Independence through Patient Education in a Spinal Cord Injury Population

Justin McTish

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INDEPENDENCE THROUGH PATIENT EDUCATION IN A SPINAL CORD INJURY POPULATION

A Capstone Project
Submitted to the Rangos School of Health Sciences

Duquesne University

In partial fulfillment of the requirements for the degree of Occupational Therapy Doctorate

By
Justin McTish

December 2018
INDEPENDENCE THROUGH PATIENT EDUCATION IN A SPINAL CORD INJURY POPULATION

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ABSTRACT

INDEPENDENCE THROUGH PATIENT EDUCATION IN A SPINAL CORD INJURY POPULATION

By

Justin McTish

December 2018

Capstone project supervised by Dr. Richard Simpson Ph.D. and Dr. Jaime P. Muñoz, PhD, OTR/L, FAOTA

The Know More, Live Better program was developed because the population of people with Spinal Cord Injuries (SCI) includes a substantial number of young people, who often readmit into hospitals for preventable causes such as pressure ulcers, respiratory infections, and bowel/bladder infections. These complications can be avoided through patient education. A needs assessment was conducted at the SCI unit at Good Shepherd Rehabilitation Hospital in Allentown, PA. This assessment included structured observation of patient education in the therapy process, semi-structured interviews about site needs and patient education topics completed with patients and occupational therapists on staff, and surveys of multi-disciplinary healthcare professionals and patients regarding the most needed and beneficial patient education topics. The results of this
needs assessment indicated that although patient education on a variety of topics was occurring throughout the therapy process, there was no established protocol to assess clients’ knowledge and application of concepts.

This project implemented an education protocol in an inpatient SCI unit to assess patient increase in knowledge of techniques that can reduce readmission. The Know More, Live Better program included a pretest on course information upon admission to the unit, an hour long, individualized patient education course, and a post-test to assess knowledge acquisition from the course. The program was implemented with 15 patients with SCI and produced significant results in patient knowledge acquisition of preventative techniques for avoiding secondary complications (p = .000). No demographic factors had a significant impact on the results, although the factor of income was near statistical significance (p = .052). Caregivers who participated in the program displayed a mean score of 94.7% (5.67/6) on knowledge test scores, but did not produce statistically significant results due to unexpectedly small number of participants. This program is significant to occupational therapy practice because it demonstrated that a short, rigorously designed patient education program can produce a significant increase in patient knowledge acquisition regarding the most prevalent issues of illness management that lead to readmission.
DEDICATION

This is dedicated to Adriana Brown and Jordyn McTish, who provided emotional and spiritual support through the entirety of the project and report.
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Chapter One

The Practice Scholar Capstone Project

According to the National Spinal Cord Injury Statistical Center, there are approximately 17,000 new spinal cord injury (SCI) cases each year in the United States and approximately 282,000 individuals living with a SCI in the United States (White & Black, 2016). Nearly one third of all people experiencing a SCI are rehospitalized within one year with an average length of stay of 22 days (White & Black, 2016). Genitourinary, respiratory, and skin-related complications, the three leading causes of rehospitalization for individuals with SCI, can be avoided through the practice of preventative techniques (DeJong et al., 2013). In order to decrease the SCI readmission rate and to increase patient independence after discharge from inpatient rehabilitation, it is critical that patients with SCI learn how to direct their own care to practice preventative techniques. These techniques will decrease the occurrence of secondary complications most likely to cause readmission.

Although inpatient rehabilitation facilities often stress the importance of patient education during their stay, there are few evidence-based educational protocols that test outcomes of patient education on knowledge of preventative techniques. In order to direct their own care, patients need to gain an understanding of the techniques that can be utilized to prevent rehospitalization. A study conducted by DeJong et al. (2013), found that the three leading causes of rehospitalization are genitourinary conditions (UTIs), respiratory conditions (pneumonia), and skin-related conditions (pressure ulcers), which are often considered preventable. Patient education on techniques such as weight
shifting, skin care, and bowel/bladder management can help prevent these secondary complications that often lead to rehospitalization in patients with SCI.

Although the conditions causing readmission in patients with SCI are preventable through techniques such as personal hygiene and weight shifting, patient education for this population is frequently ineffective due to limited staff availability (Shepherd, Badger-Brown, Legassic, Walia, & Wolfe, 2012). The length of stay in inpatient rehabilitation for patients with SCI has also been decreasing, which limits the amount of time for patients to learn these techniques. The combination of decreased staff availability and patient length of stay are some of the factors that limit the amount of patient education that can occur outside of rehabilitation sessions (Shepherd et al., 2012).

Patient readiness is another limiting factor, because a SCI is a life changing condition that can take an individual time to emotionally cope with. The amount of time that it can take a person to be ready to learn new concepts, such as preventative techniques, can vary based on age, level of injury, time since injury, or other personal characteristics (Shepherd et al., 2012).

The Know More, Live Better program was designed to provide patient education sessions on techniques to avoid secondary complications as a compliment to therapy. These sessions were timed to occur when a patient felt psychologically ready to learn. The setting for this capstone project was the Inpatient Spinal Cord Injury Unit at Good Shepherd Rehabilitation Hospital in Allentown, Pennsylvania. This 24-bed unit contained 8 full-time OTs, 6 COTAs, 15 PTs, and 15 SLPs. A needs assessment was conducted at this site over a 2-week period using a variety of methods to assess needs, including patient education needs of the unit. Semi-structured interviews were completed
with two Occupational Therapists and two current patients with SCI. Structured observations were made of the therapy process targeting when, where, and who conducts patient education. Twenty surveys targeting the most beneficial patient education topics were also distributed to the multidisciplinary staff at the site and online through the SCI support group Facebook page associated with the site. The surveys distributed to the multidisciplinary staff aimed to provide a perspective of healthcare professionals in the field of SCI. The surveys distributed to the SCI support group online aimed to provide a perspective of individuals out in the community. See Appendix A for Needs Assessment Data Collection Strategies.

The needs assessment revealed that multiple healthcare disciplines were providing patient education on a variety of topics. However, the needs assessment suggested that the site did not assess patient knowledge acquisition from their education. Healthcare professions, current patients with SCI, and individuals with SCI living in the community rated courses targeting techniques to avoid readmission and information on increasing independence in the community as the most beneficial for patient education. The Know More, Live Better program was designed to provide an education protocol that increases patient knowledge to support their confidence and independence in the management of their injury in the community. The patient education concepts included techniques to avoid readmission and self-direct their care in the community which was followed by the administration of an assessment of knowledge acquisition of patient education concepts. See Appendix B for Data Collection Tools for the Needs Assessment.

This Capstone project aimed to increase patient knowledge to support more independence, confidence, and satisfaction with training needed for managing their injury.
in the community. Pre- and post-test measures were used to assess the knowledge of specific concepts related to self-management of SCI. Course content covered beneficial information for inpatients with SCI on topics such as anatomy/physiology, community access, patient advocacy, transportation, and assistive technology/home modification. The education modules were designed to increase patient, caregiver, and staff knowledge of these critical topics that may support a reduction in hospital readmission rates. Increased patient knowledge can enhance the ability of patients to direct their own care. Increased caregiver knowledge can increase patient independence after discharge. Finally, increased staff knowledge can sustain the enhanced patient education on site. See Appendix C for Infographic with results from the Needs Assessment.

Chapter Two

Synthesis of Relevant Literature

Spinal cord injury (SCI) patients are prone to rehospitalization due to preventable causes. Effective patient education can increase patients’ knowledge of key risks and techniques that can decrease secondary complications that often cause readmission into rehabilitation. It is important that Occupational Therapists (OT) educate their patients on these key risks and techniques to prevent them in order to increase their independence in directing their own care following discharge from rehabilitation. This project aimed to increase patient knowledge acquisition of techniques to avoid readmission while in rehabilitation. In order to generate informed, evidence-based patient education protocols, a review of relevant literature was completed. The question guiding this literature review was, “Do patient education modules increase patient knowledge acquisition of techniques
to prevent secondary complications that often lead to readmission?" See Appendix D for a table of key studies informing the study.

Nearly one third of patients with a SCI readmit back to the hospital within one year of their injury. The average length of stay when returning to the hospital is 15.5 days (DeJong et al., 2013). The three leading causes of readmission are genitourinary conditions (UTI), respiratory complications (pneumonia), and skin related complications (pressure sores). All of these secondary complications are preventable through techniques such as catheter management, positional changes, and pressure relief. Several studies have researched the effectiveness of patient education regarding these techniques, with mixed results (Cogan et al., 2017; DeJong et al., 2013; Foy et al., 2011; Noonan et al., 2014; Schubart, 2012; Tederko, Krasuski, Krasuski, Długołęcka, & Tarnacka, 2017; Thietje et al., 2011).

