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Reasons for Seeking Clinical Care for Lower Urinary Tract Symptoms: A Mixed-Methods Study

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Abstract

Purpose—The primary objective of this study was to evaluate reasons for seeking care among men and women with lower urinary tract symptoms (LUTS).

Methods—Participants were recruited from urology and urogynecology clinics, and the community. The sample was enriched with persons expected to have abnormal or diminished bladder sensations (e.g., participants with lower back surgery, participants aged 65+). In-person interviews were conducted, beginning with an open-ended assessment of urinary symptoms and associated bother, followed by more directed questions, including reasons for seeking or not seeking treatment. We also examined the relationship between symptom frequency and bother using the LUTS Tool.

Results—A total of 88 participants (38 men, 50 women) with *mean [standard deviation]* age=52.2 [14.3] years provided information about their urinary symptoms, including a range of quality-of-life consequences and coping behaviors. They sought treatment mostly because of new, continuing, or bothersome symptoms. Factors associated with not seeking treatment included low symptom severity and concerns about the costs versus benefits of treatment (e.g., side effects of

medication). Symptom frequency and bother were associated with each other across symptoms assessed by the LUTS Tool.

Conclusions—In this large qualitative study, we obtained useful insights into the impact of LUTS from the perspective of the person with the symptoms. Removing barriers and misconceptions about treatment of LUTS may increase the number of people who seek clinical care and improve the clinical course of men and women who experience LUTS.

Keywords

urinary; bladder; severity; bother; quality of life

INTRODUCTION

Lower urinary tract symptoms (LUTS) are bothersome,¹ have adverse effects on health-related quality of life (HRQOL), and result in diminished functioning and productivity.² Among people who report having LUTS, some seek care, whereas others do not.³ Understanding why certain people elect to seek or not seek care is important for assessing the degree of unmet needs and devising interventions to ensure that those who might be helped receive care. This study used mixed methods to better understand reasons for seeking or not seeking treatment for LUTS.

Prior research, across various populations, has suggested that those who seek care for LUTS are motivated by the severity, bother, interference of symptoms with daily activity, and media influence.^{4–9} Barriers to seeking treatment for LUTS have also been identified, including doctors not asking about symptoms, financial issues such as delays in receiving reimbursement for out-of-pocket expenses, embarrassment, lack of awareness of treatment options, and viewing the symptoms as part of a normal life.^{10–14}

Prior studies on treatment-seeking behavior for LUTS have included quantitative research and qualitative research that used one-on-one interviews or focus groups. Previous qualitative studies suggest that the HRQOL impact of LUTS, and fears that LUTS may be indicative of more serious illness (e.g., cancer), contribute to seeking or not seeking care.¹⁵ Moreover, qualitative studies have suggested studying both symptom frequency and bother,¹⁶ and have also examined barriers to care. For example, a study showed that 18 men ages 52 and 80 with LUTS were motivated to seek care by three things: 1) reassurance about not having prostate cancer; 2) symptom bother (e.g., nocturia); and 3) seeing public information about LUTS.¹⁷ In a phone-interview study of 30 women with incontinence, the most common reason for not seeking care was viewing the problem as too small to warrant attention.¹⁸

We sought to understand care-seeking behaviors using data obtained through qualitative interviews and questionnaires from people with LUTS recruited from the community and the clinic. The data were collected as part of a questionnaire development process conducted by the Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN), which was established in 2012 to identify clinically important subtypes of LUTS in women and men

and improve the measurement of self-reported LUTS.¹⁹ The goal of the study was to describe reasons for, and for not, seeking care for LUTS.

METHODS

The data reported were collected as part of a larger study conducted by the LURN to understand how women and men describe their LUTS in order to develop novel self-report measures of LUTS.¹⁹ The protocol was approved by the Institutional Review Boards at the participating recruitment sites and the Data Coordinating Center at Arbor Research Collaborative for Health. All participants provided written informed consent.

