Published in final edited form as:
J Clin Nurs. 2013 February ; 22(0): 356–367. doi:10.1111/jocn.12042.

Long-term Urinary Catheter Users Self-Care Practices and Problems

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Abstract

Aims—The aims were to characterize a sample of 202 adult community-living long-term indwelling urinary catheter users, to describe self-care practices and catheter problems, and to explore relationships among demographics, catheter practices, and problems.

Background—Long-term urinary catheter users have not been well studied, and persons using the device indefinitely for persistent urinary retention are likely to have different patterns of catheter practices and problems.

Design—The study was a cross-sectional descriptive and exploratory analysis.

Methods—Home interviews were conducted with catheter users who provided information by self-reported recall over the previous two months. Data were analyzed by descriptive statistics and tests of association between demographics, catheter practices, and catheter problems.

Results—The sample was widely diverse in age (19–96 years), race, and medical diagnosis. Urethral catheters were used slightly more often (56%) than suprapubic (44%), for a mean of 6 yrs. (SD 7 yrs.). Many persons were highly disabled, with 60% having difficulty in bathing, dressing, toileting, and getting out of the bed; 19% also required assistance in eating. A high percentage of catheter problems were reported with: 43% experiencing leakage (bypassing of urine), 31% having had a urinary tract infection, 24% blockage of the catheter, 23% catheter-associated pain, and 12% accidental dislodgment of the catheter. Treatments of catheter-related problems contributed to additional health care utilization including extra nurse or clinic visits, trips to the emergency department, or hospitalization. Symptoms of catheter associated urinary tract infections were most often related to changes in the color or character of urine or generalized symptoms.

Conclusions—Catheter related problems contribute to excess morbidity and health care utilization and costs.

Relevance to clinical practice—More research is needed in how to minimize catheter associated problems in long-term catheter users. Information from this study could help inform the development of interventions in this population.

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Study Design: MW, JM
Data Collection and Analysis: MW, MM, JM, JB, EF, SH, WT, ES
Manuscript Preparation: MW, MM, JM, JB, EF, SH, WT, ES

Keywords

urinary catheterization; nursing; urinary tract infection; urinary retention; complications; self-care

Introduction and Background

Living with an indwelling urinary catheter presents numerous challenges that must be addressed on a daily bases. Nevertheless, it can be indicated for persons unable to use any other bladder management method, including people with persistent urinary retention who lack sufficient cognition or hand dexterity for self-catheterizations and no one to do it for them. Also a catheter can be an option to improve quality of life in selected cases of severe incontinence or when a disability makes it difficult to use the bathroom (Cottenden et al., 2009). The majority of long-term catheter users have a neurogenic bladder dysfunction related to a disability, such as spinal cord injury (SCI) or multiple sclerosis (MS) (Wilde & Dougherty 2006, Wilde et al. 2010).While catheter problems are well known—recurrent and persistent blockage, catheter-related urinary tract infection (CAUTI), accidental dislodgment, and leakage of urine (bypassing)--data on the frequency and severity of these problems are limited. Information on catheter management, such as drainage bag replacement and/or cleaning and caregiver assistance, is even less well known. Moreover, community dwelling study samples are often small (<45) in persons with long-term use, (Wilde & Carrigan 2003, Wilde & Dougherty 2006, Wilde & Brasch 2008, Wilde et al. 2010), thus making it difficult to characterize the population and their needs.

This is a report of a cross-sectional analysis of data from 202 persons with long-term indwelling urinary catheters (urethral or suprapubic [SP]). The purpose of this analysis is to describe catheter care practices and catheter-related problems to inform clinicians and researchers. Having information from a large sample will help fill a gap in the literature in which small samples have been the norm.

Methods

Design

This analysis is based on baseline data collected for a single blinded randomized trial of an educational program in urinary catheter self-management with long-term catheter users. This analysis is based on data derived through a one-time home interview of 202 study participants, prior to randomization, conducted by trained interviewers from June 2009 through June 2011. The aims of this analysis were to:

1. Characterize the sample of 202 community-dwelling long-term adult indwelling urinary catheter users who had catheter problems in the past 6–12 months or those new to a catheter within the past year.
2. Depict how persons with catheters take care of the device on a day to day basis, including others who help in this care.
3. Describe the prevalence and incidence of self-reported catheter-related problems over a two month period.
4. Explore relationships among demographics, catheter practices, and catheter problems

Setting and sample—The study was conducted at two sites—the University of Rochester, NY (Utica to Buffalo region) and at the Visiting Nurse Service of New York (VNSNY) in New York City and parts of Nassau and Westchester Counties —with separate

teams conducting the study activities using the same procedures and tools. To be eligible for the study, participants had to: (1) be 18 years of age or older; (2) expect to use an indwelling urethral or SP catheter for at least one year; (3) report having a catheter-associated problem (UTI in the last year, or blockage or dislodgement in the last six months) OR report using a catheter for less than one year (4) complete study measurements alone or with the help of a family member; and (5) communicate in English. Despite the need in the parent study to include only persons who would benefit the most from the intervention, only 3.6% of those screened were excluded for criteria #3 above. Individuals were excluded if they had a terminal illness. Institutional approval was obtained and synchronized for human subject's ethics at both sites.

Data Collection

Measures—Two instruments were used for this cross sectional analysis: 1) *Demographics and Catheter Care Questionnaire (DMC)* and 2) *Catheter Problems Questionnaire (CPQ)*. Both instruments were developed by the Principal Investigator (PI) for research in similar populations (Wilde & Dougherty 2006, Wilde & Brasch 2008) and modified for this study. For the *DMC*, 50 items measured demographics and catheter-related variables to describe the sample, and included: 1) person/family--age, race/ethnicity, type/presence of caregivers (e.g., relative or paid person), education, employment, insurance; 2) chronic conditions--diagnosis, list of medications, and functional ability through the Katz score (Katz, Ford, Moskowitz, Jackson, & Jaffee 1963) and 3) catheter related-- catheter type (e.g., silicone or latex coated), interval for catheter changes, and bag care. The content validity scores were found to be acceptable in previous studies using the same instrument (Wilde & Dougherty 2006, Wilde & Brasch 2008).

Catheter related problems (e.g., UTI, blockage [encrustation within the catheter]) were measured using the *CPQ*. Content validity scores for a previous study (Wilde & Brasch 2008) indicated that the items were acceptable. *CPQ* was modified to include additional information related to CAUTIs, i.e., severity and symptoms. Frequency of catheter related problems was asked, and for CAUTI and blockage of the catheter, associated treatments were solicited. Information was recorded for up to six CAUTI events and up to12 blockage events (as blockages were sometimes frequent).

Procedures—Study participants at the Rochester site were recruited through provider referral from clinics, home care agencies and private urological offices. In New York City, a database was used to identify people with catheters. Potential participants at both sites were screened for eligibility and interest by telephone call. At intake, participants provided informed consent, and subsequent to enrollment—but prior to random assignment-- home interviews were conducted. An electronic data collection system, Questionnaire Development System (QDS), was used to collect and manage data. Participants received an honorarium of $20 for the interview.

Data Analysis

Prior to analysis, data were verified, cleaned and checked for consistency with a full range of logic checks. Decisions about how to code missing data and outliers (Yang, Xie, & Ngee Goh 2011) were made by the team, with input from the statistician. Data were analyzed descriptively for central tendency (mean, median), dispersion (SD, range), and distribution (skew, kurtosis). Specific emphasis was on describing prevalence and incidence of major catheter problems of CAUTI, blockage, and dislodgment of the catheter. Associations were explored (*t*-tests or Pearsons' r for interval level data and Chi Sq. or odds ratios and confidence intervals (CI) for categorical data) among variables believed to contribute to

these catheter-related problems. Analyses were performed using IBM Statistical Program for Social Sciences (SPSS) 19 and SAS 9.2.

Results

Demographics

The sample was diverse by age, race, and medical diagnosis. The male to female ratio was roughly equivalent at 51 and 49% respectively. Ages ranged from 19 to 96 with a mean and median age of 61, SD of 17.4 years. The race identified most often by participants was white (57%), followed by Black (30%), Asian (2%), American Indian or Alaskan Native (2%), biracial (2%), and unknown (9%). Eleven percent of the sample was Hispanic. Diversity was also demonstrated by the marital status selections, with approximately 34% of participants reporting never having been married, over 19% separated or divorced, 18% widowed, 27% married and 2 % common law married or living with a life partner. A single diagnosis believed to affect bladder function was identified for each person and we labeled them as “primary” in Table 1, categorizing by the order in the table. Many persons had other diagnoses affecting the bladder, and these were labeled “secondary.” Spinal cord injury (SCI) and multiple sclerosis (MS) were the most common medical diagnoses, with 40% and 23% respectively.

Medications included 26 different classes, and many persons took more than one medicine in a single category, for instance heart medicine was taken by 44%, but of these patients over half took more than one cardiac medicine. Eleven percent were on antibiotics and 4% on urinary antiseptics. Other bladder medicines included: anticholinergics (20%), antispasmodic/ antimuscarinics (3%), alpha blocker (5%), and muscle relaxants (39%). Frequent medicines were for MS (13%), anticonvulsants (30%), upper gastrointestinal ([GI] 33%), laxatives (34%), psychological/depression (44%), diuretics (24%), diabetes (17%), hypertension (25%), respiratory (19%). Pain medicine was taken by many, including NSAIDS/aspirin (38%), Tylenol (26%), and narcotics (34%). Smaller numbers took medicine for cancer (8%), sleep (5%), or steroids (5%). Eighty-four percent reported taking at least one vitamin or mineral, most typically a multivitamin, calcium or vitamin D.

The majority of participants lived with another person, generally family (55%); only 8% lived with paid caregivers, and 37% lived alone. Employment rates were minimal with only 11 persons working, six of them full time. Most individuals had some type of public insurance and 48% reported having private insurance. Education levels of the subjects varied greatly with 16 % not completing high school, 27% with high school or GED, 19% with some college, and 38 %with a college degree, including 12% with a graduate degree.

Activities of daily living (ADL)--in bathing, dressing, toileting, getting out of bed, and eating---were evaluated by the Katz scale, with item responses calculated as 1 point for independent and 2 points for needs assistance. The range was 5–10 for the total scale, with a higher score indicating less functional ability; the mean was 7.75 (SD1.9) and mode was 9. Twenty-four percent reported that they were independent in all activities, 24% needed assistance with 1–3 ADLs, 35% needed assistance with 4 ADLs and 17% needed help with all 5 ADLs.

Catheter Care Practices

Catheter characteristics—The length of time of catheter use varied considerably from 1 to 470 months (39 yrs.). The mean was 72.5 months or 6 yrs. (SD 85.4months, 7yrs.). Median use was 3.25 yrs. Urethral catheters were used more often than SP, with 112 (56%) and 89(44%), respectively; one person had both types (Table 2). Fifty-eight of those with SP

had used urethral catheters in the past; whereas, only two currently using a urethral catheter had tried a SP catheter. In the past, 35% had used an intermittent catheter, 16% an external condom catheter, 29% had used Crede, and 83% had used absorbent products.

Catheter sizes and the amount of water in the balloon varied. Catheter sizes ranged from 12–30 Fr. with a mean of 18.5 (SD 3.2), and in general urethral catheters were significantly smaller (mean 17.1 Fr., SD2.1) than SP catheters (mean 20Fr., SD 3.5; t test −7.29; df 182; P< 0.01). Balloon size varied from 5–30 mL with 70% being 5–10mL; the water within the balloon was reported as 2–50mL, with the majority (55%) using 5–10mL. Some people (8%) did not know the size of the catheter and 23% did not know the balloon size or amount of water instilled. (See Table 2 for details.)

Drainage bag use—Most persons (58%) used both leg and overnight (night) bags, switching between them. Some individuals used just one type, with leg bags used alone by 17% and night bags used alone by 23%. Three persons used other collection methods: one a belly bag, one connected tubing to empty the bladder directly from the catheter, and another used a plastic cover over the end and emptied the catheter (without a clamp). Only four persons (2%) used a leg bag continuously, connecting it to the night bag later in the day. The majority switched between leg and night bag, and most also cleaned them (leg bags by 54% and night bags by 59%). Solutions for cleaning bags and the frequency for replacing and cleaning the bags are in Table 3.

Catheter changes—Catheter changes were performed by professionals (nurses, physicians) in homes, clinics and offices (Table 4). Unscheduled changes were reported in the previous two months by 37% (n=74), with 3 who said this occurred weekly, 15 said several times a month, 12 monthly, and 43 once in two months. Catheter users changed it themselves 8% (n=16) of the time for routine changes and 10% (n=20) for unscheduled; likewise spouses/family members did so 8% (n= 14) of the time for routine changes and 10% (n=19) for unscheduled. For regularly scheduled changes, out of 12 males who did this, 2 changed urethral and 10 SP; out of 4 females, all changed urethral catheters. For unscheduled changes, out of 14 males who changed their own catheter, 2 had urethral and 12 had SP; out of 6 females, five had urethral catheters, and one had SP. Physicians or home attendants also changed or assisted with catheter changes, for routine changes for 4 persons and unscheduled for 9. Noteworthy is that in the previous two months, 3.5% had used the emergency department (ED) for routine changes, and 31% among those who reported unscheduled changes. Significant differences were found for routine changes in the ED by study sites, with 6 in the NYC site and 1 in Rochester (Chi Sq. 7.0; df=1; P=.008.) However, the unscheduled changes in the ED were not significantly different, with 52 in NYC and 11 in Rochester. (Chi Sq. 2.6; df=1; P=.106).

