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The Patient Voice: Stent Experiences After Ureteroscopy—Insights from In-Depth Interviews with Participants in the USDRN STENTS Nested Qualitative Cohort Study

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Abstract

Purpose: Ureteral stents are commonly used after ureteroscopy and cause significant discomfort, yet qualitative perspectives on patients' stent experiences remain unknown. We describe psychological, functional, and interpersonal effects of post-ureteroscopy stents and whether additional patient-reported assessments may be needed.

Materials and Methods: Using a qualitative descriptive study design, we conducted in-depth interviews with a nested cohort of participants in the STudy to Enhance uNderstanding of sTent-associated Symptoms (STENTS). Participants shared their symptoms with a post-ureteroscopy stent and described symptom bother and impact on daily activities. All interviews were audio-recorded, transcribed, and analyzed using applied thematic analysis. During analysis, participants' experiences with interference in daily activities were categorized into three groups based on their impact: minimal, moderate, and substantial.

Results: All 39 participants experienced pain, although descriptions varied and differentiated between feelings of pain *vs* discomfort. Almost all experienced urinary symptoms. Only a few reported other physical symptoms, although several psychological aspects were identified. In the areas of sleep, mood, life enjoyment, work, exercise, activities of daily living, driving, childcare, and leisure/social activities, the stent had little impact on daily living among participants placed in the minimal group ($n=12$) and far greater impact for participants in the substantial group ($n=8$). For patients in the moderate group ($n=19$), some daily activities were moderately or substantially affected, whereas other activities were minimally affected.

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Conclusions: Counseling to better prepare patients for the impact of stent-associated symptoms may help mitigate symptom burden. While existing instruments adequately cover most symptoms, additional assessments for other domains, particularly psychological factors, may be needed.

Keywords: ureteroscopy, ureteral stent, quality of life, qualitative research, urinary stone disease

Introduction

URETERAL STENTS MAINTAIN ureteral patency following ureteroscopic treatment of urinary stones and are recommended where patency is critical.[1,2] Although ureteroscopy is common, qualitative descriptions of patients' experiences with post-ureteroscopy indwelling stents are missing from the scientific literature. Additionally, patient-reported outcome (PRO) assessments, such as the Ureteral Stent Symptom Questionnaire,[3] used to capture stent-associated symptoms (SAS) after ureteroscopy are limited to measuring pain, urinary symptoms, and certain aspects of quality of life.

Minimal information is available on whether patients experience any other meaningful SAS after ureteroscopy, suggesting that additional content areas for PRO assessments may be needed. We designed a qualitative study nested within the STudy to Enhance uNderstanding of sTent-associated Symptoms (STENTS)[4] to address these gaps by (1) gathering qualitative descriptions of patients' experiences with indwelling post-ureteroscopy ureteral stents and (2) assessing whether other measures specific to SAS post-ureteroscopy are needed to better capture patient experiences.

Conducted within the NIDDK Urinary Stone Disease Research Network (USDRN), STENTS is a prospective, observational cohort study focused on enhancing understanding of patient's SAS after ureteroscopy with short-term ureteral stent placement for the treatment of renal or ureteral stones.[4] A subset of the overall STENTS cohort participated in the qualitative study, for which they completed symptom assessments daily and participated in an in-depth interview to provide personal narratives about their stent experience. Nesting qualitative interviews on patients' experiences with urology care, as conducted in the STENTS study, can lead to a better understanding of patient perspectives among urologists, help identify overlooked domains in current assessments, and ultimately improve patient care. We herein describe participants' reported experiences with the indwelling ureteral stent and their implications for PRO assessments and patient counseling.

Methods

Study design, method, and sample selection

Using a qualitative descriptive study design,[5,6] we conducted in-depth telephone interviews 7–30 days after stent removal. We did not test a hypothesis as the purpose of the research was to describe patient experiences; by design, qualitative research does not test hypotheses. Adolescent and adult STENTS[4] participants were consecutively enrolled into the study ($n = 40$), and we aimed to interview all cohort participants. Adjustments in recruitment order were made to ensure a sample diverse in age, gender, and geographic location.

Data collection

We asked participants to share their experiences with having a ureteral stent, focusing first on pain and other symptoms they experienced, including blood in urine and urinary frequency, urgency, and incontinence. Participants were then asked how bothersome SAS were and the impact, if any, that their SAS had on engagement in daily activities and interactions. We also specifically asked how SAS affected the following aspects of daily living: (1) psychological (sleep, mood, and overall enjoyment of life), (2) functional (work, exercise, activities of daily living [ADLs], driving, and childcare), and (3) interpersonal (leisure/social activities, relationships with friends and family, and, for the adult participants, sexual relationships). Interviewers used a semi-structured interview guide and asked follow-up probes to thoroughly explore patients' experiences. We audio-recorded all interviews with participants' permission.

