Exploring Women’s Beliefs Regarding Urinary Incontinence

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Urinary incontinence (UI) is a common health problem. An estimated 13 million Americans suffer from the symptom of involuntary urine leakage and a majority of those suffering are women (Agency for Health Care Policy and Research [AHCPR], 1996). The annual cost in the United States of providing care for community-dwelling adults experiencing incontinence is estimated to be $11 billion, while the cost associated with long-term care (LTC) residents is estimated at $5 billion (Newman, 1997). Newman (1997) believes these costs may actually be higher based on research, which suggests that UI is grossly underreported.

Reported prevalence of UI in women varies somewhat from study to study, but is generally believed to range from 10% to 56% in community-dwelling women, and 50% to 84% in female LTC residents (Burgio, Locher, & Goode, 2000; Fultz & Herzog, 1996). Despite its high prevalence and cost, UI remains a largely untreated problem. Reported rates of treatment seeking range from 18% to 41% of those affected (Seim, Sivertsen, Eriksen, & Hunksaar, 1996). Yet effective treatment is available. Pelvic muscle exercises, behavioral treatment, medications, electrostimulation, and surgery can all produce significant improvement or cure significance (Seim et al., 1996).

The purpose of this study was to explore and describe women’s beliefs, knowledge and need for education regarding female urinary incontinence (UI). Findings suggest that almost half of the women surveyed believed UI was normal. A majority believed it is a problem for women, but felt they could not talk about it freely. Most knew professional help was available and indicated they would seek help if incontinent, but expressed a need for more information. They varied in their beliefs regarding the efficacy of various treatment modalities. Implications for nursing practice are discussed.

Significance

Hesitancy to seek professional help for UI has been attributed to embarrassment and lack of knowledge (beliefs that incontinence is normal and/or untreatable) (AHCPR, 1996). However, very few systematic investigations of knowledge of, beliefs about, and responses to UI have been undertaken (Mitteness & Barker, 1995). Therefore, there is a need to explore women’s beliefs and knowledge with regard to UI in an effort to determine if there is a need for education.

Literature Review

Urinary incontinence. For purposes of this study urinary incontinence was defined as “involuntary urinary leakage sufficient to be a problem” (AHCPR, 1996). Some researchers concern themselves solely with the involuntary loss of urine — duration and frequency of loss — and do not include how the individual perceives this symptom. The International Continence Society adds measurement and psychosocial definers to its definition: “a condition in which the involuntary loss of urine is a social and hygienic problem and is objectively demonstrable” (Seim, Hermstad, & Hunksaar, 1997). Those who experience UI may redefine the term behaviorally as wetness, or as the ability or inability to void in a manner that prevents urine from being detectable by others (Talbot, 1994). This invisibility includes both seeing and smelling. The significance of urine loss is defined by the person, and it is only recently that research is focusing on psychosocial issues
related to UI (impact on quality of life, management/coping behaviors, treatment-seeking behaviors, and beliefs and knowledge regarding UI) rather than correlates such as gender, age, cognitive impairment, and physical health.

Quality of life. Research on quality-of-life issues is sometimes contradictory. Some studies (Burgio et al., 2000) suggest that UI leads to embarrassment, loss of self-esteem, and social isolation in the elderly. In younger women, a correlation was found between incontinence symptoms and their impact on travel, social, physical, and emotional activities (Valerius, 1997). Still other research (Seim et al., 1997) suggests that women are coping effectively with their incontinence in terms of self-esteem and depression and are experiencing a normal response of anger to an unexpected and uncomfortable problem.

Management and coping behaviors. Upon developing UI a woman can respond in one of two ways. She can manage it herself or seek professional help. Beliefs and knowledge lead most women to choose self-management (Engberg, McDowell, Burgio, Watson, & Belle, 1995; Mitteness & Barker, 1995). Skoner (1994) researched women’s strategies for managing UI in a grounded theory approach. This study revealed that women deal with incontinence in the manner of a chronic illness. The women’s basic concern was dealing with incontinence in a way that enabled them to feel normal and in control (being able to do what they wanted to do and needed to do to have a normal lifestyle as they perceived it). This goal was accomplished by normalizing UI and its daily management. Normalization occurs as women contextually explain the problem of incontinence within their personal history and life experiences (incontinence as normal for other female relatives, after childbirth, with aging, etc.). They make incontinence management part of their daily routine. Normalization is also fostered by the increased availability of absorbent products.

