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

Mary Wilde, RN, PhD¹, Margaret V. McDonald, MSW², Judith Brasch, RN, BS¹, James M. McMahon, PhD¹, Eileen Fairbanks, RN, MS, PNP¹, Shivani Shah, MPH², Wan Tang, PhD¹, and Eileen Scheid, RN, MS¹

¹University of Rochester, School of Nursing

²Visiting Nurse Service of New York, Center for Home Care Policy and Research

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.

Corresponding Author: Mary Wilde, RN, PhD, Associate Professor Nursing and Center for Community Health, University of Rochester, 601 Elmwood Ave., Box SON, Rochester, NY, 14642, Work: 585-275-9682, Fax: 585-273-1270, mary_wilde@urmc.rochester.edu.

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 to 12 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 Pearson's *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., SD 2.1) 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 47 of 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 = -0.157 , 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) by 46%, 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 (11 of 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 (47 persons/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 by 23%. 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.

References

- Cameron AP, Wallner LP, Tate DG, Sarma AV, Rodriguez GM, Clemens JQ. Bladder management after spinal cord injury in the united states 1972 to 2005. *The Journal of Urology*. 2010; 184(1): 213–217. [PubMed: 20478597]

- Cottenden, A.; Bliss, D.; Fader, M.; Getliffe, K.; Buckley, B.; Wilde, MH., et al. Management using continence products. incontinence, 4th international consultation in incontinence. 4th ed.. Paris: Health Publication Ltd; 2009.
- El-Masri YWS, Chong T, Kyriakider AE, Wang D. Long-term follow-up study of outcomes of bladder management in spinal cord injury patients under the care of the midlands centre for spinal injuries in oswestry. *Spinal Cord*. 2011
- Gould, CV.; Umscheid, CA.; Agarwal, RK.; Kuntz, G.; Pegues, DA.; and the Healthcare Infection Control Practices Advisory Committee (HICPAC). Guideline for prevention of catheter-associated urinary tract infections 2009. Atlanta, GA: Centers for Disease Control and Prevention; 2009.
- Jones S, Brooks A, Foxley S, Dunkin J. Care of urinary catheters and drainage systems. *Nursing Times*. 2007; 103(42):48–50. [PubMed: 17985750]
- Katz S, Ford A, Moskowitz R, Jackson B, Jaffee M. Studies of illness in the aged. the index of ADL: A standardized measure of biological and psychosocial function. *JAMA*. 1963; 185:914–915. [PubMed: 14044222]
- MAHC. Bladder catheter infection rate comparison Q32011 Infection Surveillance Project. 2011 Missouri Alliance for Home Care.
- Maki DG, Tambyah PA. Engineering out the risk for infection with urinary catheters. *Emerg Infect Dis*. 2001; 7(2):342–347. [PubMed: 11294737]
- Massa LM, Hoffman JM, Cardenas DD. Validity, accuracy, and predictive value of urinary tract infection signs and symptoms in individuals with spinal cord injury on intermittent catheterization. *The Journal of Spinal Cord Medicine*. 2009; 32(5):568–573. [PubMed: 20025153]
- Pearman, J. Prevention and management of infection: The urinary tract. In: Bedford, SG., editor. *Lifetime care of the paraplegic patient*. New York: Churchill Livingstone; 1985. p. 106–118.
- Royal College of Nurses (England). Catheter care: RCN guidance for nurses. 2008. Pub. Code. 003–237 ed. www.rcn.org.uk.
- Wilde MH. Living with a foley. *Am J Nurs*. 1986; 86(10):1121–1123. [PubMed: 3639703]
- Wilde MH. Foley catheter management at home. *Home Healthc Nurse*. 1991; 9(3):39–45. [PubMed: 2061084]
- Wilde MH, Brasch J, Getliffe K, Brown KA, McMahon JM, Smith JA, et al. Study on the use of long-term urinary catheters in community-dwelling individuals. *Journal of Wound, Ostomy, and Continence Nursing* : Official Publication of the Wound, Ostomy and Continence Nurses Society / WOCN. 2010; 37(3):301–310.
- Wilde MH, Carrigan MJ. A chart audit of factors related to urine flow and urinary tract infection. *J Adv Nurs*. 2003; 43(3):254–262. [PubMed: 12859784]
- Wilde MH, Dougherty MC. Awareness of urine flow in people with long-term urinary catheters. commentary by B. Roe. *Journal of Wound, Ostomy, and Continence Nursing*. 2006; 33:164–175.
- Wilde MH, Brasch J. Self-monitoring of urine flow in people with long-term urinary catheters. *Res Nurs Health*. 2008; 31(5):490–500. [PubMed: 18418847]
- Yang J, Xie M, Ngee Goh T. Outlier identification and robust parameter estimation in a zero-inflated poisson model. *Journal of Applied Statistics*. 2011; 38(2):421–424.

Table 1

Primary and secondary diagnoses

Primary			Secondary n					
	#	%	MS	Diabetes	Stroke	Prostate	Spina bifida	Neuroge nic 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)	

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 # (%)			
	#(%) all	# UR-SP	# M-F	# (%) all	# UR-SP	# M-F	# M-F
(some selected more than one)							
Self	16(8)	6-10	*12-4	20(10)	*7-13	14-6	14-6
Spouse-partner	7(4)	3-4	4-3	9(5)	4-5	6-3	6-3
Family member	7(4)	5-2	2-5	10(5)	7-3	4-6	4-6
Home care Nurse	112 (55)	**73/3 9	***42- 70	96(46)	**63- 33	38-58	38-58
Nurse or physician at clinic	45(22)	*19-26	31-14	45(22)	20-25	25-20	25-20
Nurse or physician at private medical office	29(14)	12-17	19-10	22(11)	9-13	16-6	16-6
Emergency department	7(4)	6-1	3-4	63(31)	32-31	40-23	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
Leaking (bypassing urine)	86	43	9	10
Sediment	127	63	24	29
Kinks/twists	40	20	13	8
Bladder spasms	72	36	37	24
Autonomic dysreflexia	26	13	4	31
				51
				39
				40
				30
				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.