



## Bladder and bowel self-management: theory, tools and practice

W9, 29 August 2011 09:00 - 12:00

Start	End	Topic	Speakers
09:00	09:10	Introduction - What is self-management?	<ul style="list-style-type: none"> <li>• Cara Tannenbaum</li> </ul>
09:10	09:25	Incontinence and overactive bladder	<ul style="list-style-type: none"> <li>• Francine Cheater</li> </ul>
09:25	09:40	Nocturia and other LUTS	<ul style="list-style-type: none"> <li>• Jo Booth</li> </ul>
09:40	09:55	Catheter use	<ul style="list-style-type: none"> <li>• Mary Wilde</li> </ul>
09:55	10:10	Bowel management	<ul style="list-style-type: none"> <li>• Donna Bliss</li> </ul>
10:10	10:30	Questions	All
10:30	11:00	Break	None
11:00	12:00	Case examples discussed in interactive format	<ul style="list-style-type: none"> <li>• Donna Bliss</li> <li>• Jo Booth</li> <li>• Francine Cheater</li> <li>• Cara Tannenbaum</li> <li>• Mary Wilde</li> </ul>

### **Aims of course/workshop**

There is a growing need for healthcare interventions that provide individuals with the self-management support they need to take on healthy behaviors and effectively manage their urine and bowel conditions from day to day. This workshop explores the theory behind self-management, and reviews its application to urinary and bowel incontinence, as well as catheter management and other lower urinary tract symptoms (nocturia, urinary frequency). The speakers will address the latest evidence and recent emergence of various paper and on-line tools available to aid patients in self-managing bladder and bowel dysfunction. Case examples will be discussed in an interactive format.

### **Educational Objectives**

This workshop provides an interdisciplinary and international perspective of new evidenced-based scientific information with practical applications for helping patients with urinary and bowel conditions engage in self-management. The concepts of self-management, self-efficacy, goal setting, action planning and self-monitoring will be reviewed. Resources for establishing a practice that includes self-management will be shared. Participants will develop skills for implementing a self-management plan with their patients through interactive case examples. Techniques for augmenting self-efficacy and altering self-management plans will be highlighted. Clinicians and researchers will learn about the availability and appropriateness of various measures for evaluating outcomes.

**ICS WORKSHOP 9: Bladder and Bowel Self-Management:  
Theory, Tools and Practice  
Monday 29<sup>th</sup> August 2011: 09:00 – 12:00**

Self-management: an overview

Cara Tannenbaum, MD, MSC

The Michel Saucier Endowed Chair in Geriatric Pharmacology, Health and Aging  
Associate Professor of Medicine & Pharmacy, University of Montreal,  
Centre de Recherche Institut Universitaire de Gériatrie de Montréal

What is self-management?

Self-management is a philosophy of care that supports patients to identify problems, make decisions, take appropriate actions, and alter these actions as they encounter changes in circumstance or disease (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Lorig & Holman, 2003). Self-management interventions are most successful when patients are internally driven to participate in a collaborative process of care, where the patient and health care professional share responsibility for the outcomes.

Several reasons exist for encouraging a self-management approach. The most compelling rationale is that patients with a chronic condition spend on average 2 hours per year in direct contact with a healthcare provider, but have to manage their symptoms on their own during the other 8758 hours of the year (Kaptein, Klok, Moss-Morris, & Brand, 2010; McWilliam, 2009). By teaching patients self-management techniques and a better ability to monitor their symptoms, patients will feel empowered and better equipped to control their illness.