Media advertising of absorbent pads can convey the message that UI is a normal bodily function or age change, and it is something that you just have to live with (Haller, 1997).

Self-management is described as a step-by-step process involving a person’s acknowledgment of the problem, making adjustments in activities and behaviors so that they continue to do what they normally do, and being vigilant so they can stay in control. Generally, as the duration of the incontinence lengths, women become less troubled by their symptoms as long as self-management is successful (Skoner, 1994). The feeling of control over incontinence is related to choices that women perceive they have for managing their incontinence and their degree of success in achieving or maintaining a desired lifestyle. The goal is to avoid or contain urine loss by using strategies that require little effort, entail simple modifications of usual practices, and can be incorporated into regular or routine activities (Skoner, 1994). These strategies may be self-discovered or noninvasive techniques suggested by physicians.

When people do seek treatment for UI, that behavior is more often driven when self-management is no longer successful, and when the symptom of urine leakage becomes more severe affecting quality of life (Burgio et al. 2000; Costa & Mottet, 1997; Samuelsson, Victor, & Tibblin, 1997). Treatment-seeking behavior related to severity has not been associated with gender, marital status, income, employment status, educational level, or distance from health care provider (Burgio et al., 2000). Among those who say they want help for urinary incontinence, 34% to 50% actually seek assistance (Lara & Nacey, 1994; North, 1994).

Beliefs and knowledge. The involuntary or too frequent loss of urine holds a symbolic meaning for our culture (Burgio et al., 2000). The loss of continence in Western society is viewed as a violation of social norms (Palmer, 1994). Continence, linked culturally with competence in United States society, is a requisite for adulthood (Mitteness & Barker, 1995). Incontinence is generally considered a taboo topic. Sufferers may find it difficult to focus on and think clearly about the problem, often not following rational ways to tackle the problem. They may feel a sense of guilt and be reticent to discuss the urine leakage with family or friends. They see the problem as one of personal control, the lack of bodily propriety. An incontinent episode has the potential of leading to stigmatization, social isolation, shame, hopelessness, and depression. Often it is the individual’s attitude, derived from these cultural ideas of what incontinence symbolizes, that is the real disability (Telbot, 1994).

Beliefs and knowledge about UI affect treatment-seeking behavior. Reasons cited for not seeking treatment include the following: belief that incontinence is normal, lack of awareness of available treatment, low expectation of benefit from treatment, embarrassment, belief that the incontinence is only a minor problem, and effective self-management of the problem (Engberg et al., 1995; Foldspang & Mommesen, 1997; Samuelsson et al., 1997).

Incorrect beliefs about UI may be supported if health care providers are unresponsive to, or dismissive of, clients’ queries regarding urine loss. They may reinforce the myth of normalcy by saying, “don’t worry, all older people have trouble with incontinence” (Mitteness & Barker, 1995; Newman & Burns, 1994). Several studies suggest that with approximately 70 minutes of medical education devoted to UI, physicians often perceive a lack of adequate medical training in incontinence care (Dovey et al., 1996; Newman & Burns, 1994). Unfortunately, related to this lack...
of content devoted to incontinence in medical education, the therapeutic advice offered may not be accurate, useful, or sensitive. It may be nonexistent if routine medical questioning omits issues of continence. The elderly are content with this nonexplana- tion because they do not expect a cure (Mitteness & Barker, 1995).

Health care providers may also add to clients' feelings of stigmata- tion through a lack of sensitivity and negative responses to UI. In a study by Mitteness and Barker (1995) of three common conditions among the impaired elderly (confusion, mobility impairment, and UI), urinary incontinence received the most negative evaluations and emotional responses from medical social workers and home health care nurses. These professionals also tended to prescribe palliative, rather than rehabilitative, therapy when dealing with clients experiencing UI. This choice was attributed to providers' beliefs that the incontinence was the fault of the client or a normal age change, rather than something external to the person (Palmer, 1995). This suggests that the behavior of health care providers may be affected by societal beliefs which are incon- gruent with purely biomedical understanding of etiology and treatment alternatives.