Data analysis

After each interview was transcribed verbatim following a transcription protocol,[7] we used applied thematic analysis[8] to analyze participants' narratives (Supplementary Material S1).

Ethics

Institutional review boards at all participating clinical centers approved the protocol. Adult participants provided written informed consent to participate. Adolescents aged 17 years and younger provided their informed assent, and their parents provided parental permission.

Results

Study participants

In March–August 2019, we conducted in-depth interviews with 39 of the 40 participants enrolled in the substudy, on average 18 days after stent removal (range 7–30 days). Representing four geographic regions, participants' ages ranged from 13 to 77 years, 54% ($n = 21$) were female, 95% ($n = 37$) were White, and 8% ($n = 3$) were Hispanic/Latino. All but one participant reported taking pain medications at some point during stent indwelling, which ranged from 3 to 37 days (median = 8) (Table 1).

SAS experienced

All participants reported experiencing pain, but they used a variety of attributes to describe their pain experience. Burning or stinging was mentioned most often ($n = 22$), was linked to pain in the urethral area during urination by most participants and was typically described as decreasing in intensity or completely subsiding within the first few days after stent placement. Other pain attributes frequently described included cramping or spasms; discomfort; pressure; stabbing or sharp;

Table 1. Participant Demographics, Geography, Medication Use, and Medical History

Characteristic[a]	n *(%)* n=*39*
Age, years	
12–17	2 (5)
18–24	4 (10)
25–34	7 (18)
35–44	6 (15)
45–54	8 (21)
55–64	7 (18)
65–74	4 (10)
75+	1 (3)
Gender	
Female	21 (54)
Male	18 (46)
Race	
Black	2 (5)
White	37 (95)
Hispanic/Latino ethnicity	3 (8)
Education	
Less than high school graduate	3 (8)
High school graduate	7 (18)
Some college or associate degree	11 (28)
Bachelor's degree	14 (36)
Master's or higher professional degree	4 (10)
Employment status	
Unemployed/looking for work	1 (3)
Student	2 (5)
Working part-time	5 (13)
Working full time	22 (56)
Retired	6 (15)
Stay at home full time	2 (5)
Permanently disabled	1 (3)
Marital status	
Single	14 (36)
Married	18 (46)
Divorced	4 (10)
Widowed	3 (8)
Geographic residence	
Mid-Atlantic	6 (15)
Mid-West	11 (28)
Southwest	11 (28)
Pacific Northwest	11 (28)
Self-reported medication use[b]	
Oxycodone (immediate release) (Roxicodone)	6 (15)
Oxycodone and acetaminophen (Percocet)	5 (13)
Hydrocodone and acetaminophen (Lortab, Norco, Vicodin)	4 (10)
Tramadol (Ultram)	5 (13)
Ibuprofen	19 (49)
Acetaminophen	19 (49)
Ketorolac (Toradol)	7 (18)
Tamsulosin (Flomax)	30 (77)
Oxybutynin (Oxytrol, Ditropan)	20 (51)
Phenazopyridine (Azo)	18 (46)
Other pain medications	10 (26)
Medical history[c]	
Depression	9 (23)
Anxiety	8 (21)
Mood disorder	1 (3)
Neurological disorder	1 (3)
Chronic pain condition	7 (18)

[a] Self-reported via questionnaire as part of STENTS data collection.

[b] Self-reported via a medication diary on medication use the day of stent procedure through stent removal as part of STENTS data collection; selected all that applied.

[c] Assessed via medical chart review and during baseline visit as part of STENTS data collection; selected all that applied.

STENTS = STudy to Enhance uNderstanding of sTent-associated Symptoms.

dull, achy, or sore; and sense of stent presence (each attribute: $n = 6–14$). When describing cramping or spasms, participants often stated that the pain occurred in the flank or bladder area during urination or when in motion, such as upon standing.

The narratives of participants whose pain experience included stabbing or sharp feelings focused on the high intensity of the pain, describing it as ''poking,'' ''constant punching,'' ''peeing razor blades,'' and ''peeing glass.'' Those who described feeling dull, achy, or sore said that these feelings emerged after the intense pain during the days following the stent procedure subsided. Some participants also pointed out differences between pain and other feelings, such as discomfort, described as a general sense of being uncomfortable, and pressure, described as a feeling of tightness or constipation-like, neither of which were considered painful yet still could be intense.

