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Self-Management for Individuals Using Long-Term Urinary Catheterization

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SELF-MANAGEMENT FOR INDIVIDUALS USING LONG-TERM URINARY CATHETERIZATION

by

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A DISSERTATION

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DEDICATION

I would like to dedicate this body of work to my family. My parents Kim and Carolyn, you have given me so much support and encouragement throughout my life helping me to achieve all my goals and dreams. My husband Paul and boys Logan and Eric, you have helped me throughout this journey and given me the motivation to keep going even when it got difficult. To all my family your patience, encouragement and support throughout this process mean more to me than words can say. I love you all!

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ABSTACT

Implementing a Self-Management Intervention at Discharge for Urinary Catheter Users

Lisa A. Krabbenhoft, PhD, RN

University of Nebraska Medical Center, April 26, 2020

Adviser: Paula S. Schulz PhD, RN

Many individuals with adult neurogenic lower urinary tract disorder require long-term urinary catheterization for bladder management. The daily use of urinary catheterization increases the risk for chronic complications including catheter associated urinary tract infections. Previous studies have used self-management interventions to reduce chronic complications in the community setting. However, there are limited intervention studies focused on reducing chronic complications after discharge from a rehabilitation hospital. The purpose of this dissertation study is to examine the feasibility and impact of a self-management intervention on individuals after leaving rehabilitation hospital for home within the community.

This dissertation comprises two studies, the first examined the feasibility of using a three-day self-monitoring intervention in a rehabilitation hospital. This study looked at the use of a urinary diary and catheter journal to promote self-monitoring. Participants were asked to use two formats (paper and online) for three consecutive days. Evaluation was done to determine feasibility of enrollment, data collection, and acceptability of the intervention. We found that it was feasible to enroll patients in this setting, and the paper format was the preferred method for documenting information on the urinary diary and catheter journal. Participants also identified increased awareness related to fluid intake and urine output from using the self-monitoring intervention.

The second study was completed over twelve weeks and examined the impact of an intervention on urinary catheter quality of life and urinary catheter self-management. The study

also examined self-management intervention components including knowledge, self-monitoring, self-efficacy, and patient activation by groups (intervention and standard care) at baseline and twelve weeks. The intervention study found small changes in measurements from baseline to 12 weeks. There were no statistical differences between intervention and control groups on any outcomes.

The final manuscript in the dissertation describes use of healthcare resources and catheter related problems for all participants who completed the twelve-week study. Overall, 58% of the participants self-reported having a urinary tract infection and had unplanned physician visits within the 12 weeks after discharge. Indwelling catheter users also had a higher rate of self-reported urinary tract infections and use of healthcare resources compared to clean intermittent catheter users.

The findings of this study begin to address the gap to identify self-management strategies for better long-term bladder management in individuals living with adult neurogenic lower urinary tract disorders. Future research is needed to develop and test self-management strategies to enhance individual bladder self-management and prevent chronic complications. Nurses have an essential role in helping individuals develop individualized strategies that can be implemented into their daily routine contributing to a conceivable decrease in CAUTI and other urinary complications.

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LIST OF ABBREVIATIONS

CAUTI	Catheter Associated Urinary Tract Infection
ANLUTD	Adult Neurogenic Lower Urinary Tract Dysfunction
SM	Self-Management
CIC	Clean Intermittent Catheter
IC	Indwelling Catheter
SCI	Spinal Cord Injury
UTI	Urinary Tract Infection
PI	Principal Investigator
MS	Multiple Sclerosis
IFSMT	Individual Family Self-Management Theory
C-SE	Urinary Catheter Self-Efficacy Scale
PAM	Patient Activation
ICIQ-LTCqol	ICIQ-Long Term Catheter Quality of Life
QOL	Quality of Life
C-SMG	Catheter Self-Management Scale
ISC-Q	Intermittent Self-Catheter Questionnaire

CHAPTER I: INTRODUCTION

Background & Significance

The elevated risk of catheter-associated urinary tract infections (CAUTI) has been well documented and evaluated as high risk for individuals with neurological disorders impacting bladder function that may be diagnosed with adult neurogenic lower urinary tract dysfunction (ANLUTD). Neurological conditions causing ANLUTD affecting bladder function include multiple sclerosis (MS) (58.2%), spinal cord injury (SCI) (49.7%), Parkinson's disease (58.6%) and stroke (64.7%) (Ruffion et al., 2013). Symptoms and signs of ANLUTD depend on the extent of neurological function loss and the portion of the nervous system that has been affected by an SCI or neural lesion or disease of the central nervous system (Gajewski et al., 2018; Jamison, 2013). Regular urine release or micturition occurs with the coordination of a neuronal circuit between the brain and spinal cord, as well as the bladder and urethra. For many with ANLUTD, bladder management requires long-term use of urinary catheterization, which is defined as four weeks, or greater than 30 days (National Clinical Guideline Centre, 2012; Parker et al., 2009).

The daily use of urinary catheterization, regardless of the method used, increases the risk of chronic complications such as catheter-associated urinary tract infections (CAUTI), urine leakage, catheter blockage, urethral fistulas, and urethral strictures (Hollingsworth et al., 2013; Manack et al., 2011; Payne & Potts, 2012). The high prevalence of CAUTI in long-term catheter users contributes to nearly 4 billion dollars spent annually in the United States related to urinary tract infections (Litwin, 2005). Additionally, signs and symptoms of a CAUTI in the ANLUTD population presents differently due to damage to the nervous system. Common signs and symptoms may include incontinence, spasticity, fatigue, changes in urine quality or odor, discomfort, and autonomic dysreflexia (Hooton et al., 2010; Massa, Hoffman, & Cardenas, 2009; Vigil & Hickling, 2016). Poor bladder management and untreated infections can lead to renal failure and sepsis (Manack et al., 2011; Pannek et al., 2013). Long-term catheter users are

challenged with the complexity of daily bladder management. Interventions that support self-management skills are needed to decrease the risk of chronic complications in this population.

Education and catheter training for this population is often initiated in the hospital, rehabilitation, or specialty clinic with limited time for bladder self-management (SM) training. Hence, patients are discharged with few strategies for preventing chronic complications, resulting in the need for interventions that support SM. Thus far, research on urinary catheter use has primarily focused on short-term catheterization, product trials, and healthcare-associated infections (Cottenden et al., 2013). The purpose of this dissertation project was to test the feasibility and the use of an SM intervention (knowledge, catheter self-efficacy, self-monitoring and patient activation) to examine the impact on outcome variables (catheter quality of life and urine catheter SM) and self-reported healthcare utilization for long-term urinary catheter users discharging from physical rehabilitation hospital to the community setting. Specific objectives for this dissertation were to:

1. Test the feasibility of a self-monitoring intervention by evaluating: a) recruitment and screening practices, b) informed consent process, c) enrollment (recruitment efficiency, attrition, problems, and solutions), d) acceptability of the intervention, e) fidelity (delivery, completion of data entries), f) data collection (ease of use, the time required, missing data).
2. Examine the impact of the self-management intervention on catheter quality of life and urinary catheter self-management.
3. Compare the intervention components (knowledge, catheter self-efficacy, self-monitoring, and patient activation) by group (intervention and standard care) over the 12-week intervention period.
4. Identify the use of healthcare resources (unplanned physician visits, visits to the emergency department, hospitalization), describe catheter-related problems (urinary tract

infection), and examine differences by the type of catheter used (indwelling catheter and clean intermittent catheter).

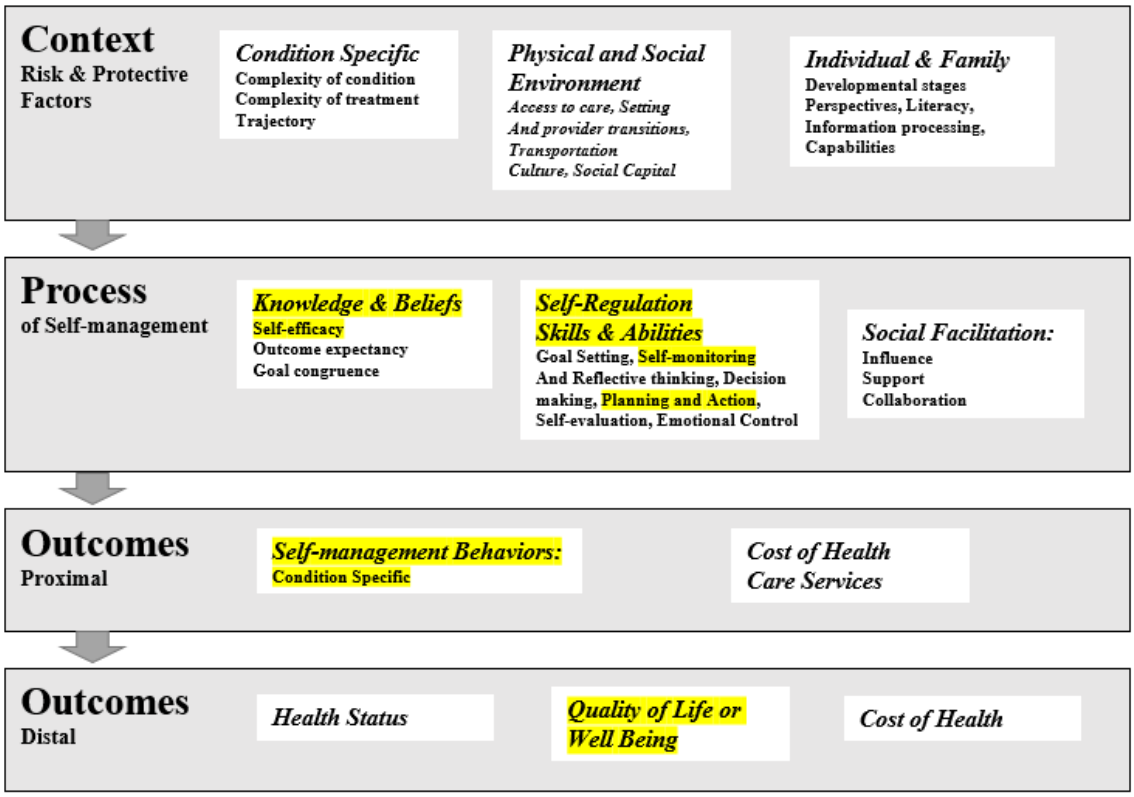
Key Concepts and Theoretical Background

The use of self-management programs and interventions have established efficacy in developing skills and improving outcomes related to behavior change, quality of life, and overall well-being (Ryan & Sawin, 2009; Wilde, Crean, et al., 2016; Wilde, McMahon, et al., 2016). Self-management is a complex multidimensional process that includes five self-management skills: problem-solving, ability to make decisions, use of resources, developing a partnership between patient and health care provider, and taking action(Lorig & Holman, 2003). Health professionals use self-management programs to prepare patients to acquire the skills, knowledge, and confidence to manage their health. (Wilde & Brasch, 2008) The chronic nature of ANLUTD necessitates urinary catheter users to engage in self-management behaviors that can impact both long and short term outcomes (Ryan & Sawin, 2009).

The Individual and Family Self-Management Theory (IFSMT) is a mid-range self-management theory used to guide this study. The adapted IFSMT (Figure 1) includes three dimensions: context, process, and outcomes. Influences on the engagement of self-management are contextual factors, including characteristics of a condition, the environment, and individual and family factors. In this framework, the process of self- management involves interventions focused on knowledge and health beliefs, self-regulation, skills, and abilities. Through the engagement of condition-specific self-management behaviors, individuals improve health outcomes, including quality of life (Ryan & Sawin, 2009). Specifically, for this dissertation, I will focus on concepts within the model, including; the process of self-management (knowledge and beliefs and self-regulation), proximal outcomes (condition-specific self-management behaviors), and distal outcomes (quality of life).

Figure 1

Model of the Individual and Family Self-Management Theory (Ryan & Sawin, 2009)



Process of Self-Management

Knowledge and Beliefs

Knowledge and beliefs are principal factors in daily activities and engaging in self-management (Ryan & Sawin, 2009). Knowledge does not directly lead to self-management behavior changes. However, the knowledge gained through education and experiences improves process factors (self-efficacy and patient activation)(Hibbard, Stockard, Mahoney, & Tusler, 2004; Ryan & Sawin, 2009) and also facilitate self-management skills related to use of urinary catheter and activities (Kelly, Spencer, & Barrett, 2014; Wilde, Brasch, & Zhang, 2011; Wilde, McDonald, et al., 2013). Research supports the use of knowledge in helping to recognize changes in urine, symptoms of UTI's, fluid management, and making adjustments bladder self-management behaviors (Fowler, Godfrey, Fader, Timoney, & Long, 2014; Wilde & Brasch, 2008; Wilde, 2011; Wilde, Zhang, et al., 2013). Improving an individual's knowledge and understanding helps enhance their self-efficacy. Knowledge in all subjects will be measured in this study by using the knowledge assessment questionnaire at baseline and 12 weeks.

Self-Efficacy

Self-Efficacy is an individual's confidence in their ability to engage in behaviors that lead to improved health outcomes (Bandura, 2012; Ryan & Sawin, 2009). Research with urinary catheter users has found a positive correlation between self-efficacy and fluid intake ($b=0.37$, $p=0.009$) and an indirect effect on catheter blockage rates (Wilde, Crean, et al., 2016). Enhancing self-efficacy using a self-monitoring intervention could potentially impact fluid intake and bladder self-management related health outcomes. The researcher will use the urinary catheter self-efficacy scale to measure self-efficacy at baseline and 12 weeks (Wilde, McMahon, Tang, et al., 2016).