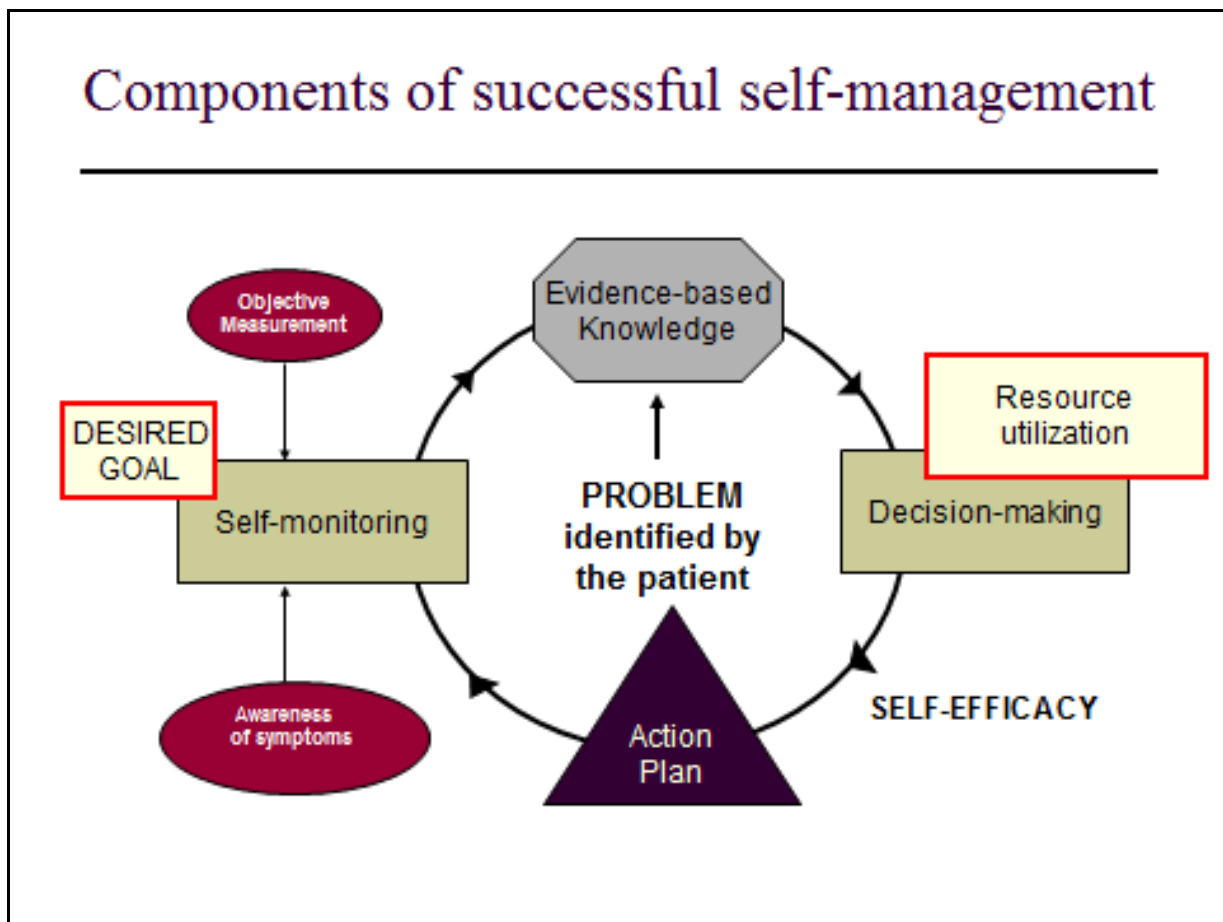
The primary tenet of self-management is that the patient identifies the health problem that needs fixing, as opposed to being told by their health care professional what to do. Subsequently (in an ideal scenario), the patient acquires evidence-based information that will provide them with a choice of interventions on how to manage their symptoms. Many patients unfortunately self-manage with techniques that are not evidence-based, and that do not lead to symptom improvement. Before initiating any self-management behaviour, it is recommended that the individual becomes attuned to their symptoms and learns to self-monitor (for example, with a bladder or bowel diary). By regularly and objectively monitoring their symptoms, the patient will be able to recognize whether a given intervention or change in behavior yields a positive or negative outcome.

Once the patient has made the decision to institute a change in behavior, for example pelvic floor muscle exercises, a detailed action plan is required that is both feasible and realistic. The patient can make their own action plan, or be guided by a health professional. An action plan for practicing pelvic floor muscle exercises might require the patient to say at what time they will do their exercises, where they will do them, for how long, in which position etc. A realistic timeline for assessing whether the intervention was successful is also required. This may be after 1-3 days in the case of a dietary intervention, or several weeks, in the case of pelvic floor muscle exercises. If the intervention was not successful, it may be because the self-management

behavior was not implemented effectively (i.e. the patient did not do their exercises). Was the action plan realistic? Was the patient able to carry it out? Were there any unanticipated barriers? Perhaps a new action plan needs to be formulated that is more feasible and realistic. Alternatively, other self-management techniques could be tried.

As the patient gains confidence for managing their symptoms, their self-efficacy, or belief in their ability to control their condition will also improve. Ultimately, goal attainment will occur. Setting goals for managing symptoms is an important part of self-management. Similar to developing an action plan, goal-setting must be realistic. Finally, it is important to reinforce that self-management behaviours should occur in partnership with health professionals. When the patient encounters difficulties, access to resources or health care professionals should be encouraged.

The box below summarizes the components of successful self-management.



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The evidence : Does self-management work?  
Professor Francine M Cheater, MA (Hons) PhD RN  
Director, Institute for Applied Research  
Glasgow Caledonian University, Scotland  
[Francine.Cheater@gcu.ac.uk](mailto:Francine.Cheater@gcu.ac.uk)

**Self Management Support: An Overview of the Evidence**

Most of us self manage our health most days, for example, if we have a headache many of us may choose to self medicate and take an aspirin and/or lie down for a while. A person with diabetes or heart failure or multiple sclerosis, for example, will have high and often complex self management demands and their needs for SMS will be much greater. In the UK 17.5 million people have one or more long term (LT) conditions (DH, 2004a) and 80-90% of care for LT conditions by patients or carers themselves (DH, 2004b). Most research effort on SMS has focused on long term conditions.

**Does Self Management Support (SMS) work?**

- For the purpose of this work shop a rapid review of the literature, undertaken by the Health Foundation (2011) and based on scrutiny of around 550 items of research (studies, systematic reviews) was used in combination with a selective review of the literature specific to SMS interventions for bladder and bowel. The SMS interventions tested varied widely in terms of aims, approach, content, duration and target group. Broadly interventions were of two types: Interventions that focus on building knowledge & technical skills and interventions that aim to build self efficacy (confidence in ability to self manage). Studies have measured one or more of the following outcomes: self-efficacy, self care behaviour, quality of life, clinical outcomes and health service use.

