Factors Impacting Self-Care For Urinary Incontinence

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Urinary incontinence (UI) is a prevalent condition that affects 17% to 25% of community-dwelling women (Hannestad, Rortveit, Sandvik, & Hunskaar, 2000; Hunskaar, Ostbye, & Borrie, 1998) and 2% to 14% of community-dwelling men (Schluman, Claesm, & Mattij, 1997). Behavioral strategies such as pelvic floor muscle exercise (PFME), bladder retraining, and dietary modification are generally considered the first line of treatment for UI because they are noninvasive and have few side effects (Sampselle, 2003; The Canadian Continence Foundation, 2001). Self-care, the ability of patients or clients to act on their own behalf to achieve and maintain health, is a fundamental component of these strategies. Despite the frequently chronic nature of UI, there is growing evidence that such maintenance is sporadic at best.

Beauavioral therapies are generally considered to be the first line of treatment for urinary incontinence (UI), yet little is understood about clients’ abilities/motivation regarding maintenance. In this qualitative descriptive study, individual and focus group interviews were conducted with community-dwelling participants to enhance understanding about how individuals manage their UI at home and why they maintain certain strategies and not others. Two major themes emerged. First, participants’ self-care efforts were motivated by their desire for a normal daily lifestyle. As such, they were likely to discontinue strategies that they viewed as more personally disruptive than the UI itself. Second, participants were motivated to maintain strategies by the ability to visualize their progress and by the knowledge that they were progressing. This understanding is critical to the design and development of educational programs that are grounded in the perceptual and contextual realities of our clients.

Introduction

Behavioral strategies such as pelvic floor muscle exercises (PFME), bladder retraining, and dietary modifications are generally considered to be the first line of treatment for urinary incontinence (UI). Yet little is understood about the client’s abilities/motivation to manage their UI in the home setting. Self-care, the ability of clients to act on their own behalf to achieve and maintain health, is a fundamental component of these strategies. Despite the frequently chronic nature of UI, there is growing evidence that such maintenance of behavioral therapies is sporadic at best.

Objective

The purpose of this study was to enhance understanding of self-care strategies that individuals with UI employ, the perceived benefits of these strategies, the factors that influence their self-care choices, and the factors that impede or facilitate maintenance of behavioral therapies.

Method

In this qualitative descriptive study, individual and focus group interviews with community-dwelling participants were conducted to enhance understanding regarding the participants’ management of UI at home and why they maintain certain strategies and not others. Data were collected via loosely constructed individual (n=25) and focus group (n=3) interviews to facilitate open discussion of participants’ perceptions.

Results

Thirty-eight individuals (33 women and 5 men) participated in the study. Analysis of data resulted in a major category of self-care strategies related to UI that was further subcategorized into factors that facilitated PFME and barriers to PFME performance. Factors that facilitated PFME included: (a) realistic goals and expectation, (b) positive affirmation, (c) follow up, and (d) maintaining an exercise routine. Barriers noted were: (a) insufficient information, (b) characteristics of the exercises, (c) competing interests, (d) financial cost, and (e) minor psychosocial impact.

Conclusions

This study described the self-care strategies that participants with UI had initiated and maintained and additionally explored the perceived facilitators and barriers to self-care choices. Two major themes emerged: (a) self-care efforts were motivated by desire for a normal daily lifestyle and (b) participants were motivated to maintain strategies by the ability to visualize progress and by knowledge that they were progressing. These findings support the need for client-focused teaching that is grounded in the individual’s daily realities and goals.

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Literature Review

Behavioral therapies for UI are conservative strategies that include PFME with or without biofeedback, bladder retraining and associated voiding regimens, and dietary modification. Experts postulate that contracting the pelvic floor musculature during PFME closes the urethral lumen and increases intra-urethral pressure by raising the urethra toward the symphysis pubis (DeLancey, 1988). Although pelvic floor muscle (PFM) contractions can occur involuntarily with increased abdominal pressure (Peschers et al., 2001; Third, Lose, Jorgensen, & Colstrup, 1990), physiological changes associated with incontinence require purposeful and progressive training to enhance voluntary recruitment of muscle fibers. Hypertrophy of the PFM generally occurs following 8 weeks of daily exercise and continues over the long term with ongoing resistance training (Berghmans et al., 1998). Biofeedback and electrical stimulation may augment PFME; however, the value of this addition is questionable (Hay-Smith et al., 2004).

