Urinary incontinence (UI) can be distressing for women of all ages. A recent report suggests the prevalence of UI varies based on definitions of UI, sampling methods, response rates, and data collection strategies (Nygaard, Thom, & Calhoun, 2007). In addition, this topic can evoke sensitive responses that may impact reporting. The prevalence rate for women experiencing a single episode of UI is between 12% and 55% (Holroyd-Leduc & Straus, 2004). It is estimated that 41% to 57% of women 40 years of age and older suffer from UI in the United States (Huang et al, 2006).

Women do not always have the opportunity to discuss urinary issues or explain the profound effects on quality of life.
UI is infrequently addressed by healthcare providers or ignored because of inadequate education or expertise, and the likelihood of screening for or successfully treating UI in the average primary care setting is low (Mardon, Halin, Pawlson, & Haffer, 2006; Resnick, 1998). Nurses provide a holistic approach to assessment and evaluation of incontinence care (Enriquez, 2004), and in any practice setting, they should be able to detect UI and refer for appropriate treatment (Henderson, Kashka, & Larson, 2000).

**Purpose of the Study**

The purpose of this study was to describe living with UI among Alaskan women. Women’s personal experiences with UI were explored based on interview responses to the question: “What is your experience of living with urinary incontinence?”

**Review of Literature**

An electronic search of nursing literature in MEDLINE and CINAHL was conducted for works published between 1991 and 2008. The search terms were “nursing,” “urinary incontinence,” “quality of life,” “women,” “experiences,” and “research.” Relevant qualitative studies focused on women’s experiences with UI are highlighted here.

Ashworth and Hagen (1993) conducted one of the first studies using qualitative methods with non-geriatric women who experienced incontinence and identified these women as the “silent sufferers” (p. 1416). Women reported incontinence as a vague and difficult problem and noted it negatively affected their self-image and lives, decreased their quality of life, and affected how they coped. Moreover, women found it difficult to discuss their problem, and sufferers were often hesitant and vague because the topic was considered “off limits” even to themselves (Ashworth & Hagen, 1993). This became a challenge when seeking help from healthcare professionals. Findings suggest that healthcare professionals need to initiate and permit discussion of UI using lay terminology and acknowledging the problem as legitimate.

Two additional studies addressed strategies for managing UI. An early study (Skoner & Haylor, 1994) revealed that women dealt with incontinence by forming a goal to normalize it so that UI became part of their daily routine. This “normality” allowed women to claim there was no problem. Certain strategies were incorporated into a routine activity, such as using sanitary pads or limiting caffeinated beverages (Skoner & Haylor, 1994). This study provided insight into why some women do not seek professional healthcare for UI and recommended that healthcare practitioners often prefer to assess, diagnose, and treat UI as a disease, while women living with UI may prefer to normalize the condition. A more recent study (Milne & Moore, 2006) reported the broad range of self-care strategies that help women and men cope with UI. These strategies did little to improve the UI; however, dietary modifications, bladder retraining, and pelvic floor muscle exercises were effective in helping individuals cope with UI.

Two studies about women’s narratives with UI were conducted. Bradway (2005) studied women with ethnic diversity using narrative analysis. Data analysis identified three plots: the “quest narrative,” “restitution and redemption narrative,” and the “victim narrative.” Findings suggest UI is a very personal and sensitive topic, and further research is needed on groups that represent minorities and non-English speaking populations. Another recent study found that women are more likely than not to seek care for long-term UI and that care-seeking behaviors are quite complex (Bradway & Strumpf, 2008). Their findings further suggest the importance of an optimal patient-provider relationship with a need to understand women’s UI experiences.

Hagglund and Ahlstrom (2007) focused on a symptom management perspective. Women voiced themes of being in a vulnerable situation and striving for adjustment. With no control over UI and experiencing powerlessness, women tried to handle their UI in ways to regain power and live as normal.

