



How do women with interstitial cystitis/bladder pain syndrome make treatment choices?

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Abstract

Introduction and hypothesis There is a relative lack of data regarding how patients weigh various factors when choosing a treatment strategy for interstitial cystitis/bladder pain syndrome (IC/BPS). Our aim is to describe patient experience with their current and prior treatments and discuss factors they consider when choosing a treatment.

Methods Twenty-one women with IC/BPS participated in five focus groups moderated by a psychologist. Focus groups were conducted until thematic saturation was reached. Group discussions were transcribed and independently coded by two reviewers. Emergent themes and concepts were identified using grounded theory methodology. Data on symptoms and beliefs regarding medications were collected using validated questionnaires: Interstitial Cystitis Symptom and Problem Index (ICSI and ICPI) and Beliefs in Medications Questionnaire-Specific (BMQ-S).

Results The median age of participants was 42 years, and all had some college education. Median score (range) for the ICSI was 12 (4, 20) and for the ICPI was 10 (3, 16), indicating moderate symptom burden. Most patients had tried only first- or second-line treatments. The median BMQ-S score was 2, indicating a neutral attitude toward medication. Several themes were identified. Patients expressed interest in self-management of symptoms using a structured care plan that incorporates guided self-care practices and care that can be delivered virtually. Patients desired to minimize treatment side effects by reducing prescription medications and avoiding surgical procedures. Finally, patients had considerable interest in alternative treatments; however, they wanted these treatments to be evidence-based.

Conclusions Women with IC/BPS have a strong interest in guided programs that teach self-care practices and deliver alternative treatments through remote platforms.

Keywords Alternative treatments · Focus group · Interstitial cystitis · Bladder pain syndrome · Qualitative · Self-management

Introduction

The American Urological Association (AUA) defines interstitial cystitis/bladder pain syndrome (IC/BPS) as “an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes” [1]. Estimates of prevalence vary based on

the diagnostic criteria used but are in the range of 2% to 6.5% [2]. IC/BPS is known to have a significant impact on quality of life, including high rates of comorbid depression and anxiety disorders [3, 4]. IC/BPS also has significant social consequences such as multiple medical appointments and wage losses of > \$4000 per year, highlighting the substantial challenges that patients with this condition face [5].

IC/BPS presents therapeutic challenges for patients and providers. Women with IC/BPS perceive providers to be dismissive or unsympathetic to their condition and that providers prescribe treatments without considering the impact of treatments on their lives [6–8]. Initial treatment options (first and second line) include behavioral changes, physical therapy, amitriptyline, pentosane polysulfate, and intravesical instillations [9]. Providers are frustrated because non-adherence to prescribed treatment is high even in the clinical trial setting. For example, in a randomized trial, adherence to amitriptyline

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was 47% [10]. Furthermore, evidence-based guidelines for the treatment of IC/BPS are based on clinical trial data and were not developed with patient input [9]. Low treatment adherence may be related to the disconnect between the treatment goals or priorities of women with IC/BPS and treatments that providers prescribe using existing guidelines.

The Institute of Medicine presented shared decision making as a fundamental approach to improve health care quality in its 2001 report *Crossing the Quality Chasm* [11]. Indeed, previous studies suggested that shared decision making can improve outcomes across a range of chronic conditions [12, 13]. The AUA guidelines recommend taking a patient's preferences into account when choosing initial therapy [1]. Incorporation of the patient perspective in management of chronic pain may lead to better outcomes and higher patient satisfaction [14].

To better understand how patients make decisions about treatment, we conducted a qualitative study among women diagnosed with IC/BPS. There has been a growing body of qualitative literature on patient experience with IC/BPS. Kanter et al. [15] described how patient-provider interaction plays a key role in how patients perceive their condition. Chen et al. [16] described the frustrations of living with IC/BPS and reviewed some specific culturally based coping strategies, such as Chinese herbal supplements or drinking warm water. Other qualitative research described the psychological impact of IC/BPS and highlighted the need for mental health services in an integrated care model [17]. Although these studies described the experience of living with IC/BPS, there is a relative lack of data regarding how patients weigh various factors when choosing a treatment strategy. The goal of the present study was to describe patient experience with their current and prior treatments and discuss factors that patients consider when choosing a treatment. In this study, we purposefully focused on patients who were primarily using early-stage first- and second-line treatments per AUA guidelines.

