Translation of evidence into a self-management tool for use by women with urinary incontinence†

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Abstract

Background: many older women with urinary incontinence remain under-treated.
Objective: to develop and evaluate an evidence-based self-management urinary incontinence risk factor modification tool for older women.
Design: the tool was developed using evidence from a systematic review and input from focus groups. A 6-month prospective cohort study using an interrupted time-series design was conducted to evaluate the tool.
Setting: the tool was developed at the University of Toronto and then evaluated at the Universities of Calgary and Montreal, Canada.
Subjects: the tool was developed with the help of focus groups of healthcare professionals and of older incontinent women. The tool was evaluated among 103 incontinent women aged 50 years or older.
Methods: the tool includes six risk factors with modification strategies. The primary outcome was successful tool usage. Secondary outcomes included urinary leakage, change in self-efficacy and quality of life.

†Also, an abstract of this project was presented at the 2010 Society of General Internal Medicine annual meeting.
Results: the tool was used by 95% [95% confidence interval (CI) 88–98] of women at some point. Urinary leakage rates were reduced by an average of 1.4 daily episodes (95% CI 1.0–1.8). Women reported significant improvement in self-efficacy and incontinence-related quality of life.

Conclusions: there appears to be a role for an evidence-based self-management urinary incontinence risk factor modification tool.

Keywords: urinary incontinence, self-management, knowledge translation, women, elderly

Introduction

Urinary incontinence (involuntary leakage of urine) [1] is of high priority to older women. In a survey of 2,500 women aged 55–95, 64% reported that urinary incontinence was of great concern to them but only 25% perceived that it was being adequately addressed by their healthcare providers [2]. The prevalence rate of urinary incontinence is up to 55% among older women [3]. Urinary incontinence is associated with poor quality of life [4], poor self-rated health [5], social isolation [6], depressive symptoms [7], decline in instrumental activities of daily living [8] and out-of-pocket expenses.

The majority of older women with urinary incontinence remain under-treated [9, 10]. This practice gap occurs despite the fact that there are several behavioural techniques that have been shown to reduce leakage episodes and to result in cure or symptom improvement when attempted by women with urge, stress or mixed incontinence [11]. Risk factor modification is a first-line intervention for incontinence, given that it is non-invasive and there is low risk for adverse events [12]. There are several modifiable risk factors for urinary incontinence that women could potentially modify [11].

This gap between evidence and practice highlights the need to improve the health services provided to women with urinary incontinence. An evidence-based self-management urinary incontinence risk factor modification tool may be one method of overcoming the current barriers to addressing this health need. Self-management is a process whereby persons function on their own behalf in health promotion, disease prevention and/or disease management [13]. Successful self-management requires that the individual be sufficiently knowledgeable about their condition and its treatment, that they perform activities aimed at managing their condition, and that they apply skills necessary for maintaining adequate psychosocial functioning [14]. Improving self-efficacy is also an important component of self-management programmes and has been shown to improve outcomes of other chronic conditions [15–17].

Given that women with urinary incontinence often do not seek help from others, self-management strategies that can be used independently may be the most effective and broad reaching as an initial step to effectively managing incontinence. The aim of this research was to develop and evaluate an evidence-based self-management urinary incontinence risk factor modification tool designed for older women.

Methods

Development of the tool

We developed an evidence-based self-management risk factor modification tool for women 50 years of age or older experiencing urinary incontinence at the University of Toronto, Canada using evidence derived from a systematic review [11]. A utilisation-focused evaluation to identify barriers and facilitators to knowledge uptake was conducted among healthcare experts in incontinence. This focus group consisted of four healthcare professionals from the disciplines of urology, geriatric nursing and rehabilitation. On the basis of their feedback, applicable evidence was incorporated in a self-management tool. This preliminary tool was evaluated by two focus groups of three to four English-speaking women 50 years of age or older who reported experiencing urinary incontinence at least twice a week for a period lasting at least 3 months during the prior 2 years. The goal was to identify barriers and facilitators to tool use and to optimise the tool to meet the target users’ needs. Specific input was obtained on the risk factors and strategies in the tool, including feedback on how to further modify the tool to help ensure its use. The focus groups included women who had and women who had not received treatment. The behavioural strategies included in the tool were further modified based on a literature search of strategies specific to the risk factors included. The tool was then sent to two other healthcare experts for additional feedback. The tool was originally written in English and then translated into French and validated with a convenience sample of French-speaking incontinent women.