Bladder retraining involves the progressive lengthening of intervals between voids and is recommended for individuals with overactive bladder with symptoms of urgency, frequency, and/or urge incontinence. Clients maintain a schedule that reflects their current voiding pattern, and then increase the intervals between voids by approximately 15 to 30 minutes a week. Achieving a “normal” voiding regimen of every 3 to 4 hours can take several months, although peak effects have been realized at 6 weeks (Wyman, Fantl, McClish, Bump, & the Continence Program for Women Research Group, 1998). Dietary modification generally denotes an increase in fluid intake and reduction or elimination of caffeine intake (Tomlinson et al., 1999).

There is empirical support for the short-term effectiveness of behavioral therapies within supervised training programs, including PFME (Hay-Smith et al., 2004) and bladder retraining (Wallace, Roe, Williams, & Palmer, 2004), and modest support for dietary modification (Bryant, Dowell, Fairbrother, 2002; Dowd, Campbell, & Jones, 1996; Tomlinson et al., 1999). Less is known about the effectiveness of these strategies over the long term, and in particular about the inclination or ability of clients to maintain them at home. Of specific concern, evidence suggests a predominance of strategies that may have a negative long-term impact, such as voiding frequently and limiting fluid intake (Engberg, McDowell, Burgio, Watson, & Belle, 1995; Fonda, Woodward, D’Astoli, & Chin, 1996; Milne, 2000). Additionally, there is literature to support that adherence to behavioral strategies is sporadic at best (Bø & Talseth, 1996; Dattilo, 2001; Hahn, Milsom, Fall, & Ekelund, 1993; O’Brien, 1996).

Whether such behavior reflects a lack of knowledge regarding treatment options or purposeful and informed decision making is not understood. Adherence to behavioral therapies is not well investigated and current long-term findings are inconsistent and confusing. When O’Brien (1996) investigated the 4-year outcome of a nurse-led program of PFME and/or bladder retraining (N=229), the majority (61%) of the 229 women who returned the followup postal survey had maintained their exercises for less than 1 year. Although outcome and adherence were measured by subjective self-report, significantly more of the women who had continued their exercises had maintained their post-treatment improvement or improved further (p=0.00002). In a study investigating the effectiveness of PFME, electrical stimulation, and dietary counseling (Dattilo, 2001), 85% of participants (n=40) reported they had maintained their post-treatment improvement at the 13 to 20 month followup, yet only 57% of these were performing their exercises daily to several times a week. Bø and Talseth (1996) reported better adherence among 23 women with stress UI who attended a weekly physiotherapy-directed program and were advised to perform 8 to 12 contractions three times a day at home. At the 5-year followup, 70% of these participants indicated they were practicing their PFME at least once a week, but incontinence levels had worsened based on pad tests. Hahn and colleagues (1993) assessed 170 women with stress UI 2 to 7 years after an intensive 4-month PFME protocol. They found 15% of the women were exercising four to six times daily as advised, 28% once a day, 51% once a week, and 6% not at all. Of note is that 27% of women who did PFME once a week noted cure or improvement, compared to 16% of those exercising once a day, and 9% of those exercising four to six times a day. It was not clear from the data whether the more frequent exercisers were also the most incontinent.

Differing treatment programs and outcome measures make comparisons between the preceding studies difficult. There is, however, noticeable variability in the rates of adherence to behavioral strategies and a non-linear relationship between adherence and outcome that have been poorly explained by demographic and physiologic variables such as age, gender, UI frequency, and severity (Dattilo, 2001; Fonda et al., 1996; Mouritsen, Frimodt-Møller, & Møller, 1991; Weinberger, Goodman, & Carnes, 1999).

In contrast, psychosocial factors such as difficulty remembering to do PFME and lack of knowledge about normal bladder function can impact adherence (Chiarelli & Cockburn, 1999; Hayn, Greco, Capuano, & Byrnes, 2000). In one study, 31% of the variance in intention to perform and compliance with PFME routines among antenatal and postnatal women (n=56) was explained by the perceived cost of performing the exercises and by received information about UI (Dolman & Chase, 1996).
Clearly, the inconsistent and sporadic nature of behavioral strategies for UI suggests a need to further our knowledge about factors that impact their performance. In this study, we aimed to extend current understanding by exploring the full range of strategies that individuals use to manage and/or treat their UI at home and by investigating why they choose to maintain certain strategies over others.

**Purpose**

The purpose of this study was to enhance understanding of the self-care strategies that individuals with UI employ, the perceived benefits of these strategies, the factors that influence their self-care choices and, in particular, the factors that impede or facilitate their ability to maintain behavioral therapies.