Materials and methods

Participants were recruited from Urogynecology and Urology practices of the Hospital of the University of Pennsylvania. Inclusion criteria were: women aged ≥ 18 years with a diagnosis of IC/BPS based on the AUA criteria [9]. Exclusion criteria included: non-English speaking, a history of diabetes mellitus, recurrent urinary tract infections, urinary retention, neurological condition known to affect the lower urinary tract, bladder calculus, pelvic floor malignancy managed with chemotherapy or radiation, or recent pregnancy. The study was reviewed and deemed exempt by the University of Pennsylvania Institutional Review Board (IRB protocol #834559).

Focus groups

Five focus groups were conducted. Given the sensitive nature of IC/BPS, we limited focus group size (three to five participants) to facilitate discussion. We developed a moderator guide designed to explore participants' experiences with IC/BPS treatment and factors that influence treatment choice (see [Appendix](#) for a sample moderator guide). Discussion prompts addressed topics including: interactions with providers, experiences with and/or perceptions of treatment options, perspectives on treatment strategies, and challenges in finding effective treatments. Focus groups were moderated by a trained psychologist with prior experience in qualitative research (LF). Focus groups were conducted until saturation of themes was reached. The first focus group was conducted in person, and subsequent focus groups were conducted via a virtual video conferencing platform because of social distancing restrictions in the context of the COVID-19 pandemic. Following each focus group, transcripts were reviewed and minor changes were made to the moderator guides to refine the discussion points. All focus group discussions were audio-recorded and transcribed verbatim.

Questionnaires

Participants provided demographic data. A series of questionnaires were administered to all participants to quantitatively measure IC/BPS symptom severity and beliefs regarding medication therapy.

Interstitial cystitis symptom index (ICSI)

The ICSI [18] is a four-item measure which assesses the frequency of lower urinary tract symptoms (urgency, frequency, nocturia, and bladder pain). Scores range from 0 to 20 with higher scores reflecting worse symptoms.

Interstitial cystitis problem index (ICPI)

The ICPI [18] is a four-item measure which assesses level of urinary symptom bother related to urgency, frequency, nocturia, and bladder pain. Scores range from 0 to 16 with higher scores reflecting greater bother.

The Beliefs about Medicines Questionnaire-Specific (BMQ-S)

The BMQ-S [19, 20] is a questionnaire-based method to quantitatively assess beliefs about medications. The instrument consists of two subscales that address the subject's sense of necessity (BMQ-SN) and concern (BMQ-SC) regarding their own medications. The necessity and concern subscales assess positive and negative attitudes toward medicines, respectively. Subtracting the BMQ-SC score from the BMQ-SN score

gives a differential score ranging from -20 to $+20$. Positive scores indicate that the subject has a net positive perception of the medicine and vice versa for a negative score [19]. Scores close to 0 indicate a neutral attitude to medication. The questionnaire has been well validated with high test-retest reliability (Cronbach's alpha 0.77) as well as criterion-related and discriminant validity [20].

Analysis

Participant characteristics and questionnaire data were assessed using descriptive statistics. Focus group transcripts were uploaded into NVIVO 12 (QSR International, Doncaster, Victoria, Australia) for analysis. Two members of the research team who were familiar with the project but did not conduct the focus groups independently coded the transcripts. New codes were discussed and added as needed until consensus was reached. Codes were grouped into themes (insights arising from participant comments), which were then grouped into emergent concepts using grounded theory methodology [21]. Illustrative quotes were then pulled from the transcripts to support themes and concepts.

Results

A total of 21 subjects were recruited and participated in the five focus groups. Patient characteristics are detailed in Table 1. The median age of participants was 42 years with IQR of 29–57. Most participants (90.5%) identified as white. All participants had some college education with most having post-college education. The median ICSI and ICPI score indicated moderate symptom severity and moderate impact on quality of life, respectively. Participants were relatively early in their treatment experience, with the majority (90%) having tried only first- or second-line treatments. The median BMQ-S differential score of 2 indicated a relatively neutral attitude to medication.

Comorbidities frequently associated with IC/BPS were assessed and are listed in Table 1. Patients had received a median of three treatments for IC/BPS at the time of participation in the focus groups.

Emergent concepts

We identified five emergent concepts regarding treatment preference during our focus groups, which are listed in Table 2 and described below.