The tool is paper-based and written at a Flesch–Kincaid grade six level. The tool requires no instruction for use. It includes six modifiable risk factors identified in the literature [11] and associated behaviour change strategies (see Supplementary data available in Age and Ageing online). The risk factors included are pelvic floor muscle strength, caffeine intake, excess weight, constipation, vision and hearing impairment and smoking. Poor pelvic floor muscle strength is an important risk factor and when exercises are performed correctly women are 23 times more likely to report symptom improvement than women who do not use these exercises [11]. High caffeine intake (>400 mg/day) increases risk for urge incontinence [11] and caffeine reduction can improve urge-related symptoms [18]. Randomised controlled trials (RCTs) have also found weight-loss
programmes to be effective at improving incontinence [19–22]. Although there is insufficient evidence on the effectiveness of modifying the other risk factors, it is generally agreed that risk factor modification is important [12]. The tool outlines how to monitor symptoms, using bladder diaries, in an effort to determine whether modification of a risk factor results in symptom improvement.

Evaluation of the tool

A prospective cohort study using an interrupted time-series design was conducted among incontinent community-dwelling women aged 50 years or older. The study was conducted at the Universities of Calgary and Montreal, Canada. The women were monitored without intervention for 3 months. Then they were given the self-management tool and monitored for another 3 months. The tool was designed to be used without formal instruction; therefore it was given to the women by a research assistant without any accompanying education. Data were collected monthly for a total of three pre- and three post-intervention data points. A research assistant collected the data through in-person interviews.

We included women who were experiencing episodes of urinary incontinence a minimum of twice per week for at least 3 months prior to enrolment. Women who had received treatment within the prior 2 years from a healthcare provider with expertise in urinary incontinence management or who had received incontinence medications within the past 6 months were excluded. Women with a history of haematuria, recurrent urinary tract infections, urinary retention, symptomatic pelvic organ prolapse, previous pelvic surgery or pelvic radiation or a related neurological condition (e.g. multiple sclerosis; spinal cord injury) were excluded and advised to speak to their physician. Women with a Mini Mental Status Examination score of < 24 of 30, who could not communicate in English or French or who did not consent to participate were also excluded. Women were compensated for their study-related travel expenses but received no other financial compensation.

The primary study outcome was successful usage of the tool. This is an important first outcome, as before the effectiveness of the tool can be examined the user has to first use it. The tool was considered to have been successfully used if a study participant reported having modified or attempted to modify one or more risk factors at any point during the post-intervention study period. Secondary outcomes included urinary leakage, self-efficacy and quality of life. An explanatory mechanism of how the tool works was explored by examining whether changes in self-efficacy explained improvements in quality of life. Baseline demographic data and incontinence information were also collected via questionnaire.

To assess changes in leakage episodes, we used bladder diaries, which duplicated the tool's diary, as they are a valid and reliable measure of incontinence [23]. Participants were instructed to bring 3 days of diaries, which they completed over the prior month, to each assessment. Average daily leakage episodes were calculated from these diaries. In order to assess self-efficacy, we used the validated Geriatric Self-Efficacy Index for Urinary Incontinence [24]. This index contains 15 items and is available in English and French. Subjects score how confident they are in holding their urine in 11 different settings and how confident they are in doing four related tasks. The index is scored out of 150 and higher scores indicate better self-efficacy. Quality of life was assessed using the Urogenital Distress Inventory-6 (UDI-6) [25], which is a validated instrument designed to evaluate symptom distress, and the Incontinence Impact Questionnaire-7 (IIQ-7) [25], which is a validated instrument designed to evaluate life impact of incontinence. Both tools are scored out of 100 and higher scores mean worse incontinence-related quality of life. The longer version of the IIQ has been previously shown to maintain its psychometric properties when translated into French [26]. The UDI-6 and IIQ-7 were therefore translated into French and validated with a convenience sample of French-speaking incontinent women.

The required sample size was calculated to be 100 based on the precision of estimating the primary study outcome, which was a tool usage rate of 75% or higher. In order to observe a 95% confidence interval (CI) whose lower limit was 75% or higher, at least 84 of the 100 study participants had to use the tool at some point during the study.

Analysis

The primary outcome of usage rate was analysed as a dichotomous variable. The subject either used or did not use the tool, as determined by whether or not they attempted to modify one or more risk factors. Percentiles were calculated to determine the usage rate. Additionally, the 95% CI was calculated using the Wilson score method [27] to determine the precision of the estimate of usage. The percentage of study subjects that attempted modification of each of the six risk factors was also calculated. The tool usage was examined at 1, 2 and 3 months post-intervention. The tool's ease of use was also examined. The percentage of persons who reported difficulty understanding the information provided or the directions provided was calculated.