Participants

Participants were recruited from four institutions: Northwestern University, NorthShore University Health System, University of Iowa, and Duke University. Community participants were recruited by online advertisements (e.g., Craigslist). Eligibility criteria included: 1) self-report of one or more LUTS based on a phone-based screening assessment; 2) willingness and ability to provide written informed consent; 3) age ≥ 18 years; and 4) able to speak and read English. To be eligible for the study, the participant had to report one or more LUTS from a phone-screening list that included storage, voiding, and post-micturition symptoms. The sample size for a qualitative study is based on the need to achieve thematic saturation, which means that no new themes would emerge if additional participants were included.²⁰

We sought to recruit at least 30 clinic-recruited participants and at least 30 community participants, split evenly by sex. Because the LURN wishes to understand subtypes related to bladder sensation, we sought to recruit at least 16 additional individuals deemed at high risk for abnormal, diminished, or absence of bladder sensation. The purpose of the sensory group was to explore novel symptoms (including diminished bladder sensations) and further diversify the sample. Because this group was targeted for other purposes within the LURN, we did not have specific hypotheses about them in terms of treatment-seeking and did not analyze these participants separately. This group included people who were aged 65 years or older, had lower back surgery, and/or uncontrolled diabetes (e.g., diagnosed, but the person was not adhering to treatment), and/or women with a vaginal childbirth, and/or radical hysterectomy. The three groups of participants (community, clinical, and sensory) were included to ensure that we had a diverse sample, not necessarily to make group-based comparisons. We sought to enroll at least 25% non-white participants (19 participants).

Procedures

Those who agreed to participate in the study were scheduled for an in-person interview with a trained member of the project staff. All interviewers were trained via didactic learning sessions and role-playing. The training included webinars about general interviewing skills, as well as open- and closed-ended questions in qualitative interviews. Interviewers had to demonstrate competence in role plays before conducting interviews in the study. Interviews were recorded and transcribed for analysis and ongoing weekly supervision to ensure quality and consistency. Following the interview, participants completed the LUTS Tool²¹ to

provide a standardized assessment of their LUTS in terms of symptom frequency and related bother. Consistent with past studies, the LUTS Tool was analyzed at the individual item level.

Qualitative Interview

Qualitative interviews were conducted in private rooms. The portion of the interview we report in this paper focused on whether the participant had sought treatment for their LUTS, and their reasons for seeking or not seeking treatment. The wording of the question was “Have you sought care or treatment for any of the symptoms that we have discussed today (give examples if needed)?”. The interviewer was prompted to record information as follows: “Depending on response, query about why or why not. Document all of the reasons.” The first part of the qualitative interview focused on specific urinary symptoms that the participant experienced, along with related concerns the participant had regarding their urinary symptoms. Participants then described the onset and duration of their symptoms, bother, and how their symptoms changed over time. The next part of the interview focused on what factors make their symptoms better or worse and what behaviors they use to cope (e.g., voiding before a long car journey). An initial set of codes (i.e., reasons for seeking/not seeking care) was developed based on an initial review of the transcripts, and codes were added to the list as needed based on further review of transcripts.

Data Analysis

Participant characteristics, including responses to the LUTS Tool items, were summarized using traditional descriptive statistics. Qualitative data analyses were examined using NVivo version 10 (QSR International Ltd, Australia). This allowed notes and analyses to be associated with blocks of text. Also, raters had access to the full transcripts for each participant, and transcripts were reviewed in-depth during coding and analysis. All qualitative responses to the questions addressing reasons for seeking and not seeking care were independently rated (by MC and JN). For each reason for seeking or not seeking care, we assessed the percent agreement (total agreement divided by agreements plus disagreements). Moreover, all discrepancies between the ratings of the reasons for seeking/not seeking care were resolved through discussion with one of the investigators (JG). The final consensus ratings were used for analyses.

In the qualitative interviews, participants discussed symptoms and bother in ways that were interchangeable. As a complement to the qualitative analyses, we examined the level of symptom frequency and bother for each symptom from the LUTS Tool. We also examined the associations (using polychoric correlations for ordinal data) between symptom frequency and bother, using ratings from the LUTS Tool. Only participants who had rated the frequency of their symptom(s) and their level of bother were included in the analyses; for symptoms that were not present, bother was not rated and was thus excluded from this particular analysis. Polychoric correlations are suitable to analyze ordinal data and do not assume an interval scale of the variables being examined. This was deemed appropriate for the LUTS Tool, which has discrete, ordered response categories (e.g., for symptom frequency: never, rarely, sometimes, often, almost always).

RESULTS

Participant Characteristics

We recruited 88 study participants across the three groups. Their demographic characteristics are shown in Table 1. The majority were white (77%); the mean age of the sample was 52.2 years (standard deviation = 14.3, range 19–77). The distribution of reported urinary symptoms and associated bother is shown in Figure 1. Data from 15 participants were excluded from qualitative analyses because the reason the person had sought or not sought treatment was ambiguous. This included participants not giving reasons for not seeking treatment, vague or unclear reasons, or the interviewer not asking enough follow-up questions about why treatment was sought.

