Women's Perceptions about the Etiology of Urinary Incontinence

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Abstract

Objective: Incontinent women have low rates of care seeking and treatment, some of which may be explained by their beliefs about the causes of their own urine loss. As little is known about these beliefs, our aim was to qualitatively assess what women perceive as the etiology of their urinary incontinence (UI).

Methods: In a written survey on urinary symptoms administered to female HMO enrollees aged 30–90 years, incontinent women were asked the open-ended question: “Why do you think you lose urine?” Qualitative analyses of the responses identified themes, which were quantified and organized into major categories. Subjects were assigned multiple themes/categories as indicated. Relationships between major categories and subject/incontinence characteristics were explored.

Results: Of the 1458 women with incontinence who completed the survey, 1192 (82%) responded to the open-ended question. Qualitative analyses identified 23 themes, with 5 themes cited by $\geq 10\%$ of subjects: pelvic floor/bladder muscles (31%), pregnancy/childbirth (18%), age (14%), exertional triggers (12%), and waiting too long to void (10%). The 23 themes were organized into 5 major categories: pelvic floor/bladder related (53%), uncontrollable factors (23%), part of being female (21%), personal/lifestyle attributes (21%), and don't know (12%). Subjects expressed a range of 1–4 themes/categories. Major categories differed by age, and significant associations were seen between major categories and incontinence severity.

Conclusions: Women attribute their UI to a number of causes, which can be condensed into workable themes and categories. By understanding women's beliefs about the etiology of incontinence, clinicians may improve their ability to educate, counsel, and treat women with incontinence.

Introduction

URINARY INCONTINENCE (UI) is a burdensome medical disorder that is highly prevalent among women in the United States. It affects up to 50% of women during their lifetime¹ and has a profound negative effect on affected women's psychological well-being² and quality of life (QOL).^{3,4} Despite these effects, half or fewer of women with incontinence discuss their UI with a healthcare provider.^{5–8} Even when healthcare providers are consulted, there are surprisingly low rates of treatment of women with leakage symptoms.^{5,9,10}

Studies on why women do not seek treatment for UI have

identified potential reasons, such as embarrassment, viewing it as a normal part of aging, feeling that they can cope on their own, and having low expectations of benefit from treatment.^{4,6,11,12} Very few studies, however, have addressed what women perceive as the cause of their leakage,^{11,13} and none of these studies was conducted in the United States. This gap in incontinence research is crucial, as comprehending perceived causes is necessary to understanding care-seeking behavior and compliance with treatment recommendations. Additionally, because limited preliminary information about these perceptions is available, quantitative data may not give an accurate representation of women's

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beliefs.¹³ This study sought to qualitatively assess women's beliefs about the etiology of their incontinence in order to improve counseling and treatment of women with UI.

Materials and Methods

The participants of this 2002 cross-sectional study were female enrollees at Group Health, a nonprofit health maintenance organization (HMO) serving approximately 550,000 individuals in Washington State. The aims of the study were to examine prevalence, risk factors, care-seeking behavior, and beliefs about incontinence in women. A 15-page self-report form was mailed to an age-stratified random sample of 6000 female enrollees aged 30–90 years. The sample was stratified by decade of age, with oversampling for the younger decades to ensure a sufficient number of respondents with UI in each age group. Using estimated prevalence rates from the literature, decades were sampled proportionately to ensure roughly equivalent numbers of participants with UI in each decade. The survey contained questions about incontinence symptoms, care-seeking behaviors, and past and current treatment. It also contained questions about medical, surgical, obstetrical, and gynecological history; medications; and demographic characteristics. Inclusion criteria were age 30–90 years and female gender. Exclusion criteria were death, inability to locate the prospective participant, disenrollment from Group Health, paralysis, severe mental or physical barriers to completing a written questionnaire, and current urinary tract infection (UTI). An initial and two reminder questionnaires were sent. A \$3 gift certificate to a local store was included in the initial mailing to encourage response. All participants provided informed consent, and the study was approved by the Group Health Human Subjects Committee.

