-reported, it is very likely that there is a self-report bias <sup>59</sup>. For example, social desirability is a factor; participants may alter answers according to what they believe may be the more appropriate answer or the more popular answer. Another example is recall bias, where in the process of recalling their history, participants may or may not remember everything correctly. Next, those subjects who have had deprivation from their healthcare needs may exhibit lowered perceptions; also, those who have experienced fulfilled needs and may have elevated perceptions <sup>64</sup>. Moreover, conducting the survey over the phone versus in-person could generate different answers for any particular participant. The dynamics of the interaction and the environment is different depending on where the survey is being conducted. This could increase the variability of the response, which is not ideal in research as controlling variability is important. Also, many patients (those who did not complete outpatient services) could not be reached by telephone, and because of this, it is possible that the full scope of opinions from this population and all the possible differences in the group was not documented in the study. Furthermore, there were several additional questions we might have asked. For instance, since accessibility was an important measure of the study, it

would have been useful to ask whether they were in a wheelchair or able to walk, as this would have included the extent of mobility impairment on their accessibility. Those in wheelchairs have much less accessibility than those walking and stratification based upon that would have proved constructive <sup>65</sup>. The measure also does not ask whether they were rehospitalized after ED use; questioning this would have gauged the severity of their condition as someone who was rehospitalized for a condition versus someone who was not rehospitalized may have had worse conditions.

## CHAPTER III

### INTERNSHIP EXPERIENCE

#### **General Internship Experience**

My experience at the Baylor Institute of Rehabilitation (BIR) has taught me a great deal about the rehabilitation process for those who have suffered through spinal cord injuries and traumatic brain injuries. Through observation I learned from many physical medicine and rehabilitation specialists, or physiatrists, working with spinal cord injury, traumatic brain injury, and even amputee patients. This included medications and techniques used on these patients to bring them back to recovery. Alongside my research mentor at BIR, I became more knowledgeable about the scope of healthcare through the rehabilitation process. My fellow researchers explained to me more about other research projects taking place at BIR and how a project is implemented. Being situated in a research facility, I was given the opportunity to witness IRB meetings, audits, and quality assurance checks. For my internship, my main objective was to complete a research thesis titled, “Utilization and Access to Health Care Services among People with Spinal Cord Injuries Living in the Community.” This consisted of researching numerous publications about conditions that individuals with spinal cord injuries experience. To retrieve data from the local community, the project required me to conduct surveys with current patients at the Baylor Institute of Rehabilitation Outpatient Clinic and telephone surveys with former patients who went through Inpatient services. In addition to my

study, I collected data for another project titled, “Are seizure prophylaxis guidelines followed in patients presenting to acute, inpatient rehabilitation?” The goal of this project is to examine the number of patients who are still on seizure prophylaxis upon admission into an acute rehabilitation facility. Fulfilling the requirements of this project led to data collection for former traumatic brain injury patients at BIR, and examining their use of seizure medications. The physicians investigating this study would like to make wiser choices for their patients’ care and avoid unnecessary tests and treatments during their stay at a rehabilitation facility. Moreover, I volunteered for Friends of Hope, a day camp for survivors of traumatic brain injury. My duties were to take reservations, mail registration packets, answer any questions that potential camp participants may have, and volunteering with any tasks needed during the day of camp. Overall, this internship has greatly expanded my knowledge of healthcare, and I am very excited to continue a career in this field.

## APPENDIX A

### INTERNSHIP DAILY JOURNAL

#### **WEEK 1**

June 9, 2014

- 10am-12pm
  - Given a tour of the Baylor Institute for Rehabilitation facility.
  - Studied the Protocol and Survey for the Utilization and Access to Care SCI Hamilton.
  - Situating myself into the system
- 12pm-2pm
  - Surveyed 3 patients for the SCI study: 2 quadriplegics and 1 paraplegic.
  - Only observed, as this is my first time.
  - Visited the Outpatient Clinic and Dr. Hamilton.
- 2pm-3pm
  - Discussed with Dr. Driver and updated version of my weekly schedule
  - Looked at the protocol for the Seizure Prophylaxis Study

June 10, 2014

- Residency Lectures/ Grand Rounds
- 7am-8am
  - Relief of Posturally Induced Autonomic Dysreflexia in Spinal Cord Injury Patients with Epidural Steroid Injection by Justin H. Thompson, MD

- Discussion of the 3 components of the Nervous system (S, PS, Ent.)
  - Discussion of background, pathophysiology, signs and symptoms, treatment of Autonomic Dysreflexia
  - Case Report
- 8am- 9am: Didactic with Residents
  - Residents from the BIR gather around a conference room to discuss patients for the week. This is my first time with an experience such as this.
- 9am-10am
  - Neuroanatomy Lecture Series- Case Reviews by David B. Salisbury, Psy. D., ABPP
- 10am-11am
  - Lumbar Epidural Steroid injections, Facet injections, and SI joints by Matt Bayazitoglu MD
- 11am-12pm
  - Anomalous innervations by Helen Z. Patel, MD MBA
- 1pm-3pm
  - Dr. Driver and I have initialized a project idea consisting of data and ideas from a previous project. The Access to Care project will serve as a stepping stone for my project at the moment and I will begin searching through articles and previous data to further assess this to create my project question and thesis.

June 11, 2014

- 10am- 12pm
  - Searched through different articles and information for my research project thesis.
- 12pm-2pm
  - Access to Care Survey at BIR Outpatient (Landry fitness center)
- 2pm-3pm
  - Meeting with Jennifer. Administrative purposes.
- 345pm-515pm
  - Working with Dr. Zaman on the Seizure Prophylaxis Study. Searched through databases and found patients' charts, medical histories, and discharge information. Learned how to fill out forms that are needed for the study.

June 12, 2014

- 7am-9am
  - Rounds with Dr. Hamilton on the 4<sup>th</sup> floor of BIR. These patients consisted of SCI's and non TBI. This was my first experience doing rounds. Visited patients bedside and Dr. Hamilton along with a resident would discuss issues or get updates.
- 9am-10am
  - worked on thesis project
- 10am-12pm

- rounds at the ICU department. First time at ICU. Very interesting to see different departments gather around and see other patients. Many different issues, however most of the causes were motor vehicle accidents.
- 2pm-3pm Trauma Grand Rounds
  - Presentation on the psychology of pain and the fear of pain.
  - Multiples studies done on how fear changes the perception of pain
- 4pm-430pm
  - Meeting for the Access to Care study
  - Discussing my project as an extension of this project

## **WEEK 2**

June 16, 2014

- 10:30am-2pm
  - Access to Care Survey at Baylor Institute of Rehabilitation Outpatient Services (Landry Fitness Center)
  - A few patients were skipped. 2 considering age limits and 1 considering health insurance plan.
  - Currently added to study, pending IRB review.
  - Lit review for my project

June 17, 2014

- 8am-830am Resident Lecture Series
  - The Medical, Ethical, and Legal Uses of Opioids in Children



- It is primary for medical knowledge and secondary for patient care.
- 830am-9am
  - Post-Polio Syndrome by Les Porter MD
- 9am-10am Research Series
  - Monica Bennett PhD – Research Steps and Statistics Review
  - Primary: Research Design
  - Secondary: Practice Based Learning
  - This lecture can come in great use for my project.
- 10am-12pm
  - Lower Extremity Cases and Ultrasound- Jit Mookerjee D.O.
    - My first time seeing how an ultrasound machine works
- 12pm-1pm PM&R Journal Club
  - Residents will bring published journal articles to a round table discussion.
  - They debate the article's strengths, limitations.
  - 2 articles were discussed.
  - Evaluation of Concomitant Methylphenidate
  - Prophylactic Inferior Vena Cava
- 1pm-2pm
  - Department meeting
  - Discussing all the different studies and the statuses for each
- 2pm-3pm
  - BRI staff meeting

June 18, 2014

- 10am-1130am
  - worked on my study and reviewed different articles
- 1130-3pm
  - Access to Care Survey at Landry fitness center
- 345-530pm
  - Working with Dr. Zaman on the Seizure Prophylaxis Study
  - Data Collection

June 19, 2014

- 715-9am
  - Rounds with Dr. Hamilton
  - Checking on the patients I originally saw last week.
  - Interesting to see how patients progress
- 9am-1130am
  - working on my study

June 20, 2014

- 10am-4pm
  - Will be working on my study most of the day and checking up on articles.
  - Later in the day I will be meeting with Dr. Driver to discuss my committee meeting for next week.

### **WEEK 3**

June 23, 2014

- 830am-930am

- Rounding with Dr. Sikka on the 4<sup>th</sup> floor of BIR. Very interesting to do rounds with the attending physicians and one of my favorite experiences so far.

- 10am-3pm
  - Access to Care Survey

June 24, 2014

- 830-1130am
  - Preparing for my Committee meeting discussing the approval of my research project.
- 1130-130pm
  - Committee meeting
- 2-4pm
  - Meeting with Jennifer on how everything is going
  - BRI staff meeting

June 25, 2014

- 10am-12pm
  - worked on my project
- 12-2pm
  - Access to care survey

June 26, 2014

- 7-9am
  - doing rounds with Dr. Hamilton
  - also checked up on some of Dr. Dubiels patients in the TBI section

- first experience doing that
- 10am- 3pm
  - working on my project

June 27, 2014

- 10am-3pm
  - Read on articles for my project
  -

#### **WEEK 4**

June 30, 2014

- 830-915am
  - Rounding with Dr. Sikka and checking up on patients in the 2<sup>nd</sup> floor rehab gym. This is my second time rounding with her and I was able to see her usual patients for the second time.
- 10am-230pm
  - Access to Care survey. I was able to add 3 more people to study.
- 3pm-315pm
  - Meeting with Dr. Driver to discuss more about my project. It will be starting soon, and I will be starting an outline draft.
- 315pm- 430pm
  - Working on my study
  - Reading articles.

July 1, 2014

- 830am-3pm

- Worked on articles and my project for the entire day

July 2, 2014

- 9-11am
  - worked on my research project. I will bring my outline today and show Dr. Driver a rough draft tomorrow.
- 11-3pm
  - Access to Care Survey on the Landry Fitness Center. There were 3 patients. I also saw a patient today who was able to walk, but still needed the occasional wheelchair. It was interesting to see progression such as this.

July 3, 2014

- 9-10am
  - I worked on my outline, which I will present to Dr. Driver today. I hope to get started on my proposal this week and have it done by the end of the month.
- 10am-12pm
  - I had an interesting time at the ICU trauma rounds today. There were many patients I saw, all with different circumstances.
- 12pm-3pm
  - I have been writing my outline, and Dr. Driver and I are looking what needs to be added and fixed.
  - Self management is an important part of the healthcare for SCI patients

## **WEEK 5**

July 7, 2014

- 830am-1030am
  - I am reading information on the Self-management documents that Dr. Driver gave me last week. This will be information that I can probably add to my project. This week, Dr. Driver will also take a look at the first part of my draft for my research proposal.
- 11am-2pm
  - Access to Healthcare Survey with Dr. Hamilton
  - We got 3 patients today and we are currently at 92 out of 100. By next week, we should reach our goal and move on to the next step.
- 3pm-4pm
  - Dr. Warren gave a interesting presentation on trauma and all the different studies that are going on in her department at the moment. I found it worthwhile to see how all the studies were originally started and how else I could maybe even start my own studies.

July 8, 2014

- 7am-8am Grand Rounds
  - “Setting Expectations and Providing Effective Feedback” –Thomas Cox Ph.D.
  - This presentation was for communication and interpersonal skills between the attendings and residents.
  - The secondary objective was for professionalism

- It was an interesting presentation that helped attending physicians see how they should interact with the residents.
- 8am-9am
  - working on my project and reading articles
- 9am-10am
  - Mile High: A Look at Altitude And Overload Training- Cristina Sanders D.O.
  - Primary objective is medical knowledge and secondary is patient care.
  - She discussed various models for exercise training and how OverTraining Syndrome can occur if there are deviations from the models.
  - She also discussed altitude training or hypoxic training.
  - We all simulated hypoxic training by jogging in place by only breathing through straws.
- 10am-11am
  - Introduction to the Central Nervous System Part 1 – David Salisbury Ph.D.
  - Systems Based Knowledge is the secondary objective
- 11am-12pm
  - Sports Medicine Exercise Prescription – Todd Daniels MD
  - Patient Care is the secondary objective
- 12pm-430pm
  - I worked on my project. I developed a script of some sort to use when I call people for my telephone surveys.