Interest in self-management of symptoms

Several participants wanted to take an active and intentional role in managing their symptoms. Participants compared IC/BPS to

Table 1 Patient characteristics ($n = 21$)

Age, median (IQR)	42 (29–57)
Parity, median (IQR)	0 (0–1)
Race, n (%)	
White	19 (90.5)
Black	1 (4.8)
Other	1 (4.8)
Education, n (%)	
Some college	1 (4.8)
Graduate from college/university	12 (57.1)
Beyond college/university	8 (38.1)
Medical history, n (%)	
Anxiety	7 (33.3)
Chronic back pain	3 (14.3)
Depression	6 (28.6)
Endometriosis	3 (14.3)
Irritable bowel syndrome	5 (23.8)
Pelvic floor dysfunction	5 (23.8)
Duration of disease in years, median (IQR)	2.5 (1–11)
Number IC/BPS treatments attempted, median (IQR)	3 (2–4)
Highest tier treatment attempted, n (%)	
First line	9 (42.9)
Second line	10 (47.6)
Third line	2 (9.5)
Questionnaire scores, median (IQR)	
ICPI score	10 (8–12)
ICSI score	12 (8–14)
BMQ-S score	2 (–4–5)

IQR: interquartile range, ICPI: Interstitial Cystitis Problem Index, ICSI: Interstitial Cystitis Symptom Index, BMQ-S: Beliefs about Medicines Questionnaire-Specific

other chronic conditions when they described why it was important that they take an active role in managing their condition. “You have to treat this as if it were diabetes or cancer or anything else. You have to be the one that’s informed and take charge of it. So I did read about it, I did my own research.”

Almost all patients described self-care practices that they were using to manage their symptoms. Fluid and diet modification emerged as a common self-management practice. Patients preferred diet modification to using medications for controlling symptoms (“I don’t really like to take [phenazopyridine].... ..depends on the case but sometimes it’s simpler to just drink lots of water”). Another common self-care practice was stress management. Many patients had recognized the role of stress in worsening their symptoms (“I’ve definitely noticed when I’ve been really stressed it’s gotten way worse, either with school or with work or something”) and were taking active, intentional steps to avoid or reduce stress such as mindfulness practice.

Table 2 Concepts, themes, and illustrative quotes

Emergent concept	Themes	Illustrative quotes
1. Interest in self-management of symptoms	- Desire for a structured care plan	<p>“She [urogynecologist] looked at my stuff, she listened to what I had to say. She said I think you have this. And this is what I think we are going to do. And this is the plan. And how do you feel about it. And just that was awesome just to finally feel like okay you know this is not going to make my pain go away but at least at least it’s something...It’s not in my head. I have a plan to move forward”</p> <p>“Before [telemedicine], it was like thinking about a UTI and it’s Friday night and the doctors are closed and these online doctors did not exist. It was a lot harder. And now with the internet world...it’s not as difficult but in the past that was what was hard”</p> <p>“I find myself, even if I get a prescription filled I will not take the whole thing I’ll keep a couple pills for when I cannot see the doctor and cannot get to the lab to get a specimen out...So that’s not good at all to do but I feel like you have to do it because there’s no alternative”</p> <p>“[Desire for a doctor to say] ‘I do not know but you should go in this direction’ kind of thing. Just knowing where to turn next. Knowing where you do not know and then do not just stop right there. Pursue, not just on my behalf but also like be my advocate. And saying well we cannot just ignore this, we need to continue to work it up and get you some answers because that’s not a way to live”</p>
	- Use of self-management strategies	<p>“I personally flood my system with water and eat something very benign like pasta or something like that and wait for it to clear the system...if I ate something we would walk home from a restaurant and I would just keep walking just to try to, thinking I could burn it out of my system and have it pass faster, so I become more mobile and more headstrong about I can get this passed sooner”</p> <p>“I think that treatments that do not interfere with my lifestyle, that would allow me to stay active, still feel like fully competent at work, not feel like I need special measures at work. Things that you can pretty easily tend to and manage yourself would be preferable”</p>
	- Recognition of chronic nature of IC/BPS	<p>“It’s like being a diabetic. You just have to make sure you take medicine, eat the right things, and its constantly, you cannot let your guard down. So, if you let your guard down, then you get sick”</p> <p>“I find that I can cohabituate with IC. It’s not comfortable, I’m still voiding 20–40 times a day but it’s manageable especially in the home environment. I have more ease...I think I’ve learned a lot of tips that I can apply to try to coexist with it”</p>
	- Support group involvement	<p>“And just attending support groups with women who had been through this most of their lives—some women started as early as kindergarten. It was very inspiring to hear their stories and how they managed it. And so it was completely on my shoulders and so it was either suicide or get a hold of it and deal with it”</p> <p>“I feel like a smaller group was very helpful. And it’s nice to talk to other people that experience the same thing”</p>
	- Insight into role of stress and attempts to mitigate stress	<p>“Like I’m trying not to stress myself out about it but it ends up happening even more because I do not want to have a flare up at work. So stress plays—I think—a huge part in it”</p> <p>“I think stress plays a big part...It just is like mind over matter a little bit”</p> <p>“If something’s coming up and I’m just getting really anxious about it the symptoms get a lot worse...once I started kind of relaxing about it and kind of just accepting that it is what it is, the symptoms started to go away”</p>
	2. Access to care	- Lack of availability of providers knowledgeable in IC/BPS
- Logistical challenges		<p>“I waited for appointments for a top doc at [academic medical center]. It blew up in my face. I waited almost a year and it was right on the heels of Sandy the hurricane and they had to cancel it and I should have taken that as a sign from god...It was a waste of time and he said it was all psychological”</p> <p>“It’s like a full time job...it’s like okay, just as long as I get down there and be able to find some new information.... It’s difficult. Logistically it’s difficult”</p>

