Published in final edited form as:

Res Nurs Health. 2011 December ; 34(6): 496–507. doi:10.1002/nur.20457.

Patients' Experiences of Seeking Health Care for Lower Urinary Tract Symptoms

Lisa C. Welch, PhD,

Research Scientist, New England Research Institutes, 9 Galen St. Watertown, MA 02472, Phone: (617) 972-3204, Fax: (617) 926-8246

Simone Taubenberger, PhD, and

Research Scientist, New England Research Institutes, Watertown, MA

Sharon L. Tennstedt, PhD, RN

Vice President, Social and Behavioral Research, New England Research Institutes, Watertown, MA

Lisa C. Welch: LWelch@neriscience.com

Abstract

A gap between experiencing symptoms and receiving effective treatment persists for people with lower urinary tract symptoms (LUTS), even for those who seek health care. In order to better understand how patients experience treatment seeking for LUTS, we interviewed a racially diverse sample of 90 men and women with a range of LUTS about their experiences seeking care. Thematic analysis revealed that patients often disclosed urinary symptoms first to primary care providers during a general examination or a visit for another health problem. Patients seek provider assistance typically when symptoms have intensified or are causing worry, and a desire for treatment trumps potential embarrassment; among women patients, feeling comfortable with a provider also is important for disclosing LUTS.

Keywords

Help seeking; urinary symptoms; primary care; provider/patient communication; qualitative research

Lower urinary tract symptoms (LUTS)—including urinary frequency, urgency, nocturia, hesitancy, incomplete emptying, and leakage—are prevalent, can be costly (Wagner & Hu, 1998; Wilson, Brown, Shin, Luc, & Subak, 2001), and are related to major diseases such as depression, cardiac disease, type II diabetes, and hypertension (Coyne et al., 2009; Fitzgerald, Link, Litman, Trivison, & McKinlay, 2007; Kupelian et al., 2009). Robertson and colleagues (2007) found that the effect of moderate LUTS on quality of life is similar to that of having diabetes, high blood pressure, or cancer, and that the effect of severe LUTS is similar to that of having a heart attack or stroke. Yet, although LUTS are treatable (Dougherty et al., 2002; Harrison & Memel, 1994), many people who experience symptoms do not receive effective treatment.

The gap between experiencing LUTS and receiving treatment persists for two reasons. On the one hand, a number of people who experience LUTS do not seek health care (Kinchen et al., 2003; Peters, Horrocks, Stoddart, & Somerset, 2004; Sexton et al., 2009). Much research

has focused on understanding barriers to seeking health care for urinary symptoms, such as embarrassment, lacking knowledge about symptoms and treatments, and believing urinary symptoms are an inevitable part of aging (Diokno, Sand, Macdiarmid, Shah, & Armstrong, 2006; Nicolson, Kopp, Chapple, & Kelleher, 2008; Shaw, Tansey, Jackson, Hyde, & Allan, 2001). On the other hand, many who do seek health care receive less than optimal care or no treatment at all (Harris, Link, Tennstedt, Kusek, & McKinlay, 2007; Shaw, Das Gupta, Williams, Assassa, & McGrother, 2006). Less is known about the experience of those who seek care and the factors that may contribute to their receiving less than optimal care. To better understand the care-seeking experience with the ultimate goal of enhancing treatment, the aim of this study was to describe (a) reasons patients give for disclosing LUTS to providers; (b) the initial contact with a provider, including type of provider first consulted and the conditions under which patients disclose symptoms; and (c) patients' perspectives on discussing urinary symptoms with a healthcare provider.

Reasons for Disclosing Symptoms

Researchers have found that increasing symptom severity can trigger help-seeking (Andersson, Johansson, Sahlberg-Blom, Pettersson, & Nilsson, 2005; Jacobsen et al., 1993; Sarma, Wallner, Jacobsen, Dunn, & Wei, 2008), but the frequency and severity of symptoms do not fully explain reasons for seeking care (Jacobsen et al., 1993; Kaplan et al., 2009). A review of previous findings indicate a range of reasons for seeking health care for urinary symptoms, including the bother and duration of symptoms (Burgio, Ives, Locher, Arena, & Kuller, 1994; Hannestad, Rortveit, & Hunskaar, 2002), impact on activities and quality of life (Jacobsen et al., 1993; Kinchen et al., 2003; Shaw et al., 2006), social influences such as conversations with friends or awareness of urological issues from media (Kinchen et al., 2003; Pinnock, O'Brien, & Marshall, 1998; Wolters, Wensing, van Weel, van der Wilt, & Grol, 2002), and regularity of utilization of healthcare services and the quality of relationship with the physician (Burgio et al., 1994; Pinnock et al., 1998).

Much of the current knowledge about triggers for care seeking has been focused on specific groups, such as older men (Pinnock et al., 1998; Wolters et al., 2002), older adults with urinary incontinence (Burgio et al., 1994), or women with urinary incontinence (Hannestad et al., 2002; Kinchen et al., 2003). Still unclear is whether these triggers for help seeking hold true across the full range of LUTS or for people from different racial or ethnic backgrounds. To address this, we included in the study reported here a racially and ethnically diverse community sample of men and women with a range of urinary symptoms.