The impact of the tool on urinary leakage episodes was examined by calculating the pre–post difference in mean daily leakage episodes and associated 95% CI. For the secondary outcomes of change in self-efficacy and quality of life, we conducted linear mixed effects modelling to determine the effect of the tool on changes in the Geriatric Self-Efficacy Index for Urinary Incontinence, UDI-6 and IIQ-7 scores. Highest posterior density (HPD) intervals were obtained for the fixed effects by Markov-Chain Monte-Carlo (MCMC) methods. Self-efficacy change scores were regressed in separate analyses on changes in UDI-6 and IIQ-7 scores, in order to determine whether changes in quality of life were explained by changes in self-efficacy.
All statistical analysis was conducted using the R language, version 2.8.0 [28]. The mixed effect analysis was conducted in R using the lme4 package, version 0.999375-28 [29].

Ethics approval was received from the ethic review boards at the Universities of Toronto (tool development), Calgary and Montreal (tool evaluation). Informed consent was obtained from participants. This work was supported by a University of Toronto Dean’s Fund New Staff award (tool development), and a Canadian Institutes of Health Research operating grant [MOP 82916] (tool evaluation). The funders played no role in the design, execution, analysis or interpretation of data, or writing of the study.

**Results**

A total of 103 women were enrolled in the study: 52 in Calgary and 51 in Montreal. Ninety women completed the study, 45 at each site. Among those who enrolled, the mean age was 63, whites were 93% and these who had post-secondary education were 66% (Table 1). Symptoms of stress incontinence were present among 95 women (92%) and urge symptoms were reported by 75 (73%).

<table>
<thead>
<tr>
<th>Table 1. Demographic data of the 103 women enrolled in the evaluation of the evidence-based self-management risk factor modification tool for urinary incontinence</th>
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<tbody>
<tr>
<td>Mean Age (range)</td>
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<tr>
<td>Race/Ethnicity, N (%)</td>
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<tr>
<td>White</td>
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<tr>
<td>Asian</td>
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<tr>
<td>Black</td>
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<td>Latin American</td>
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<td>Education, N (%)</td>
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<tr>
<td>High school or less</td>
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<td>Postsecondary education</td>
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<tr>
<td>Marital Status, N (%)</td>
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<tr>
<td>Single</td>
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<td>Married</td>
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<td>Widowed</td>
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<td>Living arrangement, N (%)</td>
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<td>Own home</td>
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<td>Relative's home</td>
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<td>Retirement facility</td>
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<tr>
<td>Self-rated health, N (%)</td>
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<tr>
<td>Poor-Fair</td>
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<tr>
<td>Good</td>
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<td>Very good-excellent</td>
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<td>Related co-morbidities, N (%)</td>
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<td>Diabetes</td>
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<td>Stroke</td>
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<td>Hearing problems</td>
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<td>Vision problems</td>
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</table>

The tool was used by 95% (89/94) of women at some point during the study to modify at least one risk factor (Table 2). The most commonly modified risk factor was pelvic floor muscle strength, followed by caffeine intake (Table 2). Women most frequently reported that modification of these factors helped improve their incontinence. Ten women (10/95 = 11%) reported having difficulty understanding the information in the tool and 9 (9/95 = 9%) reported having difficulty understanding the directions provided.

On the basis of bladder diary data among the 89 women with both pre- and post-intervention data, urinary leakage rates were reduced by an average of 1.4 daily episodes (95% CI 1.0–1.8). The average number of daily leakage episodes without the tool was 2.8 (N = 100). This decreased to 1.3 (N = 89) episodes after women started using the tool.

Women reported significant improvement in self-efficacy following the use of the tool (Table 3). There was also an improvement in incontinence-related quality of life. The UDI-6 mean scores significantly decreased, while the IIQ-7 scores also decreased but the change was not significant (Table 3). There was a positive relationship between self-
efficacy and quality of life, suggesting that improvement in quality of life is explained at least in part by improvement in self-efficacy. There was a significant decrease of 0.2 points (95% HPD interval = 0.1–0.4) in the IIQ-7 and a non-significant decrease of 0.09 points (95% HPD interval = −0.01–0.3) in the UDI-6 for every one point increase in the self-efficacy index.