Multiple studies have suggested positive results in conducting patient education in a SCI population on topics that include the prevention of genitourinary complications (Schubart, 2012; Noonan et al., 2014; Thietje et al., 2011). Despite suggesting positive results in patient knowledge acquisition while in rehabilitation, patients have displayed a decrease in the amount of knowledge they sustained when measured 30 months later (Thietje et al., 2011). Patients displayed positive results regarding knowledge acquisition of genitourinary complications when educated in an online format as well (Noonan et al., 2014; Schubart, 2012). Specifically, a program utilizing the concept of knowledge translation displayed even greater knowledge acquisition in the long term. This concept of knowledge translation is a form of patient education that assists patients in incorporating the information into their daily lives (Noonan et al., 2014).
This technique of knowledge translation was also effective in training focused on respiratory complications (Noonan et al., 2014). The ability to retain knowledge regarding respiratory complications and other body structures and functions has displayed positive results due to the patients’ ability to translate this information into habits in their daily lives (Noonan et al., 2014; Tederko et al., 2017). The most common readmission causing secondary complication is a skin related complications. Studies have displayed mixed results regarding the effectiveness of patient education for pressure injuries (Cogan et al., 2017; Noonan et al., 2014; Schubart, 2012; Tederko et al., 2017; Thietje et al., 2011).

Patient education on the prevention of pressure sores has been most effective when utilized in an online format (Noonan et al., 2014; Schubart, 2012; Tederko et al., 2017). Patients have not retained as much information regarding pressure sore prevention as they do with respiratory and genitourinary conditions when the education is provided outside of an online format (Cogan et al., 2017; Thietje et al., 2011). Studies that provided education outside of an online format suggest utilizing rigorous methods for patient recruitment, intervention fidelity, and participant adherence to optimize outcomes. These studies that were reviewed did not utilize rigorous methods and it was felt that this would be an area that future programs can explore to optimize patient knowledge retention through in-person patient education on pressure sore prevention (Cogan et al., 2017).

Despite yielding positive results, the time spent on patient education has been decreasing for patients with SCI when in rehabilitation (Foy et al., 2011; Shepherd et al., 2012; Van Wyk, Backwell, & Townson, 2015). Occupational therapy sessions,
specifically, have been spending most treatment time addressing ADL performance, strengthening/endurance, and range of motion/stretching (Foy et al., 2011). Although these interventions are also beneficial to patients with SCI, the use of patient education is important due to the high readmission rate from preventable secondary complications (DeJong et al., 2013). This decrease in patient education has been attributed, in part, to limited staff availability and patient readiness (Shepherd et al., 2012). Patient readiness is a concept referring to the ability of a patient to learn information pertaining to their injury after emotionally coping with the major life change that it caused them.

In order to increase patient education on site, it is important that facilities time patient education to ensure newly injured patients are receptive to this training by waiting until they are ready to learn before presenting them with this information (Shepherd et al., 2012; Van Wyk et al., 2015). It is also important that the site optimizes the delivery of patient education and increase the number of opportunities to learn despite the potential barriers of limited staff availability (Shepherd et al., 2012; Van Wyk et al., 2015). This allows the information to be available for when the patient is ready to learn (Shepherd et al., 2012; Van Wyk et al., 2015). There is some research that demonstrates that caregivers can also experience important benefits from education. Many caregivers experience negative symptoms such as isolation, loss of identity, and role changes when their loved one experiences a SCI. Education to caregivers provides them with an increased quality of life and provides the patient with an individual to assist them in managing their injury after discharge (Lynch & Cahalan, 2017).

Grounded in the available literature, this program aimed to increase patient and caregiver knowledge acquisition of the three leading causes of readmission (DeJong et
al., 2013). This program provided education outside of therapy sessions so patients and caregivers had more opportunities to learn and could do so when they were ready to learn (Lynch & Cahalan, 2017; Van Wyk et al., 2015). This educational information was also made available in an online format with the intention of increasing the accessibility of this information after discharge (Noonan et al., 2014; Schubart, 2012; Tederko et al., 2017). Increasing the accessibility of information can address the weakness in the literature surrounding the decrease in retention of knowledge patients experience months after learning the information (Schubart, 2012).

This program addresses the gap in the literature regarding the effectiveness of a patient education program that targeted all three leading causes of readmission in an in-person format. Although several studies have been conducted on patient education regarding the prevention of readmission, few have been administered in-person and addressed all three causes (Cogan et al., 2017; DeJong et al., 2013; Foy et al., 2011; Noonan et al., 2014; Schubart, 2012; Tederko et al., 2017; Thietje et al., 2011). This capstone project sought to address the weakness in the literature regarding the lack of effectiveness in in-person pressure sore education by ensuring methodological rigor with recruitment, intervention fidelity, and participant adherence (Cogan et al., 2017). Although this program addresses the weakness in the literature regarding in-person education on pressure sores, all three leading causes of readmission will be addressed in the education sessions in order to provide a comprehensive education on the prevention of readmission (DeJong et al., 2013).
Chapter Three

Capstone Project Methods

Project and setting. The Know More, Live Better program was a quality improvement project implemented at the Inpatient Spinal Cord Injury Unit at Good Shepherd Rehabilitation Hospital in Allentown, PA. This project aimed to educate patients with Spinal Cord Injuries (SCI), caregivers, and staff on techniques that can prevent conditions that often lead to readmission. This program also provided education on techniques that helped patients learn to self-direct their care with a goal of avoiding readmission.

Program Description

Sample. The sample consisted of 15 SCI patients, 6 caregivers, and the therapy staff at Good Shepherd Rehabilitation Hospital in Allentown, PA. Six patients were classified as quadriplegic and nine were paraplegic. The inclusion criteria used to obtain this sample were: (1) the patient must have a SCI or be the caregiver of a patient with a SCI and (2) themselves or the one they care for must be admitted on the inpatient SCI unit at Good Shepherd Rehabilitation Hospital. The sample was a convenience sample that represents all individuals that fit the inclusion criteria during the 16 week implementation of the program. The patients were recruited upon admission to the SCI unit through verbal recruitment, the use of a poster, and recruitment by other healthcare professionals on the unit. The caregivers were recruited verbally or with assistance from the patient if unavailable during the course of the day. The staff was recruited via the same resources as the patients, with the addition of an email sent to all staff.
**Primary goals and objectives of the program.** This program had three primary goals with two objectives for each. These goals and objectives were focused on patients displaying an increase in knowledge, staff demonstrating competence in providing patient education, and caregivers displaying an increase in knowledge. These goals and objectives are represented by Table 3 from Appendix E.

Table 3

*Primary Goals and Objectives of the Program*

<table>
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<th>Goal</th>
<th>Objectives</th>
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<tr>
<td>90% of SCI patients attending patient education courses will show an increase in knowledge via a pre- and post-test in 16 weeks.</td>
<td>90% of SCI patients will review any incorrect post-test answers with the instructor in one month.</td>
</tr>
<tr>
<td></td>
<td>90% of SCI patients will improve their post-test scores by at least 5% in 16 weeks.</td>
</tr>
<tr>
<td>90% of staff on the SCI unit will demonstrate competence in educating patients on patient education course topics for my program via participation in a training session in 16 weeks.</td>
<td>90% of staff will participate in a discussion on how to implement course information into their daily practice in one month.</td>
</tr>
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<td></td>
<td>100% of staff attending courses from my program will identify a new concept that they learned from the course in one month.</td>
</tr>
<tr>
<td>70% of the caregivers in the program will show an increase in knowledge via a post-test in 16 weeks.</td>
<td>70% of caregivers will review any incorrect post-test answers with the instructor in one month.</td>
</tr>
<tr>
<td></td>
<td>70% of SCI patient caregivers will receive a score of at least 80% on their post-test in 16 weeks.</td>
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**Program structure.** This capstone project ran over a 16 week period. The program structure is visually reflected in a logic model presented in Appendix F. The first three weeks were utilized for the creation of evidence-based patient education materials, recruitment documents, and program evaluation tools. The materials created were: a
poster, pre/post-tests, educational handouts, and a voiced-over PowerPoint for additional information. The creation of these materials was informed by synthesizing research conducted on SCI readmission rates, written patient education materials on site, information from the SCI support group on site, and by eliciting the knowledge and experiences of healthcare professionals on site. These efforts ensured that the education being provided could benefit from utilizing current, evidence-based research and staff experience. These resources also assisted in the creation of education materials that both SCI healthcare staff and individuals with SCI felt would be beneficial for new patients to learn.

**Theoretical framework.** The occupational therapy theoretical framework that shapes the Know More, Live Better program is the Model of Human Occupation (MOHO). MOHO shapes this program through its concepts of volition, habituation, environment, and occupational performance (Fazio, 2017). After sustaining a spinal cord injury (SCI), patients often experience decreased occupational performance. Challenges in volition, belief in self and skills, and the person’s overall motivation are often made more difficult due to the physical constraints of their injury. This program serves to educate patients on techniques to help them adapt to the new habits and roles that they must take on to live a healthy life. It also assists in providing education that can create a supportive environment for more effective self-management of their injury. By learning this information, patients are more likely to avoid secondary complications and spend more time engaging in their volitional tasks (Fazio, 2017).