Initial Contact with a Provider

Urologic conditions fall under the purview of both primary and specialty care, but the conditions under which US patients present with urinary symptoms to a specialist or a primary care provider have not been clearly delineated in the literature. Under the structure of managed care, the primary care provider may be a gatekeeper to specialty care; however, some US insurance plans do not require a referral and patients with those plans are allowed to seek initial LUTS care from a specialist. Additional relevant factors for determining the type of provider to whom patients with LUTS will present include symptom type, patient knowledge of potential comorbidities, and whether the patient has received prior specialty treatment for a urologic condition. A patient who associates urinary symptoms with potentially serious comorbidities may present symptoms directly to a specialist, while another patient with the same symptoms may consider them to be less important relative to other conditions (Botelho, Elstad, Taubenberger, & Tennstedt, 2011) and will therefore present symptoms to a general practitioner for advice. To better understand the experience of seeking care for LUTS, more information is needed about the type of provider to whom

most patients disclose their symptoms and the conditions under which patients disclose LUTS to that provider.

Discussing Urinary Symptoms

The importance of patient/provider communication for achieving quality health care is well established (Christen, Alder, & Bitzer, 2008; Mast, 2007). For urinary symptoms, a review of recent literature suggests that primary care providers do not routinely ask patients explicitly about LUTS (Shaw, Atwell, Wood, Brittain, & Williams, 2007; Smith et al., 2011; Wagner & Subak, 2010). Given that LUTS carry a social stigma (Brittain & Shaw, 2007; Elstad, Taubenberger, Botelho, & Tennstedt, 2010; Garcia, Crocker, Wyman, & Krissovich, 2005), providers may expect that patients would find it difficult to communicate these symptoms. Researchers in the UK have shown that general practitioners have concerns that asking about incontinence would cause embarrassment for patients (Shaw et al., 2007), but it is not clear whether such a concern is warranted from the patient's perspective. More information is needed about the patient perspective on talking with a healthcare provider about LUTS.

Method

We conducted a qualitative descriptive study (Sandelowski, 2000) to elicit information about respondents' experiences with seeking health care for LUTS, including (a) reasons for disclosing symptoms, (b) the initial contact with a provider, including type of provider first consulted and the conditions under which patients disclose symptoms; and (c) patients' perspectives on discussing urinary symptoms with a healthcare provider. This study involved stratified random sampling from a representative community sample, semi-structured individual interviewing, and descriptive thematic analysis within content areas of interest.

Participants

Participants in this study were drawn from respondents in the Boston Area Community Health (BACH) Survey. Full details of the BACH study design and implementation have been reported previously (McKinlay & Link, 2007); however, the BACH sampling strategy is relevant to the current study. The BACH Survey was a community-based, random sample epidemiologic survey ($N=5,506$) conducted from 2002 to 2005. In this parent study, researchers utilized a multi-stage stratified cluster design to recruit a diverse sample of men and women from three major US race/ethnic groups (non-Hispanic Black, Hispanic, and non-Hispanic White). Respondents in the BACH Survey answered questions about whether they had experienced a number of urologic symptoms.

For the study reported here, stratified random sampling was used to recruit a subsample of 151 respondents from the BACH sample who had reported ≥ 1 urinary symptom. As previously described (Welch, Botelho, & Tennstedt, 2011), this subsample consisted of approximately equal numbers of men and women aged 34 to 85 years across the three BACH race/ethnic groups (specifically, 25 Black men, 25 Black women, 25 Hispanic men, 25 Hispanic women, 25 White women, and 26 White men). These 151 respondents participated in semi-structured individual interviews during 2007-2008.

Instrument and Procedure

The interview guide was developed based on a literature review and refined with feedback from gender and race/ethnicity stratified focus groups. Fifty-eight respondents participated in a total of eight 90-minute focus groups. All focus groups occurred prior to beginning the one-on-one interviews, data from the focus groups was used only to refine the interview

guide, and no one who participated in focus groups was included in the sample of 151 interview respondents.

Interview respondents participated in a 1-hour, semi-structured interview. Respondents characterized and described their experience with urinary symptoms, their beliefs and attitudes about those symptoms, their strategies for coping and managing the symptoms, and help seeking from family/friends and/or healthcare providers.

Five data collectors (three women and two men) were trained in one-on-one semi-structured interviewing techniques and conducted the interviews. To facilitate participant openness during the interview, interviews were conducted in respondents' homes and in their preferred language (English or Spanish). Interviewers were trained to build rapport with respondents. As part of the study protocol, interviewers emphasized that they were not connected to a healthcare organization or physician but rather were interested in learning respondents' experiences and viewpoints. Interviewers also used probes as needed to ensure that each participant's viewpoint and experiences were understood.

Both the BACH Survey and the 151 follow-up semi-structured interviews were approved by a private Institutional Review Board registered with the Office of Human Research Protections. All respondents provided written informed consent prior to participating. Each participant was assigned a study number to protect confidentiality.

Data Analysis

Interviews were digitally recorded and transcribed verbatim by a professional transcription service. Interviews conducted in Spanish were transcribed and then translated into English by a professional translator. Transcripts were imported into Atlas.ti qualitative analysis software (www.atlasti.com) to facilitate data organization and coding. Analysis was conducted on the English version of interviews.