Methodology

Sample. To gather opinions from women of diverse cultures, two separate population groups were targeted in the same geographic area: female members of a local community church (non-minority group), and the female membership of a minority association (minority group). Members of both groups were asked to voluntarily participate. From these two populations, a convenience sample of 70 community-dwelling females volunteered to complete the survey. The women ranged in age from 26 to 79 years, with a mean age of 47.2 years, and included Caucasian (50%), African-American (43%), and Hispanic (7%) women. Criteria for inclusion in this research included women at least 21 years of age who had the ability to read English. Informed consent was obtained and anonymity was maintained for the participants.

Instrument. Since this research was exploratory in design and a pre-existing instrument focusing on the area(s) for study was not available, a 16-question survey was used to gather information designed by the primary author. Ten questions were developed to elicit beliefs and knowledge regarding normalcy, problematical nature, freedom of dialogue, availability of information, incidence, treatment-seeking behaviors, and efficacy of treatment for UI. Six demographic questions addressed age, ethnicity, educational level, income, number of vaginal births, and surgery on the uterus or bladder. The survey questions were created from observations made in both practice and discussions with women, as well as from selected variables that have been reported in the literature to establish face and content validity (90% agreement). No other reliability or validity measures were established (see Figure 1).

Procedure. Informed consent was obtained and the purpose of the study was explained to all of the women. A definition of UI was included on the survey itself (to insure validity of the concept of UI), with no additional comments made by the researchers. The format of introducing the purpose of the survey and the distribution of the questionnaire was kept standardized for reliability. Following this explanation the subjects were asked to complete the survey to the best of their ability. The women were asked to return their surveys by mail within a 2-week period following the explanation of the purpose of the study. The response rate was 72%, with a larger return rate from the Caucasian group.

Of the 48 surveys distributed to the nonminority women 41 (85%) were returned, with 29 (60%) of the 48 minority women returning their survey.

Findings

Data were analyzed using SPSS to determine frequencies of responses, and each survey was coded to maintain anonymity. All of the returned surveys were completed without any missing data. The demographic data were analyzed and used for descriptive purposes of the sample population. An analysis of the comments made by the participants did not reveal any consistent pattern or theme.

The following data reveal the frequency of responses to each corresponding question contained on the survey.

Almost half (47%) of the women surveyed believed that UI is a normal part of aging or a consequence of childbirth. Only 20 (29%) were aware that incontinence is not normal. Minority women (M) were more likely than nonminority (NM) women to believe that UI is not normal (see Table 1).

Most participants believed UI is a problem for women. While some women (17%) were unsure, only three (4%) believed that it was not a problem for women (see Table 2).

When asked if they were able to talk freely about UI, only 18 (26%) answered “yes.” Nonminority women were more likely to believe open discussion was
Table 1. Normalcy: Question 1

<table>
<thead>
<tr>
<th>Group</th>
<th>Yes N (%)</th>
<th>No N (%)</th>
<th>Don't Know N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
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<td>24 (59)</td>
<td>7 (17)</td>
<td>10 (24)</td>
<td>41 (100)</td>
</tr>
<tr>
<td>M</td>
<td>9 (31)</td>
<td>13 (45)</td>
<td>7 (24)</td>
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<tr>
<td>Total</td>
<td>33 (47)</td>
<td>20 (29)</td>
<td>17 (24)</td>
<td>70 (100)</td>
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</table>

NM = Nonminority
M = Minority

Table 2. Problematic Nature: Question 2

<table>
<thead>
<tr>
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<td>M</td>
<td>21 (72)</td>
<td>1 (4)</td>
<td>7 (24)</td>
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<td>Total</td>
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<td>3 (4)</td>
<td>12 (17)</td>
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</table>