Self-Regulation

Self-regulation is an essential concept in achieving health behaviors that are needed for self-management (Ryan & Sawin, 2009). This concept of self-regulation also includes both skills

and abilities such as individualized goal-setting, self-monitoring, self-evaluation, and patient activation to guide individuals in their health behavior change**.** *Goal setting/self-evaluation* helps individuals focus on specific symptoms and treatments needed for better self-management behaviors impacting overall health management. Self-evaluation occurs as part of self-monitoring. *Self-Monitoring* specific to UTI's includes the ability to become self-aware, utilize measures (signs and symptoms), recordings, and observations (color of urine) to interpret changes, and adjust care as needed (McBain, Shipley, & Newman, 2015; Wilde & Garvin, 2007). Increased awareness, which is part of self-monitoring, helps individuals evaluate their health or goals and notify healthcare providers early about changes in their health status, preventing serious complications and possible hospital readmission (Wilde & Brasch, 2008). The Urinary Diary will enable subjects to gain awareness and will be used to assess the individuals' ability to self-monitor. The self-regulation process also includes planning and action that can be measured by patient activation. *Patient Activation* is gaining knowledge, learning skills, and achieving the confidence that is needed to engage in successful health management, such as daily catheterization for bladder management (Hibbard et al., 2004). Currently, no studies have reported a measurement of patient activation in NLUDT patients performing catheterization. However, research of catheter users has identified the importance of motivation and active participation in reducing UTI's is needed (Wilde et al., 2011). Given that patient activation has been useful for other populations with chronic disorders such as cardiovascular, diabetes, and pulmonary, similar results may be seen in NLUTD patients (Hibbard & Greene, 2013; Mosen et al., 2007; Solomon, Wagner, & Goes, 2012). To evaluate patient activation, all participants will complete the Patient Activation Measure (PAM) assessment at baseline and completion of the study.

Proximal Outcomes: Self-Management Outcomes

Self-Management of Urinary Catheter

There are various methods for bladder self-management using urinary catheterization, with the most common methods being clean intermittent catheterization (CIC), and indwelling catheterization (IC). The use of CIC is the preferred method of bladder emptying because of the reduced risk of catheter-associated urinary tract infections (CAUTI) (Godfrey, 2008; Wilde, McMahon, Crean, & Brasch, 2017). Although the prevalence of CAUTI has diminished for CIC users, approximately 50% will test positive for bacteriuria (Lamin & Newman, 2016b). Indwelling catheterization (IC) includes both indwelling urethral catheter and suprapubic catheter. Indications for the use of IC include assisting with the healing of open sacral or perineal wounds for incontinent individuals, prolonged immobilization, and as a comfort measure for end-of-life care (Newman, 2010). The use of an indwelling urethral catheter is not recommended in SCI patients unless they have difficulty self-catheterizing as in, for example, cases of tetraplegia or in the presence of urethral abnormalities. A suprapubic catheter usually is more accessible for individuals to manage hygiene and catheter changes. Suprapubic catheters also reduce the risk of urethral stricture and erosion. Individuals with a tetraplegic spinal cord injury often prefer the use of a suprapubic catheter due to lower risk for complications, hygiene management, and difficulty performing CIC. However, 65% of these patients will develop a bladder stone (Taweel, 2015). Catheter self-management will be evaluated at baseline and 12 weeks for all participants in the study.

Distal Outcomes: Quality of Life

Catheter-Related Quality of Life

Quality of life for this study focuses on urinary catheterization use and health status. Wilde et al. (2015) found that individuals who received a self-management intervention had an improved health status and reported a significant decline in CAUTI at six months ($p=0.02$ rate=4.37). The authors identified that both groups showed improvement at 12 months, possibly

related to the use of the catheter calendar, which increased the participant's awareness of catheter problems. The authors also identified that increased awareness could have led to self-management behavior changes (Wilde, McMahon, McDonald, et al., 2015). More research is needed to help support a possible relationship between self-management interventions for individuals using urinary catheterization for bladder management and improved outcomes. Study outcomes will be measured, focusing on catheter related quality for all participants at baseline and 12 weeks.

Overview of Manuscripts

Three manuscripts will be presented in the following chapters to contribute to the understanding of self-management strategies for long-term urinary catheterization and healthcare utilization in this population. Chapter II presents the results of the feasibility of using a self-monitoring intervention in the rehabilitation hospital (Objective 1). This information guided the intervention that was used in the pilot of the intervention study. Chapter III describes the randomized two-group (control and treatment) pilot study, the impact of the self-management intervention (Objective 2), and compares intervention components between groups (Objective 3). Chapter IV is a description of the participants who completed the pilot study self-report use of healthcare resources and catheter complications (Objective 4) and by type of catheter (Objective 5). Chapter V presents the discussion of the research and practice implications.

CHAPTER II: Manuscript 1

Feasibility of a Self-Monitoring Intervention for Long-Term Catheter Users in Rehabilitation Settings

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(Submitted for publication in Rehabilitation Nursing Journal)

Abstract

Long-term urinary catheter users are at an increased risk for urinary tract infections and complications. Self-monitoring is a strategy that can be used to increase awareness and guide decision-making related to fluid intake and output in this population. This descriptive study examined the feasibility and acceptance of a three-day bladder self-monitoring intervention. Rehabilitation hospital patients requiring long-term catheterization (N=6) were enrolled prior to discharge to a home setting. Participants provided informed consent, demographic and clinical data, and completed the three-day urinary diary documenting fluid intake, urine output, and urine characteristics in a paper and online format. Participants used both indwelling urinary catheter (n=3), clean intermittent catheter (n=2), and a combination of an intermittent catheter and condom catheter (n=1). Evaluation of the data revealed that all participants completed the paper format for all three days with only one completing the online format. Results of the perceived value questionnaire indicated an increased level of awareness of fluid intake and urine amounts, appearance (color and sediment).intake and output. The self-monitoring intervention (urinary diary and catheter journal) in the paper format was the preferred method by participants. Results also confirmed the intervention as feasible in the rehabilitation setting and long-term urinary catheter users were interested in using this tool to help with self-monitoring. These results support further clinical investigation using interventions to improve bladder management and a conceivable decrease in urinary complications.

Introduction

Adult neurogenic lower urinary tract dysfunction (ANLUTD) is defined as "abnormal or difficult function of the bladder, urethra (or prostate in men) in mature individuals in the context of clinically confirmed relevant neurologic disorder" (Gajewski et al., 2018). ANLUTD is present in a variety of neurological conditions and varies based on the level of neurological involvement (Tudor, Sakakibara, & Panicker, 2016). The prevalence of neurogenic urinary symptoms has been reported by approximately half of the patients with multiple sclerosis (MS) (58.2%), spinal cord injury (SCI) (49.7%), Parkinson's disease (58.6%) and stroke (64.7%) (Ruffion et al., 2013). Many of these individuals struggle with urinary retention or incontinence and require the use of long-term urinary catheterization for bladder management (Lamin & Newman, 2016a). The use of urinary catheterization increases the risk of developing catheter-associated urinary tract infections (CAUTI) due to the introduction of organisms into the bladder and promoting colonization (Vergidis & Patel, 2012). Research data on the frequency of CAUTI for long-term urinary catheter users is limited. However, research estimates incidence of UTI at 2.5 episodes per year in the SCI population (Siroky, 2002). The high prevalence of CAUTI in those using an indwelling catheter (IC) and clean intermittent catheter (CIC) for bladder management contributes to the nearly 2.8 billion spent on hospitalization (Simmering, Tang, Cavanaugh, Polgreen, & Polgreen, 2017). The daily use of urinary catheterization also increases the risk for chronic noninfectious complications such as; urine leakage (52.1%), catheter blockage (28.7%), hematuria (43.6%), urethral strictures or erosion (8.7%) (Hollingsworth et al., 2013).

Prevention of complications, specifically CAUTI, is imperative to reduce morbidity and improve the quality of life in patients with adult neurogenic lower urinary tract disorder. Self-management programs have established that individuals who establish healthy behaviors can impact both long term and short-term outcomes (Ryan & Sawin, 2009). Bladder self-management involves a variety of complex interventions requiring patients or caregivers to make daily

decisions regarding catheterization technique, frequency of catheterization, fluid intake, and urine assessment.

The purpose of this study is to test the feasibility of a self-monitoring intervention by evaluating: a) recruitment and screening practices, b) informed consent process, c) enrollment (recruitment efficiency, attrition, problems, and solutions), d) acceptability of the intervention, e) fidelity (delivery, completion of data entries), f) data collection (ease of use, the time required, missing data) over a three-day data collection period.

Background

To effectively integrate self-management strategies requires insight into the body's responses to events, situations, or interventions (Thorne, Paterson, & Russell, 2003). Self-management programs or interventions require individuals to engage in healthful behaviors and disease management (Lorig & Holman, 2003). Current research suggests that the implementation of self-management strategies has resulted in positive health outcomes for individuals with chronic diseases such as diabetes, heart disease, asthma, and arthritis (Lorig, Ritter, Laurent, & Plant, 2006). One strategy to enhance self-management is the use of self-monitoring. Self-monitoring includes monitoring of clinical parameters, symptom measures, and daily activities (Wilde & Garvin, 2007). Self-monitoring has been used successfully in chronic diseases such as asthma, diabetes, hypertension, rheumatism, migraines, and other neurological disorders (Huygens et al., 2017). Strategies of self-monitoring include activities such as measuring blood pressure, blood glucose or urine output, reviewing the results, and making decisions about the meaning of the measurement (Huygens et al., 2017). In 627 patients with chronic disease, willingness to self-monitor was associated with disease controllability ($r = .0.547$, $p<.05$); patients with hypertension, diabetes, and asthma were the most willing to self-monitor (Huygens et al., 2017).

Limited research has investigated self-monitoring in long-term catheter users. Self-management research focused on urinary catheter use has identified that self-monitoring includes

"awareness of symptoms or bodily sensations that are enhanced through periodic measurements, recordings and observations to provide information for improved self-management (Wilde & Garvin, 2007). A year-long interventional study (N=202) found that using a urinary diary tool helped community-dwelling individuals with their awareness, contributing to fewer blockages in the intervention group in the first six months (Wilde, McMahon, McDonald, et al., 2015). However, both groups improved with fewer CAUTIs, dislodgements, and hospitalizations for CAUTI. The awareness of possible catheter problems may have also led individuals to develop self-management behaviors, such as adjusting fluid intake and consistent fluid intake (Wilde, McMahon, McDonald, et al., 2015).

Initiating self-monitoring strategies before discharge from the rehabilitation setting is ideal for preventing CAUTI and other catheter-related complications. In spinal cord injury (SCI) patients, the infection was the most frequently reported complication in the first year after discharge from rehabilitation settings (Stillman et al., 2017) and the most common condition leading to rehospitalization (DeJong et al., 2013). Current strategies used for prevention include education; however, it has not shown positive outcomes when implemented alone (Evardone, Wilson, Weinel, Soble, & Kang, 2018). Evardone et al. (2018) did not find that attendance by SCI patients at education sessions about secondary complications during acute rehabilitation was associated with CAUTI incidence or other health outcomes.

Design and Methods

This study is a one-group feasibility study used to examine a self-monitoring tool use at one midwestern rehabilitation center in individuals using urinary catheterization for long-term bladder management.

Sample/Setting

The study was conducted after obtaining appropriate institutional review board approval from both the university and the rehabilitation center. After a discussion with the research team, a sample size of 6 was deemed sufficient to examine feasibility. Inclusion criteria were as follows:

(1) English speaking; (2) age 19 years or older; (3) within three weeks of discharge from post-acute care; (4) diagnosed with a medical condition requiring long-term catheterization for bladder management; (5) trained during hospitalization on bladder catheterization; (6) able to access a device with an internet connection. Exclusion criteria were chosen to assure study participants would be able to participate in the three-day urinary diary data collection. Exclusion criteria were: (1) diagnosed with a terminal illness with a life expectancy of fewer than six months or (2) have a diagnosis of cognitive impairment such as dementia.

Self-Monitoring Intervention

The self-monitoring intervention (urinary diary and catheter journal) was adapted from a research study of one of the authors (MHW) focused on long-term intermittent urinary catheter use in the community setting (Wilde, McMahon, et al., 2016). The 24-hour urinary diaries prompted participants to document all their daily fluid intake, urine output, the appearance of urine (including the color of urine, presence of mucus, blood clots, and sediment). The catheter journal prompted participants to document specifics about "what was noticed" and "what was going on, or done about it." Staff or family caregivers could assist in diary completion. Patients were instructed to complete the diary and journal using an online format and paper format for three consecutive days.

Data Collection

Demographic data (gender, date of birth, ethnicity, marital status, education, employment, type of health insurance, housing, care after discharge), medication history, level of injury, medical diagnosis, the reason for catheterization, and bladder sensation were collected after enrolment into the study. Participants type of catheter care (indwelling or intermittent) was obtained from a medical record review and interview after consent was obtained. Urinary diary and catheter journals were collected after participants' completion of the three consecutive days. Feasibility data on enrollment (recruitment and attrition) and data collection procedures (online and paper format) were evaluated by the Principal Investigator (PI) after the study.

Measures

A 12-item perceived value questionnaire was used at the end of the three days. The questionnaire was adapted from previous research and used to evaluate the usefulness, satisfaction, and ease of use of the intervention (Wilde, Zhang, et al., 2013). The tool question included yes/no responses, a 5-point Likert scale from strongly disagree to strongly agree, and opportunities to write answers and comments.

Procedure

Following informed consent, demographic and clinical data was collected via medical chart review and face to face interview. Subjects were then oriented to the self-monitoring intervention. Each participant received the 24-hour urinary diary and catheter journal in two formats: paper and online. Baseline data were collected at enrollment with follow-up data collected three days post-enrollment. The PI followed-up with all participants within 24-hours of starting the study to answer questions about the use of both the online and paper format of the urinary diary and catheter journal.

Data Analysis

Demographic, clinical, and urinary diary data were analyzed using descriptive statistics. Urinary diary and catheter journal data were separated by day (day one, day two, and day three) and method used for data entry (online and paper formats) to see if comments were similar or different. Data and written responses in the perceived value questionnaire was analyzed using simple coding by PI (LK) and another researcher (PS).

Results

This study aimed to examine the feasibility of recruitment, enrollment, retention, the informed consent process, acceptability of intervention (online vs. paper format), and data collection. The description of patient characteristics and feasibility attributes are described below.

