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CONTINENCE CARE

Cognitive, Affective, and Behavioral Dimensions of the Lower Urinary Tract Symptom Experience in Men With Parkinson's Disease

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ABSTRACT

OBJECTIVE: Lower urinary tract symptoms (LUTS) in persons with Parkinson's disease (PD) have received little research attention. To address this gap in our knowledge, we examined the LUTS experience in men with PD, guided by The Theory of Unpleasant Symptoms.

METHODS: A qualitative design was used to explore the LUTS experience in this population. Participants were recruited from a Veterans' Affairs PD Center. Maximum variation sampling was used to select diverse participants for audiotaped open-ended interviews. Additional data sources included field notes collected during interviews and observation of a PD support group. The template organizing analytic approach was used to code transcribed interviews and field notes.

RESULTS: Cognitive, affective, and behavioral dimensions of the LUTS experience were identified. Participants attributed LUTS to aging, medications, and effects of motor symptoms on their ability to respond to the urge to void. There was little awareness of the neurologic contributions of PD to LUTS, and most viewed LUTS as "something that you have to put up with." Negative effects of LUTS on self-identity were noted, which jeopardized relationships, intimacy, participation in social activities, and travel. Affective responses to LUTS, particularly embarrassment, had a profound impact on quality of life. Behavioral strategies to manage LUTS focused on "being prepared to go when you need to go" and consisted mostly of trial-and-error efforts.

CONCLUSION: Misconceptions about LUTS among men with PD may result in underreporting, missed opportunities for professional assistance, and diminished health-related quality of life. Future research should focus on developing and testing nursing interventions to address cognitive, affective, and behavioral aspects of the LUTS experience in men with PD.

KEY WORDS: lower urinary tract symptoms, military veterans, Parkinson's disease, symptom experience, urinary incontinence

Introduction

Extensive research has focused on motor symptoms of Parkinson's disease (PD), but lower urinary tract symptoms (LUTS) have received less attention. Lower urinary tract symptoms occur frequently in persons with PD, with prevalence rates up to 71%.[1] They are defined as "symptoms that result from conditions and diseases affecting the bladder and urethra."[2(p3)] Common LUTS in men with PD include incontinence, urgency, frequency, nocturia, postmicturition dribble, hesitancy, weak stream, and the sensation of incomplete bladder emptying.[1]

Researchers have examined the prevalence, pathophysiology, etiologies, impact, and treatment of LUTS.[1,3–11] Almost all have employed quantitative methods of data collection and analysis. A recent search of CINAHL, Ovid MEDLINE, and Scopus databases using the search terms LUTS, urinary incontinence (UI), male, PD, and qualitative research (individually and in combination) revealed no qualitative studies of LUTS in men with PD. One qualitative study of women with PD[12] was found that explored changing perceptions of "womanhood" when living with PD, including responses to LUTS. Data were collected via

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individual and group interviews, diaries, and creative writing from 19 women with PD whose mean age was 44 years. Two areas associated with continence and toileting were highlighted: (1) participants described their inability to get to the toilet on time and resultant UI within the theme of having a negative "body image" and (2) the "increasing dependence" associated with asking a partner to help them get to the bathroom to avoid falls or injury.[12]

The purpose of this study was to explore the LUTS experience in men with PD, guided by The Theory of Unpleasant Symptoms.[13,14] This theory posits that every symptom is a multidimensional experience and that internal and external factors influence the symptom experience. Furthermore, it purports that the symptom experience impacts health-related quality of life. This theoretical framework helped us to appreciate the experiential nature of symptoms and led to our interest in describing men's understanding and experience of LUTS and the impact on their lives.

■ Methods

This descriptive qualitative study was approved by the institutional review boards of participating institutions. Informed consent was obtained from all participants.

The sample consisted of selected participants from a cross-sectional parent study that examined LUTS in male veterans receiving care at a Parkinson's Disease Research, Education and Clinical Center at a Veterans Affairs Medical Center. Eligibility criteria included self-reported LUTS, diagnosis of idiopathic PD, score of 24 or more on the Mini-Mental State Examination,[15] and ability to understand English. Maximum variation sampling[16] was used to select a diverse subsample of informants from the parent study[17] to participate in open-ended interviews. We employed this sampling method to ensure that participants varied in age, race, education, PD severity, PD duration, and depression diagnosis. Field notes collected during interactions with additional participants in the parent study and during observations of a PD support group also served as data sources.