Catheter irrigations—Irrigating the catheter, which is not a recommended practice (Cottenden et al. 2009, Gould et al. 2009), was done by 42%. Of those who irrigated, 18% did so daily or more often, 13% did it one or more times a week, 43% did it one or more times a month, and 25% once in two months, and persons who irrigated daily were more likely to have had blockage (Chi-Sq. 13.50, df =1, P = .019). Preventive irrigations were done by 37%, for urine flow problems by 34%, and both preventively and for problems by 39%. Those who irrigated for prevention and problems were more likely to also have had blockage, (Chi-Sq. 13.57, df =1, P = .001). Solutions for irrigation included: saline 76%, sterile water 23%, tap water 9%, and Renacidin ™ (an acidic solution for instillation) 4%. Irrigating the catheter was significantly related to blockage (Chi-Sq. 15.94, df =1, P = <.001) but the pattern of irrigation and blockage vs. CAUTI varied by the individual. Out of 83 who irrigated, 14 had both blockage and CAUTI, 17 had only blockage, 18 had only CAUTI, 32 had no blockage or CAUTI, and 2 did not know.

Catheter Problems

Prevalence and incidence of self-reported catheter related problems for the previous two months are described in Table 5, including means, SDs, and rates per 1000 catheter use days for CAUTI, blockage, and dislodgement. CAUTI was defined as a urinary infection treated with an antibiotic. Self-reported prevalence of CAUTI was 31% (63/202). In 63 persons, there were 75 episodes reported, with 54 persons having 1 event, seven having 2, one having 3 and one having 4. Blockage in the previous two months was reported by 48 persons (24% prevalence) and frequency of the event was reported by 47of 48 persons: from 1–2 times in 31 persons, 3–4 times in 9, 7–9 times in 4, and 20 or more times in 3. Frequencies and other details are reported in Table 5 of leakage (bypassing), sediment, kinks/twists, bladder spasms, and autonomic dysreflexia (AD), a painful syndrome caused by injury to central nerves.

Relationships among demographics, catheter practices, and complications— No significant associations were found related to CAUTI in the past two months (Yes/No) for catheter size, type of catheter (urethral or SP), leakage, kinks/twists or dislodgement of the catheter. Younger persons were more likely to have reported CAUTI, with a mean age of 57.5 years (SD 16.3) as compared with 63 years (SD 17.6) for those who did not (t test= 2.11, df 199, P=. 0.036) and to have used the catheter for a longer period of time (Pearson's r= −.157, P= 0.026). Catheter size and length of time using a catheter were not significantly correlated with the number of CAUTIs.

All chi-square tests of associations were not significant for CAUTI or blockage (Yes/No) for catheter management issues related to caregivers who assist with catheter care (e.g., spouse, family, paid helpers); frequency of bag changes (night and/or leg bag); or cleaning the bag.

Blockage was significantly related to CAUTI, with the odds of having a CAUTI were 2.29 times as great (95% CI= 1.17, 4.48) among those with blockages compared with those reporting no blockages. Out of 47 persons reporting frequency of blockage at least once in two months, 22 had at least one UTI (46%); in contrast, out of 152 persons with no blockage, 41 reported UTI (27%).

Treatments—Treatments associated with excess healthcare utilization for UTI or blockage, such as extra nurse home visits or hospital visits, are listed in Table 6. All persons reporting UTI had associated treatments, 96% of those with blockage had excess treatments, and only one person out of 88 with either UTI or blockage had no excess treatments. Some treatments required additional family or patient time or use of extra supplies. For example, in those with blockage, the catheter position was adjusted by 19% in relation to blockages, and irrigation was done for blockages by 49%. Doubtless some of the irrigations also were done by the catheter users or caregivers in the home, not nurses. In the previous two months, 17 study participants reported they were hospitalized for UTI for a total of 165 days. The mean number of days hospitalized was 9.71 (SD 7.41), and if including all of those who had UTI but were not hospitalized, the mean days per hospitalization was 2.62 (SD 5.75).

Symptoms of UTI—Questions of frequency and severity of UTI symptoms were asked. Symptoms associated with 75 episodes of UTI were asked, with yes or no to each symptom (Table 7). The most frequent symptoms were related to a change in the color (#1) or character of the urine (odor #2; sediment #5). Generalized symptoms also were reported often (malaise #3, bladder spasm #4). Severity of UTI symptoms were reported also for 74 events in two months. On a scale of 1–10 with 1 being very mild and 10 being the most severe UTI you can imagine, a score of 1–4 was reported 22% of the time, a score of 5–7 was reported 43% of the time, and a score of 8–10 was reported 35% of the time.

Leaking/sediment—Of the 86 persons (43%) who reported leaking (bypassing of urine), 8% indicated it was not a problem, 31% a small problem, 29% a moderate problem, and 32% a large problem. Sediment was noticed by 127 (63%), of these 41% saying it was a small amount (hardly noticeable); 34% a moderate amount (can be seen in tubing and bag if looking for it); and 25% a large amount (very easy to see in tubing and bag. In the previous two months, presence of sediment was associated with blockage (Chi-Sq. 13.93, df=1, P<. 001) but not CAUTI (Chi-Sq. .48, df=1, P=0.49).

Pain—Catheter related pain was reported by almost a quarter of the sample (n=46, 23%), and of those with catheter pain it was attributed to positioning (e.g., sitting on it) by46%, bladder spasms 46%, some catheter changes 30%, and every catheter change 26%. Fifteen percent said that the pain bothered them very little, 46% said somewhat, and 39% said a great deal. Three percent (n=6) said they have catheter pain all the time. In addition, AD can be painful, and this was experienced by 41 persons (20%) at some time, most within the past two months (Table 5). Primarily those with AD had SCI (38 of 41).

Difficult insertions/removals—Twenty-four individuals (12%) reported having difficulty with the insertion of their catheter in the previous 2 month and 11 (5%) persons had difficulty during removal. While 31 of 35 people said this difficulty had occurred just once or twice in the past two months (mean 1.7, SD 1.1), four persons had experienced it between 3 and 6 times. For those reporting any difficulty, the level of difficulty for the most difficult insertion or removal experienced (defined as difficult or challenging for the patient) was assessed with a visual analogue scale from 1–10, with 1 being just a little more difficult than usual and 10 being a very challenging situation. The difficulty mean score was 6.9 (SD 3.0), and more than half (54%) were rated from 8–10.

When asked if the catheter interfered with daily life, 29% said not at all, 26% said very little, 29% said somewhat and 16% said it interfered a great deal. However, in further analyses, the catheter significantly interfered “a great deal” in persons with blockage (14 of 31; Chi Sq. 9.53, df 3, P= 0.023) and those with difficult catheter changes (11of 32; Chi Sq. 8.65, df 3, P= 0.034).

Discussion

Although the majority of the persons enrolled in this study were recruited from a home care agency in New York City (75%), the sample is believed to be a good representation of this population because recruitment also took place through clinics and private offices in the Rochester site. Only 3.6% of the persons recruited were not eligible because of not having any major catheter problems, which is consistent with another study in this population in which not one of the 43 persons were problem free during the eight months’ study (Wilde et al. 2010). The sample was older than in some previous studies, with a mean of 61 yrs. as compared with a mean of 49yrs. in two recent studies (Wilde et al. 2010, Wilde & Brasch 2008) with similar populations that had more persons with SCI. The current sample, with a total of 87% recruited through home care agencies, may reflect a more vulnerable population than in earlier studies. Multiple secondary diagnoses and co-morbidities were reported as well as a wide range of medications. Often large studies with catheter users involve retrospective chart audits related to a single medical diagnosis, most often SCI, aimed at finding out about urinary health or catheter management strategies over time (Cameron et al. 2010, El-Masri, Chong, Kyriakider, & Wang 2011).

Catheter Practices and Care

This is the first known large study (N=202) providing great detail on catheter management practices and problems. Many people lacked knowledge about their catheters, such as the balloon size (47persons/23%) and a few gave us information that was questionable for accuracy, such as catheter sizes of 15 and 17Fr, which are not known to exist. Also, 34% said the catheter was all latex; it is possible that some did not know it might have a Teflon ™ coating, as this is a commonly used coating over latex and only one person indicated this type. It was of concern that 29 persons said the balloon was size 30 mL since this is only recommended for postoperative bleeding. The 8 persons who said their 30mL balloons were inflated part way might also be mistaken, but if they were correct, inflating between 16–29 mL could contribute to asymmetry of the balloon and possible erosion into the bladder mucosal lining (Cottenden et al. 2009). Patients and their caregivers need to know more about the proper size of catheters and balloons so that the sizes can be decreased if increased for a specific reason, such as bleeding.

It was not surprising that most people received help with managing their catheters (Table 2), given the large number of people with neurological disorders and the high mean Katz score of 7.8, which indicates a high level of disability. The level of disability is similar to the score of 7.6 (Wilde & Dougherty 2006) cited in a study of 30 catheter users, and in another study with 43 individuals, 44% required assistance from another to dress the upper body, and 91% were in wheelchairs (Wilde et al. 2010).

Drainage bag replacement and cleaning—There was much variation in how often the drainage bag was replaced by a brand new one and/or cleaned, but the reason for the frequency was not asked. Logically, the percentage of persons cleaning the leg bag increased as the number of days between replacements extended. However, some people replaced the bag infrequently (e.g., within 22–30 days or >30 days) and not all cleaned the bag between replacements (Table 3). It was unanticipated that so few used a bleach solution to clean since it is the only product recommended for cleaning drainage bags (Gould et al. 2009); however, bleach is caustic and it can damage clothing and irritate the skin or eyes. Nor was vinegar used much, and this had been the standard in home settings in the past (Wilde 1986, Wilde 1991). A lack of research in this area, as well as whether supplies are reimbursed, puts catheter users in a position to make their own decisions about cleaning and reuse of bags. Somewhat surprising was that only 2% indicated they kept the leg bag attached all the time, adding a night bag to it for continuous evening drainage. This practice is recommended at the VNSNY and it is commonly recommended in the United Kingdom due to a belief that this keeps the catheter less disturbed and more of a closed system.(Jones, Brooks, Foxley, & Dunkin 2007, Royal College of Nurses (England 2008). In contrast to our sample, in the U.K., leg and night bags are routinely changed every seven days or more often if needed, i.e., appear dirty or have an odor. (Personal communication, M. Fader, August 2011).

Catheter changes—This is the first time detailed information about who changes catheters was reported and that catheter users and family members sometimes changed it (Table 4). People in home settings with chronic illnesses often manage complex technology, even as complicated as total parenteral nutrition. Yet catheter changes are not always simple, particularly in men. However, significantly more males routinely changed their catheters more often than females, and SP catheters were significantly more often changed than urethral for unplanned changes. Providing careful teaching for those changing their own catheters is essential to prevent traumatic insertions, especially when taking into consideration the proportion of people who experienced difficult insertions (12%) and removals (5%). Home care nurses changed the great majority of catheters, understandably

since the majority of the sample came through home care agencies. Thus, it was particularly surprising that unscheduled changes were often done in the emergency department (31% of the time) and more often in NYC than in the Rochester site. Also ED visits for routine changes (3.5%) contribute to substantial costs that could be reduced through planning and use of home care agencies. The homebound restrictions in Medicare might have contributed to this as people who are able to get out, hold a job, etc. are not eligible for home care services under Medicare. Further research in reasons for catheter related ED use is warranted.

Catheter Problems

Even though this is a selected group of patients who experienced catheter related problems in the past year or were relatively new to catheter use, this analysis related to data from a two month period confirms the widespread prevalence of catheter related problems. The current report on nine catheter related problems, frequency of occurrence, and their associated professional treatments is the first with this level of detail. In just two months prior to study enrollment, 31% reported having had a CAUTI, blockage of the catheter was reported by 24%, dislodgement by 12%., leakage by 43%, and pain by23 %. Though the rates of CAUTI was 6.2/1000 catheter days (95% CI= 4.8, 7.6), lower than the 8.4/1000 days reported in a study of 43 long-term catheter users over a six month period (Wilde et al. 2010), it is much higher than the rate of 1.7/1000 days reported through a home care benchmarking project which includes short and long-term catheter users (MAHC 2011). In comparison with other research, (Maki & Tambyah 2001, Wilde et al. 2010) catheter size and gender were not associated with CAUTI.

The rates for blockage and dislodgment are the first known to be published. This report affirms the relationship of blockage and CAUTI reported in previous samples of 24 (Wilde & Carrigan 2003) and 30 (Wilde & Dougherty 2006). Research is needed to explicate the relationship between CAUTI and blockage, such as bladder mucosal bleeding from distension related to poor urine flow (Pearman 1984) or bladder stones.

