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# The Impact of Urge Urinary Incontinence on Quality of Life: Importance of Patients' Perspective and Explanatory Style

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**OBJECTIVES:** The impact of urinary incontinence (UI) on health-related quality of life (QoL) is significant yet variable, but little is known about patient-defined content areas regarding the influence of UI on QoL and whether patient-specific factors correlate with specific content areas of UI-related QoL. In order to identify the most valid content areas for a new UI-related QoL questionnaire, our primary goal was to determine the content areas of greatest concern regarding UI-related QoL among older persons with urge incontinence. The second goal was to examine the possible role of patients' explanatory style as a mediator of UI impact on health-related QoL. Data on the questionnaire will be presented elsewhere.

**DESIGN:** Focus groups comprising urge-incontinent persons were used to obtain verbatim descriptions of the impact of UI on QoL.

**SETTING:** A university-affiliated tertiary hospital.

**PARTICIPANTS:** Community-dwelling women (n = 25) and men (n = 5) more than 60 years of age, with urge incontinence, recruited from newspaper, newsletter, and radio advertisements.

**MEASUREMENTS:** Qualitative content analysis of focus group transcripts was used to determine QoL items. These were compared with previously described UI-related QoL items obtained from the literature. Subjects' statements regarding causes of UI were evaluated for predominant explanatory style.

**RESULTS:** Thirty-two UI-related QoL items were identified, more than half of which were not described previously. Compared with expert-defined UI-related QoL items from the literature, patient-defined items focused more on coping with embarrassment and interference from UI than on prevention of actual activity performance. Explanatory statements were made frequently by patients talking about their UI. Although positive style explanatory statements were most common, they did not correlate with any QoL items. By contrast, there was a significant correlation between negative explanatory style and six specific UI-related QoL items.

**CONCLUSIONS:** Focus groups of older persons with urge incontinence suggest that experts and patients view the impact of urge UI on QoL differently. Whereas experts focus more on functional impact, patients more often cite the impact of UI on their emotional well-being and on the interruption of activities. In addition, the association between negative explanatory style and specific UI-related QoL items suggests that explanatory style may be an important mediator of patients' perceptions of UI-related QoL. **J Am Geriatr Soc 46:683–692, 1998.**

U rinary incontinence (UI) is prevalent among older persons. It affects multiple aspects of their lives and, thus, their general quality of life (QoL). Quality of life is a multidimensional concept reflected in the World Health Organization's definition of health as "not merely the absence of disease, but complete physical, mental and social wellbeing."[1] QoL is an attribute of the patient or individual[2] and typically includes domains such as physical function, social function, role function, mental health, and general health perceptions.[3] In recognition of the impact of UI on patients' quality of life (QoL),[4] several tools for measuring UI-related QoL have been developed.[5–13] Patient-identified QoL concerns may differ from those of clinicians and researchers, yet only two of the current UI-related QoL measures were derived solely from interviews with incontinent persons.[7,9]

Because the derivation populations for these two measures were relatively young (mean age 64–67) and were comprised primarily of persons with stress or mixed incontinence,[7,9] these measures may not represent the concerns of older persons, in whom urge incontinence is the most common incontinence type.[14]

The influence of UI on QoL varies across individuals: some find it personally and socially devastating, whereas others describe it as having limited impact on their lifestyle or emotional well-being.[15–17] Although intuitively one would

expect that some of this variability is caused by heterogeneity in disease severity (usually measured as the number of incontinence episodes), studies have not consistently found a relationship between UI impact on QoL and UI severity.[4] Furthermore, when correlations between QoL and severity have been described, they are weak and explain only a small part of the variance in how bothersome patients find the symptoms of UI.[6] Thus, other patient-based factors may be important mediators of the impact of UI on an individual's QoL. One potential factor is explanatory style, the habitual manner in which persons explain how and why uncontrollable adverse events such as illness occur to them.[18] An individual's explanatory style is categorized by three aspects of the content of their explanations: locus of blame (external versus internal), duration (transient versus ongoing), and specificity (specific versus global).[19] Persons with a negative explanatory style typically describe the causes of illness with self-blaming, ongoing, and global terms, e.g., "I don't take good care of myself and therefore always get colds"; those with a positive explanatory style tend to use external, transient, and specific terms, e.g., "I caught the cold from my husband who had the flu." Explanatory style is a good candidate mediator of the impact of UI on QoL because it has been shown to correlate with the range of responses individuals have to other illnesses.[20]

The purpose of this study was to explore with older, urge incontinent individuals their own descriptions of the impact of UI on their QoL in order to determine valid content areas for a UI-related QoL questionnaire. Evaluation of the questionnaire will be presented elsewhere. Our specific goals here were (1) to use focus group methodology to obtain verbatim descriptions of the effects of UI on QoL from older persons with urge incontinence; (2) to compare the patient-defined UI impact on QoL with provider/expert-defined impact from the literature; and (3) to determine the association between explanatory style and the impact of UI on QoL.