Meade-D’Alisera, Merriweather, Wentland, Fatal, and Ghafar (2001) found women who suffered from UI were more likely to suffer from depression. While women in this study did not mention depression, worry and embarrassment can feel depressing. Their biggest fear was not having a bathroom accessible to change clothing once the leakage occurred. One additional study focused on exploring women’s beliefs, knowledge, and the need for education regarding UI (Bush et al., 2001). Women did not seek treatment because of cultural beliefs, and a lack of knowledge and information about UI. It was further reported that health care providers had limited knowledge regarding their symptoms.

In summary, although a handful of studies focus on women’s experiences with UI, no studies were found focusing on women in Alaska, the 49th state, referred to as “The Last Frontier.” When studies are limited, a qualitative research design is relevant to explore the topic.

**Methods**

The purpose of this study was to explore Alaskan women’s experiences of living with UI. A descriptive qualitative design was used. The goal was to gain a better understanding of the experience from each participant’s view.

**Selection and Description Of Participants**

Inclusion criteria included 1) currently experiencing UI (involuntary or accidental loss of urine defined as a problem), 2) ability to communicate in English, and 3) a woman 18 years of age or older. Flyers were placed at uro-
logical, women’s health, and family practice clinics, and at senior centers to recruit participants. Participants then contacted the researcher by telephone. Women who were interested in participating and who met the inclusion criteria were given a verbal explanation of the research. When they agreed to participate, a date and meeting site were mutually arranged. A consent form was signed noting that participation was entirely voluntary. Interviews were conducted in both urban and rural settings in Alaska.

The urban setting had a population of 274,397 community members (U.S. Census Bureau, 2007a), and the rural setting had a population of 2,454 (U.S. Census Bureau, 2007b). All participants resided in the state for more than 20 years. Most individuals were community-dwelling, with several living in an assisted-living or senior-housing environment. One rural participant heard about the flyer and called to see if interviews were possible in her fly-in or ferry-accessible community. She was interested in having this study be available to these very rural women and arranged for a local radio station to announce information about the study over the air. A local hotel room was arranged for the confidential interviews in this rural setting.

Seventeen women participated in unstructured interviews over a period of 4 months. Their average age was 57 years, with an average time experiencing incontinence of 9.8 years. Fourteen women had sought care for their incontinence. During the interviews, all described symptoms of the five types of UI – stress, urge, mixed, overflow, and functional (McCallig-Bates, 2000). Pelvic muscle exercises were the most frequently used treatment strategies; behavior modification was least used. Containment of leakage varied from use of one to six pads or more within 24 hours. Two participants with a history of prior bladder surgery to eliminate their UI were still experiencing UI post-procedure (see Table 1).

**Table 1. Participant Data**

<table>
<thead>
<tr>
<th>Age</th>
<th>33 to 86</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Participants</td>
<td>N = 17</td>
</tr>
<tr>
<td>Time Period of UI</td>
<td>3 months to “all my life”</td>
</tr>
<tr>
<td>Ethnic Background</td>
<td>13 – Caucasian</td>
</tr>
<tr>
<td></td>
<td>4 – Alaska Native or Native American</td>
</tr>
<tr>
<td>Living Environment</td>
<td>1 – Senior Housing</td>
</tr>
<tr>
<td></td>
<td>2 – Assisted Living</td>
</tr>
<tr>
<td></td>
<td>14 – Community Dwelling</td>
</tr>
<tr>
<td>Demographics</td>
<td>6 – Rural</td>
</tr>
<tr>
<td></td>
<td>11 – Urban</td>
</tr>
<tr>
<td>Visit to Healthcare Provider Regarding UI</td>
<td>4 – Yes</td>
</tr>
<tr>
<td></td>
<td>3 – No</td>
</tr>
<tr>
<td>Types of Treatment Recommended</td>
<td>• Pelvic muscle exercises (most frequently suggested)</td>
</tr>
<tr>
<td></td>
<td>• Medications</td>
</tr>
<tr>
<td></td>
<td>• Surgery only (no other treatment options)</td>
</tr>
<tr>
<td></td>
<td>• Behavior modification (least suggested)</td>
</tr>
<tr>
<td></td>
<td>• Intermittent catheterization (single participant)</td>
</tr>
<tr>
<td>Containment of Leakage (varied)</td>
<td>• 1 to 6 pads or more/24 hours</td>
</tr>
<tr>
<td></td>
<td>• Frequent changing of underwear/clothing even with pad use</td>
</tr>
</tbody>
</table>