Table 2 (continued)

Emergent concept	Themes	Illustrative quotes
3. Interaction with providers	- Cost concerns	<p>“It’s also difficult: you got to find an acupuncturist, you got to go to the acupuncturist. It takes time to work and costs a whole lot of money.... It’s discouraging because it’ll probably not work”</p> <p>“She gave me a prescription for Urelle and so I started taking that. I had a really hard time finding it and it’s expensive but I got it and that does help”</p>
	- Importance of clear communication regarding diagnosis and treatment plan	<p>“When I saw this new doctor who was like a pain doctor it was way, way better. She was great and I felt really comfortable and I’m really thankful for that experience because now I feel like I’m more likely to go to the doctor and like you know partner with them to make my life easier, than being scared to go and avoiding it entirely”</p> <p>“I think for me, I feel like since I’ve seen so many doctors and I have got that brushoff. When I finally got to the urogynecologist...I felt like I was finally being heard and instead of being just written off. And I think that’s really important”</p>
	- Positive interactions with providers improve perception of disease state	<p>“I am thinking, why am I hurting and I would actually concentrate on this pain and it would hurt even more. So the fact that with the other doctor it was like ‘do not worry, it’s normal, you have this pain, you have something wrong, kind of, but there are treatments.’ And the fact that you say, ok there are treatments...It kind of relieves the pressure. And you know what you have to work on”</p> <p>“I drove...two or three times a week for physical therapy and they were among the most kind and loving individuals, highly trained, that I’d found. And sympathetic, kind, gentle”</p>
	- Negative interaction with providers hinders care	<p>“I feel like this is a pretty devastating diagnosis...to find out that you are going to be suffering the rest of your life with no real hope in sight. And they are just very blasé about it. ‘Oh, looks like you have interstitial cystitis. This is your new normal.’ That was a quote”</p> <p>“I felt like I kind of fell through the cracks a bit...They’ve done the testing. They kind of put me off. I did not really get any additional suggestions or advice at that point”</p>
	- Desire for remote access to healthcare	<p>“I just wish there were a better way to connect with other people. Just to even share ideas and experiences. I think that would actually take down a lot of the barriers to treatment”</p> <p>“I think my biggest issue in the past was access to meds, so getting a hold of the doctor. I do not find that I have that issue now because the doctor now – even with the online portal you are able to get a hold of people a lot easier and then knowing what’s wrong, I already have the medicine on hand...”</p> <p>“One of the things I’ve really enjoyed...is being able to leave messages with my providers, which I did not have a great way to do that in the past...so it’s kind of nice to feel like, well if I have a question or if I have trouble, it’s easier for me to reach out and be like “hey things aren’t going the way we thought they were going to go”</p>
4. Desire for treatments supported by evidence/grounded in pathophysiology	- Awareness of current literature	<p>“I read an article not that long ago...that some doctors think that...interstitial cystitis is an infection that’s such a low level that they cannot test it”</p> <p>“And I’m thinking am I getting—is this an autoimmune thing? Because I’ve read some things say that it could”</p> <p>“I remember there’s definitely a thought process that histamine release is a factor. And then autoimmune also came up”</p> <p>“I’ve read somewhere that there’s some thought that it could be a constellation of issues that are just falling under this umbrella of IC, and that makes it so complicated to figure out what may or may not be helpful for anyone who’s suffering with it because like you said what’s good for you may be terrible for someone else and vice versa”</p>
	- Desire for further research	<p>“I just feel like there’s not enough research done. I just do not think they have enough information to diagnose us with anything”</p> <p>“With any medication out right now, there is not a probability of it working and a lot of them have side effects. So I think if there was enough science-based evidence into IC and there was people saying, ‘ok we took this, and this helped us’, I think a lot of us would be like ‘ok we’ll do that.’ Or if there was a surgery that we knew was going to have a high chance. So I think we just need a team of doctors and a higher probability of something working for all of us”</p> <p>“There needs to be more research especially associated with neurology. Because I think that’s a huge component and obviously we need more research”</p>
5. Desire to minimize side effects	- Concern regarding adverse effects of prescription drugs	<p>“When the doctor mentioned the [pentosan polysulfate sodium], I had just been reading about how it’s been found to lead to some eye problem. Like serious</p>