**Method**

The Health Promotion Model (HPM) (Pender, Murdaugh, & Parsons, 2002) guided the qualitative and descriptive design of the study. The HPM was developed to explain the thought processes that underlie health behavior (Grubbs & Carter, 2002). With its emphasis on the simultaneous role that human perception and contextual factors play in health-related decisions, the HPM provided a broad framework for exploration of factors impacting UI self-care.

Since the phenomenon of self-care for UI is poorly understood, fundamental qualitative description was selected as the method of choice (Sandelowski, 2000). The aim of this method is to accurately capture and represent participant meaning with minimal interpretation from the researcher. As a research tool, qualitative description involves going to the source, to individuals experiencing UI, to identify and describe their perceptions of UI, and the strategies they use to manage it. Semi-structured individual and focus group interviews helped to ensure participant-driven data as participants themselves determined the direction and flow of discussion. Moreover, since the codes emerged from within the data rather than being superimposed on to them, qualitative description facilitated staying true to participant meaning.

**Sample**

Inclusion criteria were purposefully broad and nonspecific to reflect the lack of current understanding related to UI self-care and the need to explore the broad range of choices made by the participant. Eligible participants (a) were community-dwelling adults 18 years of age and older, (b) had a history of UI, (c) were independent in activities of daily living, (d) were able to provide informed consent in English, and (e) were able to articulate the self-care strategies they had initiated. Those who were continent at the time of the study but had experience with self-care strategies were not excluded. Prior professional help seeking was not mandatory as people with UI seek help in diverse ways, including the Internet.

**Procedure**

Participants were recruited in two phases. After 7 months of advertising in health clinics, local newspapers, and at monthly women’s health educational sessions, 14 participants had volunteered, two by word of mouth from another participant. Since so few individuals volunteered, a second wave of recruitment involved purposive sampling from three local clinics specializing in treatment of UI: (a) a physiotherapist-led clinic, (b) a nurse-led clinic, and (c) a multidisciplinary clinic. Recognizing that disciplinary approaches to UI treatment vary despite standardized clinical care guidelines (The Canadian Continence Foundation, 2001), clinics were selected to enhance the likelihood that participants had a variety of therapeutic experience. Information about the study was mailed to 160 physiotherapy clients, who were stratified according to the year of treatment to ensure short and long-term experience, and to all 80 clients of the nurse-led clinic for older adults. Sixty letters were also given to clients of the multidisciplinary hospital-based clinic (physician and nurse-led) over a 6-week period. No follow-up mailing occurred due to the prompt responses from 24 eligible subjects and the time restrictions associated with the study.

Participants were assigned to individual or focus group interviews based on the order of their phone call to the researcher. The first 15 participants were interviewed individually. As analysis revealed that no new categories or areas of substantive content were emerging, subsequent callers (n=23) were invited to attend group interviews to enhance the scope of the data. All were given the choice of a one-on-one interview due to the personal nature of the subject area. Those willing were purposefully assigned to one of three focus groups to ensure homogeneity with respect to variables that could impact openness and opportunity for dialogue (Sharts-Hopko, 2001), most notably gender and experience with particular strategies.

Thirty-eight individuals (33 women and 5 men) participated in this study. This resulted in 25 individual and three focus group interviews of three, three, and seven participants each. Ages ranged from 24 to 86 years, with a mean age of 65 years. Fifty-eight percent had a minimum of a college education.

**Data Collection**

Data were collected during the year 2002. All participants were encouraged to share stories about their UI at the start of each interview. Following these initial introductions, interviews were largely participant driven with minimal direction from the interviewer. A topic guide was useful in ensuring content relevant to the study by refocusing the discussion, as necessary, to self-care strategies for UI and factors that participants believed had im-
pacted self-care choices.

Individual face-to-face interviews were conducted first to ensure rich and deep data that could stimulate focus group discussions (McLafferty, 2004). Interviews were conducted in participants’ homes, recorded on tape, and lasted approximately 1 hour. Brief notes allowed the researcher to summarize what had been discussed and to validate content and meaning with the individual participant at the end of each interview. Focus group interviews were conducted to promote discussion and reflection and facilitate disclosure through recognition of shared experience (Goss, 1998; Robinson, 1999). Interviews were approximately 2 hours in length. Two interviews were held at the local university. Three individuals who knew each other chose to meet at a participant’s home. The researcher acted as moderator, guiding the discussion and ensuring all participants had the ability to contribute. A colleague with focus group experience acted as observer and took comprehensive notes diagraming seating, detailing who was talking, summarizing content, and noting contextual issues such as group dynamics. The moderator and observer met following each interview to discuss issues that could affect the findings.