UI was defined as leakage of any amount that occurred at least monthly. Symptoms were classified as stress, urge, or mixed based on the description of events preceding leakage. The questions used to assess incontinence were modeled after the Norwegian EPICONT study¹⁴ and have been described fully elsewhere.¹⁵ The study employed validated measures to characterize UI severity (Sandvik severity index)^{14,16} and UI-specific QOL [Incontinence Quality of Life Instrument (I-QOL)].¹⁷ The Sandvik severity index uses the amount and frequency of leakage to yield categorical variables of mild, moderate, and severe UI, and the I-QOL yields a continuous score. To address the perceived causes of their UI, subjects were asked the open-ended question: "Why do you think you lose urine?" and were given a large blank area in which to reply.

The hand-written responses to the open-ended question were transcribed into the dataset by TeleForm® v8 scanning software (Cardiff Inc., Vista, CA), with verification of the accuracy of each response by the research staff. Analyses used constant comparative analysis following the grounded theory method, which employs deductive and inductive approaches to identify patterns or themes.¹⁸ Using this methodological framework, the data are read and reread to discover the concepts and interrelationships that best describe the data. Responses were coded into themes, defined as a group of similar responses provided by at least three participants.¹⁹ The data were coded using both themes obtained from previous research^{11,13} and themes that emerged from initial re-

view of the responses. New themes arose as the data were assessed, and coding was adapted and restructured. This cycle of data review and coding adaptation was repeated several times until no new themes were generated. Respondents were assigned multiple themes if they indicated more than one belief about the cause of their UI. Two investigators independently coded each response, and discrepancies were brought to consensus to ensure accuracy of interpretation. The response themes were then quantified and because of the large number of themes generated, further organized into major categories by consensus of the investigators. These major categories were created to provide a framework for organizing the numerous themes in the readers' minds. Subjects were assigned multiple themes or major categories or both as appropriate to fully code their response. Examples of subject responses coded as common themes are reported in the text in quotations to better enable the reader to relate themes to actual subject responses. A breakdown of themes by age group was performed, with age groups chosen by likely menopausal status (30–44 years, premenopausal; 45–59 years, menopausal transition; ≥60 years, postmenopausal). Potential associations between major categories and Sandvik UI severity scores and I-QOL scores were examined using chi-square for categorical variables and analysis of variance (ANOVA) for continuous variables.

Results

The characteristics of the sample have been described in detail elsewhere.¹⁵ Briefly, the response rate was 64% ($n = 3536$) after applying exclusion criteria. Among these 3536 respondents, the prevalence of UI (any leakage that occurs at least monthly) was 42% ($n = 1458$). Of the 1458 women with UI, 1192 (82%) wrote in a response to the question: "Why do you think you lose urine?" Analyses of these 1192 responses identified 23 themes (Table 1). The 5 most common themes, mentioned by ≥ 10% of subjects, were pelvic floor/bladder muscles, pregnancy/childbirth, age, exertional bladder triggers, and waiting too long to void. The 23 themes were organized into 5 major categories: pelvic floor/bladder related, uncontrollable factors, part of being female, personal/lifestyle attributes, and don't know. The majority of subjects gave a response that generated 1 theme ($n = 799$, 67%), and the remainder of responses generated 2 ($n = 299$, 25%), 3 ($n = 81$, 7%), or 4 ($n = 13$, 1%) themes. For some subjects, these multiple themes belonged to the same major category, whereas for other subjects, the multiple themes belonged to more than one major category. The majority of women responded with themes corresponding to only 1 of the 5 major categories ($n = 885$, 74%), but others had responses encompassing 2 ($n = 258$, 22%), 3 ($n = 48$, 4%), and 4 ($n = 1$, 0.1%) categories. Of the 1192 subjects, 20% reported mild, 37% reported moderate, and 43% reported severe UI. This is nearly identical to the UI severity distribution of the larger sample ($n = 1458$, with 21% mild, 36% moderate, and 42% severe UI).¹⁵

Pelvic floor/bladder related

More than half of the women surveyed attributed their urine loss to a difficulty with their pelvic floor or bladder ($n = 631$, 53%). Both themes with explicit reference to the pelvic floor or bladder (pelvic floor/bladder muscles, pelvic organ prolapse, bladder attributes other than muscle, blad-