Table 2 (continued)

Emergent concept	Themes	Illustrative quotes
	- Interest in alternative treatments	<p>retinal issues in addition to all the other horrible side effects it sounded like it had”</p> <p>“I mean whatever I can do that’s not another medication on top of whatever else I’m on I’m totally down for”</p> <p>“THC helps me sleep, CBD helps with pain. Like I said the pills [other prescription medications] I had did not work”</p> <p>“I think those are things that, yeah they are good for our body as a whole so I’m always open to the natural treatments before I go to anything else. But again I think these are all things that we are all so desperate to do anything to help ourselves and those are just the first things that we go to”</p> <p>“Meditation has definitely really helped me. Just a kind of take a break and get out of your head of being like ‘oh this stinks I’m in so much pain’ and you just cannot get over anything else”</p> <p>“I also do mindfulness meditations and I practice every single day. And so I know that has helped. Truly, diet and meditation has kind of kept things at bay a good amount of time for me”</p> <p>“I’m just amazed at how much CBD can do a variety of things and what science has shown. Especially with things like seizures and stuff like that. It’s impressed me. And so, let us see what else it can do. It clearly worked in some areas of medicine and body health conditions. So seems like it has a little bit of a leg to stand on”</p>

Patients recognized that a structured plan was essential for allowing them to self-manage their condition. Such a plan was especially important for managing acute worsening of symptoms or “flares” with patients expressing frustration when such a plan was not in place (“You feel sick that day, but you can’t get into the doctor. I mean I know I have prescriptions waiting to just drop off urine...And then if it comes back negative, then what?”). In the absence of a plan from their own provider, patients frequently turned to the internet to identify solutions. While some patients found internet chat groups stressful, stating that they stayed away from them, others had identified reputable websites that had provided useful information (“I think the IC network has been a real bevy of information and it’s been very good for me as well”). Patients also reported that support groups were useful for both emotional support and learning self-care practices.

Self-management empowered patients to cope with IC/BPS despite periods of hopelessness. “There’s no cure. I don’t know if I’m going to die with it. I imagine I will have it for the rest of my life. I don’t have any hope there but as long as I can peacefully coexist with it I can handle it.” Some patients used acceptance as a coping mechanism using terms such as “deal with it” and “grin and bear it.”

Access to care

Study participants identified lack of knowledgeable providers as a major barrier to treatment. Several patients described difficulty in finding a provider who was both knowledgeable and willing to take care of them. A common experience among our focus group participants was interaction with providers who

they felt were either not knowledgeable about IC/BPS or not interested in managing their condition (“You’d like to find somebody that has at least heard of this condition, so they can really understand what’s happening”). Many participants had visited multiple practitioners before they identified a provider who was knowledgeable and willing to manage their condition. Participants indicated that early referral to a specialist who was knowledgeable about IC/BPS would have greatly facilitated their treatment (“Once I found the urogynecologist, she’s definitely been the most helpful and from there it’s been good. But I think just that path of getting to that point was long and pretty frustrating”).