July 9, 2014

- 10am-2pm
  - Access to care survey. Today there was only one patient. Although it was a very interesting meeting. I met a man who was my age and had spinal cord injuries. He had recovered remarkably from the injury, however was still not able to walk. Although he had gone through this traumatic injury, he still had a good outlook on life. It was refreshing to see someone happy.
- 2pm-4pm
  - Working on my rough draft with Dr. Driver and figuring out the flow that it should go through. It is starting nicely
- 4pm-6pm
  - Working Dr. Anwar Zaman on the Seizure Prophylaxis study
  - I am learning how to look up patients and look at medication charts for the project.

July 10, 2014

- 730am-9am
  - Shadowing with Dr. Hamilton.
  - I have gotten to see the same patients over the past few months and I have seen many of them progress tremendously during their rehab. It is amazing to witness such remarkable improvements.
- 10am-130pm
  - Dr. Wilson's amputee clinic in the Landry fitness center.



- It was a fascinating experience. It was my first time seeing amputees that extensively. Doctors at this clinic give much support to the patients and help them to recover.
- 2pm-3pm – Trauma Grand Rounds
  - There was a presentation on illicit drug use in Dallas. A very interesting presentation by former Dallas detective Steve Ledbetter.

## **WEEK 6**

July 14, 2014

- 8am-930am
  - Weekly Rounding with Dr. Sikka.
  - Also visited a few TBI patients as well.
- 10am-330pm
  - Access to Care Survey at Landry Fitness Center
- 430pm-5pm
  - Meeting with Dr. Driver on updates and etc

July 15, 2014: These didactics were all Medical Knowledge for the primary objective and Patient Care for the secondary objective. Although for Dr. Driver's presentation, it was primarily for Practice Base Learning and Improvement.

- 7am-930am
  - Sideline Sports Medicine – Howard Moore M.D.
  - Interesting presentation on the different injuries seen in sports. Mainly for football, however others were mentioned
  - 10 most common major joint sports injuries.

- I watch a lot of sports, so it would be cool to shadow him. (also he said he has seen a lot of famous people!)
- 930am-10am
  - Biomechanics of Sports: running, jumping, throwing, & swimming – Tyson Sloan D.O.
  - A well presented topic, with a multiple choice quiz
  - Although it was brief, it mentioned some injuries that I often see in sports. So I was able to understand some more on how they occur.
- 10am-11am
  - Research Office and Support – Simon Driver Ph.D.
  - Dr. Driver came to resident didactics and introduced his office to us.
  - He also discussed the framework and development for how the residents would conduct their study.
- 11am-12pm
  - EMG series: Intro to machine and set ups- Stephen Thomasson D.O.
- 12pm-1pm PM&R Journal Club
  - Cristina Sanders D.O. presented “Treatment of Acute Achilles Tendon Ruptures. A Meta-Analysis of Randomized Controlled Trials”.
  - Dr. Bayazitoglu presented “The Ability of a Computed Tomography to Identify a Painful Zygapophysial Joint in Patients with Chronic Low Back Pain”.

July 16, 2014

- 10am-345pm

- Worked on my project as the rough draft is due soon
- 345-530pm
  - Worked with Dr. Zaman on the Seizure Prophylaxis study. Starting to be much quicker at the study and enjoying it a lot more as well.

July 17, 2014

- 730am-9am
  - Roundings with Dr. Hamilton. Saw about 8 patients today and learning more about the medicines commonly used for SCI patients.
- 9am-12pm
  - Worked on my project and I have now sent in my rough draft for Dr. Driver to edit.
- 12pm-130pm
  - I attended an IRB meeting to observe how the process is carried out.
  - I found it much more laid back than I thought it would be.
  - Committee sat around tables and discussed/voted on different research projects.
  - Lunch was also served, which added to the informal format of the meeting.
  - I met with the committee heads and introduced myself. And mentioned my study.
- 130pm-3pm
  - searched through medilinks for patients numbers to call for my survey.

## **WEEK 7**

July 21, 2014

- 8am-9am
  - Rounding with Dr. Sikka on the 4<sup>th</sup> floor of the BIR
  - There were more patients than usual, and I have been noticing some patients are getting better and have more motion in their feet.
  - Learned a few more medicines as well.
  - I am starting to feel more comfortable rounding now and asking more questions.
- 10am-3pm
  - I finally completed the outpatient survey portion of my project.
  - I had 2 patients for today.

July 22, 2014

- 8am-245pm
  - The whole day I spent editing my paper. I have been making a lot of progress on the paper and I am close to submitting the final draft.

July 23, 2014

- 10am-345pm
  - I spent the majority of the day looking up phone numbers in the medilinks system.
  - Dr. Hamilton provided these names to me as patients who she was not familiar with.
  - I have been calling many of these numbers however they seem to be disconnected. A lot of the numbers are not reaching.

- I have only had 3 patients pick up and 2 of them had referred me to call at another time.
- I will be needing around 100 participants for this part of the survey, which is counterpart to the previous section.
- 345pm-530pm
  - Worked with Dr. Zaman on the Seizure prophylaxis study
  - Find out a system to where I will be able to do some of the work on my own.
  - So now I will not have to wait for Dr. Zaman anymore to meet on Wednesday afternoons

July 24, 2014

- 730-9am
  - Rounds with Dr. Hamilton
  - Seeing the same patients and seeing how they progress
  - Its been a great experience to witness this.
- 9am-1pm
  - Dr. Wilsons Amputee clinic
  - I got to see around 6 patients come in today. It is one of my favorite things to do here.
  - Different people come in with different backgrounds. But they all relate to each other with this single problem.
- 1-230pm
  - Worked on my paper and telephone surveys

July 25, 2014

- 10-1130
  - Worked on my paper and telephone surveys.
  - I was collecting numbers to call as well.
- 1230-1pm
  - Meeting with Jennifer on status here.
- 2pm-245p
  - Meeting with Dr. Driver on the paper edits. Paper will be finished next week most likely. Excited to be moving along the process
- 3-4pm
  - Working on telephone surveys and conducting more calls.

## **WEEK 8**

July 28, 2014

- 10am-445pm
  - Today I spent the majority of the day working on my proposal, which is due in the next few days.
  - I was editing the comments made by Dr. Driver and adding in some extra points into the paper.
  - The proposal is around 13 pages at the moment, which I believe is actually above the average length for proposals.
  - The end of the day was spent on calling people for the survey that had requested of me to call them on Monday.
  - I was able to get two more people added to the list. I am at a total of 3.

- Calling people for the survey is proving to be the hardest part because many of the numbers are disconnected. I also believe an issue is that many of the people are SCI patients, which makes it difficult for them to answer their phone sometimes.

July 29, 2014

- 930am-530pm
  - The entire day was spent on revising the proposal.
  - Every section was looked at.
  - I looked up many different articles and was able to add in a lot more to the paper.
  - There were some edits done on the same sections, and the paper ended up being 15 pages.
  - I am going to be submitting the paper in today to Dr. Driver for edits.
  - The paper is due in the next few days so I will have to be working on it for the remainder of the week.

July 30, 2014

- 10:30-12:30pm
  - Since I was waiting for Dr. Driver to make some edits, this morning I collected some phone numbers to call on for the telephone survey.
- 12:30- 530pm
  - I have been working on my paper and making additions, as they are necessary.

July 31, 2014

- 1030am-4pm
  - I attended the BRI new employee orientation.
  - It consisted of different seminars introducing how to conduct research and related topics.
  - Many people in BRI leadership came by and had presentation throughout the day
  - Lunch was served by Jason's Deli, which is a great deli restaurant
  - I met many different students such as myself who are working in research and want to apply to medical school.
  - I enjoy meeting these people as they have a similar background as myself

August 1, 2014

- 8am-1030am
  - a Human Resources orientation was held this morning for new employees as well.
  - I met many of the same people that were here the day before.
  - It was located in the same room on the BRI 4<sup>th</sup> floor.
  - Most of this will not apply to me as I am not a paid employee
- 11am-2pm
  - I worked my paper, which I will be submitting this Monday to the committee.

## **WEEK 9**

August 4, 2014

- 730-830am



- Shadowing Dr. Sikka. I am able to see many of the same patients and get to know more about their conditions.
- An interesting case with an Asperger's patient
- Dr. Sheena Bhuvra, a second year resident is also following Dr. Sikka as well. So it is nice to see how another doctor works as well.
- 10am-12pm
  - Working on my paper. I have submitted the next draft to Dr. Driver
  - I am making a lot of progress and it looks really good right now
- 1pm-230pm
  - I had some downtime, So I worked on some medical school secondary applications.
- 230pm-4pm
  - I helped set up for a research lecture by Karen McCain from UT SW.
  - She presented a lecture about the current research projects at Crowley Research and Rehab Lab
  - Some of her topics were Neuroplasticity, orthosis, ESTT, American Heart Association, Parkinson's Disease, and Multiple Sclerosis
- 4pm-530pm
  - There was a PICO meeting on the TBI Model Systems project.
  - There were many different doctors there like Dr. Shafi and Dr. Dahdah.
  - It was my first time at a PICO meeting,
  - Researchers from different departments who were all working on the same study sat around the table and rated the articles they had read and

August 5, 2014

- 7am-730am
  - I shadowed 1 patient with Dr. Porter.
  - He said I could shadow him when I was available to.
- 8am-9am
  - Medical Grand Rounds in Beasley Auditorium
  - A presentation on Lung Cancer in Elderly Patients by Claude Denham MD
- 930am- 530pm
  - Spent the rest of the day working on the paper.
  - Tomorrow is the deadline and I am going to do my best to finish as much as I can today.
  - I also met with Dr. Driver and made some final changes to the paper

August 6, 2014

- 10am-230pm
  - The whole day was spent working on the paper.
  - Today I will be submitting the proposal.
  - Around 2:30 the paper was submitted
- 3pm-5pm
  - I worked on the Seizure Prophylaxis study for Dr. Zaman.
  - I finished around 5 patients for the day.
  - I am starting to get much better at the project.
  - And looking forward to working on more of it.

August 7, 2014

- 7am- 730am
  - Shadowed Dr. Hamilton for the morning. Only saw a few patients.
- 730-930am
  - Getting signatures for my proposal from Jennifer and Dr. Driver.
  - These are required so I can turn in the proposal and have it looked over by Dr. Gwartz
- 10am-1pm
  - I am driving to Ft. Worth so I can now get signatures from Dr. Gwartz and Dr. Reeves.
  - I am required to turn in a hard copy of my proposal to Dr. Gwartz.
  - My proposal is complete and now I will begin the next phase of the project.
  - Had some good discussions with both Gwartz and Reeves on the internship and the paper.
  - They were pretty happy and impressed with the paper, so I would say that I am on a good track at the moment.

August 8-August 15, 2014: Out of town

## **WEEK 11**

August 18, 2014

- 8am-930am
  - Shadowed Dr. Sikka this morning.

- Building on the information that I am learning for SCI.
- 10am- 2pm
  - Dr. Driver ordered me a phone, so now I will be able to make calls when I need to for the study.
  - I made calls during the day. I was able to get two calls back and added them to the study.

August 19, 2014

- 9am-10am Resident Didactics
  - Myopathies- Cristina Sanders D.O.
  - Primary is Medical Knowledge and Secondary is Patient Care
- 10am-12pm
  - Brachial plexus by Omar Selod D.O.
  - He also discussed insurance and billing companies
  - I learned a lot of the brachial plexus in grad school, although the information discussed in this lecture was a bit more complex.
- 12pm-1pm
  - PM&R Journal Club
  - Two presenters today were Sonesh Patel D.O. and Benecia Williams D.O.
  - First article was CT-Guided Piriformis Muscle injection for the Treatment of Piriformis Syndrome.
  - Techniques to Improve Function of the Arm and Hand in Chronic Hemiplegia was the second article.
- 1pm-4pm

- I am working on making survey calls for participants.