The results of what works is mixed- but overall the evidence indicates that:

- proactive, behaviourally focused SMS designed to increase self-efficacy can have positive impact on clinical symptoms, attitudes, & behaviours, QoL and patterns of resource use.
- Information provision alone insufficient - proactive strategies targeting behaviour change and self-efficacy work best (e.g. involving people in DM, emphasising problem solving, goal setting and follow-up).

## What is the evidence for bladder SMS?

Study	Target group/intervention	outcomes
Tannenbaum <i>et al</i> 2010	Community living women 55+ with UI/interactive workshop x1	Increased self treatment, increased help seeking
Kincade <i>et al</i> 2007	Community living women with UI 18yrs + / individual counselling, reminders, information	Decreased urine leakage
Wagg <i>et al</i> 2007	Community living women LUTs 45-64/self help leaflet plus continence clinic	Improved urinary symptoms
Brown <i>et al</i> 2007	Community living men 40+/3 group ed. sessions	Improved urinary symptoms
Williams <i>et al</i> 2006	Community living women 40 + / nurse led clinic	Decreased urine leakage
Boyington <i>et al</i> 2005	Community living women 50 +/on-line intervention	Improved QoL and reduced symptom distress
Diokno <i>et al</i> 2004	Community living women 60 +/- behavioural modification	Decrease urine leakage
Dougherty <i>et al</i> 2002	Rural community living women 55 + UI/ individual counselling	Decreased urine leakage, episodes urine, QoL
Milne 2000	Community living men and women 55+ with UI/ one to one education	urinary symptoms, help seeking and self care

## What does this tell us?

- Small number trials of SMS in the field of continence
- Most research on SMS conducted in middle age to older women –comparatively few studies in men
- Most studies used a behavioural approach – but the theoretically predicted mechanisms of action rarely defined
- Combination of components in intervention ‘package’ and SMS approaches vary - making comparisons across studies problematic.
- Often small samples, and short follow-up periods

- Economic impact not assessed
- But...**
- Overall – the results suggest that SMS can have a positive effect on clinical symptoms, attitudes, behaviours and QoL
- 

### **What do we still need to know?**

- The evidence base for SMS for continence care is small but growing.
- The volume of high quality research needs to increase to know *how* SMS works, *for whom, in what circumstances and why?*
- We need more modelling and feasibility/pilot work to better define and refine SMS content & delivery approaches, before proceeding to definitive trials
- How can we better support people in SM who have multiple co-morbidities?
- How can clinicians be better supported to engage in SMS with their patients (clinician-led care vs collaborative partnership)?

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A focus on incontinence, nocturia and other LUTS

Jo Booth, BSc (Hons), BA, PhD, RN, RNT, Senior Research Fellow, Centre for Gerontological Practice, Glasgow Caledonian University, Glasgow, UK

[Jo.Booth@gcu.ac.uk](mailto:Jo.Booth@gcu.ac.uk)

Urinary incontinence (UI) and other lower urinary tract symptoms (LUTS) are highly prevalent public health problems in the adult population increasing in prevalence and severity with age (Coyne et al 2008, Robertson et al 2007, Herschorn et al 2007; Perry et al 2000). The EPIC population study indicated an overall prevalence in four European countries and Canada of 64.3% of the adult population, using the current ICS definitions (Milsom & Irwin 2007). Storage LUTS (frequency, urgency, nocturia, urge UI) were considerably more prevalent than voiding (weak stream, straining, hesitancy, intermittency, terminal dribble) or post micturition (incomplete emptying, post micturition UI) LUTS for both men and women. The most common LUTS is consistently found to be nocturia, defined as waking one or more time nightly to void (ICS), and reported by 48.6% men and 54.5% women in the EPIC study (Milsom & Irwin 2007), 36% adults in Canada (Herschorn et al 2007) and 84% those aged 60 and over in two GP practices (Booth et al, 2010).

UI and LUTS are known to be bothersome, significantly impacting on health and health-related quality of life and associated with high costs to the individual and their carers in terms of social, physical, psychological, work productivity and sexual health (Coyne et al, 2008, Robertson et al 2007, O'Donnell et al 2005). More than a third of UK adults aged 40 and over will have a healthcare need in relation to storage LUTS each year, constituting a public health problem comparable in scale to musculoskeletal disorders (McGrother et al 2004) and recent work has highlighted the unnecessary suffering of people of all ages with bladder and bowel incontinence but particularly vulnerable groups, such as frail older people (RCP National Audit of Continence Care Sep 2010). These conditions are also costly to health services, for example clinically significant storage symptoms represented 1.1% overall UK National Health Service spending in 1999/2000 (Turner et al 2004).