## METHODS

### Subjects

Men and women more than 60 years of age with urge incontinence were recruited in the metropolitan Boston, Massachusetts, area through newspaper and radio advertisements and a newsletter on aging research. Urge incontinence was defined as precipitant urgency with associated leakage of urine.[21] We excluded persons who had other types of incontinence (e.g., stress), who did not speak English, or who were cognitively impaired. All participants were white and were predominantly of high socioeconomic status.

### Focus Groups[22,23]

The study used a structured protocol and an experienced facilitator to conduct the focus groups. Groups were scheduled to have 6 to 14 participants each, separated by gender. Four focus groups were conducted, three with women (n = 25, age range 63–88, mean 73.6 ± 6.7) and one with men (n = 5, age range 70–78, mean 74.6 ± 3.0). All groups were held at an academic medical center. Written informed consent was obtained. All protocols were approved by an institutional review board.

Each group was conducted by a facilitator (CMM or CED), whose main goal was to encourage all members to participate and to balance qualitatively the amount of con-

tent that came from any one participant. A co-facilitator took notes and provided a summary. The 1.5 to 2-hour discussions were guided by a script designed to elicit responses to a range of possible ways to think about how UI might affect quality of life. The script was prepared by a geriatrician with research and clinical experience in geriatric voiding dysfunction (CED) and a general internist with research experience in focus group methodology (CMM). Participants were first asked to describe their UI in their own words. They were then asked open-ended questions about what aspects of their daily life were most affected by their UI. Additionally, participants answered open-ended questions about the influence of UI on specific areas of physical health, self-care, work, household activities, finances, social activities, and hobbies; discussion was driven primarily by subject responses. Focus group members were also asked to share advice about their coping strategies for incontinence with other members of the group. Each session was audiotaped and transcribed.

### Content Analysis

Two analysts (CED, BL) separately verified the accuracy of the audio-transcripts against both the tapes and co-facilitators' notes. Comments were attributable to a specific person for 78% of mentions of QoL content. The content analysis[24] consisted of line-by-line qualitative analysis of the transcripts and development of a data-organizing system, using methods based on Tesch[25] and other content analyses of focus group data used to develop health surveys.[26] Each analyst read through all transcripts and reviewed co-facilitators' notes to familiarize herself with the content and to generate initial ideas about QoL items or specific content that would be used to generate later QoL questions.[27] Working separately, each then noted in the transcript margins any QoL items that occurred, with an emphasis on determining the topic — "what was this talk about"[25] — rather than the content of participant's speech, the "what was said."[25] The analysts then reviewed their observations with each other to generate lists of all items, which were codified, combined, and refined to eliminate redundancy; a total of 33 QoL items resulted. Fresh copies of the transcripts were then re-reviewed and coded separately by each analyst using the 33 items. Next, the analysts met and re-reviewed these codings, discussed any discrepancies, and made modifications to provide final consensus analysis for each transcript. In this process, one item (pain) was deleted because it was coded by only one analyst and occurred only once; all other items had been identified independently by both analysts more than once. The verbatim speech associated with each occurrence of a QoL item was collected, grouped by item, and reviewed for consistency.

### Explanatory Style

Explanatory statements in the transcripts were identified using a combination of the above content analysis methodology and a modification of the Content Analysis of Verbatim Explanations technique.[19,28,29] Subject speech was considered explanatory if it described causes of UI in general or causes specific to the individual. Each analyst identified explanatory statements in the transcripts separately and coded them for three domains: locus of blame for UI (external or internal), duration (transient or ongoing), and specificity (specific or global).[19] Examples of the explanatory style of verbatim explanations of incontinence are given in Table 1.