Symptoms of CAUTI—In a recent report of a study in 43 community dwelling adults, the most frequently reported symptoms of CAUTI were urinary sediment, foul odor, general malaise and changes in the color of the urine.(Wilde et al. 2010) In three other studies, foul urine odor was a common symptom (Wilde 1986, Wilde & Dougherty 2006, Wilde & Brasch 2008) though other symptoms varied. These symptoms were confirmed in the current study with the top five being: changes in urine color and odor, malaise, weakness, and sediment. While there are individual differences, this population did not report as often the typical symptoms of UTI in the general public (i.e., burning, urgency, and fever). Of concern, in a study of patients with intermittent urinary catheters, accuracy in predicting UTIs based on their symptoms was not well validated (Massa, 2009). Although cloudy urine was the most accurately reported symptom of UTI, the researchers concluded that most patients were better at identifying when they did not have a UTI, rather than when it was present. This study underlines the need for further symptom research in long-term catheterized patients. Without better knowledge in this area, it is not known whether symptom awareness alone can prevent episodes of symptomatic CAUTI. Thus for patients to seek early treatment, they must know what symptoms to watch for and in particular which ones are their own valid symptoms. This could benefit their health and reduce excess healthcare utilization, especially if ED visits and/or hospitalization can be avoided.

Limitations

All data are self-reported, and thus we expect some errors. Also there were limitations in sampling because the majority was recruited through one large home care agency and there

were differences in recruitment processes (referral versus database). Persons more bothered by catheter problems might have been more willing to join the study, contributing to selection bias. Some information from study participants might have been inaccurate, for instance catheter sizes of 15 and 17Fr. described above. However, we have confidence in the accuracy of our self-reported data. In a comparison of self-report to chart accuracy in a small sample of a similar population of catheter related problems, congruence was reported as 97% (Wilde et al. 2010).

Conclusion and Relevance to Clinical Practice

This report characterizes a diverse sample of the population of long-term indwelling urinary catheter users in a way not reported before, providing detailed information about demographics, catheter care practices, and numerous catheter related problems and associated healthcare utilization. The widespread report of catheter problems is of concern because the timeframe was just two months, this population is likely to need an indwelling catheter indefinitely, and many of these problems negatively impact personal health and associated healthcare expenditures. Gaps in research include optimal frequency for replacement and methods of cleaning urinary drainage bags, increasing the predictive value of CAUTI symptoms, decreasing excess ED use (especially for catheter changes), and best practices for educating caregivers (family and paid carers). To better portray this vulnerable population, prospective longitudinal research is needed with long-term catheter users having a range of diagnoses. Also, for surveillance, CAUTI rates for short and long-term users should be distinguished.

Implications for practice involve providing complete information about the catheter to those who use the device, using the appropriate catheter balloon size and water inflation, and consideration of criteria for teaching catheter changes to patients and caregivers. Moreover, since disability levels can change over time, such as in those with MS, monitoring catheter self-care capability over time could proactively identify people whose caregivers need to learn more about catheter management.

Many of the catheter-related problems reported in this study could be prevented or minimized with more attention to catheter management, early identification of problems, and more evidence-based catheter practices. Therefore, information from this study is critical to researchers who wish to plan interventions to address the persistent catheter related problems that affect large proportions of long-term indwelling urinary catheter users.

Acknowledgments

We wish to thank persons who assisted in this study with: data collection, Yessica Terrero, Christopher Clinton, Laura Edilitz, JoAnn Moda, Manny Schwimmer, Paula Wilson, and Maria Viterbo-Verna; information technology, Brian Harrington, Michael Fisher, Annette Curtis, Sridevi Sridharan, Timothy Peng, Richard Dumpson; nursing consultation, Paula Wilson, Seon Lewis-Holman, Yanick Martelly; medical consultation, Bob Mayer; data and safety monitoring, Susan Fisher, Christopher Murtaugh; and administrative guidance Penny H. Feldman, Pamela Sawdey.

Funding for this study was through the United States National Institute of Nursing Research, National Institutes of Health #R01 NR0155.

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Table 1

Primary and secondary diagnoses

Primary			Secondary n					
	#	%	MS	Diabetes	Stroke	Prostate	Spina bifida	Neurogenic bladder
SCI	81	40	1	20	9	8	1	39
MS	46	23		7	4	3		23
Diabetes	25	12	7		7	5		10
Stroke	4	2	4	7		3		2
Prostate	20	10	3	5	3			13
Spina bifida	2	1						1
Neurogenic Bladder	16	8	23	15	2	13	1	
Parkinsons	3	2						
Other	5	3						

Table 2

Catheter characteristics and catheter care practices

Time using catheter		**%**		**Catheter material**		**# (%)**	
Up to 1 yr.		22		All latex		69/34	
> 1 to 3 yrs.		26		Teflon™ coated latex		1/1	
> 3 to 5 yrs.		13		Silicone coated		71/35	
> 5 to 10 yrs.		22		All silicone		12/6	
>10 to 15 yrs.		8		Hydrogel coated		3/2	
>15 to 20 yrs.		6		Silver coated		5/3	
> 20 to 40 yrs.		5					
Catheter size (Fr) all # (%)		Urethral #	SP #	**Balloon size** all #/%		Urethral #	SP #
12	1(1)	1	0	5–10 mL.	124(61	62	62
14	8(4)	7	1	30 mL.	29(14	19	10
15–16	62(31)	45	17	Don’t know	47(23		
17–18	57(28)	34	23	Other Text 15	2(1		
20	16(8)	7	9	**Amount of water in balloon** all # (%)		Urethral #	SP #
22	18(9)	2	16	<5cc	2(1)	1	1
24	17(8)	3	14	5–10	110(55)	54	56
26	3(2)	0	3	11–15	10(5)	8	2
28	1(1)	0	1	16–29	12(5)	8	4
30	2(1)	0	2	30	9(5)	7	2
Not known	17(8)	14	3	40–50	2(1)	2	0
Helps with catheter #(%) (some selected more than one)							
No one		47(23)		Friend		7(4)	
Spouse/partner		38(19)		Paid aide		126(62)	

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Time using catheter	%	Catheter material	# (%)
Other family member	34(17)	Other	1(1)

Table 3

Drainage bag cleaning and replacements

Type of bag used	**(%)**	**Cleaning solutions**	**Percentage in leg bag users**	**Percentage in night bag users**
Leg bag only	17	Soap & water	29	27
Night bag only	23	Water alone	35	31
Both leg and night bag	58	Vinegar & Water	33	36
Leg bag always attached, & adds night bag	2	Bleach and water	16	22
Other (e.g., homemade clamp)	2	Commercial product, e.g., Urolux™	1	1
		Household cleaners, e.g., Lysol™	12	12
		Other	1	2
Replacement with brand new bag, within:	Leg bag users (%)		Night bag users (%)	
	Replacement	Also cleans leg bag (%)	Replacement	Also cleans night bag (%)
1–7 days	49	62	31	64
8–14 days	20	77	26	69
15–21 days	11	88	14	83
22–30 days	16	75	20	76
>30 days	5	86	9	93

Table 4

Routine & unscheduled catheter changes

Person changing catheter	**Routine changes # (%)**			**Unscheduled changes # (%)**		
(some selected more than one)	#(%) all	# UR-SP	# M-F	# (%) all	# UR-SP	# M-F
Self	16(8)	6–10	*12–4	20(10)	*7–13	14–6
Spouse-partner	7(4)	3–4	4–3	9(5)	4–5	6–3
Family member	7(4)	5–2	2–5	10(5)	7-3	4–6
Home care Nurse	112 (55)	**73/39	***42–70	96(46)	**63–33	38–58
Nurse or physician at clinic	45(22)	*19–26	31-14	45(22)	20–25	25-20
Nurse or physician at private medical office	29(14)	12–17	19-10	22(11)	9–13	16-6
Emergency department	7(4)	6-1	3–4	63(31)	32-31	40-23

UR= urethral; SP= suprapubic catheter. Significant differences in Chi Square tests

* P= ≤ .05

** ≤ .01

*** <.001

Table 5

Catheter problems

Key catheter problems in past two months	**Number persons**	**Percentage ***	**Mean (SD) entire sample**		**Rate/1000 catheter days**	
UTI	63	31	0.37 (0.63)		6.22	
Blockage	48	24**	0.67 (1.71)		6.22	
Dislodgement	25	12	0.21 (0.68)		11.08	
Other catheter problems in past two months	Number persons	Percentage *	Frequency of those with problem (%)			
			Daily	Once - several Times week	Once - several Times month	Once in past 2 months
Leaking (bypassing urine)	86	43	9	10	51	29
Sediment	127	63	24	29	39	7
Kinks/twists	40	20	13	8	40	40
Bladder spasms	72	36	37	24	30	10
Autonomic dysreflexia	26	13	4	31	38	27

* Indicates the percentage of study participants who had this happen at any time during the previous two months, rounded to nearest percent.

** The outlier test based on zero-inflated Poisson models (Yang et al. 2011) identified three observations in blockage variable. Outliers were replaced with the observations closest to them, 9, for the calculation of means.

Table 6

Treatments associated with catheter problems in two months

Treatments/	UTI (n=63)			Blockage (n=47)*		
	Total # events	% affected	**Mean (SD)	Total # events	% affected	**Mean (SD)
Extra nurse home visit	14	19	0.22 (0.49)	26	30	0.55(.99)
Extra office visit	18	25	0.29 (0.52)	13	23	0.28 (0.54)
ED visit	25	35	0.40 (0.61)	16	19	0.34 (0.84)
Hospitalized**	20	27	0.32 (0.56)	N/A		
Rehab or nursing home stay						
Catheter changed	48	65	0.76 (0.64)	58	70	1.23 (1.22)
Urine cultured	54	76	0.86 (0.59)	N/A		
Antibiotic prescribed	75	100	1.19 (0.53)			

*One additional person had blockage but did not know the frequency.

**Means (SDs) calculated only for those affected with the problem, i.e., 63 with UTI and 47 with blockage. Treatments were not asked for blockages over 12 events/person, which was reported by three persons.

Table 7

Symptoms of UTI (n=63)

Symptom	Mean (SD)	Times reported	Percent with symptom*	Rank order of frequency
Urine color change	0.94 (0.74)	59	76	1
Odor in urine	0.84 (0.77)	53	68	2
Malaise	0.71 (0.77)	45	59	3
Weakness	0.60 (0.73)	38	51	4
Sediment	0.59 (0.75)	37	48	5
Pain Bladder	0.57 (0.76)	36	46	6
Burning	0.57 (0.78)	36	44	7
Bladder Spasm	0.51 (0.64)	32	43	8
Chills	0.49 (0.72)	31	41	9
Blood	0.49 (0.69)	31	40	10
Fever	0.44 (0.62)	28	40	11
Pain Back/Side	0.44 (0.67)	28	37	12
Muscle Spasm	0.40 (0.71)	25	32	13
Other	0.29 (0.52)	18	25	14
Mental Changes	0.27 (0.51)	17	24	15
Leakage	0.25 (0.47)	16	24	16
Autonomic dysreflexia	0.21 (0.63)	13	14	17

*Percentage with symptom rounded to a whole number.

Published in final edited form as:
Nurs Res. 2015 ; 64(1): 24–34. doi:10.1097/NNR.0000000000000071.

Self-Management Intervention for Long-Term Indwelling Urinary Catheter Users: Randomized Clinical Trial

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Clinical Trial Registration number from clinicaltrials.gov is NCT00883220.

Conflicts of Interest Statements: Mary H. Wilde has been a consultant with NovaBay Pharmaceutics Inc. since June 2013. The remaining authors have no conflicts of interest to report.

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Abstract

Background—People using long-term indwelling urinary catheters experience multiple recurrent catheter problems. Self-management approaches are needed to avoid catheter-related problems.

Objectives—The aim was to determine effectiveness of a self-management intervention in prevention of adverse outcomes (catheter-related urinary tract infection, blockage, and accidental dislodgement). Healthcare treatment associated with the adverse outcomes and catheter-related quality of life was also studied.

Method—A randomized clinical trial was conducted. The intervention involved learning catheter-related self-monitoring and self-management skills during home visits by a study nurse (twice during the first month and at four months—with a phone call at two months). The control group received usual care. Data were collected during an initial face-to-face home interview followed by bimonthly phone interviews. A total of 202 adult long-term urinary catheter users participated. Participants were randomized to treatment or control groups following collection of baseline data. Generalized estimating equations (GEE) were used for the analysis of treatment effect.

Results—In the intervention group, there was a significant decrease in reported blockage in the first six months ($p = .02$), but the effect did not persist. There were no significant effects for catheter-related urinary tract infection or dislodgment. Comparison of baseline rates of adverse outcomes with subsequent periods suggested that both groups improved over 12 months.