Storage LUTS are associated with overactive bladder, mixed and urge urinary incontinence. They are more distressing than urinary stress symptoms and linked to falls, poorer physical health and reduced quality of life (Chiarelli *et al.* 2008; Mons *et al.* 2005). Studies have highlighted anxiety, fear of leakage, depression and hopelessness in people with overactive bladder and demonstrated that these effects are worse in those who also experience incontinence (Nicolson *et al.* 2008). Despite the considerable impact on the individual, their carers and society, UI and LUTS are under-reported and consequently under-recognised by healthcare professionals (Booth *et al.* 2010; Rodriguez et al 2007; Horrocks *et al.* 2004; Shaw *et al.* 2001). Current health policy emphasises the importance of self-care for the ongoing management of long term conditions in particular, but there has been minimal focus to date on UI or LUTS. As well as being conditions in their own right UI and LUTS are also key debilitating features of many chronic diseases, including diabetes, stroke, heart disease and neurological conditions). There is evidence that self-management is the most common approach to care in those with UI and LUTS (Booth et al 2010; Hagglund & Ahlstrom 2007, Gannon et al 2004). Reasons cited for



not consulting a healthcare professional include believing their condition to be part of normal ageing, not serious enough to disturb a busy person or assuming that no effective treatment is available. Thus the propensity for self-initiated management strategies and self-monitoring of effect is evident among those with UI and LUTS.

Studies have identified the types of self-management strategies that people commonly initiate when they identify they have a problem with urinary symptoms and /or UI. The strategies have been categorised as avoidance strategies, concealment strategies or treatment strategies (Milne & Moore, 2006; Diokno et al 2004) or problem focused and emotion focused (Booth et al 2010). Specific activities include fluid management (restricting amount, changing type and timing), use of aids to continence (absorbent products, urinals/commodos), voiding programmes (bladder training, double voiding, anticipatory voiding), pelvic floor muscle exercises and urge suppression, self discovered comfort and sleep hygiene measures. Many people also limit their participation in physical and social activities including travelling, overnight stays and holidays, which impacts on their quality of life. Some of the self-initiated treatments may be potentially harmful, for example drastic reductions in fluid intake (Elstad et al 2010), or manipulating prescribed medication regimes. While many people do entirely self-manage their bladder condition, in order to help the person to avoid inappropriate or ineffective behaviour practitioners are advised to explore with them their urinary symptoms and bladder related self-management activities.

Given the current policy emphasis on health promotion, anticipatory care and preventative interventions healthcare professionals should be seeking to promote self-care and support people to self-manage their LUTS and UI. There is a small but growing evidence base for the effectiveness of educational interventions to enable people to identify and understand their bladder condition as well as learn goal setting and problem solving techniques designed to help them gain improved control. Different delivery mechanisms for the health education and ongoing support for behavioural changes have been studied including individual face to face counselling (Kincade et al 2007, Williams et al 2006, Dougherty et al 2002, Milne 2000); small group workshop sessions (Tannenbaum et al 2010, Brown et al 2007, Diokno et al 2004), paper based information (Holroyd-Leduc et al 2011, Fransen et al 2008, Wagg et al 2007) and computer-based learning (Boyington et al 2005). A range of positive continence and quality of life related outcomes have been reported. Reductions in amount of urine leakage (Kincade et al 2007, Williams et al 2006, Dougherty et al 2002) and number of episodes of leakage (Holroyd-Leduc et al 2011, Williams et al 2006, Diokno et al 2004, Dougherty et al 2002) have been found. Improved urinary symptom status (Brown et al 2007, Wagg et al 2007, Diokno et al 2004) and quality of life (Holroyd-Leduc et al 2011, Kincade et al 2007, Boyington et al 2005, Dougherty et al 2002) have also been reported. People have initiated self-treatment as a result of supported self-management interventions (Tannenbaum et al 2010, Franzen et al 2008, Milne 2000), and a single continence promotion workshop has been shown to increase help seeking among older women (Tannenbaum et al 2010).

There is developing evidence that supported self-management may be effective in promoting urinary continence and reducing the impact of mild to moderate urinary symptoms in the adult population. The range of interventions, particularly those designed to support the individual's capabilities for goal setting and problem solving may enhance individual self-efficacy and enable improved bladder control. Potentially such self-management skills may be transferable to improve other aspects of the person's health, however more research is needed to establish a sound evidence base for supported self-management for LUTS and UI, the variety and

effectiveness of its components and long-term outcomes.

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Urinary Catheters: self-monitoring and body awareness  
Mary H. Wilde, PhD, RN  
University of Rochester, Rochester, NY, USA  
[Mary\\_Wilde@urmc.rochester.edu](mailto:Mary_Wilde@urmc.rochester.edu)

1. Case study presentation for Carol, an indwelling catheter user

2. Catheter use over time in persons with SCI

Bladder management	Percent Use: 1972	Percent Use: 1991	Percent Use: 2005	Continued use at 30 years
CIC	13 %	52%	50%	20%
Indwelling catheter	33%	17%	23%	71%
Condom (sheath)	35%	4.7%	1.5%	35%

Table 1. From US data base of SCI, surveys of bladder management every five years for 30 years. (Cameron et al, 2010).