TABLE 1. RESPONSE CATEGORIES AND THEMES FOR URINE LOSS ETIOLOGIES

Response categories and themes	n (%) of women
Pelvic floor/bladder related	631 (52.9)
Pelvic floor/bladder muscles	370 (31.0)
Stress incontinence triggers	147 (12.3)
Pelvic organ prolapse	60 (5.0)
Urge incontinence triggers	45 (3.8)
Bladder attributes (other than muscle)	43 (3.6)
Bladder irritants	31 (2.6)
Urinary tract infections	16 (1.3)
Incomplete voiding	15 (1.3)
Uncontrollable factors	271 (22.7)
Age	166 (13.9)
Medical comorbidity	47 (3.9)
Prior surgery	38 (3.2)
Medication	33 (2.8)
Hereditary	10 (0.8)
Part of being female	252 (21.1)
Pregnancy and childbirth	216 (18.1)
Hormonal/menopause	16 (1.3)
Female gender/normal	13 (1.1)
Menstrual cycle related	12 (1.0)
Personal/lifestyle attributes	250 (21.0)
Waiting too long to void	122 (10.2)
Being overweight	67 (5.6)
Excess fluid intake	51 (4.3)
Decreased physical activity	15 (1.3)
Increased stress/anxiety	10 (0.8)
Don't know	145 (12.2)

^aMany subjects expressed >1 theme and/or category; thus, percentages add up to >100%.

der irritants, urinary tract infections, and incomplete voiding) and themes espousing accepted stress and urge incontinence triggers (exertional triggers and urgency triggers) were grouped into this category. Almost one third of all participants attributed their UI to a weakening or a loss of control of their pelvic floor or bladder muscles ($n = 370$, 31%); this was also the most common theme cited overall. Many women used the terms “weak bladder” and “poor muscle control” to describe the etiology of their urine loss. Another representative subject indicated weak pelvic musculature by reporting that she lost urine “If I forget to do my Kegels for a week or so.”

Specific exertional triggers consistent with stress incontinence, such as coughing, sneezing, laughing, exercising, and jumping, were mentioned by 12% ($n = 147$) of women, and this was the fourth most common theme overall. One representative woman reported that she lost urine “because of strenuous activity or spontaneous bursts, such as sneezing or coughing.”

Other women ascribed the loss of urine to attributes of the bladder other than its musculature ($n = 43$, 3.6%). Several women theorized that the cause of their UI was an overactive bladder or small bladder, and another responded, “Some problem in [my] urinary tract.”

Uncontrollable factors

Responses suggesting that UI was a result of factors perceived as beyond the management of the respondent were

categorized as uncontrollable factors ($n = 271$, 23%). This included the themes age, medical comorbidity, prior surgery, medications, and heredity. The most commonly cited uncontrollable factor, and third most common theme overall, was age ($n = 166$, 14%). The majority of women used the terms aging or old age, yet urine loss was also attributed to middle age, with one woman answering, “relaxation of muscles due to middle age (age 50)” (coded as age and pelvic floor muscles).

Some women believed their UI was secondary to a medical condition or illness ($n = 47$, 3.9%). Comorbidities faulted included diabetes, asthma, fibroids, arthritis, and multiple sclerosis. Prior surgery was also suggested as a cause of UI ($n = 38$, 3.2%). Of these subjects, half ($n = 19$) indicated the effects of a hysterectomy, for example, “Loss of muscles due to hysterectomy and pregnancies” (coded as prior surgery, pregnancy, and pelvic floor muscles). Other surgeries implicated included bladder repairs and urethral operations.

Part of being female

This category includes themes that are consistent with the traditional course of womanhood. These themes were pregnancy/childbirth, hormonal/menopause, female/normal, and menstrual cycle related. The most common theme in this category, and second most common theme overall, was the effects of pregnancy and childbirth ($n = 216$, 18%). Women perceived this association as both temporal, “After having a baby I began to notice this problem,” and physiological, “I just assumed that delivering a baby a few years ago made me undergo some anatomical changes.” Some women believed UI came from the cumulative effect of multiple pregnancies, for example, “because of having 6 children.”

Women often associated pregnancy and childbirth with a weakening of the pelvic floor and bladder muscles. One woman said, “Because of having children. Muscles aren’t strong enough anymore to prevent [urine loss]” (coded as pregnancy and pelvic floor muscles), whereas another stated involuntary leakage was from “lack of muscle tone due to stretching during delivery of babies” (coded as pregnancy and pelvic floor muscles).