Patients with SCI often have difficulty maintaining their occupational performance in volitional tasks because of their decreased sensory and motor functions. This program
includes information about resources in the nearby area that can be utilized to find adaptive activities that individuals may enjoy. Patients with SCI also have a high rate of readmission, therefore, they are spending more time in rehabilitation rather than engaging in their volitional tasks. This program provided education to patients on techniques to utilize so they do not acquire a secondary complication. The goal was to help patients learn skills to lead a healthier lifestyle so they could increase their occupational performance in meaningful, volitional activities (Fazio, 2017).

After experiencing a SCI, patients also need to take on new habituation in order to live a healthy lifestyle. This program educated patients on the benefits of developing healthy habits for managing their illness such as pressure reliefs, positioning, and catheter management. These habits are essential to practice in order to avoid secondary complications. This program also educates caregivers on how to assist patients in managing their injury at home. This program assists caregivers who may be new to this role when the patient initially experienced their injury. By learning this information, new caregivers learn how to not only be a caregiver, but also an advocate for their loved ones needs if the patient cannot advocate for themselves (Fazio, 2017).

The final aspect of MOHO addressed in this program is the patients’ environment. Their environment is impacted because of their limited motor and sensory functioning. Both home and community environments can be difficult to maneuver. This program provides education on ways to make an environment more accessible. It also creates a more supportive social environment through the education of caregivers. This allows patients to have another individual who can assist them in integrating the new habituation aspects into their environment after discharge (Fazio, 2017)
Program implementation. The plan for program implementation is visually reflected in the Infographic in Appendix G. Over the first three weeks, the patients, caregivers, and staff were recruited for the program using the resources of healthcare professionals on site, the SCI support group, time outside the therapy sessions, and space in the therapy gym. The patients and caregivers also were recruited as more were admitted, through awareness of the patient education courses during their initial evaluation, awareness at SCI support group meetings, speaking with the doctoral candidate outside of their therapy sessions, posters hanging in the therapy gym, and utilizing research on SCI readmission rates to communicate the importance of patient education. The caregivers were more difficult to recruit than anticipated; therefore, the course information had been adapted to a handout version to accommodate the busy schedule of caregivers.

Throughout weeks 4-13, the patient education program was implemented. Patients were recruited upon their admission to the SCI unit through healthcare professionals, the OTD candidate, and materials such as the poster hanging in the gym. Once the patient was comfortable at the site and psychologically ready to learn after their injury, a pretest on the course information was administered. Within a week of administering the pretest, an hour long patient education session was provided on the course material. The day after the course was taught, a post-test was administered to gain a measure of how much the patient learned from the course. The patient was also provided with a demographic and patient satisfaction survey to assist with data analysis and program evaluation. Once the course was completed, the patient was provided patient education handouts including the answer key to the tests with justification for the
right answer and directions for accessing the voiced-over PowerPoint online for more information.

Originally, the plan was to implement a similar patient education course with caregivers, however, there were unexpected time constraints for many caregivers that made it difficult to reach them. The most effective way to reach them was to provide caregivers with a one-page handout with information on the most common causes of readmission for their loved one’s level of injury (paraplegia or quadriplegia). This handout also included techniques to prevent those causes of readmission so they could practice implementing these with the patient. A post-test was also given along with this handout in order to gain a measure of caregiver knowledge of concepts.

A patient education in-service was also conducted for SCI staff towards the end of program implementation to discuss the results of this program and provide suggestions on how to incorporate this information into daily practice. Once this in-service was completed, a staff email was sent out with more written details on how the program was implemented and how it could be sustained after it was finished. This email included attachments of all patient education materials developed for this project so staff would have continued access to all materials. Once all patient, caregiver, and staff programs were completed, the final week was utilized to analyze all data that was collected.

**Capstone project evaluation tools.** The evaluation tools that were created include a pre/post knowledge test for patients, a post knowledge test for caregivers, and a patient satisfaction survey. The pre/post test for patients includes 15 multiple choice questions, while the post-test for caregivers included 6 multiple choice questions. See Appendix H for Patient Pre/Post Test. Both of these tests contained items that were
scenario-based in order to provide the recipient with an opportunity to identify and apply key concepts taught in the patient education course. Each question included 4 answer choices that serve as distractors, however, no answers were worded in a way that aims to trick the recipient. All unnecessary medical jargon was replaced with a description that is easier to understand. This was checked by utilizing the Microsoft Word Readability Statistics tool. Any words over a tenth grade reading level were changed to be at or below a tenth grade level. Any questions that are worded in a way that requires the recipient to identify which answer would not be applicable, is made clear through the use of italicizing (Morrison & Free, 2001).

The patient satisfaction survey includes 9 questions using a 4 point Likert scale in order to gain an understanding of how the recipient felt the course was implemented and designed. The survey also includes 4 open ended questions that ask for ways to improve the program through starting, stopping, or continuing different aspects of the course (Morrison & Free, 2001). The patient also could provide additional comments that they felt would be beneficial for the evaluation process.

**Capstone project evaluation processes.** The patients were administered a patient satisfaction survey to anonymously evaluate the process utilized. Patients were then asked to fill out a demographic survey to assist with data analysis. The patients were provided with a handout that included course information and information on how to access the voiced-PowerPoint online. The patients were also provided with an answer key for the test, including descriptions for why the answer was correct in case they wanted to access the information again. If patients had a cognitive deficit or still required further
education, then they were followed up with throughout the rest of their time on the unit to ensure their understanding of concepts.

Due to the time constraints of caregivers, their education occurred via the use of a handout after the patient completed the education course. See Appendices I through P for surveys, tests, and handouts that were utilized for this program.

**Data analysis.** The quantitative data collected from the patient pre/post test, caregiver post-test, patient satisfaction surveys, and demographic surveys were recorded and analyzed with the SPSS program. In order to test the normality of the patient pre/post tests, the mean difference between the scores needed to be calculated. Once calculated, the Shapiro-Wilk test of normality was ran with the mean difference values. A t-test was also run on the mean difference values. The patient mean difference values were then run in an ANOVA test with key data gathered from the demographic surveys. The data used in this analysis were; age, gender, ethnicity, income, level of SCI, and whether the patient came to rehabilitation with a new or old injury. The numeric data from the patient satisfaction surveys and caregiver post-tests all will be analyzed to determine the mean and standard deviation of each score.

**Summary.** This program has met the needs of the SCI population, interdisciplinary staff on the SCI unit, and caregivers of patients with SCI because it aims to educate on topics that are most beneficial to increase their ability to independently manage a SCI in the community and decrease the rate of readmission. Specifically, it did so through implementing a course on information regarding patient advocacy and techniques to avoid common secondary complications for patients with SCI. These courses are important because the leading causes of readmission are all preventable
causes through skin checks, personal hygiene, and pressure relief. The data collected from these courses was analyzed using normality testing, t-tests, ANOVA tests, and descriptive statistics in order to gain an understanding of the significance of the findings.

Chapter Four

Results

Broad overview of findings. The findings of this program suggest that the patient education course implemented at the inpatient SCI Unit at Good Shepherd Rehabilitation Hospital had a statistically significant impact in increasing patient knowledge of concepts aimed at reducing readmission and increasing independence for this small sample of clients. All but one of the 15 participants presented an increase in knowledge. One participant’s pre and post-test scores reflected no change. None of the demographic characteristics gathered from the surveys resulted in a statistically significant impact on the mean difference of test scores in patients. However, females demonstrated greater increases in their knowledge score after the intervention compared to males, and individuals with old SCI presented higher knowledge scores than those with new injuries. All of the data gathered from the surveys was organized by the standards set in the International Spinal Cord Injury Core Data Set (version 2.0). This sets the standard values for analyzing SCI research such as age ranges or ranges to use for the level of injury. (Biering-Sørensen et al., 2017).

Description of Participants. This program was implemented with 15 patients over a 13 week period. This sample is representative of patients with SCI admitted to Good Shepherd Rehabilitation Hospital’s inpatient SCI Unit over this 13 week time period. All participants resided in eastern Pennsylvania or New Jersey. The sample
ranged in age as 27% (4/15) of participants were less than 29 years old, 40% (6/15) were between the ages of 30-59, and 33% (5/15) were above the age of 60. Most of the participants, (60%; 9/15) were male and 40% (6/15) of participants were female. The sample ranged in level of SCI as 20% (3/15) had a SCI between the levels of C1-C4, 20% (3/15) had an injury between the levels of C5-C8, and 60% (9/15) had an injury at or below the level of T1. Most of the participants (73%; 11/15) were patients who experienced a new SCI, while 27% (4/15) were in rehabilitation from an old SCI.