**Data Collection**

Data were collected in 2003 through in-depth unstructured interviews at sites mutually arranged between the researcher and participant. Participants provided written consent and demographic data followed by an exploratory question, “What is your experience of living with urinary incontinence?” This broad, open-ended question allowed women’s voices to be heard and revealed an understanding of living with UI. Each interview was audio-taped and transcribed verbatim by a transcriptionist. The setting, body language, and nonverbal messages were observed and documented in field notes to assist in data analysis. Most interviews lasted from 30 to 60 minutes. The interviews continued until evidence of theoretical saturation was obtained (Streubert & Carpenter, 1995), and all interested participants were interviewed.

**Data Analysis**

Qualitative content analysis was used for this study (Graneheim & Lundman, 2004). The audio-recorded interviews were transcribed verbatim and included paraverbal communication. The texts were read and reread to immerse in and reflect on the data. Textual data were audited several times by the first author for accuracy. This involved listening to the audiotape while reading and re-reading the text. Data analysis proceeded through a process of condensation. The text was examined line by line and then divided into meaning units (vanManen, 1990). A meaning unit was a phrase or few words that described each participant’s experience. Next, condensed meaning units were formed, which consisted of a few words that captured the central idea of the participants’ experiences. From this process, 20 subthemes were formulated, each composed of a few words. The 20 subthemes were clustered into 6 main themes that answered the research question. All participants were contacted by the first author and given the opportunity to review the text of their interview and the themes from the
data analysis and make corrections. Two participants declined to do so due to visual impairment. The other 15 participants affirmed the themes. The first author analyzed all data, identifying recurring themes in both the text and field notes using techniques described by Morse and Field (1995). Field notes described participants’ nonverbal behaviors/communication and the setting where the interview occurred. The data analysis process was audited by two researchers with experience in qualitative nursing methods, who confirmed the findings.

**Ethical Review**

The study was approved by the University of Alaska Institutional Review Board in 2003 and conducted according to ethical guidelines. Trustworthiness was maintained in several ways (Lincoln, 1995). Participants had the opportunity to read transcripts of their own interview and make revisions. The researcher acknowledged her awareness of possible biases throughout the research process. Interviews were transcribed verbatim to reflect the voices heard. Field notes documented observations, thoughts, and perceptions as interviews were conducted and analyzed for deeper meaning of the data. All participants were respected while the researcher learned from their experiences.

**Findings**

Six themes and 20 subthemes that stayed close to the participant’s descriptions emerged. The 6 themes were *Sharing the Secret, Trying to Fit It into the Day, Worrying about Leaking, Searching for a Solution, Encounters with Healthcare Providers,* and *Getting the Problem Solved* (see Table 2).

![Table 2. Themes and Subthemes of Experiences of Women Living with Urinary Incontinence](image)

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sharing the Secret</strong></td>
<td>You’re the First Person&lt;br&gt;I Didn’t Want to Tell&lt;br&gt;Nobody’s Ever Asked&lt;br&gt;The Only One Who Knows</td>
</tr>
<tr>
<td><strong>Trying to Fit It into the Day</strong></td>
<td>Just Dealing With It&lt;br&gt;Fight for the Bathroom&lt;br&gt;I’ve Lived with It for so Long</td>
</tr>
<tr>
<td><strong>Worrying about Leaking</strong></td>
<td>Maybe It Will Go Away&lt;br&gt;It Happens So Fast&lt;br&gt;That Was the Worst&lt;br&gt;Control Is Just No Control&lt;br&gt;Those Days Are Gone</td>
</tr>
<tr>
<td><strong>Searching for a Solution</strong></td>
<td>Trying to Figure This Out&lt;br&gt;One Time Big Cure&lt;br&gt;I’ll Try Anything</td>
</tr>
<tr>
<td><strong>Encounters with Healthcare Providers</strong></td>
<td>The Positive&lt;br&gt;The Negative</td>
</tr>
<tr>
<td><strong>Getting the Problem Solved</strong></td>
<td>Seek Help Early On&lt;br&gt;Talk About It&lt;br&gt;A Long Way to Go</td>
</tr>
</tbody>
</table>