NM = Nonminority
M = Minority

Table 3. Dialogue Regarding Urinary Incontinence: Question 3

<table>
<thead>
<tr>
<th>Group</th>
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<td>21 (53)</td>
<td>7 (15)</td>
<td>41 (100)</td>
</tr>
<tr>
<td>M</td>
<td>5 (17)</td>
<td>17 (59)</td>
<td>7 (24)</td>
<td>29 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>18 (26)</td>
<td>38 (55)</td>
<td>13 (19)</td>
<td>70 (100)</td>
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</tbody>
</table>

NM = Nonminority
M = Minority

Table 4. Information Available: Questions 4, 5, 6

<table>
<thead>
<tr>
<th>Group</th>
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<th>Don't Know N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>NM</td>
<td>5 (12)</td>
<td>22 (54)</td>
<td>14 (34)</td>
<td>41 (100)</td>
</tr>
<tr>
<td>M</td>
<td>2 (7)</td>
<td>14 (48)</td>
<td>13 (45)</td>
<td>29 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>7 (10)</td>
<td>36 (51)</td>
<td>27 (39)</td>
<td>70 (100)</td>
</tr>
</tbody>
</table>

NM = Nonminority
M = Minority

possible (see Table 3).

Results to the questions regarding the adequacy of information on UI showed that a majority of the women (51%) believed there is not enough available information about urinary incontinence. Twenty-seven (29%) were unsure (see Table 4).

Those in the nonminority group who believed there was enough available information reported that it was accessible from (listed in order of frequency of response): talking with physicians, brochures, talking with the nurse, books, and other (magazines). Those in the minority group who believed that there was enough information stated that the information is obtainable from the following sources: books, brochures, talking with the physician or nurse, newspaper, television, and group meetings. Both the nonminority and minority group(s) of women, who did not believe there was adequate information, reported their preference to receive information similarly: brochures, talking with the physician or nurse, books, group meetings, television, and newspaper.

Of the 70 women surveyed 30 (43%) had experienced UI (see Table 5). Mean age of the incontinent women was 49.4 (NM) and 43 (M), and mean number of vaginal deliveries was 1.6 and 1.7 respectively (in the total population, mean number of vaginal deliveries was 2.3 and 2.6 respectively). Of those experiencing incontinence, 25% of the nonminority group and 40% of the minority group had a history of surgery on the uterus or bladder (those not experiencing incontinence reported incidence of surgery at the rates of 19% and 16%, respectively).

Of those experiencing urinary incontinence, 21(58%) said they would consider seeking professional help. A higher percentage of nonminority women were unsure if they would seek professional treatment (see Table 6). When questioned regarding the availability of professional assistance for UI, 43 (61%) knew
there were people in their community who provided help for urinary incontinence. Twenty-six (38%) did not know if professional help was available (see Table 7).

When questioned regarding the efficacy of three treatment modalities (behavioral therapy, medications, surgery) for UI, a majority of the participants (52%) believed surgery could improve or cure incontinence. With regard to behavioral therapy and medications, a majority (56%) were unsure if the nonsurgical treatment could be effective. Nonminority women were more likely to believe all three modalities are effective (see Table 8).

Interestingly, the survey provided for additional comments and while these remarks revealed no consistency of patterns or themes, their overall content was similar to what previous research has reported. For example: “Feel this is serious enough to receive far more attention than it does and the stigma of shame and/or embarrassment be removed.”

The results of this assessment revealed that a majority of nonminority women 24 (59%) believed urinary incontinence was a normal part of aging or childbirth; while only 9 (31%) of minority women believed incontinence is normal. An overall majority of women also considered it to be a significant problem for women (76%). Despite the significance of the problem, only 24% stated they are able to talk freely about incontinence. A minority of the sample believed there is enough information available to help women who experience UI. Those who want more information would like to receive it either in brochures, talking with the physician or nurse, books, seminars, television, and or newspaper.