Patient Characteristics

Six patients were enrolled and completed the study. The sample included three men (50%) and three women (50%), mean age 43.7 years (range 23-66). Educational background was high school/GED (n=2), some college (n=3), and graduate degree (n=1). The patient's primary diagnoses included SCI (n=4), Multiple Sclerosis (n=1), and wound management (n=1). Specifically, spinal cord injured patients included both cervical injuries (n=2) and thoracic injuries (n=2). Fifty percent of the patients (n=3) had no bladder sensation, one patient had partial sensation, and two had full sensation. All care plans included discharge from a rehabilitation center to home and continued use of long-term urinary catheterization. Current bladder management methods included IC (n=3), CIC (n=2), and a combination of CIC and condom catheter (n=1).

Feasibility

Recruitment and Enrollment: Recruitment was done on two rehabilitation care units. Unit charge nurses helped to identify potential patients. Recruitment was more favorable during evening hours when patients were not in therapies, and caregivers were present. Twelve patients were referred to the PI for screening, and nine patients met the inclusion criteria. Three patients refused to participate in the study. Six patients were enrolled and completed the study.

Informed Consent Process

This process took an average of 15-20 minutes. We used the teach-back method to assess comprehension of informed consent. All patients were able to state consent to participate in the research study.

Acceptability and Data Collection

Comparing the amount of data from the online and paper formats of the urinary diary, we found that all patients (n=6) had complete entries in the paper format while only one patient had complete entries in the online format for the three consecutive days. Missing data for the online format were noted to increase for diary day two and three. One patient did not access the online diary after completing orientation.

We found in the perceived value questionnaire that all patients agreed (n=3) or strongly agreed (n=3) that the urinary diary documentation was useful. Patient satisfaction with the urinary diary ranged from strongly agree (n=4), agree (n=1), and neutral (n=1). Fifty percent of the patients (n=3) were not able to enter any data online. Three patients reported to PI that they needed assistance from caregivers to enter data online and that caregivers were more likely to help with the urinary diary in the paper format.

Comments. In the comments section, patients reported that the paper format was "easily available," "easier to use," and "easier and faster" to complete. A common theme identified within the open-ended section was that all patients reported increased awareness related to fluid intake and types of fluid (n=5); urine and urine output (n=3); increased caregiver awareness (n=2); adjusting fluid intake based on diary information (n=4). Two patients reported being diagnosed with a CAUTI after completing day one of the urinary diary, and these patients reported being more aware of their urine and the changes that occurred with a CAUTI. Many of the patients identified that the nursing staff had monitored their fluid intake and urinary output but did not consistently share that information with them.

Discussion

This study assessed the feasibility and acceptance of a urinary diary to assist with bladder self-monitoring for long-term urinary catheter users before discharge from rehabilitation care. Establishing patients' acceptability of using the urinary diary and identifying which method was preferred were primary aims for this study. Comparing the use of the online urinary diary and paper urinary diary revealed that patients completed the paper format diary more accurately with less missing data due to the ease of use. Patients who were not able to independently document online reported that they were able to complete the paper format of the urinary diary with assistance from healthcare staff and family caregivers. Based on conversations with the PI, all the patients reported a decrease or lack of involvement in monitoring their fluid intake and urinary output before beginning the study. Importantly patients commented that they had increased

communication with hospital staff related to fluid intake and urine output during the time of the study. This was particularly true for individuals with lower levels of independence and using a urethral catheter who needed help with the urinary diary documentation.

Limitations

Limitations of this study include the small sample size. Not all patients had full-hand dexterity and needed assistance with using the online intervention, possibly impacting their participation. Therefore, the small sample might not represent the population entirely.

Clinical Implications

Many individuals diagnosed with neurogenic bladder are trained in urinary catheter management while in the hospital, rehabilitation, or specialty clinic. Due to changes in healthcare, there is less time for patient education making it more challenging to provide appropriate self-management strategies to individuals to prevent chronic complications (Kroll, Neri, & Ho, 2007; Ljungberg, Kroll, Libin, & Gordon, 2011). Studies have also found that individuals feel unprepared or lack the training needed to effectively implement urinary catheterization (Munce, Fehlings, et al., 2014; Wilde et al., 2011). The chronic nature of long-term catheterization necessitates users to engage in healthy behaviors such as fluid management and self-monitoring of bladder care (Elstad, Maserejian, McKinlay, & Tennstedt, 2011; Wilde, McMahon, et al., 2016).

Nursing research in this area is unique due to the perspective and focus on the whole person. Nurses have an essential role in helping individuals develop bladder self-management strategies. In rehabilitation settings, the nurse is often considered the expert in bladder management and implementing self-monitoring skills. Nurses are vital to assessing individual needs and providing education and support to help them achieve self-monitoring into their daily routine. Nurses' knowledge and experience help patients develop skills, comfort, and confidence in adapting urinary catheterization to their lives (Cave, 2016; Logan, Shaw, Webber, Samuel, & Broome, 2008).

Conclusions

To our knowledge, this is the first study assessing the feasibility of a self-management intervention in the post-acute care setting for long-term urinary catheter users. This study supports the usefulness of the urinary diary as a self-management strategy to increase patient awareness and active participation in their bladder management. Patients in this study were able to use the urinary diary in the paper format, which was identified as the preferred method based on findings related to the amount of recorded data and patient comments. Further research is needed to validate the use of a urinary diary during the patient transition time before and after discharging from post-acute care. By increasing awareness of urine amounts, appearance (color and sediment), it is possible that the use of a urinary diary may have a positive impact on patient bladder management, knowledge, and confidence leading to a conceivable decrease in UTI and other urinary complications.

CHAPTER III: Manuscript 2

Pilot Study of a Self-Management Intervention for Urinary Catheter Users

Background

Research continues to show evidence that the risk of developing catheter-associated urinary tract infections (CAUTI) increases with the use and duration of urinary catheterization (Kennelly et al., 2019). Nevertheless, for many individuals with adult neurogenic lower urinary tract disorder (ANLUTD), the use of a urinary catheter is required for bladder management. Urinary catheters are routinely used to manage urinary retention and urinary incontinence (Lamin & Newman, 2016a) in this population. Within the United States, we continue to see a rise in the number of individuals impacted by ANLUTD. The increase in ANLUTD is due to the prevalence of diagnoses such as spinal cord injury (SCI), multiple sclerosis (MS), Parkinson's, strokes, diabetes, and other diagnoses causing bladder dysfunction, which can require a urinary catheter (Kinnear et al., 2019).

Individuals with ANLUTD needing to use urinary catheterization for long-term bladder management (>30 days) (National Clinical Guideline Centre, 2012) may benefit from the assistance of health care professionals to improve acceptance and education about catheter use. It is important to note that acceptance of the use of catheterization is not dependent on the presence or absence of problems (Godfrey, 2008). Successful acceptance is more dependent on the individual's ability to adjust to catheterization by modifying personal hygiene, developing strategies to include the catheter as part of their life, and develop problem-solving approaches to use for catheter difficulties and management (Fowler et al., 2014; Godfrey, 2008). Some specific adjustments include drinking sufficient fluids (Godfrey, 2008), adjusting fluid intake when away from home, preventing blockage (Fowler et al., 2014), and adjusting fluid intake to decrease urine loss between catheterization (Wilde, McMahon, et al., 2016).

The use of self-management (SM) programs and interventions have established efficacy in developing skills and improving outcomes related to behavior change, quality of life and overall well-being (Ryan & Sawin, 2009; Wilde, Crean, et al., 2016; Wilde, McMahon, et al., 2016). Self-management is a complex multidimensional process that includes five self-

management skills: problem-solving, ability to make decisions, use of resources, developing a partnership between patient and health care provider, and taking action (Lorig & Holman, 2003). Health professionals use self-management programs to prepare patients to acquire the skills, knowledge, and confidence to manage their health (Wilde & Brasch, 2008). Achieving healthy behaviors as part of a self-management program can impact both long term and short term outcomes (Ryan & Sawin, 2009).

Research has primarily focused on short-term catheterization, product trials, and healthcare-associated infections (Cottenden et al., 2013). The complexity of daily bladder management and the increased risk for chronic complications results in the need for interventions that support SM in this population. Limited research has been done focusing on self-management in long-term urinary catheter users.

Purpose

The purpose of this randomized pilot study was to examine the impact of a 12-week self-management intervention (bladder management education/resources, urinary diary and catheter journal) on the outcome variables (catheter quality of life and urinary catheter self-management) for long-term urinary catheter users discharging from inpatient rehabilitation to the community. We propose the intervention components: knowledge and beliefs, self-efficacy, self-regulation, and patient activation will improve the outcome variables. This study helps to address a gap in research by focusing on self-management and promoting independent self-monitoring for long term catheter users, leaving a rehabilitation hospital setting for the home. Specific aims were to:

1) Examine the impact of the self-management intervention on catheter quality of life and urinary catheter self-management.
2) Compare the intervention components (knowledge, catheter self-efficacy, self-monitoring, and patient activation) by group (intervention and standard care) over the 12-week intervention period.

Pilot Study Framework

The self-management intervention was guided by the Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009). The IFSMT is a mid-range, self-management theory that includes three dimensions: context, process, and outcomes. Engagement in self-management is influenced by contextual factors, including characteristics of a condition, the environment, and individual and family factors. In this framework, interventions are focused on the self-management processes of knowledge and beliefs and self-regulation, skills, and abilities (Ryan & Sawin, 2009).

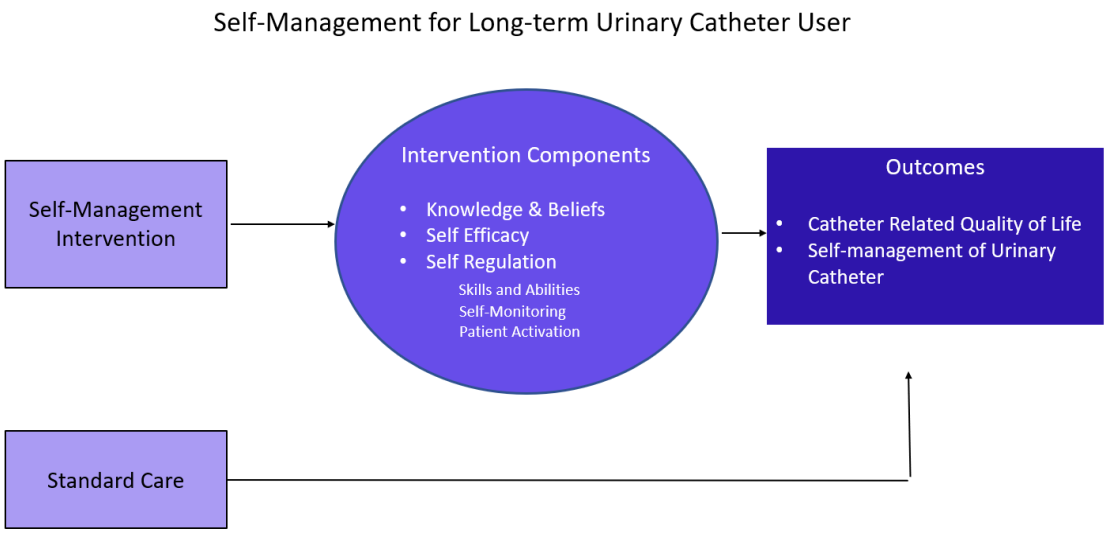
Knowledge gained through education and experiences may improve self-efficacy (Hibbard et al., 2004; Ryan & Sawin, 2009). It may also facilitate self-management skills related to the use of urinary catheters and activities (Kelly et al., 2014; Wilde et al., 2011; Wilde, McDonald, et al., 2013). Research supports the use of knowledge in helping to recognize changes in urine, symptoms of CAUTI's, fluid management, and making adjustments in bladder self-management behaviors (Fowler et al., 2014; Wilde & Brasch, 2008; Wilde et al., 2011; Wilde, Zhang, et al., 2013). **Self-efficacy** focuses on the individual's belief in their abilities to engage in behaviors that lead to improved health outcomes (Bandura, 2012; Ryan & Sawin, 2009). Improving an individual's knowledge, understanding and ability to self-monitor may also contribute to enhanced catheter self-efficacy

Self-regulation is an essential process in achieving health behaviors that are needed for self-management. Self-regulation includes skills such as self-monitoring to guide individuals in their health behavior change (Ryan & Sawin, 2009). **Self-monitoring** helps individuals focus on specific symptoms and evaluate changes needed for better self-management behaviors impacting overall health management (Wilde, McMahon, McDonald, et al., 2015). Through the engagement of condition-specific self-management behaviors, individuals improve health outcomes (Ryan & Sawin, 2009). The self-regulation process also includes planning and action that can be measured by patient activation. **Patient activation** is the process of gaining knowledge, learning skills, and

achieving the confidence that is needed to engage in successful health management (Hibbard et al., 2004), such as daily catheterization for bladder management. Research of catheter users has identified the importance of motivation and active participation in reducing urinary tract infections (Wilde et al., 2011). Given that patient activation has been useful for other populations with chronic disorders such as cardiovascular, diabetes, and pulmonary diseases, similar results may be seen in long-term urinary catheter users (Hibbard, Greene, & Overton, 2013; Mosen et al., 2007; Solomon et al., 2012). The conceptual model for the self-management intervention used in this study and the study outcomes are depicted in Figure 1.

Figure 1

Pilot Study Framework for Self-Management in Urinary Catheter Users



Methods

Design

This pilot study was a two-group, randomized, repeated measure (baseline and 12 weeks) design to measure the impact of a self-management intervention. The independent variable was the self-management intervention, and the outcomes were catheter quality of life and urinary catheter self-management. The intervention in this study was a self-management intervention that focused on knowledge and beliefs, self-efficacy, and self-regulation (skills and abilities, self-monitoring, and patient activation).