Discussion

This self-management tool was developed to communicate high-quality evidence about incontinence to the user, to empower the user to make change, and to help the user set goals and implement problem-solving strategies to address their incontinence. This intervention uses the knowledge-to-action cycle [30]. It predisposes the user to change by increasing their knowledge and skills, enables the change by giving the user the flexibility to use the tool in an environment they find conducive to change and then reinforces the change through self-monitoring [31]. Self-management is an important component of effective chronic disease management [32, 33]. Several studies have demonstrated that providing individuals with information and guidelines for self-management can lower healthcare service use by 7–17% at a low cost [32]. The assumption is that, where appropriate, self-management is preferred to professional care and that the individual can determine when professional care is required if provided with relevant information. Self-management strategies have already been shown to be effective in the management of several chronic conditions. Urinary incontinence is another chronic condition for which evidence-based self-management strategies may improve outcomes. Many women would prefer to self-manage their incontinence [34]. Over 70% of incontinent individuals already attempt measures that do not require physician involvement, which may or may not be effective, in an effort to cope with their condition [35]. This evidence-based self-management tool has the potential to empower women to make changes that will help them to effectively manage their incontinence. Our results are comparable to results seen in pharmacological trials [11]. We have shown that the tool decreased the number of daily urinary leakage episodes by about 50% and improved both self-efficacy and quality of life. The 8.7-point change in the Self Efficacy Index suggests a clinically significant improvement in incontinence-related self-efficacy [36]. This improvement in self-efficacy appears to contribute to improvement in quality of life. The tool not only has the potential to directly improve incontinence symptoms, it could also be a catalyst step towards empowering women to seek further help.

Limitations

Very few people attempted to modify sensory problems and no one modified smoking. It is not clear whether these risk factors were not considered to be important or relevant by the study participants, or whether the fact that they were listed last in the tool had an impact. Specifically, we did not collect information around smoking status. Although several women reported sensory impairment, and observational studies have identified hearing and vision as independent risk factors, it is unclear whether these remained an issue. Women did continue to use the tool throughout the 3-month post-intervention period and tool usage rates increased over time.

Although it is a weaker design, an interrupted time-series was chosen because it was feasible for the scope of this study, and it is a technique that can handle trends or seasonal/cyclical observations both before and after an intervention is introduced. At an early phase of evaluation such as our study, an RCT methodology would not be appropriate because the identification of variables that may influence practices have not yet been identified, and the fundamental understanding of how practices in different settings might be influenced by this tool have not yet been established.

Conclusions

This research will positively impact women’s health, by making evidence-based urinary incontinence management resources more accessible. This project demonstrates the role of an evidence-based self-management tool as a model of healthcare delivery that actively uses the healthcare consumer in decision-making. Getting evidence into patients’ hands may be one way of ensuring effective translation of research evidence into practice and of reducing unmet health priorities.

Keypoints

- Self-management tools can be effective at managing incontinence.
- Knowledge can be translated into tools directly usable by patients.
- Incontinent women are receptive to self-management tools.

Supplementary data

Supplementary data mentioned in the text is available to subscribers in Age and Ageing online.

Acknowledgement

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Conflicts of interest

Dr Tannenbaum has served on an Advisory Board for Allergan (Dec. 2009). No products by Allergan are referred to in the article or studied in this research project. The other authors have no conflicts to declare.

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Barriers to providing palliative care for older people in acute hospitals

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Abstract

Background: the need for access to high-quality palliative care at the end of life is becoming of increasing public health concern. The majority of deaths in the UK occur in acute hospitals, and older people are particularly likely to die in this setting. However, little is known about the barriers to palliative care provision for older people within acute hospitals.

Objective: to explore the perspectives of health professionals regarding barriers to optimal palliative care for older people in acute hospitals.

Methods: fifty-eight health professionals participated in eight focus groups and four semi-structured interviews.

Results: participants identified various barriers to palliative care provision for older people, including attitudinal differences to the care of older people, a focus on curative treatments within hospitals and a lack of resources. Participants also reported differing understandings of whose responsibility it was to provide palliative care for older people, and uncertainty over the roles of specialist and generalist palliative care providers in acute hospitals.

Conclusions: numerous barriers exist to the provision of high-quality palliative care for older people within acute hospital settings. Additional research is now required to further explore age-related issues contributing to poor access to palliative care.

Keywords: palliative care, hospitals, older people, elderly

Background

Demographic trends coupled with a rise in long-term health conditions and chronic diseases mean that the core population of patients requiring palliative care is ageing [1]. This is a particular challenge for palliative care whose demographic profile has tended to be younger and whose historic disease focus has predominantly been cancer. Ensuring that palliative care becomes more accessible to older people and their particular complex and co-existing conditions requires a comprehensive understanding of the barriers to its provision in acute hospital settings.