Discussion—A simple–to–use catheter problems calendar and the bimonthly interviews might have functioned as a modest self-monitoring intervention for persons in the control group. A simplified intervention using a self-monitoring calendar is suggested—with optimal and consistent fluid intake likely to add value.

Keywords

longitudinal research; quality of life; randomized clinical trial; self-management; urinary catheterization

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Indwelling urethral or suprapubic catheters are used by individuals with chronic urinary retention who are unable to perform intermittent-catheterization because of poor hand dexterity, no caregiver assistance, difficulty in using the bathroom, or in select cases of incontinence. While many catheter users have spinal cord injury (SCI) or multiple sclerosis (MS), the population also includes those with other neurological disorders, diabetes, or disease/injury to the bladder region. Unfortunately, indwelling urinary catheters are seldom trouble free (Cottenden et al., 2013; Wilde, McDonald et al., 2013). Data collected in a longitudinal study of 43 long-term catheter users indicated that recurrent problems affect the great majority. Prevalence rates during eight months of catheter use were 70% for catheter-associated urinary tract infection (CAUTI) with a rate of 8.4/1000 catheter days; 74% for

blockage; and 33% for catheter expulsion or dislodgement (Wilde, et al., 2010). For a two-month period prior to the beginning of this randomized clinical trial (RCT), catheter problems were reported as: 31% for CAUTI, 24% blockage, and 12% dislodgment (Wilde, McDonald et al., 2013).

These complications are distressing to patients/families (Wilde & Cameron, 2003; Wilde, 2003) and contribute to increased healthcare expenses, such as additional clinic, home care, or emergency department visits or hospitalization (Wilde, McDonald et al., 2013). Interventions to address prevention of CAUTI in long-term catheter users such as the use of silver coated or antimicrobial coatings on the catheter (Parker et al., 2009) installations to the drainage bag (Thompson et al., 1984), or special cleaning of the urinary meatus (Burke, Jacobson, Garibaldi, Conti, & Alling, 1983) have not been successful. Although research in self-management of chronic conditions in diabetes (Coyle, Francis, & Chapman, 2013), stroke (Lennon, McKenna, & Jones, 2013), and asthma (van Gaalen et al., 2013) has grown, no self-management clinical trials have been found in catheter users (Cottenden et al., 2013; Niël-Weise, van den Broek, Peterhans, da Silva, & Silva, 2012).

The research clinical trial (RCT) for the current report was developed inductively through six previous studies conducted primarily by the first author (MHW). These studies included research with 30 individuals who kept a urinary diary and were interviewed twice to determine what their self-care practices were (Wilde & Dougherty, 2006). A concept analysis was next conducted of self-monitoring, delineating key attributes and how it fit within self-management literature (Wilde& Garvin, 2007). Then a pilot study teaching self-monitoring of urine flow in long-term catheter users was conducted. The results of the pilot study indicated that optimal fluid intake and preventing dislodgment were the most useful self-management components reported by study participants. Importantly, CAUTI decreased in the six months during the single group pilot (Wilde & Brasch, 2008a). Taken together, the theoretical model for the current study proposed that the intervention would affect catheter self-management indirectly through self-efficacy, and directly; and that higher levels of awareness, monitoring, and behaviors related to catheter care would improve outcomes (Figure 1; Wilde, Zhang et al., 2013).

The aim of the study was to determine the effect of the self-management intervention on health outcomes compared to the usual care control. It was hypothesized that the self-management group would: (a) have fewer episodes of UTI (and severity), blockage, and dislodgement of the catheter; (b) have decreased unplanned catheter-related healthcare utilization, including hospitalizations, emergency department visits, and fewer nurse home/or clinic visits; and (c) report higher catheter-related quality of life.

Methods

Design

The study was a randomized, single-blinded experimental design with repeated measures every two months over a 12-month period. The design called for 101 individuals to receive the self-management intervention and 101 to receive usual care (catheter-related care provided by home care nurses, clinics, or private providers).

Inclusion/Exclusion Criteria

Eligible participants were adults age 18 and over. Inclusion criteria were: (a) expect to use an indwelling urethral or suprapubic catheter for at least one year, and will be in the study region for at least four months; (b) can complete study measurements alone or with the help of a caregiver; (c) speak English; and (d) have access to a telephone for data collection. Because we wanted to target only individuals who might benefit from this study and, thus, better determine effectiveness, our participants also must have had a catheter problem of CAUTI within the last year, or blockage or dislodgement within the last six months, or be new to a catheter within the last year. Individuals were excluded for terminal illness or cognitive impairments. Children under 18 were not included because they might not have the capacity for self-care, which includes directing others.

Setting and Recruitment

Participants consisted of community-dwelling individuals recruited in two distinct regions by two study sites: (a) a university in a large northeastern U.S. state, and (b) a home care agency which conducts research in a large metropolitan area in the same state. For the university site, participants were recruited through nurses or physicians in home care agencies, medical center clinics, hospitals, and private medical offices (e.g., urology). Screening for eligibility and interest in participation was conducted by phone by the first author (MHW) or the project coordinator after contact information was received from providers who had permission to do so from potential participants. Some catheter users contacted the researchers themselves. In the home care agency, their database was used to identify potential participants with a catheter for telephone call screenings and recruitment by trained study interviewers. Using data from the agency's U.S. Outcome and Assessment Information Set (OASIS) for home care, catheter users were screened and excluded if they had a poor prognosis/life expectancy, cognitive impairment, confused, severe speech impairment, behavior problems, diagnosis indicating dementia, or had been previously interviewed (in another study or declined). Data were collected from June 2009-June 2012 in the homes of community-dwelling individuals and through telephone contacts over 12 months of participation.

Sample Size and Power Calculations

Power calculations were performed to determine a sample size for an adequately powered study to detect clinically meaningful effects across multiple outcomes. For each of the primary outcomes, *a priori* range of clinically meaningful effect sizes was determined based on previous research. All calculations employed a significance level of .05 and 80% power. Power analyses were performed with SAS 9.1 using Monte Carlo simulation resampling techniques for general estimating equation (GEE) analysis (Gastañaga, McLaren, & Delfino, 2006; Yuan & Hayashi, 2003). The analysis indicated that a sample of 220 (160 completers) would provide sufficient power to detect medium effect sizes (15% to 30% differences between groups) for the primary health status outcomes. However, health care utilization measures, such as hospitalizations and ED visits, require larger samples due to their relatively rare frequency of occurrence.

Ethics/Human Subjects

The study was approved at each site by their respective bodies for protection of human subjects. A coordinated approach assured that the same processes were used, including the same consent form with stamps and contact information from both sites. A Data Safety Monitoring Board was formed and convened annually to assess interim results and potential adverse events.

Randomization and Blinding

Randomization was conducted by the main study statistician who directed the processes with the study coordinators at each site—each of whom subsequently enrolled participants at their own site and allocated them to treatment or usual care after completion of the baseline home visit (HV) interview. Participants were stratified by site to balance the large number of study subjects in the large metropolitan area (75% of participants), as compared with the university site (25% of participants) which was a combination of urban, suburban, and rural areas. Block randomization with random block sizes of 4, 6, or 8 was carried out independently at the two sites to balance the two treatment groups. For each site, a sequence of random assignments was generated by the study statistician and sealed in sequentially numbered envelopes by the study coordinator. The participants were sequentially assigned the treatment after completing the consent and initial HV interview; then, the study nurse called those allocated to the intervention and made arrangements for the first nurse contact in the home. Study investigators, data gathering teams, and statisticians were blinded to allocation status until the final analyses were completed.

The Urinary Catheter Self-Management Intervention

The intervention designed to improve self-management in people with long-term, indwelling urinary catheters was based on self-efficacy theory (Bandura, 1997). Sources of urinary catheter self-efficacy were targeted in the nurse home visit interventions—specifically mastery experiences—vicarious observation, verbal persuasion, and knowledge about physiological status.

Each of the two study sites followed identical intervention protocols, which consisted of three home visits and one telephone call by a trained registered nurse to deliver the intervention. Two home visits took place in the first month and a third (booster) visit occurred at four months. During the first home visit, participants were taught to conduct self-monitoring using a three-day urinary diary to record observations and measurements of fluid intake and output (I & O), urine characteristics, and sensations of flow. This was to teach awareness of urine flow, basic self-monitoring skills, and to increase their level of mastery, thus, contributing to increased catheter related self-efficacy. During the second home visit, about a week later, self-management skills were taught first by reviewing the information from the urinary diary, calculating the intake and output averages and comparing these to an optimal volume (30ml/kg body weight), and identifying the individual’s catheter-related problems. Anything notable about I & O, the color/character of urine, or of urinary sensations, was discussed and implications for self-management pointed out.

An educational booklet which had been piloted and viewed as very helpful (Wilde, Zhang, et al., 2013) was then provided and discussed, which focused on basic catheter self-management skills related to: (a) maintaining optimal and consistent fluid intake; and (b) preventing catheter dislodgement—which were the key components of the intervention. In the presence of certain bacteria which cause urea in the urine to split, sodium, magnesium, and calcium will precipitate from the urine—often at about a pH of 6.8, causing sediment and encrustation. However, researchers found that urine pH could increase to as high as 9 or 10, and the catheter might not block if fluid intake is increased to dilute the concentration of minerals (Khan, Housami, Melotti, Timoney, & Stickler, 2010). This is our foundation for the fluid intake requirements, which we set at 30ml/kg body weight (Gray & Krissovich, 2003).

Other modules of the booklet were reviewed briefly or in-depth, depending on interest or need. These were: recognizing early symptoms of CAUTI; living with the catheter; promoting optimal catheter change intervals; decreasing caffeine; decreasing leakage; emptying and cleaning the drainage bag; making adjustments for sex; and recognizing early symptoms of autonomic dysreflexia (for people with spinal cord injury/disease). Goals, if any, were written in the educational booklet. A motivational bookmark with quotes and pictures was reviewed to help encourage participants to be attentive to urine flow.

Two weeks later, the study nurses called to answer questions and, if needed, helped the participants revise goals or plans. At four months, a third home visit served as a booster of the intervention to further refine or modify goals/plans as the catheter user desired. Family or caregivers were encouraged to be present, but the intervention was delivered to the catheter user.

Intervention compliance and fidelity—Two study nurses (one at each site), who were trained together at the beginning of the project, delivered all the intervention components. Multiple strategies were used to establish and sustain the fidelity and integrity of the intervention. These involved: (a) standardization of the intervention and training, including use of a detailed training manual that incorporated Bandura's self-efficacy concepts (Bandura, 1997); (b) randomly selected fidelity assessments of 10% of the interventions—half by audiotape and half in-person home observations; (c) at least monthly conference calls; (d) training study nurses together; (e) tracking study nurse activities and responsiveness of the participants; (f) assessment of participant skills at the end of the study; and (g) inclusion of fidelity assessment in the analysis plan. The results of the audiotape and in person fidelity assessment indicated that competence and adherence to the intervention parameters were highly scored with most means between 4–5 (5 was the highest possible score). Also, because there was little variability in the proportion of the intervention participants who received the intervention contacts (i.e., 98% for HV1, 95% for HV2, 93% TC at two weeks, and 91% HV3 at four months), we decided it was not necessary to adjust for fidelity in the main outcomes analysis. All participants, regardless of group allocation, continued to receive usual nursing and medical care.

Usual Care

Participants randomized to the control group received usual care.

Measures

Measures were developed for this study based on previous research of the first-author's team (Wilde & Brasch, 2008a; Wilde & Dougherty, 2006). Instrumentation was modeled on the Stanford Chronic Disease Self-Management programs (http://patienteducation.stanford.edu/). Participants in both groups were administered identical data collection instruments. At baseline, self-report was used for data collection related to the two-month timeframe prior to the study (for evaluating equivalence of the groups), and every two months for 12 months thereafter through telephone call interviews. To improve accuracy of recall, all participants were asked to maintain an ongoing catheter calendar over the 12 months of the study, using letter symbols for problems: CAUTI (U), blockage (B), and dislodgement (D). Treatments were identified as antibiotic (A), extra nurse home visit (HV), extra office visit (O), hospitalization (H), and emergency department visit (ED). For missed interviews, data were collected for the primary outcomes at the next scheduled interview—if the study participant had kept track of problems in their catheter calendar. This occurred only nine times.

Outcomes

Primary outcomes consisted of catheter-related complications of CAUTI, blockage, and dislodgement. CAUTI was defined as a urinary tract infection that was treated with an antibiotic prescribed by the person's healthcare provider. Blockage was defined as an occurrence in which the urine would not flow through the catheter due to an obstruction of the catheter tube. Blockage was distinguished from kinks or twists that are external to the catheter tube. Dislodgement occurred when the catheter fell out or became displaced accidentally due to traction (i.e., pulling on it). Catheter-related quality of life was also a primary outcome using our previously developed measure with a five-point Likert scale from 1 = *strongly agree* to 5 = *strongly disagree*; higher scores reflect better quality of life (Wilde, Brasch, Getliffe, McMahon et al., 2010).