Patients also reported logistical challenges with managing multiple appointments and the impact this had on their lives. Though most patients were very interested in pursuing physical therapy, they described the difficulties of accessing a treatment that required multiple appointments. “When I had to get the physical therapy, I had to make special arrangements in order to be able to travel far enough to get it... And going to your boss and saying, ‘Hi I’m wondering if we can make an arrangement so that each Wednesday I can leave an hour early in order to do a special kind of physical therapy?’” Another patient cited cost of physical therapy as a barrier. “My insurance is actually just obnoxious so I have to make sure I go through the right channel. But I do want to pursue that...” Similar issues were described with other treatments that required appointments such as acupuncture.

Patients described how telemedicine had improved access to care. Patients spoke positively of platforms which allowed them to message with a care provider without requiring an in-person appointment. “I like the telemedicine...it’s very

helpful I think. Because then you can kind of do it from anywhere. You don't have to necessarily go into the office."

Interactions with providers

Participants frequently described how the quality of their interaction with a provider influenced the course of their disease. Several participants reported that interactions with an empathetic and knowledgeable provider had a positive impact on their condition. "And the fact that you say, ok there are treatments...It kind of relieves the pressure. And you know what you have to work on." A sense of validation and empathy from care providers was frequently brought up as an effective aspect of treatment experience. "He [urologist] was just very understanding and he reinforced the fact that this is a big problem and that he wants to help people and there is a way to feel better and he was sort of validating everything I felt and so that was very positive." Similarly, patients described how negative interaction with a provider adversely affected their condition. "I remember when I initially saw my first urologist I think I even went there in a flare...And it was sort of like a traumatizing experience because it was my first time there, I was in so much pain, and there was not a lot of communication."

Desire for treatments supported by evidence/grounded in pathophysiology

Focus group participants expressed preference for treatments that addressed an underlying disease mechanism. Most patients were aware that the cause of IC/BPS remains unknown and had taken the initiative to read extensively about IC/BPS. "I learned how to read medical journals ad nauseum." They described various theories underlying IC/BPS including allergies, autoimmunity, inflammation, neurological dysfunction, and stress-based etiologies. Few patients were interested in empirical treatments not supported by evidence with one patient stating, "I'm a very science-based person..." Another patient was unwilling to try alternative treatments that were not evidence based. "I think if I went to a doctor and they said to me sincerely 'we think you should try CBD' or 'we think you should try acupuncture'...it's not that I'm not willing to try it...but I think...it does make a difference to have a doctor that could say to you, 'I have some patients that use it and it's working for them' and it does lend a little bit more credibility to things that are not really mainstream medicine."

Several participants acknowledged the need for further research into IC/BPS and stated that their willingness to pursue treatment options is contingent on the level of evidence available to support their use. In particular, there was interest in further research regarding alternative and complementary medicine options to treat IC/BPS. "CBD oil I'm curious about, but I'm kind of waiting to see what the verdict is on

it. I know inflammation—it's supposed to help with it so it sounds great."

Desire to minimize side effects

A common theme among focus group participants was concern regarding side effects of medication and a desire to limit medication use. "I have not tried any of the treatments or the medication out there just because I've been really scared of the side effects that I've read about." This concern was related to their understanding that IC/BPS was a chronic condition and that long-term medications carried a greater risk of side effects. "I mean I just don't like the idea of it long term. There's always the fear that 'ok am I going to need a higher dose as I get older or become more immune to it or is my body going to respond or change because of it.'" However, patients were willing to take medications short term to manage flares. "I'd rather do things more naturally which I do try to do but I do take the Urelle [Methen-M.Blue-S.Phos-Phsal-Hyo] when I do feel I like I need it."

Similarly, patients wanted to avoid invasive treatments stating that they would undergo surgical management only if they offered a high possibility of improving symptoms. "Unless somebody can show me the research of positive outcomes I'm going to probably pass on something invasive like (cystoscopy with hydrodistension)."

The desire to minimize side effects and avoid surgical procedures led these patients to seek out physical therapy, complementary and alternative treatments. Most patients viewed physical therapy as having no side effects. Participants specifically identified self-directed meditation, hypnosis, and yoga as strategies that they had already used or were interested in using in the future to manage their symptoms. "I was like happy to know that a lot of the treatments are like integrative medicine based, so like meditation, and stuff like working on your diet and just stuff that's kind of like natural as opposed to like, I need to rely on medications to like manage this." An important goal for patients interested in alternative treatments was that these treatments would allow them to discontinue prescription medications. "I think ideally I'm almost trying to not be on any medications. I really work on that." Specific complementary drugs mentioned included tetrahydrocannabinol (THC), cannabidiol (CBD), and turmeric, which some women had used successfully to control symptoms.