Less than half (40%; 6/15) of the patients’ caregivers completed the program. This number is lower than expected due to the unexpected time constraints of many of the caregivers while visiting their loved one. Most (90%) of SCI Unit staff also attended a training session in-service and received a staff training email with access to all patient education materials to ensure the sustainability of the program. This staff did not complete any measurable tests, however. Initially, measurable tests were intended to be implemented to ensure staff understanding, however, the limited time available for the education of the staff on the unit did not allow for this. This could be an area of future research.

**Specific Descriptions of Findings.** In order to analyze the results of the pre/post knowledge tests tests, a mean difference was calculated between these scores. This provided a numerical value that reflects the change in knowledge of the participants. Once this was calculated, a Shapiro-Wilk Test was conducted to determine if the data was normally distributed. The data was found to be normally distributed with a Shapiro-Wilk significance level of 0.537. See Appendix Q for the Mean Difference Normality Test Values. A t-test was then run on the mean difference of the pre/post test with Mean
Difference- t(15)= 6.758, p = .000. This means that the intervention of patient education courses had a significant impact on the knowledge acquisition of patients. See Appendix R for the Mean Difference T-Test Values.

A mixed ANOVA test was completed to determine if any demographic variables collected in surveys had a significant impact on the knowledge acquisition of the patients. None of the variables were statistically significant related to the results. The closest variable to statistical significance was income (p = .052). The goal for the program of 90% of patients increasing their knowledge was achieved (14/15). The objectives of reviewing any incorrect answers (15/15) and improving their test scores by at least 5% (14/15) were both met as well. See Appendix S for ANOVA Test Values.

Due to an unexpectedly small number of caregiver post-test scores, this data was run through descriptive statistics to determine the mean and standard deviation of the 6 post-test scores. The mean of these scores is 94.5% (5.67/6) and the standard deviation is .516. The goal of 70% of caregivers showing an increase in knowledge was not achieved due to the unexpected time constraint of caregivers. This goal was not reached because there was not enough data to make and effective analysis. The caregivers that did complete the program displayed an increase in knowledge, however, this was not a large enough sample size. Out of the 15 possible caregivers, only 40% (6/15) of the caregivers completed the program through and each of those caregivers completed the objectives of reviewing any incorrect answers and scoring at least an 80%. Future research should take this into account and offer a modified course for caregivers from the beginning to accommodate to their schedules. See Appendix T for Caregiver Descriptive Statistics.
The patient satisfaction scores were also run through descriptive statistics to determine the mean and standard deviation of each Likert scale item. The means of the 9 Likert scale items ranged from 93.25% (3.73/4) to 98.25% (3.93/4). The standard deviations ranged from .258 to .458. Based on the means and standard deviations, the patients reported strong satisfaction with the educational training. See Appendix U for Patient Satisfaction Descriptive Statistics.

Although a staff training in-service and email were conducted, there were no measurable tests distributed. This could be an area of future research to ensure staff knowledge of concepts to avoid common secondary complications of SCI. The goals of increasing staff competence were not achieved, although the goal of 90% attendance in a training was achieved. The objective of 90% participation in a discussion was also achieved. The objective of 100% of staff identifying a new concept was not achieved, however, due to the time constraint of the training session. There was not enough time for all staff to identify a new concept that they learned from the training session. Rather than spending the available time on identifying a new concept which was the original plan, it was spent on ensuring that the staff understood the educational training, findings of the program, and how the program can be sustained in the future. Implementing a training session with a greater time allotted for it could be an area for future research.

Chapter Five

Discussion

The Know More, Live Better program displayed statistically significant results regarding knowledge acquisition in an inpatient spinal cord injury (SCI) population ($p = .000$). Specifically the results suggest that a patient education program aimed at
educating patients with SCI on readmission causing secondary complications can result in significant knowledge acquisition in patients. Although no variables collected in surveys displayed a statistically significant impact on the knowledge acquisition of patients, the variable of income was close (p = .052). The reason as to why income was near statistical significance is unknown, however, it could be due to individuals with greater incomes receiving a higher level of education. Future research could collect education level as a demographic variable to consider to determine if this had a significant impact on knowledge acquisition.

The findings of a statistically significant increase in knowledge acquisition on readmission causing secondary complications can be situated in several gaps in previous literature. These findings are one of the few that have administered in-person patient education that addresses all three causes of readmission (Cogan et al., 2017; DeJong et al., 2013; Foy et al., 2011; Noonan et al., 2014; Schubart, 2012; Tederko et al., 2017; Thietje et al., 2011). It also addresses the weakness of previous literature in providing education on pressure sore prevention. Previously, there was very little evidence on pressure sore prevention with methodological rigor (Cogan et al., 2017).

These results also provide support for the literature advocating for increased patient education in an inpatient SCI setting. The time spent on patient education has been decreasing for occupational therapists, however, significant knowledge acquisition results provide support to increase education (Foy et al., 2011; Shepherd et al., 2012; Van Wyk et al., 2015). The results also provide support for increasing caregiver education in inpatient SCI settings. Although statistically significant results were not displayed, all caregivers displayed an increase in knowledge after their post-test.
The results from this program can also inform others conducting future research in this area of practice. Future studies should continue to provide caregiver education for caregivers of patients with SCI with rigorous methodology in order to provide statistically significant results in support of caregiver education (Lynch & Cahalan, 2017; Van Wyk et al., 2015). In order to optimize training for caregivers, the education should be provided in a way that considers the busy schedule of caregivers. Recommendations for this include: shorter sessions, training using handout formats, or online formats. This would allow caregivers to complete the training at the site within their time constraints or at their convenience when they are not visiting their loved one. The online format could also include a post-test to ensure that caregiver knowledge is assessed directly after learning the information. It would also allow the caregivers to be able to take the post-test at their own convenience as well, rather than needing to take a paper post-test in-person.

Future studies should also conduct staff training on SCI units to ensure staff is educating patients on the best practices for secondary complication prevention. These studies should ensure that staff learning is assessed to ensure the effectiveness of the education sessions. This could be accomplished by conducting several shorter sessions to increase the amount of time available for educating the staff. It could also be accomplished through an online format with a post-test. This would allow staff to learn the information at their own convenience and assess their knowledge as well.

Future studies could also measure the retention of knowledge in patients, caregivers, and staff rather than just the knowledge gained from the courses. Studies could also determine the correct amount of education that patients, caregivers, and staff
typically need to learn and retain the knowledge. These studies could also determine the long-term benefits of this program on the readmission rates of patients at sites. It could be beneficial to determine if increasing the knowledge of patients on readmission causing secondary complications produces a significant decrease in the number of patients readmitting back into the hospital.

It was also observed during the implementation of this program that patients who were hospitalized with an old SCI injury typically required less time before learning the material than new patients with SCI. This is an area that could require further research though. It was unexpected that some concepts were still unknown to patients with old SCI after their first time in rehabilitation. This could mean that either the information was not covered in their first time in rehabilitation or the information was not retained. Further research could be conducted on the retention of concepts.

This capstone project presents statistically significant results supporting the claim that an hour long session can increase the knowledge of patients regarding readmission causing secondary complications. A handout version was effective in increasing knowledge in caregivers for this program, however, the sample size was not large enough to produce statistically significant results. Future studies could increase the sample size and implement knowledge assessments to determine an effective amount of education for caregivers and staff. Future studies could also determine if an hour long session is the most effective length in increasing patient knowledge, or if patients could continue to increase their knowledge with more education.

A limitation of this study is that there was a limited number of variables collected. Further research could be replicated on knowledge acquisition of patients with SCI to
determine which variables produce more effective results. Other variables that could be analyzed include the time spent in rehabilitation and time since their injury. Further research could also utilize a larger sample size. Another limitation of this study was the small number of caregivers that participated. The program needed to be adapted into a handout version in order to accommodate the time constraints of caregivers in an inpatient rehabilitation setting. Further research should take this into account and determine the impact of an education program on caregiver knowledge acquisition. This program produced positive results, however, the small sample size was not large enough to be considered statistically significant.

Further research can also provide a measurable test to interdisciplinary staff in order to determine their knowledge acquisition of readmission causing secondary complications. This was a limitation because of the time constraints of the staff in an inpatient rehabilitation setting. In future studies, this program could be replicated, except with a measurable test for staff would provide data to determine if an educational program produces statistically significant results in knowledge acquisition for an interdisciplinary staff.

Chapter Six

Summary

The spinal cord injury (SCI) population is a large number of individuals who receive inpatient rehabilitation. Despite receiving care, nearly a third of these individuals will readmit back into the hospital due to a preventable secondary complication (White & Black, 2016). Several studies have analyzed patient education for patient with SCI, however, very few addressed the most common reasons for readmission (Cogan et al.,
The most common complications include genitourinary, skin, and respiratory. The Know More, Live Better program was designed to provide education to patients with SCI, along with their caregivers and multidisciplinary staff in order to increase knowledge acquisition on secondary complications.