Study Procedures

Demographic and illness-related data were obtained from self-report and the electronic medical record, respectively. The number of LUTS was obtained from the Male Urogenital Distress Inventory, a 27-item questionnaire measuring the presence or absence of selected LUTS and degree of bother associated with each symptom.[18]

Following informed consent procedures, structured interviews using quantitative instruments were conducted with participants in private offices. This was followed by audiotaped qualitative interviews with selected participants; interviews lasted 15 to 20 minutes. The interviewer assured participants that there "are no right or wrong answers to the questions," and that we were interested in their experiences. Qualitative interviews were guided by open-ended questions: (1) "Tell me about whether you think PD has affected your bladder and/or ability to get to the bathroom. If yes, how?" (2) "Tell me about any urinary symptoms that we haven't covered, how bothersome they are, and how they affect your life." (3) "Tell me about how you deal with or manage the urinary symptoms that you have." Qualitative data collection ended when no new themes emerged during the analytic process.[16]

Qualitative Analysis

Interviews and field notes were transcribed verbatim and analyzed using HyperRESEARCH software.[19] A template organizing analytic approach[20] organized data into a priori categories corresponding to our interview questions: LUTS attribution, PD influence, symptoms, bother, impact, and management. Open coding using in vivo terminology (actual words) within each category was performed. Codes were clustered within and then across categories using axial coding; this process yielded 3 aspects of the LUTS experience. Our coding procedure (Table 1) maximized the trustworthiness and efficiency of coding.

Criteria for rigor in qualitative research[21–23] were followed to ensure trustworthiness of the data. Credibility was maximized by engagement in the field for 12 months of data collection. A member check also supported credibility; the team reviewed findings with 3 participants and all agreed that the findings reflected their experiences. Dependability of findings was enhanced through group coding for analyses. During coding, the investigators also

TABLE 1.

Protocol for Group Coding

Initial coding of 5 audiotaped interviews and 2 field notes was completed by one investigator, yielding 104 discrete codes in the following categories: attribution, bother, impact, management, PD influence, and symptoms. After consultation from three seasoned qualitative nurse investigators, we developed a protocol for group coding of the remaining audiotaped interviews:

1) development of clusters of existing codes (by one investigator)
2) compilation of a code book for all subsequent coding (by one investigator)
3) meeting to jointly code one interview (with 3 investigators)
4) independent coding of the next interview by all three coders with follow-up comparison to evaluate consistency
5) after consistency in coding is achieved, independent coding of subsequent interviews by a primary coder, who will memo and annotate liberally
6) independent coding of selected interviews by a secondary coder with follow-up comparisons to assess consistency
7) one external audit of selected coded data by a seasoned qualitative investigator

TABLE 2.

Demographic and Illness-Related Characteristics of the Sample (N = 11)

Characteristic	Range	Number
Age, y	60-80+	
60-69		5
70-79		4
80+		2
Race		
White		9
Black		2
Education	<12 y to > 12 y	
<12 y		2
12 y		3
>12 y		6
Marital status		
Married		8
Widowed		3
Employment		
Yes		2
No		9
Depression diagnosis		
Yes		3
No		8
Urinary incontinence		
Yes		10
No		1
PD severity		
Unilateral disease		1
Bilateral disease without balance impairment		5
Mild to moderate bilateral disease; some postural instability; physically independent		5
PD duration, y	< 1 y to 10+ y	
<1		2
1-5		4
6-10		4
10+		1
ADL function		
Completely independent		2
Completely independent but with some slowness and difficulty		3
Completely independent but takes twice as long		3
Some dependence; takes 3 to 4 times as long in some ADL; spends large part of day with chores		2
Needs help with half of chores; difficulty with all		1
Number of LUTS	6-20	
6-10		5
11-20		6

Abbreviations: ADL, activities of daily living; LUTS, lower urinary tract symptoms; PD, Parkinson´s disease.

created an audit trail by recording theoretical and operational memos. An independent party (coauthor C.W.B., who was not involved in data collection or initial analysis) reviewed the audit trail for credibility of the findings—the fit between raw data and conclusions reached through data analysis.[24]

■ Findings

Sample characteristics are included in Table 2. Eleven persons with PD participated in the study; their age ranged from 60 to 80+ years. Participants were predominately white, married, and unemployed. Parkinson's disease duration ranged from less than 1 year to more than 10 years. Ten participants had bilateral disease, yet there was variability in activities of daily living functioning. All but one reported UI, and all reported 6 to 20 LUTS. Three had a diagnosis of major depression documented in the medical record.