Data Analysis

Demographic data were analyzed descriptively. Content analysis of narrative data facilitated staying true to participant meaning (Sandelowski, 2000). Audiotape interviews were transcribed verbatim, and the researcher, JM, reviewed the transcriptions for accuracy. The researcher conducted two indepth readings of each transcribed interview and accompanying field notes, then applied the first level of coding. These preliminary codes denoted the category of broad substantive content for each unit of analysis, such as help-seeking, psychosocial impact, and PFME. Units of analysis were short phrases, sentences, and at times segments of discussion as relevant and necessary to maintain context. Subsequent levels of coding involved the researcher re-examining the content of each category that had been developed in order to identify patterns such as commonalities and differences. For example, data within the category help-seeking were subcategorized as “Factors that motivate help-seeking” and “Barriers to help-seeking.”

Codes and categories were reviewed with another qualitative researcher to ensure they were participant driven and emerged from the data rather than being superimposed upon them (Sandelowski, 2000). Analysis of focus group interviews proceeded in the same manner, taking into account the importance of group effect (Kidd & Parshall, 2000). The researcher re-read the transcriptions and observer/moderator notes with particular attention to issues related to acquiescence and self-censoring, whereby participants appear to surrender their own perspective for that of the group, or purposely decline to discuss their perspective at all.

The final level of analysis involved numerous re-readings of categorized data, in-depth review of the patterns that had emerged, and an additional level of interpretation by the researchers. This analysis served to identify unifying links or threads that existed within and between categories (Sandelowski, 2000). There can be little doubt that the theoretical perspective, professional commitments, and expertise of the researchers all contribute to how the themes unfold. However as noted by Frank (1997, p. 93), to omit this final stage of analysis would be to drain the “life blood of experience” from the research findings.

Ethical Considerations

Ethical approval was obtained from the Conjoint Health Research Ethics Board of Calgary, Alberta. Individuals self-selected to participate and provided informed written consent following full disclosure of the study. Anonymity was protected by ensuring there was no possible link between the data and individual respondents. Letters advertising the study were mailed directly from the clinics. The researcher did not know to whom the letters were mailed and those working at the clinics did not know who responded. Audiotapes were erased upon study completion. Other data have been stored in a locked cabinet accessible only to the researcher.

Findings

Individual and focus group interviews were, as reported earlier, loosely structured and primarily participant led. As a result, three major categories of findings emerged: (a) perceptions of urinary incontinence, (b) help-seeking behavior, and (c) self-care strategies related to UI. This research article, however, will only focus on self-care strategies related to UI. It is also important to note that reported frequencies, such as the number of participants who commented on the importance of positive affirmation for PFME, are descriptive and should not be interpreted in terms of percentages or proportions (Hickey & Kipping, 1996). How often a comment was made may have been as much a factor of the direction of each conversation as agreement or disagreement about an issue/topic.

Sample characteristics. Fifty percent of the participants experienced leakage at least once a day and wore one or more protective pads daily. The duration and frequency of participants’ incontinence are illustrated in Figures 1 and 2.

Two of the 38 participants had never sought professional help. Twenty-six of 38 (68%) had sought help within the previous 5 years. Although substantial effort was made to obtain participants from a variety of clinical settings, 14 participants had sought help from the same physiotherapist in private practice (see Table 1).
Two of 38 participants had recently undergone successful continence-related surgery and described themselves as dry. Three of 38 had undergone surgery over 20 years ago and were leaking at the time of the study. Six of 38 participants reported they had tried medication for their UI but commented negatively on side effects such as dry mouth. Four of 38 stated their medication “helped a lot” and “increased capacity.” Four others, however, perceived the use of medication as a “last resort.”

Self-care strategies. Participants discussed a broad range of self-care strategies related to their UI. Many of these strategies facilitated coping but did little to improve the underlying condition. The majority of the participants had focused their days around voiding through planned awareness of bathroom locations, voiding before going out, and voiding frequently. As one remarked, “At least I knew enough in advance that I could sort of pace myself and think okay, I’ve got 20 minutes until I get to the next washroom.” The use of pads was associated with the ability to maintain a normal daily lifestyle. A male participant who had not sought professional help stated, “They [the pads] saved my life many a time.” Seven of 38 restricted their fluid intake, particularly before going out. Two of 38 gauged their fluid intake carefully before trips, and four of 38 had stopped drinking in the evening to reduce nocturia.