We began our analysis by developing an initial code list that emerged from the full interview, a process known as “initial coding” (Lofland & Lofland, 1995, p. 192). To enhance the validity of results, three analysts (including ST) developed the initial code list. During this process, the analysts individually coded a subset of transcripts and met to discuss their coding. Differences among analysts were resolved through discussion and consensus. A codebook with the initial codes and their definitions was stored in Atlas.ti, and the analysts applied these codes to another subset of transcripts. Again, analysts met to compare their coding and resolve disagreements through consensus, adding and revising codes as needed. This process was repeated until the analysts agreed on a code list with definitions, and they were applying the codes consistently. The initial code list included codes related to help seeking as well as the other areas raised during the interviews (e.g., attitudes and beliefs, social support, and stigma).

After the initial code list was established, analysts individually coded the remaining transcripts for the full sample of 151 respondents using Atlas.ti. One of these analysts also conducted a portion of the interviews. For cases in which the existing code list did not adequately capture the meaning of the data in a transcript, analysts met to discuss the data and the code list. When codes were added or revised, the process used for developing the initial code list (i.e., multiple analysts discussing the coding and coming to consensus) was repeated until agreement was reached.

Following open coding, a single analyst (LCW) developed and applied detailed sub-codes. Because this analysis was focused on experiences of seeking health care for LUTS, sub-codes focused on the subsample of respondents who had sought health care ($n=90$) in order

to identify the reason for disclosing symptoms, the provider with whom the patient first spoke about LUTS, who initiated the conversation (patient or provider), and the ease or difficulty of communication. At this stage, the analyst engaged in “focused coding” (Lofland & Lofland, 1995, p. 192) by elaborating the codes that were being used more often. A single analyst engaged in developing sub-codes and focused coding to enhance consistency.

The analyst who conducted sub-coding and focused coding proceeded with thematic analysis within content areas of interest. For the identified content areas of interest, the frequencies of the most commonly occurring codes were identified and compared across gender, race/ethnic group, and SES. To develop themes within content areas, quotations were examined to elicit the meaning of each category.

Several steps were taken to enhance the credibility of the interpretation. Following Silverman (Silverman, 2004) the analysis included all transcripts and cases that deviated from the main trends. The analysis also included tabulations to demonstrate the extent of the trends. In addition, the interpretation focused on developing findings that are applicable to real settings (Corbin & Strauss, 2008), in this case the healthcare setting.

Results

Overall, 90 of 151 respondents (60%) reported that they had “talked with a doctor, nurse, or some other kind of healthcare professional” about their urinary symptoms. As detailed in Table 1, the sample of 90 respondents consisted of roughly equal numbers of men and women (49 and 41, respectively) distributed fairly evenly across racial and ethnic backgrounds (33 non-Hispanic Black, 29 Hispanic, and 28 non-Hispanic White respondents), with a range of ages within each group. Respondents in the sample reported a range of urinary symptoms at varying levels of severity.

Reasons for Disclosing Symptoms

Across the full sample, the most common reasons for disclosing symptoms included symptom severity (42%); perceived bother or impact on activities (28%); worry due to symptoms (22%), particularly a fear that symptoms indicated another health problem; and symptom persistence (10%; Table 2). Less common reasons for disclosure included following someone else's advice to see a provider about symptoms (2%), having a pattern of telling providers about all new symptoms (4%), and discussing side effects of treatment for another comorbid condition (1%).

Symptoms “got out of hand”—Those who reported symptom severity as the reason for disclosure described a period leading up to disclosure in which symptoms worsened to a point that “things got out of hand” (74-year-old Black man) or “it was an emergency” (53-year-old Hispanic woman). For example, when asked what happened that led her to seek health care for LUTS, a 54-year-old Black woman explained, “Well, probably the night before I had to see the doctor I probably had to go to the bathroom...10 or 15 times. Some nights I have to go very often; I mean, very often.” A 69-year-old White man said, “Oh, Lord! I didn't even mention it [to my doctor] for a couple of years. I've only mentioned it in the last year when it really got bad.”

The impact became bothersome—The second most common reason for disclosure was that symptoms had intensified enough to cause bother or interfere with their activities. This reason was given more often by women than men (35% vs. 21%, respectively) and by White respondents compared to Hispanic or Black respondents (40% vs. 27% and 18%, respectively). For example, a 79-year-old White woman explained, “I don't sleep well now. The most I can sleep is 2 hours every time because I have to get up and go to the bathroom.

... So during the day I feel kind of sluggish. ...It's a nuisance to me, [and] I went to the doctor." Another White woman (77 years old) said that she wanted to talk to her doctor again about her symptoms "because like you can't go out. You can't go someplace." Similarly, a 73-year-old White man explained that he sought health care after he felt "really annoyed" by his urinary urgency. In his words, "Well, basically, I was sitting in the movies, and I'd experienced [urgency] before, but [this time] I was not sitting somewhere where I was near a john. And that convinced me that this is something I've got to find out about."

Worry that symptoms indicated a "serious" problem—About one-fifth of respondents identified worry over their symptoms as the reason for seeking health care, and this response was somewhat more common for men (26%) than women (16%). Although one respondent reported that a worry about symptoms worsening led her to seek help, the most common cause of worry was the fear that urinary symptoms indicated a serious health problem. Among men who identified worry as the reason for seeking help, most named a particular condition about which they were concerned, most commonly cancer or prostate problems. In contrast, women who identified worry as the reason for seeking help typically described a more general concern that "there's something seriously wrong."