Excess healthcare expenditures (treatments) related to catheter problems were also primary outcomes; these included extra nurse or clinic visits, hospitalizations, rehabilitation, and emergency department visits. Additional information was asked about each episode of CAUTI regarding the perceived severity of the infection (on a scale of 1–10, with 1 = *very mild* and 10 = *most severe imaginable*), and the number of days hospitalized or in rehabilitation specifically related to the CAUTI.

Data Analysis

Standard data cleaning procedures were applied to screen for errors and potential univariate and multivariate outliers. These procedures led to the removal of blockage data (percentages/month, counts, treatments) for one participant due to inconsistent and contradictory responses. All other data were used; several outliers for blockage were

adjusted by windsorizing to 9 as the maximum number of events in a two-month period for testing group differences.

Intention-to-treat analysis was used. Data were analyzed with SAS 9.3 (SAS Institute Inc., Cary, NC, USA). Generalized linear models were utilized with an identity link function for continuous outcomes (CAUTI severity and QOL) and a logit link function for binary outcomes. Randomization achieved comparability on demographic characteristics of participants and aspects of catheter use (Tables 1 and 2) in treatment and usual care groups. The groups were similar on key outcome variables during the two months prior to the study, except for catheter blockage ($p < .05$) and days hospitalized ($p < .01$) (Table 2). Thus, we fitted each of the models with and without controlling for baseline information on the outcome variable. First, data for the first six months were modeled; then, data from the entire 12 month period of the study were modeled.

First six months—We let "group" be the indicator of treatment assignment (0 = *usual care;* 1 = *treatment*), and y_{it} be the outcome for the i^{th} subject at month t. Three models were developed for each outcome over the first six months of the study: a group differences model, a model for interaction of group and time; and a model controlling for baseline and time. The group differences model is

$$\mu_{it}=E(y_{it})=f(\beta_0+\beta_1*\text{group}) \quad (1)$$

where f is the appropriate link function, the intercept β_0 is the y-intercept in the usual care group when f is an identity function and mean log odds for the usual care group when f is the logit link, β_1 is the treatment effect, and the "*" symbol denotes multiplication. The interaction model, controlling for baseline and time is

$$\mu_{it}=E(y_{it})=f(\beta_0+\beta_1*\text{group}+\beta_2*\text{y}_{\text{i0}}+\beta_3*\text{month}+\beta_4*\text{group}*\text{month}). \quad (2)$$

When the interactions in Equation 2 were not significant, we further modeled the data controlling for baseline and time, with

$$\mu_{it}=E(y_{it})=f(\beta_0+\beta_1*\text{group}+\beta_2*\text{y}_{\text{i0}}+\beta_3*\text{month}). \quad (3)$$

In the models given in Equations 1 and 3, inference about β_1 provides information about the treatment effect, either as difference in outcome (CAUTI severity, quality of life) or difference in log odds of the outcome (binary outcomes) as a function of group (Equation 1) or group, baseline, and time in months (Equation 3).

Complete 12 month outcomes—We applied the same group difference model in Equation 1 to the 12-month data (i.e., t = 2, 4, 6, 8, 10 and 12). For the models controlling for baseline and time (Equations 2 and 3), an indicator variable "second" was added to allow modeling differences between the first and second six months of the study (scored 0 when t = 2, 4, or 6 months and 1 when t = 8, 10, and 12 months). An interaction term between

"second" and "group" was added to the models described in Equations 2 and 3 to detect possible treatment effects between the first and last six months of the study, shown as

$$\mu_{it}=E(y_{it})=f(\beta_0+\beta_1*\text{group}+\beta_2*\text{y}_{\text{i0}}+\beta_3*\text{month}+\beta_4*\text{second}+\beta_5*\text{group}*\text{second}) \quad (4)$$

and

$$\mu_{it}=E(y_{it})=f(\beta_0+\beta_1*\text{group}+\beta_2*\text{y}_{\text{i0}}+\beta_3*\text{month}+\beta_4*\text{second}). \quad (5)$$

To deal with the dependency among the repeated measures, generalized estimating equations (GEE) with a first order autoregressive structure for the working correlation were utilized. We chose to use GEE because of the complexity and difficulty in modeling the correlations among the repeated measures—especially for discrete outcomes. As a semiparametric approach, GEE has the advantage that the inference is robust to the misspecification of the working correlation matrix—in the sense that estimates are consistent even when the working correlation departures from the true correlations among repeated measures (Diggle, Heagerty, Liang, & Zeger, 2002). Nominal *p*-values of .05 for two-tailed tests were used.

Results

Sample Description

Baseline characteristics of participants are displayed in Table 1. Ages ranged from 19–96 years (*Mdn* = 61). The range in duration of catheter use was 1 to 470 months (39 years). Self-reported diagnoses involved SCI (40%), MS (23%), diabetes (12%), stroke (2%), prostate (10%), spina bifida (1%), neurogenic bladder not otherwise reported (8%), Parkinson's disease (2%), and other (3%). Indications for indwelling catheter use were: immobility or difficulty moving around (58%), incontinence (57%), neurogenic bladder (54%), obstructed urine (32%), healing wounds (11%), and other reasons (11%). More than one indication could be listed. Additional detailed information about the participants at baseline is available in Wilde, McDonald et al. (2013).

Table 2 lists catheter-related health status, healthcare related to CAUTI, healthcare related to blockage, and quality of life at baseline by treatment group. Following randomization, groups appeared equivalent except that, during the two months prior to the study, the percentage of participants who had catheter dislodgement and the number of days hospitalized for a catheter-related CAUTI were higher in the control group.

Attrition was similar in both groups (Figure 2). There were more deaths in the experimental group than the control group (10 vs. 7). More participants whose catheters were removed were in the control group, mostly late in the study (3 vs. 10). Three persons withdrew from each arm of the study.

Treatment Effects

Table 3 lists treatment effects for primary outcomes for models depicted in Equation 3 (short term effects during the first six months of the study, controlling for baseline value and time) and Equation 5 (longer-term effects, controlling for baseline value, time, and first vs. second half of study). Complete statistical results are available from the authors (MHW).

First six months—Without controlling for any covariates, the overall short-term effect of the intervention relative to the control condition was assessed over the first six months (Equation 1). During the first six months, patients in the experimental group were less likely to report catheter blockage ($p < .05$) and fewer blockage-related nurse visits ($p < .05$), but they reported experiencing more severe CAUTI ($p < .001$) and significantly more CAUTI-related emergency room visits ($p < .05$), in terms of the percentage reporting such events. As shown in Table 3, we obtained similar conclusions controlling for the outcome variables at baseline (such as CAUTI) as well as time (Equation 3).

Complete 12 month outcomes—Without controlling for any covariates, the overall long-term effect of the intervention compared to the control condition was assessed over the whole 12-month period (Equation 1, with $t = 2, 4, 6, 8, 10, 12$). However, the overall difference in blockage between the two groups was not significant over this longer period. The experimental group continued to report significantly higher CAUTI severity scores ($p < .01$) and CAUTI-related emergency room visits (percentage reporting these events [$p < .001$] and frequencies of events [$p < .01$], as well as more hospitalizations for CAUTI (percentage [$p < .01$], frequencies [$p < .01$], and days hospitalized [$p < .05$]; Table 3; Table 4 [days hospitalized]).

Additional statistical tests of treatment effect controlling for baseline outcomes, time, and study period ("second") were conducted (Equation 4, not shown in a table.). The experimental group tended to report more CAUTI compared to the control group in the second half ($\hat{\beta}_1 = 0.66$; 95% CI [0.03, 1.30], $p = .04$), and no difference between the two groups during the first half year. The experimental group reported higher CAUTI severity than the control group in the first half year ($\hat{\beta}_1 = -2.80$; 95% CI [−4.62, −0.97], $p < .0001$), but no difference between the two groups during the second half. This indicates that the experimental group's CAUTI severity scores decreased relative to the control group from the first to the second half of the year. Blockages were fewer in the experimental group (by percentage) compared with the control group in the first half of the year ($\hat{\beta}_1 = 1.17$, 95% CI [0.38, 1.97], $p < .05$), but not in the second half of the year.

For other outcomes, the interaction was not significant, and was therefore removed. Treatment effect was estimated controlling for baseline outcomes and time. The experimental group had higher hospitalization for CAUTI ($p < .01$) and emergency room visits ($p < .001$; Table 3). Catheter-related quality of life did not differ significantly by group (Table 3).

Rates Comparisons

Table 4 provides detailed information about rates of blockage, CAUTI, dislodgement, and hospitalizations within groups over the course of the study and between groups. See Table 4 for a figure displaying the percentage of persons who reported experiencing catheter adverse outcomes of blockage, CAUTI, or dislodgement by group over time.

Catheter-related health status—Comparison of between- and within-groups rates per 1000 catheter days from baseline provided further details about changes in the primary outcomes over the first six months, second six months, and full study of 12 months. Blockage rates were significantly lower in the experimental group during the first six months ($p < .01$) and for the full study ($p = .03$), but there were no differences during the second half of the study ($p = .31$). Blockage improved significantly within each group at each assessment time from baseline.

For CAUTI, there were significant rate differences favoring the control group during the second half of the study ($p = .01$), but no differences for the first half ($p = .55$) or the full study ($p = .16$). Compared with baseline rate estimates, the experimental group had significant decreases in CAUTI rates during the first half of the study ($p = .02$), and for the overall full study time period of 12 months ($p = .05$). The control group had a significant decrease in CAUTI during the second half of the study ($p = .02$).

For dislodgement, rates decreased steadily in both groups by six months and 12 months, and there were no significant group differences. Dislodgement rates were lower in the experimental group at baseline, and larger decreases in dislodgement took place over time in the control group. During the second half of the study, the experimental group rate was slightly better than the control, but not significantly so ($p = .06$).

Hospitalization rates—Hospitalizations were significantly higher in the experimental group for most time points (Table 4). While the hospitalization rates favored the control group, rates decreased in both groups compared with their respective rates at baseline. Slight increases in rates were found during the second six months in the experimental group, compared with the first six months, but control group rates continued to decrease during the second six months. With further analysis at the individual level, we found that one person (in the experimental group) was hospitalized six times during the study, and five of these occurred in the second six months of the study. All others hospitalized in either group were hospitalized either once or twice during the study.

Discussion

Key Findings

Four Cochrane reviews concluded that there was an astounding lack of evidence to guide practice in long-term catheter use (Cottenden et al., 2013). Almost all intervention research in the past has focused on applications such as silver or antibiotic coatings (Johnson, Kuskowski, & Wilt, 2006) to the catheter, special cleaning of the urinary meatus (Burke, Jacobson, Garibaldi, Conti, & Alling, 1983), or drainage bag additives (Washington, 2001). None have proven effective in long-term catheter users. We believe this study is a unique

contribution because it is the first known study of its kind using a randomized clinical trial with an inductively derived, theory-based behavioral intervention (Wilde, 2002; Wilde & Brasch, 2008b; Wilde and Dougherty, 2006; Wilde & Garvin, 2007) to assess whether teaching catheter users self-management skills could decrease short-term, catheter-related problems, and whether improvements could be sustained over 12 months.

The GEE analyses indicated that there was a significant group difference in the first six months only for the blockage outcome—favoring the experimental group. Several interactions suggested that effects of the intervention were stronger for the first six months than the long-term effects over 12 months. Comparisons of rates for the first six months, second six months, and full study of 12 months—as well as the changes in rates from baseline—provided additional information suggesting that both groups improved over time. The line graphs (see Supplemental Digital Content) also indicate a general downward trend for both groups over the 12-month study.

The decreases in rates for CAUTI and blockage are believed to be clinically meaningful in both groups. In a recent report from the Agency on Healthcare Research and Quality (2013, p. 26), decreases in CAUTI in hospitalized persons went down in two months from 2.56 to 2.39/1000 catheter days—a relative reduction of 6.3%. The rate decreased even further at 14 months to 2.14/1000 catheter days—a 16.1% relative reduction in 14 months. These changes reflected that “progress has been made” toward national goals. CAUTI rates in community-dwelling persons can be as high as 8.4/1000 catheter days (Wilde, Brasch, Getliffe, Brown et al., 2010). In our study in the experimental group, the baseline CAUTI rate of 6.93/1000 catheter days decreased to 4.89 (a 29% relative reduction) and in the control group from 5.5/1000 catheter days to 4.12 (a 25% relative reduction; see Table 4).

Blockage prevalence is often cited as about 50% (Getliffe, 2003), but our previous research reflects a wide range of 74% over eight months in 43 persons (Wilde, Brasch, Getliffe, Brown et al., 2010) to 24% in our cross-sectional analysis—before random assignment at baseline in the current study (Wilde, McDonald et al., 2013). Importantly, there is no agreement of whether blockage is a one-time occurrence or a persistent pattern, and this might explain the wide range in blockage prevalence. Because our study tested group differences in this randomized trial, the blockage rates reported should be viewed with caution because blockage outliers were adjusted statistically to a maximum of 9 in a two-month time period. Prior to our study, there were no known reports of dislodgement rates. Therefore, we recommend that in future research, rates per 1000 catheter days should be calculated for blockage and dislodgement, as well as CAUTI.