Three major themes in the data that reflected cognitive, affective, and behavioral dimensions of the LUTS experience can be summarized as follows: (1) what men think about the cause of the symptoms (cognitive), (2) what they feel about the symptoms (affective), and (3) what they do to manage the symptoms (behavioral) (Figure 1).

Cognitive Dimensions

Participants expressed the common idea that LUTS results from aging, medications, and PD symptoms. They reported that sensory, motor, and cognitive symptoms of PD (eg, loss of smell, balance and gait problems, tremors, disordered thinking) represented their main challenges to bladder control. For example, they described how PD motor symptoms "slow you up" by making it difficult to walk to the bathroom and pull clothing down quickly enough to direct their urine stream into the toilet. Little or no awareness was expressed concerning the direct neurogenic effects of PD on the bladder. Consequently, participants did not believe that LUTS could be treated, and most did not raise the issue of LUTS with their PD providers, leading to missed opportunities for treatment.

Statements from 2 men exemplified the prevailing thinking that aging and PD motor symptoms cause LUTS. When referring to LUTS, 1 respondent stated, "It's just another sign of aging and it annoys the hell out of me." Another noted, "The Parkinson's definitely hangs me up because I can't walk the way I normally walk. I mean, prior to having Parkinson's, I could just get up and go to the bathroom, but now it's more difficult."

Affective Dimensions

Affective dimensions of the LUTS experience centered on 2 main areas, bother and embarrassment. Participants reported that LUTS bothered them in 2 ways. First, urinary elimination, once experienced as a "mindless task," was now perceived as "work" or a complex process that "slows

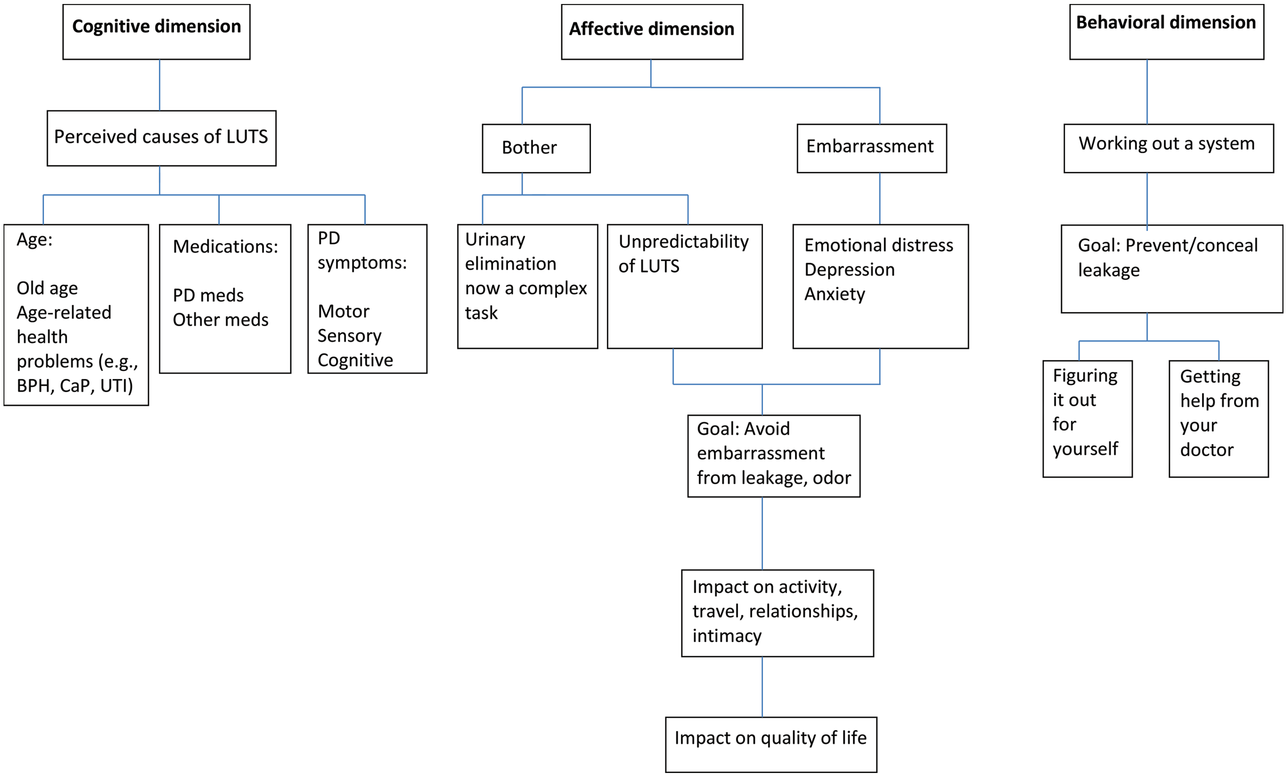

FIGURE 1. Cognitive, affective, and behavioral dimensions of the LUTS experience. LUTS indicates lower urinary tract symptoms; UTI, urinary tract infection.