Statistically significant results were displayed for knowledge acquisition of patients, but time constraints were limitations for the results for caregivers and staff. Future research could replicate this program to analyze the knowledge acquisition in caregivers and staff with larger sample sizes. It would also be beneficial to analyze more variables in patients to determine what leads to knowledge acquisition. Future studies could also analyze the retention of knowledge in patients, caregivers, and staff to determine the appropriate amount of patient education that is effective.
BIBLIOGRAPHY


Fazio, L. S. (2017). Developing and finalizing the projected impact and outcomes for your population, developing program-specific goals and objectives, and


Tederko, P., Krasuski, T., Krasuski, M., Długolecka, A., & Tarnacka, B. (2017). Determinants of health knowledge and health perceptions from the perspective of


Appendix A

Needs Assessment Data Collection Strategies

Table 1

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description of Tool</th>
<th>Who</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survey</td>
<td>8-items: 6 items with a 5 point Likert Scale with the option to leave comments, 2 open-ended items Both paper copies and online</td>
<td>Multidisciplinary SCI unit staff, current SCI patients, SCI individuals living in the community</td>
<td>Handed out to individuals during 2 week needs assessment, posted on SCI Support Group Facebook page during 2 week needs assessment</td>
</tr>
<tr>
<td>Observation</td>
<td>Observed patient therapy sessions while in inpatient rehab in the therapy gym</td>
<td>Multidisciplinary SCI unit staff and current SCI patients</td>
<td>2 week needs assessment</td>
</tr>
<tr>
<td>Semi-structured interviews</td>
<td>Asked questions regarding the greatest needs of the site and what they felt would be beneficial to the site</td>
<td>2 SCI unit OTs, 2 current SCI patients who were a week away from discharge</td>
<td>2 week needs assessment</td>
</tr>
</tbody>
</table>
Appendix B
Data Collection Tools for the Needs assessment

Survey:

Patient Education Survey

Objective: My name is Justin McTish and I am an Occupational Therapy Doctorate Student from Duquesne University. I am currently completing a needs assessment for a patient education capstone project that I will be implementing over the summer on the Spinal Cord Injury Unit. Below I have listed my current topic areas of the education modules. I was hoping to receive feedback from multiple disciplines over the next few days. If you have time, please rate these courses on a scale from 1 = not beneficial at all, to 5 = very beneficial. I will also leave space at the end for additional course ideas that you may feel would be beneficial to the Spinal Cord Injury population. Thank you in advance for your participation!

Courses:

Community Access (accessible areas in the community) Rating: ___________

Comments: _______________________________________________________

Transportation (traveling on a plane, staying in a hotel, etc.) Rating: __________

Comments: _______________________________________________________

Anatomy and Physiology (Spinal cord and pain management techniques) Rating: __________

Comments: _______________________________________________________

Family/Caregiver Education Rating: __________

Comments: _______________________________________________________

Assistive Technology/Home Modifications Rating: __________

Comments: _______________________________________________________

Patient Advocacy/Self-Directed Care Rating: __________

Comments: _______________________________________________________

What healthcare discipline are you from?

_________________________________________________________________________

Do you have any additional ideas for patient education courses?

_________________________________________________________________________
**Observation Guide:**

When does patient education take place in the therapy process?

Who conducts patient education?

What topics are covered most frequently?

How often are the families/caregivers educated?

Where is most of the patient education taken place?

Does the patient feel comfortable to ask questions?

Is there any evidence that the patient understands the concepts being taught?

Does the site provide the patients with any educational materials?

Look at how often therapists billed for patient education.

**Semi-Structured Interview Questions:**

**Site Supervisor:**

- What are the greatest needs of the site?
- Is there any program that the site could use but does not have?
- Who conducts most of the patient education at the site?
- What topics are most frequently covered?
- Is there any follow-up to determine if the patient understands the concepts?
- Are families/caregivers educated?
- Have prior patients expressed which patient education topics helped the most?
- Have prior patients expressed a need for further education in a specific area?
- Where are patients typically educated?
- Did patients appear comfortable to ask questions in this setting?
- Are they provided with any reference materials following the course?

**Past Patients:**

- What are the greatest needs of the site?
- Is there any program that the site could use but does not have?
- What education topics were most beneficial prior to discharge?
- Who conducted this education?
- Did you feel that you understood the concepts that were taught?
- Was there any reference material that you could utilize after the course?
- What topics did you wish you were taught when you look back?
- Tell me a story about a past experience when you were taught a concept for patient education?
Appendix C

Infographic with Results from Needs Assessment

Figure 1

Infographic with Results from Needs Assessment

Independence Through Patient Education in a Spinal Cord Injury Population

Justin McTish OTS, OTD Candidate

Who Educates Patients?

Why implement patient education courses?

Educators do not check patient understanding

Topics Taught On Site

Survey on Educational Course Ideas

Survey Respondents

On Site Educational Resources

On site data obtained through semi-structured interviews with 2 OTs and 2 current patients
Survey distributed to multiple disciplines on site and on an online SCI support group with 20 total respondents

Needs assessment conducted at the 24-bed inpatient SCI Unit Good Shepherd Rehabilitation Hospital in Allentown, PA.
Appendix D

Key Studies Informing the Study

Table 2

<table>
<thead>
<tr>
<th>Citation</th>
<th>Study Purpose/Research Question</th>
<th>Design</th>
<th>Sample</th>
<th>Data Collection Strategies</th>
<th>Findings that Inform This Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cogan (2017)</td>
<td>Determine efficacy of behavioral or educational interventions in pressure ulcer prevention in adults with SCI</td>
<td>Systematic Review</td>
<td>513 participants from 444 articles that met the inclusion criteria</td>
<td>Search terms related to pressure ulcers, SCI, and behavioral intervention. Inclusion criteria: published in a peer-reviewed journal, evaluated a behavioral or educational intervention for pressure ulcer prevention, included community-dwelling adult participants aged 18 years and older with SCI, measured pressure ulcer occurrence, recurrence, or skin breakdown as an outcome, had a minimum of 10 participants</td>
<td>Method of pressure ulcer or skin breakdown measurement varied widely among studies. Results on pressure ulcer outcomes were null in all studies. Considerable methodological problems with recruitment, intervention fidelity, and participant adherence were reported.</td>
</tr>
<tr>
<td>Author (Year)</td>
<td>Topic</td>
<td>Methodology</td>
<td>Participants</td>
<td>Data Collection Methods</td>
<td>Findings</td>
</tr>
<tr>
<td>--------------</td>
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</tr>
<tr>
<td>DeJong (2013)</td>
<td>Determine rates of readmission in discharged rehab patients with traumatic SCI in a year after injury, and to identify factors associated with readmission</td>
<td>Prospective observational cohort study</td>
<td>Individuals with new traumatic SCI (N=951), discharged from rehab centers and participated in 1 year follow-up survey</td>
<td>Surveys: occurrence, length, and reason for readmission</td>
<td>Readmission rates remain high and vary by injury. Increased rate if: younger age, being a woman, unemployment and retirement, and Medicaid coverage. More intensive physical therapy lowered rate.</td>
</tr>
<tr>
<td>Foy (2011)</td>
<td>Describe the type of SCI rehab OT activities, including amount of time spent evaluating and treating, and discuss predictors of the time dedicated to OT treatment activities</td>
<td>Quantitative, practice-based evidence methodology, variance and contingency tables/chi-square tests</td>
<td>Six inpatient rehab centers enrolled 600 patients with traumatic SCI in the first year of rehab OTs documented 32,512 therapy sessions</td>
<td>Observation of OT documentation of therapy sessions</td>
<td>Almost all patients with SCI participated in strengthening/endurance and ROM/stretching exercises during OT treatment. ADL consumed the most time in individual therapy sessions.</td>
</tr>
<tr>
<td>Lynch (2017)</td>
<td>Provide a review of the literature available on the impact of caregivers who assume the role of the primary caregiver of an individual with a SCI</td>
<td>Systematic Review</td>
<td>25 relevant peer reviewed studies (4 qualitative, 21 quantitative)</td>
<td>Inclusion criteria, 25 peer reviewed studies</td>
<td>Negative symptoms such as isolation, loss of identity, and role changes occurred in caregivers of SCI patients. Interventions such as family training, problem-solving changes, and support groups are effective in increase caregiver quality of life.</td>
</tr>
<tr>
<td>Noonan (2014)</td>
<td>Identify the effectiveness of knowledge translation interventions in SCI patients</td>
<td>Systematic Review</td>
<td>13 articles containing 10 studies</td>
<td>MEDLINE/PubMed, CINAHL, EMBASE and PsycINFO searched for studies from January 1980 to July 2012</td>
<td>The field of KT in SCI is new with only a few relevant publications. Some evidence that KT interventions may change clinician behavior</td>
</tr>
<tr>
<td>Schubart (2012)</td>
<td>Describe the feasibility of using the learning portion of an e-learning program designed to education adults with SCI on pressure ulcer prevention</td>
<td>Quantitative, Double-blinded, peer reviewed</td>
<td>14 outpatient SCI patients</td>
<td>Pre- and post-questionnaires</td>
<td>The questionnaire on the e-learning program resulted in the greatest increase in knowledge and practice questions about skin checks and preventing skin problems (P&lt;0.005)</td>
</tr>
<tr>
<td>Shepherd (2012)</td>
<td>Develop an online patient education resource for use in SCI rehab</td>
<td>Qualitative, grounded theory</td>
<td>100 subject-matter experts (rehab professionals and consumers) from Canada</td>
<td>Iterative development process was coordinated by project team; SMEs and patients developed content in working</td>
<td>Effective process for developing multimedia patient education resources</td>
</tr>
<tr>
<td>Tederko (2017)</td>
<td>Identify the determinants in SCI patients of health knowledge and health perception</td>
<td>Systematic Review</td>
<td>16 papers with quantitative health knowledge and health perception measurement in SCI patients</td>
<td>Search strategy consisting of three key concepts: SCI, education, HA, and HP</td>
<td>Increased HK and HP with health condition, body functions and structures, activities, social and vocational participation, environmental factors, and personal factors.</td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Methodology</td>
<td>Number of Patients</td>
<td>Knowledge Assessment</td>
<td>Results</td>
</tr>
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<td>----------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Thietje (2011)</td>
<td>Describe the acquisition of knowledge in SCI patients about complications that can occur based on their condition</td>
<td>Monocentric cohort study</td>
<td>214 SCI patients in a Level 1 trauma center</td>
<td>Knowledge score (0-20 points) at admission, post-admission (1 and 3 months), and post-discharge (6, 18, and 30 months)</td>
<td>Using the Friedman test, the results of the study state that at discharge patients increased their knowledge score to 11.2 compared to 5.4 at admission, but after 30 months the average score decreased to 10.8. The study also states that in the study, less than 50% of SCI patients had a good knowledge score regarding bladder management and pressure ulcers after discharge.</td>
</tr>
<tr>
<td>Van Wyk (2015)</td>
<td>Summarize evidence on SCI education literature; looking at barriers, solutions, benefits, and patient preferences</td>
<td>Systematic Review</td>
<td>14 articles (7 quantitative, 3 qualitative, 4 mixed-method)</td>
<td>Quality appraisal instruments and inclusion criteria</td>
<td>To improve SCI education during rehabilitation, programs should maximize the receptiveness of newly injured patients to SCI-related information, optimize the delivery of SCI education, increase the number of opportunities for learning, promote and support lifelong learning, and include patient and program evaluation</td>
</tr>
</tbody>
</table>
## Primary Goals and Objectives of the Program