Self-care strategies that participants had initiated to treat their UI or reduce symptoms included dietary modification, bladder retraining, and PFME. The majority had modified their diet in some way. Nine had decreased their daily caffeine intake, and one had stopped drinking milk because it “irritated” her bladder. One woman had been on a rigid diet for 2 years, avoiding most fruit, cheese, and juices, which she stated improved her symptoms. Six others had increased their daily water intake, often in place of caffeinated beverages; “I never used to drink water, now I’m up to four glasses a day.” Two reported their urine was less concentrated and “smelly” as a result. Of note, however, participants commented more often on the negative than the positive impact of drinking more; “It just seems to go straight through me.” One reported, “The worst thing I can do is drink water” and a young mother asked, “Which is going to make me hold it longer...me not drinking and not having much go through my kidneys and into my bladder, or me drinking and having it irritate it less?”

None of the participants referred to bladder retraining as
an identified strategy. Nine, however, reported they had tried to increase the intervals between voids and may therefore have initiated a form of retraining. The most common barrier they discussed was the negative impact of adhering to a strict voiding schedule on their daily lifestyle. Although several participants had been taught urge control strategies, such as counting backwards, only two commented that this strategy had provided them with a sense of mastery over their symptoms. Participants generally associated increasing the intervals between voids with increased fear of being wet. None of the participants had maintained the voiding schedule for more than a few days.

The most common therapy, reported by 26 participants (68%), was PFME either alone (n=12) or in combination with other therapies (n=14) such as dietary modification and medication. Information regarding PFME had been gleaned from several different sources, including the Internet, word of mouth, and health care professionals. Diverse perceptions existed about the required frequency and duration of the exercises. Nine reported difficulty maintaining the exercises once they stopped seeing a health care professional, but the majority performed their PFME once daily.

As a result of the predominance of PFME as a reported self-care strategy for UI, the majority of the study findings reflect participants’ perceptions about factors that impact their performance of, and ability to maintain, these exercises. Consistent with subcategories assigned during data analysis, these findings are presented as factors that facilitated PFME and barriers to PFME performance. These factors are listed in no particular order (see Table 2).

**Factors That Facilitated Pelvic Floor Muscle Exercises**

**Realistic goals and expectations.** Participants emphasized the benefit of having a realistic goal to work toward. For two, this goal was fewer episodes of UI. As one woman reported, “If it would go down 50% I’d be really happy with that.” For three others, the goal was resuming what they perceived as a normal lifestyle: “…with me it was hoping to get back hiking and skiing, which were a big part of my life before.” An older, retired participant commented, “I wanted to be able to do what I wanted to do without having to think I can’t do that because there’s no washroom along the way.”

Realistic expectations of what they could accomplish on a daily basis may have been most important to ongoing motivation. Therapy routines were time consuming and three participants expressed relief when recommendations became more flexible. One commented, “I was thrilled when I got the first weekend off…it really is freeing.” Accepting what was personally realistic enhanced their self-confidence and reduced their frustration when unable to “keep up” with professional recommendations.

**Positive affirmation.** Professional involvement in PFME teaching and affirmation of progress was noted as very beneficial. For one, the manual assessment of pelvic strength had been helpful: “It made me more aware of what was going on.” Three commented that visual biofeedback with vaginal probes had provided them with a better sense of what the exercises were actually doing: “Sometimes you can’t tell if you’re squeezing properly, and it’s like, when you see the dial you go, oh, I guess I am, and then you begin to figure out where it is you are squeezing.” A younger participant stated, “I sensed more definition, and then I could feel that I did squeeze it tighter.”

This feedback was encouraging and motivating, and “helped morale.” As one participant noted, “You felt like you were doing something worthwhile if you could make it move.” Of note, one woman reported she

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had discontinued her PFME after 3 months because she had not seen any positive results. In contrast, she had maintained a daily exercise routine for her osteoporosis because, “When I went back for my last appointment I had improved…I see that, so I keep doing it.”

Followup. Regular visits to a health care professional had a positive impact, particularly since minor improvements were difficult to detect. Several believed they needed a “watchdog” to remain motivated. One commented that even the researcher’s impending visit had been motivating. Three thought they could benefit from a pep talk to encourage them to continue with their PFME and to remind them of the benefits: “I’ve always led a busy life and the things that don’t give you a reason to be on top of them, you forget.” Only two participants believed they would not attend followup visits, citing transportation issues.