Although blockage decreased significantly in the first six months in the experimental group—as compared with the control group—it is not known whether this was truly of benefit since the control group also improved and started with more blockages. In addition, since this effect did not last over the full 12 months, and the three nurse home visits took place in months one and four, there might be a benefit in expanding the intervention dose over time.

One major issue remains: whether the self-management intervention contributed to more hospitalizations, whether the experimental group was sicker and more prone to severe

CAUTIs requiring hospitalization, or whether this group simply noticed signs of CAUTI and acted on them more quickly. A priori, we had identified hospitalization as an indicator of CAUTI severity. Nevertheless, we had hypothesized that the intervention participants would contact care providers earlier and, thus, avoid some of the hospitalizations. However, if the experimental group were to have been more prone to serious CAUTIs—as severity scores suggested—then seeking early care—even if it included hospitalization—might have kept them from more serious consequences, such as long hospitalizations, sepsis, or death. There is no way to know this.

In a recent analysis addressing reasons for rehospitalization, chronic disease and vulnerability in patients' conditions seem to play a big role. Also, morbidity and mortality appeared to be inversely related, meaning sicker patients were treated more often at a hospital and extending their lives. Thus, hospitalization is not necessarily an indicator of poor quality in care (American Hospital Association, 2011). As with the other primary outcomes, we found a pattern of both groups improving over time in relation to hospitalization. That is, rates in hospitalization (times hospitalized and days hospitalized) decreased in both groups, and there were larger decreases in the first six months of the study (see Supplemental Digital Content).

The experimental and control groups both appeared to have improved during the study. Simple self-monitoring through use of the catheter calendar for bimonthly data collection by study participants in both groups could have contributed to fewer catheter problems overall. Essentially, it is possible that study participants in both groups became more aware of catheter problems due to the calendar, and were reminded of their catheter through the phone call interviews every two months. This could have contributed to changes in self-management behaviors, such as increasing fluids for early CAUTI symptoms. Teaching people with indwelling urinary catheters to keep track of key catheter problems (self-monitoring) in a simple notation calendar could be easy and practical to implement in practice. Because blockage decreased significantly in the first six months of the study, in the intervention group, there could be added value in teaching about optimal and consistent fluid intake.

Research implications include replication with additional nurse contacts over time, simplifying the intervention to focus on optimal fluid intake and preventing dislodgement, and using a simple catheter calendar as a self-monitoring intervention. Testing in a multisite RCT using data collection forms embedded in the home care patient records could eliminate self-reported data for outcomes. Evidence-based policies will lag until more randomized trials—or other forms of scientifically sound research—are conducted in this understudied and vulnerable population that use indwelling catheters for long-term bladder management.

Limitations

Self-reported data were used because standardized health records were not available. The catheter calendar was used to minimize self-report error. In addition, recall during the pilot study was excellent using bimonthly telephone interviews (Wilde & Brasch, 2008a). Agreement between self-reported catheter problems (CAUTI, blockage, dislodgement) and chart data was high in another study (97%; Wilde, Brasch, Getliffe, Brown et al., 2010).

Use of a medical diagnosis with antibiotic treatment for defining CAUTI could include some inaccurate diagnoses because some providers could have treated asymptomatic bacteriuria. Because bacteriuria is universal in this population after 30 days, colony counts would be useless. It was not possible to review multiple sources of data in multiple agencies to determine symptoms which might have been used for treatment decision making. Moreover, symptoms vary among individuals and over time. Thus, the decision for treating symptomatic CAUTI is complex, and it requires clinical judgment of the provider.

Attrition was similar in both groups. It was addressed regularly by the team during monthly meetings. Each of the 17 deaths that occurred during the study was evaluated. At the large home care agency site, charts were audited to determine whether there was any person whose death might have been related to the study. In one or two instances, details about comorbidities were discussed with the urologist on the team. The data safety monitoring board (DSMB) met annually with the lead investigators, statistician, urologist, and an outside researcher to review information about each death. The DSMB conclusion was that no deaths were related to the study, and that comorbidities contributed to each event.

Conclusions

Adults with a variety of health conditions are challenged with managing urinary catheter self-care to avoid complications and enhance quality of life. In a one-year RCT setting, participants receiving a self-monitoring, self-management intervention had less catheter blockage during the first six months. No other differences between treatment and control groups were noted. Participants in experimental and control groups improved over 12 months, compared with baseline. The simple-to-use catheter problems calendar and bimonthly interviews used for data collection may have served as a modest intervention in both groups.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

The authors acknowledge funding by National Institute of Nursing Research, National Institutes of Health (U.S.) #R01 NR01553.

The authors also acknowledge Penny Feldman, PhD, Sr. Vice President at the Center for Home Care Policy and Research, Visiting Nurse Service of New York; Harriet Kitzman, RN, PhD, Senior Associate Dean for Research, University of Rochester School of Nursing; and Robert Mayer, MD, Professor, University of Rochester/Strong Memorial Hospital.

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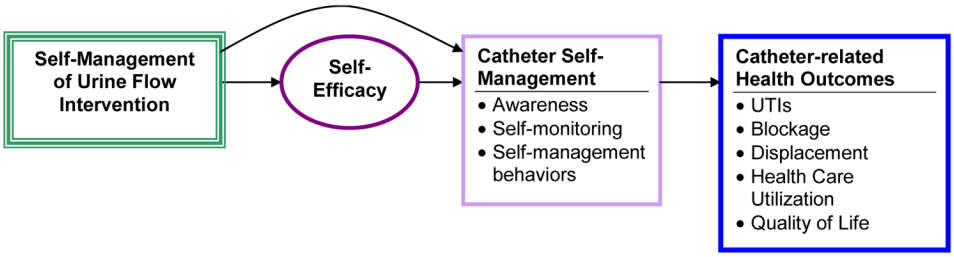

FIGURE 1.

Theoretical model for self-management of urine flow intervention (Wilde, Zhang et al., 2013). Used with permission.

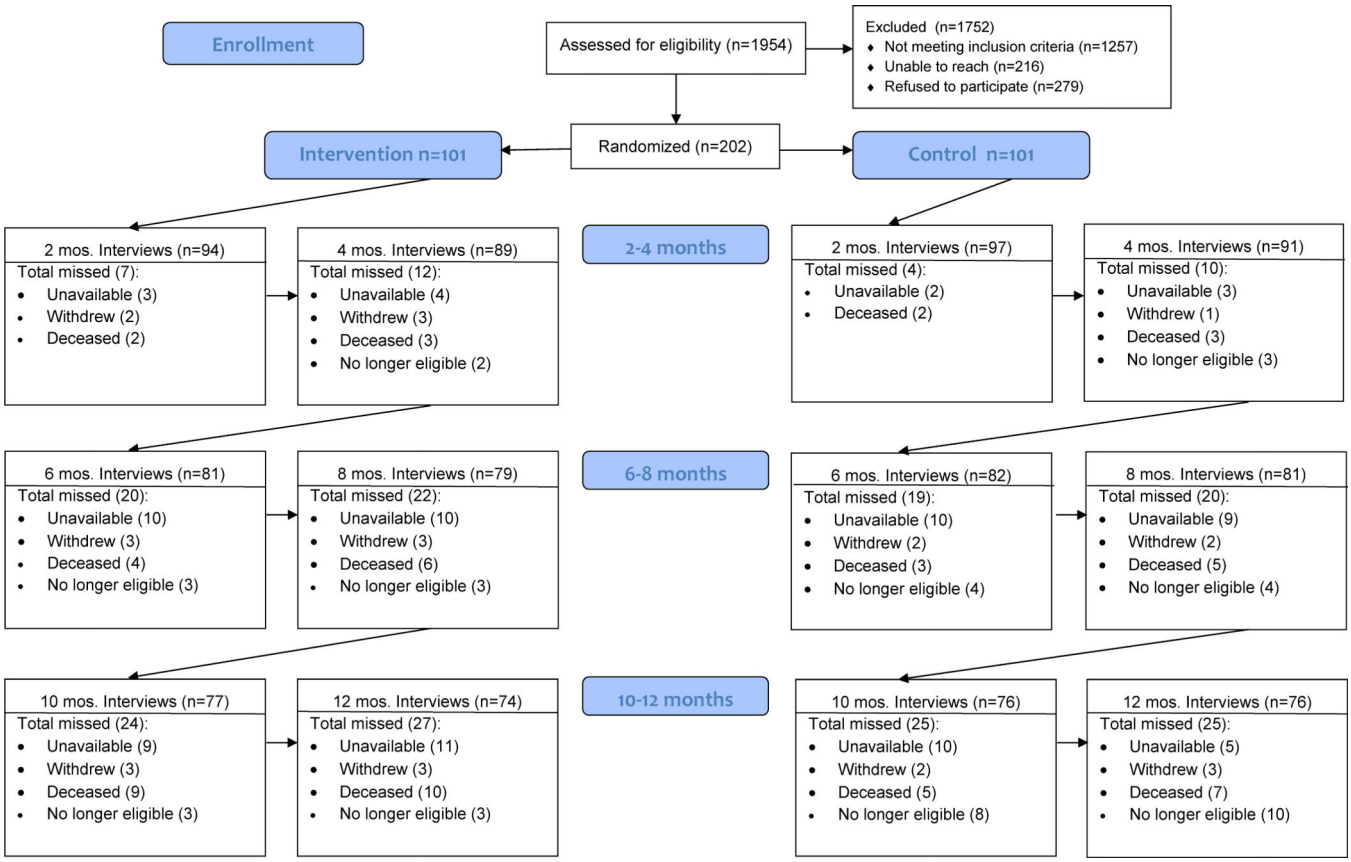

FIGURE 2.
CONSORT flow diagram

TABLE 1

Baseline Characteristics by Group

	Intervention		Control	
Characteristic	***M***	**(*SD*)**	***M***	**(*SD*)**
Age (years)	60.6	(*16.6*)	62.2	(*18.2*)
Catheter (months)	73.1	(*87.4*)	71.9	(*83.8*)
Catheter size (Fr)	18.4	(*3.3*)	18.7	(*3.2*)
	n	**(%)**	***n***	**(%)**
Gender (male)	53	(*52.4*)	50	(*50.0*)
Catheter type				
Urethral	57	(*56.4*)	55	(*54.5*)
Suprapubic	43	(*42.6*)	46	(*45.5*)
Both	1	(*0.0*)	0	(*0.0*)
Catheter balloon size				
5–10 ml	64	(*63.4*)	60	(*59.4*)
30 ml	11	(*10.9*)	18	(*17.8*)
Other	1	(*1.0*)	1	(*1.0*)
Unknown/no answer	25	(*24.8*)	22	(*21.8*)

Note. There were 101 participants in each group. None of the characteristics was significantly associated with treatment group assignment. Median duration of catheter use in the intervention group was 42 months; control group median was 37 months. Additional detailed information about the sample is available in Wilde, McDonald et al. (2013).

TABLE 2

Baseline Comparison of Key Outcomes by Group (For the Two Months Prior to the Study)

	Intervention					Control					
Outcome	***M***	**(*SD*)**	**%[a]**	**Rate[b]**	**95% CI**	***M***	**(*SD*)**	**%[a]**	**Rate[b]**	**95% CI**	***p***
Catheter-related health status											
Urinary tract infection (yes)	.42	(*0.71*)	33	6.9	[5.0, 9.4]	.33	(*0.53*)	30	5.50	[3.8, 7.7]	ns
Catheter blockage (yes)	.56	(*1.55*)	21	9.3	[7.0, 12.1]	.69	(*1.67*)	26	11.50	[9.0, 14.6]	.05
Dislodgement (yes)	.17	(*0.68*)	8	2.8	[1.6, 4.5]	.26	(*0.68*)	17	4.33	[2.8, 6.4]	ns
Healthcare related to CAUTI											
Hospitalization (number)	0.11	(*0.37*)	9	1.8	[0.9, 3.3]	0.1	(*0.32*)	8	1.50	[0.69, 2.85]	ns
Hospitalization (days)	0.61	(*2.33*)	9	10.2	[7.8, 13.1]	1.0	(*4.26*)	8	17.17	[14.01, 20.82]	.01

Note. CAUTI = catheter-associated urinary tract infection; CI = confidence interval; ns = not significant at $p < .05$; *SD* = standard deviation.

[a] Percent experiencing the event during the two months prior to the study.

[b] Rate per 1000 catheter days.