Treatment-Seeking Behaviors and Reasons

Across the two raters, the median percent agreement (total agreements/agreements + disagreements) was 92% (range: 62%–99%). Among the 73 participants who had a clear reason for seeking or avoiding treatment, 54 (74%) sought treatment for LUTS. The frequency of the explanations for seeking and not seeking treatment, along with examples, are presented in Tables 2 and 3, respectively.

Most (94%) of the participants who sought care indicated that they were motivated by a particular symptom's presence and/or adverse effect on their quality of life (Table 2). Among participants who did not seek treatment, nearly one-half (47%) cited their symptoms as not being severe enough to motivate them to seek treatment. Other reasons included a belief that the symptoms were normal, that no treatments were available for their symptoms, that the available treatments were not worth it (e.g., the participant did not want to take more medicine or deal with side effects), they lacked the money/insurance to pay for treatment, and fear that seeing a provider would lead to discovery of serious health conditions.

Symptom Frequency and Bother

Figure 1 describes LUTS in this sample in terms of symptom frequency (Panel A) and bother (Panel B). Darker areas of the bars for each symptom indicate more frequent symptoms (Panel A) and higher level of bother (Panel B). Table 4 shows the polychoric correlations between symptom frequency and level of bother, as measured by the LUTS Tool. Across all items, the associations were large (≈ 0.5 or greater),²² and all but four were 0.7. In general, these data support a strong association between the frequency and the bother of LUTS.

DISCUSSION

Among people with LUTS, the nature of self-reported symptoms is diverse and variable in severity, and this diversity was well-represented in this study. Our study was unique, in that we also included people with LUTS who indicated they had not sought care. We also recruited a diverse sample by including both clinic-referred and community participants, as well as participants who we hypothesized might have diminished bladder sensation. The results of the present study suggest that symptom severity and/or bother appears to be the

primary determinant of who seeks or does not seek treatment, which is consistent with other studies.²³ Quantitative analyses of the correlation between symptom frequency and bother suggest that these concepts are closely related for most LUTS (polychoric correlations ranged from 0.49 to 0.98). For some symptoms, frequency and bother might be best interpreted to reflect a single dimension of severity, rather than as two separate concepts, as implied by the LUTS Tool. The practical implication of this is that severity and bother might not need to be measured separately, but additional research is needed on this issue to determine whether bother results in added diagnostic and predictive value beyond severity alone. The LUTS Tool, which is included in the LURN, has separate items for these dimensions, so our future research will be able to discern the separate contributions of the symptom frequency versus symptom bother questions.

It is not surprising that participants said they had not sought care because their symptoms were not severe or bothersome enough. Not seeking care for mild and/or non-bothersome symptoms would be appropriate in some cases, but the other reasons that people provided for not seeking care (Table 3) suggest a number of barriers and misconceptions regarding the treatment of LUTS. Some participants reported financial obstacles (e.g., not having insurance). It is possible that, for low-income individuals, a higher level of severity might be needed to lead a person to seek care. Some participants reported not being aware that treatment was available, or were aware of treatment options (e.g., medication), but were averse to the possibility of side effects. For these individuals, more education might be needed from the physician to inform the patient about treatment options and discuss handling side effects.

With the exception of financial difficulties, the remaining reasons for not seeking care were based on individuals' perceptions of symptom severity, or whether a symptom indicated a potentially serious problem. Although the decision to seek care for LUTS is ultimately up to the individual, people may benefit from receiving assessment and education from a health care professional regarding underlying causes of the symptoms, whether he or she may benefit from treatment, and what the risk-benefit ratios of potential treatments would be.

Strengths and Limitations

This is one of the first multi-center studies to perform qualitative interviews of a large number of participants about various aspects of LUTS. However, the study should be viewed in light of some limitations, including the fact that the majority of participants were white. Additional work is needed to explore reasons for seeking and not seeking care in other cultural and racial/ethnic groups. This is especially important because research suggests that black or African Americans are less bothered by LUTS and may have a higher threshold for reporting symptoms and seeking care.²⁴ Although we attempted to enrich the study population with participants likely to have symptoms, most of the participants recruited from the community reported mild symptoms and had not sought treatment. The community participants were recruited mostly from online advertisement. It is possible that we would have obtained different results recruiting participants directly from sites in the community (e.g., public libraries). Care-seeking participants were recruited from specialty clinics, but LUTS may present first to primary care practices. Thus, future studies should examine what

factors lead people to mention LUTS or not to their internist. Moreover, our specialty clinics included urogynecology and urology, which focus on sex-specific issues (e.g., LUTS that might occur after pregnancy). Seeking treatment based on symptoms applied to both men and women in this study, but future research is needed on possible sex differences.