Occasionally, women expressed the belief that menopausal or hormonal changes caused their loss of urine ($n = 16$, 3.1%). One respondent noted, “Change due to menopause—less estrogen affects muscle tone” (coded as menopause and pelvic floor muscles), and others used the terms premenopause, perimenopausal, and postmenopausal.

A small number of women suggested that UI is a normal part of being female ($n = 13$, 1.1%). One woman thought the loss was from “bad female body design.” Another wrote, “Don’t find it unusual,” and one woman simply responded, “Normal.”

Personal/lifestyle attributes

Responses suggesting a personal responsibility for urine loss were categorized as personal/lifestyle attributes ($n = 250$, 21%). This category includes the themes waiting too long to void, being overweight, excess fluid intake, decreased physical activity, and increased stress/anxiety. The most common theme to emerge in this category, and fifth most common theme overall, was waiting too long to void ($n = 122$, 10%). Women reported that they often delayed urina-

tion, most frequently because of a busy lifestyle. One representative woman explained that she leaked urine because she “typically put off going to the [bathroom] when involved with work or other activities.” Other subjects report that ignoring the initial urge to urinate resulted in leakage, for example, “I have a habit of waiting until the last minute and then I can’t hold it like I used to.”

Another common theme was urine loss resulting from excess weight ($n = 67$, 5.6%). Some women blamed a history of being overweight, with one subject explaining, “perhaps from being at one time 150+ lbs overweight!” Most women who thought their weight was responsible for their UI, however, stated that it was from being currently overweight.

Another personal behavior commonly perceived as causing UI was drinking too many fluids ($n = 51$, 4.3%). Subjects believed that their amount of fluid intake was a significant contributing factor to their leakage. Some women stated that they tried to drink prescribed amounts of water for health reasons but that consuming this amount of water made them leak. Others blamed urine loss on the time of day they drank fluid, for example, “drink[ing] liquid after 3 PM.”

Don't know

A number of women ($n = 145$, 12%) were uncertain, bewildered, or lacked knowledge as to why they lost urine, with responses such as “don’t know” or simply writing in a question mark. This category also includes responses with indiscernible meaning.

Major categories by subject and UI characteristics

When the sample was divided into the broad age groups of 30–44 years ($n = 348$), 45–59 years ($n = 365$), and ≥ 60 years ($n = 479$), striking differences in beliefs about the etiology of UI were observed (Fig. 1). Although all age groups espoused themes in the pelvic floor/bladder related and personal/lifestyle attributes categories in approximately the same proportion, there were notable differences in the other categories. The belief that UI was caused by uncontrollable factors (e.g., age, medical comorbidity, prior surgery) increased with age group, from 10% of those aged 30–44 years to 30% of those ≥ 60 years. A lack of knowledge about what may be causing UI also increased with age, from 8% of those aged 30–44 years to 17% of those ≥ 60 . In contrast, a belief that UI was part of being female (e.g., pregnancy, childbirth, hormonal status) decreased markedly with age, from 43% of those aged 30–44 years to only 6% of those ≥ 60 years.

Significant associations were seen between major categories and UI severity but not between major categories and I-QOL scores. Subjects endorsing uncontrollable factors (e.g., age, medical comorbidity, prior surgery) were significantly more likely to have severe UI than those not endorsing these factors (50% vs. 41%, chi-square = 7.63, $p = 0.022$). Similarly, subjects citing a lack of knowledge were significantly more likely to have severe UI than those not citing this category (60% vs. 40%, chi-square = 23.02, $p < 0.001$). Alternatively, subjects endorsing personal/lifestyle attributes were significantly less likely to have severe UI than those not endorsing this category (32% vs. 46%, chi-square = 24.00, $p < 0.001$). After adjusting for UI severity, there were no significant differences in I-QOL scores between groups.