TABLE 3

Treatment Effects for Primary Outcomes

	First six months[a]				Full 12 months[b]			
Outcome	$\hat{\beta}_1$	**(*SE*)**	***p***	**95% CI**	$\hat{\beta}_1$	**(*SE*)**	***p***	**95% CI**
Catheter-related health status								
CAUTI (yes)	−0.17	(*0.266*)	ns	[−0.69, 0.35]	0.16	(*0.222*)	ns	[−0.27, 0.60]
CAUTI severity[c]	2.76	(*0.590*)	< .001	[1.60, 3.92]	1.60	(*0.467*)	< .01	[0.68, 2.51]
Blockage (yes)	−0.74	(*0.343*)	< .05	[−1.42, −0.07]	−0.23	(*0.291*)	ns	[−0.81, 0.34]
Dislodgment (yes)	0.29	(*0.328*)	ns	[−0.36, 0.93]	0.01	(*0.287*)	ns	[−0.55, 0.57]
Healthcare for CAUTI								
Hospitalized (yes)	0.81	(*0.527*)	ns	[−0.23, 1.84]	1.33	(*0.428*)	< .01	[0.49, 2.17]
Emergency visit (yes)	0.88	(*0.373*)	< .05	[0.15, 1.61]	1.06	(*0.337*)	< .001	[0.40, 1.72]
Nurse home visit (yes)	−0.06	(*0.402*)	ns	[−0.85, 0.73]	0.00	(*0.317*)	ns	[−0.62, 0.62]
Clinic visit (yes)	−0.37	(*0.408*)	ns	[−1.17, 0.43]	−0.06	(*0.333*)	ns	[−0.71, 0.59]
Healthcare for blockage								
Emergency visit (yes)	−0.62	(*0.978*)	ns	[−2.53, 1.30]	1.10	(*0.575*)	ns	[−0.02, 2.23]
Nurse home visit (yes)	−1.35	(*0.642*)	< .05	[−2.61, −0.09]	−1.02	(*0.470*)	< .05	[−1.95, −0.10]
Clinic visit (yes)	−0.62	(*0.629*)	ns	[−1.86, 0.61]	−0.42	(*0.560*)	ns	[−1.52, 0.68]
Quality of life[d]	−1.66	(*1.581*)	ns	[−4.76, 1.44]	−2.03	(*1.389*)	ns	[−4.75, 0.69]

Note. CAUTI = catheter-associated urinary tract infection; CI = confidence interval; ns = not significant at $p < .05$; *SE* = standard error. A positive sign for B_1 favors the control (usual care group); a negative sign favors the intervention group. Complete statistical results are available from the authors (MHW).

[a] Treatment effects were obtained controlling for baseline outcomes and time (Equation 3).

[b] Treatment effects were obtained controlling for baseline outcomes, time from 2 to 12 months, and first vs. second half of the study (Equation 5).

[c] Scored from 1 = *very mild* to 10 = *most severe imaginable*.

[d] Scored from 1 = *strongly agree* to 5 = *strongly disagree*; higher scores reflect better self-rated quality of life.

TABLE 4

Rates of Blockage, CAUTI, Dislodgement and Hospitalization in Treatment and Control Groups Over Time

	Experimental		Control			Within groups[a] (*p*)	
Outcome	**Rate[b]**	**95% CI**	**Rate[b]**	**95% CI**	***p***	**E**	**C**
Blockage							
Baseline	9.26	[6.98, 12.05]	11.50	[8.95, 14.55]	ns		
First 6 months	4.28	[3.32, 5.43]	7.41	[6.14, 8.86]	< .01	< .0001	.004
Second 6 months	5.31	[4.15, 6.67]	4.45	[3.41, 5.71]	ns	< .0001	< .0001
Full 12 months	4.76	[4.00, 5.62]	6.04	[5.20, 6.99]	.03	< .0001	< .0001
CAUTI							
Baseline	6.93	[5.00, 9.37]	5.50	[3.79, 7.72]	ns		
First 6 months	4.37	[3.40, 5.53]	4.83	[3.82, 6.03]	ns	.02	ns
Second 6 months	5.48	[4.31, 6.87]	3.29	[2.41, 4.39]	.01	ns	.02
Full 12 months	4.89	[4.12, 5.75]	4.12	[3.42, 4.91]	ns	.05	ns
Dislodgement							
Baseline	2.80	[1.63, 4.49]	4.33	[2.83, 6.35]	ns		
First 6 months	2.60	[1.86, 3.52]	2.74	[1.99, 3.67]	ns	ns	ns
Second 6 months	1.45	[0.89, 2.24]	2.44	[1.69, 3.41]	ns	.05	.03
Full 12 months	2.06	[1.58, 2.65]	2.60	[2.06, 3.24]	ns	ns	.02
Hospitalizations (number)							
Baseline	1.82	[0.91, 3.25]	1.50	[0.69, 2.85	ns		
First 6 months	1.01	[0.58, 1.65]	0.43	[0.17, 0.89]	ns	ns	.01
Second 6 months	1.68	[1.07, 2.52]	0.22	[0.04, 0.63]	<.001	ns	.004
Full 12 months	1.32	[0.94, 1.81]	0.33	[0.16, 0.61]	<.001	ns	.001
Hospitalization (days)							
Baseline	10.23	[7.84, 13.12]	17.17	[14.01, 20.82]	.01		
First 6 months	7.73	[6.4, 9.23]	4.03	[3.11, 5.13]	.01	ns	< .0001
Second 6 months	8.26	[6.81, 9.93]	1.01	[0.55, 1.69]	.001	ns	< .0001
Full 12 months	7.98	[6.99, 9.06]	2.63	[2.08, 3.28]	.001	ns	< .0001

Note. C = control; E = experimental.

[a]Change from baseline.

[b] Rate is per 1000 catheter days.

Published in final edited form as:
Home Healthc Nurse. 2013 October ; 31(9): 465–473. doi:10.1097/NHH.0b013e3182a89791.

Perceived Value of a Urinary Catheter Self-Management Program in the Home

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Abstract

A long-term indwelling urinary catheter intervention was tested in a randomized trial that is described in this article. The perceived value of the intervention to the catheter users, one of the study's specific aims, was assessed at the end of their 12-month participation and is reported here. Study participants' responses, our findings, and implications for home healthcare are discussed.

Introduction and Purpose of the Study

There is limited evidence to guide long-term urinary catheter users for self-management. They ordinarily are not in support groups of any sort and might not know others using such a device, yet many use an indwelling urinary catheter (suprapubic or urethral) for years (Wilde et al., 2013) or indefinitely. Those with intractable urinary retention who are unable to perform intermittent catheterization or have no one to do it are sometimes without other options. This type of urinary retention is most often caused by a neurologically based injury or disease, such as a spinal cord injury, multiple sclerosis, diabetes, or by obstructive prostate disease (Cottenden et al., 2013). In our experience, individuals with long-term catheters often learn about self-managing through piecemeal instruction from healthcare providers and by trial and error.

This report describes a new intervention to teach self-management to community-living long-term indwelling urinary catheter users and their perceived value of the intervention.

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The authors declare no conflicts of interest.

Understanding how the study participants responded provides information that could be useful in dissemination and/or changes in the research.

Background and Literature Review

Although policies and procedures are well developed for patients with indwelling urinary catheters in home care and in clinics, an emphasis on self-management is not the norm. Self-management is a form of collaborative care with a healthcare provider (nurse or physician) in which the patient learns to pay attention to bodily symptoms, makes observations and recordings (e.g., diaries), and determines how behavioral changes they are making affect the condition. Self-management research is often conducted with people having chronic conditions, such as arthritis (Ackerman et al., 2013), diabetes (Rothman et al., 2008), or asthma (Kaptein et al., 2010), but self-management research has not been done in indwelling urinary catheter users.

The National Home and Hospice Care Study conducted in 2000 by U.S. National Center for Health Statistics estimated that there are 148,400 urinary catheter users in the United States, for a prevalence of 0.05% in the adult population in community settings (CDC, 2013a). A more recent National Home and Hospice Care Survey in 2007 reported catheter prevalence in home care (excluding hospice) at 9% (n = 4683) (CDC, 2013b) or 135,000 people with catheters of the 1.5 million home care patients in 2007 (http://www.cdc.gov/nchs/fastats/homehealthcare.htm). However, it is not known how many of them have long-term catheters nor whether they use indwelling or nonindwelling catheters (Lisa Dwyer, National Center for Health Statistics, personal communication, June 20, 2013).

Persistent catheter-related problems are common in long-term catheter users. In one recent study of 43 people over an 8-month period, 74% experienced blockage of the catheter from encrustations, 70% had catheter-associated urinary tract infection (CAUTI), 79% had leakage of urine (bypassing), and 33% had accidental dislodgement (Wilde et al., 2010). In a larger study with 202 long-term indwelling urinary catheter users, catheter problems were recorded by recall for the previous 2-month period, and in this short period of time, 31% had experienced CAUTI, 24% had blockage, 12% had accidental dislodgment, 43% had leakage of urine, and 23% had catheter-associated pain (Wilde et al., 2013).

Most research in the past has focused on improving the catheter itself through: coatings, such as silver or antibiotic (Johnson et al., 2006), catheter materials like silicone (Schumm & Lam, 2008), instillations into the drainage bag (Washington, 2001), and special care to the urinary meatus (Burke et al., 1983), but none have proven effective in preventing blockage or CAUTI (Parker et al., 2009). Other interventions, commonly believed to be of value, such as smaller catheter size, cranberry juice consumption (Jepson & Craig, 2008), and acidic instillations or irrigations, have not been tested in randomized controlled trials in people with catheters (Moore et al., 2009). Closed drainage, which has been shown to significantly reduce the rate of CAUTI, is the only critical innovation in the last 40 years to prove beneficial (Stickler & Feneley, 2010). However, many persons with catheters open them daily to switch from leg to night bags or to clean the bags between uses. In the aforementioned larger study of 202 long-term catheter users, 58% used both leg and overnight bags, and a majority cleaned their bags, using water, soap and water, or a solution of water with bleach or vinegar (Wilde et al., 2013). Cleaning with a diluted bleach solution was shown in a seminal study to increase bag life to 1 month; however, rates of CAUTI remained unchanged (Dille et al., 1993). Consumption of a citrated drink (water with lemon juice) or additional fluids was tested in one study, and results are promising that either can decrease catheter blockage (Khan et al., 2010), but trials have not been done. Thus, evidence-based self-management strategies for persons using indwelling urinary catheters remain in a preliminary stage.

A first step for catheter users to prevent or minimize catheter-related problems (e.g., CAUTI, blockage, or accidental dislodgement) is to become aware of what to notice and how to self-monitor urine flow. Strategies can then be selected for self-managing the catheter based on this knowledge to address problems early to prevent more serious complications, such as an insidious CAUTI requiring intravenous antibiotics and hospitalization.

Study Description

A research study was conducted, building on the prior investigations. A new catheter self-management educational intervention was piloted (Wilde & Brasch, 2008a, 2008b) and tested for effectiveness in a randomized clinical trial in long-term indwelling urinary catheter users. The 4-year study was conducted in one northeastern U.S. state, including a large city and a mix of urban/suburban and rural areas. Two hundred and two adult persons with long-term indwelling catheters (56% urethral and 44% suprapubic) who were expecting to use catheters indefinitely, or at least for a year, were enrolled in the study for 12 months. Equal numbers of 101 were assigned to the intervention group or the control group. One hundred seventy-five study participants (87%) were recruited through home care agencies (one large city agency enrolled 152 persons); the rest were referred through a combination of clinics or private urological offices. Approximately equal numbers of men and women were enrolled, aged 19 to 96 years (mean 61, SD 17.4), with racial and ethnic diversity (White 57%, Black 30%, other races 13%).

The self-management intervention was theoretically based on Bandura's self-efficacy theory (Bandura, 1997). Self-efficacy is the confidence to perform a specific behavior and, in this study, optimal and consistent levels of fluid intake and preventing accidental dislodgment were the key behaviors targeted. Study participants were taught to pay attention to urine flow, self-monitor bodily changes, and choose appropriate self-management behaviors. The theoretical concepts of awareness, self-monitoring, and self-management (Wilde & Garvin, 2007) were central to the intervention, and Stanford's Chronic Disease Self-management program (Lorig et al., 2001) provided the overall model (Figure 1). The intervention was designed to enhance self-management of urine flow in the intervention group. The control group received only their usual care.

Study outcomes were: (a) catheter-related complications (CAUTI, catheter blockage, and accidental dislodgement), (b) complications' associated costs, and (c) quality of life. To measure study outcomes, data were collected from both groups about catheter-related problems for a year, once face to face in their homes when enrolled and then in six follow-up bimonthly telephone interviews with trained interviewers.

The intervention group was visited by a study nurse in their home three times, for a total of three home visits. Two of them occurred in the first month. The first home visit was to teach about self-monitoring using a urinary diary, and the second home visit was to use this information to plan for improved self-management and to introduce an educational booklet. This was followed by one phone call 2 weeks later to identify any additional issues and to reinforce the teaching. The third home visit was a "booster" of the intervention at 4 months to further refine teaching.

Specifically, study participants were taught to increase their awareness of sensations of urine flow and to learn how these change with daily activities or catheter-related problems. Problem areas were identified in conjunction with information from the 3-day urinary diary (intake and output and open-ended journal). After learning about basic catheter self-management (Table 1 from the Paying Attention Educational Booklet), all were taught to pay attention to fluid intake and catheter position to prevent dislodgement. Then the study

nurse reviewed all sections of the educational booklet, focusing on areas of individual interest (Table 2 and Figure 2). The study nurse filled out forms after each encounter, which were similar to a care plan, to remind her of the participant's catheter problems and interests or goals. Whenever possible, measurable goals were set and written into the educational booklet.