Discussion

Our qualitative study provided insights into how women with IC/BPS make treatment decisions. We purposefully focused on patients who were using first- and second-line treatments and asked probing questions about each of the treatments

outlined in the AUA guidelines. A prominent theme that emerged was a desire for self-management of symptoms. Providers frequently view chronic pain patients as needy and demanding [22]. However, most patients in our study expressed frustration with having to call their provider and instead wanted a care plan that would allow them to manage their symptoms on their own. Prior focus group studies have identified the importance of a well-organized plan that present an array of treatment options for managing IC/BPS [22]. Our study advances this concept by demonstrating that IC/BPS patients want to be actively engaged in developing this plan with many choosing to minimize prescription medications and avoid invasive procedures. Additionally, IC/BPS patients wanted to use self-care practices such as diet and fluid modification and stress reduction techniques for both preventing symptoms and managing flares. Finally, patients were reluctant to call providers and wanted to do this only if they were unable to control symptoms on their own.

Self-management programs have been used with success in the management of patients with chronic conditions and specifically in those with chronic pain [22, 23]. Lorig et al. described that these programs are built on five key tenets: problem solving, decision making, resource identification and utilization, patient-provider partnerships, and taking action [22]. Patients in our focus groups either demonstrated or expressed the desire for their care plan to be based on these tenets. Specifically, patients demonstrated problem solving by taking initiative to extensively educate themselves about IC/BPS and learn self-care practices. Autonomy in decision making emerged as a key theme with patients wanting to take an active role in choosing treatments. Resource utilization and taking action were seen through patients seeking out educational resources including internet websites and support groups through which they could learn self-care practices and receive emotional support. Finally, recognizing the importance of patient-provider partnerships, our patients had visited multiple providers until they identified one who was willing to allow them to be actively engaged in their own care. Though patients wanted autonomy, they still wanted to engage with a knowledgeable provider who would help them construct a plan for guided self-care. Research in other chronic conditions has demonstrated that self-management care plans allow patients to gain self-efficacy or the belief in one's ability to self-manage a condition [24]. Our findings provide a useful framework for how clinicians can support IC/BPS patients in achieving self-efficacy. A structured care plan can be created by encouraging patients to choose evidence-based treatment options that are in line with their values. Providers too should be prepared to develop treatment strategies that allow for guided self-care for patients with IC/BPS. Such treatments could include cognitive behavioral therapy that not only addresses coexisting anxiety [25] but also encourages patients to deepen their insight into the role of stress in IC/BPS. For flare

management, a structured plan could include orders for urine tests, urinary analgesics, and even antibiotics that patients with high medical literacy could access without calling the provider.

Another important theme that emerged from our focus groups was the presence of barriers to accessing care for IC/BPS. Patients had faced considerable difficulties in finding knowledgeable providers willing to manage IC/BPS and then faced additional challenges in accessing treatments. Prior studies indicate that IC/BPS patients have 7–10 healthcare encounters annually that contribute to wage losses of > \$4000 per year [5]. These findings suggest that telemedicine and/or remote delivery platforms could reduce the burden of IC/BPS on both patients and providers. Remote platforms have been used to deliver a variety of treatment options including cognitive behavioral therapy and mindfulness to chronic pain patients [26]. During the recent COVID pandemic, physical therapy was delivered through telemedicine. More research is required for developing and validating structured programs to deliver treatments remotely to IC/BPS patients.

We also specifically examined patient hesitation regarding prescription medication. We explored the possibility that this preference may be related to bias against mainstream medicine. However, BMQ-S questionnaire scores revealed that subjects had an overall neutral attitude to medication. Analysis of focus group scripts revealed that reluctance to take prescription medications was related to concerns regarding side effects of medications. This was especially a concern in younger patients, who recognized that they would likely require long-term treatment for a chronic condition. Stemming from this concern was an interest in alternative treatments, such as meditation, yoga, and cannabis-derived products, which were largely perceived as safer than standard prescription medications. Prior studies suggest that younger age, female sex, higher education level, presence of urinary symptoms, dissatisfaction with conventional treatments, and presence of anxiety, depression and hopelessness are predictors of seeking out alternative treatments [27, 28]. Given that many of these features are present in patients with IC/BPS, it is not surprising that women with IC/BPS seek out such treatments. Despite interest in alternative therapies, patients wanted to try out these treatments only if they were evidence-based. These findings point to the need for more research into the efficacy of treatments such as hypnosis, mindfulness, and cannabinoids for the treatments of IC/BPS.