Nearly all participants also mentioned having blood in their urine ($n = 37$) and increased urinary frequency ($n = 35$), with just over half ($n = 22$) experiencing a sense of urinary urgency. Far fewer ($n = 12$) experienced urinary incontinence. Beyond pain and urinary symptoms, a small percentage of participants ($n = 4–6$) described having nausea, fatigue, and general malaise. See Table 2, Section 1 for participant quotes.

Most bothersome SAS

Many participants ($n = 24$) said that pain was their most bothersome SAS, and more than half of these participants linked their pain to urination, noting that this also produced anticipatory anxiety. Numerous participants ($n = 9$) said that urinary frequency was their most bothersome symptom. These participants expressed that frequent urination disrupted both their usual daytime activities and nighttime sleep and that it was frustrating to have no control over urinary frequency. See Table 2, Section 2 for participant quotes. Other SAS, such as blood in urine and discomfort, were also mentioned as bothersome, although by a smaller number of participants.

Table 2. Participant Experiences with Stent-Associated Symptoms

Topic	*Participant quote*
Section 1: SAS experienced	
Pain	
Burning or stinging	*[I had an] incredible burning sensation when I peed, to the point that on a 1–10 scale, I was in my mind at a seven and a half … It would make me cry out. I would involuntarily make a noise when I peed.*—Male, age 54
Cramping or spasms	*As I got closer to emptying my bladder or towards the middle of peeing and you still feel like you have a little bit more, the kidney would start to cramp. I could almost feel when it finally pushed everything out because it would be totally cramped up. That would actually last a few minutes after I was all done using the restroom and I had left the restroom. … it would gradually uncramp and go back 15–20 minutes later, sometimes.*—Male, age 29
Discomfort	*Just the UTI feeling. Just the discomfort. [On the day of removal] I was, at that point, just extremely depressed, and I was thinking, ''I can't continue this.'' It was just this continued discomfort. Rather than – it's not pain.*—Female, age 67
Pressure	*It would be like emptying a glass of water through a straw and it couldn't keep up with it. You know what I'm saying? It was more of a pull more than it was a pain. Just an uncomfortable pressure, I guess, if you want to call it. That was really the biggest symptom that I had that I wasn't having before the stent was in.*—Male, age 60
Dull, achy, or sore	*I had planned to not care for my grandchildren that week before I had the stent removed. But, I missed them and I did, and it hurt much worse after I was physically exerting caretaking them – they're 1 and 3 – picking them up, doing whatever … I guess it was four days after the stent was put in, and I crawled home, got in bed, and stayed there until I went back to get the stent out because it ached, really ached, after my physical exertion … I came home. I got in bed and said, ''I'm done. I can't do anything else.''*—Female, age 62
Stabbing or sharp	*The sharp pain is what's least fun. The constant pain you can slightly manage, and at least kind of mitigate to a point where you can accept it. But, the sharp pains that happen, you can't stop them and you don't know how high the pain is going to go because it's a sharp, sudden pain. You just know it's going to suck. You just don't know how bad.*—Male, age 39
Sense of stent presence	*It wasn't like it was a sharp pain or a knife sticking you or something. It was just you could tell there was something … It was just one of these inside pains that you really couldn't pinpoint exactly, but you knew that it was kind of irritating.*—Female, age 62
Blood in urine	*I feel like everyone always says, ''Hey, you're going to have some blood in your urine.'' But, there are the questions you do daily with this research thing. I feel like it kept asking me is there some blood in your urine, a lot of blood, a ton, blood clots, like what's going on? And, I was like, oh, does everyone not have gigantic blood clots and disgusting urine? I will say the last day before I got it out, my urine looked like it was passable for normal urine and I was shocked when that happened. So, it does gradually get better over the time that it's in. But, it's a lot at the front.*—Female, age 33
Urinary frequency	*[Frequent urination] lasted the whole time, but I would say probably the first half of the week or the first four days of the week [after stent placement] it was like every hour or more frequently than every hour. Then, the last two days, I could do every hour and-a-half, but it was still like the forefront of my brain was trying to work that out.*—Female, age 18 *They told me to drink a lot of water, so I had to go to the bathroom a lot. … It almost prevented me from drinking water because I'm like, hey, every time I go to the bathroom, it's very severe pain. I'm supposed to drink a lot of water, but I know what's going to happen to me.*—Male, age 40
Urinary urgency	*It is horrible. I will put it to you like that. If you get that first urge that you've got to go to the bathroom, you better be near a bathroom because you'll wet yourself. It's very embarrassing.*—Female, age 62 *But there were times where I'd pee every six minutes. You know? I'd be literally getting out of there after sitting in there for 10 minutes, come out, and then suddenly just have an urgency to run right back in. And, maybe I'd pee a teaspoon or a tablespoon, but the urgency was just like, ''If you don't go now, you're peeing your pants.''*—Male, age 54
Urinary incontinence	*I actually wet my pants two or three times throughout that week. Now, what would be – I especially being a nurse, I hold it a lot of times too long, and then I'll get called, but this was, I absolutely had no control over it.*—Female, age 51