you up." As one participant noted, "Well in the past, it was just a mindless task; you just reach in and…pass your water; now I can't get it out through the clothes." Second, the unpredictability of LUTS created strong feelings of bother. Unpredictability thwarted participants' attempts to control LUTS, and it interfered with their activities. As one man described, "I had to go to the bathroom and I didn't know it until it hit me. When it hit me, it was already running so by the time I had got to the bathroom, I had already wet myself and had to change my clothes and that is why I don't like to go out too much now. So, I guess it sort of invades my social life…."

In the affective dimension, participants frequently reported that embarrassment was the most difficult source of emotional distress. Embarrassment was related to the impact of leakage on others, for example, feeling embarrassed with accidents, leakage, wet pants, and smell in social activities, relationships, and partner intimacy. Comments from 3 men illustrate the emotional distress associated with embarrassment. The first commented, "Here I am trying to make love to my wife and it is leaking and it just does not make sense. And sometimes I get very depressed over it. It bothers me a great deal and it is embarrassing and humiliating and it makes you feel less than a man…." A second respondent observed, "It is embarrassing a lot and it makes you feel less than a man, at times. You know, it is almost like you revert to your childhood…." The third participant noted, "When I am out…the urination just piles up on my undergarments and it has an odor, a horrible odor to it. So I am concerned about that… I don't want to offend anybody with that."

Given the degree of distress associated with embarrassment, the goal for most men was to avoid embarrassing situations. Many sought to meet this goal by withdrawing from aspects of life that were once sources of joy and social connection. They either eliminated or curtailed their activities, minimized travel, or withdrew from relationships, leading to a profound negative impact on their friendships, social networks, and intimacy. One described the situation as follows, "So it affects who I go to, where I go, who I see … you know it's affected my life to a point where you don't enjoy as much as you used to because you can't go long without having a release." Another stated, "It has curtailed activities I would participate in…I played a lot of softball and football…and there were no facilities…so I never went." A third reported, "…my sex life is horrible, I don't have a sex life to say; I wonder why my wife is still with me…She is a very attractive lady."

One participant described a lifelong love of baseball, and it was a source of socialization for him. He reported giving up baseball and the joy that went with it because there was no bathroom near the field and he did not wish to be embarrassed with leakage. For him and several others, LUTS resulted in curtailed activities and relationships even before PD motor symptoms affected these areas.

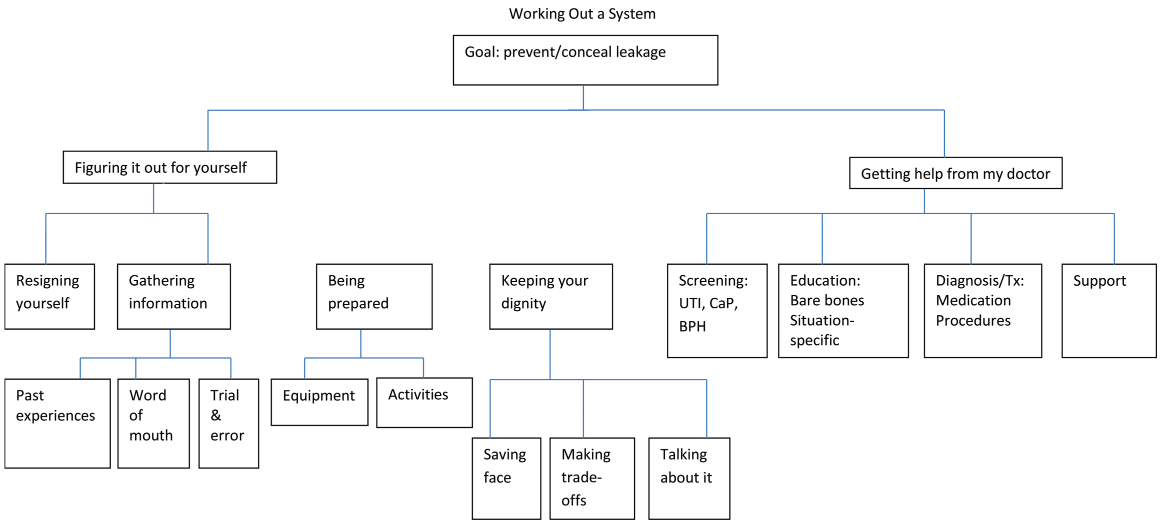

FIGURE 2. Behavioral dimensions of the LUTS experience. LUTS indicates lower urinary tract symptoms.