3. The typical problems of urinary catheter users (estimated at 148,000 in home care agencies the U.S.) urinary tract infection (UTI), blockage, dislodgement, and leakage, leading to poor quality of life indicators. Catheter-related problems often require health care utilization resulting in increased health care costs.

4. Progression of Wilde research, which was inductive and iterative. Brief summary. Four studies in bold will be discussed.

- 1986 Descriptive study interviews--What are the problems of long-term catheter users-uti, blockage, leakage (bypassing)
- 1999 Phenomenological—What is it like –urine flowing; stigma or a “part of me”
- 2001 Chart audit—What is happening—between uti, blockage, fluids, urine flow
- 2003 Sensations of urine flow--More details—3 day diary and interviews, self care tips
- **2005 Pilot of self-monitoring What would happen if (predictive)**
- **2006-09 Longitudinal repeated measures to characterize catheter practices and problems every 2 months for 6 months**
- **2008-12 Randomized trial of self-management—ongoing**
- **2009 Qualitative phone interviews with intermittent catheter users to identify problems and issues**
- 2011- Urinary drainage bag decontamination, planning with Mandy Fader

5. Recent evidence—Self-reported repeated measures, longitudinal study (Wilde et al., 2010a)
- Participants (and/or caregivers) keeping track of catheter problems
  - Observing/recording urine output for three days at baseline, 2, 4, and 6 months
- Home care (n=10) and Internet (n=33)

Demographics

<b>43 participants: 23 females and 20 males</b> <b>Ages 23-91years (mean 49, median 46 years)</b>	<b>Racial background: (some with more than one race)</b> <b>4 American Indian or Alaskan Native</b> <b>3 Black; 1 Asian; 39 White; 2 Hispanic</b>
<b>Mean years of catheter use 11.7; median 8.8</b> <b>1-4 years: n= 12</b> <b>5-9 years: n= 11</b> <b>10-19 years: n=13</b> <b>20-49 years: n= 7</b>	<b>Diagnoses</b> <b>17 Spinal cord complete;14 Spinal cord incomplete</b> <b>1 Spinal cord unsure</b> <b>5 MS; 2 Diabetes</b> <b>3 Other neurological; 1 Pressure ulcer</b>

Table 2 Demographics of repeated measures study (Wilde et al, 2010A)

Key findings:

PROBLEM	Percent affected	Problems	Percent affected
<b>Catheter-associated UTI (CAUTI)</b>	70%	Pain	54%
<b>Blockage</b>	74%	Problems	44%
<b>Leakage (bypassing)</b>	79 %	Constipation	70%
<b>Accidental dislodgement</b>	33%	Irrigation	42%

Table 3. Prevalence of self-reported catheter problems over 8 month period (retrospective for two months at baseline and 2, 4, and 6 months. (Wilde et al., 2010A)

6. Pilot study to teach self-monitoring of urine flow Wilde, M.H. & Brasch, J. (2008a & b).

Single group design with 11 individuals over six months.

- Test feasibility of the intervention & new measures
- Nine of 11 participants reported that the intervention had helped them to pay attention to fluid intake.
- Episodes of UTI decreased over the course of the intervention, with the greatest drop between 2 and 4 months.

Awareness: How has your thinking changed?	Self-monitoring: What are you doing to monitor urine flow?	Self-management: What is done to maintain urine flow?
<b>Know I need to get more [fluid] <u>input</u> to manage catheter.</b>	Not changed much. Thinking about it every day.	Think how much I am <u>drinking</u> . It has become a way of life...Made me more aware and change bad habits. A couple of times did not do and had UTI.
<b>Know I need to get more [fluid] <u>input</u> to manage catheter.</b>	Puts cloth between skin and catheter. No more blisters.	<u>Drinking</u> more, continually all day long.
<b>Know I need to get more [fluid] <u>input</u> to manage catheter.</b>	More aware. Not doing anything	Getting catheter changed at right interval of 4 weeks. (Had not been consistent.)

Table 4. Comments from pilot study participants about awareness, self-monitoring, and self-management. (Wilde 2008a)

### Theory

7. Theory and research often are viewed sometimes as distinct activities, but in reality theory, research, and clinical practice intertwine and develop as researchers develop theory and test it in practice. For over 25 years, I have worked with profoundly disabled individuals who use long-term indwelling urinary catheters. I started with a clinical problem that perplexed me, how to prevent persistent catheter blockage and UTI. Recently my research has moved to the intervention level, from description, and theory is what brought me to this point.

8. Much literature is available on self-management for persons with diabetes, asthma, and weight control.

- There is very little known on self-management for catheter users.
- Theory guided work to intervention research.
- Developed ideas about symptom awareness and self monitoring as part of self-management.

9. Self-efficacy—confidence to do something (Bandura 1997)

- Much evidence that SE is good predictor of behavior
- SE is behavior specific

10. Awareness and Self-monitoring Wilde, M.H. & Garvin, S. (2007)

- Know what to notice (awareness)
- Observe & make notations, e.g., intake and output, description of symptoms, (self-monitoring)

11. Paying attention as an embodied process. (Wilde, 1999, 2003) Embodied knowledge of living with a chronic condition ties together awareness and self-monitoring activities, e.g., tools, diaries, journal, consistent observations.