Symptoms did not subside—A smaller group of respondents (10%) reported that the persistence of their symptoms led them to consult a provider. This reason for disclosure was more common for Black respondents than Hispanic or White respondents (25% vs. 0% and 4%, respectively). For example, a 45-year-old Black woman who experienced incomplete emptying explained that she consulted her doctor after waiting to "see whether it'd go away, but it didn't." A 57-year-old Black man who had experienced urinary frequency for 5-6 years explained that he consulted his doctor about his symptoms because "it's an ongoing thing. It's always there. It's not like, you know, today it might be bad, but tomorrow it's going to be better. ...It's like constantly staying with me as years go by."

Interpreting symptoms in the context of diabetes—A thread running through the four main reasons for disclosure was the interpretation of symptoms in the context of diabetes. This was more common among Black and Hispanic respondents, which was consistent with the sample composition, as most of the respondents who reported having diabetes were Black or Hispanic (22 of 26 respondents). For example, a 52-year-old Hispanic man explained that he initially interpreted his frequent urination in relation to diabetes. As he observed, "Well, I'd lie down and I'd have to go to the bathroom about 15 minutes later, then another 15 minutes later and so on. ...I said, 'No, this isn't normal; this can't be my diabetes, because my diabetes is under control.' ...So, I went to the doctor." When having diabetes was not a sufficient explanation for symptoms, health care was sought.

Even among those without a diagnosis of diabetes, concern that urinary symptoms were a sentinel for diabetes could prompt help seeking. As a 53-year-old Black man with frequent urination and nocturia explained, "I drink a lot of water and I pee a lot. I mean at one time I thought I had sugar diabetes. I took tests of it; I don't have it. ...And sugar diabetes do run through my family."

Initial Contact with a Provider

The vast majority of respondents across the sample (84%) initially sought health care for their urinary symptoms from a primary care physician or nurse. Among the 15% of respondents who consulted a specialist initially, men sought care from urologists and women most often spoke with gynecologists. Hispanic women more often than Black or White

women initially sought care from a specialist, usually a gynecologist (31% vs. 7% and 16%, respectively).

Two-thirds of the respondents (67%) visited a provider for a primary reason other than LUTS when they first discussed their urinary symptoms. Urinary symptoms were the reason for the visit for a third of patients, but the visit most often was a routine examination or physical (43%), and a sizeable proportion (24%) brought up urinary symptoms during a visit for another health issue. As a result, the majority of patients raised their urinary symptoms in a context in which providers were also considering other health issues rather than these symptoms being the reason for the visit.

Taking advantage of the opportunity—Respondents who raised their urinary symptoms with a provider during a routine examination typically explained that they “took the opportunity” to tell the provider about LUTS in the midst of the exam. For example, a 45-year-old Black woman with urinary frequency and urgency expressed the idea in this way: “It was just a general physical, and she wants to know anything I needed, [that] she could assist me with. And that was one thing.”

LUTS “came up” during a health care visit—Similarly, respondents who presented their urinary symptoms during a visit for another health problem typically explained that LUTS “came up” as one of a number of symptoms they were experiencing (e.g., multiple symptoms of diabetes) or in conjunction with taking a history of another condition. For example, as a 70-year old White man with frequent urination explained, “I didn't really seek help for that. I went to the clinic. I was getting these nose bleeds, ...and they found out I had high blood pressure. ...And, during the conversation in the physical [exam], the urination thing came up.”

Presenting symptoms in a context in which other issues are being considered may influence the attention received for those symptoms. That is, under conditions of managing a variety of issues involved in a complete physical examination or of seeking a diagnosis for a set of symptoms, urinary symptoms may not receive full attention. For example, a 76-year-old White woman with nocturia explained that her doctor “paid attention for my high blood pressure and other problems, but not really for this [nocturia].”

Discussing Urinary Symptoms

Ninety percent of respondents reported that they initiated the discussion with their providers about LUTS. A similar proportion of respondents (89%) reported that it was “not difficult” to talk with their providers about their urinary symptoms. The ease of talking with providers was somewhat surprising given the social stigma that may accompany LUTS.

It's for my own good—Respondents across all subgroups explained that the search for effective treatment trumped any potential embarrassment when talking with their providers. For example, when asked how she felt while talking with her provider about urinary symptoms, a 61-year old White woman who experienced both urinary urgency and straining to void said, “It was not a problem at all. ...You have to get behind some false modesty factor and cut to the chase and get things resolved.” A 44-year-old Hispanic man explained that it was not difficult to talk with his provider about his urinary frequency “...because really I can't hide anything from him because it's for my own good.” Similarly, a 60-year-old Black man with urinary frequency said, “It's my health. I felt just fine. ...I wanted to make sure that if there was an issue, I wanted to catch it early, not late.”

The patient/provider relationship engendered comfort—For women, the patient/provider relationship was an additional important factor for their comfort level when discussing urinary symptoms. Many women explained that it was easy for them to discuss LUTS because their doctors were “nice” or “concerned.” For example, a 69-year-old White woman with daytime frequency and nocturia said, “...when you go in to her it's like talking to your best friend.” A 47-year-old Black woman with incontinence explained, “My doctor's great. ...If I have anything, I can go right to him...And he's patient and [has a] good bedside manner, and he listens to you...and what you want, and how you feel and everything.” For these and other women, having a relationship with a doctor in which they felt comfortable and listened to was central for how they described seeking help for LUTS.