Thus, for some men, LUTS affected their quality of life before the motor symptoms did.

Behavioral Dimensions

Participants engaged in a process named "working out a system" to manage LUTS (including UI) (Figure 2). The most important goal of this process was to prevent and/or conceal leakage, and it consisted of 2 basic strategies: "figuring it out for yourself" and "getting help from your doctor" (Tables 3 and 4).

"Figuring it out for yourself" included 4 possible tasks. The first, labelled resigning yourself, meant accepting LUTS as "something that you have to put up with." The second task, gathering information, encompassed seeking information from past experiences (eg, using a diaper as done with a baby), word of mouth (from wife, news, TV), and trial and error. One man recalled how he obtained information: "And good old doctor…who writes in the newspaper says you don't have to drink 2 gallons of water a day, you can drink when you're thirsty." Another man relied on trial and error to determine he could "go 5 to 7 times" in a pad before leakage would occur. The third task, keeping your dignity, referred to saving face by joking about LUTS, making lifestyle trade-offs to avoid "making a mess," and talking about LUTS with select persons.

The fourth task, being prepared for activities, required planning. Most men reported that they rarely went anywhere without knowing the location of bathrooms and being sure they could get there. Many men paced fluids by decreasing fluids prior to a public activity, but for some this consisted of limiting fluids in general, as articulated by one man: "I tend not to drink fluids to help alleviate the problem of having to go." Another described using a technique he read about to manage dribbling: "The urine passes through … the ureter [urethra]. And, sometimes you can speed it up by passing your finger over your [penile] area, where that little tube passes. And it increased the pressure and makes it [the urine] go out faster." Being prepared with equipment referred to the use of absorbent products ("pads" and "diapers") and containers for urine. One participant also described reliance on dark underwear in public to make leakage less visible.

The second basic strategy, getting help from your doctor, was referenced less frequently. It consisted of 4 types of help: screening; diagnosis and treatment; education; and support (see Table 4 for examples).

■ Discussion

To our knowledge, this is the first qualitative study of the LUTS experience in men with PD. Because LUTS remain a taboo subject for men,[25] our findings are valuable in shedding light on the experience of men with PD and LUTS, a group that may be particularly reluctant to disclose LUTS to healthcare professionals.

Our findings are consistent with those from a qualitative study of women with PD that identified changing perceptions of womanhood when living with PD.[12] Although questions about LUTS were not specifically elicited, the women described their inability to get to the toilet in time ("I have to think to pull my trousers down, to pull my knickers down before I go to the toilet. Nine times out of ten I have already done the toilet")[12(p518)] and the negative impact on their body image and sexual identity, findings that resonate with those in the current study.

The Theory of Unpleasant Symptoms[13,14] provided a useful framework for understanding the multidimensional nature of LUTS. Our findings centered on the cognitive, affective, and behavioral dimensions of LUTS, providing an in-depth picture of the LUTS experience from the perspective of men with PD.

In the cognitive dimension, most men did not recognize the direct neurogenic effect of PD on the bladder.

TABLE 3.

Behavioral Dimension: 5 Strategies for Figuring It Out for Yourself

Figuring It Out for Yourself Consisted of:	Examples
Resigning yourself to put up with it	Accepting it as a part of aging, accepting it as the norm
Gathering information about how to manage LUTS	Through past experiences, word of mouth, trial and error
Being prepared—with activities	Locating self near the bathroom, scanning for places to go, pacing fluids, counting pads, defensive voiding, bulbar massage, deep breathing, washing body frequently for odor control
Being prepared—with equipment	Though the use of containers, clothing, absorbent products that collect urine; use of a flash light to find the bathroom at night
Keeping your dignity	By saving face, making trade-offs, talking about it

Abbreviation: LUTS, lower urinary tract symptoms.

