Reducing Barriers and Improving Access to Continence Care: Examining the Evidence

Julie Spencer

Urinary incontinence (UI) has a great impact on the quality of life (QOL) of many women. Incontinence is frequently under-diagnosed and goes largely untreated (Spencer, 2009). Although UI is not a life-threatening problem, it affects all strata of society, and has many social and medical ramifications, such as social embarrassment, urinary tract infections, and possible cause for nursing home admittance (Coyne, Zhou, Thompson, & Versi, 2003).

The lack of understanding of causes and available treatments for UI has led to delayed access to care for patients (Kinchen et al., 2003). This delay significantly impacts the patient’s QOL. Variables associated with why individuals eventually seek treatment for incontinence include age, duration and severity of symptoms, impact on QOL, and comfort disclosing the problem to their health care professional (Kinchen et al., 2003).

There is a great need for increased community awareness to encourage women to seek treatment for urinary incontinence (UI). This article reviews the literature pertaining to the efficacy of increased awareness and knowledge of UI in reducing barriers to health care access and early intervention. Discussion focuses on the implications for clinical practice based on the available evidence.

Key Words: Urinary incontinence, barriers, community education, quality of life, health-seeking behaviors.

Objectives
1. Identify reasons why individuals seek treatment for incontinence.
2. Discuss the literature findings that provide evidence of health-seeking behaviors and barriers to care of urinary incontinence.
3. Describe examples of community education of urinary incontinence.
4. Discuss studies presented in the literature that have translated research into practice.
5. Outline examples of the need for further research.

Public Education for UI
In the U.S., there have been several campaigns to heighten public awareness of the prevalence of UI that have been backed by both public and private funding (Melchior, Kumar, Muller, van Maanen, & Norton, 1998). The media has played a great part as well, with commercials on television and advertisements for medications and other treatments in newspapers and magazines. National organizations, such as the Society for Urologic Nurses and Associates (SUNA), the International Continence Society (ICS), the National Association for Continence (NAFC), and the Simon Foundation for Continence, have made great strides in advocating for better awareness and education not only on the community level, but at the professional level as well.

It is estimated that almost 50% of the older adult population residing in nursing homes in the U.S. are incontinent, with a financial burden of $16.4 billion for

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Note: Objectives and CNE Evaluation Form appear on page 414.
the treatment and management of incontinence (Melchoir et al., 1998). According to Melchoir et al. (1998), effective continence promotion can lead to a change in attitude of the patient and provider, improved treatment, and much needed improved outcomes. The female population as a whole is uneducated regarding incontinence, ways for prevention, and treatment options. The purpose of this article is to provide a literature review pertaining to the efficacy of increased awareness and knowledge of UI in reducing barriers to health care access and early intervention. It will also discuss implications for clinical practice based on the available evidence.

Evidence Search

To examine the help-seeking behaviors for women who are incontinent and possible barriers to treatment, a systematic literature review was performed. The PubMed (1998-2007) database was searched using the following keyword phrases: clinical guidelines for UI, incontinence, continence promotion, and care (help) seeking behavior. The search was limited to studies involving human subjects and those written in English. A hand search of the returned articles’ reference lists was also performed to enrich the search. Because of few continence promotion studies and strategies identified in the U.S., international studies were allowed and reviewed. Twenty-nine articles were found to be pertinent to this review. Relevance was organized based on impact of quality of life, barriers to early care, and efficacy of community education (see Table 1).