August 20, 2014

- 10am-430pm
  - For the day I worked mostly on making calls for participants to add to my survey.
  - I was also able to work on some of the seizure study for Dr. Zaman. I had one issue today with the study so I had to email him and ask for his opinion on the issue.
  - Starting to get more calls now for the Access to Care study

August 21, 2014

- 730am-9am
  - Roundings with Dr. Hamilton
  - Went by as usual and was able to talk more about heterotopic ossification with Dr. Hamilton.
  - It is a process that is not well known by many people and how it works.
  - Dr. Hamilton would like me to come look at some x-rays for heterotopic oss. Tomorrow.
- 930am- 130pm
  - At Dr. Wilson's amputee clinic and enjoying seeing the great work they do here.
  - She is helping amputee patients adjust to their new legs and making sure they feel comfortable.

- There were a good amount of patients today who came. One patient did not have a prosthetic, but rather was on a wheelchair. He was not capable of getting a prosthetic.
- 130pm-3pm
  - I worked on calls for the survey. I was able to get 1 patient today
  - Although many patients will want to call soon.

August 22, 2014

- 930am-230pm
  - Today I spent the majority of the day working on calling patients.
  - I was able to get 3 calls today and at the moment we have 11 patients.
  - I am getting a lot more calls, especially since my phone is now set up with voicemail.
  - I am also starting a new project with the social work department- the event is called Friends of Hope. This is a social gathering for TBI patients. It is a day of camp activities and games.
  - I will be doing some logistics with gathering and folding flyers and mailing them out.
  - I will also be taking reservations. It is a good responsibility and I am excited to start this new project.

## **WEEK 12**

August 25, 2014

- 830am-930am
  - Shadowing Dr. Sikka.

- Usually Dr. Sheena Bhuvra is with us, but also today a medical student from TCOM was also with us. Her name is Sabrina.
- 930am-10am
  - Talked to Sharon Rowland about the Friends of Hope project.
  - She brought flyers for me to fold and put into envelopes.
- 1030am-11am
  - Talked with Jennifer and had our weekly meeting.
  - We are just talking about what I need to do and making sure everything is ok.
- 12pm- 330pm
  - I am starting survey calls at this time and finding numbers to call on the Medilinks website.
  - I also updated some of the work I have been doing for Dr. Zaman on the seizure prophylaxis study.
  - Simultaneously, I am folding flyers for the Friends of Hope project.
- 330pm-4pm
  - I joined in the TBI studies meeting in the BIR research office.
  - Everyone in the office and other members such as Dr. Dahdah and Dr. Shafi came and talked about their studies.
  - I just wanted to listen and see how these meetings were taken place.

August 26, 1014

- 10am-12pm

- Did a few data collection forms for Dr. Zaman on the seizure prophylaxis study.
- I was able to get 3 done today
- 12pm-1pm
  - Made one call for the Access to Care Survey
  - We are currently at 15
- 1pm-130pm
  - Meeting with office on current studies
  - I gave everyone an update on all my work and they were glad to hear that everything was running smoothly
- 130pm-2pm
  - Meeting with Dr. Driver on my progress and current work
  - He thought I have progressed and gotten better as well.
  - I feel like I am getting more confident with my work here as well
- 230pm-4pm
  - Clinical Trials Officers meeting at the Davis Auditorium in the Roberts building.
  - All departments under Jennifer meet together.
  - Talk about how to improve our work and work better together
  - It was nice seeing people from different departments.

August 27,2014

- 10am-12pm
  - Working on data collection for Dr. Zaman.



- I was able to get 3 more patients out of the way.
- 12pm- 430pm
  - Survey calls for the Access to healthcare survey
  - I was able to spend time folding and putting the Friends of Hope flyers in the envelopes to send out the to the patients.

August 28, 2014

- 830am-930am
  - Shadowing with Dr. Hamilton
  - Saw patients as usual.
  - Today, I saw a patient, who was being very emotional.
  - I asked Dr. Hamilton how to help patients through this stress
- 10am-3pm
  - Shadowing Dr. Wilson at the Amputee Clinic
  - All the physicians are using a new computer system/ electronic medical records so the process was very slow today
  - First time shadowing a stroke patient
  - It was interesting to see how their diagnoses are similar to okther patients in the rehab area. This patient had a paralyzed leg.
- 3pm-330pm
  - Worked on sending in the envelopes for Friends of Hope (FOH)
  - Tomorrow is the deadline

August 29, 2014

- 930am-12pm

- I worked on finishing the envelopes for FOH and sent them all down to the mail room.
- We had to print labels for anyone that was missing.
- 12pm-1pm
  - I did one call for the Access to Care survey.
- 2pm-4pm
  - Working on the Seizure Prophylaxis project.
  - Dr. Zaman came to visit and see how all the work is coming along.
  - He gave me some pointers on the completing the surveys.

### **WEEK 13**

September 2, 2014

- 830am-10am
  - Worked on Dr. Zaman's Seizure Prophylaxis Study
- 10-11am
  - Introduction to clinical research and statistics by Monica Bennett PhD
  - Discussed basic principles of research and the necessary parts of a research paper.
  - Protocol Development was mainly discussed
  - I found it very helpful and worthwhile to understand it.
- 12pm-5pm
  - Worked on the Access to Care survey. I got two patients today.

September 3, 2014

- 830am- 3pm

- Access to Care Survey- I retrieved numbers for this study
- I also worked on the Seizure prophylaxis study at the same time.
- Made a lot of progress in these projects
- I also was able to get more things organized for the FOH event.
- 3-6pm
  - Dr. Zaman came by and we worked on the Seizure study some more. He gave me some tips on data collection and he checked my work.

September 4, 2014

- 9am- 11am
  - Working on getting numbers for the access to care survey
- 11am-1145am
  - Meeting with Dr. Driver and Libby on data for my paper. We are collecting data at the moment and trying to figure out how to complete the next step.
- 1245pm-5pm
  - Going through medilinks and finding the ASIA scores for patients that I have done survey calls with. With these patients, we will use their data, after they are entered into survey monkey, and see any preliminary correlations we can find.
  - This will be compared to data collected from those patients who were in outpatient.
  - I am continuing to make calls for the Access to Care Survey.

September 5, 2014

- 9am-12pm
  - I am working on data collection for both the Seizure Prophylaxis study and the Access to Care survey.
- 2pm-3pm
  - Meeting with Jennifer. Just making updates.
  - She will be looking for doctors for me to shadow.
- 3pm-430pm
  - Working on more calls to make to patients for the Access to Care survey.

## **WEEK 14**

Sept. 8, 2014

- 9am-10am
  - This time was spent on the Seizure Prophylaxis study, although I have encountered an issue and will not be able to fix it until I see Anwar.
- 10-5pm
  - The rest of the day is being spent on making calls to patients. I am getting close to the point where I need to start on my paper.
  - Calls are starting to get more important.
- 5-530pm
  - I watched Cindy consult with a patient and do an informed consent. It was for the Twilight study and TBI Model Systems.
  - I saw there was a lot that went into it and a lot of paperwork.

September 9, 2014

- 7am-8am – PM&R Grand Rounds

- Advanced Wound Care: Beyond Bandages and Biologics by Dr. Applewhite
- He discussed basics of wound care.
- There are hundreds of thousands of different dressings for wounds and forms for caring for wounds.
- He discussed how to properly diagnose a wound and the steps needed to do so.
- Compliance was an interesting topic: out of all topics this is the one that doctors cannot control, because it is up to the patient to do so.
- 8am-12pm
  - Working on making calls for the Access to Care Survey.
  - Also writing down RSVP's for the FOH event.
- 1pm-2pm
  - Staff meeting over updates for the week

September 10, 2014

- 9am-5pm
  - Today I spent most of the time collecting numbers, so I could have a larger list when I want to make calls for the Access to Care surveys.
  - I was able to get 4 patients for the survey.
  - I also did some work for the Friends of Hope event.
  - Called patients who wanted to attend the event and updated the spreadsheets for any change in addresses.
  - There were some RSVP's that I also wrote down.

- By the end of the month, I should be able to hit my target goal of the number of survey calls I need.

September 11, 2014

- 9am- 10am
  - From the returned mail for the FOH event, I sorted out the ones that needed to be resent, and for those with no returning addresses I am noting in the address list that there are no forwarding addresses available.
- 10am-1230pm
  - Looking at Medilinks to find numbers for me to call for the survey.
  - Discussed with Dr. Driver about reading about Health Literacy.
  - He wants to talk more about that tomorrow.
- 130pm-430pm
  - making calls for the survey

September 12, 2014

- 9am-12pm
  - Reviewing the Health Literacy document that Dr. Driver gave me
  - Doing some work for FOH
- 12pm-1pm
  - Office Lunch at Pepe's & Mito's
- 1pm-430pm
  - Calling patients for the Access to Care Survey
  - I am currently at 30 and thinking I can get 40 by the end of the month.

**WEEK 15**

September 15, 2014

- 930am-12pm
  - Worked on finding out the numbers for the seizure study.
  - Mailed out packets for anyone who wanted to come to FOH
- 12pm-3pm
  - Data collection for the Seizure study
- 3pm-6pm
  - Called people for the Access to Care Study
  - Was able to get 2 patients.

September 16, 2014

- 9am-1030am
  - During the resident lecture series, I attended a research lecture by a librarian.
  - He discussed how to use PubMed and to best find articles for research
- 1030am-12pm
  - Data collection for the seizure study
- 12-1pm
  - A man with a SCI came to talk to us about the Miami Project in the therapy area.
  - The Miami Project to Cure Paralysis is a research center at the U of Miami Medical School.

- Very inspiring talk. He discussed how the scientists and doctors are working on a way to cure paralysis and spinal cord injuries by injecting schwann cells into spinal cords of patients.
- They are currently doing tests on pigs and are about to start human trials.
- 2-430pm
  - Conducting survey calls for my project

September 17, 2014

- 830am-12pm
  - Data collection for the seizure prophylaxis study
- 1pm- 430pm
  - Survey calls for my project
  - I was able to get two today.

September 18, 2014

- 8-12pm
  - data collection for the seizure prophylaxis study
- 1-4pm
  - survey calls for the Access to Care study

September 19, 2014

- 8-12pm
  - Did one call for the Access to Care survey
  - Data collection for the seizure study
- 1pm-4pm
  - more data collection for the seizure survey



- Calling patients for the Access to Care Survey
- I am close to a good number before I can start finishing my project.
- I am currently at 37 calls and I think the goal is 40.

## **WEEK 16**

September 22, 2014

- 8-12pm
  - I was collecting numbers for the Access to Care survey
  - Also taking down RSVP's for FOH.
- 12-3pm
  - Calling patients for the Access to Care survey
  - I am at 40 calls at the moment.
- 3-4pm
  - TBI Model Systems Team meeting
  - Dr. Shafi came in today to meet with group.
  - The team basically discussed all their projects such as the Dopamine study and Twilight study.
  - I sat in to observe.

September 23, 2014

- 915-11am
  - Seizure study data collection
- 11am-12pm

- Attended a meeting on research collaboration between Baylor University, Baylor Health Care System, Scott & White, and Baylor College of Medicine.
- 1pm-2pm
  - Meeting with the office staff.
  - Breaking down all the studies and discussing updates.
- 2-430pm
  - Data collection for the seizure study

September 24, 2014

- 8-4pm
  - I shadowed an OT today for the experience.
  - I was curious to see what their job was like and it was very interesting. I can see why the job makes such an impact.
  - She discussed the improvements patients would have throughout the years.
  - She had around 5 patients. She had about a few treatments per patient.
  - Therapy treatments were utilized to help a patients with 5 main factors: eating, dressing, grooming, bathing, and toileting.

September 25, 2014

- 8-12pm
  - Shadowed Mary deHaas from BRI.
  - I watched her do a study monitora the Institute of Metabolic Diseases at the Baylor University in Dallas.