(*continued*)

Table 2. (Continued)

Topic	*Participant quote*
Nausea	*I was the sickest I've been in a long time. … I didn't even want to eat the first two days, I was so nauseous.*—Female, age 38
Fatigue	*It just was a nuisance because I couldn't do much. I couldn't get back to my activity, what I was used to doing … just playing with the dog, getting back to work, being able to walk around. … I couldn't really just go and go and go. I had trouble getting myself going. … It drained my energy.*—Female, age 51
General malaise	*The whole thing just made me feel really gross. [The stent and the medicine] both independently and together made me feel terrible.*—Female, age 42
Section 2: Most bothersome SAS	
Pain	*It was just very intense. Not a feeling I'm familiar with, and it lasted as long as I was going to the bathroom for. I think a little bit was anticipation. Every time I went to the bathroom, it was like, ''Oh, is it going to hurt this time? Is it not going to hurt?'' I think there was a little bit of that going on, too.*—Male, age 33 *The cramps, the spasms. Because, that would just bring on a wave of literally nauseating – physically nauseating, overwhelming pain. … It almost felt like if I could visualize it, a rush of something going up through my kidney and back out. It was just so crazy. And then, it was almost like the worst charley horse you could ever imagine.*—Female, age 38
Urinary frequency	*The most annoying thing about the stent was urinary frequency. I mean, I'd go a dozen times a day, maybe more. Probably 15. … The frequency interrupting sleep, and having to go at work all the time, knowing that I'm going to have to drive for 45 minutes, stopping to think where can I go to the bathroom if I have to stop right away. … It was the frequency that was the worst.*—Female, age 52 *I would say probably the most bothersome would've been having to go to the bathroom a lot. A lot more than normal. … It wasn't like I could control that. I think it was probably because it controlled me.*—Female, age 62
Section 3: Reason for SAS bother	
Pain sensations	*When a stent is there, it's the most painful when you're going to the bathroom. Basically, as long as you have that stent in, going to the bathroom is something to be feared rather than just a normal thing that happens. That sucks having that fear, looking at everything that you're drinking and thinking, ''Should I keep drinking this much because you know this is going to make it so it hurts?'' and weighing every liquid decision is not fun.*—Male, age 39
Psychological factors	*The blood in the urine was just weird. Very weird. … It was always in the toilet … and looked strange. That did give me discomfort. Probably the worry because it kept going on almost a week later. So, that just made me concerned, ''Oh, is there something wrong?'' … There was just really, more anxiety over ''Is this normal?'' once it kept going for a while.*—Female, age 38 *So for me, I think it's because of how active I am … [now] being sedentary and not being able to move around a lot … because of my mentality … because I do like to move and get out, and be social, or go dancing. So, for me that was probably kind of the hardest part… it was emotionally and mentally draining…Physical pain I can kind of tolerate or mentally overcome, but the mental pain annoys me the most.*—Male, age 29
Interference with usual activities	*Definitely, definitely the frequent urination. That was so frustrating for me. I like to have control of my life, and that whole week was very like; you are not in control at all. … My entire week was dictated by the stent. It was 100 percent impactful and in the way of everything.*—Female, age 18
Section 4: Engagement in sex	
Impact	*I abstained during that time because I didn't want to figure out – didn't want to find out what it would cause. I was afraid of … Well, you know, I knew how painful it was to urinate. I didn't want to experience what it would be like to have sex.*—Male, age 53 *I was not in the mood. … It did reduce my sex life, just because I didn't feel like it with the stent in there.*—Male, age 54

SAS = stent-associated symptom; UTI = urinary tract infection.

Reasons for SAS bother

Participants most frequently mentioned pain sensations, psychological factors, and interference with usual activities when describing why they were bothered by their SAS. Participants stressed that the pain itself was bothersome and that it also exacerbated the effect of their other SAS. Participants also often linked their pain to psychological factors they found bothersome, primarily apprehension or anxiety caused by knowing that urination would be painful, and resentment for the recommendation to drink more water as it would ultimately lead to painful urination. Participants described that not being able to resume usual activities when the stent was indwelling, primarily due to pain and urinary frequency, left them frustrated. See Table 2, Section 3 for participant quotes.

Interference with usual activities

Table 3 summarizes participants' experiences with psychological, functional, and interpersonal effects of post-ureteroscopy stents in each of the three interference groups. Below, we expand on a variety of participant experiences in each group.