Table 1. Examples of Explanatory Styles in Verbatim Explanations of Incontinence

| Explanatory Style | Verbatim Example |
|---|---|
| **Positive** | |
| External, temporary, specific | You go out in the cold and get an urge right away. |
| External | It's been just, to use another phrase, leaking on its own. |
| **Negative** | |
| Internal, ongoing, global | If you're incontinent that's part of your problem in getting old. |
| Ongoing, global | I just always assumed it was one of those inevitable things. |
| **Mixed** | |
| External, ongoing, specific | It seems to me that since that operation I don't think I've ever been right since, because I go more now than I ever did. |
| Internal, external, temporary | I don't know if there's tension or what it is (when I'm out), I don't have any trouble (at home). But at home I think you're more relaxed. |

The coding attempted to capture only those domains present in the speech, even if they were incomplete or contradictory. Thus, not every explanatory statement was coded for each domain, and some statements contained both possible elements for a domain (e.g., internal and external). For example, the statement, "I just always assumed it was one of those inevitable things," was coded "ongoing, global" because we took "inevitable" to imply a factor of ongoing duration with general effects and because the nonspecific word "thing" did not establish whether the locus of blame was internal or external to the speaker. The analysts together re-reviewed all coding, discussed any discrepancies, and made modifications to provide final consensus coding. In order to examine any association between explanatory style and specific QoL items, the verbatim speech associated with each explanatory statement was collected along with any associated QoL item coding for each statement. The overall explanatory style of a statement was considered positive if it contained only external, transient, and/or specific domain elements, and negative if it contained only internal, stable, and global domain elements.[19] Statements that contained a combination of positive and negative domain elements were considered mixed style.

### Incontinence Severity

A subset of focus group subjects (n = 11) also participated in a drug treatment trial for urge incontinence, for which they completed pretreatment 7-day voiding records. Data from these voiding records were used to calculate the mean number of incontinent episodes per day as a measure of incontinence severity.

### Statistical Analysis

Frequency counts of the total number of mentions of each QoL item were tabulated, separated by the gender of the group in which the item was mentioned, and ranked. Chi-square tests of association were used to evaluate gender differences in the frequency count of each item. To evaluate the association of the source of UI-related QoL items (patients versus providers/experts) with specific item domains (general areas of behavior or experience),[27] chi-square tests of association were used.

For analysis of explanatory style, frequency counts of the explanatory style, associated UI-related QoL items, and the gender of the group in which the statement was made were tabulated for all explanatory statements. Chi-square or Fisher's exact tests were used to evaluate the association of gender and specific QoL items with explanatory style. Rank-sum tests were used to evaluate the effect of incontinence severity on explanatory style. P values are reported for 2-sided testing (except for rank-sum tests) and considered significant if less than .05.

## RESULTS

### Incontinence-Related QoL Items

The 32 UI-related QoL items identified and verbatim examples of each are listed in Table 2 and ranked by frequency of the overall number of mentions. The frequency rankings in women and men were generally similar. Although we may have missed other gender differences because of low power, several significant differences in the number of mentions of QoL items between women and men were found despite the small sample size. Two items — "treatment burden" and "stress from anticipation of UI" — occurred more frequently in women (P = .02 and .03, respectively), and two others — "fear of aging" and "taboo" — occurred more frequently in men (P = .03 and .004, respectively).

We then compared our UI-related QoL items with those identified by other investigators. More than half of the items we identified (18, 56%) were not described previously. Table 3 lists the UI-related QoL items available from the published literature to date together with those we identified (total n = 82), codified to reduce redundancy between studies. Items were aggregated a priori into eight general domains (specific area of behavior or experience)[27]: Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Recreational Activities, Social Activities, Coping, Interpersonal, Self Concept and Perceptions, and Health Perception. Analysis of data sources — solely patient-defined[7,9] versus expert-defined (expert opinion/literature review,[5,11,12] some supplemented with patient interviews[6,8,13])— revealed that nearly all (95%) of the items in the ADL, IADL, Recreation Activities, and Social Activities domains were expert-defined, whereas those in the Coping, Interpersonal, Self Concept and Perceptions, and Health Perception domains were derived from the patient-defined (48%) and the expert-defined data (52%) (P = .001).

### Explanatory Statements Regarding Incontinence

A total of 157 explanatory statements were identified, 134 from women and 23 from men, with an average of 4.4