- In the morning, I got a tour from the nurse of the research center. Many labs were scattered around the area, although the research center was somewhat empty. Many of the diseases that are studied there are rare, mainly because metabolic diseases are rare in general.
- We monitored the study, “A Treatment Trial of Triheptanoin in Patients with Adult Polyglucan Body Disease”
- She explained the differences between audits and monitorings.
- 1pm-4pm
  - Worked on the seizure study and FOH stuff.

September 26, 2014

- 8-3pm
  - Seizure Study data collection and FOH
  - Submitted the data collection for my project to Libby, and then she will compile it into Survey Monkey. After it goes into Survey Monkey, Dr. Driver, Libby, and I will review it and see what connections or assumptions we can make with the data.
  - Once we meet, I will then submit the data to Monica. Monica is our data analyst. She will break down the information further.
  - After this is when I start writing my paper.

## **WEEK 17**

September 29, 2014

- 2pm-530pm
  - Seizure data collection

September 30, 2014

- 930am- 1pm
  - making packes for FOH
  - data collection for the seizure survey
- 2pm-5pm
  - data collection for the seizure survey
  - calling patients for the Access to Care survey

October 1, 2014

- 9am-12pm
  - Seizure survey data collection
- 1pm-4pm
  - Calling patients for the access to care survey

October 2, 2014

- 9am-12pm
  - Calling patients for the Access to Care survey
  - Discussed with Dr. Driver and Libby about what I should do next to complete my paper
- 1pm-4pm
  - Called 1 patient for the survey and completed all my calls at this moment.  
I am at 42 calls.
  - Review the Access to Care protocol for anything that would help my project.

October 3, 2014

- 10am- 12pm
  - I am currently done with Access to Care survey calls and Seizure Prophylaxis study data collections. I will wait on the next steps.
  - I am reviewing articles for their Rationale and Discussions sections and seeing how I can relate it to my paper.
- 1pm- 4pm
  - Reviewing articles so that I can use parts of those for my paper. I am going to make an outline of things I would like to write about.

## **WEEK 18**

October 6, 2014

- 930am-12pm
  - Creating an outline and objectives for my Results and Discussion Section
- 12pm-1pm
  - Lecture by the Neuropsychology department hosted by Dr. David Salisbury Psy. D.
  - Neuroanatomy lecture
- 1pm- 3pm
  - Finished working on my outline for the end of my research paper
- 3pm-4pm
  - Research Lecture by the research nurses in the NICU from BUMC
  - Discussing the usage of FEES

October 7, 2014

- 9am-10am

- Research Lecture Series with Monica Bennett Ph.D.
- Primary objective is research design and secondary objective is practice based learning
- 10am-12pm
  - Working on the Seizure Prophylaxis Study
  - Having issues with the Microsoft Access database and not getting it to work
  - The issue may be that the Access version is old and not transferring data well.
- 2-4pm
  - Assisting Libby with filing in the office

October 8, 2014

- 9am-12pm
  - Working on my outline and more objectives to discuss with Dr. Driver for my paper
- 1pm-5pm
  - Fixing up my resume for medical school

October 9, 2014

- 8am-10am
  - Working on my resume
- 10am-12pm

- A friend of mine is a 4<sup>th</sup> year medical student from Texas Tech. He is doing a rotation in radiology and I asked if I could watch him for a few hours.
- Went to the ED CT room
- Saw some thoracic CT's, pulmonary embolism CT
- 1-2pm
  - Worked on the results and discussion section of my paper

October 10, 2014

- 8am- 11am
  - Revising the results and discussion section of the paper
- 11am-12pm
  - Employee Appreciation Festival
- 12pm- 1pm
  - Revising outline
- 2pm-3pm
  - Met with Dr. Driver about the revisions and what I should do next for my paper.

## **WEEK 19**

October 13, 2014

- 930-12
  - Working on emails for the FOH event, which is happening this Saturday.
  - Revisions for my paper
  - Working on my resume as well

- 1-4pm
  - Quality assurance checks for Sam's spiritual study
  - Quality assurance checks for Cindy's TBIMS study

October 14, 2014

- 930-12pm
  - Working on emails and RSVPs for the FOH event. Getting everything in order. Very excited for the event.
  - Revisions for my paper
  - Working on my resume as well
- 1-5pm
  - Quality assurance checks for Sam's spiritual study
  - Quality assurance checks for Cindy's TBIMS study

October 15, 2014

- 915am- 12pm
  - Finishing RSVPs to Friends of Hope and coordinating with Sharon on everything that needs to be done for the event
  - Looking at UNTHSC requirements for my graduation and defense date
  - Looking at my outline and preparing for my meeting tomorrow
- 1pm-4pm
  - Quality assurance checks for Sam's spiritual study
  - Quality assurance checks for Cindy's TBIMS study

October 16, 2014

- 8am-10am



- Meeting with Monica on the analysis she did for my project
- We looked at multiple factors that we could discuss.
- It helped me think about where to go next with the project
- 10-12pm
  - Looking further into what I can do for the project.
  - Researching databases on national health statistics
- 1pm-4pm
  - Quality assurance checks for Sam's spiritual study
  - Quality assurance checks for Cindy's TBIMS study

October 17, 2014

- 9am-10am
  - Since the research office added a new member, we started off Friday with a team building exercise
  - We all went around and talked about our personal favorite things.
- 10am-1130am
  - Worked on my outline
  - Worked on some of the FOH stuff. FOH is this weekend.
- 1-3pm
  - Looked at the formatting for my research project.

## **WEEK 20**

October 20, 2014

- 930am-4pm

- Got signatures from Jennifer and Dr. Driver for my Intent to Defend Form
- Went to UNTHSC to get signatures from Dr. Reeves and Dr. Gwartz

October 21, 2014

- 9am-10am
  - Research Lecture Series with the residents at BUMC
  - Presented by Monica Bennett Ph.D.
  - Main topic was over Research design
- 10am-12pm
  - Met with Monica on some new data she gathered for the project
  - Hopefully this will add great data to my thesis
- 1pm-3pm
  - Preparing for a mock medical school interview with Dr. Anwar Zaman
- 3pm-4pm
  - Quality Assurance Testing for Cindy on the TBIMS project
- 4pm-6pm
  - Preparing for a mock medical school interview by looking up interview questions and reviewing my documents
  - Interview lasted about 30 minutes

October 22, 2014

- 10am-12pm
  - Finished the Quality assurance checks for Cindy for the TBIMS study
- 1-2pm
  - Made some copies for the TBIMS project

- 2-3pm
  - Started writing the paper
  - Will meet again with Monica and Dr. Hamilton this week before I start most of my draft.

October 23, 2014

- 930am-12pm
  - Working on quality assurance checks for Sam for the spirituality study

October 24, 2014

- 1pm-3pm
  - Filing for the TBIMS study
  - Reviewed articles that discussed healthcare utilization for SCI for any ideas for my project

## **WEEK 21**

October 27, 2014

- 9-5pm
  - Worked at home for the day on my paper.
  - Will review with Dr. Driver tomorrow on any progress I can make.

October 28, 2014

- 9am-11pm
  - The deadline for my research thesis is approaching and most of my time has been spent on researching articles and writing my paper.
- 11-12pm

- I did some more quality assurance checks for the spirituality study.
- 1pm-3pm
  - Reviewing articles for my discussion so that I can find evidence of facts that I have found in my discussion.
- 3pm-4pm
  - Met with Dr. Driver after he edited my paper. I will meet with him again to edit on Thursday.
- 4pm-5pm
  - I did some more quality assurance checks for the spirituality study. The files are almost finished. There are about like 8 files left.

October 29, 2014

- 9am-12pm
  - I spent most of the day working on my thesis.
  - looking up information for my discussion
  - Rewriting my results section along with the edits that Dr.Driver did for me
- 12pm-3pm
  - BIR is doing a pumpkin decorating contest, so Sam and I went to pick up supplies to decorate our pumpkin.
  - We started decorating it into a minion from the movie, Despicable Me.
- 3pm-5pm
  - Finished on more of my edits and will work on more at home.

October 30, 2014

- 9am-5pm

- The entire day was spent on writing for my thesis. I edited the results section further and looked up statistics for my discussion.
- Tomorrow afternoon I will show Dr. Driver what I have so that he can edit and help me further.

October 31, 2014

- 9am-10am
  - started the morning by filing patient files for the TBIMS
  - Also, more quality assurance checks for the spirituality study for Sam
- 10am-12pm
  - Worked on some of the paper that Dr. Driver and I will discuss for today
- 12pm-1pm
  - I went to go look at the pumpkins in the Halloween party that BIR has today. Our pumpkin is in the contest as well.
- 130pm-3pm
  - I met with Dr. Driver and we discussed what I need to do next for my paper and how my edits should go.
  - Paper is due within the next few days.

## **WEEK 22**

November 3, 2014

- 930am-12pm
  - Working on a few things around the office.

- Met with Dr. Driver, and he made further edits on my results and discussion as it is coming together well. About to start on the next question and I will send in another draft to him later this afternoon.
- 1pm-3pm
  - Worked on the second question for my paper.
  - Looked up references and working on writing the paragraph for this last part of my paper.
- 3pm-4pm
  - Presentation by Dr. Kimberly Monden and Dr. Zena Trost in the BIR Board Room
  - Perceived Injustice of those with SCI

November 4, 2014

- 930-4pm
  - Seizure Study data collection for Dr. Zaman
  - Looking up some things for my paper and working on the second portion of the paper.
- 1-2pm
  - Office meeting on updates around the office.

November 5, 2014

- 1030am-12pm
  - Writing the conclusion, internship experience, and the future clinical implications of my paper.
  - Also looking up data for the seizure study.

- I met with Dr. Driver, where we discussed more revisions to my paper. I think I will be submitting it tomorrow or Friday at some point.
- 1pm-3pm
  - Writing the finishing touches to my paper

November 6, 2014

- 9-12pm
  - Met with Dr. Reeves this morning to discuss my paper
  - He is feeling good about it and wants to see the completed paper by next week.
- 2-5pm
  - Data collection for the Seizure Study
  - Looking up SS# for the subjects

November 7, 2014

- 9-12pm
  - Data collection for the Seizure study
  - Completing CRF's
- 12-1pm
  - Office Lunch
- 1pm-3pm
  - Working on the conclusion and limitations portion of my paper. I will begin formatting it into the document, as this will take some time.
- 3-4pm
  - Meeting with Jennifer at the BRI Location.

- Just updating her on the project and what happens next in the next few weeks.



## APPENDIX B

### TABLES & FIGURES

Table 3: Doctor visits in the last 12 months

Type of doctor seen in the last 12 months	Overall (N=142)	Phone (N=42)	Visit (N=100)
None	2 (1%)	2 (5%)	0 (0%)
Primary Care	112 (79%)	37 (88%)	75 (75%)
	14/50 (28%)	6/13	8/37
Obstetrician/Gynecologist (includes women only)		(46%)	(22%)
	109 (77%)		100
SCI/Rehab Doctor		10 (24%)	(100%)
Pain Management	31 (22%)	11 (26%)	20 (20%)
Urologist	71 (50%)	15 (36%)	56 (56%)
Orthopedic Surgeon	18 (13%)	4 (10%)	14 (14%)
Neurosurgeon	27 (19%)	7 (17%)	20 (20%)
Wound Care	38 (27%)	13 (31%)	25 (25%)
Other	35 (25%)	4 (10%)	31 (31%)

Table 4: Summary of the accessibility of doctor's offices and/or equipment.