### Table 1.
**Evidence Search**

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<tr>
<th>Number</th>
<th>Author</th>
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<th>Evidence Type</th>
<th>Sample and Sample Size</th>
<th>Results/Recommendations</th>
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<tbody>
<tr>
<td>1</td>
<td>Spencer</td>
<td>2009</td>
<td>Review</td>
<td>N/A</td>
<td>Discussion of the need for further policy and guidelines for UI for primary care provider (PCP) to encourage screening.</td>
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| 2      | Waetjen et al.            | 2008 | Prospective cohort study   | 2,415 women            | • Over 6 years, 14.7% of incontinent women reported worsening, 32.4% reported improvement, and 52.9% reported no change in frequency of UI symptoms.  
  • Comparisons with pre-menopause, peri-menopause, and post-menopause were not associated with worsening incontinence.  
  • Each pound of weight gain increased odds of worsening and reduced odds of improving incontinence. |
| 3      | Minassian, Stewart, & Wood| 2008 | Cross-sectional analysis   | 2,875 women 20 years old or older | • Overall prevalence of stress, urge, mixed, and any UI was 23.7%, 9.9%, 14.5%, and 49.2% respectively.  
  • Prevalence of SUI peaked at the 5th decade.  
  • Age, ethnic background, and weight were significant risk factors common to all UI severity levels. |
| 4      | Dooley et al.             | 2008 | Survey study               | 4,229 women older than 20 years | • 49.6% of the sample reported UI symptoms; of those, 49.8% reported pure stress incontinence, 34.3% mixed, and 15.9% pure urge incontinence.  
  • Odds of pure stress incontinence are at least 2.5 fold higher in White and Mexican-American women than in African-American women. |
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<tr>
<td>5</td>
<td>Waețjen et al.</td>
<td>2007</td>
<td>Comparative Cohort Study</td>
<td>16,065 women</td>
<td>• For midlife women, 46.7% were incontinent in the study, average incidence was 11.1% per year, and most women reported stress UI.</td>
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<td>• African Americans (29.5%) and Hispanics (27.5%) had lowest prevalence of incontinence.</td>
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<td>• Parity, diabetes mellitus, fibroids, and poor social support were associated with prevalent incontinence, while high body mass index, high symptom sensitivity, and poor health were associated with incident incontinence.</td>
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<td>6</td>
<td>Anger, Saigal, Madison, Joyce, &amp; Litwin</td>
<td>2006</td>
<td>Medicare claim review 1992, 1995 and 1998, cost analysis</td>
<td>N/A</td>
<td>From 1992 to 1998, medical expenditures for UI among female Medicare beneficiaries 65 years old or older nearly doubled. The increase in total spending was due almost exclusively to the increase in the number of women treated for incontinence.</td>
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<td>7</td>
<td>Melville, Delaney, Newton, &amp; Katon</td>
<td>2005</td>
<td>Cross-sectional study Age-stratified postal survey</td>
<td>6,000 women aged 30 to 90</td>
<td>• 64% response rate; prevalence of UI was 42%, prevalence of major depression was 3.7%, with 2.2% in those without incontinence, and 6.1% in those with incontinence.</td>
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<td>• Compared with women with incontinence alone, women with co-morbid incontinence and major depression had significantly greater decrements in quality of life and functional status and increased incontinence symptom burden.</td>
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<td>8</td>
<td>Melville, Katon, Delaney, &amp; Newton</td>
<td>2005</td>
<td>Population-based, age-stratified postal survey</td>
<td>6,000 women aged 30 to 90</td>
<td>• Prevalence increased with age, from 28% for women 30 to 39 years to 55% for women 80 to 90 years.</td>
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<td>• Several risk factors associated with UI, increases linearly with age.</td>
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<td>9</td>
<td>Wyman et al.</td>
<td>2004</td>
<td>Executive summary</td>
<td>N/A</td>
<td>Twenty-one recommendations were derived: 11 recommendations focused on new approaches to incontinence research, 8 on reinvigorating and reprioritizing nursing research on incontinence, and 2 on attracting and mentoring new investigations.</td>
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<td>10</td>
<td>Hu et al.</td>
<td>2004</td>
<td>Comparative study</td>