In addition, women (particularly Hispanic women) more commonly than men said that the gender of the provider was important for feeling comfortable discussing LUTS. Among those who expressed a preference for the gender of the provider, all but one respondent felt more comfortable with a woman doctor for urinary symptoms. A 59-year old Hispanic woman offered a typical sentiment, “Well, I feel okay [talking with the doctor] because she's a woman, not a man doctor. ...[For] another issue, I don't mind a man doctor; but for this issue, for me, I feel comfortable with a woman doctor.”

Discussion

The findings of this study extend knowledge about patients' perspectives on seeking care for LUTS in multiple ways. First, the finding of the most common reasons for disclosing symptoms confirmed prior research about the triggers for seeking health care for urinary symptoms. The diversity of this sample in terms of the range of urinary symptoms as well as race and ethnic background demonstrated that that previously established reasons for seeking care extend across the full range of LUTS and for different race/ethnic groups.

Second, across social groups, most patients who seek care for LUTS disclose their symptoms to a primary care provider in the context of a general physical or a visit for another health problem. As a result, LUTS often are raised in a time-limited setting in which many other issues and comorbidities are being considered. Presenting symptoms in this context may partially explain why many who seek care for LUTS receive less than optimal care or no treatment at all (Harris et al., 2007; Shaw et al., 2006). More research is needed to understand current primary care processes for prioritizing LUTS for treatment in relation to other conditions and symptoms.

Studies demonstrating that LUTS are prevalent, associated with comorbidities (Coyne et al., 2009; Fitzgerald et al., 2007; Kupelian et al., 2009), and treatable provide a solid evidence base for the recommendation that primary care providers adopt direct query about urinary symptoms as a standard care practice (Easton, 2010). Furthermore, a recent intervention to encourage primary care providers to screen for and treat incontinence among older patients has been effective in increasing levels of recommended care (Wenger et al., 2010). Results from this study indicate that similar interventions for primary care of adults across the lifespan would need to address how providers manage and prioritize multiple symptoms and conditions.

Third, the relationship between LUTS and comorbid conditions such as heart disease (Kupelian et al., 2009) underscores the need for medical education for primary care providers to continue to emphasize addressing urinary symptoms in the context of a patient's overall health status and potentially screening for undiagnosed conditions. For example, the importance of screening for diabetes at the presentation of urinary symptoms has been emphasized for urologists (Goldstraw, Kirby, Bhardwa, & Kirby, 2007), but respondents in

this community sample most commonly presented to a primary care provider. Further, in patients diagnosed with diabetes, it is important to follow up about urinary symptoms. Given that some patients in this sample (particularly Black and Hispanic respondents) interpreted urinary symptoms in the context of diabetes, patients may continue to have urinary symptoms related to other etiologies but not re-report those symptoms because they think that they are diabetes-related polyuria (Hill, Fayyad, & Jones, 2008).

Fourth, providers should be aware that when a patient raises the issue of LUTS, s/he likely has been experiencing an intensification of symptoms or worry associated with symptoms. Although men as well as Black and Hispanic respondents may be less likely to raise the issue of urinary symptoms because of bother or impact on activities, this does not necessarily mean that they are not experiencing bother or an impact on their activities. In addition, Black and Hispanic patients, who suffer from diabetes at higher rates (National Diabetes Information Clearinghouse, 2008), appear more commonly to worry that their urinary symptoms could be the initial presentation of or connected to their diagnosed diabetes mellitus.

Finally, and somewhat surprising, most treatment seekers did not experience communicating about their symptoms as difficult. Whereas providers may be reluctant to discuss LUTS for fear of embarrassing a patient, treatment seekers reported that their goal of finding relief trumped any potential embarrassment. Building on prior research that showed a lack of embarrassment to be a factor associated with treatment seeking (Kinchen et al., 2003), the results of this study indicate that many patients may be more willing to discuss LUTS than previously acknowledged. Providers need not hesitate to discuss urinary symptoms for fear of patients feeling uncomfortable.

For women, a comfortable patient/provider relationship was important for discussing urinary symptoms. This reinforces the need to listen carefully and responsively to patient complaints—even those that may be a lower priority on a problem list—so as to maintain an open line of communication. Because women (particularly Hispanic women) more often than men reported that the provider's gender affected their level of comfort for discussing LUTS, providers might consider presenting the option of patients talking with an associate of their preferred gender about urinary issues. The importance among Hispanics of trust and personalized care for seeking help (Larkey, Hecht, Miller, & Alatorre, 2001; Martinez, Maislos, & Rayford, 2008) and disclosure of medical information (Julliard et al., 2008) appear to intersect with the gender of the provider in the case of LUTS.

Limitations and Future Research Directions

An important limitation of this study is that it does not include the provider's perspective. Future research is needed to investigate how providers—particularly primary care providers—perceive the initial help-seeking discussion about LUTS. Specifically, how do providers prioritize LUTS during a visit for a physical or a different health problem? A direct examination of this question would enhance understanding of how providers respond to patient-initiated discussions about urinary symptoms and, if appropriate, would inform medical education.

Given the focus on those who seek help, this study does not reflect the viewpoints of people with LUTS who do not seek health care. As a result, the finding that communication with a healthcare provider about LUTS was not difficult for most respondents is limited to those who raised their symptoms during an office visit. Those who do not seek help may find raising the topic of urinary symptoms with a provider to be difficult or stigmatizing, as a review of prior research indicates. Additional research about reasons for not seeking health care for LUTS should include diverse samples, including race and ethnic background

(Welch et al., 2011), as this may reveal differences across social groups such as those identified here.