	Overall	Phone	Visit
<b>Doorway (# of subjects)</b>			
Primary care	95 (87%)	31 (91%)	64 (85%)
OB/GYN	12 (86%)	4 (67%)	8 (100%)
SCI/Rehab	108 (99%)	10 (100%)	98 (99%)
Pain Management	26 (84%)	8 (73%)	18 (90%)
Urologist	61 (85%)	13 (87%)	48 (84%)
Orthopedic Surgeon	17 (94%)	3 (75%)	14 (100%)
Neurosurgeon	26 (96%)	7 (100%)	19 (95%)
Wound Care	31 (86%)	10 (83%)	21 (88%)
<b>Exam Room (# of subjects)</b>			
Primary care	94 (86%)	30 (88%)	64 (85%)
OB/GYN	-	-	-
SCI/Rehab	26 (87%)	8 (80%)	18 (90%)
Pain Management	26 (84%)	8 (73%)	18 (90%)
Urologist	65 (90%)	13 (87%)	52 (91%)
Orthopedic Surgeon	16 (89%)	3 (75%)	13 (93%)
Neurosurgeon	-	-	-
Wound Care	-	-	-
<b>Exam Table (# of subjects)</b>			
Primary care	52 (53%)	16 (62%)	36 (50%)
OB/GYN	9 (69%)	4 (80%)	5 (63%)
SCI/Rehab	98 (96%)	7 (78%)	91 (98%)
Pain Management	14 (67%)	5 (71%)	9 (64%)
Urologist	49 (74%)	9 (64%)	40 (77%)
Orthopedic Surgeon	12 (67%)	3 (75%)	9 (64%)
Neurosurgeon	17 (74%)	3 (60%)	14 (78%)
Wound Care	33 (92%)	11 (92%)	22 (92%)
<b>Bathroom (# of subjects)</b>			
Primary care	71 (89%)	24 (83%)	47 (92%)
OB/GYN	8 (80%)	4 (80%)	4 (80%)
SCI/Rehab	62 (93%)	7 (78%)	55 (95%)
Pain Management	17 (85%)	6 (67%)	11 (100%)
Urologist	44 (92%)	12 (100%)	32 (89%)
Orthopedic Surgeon	12 (67%)	3 (75%)	9 (64%)
Neurosurgeon	12 (100%)	3 (100%)	9 (100%)
Wound Care	19 (95%)	7 (88%)	12 (100%)
<b>Imaging (# of subjects)</b>			

Primary care	41 (87%)	14 (82%)	27 (90%)
OB/GYN	5 (71%)	3 (100%)	2 (50%)
SCI/Rehab	30 (97%)	5 (100%)	25 (96%)
Pain Management	12 (100%)	7 (100%)	5 (100%)
Urologist	35 (92%)	9 (100%)	26 (90%)
Orthopedic Surgeon	14 (88%)	4 (100%)	10 (83%)
Neurosurgeon	16 (100%)	3 (100%)	13 (100%)
Wound Care	17 (100%)	6 (100%)	11 (100%)
<b>Labs (# of subjects)</b>			
Primary care	97 (91%)	32 (97%)	65 (88%)
OB/GYN	11 (85%)	5 (83%)	6 (86%)
SCI/Rehab	23 (77%)	9 (82%)	14 (74%)
Pain Management	59 (84%)	12 (80%)	47 (85%)
Urologist	16 (89%)	4 (100%)	12 (86%)
Orthopedic Surgeon	26 (100%)	6 (100%)	20 (100%)
Neurosurgeon	16 (89%)	4 (100%)	12 (86%)
Wound Care	33 (94%)	10 (83%)	23 (100%)
<b>Parking (# of subjects)</b>			
Primary care	97 (91%)	32 (97%)	65 (88%)
OB/GYN	11 (85%)	5 (83%)	6 (86%)
SCI/Rehab	88 (83%)	9 (90%)	79 (82%)
Pain Management	23 (77%)	9 (82%)	14 (74%)
Urologist	59 (84%)	12 (80%)	47 (85%)
Orthopedic Surgeon	16 (89%)	4 (100%)	12 (86%)
Neurosurgeon	26 (100%)	6 (100%)	20 (100%)
Wound Care	33 (94%)	10 (83%)	23 (100%)

---

\*All percentages are calculated using the total number of patients for which each preventative care measure is applicable.

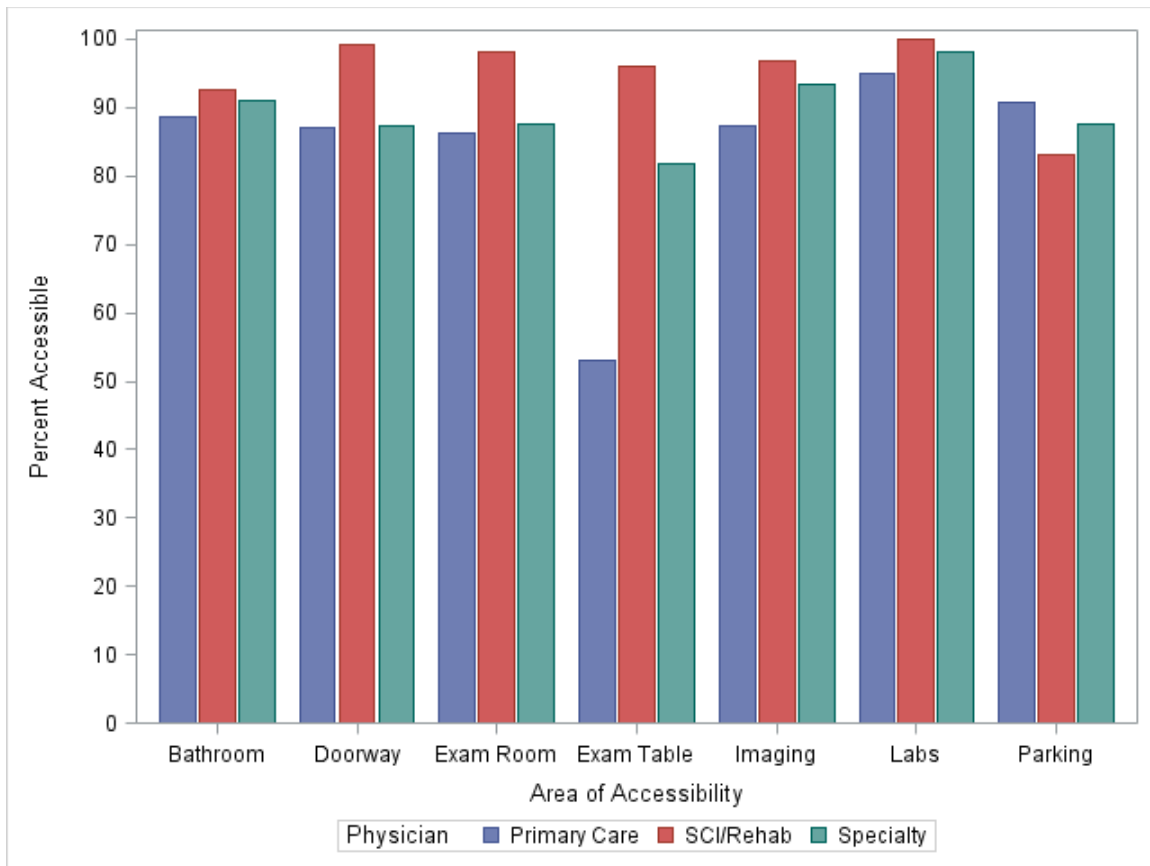


Figure 1: Accessibility of primary care, SCI/Rehab, and specialty doctor's office.

Table 5: Physician knowledge and communication

<b>Statement</b>	<b>Overall (N=142)</b>	<b>Phone (N=42)</b>	<b>Visit (N=100)</b>
<b>My primary care physician is knowledgeable about my spinal cord injury needs (# of subjects)</b>			
Strongly Disagree	10 (7%)	3 (7%)	7 (7%)
Disagree	8 (6%)	6 (14%)	2 (2%)
Somewhat Disagree	9 (6%)	2 (5%)	7 (7%)
Somewhat Agree	26 (18%)	7 (17%)	19 (19%)
Agree	41 (29%)	15 (36%)	26 (26%)
Strongly Agree	27 (19%)	6 (14%)	21 (21%)
N/A	21 (15%)	3 (7%)	18 (18%)
<b>My spinal cord injury doctor is knowledgeable about my spinal cord injury needs (# of subjects)</b>			
Strongly Disagree	0 (0%)	0 (0%)	0 (0%)
Disagree	0 (0%)	0 (0%)	0 (0%)
Somewhat Disagree	0 (0%)	0 (0%)	0 (0%)
Somewhat Agree	4 (3%)	3 (7%)	1 (1%)
Agree	9 (6%)	3 (7%)	6 (6%)
Strongly Agree	98 (69%)	8 (19%)	90 (90%)
N/A	31 (22%)	28 (67%)	3 (3%)
<b>My physicians communicate well with each other about my health (# of subjects)</b>			
Strongly Disagree			
Disagree	8 (6%)	6 (14%)	2 (2%)
Somewhat Disagree	11 (8%)	1 (2%)	10 (10%)
Somewhat Agree	12 (8%)	3 (7%)	9 (9%)
Agree	22 (15%)	9 (21%)	13 (13%)
Strongly Agree	45 (32%)	12 (29%)	33 (33%)
N/A	40 (28%)	8 (19%)	32 (32%)

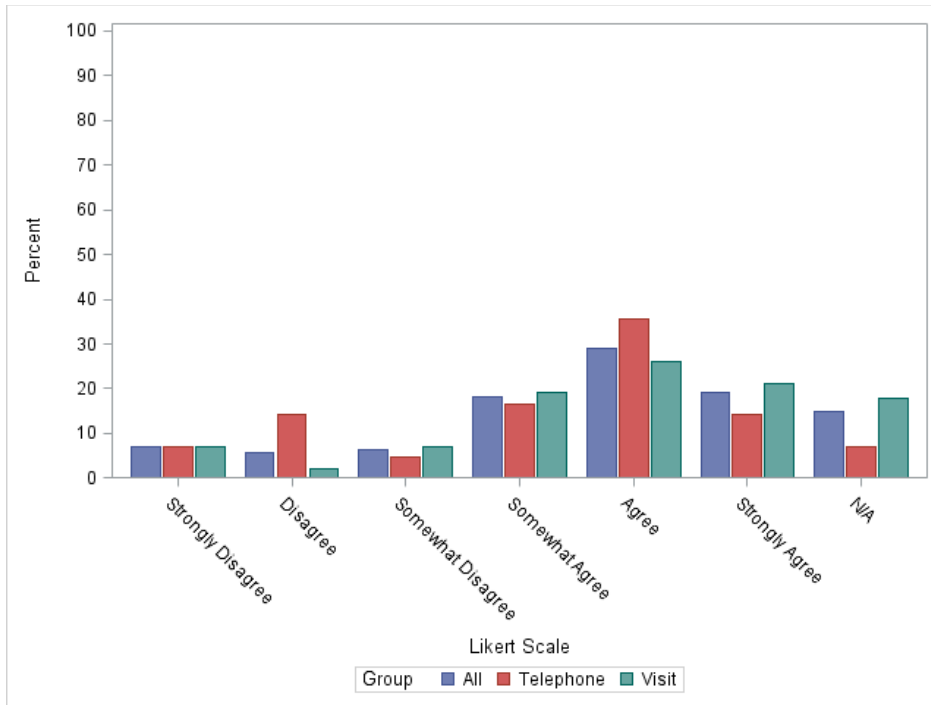


Figure 2a: My primary care physician is knowledgeable about my spinal cord injury needs