<td>N/A</td>
<td>• The total cost of UI and overactive bladder (OAB) was $19.5 billion and $12.6 billion respectively (year 2000).</td>
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<td>• OAB affects 34 million individuals compared with 17 million with UI.</td>
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<td>• Despite epidemiology, total and per-person costs of UI were higher than the OAB costs.</td>
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<td>11</td>
<td>Nygaard, Turvey, Burns, Ctschilles, &amp; Wallace</td>
<td>2003</td>
<td>Cross-sectional study</td>
<td>5,701</td>
<td>Women with severe and mild-moderate incontinence were 80% and 40% more likely, respectively, to have depression than continent women.</td>
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<td>12</td>
<td>Coyne, Zhou, Thompson, &amp; Versi</td>
<td>2003</td>
<td>Nested case-control study</td>
<td>919 participants</td>
<td>• Of the 919 participants, 171 reported UI: urge (69), stress (62), mixed (40).</td>
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<td>• 82% female, 85% Caucasian, mean age 56 years.</td>
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<td>• Respondents with urge and mixed UI had significantly greater ratings of urinary urge intensity and also significantly worse health-related quality of life scores.</td>
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<td>13</td>
<td>Stewart et al.</td>
<td>2003</td>
<td>National telephone survey</td>
<td>5,204 adults older than 18 years of age</td>
<td>OAB, incontinence prevalent and associated with lower quality of life score, higher depression scores, poorer quality of sleep than matched controls.</td>
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| 14     | Chang, Gonzalez, Lau, & Sier | 2008 | Cross-sectional, observational study  | 82,196                 | • 75% of the group identified UI as problematic, 50% had discussed with PCP, and of this group, 50% received treatment.  
• Study highlights the need for early detection, proper education, and access to effective treatment. |
| 15     | Koch                    | 2006 | Literature review                     | N/A                    | Factors affecting help seeking included quality-of-life scores, perception women had regarding the normalcy of UI, and belief’s about treatment options available for the problem. |
| 16     | Roe et al.              | 2004 | Literature review                     | N/A                    | Several methods to effect translation of incontinence research into practice are described, including clinical practice guidelines and protocols, clinical pathways, partnerships between organizations, and implementation strategies that incorporate change theory and considerations of barriers. |
| 17     | Margalith, Gillon, & Gordon | 2004 | Questionnaire study                   | 131 women              | • 74% delayed seeking help for at least 1 year, 46% delayed for 3 years.  
• Reasons: lack of time (36%), shame (15.7%), fear of surgery (14.7%). |
| 18     | Kinchen et al.          | 2003 | Two stage cross-sectional survey      | 1,970 women with UI symptoms | • 38% of women with UI symptoms had initiated conversation with physician about incontinence.  
• Factors associated with treatment seeking included the impact of incontinence on quality of life, lack of embarrassment about talking to a physician about urinary symptoms, and attitudes toward health care use. |
| 19     | Hagglund, Walker-Engstrom, Larsson, & Leppert | 2003 | Cross-sectional population-based cohort study | 95 women | 74% of the women with long-term UI had not sought help. Women who did seek professional help had more severe urine leakage than those who did not seek help. |
| 20     | Shaw, Tansey, Jackson, Hyde, & Allan | 2001 | Qualitative study                     | 31 women               | Most common theme was lack of knowledge of the condition and of available treatments. Older people are more likely to accept symptoms and less likely to bother PCP.  
• Length of delay of treatment sought for UI did not correlate with reported distress.  
• Elderly women delayed treatment for more than 5 years. Two-fifths delayed within 1 year, one-third delayed 1 to 5 years, one-quarter waited more than 5 years. |
<p>| 21     | Norton, MacDonald, Sedgwick, &amp; Stanton | 1988 | Survey study                          | 201 women              |                                                                                                           |</p>
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<tr>
<td>22</td>
<td>O’Connell, Wellman, Baker, &amp; Day</td>