### Table 3

<table>
<thead>
<tr>
<th>Goal</th>
<th>Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>90% of SCI patients attending patient education courses will show an increase in knowledge via a pre- and post-test in 16 weeks.</td>
<td>90% of SCI patients will review any incorrect post-test answers with the instructor in one month.</td>
</tr>
<tr>
<td></td>
<td>90% of SCI patients will improve their post-test scores by at least 5% in 16 weeks.</td>
</tr>
<tr>
<td>90% of staff on the SCI unit will demonstrate competence in educating patients on patient education course topics for my program via participation in a training session in 16 weeks.</td>
<td>90% of staff will participate in a discussion on how to implement course information into their daily practice in one month.</td>
</tr>
<tr>
<td></td>
<td>100% of staff attending courses from my program will identify a new concept that they learned from the course in one month.</td>
</tr>
<tr>
<td>70% of the caregivers in the program will show an increase in knowledge via a post-test in 16 weeks.</td>
<td>70% of caregivers will review any incorrect post-test answers with the instructor in one month.</td>
</tr>
<tr>
<td></td>
<td>70% of SCI patient caregivers will receive a score of at least 80% on their post-test in 16 weeks.</td>
</tr>
</tbody>
</table>
Appendix F

Logic Model

Figure 2

Logic Model

Project Name: Independence Through Patient Education in a Spinal Cord Injury Population
Author: Judith McIntosh
Organization: Good Shepherd Rehabilitation Hospital
Description: Implementing patient education courses to increase functional independence at discharge from inpatient rehab

Works Cited:


Appendix G

Program Implementation Plan

Figure 3

Program Implementation Plan
Appendix H

Patient Pre/Post Test

1. Which technique is *most* effective in the prevention of a urinary tract infection (UTI)?
   a. Frequent pressure reliefs
   b. Regular catheter management
   c. Loosen clothing
   d. Eating healthy diet

2. Which area of the body is *most* likely to form a pressure sore?
   a. Knee
   b. Tailbone
   c. Shoulder
   d. Bottoms of your feet

3. Which type of pressure relief involves the *greatest* risk for harm to your shoulder muscles?
   a. Alternate techniques
   b. Leaning from side to side
   c. Tilt or Recline
   d. Wheelchair pushups

4. How frequently should you perform a pressure relief?
   a. Every 15-30 minutes for 30-90 seconds
   b. Every 30-90 minutes for 15-30 seconds
   c. Every 5-10 minutes for 15-30 seconds
   d. Every 100-120 minutes for 5-10 seconds

5. Which of the following techniques is *most* effective in preventing a pressure sore?
   a. Regular catheter management
   b. Range of motion
   c. Daily skin checks
   d. Eating healthy diet

6. Which of the following is the *most* effective recommendation to avoid respiratory complications?
   a. Positioning and posture changes
   b. Eating healthy diet
   c. Electric nerve stimulation
   d. Loosen clothing
7. Which of the following is the most beneficial technique in managing pain?
   a. Daily skin inspections
   b. Weight bearing exercises
   c. Range of motion
   d. Eating healthy diet

8. What position is recommended when experiencing a sudden drop in blood pressure when moving from a laying to sitting position?
   a. Laying on back
   b. Laying on side
   c. Sitting upright
   d. Laying on chest

9. Which of the following positions is recommended when experiencing a sudden rise in blood pressure?
   a. Lay on back
   b. Sit upright
   c. Lay on side
   d. Lay on chest

10. Which of the following is not recommended when advocating for yourself?
    a. Be assertive
    b. Speak up
    c. Have emotional support
    d. Trust that doctors know your body

11. Which of the following organizations provide benefits to individuals who cannot work for a year or more until they are able to work again?
     a. Office of Vocational Rehabilitation (OVR)
     b. Social Security Disability (SSDI)
     c. Medicaid
     d. Spinal Cord Injury Network International (SCINI)

12. Which of the following home modifications is most beneficial to increase accessibility of the home environment?
    a. Place cabinets and piping under the sink
    b. Install ramps at 1 foot of rise to 1 inch of length
    c. Install a stove with front burners and controls
    d. Ensure that doors have round knobs

13. Which of the following is not a benefit of Smart Home Technology?
    a. Control lighting
    b. Operate appliances
    c. Covered by insurance
d. Voice-operation

14. Which of the following is recommended to increase safety and comfort of your home?
   a. Good insulation and temperature control
   b. High carpeting and no hardwood flooring
   c. Light switches at 4 feet off the ground
   d. Store commonly used items in upper cabinets

15. If being helped down a curb cut, which body positioning is recommended?
   a. Leaning backward
   b. Leaning forward
   c. Lift wheelchair on back two wheels and lean forward
   d. Lift wheelchair on back two wheels and lean backward
Appendix I

Patient Satisfaction Survey

**Know More, Live Better!**

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Disagree (1)</th>
<th>Disagree (2)</th>
<th>Agree (3)</th>
<th>Strongly Agree (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>This program educated me on the topics that I felt were most beneficial.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The program instructor taught the courses in an effective manner.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt that I was able to ask questions to gain further information if needed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt as though the instructor made themselves available to go over further information.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I have gained valuable information through this program.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>The courses were organized in a way that enhanced my learning.</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I felt the instructor was knowledgeable on the course topics.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I felt this program was implemented in an effective timeframe.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>I was satisfied with this program.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This program could be improved by:

_____________________________________________________________________

This program should stop doing:

_____________________________________________________________________

This program should start doing:

_____________________________________________________________________

Any additional comments:

_____________________________________________________________________
Appendix J

Demographic Survey

Demographic Survey

This survey is in conjunction with the Know More, Live Better program implemented at Good Shepherd Rehabilitation Hospital. This information will be anonymous and used to gain an understanding of the participants of this program to assist in program evaluation. Your participation is greatly appreciated!