Our study has several limitations. Most of our subjects were young white college-educated women with moderate symptom burden, using first- and second-line AUA treatments. The perspective of IC/BPS patients who are older, have less education, have more severe symptom burden, or have tried more advanced AUA treatments may be different from those who are relatively early in their disease course. This limits the generalizability of our findings. Future studies will

be required to gain insight into the perspectives of a more diverse group of patients with more severe symptoms. Our sample size was small, and therefore may have differing demographics compared to the general population of patients with IC/BPS, but is comparable to prior focus group studies on urinary symptoms [15, 17]. Additionally, our fifth focus group revealed that we had reached saturation of themes by the fourth focus group suggesting that additional focus groups would not have added to the themes identified.

Strengths of this study include inclusion of both qualitative and quantitative data. The inclusion of the BMQ-S allowed us to better characterize our patient population and indicates it was relatively unbiased regarding medication use. Inclusion of women with a broad age range allowed for varying perspectives and some diversity of experience. Another strength of our study was the rigor of our qualitative methodology. The moderator for our focus groups was a trained psychologist with experience in the field, and this person was not involved with identifying emerging themes from the data.

In conclusion, our study provides important insights into the factors that IC/BPS patients consider when making treatment choices. Our study provides useful guidance to clinicians taking care of women with IC/BPS and directions for future research.

Appendix

Sample Moderator Guide

A. Patient-provider interaction

Today we will begin by discussing your interaction with your medical providers. This includes doctors, nurses, physical therapists, and any other providers who you have seen regarding your urinary symptoms. Be sure to talk about all your providers today.

1. Could you share your experiences with doctors on the topic of IC/BPS?
 - a. Do you feel your doctors have taken your perspectives into account in choosing a treatment strategy? Has the doctor been willing to understand the kinds of treatment you value?
 - b. What has worked well in an interaction with a doctor?
 - c. What has not worked well in an interaction with a doctor? Give specific examples
2. Talk to us about your interaction with other providers. Nurses? Physical therapist?

- d. What do you think could improve your interaction with doctors? Nurses? Physical therapists? Other providers?
- e. What happens when you call your doctor/nurse back with questions re your symptoms or medications?
3. What have been your experiences with handling medical appointments related to your IC/BPS? Specific examples: multiple providers, PT appointments, psychologists, etc.
4. Based on your experiences, what would you like IC/BPS providers to know? What do you wish they would do differently?

B. Treatments

Tell us about sources of information for IC/BPS treatments. Where/how have you learned about treatment options (e.g., recommendations from providers? Independent research?)

5. What have been your experiences with various types of treatments? What has worked, what has not worked?
 - f. We will next discuss several treatment options. If you have experience with them, please tell us about what that has been like. If you do not have experience with them, please let us know what your thoughts are about potentially trying it or not trying it in the future.
 - i. Diet?
 - ii. Stress management?
 - iii. PT?
 - iv. Long-term oral medications?
 - v. Bladder instillations?
 - vi. Cystoscopy with hydrodistension?
 - vii. Botox?
 - viii. Neuromodulation therapy?
6. There has been a lot of recent awareness and discourse about alternative or complementary treatment options (including things like cannabis, CBD formulations, hypnosis, acupuncture) for various types of pain syndromes.
 - g. What are your perspectives on this?
 - h. Why would or would you not pursue some of these options? Dive in: Did you ever bring it up with your provider? What has the reaction of your provider been?
7. What are some features of a treatment strategy that would be appealing to you?
 - i. What do you want for baseline treatment? Prescription drugs vs surgery vs herbal medication vs hypnosis/mindfulness

- j. What do you do when your symptoms worsen or you are in a flare? What coping strategies have you found?
 - k. What sort of treatment access strategies would be appealing to you? Examples: telehealth? Online modules for pain management strategies? Fewer appointments with doctors? More appointments with doctors?
8. What would you say have been some of the barriers or challenges in finding an appropriate treatment?

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Declarations

Conflict of interest None.

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