The purpose of this study was to use narrative analysis as a method for examining the lived experience and meaning of long-term, female urinary incontinence (UI). Seventeen community-dwelling women participated in in-depth interviews. Three dominant plot types were discovered in informant’s narratives: the Urinary Incontinence Quest Narrative, Urinary Incontinence Restitution and Redemption Narratives, and the Urinary Incontinence Victim Narrative. Findings suggest that long-term female, UI is primarily conceptualized as a condition integrated into a larger life story and that women with long-term UI relate stories that follow a narrative format. Implications for clinical practice and research are also included.

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Note: The informant’s name/initials, places, other individuals, and references that could lead to informant identification have been changed or deleted. The initials “CB” are used throughout to indicate the investigator.

Purpose
The purpose of this study was to use narrative analysis as a method for examining the lived experience and meaning of long-term, female urinary incontinence (UI).

Method
Cognitive anthropology and critical medical anthropology provided the overall framework for this study. Theoretical saturation (Strauss, 1987) was achieved after 17 community-dwelling women with long-term (greater than 5 year’s duration) UI were interviewed. Informants participated in two face-to-face, audiotaped, interviews and a semi-structured, topical outline for each interview was used. A field journal was used to supplement and validate other data. Informant’s narratives were analyzed to emphasize the overall plot type of their stories.

Findings
In this study, three dominant plot types emerged from women’s narratives: the UI Quest Narrative, UI Restitution and Redemption Narratives, and the UI Victim Narrative. These plot types provide a beginning understanding of the lived experience and meaning of long-term female UI.

Conclusions
Study findings suggest (a) long-term female UI is primarily conceptualized as a condition integrated into a larger life story, (b) women with long-term UI relate stories that follow a narrative format, and (c) long-term, female UI is heterogeneous. Findings go beyond existing literature by suggesting that women’s UI narratives serve an important function in understanding the lived experience and the meaning of UI.
Theoretical Perspective
Cognitive anthropology (CA) and critical medical anthropology (CMA) provided the overall framework for this study. CA emphasizes how individual and shared experiences shape and transmit the meaning of those experiences, and was relevant as the women in this study described individual and shared experiences associated with long-term UI. In general, CMA questions the underlying assumptions of traditional biomedical and societal viewpoints and myths regarding the causes, impact, and treatments for female UI.

Literature Review
Most UI research follows a traditional biomedical format and has focused on the epidemiology and underlying pathophysiology, treatment, and impact of UI on health-related quality of life (QoL); however, several investigators have used qualitative methods to examine the meaning and lived experience of female UI.

In an early ethnography, Mitteness (1987) studied 30 community-dwelling older men and women to understand the impact of UI on their lives. Impact translated into a variety of management strategies, including keeping the incontinence secret. Mitteness and Barker (1995) then went on to describe a cultural model of UI for older adults which suggests that the experience of UI is significantly different from existing biomedical knowledge. Within this model, UI is seen as an inevitable part of the aging process and as symbolic of the growing dependency associated with aging.

Two studies of older women suggest that self-esteem plays an important role in the meaning of UI. Dowd (1991) used open-ended interviews to examine the experience of UI in community-dwelling older women. UI emerged as a threat to self-esteem and as a result, informants described elaborate “continence care systems” that if successful, served to protect self-esteem. In another study, nursing home residents were interviewed and observed to examine reactions to UI and wearing absorbent products (Bjurbrant Birgersson, Hammar, Widerfors, Hallberg, & Athlin, 1993). Findings suggest that self-esteem and individual UI experiences were dependent on women’s basic view of themselves, strategies for controlling UI, and how their UI was “handled.” For example, if UI was handled in a “bad” way (by nursing staff or the women themselves), feelings of shame, guilt, dependency, insecurity, and discomfort occurred.