In addition, as is common with interview-based research, data from this study is retrospective in nature. As a result, respondents' memories about how they felt when initiating a discussion about urinary symptoms with their providers may differ somewhat from their feelings at the time of that discussion. Still, it seems important for providers to know that patients in this study who raised the topic of urinary symptoms did not remember their discussions to be difficult or uncomfortable. In addition to confirming this finding in a larger sample, future research should examine the comfort level of providers in discussing this stigmatized condition with patients.

Conclusion

We explored the experience of seeking health care for LUTS to better understand the persistent gap between experiencing these symptoms and receiving effective treatments. Treatment seekers typically disclosed their urinary symptoms first to a primary care provider during a visit for a general examination or another health problem. This context in which symptoms commonly are raised suggests that LUTS may not receive full attention. In addition, this study provides information for primary care providers regarding patients' perspectives about disclosing their urinary symptoms. For patients who seek health care for LUTS, symptoms typically have intensified or are causing worry, and a desire for treatment trumps potential embarrassment; among women, feeling comfortable with a provider also is important for facilitating discussion about urinary symptoms.

Acknowledgments

The authors thank Elizabeth M. Botelho, M.S., and Jean Journal Joseph, B.A./B.S., for their assistance with data collection and coding the transcripts. The project was supported by Grant Number DK073835 from the National Institute of Diabetes and Digestive and Kidney Diseases. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Institute of Diabetes and Digestive and Kidney Diseases or the National Institutes of Health.

References

- Andersson G, Johansson JE, Sahlberg-Blom E, Pettersson N, Nilsson K. Urinary incontinence--why refraining from treatment? A population based study. *Scandinavian Journal of Urology and Nephrology*. 2005; 39:301–307. [PubMed: 16118105]
- Botelho EM, Elstad EA, Taubenberger SP, Tennstedt S. Moderating perceptions of bother reports by individuals experiencing lower urinary tract symptoms. *Qualitative Health Research*. 2011 April 11, (Epub ahead of print). 10.1177/1049732311405682
- Brittain KR, Shaw C. The social consequences of living with and dealing with incontinence--a carer's perspective. *Social Science & Medicine*. 2007; 65:1274–1283. [PubMed: 17509743]
- Burgio KL, Ives DG, Locher JL, Arena VC, Kuller LH. Treatment seeking for urinary incontinence in older adults. *Journal of the American Geriatrics Society*. 1994; 42:208–212. [PubMed: 8126338]
- Christen RN, Alder J, Bitzer J. Gender differences in physicians' communicative skills and their influence on patient satisfaction in gynaecological outpatient consultations. *Social Science & Medicine*. 2008; 66:1474–1483. [PubMed: 18222586]
- Corbin, J.; Strauss, A. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. 3. Thousand Oaks, CA: Sage; 2008.
- Coyne KS, Sexton CC, Thompson CL, Milsom I, Irwin D, Kopp ZS, et al. Wein AJ. The prevalence of lower urinary tract symptoms (LUTS) in the USA, the UK and Sweden: Results from the Epidemiology of LUTS (EpiLUTS) study. *British Journal of Urology International*. 2009; 104:352–360.