<td>2006</td>
<td>Descriptive exploratory study</td>
<td>111 participants (78 female, 33 male)</td>
<td>Two-thirds of the total sample of participants sought help for their continence problem after reading the brochure; 44% of total participants indicated they had discussed the issue of bowel/bladder problems with someone directly because of study or information contained in the brochure.</td>
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<tr>
<td>23</td>
<td>Schim, Baumgardner, Dowd, Gregor, &amp; Kolcaba</td>
<td>2004</td>
<td>Descriptive study</td>
<td>180 older adults</td>
<td>Healthy bladder program devised to provide education promoting bladder health and to offer individualized assessment, intervention and evaluation; program successful in providing information for immediate use.</td>
</tr>
<tr>
<td>24</td>
<td>Palmer</td>
<td>2004</td>
<td>Literature review</td>
<td>N/A</td>
<td>Although some factors associated with UI are not modifiable, there is no evidence that primary prevention does not work. Preferable future for primary prevention of UI in adults is the identification of effective interventions that are low-cost and easily adapted and maintained.</td>
</tr>
<tr>
<td>25</td>
<td>Sampselle, Palmer, Boyington, O’Dell, &amp; Wooldridge</td>
<td>2004</td>
<td>Literature review</td>
<td>N/A</td>
<td>Key populations identified to be at risk for UI are women in selected occupations, childbearing women, older adults with lifestyle risk factors and with co-morbid conditions, and nursing home residents. Nursing research is needed to test prevention programs for UI using a population-based public health focus.</td>
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<td>26</td>
<td>Lauver, Gross, Ruff, &amp; Wells</td>
<td>2004</td>
<td>Literature review</td>
<td>N/A</td>
<td>Research is needed to demonstrate the efficacy of patient-centered interventions in outcomes, to determine bio-psycho-social factors of subgroups to more accurately describe prevalence rates, create effective interventions, and to find common variables among successful interventions.</td>
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</table>
| 27     | Chiarelli & Cockburn                       | 2002 | Prospective randomized controlled trial | 108 intervention group/125 control group | • 3 months after giving birth, prevalence of incontinence in the intervention group was 31%, usual care group 38.4%.  
• Significantly fewer women with incontinence were classified as severe in the intervention group.  
• Promoting continence, which included training in pelvic floor exercises and strategies to improve adherence to exercises, reduced prevalence of UI after giving birth. |
| 28     | Robinson                                    | 2000 | Interview study                    | 33 nursing home residents | Residents were found to have strategies for management: speaking up to physicians in regard to UI, improvising with absorbent products, limiting fluid intake, and learning locations of accessible bathrooms. |
| 29     | Haugen & Moore                             | 1995 | Descriptive study                  | N/A                    | Implementation of “I’ll Manage” program to provide education to the community was successful.                                                                 |
| 30     | Primomo, Bruck, & Davis                    | 1994 | Review                             | N/A                    | Program in Washington State that demonstrated community was interested in learning more about incontinence when given the opportunity to learn via an education brochure. |
| 31     | Gartley                                    | 2006 | Review                             | N/A                    | Bladder Health Mobile initiative developed by The Simon Foundation for Continence shows promise for increasing community education regarding incontinence. |
Several studies found reviewed surveys evaluating care-seeking behavior of incontinent women and reasons for delay. Norton, MacDonald, Sedgwick, and Stanton (1988) performed a study to examine the initial delay in seeking treatment in women with UI, nocturia, frequency, and urgency. In this study of 201 women with a mean age of 49, it was found that the delay of treatment time was associated with older age and marital status; older women tended to wait longer, and married women tended to delay seeking treatment 5 years or more. Of the women studied, two-fifths consulted a doctor within 1 year of the symptoms becoming troublesome, one-third delayed treatment 1 to 5 years, and one-fourth waited more than 5 years before seeking treatment.