Below is a report of one of the specific aims of this study, to describe the perceived value of the self-management intervention received by the intervention group. A full report of the main outcomes for this research will be published elsewhere.

Perceived Value of the Catheter Self-Management Program

Methods

Study participants who received the catheter self-management intervention were contacted by phone by one of the two study coordinators within a month of their year-long study participation to assess their perceived value of the intervention. Not everyone was able to be reached or was not able to be interviewed; therefore, out of the 74 persons who completed the intervention arm of the study, 60 brief telephone interviews were conducted. Study participants were asked several quantitative questions about helpfulness of each component of the intervention, using a modification of items previously piloted (Wilde & Brasch, 2008a, 2008b), on a scale of 1 to 10, with 1 being not helpful at all and 10 being very helpful. Study participants were also asked five open-ended questions, allowing for comments to be shared, related: (a) goals, (b) changes to behavior, (c) impact on self-management, (d) helpfulness of the program, and (e) suggestions for improving the program. The interviewers took brief notes to obtain the comments data, which were entered into a spreadsheet and SPSS.

Data Analysis

Quantitative items were analyzed descriptively for means and standard deviations. For the comments data, a descriptive analysis was conducted using simple coding by two researchers, the principal investigator and a doctoral student. Coded comments were then organized into tables before writing a descriptive summary of responses for each item. Both coders agreed on the final codes, the organization of data, and the summary.

Results

Based on the scores, the study nurse visits and the intake and output part of the urinary diary were the most favored elements of the intervention (Table 3). A large majority of the persons rated each component of the intervention (i.e., intake and output, journal, educational booklet, study nurse encounters, and learning self-management) between 8 and 10 on the 10-point scale. The means (SD) for each component ranged from 7.25 (2.40) to 8.33 (3.15). The open-ended journal, which was identified in the study nurses' process recordings (not reported in this article) as being used by only 2% of the intervention sample, was valued less with the lowest mean score 7.25 (3.15).

Out of the 60 persons interviewed, goals were recalled by 21 persons (35%), not set by 36 (60%), and 3 (5%) did not remember. Responses to whether they were doing anything differently with the catheter because of the study were: 25 (42%) said no, 18 (30%) said yes somewhat, and 17 (28%) said yes greatly. 43 (71%) had suggestions for improving the program and 17 (29%) did not.

Goals Set During the Study

Fifteen persons had goals related to hygiene or preventing urinary tract infections (UTI), specifically cleaning near the catheter, drinking adequate fluids, and preventing UTI. Self-monitoring goals by 14 persons involved noticing changes in the urine, such as watching for sediment or urine color, or in paying attention to the catheter to maintain an appropriate position, or prevent dislodgment, kinks/twists, or leaks. Two persons also stated they wanted to stay healthy urologically.

Changes to Behavior

Study participants who had said they were doing things differently because of the study were asked to describe in what ways. Some reported changes that were similar to the goals they cited. Self-monitoring of the catheter was identified by nine persons related to repositioning the catheter to prevent leakage and twists, or checking the catheter position in relation to the bag or body; or watching for changes in the urine, sediment, or color. Eight said they paid attention more often to urine output or to avoid letting the bag get too full. Nine said they have increased their fluid intake and two said they keep better track of fluids. Eleven were focused more on the catheter itself, such as knowing the exact amount of water in the balloon, about irrigation or cleaning the bag, changing the catheter more often, and in managing the catheter when traveling by using a larger bag at home and smaller one for travelling, or knowing the locations of available bathrooms. Two stated they knew better when to call the provider for catheter problems. One worked on bowel management more and one stays away from caffeine. One reported fewer UTIs.

Impact on Self-Management

Participants also were asked how the study affected their catheter self-management. Six said they were more aware in relation to: cleaning the catheter, noticing urine color, emptying the bag to prevent urine buildup, and knowing where bathrooms were. Six reported having fewer UTIs, and two had less sediment, blockage, or mucus. One individual had more catheter comfort and was pain-free. Five people spoke of being more knowledgeable about and supported with the catheter, or knew when to call the provider. A few recognized patterns of problems, such as burning sensations and kinks. One noted being hospitalized four times recently (but we are not sure what that meant).

Helpfulness of the Program

The comments related to whether learning self-management was helpful or not were aimed at understanding more about the value of the catheter self-management intervention. Comments from 17 individuals were primarily about catheter-related knowledge gained, skills acquisition (including enhanced awareness of their bodily symptoms related to the catheter), and feeling cared for by the study nurse making home visits. There were just four negative comments: three who did not learn anything new and one who did not think program helped. Also three persons said they do not self-mange, but one said it was helpful to know.

Suggestions for Improving the Self-Management Program

Many suggestions and comments were received also, including more use of Web sites, combining the urinary diary forms (i.e., intake and output forms with the journal), managing pain, and sketches of instructions. Several asked for better designed catheters and equipment.

Discussion

For the quantitative assessment of intervention components, there was a possible small ceiling effect with higher percentages reporting 10 (very helpful) for the study nurse encounters and intake and output, by 41% and 32% of the sample respectively. The open-ended journal was not used by most study participants (2%) and this was the case also during the pilot study (Wilde & Brasch, 2008a, 2008b), and thus it should probably be eliminated from future tests of this intervention.

The information solicited about goals at the end of this 12-month intervention with 60 individuals is in stark contrast to the information collected by the study nurses in their process forms in which 82 persons set initial goals (81% of 101 in the self-management intervention group), and over 70% said they met their goals during the phone call in month 2 or the home visit in month 4. Perhaps goal setting was not a high priority or there was insufficient recall at 12 months, when so much time had passed after the intervention visits. However, those persons who did set goals used language to reflect the key components taught in the intervention, such as goals about fluid intake, preventing UTI, and noticing changes in urine or in the position of the catheter.

Intervention participants showed that they understood key study concepts because they described activities that demonstrated awareness, self-monitoring, and self-management related to fluid intake, preventing CAUTI, and proper positioning of the catheter. Some seemed to have an emotional connection with the study nurse, saying they felt “cared for” by her. A few said that no one else has talked with them like this about the catheter and in such depth, and this made them feel valued as persons. Responses also illustrated individual variation in how much the self-management intervention was liked and for what reasons.

Implications for Practice

Long-term indwelling catheter users can be taught to pay attention to urine flow. Specifically they should know how much fluid intake is right for them and what types of fluids should be monitored (e.g., caffeine). By noticing catheter-related changes—such as the color or character of the urine, catheter position, or kinks/twists in the tubing—and by responding quickly, catheter-related problems might be avoided or minimized. In this study, catheter users’ comments indicated how they valued and learned from the self-management intervention. Home care nurses are in an important and unique position to partner with their patients with catheters and their families to improve care and quality of life.

Conclusion

This may be the first self-management intervention in long-term indwelling urinary catheter users. Knowing how the study participants responded to the intervention is critical in determining its dissemination and overall research value. In summary, research participants seemed to like the intervention, were able to identify what they should pay attention to, and told us what they were doing differently related to their catheter. These new behaviors should be beneficial in their catheter-related health. Although this intervention is not ready yet for full dissemination—due to ongoing analysis and writing reports of the main study results—many of the components, such as the urinary diary (I and O), the basic self-management tips in Table 1, and the sample educational page on identifying UTI, could be useful for home care nurses teaching catheter self-management to long-term indwelling urinary catheter users.

Acknowledgments

Funding by National Institute of Nursing Research, National Institutes of Health (U.S.) #R01 NR01553.

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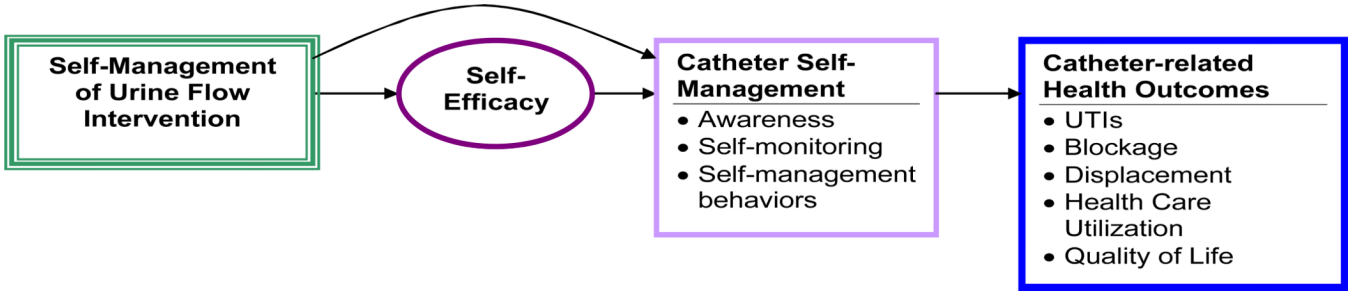

Figure 1.
Theoretical Model of the Study. UTI = urinary tract infection.

Recognize early symptoms of urinary tract infections (UTI) and act on it

- Early recognition might prevent serious problems, such as severe UTI requiring hospitalization.
- Quote from catheter user: "I think about how much I am drinking. It has become a way of life. The study made me more aware and I changed bad habits. A couple of times, I did not do what I was supposed to do and had a UTI."

Paying Attention	Things You Can Do
Signs of UTI: Urine Changes: Color—discolored, cloudy, dark, blood stained Odor—foul smelling, change in smell from usual Sediment (grit)—increased amount Pain and/or pressure in bladder area or back (burning possible, not common) Temperature—fever chills, sweaty/clammy General Symptoms—blahs!, feeling sick Functioning or mental changes—weakness, spasticity, change in the level of alertness Early, mild symptoms of autonomic dysreflexia (e.g., goosebumps, headaches, sweats) mainly in people with spinal cord injury	*"Stay on top of it psychologically."* Be sure you know when and how to contact your physician or nurse if you suspect that you are getting a UTI. Increase fluid intake especially water. Record in journal when you have a difficult catheter insertion and notice if a UTI develops afterward. Keep urine bag below bladder level. The tubing should be above the bag. Ask your healthcare provider about whether cranberry tablets or juice might help you. *"If something doesn't feel right, act on it quickly."* 

Figure 2.
Sample of educational module (Note: the quotes are from previous study participants (Wilde & Brasch, 2008a, 2008b).[1] UTI = urinary tract infection.

Table 1

Basic Catheter Self-Management

- **Stay aware**. Having a catheter requires that you *stay aware of your body* and how you feel.

- **Drink more water** than any other beverage! Limit coffee, and consider substituting tea and decaffeinated beverages.
- **Drink consistently**. Fluid intake needs to be at a good *level for your weight* and you need to drink in a *consistent* way to help prevent catheter blockage.
- **Your body needs fluids**. Most people need 2,000 to 3,000 cc of fluid a day. For instance, a 150-lb person would need 2,550 cc that is equivalent to about 10.5 glasses per day. More fluids are needed for hot weather or when exercising. My fluid goal is _____.
- **Pay attention** to the *color* of your urine. It should be light yellow all day long. The color of urine can be used a quick way to know whether you are drinking enough during the day.
- **Notice changes**. If the urine color changes, notice if you are doing something different, such as drinking less water or more caffeinated beverages or are using a diuretic medicine or water pill, such as furosemide or chlorothiazide.
- **Notice catheter position**. Notice where the catheter is after each change in your position and reposition it if needed. If you have others who help you, teach them to do this.
- **Check for kinks and twists** in the catheter by feeling with your hand from where the catheter leaves your body all the way to the drainage bag.
- **Ask for help**. If you need assistance with the catheter, learn to ask for help.

Table 2

Quick Guide to Catheter Problems (from the Paying Attention Educational Booklet)

Problem	Action Strategies
Decreased/inconsistent fluid intake	Increase fluid intake
Urinary tract infection	Increase fluid intake Recognize early symptoms of urinary tract infection and act on it
Catheter blocks	Increase fluid intake Promote catheter changes at best intervals
Adjustment to living with a catheter	Approaches for living with a catheter
Not sure of the best schedule for catheter changes	Promote catheter changes at best intervals
Kinks, twists, or tugs on catheter	Prevent kinks, twists, or tugs on catheter
Too much caffeine	Decrease caffeine
Catheter leaks	Decrease catheter leakage Empty urine bag
Urine bag odor	Clean urine drainage bag
Changes with sex	Make adjustments for sexual activity

Table 3

Helpfulness of the Self-Management Program Components

On a scale of 1–10, With 1 Being Almost No Help, and 10 Meaning It Was a Very Big Help	*n*	M	SDs	1–4	5–7	8–10
1. Intake and output	56	8.04	2.40	11%	12%	77%
2. Catheter journal	56	7.25	3.15	20%	14%	66%
3. Educational booklet	57	7.72	2.79	12%	19%	68%
4. Study nurse's home visits and TC	58	8.33	2.53	10%	12%	78%
5. How helpful was learning self-management	60	8.18	2.65	10%	18%	63%