Table 2. Incontinence-Related Quality of Life Items

| Item | Verbatim Example | Ranking by Frequency* | | |
|---|---|---|---|---|
| | | Total | Women | Men |
| Need for pre-emptive strategies to avert UI | I take precautions. | 1 | 1 | 1.5 |
| Lack of self-control | I . . . am out of control with that part of me. | 2 | 3 | 1.5 |
| Adaptation of daily routine | I have to stop living my life the way I would ordinarily | 3 | 2 | 5 |
| Shame | It [leaking] was mortifying. | 4 | 4 | 6 |
| Fear of public embarrassment | . . . [the] tension that you might have a problem in public. | 5 | 5 | 8.5 |
| Lack of predictability | I would choose to know when I had to void. | 6 | 6 | 3.5 |
| Loss of sleep | I have to go . . . [many] times a night and I'm so tired. | 7 | 7 | 7 |
| Resignation | I'm in a position where I can't do too much about it. | 8 | 8 | 3.5 |
| Self-concept | I'm sure [UI] must have affected my self image. | 9 | 9.5 | 15 |
| UI psychological, not physical problem | I think a lot of mine is psychological. | 10 | 11 | 15 |
| Treatment burden | The side effects [are awful]. | 11 | 9.5 | 26.5 |
| Concern about UI causes | That's the one thing that puzzles me, because—why? | 12.5 | 12 | 18.5 |
| Constant preoccupation | [UI] is always on your mind. | 12.5 | 18 | 8.5 |
| Inevitability | I just always assumed [UI] was one of those inevitable things. | 16 | 17 | 11.5 |
| Vigilance | Wherever I go, whatever I do, I always have to know right away where the bathroom is. | 16 | 14.5 | 22 |
| Fear of aging | [UI] makes me more aware of my age, which I think bothers most of us older people. | 16 | 19 | 11.5 |
| Constant burden | [UI] is something that is always on your mind. | 16 | 16 | 18.5 |
| Burdensome compensatory activities | I do wear a pad and I resent it terribly. | 18 | 14.5 | 24 |
| Body odor and cleanliness | [UI] is unhygienic, very unclean. | 19 | 20.5 | 15 |
| Stress from anticipation of UI | I do dread the thought of not getting to the bathroom in time at night. | 21 | 13 | 29.5 |
| Competing morbidities take precedence | [UI] is a very minor thing compared with, you know, health in general. | 21 | 22.5 | 11.5 |
| Interruption of activities | It's inconvenient to have to stop every two minutes. | 21 | 22.5 | 11.5 |
| Financial expenses | The products are very expensive. | 23 | 20.5 | 25 |
| Alone with UI problem | I don't have any friends that have [UI]. | 24 | 25.5 | 18.5 |
| Loss of dignity | Even with your husband [UI] is embarrassing. | 25 | 24 | 26.5 |
| Self-esteem | [UI is] another reason not to feel good about yourself. | 26 | 29 | 22 |
| Fear of dependency | I wouldn't want to burden anyone with [my UI]. | 27 | 30 | 22 |
| Intimate relationships | I keep a pail beside the bed . . . I think that's very unromantic. | 28 | 25.5 | 32.5 |
| Lack of legitimization of problem | I'm not sure how seriously [my doctor] takes this problem. | 29 | 27.5 | 29.5 |
| Taboo/forbidden topic | I think [UI] was a hush-hush subject. | 30 | 32 | 18.5 |
| Association with women's biology | [UI] is a reminder of the old tampon days, and that's not good. | 31 | 27.5 | 31.5 |
| Alteration in social/gender role | You know how children are at taking care of the parents, parents can take care of the children but, you know . . . | 32 | 31 | 29 |

*Ranking by frequency of all mentions: rank 1 = highest number of overall mentions.

statements per person regardless of gender. Examples of explanatory statements are given in Table 1. Overall, the majority of explanatory statements (57%) were positive in style, 23% were negative in style, and 20% were mixed. Women made predominantly positive statements (60%) whereas men made a similar number of positive (43%) and mixed statements (49%) ($P = .001$). If mixed style statements were grouped with either positive or negative style statements, however, there were no significant gender differences.

### Association Between Explanatory Style and UI-Related QoL

Nearly half (42%) of all explanatory statements had associated QoL items (Table 4); that is, the statements contained both explanatory and QoL content. In women, asso-