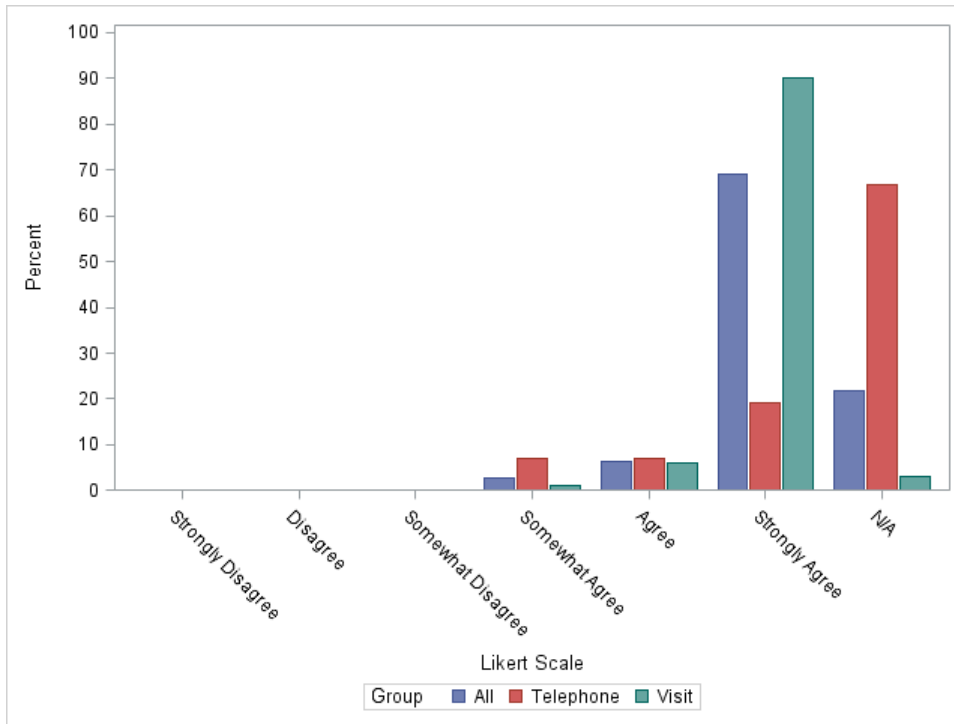


Figure 2b: My spinal cord injury doctor is knowledgeable about my spinal cord injury needs

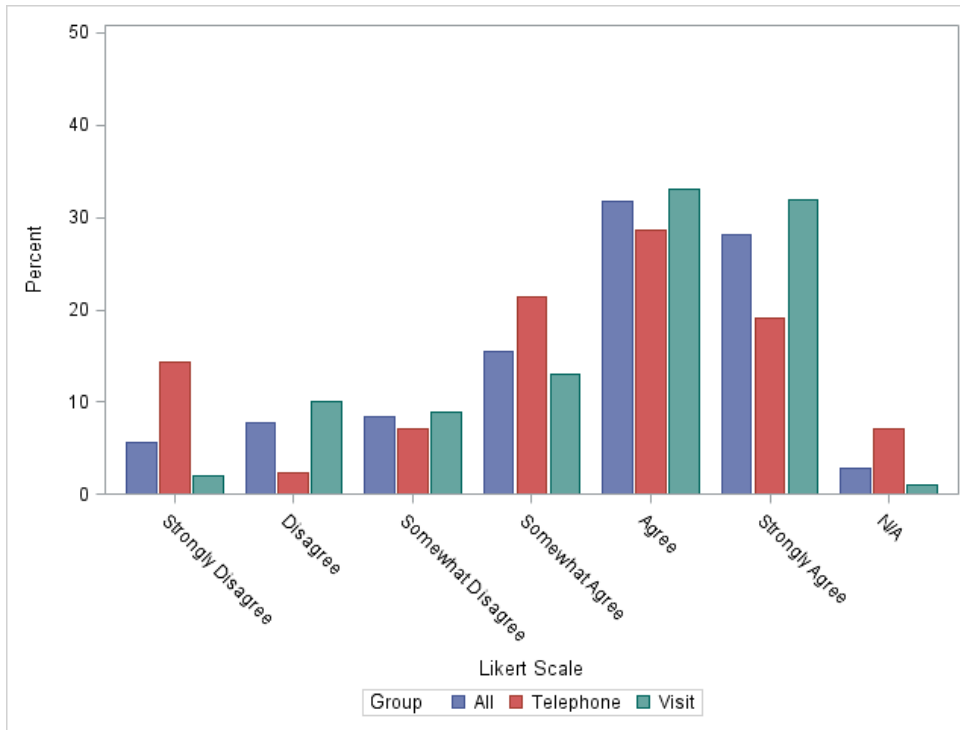


Figure 2c: My physicians communicate well with each other about my health



Table 6: Emergency room visits

<b>Characteristic (# of subjects)</b>	<b>Overall (N=142)</b>	<b>Phone (N=42)</b>	<b>Visit (N=100)</b>
<b>ER Visit</b>	61 (43%)	18 (43%)	43 (43%)
<b>Multiple ER Visits</b>	30 (21%)	11 (26%)	19 (19%)
<b>Reason for Visit</b>			
Genital/Urological	22 (15%)	8 (19%)	14 (14%)
Pain	3 (2%)	1 (2%)	2 (2%)
Falls/Fractures/Broken bones	4 (3%)		3 (3%)
Mental Health	1 (1%)	1 (2%)	1 (1%)
Constipation	3 (2%)	0 (0%)	2 (2%)
Wounds, Skin Problems	7 (5%)	1 (2%)	2 (2%)
Spasticity	2 (1%)	2 (5%)	5 (5%)
Autonomic Dysrexia	2 (1%)	0 (0%)	2 (2%)
Pneumonia	2 (1%)	0 (0%)	2 (2%)
Other	5 (4%)	3 (7%)	2 (2%)
	32 (23%)	7 (17%)	25 (25%)

Table 7: Preventative care

<b>Preventative care (if applicable)*</b>	<b>Overall</b>	<b>Phone</b>	<b>Visit</b>
<b>Percentage of completed measures</b>	66%±16%	66%±17%	66%±16%
<b>Per health guidelines (# of subjects)</b>			
PAP smear	31 (63%)	7 (58%)	24 (65%)
Mammogram	15 (71%)	3 (75%)	12 (71%)
Colonoscopy	26 (54%)	7 (50%)	19 (56%)
<b>Annual checkup (# of subjects)</b>			
Flu Shot	78 (55%)	21 (50%)	57 (57%)
Exercise 5 days a week	40 (28%)	13 (31%)	27 (27%)
Cholesterol checked	80 (57%)	27 (68%)	53 (53%)
Blood glucose checked	90 (64%)	25 (63%)	65 (65%)
Blood pressure	138 (99%)	39 (98%)	99 (99%)
Weight checked	83 (59%)	24 (60%)	59 (59%)
Asked about tobacco products	102 (73%)	26 (65%)	76 (76%)
Asked about alcohol consumption	100 (71%)	25 (63%)	75 (75%)
Asked about diet	79 (56%)	25 (63%)	54 (54%)
Asked about contraception use	25 (19%)	9 (13%)	16 (17%)

\*All percentages are calculated using the total number of patients for which each preventative care measure is applicable.

Table 8: Summary of demographic and injury related characteristics for patients with an SCI/Rehab visit vs. patients without SCI/Rehab visits.

<b>Characteristic (# of subjects)</b>	<b>SCI Visit (n=110)</b>	<b>No SCI Visit (n=32)</b>	<b>p-value</b>
<b>Age at time of survey</b>	40.4±13.1	42.3±12.7	0.4793
<b>Male Gender</b>	70 (64%)	22 (69%)	0.5940
<b>Hispanic Ethnicity</b>	10 (9%)	6 (19%)	0.1283
<b>Minority Race</b>	15 (14%)	8 (25%)	0.1246
<b>Geo Unit Quality Score</b>	102±14	98±12	0.2130
<b>Lives in DFW Metroplex*</b>	85 (77%)	17 (53%)	0.0075
<b>Zipcode population ≥10,000</b>	96 (87%)	28 (88%)	0.9729
<b>Post-Secondary Education</b>	58 (53%)	19 (59%)	0.5065
<b>Married</b>	47 (43%)	11 (34%)	0.3976
<b>Yearly household Income prior to injury ≥50,000</b>	52 (52%)	14 (54%)	0.8666
<b>Current Yearly household Income ≥50,000</b>	43 (41%)	7 (30%)	0.3324
<b>Drop in income category*</b>	34 (34%)	14 (64%)	0.0100
<b>Private Insurance*</b>	83 (75%)	12 (38%)	<.0001
<b>Age at injury*</b>	31.6±13.1	37.2±12.9	0.0377
<b>Years since injury*</b>	9.0±9.4	5.3±6.6	0.0176
<b>Paraplegic*</b>	54 (50%)	16 (55%)	0.6208
<b>Level of injury</b>			0.3748
Cervical	52 (49%)	15 (48%)	
Thoracic	48 (45%)	12 (39%)	
Lumbar	6 (6%)	4 (13%)	
<b>ASIA Impairment Scale</b>			0.1908
A=Complete	62 (59%)	11 (44%)	
B=Sensory Incomplete	10 (10%)	4 (16%)	
C=Motor Incomplete	14 (13%)	7 (28%)	
D=Motor incomplete	19 (18%)	3 (12%)	

\*Excludes patients who did not respond/did not know.

Table 9: Healthcare utilization and preventative care for patients with an SCI/Rehab visit vs. patients without SCI/Rehab visits.

Utilization in previous 12 months (# of subjects)	SCI Visit (n=110)	No SCI Visit (n=32)	p-value
<b>Seen Specialist*</b>	93 (85%)	17 (53%)	0.0002
<b>ER Visit</b>	48 (44%)	13 (41%)	0.7620
<b>Multiple ER Visits</b>	22 (20%)	8 (25%)	0.5420
<b>Percentage of completed measures Per health guidelines*</b>	66%±16%	65%±17%	0.6531
PAP smear	26 (65%)	5 (56%)	0.5954
Mammogram	13 (68%)	2 (100%)	1.000
Colonoscopy	19 (49%)	3 (33%)	0.4037
<b>Annual checkup</b>			
Flu Shot	60 (55%)	18 (56%)	0.8646
Exercise 5 days a week	31 (28%)	9 (28%)	0.9950
Cholesterol checked	62 (56%)	18 (60%)	0.7213
Blood glucose checked	74 (67%)	16 (53%)	0.1578
Blood pressure	109 (99%)	29 (97%)	0.3839
Weight checked	64 (58%)	19 (63%)	0.6107
Asked about tobacco products	84 (76%)	18 (60%)	0.0740
Asked about alcohol consumption	82 (75%)	18 (60%)	0.1180
Asked about diet	61 (55%)	18 (60%)	0.6563
Asked about contraception use	21 (21%)	4 (13%)	0.3727

\*All percentages are calculated using the total number of patients for which each preventative care measure is applicable.

Table 10: Summary of demographic and injury related characteristics for patients with an ER visit vs. patients without ER visit in the past 12 months.

Characteristic (# of subjects)	ER Visit (n=61)	No ER Visit (n=81)	p-value
Age at time of survey	39.6±13.1	41.7±12.9	0.3378
Male Gender	35 (57%)	57 (70%)	0.1086
Hispanic Ethnicity	7 (11%)	9 (11%)	0.9458
Minority Race	8 (13%)	15 (19%)	0.3869
Geo Unit Quality Score	98±12	104±15	0.0170
Lives in DFW metroplex	42 (69%)	60 (74%)	0.4935
Zipcode population ≥10,000	52 (85%)	72 (89%)	0.5183
Post-Secondary Education	27 (44%)	50 (62%)	0.0386
Married	20 (33%)	38 (47%)	0.0900
Yearly household Income prior to injury ≥50,000	25 (47%)	41 (56%)	0.3183
Current Yearly household Income ≥50,000	12 (22%)	38 (53%)	0.0004
Drop in income category*	24 (47%)	24 (34%)	0.1393
Private Insurance	39 (64%)	56 (69%)	0.5144
Age at injury*	32.2±13.4	33.6±13.2	0.5563
Years since injury*	7.8±9.5	9.8±8.5	0.7259
Paraplegic*	32 (53%)	38 (49%)	0.6436
Level of injury			0.9191
Cervical	29 (48%)	38 (50%)	
Thoracic	27 (44%)	33 (43%)	
Lumbar	5 (8%)	5 (7%)	
ASIA Impairment Scale			0.3702
A=Complete	35 (64%)	38 (51%)	
B=Sensory Incomplete	6 (11%)	8 (11%)	
C=Motor Incomplete	8 (15%)	13 (17%)	
D=Motor incomplete	6 (11%)	16 (31%)	

Table 11: Healthcare utilization and preventative care for patients with an ER visit vs. patients without ER visit in the past 12 months.