Sample/Setting

The target population involved individuals initiating the use of urinary catheterization for adult neurogenic lower urinary tract disorder (ANLUTD) and planning to be discharged to the community from a Midwestern inpatient rehabilitation hospital, which had been certified by the Commission on Accreditation of Rehabilitation Facilities (CARF). Participants were eligible for the study if: able to speak and read English (intervention was in English only); age 19 years or older; were to be discharged from post-acute care; had a medical condition requiring long-term catheterization (>30 days) for bladder management, and had received training on bladder catheterization. Participants were excluded if they had been diagnosed with a terminal illness with a life expectancy of less than six months or a diagnosis of cognitive impairment such as Alzheimer's and dementia.

Self-Management Intervention

The intervention was derived from previous research focused on the use of an SM intervention for urinary catheter users in the community (Wilde, McMahon, et al., 2016; Wilde, McMahon, McDonald, et al., 2015). The intervention included providing additional educational materials and online resources for catheter management, urine flow, types of fluids, the daily fluid volume intake recommendations, and to help answer questions and enhance participants' knowledge. The intervention also included instructions and reviews in the use of a urinary diary

and catheter journal to promote self-monitoring skills based on the previous research of one of the authors (MHW). The urinary diary prompted participants to document their daily fluid intake, urine output, and assessment of their urine (including the color of urine, presence of mucus, blood clots, and sediment). The catheter journal asked participants to document specifics about "what was noticed" and "what was going on or done about it" during the three days. During the initial visit, teaching was done with participants on how to document in both the diary and journal using an example entry. Participants were asked to complete three consecutive days of urinary diary and catheter journal data entry at the beginning of the study (week 1). The study principal investigator (PI) reviewed the initial urinary diary and catheter journal entries with participants, and guidance was given for documenting daily fluid intake and output on the urinary diary and noteworthy information that may pertain to a catheter-related problem. In addition to week one, urinary diaries and catheter journals with instructions were mailed to participants after discharge (week 3), week 7, and at the completion of the study (week 12). Stamped pre-addressed envelopes were included for the return of documents. The PI assessed all returned urinary diaries and catheter journals. The catheter journals were checked for information related to noticeable changes in urine color, odor, intake, and output.

Usual Care

All participants enrolled in this study received the rehabilitation hospital's usual standard of care, including nurse and therapy guided education focused on urinary catheter management and discharge care. SCI participants also received *A Guide to Self-Care for Persons with Spinal Cord Injur*y (Burns & Hammond, 2009). This manual was used to guide rehabilitation education to promote adjustment to life with a spinal cord injury and to be as independent as possible within their ability. It is also a resource for individuals to use after discharge and includes information on bladder management, the use of urinary catheterization, and the prevention of infection. The participants who were enrolled in the control group received the usual care provided by the rehabilitation hospital.

Instruments and Measures

Demographic Questionnaire

The demographic questionnaire included information about person/family characteristics, including age, race/ethnicity, type/presence of caregivers (e.g., family or paid person); clinical variables including chronic conditions, diagnoses, medications, and functional ability; catheter-related issues, including the type of catheter (urethral catheter, suprapubic catheter, intermittent catheter, and condom catheter), initiation of permanent use, interference with daily life, and autonomic dysreflexia. The data were collected through chart review and in-person interviews.

Process Variables

Knowledge Assessment

The Knowledge Assessment used a 12-item assessment of urinary catheter knowledge developed by the principal investigator (PI) from *A Guide to Self-Care for Persons with Spinal Cord Injur*y (Burns & Hammond, 2009) and SM intervention materials. Face validity was established with three expert rehabilitation care providers (physiatrist, a certified rehabilitation nurse, and masters prepared nurse) reviewing questions to evaluate clarity and comprehensiveness. True and false questions were used to assess participants' basic knowledge related to bladder management, and scores ranged from 0 to 12; higher scores (correct responses) indicated greater bladder management knowledge (see Appendix D).

Urinary Catheter Self-Efficacy

Urinary Catheter Self-Efficacy Scale (C-SE) included 15 items designed to assess confidence related to communication with physician/nurse, general catheter management, management of symptoms and problems, and performance of self-management (Wilde, 2016). The C-SE uses a 10-point Likert-type scale with a rating of one as "not at all confident" and ten as "totally confident" (seep Appendix E). A total score was calculated with a higher score indicating higher self-efficacy. Construct validity was believed to be adequate for this measure using confirmatory factor analysis with a CFI of 0.93, TLI 0.94; RMSEA 0.07 (Wilde, 2016). The

Cronbach alpha of .89 has been reported (Wilde, 2016). The calculated Cronbach alpha for this study is .84.

Patient Activation Measure (PAM)

The patient activation measure is a 13-item measurement tool (see Appendix F) that uses a 5-point Likert scale (one equals disagree strongly, and five equals agree strongly) to assess individuals' self-reported knowledge, skill, and confidence for self-management of current health (used with permission) (Hibbard et al., 2004; Hibbard, Mahoney, Stockard, & Tusler, 2005). The PAM scores are categorized into four levels of patient activation ranging from least activated (level 1 PAM) to highly activated (level 4 PAM) (Hibbard et al., 2013; Hibbard et al., 2004). The PAM was used in multiple sclerosis patients (N=199) and established discrimination validity (Stepleman et al., 2010). The reliability of the PAM short-form has been reported as alpha=.87; Cohen's kappa=.80, .90, and .90 (Hibbard et al., 2004; Hibbard et al., 2005). The Cronbach alpha was calculated as .85 for this pilot study.

Outcome Measures

Catheter Quality of Life (QOL)

Quality of life was assessed using two different instruments based on the type of urinary catheter used. Each tool helps to determine how the self-management intervention impacts QOL over time based on the type of catheter used by the individual for long-term bladder management.

The ICIQ-Long Term Catheter Quality of Life (ICIQ-LTCqol) was completed by participants with indwelling catheters (IC). This tool is a 16-item questionnaire using a 0 (never) to 4 (always) scale to assess catheter function and lifestyle factors (see Appendix G). Scores could range from 0 to 64; lower scores reflect better self-rated quality of life. Reliability for this tool is reported for catheter function, and lifestyle factors (Cronbach alpha .76 and.74) (Cotterill et al., 2016). In the current study, the Cronbach alpha scores were .39.

The Intermittent Self-Catheterization Questionnaire (ISC-Q) was completed by study participants using clean intermittent catheterization (CIC). This study used 6-items from the ISC-

Q focused on the psychological well-being domain. These items used a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), where lower scores represent better self-rated quality of life (see Appendix H). Validity and reliability have been reported with convergent validity established by benchmarking it against two valid urinary disorder quality of life measures. High correlations (-0.77 and -0.73) were reported in the psychological well-being domains. Known group validity was established by comparing groups with different levels of hand dexterity ($P \leq 0.001$). The reliability of the questionnaire is reported as alpha .83 (Pinder, 2012). For this study, the reported alpha is .59.

Catheter Self-Management

The Catheter Self-Management Scale (C-SMG) was modified with the collaboration of the original author to a Likert scale (1 equals strongly agree to 5 equals strongly disagree) with questions for both IC (25 items) and CIC (20 items) users (see Appendix I) (Wilde, McMahon, Tang, et al., 2015). Lower scores represented a higher level of urinary catheter self-management, with scores ranging from 20 to 125. This tool focused on catheter activities performed, observations, and recordings that contribute to bladder self-management. Cronbach's alpha scores for the questions (25 items) completed by IC users were .87, and the CIC (20 items) Cronbach alpha score was .84.

Procedure

Following human subjects' Institutional Review Board (IRB) approval, participants were recruited with assistance from nurse managers at the rehabilitation hospital. Each potential participant was screened to determine eligibility based on inclusion and exclusion criteria. After obtaining consent, the participants of this study were randomly assigned, using a statistician-generated schedule, in either the intervention group or the standard care (control) group. Both process variables (knowledge, catheter self-efficacy, and patient activation) and outcome variables (catheter quality of life and urine catheter self-management) were measured for all

participants at baseline (enrollment) and completion of the study (12 weeks). Data were uploaded to the University's REDCap system.

Data Analysis

Descriptive statistics were calculated (means, medians, standard deviations) for continuous variables with counts and percentages calculated for categorical variables. Demographic data were compared between groups to assess for significant differences that may affect study outcomes using chi-square, Fisher exact, and independent t-tests.

Data were collected at two-time points for aims one and two to assess changes from baseline to final visit (12 weeks) measuring knowledge, catheter self-efficacy, patient activation, catheter quality of life, and urinary catheter self-management. The impact of the self-management intervention was determined using t-tests to examine differences between groups on outcome variables (catheter quality of life and urine catheter self-management) and process variables (knowledge, catheter self-efficacy, self-monitoring, and patient activation). Participants that had missing data due to not completing the post-test measurements were excluded from the primary analyses. Subscale and total scores were calculated for a participant if the number of missing items on a scale did not exceed 25%. For the intervention group, only the ability to self-monitor using the urinary diary and catheter journal was evaluated through frequency counts of returned diaries and journals at baseline, 3, 7, and 12 weeks.

Results

Characteristics of the sample

Forty-seven persons were enrolled in the study (control group n=24, intervention group n=23). Four study participants dropped out of the study; one individual no longer needed the use of a urinary catheter, two participants due to time limitations, and one person due to changes in health status. Twenty-one participants were lost to follow-up due to being unable to contact them by phone or mail. Attrition rates were similar between groups. Using telephone interviews, a total

of 26 study participants (control group n=16, intervention group n=10) completed the final survey instruments at 12 weeks.

Baseline characteristics for participants, based on group, are displayed in Table 1 and 2. There were no significant differences between groups in demographic characteristics at baseline; therefore, overall demographic data (N=47) will be presented. Overall, the age for study participants was very diverse, ranging from 19 to 71 years old (Mean=45.4, SD 18.7). The majority (66%) of the participants were male (n=31), Caucasian (n=41), married (n=23), live with family (n=38), had some college education or more (n=26) and employed (n=21). All participants had a medical diagnosis of a neurogenic bladder requiring the use of a urinary catheter for bladder management. The most common medical diagnosis in the sample was spinal cord injury (n=42). From the chart review, neurological impairments include cervical injury (50%), thoracic (45%), and lumbar (5%). Patient-reported level of bladder sensation (ability to feel the need to empty their bladder) ranged from no sensation (46.8%), partial sensation (44.7%), and full sensation (8.5%). The type of catheter used by participants included urethral indwelling catheter (38.3%), suprapubic indwelling catheter (10.6%), and intermittent catheter (51.1%).

Table 1

Baseline Participant Characteristics

	Overall (N=47)			Intervention Group (n=23)			Control Group (n=24)			Test statistic	p-value
Participant Characteristics	Range	M	SD	Range	M	SD	Range	M	SD		
Age	19-71	45.4	18.7	22-71	45.6	18.7	19-70	45.2	18.7	t = .073	.94
	n (%)			n (%)			n (%)				
Gender										χ^2 = .261	.61
Male	31 (66.0)			16 (69.6)			15 (62.5)				
Female	16 (34.0)			7 (30.4)			9 (37.5)				
Race										χ^2 = .197	.66
Caucasian	41 (87.2)			22 (95.7)			19 (79.2)				
Non-Caucasian	6 (12.8)			1 (4.3)			5 (20.8)				
Marital Status										χ^2 = 1.04	.31
Married	23 (48.9)			13 (43.5)			10 (41.7)				
Non-married	24 (51.1)			10 (56.5)			14 (58.3)				
Who lives with participant										χ^2 = .090	.76
Family	38 (80.9)			19 (82.6)			19 (79.2)				
Non-family	9 (19.1)			4 (17.4)			5 (20.8)				
Employment Status										χ^2 = .180	.67
Currently Employed	21 (44.7)			11 (47.8)			10 (41.7)				
Not Currently Employed	26 (55.3)			12 (52.2)			14 (58.3)				
Education Completed										χ^2 = 3.70	.06
High School or Less	21 (44.7)			7 (30.4)			14 (58.3)				
Some College or More	26 (55.3)			16 (69.6)			10 (41.7)				

Table 2

Baseline Participant Clinical Characteristics

Clinical Characteristics	Overall (N=47) n (%)	Intervention Group (n=23) n (%)	Control Group (n=24) n (%)	Test statistic	p-value
Medical Diagnosis				Φ=0.06	1.0
SCI	42 (89.4)	21 (91.30)	21 (87.5)		
Non-SCI	5 (10.6)	2 (8.7)	3 (12.5)		
Neurogenic Bladder	47 (100.0)	23 (100.0)	24 (100.0)	*	*
Non-neurogenic Bladder	0 (0.0)	0 (0.0)	0 (0.0)		
Catheter Type				χ^2 = 1.73	.19
Indwelling (urethral/suprapubic)	23 (48.9)	9 (39.1)	14 (58.3)		
Intermittent (CIC)	24 (51.1)	14 (60.9)	10 (41.7)		
Catheter Assistance				χ^2 = .236	.63
Need Catheter Assistance	29 (61.7)	15 (65.2)	14 (58.3)		
No Catheter Assistance	18 (38.3)	8 (34.8)	10 (41.7)		
Bladder Sensation				χ^2 = 2.62	.11
No Sensation	22 (46.8)	8 (34.8)	14 (58.3)		
Partial/Full Sensation	25 (53.2)	15 (65.2)	10 (41.7)		
Catheter Type				χ^2 = 1.73	.19
Indwelling (urethral/suprapubic)	23 (48.9)	9 (39.1)	14 (58.3)		
Intermittent (CIC)	24 (51.1)	14 (60.9)	10 (41.7)		
Catheter Assistance				χ^2 = .236	.63
Need Catheter Assistance	29 (61.7)	15 (65.2)	14 (58.3)		
No Catheter Assistance	18 (38.3)	8 (34.8)	10 (41.7)		

*Not able to compute due to lack of variation
Abbreviations: SCI = Spinal cord injury; CIC = clean intermittent catheterization

Use of Self-Monitoring Intervention

The return rate for the three-day urinary diaries varied at each of the time points, with only 19% (n=4) returned at three weeks, 24% (n=5) at seven weeks, and 52% (n=11) at 12 weeks. Returned urinary diaries and catheter journals were evaluated for completeness. Of the 23 participants initially enrolled in the treatment group, 21 documented information on the urinary diary and catheter journal at the baseline data collection time point. Diaries and journals were reviewed with participants with feedback and education if incomplete data was entered. Returned journals at all follow-up points had no or very minimal information in them.