Table 3. Summary of UI-Related Quality of Life Items, by Domain and Data Source

| Domain Item | Patient-Defined | | | Expert-Defined | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Reference: | * | 9 | 7 | 6 | 5 | 11 | 8 | 12 | 13 |
| **ADL** | | | | | | | | | |
|   ADL | | | | | | X | | | |
| **IADL** | | | | | | | | | |
|   Cooking | | | | X | | | | | |
|   Housecleaning | | | | X | | | X | | |
|   Laundry | | | | X | | | | X | |
|   Household repair | | | | X | | | | | |
|   Shopping | | | | X | | | | | |
| **Recreational activities** | | | | | | | | | |
|   Hobbies | | | | X | | | | | X |
|   Volunteer activity or work | | | | X | | | | | |
|   Physical recreation | | | | X | | X | X | | |
|   Church/temple attendance | | | | X | | | | | |
|   Travel (</>30 min) | | | | X | | | X | | |
|   Vacation | | | | X | | | | | X |
|   Visits to places with unknown bathrooms | | | | X | | | | | |
| **Social activities** | | | | | | | | | |
|   Having friends visit | | | | X | | | | | |
|   Visiting friends | | | | X | | | | | |
|   Social activities outside home | | | | X | | | X | | X |
|   Entertainment | | | | X | | X | X | | X |
|   Financial expenses | X | | | | | X | | | |
| **Coping** | | | | | | | | | |
|   Adaptation of daily routine | X | | X | | | | | | |
|   Pre-emptive strategies/avert UI | X | | X | | | | | | |
|   Vigilance | X | | X | | | | | | |
|   Interruption of activities | X | | | | | | | | |
|   Constant burden | X | | | | | | | | |
|   Burdensome compensatory activities | X | | X | | | | | | |
|   Lack of predictability | X | | | | | | | | |
|   Way one dresses | | | | X | | | | | |
|   Treatment burden | X | | | | | | | | |
|   Constant preoccupation | X | | X | | | | | | |
|   Stress from anticipation of UI | X | | X | | | | | | |
|   Worry re sneezing, cough | | | X | | | | | | |
|   Concern about UI causes | X | | | | | | | | |
|   Efficacy of efforts to decrease UI | | X | | | | | | | |
| **Interpersonal** | | | | | | | | | |
|   Relationship with friends | | X | | X | | X | | | X |
|   Relationship with family | | | | X | | | | X | X |
|   Relationship with spouse | | | | X | | X | | | |
|   Sexual relations | X | | | X | | X | | | X |
|   Establish new relationships | | | | | | X | | | |
|   Effect on family | | X | | | | | | | |
|   Avoidance by others | | X | | | | | | | |
|   Social isolation | | | | | X | | | X | |
|   Isolation by others | | | | | | X | | | |
|   Alone with UI problem | X | | | | | | | | |
|   Alteration in role | X | | | | | X | | | |
| **Self-concept and perception** | | | | | | | | | |
|   Lack of self-control | X | X | X | | | | | | |
|   Sense of shame, disgrace | X | | X | | X | | | | |
|   Fear of public embarrassment | X | | X | X | X | | | X | X |
|   Resignation | X | | | | | | | | |
|   Self-concept | X | | | | | | | | |

**Table 3. Continued**

| Domain Item | Patient-Defined | | | Expert-Defined | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Reference: | * | 9 | 7 | 6 | 5 | 11 | 8 | 12 | 13 |
| Lack of legitimization for UI | X | | | | | | | | |
| Taboo/forbidden topic | X | | | | | | | | |
| Loss of dignity | X | X | | | X | | | | |
| Body odor and cleanliness | X | | X | X | | | | X | X |
| Self-esteem | X | | | | | | | | |
| Fear of dependency | X | | | | | | | | |
| Frustration | | | X | | | | X | | |
| General QoL | | X | | | | | | | |
| Inevitability | X | | | | | | | | |
| Self-confidence | | | X | | | | | | |
| Dampness | | | | | X | | | | |
| Insecurity | | | | | X | | | | |
| Anger | | | | | X | | | | |
| Impatience | | | | | X | | | | |
| Helplessness | | | | | X | | | | |
| Feels outcast | | | | | X | | | | |
| Dependence | | | | | X | | | | |
| Guilt | | | | | X | | | | |
| Self-blame | | | | | X | | | | |
| Nervousness/anxiety | | | | | | X | | | |
| Worthlessness | | | | | X | | | | |
| Depression | | | | | X | | | X | |
| Burden to others | | | | | X | | | | |
| Worry | | | | | X | | | | X |
| Easily upset/irritability | | | | | X | | | | |
| Punishment by others | | | | | X | | | | |
| Women's biology | X | | | | | | | | |
| Health perception | | | | | | | | | |
| Self-perception-physical health | | | | X | | X | | | |
| Self-perception-mental health | | | | X | | | X | | |
| UI psychological not physical problem | X | | | | | | | | |
| Loss of sleep | X | X | X | | | | | | |
| Fear of aging | X | | | | | | | | |
| Competing morbidity | X | | | | | | | | |
| Energy level | | | | | | X | | | |

* = present study; ADL = activities of daily living, IADL = instrumental activities of daily living, UI = urinary incontinence, QoL = quality of life.

ciated QoL items occurred significantly more frequently with negative style statements ($P < .0001$), whereas in men they occurred significantly more frequently with mixed style statements ($P = .02$); this gender difference was itself statistically significant ($P = .02$). There were eight specific QoL items associated statistically with explanatory statements. Six of these items were associated significantly with negative style statements: sense of inevitability ($P < .0001$); poor self-concept ($P < .0001$); concern that UI is a psychological rather than physical problem ($P < .0001$); association with women's biology (e.g., menstruation and childbirth) ($P = .002$); fear of aging ($P = .006$); and shame ($P = .02$). No QoL item was associated significantly with positive style explanatory statements. Two QoL items — "lack of control" and "inevitability" — were associated significantly with negative explanatory style statements in women but with mixed style statements in men.