Minimal interference (*n*=12, 31%).

Participants in this group generally reported that the stent had little to no impact on their daily lives in most (if not all) domains explored (Table 3), and a higher proportion said that they were bothered more by urinary frequency than by pain. Focusing on sleep as an example, some participants said that the stent did not affect their quality of sleep. Those who reported a minimal impact on sleep quality focused their narratives on increased urinary frequency, although they explained their nighttime waking to urinate did not affect their ability to fall back asleep. None described any nighttime stent pain or discomfort that affected sleep.

Moderate interference (*n*=19, 49%).

For participants in this group, the stent moderately or substantially impacted many but not all of the domains explored. For example, focusing on mood, some participants in this group reported little to no change in their mood. However, other participants described negative emotions related to the SAS and struggling to remain positive for the duration of the stent period, primarily due to pain, discomfort, and activity restriction. Participants categorized as having their mood moderately affected used words such as ''cranky'' and ''grouchy'' to explain their mood, and said that they were ''frustrated'' and ''disappointed'' because the SAS prevented them from engaging in their usual daily activities.

Among participants who were employed, some said that they were able to work part-time with the stent, but working was difficult due to pain, urinary symptoms, and mental fog. More participants indicated that they were unable to work, even from home due to similar symptoms, leading to work absences and reduced work hours.

Several participants said that SAS had little impact on their ability to perform ADLs, such as housework. A few more participants, however, described modifications necessary to carry out daily activities, particularly during the first few days after stent placement. These participants said that they performed activities in short bursts and rested more often in between activities, asked others to help with daily activities, and prioritized certain activities, such as self-care and cooking. Most participants ascribed these limitations to pain or discomfort, and fatigue resulting from the stent being in place. Several said that their ability to perform daily activities returned to normal by the time of stent removal.

Focusing on leisure and social activities, some participants described curtailing activities, particularly for the few days after stent placement, although activities resumed before stent removal. More participants, however, reported a substantial reduction in their desire or ability to participate in social activities and ceased most activities until the stent was removed.

Substantial interference (*n*=8, 20%).

Participants in this group described experiencing considerable and pervasive psychological, functional, and interpersonal impairments related to the severity of their symptoms, and a higher proportion said that they were bothered more by pain than by urinary frequency. For example, with sleep interference, participants described an inability to fall or stay asleep, unusual sleep patterns, inability to find comfortable positions, needing to sleep in unfamiliar positions, and interrupted sleep because of increased urinary frequency, or because of pain and needing to take pain medication. Several also said that they experienced daytime exhaustion and fatigue stemming from sleepless nights.

Participants described their mood as ''miserable,'' ''depressed,'' ''anxious,'' and ''angry'' because of the pain, with anger about their pain experiences being the predominant emotion expressed. Participants' narratives also reflected a significant decline in overall enjoyment of life while the stent was in place, largely because of their inability to perform regular activities due to pain and urinary symptoms, including emotional distress caused by SAS anticipatory anxiety. Some participants described this time as a continuation of their experience with having a kidney stone.

Focusing on employment, most participants described not working at all for the duration the stent was in place. Those who did struggled with working effectively. Participants also expressed an inability to perform ADLs or maintain their daily routines due to lingering pain, which resulted in doing the minimal amount of activities only or having others help.

All participants indicated that the stent negatively impacted their participation in leisure and social activities in some way, primarily due to pain but also urinary frequency and urgency. Participants described completely disengaging from nearly all individual and group activities for the duration of the indwelling stent, and remaining house-bound and resting instead. Participants shared that having the stent in place affected more of their daily living activities than they had initially anticipated.

Interpersonal relationships

Most participants, across all three groups, described little to no change in their relationships with others while the stent was in place. Some remarked on being more irritable than usual and explained that others understood the short-term circumstances and became responsible for the day-to-day household activities.

Among adult participants who had active sex lives before the stent, most said that having the stent significantly impacted their sexual activity. Their narratives ranged from not even thinking about having sex to abstaining while the stent was in place due to concerns and nervousness about pain and what sex might feel like, not being in the mood, or because of general pain and malaise. A handful of participants said that

Table 3. Summary of the Psychological, Functional, and Interpersonal Effects of Post-Ureteroscopy Stents by the Interference Group