CONCLUSION

In this qualitative study, we obtained useful insights into the impact of LUTS from the perspective of people with symptoms. Removing barriers and misconceptions about treatment of LUTS may increase the number of people who seek clinical care and improve the clinical course of men and women who experience LUTS.

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Figure 1. (A) Urinary symptom severity and (B) bother ($N = 88$)

[Panel A:] Responses to LUTS Tool from Qualitative Interviews (Severity Questions Only)

*Scale for question 2 is: 1–3 times a day, 4–7 times a day, 8–10 times a day, 11–13 times a day, and 14 or more times a day.

**Scale for question 3 is: None, 1 time a night, 2 times a night, 3 times a night, and 4 or more times a night.

[Panel B:] Responses to LUTS Tool from Qualitative Interviews (Bother Questions Only)

Table 1

Participant demographics

	Participant Group									
	Clinic (N = 34)		Community (N = 33)		Sensory ^d (N = 21)		Total (N = 88)			
	N	%	N	%	N	%	N	%	P value	%
Sex	34	100.0	33	100.0	21	100.0	88	100.0	0.27	100.0
<i>Female</i>	23	68	17	52	10	48	50	57		
<i>Male</i>	11	32	16	49	11	52	38	43		
Ethnicity	34	100.0	33	100.0	21	100.0	88	100.0	0.16	100.0
<i>Hispanic or Latino</i>	2	6	2	6	1	5	5	6		
<i>Non-Hispanic/Non-Latino</i>	31	91	31	94	20	95	82	93		
<i>Unknown/Missing</i>	1	3	0	0	0	0	1	1		
Race	34	100.0	33	100.0	21	100.0	88	100.0	0.55	100.0
<i>Asian/Asian American</i>	0	0	0	0	1	5	1	1		
<i>Black/African American</i>	5	15	7	21	1	5	13	15		
<i>Native Hawaiian/Pacific Islander</i>	1	3	0	0	0	0	1	1		
<i>White</i>	26	77	24	73	18	86	68	77		
<i>Other/Multi-Racial</i>	2	6	2	6	1	5	5	6		
Age	<i>M (range)</i>	<i>SD</i>	<i>M (range)</i>	<i>SD</i>	<i>M (range)</i>	<i>SD</i>	<i>M (range)</i>	<i>SD</i>	<i>< 0.001</i>	<i>M (range)</i>
	50.6 (20–63)	11.2	45.5 (19–68)	12.9	65.3 (21–77)	12.5	52.2 (19–77)	14.3		

Note.

^a“Sensory” refers to individuals who were aged 65+, or with recent lower back surgery or uncontrolled diabetes, or women with recent vaginal childbirth or recent radical hysterectomy.

Table 2Why people sought treatment ($N = 54$)

	Count	Percentage	Examples ^a
Symptoms were a side effect of treatment	3	6%	Urgency and incontinence as side effects of lithium
			Decreased bowel and bladder control due to spinal surgery
Treatment was recommended by a professional	14	26%	Patient (Pt): Early on, I just thought this was something I lived with. A colleague of mine (a urogynecologist) said, <i>You should come in. We have something for this.</i> That's when she fit me for pessary.
			Pt: I was having a lot of inflammation and soreness in my vulvar area. I didn't know what that was from. My family physician said, <i>You probably need to see a urogynecologist.</i> He sent me to her, and she did a vulvar biopsy. It came back as chronic inflammation or irritation. For the incontinence, that's the first time she said, <i>Why have you not been to a doctor about this?</i> I said, <i>I just figured it was something I had to live with.</i>
Sought treatment because of symptoms	51	94%	From a man with overactive bladder symptoms: Pt: It's getting to the point that there's a slight incontinence, which was never there before. That's when I panicked and said, <i>I've got to get in to see the doctor now.</i>
			Pt: I talked to my GYN the last few times about it, that it was more frequent. He asked me, <i>On a scale of 0 to 10, how often does it bother you?</i> I said, <i>When I have a cold, closer to 10, but typically, probably a 4–5.</i> He said, <i>When you're getting close to the 10 all the time, we can take care of it. Or, if that 5 could be someone else's 10. You'll know.</i>

Note. Percentages do not sum to 100% because multiple reasons were possible.