1. What is your date of birth?

2. What is your gender?
   a. Male
   b. Female
   c. Other

3. What is your ethnicity?
   a. African American
   b. Asian / Pacific Islander
   c. Caucasian
   d. Hispanic or Latino
   e. Native American or American Indian
   f. Other:_____________________

4. What town/city do you live in?

5. What is your household’s annual income?
   a. $25,000 or less
   b. $26,000-$50,000
   c. $51,000-$75,000
   d. $76,000-$100,000
   e. Greater than $100,000
6. Who is able and willing to help you at home (select all that apply)?
   a. Children
   b. Friends
   c. Parents
   d. Siblings
   e. Significant Other
   f. Other: ______________

7. What is your current living arrangement?
   a. Apartment
   b. Condo
   c. House
   d. Other: ______________

8. What is your level of injury?

9. Upon admission, is this a new injury or old injury? If old, what brought you back to the hospital?
Appendix K

Patient Handout

Know More, Live Better
Justin McTish, BS, OTD Candidate
Duquesne University

Nearly 1/3 of people with SCI readmit within a year!

Remember to Self-Advocate!
1. Know your body
2. Speak up and be persistent
3. Be assertive, not aggressive
4. Meet peer mentors
5. Have emotional support
6. Do not feel you are alone

Leading Causes of Readmission

- Respiratory
- Skin-Related
- Urinary

All are preventable

Positioning and posture changes
Breathing techniques
Cough assistance
Suctioning
Respiratory muscle training
Vaccinations

Tilt or Recline
Lean to side
Lean Forward
W/C Pushups
Alternate Techniques

Regular catheter management
Directions to access voiced-over presentation:

1. Type in the following link:

   https://www.dropbox.com/s/ojyb0m39l434m9a/Know%20More%20Live%20Better%20Presentation%20Voiced.pptx?dl=0

   Or scan the QR code:

2. Click on the “Download” button in the top right corner, then click “Direct Download”

3. The file should pop up in the bottom left corner of your screen or it will be in a “downloads” folder on your computer

4. Click on the file to open it

5. Click on the “Slideshow” button on the top of the screen

6. Click on “From Beginning” on the top of the screen

7. Turn your volume up to hear the presentation and click once to go to the next slide
Appendix L  
Pre/Post Test Answer Key

1. Which technique is most effective in the prevention of a urinary tract infection (UTI)?
   a. Frequent pressure reliefs  
   b. Regular catheter management  
   c. Loosen clothing  
   d. Ensure proper nutritional intake  
Correct Answer: B  
Justification: Patients with a SCI often experience UTI through permanent indwelling catheters. It is recommended that frequent management of catheters and skin hygiene in the genital region be practiced in order to avoid infection (B). Pressure reliefs are effective in the prevention of pressure sores but do not directly correlate to UTI (A). Loosening clothing should be used when experiencing autonomic dysreflexia (C). Poor nutritional intake is a risk factor for both pressure sores and osteoporosis (D).

2. Which area of the body is most likely to form a pressure sore?  
   a. Knee  
   b. Tailbone  
   c. Shoulder  
   d. Bottoms of your feet  
Correct Answer: B  
Justification: Pressure sores are most likely to occur at boney areas of the body. The tailbone is one of the most common, especially with individuals who spend extensive periods of time in a seated position (B). The knee is unlikely to experience a pressure sore but could if resting against a hard surface (bedrail or leg rest) for a long period of time (A). The shoulder is unlikely to experience a pressure sore because weight is not typically distributed through the shoulder (C). The bottoms of your feet are not likely to experience a pressure ulcer, however, heels of feet are a common location because they are a boney area (D).

3. Which type of pressure relief involves the greatest risk for harm to your rotator cuff?  
   a. Alternate techniques  
   b. Leaning from side to side  
   c. Tilt or Recline  
   d. Wheelchair pushups  
Correct Answer: D  
Justification: Wheelchair pushups put a great deal of strain on the rotator cuff, however, this is an effective strategy for pressure relief and upper extremity strengthening. It is important to be aware of potential damage that this strategy could cause (D). Alternate techniques is an effective strategy for pressure reliefs that involves switching between crossing your legs (A). Leaning from side to side is an effective strategy for pressure reliefs, which involves leaning your body weight over to one side at a time to take
pressure off of the opposite side (B). Tilting or reclining is an effective strategy for pressure relief when in a tilt in space wheelchair. This technique takes pressure off of your buttocks and tailbone and puts more pressure on your back for that period of time (C).

4. How frequently should you perform a pressure relief?
   a. Every 15-30 minutes for 30-90 seconds
   b. Every 30-90 minutes for 15-30 seconds
   c. Every 5-10 minutes for 15-30 seconds
   d. Every 100-120 minutes for 5-10 seconds
Correct Answer: A
Justification: It is recommended that pressure reliefs be performed every 15-30 minutes for 30-90 seconds to take pressure off of boney areas of your skin (A). (B) is not frequent enough and for too short of a time period. (C) is more frequent than necessary and for too short of a time period. (D) is not frequent enough and for too short of a time period.

5. Which of the following techniques is most effective in preventing a pressure sore?
   a. Regular catheter management
   b. Range of Motion
   c. Daily skin checks
   d. Ensure proper nutritional intake
Correct Answer: C
Justification: Daily skin checks can serve to recognize if a pressure sore is forming and prevent it from continuing to develop to a greater stage (C). Regular catheter management is an effective technique in preventing a UTI, but does not directly apply to pressure sores (A). Range of motion is an effective technique in the prevention of pain but does not directly prevent pressure sores (B). Poor nutritional intake is a risk factor for pressure sores but is not the most effective technique for the prevention of a pressure sore (D).

6. Which of the following is the most effective recommendation to avoid respiratory complications?
   a. Positioning and posture changes
   b. Provide proper nutritional intake
   c. Electric nerve stimulation
   d. Loosen clothing
Correct Answer: A
Justification: Positioning and postural changes can ensure that efficient capacity of the lungs is being reached due to weak respiratory muscles (A). Poor nutrition is a risk factor for osteoporosis and pressure sores but not directly related to respiratory complications (B). Electric nerve stimulation is a technique used to manage pain but does not directly relate to respiratory complications (C). Loosening clothing is a technique used when experiencing autonomic dysreflexia but does not directly relate to respiratory complications (D).
7. Which of the following is the most beneficial technique in preventing pain?
   a. Daily skin inspections
   b. Weight bearing exercises
   c. Range of motion
   d. Proper nutritional intake
Correct Answer: C
Justification: Range of motion is a beneficial technique in preventing pain because it prevents the occurrence of muscle contractions (C). Daily skin inspections is effective in preventing pressure sores, which can be painful, however often are not painful because they occur in areas of the body that cannot be felt (A). Weight bearing exercises are effective in the prevention of osteoporosis in order to strengthen bones (B). Proper nutritional intake is effective in preventing osteoporosis and healing pressure sores but does not directly relate to pain (D).

8. What position is recommended when experiencing orthostatic hypotension?
   a. Laying on back
   b. Laying on side
   c. Sitting upright
   d. Laying on chest
Correct Answer: A
Justification: Laying on your back is recommended when experiencing orthostatic hypotension (A). This is characterized by dizziness, light headedness, headache, sweating, weakness, fatigue, yawning when moving from a laying down to upright position. Laying on side and chest are not associated with orthostatic hypotension (B, D). Sitting upright is the position recommended when experiencing autonomic dysreflexia (C).

9. Which of the following positions is recommended when experiencing autonomic dysreflexia?
   a. Lay on back
   b. Sit upright
   c. Lay on side
   d. Lay on chest
Correct Answer: B
Justification: It is important to sit upright when experiencing autonomic dysreflexia to decrease blood pressure (B). It is also important to find the stimulus causing it, which is often involving the catheter. Laying on your back is associated with orthostatic hypotension (A). Laying on your side or chest are not associated with autonomic dysreflexia (C, D).

10. Which of the following is not recommended when advocating for yourself?
    a. Be assertive
    b. Speak up and be persistent
    c. Have emotional support
d. Trust that doctors know your body
Correct Answer: D
Justification: It is recommended to advocate for yourself by; being assertive but not aggressive, speaking up and being persistent, and having emotional support (A, B, C). It is not recommended to trust that doctors know your body (D). While doctors are very knowledgeable, it is important to communicate what you expect out of your care because no one knows your body better than you.

11. Which of the following organizations provide benefits to individuals who cannot work for a year or more until they are able to work again?
   a. Office of Vocational Rehabilitation (OVR)
   b. Social Security Disability (SSDI)
   c. Medicaid
   d. Spinal Cord Injury Network International (SCINI)
Correct Answer: B
Justification: SSDI provides benefits to individuals who cannot work for a year or more if they had a job covered by SS previously. Denials are common on the first application but benefits will continue until a person can work again (B). OVR serves to help individuals find and maintain employment opportunities (A). Medicaid provides benefits to individuals based on income, age, household size, and disability (C). SCINI is an international advocacy network for individuals with spinal cord injuries (D).