	Participant interference group		
Domain	*Minimal* (n = *12*)	*Moderate* (n = *19*)	*Substantial* (n = *8*)
Psychological			
Sleep	Little to no impact on sleep quality When sleep was impacted, it was due to urinary frequency and not pain, and participants were easily able to get back to sleep after waking to urinate *But other than that, there was no impact, and I was able to go right back to sleep. So, it didn't affect sleep other than urinary frequency.—Female, age 52*	Impact on sleep was mixed About half of participants attributed some level of sleep disruption to the stent, most commonly related to urinary frequency *The stent being in there caused me to urinate more often, which then I woke up more times in the night to urinate. I would wake up more tired in the morning, since I'd been woken up multiple times throughout the night.—Male, age 20*	Significant impact on sleep Most participants noted substantial disruption in sleep patterns and sleep quality Quality of sleep was affected by urinary frequency and some pain *Sleep was definitely not fun either. Like I said, I wasn't very comfortable, I couldn't stay asleep for very long at times.—Female, age 38*
Mood	Little to no impact on mood Participants were able to maintain a positive outlook, with only brief periods of negative mood linked to pain *Very little [effect on mood]. I mean at times I'd get aggravated, but it's about all of it. But, no, I think my mood was pretty consistently positive.—Female, age 58*	Impact on mood was mixed Some participants had no impact on mood Some reported increases in negative mood as a result of both pain and restrictions on usual activity Participants tended to use words such as ''cranky,'' ''irritable,'' and ''frustrated'' to discuss their experience *Sometimes I would be grouchy and sometimes I would just be very emotional. I just wanted to be better. I just wanted to feel better.—Female, age 25*	Significant impact on mood Participants expressed anger at being in pain, as well as using stronger terms such as ''depressed,'' ''anxious,'' and ''isolated'' to describe their emotions *I was in a real bad mood. I was irritated and angry.—Female, age 36*
Overall enjoyment of life	Little to no impact on enjoyment of life Participants continued with their usual activities and recognized that the stent was a temporary inconvenience *[Enjoyment of life] was barely impacted. The only impact was the annoyance of going to the bathroom. It was just annoying. So, as far as enjoyment of life, I could put up with a little bit of annoyance for a few days. That was not greatly impacted.—Female, age 52*	Moderate or significant decrease in enjoyment of life Many activities were curtailed or uncomfortable for participants, mainly due to pain The stent was also mentally burdensome *I would say [enjoyment of life] decreased a little bit just because of that mental expectation you have of all the things that you can go do, and obviously you think about things you want to do during those times that you're kind of missing out on … [it] definitely was not as enjoyable not being able to do the things that I would want to do or like to do.—Male, age 29*	Significant decrease in enjoyment of life Both pain and urinary frequency adversely affected participants' ability to engage in and enjoy most activities Anticipatory anxiety about the impending experience of pain and urinary frequency further impacted enjoyment *I would say that it greatly impacted. Just because like if you knew that somebody was going to stab you in the kidney every two hours, that's not a good life. So just from that point of view, just because like maybe the pain wasn't there the entire time, but the fact that I knew there was going to be pain, and it would be very, very bad, and it's going to happen pretty regularly just because of what I have to do, which is drink tons of water.—Male, age 40*

(*continued*)

Table 3. (Continued)

Domain	Participant interference group Minimal (n = 12)	Moderate (n = 19)	Substantial (n = 8)
Functional			
Work	No stent-related disruptions in ability to work *Yeah, I actually went back to work the next day.—Male, age 60*	Moderate or significant impact on ability to work Participants tended to take some time off or worked part-time after the stent surgery, worked fewer hours than usual once they returned to work, and worked less effectively with the stent in place *I took a couple days off for the surgery, and then I was able to go back. I worked a couple of hours at a time.—Female, age 19*	Significant impact on ability to work Participants mostly did not work for the duration of the stent, primarily due to pain and/or pain medication Participants struggled with their ability to accomplish work-related tasks if they did resume working before stent removal *I assumed that after a couple days on the couch – I took off a couple days of work and had a weekend – and I was like, ''Oh, four days will be plenty. Five days will be plenty'' and then I was like, ''I'll go back to work.'' And I would try to go back to work and I'd have to leave because the pain – like I said – the more I moved, the more uncomfortable I was.—Female, age 31*
Exercise	Little to no impact on ability to exercise as usual *I even went paint balling three days after that, and I was very active and everything was fine, fine. I didn't change one thing.—Male, age 45*	Moderate or significant reduction in desire or ability to exercise Many participants did not bother to try exercising with the stent in place Those who did exercise resumed activity toward the end of the indwelling stent period and/or substituted less arduous exercises for more strenuous ones *I mean, I didn't even attempt [exercise] because just with a little walking … and when I went to the store or tried to go out to eat, I mean, that would just drain me, so there's really no way I could engage in those activities.—Male, age 57*	Significant reduction in ability to exercise, relative to participants' usual levels of physical activity; participants did not exercise at all while the stent was in place Pain kept many participants from both formal exercise and from other types of physical activity, such as walking *I wasn't able to exercise. I wasn't able to even walk my dog. I wasn't really able to do anything around the house. I was kind of annoyed because I'm a pretty active person, so I thought for sure I'd feel fine.—Female, age 31*
ADLs	Little to no impact on ability to perform ADLs, such as housework, cooking, and self-care A few participants described being more tired or moving more cautiously than usual, while still successfully carrying out these activities *I was able to do those things. There wasn't any major issues. I just felt like I had to be more careful.—Male, age 33*	Limited impact on ADLs for some Moderate limitations on ability to perform ADLs for others, due to both pain and fatigue Participants were unable to carry out daily activities for the first few days but returned to normal activity levels by the time of stent removal Participants also made trade-offs by prioritizing some tasks over others and allowing ample time to rest between tasks	Significant limitations on ability to carry out daily activities Pain kept participants from doing their usual activities, with most doing as little as possible Limitations on ADLs persisted for the duration of the time that the stent was in place *I did the bare minimum that was required, like if I tried to take a shower, and stuff like that, and take out the trash, but I did the absolute minimum amount that I could.—Female, age 23*