Aim 1 Impact of the Self-Management Intervention on Outcome Variables

Table 3 presents the descriptive statistics of outcome variables (catheter quality of life and urinary catheter self-management) at baseline and completion of the study. Study participant scores were similar between groups. In general, scores for both the control and intervention group decreased between baseline and completion of the study.

ICIQ-Long Term Catheter Quality of Life (ICIQ-LTCqol)

This ICIQ-LTCqol tool was completed at the intake and completion of the study by participants with an indwelling urethral catheter. The results were similar between groups indicating a small improvement in quality of life. The mean change score decreased across both groups between baseline and completion of the study with a mean change of -3.97 for both groups, -4.26 for the control group, -3.39 for the intervention group, and a total mean difference of 0.817. Data analysis of the overall change scores showed no significant differences between the two groups, t (12.77) = -0.24, p = .82.

Intermittent Self-Catheterization Quality of Life Questionnaire (ISC-Q)

The ISC-Q tool was completed at intake and completion of the study by participants using intermittent catheterization. The ISC-Q overall mean change score across both groups was -.35; mean change scores were -0.233 for the control group, -0.467 for the intervention group, and

a total mean difference of 0.233. The change scores indicate that both groups had slightly lower mean scores (indicating small improvement in quality of life) at the completion of the study compared to baseline. However, the overall change scores were not significantly different between the two groups, t (8) = 0.90, p = .39.

Catheter self-management scale (C-SMG)

The C-SMG was completed at the intake and completion of the study. The first 16 questions of the measure were completed by all participants regardless of the type of catheter the overall mean change score across groups was -.08, with the mean change scores of -0.02 for the control group, -0.17 for the intervention group, and a total mean difference 0.15 (95% CI= -0.359, 0.67). Data analysis of the overall change scores showed no significant differences between the two groups, t (24) = 0.62, p = .54.

The C-SMG questions for the indwelling catheter users mean change score across both groups was .92, mean change scores of -1.19 for the control group, 4.30 for the intervention group, with a total mean difference of -5.35 (95% CI= -16.53, 5.55). There were no significant differences between the two groups in change scores, t (24) = -1.03, p = .32

The C-SMG questions for the clean intermittent catheter users mean change score across both groups was 2.23, mean change scores of 1.50 for the control group, 3.40 for the intervention group, with a total mean difference of -1.90 (95% CI= -11.97, 8.17). There were no significant differences between the two groups in change scores, t (24) = -.39, p = .70

Table 3

Outcome Variables Baseline and Completion

	Control Group				Intervention Group				Mean Change Score
	Pre (n=16)		Post (n=16)		Pre (n=10)		Post (n=10)		Overall (n=26)
Outcome Variables	M	SD	M	SD	M	SD	M	SD	M
ICIQ-LTCqol	66.83	8.52	62.05	11.31	75.94	4.01	68.29	6.19	-3.97
ISC-Q	2.47	.65	2.07	.56	2.53	.40	2.07	.73	-.35
C-SMG for CIC users	50.17	9.91	45.83	14.47	49.80	15.06	47.80	9.37	.92
C-SMG for IC users	59.10	13.49	60.60	12.92	61.80	9.91	55.60	7.96	2.23

Abbreviations: ICIQ-LTCqol = ICIQ-Long Term Catheter Quality of Life, ISC-Q = Intermittent Self-Catheterization Questionnaire, IC = Indwelling Catheter CIC = Clean Intermittent Catheter, C-SMG = Catheter Self-Management Scale

Aim 2 Impact of the Self-Management Intervention on Process Variables

Table 4 presents the descriptive statistics of process variables (knowledge, self-efficacy, and patient activation) at baseline and completion of the study. The scores for study participants were similar between groups. The results indicate that the self-management intervention did not influence the process variables.

Knowledge Assessment

The knowledge assessment was completed at intake and completion of the study, with scores ranging from eight to nine on a ten-point scale in both groups (See Table 4). The mean change score across both groups was -.50, with changes in mean scores of -0.31 for the control group -0.80 for the intervention group, with a total mean difference of 0.45. The reported scores were slightly lower on the knowledge assessment at the completion of the study compared to baseline scores with no significant differences in the overall change scores between the two groups, t (11.05) = 0.780, p = .45.

Urinary catheter self-efficacy scale (C-SE)

The C-SE was completed at intake and completion of the study, resulting in increased mean scores for both groups. Participants in both groups reported a slight overall increase in urinary catheter self-efficacy from the time they left the rehabilitation hospital to approximately 12 weeks later. The change score across groups was 0.56, mean change scores of .82 for the control group, 0.15 for the intervention group, with a total mean difference of 0.673 (95% CI= -0.45, 1.80). There were no significant differences between the two groups in change scores, t (24) = 1.24, p = .23. Specific items related to fluid intake self-efficacy (three items) were examined for differences between groups. No trends were noted between groups on specific questions related to fluid intake self-efficacy.

Self-Monitoring

The intervention group return rate for the three-day urinary diaries varied at each of the time points, with only 19% (n=4) returned at three weeks, 24% (n=5) at seven weeks, and 52% (n=11) at 12 weeks. Returned urinary diaries and catheter journals were evaluated for completeness. Of the 23 participants initially enrolled in the treatment group, 21 documented information on the urinary diary and catheter journal at the baseline data collection time point. However, adherence to diaries and journals dissipated over the 12 weeks. Despite, feedback, and education at baseline during the diary review, minimal information was entered on the returned journals at follow-up points.

Patient Activation Measure (PAM)

The PAM was completed at intake, and completion of the study with a mean change score of 6.78 for the control group, 1.84 for the intervention group, and a total mean difference of 4.91. Patient activation scores improved slightly at the completion of the study compared to baseline. Data analysis of the overall change scores showed no significant differences, p=0.38, between the two groups.

Table 4

Process Variables Baseline and Completion

	Control Group				Intervention Group				Mean Change Score
	Pre (n=16)		Post (n=16)		Pre (n=10)		Post (n=10)		Overall (n=26)
Process Variables	M	SD	M	SD	M	SD	M	SD	M
Knowledge Assessment	8.50	1.37	8.19	1.38	9.00	1.25	8.20	1.32	-.50
Urinary Catheter Self-Efficacy Scale	7.89	1.40	8.72	.93	8.65	1.12	8.80	.81	.56
Patient Activation	2.63	.89	3.13	.72	2.80	.79	2.90	.74	6.78

Discussion

This study was designed to pilot test implementing a self-management intervention on catheter quality of life and urine catheter self-management for long-term urinary catheter users discharging from inpatient rehabilitation to the community.

Ryan and Sawin (2009) postulate that to have effective self-management, individuals must engage in healthy behaviors, using learned skills to manage chronic conditions and risk factors. Self-monitoring specific to urinary catheter users focuses on preventing complications such as CAUTI and for indwelling catheters blockages. This task includes the ability to become self-aware; notice and utilize knowledge of signs and symptoms of problems, recordings, and observations (e.g., the color of urine) to interpret changes; and adjust care as needed (McBain et al., 2015; Wilde & Garvin, 2007). At discharge from the rehabilitation hospital, 91.3 % of the subjects in this study completed components of the urinary diary and catheter journal, thus demonstrating an overall awareness of how to monitor fluid intake, types of fluid, urine output, and adjusting behaviors based on urine flow. The self-monitoring mechanism (urinary diary and catheter journal) completion rates were lower for weeks three and seven compared to baseline and 12 weeks. These time points occurred when participants were adjusting and adapting to their new living situations. Several participants reported they had moved at least twice since discharge and had to adjust the urinary catheterization technique to fit the current living situation. Others reported rehospitalization due to various medical reasons causing an interruption in their bladder management routine. Future studies need to consider extra support and easier documentation methods to enhance self-monitoring during this time.

Research has shown the importance of evaluating self-efficacy in individuals with chronic conditions (Bandura, 2012; Ryan & Sawin, 2009). A one-year interventional RCT (N = 202) focused on self-monitoring in long-term urinary catheter users. In a subsample of this study (N=180), a model was tested showing a positive association between self-efficacy and fluid intake (b=0.37, p=0.009) and an indirect effect on decreasing catheter blockage rates (Wilde,

Crean, et al., 2016). Fluid intake self-management was also found to be a mediator between fluid intake self-efficacy and the occurrences of catheter blockage. These findings support a positive relationship between urinary catheter self-efficacy and catheter self-management. However, in the current study, no statistically significant differences were found between groups on catheter self-efficacy. More education (as in the above large RCT which included three intervention home visits and a phone call in the first three months) (Wilde, McMahon, et al. 2015) may be needed to review how fluid intake can impact urine flow and urinary output; and the awareness of both details to prevent complications and promote better self-management. Follow-up education with a health care professional may have strengthened urinary catheter self-efficacy and thus improved catheter self-management.

Another consideration for better self-management is understanding the individual's support system. Social support (family members or caregivers) were not enrolled in this study. However, 62% of the participants identified in the demographic questionnaire that they would need assistance with their catheter management after discharge and identified that their primary support includes family members such as spouses, parents, children, and other relatives. Qualitative research has helped researchers identify that social support is very individualized. Examples of the support include healthcare providers, family, friends and others who shared similar healthcare needs (Chuang, Yang, & Kuo, 2015; Hirsche, Williams, Jones, & Manns, 2011; Munce, Webster, et al., 2014; Ploughman et al., 2012). Caregiver support may be an influential variable to consider for future self-management implementation studies.

A major limitation of this study was the small sample size and the intervention length of time. To be able to assess behavior change and pre-post analysis of effect, a larger study sample is needed and at least six months after the intervention is delivered to detect a significant effect on self-management improvements from baseline to follow-up after the intervention. Our sample was comprised of one rehabilitation hospital in the Midwest, resulting in a mostly Caucasian population. Recruitment for future studies would benefit from using multiple sites to increase

diversity and sample size. It is also important for future studies to implement strategies to help promote study retention. Some strategies to consider would be increased contact or follow-up with participants after discharge and identifying a caregiver or support person to aid in the use of a self-monitoring intervention. Qualitative research or open-ended questionnaires also may help to identify educational needs and barriers for individuals after discharge.

Conclusion

Healthcare today continues to focus on the importance of prevention and developing strategies to promote health. For many individuals, the transition from rehabilitation programs to home requires support and adjustments. In this study, there was limited success in the implementation of the self-monitoring intervention in the 12-week after discharge from the rehabilitation hospital. Self-management interventions implemented over a more extended time may enhance individuals' knowledge through education, catheter self-efficacy, and the ability to self-monitor may help reduce risks of chronic complications. This study begins to address the gap related to identifying self-management needs in this population. This information will help guide both health care providers and individuals living with adult neurogenic lower urinary tract disorders in the community to identify strategies for better long-term bladder management.

CHAPTER IV: Manuscript 3

Spinal Cord Injury Use of Healthcare and Catheter Associated Urinary Tract Infection After Discharge from Rehabilitation Center

Introduction

In the United States, urinary tract infection results in an estimated 10.5 million outpatient care visits, including 1 million emergency department visits and over 100,000 hospitalizations with an associated annual cost of 1.6 billion (Foxman, 2003; Schappert & Rechtsteiner, 2011). The long-term use of urinary catheterization (>30 days) continues to cause chronic health complications, including catheter-associated urinary tract infections (CAUTI). Urinary catheterization is commonly used for people who have adult neurogenic lower urinary tract disorder (ANLUTD) (Gajewski et al., 2018; Kinnear et al., 2019). Medical diagnoses that can impact bladder function and result in ANLUTD include spinal cord injury (SCI), multiple sclerosis (MS), Parkinson's, strokes, and diabetes (Kinnear et al., 2019). In these patients, common lower urinary tract symptoms and signs (LUTS) experienced are urine storage symptoms (urinary retention, increased urinary frequency, nocturia, urgency, and urinary incontinence), changes in bladder sensation, voiding symptoms, and post micturition symptoms (incomplete emptying and dribbling) (Gajewski et al., 2018).

Many people with SCI will develop a bladder management program in the rehabilitation hospital before discharge. The two common methods for bladder management are clean intermittent catheterization (CIC) and indwelling catheterization (IC). Despite improvements to bladder management techniques, prevention of catheter-associated urinary tract infections (CAUTI) continues to be problematic. Research has found that individuals with an SCI are 2.6 times more likely to be re-hospitalized and spend 3.3 more days in the hospital related to CAUTI compared to those without an SCI (DeJong et al., 2013). DeJong et al. (2013) report that 36.2% of people with SCI had been re-hospitalized at least once, and 12.5% had been hospitalized at least two times within the first year of injury. The average length of stay for rehospitalization was reported at 15.5 days (DeJong et al., 2013). Research has focused considerable efforts in reducing hospital rates of catheter-associated urinary tract infections (CAUTIs); however, there is limited research focused on the outpatient setting.

Catheter-associated urinary tract infections are often managed using outpatient services, and treatment is done at home. Unfortunately, due to the increased prevalence of antimicrobial resistance, outpatient treatment has become more challenging and has increased the number of hospitalizations for CAUTIs (Simmering et al., 2017). Long-term urinary catheter users typically show the chronic presence of bacteria in their urine; therefore, CAUTI diagnosis often is confirmed by screening for signs and symptoms (Lamin & Newman, 2016a; Nicolle et al., 2005). Frequent urinary tract infection signs and symptoms in this group may include incontinence, spasticity, fatigue, changes in urine quality or odor, discomfort, and autonomic dysreflexia (Hooton et al., 2010; Massa et al., 2009; Vigil & Hickling, 2016). Untreated urinary tract infections with poor bladder management can have serious complications that may lead to renal failure and sepsis (Manack et al., 2011; Pannek et al., 2013).