Maintaining an exercise routine. Setting aside specific time for an exercise routine was deemed important since participants reported the PFME took between 15 and 60 minutes daily to complete. The majority of individuals who had maintained their PFME were doing their exercises once daily, usually in the morning before going out. One concluded, “If I don’t, well then, it [the time needed] is usually gone.” Another reported that by doing her exercises first thing in the morning, she was able to put her incontinence in the background for the rest of the day.

Exercising once a day seemed to be a reasonable compromise for participants, including those who believed they should be doing them more often, “I still don’t do them as often as I should…more like once a day.” Another who commented she should do her PFME four times a day was doing them once, but trying to perform more contractions during that routine. Participants who were exercising twice a day had generally added an evening session to their morning routine; however, this session was inconsistent.

In contrast, three women believed the only way to get the exercises done were to fit them in whenever time allowed. All three, however, reported that they exercised sporadically, with little consistency.

Barriers to Performance Of Pelvic Floor Muscle Exercises

Insufficient information. Participants generally considered written information alone, whether from the Internet or from pamphlets, to be insufficient for the performance of PFME. One participant emphasized: “Unless you went to someone who helped you I don’t think you would ever be able to do them.” Another had required three visits to a physiotherapist to perform the exercises correctly. A third participant had read a booklet instructing her to do her “Kegels” and reported thinking, “I don’t even know where my Kegel is.”

Individuals who said they had read or heard about PFME “somewhere” had either not maintained them or were performing them only “in fits and starts.” The majority was unaware that it could take several months to notice improvement. Two had been given written instructions by their family doctors but no hands-on instruction or vaginal examination to assess pelvic muscle contraction. Nor had they been told about “any length of time or routine to it.” Both had exercised sporadically. Participants were also unaware that PFME should be maintained to avoid recurrence of symptoms. Perceptions of the appropriate number of daily contractions ranged from 10 to 100. Three participants believed that other, more generalized exercises were an adequate substitute for PFME: “I did most of the other isometrics and stuff until we started swimming about 2 or 3 years ago, and I figured 1 hour in the pool was exercise enough.”

Participants who were exercising twice a day had generally added characteristics of the exercises. Characteristics of the PFME themselves seemed to influence participants’ ability and/or motivation to maintain the exercises. Participants were frustrated by the time it took to see any real progress, “You feel like something should have happened by now.” Six commented on their obscure nature, including how difficult it was to know if the contraction was being done correctly or if there was any improvement. One stated, “I can’t exactly say I know what I’m doing with my pelvis all the time, but I know what I’m doing with my stomach when I’m doing those [other] exercises.” Another noted, while flexing her bicep muscle, “It’s not like this…I can tell if I’m using this muscle.” A third summarized, “It felt so insignificant to try and use these muscles.” Finally, a focus group member attributed some of the difficulty to age and childbirth, “We’re trying to do it [PFME] after a couple of kids, and we don’t even know where those muscles are anymore. It’s hard to visualize or feel those muscles when you haven’t used them for years.”

Competing interests. Competing interests made it difficult for many participants to fit the exercises in, particularly three times a day as recommended by the physiotherapist. Seven participants who were employed outside the home and three who were retired commented on how time consuming the exercises were. One who had been advised to do three sets a day stated, “I’m sorry, like, there’s no way I can do stuff when I’m at work…sometimes I don’t come home for supper.” Another commented that finding the time she needed twice a day was the biggest problem she faced, while a retired male who was no longer doing the exercises stated he “begrudged the time; a quarter of an hour in the morning and a quarter of an hour in the evening.”

Participants had clearly been faced with choices. A younger
participant with severe postpartum UI, who generally performed one set of exercises a day, summarized, “It’s do the exercises and skip everything else or do those other things and skip the exercises.” In contrast, a retired male participant with severe UI post-prostatectomy performed two sets every day, and got up at 4:30 am on golfing days to fit the morning set in.

Financial cost. Participants commented on the cost of continence care. In many cases, this related to the cost of seeing a physiotherapist in private practice. Most participants were surprised and annoyed that their care was not covered by the health care system. A younger participant commented she had spent “a fortune,” approximately $1,300 (Canadian), on physiotherapy services. For three, the cost had been a barrier to pursuing further care.

Minor psychosocial impact. Participants who stated their UI had a minor impact seemed less motivated to perform regular PFME. Two participants who had not maintained the exercises commented, “I think as much as anything it’s because I’m getting by” and “It was something I lived with, I guess; I didn’t think it was that big of a problem.” Three others had maintained an exercise routine until their UI had improved, but once better had to force themselves to “think about it” or they would not do them at all.