- Diokno AC, Sand PK, Macdiarmid S, Shah R, Armstrong RB. Perceptions and behaviours of women with bladder control problems. *Family Practice*. 2006; 23:568–577. [PubMed: 16731545]
- Dougherty MC, Dwyer JW, Pendergast JF, Boyington AR, Tomlinson BU, Coward RT, et al. Rooks LG. A randomized trial of behavioral management for continence with older rural women. *Research in Nursing & Health*. 2002; 25:3–13. [PubMed: 11807915]
- Easton WA. Overactive bladder symptoms in women: Current concepts in patient management. *The Canadian Journal of Urology*. 2010; 17(Suppl 1):12–17. [PubMed: 20170596]
- Elstad EA, Taubenberger SP, Botelho EM, Tennstedt SL. Beyond incontinence: The stigma of other urinary symptoms. *Journal of Advanced Nursing*. 2010; 66:2460–2470. [PubMed: 20735505]
- Fitzgerald MP, Link CL, Litman HJ, Trivison TG, McKinlay JB. Beyond the lower urinary tract: The association of urologic and sexual symptoms with common illnesses. *European Urology*. 2007; 52:407–415. [PubMed: 17382458]
- Garcia JA, Crocker J, Wyman JF, Krissovich M. Breaking the cycle of stigmatization: Managing the stigma of incontinence in social interactions. *Journal of Wound Ostomy and Continence Nursing*. 2005; 32:38–52.
- Goldstraw MA, Kirby MG, Bhardwa J, Kirby RS. Diabetes and the urologist: A growing problem. *British Journal of Urology International*. 2007; 99:513–517.
- Hannestad YS, Rortveit G, Hunskaar S. Help-seeking and associated factors in female urinary incontinence. The Norwegian EPINCONT Study. *Epidemiology of Incontinence in the County of Nord-Trondelag. Scandinavian Journal of Primary Health Care*. 2002; 20:102–107. [PubMed: 12184708]
- Harris SS, Link CL, Tennstedt SL, Kusek JW, McKinlay JB. Care seeking and treatment for urinary incontinence in a diverse population. *The Journal of Urology*. 2007; 177:680–684. [PubMed: 17222656]
- Harrison GL, Memel DS. Urinary incontinence in women: Its prevalence and its management in a health promotion clinic. *British Journal of General Practice*. 1994; 44:149–152. [PubMed: 8185987]
- Hill SR, Fayyad AM, Jones GR. Diabetes mellitus and female lower urinary tract symptoms: A review. *Neurourology and Urodynamics*. 2008; 27:362–367. [PubMed: 18041770]
- Jacobsen SJ, Guess HA, Panser L, Girman CJ, Chute CG, Oesterling JE, et al. Lieber MM. A population-based study of health care-seeking behavior for treatment of urinary symptoms. The Olmsted County Study of Urinary Symptoms and Health Status Among Men. *Archives of Family Medicine*. 1993; 2:729–735. [PubMed: 8111497]
- Julliard K, Vivar J, Delgado C, Cruz E, Kabak J, Sabers H. What Latina patients don't tell their doctors: A qualitative study. *Annals of Family Medicine*. 2008; 6:543–549. [PubMed: 19001307]
- Kaplan SA, Roehrborn CG, Chapple CR, Rosen RC, Irwin DE, Kopp Z, et al. Mollon P. Implications of recent epidemiology studies for the clinical management of lower urinary tract symptoms. *British Journal of Urology International*. 2009; 103(Suppl 3):48–57.
- Kinchen KS, Burgio K, Diokno AC, Fultz NH, Bump R, Obenchain R. Factors associated with women's decisions to seek treatment for urinary incontinence. *Journal of Women's Health*. 2003; 12:687–698.
- Kupelian V, Rosen RC, Link CL, McVary KT, Aiyer LP, Mollon P, et al. McKinlay JB. Association of urological symptoms and chronic illness in men and women: Contributions of symptom severity and duration--results from the BACH Survey. *The Journal of Urology*. 2009; 181:694–700. [PubMed: 19091335]
- Larkey LK, Hecht ML, Miller K, Alatorre C. Hispanic cultural norms for health-seeking behaviors in the face of symptoms. *Health Education & Behavior*. 2001; 28:65–80. [PubMed: 11213143]
- Lofland, J.; Lofland, LH. *Analyzing social settings: A guide to qualitative observation and analysis*. Belmont, CA: Wadsworth; 1995.
- Martinez M, Maislos S, Rayford W. How to engage the Latino or African American patient with benign prostatic hyperplasia: Crossing socioeconomic and cultural barriers. *American Journal of Medicine*. 2008; 121(8 Suppl 2):S11–S17. [PubMed: 18675612]
- Mast MS. On the importance of nonverbal communication in the physician-patient interaction. *Patient Education and Counseling*. 2007; 67:315–318. [PubMed: 17478072]

- McKinlay JB, Link CL. Measuring the urologic iceberg: Design and implementation of the Boston Area Community Health (BACH) Survey. *European Urology*. 2007; 52:389–396. [PubMed: 17383808]
- National Diabetes Information Clearinghouse. National diabetes statistics, 2007. Bethesda, MD: National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health; 2008.
- Nicolson P, Kopp Z, Chapple CR, Kelleher C. It's just the worry about not being able to control it! A qualitative study of living with overactive bladder. *British Journal of Health Psychology*. 2008; 13(Pt 2):343–359. [PubMed: 17535499]
- Peters TJ, Horrocks S, Stoddart H, Somerset M. Factors associated with variations in older people's use of community-based continence services. *Health & Social Care in the Community*. 2004; 12:53–62. [PubMed: 14675365]
- Pinnock C, O'Brien B, Marshall VR. Older men's concerns about their urological health: A qualitative study. *Australian and New Zealand Journal of Public Health*. 1998; 22(3 Suppl):368–373. [PubMed: 9629824]
- Robertson C, Link CL, Onel E, Mazzetta C, Keech M, Hobbs R, et al. McKinlay JB. The impact of lower urinary tract symptoms and comorbidities on quality of life: The BACH and UREPIK studies. *British Journal of Urology International*. 2007; 99:347–354.
- Sandelowski M. Whatever happened to qualitative description? *Research in Nursing & Health*. 2000; 23:334–340. [PubMed: 10940958]
- Sarma AV, Wallner L, Jacobsen SJ, Dunn RL, Wei JT. Health seeking behavior for lower urinary tract symptoms in Black men. *The Journal of Urology*. 2008; 180:227–232. [PubMed: 18499182]
- Sexton CC, Coyne KS, Kopp ZS, Irwin DE, Milsom I, Aiyer LP, et al. Wein AJ. The overlap of storage, voiding and postmicturition symptoms and implications for treatment seeking in the USA, UK and Sweden: EpiLUTS. *British Journal of Urology International*. 2009; 103(Suppl 3):12–23.
- Shaw C, Atwell C, Wood F, Brittain K, Williams K. A qualitative study of the assessment and treatment of incontinence in primary care. *Family Practice*. 2007; 24:461–467. [PubMed: 17670805]
- Shaw C, Das Gupta R, Williams KS, Assassa RP, McGrother C. A survey of help-seeking and treatment provision in women with stress urinary incontinence. *British Journal of Urology International*. 2006; 97:752–757.
- Shaw C, Tansey R, Jackson C, Hyde C, Allan R. Barriers to help seeking in people with urinary symptoms. *Family Practice*. 2001; 18:48–52. [PubMed: 11145628]
- Silverman, D. *Doing qualitative research*. 2. Thousand Oaks, CA: Sage; 2004.
- Smith AL, Nissim HA, Le TX, Khan A, Maliski SL, Litwin MS, et al. Anger JT. Misconceptions and miscommunication among aging women with overactive bladder symptoms. *Urology*. 2011; 77:55–59. [PubMed: 20970839]
- Wagner TH, Hu TW. Economic costs of urinary incontinence in 1995. *Urology*. 1998; 51:355–361. [PubMed: 9510336]
- Wagner TH, Subak LL. Talking about incontinence: The first step toward prevention and treatment. *JAMA*. 2010; 303:2184–2185. [PubMed: 20516420]
- Welch LC, Botelho EM, Tennstedt SL. Race and ethnic differences in health beliefs about lower urinary tract symptoms. *Nursing Research*. 2011; 60:165–172. [PubMed: 21522033]
- Wenger NS, Roth CP, Hall WJ, Ganz DA, Snow V, Byrkit J, et al. Reuben DB. Practice redesign to improve care for falls and urinary incontinence: Primary care intervention for older patients. *Archives of Internal Medicine*. 2010; 170:1765–1772. [PubMed: 20975026]
- Wilson L, Brown JS, Shin GP, Luc KO, Subak LL. Annual direct cost of urinary incontinence. *Obstetrics and Gynecology*. 2001; 98:398–406. [PubMed: 11530119]
- Wolters R, Wensing M, van Weel C, van der Wilt GJ, Grol RP. Lower urinary tract symptoms: Social influence is more important than symptoms in seeking medical care. *British Journal of Urology International*. 2002; 90:655–661.