Purpose

Little is known about the use of healthcare resources related to spinal cord injury and CAUTI within the first year after discharge from a rehabilitation hospital. In this study, healthcare resources were identified as unplanned physician visits, visits to the emergency department, and hospitalization. The purpose of this study was to describe the use of healthcare by long-term urinary catheter users with spinal cord injury recently discharged from a rehabilitation center. The specific aim of this study was to examine data at 12 weeks after discharge to identify the use of healthcare resources (unplanned physician visits, visits to the emergency department, hospitalization), describe catheter-related problems (urinary tract infection) and examine differences by the type of catheter used (indwelling catheter and clean intermittent catheter).

Method

Design/Sample

This analysis was based on a randomized two-group repeated measure (baseline and 12 weeks) design to determine the effectiveness of a self-management intervention (Krabbenhoft, Schulz, Wilde, Zimmerman, & Kupzyk, 2020). The pilot study involved a self-management

intervention that included education and self-monitoring tools designed to improve bladder management. The comparison group received standard care only (Krabbenhoft et al., 2020).

The study sample included 47 participants randomly assigned to the intervention or control group (control group n=24, intervention group n=23) using long-term (>30 days) urinary catheterization (indwelling catheter or clean intermittent catheter) for bladder management after discharging from a post-acute care rehabilitation hospital to home within the community. The intervention promoted individual self-monitoring using a urinary diary and catheter journal. Individuals in the intervention group were asked to complete a three-day urinary diary and catheter journal at baseline, 3, 7, and 12 weeks. They returned the data to the principal investigator (PI) using a stamped, pre-addressed envelope.

The analysis of the pilot study found that there were no significant differences between control and intervention groups related to demographic characteristics and outcomes measured at baseline and 12 weeks (Krabbenhoft et al., 2020). This study describes the use of healthcare resources for the 26 participants who completed the follow-up questionnaire at the end of the study.

Procedure

Recruitment for this study was done at a Midwest rehabilitation hospital with assistance from the hospital's nurse managers after obtaining approval from the Institutional Review Board (IRB). Screening using inclusion and exclusion criteria was done to determine if individuals were eligible for the study by the PI. The inclusion criteria were: (1) English speaking; (2) age 19 years or older; (3) within three weeks of discharge from post-acute care; (4) diagnosed with a medical condition requiring long-term catheterization for bladder management; (5) trained during hospitalization on bladder catheterization; (6) able to access a device with an internet connection. Exclusion criteria were chosen to assure study participants would be able to participate in the three-day urinary diary data collection. Exclusion criteria were: (1) diagnosed with a terminal illness with a life expectancy of less than six months or (2) have a diagnosis of cognitive

impairment such as dementia. Participants were randomly assigned to the intervention and control group by the PI using a statistician generated schedule after obtaining consent to participate in the study. Demographic data were obtained at intake. The healthcare resource use and catheter-related complications information was obtained through a telephone interview at the completion of the intervention study. The PI conducted the telephone interviews using the follow-up questionnaire with study participants (n=26) 12 weeks after discharge.

Measures

Demographic Questionnaire

The demographic questionnaire for this study was collected using chart review and in-person interviews. Information about personal characteristics obtained includes age, race/ethnicity, education, marital status, employment status, and who lives with them at home. Clinical information was also collected, including medical diagnosis, bladder sensation, type of urinary catheter being used (e.g., urethral catheter, suprapubic catheter, and clean intermittent catheter), and if assistance was needed with their urinary catheter use.

Follow-up Questionnaire

The follow-up questionnaire was comprised of eight questions developed by the PI. It included questions for participants to self-report their use of healthcare resources, including the reason for a visit to the healthcare provider, and if they have had a urinary tract infection since discharging from rehabilitation. Participants were asked yes and no questions for all five questions related to the use of healthcare resources. If they answered yes, they were asked to quantify how many times the healthcare resource was used and the reason for the visit. There were three questions related to urinary tract infections. Participants were asked if they had been diagnosed with a urinary tract infection since discharge. If participants answered yes, they were then asked how many, if they prescribed an antibiotic and the name of the antibiotic prescribed.

Data analysis

The aims of the study were tested using descriptive statistics for continuous variables (means, medians, standard deviations), and counts and percentages were calculated for all categorical variables. Frequency counts for the self-reported use of healthcare resources were calculated and compared by catheter type (indwelling and clean intermittent catheter) to determine if there were significant differences using chi-square analysis.

Results

Characteristics of the sample

Twenty-six people completed the three-month follow-up questionnaire. Data for this analysis are presented for the total subjects completing the study. The study participants' age ranged from 19-71 (mean= 44.2) years old, and all had a medical diagnosis of spinal cord injury with neurogenic bladder. Approximately 69% of the participants were male (n=18) and primarily Caucasian (n=22). Education ranged from some high school/high school (n=15) to some college education (n=11). All participants used urinary catheterization for bladder management, including indwelling urethral catheter (n=11), a suprapubic catheter (n=3), and a clean intermittent catheter (n=12). Fifty-four percent (n=14) identified that they needed assistance to manage urinary catheterization. Participants needing assistance identified that they received assistance from one or a combination of caregivers including spouse/partner (n=5, 36%), family (n=7, 50%), friend (n=1, 7%), and paid caregiver (n=9, 64%).

Use of Healthcare Resources and Urinary Tract Infections

Table 1 presents the descriptive statistics of the use of healthcare resources (unplanned physician visits, visits to the emergency department, hospitalization) and catheter-related problems (urinary tract infection) by participants 12 weeks after discharge from the rehabilitation center. There were no significant differences by group on the use of healthcare resources or catheter-related problems. At 12 weeks after discharge, 92% (n=24) of the participants reported seeing a healthcare provider after discharge, and 35% (n=9) were seen by more than one provider.

Fourteen participants reported primary care physicians' visits. Participants (n=18) reported specialty physician visits such as urologist, neurosurgeon, and wound care. Fifteen participants reported unplanned physician visits, and 60% of those visits were related to bladder management (urine flow and catheter-related problems). Other reasons for physician visits were for new wounds (n=2), seizure (n=1), injury (n=1), pain management (n=1), and other medical care needs (n=2). Emergency department (ED) visits were reported by 54% of the participants (n=14), and 57% of those visits were related to urine flow and catheter problems. Seven participants reported rehospitalization after discharge, and one was related to urine flow/catheter problems. Other self-reported reasons for rehospitalization included wound management (n=2), complications associated with autonomic dysreflexia (n=1), and other medical care needs (n=3).

Urinary tract infections were reported by more than half of the participants (n=15). Self-reported urinary tract infections ranged from 1 (n=5) to 5 (n=2) infections since discharge, and 1 participant reported having ten infections.

Statistics describing the use of healthcare resources (unplanned physician visits, visits to the emergency department, hospitalizations) and catheter-related problems (urinary tract infection) by type of urinary catheter used are described in Table 2. Follow-up data showed that indwelling catheter users had a higher frequency of self- reported use of healthcare resources and catheter-related problems compared to clean intermittent catheter users. Indwelling catheter users had more unplanned physician visits (n=10) and ED visits (n=11) at the 12-week follow-up. Indwelling catheter users also had a higher occurrence of self-reported rehospitalization (n=5) after discharge compared to clean intermittent catheter users (n=2). The prevalence of self-reported urinary tract infections differed significantly by type (indwelling or clean intermittent) of bladder management method used. Eleven participants (79%) with an indwelling catheter reported having a urinary tract infection, while four subjects (33%) using clean intermittent catheter reported having a urinary tract infection.

Table 1

Urinary Tract Infections (UTI) and Use of Healthcare Resources

UTI and Use of Healthcare Resources	Participants (n=26)	
	f (%)	range
Urinary Tract Infection	15(58)	1-10
Unplanned Physician Visit	15(58)	1-3
Visit Related to Urine Flow/CAUTI	9(35)	
Emergency Department Visit	14 (54)	1-4
Visit Related to Urine Flow/CAUTI	9 (35)	
Hospitalized	7 (27)	1-3
Hospitalized Related to Urine Flow/CAUTI	1 (4)	

Table 2

Urinary Tract Infections (UTI) and Use of Healthcare Resources by Type of Urinary Catheter Used

Use of Healthcare Resources and UTI	Indwelling Catheter (n=15)		Clean Intermittent Catheter (n=11)		Test Statistic	p-value
	f (%)	range	f (%)	range		
Urinary Tract Infection (UTI)	12(80)	1-5	3 (27)	2-10	$\chi^2 = 7.23$**	.007
Unplanned Physician Visit	10 (67)	1-3	5 (46)	1-3	$\chi^2 = 3.33$	.07
Visit Related to Urine Flow/CAUTI	7 (47)		2 (18)			
Emergency Department Visit	11 (73)	1-4	3 (27)	1-3	$\chi^2 = 5.42$*	.02
Visit Related to Urine Flow/CAUTI	7 (47)		2 (18)			
Hospitalized	5 (33)	1-3	2 (18)	1	$\chi^2 = 0.74$	.39
Hospitalization Related to Urine Flow/CAUTI	1 (7)		0 (0)			

*p < .05. **p < .01.

Discussion

This study describes recently discharged SCI participant's self-reported use of healthcare resources and catheter-related problems. Participants in this study were primarily male (69%); this is comparable to research showing that males are more likely than females to have a diagnosis of SCI (National Spinal Cord Injury Statistical Center, 2018). After discharge, routine follow-up care with a primary care provider is expected for daily care needs and medication management. However, in this study, 58% of the participants had unplanned physician visits, including emergency department visits. More than half (54%) reported visiting the emergency department at least one time since discharge from rehabilitation. This finding is consistent with Skelton, Hoffman, Reyes, and Burns (2015), who reported that 57% of people with spinal cord injuries visited the ED in the first year. The most common reasons for ED visits were related to genitourinary and musculoskeletal conditions. Their research also found that urinary tract infections were the most common cause of rehospitalization within the first year (Skelton et al., 2015). Although the time frame in our study was only three months after discharge, one subject self-reported being re-hospitalized related to urinary problems.

In this study, participants using an indwelling catheter had a higher self-reported rate of use of healthcare resources and urinary tract infections compared to clean intermittent catheterization. Research continues to investigate bladder management methods to determine the best method for the prevention of catheter complications and CAUTI. The prevalence of catheter-associated urinary tract infections for community-dwelling individuals using an indwelling catheter has been reported as 4.49 per 1000 catheter days (Wilde et al., 2017). Wilde et al. (2017)found that within a year, 57% of the participants reported at least one occurrence of CAUTI. For this study, the range of reported CAUTI for indwelling catheter users was 1-5 events per person and a total of 12 events within 12 weeks for 15 participants. Current evidence has established that the use of clean intermittent catheterization reduces the frequency of urinary tract infections (Esclarin De Ruz, Garcia Leoni, & Herruzo Cabrera, 2000). Comparing IC and CIC,

Esclarin De Ruz et al. (2000) reported the prevalence of UTI for the CIC technique at .41 episodes per 100 persons-days while IC prevalence was much higher at 2.72 episodes per 100 persons-days. These findings suggest that there is a difference between the type of catheter used and UTI occurrences. The prevalence of CAUTI continues to a complication experienced by all urinary catheter users underscoring the assertion that adherence to bladder management strategies remains a challenge requiring skills, knowledge, and awareness of the condition.

The use of self-management strategies in chronic disease management has been shown to be effective (Lorig et al., 2006). Self-management for long-term urinary catheter users would include strategies to improve awareness through self-monitoring (fluid intake and output), knowledge (about complications and optimal ways to perform catheterization), skills, and the ability to perform catheter-related tasks with the necessary supplies. In this study, all participants received written educational materials identifying methods of bladder management and signs and symptoms of catheter-associated urinary tract infections. In addition, individuals in the intervention group received self-monitoring diaries and catheter journals to facilitate bladder management, with no apparent benefit from the parameters examined.

Limitations of this study include the small sample size and self-reported data. The small convenience sample was comprised of one rehabilitation hospital in the Midwest with a primarily Caucasian population. The study did have a high attrition rate from baseline to completion of the study, mainly due to difficulty in contacting subjects. No probing or suggestions were made during the follow-up interview, which may have resulted in additional information. The timing of the follow-up interviews and the short-term nature of the intervention also limited the results.

Future research to better assess the relationship between the type of urinary catheter used and self-reported use of healthcare resources and CAUTI incidence should be conducted using a larger sample size. Research studies would benefit from incorporating multiple sites or a more substantial city to increase diversity and sample size. Using validated health care utilization data or medical records would reduce bias from self-report. Qualitative research using focus groups

may be beneficial in helping to identify difficulties related to bladder management and transitioning to home.

Conclusion

As we continue to identify interventions to improve spinal cord injury bladder self-management, one approach could be to help patients understand the importance of learning these skills and include them in all aspects of decision making. When individuals have a better sense of understanding, they may take more ownership of their health. Understanding and involvement may also help increase the likelihood of improved self-management behaviors lasting for more extended periods. Improved self-management is a long-term goal that must be individualized and personalized by the patient. An individualized intervention gives a sense of control to the patient, minimizes the level of burden, allows flexibility, and possibly improves participation in the implementation of an intervention (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Karlson & Rapoff, 2009). Continued research is needed to identify interventions that help individuals improve self-management behaviors related to long-term urinary catheterization. Research focusing on health promotion and prevention strategies may identify crucial variables to guide nurses and healthcare professionals as they assist patients in effective bladder management.

CHAPTER V: DISCUSSION

Summary

The research presented in this dissertation adds to the literature on self-management in long-term urinary catheter users. Specifically, this study provides evidence of the need for continued research on identifying specific self-management needs related to daily use of urinary catheterization and the role of the caregiver. The theoretical framework used throughout the dissertation work was adapted from the Individual Family Self-Management Theory (IFSMT) using the concepts knowledge and beliefs, self-efficacy, self-regulation (self-monitoring and patient activation), and quality of life (Ryan & Sawin, 2009). The intervention tested in this study was adapted from research that implemented self-management and self-monitoring in an established community setting (Wilde, McMahon, et al., 2016) compared to this study with patients being discharged from a rehabilitation hospital to the community. The self-management intervention for this study included self-monitoring using a urinary diary and catheter journal to promote awareness of fluid intake and output similar to the intervention provided in the Wilde, McMahon, et al. (2016) study. The intervention also provided education and resources focused on bladder management methods, fluid intake, fluid output, symptoms, and signs of complications related to urinary catheter use.

