

A QUALITATIVE DESCRIPTIVE STUDY OF SELF-MANAGEMENT ISSUES IN PEOPLE WITH LONG-TERM INTERMITTENT URINARY CATHETERS

Hypothesis / aims of study

The aim was to identify and describe issues and concerns of intermittent urinary catheter users for future self-management research and/or training programs. Self-management research related to clean intermittent catheterisation (CIC) could lead to improved compliance with the method as well as better quality of life.

Study design, materials and methods

This qualitative descriptive study involved in depth tape-recorded telephone interviews in 2008-09 with 34 people in the U.S. using permanent CIC, mostly those with spinal cord injury or multiple sclerosis. Recruitment was through Internet sites where individuals could link to the study website and then contact the researchers. Usual descriptive techniques were used for quantitative data obtained from the survey component of the interview. Content analysis for qualitative data (semi-structured conversational narrative data from the interview) involved comparing data from transcripts, summaries of interviews, codes, and memos. Miles and Huberman's [1] qualitative data analysis techniques were used, including data reduction, data display in tables, drawing conclusions, and verification. Themes and key quotes were identified to depict major findings.

Results

The sample included 13 males and 21 females, ranging in age from 21-72 (mean 42 years). The length of time doing intermittent catheterisation ranged from 4-368 months, with a mean of 140 months (95% CI= 107, 174 months) or 11.7 years. The mean frequency of catheterisations per day was 5.6 (95% CI= 5, 6.2).

Several concerns were identified: inadequate bathrooms, worries about urinary tract infection, and dealing with the inconvenience of CIC in everyday activities. Bathrooms were often inaccessible, too small, lacking in privacy, and/or unclean. In addition, many people did not have adequate insurance coverage, thus limiting choice in catheters and supplies. More experienced catheter users learned to plan for CIC in relation to fluid intake and daily routines as well as travel. Self-reported symptomatic urinary tract infection (treated with an antibiotic) over the previous year was 77 for the full sample ranging from 0 to 8 episodes (mean 2.3 95% CI= 1.8, 3). Three people were hospitalized for a total of 20 days during this time. Themes and selected quotes are in Table 1 and additional information describing intermittent catheter care is in Table 2.

Table 1. Themes and Selected Quotes

Themes	Quotes
1) Embodied knowledge: "Know your own body"	"Listen to your body and then if you have sensation of when you need to go then...listen to that and just know." "It's kind of this back and forth battle with me knowing am I getting enough fluid intake?...I don't want to pee my pants, but yet I also don't want to not be having enough fluid intake where I'm dehydrating myself".
2) CIC procedure: "Practice, practice, practice"	"...the further you scoot down the easier it is to insert the catheter". [female participant] "...I just practice and practice and practice, and the more I got it, then the better I got at it, and after the first year, it's just been like rote, easy, simple, I don't even think about it".
3) Catheter equipment: "If cost was not an issue"	: "...if cost was not an issue, then I would have been using the ones that are in the bags, self-contained. Then the cleanliness issue would be handled".
4) Bathroom access: "They don't have accessible bathrooms"	"It's funny that they'll make the door wide enough, but once you get in you can't shut the door".
5) Stigma and hassles "I would rather have the use of my bowel and bladder"	"It can be hard; it can be almost harder to deal with the whole loss of bowel and bladder than it can be being paralyzed....if I had the choice to either walk again or get back the use of my bowel and bladder, I would rather have the use of my bowel and bladder and use a wheelchair the rest of my life and never walk again".
6) Adjustment: "It's part of your life now"	"This is a part of your life now, it's something you have to deal with ... so deal with it and just make the best out of it... before you know it, it will be ...years down the road and it's like no big deal".

Table 2. Intermittent Catheter Care
Catheter material

Frequency of CIC

Plastic not coated	22	2-4 times a day	6
Latex	8	5 times a day	12
Hydrophilic	2	6 times a day	7
Silicone	2	7-9 times a day	9
Catheter types		Cleaning catheters	
Straight	15	New each time	22*
Female	8	Cleaned each use	11*
Coudé	3	Cleaned once daily	1
Self-contained	7	Cleaning solutions	
Catheter lubrication		Plain water	4
Lubricant besides water	17	Soap and water	10
KY	13	Antiseptic solutions	6
Unknown	3	Boil catheter	3
Saliva	1	Assistance with CIC	
Water lubricants	5	Independent	29
Hydrophilic	2	Assistant needed	5
KY & water	1	Spouse/family/friend	1/4/1
Just water	1	Paid caregiver	3
Soapy water	1		
No lubricant at all	12		

*Three people used a new catheter the majority of the time, but at times when out they would clean and reuse it.

Interpretation of results

Training for CIC could include additional information about types of catheters and supplies, how to acquire sample products, how to navigate public and private bathrooms, and how to balance CIC with daily living. Internet or in person group support might be beneficial in sharing information and personal knowledge as an ongoing supplement to initial CIC training. Further research in this area is needed.

Concluding message

Individualized training with people learning CIC could help them determine what works best and improve self-management capacity over time. This might equip CIC users to better plan for optimal frequencies of catheterisations and help prevent unnecessary use of indwelling catheters.

References

1. Miles, M. & Huberman, A., 1994. Qualitative Data Analysis, 2nd Ed. Newbury Park, CA: Sage.

<i>Specify source of funding or grant</i>	Unrestricted grant from Hollister International
<i>Is this a clinical trial?</i>	No
<i>What were the subjects in the study?</i>	HUMAN
<i>Was this study approved by an ethics committee?</i>	Yes
<i>Specify Name of Ethics Committee</i>	University of Rochester Research Subjects Review Board
<i>Was the Declaration of Helsinki followed?</i>	Yes
<i>Was informed consent obtained from the patients?</i>	Yes