**12. Self-management of Urine Flow in Long-term Urinary Catheter Users  
(Funded through NIH/National Institute of Nursing Research (2008-2012); 5R01NR10553)**

- Based on five previous studies (3 descriptive, 1 qualitative, & pilot)
- University of Rochester grant from NIH (NINR)
  - Wilde, PI, UR
  - Feldman, Co-I (Subcontract) VNSNY
  - 220 study participants-170 VNSNY and 50 UR- randomized to intervention or usual care control

***Intervention***

- Four contacts with Intervention nurse: 3 home visits, 1 telephone call
- Teaching self-monitoring for 3 days
- Urinary diary I & O and catheter journal
- Educational booklet
- To increase awareness, self-monitoring (observations and recordings), and self-management behaviors

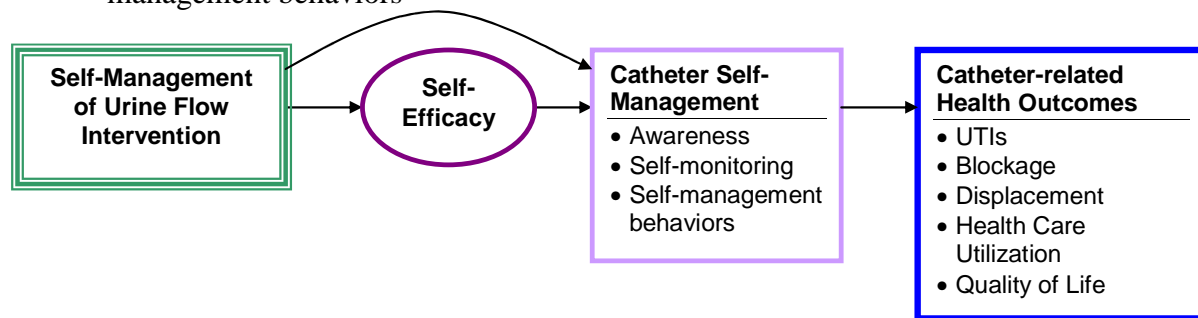


Fig. 1. Theoretical model for Self-management of Urine Flow Intervention (RCT)

***Data collection***

- Intake interview in the home
- Then randomized
- TC interviews at 2, 4, 6, 8, 10, 12 months
- Slightly longer interviews at 6 and 12 months for additional measures

*Following are examples of information in the catheter self-management educational booklet.*

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University of Rochester School of Nursing  
Mary H. Wilde, PhD, RN

### *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 2000 to 3000 cc of fluid a day. For instance a 150 pound person would need 2045 cc which is equivalent to about 8½ 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 Lasix, or Diuril.

**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.



## Quick Guide to Problems and Action Strategies

Problem	Action Strategies	See Page Number
Decreased/inconsistent fluid intake	Increase fluid intake	7
UTI	Increase fluid intake Recognize early symptoms of UTI and acting on it	7 8
Catheter blocks	Increase fluid intake Promote catheter changes at best intervals	7 11
Adjustment to living with a catheter	Approaches for living with a catheter	9
Not sure of the best schedule for catheter changes	Promote catheter changes at best intervals	11
Kinks, twists, or tugs on catheter	Prevent kinks, twists, or tugs on catheter	13
Too much caffeine	Decrease caffeine	14
Catheter leaks	Decrease catheter leakage Empty urine bag	15 16
Urine bag odor	Clean urine drainage bag	17
Changes with sex	Make adjustments for sexual activity	18
Autonomic Dysreflexia (for people with spinal cord injury)	Recognize early symptoms of Autonomic Dysreflexia	19


Goals

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

### Example of page in educational booklet: Increase fluid intake

- Low fluid intake might be associated with blockage and urinary tract infection (UTI).
- 17 cc./pound of body weight is recommended. This is an estimate; you need more in warm weather or for extra activity.

- “I am more conscious of what I drink. I am adamant about drinking 6 bottles of water, plus other fluids.”

Paying Attention	Things You Can Do
<p data-bbox="188 348 605 449">Notice whether you are getting enough fluids throughout the day.</p> 	<p data-bbox="631 348 1490 485">Drink approximately 2000-3000 cc. fluid or 8-12 cups (64-96 oz) per day unless you have a fluid restriction. More fluid than this is not advised as it can interfere with body defenses and/or electrolytes.</p> <p data-bbox="631 531 1463 596">If you like the water cold, keep several bottles in the fridge and refill them with fresh water every day.</p> <p data-bbox="631 642 1500 707">To add flavor to water, try 2 oz of cranberry or apple juice to 8-10 oz of water. You may also try adding a little lime or lemon juice.</p> <p data-bbox="654 753 1289 777">Keep fresh glasses of water throughout the house.</p> <p data-bbox="654 823 1294 846">Secure a jug or bottle of water to your wheelchair.</p> <p data-bbox="654 892 1276 915">Use a rigid straw so you don't have to suck hard.</p> <p data-bbox="654 961 1398 984">You may want to drink around meal times and before bed.</p> <p data-bbox="654 1031 1219 1054">Have a caregiver remind you to drink water.</p>
<p data-bbox="188 1163 591 1228">Notice changes color of urine every time bag is emptied.</p>	<p data-bbox="654 1163 1373 1228">Color should remain light yellow all day. If color gets dark or urine has foul smell, increase water.</p>
<p data-bbox="188 1276 591 1373">If you are on fluid restriction, make sure you stay within restricted range.</p>	<p data-bbox="631 1276 1442 1341">Record fluid intake occasionally to check that you are staying within range.</p>
<p data-bbox="188 1390 599 1486">Be aware of changes in daily activities, such as stress, illness, or travel.</p>	<p data-bbox="631 1390 1471 1455">Use a journal to increase awareness of how activity affects fluid intake, as changes may lead to inconsistent intake and output.</p>