Discussion

Women’s perceptions about the etiology of their incontinence are myriad but can be condensed into workable themes and categories that can be of use to women’s health-care providers. We found that half of the women surveyed consider a malfunction of their bladder or pelvic floor, including accepted incontinence triggers, to be the cause of their UI. One fifth of women perceived leakage to be due to personal or lifestyle attributes, blaming an increase in weight, excess fluid intake, or waiting too long to urinate. A similar percentage thought that UI resulted from factors beyond their control, faulting heredity, the aging process, medical illness, surgeries, or medications. Others believed that standard aspects of womanhood, including menstruation, pregnancy, and menopause, were responsible for urine loss. Perhaps most interestingly, several women believed that UI was simply a normal part of being female.

A notable finding in our study is that by giving women an opportunity to provide their own beliefs for the cause of their UI, approximately 50% of women suggested an inherent problem with their pelvic floor or bladder. This finding, which implies some understanding of the physiology of continence, is unique to our study. When consulting Arabian Gulf women via questionnaires with close-ended questions, Saleh et al.¹¹ found the majority of women perceived childbirth (51.9%) as the major cause of UI, followed by aging (49.5%) and menopause (34.2%). These themes were also found in our subjects’ responses, although at lower percentages. In a small study of Australian women, Peake et al.¹³ similarly found that childbirth (48%), aging (12%), and

FIG. 1. Major categories of UI belief by age. A subject may be included in more than one major belief category.

menopause (7%) were the leading perceived causes. When a portion of these women underwent face-to-face interviews, Peake et al. found that UI was often considered an aspect of the "histories of their bodies" instead of being caused by a single factor. One third of the women in our study likewise attributed UI to multiple causes, perhaps attempting to explain their incontinence as a part of their personal histories. Women in our study also had substantial insight into associations that epidemiological research has shown to be true, such as those between UI and age, medical comorbidity, and body mass index (BMI). We found differences in UI belief categories by age and UI severity, exhibiting the richness of our large number of subject responses. Women citing uncontrollable factors or lack of knowledge were likely to be older and have more severe UI, whereas those viewing UI as part of being female were likely to be younger.

Strengths of our study include the large number of women surveyed, our population-based sampling, and the use of an open-ended format that allowed subjects to express their own beliefs without bias from choices provided in a closed-ended, multiple-choice format. Our study is limited, however, in that women provided their responses in writing, which did not allow for further questions, clarifications of statements, or expansion of beliefs, as can be obtained in interview studies. Our study design also did not allow us to query women, and this investigation should be viewed as a starting point from which more in-depth investigations may follow. These limitations can be viewed as a tradeoff between the large sample size with the resultant variety of beliefs obtained here and the more in-depth but less representative information that can be obtained from interviewing smaller numbers of subjects. Additionally, although our response rate was good (64% for the initial survey and 82% of those with UI for the qualitative portion), it is still possible that response bias may have influenced our results either by missing themes or by giving an inaccurate snapshot of the frequency with which certain themes were expressed.

The reason for the lack of care seeking in $\geq 50\%$ of women with incontinence⁵⁻⁸ remains puzzling, as the majority of women in our study understood that inherent difficulties with their pelvic floor or bladder contributed to their incontinence. It may be that even though women understand that damage to the pelvic floor or bladder is related to UI, they are not aware that effective treatments exist when this damage has occurred. There is often a delay between development of effective treatments and knowledge among the public that these treatments exist. The belief held by many women that UI is caused by factors either out of or completely within their control may also contribute to lack of care seeking. Women who believe that the cause of their UI is out of their control (e.g., normal part of aging) or a part of being female (e.g., due to childbirth) may think that nothing can be done to help them. Conversely, women who believe that their UI is at least partly their responsibility (e.g., weight gain, waiting too long to void) may think they need to change the offending behavior themselves. Women in each of these groups may be unlikely to consult their physician or other healthcare practitioner. Healthcare providers, however, can use these results to help counsel women with UI about modifiable risk factors, such as weight gain and bladder irritants, and to encourage treatment of those with nonmodifiable histories, such as childbirth and prior surgeries. Above all, these perceptions should be taken into ac-

count when approaching the female patient with UI, as her belief system will have an important impact on her acceptance of the diagnosis and adherence to treatment. Further, given the high prevalence of UI, our findings suggest that widespread education about UI treatment options, either at the clinical or public health level, needs to be undertaken.

Disclaimer Statement

No competing financial interests exist.

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