Summary of Findings
In summary, participants reported a variety of self-care strategies that helped them to cope with their UI, such as voiding frequently and the use of containment pads, as well as strategies that were aimed at improving symptoms. The majority had altered their dietary intake by increasing fluid consumption and/or decreasing caffeine consumption. None of the participants named bladder retraining as a therapeutic strategy. Those who had in fact worked to lengthen their voiding intervals had not been able to maintain the routines for more than a few days. PFME was clearly the predominant strategy among participants. Performance of the exercises was facilitated by factors that included: (a) maintaining a daily routine as opposed to trying to fit the exercises in whenever they thought of them, (b) positive affirmation, and (c) followup. In contrast, characteristics of the PFME themselves, such as their obscure nature, and the perceived difficulty of performing a correct contraction, impeded their performance.

Taking the analysis one step further, it is important to reflect on the themes that resonate beyond categorical borders to give the data a deeper sense of meaning and illuminate the implications. These themes are presented in the discussion section in order to clearly acknowledge the additional level of interpretation required.

Discussion
Limitations of the study. Certain design and recruitment issues may have affected the results. First, participants were mostly female (n=33; 86%) with a mean age of 65 years. Only five men were recruited, making it difficult to compare self-care strategies between genders. Fifty-eight percent had a college education and the sample may not be representative of the population of community-dwelling individuals with UI. Second, recruitment challenges resulted in a smaller sample (n=38) than the 50 originally proposed to enable 10 to 20 individual and five focus group interviews. Twenty-five of these 38 participants were interviewed individually, 15 prior to the emergence of consistent categories of data and an additional 10 by personal preference. These one-on-one interviews contributed substantial depth to the findings as participants conversed openly, but resulted in fewer focus group interviews (n=3) with seven, three, and three female participants respectively. Although Krueger (1994), a pioneer in focus groups as a research method, recommended 3 to 12 members, the smaller groups were easier to manage and increased the likelihood of interaction (Carey, 1995; Morgan, 1996). In addition, discussion was stimulated rather than limited by the pre-existing friendship of three focus group members who openly shared their unique self-care experiences and expressed varied perceptions. The 100% female membership in focus groups likely enhanced comfort levels and discussion.

Fourteen of the 38 participants had sought help from a single physiotherapy practice and their experience does not necessarily reflect all practice settings and recommendations. The lack of substantive research on the optimum type and number of PFME contractions to achieve therapeutic benefit is problematic and protocols may vary. This study’s main focus, however, was not to correlate specific teaching modalities with adherence and outcome but rather to explore the strategies individuals actually maintain at home and the factors they believe influence their choices. The factors participants believed impacted their performance reflected their daily lifestyles and generalized characteristics of the exercises rather than specific recommendations of any one health care professional or health discipline.

Emergent Themes
The two themes that emerged from the findings seem to cut across disciplinary boundaries.

Participants’ major self-care goal was maintaining a normal lifestyle. The major emphasis of participants’ UI self-care was maintaining a normal daily lifestyle. Consistent with this goal, participants did not pursue strategies such as dietary modification, bladder retraining, or PFME that were, in and of themselves, personally disruptive. Those who perceived a direct relationship between drinking more and increased urgency to void had, in fact, restricted fluids in order to leave their homes for
extended periods as required, without fear of being wet. Strict voiding regimens associated with bladder retraining also negatively affected lifestyle and none of the participants had maintained them for more than several days.

Similarly, participants who had been advised to exercise three or more times a day were more likely to have altered this routine than their lifestyles. Remarking that the PFME took between 15 and 60 minutes to complete, the majority of participants performed the exercises once daily, generally in the morning before going out. This routine, one participant remarked, allowed them to put their UI into the background throughout the day, thereby maintaining a normal lifestyle and minimizing perceived UI impact.

The need to maintain a normal lifestyle may have been the biggest factor affecting participants’ care-related decisions and may explain the predominance of management-based strategies found by other researchers (Ashworth & Hagan, 1993; Milne, 2000; Skoner, 1994). As noted by Thorne (2002), the major concern of individuals living with a chronic condition is often how to live as well as possible.