Two studies focused on UI in younger women. Ashworth and Hagan (1993) explored the meaning of UI for 28 young and middle-aged women. Three main themes emerged: (a) UI is vague and difficult to grasp, (b) affects self-image, and (c) has an impact on daily life. In another study, postpartum women were asked to describe how stress UI affected their life (Mason, Glenn, Walton, & Appleton, 1999). Responses were sufficiently contradicting to make speculation about the meaning of UI difficult. For example, some women felt their UI was distressing enough to seek professional advice, but later in the same interview...
described the UI as “not a problem” (p. 169).

Ethnic minority women were interviewed to examine the effect of religious and cultural practices on ideas and experiences associated with UI (Chaliha & Stanton, 1999). Most felt some degree of taboo associated with an “unclean” condition such as UI; some modified prayer routines to allow for their UI, and others identified decreased libido associated with “feeling unclean.” Conclusions clearly suggest that sensitivity to the emotional, cultural, and social aspects of UI is essential to understanding the experience of UI on women’s lives.

UI is a female dominant condition, yet only one study has examined female UI in terms of its “gendered meanings” (Peake, Manderson, & Potts, 1999). Using a narrative framework, 75 middle-aged women described their experiences with UI. Informants incorporated their experience of UI into the history of their bodies and their overall life story. Their narratives also revealed the importance of personal control, managing their UI and in turn, maintaining self-worth and social membership.

In summary, a beginning understanding of the lived experience and meaning of female UI exists, yet only one study has used narrative as a primary methodology.

Purpose
The purpose of this study was to use narrative analysis as a method for examining the lived experience and meaning of long-term, female UI.

Methods
Sample. Theoretical saturation (Strauss, 1987) was achieved after 17 community-dwelling women with long-term (greater than 5 year’s duration) UI were interviewed. Additional inclusion criteria included residence in the same eastern United States city or immediate suburbs, English as a first language, and commitment to the project until completion (Agar, 1996; Taylor & Bogdan, 1984). Demographic, general health, and continence profiles of the 17 informants are found in Table 1.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Informants (N=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>65 ± 17.3 (range 28-86)</td>
</tr>
<tr>
<td>Ethnicity (%)</td>
<td></td>
</tr>
<tr>
<td>European-American</td>
<td>64.7% (n=11)</td>
</tr>
<tr>
<td>African-American</td>
<td>35.3% (n=6)</td>
</tr>
<tr>
<td>Marital Status (% currently married)</td>
<td>47.1% (n=8)</td>
</tr>
<tr>
<td>Education (%)</td>
<td></td>
</tr>
<tr>
<td>High school or less</td>
<td>35.3% (n=6)</td>
</tr>
<tr>
<td>Some college/college grad</td>
<td>29.4% (n=5)</td>
</tr>
<tr>
<td>Post-graduate degree</td>
<td>35.3% (n=6)</td>
</tr>
<tr>
<td>Employment (%)</td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>29.4% (n=5)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>11.8% (n=2)</td>
</tr>
<tr>
<td>Retired</td>
<td>58.8% (n=10)</td>
</tr>
<tr>
<td>Number of Pregnancies</td>
<td>2.5 ± 2.0</td>
</tr>
<tr>
<td>Number of Live Births</td>
<td>1.9 ± 1.4</td>
</tr>
<tr>
<td>Post-Menopausal (%)</td>
<td>88.2% (n=15)</td>
</tr>
<tr>
<td>Previous Hysterectomy (%)</td>
<td>58.8% (n=10)</td>
</tr>
<tr>
<td>Type of UI (%)</td>
<td></td>
</tr>
<tr>
<td>Stress UI only</td>
<td>5.9% (n=1)</td>
</tr>
<tr>
<td>Urge UI only</td>
<td>41.2% (n=7)</td>
</tr>
<tr>
<td>Mixed UI (stress and urge)</td>
<td>35.3% (n=6)</td>
</tr>
<tr>
<td>Other (enuresis; nonspecific)</td>
<td>17.6% (n=3)</td>
</tr>
<tr>
<td>Years with UI</td>
<td>12.8 ± 9</td>
</tr>
<tr>
<td>Number of Episodes UI/Week</td>
<td>10 ± 7.9</td>
</tr>
<tr>
<td>Sought Professional UI Treatment (%)</td>
<td>75.6% (n=13)</td>
</tr>
</tbody>
</table>

Table 1. Demographic, Health, and Continence Profiles of Informants

Participant selection. Initially, women were recruited from local physician or continence nurse specialist clinical practices. This approach primarily identified a group of European American women undergoing UI evaluation and treatment. To reach a more diverse population and those women who were not actively seeking professional UI care, informants were also recruited via a snowballing technique (such as asking initial informants to provide contact information for other women with UI [Bernard, 1995]), and through other non-urologic health care practices.