<b>Utilization in previous 12 months (# of subjects)</b>	<b>ER Visit (n=61)</b>	<b>No ER Visit (n=81)</b>	<b>p-value</b>
<b>Seen Specialist</b>	50 (82%)	60 (74%)	0.2651
<b>Percentage of completed measures</b>	68%±15%	64%±17%	0.1523
<b>Per health guidelines*</b>			
PAP smear	15 (63%)	16 (64%)	0.9133
Mammogram	3 (50%)	12 (80%)	0.2906
Colonoscopy	9 (50%)	13 (43%)	0.6536
<b>Annual checkup</b>			
Flu Shot	31 (51%)	33 (41%)	0.2321
Exercise 5 days a week	17 (28%)	23 (28%)	0.9450
Cholesterol checked	33 (54%)	47 (59%)	0.5224
Blood glucose checked	43 (70%)	47 (59%)	0.1781
Blood pressure	61 (100%)	77 (97%)	0.5047
Weight checked	41 (67%)	42 (53%)	0.0934
Asked about tobacco products	48 (79%)	54 (68%)	0.1728
Asked about alcohol consumption	47 (77%)	53 (67%)	0.1958
Asked about diet	40 (66%)	39 (49%)	0.0552
Asked about contraception use	13 (23%)	12 (16%)	0.2819

## APPENDIX C

### SURVEY

Inclusion Criteria	
<i>All responses must be "Yes," in order for the subject to be eligible</i>	
1. Is the subject between 18 and 64 years old?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Did the subject have a traumatic or non-traumatic spinal cord injury?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Has the subject been living in the community for at least 12 months post inpatient rehabilitation discharge?	<input type="checkbox"/> Yes <input type="checkbox"/> No

Exclusion Criteria	
<i>All responses must be "No," in order for the subject to be eligible</i>	
1. Does the subject have a severe cognitive impairment?	<input type="checkbox"/> Yes <input type="checkbox"/> No
2. Does the subject have premorbid mental illness or premorbid developmental disability?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3. Is the subject a prisoner?	<input type="checkbox"/> Yes <input type="checkbox"/> No

Type of survey
<input type="checkbox"/> In person/Outpatient <input type="checkbox"/> Telephone

Demographic Information	
1. What is your gender?	<input type="checkbox"/> 1. Male <input type="checkbox"/> 2. Female
2. What is your birthdate? <i>Enter 09/09/9999 if unknown or missing.</i>	<div> <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </div>
3. What is your ethnicity? Unknown	<input type="checkbox"/> 1. Hispanic <input type="checkbox"/> 2. Non-Hispanic <input type="checkbox"/> 9. Unknown
4. What is your race?	<input type="checkbox"/> 1. American Indian/Alaska Native <input type="checkbox"/> 2. Asian <input type="checkbox"/> 3. Native Hawaiian/Pacific Islander <input type="checkbox"/> 4. Black/African American <input type="checkbox"/> 5. White <input type="checkbox"/> 6. More than one race <input type="checkbox"/> 7. Other <input type="checkbox"/> 9. Unknown/Missing
5. What is your zip code? <i>Enter '99999' if unknown or missing.</i>	<div> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> </div>
6. What is the highest level of education you have completed?	<input type="checkbox"/> 1. Elementary School <input type="checkbox"/> 2. High School Diploma or Equivalent (e.g., GED) <input type="checkbox"/> 3. Associate's Degree <input type="checkbox"/> 4. Vocational/Technical Degree <input type="checkbox"/> 5. Bachelor's Degree <input type="checkbox"/> 6. Master's Degree <input type="checkbox"/> 7. Doctorate Degree <input type="checkbox"/> 8. Professional Degree (e.g., MD, JD) <input type="checkbox"/> 9. Would Rather Not Say/Unknown
7. What is your current relationship status?	<input type="checkbox"/> 1. Single <input type="checkbox"/> 2. Married <input type="checkbox"/> 3. Divorced <input type="checkbox"/> 4. Separated <input type="checkbox"/> 5. Widowed <input type="checkbox"/> 6. Common Law/Cohabitation <input type="checkbox"/> 9. Would Rather Not Say/Unknown
8. What was your yearly household income	<input type="checkbox"/> 1. Less than \$25,000 <input type="checkbox"/> 2. \$25,000 - \$49,000

prior to your injury?	<input type="checkbox"/> 3. \$50,000 - \$74,000 <input type="checkbox"/> 4. \$75,000 - \$99,000 <input type="checkbox"/> 5. \$100,000 or more <input type="checkbox"/> 9. Would Rather Not Say/Unknown
<b>Demographic Information</b>	
9. What is your current yearly household income?	<input type="checkbox"/> 1. Less than \$25,000 <input type="checkbox"/> 2. \$25,000 - \$49,000 <input type="checkbox"/> 3. \$50,000 - \$74,000 <input type="checkbox"/> 4. \$75,000 - \$99,000 <input type="checkbox"/> 5. \$100,000 or more <input type="checkbox"/> 9. Would Rather Not Say/Unknown
10. What type of medical Insurance do you have?  specify_____	<input type="checkbox"/> 1. Self Pay or Uninsured <input type="checkbox"/> 2. Medicare <input type="checkbox"/> 3. Medicaid <input type="checkbox"/> 4. Private Insurance <input type="checkbox"/> 5. Tricare <input type="checkbox"/> 6. Other, please  <input type="checkbox"/> 9. Unknown



Injury Related Information	
1. What date did your spinal cord injury occur?	<div> <div><div></div><div></div></div> <div>/</div> <div><div></div><div></div></div> <div>/</div> <div><div></div><div></div><div></div><div></div></div> </div> <div>Enter 07/07/7777 if non-traumatic SCI. Enter 09/09/9999 if unknown/missing.</div>
2. Are you paraplegic or tetraplegic (quadriplegic)?	<div> <input type="checkbox"/> 1. Paraplegic           <input type="checkbox"/> 2. Tetraplegic (quadriplegic)           <input type="checkbox"/> 9. Unknown         </div>
3. What is your level of spinal cord injury?	<div> <input type="checkbox"/> 1. Cervical           <input type="checkbox"/> 2. Thoracic           <input type="checkbox"/> 3. Lumbar           <input type="checkbox"/> 9. Unknown         </div>
4. What is your ASIA Impairment Scale (AIS)?	<div> <input type="checkbox"/> 1. A = Complete           <input type="checkbox"/> 2. B = Sensory Incomplete           <input type="checkbox"/> 3. C = Motor Incomplete           <input type="checkbox"/> 4. D = Motor Incomplete           <input type="checkbox"/> 5. E = Normal           <input type="checkbox"/> 9. Unknown         </div>

Health Care Related Information								
1. Have you seen a doctor in the last twelve months?		<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Unknown						
2. If yes, please check all types of doctors you see on a in the last twelve months.		<input type="checkbox"/> 1. Primary Care (Family Doctor/Internal Medicine) <input type="checkbox"/> 2. If female, Obstetrician/Gynecologist <input type="checkbox"/> 3. Spinal Cord Injury/Rehabilitation doctor <input type="checkbox"/> 4. Pain management <input type="checkbox"/> 5. Urologist <input type="checkbox"/> 6. Orthopedic Surgeon <input type="checkbox"/> 7. Neurosurgeon <input type="checkbox"/> 8. Wound Care <input type="checkbox"/> 9. Other, please						
specify_____								
3. Indicate whether or not the following doctors' offices and/or equipment were accessible for –								
	Internal Medicine	Ob-gyn	SCI/Rehab Doctor	Pain Mgmt.	Urologist	Ortho-pedic surgeon	Neuro-surgeon	Wound Care
a. Doorways	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A
b. Exam room	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A
c. Exam table	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A
d. Bathroom	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A
e. Radiology/ Imaging	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<input type="checkbox"/> 1. Yes	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<input type="checkbox"/> 1. Yes	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No

	<input type="checkbox"/> 9. N/A	<input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 9. N/A	<input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 9. N/A	<input type="checkbox"/> 9. N/A	<input type="checkbox"/> 9. N/A	<input type="checkbox"/> 9. N/A
f. Labs	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A
g. Parking	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. N/A

Health Care Related Information							
<p><b>4. Please indicate how strongly you agree or disagree with the following sentences. Mark one box on each line.</b></p>							
	1. Strongly Disagree	2. Disagree	3. Somewhat Disagree	4. Somewhat Agree	5. Agree	6. Strongly Agree	7. Not applicable
a. My primary care physician is knowledgeable about my spinal cord injury needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> (No primary care doctor)
b. My spinal cord injury doctor is knowledgeable about my spinal cord injury needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. My physicians communicate well with each other about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p><b>5. Have you been to the Emergency Room in the last twelve months?</b></p> <div style="display: flex; justify-content: flex-end;"> <input type="checkbox"/> 1. Yes  <input type="checkbox"/> 2. No  <input type="checkbox"/> 9. Unknown         </div> <p><i>If 'No,' go to the next page.</i></p>							
<p><b>6. How many times have you been to the Emergency Room in the last twelve months?</b></p> <div style="border-bottom: 1px solid black; width: 80%; margin-left: auto;"></div>							
<div style="display: flex;"> <div style="flex: 1;"> <p><b>7. Check all the reasons why you went to the Emergency Room in the last twelve months.</b></p> <div style="border-bottom: 1px solid black; margin-top: 10px;"></div> <div style="border-bottom: 1px solid black; margin-top: 10px;"></div> </div> <div style="flex: 2;"> <div style="display: flex; flex-direction: column;"> <div style="margin-bottom: 10px;"><input type="checkbox"/> 1. Genital/Urological (e.g. Urinary Tract Infection)</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 2. Pain</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 3. Falls/Fractures/Broken bones</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 4. Mental Health (e.g., anxiety, depression)</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 5. Constipation</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 6. Wounds, Skin problems</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 7. Spasticity</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 8. Autonomic dysreflexia</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 9. Other, please specify</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 10. Other, please specify</div> <div style="margin-bottom: 10px;"><input type="checkbox"/> 88. Not Applicable, no ER visit.</div> </div> </div> </div>							

Preventative Health Information	
1. If you are a female aged 21 or older, do you get a PAP smear at least every 3 years?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
2. If you are female over the age of 50, do you get a mammogram at least every other year?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
3. Have you had a flu shot in the past twelve months?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No
4. Do you exercise five days a week for 30 minutes per day at a moderate intensity?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No
5. If you are over the age of 50, have you had a colonoscopy?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable

Preventative Health Information	
If you have seen your doctor in the past twelve months, answer yes or no for questions 6-13, otherwise select "Not applicable."	
6. Have you had your cholesterol checked in the past twelve months?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
7. Have you had your blood glucose/blood sugar checked in the past twelve months?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
8. Have you had your blood pressure checked in the past twelve months?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
9. Has your doctor checked your weight in the past twelve months?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
10. In the past twelve months, has your doctor asked you if you smoke cigarettes, cigars or dip tobacco?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
11. In the past twelve months, has your doctor asked you if you drink alcohol?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
12. In the past twelve months, has your doctor asked you about your diet?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable
13. In the past twelve months, has your doctor asked you about contraception use?	<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 9. Not applicable

APPENDIX D  
LIST OF ABBREVIATIONS

Spinal Cord Injury – SCI

Emergency Room – ER

Emergency Department – ED

Urinary Tract Infection – UTI

Primary Care Physician – PCP

Odds Ratio – OR

High Blood Pressure – HBP

Standardized Mortality Ratio – SMR

World Health Organization – WHO

Papanicolaou – PAP

Baylor Institute of Rehabilitation – BIR

National Health and Nutritional Examination Survey – NHANES

Institutional Review Board – IRB

## REFERENCES

1. Learn about spinal cord injuries. Shepherd Center Web site.  
<http://www.shepherd.org/patient-programs/spinal-cord-injury/about>. Accessed August/5, 2014.
2. Spinal cord injury statistics. BrainAndSpinalCordInjury.Org Web site. Accessed August/5, 2014. <http://www.brainandspinalcord.org/spinal-cord-injury/statistics.htm>.
3. Paker N, Soy D, Kesiktas N, et al. Reasons for rehospitalization in patients with spinal cord injury: 5 years' experience. *Int J Rehabil Res*. 2006;29(1):71-76. doi: 10.1097/01.mrr.0000185953.87304.2a [doi].
4. Hammell KW. Quality of life after spinal cord injury: A meta-synthesis of qualitative findings. *Spinal Cord*. 2006;45(2):124-139.
5. Bloemen-Vrencken JH, Post MW, Hendriks JM, De Reus EC, De Witte LP. Health problems of persons with spinal cord injury living in the netherlands\*. *Disability & Rehabilitation*. 2005;27(22):1381-1389.
- 6.
7. Anson CA, Shepherd C. Incidence of secondary complications in spinal cord injury. *Int J Rehabil Res*. 1996;19(1):55-66.
8. Widerström-Noga EG, Felipe-Cuervo E, Broton JG, Duncan RC, Yeziarski RP. Perceived difficulty in dealing with consequences of spinal cord injury. *Arch Phys Med Rehabil*. 1999;80(5):580-586.
9. Savic G, Short DJ, Weitzenkamp D, Charlifue S, Gardner BP. Hospital readmissions in people with chronic spinal cord injury. *Spinal Cord*. 2000;38(6):371-377.