Chapter II examined the feasibility of recruiting individuals in the rehabilitation setting and their acceptance of a three-day self-monitoring intervention. Subjects (n=6) were recruited from a rehabilitation center and asked to use both an on-line and paper self-monitoring intervention (urinary diary and catheter journal). The intervention prompted participants to document information about their daily fluid intake and urine output. If participants identified changes in fluid intake or output, they could record this in the urinary diary and catheter journal.

The results of this study showed that there was a higher three-day completion rate (n=6) using the paper format of the intervention compared to the on-line format (n=1). Feasibility data showed that urinary catheter users could be recruited, found the intervention useful, and that

participants were willing to use the paper format of the intervention for three-days. Using the urinary diary and catheter journal, participants reported an increased level of awareness. This information was used to guide the intervention method (urinary diary and catheter journal in paper format) and the consent process for the intervention study.

Chapter III presented the findings from a randomized, two-group repeated measure design using a self-management intervention (education, urinary diary, and catheter journal) focused on long-term urinary catheter users. The self-management intervention used in this study was derived from research focused on long-term urinary catheter users who have established living within the community (Wilde, McMahon, et al., 2016; Wilde, McMahon, McDonald, et al., 2015). Participants for this study were recruited from a rehabilitation center that prepares patients to discharge home within the community.

All participants in the study received the rehabilitation center usual standard of care that includes bladder management education, discharge planning, and education. In addition, the intervention group received the self-management intervention and were asked to complete a urinary diary and catheter journal data entry at the beginning of the study (week 1), after discharge (week 4), week 7, and at the completion of the study (week 12). Measurements of knowledge related to bladder management, urinary catheter self-efficacy, catheter quality of life, and catheter self-management measures were done at baseline and 12 weeks. There were no significant intervention effects, with data from both groups showing only small changes in their measurement scores. The intervention and control group change scores improved with slight differences in urinary catheter self-efficacy and self-management. However, scores for the fluid intake self-management items in the intervention group decreased at 12 weeks. These results may have been related to the lack of use of the urinary diary and catheter journal at weeks three and seven. Upon reflection, participants may have recognized their lack of self-monitoring (completion rate for week three, 19%, and week seven 24%). This awareness may have impacted how the participants rated themselves on the items related to fluid intake.

The sample size and study length of time were limitations for this study. More time is needed to implement self-management strategies, and individuals need time to adjust to living at home within the community. Recruitment from multiple sites would increase the sample size and diversity. A larger study sample is required to assess behavior change and pre-post analysis. Many of the participants in the study identified that caregivers have an active role in their bladder management. Increased contact or follow-up with study participants and caregivers may aid in follow up interventions or evaluations after discharge from rehabilitation centers.

Chapter IV described findings from the pilot study focusing on self-reported use of healthcare resources catheter problems. The study sample was derived from the pilot study reported in Chapter III. All participants (n=26) in this descriptive study had a medical diagnosis of a spinal cord injury and used an indwelling catheter (urethral or suprapubic catheter) or a clean intermittent catheter. The study found that 92% of participants self-reported seeing a healthcare provider after discharge from the rehabilitation center, and 58% reported having unplanned physician visits. Many of the participants (n=14, 54%) reported visiting the emergency department, and more than half (n=8) of those visits were related to urine flow and catheter problems. Participants requiring assistance (n=14) with bladder management also had a higher reported number of CAUTI (n=11) and unplanned visits to physicians (n=9). There was no significant association between the type of urinary catheter used or needing assistance and healthcare utilization and CAUTI.

Practice and Research Implications

This study has implications for healthcare providers and researchers interested in improving an individual's ability to self-manage using long-term urinary catheterization. Healthcare changes have resulted in shortened hospital lengths of stays causing many individuals to continue to learn and adapt to urinary catheterization at home. Research has found that many individuals feel unprepared or have insufficient training needed to effectively implement urinary catheterization (Munce, Fehlings, et al., 2014; Wilde et al., 2011). It is vital to continue to provide

individualized support and education to help promote self-management strategies, thereby reducing chronic complications. There is limited research to guide effective implementation of self-management strategies. However, intervention research has found that including healthy behaviors such as self-monitoring of fluid intake and output may help to reduce urinary catheter complications (Elstad et al., 2011; Wilde, McMahon, et al., 2016).

Nursing research in this area is unique due to the perspective and focus on the whole person and the ability to individualize self-management interventions. Nurses have an essential role in helping individuals develop bladder self-management strategies. In rehabilitation settings, the nurse is often considered the expert in bladder management and implementing self-monitoring skills. Nurses' knowledge and experience help patients develop skills, comfort, and confidence in adapting urinary catheterization to their lives (Cave, 2016; Logan et al., 2008). Nurses are crucial to assessing individual needs and providing education and support to help long term catheter users achieve self-monitoring into their daily routine.

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APPENDIX A

University of Nebraska Medical Center

NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

July 3, 2019

Lisa Krabbenhoft, MSN
UNMC

IRB # 481-17-EP

TITLE OF PROPOSAL: Self-Management Intervention for Urinary Catheter Users

DATE OF EXPEDITED REVIEW: 07/03/2019

VALID UNTIL: 07/03/2020

EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110; 21 CFR 56.110, Category 5,7

The UNMC IRB has completed its review of the Application for Continuing Review for the above titled research project including the complete protocol file and has expressed it as their opinion that you have provided adequate safeguards for the rights and welfare of the subjects involved in this study and are in compliance with HHS regulations (45 CFR 46) and FDA regulations (21 CFR 50.56) as applicable.

This letter constitutes official notification of the re-approval of your research project (Application V.3, Adult CF V.3 & Adult CF V.1 Web) by the IRB for the IRB approval period indicated above. You are therefore authorized to continue this study. **All copies of the outdated consent forms must be discarded immediately.** The original IRB stamped forms may be archived.

We wish to remind you that, under the provisions of the Federal Wide Assurance (FWA 00002939) from the Institution to HHS, the Principal Investigator is directly responsible for keeping the IRB informed of any proposed changes involved in the procedures or methodology in the protocol and for promptly reporting to the Board any unanticipated problems involving risks to the subjects or others.

In accordance with HRPP policies, this project is subject to periodic review and monitoring by the IRB and, as part of their monitoring, the IRB may request periodic reports of progress and results. For projects which continue, it is also the responsibility of the Principal Investigator to initiate a request to the IRB for Continuing Review of the research project in consideration of the IRB approval period.

On Behalf of the IRB,

Signed on: 2019-07-03 15:01:00.000

Academic and Research Services Building 3000 / 987830 Nebraska Medical Center / Omaha, NE 68198-7830
402-559-6463 / FAX: 402-559-3300 / Email: irbora@unmc.edu / http://www.unmc.edu/irb

University of Nebraska Medical Center
NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

Bobbi Chapman, MS
IRB Administrator/Continuing Review Coordinator
Office of Regulatory Affairs

APPENDIX B

MADONNA
RESEARCH INSTITUTE
Rehabilitation Science and Engineering

July 18, 2018

Lisa Krabbenhoft, MSN

Dear Ms. Krabbenhoft,

This letter is to inform you the annual project report for the study titled: ***Web-Based Self-Management Intervention for Urinary Catheter Users (17-006-FB)*** has been approved through the Expedited Review by the IRB Chairperson.

Your Continuing Review for the above project was received with the Project Status: Active (continues to enroll new subjects.

Should you find it necessary or desirable to alter the proposal, please submit this information to the Review Board for approval before initiating changes in your research protocol.

Please note the Research Review Board will request a written continuing review prior to July 17, 2019.

Sincerely,

Rachel Wenzl, CIP
Interim IRB Chairperson
Madonna Rehabilitation Hospital
rwenzl@madonna.org
402-472-8196

APPENDIX C

Baseline Demographics Questionnaire

Study ID#: /__/__/__/

Intake Date: *(entered for all but intake interview):* /__/__/ / /__/__/ / /__/__/__/__/

Date of Interview: / / / / / / / / / / / /

Gender:

Male---------- 1
Female---------- 2

Interviewer Name: _____

DM 1. *Date of birth?*

/__/__/ / /__/__/ / /__/__/__/__/

DM 2. Racial/ethnic background is:

American Indian or Alaska Native ----------	1
Native Hawaiian, or Other Pacific Islander ----------	2
Black or African American ----------	3
Asian----------	*4*
White ----------	*5*
Hispanic or Latino----------	*6*
Other (Specify:_____)--	*7*

DM 3. Marital status?

Legally Married ----------	1
Common-Law or living together as married----------	2
Partner----------	*3*
Separated ----------	4
Divorced ----------	5
Widowed ----------	6
Never Married ----------	7

DM 4. Who lives with patient? {Check all that apply. Do not read, just circle all that apply from subject's responses. Spouse = legally married}

Spouse (husband or wife)----------	1

Boyfriend/Girlfriend/partner ---------- 2
Mother ---------- 3
Father ---------- 4
Children ---------- 5
Other family member, such as in-laws, step parents, niece or nephew- 6
Friends or other non-relatives ---------- 7
Paid caregiver ---------- 8
Other: Specify_____-------- 9

DM 5. What is the highest grade or level of education completed?

8th grade or less ---------- 1
Some high school but did not graduate---------- 2
High school diploma or GED ---------- 3
Some college (not having completed a degree program) ---------- 4
College (Associate degree) ---------- 5
College (Bachelor degree) ---------- 6
Graduate degree (Masters or higher) ---------- 7

DM 6. Currently employed?

No ---------- 0 **[Go to DM 10]**
Yes ---------- 1

DM 7. Do you work full or part time? (Full time is >35 hrs./week.)

Full time ---------- 1
Part time ---------- 2

DM 8. What kind of health insurance do you have? {**Check all that apply** ***If you are unsure what to check – check other and write name of insurance}***

Medicare ---------- 1
Medicaid ---------- 2
VA ---------- 3
Private insurance - which is insurance through your employer or insurance that you pay for out of pocket---------- 4
Workman's Comp---------- *5*
Other (specify)_____ -------- *6*
No health insurance---------- *7*

DM 9. What type of housing do you live in?

Single family house or duplex---------- 1
Apartment ---------- 2

Multifamily house, condo or co-op---------- 3
Rented room or boarding house---------- 4
Group home or assisted living---------- 5
Senior housing---------- 6
Residence for people with a disability ------- 7
Other (Specify: _____)-- *8*

DM 10. Who will help with catheter care after discharge? **{Check all that apply.}**

No one helps me---------- 1
Spouse/partner ---------- 2
Other family member ---------- 3
Friend ---------- 4
Paid aide or caregiver – paid whether by insurance or from your own pocket---------- 5
Other {specify:_____)---- 6

SECTION MED-HX

MED HX 1. Spinal cord injury? Yes No

MED HX 2. ASIA score: _____

MED HX 3. FIM score: _____

MED HX4. What is the level of your injury?
Level of spinal cord injury (Enter C1, T2 etc): |__ |__ |__|

MED HX5. Diagnosis of:

Multiple Sclerosis ---------- 1
Diabetes ---------- 2
Stroke ---------- 3
Prostate Disease---------- 4
Spina Bifida ---------- *5*
Parkinson's disease ---------- *6*

MED HX 6. A medical condition that may affect your bladder? *{examples: diabetes or cancer can cause damage to the nerves for the bladder}*

No ---------- *0*

Yes (Specify: _____) ----- *1*

MED HX 7. Reason for catheter:

Neurogenic bladder -not being able to empty the bladder --------	1
Incontinence or wetting yourself----------	2
Obstructed or blocked urine flow *{probe if prostrate disease checked}*--	3
Healing wounds ----------	4
Immobility or difficulty moving around ----------	5
Other *{Specify_____}* ----------	6

MED HX 8. Sometimes illness or injury can affect people's ability to feel in various parts of their bodies. Please tell me how much sensation or feeling you have in the bladder.

No sensation ----------	0
Partial sensation----------	1
Full sensation----------	2

MED HX 9. Current medications **[*Only need to enter names – not dosages or how often*]**

*Med1*_____

*Med2*_____

*Med3*_____

*Med4*_____

*Med5*_____

*Med6*_____

*Med7*_____

*Med15*_____

MED HX 10. Cranberry pills or tablets?

No ----------	*0*
Yes ----------	*1*

MED HX 11. Do you drink cranberry juice?

No ----------	*0*
Yes ----------	*1*

SECTION CC: CATHETER CARE

CC 1. Type of catheter currently used:

Urethral ---------- 1
Suprapubic ---------- 2
Both at the same time ---------- 3
Intermittent Catheter ---------- 4

CC 2. What year and month did patient first start using a urinary catheter on a permanent basis? *(List month and year first started using an indwelling type - suprapubic or urethral- whichever came first.)*

/__/__/ *MONTH STARTED* /__/__/__/__/ *YEAR STARTED*

Unsure: _____

CC 3A. When was Intermittent Catheterization started:

/__/__/ *MONTH STARTED* /__/__/__/__/ *YEAR STARTED* *NA*

CC4. Used a urethral catheter?

Yes----------1
No----------0

CC5. Used a suprapubic catheter?

Yes----------1
No----------0

CC6. Used intermittent catheter?

Yes----------1
No----------0

CC7. Have you used a condom catheter? *This is called a Texas or external catheter.*

Yes----------1
No----------0

CC 8. How much does the catheter interfere with your daily life?

Not at all ---------- 0
Very little ---------- 1
Somewhat ---------- 2
A great deal ---------- 3

AD SECTION: AUTONOMIC DYSREFLEXIA

INTAKE ONLY

Autonomic dysreflexia usually happens in people with spinal cord injuries. AD is caused by nerve impulses that come out at the level of the spinal injury. This causes elevation of blood pressure, severe headaches, goose bumps and other symptoms. These headaches can be very painful. These symptoms are often brought on by pressure build up in the bladder.

AD 1. People have symptoms of autonomic dysreflexia (AD), which is caused by pressure buildup in the bladder, often from catheter-related problems. Have you ever experienced autonomic dysreflexia?