The first theme, *Sharing the Secret,* had four subthemes (“You’re the First Person,” “I Didn’t Want to Tell,” “Nobody’s Ever Asked,” and “The Only One Who Knows”). Participants identified the importance of maintaining a certain level of privacy about their episodes of incontinence. For example, Ms. H. said:

“I would think there’s a lot of people out there that have this problem, and they just don’t want to talk about it. Because it’s personal! It’s like…who wants to be peeing on themselves… It’s not a really comfortable subject to talk about to too many people. Yet if I were to see this flyer hanging up someplace, I would have laughed. Are you kidding, you think I’m going to tell anybody?

The second theme, *Trying to Fit It into the Day,* had three subthemes (“Just Dealing with It,” “Fight for the Bathroom,” and “I’ve Lived with It for so Long”). Participants discussed their experience with UI and how it affected their daily life. Ms. F. said:

“Let’s see what else I had to do to alter my life. Well, one major thing, where I work is under construction, and eventually, we’ll have a lovely restroom to accommodate all of the people that work there, but right now the females have one toilet. So I’ve given up trying to self-cath at work. It’s just...it just doesn’t work, and every female...ends up...and I can’t hold it, and it’s hurry up, hurry up, hurry up. So, that’s been difficult to deal with. In the future, one thing I ask is, please, with all these females that I work with, have enough toilets.

The third theme was *Worrying about Leaking,* which had five subthemes (“Maybe It Will Go Away,” “It Happens so Fast,” “That Was the Worst,” “Control Is Just No Control,” and “Those Days Are Gone”). Participants discussed in detail embarrassing events. An example from Ms. C’s interview highlights this theme:

“I was working, and I changed my pad in the morning, and I think maybe that was overflow because all of a sudden, I knew I was really soaking the pad. And I was in school with my kids, and all of a sudden, one of them said, “There’s a wet spot on the back of your slacks.” And I said, “Oh my God,” and for a
kid to recognize it. “You wet your pants!” Just out loud in front of everybody in the class, and that was my most embarrassing moment. I ran out of the classroom.

The fourth theme, Searching for a Solution, had three subthemes (“Trying to Figure this Out,” “One Time Big Cure,” and “I’ll Try Anything”). Most participants did attempt to find some solution to deal with their UI. For example, Ms. B. said:

If there’s a Web site where I could look and read something, I would. I mean I have to try to figure this out all by myself like some professional or something...I mean I’ve tried...you know when you see a news flash on the TV “Bladder Control” or whatever, you know, if you have trouble holding it or whatever. I’ve seen a couple.

Encounters with Healthcare Providers, the fifth theme, had two subthemes (“The Positive” and “The Negative”). Most participants reported visiting a health care provider at some time. Responses to these visits varied. Ms. F.’s interview contained an example of a positive encounter with a physician.

At that point, I sought a urologist, and I was very much hoping for a quick fix, and I was upset to find out that I wasn’t a candidate for a quick fix and would need a graft and a lot more work...than I had anticipated. I respected the doctor because I think to go through all of that and then have problems, it would have been devastating. My alternative, and this works well. It was a little harder in the beginning; it’s self-catheterization, and it’s really improved my life a lot.

Some participants reported being dissatisfied with the visit when seeking help from a health care provider. Ms. M. said:

I couldn’t even get an answer about anything, and I wanted to know various things, and she would look at me and would...forget to tell me the answer to whatever it was I wanted. I don’t know why...anyway, she wouldn’t talk to me. I wanted to ask her a lot of questions, and she wouldn’t even talk to me.

The last theme, Getting the Problem Solved, had three subthemes (“Seek Help Early On,” “Talk about It,” “A Long Way to Go”). Several participants offered suggestions for other women or health care providers regarding treatment of women. Ms. F. said:

Many of my female friends also have incontinence, so the more I talk about it, the more it’s an outside thing, and I encourage them to seek care. There are so many women that suffer in silence, and being a nurse, I see it all the time... I think it’s important for nursing schools and medical schools to instruct their students about this silent problem. I think it’s getting a little bit better, but I think we have a long way to go. You’d hope that when they come in for a yearly check-up...that’s a great time to encourage women to relate their problems. It’s the right environment if they feel safe.