(*continued*)

Table 3. (Continued)

	Participant interference group		
Domain	*Minimal* (n = *12)*	*Moderate* (n = *19)*	*Substantial* (n = *8)*
		I set them aside, or I did them on maybe the third day, when I felt better. Or I'd have a few hours where I was feeling pretty good, and I'd bust out and do some cleaning or something like that, and then end up being so tired that I couldn't do making dinner or something like that. So, it was a tradeoff.—Male, age 54	
Driving	Little to no impact on ability to drive *I still did the grocery store, and some of the shops I go to, and drove around.—Female, age 62*	Moderate impact on ability to drive Many participants did not drive for the first few days after stent placement, found driving uncomfortable, and limited the number and length of trips for which they drove *The only time I drove, I think it was twice. Once I went to get some groceries, and the other time I drove to the stent removal. So, out of those both times, it just wasn't comfortable at all. … I guess the bumps in the road made it more painful.—Male, age 39*	Significant impact on ability to drive A combination of pain and pain medication kept these participants from driving Some also did not feel well enough to consider going anywhere and thus did not attempt to drive *I couldn't sit up that straight to drive [because of the pain when I moved].—Female, age 67*
Childcare[a]	Little to no impact on ability to care for children or grandchildren as usual *The first day, like the first 24 hours, I avoided lifting them, and we were able to just kind of keep them at arm's length, but beyond that, no, absolutely not. I was back to all normal interactions with them.—Female, age 52*	Moderate impact on ability to care for children Picking up children exacerbated pain and bleeding Participants sought help with childcare from others and/or modified the ways in which they interacted with children *My husband actually had to stay home and help take care of the kids, because with getting sick and having to rush off to the bathroom and not being able to pick up my two-year-old, and all that kind of stuff. He had to stay home and help for a couple of days. … I want to say he took maybe three days off.—Female, age 25*	Significant impact on childcare Participants significantly curtailed their interactions with children for the duration of the stent They also placed restrictions on how they interacted when they did see children or grandchildren *I just stayed away. [I didn't have the grandkids over and didn't visit.] … I just felt like I was missing out on a lot.—Female, age 67*
Interpersonal			
Leisure/ social activities	Little to no impact on ability to engage in leisure and/or social activities as usual *…because I knew I always had to be kind of close to a restroom, I tried not to be out for too long, if I was out. But, overall, I was able to live my life pretty normally.—Male, age 33*	Moderate or significant impact on desire or ability to participate in leisure and social activities Participants engaged in enjoyable activities on a more limited basis, took a hiatus for a few days before resuming leisure/social activities, or entirely curtailed these activities when the stent was in place	Significant impact on leisure and social activities Participants almost completely disengaged from leisure and social activities and did very little for the duration of the indwelling stent Limitations were primarily due to pain and urinary frequency *It also happened over [a holiday] weekend, so I just canceled a bunch of plans. …*

(*continued*)

Table 3. (Continued)

Domain	*Participant interference group* *Minimal* (n = *12)*	*Moderate* (n = *19)*	*Substantial* (n = *8)*
		Limitations were due to pain, urinary frequency, and other stent symptoms *I didn't even want to play video games, that was a surprise. Okay, we got a week of video games, and I was like, "Nah. I don't really have that concentration level or something." It's weird. … We had one of our friends from a local area over for dinner one night, and I just kind of said, "Hey, I'm low-action. I'm not going to be pretty vibrant today." And that was about it. I hung out with very close friends, but not casual.—Male, age 54*	*I didn't socialize. I really didn't leave the house. … I didn't hang out with my family. … I watched a lot of TV.—Female, age 42*

[a] The number of participants for which childcare was relevant was small.
ADLs = activities of daily living.

they had sex with the indwelling stent and explained that their symptoms did not become worse. See Table 2, Section 4 for participant quotes.