Data collection. After obtaining informed consent, informants participated in two face-to-face, audio-taped interviews. A semi-structured, topical outline for each interview was used (available by request). All interviews were transcribed verbatim. After the first interview was completed, the investigator reviewed the transcript and tape, made corrections as necessary, did prelimi-
nary coding, and made notes for the second interview. The investigator also kept a field journal that was used to supplement and validate other data.

Data analysis. Informant’s narratives were analyzed to emphasize the overall plot type of their stories. First, the rough transcription was reviewed.

Next, parts of the rough transcription were deleted (at least for a time) and remaining portions were retranscribed for evidence of Labov’s (1982) approach to narrative analysis. Finally, portions of individual interviews were also transformed to reflect alternate approaches suggested by Gee (1991) and Riessman (1993) (see Table 2). This method allowed the dominant plot type of each narrative to emerge.

Evaluation criteria. A valid finding in narrative research is one that is well-grounded and supportable; reliability refers to the trustworthiness of the data (Polkinghorne, 1988). Measures to ensure the trustworthiness of this study included (a) devising explicit transcription rules and notation systems, (b) returning to the original data as often as necessary during transcription and analysis, (c) using member checks to verify information and validate interpretations, (d) engaging in audits with a peer group, and (e) describing how interpretations were produced.

Findings

The kinds of stories women tell, what happens in their stories, and who is included in the story is one way of understanding the lived experience and meaning of long-term UI. In this study, three dominant plot types emerged from women’s narratives; the UI Quest narrative, UI Restitution and Redemption narratives, and the UI Victim narrative. Unique features of these plot types are found in Table 3 and examples of each type are presented in more detail in this section.

The UI Quest Narrative

These stories very closely resemble Frank’s (1995) basic
Table 3.
Features of the Three Plot Types Identified in This Study: UI Quest, UI Restitution, and UI Victim Narratives

<table>
<thead>
<tr>
<th>The UI Quest Narrative</th>
<th>The UI Restitution Narrative</th>
<th>The UI Victim Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Matter-of-fact identification and acknowledgement of UI.</td>
<td>• Specific and nonspecific UI stories mixed with life and laughter.</td>
<td>• UI happens because of...(surgery, sex, doctors).</td>
</tr>
<tr>
<td>• UI is bothersome, but part of life.</td>
<td>• Works with the UI.</td>
<td>• Tries to forget it and/or fix it.</td>
</tr>
<tr>
<td>• Learning from it and figuring out management strategies.</td>
<td>• Has a positive view of help from others.</td>
<td>• Unable to resolve or “get anywhere.”</td>
</tr>
<tr>
<td>• Keeps going and lives with it.</td>
<td>• Does not like UI, but lives with it.</td>
<td>• Keeps living, despite UI.</td>
</tr>
<tr>
<td>• Has advice for others.</td>
<td>• Compares self with others and realizes some things are worse than UI.</td>
<td>• Tries to be positive about the future, but unsure of this.</td>
</tr>
</tbody>
</table>

Quest narrative in which illness is conceptualized as a journey, the teller meets challenges associated with the illness head on, and believes that something is gained as a result of the experience. UI Quest narratives were told by many older women and by Ms. T., who despite her young age, lives with many chronic health conditions. At 28, Ms. T. was the youngest informant; despite having long-term UI, she is unable to recall a specific first episode; rather she describes the onset and her initial reactions to UI in a matter-of-fact manner.