Robinson (2000) found that residents of long-term care facilities accepted incontinence as inevitable and responded by developing self-management plans to meet common goals of comfort, physical safety, and psychological and social integrity. Shaw, Tansey, Jackson, Hyde, and Allan (2001) found similar results when evaluating 31 participants (23 female with a mean age of 57, and 8 male with a mean age of 59) in a study for barriers to help seeking for urinary symptoms. The participants either agreed to treatments as part of a different intervention study or were currently receiving treatment at a hospital outpatient clinic for urinary problems (Shaw et al., 2001). The participants were questioned about their views on help seeking for incontinence and their previous experience (Shaw et al., 2001). Older women were found to be more likely to adapt to their symptoms and learn to live with them, rather than “bother” their general practitioner with their problem. Many women studied did not have a clear understanding of the condition and available treatment options.

Kinchen and colleagues (2003) conducted a cross-sectional survey study evaluating factors associated with women’s decisions to seek treatment. They also found that less than half of the women polled with reported symptoms of UI had talked with their provider about their symptoms (Kinchen et al., 2003). The factors associated with treatment seeking were similar to findings in other studies: impact of QOL, embarrassment associated with talking about the problem, and overall health of the patient.

In the study by Hagglund, Walker-Engstrom, Larsson, and Leppert (2003), the most common reasons given by the women studied was that the disorder was considered minor and that they felt a low sense of burden. They assumed they were supposed to cope and learn how to manage their symptoms. Women who sought help did so most frequently because of urine odor and the perception that the leakage was shameful and embarrassing. Margalith, Gillon, and Gordon (2004) evaluated patterns of seeking health care for young and middle-aged Israeli women with UI and found that help-seeking was delayed by at least 1 year. The most common reasons for delay were similar to those identified by Hagglund et al. (2003): lack of time (36.3%), shame (15.7%), and fear of surgery (14.7%) (Margalith et al., 2004).

One survey study showed that 74% of the women participating delayed treatment for UI (Hagglund et al., 2003; Margalith et al., 2004). Chang, Gonzalez, Lau, and Sier (2008) performed a cross-sectional observational study with a large number of male and female participants (82,196, respectively) over 65 years of age, in which 75% of the group identified UI as problematic, 50% had discussed the problem with their primary care provider, and of that group, 50% had received treatment. This study provides evidence of the small number of patients who actually choose to discuss the problem of UI with their provider, even when experiencing bothersome symptoms. The findings highlight the need for early detection and proper education of the patient to enhance access for treatment.

Evidence of Efficacy of Community Education

To date, few recent health education programs have been evaluated to determine their effect on patient awareness and help-seeking behaviors regarding UI (Schirm, Baumgardner, Dowd, Gregor, & Kolcaba, 2004). The “I Will Manage” (IWM) program was founded by the Simon Foundation for Continence in 1983, with a goal to increase public awareness of incontinence and treatment options, with a specific focus on the local Chicago area (The Simon Foundation, 2009). This 4-week IWM program was implemented with revisions by nurses in 1995 in a hospital in Minnesota and showed promise in education of the participants regarding urinary incontinence (Haugen & Moome, 1995). Another program developed in Kings County, Washington, demonstrated that the community-dwelling population was interested in learning more about incontinence when given the opportunity (Primomo, Bruck, & Davis, 1994). However, specific findings related to changes in knowledge or treatment-seeking were not evaluated in that study.

The Healthy Bladder Program, funded by the Department of Health and Human Services Administration on Aging in 2002, was evaluated related to its aim of providing general bladder health education to older adults residing in independent and assisted living facilities (Schirm et al., 2004). The authors concluded that the 180 older adults who attended various hour-long educational programs during the selected time frame demonstrat-
ed increased UI awareness and improved ability to manage symptoms.

The most recent noted community education attempt was the Bladder Health Mobile initiated by the Simon Foundation for Continence in 2003 (Gartley, 2006). This mobile center is designed to “provide education, increase public awareness, and promote early diagnosis and proper treatment of incontinence and other bladder control problems, while also facilitating dialogue between consumers and their health care professionals” (Gartley, 2006). Little evidence of continued initiative could be found in the literature. Since 2003, there has been continued talk about the stigma of incontinence and need for public education. Most recently, in 2009, the ICS sponsored a World Continence Week from June 22-28 to help promote national continence awareness.

Evidence of Research that Translates into Practice

A seminal Australian study by O’Connell, Wellman, Baker, and Day (2006) evaluated continence promotion and health-seeking behaviors. This descriptive exploratory study evaluated whether participants who were given a continence education package because they indicated they were bothered by incontinence symptoms changed health-seeking behaviors. One hundred and eleven men and women who had documented bothersome urinary symptoms were evaluated. All participants were given a continence educational brochure that contained educational material regarding incontinence and treatment options available to them. Participants were then interviewed 2 to 3 months later as follow up. It was found that two-thirds of the sample sought help for their continence problem. Forty-nine percent indicated they had discussed the issue of bladder/bowel problems with someone directly because of the study or information in the brochure (O’Connell et al., 2006). Seventy-four of the 111 participants reported they had sought treatment for their incontinence (O’Connell et al., 2006). Of significance, 94% of participants indicated they believed the brochure would be helpful if given to other people (O’Connell et al., 2006).