In this study, 20 (49%) of the nonminority women and 10 (34%) of the minority women reported experiencing UI, with the mean age of

| Table 5.  
| Experiencing Urinary Incontinence: Question 7 |

<table>
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<tr>
<th>Group</th>
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<tr>
<td>NM</td>
<td>20 (49)</td>
<td>21 (51)</td>
<td>41 (100)</td>
</tr>
<tr>
<td>M</td>
<td>10 (34)</td>
<td>19 (66)</td>
<td>29 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>30 (43)</td>
<td>40 (57)</td>
<td>70 (100)</td>
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</table>

NM = Nonminority
M = Minority

| Table 6.  
| Seeking Treatment: Questions 8, 9,10 |

<table>
<thead>
<tr>
<th>Group</th>
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<th>Don’t Know N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
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<td>13 (54)</td>
<td>4 (17)</td>
<td>7 (29)</td>
<td>41 (100)</td>
</tr>
<tr>
<td>M</td>
<td>8 (67)</td>
<td>4 (33)</td>
<td>0</td>
<td>12 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>21 (58)</td>
<td>8 (22)</td>
<td>7 (20)</td>
<td>36 (100)</td>
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</table>

NM = Nonminority
M = Minority

| Table 7.  
| Assistance Available |

<table>
<thead>
<tr>
<th>Group</th>
<th>Yes N (%)</th>
<th>No N (%)</th>
<th>Don’t Know N (%)</th>
<th>Total N (%)</th>
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</thead>
<tbody>
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<td>26 (63)</td>
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</tr>
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<td>M</td>
<td>17 (59)</td>
<td>0</td>
<td>12 (41)</td>
<td>29 (100)</td>
</tr>
<tr>
<td>Total</td>
<td>43 (61)</td>
<td>1 (1)</td>
<td>26 (38)</td>
<td>70 (100)</td>
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</table>

| Table 8.  
| Treatment is Effective |

<table>
<thead>
<tr>
<th></th>
<th>Behavioral</th>
<th>Medication</th>
<th>Surgery</th>
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<tr>
<td></td>
<td>Yes %</td>
<td>No %</td>
<td>Don’t Know %</td>
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<tr>
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<td>56</td>
<td>5</td>
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</tr>
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<td>M</td>
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<td>8</td>
<td>70</td>
</tr>
<tr>
<td>Total</td>
<td>42</td>
<td>6</td>
<td>52</td>
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</table>
Figure 1.
Survey

**Definitions of urinary incontinence: involuntary urine leakage sufficient to be a problem.**

1. Do you think urinary incontinence is a normal part of aging or childbirth?
   a. Yes
   b. No
   c. Don’t know

2. Do you think urinary incontinence is a problem for women?
   a. Yes
   b. No
   c. Don’t know

3. Do you think women are able to talk about urinary incontinence freely?
   a. Yes
   b. No
   c. Don’t know

4. Do you think there is enough information available to help women who experience urinary incontinence?
   a. Yes
   b. No
   c. Don’t know

5. If "yes" to number 4, where can this information be found (check as many as applies)?
   a. Books
   b. Brochures
   c. Talk with doctor
   d. Talk with nurse
   e. Newspaper
   f. Television
   g. Group meetings/presentations
   h. Other (specify)

6. If "no" to number 4, where/how would you prefer to receive this information (check as many as applies)?
   a. Books
   b. Brochures
   c. Talk with doctor
   d. Talk with nurse
   e. Newspaper
   f. Television
   g. Group meetings/presentations
   h. Other (specify)

7. Do you ever experience urinary incontinence?
   a. Yes
   b. No

8. If "yes" to number 8, would you consider seeking professional help?
   a. Yes
   b. No
   c. Don’t know

9. Are there people in your community (doctor/nurse/hospital/clinic) who can assist women who want help for urinary incontinence?
   a. Yes
   b. No
   c. Don’t know

10. Listed below are several possible treatments for urinary incontinence. Can they improve or cure incontinence?
    a. Behavioral therapy
    b. Medications
    c. Surgery

**Demographic Information**

11. Age

12. Ethnicity (Choose one):
    a. African-American
    b. American Indian
    c. Asian
    d. Caucasian
    e. Hispanic
    f. Other (specify)