*Explanatory Style and UI Severity*

Complete data from baseline voiding records were available for 11 subjects (nine women and two men). For each of these subjects, all explanatory statements and style were reviewed (Table 5). Notably, none of these subjects made predominantly negative style explanatory statements. We found no significant correlation between UI severity and explanatory style whether we looked at subjects with the greatest proportion of negative style statements (women 6 and 9, mean severity $3.2 \pm 2.7$ episodes/day compared with $1.2 \pm .8$ for all others, rank sum one-tailed $P = .16$) or subjects without a majority of positive style statements (women 7, 8, 9, and man 2, mean severity $1.9 \pm 2.2$ compared with $1.3 \pm .8$ for all others, rank sum one-tailed $P = .60$).

Table 4. Association of Explanatory Style and Incontinence-Related Quality of Life

|  | Explanatory Style | | | P Value |
|  | Positive | Negative | Mixed |  |
|---|---|---|---|---|
| Explanatory statements, n | 75 | 30 | 27 | <.0001 |
| With associated QoL items, n (%) | 15 (20%) | 25 (83%) | 16 (59%) |  |
| Associated QoL Items |  |  |  |  |
| Concern regarding UI etiology | 8 | 4 | 3 | .93 |
| Lack of control | 5 | 5 | 4 | .24 |
| Inevitability | 0 | 8 | 3 | <.0001 |
| UI psychological not physical problem | 1 | 9 | 4 | .0001 |
| Self-concept | 0 | 7 | 2 | .0001 |
| Shame | 0 | 2 | 0 | .03 |
| Women's biology | 0 | 4 | 1 | .005 |
| Fear of aging | 0 | 3 | 0 | .005 |

Table 5. Explanatory Style and Incontinence Severity

| Subject/Sex | Number Explanatory Statements | Explanatory Style (% of Statements) | | | Incontinence Severity (Mean Episodes/Day) |
|  |  | Positive | Negative | Mixed |  |
|---|---|---|---|---|---|
| Woman 1 | 1 | 100 |  |  | 0.17 |
| Woman 2 | 2 | 100 |  |  | 2.11 |
| Woman 3 | 10 | 80 |  | 20 | 1.57 |
| Woman 4 | 4 | 75 |  | 25 | 2.43 |
| Woman 5 | 3 | 67 |  | 33 | 0.57 |
| Woman 6 | 5 | 60 | 40 |  | 1.33 |
| Woman 7 | 2 | 50 |  | 50 | 0.80 |
| Woman 8 | 4 | 50 | 25 | 25 | 0.29 |
| Woman 9 | 14 | 43 | 36 | 21 | 5.13 |
| Man 1 | 3 | 67 |  | 33 | 1.25 |
| Man 2 | 5 | 40 |  | 60 | 1.40 |

## DISCUSSION

Using content analysis of focus group data from older persons with urge incontinence, we identified 32 UI-related QoL items, more than half of which have not been described previously. We found that explanatory statements were made frequently by patients when talking about their UI; women were more likely to make positive style and men positive and mixed style explanatory statements. Although our subjects most commonly made positive style explanatory statements, we found a significant correlation between negative explanatory style and six specific UI-related QoL items (inevitability, UI as psychological and not physical problem, self-concept, shame, association with women's biology, and fear of aging).

The focus group methodology we used is an empirical approach for defining the content areas of most importance from the patients' perspective. Our focus group data may have identified new areas of patient concern regarding the influence of UI on multidimensional QoL because our patients were older (mean 74 years) and all had urge incontinence, compared with the two other studies using patient-defined data to derive UI-related QoL items (in which the mean subject age was 64 to 67 years and the percent with urge incontinence was 35% and 7%[7,9]). It is likely that the QoL items we identified will be more relevant for older adults, who are most likely to have urge incontinence attributable to detrusor overactivity.[14] A UI-related QoL questionnaire representing the items we identified has been developed, and its evaluation will be reported elsewhere.