### Symptom awareness of UTI

- Urine Changes:
  - Color – Discolored, cloudy, dark, blood stained
  - Odor – Foul smelling, change in smell from usual
  - Sediment (grit) – Increased amount
- Temperature – Fever chills, sweaty/clammy
- Pain and/or pressure in bladder area or back (Burning possible, not common)
- 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

Examples of some tips from experienced catheter users to promote vicarious observation, and improve self-efficacy.

- **“Drink the water and go!”**,
- “I measure intake and caffeine and notice the color of urine, and sediment in the tubing. I am really being aware.”
- “I check the position of the catheter when getting in and out of bed.”
- “Stay on top of it psychologically.”
- **“If something does not feel right, act on it quickly!”**

### Measures for Catheter Self-management

*Indwelling urinary catheter quality of life I-CQoL*—26 items; revised since publication (Wilde et al., 2010b)

- Testing now in RCT; Likert scale: SA, A, N, D, SD. Examples:
  - Q 1. I am concerned about not being able to empty my drainage bag before it gets too full.
  - Q 2. I am concerned about catheter blockage.
  - Q 3. I am concerned about getting a urinary tract infection.
  - Q 4. I am concerned about catheter leakage.
  - Q 5. I am concerned about the catheter getting pulled out by accident.
  - Q 6. I am concerned about difficult or painful catheter changes.
  - Q 7. I am concerned about where toilets are in new places.

### *Indwelling catheter self-efficacy*

- 15 items piloted and testing in RCT; examples:

*How confident are you that you can.....? (1-10)*

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

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

### ***Indwelling urinary catheter self-management***

- Piloted and testing in RCT now; examples:

*I want you to tell me how often you do these activities, if at all. The choices are: 1-Not at all, 2-sometimes or 3-most or all of the time.*

- 1. Pay attention to the types of fluids you drank, such as water or caffeine.
- 2. Make changes in types and amounts of fluids if urine color or composition changes.

### **Intermittent Catheterization**

13. Case study—

14. Intermittent catheter problems

- Psychological and concerns about stigma and worry. (Shaw et al., 2008).
- Adherence to regime critical (Woodbury et al., 2008)
- Most did not consider it a burden; 60% increased qol and 12% decreased qol (Kessler-2009)
- Communication skills of nurses and a friendly environment can enhance teaching catheterisation skills (Logan et al. 2008)

15. Recent Qualitative Descriptive study with CIC users (Wilde et al., 2011)

- Recruitment through Internet in U.S.
- In-depth telephone interviews
- N=34: 13 males & 21 females using permanent intermittent urinary catheters
- Ages 21-72 (mean 43 years)
- Length of time using CIC 4-368 months (mean 140 or 11.7 years)
- Diagnoses:
  - 24 Spinal cord injury
  - 6 Multiple sclerosis
  - 3 Other neurological
  - 1 Diabetes

#### Findings

- Worries about urinary tract infection
  - 77 self-reported symptomatic CAUTI (treated with antibiotic) in past year
  - Range 0-8 episodes (mean 2.3, 95% CI= 1.8, 3)
  - Four people hospitalized for total of 20+ days
- Inconvenience of CIC in everyday activities
- Many without adequate insurance coverage
- Limited/inadequate choice in catheters and supplies
- Inaccessible bathrooms
- Often too small, lacking in privacy, and/or unclean

## Self-management Themes

<b>1) Embodied knowledge—awareness and self-monitoring</b>	<p>“Listen to your body and then if you have sensation of when you need to go then...listen to that and just know.”</p> <p>“ 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”.</p>
<b>2) CIC procedure—self-management</b>	<p>“...the further you scoot down the easier it is to insert the catheter”. [female participant]</p> <p>“...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”.</p>
<b>3) Catheter equipment—self-management</b>	<p>“...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”.</p>
<b>4) Bathroom access—awareness &amp; self-management</b>	<p>“It’s funny that they’ll make the door wide enough, but once you get in you can’t shut the door”.</p>
<b>5) Stigma and hassles--awareness</b>	<p>“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”.</p>
<b>6) Adjustment—self-management</b>	<p>“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”.</p>

Table 5. Themes and quotes related to self-management of CIC (Wilde et al., 2011)