Seeing enhanced believing. A second theme to emerge is that seeing enhanced believing for participants. Experiencing both positive and negative consequences of their own self-care behavior exerted considerable influence on participants. As one reported, “If I drink lots of water and minimize coffee, it just all works better.” Those who had successfully initiated urge control strategies even once to avoid a public accident had a renewed sense of confidence and control. Participants were more likely to make those connections, however, when they were aware of what to look for. Many of the participants reported a general lack of understanding about normal bladder function and their own bladder habits. In a recent study, Dowd, Kolcaba, and Steiner (2003) emphasized how surprising this lack of generalized knowledge is, noting the positive impact basic information had on participants’ (n=39) perceptions of well-being. Due to the habitual nature of their voiding, however, participants had no baseline by which to judge their improvement, or lack thereof.

The motivating and enabling role that information, biofeedback, and followup had on participants’ performance of behavioral therapies was clear. Participants frequently stressed the importance of positive affirmation of progress through vaginal probes, digital assessment, and visual biofeedback, stating the exercises by themselves felt insignificant. Other researchers have noted similar concerns. Kincade and colleagues (1999) reported subjects found the exercises boring and were unsure of their technique, while subjects in an earlier study (Ashworth & Hagan, 1993) commented on their “nebulous payoff.”

It is unclear whether biofeedback-assisted PFME are more effective than PFME alone in reducing UI (Hay-Smith et al., 2004). Yet participants were clearly motivated by the ability to visualize their progress and by the knowledge that they were progressing. Participants emphasized the difficulty of learning PFME from written information alone, including pamphlets provided by physicians and instructions on the Internet. This is supported by earlier findings that only 30% who received written information were able to do a PFME correctly on followup vaginal examination (Bump, Hurt, Fantl, & Wyman, 1991).

Participants also stressed the importance of followup to keep them motivated and to affirm their progress, and to provide encouragement. This lends support to what health care professionals have long advocated (Diokno & Yuhico, 1995). In a review of seven studies with followup intervals of 1 to 7 years, the poorest outcomes were associated with participants who practiced PFME at home with minimal guidance from health care professionals (Alewijnse, Mesters, Metsemakers, Adriaans & van den Borne, 2001).

Participants, then, were motivated by the ability to visualize or perceive change. This change, however, was often slow and apparently insignificant, and frustrated participants gave up on therapies such as PFME. Knowing what to expect made goals more realistic and provided context for their perceptions. However, awareness of progress, no matter how small, facilitated persistence with exercises that, for seemingly long periods, provided little external reward.

Conclusions

In this study participants described in detail the barriers in the performance of behavioral strategies, including time restrictions and competing demands. Barriers had immediate and lasting impact on self-care behavior, demonstrating the importance of followup to encourage clients and discuss alternate strategies as necessary. As stated by Pender and colleagues (2002), such barriers were condition and behavior specific. Participants who had maintained other daily exercise routines were no longer performing their PFME due to the obscure and seemingly insignificant nature of the contractions. Perceived benefits, including enhanced PFM control and strength, were less apparent. Participants emphasized the importance of professional input and biofeedback in bringing benefits to the foreground.

These findings support the need for client-focused teaching that is grounded in the individual’s daily realities and goals, to ensure that the recommended therapies are not more troublesome than the UI itself. Allowing room to maneuver and adapt strategies to maintain their individualized lifestyle, setting realistic goals, and encouraging followup visits may enhance adherence. PFME may be easier to maintain within a defined daily
routine, rather than performing contractions sporadically throughout the day. Group teaching may be a particularly useful strategy; participants discussed the perceived benefits of group support and focus group participants learned much from each other.

Finally, although therapeutic recommendations vary according to the type and intensity of the UI, consistent and standardized information is needed at the primary care level. Clients need to know the length of time it may take to notice improvement, the importance of persistence, the average frequency with which the exercises should be performed, and methods to assess correct performance at home. Written information alone is generally inadequate due to the obscure nature of PFME and the difficulty clients can have isolating the correct musculature. Access to continence care must become a priority and can be enhanced by ensuring a fundamental level of knowledge among nurses and other professionals at the primary health care level.

Implications for Future Research

While the aim of this study was to establish a generalized understanding of factors that impact UI self-care, it will be important to understand if patterns are consistent between older and younger women and men. Understanding self-care behavior in men with UI will be an important step in addressing the current gender bias in continence research. Investigating the minimum level of PFME that is required to maintain improvement over the longer term is critical to ensuring that teaching is both realistic and informed. Future research should also explore the relationship between standardized guidelines for practice, group teaching, and individualized care. All approaches should be developed as a team effort, wherein the health care practitioner is viewed as an expert in the knowledge of inter-

ventions and the patient is viewed as expert in his/her realities of daily living. This understanding is critical to the design and development of educational programs that are grounded in the perceptual and contextual realities of our clients.

References