Discussion

This study highlights the multifaceted and ongoing experiences of women living with UI. Women voluntarily and openly described sharing, managing, worrying, searching, encountering health care providers, and solving the problem. These findings support and add to previous research on this topic.

Sharing the Secret

Sharing the secret was most often the first topic described. At the beginning of the interview, women revealed the researcher was the first person to know about their UI. Next, women expressed reasons for not wanting to tell, and also disclosed the only individuals who knew about their UI. None of the participants implied UI was normal, but consistent with previous research (Skoner & Haylor, 1994), they attempted to “normalize” their UI.

Some participants also noted that health care providers did not ask about UI during office or annual visits. Several reported forgetting to mention the problem during their annual examination. Others were uncomfortable introducing the topic and felt the health care provider would inquire about it if it was important. In addition, for most of the women in this study, their husband or significant other was the only one aware of their urinary leakage. These struggles with sharing the secret are similar to previous studies where UI is understood by women as a stigmatized condition (Haller, 1997) or social taboo (Meade-D’Alisera et al., 2001; Newman, 2007; Palmer, 1994; Roe & May, 1999).

Trying to Fit It into the Day

Participants referred to various strategies of daily coping with UI and management strategies necessary to try and fit it into the day. They used absorbent pads and other products for containment, as well as pelvic muscle exercises. Fluid intake was often limited, and frequent attempts to urinate helped prevent urine leakage. Most continued to work, exercise, and volunteer in the community. Although UI was described as a challenge for most participants, it was managed in a way that was part of their daily routine.

Most women experienced UI on a daily basis, and it altered their life. Some felt that due to their age, it was “almost inevitable.” These women went about their day with little change in their routine because they had been dealing with incontinence for so long. Other women carefully planned their day to prevent signs of UI. Some selected clothing, such as dark or light colors, to hide urinary leakage if it occurred. Others brought extra clothing to the workplace.
Worrying about Leaking

Results of this study suggest that women expressed worrying about potential leaking and the possibility of embarrassment throughout their day. They reported UI as a loss of control in their life. Similarly, Meade-D’Alisera and colleagues (2001) questioned whether or not depression resulted from incontinence or was more prominent because of UI. It makes sense that worry and embarrassment can feel depressing. This theme also relates to Palmer’s (1994) view about involuntary loss of urine as a social violation. It also echoes Kasper, Simonsick, Phillips, Skinner, and Davis (1997) who reported social contact and activity as important indicators of quality of life for women with UI. They concluded that UI is socially embarrassing and potentially disruptive to daily activities and social relationships.

Searching for a Solution

Most women attempted to search for a solution to improve their UI; many chose to seek professional help. In addition, many participants attempted to find a solution by looking for UI information via lay sources. Unfortunately, many noted that UI information was not always accessible, and self-help resources were limited. These findings reflect issues related to public awareness and the need for education (Roe, Wilson, & Doll, 2001). In the current study, several women were hopeful it would improve within a period of time after childbirth, similar to the study by Goldstein, Hawthorne, Engeberg, McDowell, and Burgio (1992). Most prepared in some way for the possibility of urinary leakage. Others reported how quickly the urinary leakage occurred and were prepared with absorbent products. Some women chose to frequently use the bathroom because UI would occur without much warning, interrupting their activities. They identified timing as a crucial factor in dealing with it.

Encounters with Health Care Providers

Results of this study revealed negative and positive encounters with health care providers. Most participants in this study had seen a health care provider, and some had seen multiple health care providers throughout their lifespan, including urologists, gynecologists, internal medicine physicians, and nurses. Although women were not directly asked to discuss these encounters, many reflected on this as part of their experience of living with UI. These encounters, some of which occurred years ago, were vividly described, especially those that were negative, and prevented them from seeking further health care related to their incontinence. This is consistent with Milne and Moore (2006) who noted that a significant number of participants who sought professional health care were negatively affected by the encounter.