12. Which of the following home modifications is most beneficial to increase accessibility of the home environment?
   a. Place cabinets and piping under the sink
   b. Install ramps at 1 foot of rise to 1 inch of length
   c. Install a stove with front burners and controls
   d. Ensure that doors have round knobs
Correct Answer: C
Justification: Front burners and controls eliminate the need to reach over hot burner to control the temperature of the stove (C). It is best to have an open area under the sink in order to pull right up to it with a wheelchair (A). Ramps are recommended to be 1 foot of length to 1 foot of rise (B). The ramp used for the answer would likely be too steep. It is recommended that doors have lever knobs to eliminate the need for grasp (D).

13. Which of the following is not a benefit of Smart Home Technology?
   a. Control lighting
   b. Operate appliances
   c. Covered by insurance
   d. Voice-operation
Correct Answer: C
Justification: Smart Home Technology is not covered by insurance which is a major negative towards its utilization (C). Smart Home Technology is beneficial for its control of lighting, operation of appliances, and hands-free voice-operation (B, C, D).
14. Which of the following is recommended to increase safety and comfortability at home?
   a. Good insulation and temperature control
   b. High carpeting and no hardwood flooring
   c. Light switches at 4 feet off the ground
   d. Store commonly used items in upper cabinets

Correct Answer: A
Justification: The home can be made more safe and comfortable through the use of good insulation and temperature control due to the lack of temperature control experienced my individuals with SCI (A). It is recommended that homes have low carpet or hardwood flooring in order to increase wheelchair mobility (B). Light switches should be 3 feet off the ground to increase accessibility from a wheelchair (C). Commonly used items should be in lower cabinets to increase accessibility (D).

15. If being helped down a curb cut, which body positioning is recommended?
   a. Leaning backward
   b. Leaning forward
   c. Lift wheelchair on back two wheels and lean forward
   d. Lift wheelchair on back two wheels and lean backward

Correct Answer: A
Justification: It is recommended to lean backward when going down a curb cut in order to control the speed on a downhill slope (A). Leaning forward is recommended when going up a curb cut in order to increase speed and push (B). It is not recommended to lift wheelchair on back two wheels due to safety reasons (C, D).
Appendix M

Caregiver Handout (Cervical Injury)

Caregiver Spinal Cord Injury (SCI) Education

Background
- Nearly 1/3 of SCI patients readmit to the hospital within the first year for an average of 22 days
- The 3 leading causes of readmission are all preventable
  - Urinary Complications
  - Respiratory Complications
  - Skin Related Complications

Urinary Complications (UTI)
- More common in permanent catheters
- Avoided through regular catheter management and monitoring
- Also can be avoided through proper skin hygiene

Respiratory Complications (Respiratory infection)
- Avoided through positioning and postural changes
- Cough assist techniques when needed
- Proper suctioning when needed

Skin Related Complications (Pressure Sores)
- Avoided through daily skin checks and pressure reliefs
- Pressure reliefs should be performed every 15-30 minutes for 1 minute when sitting in wheelchair, or every 2 hours in bed
  - Common pressure relief strategy while in chair is tilting the chair back to take weight off of their bottom or other boney areas that have the person’s weight on them
  - Common pressure relief strategy while in bed is rolling the person on their side

Other Complications to Consider
- Orthostatic Hypotension
  - Drop in blood pressure (BP) when moving from a lying to upright position
    - May feel dizzy or lightheaded
  - Lay person back down if occurs until BP rises
  - Once BP rises again, the person can be brought up to an upright position slowly to allow body to get used to this new position
  - Accessories such as TED stockings or an abdominal binder can also assist with keeping BP up
- Autonomic Dysreflexia (AD)
  - Rise in blood pressure (BP) due to the body reacting to an undesired stimulus below the level of injury
    - May feel sweaty, clammy, and/or experience a headache
  - Sit person up if occurring so BP can begin to lower and search for the stimulus
  - Most common stimuli include a full catheter bag or something pinching the individual’s skin (symptoms typically go away once the stimulus is removed)
Appendix N
Caregiver Handout (Thoracic Injury)

Caregiver Spinal Cord Injury (SCI) Education

Background
- Nearly 1/3 of SCI patients readmit to the hospital within the first year for an average of 22 days
- The 3 leading causes of readmission are all preventable
  - Urinary Complications
  - Respiratory Complications
  - Skin Related Complications

Urinary Complications (UTI)
- More common in permanent catheters but can be in any individual who requires catheterization
- Avoided through regular catheter management and monitoring
- Also can be avoided through proper skin hygiene

Respiratory Complications (Respiratory infection)
- Avoided through positioning and postural changes
- Aerobic exercises (arm bike or other prolonged low intensity workouts) or breathing exercises recommended to build up strength in lungs

Skin Related Complications (Pressure Sores)
- Avoided through daily skin checks and pressure reliefs
- Pressure reliefs should be performed every 15-30 minutes for 1 minute when sitting in wheelchair, or every 2 hours in bed
  - Common pressure relief strategy while in chair is leaning side to side or performing a wheelchair push up
    - Takes weight off of their bottom or other boney areas that have the person’s weight on them
    - Wheelchair push ups do risk harm to shoulder muscles
  - Common pressure relief strategy while in bed is rolling the person on their side

Other Complication to Consider
- Orthostatic Hypotension
  - Drop in blood pressure (BP) when moving from a lying to upright position
    - May feel dizzy or lightheaded
  - Lay person back down if occurs until BP rises
  - Once BP rises again, the person can be brought up to an upright position slowly to allow body to get used to this new position
  - Accessories such as TED stockings or an abdominal binder can also assist with keeping BP up
Appendix O

Caregiver Post-Test (Cervical Injury)

1. Which technique is most effective in the prevention of a urinary tract infection (UTI)?
   a. Frequent pressure reliefs
   b. Regular catheter management
   c. Loosen clothing
   d. Eating healthy diet

2. How frequently should you perform a pressure relief?
   a. Every 15-30 minutes for 30-90 seconds
   b. Every 30-90 minutes for 15-30 seconds
   c. Every 5-10 minutes for 15-30 seconds
   d. Every 100-120 minutes for 5-10 seconds

3. Which of the following techniques is most effective in preventing a pressure sore?
   a. Regular catheter management
   b. Range of motion
   c. Daily skin checks
   d. Eating healthy diet

4. Which of the following is the most effective recommendation to avoid respiratory complications?
   a. Positioning and posture changes
   b. Eating healthy diet
   c. Electric nerve stimulation
   d. Loosen clothing

5. What position is recommended when experiencing a sudden drop in blood pressure when moving from a laying to sitting position?
   a. Laying on back
   b. Laying on side
   c. Sitting upright
   d. Laying on chest

6. Which of the following positions is recommended when experiencing a sudden rise in blood pressure?
   a. Lay on back
   b. Sit upright
   c. Lay on side
   d. Lay on chest
Appendix P

Caregiver Post-Test (Thoracic Injury)

1. Which technique is most effective in the prevention of a urinary tract infection (UTI)?
   a. Frequent pressure reliefs
   b. Regular catheter management
   c. Loosen clothing
   d. Eating healthy diet

2. Which type of pressure relief involves the greatest risk for harm to your shoulder muscles?
   a. Alternate techniques
   b. Leaning from side to side
   c. Tilt or Recline
   d. Wheelchair pushups

3. How frequently should you perform a pressure relief?
   a. Every 15-30 minutes for 30-90 seconds
   b. Every 30-90 minutes for 15-30 seconds
   c. Every 5-10 minutes for 15-30 seconds
   d. Every 100-120 minutes for 5-10 seconds

4. Which of the following techniques is most effective in preventing a pressure sore?
   a. Regular catheter management
   b. Range of motion
   c. Daily skin checks
   d. Eating healthy diet

5. Which of the following is the most effective recommendation to avoid respiratory complications?
   a. Positioning and posture changes
   b. Eating healthy diet
   c. Electric nerve stimulation
   d. Loosen clothing

6. What position is recommended when experiencing a sudden drop in blood pressure when moving from a laying to sitting position?
   a. Laying on back
   b. Laying on side
   c. Sitting upright
   d. Laying on chest
Appendix Q

Test of Normality

Table 4

*Mean Difference Shapiro-Wilk Test of Normality*

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Figure 4

*Histogram of Mean Difference Normality Test*
Appendix R

T-Test

Table 5

*Mean Difference T-Test*

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Appendix S

ANOVA Test Scores

Table 6

*ANOVA Test Scores*

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Appendix T

Caregiver Test Descriptive Statistics

Table 7

*Descriptive Statistics of Caregiver Test*

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### Appendix U

Patient Satisfaction Score Descriptive Statistics

Table 8

*Descriptive Statistics of Patient Satisfaction Scores*

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