No ---------- 0 {Go to next section}
Yes ---------- 1

AD2. In the past two months have you experienced autonomic dysreflexia?

No ---------- 0 {Go to next section}
Yes ---------- 1

AD 2. How often in the past two months did you experience autonomic dysreflexia?

Daily or several times a day---------- 1
Several times a week ---------- 2
Once a week ---------- 3
Several times a month ---------- 4
Once a month ---------- 5
Once every two months ---------- 6

APPENDIX D

SECTION KNOWLEDGE:
URINARY CATHETER KNOWLEDGE INVENTORY

1. Fluid intake should be monitored four times a week. T or **F**

2. You can reduce the risk for urinary tract infections by drinking caffeinated beverages and coffee. T or **F**

3. How much daily urine output should your produce a day?

    a. Less than 1,500mL per day
    b. **About 1,500 mL per day**
    c. About 1 quart per day
    d. Less than 1 quart per day

4. Normal urine is sterile. T or **F**

5. There are many different types of bacteria that can cause urinary tract infections. **T** or F

6. If an infection in the bladder is not treated it can move up to the kidney, causing damage. **T** or F

7. Feeling tired, chills and flank pain are symptoms of a urinary tract infection. **T** or F

8. Many UTI's can be cured with 1 to 2 days of treatment. T or **F**

9. A urinary tract infection can be treated best by drinking more fluids or cranberry juice. T or **F**

10. If I am active or outside in the heat, I will need to drink more fluids. **T** or F

11. You only need to contact healthcare providers about urine if you see bloody urine or have foul smelling urine. T or **F**

12. Hand hygiene or hand washing helps reduce the risk for urinary tract infections. **T** or F

APPENDIX E

Section SE: Urinary Catheter Self-efficacy

We would like to know how confident you are in doing certain activities. *On a scale of 1-10 with "1" being not confident at all and "10 being totally confident* - please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time. (Use Show Card B.)

How confident are you that you can…….? {Repeat stem as needed}

SE1 Drink adequate fluids, in a consistent way, throughout the day?

|__|__|
Confidence Level

SE2 Make changes in fluids related to activity, temperature of the air, and travel outside the home?

|__|__|
Confidence Level

SE3 Keep your intake of water and caffeine to a level that is good for you?

|__|__|
Confidence Level

SE4 Pay attention to the urine throughout the day (color, clarity, sediment, etc.).

|__|__|
Confidence Level

[If patient is using Intermittent Catheterization Go to SE8]

SE5 Keep the catheter secured or tied down so that it does not get pulled?

|__|__|
Confidence Level

SE6 When transferring, keep the catheter from becoming caught onto something and being pulled out?

|__|__|
Confidence Level

SE7 Keep the catheter and tubing from having kinks or twists in it?

|__|__|
Confidence Level

SE8 Ask your doctor or nurse things about your *catheter* that concern you?

|__|__|
Confidence Level

SE9 Discuss openly with your doctor or nurse any personal problems that may be related to your *catheter*?

|__|__|
Confidence Level

SE10 Work out differences with your doctor or nurse when they arise *(such as the best amount of time between catheter changes)*?

|__|__|
Confidence Level

SE11 Keep any physical discomfort or pain related to the *catheter* from interfering with the things you want to do?

|__|__|
Confidence Level

SE12 Keep the emotional distress caused by your *catheter* from interfering with the things you want to do?

|__|__|
Confidence Level

SE13 Keep catheter-related symptoms or problems *(such as leakage, blockage or UTI)* from interfering with what you want to do?

|__|__|
Confidence Level

SE14 Do the different tasks and activities needed to manage your *catheter* to reduce your need to see a doctor *or nurse*?

|__|__|
Confidence Level

SE15 Judge when the changes in your *catheter* mean you should *contact a* doctor *or nurse*?

|__|__|
Confidence Level

APPENDIX F

Activation Measure

Instructions: Below are some statements that people sometimes make when they talk about their health. Please indicate how much you disagree or agree with each statement as it applies to you personally by checking your answer. Your answers should be what is true for you and not just what you think others expect of you. If the statement does not apply to you, check "N/A."

	Disagree strongly	Disagree	Agree	Agree strongly	N/A
1. When all is said and done, I am the person who is responsible for managing my health.					
2. Taking an active role in my own health care is the most important factor in determining my health and ability to function.					
3. I am confident that I can take actions that will help prevent or minimize some symptoms or problems associated with my health.					
4. I know what each of my prescribed medications does.					
5. I am confident that I can tell when I need to go get medical care and when I can handle a health problem myself.					
6. I am confident I can tell a doctor concerns I have even when he or she does not ask.					
7. I am confident that I can follow through on medical treatments I need to do at home.					
8. I understand the nature and causes of my health problems.					
9. I know the different medical treatment options available for my health condition.					
10. I have been able to maintain the lifestyle changes for my health that I have made.					
11. I know how to prevent further problems with my health.					
12. I am confident I can figure out solutions when new situations or problems arise with my health.					
13. I am confident I can maintain lifestyle changes, like diet and exercise, even during times of stress.					

APPENDIX G

ICIQ-LTCqol 12/12

Initial number

CONFIDENTIAL

DAY MONTH YEAR
Today's date

Living with a long term catheter

This form can be filled in by a carer, friend or family member, as well as, or instead of by you, but it needs to be your own opinions about your catheter (not theirs). We have used "**you**" to refer to the **person with the catheter** throughout the form – no matter who fills in the form.

Please could you tell us who is answering the questionnaire by ticking the box:

Catheter user ☐ 1 Carer ☐ 2 Family member/friend ☐ 3 Other ☐ 4

1. **Is the catheter user** *(tick one)*: Female ☐ Male ☐

2. **Please write in the catheter user's date of birth:** DAY MONTH YEAR

3. **What type of catheter do you <u>currently</u> have?** *(Tick one box)*
   - urethral (between the legs/into the penis) ☐ 1
   - supra-pubic (into the abdomen) ☐ 2

<u>Catheter function and concern</u>

4a. **Do you have confidence in your catheter equipment (catheter, tubing and bag)?** *(Tick one box)*
   - never 4
   - occasionally 3
   - sometimes 2
   - most of the time 1
   - all of the time 0

4b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

5a. **Is the possibility of the catheter <u>leaking</u> on your mind?** *(Tick one box)*
   - never 0
   - occasionally 1
   - sometimes 2
   - most of the time 3
   - all of the time 4

5b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

6a. **Is the possibility of the catheter blocking on your mind?** *(Tick one box)*

never	0
occasionally	1
sometimes	2
most of the time	3
all of the time	4

6b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

7a. **How problematic is your catheter?** *(Tick one box)*

problem free	0
some problems but I would rather keep it	1
some problems but I have to keep it	2
lots of problems	3

8a. **How often do you have 'urine infections' that make you feel unwell or require you to take antibiotics?** *(Tick one box)*

several times per month	5
about once a month	4
once every 2-3 months	3
a couple of times a year	2
less than once a year	1
never	0

8b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

9a. **Does your catheter cause you to worry about smell?** *(Tick one box)*

never	0
occasionally	1
sometimes	2
most of the time	3
all of the time	4

9b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

10a. **Are you embarrassed by having a catheter?** *(Tick one box)*

never	☐	0
occasionally	☐	1
sometimes	☐	2
most of the time	☐	3
all of the time	☐	4

10b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

11a. **Do you feel you have adapted to life with a catheter?** *(Tick one box)*

not at all	☐	4
not really	☐	3
somewhat	☐	2
mostly	☐	1
completely	☐	0

11b. **How much does this bother you?**
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

11c. **Please provide further details if you would like**

12a. **Overall, how much does having a catheter affect your everyday life?**
Please ring a number between 0 (overall having a catheter is good) and 10 (overall having a catheter is bad)

0 1 2 3 4 5 6 7 8 9 **10**
overall good — overall bad

Lifestyle impact

13. Does your catheter affect your ability to travel? *(Tick one box)*

I don't travel but for other reasons	5
I don't travel because of my catheter	4
the catheter limits my ability to travel	3
the catheter has no effect on my ability to travel	2
the catheter has helped my ability to travel	1

14. Does your catheter affect your social activities (for example, going out for a meal)? *(Tick one box)*

I don't take part in social activities but for other reasons	5
I don't take part in social activities because of my catheter	4
the catheter limits my ability to take part in social activities	3
the catheter has no effect on my social activities	2
the catheter has helped my ability to take part in social activities	1

15. Does your catheter affect your ability to go out of the house? *(Tick one box)*

I don't go out but for other reasons	5
I don't go out because of my catheter	4
the catheter limits my ability to go out	3
the catheter has no effect on my ability to go out	2
the catheter has helped me to go out	1

Lifestyle impact score: sum scores 13-15 ☐☐

Unscored items

16a. Do you use pads as well as your catheter because of your bladder? *(Tick one box)*

never	0
occasionally	1
sometimes	2
most of the time	3
all of the time	4

16b. How much does using pads because of leaks bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

17a. Does your catheter cause you any pain, discomfort or soreness? *(Tick all that apply)*

never	0
occasionally	1
sometimes	2
most of the time	3
always	4

17b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

~~18a. Do you experience any bladder spasm (tightening of the bladder when you don't want it to)?~~ *(Tick one box)*

never	0
occasionally	1
sometimes	2
most of the time	3
always	4

18b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

19a. Does having a catheter prevent sexual activity? *(Tick one box)*

never	0
occasionally	1
sometimes	2
most of the time	3
all of the time	4
not applicable	8
don't wish to answer	9

19b. How much does this bother you?
Please ring a number between 0 (not at all) and 10 (a great deal)

0 1 2 3 4 5 6 7 8 9 **10**
not at all — a great deal

Thank you very much for answering these questions.

APPENDIX H

The Intermittent Self-Catheterization Questionnaire (ISC-Q)

Psychological well-being					
19. I am self-conscious about my need to self-catherize	☐	☐	☐	☐	☐
20. I would feel embarrassed if people saw my catheter in its packet	☐	☐	☐	☐	☐
21. My need to use a catheter sometimes makes me feel embarrassed	☐	☐	☐	☐	☐
22. I worry that my catheter doesn't always empty my bladder fully	☐	☐	☐	☐	☐
23. My need to use catheters stops me from visiting friends and family as often as I would like	☐	☐	☐	☐	☐
24. I worry about the risk of long-term problems from using my catheter	☐	☐	☐	☐	☐

APPENDIX I

URINARY CATHETER SELF-MANAGEMENT INVENTORY

I would like you to tell me what you usually do—if anything—for self-management of your catheter. These can be things you do alone or with others, like family, caregivers, or health care providers.

For all of these questions, I want you to tell me how often you do these activities, if at all. The choices are: 1 Strongly Agree, 2 Agree, 3 Neutral, 4 Disagree, or 5 Strongly Disagree. Look at SHOW CARD G. {If the question is not applicable and it's not a concern – choose 5 – strongly disagree. If it doesn't matter one way or the other, choose 3 neutral. If person says NA write down why it's NA} ***{Can repeat stem as needed. If asked about time frame say "These are not related to any specific time but what you generally do now. "If asked whether they should be doing this –do NOT say that they should do this- just say "we're just trying to find out what people do". You do not want to do any teaching – only data collection.}***

	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
Q 1. Pay attention to the amount of fluids consumed.	1	2	3	4	5
Q 2. Keep track of fluid intake amount by writing it down or thinking about it.	1	2	3	4	5
Q 3. Make sure to drink enough fluids consistently throughout the day.	1	2	3	4	5
Q 4. Pay attention to the types of fluids you drank, such as water or caffeine.	1	2	3	4	5
Q 5. Keep track of the information about types of fluids you drank by writing it down or thinking about it.	1	2	3	4	5
Q 6. Make sure to drink enough water.	1	2	3	4	5
Q 7. Make sure to limit caffeinated beverages.	1	2	3	4	5

	Strongly agree	Agree	Neutral	Disagree	Strongly Disagree
Q 8. Pay attention to the urine such as color, sediment, odor and amount of urine.	1	2	3	4	5
Q 9. Keep track of information about the urine such as the color, sediment, odor or amount **by writing it down or thinking about it.**	1	2	3	4	5
Q 10. Make *changes* in types and amounts of fluids if urine color or composition changes.	1	2	3	4	5
Q 11. Contact the healthcare provider if a catheter problem seems to be starting (such as leaking, blocking or UTI).	1	2	3	4	5
Q 12. Discuss medicine if bladder spasms are causing pain or leakage.	1	2	3	4	5
Q 13. Write down information about catheter related problems.	1	2	3	4	5
Q 14. Use this *written/online* information to make decisions about catheter management.	1	2	3	4	5
Q 15. Talk with other people to get support when the catheter is causing problems.	1	2	3	4	5
Q 16. Prevent serious symptoms of Autonomic Dysreflexia by recognizing early symptoms and taking action.	1	2	3	4	5

APPENDIX J

Follow-up Questionnaire

Study ID#: /__/__/__/

Date of Interview: /__/__/ / /__/__/ / /__/__/__/__/

Health Care Utilization

1. Since you discharged from Rehabilitation, have you seen any health care provider? _____Yes _____No
   What type of specialist? _____

2. Since you discharged from Rehabilitation, how many times did you go to an UNPLANNED PHYSICIAN VISIT? _____
   Reason for Visit? _____

3. Since you discharged from Rehabilitation, how many times did you go to the EMERGENCY DEPARTMENT? _____
   Reason for ED visit? _____

4. Since you discharged from Rehabilitation, how many times did you go to an URGENT CARE CENTER? _____
   Reason for visit? _____

5. Since you discharged from Rehabilitation, how many times did you stay in a HOSPITAL as an inpatient? _____
   Reason for Hospital visit? _____
   How many TOTAL NIGHTS did you spend in the hospital? _____

6. Have you been diagnosed with a URINARY TRACT INFECTION since discharging from Rehabilitation? _____Yes _____ No
7. If YES, how many? _____

8. Were you prescribed an antibiotic? _____Yes _____No
   If yes, please list. _____