“Well let’s see. I had it for a while, 10 years or so I guess and, ‘cause I have cystic fibrosis almost always coughing really and if not coughing then I have a little doodad here called “The Flutter.” And this is a way to do airway clearance but it [makes me cough] hard so sometimes I have to sit on the toilet when I do this to make sure I don’t pee right out...but yeah I guess 10 years or so...Since I was 18 or so. I can’t...it might of been before that but I don’t think it’s much after that.”

Individuals who tell UI Quest narratives may talk about UI as something that is “bothersome,” or that they prefer not to have at all. Such sentiments, however, are balanced by comments or stories illustrating how UI is not a primary focus, but rather part of a larger illness narrative or life story. For example, Ms. T says:

“There’s already so much discussion of my poop and my mucus my sinus and my lungs sort of one more thing to joke about.

Nothing’s sacred honestly. so many more embarrassing things and other scary things like I get hemoptysis had it where it’s just gushing when you have stuff like that everything else is just funny. (Laughs)

It’s not that serious sort of HA, HA, HA. It plays a minor humorous role. Like a side character of Shakespeare.”

Many telling UI Quest narratives also had advice to offer others. For example, “Treat your body like a soft towel. Don’t let anybody abuse your body. You get in a situation where you have a hard time with your bladder, go see about (it); talk to a doctor. Maybe there’s a treatment.”

UI Restitution and Redemption Narratives
The UI Restitution stories identified in this study also follow Frank’s (1995) general structure and were evident in many narratives. Frank’s basic Restitution narrative is described as a culturally preferred story and characterized by a basic plot line of yesterday I was sick, tomorrow I will be healthy again. Although Ms. F. “hates being incontinent,” she’s spent very little time wondering about its causes, or looking for answers or cures. In this example, she describes her first episode of incontinence.

“Treat your body like a soft towel. Don’t let anybody abuse your body. You get in a situation where you have a hard time with your bladder, go see about (it); talk to a doctor. Maybe there’s a treatment.”

“I was on my way when I really found out what was going on.

Was on my way from North Carolina. I go to the bathroom. I wet myself. What? I never wet myself. (Laughs)

I will never, ever, go without anything anymore.

I was so embarrassed. I wet myself. I never done that.

So that’s what happened.”

Laughter is prominent in the UI Restitution stories. Ms. F., for example, laughs as she relates the details of her “fur coat story.”

“(Laughs) “One thing that uh...when I first got the fur coat I come from church and I had to go to the bathroom and it was cold.

And this is funny.
I’m not wetting my coat. (Laughs)

I was trying to open the door. I took the coat off and put it on my arm (Laughs) so to not wet myself.

Yeah. (Laughs). I’m not wetting my coat. No way.”

As the UI Restitution narrative continues, it becomes clear that the protagonist does not focus on the struggles associated with UI. In this example, Ms. F. explains how she orders absorbent products from a mail-order company. Rather than focusing on UI, she compliments the expertise of company employees.

“...but, I’ve gotten in with a good company. The saleslady that spoke to me was very nice about it. She felt that I was getting the one box. She felt that I needed the two boxes because I was ordering earlier. And so that was great. I’d like to commend them on that...because we do need it...”

Ms. F. also compares herself with others, and concludes that she can “live with” her UI. Once she learned “how to handle what’s going on” she has been “happy.”

“It’s just a problem (Laughs) that’s all. It’s just a problem that you have to live with and uh, it does something to your way of living. It’s like I said, you have to learn to control what you’re going to do and don’t let it control you. But in the beginning, it will control you, because this is something new...And you don’t know how to handle it. You sit down and think about it. And then you learn how to handle what’s going on with your body...So uh, you learn to live with it. As I said, it stopped me from going places and doing things until I learned what to do with it. But now I’m happy.”

A variation of the UI Restitution narrative identified in this study is the UI Redemption narrative. Ms. A.’s story is similar to that of Ms. F., but also includes several redemption sequences (McAdams & Bowman, 2001). In these stories, the teller describes a painful episode, and as the story unfolds, negative scenes are redeemed by positive outcomes (McAdams & Bowman, 2001). For Ms. A., this translates to how UI has been beneficial to her.