Despite the small sample size, we did find significant gender differences in the frequency ranking of four QoL items. It is possible that women cited "treatment burden" and "stress from anticipation" more frequently, and "taboo" less frequently, than men because women managing incontinence have greater use of and reliance on protective undergarments (22% vs 4% in a British survey[30]), which are similar to the menstrual pads that were part of their lives for years. This may also account for our identification of "association with women's biology" as a QoL item with a negative impact. The same British survey found that men were more likely to feel that old age caused incontinence (15% vs 5% of women),[30] which may explain why men cited "fear of aging" more frequently than women. These explanations must remain speculative because other important gender differences may have been missed because of low power.

Important differences in patient- versus expert-defined UI-related QoL emerged when we examined our findings in combination with UI-related QoL items from the litera-

ture.[5–13] Nearly all (97%) of the QoL items in the ADL, IADL, Recreational Activities, and Social Activities domains were derived from expert-defined data, whereas items in the Coping, Interpersonal, Self-Concept and Perceptions, and Health Perception domains were derived from both patient- and expert-defined data. These associations with the source of the content areas for published surveys suggest that the functional impact of UI emphasized by experts (that is, providers) is not as important for patients, who emphasize instead the impact of UI along the construct of emotional well-being. Older persons experience a greater influence of urge UI on coping with embarrassment and the interruption of activities (especially by a condition of which one is ashamed) than on the performance of activities. As one subject related:

"You know, you're enjoying [what you are doing], or you're interested, then you have to stop and go pee. You know, it's a pain."

Our work corroborates Mitteness's supposition that "one of the major tasks for [elderly] incontinent people is to control negative feelings about themselves."[31] The identification of the tremendous psychological burden of UI, as defined by patients in their own words, was an important element in the development of our UI-specific QoL measure that we hope will represent the influence of UI on these other more psychologically oriented aspects of QoL.

Thus, the evaluation of UI-related QoL in older patients may deviate from the classic geriatric assessment model, which emphasizes the impact of physical and mental health on functional ability in everyday living.[32] One reason for this difference may be that subjects in the patient-defined UI-related QoL studies were relatively young and living independently in the community: that is, they were the "young-old," whose sufficient physiological reserve could reduce the functional impact of disease. Although one could postulate that any functional impact would be more important for such generally healthy and, therefore, more active older persons, we did not find this to be the case. A more important reason for this deviation from the geriatric assessment model may be that there is a greater effect of the negative societal view of incontinence on otherwise healthy persons; as seen in Table 3, "fear of embarrassment" was the UI-related QoL item found most frequently in the literature, and patients ranked it highly as well.

Other work regarding QoL in incontinent persons supports the conclusion that the QoL impact of UI is greater on coping with embarrassment and activity interference than on activity performance. Brocklehurst found that 55 to 70% of incontinent individuals "lost confidence" in major lifestyle and social activities.[30] Similarly, Grimby et al., using the Nottingham Health Profile, found that incontinent older women differed from age-matched controls on the Emotional Disturbance and Social Isolation subscales but had similar scores on the Lack of Energy and Mobility subscales.[33] However, Hunskaar and Vinsnes, using the Sickness Impact Profile (SIP), found that older urge incontinent women had similar scores in the Physical domain compared with the Psychosocial domain and that their scores in the Home Management and Recreation domains were somewhat higher (indicating worse disability).[34] The SIP scores in that study, however, were markedly worse than those in a separate study of healthy community-based older people[35] in which the SIP

(but not the Medical Outcomes Study SF-36 and the Quality of Wellbeing Scale) scores were markedly skewed toward very healthy levels; thus, SIP scores in the Hunskaar and Vinsnes study may have been confounded by other diseases or conditions that were not routinely evaluated.

Confounding of QoL impact by comorbid conditions is a concern in assessing UI-related QoL, especially in older persons. In community-dwelling older persons, UI is associated significantly with congestive heart failure, obesity, mobility problems, and chronic obstructive lung disease.[36] These conditions appear to influence QoL primarily by their effect on physical function: studies of persons with heart failure,[37] osteoarthritis requiring arthroplasty,[38] Parkinson's disease,[39] and chronic obstructive pulmonary disease[40] demonstrate that these conditions have greater impact on the physical function domains of the Medical Outcomes Study SF-36 QoL questionnaire than on the mental health, emotional role function, and general health perception domains. In contrast, two studies[41,42] of persons with voiding dysfunction using the SF-36 found greater disability in the role function, mental health, and general health perception domains. Hunter found that men with voiding symptoms (other than incontinence) had significantly greater disability in physical and emotional role, bodily pain, mental health, and general health perceptions than the general population, whereas their physical function scores were similar.[41] A small study of older incontinent persons found generally low scores (indicating greatest disability) in physical and social function and general health perception; there was considerable intra-individual variation in baseline scores and no change in scores after incontinence treatment, however, leading the authors to conclude that comorbid conditions likely accounted for the low scores.[42] Additionally, the authors found a striking difference between the lack of change in the SF-36 and the patients' own reports of improvement in feelings about their day-to-day lives and general mood and outlook.[42] Thus, together with our findings, these studies suggest that the QoL impact of UI can be separated from that of comorbid diseases by their differential effects on physical and emotional function and that general health-related QoL scales such as the SF-36 may aid in this differentiation.