13. What is your highest level of completed education?
    a. Didn't complete high school
    b. High school grad or GED
    c. Technical school
    d. Associate or bachelor's degree, nursing diploma
    e. Master's degree
    f. Doctorate

14. What is your family's total gross income?
    a. Less than $10,000
    b. Between $20,000 and $30,000
    c. Between $30,000 and $50,000
    d. Between $50,000 and $70,000
    e. Between $70,000 and $90,000
    f. More than $90,000

15. How many children have you delivered vaginally?

16. Have you ever had surgery on your uterus or bladder?
    a. Yes
    b. No

17. Additional comments.
incontinent women being 46 years of age. Of those experiencing UI, approximately 60% responded they would seek treatment, and a majority knew there was professional help available in their community (61%).

Discussion

This exploratory study revealed differences between the nonminority and minority women with regard to urinary incontinence being perceived as a normal part of aging or childbirth. While minority women were less likely to consider incontinence normal, no reasons for this difference were found as part of this study. An assumption may be that this difference is attributed to lack of knowledge or strongly held beliefs by the nonminority group of women. Urinary incontinence was identified as a problem by a majority of the women, and the percentage finding it problematic increased if UI was experienced. Most research on the problematic nature of UI deals with self-management (Reymert & Hunskaar, 1994). Research among women who are self-managing their incontinence suggests they believe it is a minor problem. That opinion differs from the results of this survey, but in this case UI is approached as a global problem, rather than a personal one, and opinions include those of continent women.

Incidence of UI in these two groups was within the broad range noted in the research (Burgio et al., 2000; Fultz & Herzog, 1996). High percentages of these women (54% nonminority, 67% minority) said they would consider seeking professional help (the actual treatment-seeking behavior of the participants is unknown and unpredictable). Current research indicates reported rates of treatment-seeking range from 18% to 41% of those affected (Seim et al., 1995). Also of note is that among women who say they want help, only 34% to 50% actually seek professional assistance (Lara & Nacey, 1994; North, 1994).

A majority of women in both participant groups knew professional help for UI was available in the community. Knowledge of treatment modalities suggested a wide range of beliefs in treatment efficacy. It is unknown if these beliefs are based on personal experience, experiences of others, or cultural beliefs.

Limitations

Study limitations involved the convenience sampling to acquire the participants for this investigation. While appropriate for purposes of this study, any generalizations to the larger population are inappropriate, as the findings are only relevant to the participants included in the sample. Further, the survey that was created by the primary author for purposes of exploring beliefs and knowledge is new. Even though validity was established through face validity and content experts, and reliability was obtained by the standardization within which the surveys were distributed, more research and refinement of the instrument must be completed. The comments from the participants were diverse and therefore no consistent patterns or themes emerged from the data. If this survey were to be used in the future, additional reliability and validity would need to be determined, and consideration given to revising the tool to include a guided interview to enhance reliability and validity. Another limitation is the sensitive nature of the topic of urinary incontinence. Related to this sensitivity, there is the possibility that the women in the study may have answered the questions with an inherent bias related to societal and cultural perceptions.

Future Implications

Answers to questions regarding normalcy, problematic nature, availability of information, and treatment for urinary incontinence all tend to support the need for unambiguous, accessible, and widespread information. Information that treats the subject in an open and frank manner can incense the likelihood that people suffering from this socially isolating complaint will seek help. Women’s beliefs and knowledge regarding UI should continue as a focus in future nursing research. This study indicates the need for additional, systematic investigations with larger samples and diverse cultural and socioeconomic populations. Additional research will enable urology nurses to determine what women’s educational needs are in an effort to improve their understanding of UI.

Summary

Urinary incontinence is a major health issue for women today. Cultural beliefs and taboos, lack of knowledge and information, and lack of health care providers’ knowledge regarding this symptom all contribute to a lack of treatment seeking.

When attempting to clarify the sources and extent of distress regarding UI and underutilization of health care services, providers must distinguish between the knowledge that people have about incontinence, their beliefs about the meaning of the incontinence, and their reactions or attitudes toward people who are incontinent or toward their own incontinence.

References