Table 1

Sample Description[†]

	All		Men		Women		
	Black	White	Black	Hispanic	White	Black	Hispanic
	n=19	n=15	n=15	n=14	n=13	n=14	n=13
Age (years)							
Mean	58.9	60.3	52.5	64.4	57.2	62.7	58.9
Range	37-84	40-79	37-73	39-84	43-81	40-75	36-80
Urinary Symptoms^{††}							
Urinary incontinence	29 (32%)	4 (21%)	2 (13%)	1 (7%)	5 (36%)	8 (57%)	9 (69%)
Frequency	69 (77%)	17 (89%)	11 (73%)	14 (93%)	7 (50%)	10 (71%)	10 (77%)
Nocturia	38 (42%)	9 (47%)	10 (67%)	7 (47%)	3 (21%)	3 (21%)	6 (46%)
Urgency	38 (42%)	6 (32%)	11 (73%)	6 (40%)	4 (29%)	6 (43%)	5 (38%)
Incomplete emptying	7 (8%)	2 (11%)	3 (20%)	1 (7%)	1 (7%)	0 (0%)	0 (0%)

[†]The race/ethnicity categories are mutually exclusive. Participants included in the Black and White categories did not report Hispanic ethnicity, and all participants who reported Hispanic ethnicity (regardless of racial category) are included in the Hispanic category.

^{††}Some respondents reported more than one symptom

Table 2
Initial Contact and Communication with a Healthcare Provider by Gender and Race

	All [†]	Gender		Race		
		Men	Women	Black	Hispanic	White
Reason(s) for disclosure ^{††}	n=79	n=42	n=37	n=28	n=26	n=25
Symptom severity	33 (42%)	16 (38%)	17 (46%)	11 (39%)	11 (42%)	11 (44%)
Symptom persistence	8 (10%)	6 (14%)	2 (5%)	7 (25%)	0 (0%)	1 (4%)
Bother / impact	22 (28%)	9 (21%)	13 (35%)	5 (18%)	7 (27%)	10 (40%)
Worry	17 (22%)	11 (26%)	6 (16%)	7 (25%)	6 (23%)	4 (16%)
Type of provider	n=83	n=44	n=39	n=32	n=25	n=26
Primary care	70 (84%)	39 (89%)	31 (79%)	28 (88%)	20 (80%)	22 (85%)
Specialist	12 (15%)	5 (11%)	7 (18%)	3 (9%)	5 (20%)	4 (15%)
Hospital	1 (1%)	0	1 (3%)	1 (3%)	0	0
Reason for visit	n=81	n=45	n=36	n=31	n=28	n=22
General / physical	35 (43%)	16 (36%)	19 (53%)	15 (48%)	11 (39%)	9 (41%)
Non-urinary problem	19 (24%)	12 (27%)	7 (19%)	9 (29%)	6 (21%)	4 (18%)
Urinary symptoms	27 (33%)	17 (38%)	10 (28%)	7 (23%)	11 (39%)	9 (41%)
Conversation initiator	n=77	n=43	n=34	n=28	n=24	n=25
Patient	69 (90%)	39 (91%)	30 (88%)	26 (93%)	21 (88%)	22 (88%)
Communication	n=84	n=43	n=41	n=32	n=26	n=26
Not difficult	75 (89%)	40 (93%)	35 (85%)	30 (94%)	22 (85%)	23 (88%)

[†] Sub-samples include respondents who addressed each topic.

^{††} Some respondents indicated more than one reason for disclosure. As a result, the sum of the number of respondents reporting each reason for disclosure is greater than the total number of respondents who addressed the topic in some way in each group (n). Percentages reflect the number of respondents reporting each reason out of the total number of respondents who addressed the topic in each group (n).