^aText in these examples is not a direct quotation. Patient responses are summarized from transcripts for concise presentation of main points provided in their feedback. Urinary symptoms in these cases arose in the course of treatment for other conditions and were followed thereafter.

Table 3Why people did not seek treatment ($N = 19$)

	Count	Percentage	Example ^a
Symptoms not severe enough	9	47%	Interviewer (Int): Have you ever sought any treatment for the symptoms that we've discussed today? Pt: No, I haven't. They haven't been that severe.
			Pt: We have been self-employed for a really long time, and our insurance isn't super great. As long as I feel like it's not detrimental to my health in any way, I prefer not going and getting on a prescription that may have side effects.
Thought symptoms were normal	5	26%	Pt: I go for physical checkups, and they don't see anything drastically wrong with me.
			Int: Have you ever sought treatment or care for any of the symptoms that we've discussed? Pt: No. I might have mentioned it to the doctor once. That's where we just probably decided that I have a small bladder, but nothing more than that.
Thought no treatments were available	3	16%	Int: Have you sought care or treatment for any of these things? Pt: No. Int: Why not? Pt: I sought just a prostate exam because, maybe it's my age, I didn't think there's anything really available out there unless you have a serious problem. I go for physical checkups, and they don't see anything drastically wrong with me. At my age, nobody really wants to be big on doctors unless you have a serious problem. At least I don't, anyway. Sometimes you check in and you don't check out. (*laughs*) [Note: This person was also coded as <i>Thought symptoms were normal</i> because he went for regular checkups, but his doctors never saw anything "drastically wrong" with him. He was also coded for <i>Fear of health problems</i> . Thus, his responses are noted above and below.]
			Pt: I thought it was just how I am. I didn't really know if there was anything to do that could help.
Did not think that treatment was worth it	5	26%	Int: My next question was if you've sought care, so we've answered that. Pt: Right. Int: And you said it's mainly because you don't want any more medicines. Pt: I would like to not take more medication if possible. I don't know if it's bad enough for me to request medication yet. I guess I don't know a lot about it because I try to deny that it's happening.
			Pt: No. I saw a commercial on TV, but it's like, <i>Well, it's so many side effects</i> . I think I can live with it.
Lack of finances or insurance	3	16%	Int: Have you sought care or treatment for any of the symptoms that we discussed today? Pt: I haven't. Int: Not for either the frequency or the leaking? Pt: No. Int: Why not? Pt: We have been self-employed for a really long time, and our insurance isn't super great.
			Pt: I've had no doctor for a couple years. The doctor I had moved away, and then I had no insurance. I don't consider it to be a real major problem, but more of an inconvenience. And it's not gotten worse, either. I don't think, so, it's pretty stable.
Fear of health problems	2	11%	Int: Have you ever sought care or treatment for any of these symptoms that we've discussed today? Pt: No I haven't. Int: Why not? Pt: Basically, like a lot of people do, they might have a problem – fear of being diagnosed with something that's going to be some kind of health risk.
			Pt: At my age, nobody really wants to be big on doctors unless you have a serious problem. At least I don't anyway. Sometimes you check in and you don't check out. (*laughs*) [This person had multiple reasons, as noted above.]

Note. Percentages do not sum to 100% because multiple reasons were possible.^aText in these examples is not a direct quotation. Patient responses are summarized from transcripts for concise presentation of main points provided in their feedback.

Table 4

Association between symptom frequency and bother from the LUTS Tool

Symptom	N	Polychoric correlation
Pain or discomfort	34	0.98
Leaked during sexual activity	24	0.95
Urgency	62	0.94
Intermittency	42	0.93
Leaked while doing physical activities	36	0.93
Straining	31	0.91
Leaked while laughing/sneezing/coughing	37	0.90
Leaked at night	33	0.88
Leaked for no reason	33	0.88
Frequency (urinating too often)	65	0.88
Hesitancy	51	0.88
Burning sensation	26	0.88
Urgency w/fear	52	0.84
Leaked while rushing	47	0.80
Incomplete emptying	56	0.74
Splitting or spraying	50	0.72
General incontinence	48	0.70
Leaked after voiding	46	0.70
Nocturia	67	0.69
Terminal dribble	68	0.65
Weak stream	48	0.52
Daytime frequency	64	0.49

Note. Correlations are sorted by magnitude. *N*s vary because only participants who rated both symptom frequency and bother are included; if a symptom was not present, bother was not rated. Note that the participants who were excluded from the qualitative analyses were not excluded here because their data are informative about the frequency-bother associations analyzed here. All *p*-values were < 0.0001.