### 16. Next study: Interventional study CIC --Awareness, self-monitoring, self-management

- Internet based
- Study nurses and Peer forum leaders
- Intake and observation of self-cathing patterns (frequency, time of day, color of urine, amount)
- Online database
- FAQs and links

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**ICS WORKSHOP 9: Bladder and Bowel Self-Management:  
Theory, Tools and Practice  
Monday 29<sup>th</sup> August 2011: 09:00 – 12:00**

Bowel Management: the patient's perspective  
Donna Bliss, PhD, RN, FAAN, FGSA  
Horace T. Morse/Alumni Association Distinguished Teacher  
School of Nursing Foundation Research Professor, University of Minnesota  
[bliss@umn.edu](mailto:bliss@umn.edu)

Fecal incontinence occurs in approximately 10% of community-living adults and approximately one-quarter also have urinary incontinence.<sup>1,2</sup> Findings from qualitative research reveal that self-management is a common strategy of individuals with fecal incontinence.<sup>3-6</sup> The reasons for self-management relate in part to the chronic nature of FI that demands ongoing vigilance for prevention of unpredictable leaks and public embarrassment and the lack of care seeking from health professionals. Many individual do not experience FI on a daily basis.<sup>7,8</sup> As many as 40% of individuals with FI do not discuss the problem with their healthcare provider because of both under-reporting by the patient and under- inquiring by the clinician.<sup>7-9</sup> Low health literacy of patients about fecal incontinence and unfamiliarity of non-pharmacological interventions by primary care providers deter discussion and contribute to missed therapeutic opportunities.<sup>10-12</sup> Many patients are unfamiliar with the term of incontinence; when seeking care from a clinician, they describe other gastrointestinal problems such as diarrhea or colitis and omit mentioning their leakage.<sup>10,12</sup> Patient perceptions of clinicians' lack of satisfactory advice about FI management and minimization of their stress and daily burden deter future care seeking and resign them to reliance on self-management.<sup>3,5,13</sup>

Self-management for FI is characterized by a trial and error approach as information about FI in the lay literature is lacking.<sup>3,5,6,13,14</sup> As part of self-management individuals devise complex daily routines that are often inflexible. Routines involve planning and preparedness that include scheduling appointments and public outings around anticipated morning bowel patterns to carrying kits containing supplies for cleansing and changing in purses and cars to taking anti-diarrheal medication on a preemptory basis. When in public individuals, feel anxious and "unsafe" because of worry over possible soiling and discovery of their problem. Therefore, they develop self-management skills to scan the environment to become knowledgeable of locations of toilets and plan travel routes to be near them. Individuals also modify and manipulate their diet and eating habits as a self-care strategy. Foods considered as worsening FI such as greasy food, dairy products, gas producing food, are avoided or their intake reduced. Some foods believed to have therapeutic effects, such as prunes and yogurt, although are eaten for that purpose even though their benefits are inconsistent. The preparation of food is also altered to avoid spices and frying. Self-management includes modifications of eating patterns especially by women. Individuals schedule regular times to eat and fast as early as the night before a public event to reduce leakage. While in social settings, individuals with FI limit their intake, carefully select foods, or refuse to eat at all. Self-management also includes modifying social behaviors to minimize the risk of leakage such as leaving an event early.

Absorbent product such as pads, pantliners, and briefs/diapers are essential self-management strategies for many community-living people with FI.<sup>5,14-16</sup> On the other hand, some individuals, especially those with mild FI, do not wear an absorbent product.<sup>15,17</sup> Reasons include



the intermittent nature of the leakage, lack of a design specific to fecal leakage, cost, and male self-image. Women are more likely to wear an absorbent product.<sup>9</sup> The size of an absorbent product is considered a symbol of the severity of leakage and the smallest size is usually worn.<sup>6</sup>

Self-management requires the patient to teach and learn on their own therefore the number and extent of practices can vary. Those with more severe FI have more self-care practices as do women compared to men.<sup>9</sup> Thirty percent of community-living elderly with FI indicated they did have a set of self-care practices to manage FI.<sup>9</sup> Individuals allow themselves respite from their diet restrictions and other self-control requirements by eating foods they enjoy despite the likely consequence of leakage afterward.<sup>13</sup> Unplanned leakage during a self-management plan can have negative emotional consequences of self-blame and guilt.<sup>3,5,13</sup>

Patients with FI identify goals of management toward which they strive when complete cure is not possible.<sup>18</sup> Patients seek a lesser frequency of FI than more formed stool. They would also like to feel more control so strengthening successful self-management approaches seems a positive outcome. Women desire to be able to use smaller and more absorbent products.<sup>18</sup> Younger patients would find satisfaction with less leakage during sex while older individuals desired to require less anti-diarrheal medication.

Many individuals with fecal incontinence engage in self-management for their condition. Some elderly, however, may lack this knowledge and skill. Health literacy seems to play a role. Communication about self-management between patients and clinicians is encouraged as is making more information known directly to the public by support groups and professional societies. Clinicians are also advised to inquire about self-care practices and their effectiveness and burden. Several self-practices have been identified and seem to increase a sense of control and hope in the users without causing harm. Further research is necessary so that recommendations might be evidence-based.

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