Discussion

The findings from our novel qualitative exploration of patients' experiences with a post-ureteroscopy ureteral stent illuminate how SAS affect patients' daily lives in a wide variety of ways, depending on severity of the symptoms. Participants' varying narratives on interference with daily activities due to pain and urinary symptoms, primarily urinary frequency, led us to categorize participants' stent experiences into minimal, moderate, and substantial interference groups.

For participants in the minimal interference group, the stent had little to no impact on participants' usual activities. Although these participants described experiencing both pain and urinary frequency, pain bothered them less than urinary frequency. Participants in the moderate group experienced minimal interference for some activities yet moderate or substantial interference for other activities. For those in the substantial group, most if not all their usual activities were negatively affected in some way, with pain bothering them more than urinary frequency. These findings suggest that an important group of patients experience pervasive and debilitating interference in their lives following stent placement; stentless ureteroscopy could be evaluated for high-risk individuals.[9] They also provide evidence of the importance to assess patient-reported pain and urinary symptoms separately rather than in a composite index.

Our findings also suggest that current PRO assessments for individuals with ureteral stents adequately cover the most impactful physical SAS. However, some participants described substantial impact on their psychological health, providing evidence that psychological factors, such as anticipatory anxiety and mood, may need to be added into PRO assessments; psychological factors are not well captured with current instruments.

These patient experiences support opportunities to guide patient expectations following ureteroscopy. Patients are often counseled to increase fluid intake, yet the need to

Box 1. Messages to Guide Patient Expectations with a Post-Ureteroscopy Stent

- Pain after ureteroscopy with stent placement can come and go, and sometimes be unpredictable.
- Pain may include urethral pain with urination after the ureteroscopy procedure. This should decrease over time.
- Expect to see blood in your urine after ureteroscopy. Blood may also be in your urine until the ureteral stent is removed.
- Expect to urinate more frequently because of the increased fluid intake. Focus on increasing your fluid intake earlier in the day to reduce possible sleep disruptions to urinate.
- You may not feel like doing some of your usual activities for a few days.
  - Prioritize certain activities, such as self-care and cooking, in the days following your procedure.
  - Have a backup plan for child care and other essential tasks, in case your symptoms interfere with your daily activities.
  - Do your daily activities in short bursts and rest in between activities.
  - Ask for others to help you with your daily activities.
  - You may want to plan to take a few days off work following your procedure.
  - You may want to plan to grocery shop or run other essential errands in the days before your procedure.

urinate frequently creates anticipatory anxiety. Guiding expectations, and perhaps modifying counseling, could reduce this burden. Likewise, guiding expectations that urethral pain is common and often resolves within a few days could potentially help patients manage symptoms with more certainty (Box 1).

Regarding the strengths and limitations of the study, we were able to facilitate information recall by conducting all interviews within 30 days of stent removal. We also enrolled a diverse sample in terms of gender and age, which is critically important for informing PRO measures and provider–patient communications. Given the number of participants interviewed and the breadth of experiences shared, we believe that we would not discover any new conceptually meaningful information with additional interviews from these sites. However, it is unknown whether a different group of participants from other locations would have shared similar or different experiences, particularly if we had greater diversity in participant race and ethnicity. Our study did not capture parent/caregiver impact from pediatric patient discomfort, which may benefit from future studies. While the number of pediatric patients is small, we felt that it important to record these perspectives. Finally, individuals with stents for other indications may experience symptoms to a different degree.[10]

Conclusions

SAS imposes a substantial burden for some patients after ureteroscopy and considerably decrease enjoyment of many aspects of life for the duration of the indwelling stent. Other patients, however, experience only moderate or mildly bothersome SAS, with little impact on daily living. We have used these findings to suggest counseling messages that urologists can communicate to patients before stent placement on the expectations for daily living with a ureteral stent post-ureteroscopy (Box 1). These findings also suggest that while current PRO assessments adequately cover the most impactful physical SAS, psychological factors are not well captured and represent an important opportunity for future investigations.

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Supplementary Material

Supplementary Data S1

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Abbreviations Used

NIDDK = National Institute of Diabetes and Digestive and Kidney Diseases
PRO = patient-reported outcome
SAS = stent-associated symptoms
STENTS = STudy to Enhance uNderstanding of sTent-associated Symptoms
USDRN = Urinary Stone Disease Research Network
UTI = urinary tract infection