This study has practice implications for UI and promotion. It showed that patients educated with a brochure could affect health-seeking behaviors in various ways. It prompted patients to speak to their health care provider regarding their urinary problem, it encouraged participants to discuss their UI problem with others, and it prompted them to consider change with their current treatment or management of their incontinence (O’Connell et al., 2006). Most importantly, this study shows evidence of a continence health promotion strategy being effective and provides evidence that further research and analysis are needed (O’Connell et al., 2006).

Future Research

Further research is needed to clarify the various types of incontinence interventions, the use of new technologies and treatment strategies, and the use of community education to enhance clinical practice and research (Wyman et al., 2004). Roe et al. (2004) have several recommendations regarding future incontinence research as it relates to the translation into evidence-based practice, which are based on the conclusions reached during a nursing research summit on UI. Some of these recommendations include involving a whole systems approach (families and patients, providers and consumers), making sure the research is able to be used in all areas of care (long-term care and out-patient settings), and making sure it accounts for the variance in care-seeking behaviors across different cultures and ages.

Laaber and colleagues (2004) state that when evaluating incontinence, past researchers have focused primarily on the physiologic factors and outcomes using a one-size-fits-all approach. There has been little investigation into the different population groups and the various interventions applied. The clinical condition, age, gender, race, and ethnicity may greatly affect one’s willingness to report UI, an individual’s general knowledge regarding the condition, and experiences of incontinence endured by the patient (Laaber et al., 2004).

There have been many documented studies showing the prevalence of UI and the impact on QOL for the women affected (Coyne et al., 2003; Dooley et al., 2008; Melville, Katon, Delaney, & Newton, 2005; Stewart et al., 2003; Waetjen et al., 2007). Furthermore, there have been several studies identifying the various barriers associated with delayed help-seeking behaviors of these women (Hagglund et al., 2003; Kinchen et al., 2003; Månglith et al., 2004; Norton et al., 1988; Shaw et al., 2001). Based on this evidence, there is a significant gap in the research that evaluates the interventions that affect patients’ poor health-seeking behaviors in respect to UI. To date, only one study (O’Connell et al., 2006) exists that explores this issue.

With the prevalence of UI becoming more well-known and the stigma being lifted from discussing this topic, primary prevention of incontinence might become more of a possibility. Prevention strategies for other chronic diseases, such as hypertension, heart disease, cancer, and obesity, have proven to be effective, and might serve as a guide for the prevention of UI (Sampselle, Palmer, Boyington, O’Dell, & Wooldridge, 2004). Some of these programs have been designed to focus on indi-
vidual behavioral changes to prevent or control urinary symptoms or incontinence (McFall, Yerkes, & Cowan, 2000; Sampselle et al., 2004). However, there are few continence promotion and prevention inventions that are well defined and have been implemented within the community. The need for future research regarding implications for best practice interventions for education strategies of UI is imperative to decreasing the barriers to help-seeking behaviors for women with incontinence.

Conclusion

It is imperative that the outlook for continence education and promotion change to better enable patients prevent and/or manage the problem on their own. Getting out into the community to help remove the stigma of UI is an important component of this effort. Patient-centered interventions involve explaining, counseling, and building skills to help the patient adopt health-related behaviors and encourage change (Lauver et al., 2004). Tailored interventions have been shown to be the most helpful type of intervention in promoting health behaviors (Lauver et al., 2004). According to Shaw (2001), appraisals of illness and coping resources are important factors that need to be readily available to influence a woman’s decision to seek treatment.

Based upon the review of literature, there is evidence of the need for improved and widespread education to help women better understand the physiologic changes that lead to the development of UI. Through continence education, women can be encouraged to engage in preventive activities, or take charge of the problem and work toward management or cure. A proactive approach to continence education that involves individual patients as well as the community is crucial to decrease the barriers associated with access to health care services and increase early intervention for UI.

References


Translating research on incontinence into practice. *Nursing Research*, 53(6S), S56-S60.


**Additional Readings**