10. Cardenas DD, Hoffman JM, Kirshblum S, McKinley W. Etiology and incidence of rehospitalization after traumatic spinal cord injury: A multicenter analysis. *Arch Phys Med Rehabil*. 2004;85(11):1757-1763.
11. Berkowitz M. Assessing the socioeconomic impact of improved treatment of head and spinal cord injuries. *J Emerg Med*. 1993;11 Suppl 1:63-67.
12. Kirshblum S, Campagnolo DL. *Spinal cord medicine*. Second ed. Philadelphia, PA: Lippincott Williams and Wilkins; 2011:688.
13. Rimmer JH, Rowland JL. Health promotion for people with disabilities: Implications for empowering the person and promoting disability-friendly environments. *American Journal of Lifestyle Medicine*. 2008.
14. Dunn M, Love L, Ravesloot C. Subjective health in spinal cord injury after outpatient healthcare follow-up. *Spinal Cord*. 2000;38(2):84-91.
15. Post M, Noreau L. Quality of life after spinal cord injury. *Journal of Neurologic Physical Therapy*. 2005;29(3):139-146.
16. Dryden D, Saunders L, Rowe B, et al. Utilization of health services following spinal cord injury: A 6-year follow-up study. *Spinal Cord*. 2004;42(9):513-525.
17. Meyers AR, Feltin M, Master RJ, et al. Rehospitalization and spinal cord injury: Cross-sectional survey of adults living independently. *Arch Phys Med Rehabil*. 1985;66(10):704-708.
18. Levi R, Hultling C, Seiger Å. The stockholm spinal cord injury study. 3. health-related issues of the swedish annual level-of-living survey in SCI subjects and controls. *Spinal Cord*. 1995;33(12):726-730.

19. Williams S. Improving the continuing care for individuals with spinal cord injuries. *British journal of nursing*. 2005;14(3):161-165.
20. Khazaeipour Z, Norouzi-Javidan A, Kaveh M, Mehrabani FK, Kazazi E, Emami-Razavi S. Psychosocial outcomes following spinal cord injury in iran. *J Spinal Cord Med*. 2013.
21. Fischer M, Krishnamoorthi V, Smith B, et al. Prevalence of chronic kidney disease in patients with spinal cord injuries/disorders.. *American Journal of Nephrology*. 2012;36(6):542.
22. LaVela SL, Evans CT, Prohaska TR, Miskevics S, Ganesh SP, Weaver FM. Males aging with a spinal cord injury: Prevalence of cardiovascular and metabolic conditions. *Arch Phys Med Rehabil*. 2012;93(1):90-95. doi: <http://dx.doi.org/10.1016/j.apmr.2011.07.201>. Accessed August/5, 2014.
23. Lin JL, Armour D. Selected medical management of the older rehabilitative patient. *Arch Phys Med Rehabil*. 2004;85, Supplement 3(0):76-82. doi: <http://dx.doi.org/10.1016/j.apmr.2004.04.015>. Accessed August/5, 2014.
24. Imai K, Kadowaki T, Aizawa Y. Standardized indices of mortality among persons with spinal cord injury: Accelerated aging process. *Ind Health*. 2004;42(2):213-218.
25. Cragg JJ, Noonan VK, Dvorak M, Krassioukov A, Mancini GB, Borisoff JF. Spinal cord injury and type 2 diabetes: Results from a population health survey. *Neurology*. 2013;81(21):1864-1868. doi: 10.1212/01.wnl.0000436074.98534.6e [doi].
26. Myers J, Lee M, Kiratli J. Cardiovascular disease in spinal cord injury: An overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil*. 2007;86(2):142-152. doi: 10.1097/PHM.0b013e31802f0247 [doi].

27. Bauman WA, Adkins RH, Spungen AM, et al. Is immobilization associated with an abnormal lipoprotein profile? observations from a diverse cohort. *Spinal Cord*. 1999;37(7):485-493.
28. Bauman WA, Spungen AM. Disorders of carbohydrate and lipid metabolism in veterans with paraplegia or quadriplegia: A model of premature aging. *Metabolism*. 1994;43(6):749-756.
29. Choi SE, Chow VH, Chung SJ, Wong ND. Do risk factors explain the increased prevalence of type 2 diabetes among california asian adults? *Journal of Immigrant and Minority Health*. 2011;13(5):803-808.
30. Harjo TC, Perez A, Lopez V, Wong ND. Prevalence of diabetes and cardiovascular risk factors among california native american adults compared to other ethnicities: The 2005 california health interview survey. *Metabolic syndrome and related disorders*. 2011;9(1):49-54.
31. Krause JS, Saunders LL. Health, secondary conditions, and life expectancy after spinal cord injury. *Arch Phys Med Rehabil*. 2011;92(11):1770-1775. doi: <http://dx.doi.org/10.1016/j.apmr.2011.05.024>.
32. DiMarco AF, Dawson NV. Risk factors for mortality in spinal cord injury. *J Spinal Cord Med*. 2014. doi: 10.1179/2045772314Y.00000000208 [doi].
33. De Vivo MJ, Stuart Krause J, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil*. 1999;80(11):1411-1419.
34. Lidal IB, Snekkevik H, Aamodt G, Hjeltne N, Stanghelle JK, Biering-Sørensen F. Mortality after spinal cord injury in norway. *J Rehabil Med*. 2007;39(2):145-151.

35. Max W, Rice DP, Trupin L. *Medical expenditures for people with disabilities*. US Dept. of Education; 1996.
36. Berkowitz M. *Spinal cord injury: An analysis of medical and social costs*. Demos Medical Publishing; 1998. New York, New York.
37. DeVivo MJ. Causes and costs of spinal cord injury in the united states. *Spinal Cord*. 1997;35(12):809-813.
38. Priebe MM, Chiodo AE, Scelza WM, Kirshblum SC, Wuermsers L, Ho CH. Spinal cord injury medicine. 6. economic and societal issues in spinal cord injury. *Arch Phys Med Rehabil*. 2007;88(3):S84-S88.
39. The 2005 annual statistical report for the model spinal cord injury care systems. . In: Birmingham, Alabama: National SCI Statistical Center; June 2005.
40. Spinal cord injury facts and figures at a glance. National Spinal Cord Injury Statistical Center Web site. <https://www.nscisc.uab.edu>. Published 2013. Accessed August/5, 2014.
41. World Health Organization. *International classification of functioning, disability, and health: Children & youth version: ICF-CY*. World Health Organization; 2007.
42. Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: Patterns and predictors. *Arch Phys Med Rehabil*. 2003;84(10):1417-1425. doi: [http://dx.doi.org/10.1016/S0003-9993\(03\)00268-5](http://dx.doi.org/10.1016/S0003-9993(03)00268-5).
43. Centers for Disease Control and Prevention (CDC). Environmental barriers to health care among persons with disabilities--los angeles county, california, 2002-2003. *MMWR Morb Mortal Wkly Rep*. 2006;55(48):1300-1303. doi: mm5548a4 [pii].

44. Spinal cord injury. John Hopkins Medicine Health Library Web site.  
[http://www.hopkinsmedicine.org/healthlibrary/conditions/physical\\_medicine\\_and\\_rehabilitation/spinal\\_cord\\_injury\\_85,P01180/](http://www.hopkinsmedicine.org/healthlibrary/conditions/physical_medicine_and_rehabilitation/spinal_cord_injury_85,P01180/). Accessed August/5, 2014.
45. Donnelly C, McColl M, Charlifue S, et al. Utilization, access and satisfaction with primary care among people with spinal cord injuries: A comparison of three countries. *Spinal Cord*. 2006;45(1):25-36.
46. Stillman MD, Frost KL, Smalley C, Bertocci G, Williams S. Health care utilization and barriers experienced by individuals with spinal cord injury. *Arch Phys Med Rehabil*. 2014;95(6):1114-1126.
47. Gontkovsky ST, Russum P, Stokic DS. Perceived information needs of community-dwelling persons with chronic spinal cord injury: Findings of a survey and impact of race. *Disability & Rehabilitation*. 2007;29(16):1305-1312.
48. Van Loo M, Post M, Bloemen J, Van Asbeck F. Care needs of persons with long-term spinal cord injury living at home in the netherlands. *Spinal Cord*. 2009;48(5):423-428.
49. Bowers B, Esmond S, Lutz B, Jacobson N. Improving primary care for persons with disabilities: The nature of expertise. *Disability & Society*. 2003;18(4):443-455.
50. Grotkamp SL, Cibis WM, Nüchtern EA, von Mittelstaedt G, Seger WK. Personal factors in the international classification of functioning, disability and health: Prospective evidence. *The Australian Journal of Rehabilitation Counselling*. 2012;18(01):1-24.
51. De Vivo MJ, Richards JS, Stover SL, Go BK. Spinal cord injury. rehabilitation adds life to years. *West J Med*. 1991;154(5):602-606.

52. Who will help after spinal cord injury. The University Of Iowa Orthopaedics and Rehabilitation Web site. <http://uiortho.com/index.php/who-will-help-after-spinal-cord-injuries.html>. Accessed August/5, 2014.
53. Wagner EH. Chronic disease management: What will it take to improve care for chronic illness? *Eff Clin Pract*. 1998;1(1):2-4.
54. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004;39(4p1):1005-1026.
55. Kooijmans H, Post M, Van der Woude L, de Groot S, Stam H, Bussmann J. Randomized controlled trial of a self-management intervention in persons with spinal cord injury: Design of the HABITS (healthy active behavioural IntervenTion in SCI) study. *Disabil Rehabil*. 2013;35(13):1111-1118.
56. *Health, United States*. Hyattsville, MD: National Center for Health Statistics; 2013.
57. Levi R, Hultling C, Seiger Å. The stockholm spinal cord injury study. 3. health-related issues of the swedish annual level-of-living survey in SCI subjects and controls. *Spinal Cord*. 1995;33(12):726-730.
58. Munce S, Guilcher S, Couris C, et al. Physician utilization among adults with traumatic spinal cord injury in ontario: A population-based study. *Spinal Cord*. 2009;47(6):470-476.
59. Skelton F, Hoffman JM, Reyes M, Burns SP. Examining health-care utilization in the first year following spinal cord injury. *J Spinal Cord Med*. 2014.
60. Guilcher S, Munce S, Couris C, et al. Health care utilization in non-traumatic and traumatic spinal cord injury: A population-based study. *Spinal Cord*. 2009;48(1):45-50.

61. Disability and health objectives. [healthypeople.gov](http://healthypeople.gov). Accessed November/5, 2014.
62. What is universal design? [universaldesign.com](http://universaldesign.com). Accessed November/5th, 2014.
63. Koh HK, Brach C, Harris LM, Parchman ML. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health Aff (Millwood)*. 2013;32(2):357-367. doi: 10.1377/hlthaff.2012.1205 [doi].