“I have really...you know; actually now I’ve made it into a positive. ‘Cause I need to drink plenty of water and it helps me get my water in during the day. That’s the way I look at it...”

Ms. A.’s outlook is positive. Every time she has a bad experience, she learns from it, and continues to move toward improvement or wellness. Redemption narratives may also include religious metaphors with references to being “saved” or “delivered” (McAdams & Bowman, 2001). Ms. A. talks about her “faith” in the future.

“Old age? Well, my question is: ‘Am I going to be incontinent?’ But I don’t know. I have faith that they’re going to develop stuff...I’m hoping that by the time I get there where I’m really at the incontinent phase that they’ll have something we can do about it.”

The UI Victim Narrative

Two women in this study told compelling stories resembling Frank’s (1995) Chaos narrative in which the teller imagines life never getting better. The UI Victim narratives identified in this study are similar, yet quite different from other narrative types described in the literature or identified in this study. Ms. R., for example, is a victim of men, family members, and society; UI is part of her overall life story. Her memories of UI and many other events in her life are painful. She lives with multiple health problems, yet her narrative rarely includes health care professionals. Instead, she focuses on “abuse” and victimization by men, family members, and society. Despite her trials and tribulations, she has tried to “fix” her UI and tries to maintain energy to “fight it.” In the following example, she talks about some of the possible causes of her UI.

“My incontinence seems to have come on after different procedures after a long period [menses] or certain medications.

Depends sometimes even on the weather or my mental state.

Sometimes it [mental state] makes me more anxious. Makes me tend to lose my control

My bladder sort of slips.

Maybe tinkle a little depending on how upset or how anxious I am.

Maybe just lose it all together sometime.”

As the interview continues Ms. R. opens up, and talks about other significant events in her life. These comments shape the UI Victim narrative with “atypical” explanations for UI. For example, during the second interview, Ms. R. was asked if she could give a title or name to her UI story. Without hesitation, she said: “I’ve been uh, ‘my vagina has been used a lot’ (Laughs). My husband banging on me and never caring about being gentle with me. And mostly I have took it...my vagina’s worn out.” Ms. R.’s experiences with societal abuse are also woven into stories about her life. In this example she was asked if she ever talked to anyone about UI. She responded:

“Never let anybody know a thing like that. They knew you had an incontinence problem along with all the other problems you have “Good God.” See society, I’ll tell you. Society...society thinks you’re more worthless...losing your worth. They want perfect people. That’s their goddamn image. Excuse my language...They want pretty people. They want skinny people. They want people that are not pregnant. Or who don’t have real lives. They want everybody that looks good in the picture. Photogenic in a yearbook. That’s the kind of people they want.”

CB: Not people who are
incontinent?

Ms. R: “Hell no. No way. No way.”

Informants telling UI. Victim narratives may identify strategies to fix or manage UI but in the end, are unable to move toward improvement or wellness, yet their stories show evidence of perseverance to keep living and respond to UI and the interventions health care providers suggest, in very different ways. Previous literature suggests that existing QoL and patient satisfaction questionnaires may be helpful in explaining these differences, yet in other instances, this information is insufficient (Phillips, Zeidman, Thompson, Smith, & Leggett, 1992). It may be that the type of stories patients tell can provide additional possibilities for understanding variations in the clinical presentation of UI, treatment-seeking behaviors, and the impact of UI.

Research is needed on a wider variety of ethnic minority groups, and with non-English speaking women. Important questions remain unanswered; for example, can the impact of UI be adequately assessed and explained via the existing biomedical model for the evaluation and management of UI? To begin to address this, some researchers have suggested a “bother” question be added to pre-existing health-related QoL instruments (Moller, Lose, & Jorgensen, 2000; Robinson et al., 1998). Such a question might illuminate in greater depth the individual impact and meaning of UI, although many questions remain to be explored in future research. For example, it may be that asking women to describe memorable “UI events,” or to “name” their UI story might be more useful than some items on existing QoL instruments. Devoting space and time for narrative inquiry regarding the lived experience of UI is recommended for future clinical practice and research initiatives.

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