For some participants in this study, their encounter with the nurse researcher seemed to be a therapeutic and safe place to talk about prior encounters regardless of the outcome of the visit. This was likely because the nurse researcher respected and maintained their dignity, allowing them to share their experiences and hear their voices without preconceptions (Lincoln, 1995).

Getting the Problem Solved

Results of this study showed that most women can achieve marked improvement or solve the problem with the many emerging technologies used in managing UI. Quality of life can be improved by using an approach that is matched with the woman’s preferences and capabilities (Newman, 2000). Even though some women waited extended time periods before seeking help for UI, they encouraged other women to seek help early. Finding a health care provider who was knowledgeable about UI was also important. Women voiced concerns about their lack of knowledge about self-care options and health care professionals who had limited understanding about UI. They noted a need for increased education to improve the care of women who suffer from UI at any time in their lifespan.

Implications for Nursing

Results of this study have implications for nursing practice, education, and research. The authors assert that continence has been undervalued, and as a result, UI remains significantly under-detected and under-treated, even with available products, devices, medications, and behavioral approaches. However, results of this study begin to add to the body of knowledge of women’s experiences with UI.

Nursing Practice

With UI increasing as a costly public health problem in the U.S. (Anger, Saigal, Madison, Joyce, & Litwin, 2006), nurses need to assume more ownership in preventing and managing this condition. Educational continence care competencies were developed to improve nurses’ preparation related to continence care and address this major health care problem (Jirovec, Wyman, & Wells, 1998). There is little evidence that the clinical practice guidelines (Fantl et al., 1996) developed for health care practitioners (medical, nursing, and other disciplines) have been used, while the prevalence of UI is increasing (Mason, Newman, & Palmer, 2003).

Nurses need to examine their own values, attitudes, beliefs, and behaviors about UI, a taboo subject and stigmatizing topic (Newman, 2007; Palmer, 1994). When nurses can openly discuss UI issues and provide patient education about UI, public awareness will increase, and women will more likely disclose the problem. Patient education needs to include information about bladder health, UI, and its evaluation and management.

Nursing Education

Nursing education needs to
respond to the needs of nursing practice. Many years ago, the Agency for Healthcare Research and Quality (AHRQ), formerly the Agency for Health Care Policy and Research (Fantl et al., 1996), recommended that evaluation and treatment of UI be included in the basic curricula for undergraduate and graduate programs educating health care providers. A more recent report documents the increasing prevalence of UI and highlights strategies for reducing the risk of incontinence (Shamiyeh, Wyman, Bliss, Kane, & Wilt, 2007). This report further suggests routine clinical evaluations, including an assessment of risk factors, symptoms, and signs of incontinence. It is paramount that nursing students as well as students in other health care professions are educated to care for the increasing numbers of individuals living with UI.

**Nursing Research**

While attitudes and beliefs about continence and incontinence are documented, and some qualitative research contributes to the understanding of UI, further research is needed to address nurses’ attitudes, as well as their cultural and ethnic perspectives, about UI. Of importance is developing evidence-based practice. Additional needs include investigation of the cost effectiveness of continence care provided by nurses. Results of this study showed that women were interested in obtaining accessible and understandable information via the Internet, health care sites, or published material. Related research questions could address more specifically what women want to learn, how they like to learn, and where they want to learn about preventing or managing UI.

**Limitations**

There are several limitations to acknowledge concerning this research. First, this was a convenience sample. Participants may have had prior knowledge about the researcher through local health care providers in their communities. The researcher is board-certified in urology nursing with extensive experience in this practice area. This background may have influenced her interpretation of the themes. Even so, she was very aware of listening intently to the participants without preconceptions and giving voice to their experience.

**Summary**

Study findings highlight women living with UI in Alaska, a population not previously addressed in the nursing literature. Six themes reveal in-depth insights of women’s experiences of living with UI. These results add to the body of nursing knowledge, enhancing the understanding of this condition. Nurses can make a difference in the lives of women who experience UI by asking, listening, and helping them expand their knowledge of treatment options. A better understanding of these experiences is important for all health care providers.

**References**


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