They viewed LUTS as caused by unavoidable issues, such as aging, and therefore, they did not believe that LUTS could be treated. Men with this belief typically did not report LUTS to their PD providers and missed opportunities for assistance, a finding consistent with research showing that older women who perceived LUTS as part of normal aging were unlikely to seek treatment.[26–28] Because of this belief, LUTS in men with PD remain underassessed and undertreated.[1] Nurses interacting with persons with PD in outpatient and inpatient settings must explicitly ask about LUTS in standard assessments, not simply expecting patients to raise the issue. Of note, the updated version of the most commonly used measure of PD severity, the Unified Parkinson's Disease Rating Scale, now includes evaluation of LUTS.[29] Our findings and clinical experience suggest that when clinicians routinely raise questions about LUTS, patients with PD will reply with candor and even with relief, after learning from clinicians that LUTS are common in PD.

Affective responses to LUTS, particularly embarrassment, were distressing for men and exerted a major impact on health-related quality of life. Respondents were distressed and embarrassed by the impact of LUTS on their relationships, partner intimacy, and activities with friends, leading them to withdraw from social activities. These findings were also noted in a review of studies of UI in adults,[30] and in qualitative studies of adults with UI,[31] and men with LUTS.[32] Feelings of bother experienced by our sample corroborate bother elicited through a quantitative survey of men with LUTS.[33] Affective responses to LUTS may also contribute to the depression observed in up to 50% persons with PD.[34–36]

Nurses in diverse settings can minimize embarrassment by providing education around LUTS and PD, and by conveying the message that men are not alone in this affective experience. Nurses also have the responsibility to educate family members about LUTS, distress from LUTS, and how family members can be supportive to loved ones with LUTS. The painful issues around sexuality and intimacy, poignantly articulated by our participants, demonstrate the need for clinicians to pay closer attention to these sensitive but significant areas in men's lives. Facilitating communication between couples around distressing aspects of LUTS will help couples address sensitive areas as well as less sensitive ones. Enhanced communication within couples may also minimize conflicts that occur when caregivers believe that their partner is denying LUTS or is less concerned about LUTS than they are, problems articulated by caregivers in our ongoing study.[37] Because most persons with PD live in their own homes and are cared for by a family member,[38] communication around troubling PD symptoms, such as LUTS and other symptoms, is essential. As the general population ages, the prevalence of persons living with PD is likely to rise. We believe that healthcare professionals will increasingly be called upon to recognize the implications of PD within the

TABLE 4.

Behavioral Dimension: 4 Ways of Getting Help From Your Doctor

Getting Help From Your Doctor Consisted of the Following:	Examples
Screening for other causes of LUTS	Screening for urinary tract infections, prostate cancer, benign prostatic enlargement
Diagnosis/treatment of LUTS	Medications, procedures
Education	Barebones and situation-specific education on voiding position, use of sample pads and external collection devices, pacing fluids, urinary tract infections
Support	Talking with doctor, expressing self with doctor

Abbreviation: LUTS, lower urinary tract symptoms.

family. WOC nurses who ask affected patients and family caregivers, "How do LUTS affect your life and relationships?" are better able to discern the impact of LUTS, provide education on self-management, and offer psychosocial support.

In the behavioral dimension, participants expressed motivation to "work out a system" to manage LUTS. But in the context of having little knowledge and variable professional guidance, working out a system often involved trial and error and resulted in the use of some ineffective strategies. Strategies for being prepared in activities and equipment, described by our sample, have been employed by community-dwelling adults with LUTS and reported in varied quantitative[39,40] and qualitative studies[31,41] with men and women. Sadly, no one in our sample mentioned the use of pelvic floor muscle exercises, which can be effective in alleviating urinary urgency and urge incontinence[42] common in patients with PD. Our findings underscore the need to ask every patient with PD, "What do you do to manage your LUTS?" The response to this question provides an opportunity to assist patients to formulate and implement strategies for managing their LUTS. For example, pacing fluids may be useful in reducing LUTS during social activities, as compared to chronically limiting fluid intake that may contribute to dehydration.[43,44]

Conclusion

Our findings reinforce the need to develop and test nursing interventions to improve assessment and management of LUTS in this population. Findings from this study demonstrate that men with PD and LUTS wish to learn how to manage their symptoms. They also struggled with intimacy and sexuality issues, areas virtually ignored in research with this population. Nurses play a critical role in identifying LUTS in men with PD, in educating men and family caregivers about LUTS, and in working closely with men to implement management strategies for LUTS that are evidence-based and congruent with their values and lifestyle. Research is needed to expand the repertoire of evidence-based interventions to manage LUTS in men with PD.

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