The many explanatory statements made by older persons when discussing their UI allowed us to examine the relationship of explanatory style to UI-related QoL. Peterson and Seligman first described explanatory style, or the habitual way in which persons explain uncontrollable bad events in their lives, as an extension of the learned helplessness model for explaining the range of responses to bad events.[18] Negative explanatory style — in which persons use self-blaming, stable, and global explanatory terms — appears to be stable over the life-span[43] and across situations[44] and is likely a risk factor for low achievement, depression, physical illness, and more frequent use of medical care.[18] Possible explanations for these associations range from the helpless reactions of such pessimistic individuals to problems and symptoms[20] to depressed immune function.[45] It is not surprising that negative explanatory style and perceived helplessness are relevant in UI: at least half of incontinent persons do not report their symptoms to health providers,[46,47] and 43% of women who did not seek help for their UI feel that UI is either "not serious," a "usual female complaint," or were too embarrassed to mention it.[48]

We found that negative explanatory style was associated with six QoL items, suggesting that explanatory style may be a mediator of the impact of UI in individuals. These items appear particularly reflective of a sense of inescapable destiny (sense of inevitability, association with women's biology, fear of aging) and self-blame (self concept, concern that UI is a psychological rather than physical problem, shame), consistent with a general helplessness that may explain, in part, patients' low rates of reporting UI to their health providers.[46,47]

The only other identified correlate of UI impact is incontinence severity: the greater the number of incontinence episodes, the greater the impact.[4] Severity alone, however, is not a sufficient proxy for UI effects on QoL because, at most, it accounts for only one-third of the variance in QoL.[6] In addition, there are significant ceiling effects: 69% of women with severe UI report no activity restriction, and 70% are "not worried" about their condition.[36] Others have found that women with severe UI had an increased likelihood of seeking help.[36,49] Therefore, outcomes evaluations of UI treatment cannot rely on changes in UI severity to reflect the impact of treatment on UI-related QoL. We did not find a consistent relationship between severity and explanatory style, possibly because of low power; among the three subjects with the most severe UI, however, two had a predominantly positive explanatory style. Further work will be necessary to confirm whether explanatory style influences the QoL impact of UI independent of UI severity.

Our study has several limitations. Content analysis has subjective elements that may have affected our identification of QoL items. We used two analysts and multiple levels of consensus agreement to minimize this effect. Generalizability is another concern inasmuch as we used only 30 subjects, all of whom were white, of relatively high socioeconomic status, lived in a single metropolitan area, were in relatively good health, and had responded to advertisements to participate in research. Men were underrepresented in our sample, as they have been in other patient-based UI QoL studies,[7,9] reflecting incontinence epidemiology and perhaps recruitment issues. Despite the possible subjectivity and small numbers of subjects, 14 (44%) of the items we identified were similar to those identified by other investigators using larger samples and different methodologies,[5–7,9,11,13] supporting the validity of our methodology. On the other hand, the identification of 18 novel QoL items supports the utility of using patient focus groups to provide important QoL information about UI. That these new items were from patients with urge incontinence — a cohort underrepresented in other patient-based incontinence QoL studies — supports other observations of a differential QoL effect of urge versus stress incontinence[4] and suggests that different QoL measures may be necessary. The new items also indicate that our content analysis was not biased by previous work in UI-related QoL. Type II error was possible because of the small number of subjects and may have limited our ability to detect significant gender differences, associations between explanatory style and additional QoL items, and the relationship between explanatory style and UI severity.

In summary, focus groups of older persons with urge incontinence suggest the existence of a discrepancy between the way experts and patients view the impact of urge UI on QoL. Whereas experts focus more on functional impact, patients more often cite its impact on their ability to cope. In addition, the association between negative explanatory style and specific UI-related QoL items suggests that explanatory style may be an important mediator of UI-related QoL. Further work is needed is corroborate our findings and determine additional predictors of UI-related QoL.

## ACKNOWLEDGMENTS

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