Published in final edited form as:

Int Urogynecol J. 2015 July ; 26(7): 1047–1060. doi:10.1007/s00192-015-2652-6.

UROLOGIC CHRONIC PELVIC PAIN SYNDROME FLARES AND THEIR IMPACT: QUALITATIVE ANALYSIS IN THE MAPP NETWORK

Siobhan Sutcliffe¹, Catherine S. Bradley^{2,3}, J. Quentin Clemens⁴, Aimee S. James¹, Katy S. Konkle⁴, Karl J. Kreder³, H. Henry Lai⁵, Sean C. Mackey⁶, Cody P. Ashe-McNalley⁷, Larissa V. Rodriguez⁸, Edward Barrell⁹, Xiaoling Hou⁹, Nancy A. Robinson⁹, Chris Mullins¹⁰, and Sandra H. Berry¹¹

¹Division of Public Health Sciences and the Alvin J. Siteman Cancer Center, Department of Surgery, Washington University School of Medicine, St. Louis, MO

²Department of Obstetrics and Gynecology, College of Medicine; and Department of Epidemiology, College of Public Health, University of Iowa, Iowa City, IA

³Department of Urology, College of Medicine, University of Iowa, Iowa City, IA

⁴Division of Neurology and Pelvic Reconstructive Surgery, Department of Urology, The University of Michigan Medical Center, Ann Arbor, MI

⁵Division of Urologic Surgery, Department of Surgery, Washington University School of Medicine, St. Louis, MO

⁶Division of Pain Medicine, Department of Anesthesiology, Perioperative and Pain Medicine, and the Departments of Neurosciences and Neurology, Stanford University School of Medicine, Palo Alto, CA

⁷Center for Neurobiology of Stress, David Geffen School of Medicine, University of California - Los Angeles, Los Angeles, CA

⁸Institute of Urology, University of Southern California, Beverly Hills, CA

⁹Department of Biostatistics and Epidemiology, University of Pennsylvania Perelman School of Medicine, Philadelphia, PA

¹⁰National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, MD

¹¹Rand Corporation, Santa Monica, CA

Corresponding author: Siobhan Sutcliffe, Washington University School of Medicine, 660 S. Euclid Ave., Box 8100, Rm. 208S, St. Louis, MO 63110, USA; tel: 314-362-3788; fax: 314-747-3936; sutcliffes@wudosis.wustl.edu.

Author contributions:

SS, CSB, JQC, ASJ, KSK, KJK, HHL, LVR, EB, NAR, CM, and SHB were involved in the conception and design of the study; SS, EB, NAR, SHB were involved in acquisition of the data; SS, CSB, ASJ, XH, and SHB were involved in analysis or interpretation of the data; SS and SHB drafted the manuscript; and all authors were involved in revising the manuscript critically for important intellectual content. Each of the authors has read and approved the final version submitted.

Conflicts of interest:

None of the authors have financial arrangements that might represent a conflict of interest with the present study. KJK is a consultant for Symptelligence, Medtronic, and Tension (not related to the present study).

Abstract

Introduction—Although in-depth qualitative information is critical for understanding patients' symptom experiences and for developing patient-centered outcome measures, only one previous qualitative study has assessed urologic chronic pelvic pain syndrome (UCPPS) symptom exacerbations ("flares").

Methods—We conducted eight focus groups of female UCPPS (interstitial cystitis/bladder pain syndrome) patients at four sites of the MAPP Research Network (n=57, mean=7/group) to explore the full spectrum of flares and their impact on patients' lives.

Results—Flare experiences were common and varied widely in terms of UCPPS symptoms involved, concurrent non-pelvic symptoms (e.g., diarrhea), symptom intensity (mild to severe), duration (minutes to years), and frequency (daily to <once/year), although the most commonly described flares were painful, days-long flares. These latter flares were also most disruptive to participants' lives, causing some to cancel social events, miss work or school, and in the worst cases, go to the emergency room or on disability leave. Participants also reported a longer-term impact of flares, including negative effects on their sexual functioning and marital, family, and social relationships; and loss of employment or limited career or educational advancement. Emergent themes included the need for a sense of control over unpredictable symptoms and reduced social engagement.

Conclusions—Given their negative impact, future research should focus on approaches to prevent flares, and to reduce their frequency, severity, and/or duration. Patients' quality of life may also be improved by providing them with a sense of control over their symptoms through ready access to flare medications/therapy, and by engaging them socially.

Keywords

urologic chronic pelvic pain syndrome; interstitial cystitis; bladder pain syndrome; symptom exacerbation; flare; focus group

INTRODUCTION

Female urologic chronic pelvic pain syndrome (UCPPS, or interstitial cystitis/bladder pain syndrome (IC/BPS)) is a common condition characterized by pain, pressure, or discomfort perceived to be related to the bladder, and lower urinary tract symptoms, such as urinary urgency and frequency, of at least six weeks duration, in the absence of infection or other identifiable causes [1]. It affects 1–7% of American women [2, 3] and there is no cure or consistently effective therapy [4].

Although the natural history of UCPPS is widely believed to include symptom exacerbations ("flares") and remissions, few studies have described or defined these exacerbations [5–10], and only one previous qualitative study, to our knowledge, has explored flares from the patient's perspective [11]. The importance of this question was highlighted recently in a small longitudinal study of flares, in which some participants reported flares lasting only a few minutes [8] – a shorter duration of flare than had been documented previously in the literature [5, 7, 10] and one that we have since found to be fairly common (30% of female

participants reported experiencing minutes-long flares in response to a short survey [9]). This unexpected finding raised the possibility of other lesser-recognized aspects of flares. Additionally, only a few previous studies have examined patient-reported triggers and self-care strategies for flares [11–15], and only one study – our previous survey – has explored the impact of flares on patients’ lives [9]. Although we found that both flare duration and pain severity influenced the degree of flare-related disruption and bother in that study [9], we did not examine the specific impact of flares on patients’ lives (e.g., impact on work and relationships). Therefore, to explore this impact further and to examine the full spectrum of flares, as well as their associated triggers and treatment, we conducted focus groups of UCPPS participants in the Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network. This type of formative, in-depth, qualitative research is critical to inform the development of patient-centered outcome measures for use in future studies of UCPPS flare etiology, treatment, and management.

MATERIALS AND METHODS

Study design and population

The MAPP Research Network’s central protocol, the MAPP Epidemiology and Phenotyping (EP) Study [16], is a longitudinal, observational study of the treated natural history of UCPPS. In the MAPP Network, the phrase “treated natural history” is used to refer to the clinical course of patients observed over time while receiving standard of care, and the term “UCPPS” is used to encompass IC/BPS in men and women, and chronic prostatitis/chronic pelvic pain syndrome in men. Eligibility criteria for female MAPP participants includes a diagnosis of IC/BPS, age ≥ 18 years, and a non-zero score for bladder and/or pelvic pain, pressure, or discomfort in the past two weeks.

For the present study, we performed eight focus groups of female UCPPS patients, two each at four participating Discovery Sites of the MAPP Research Network. Each of these sites was asked to recruit one group of participants enrolled in the MAPP EP study (“MAPP”) and one group who would otherwise qualify for the EP study but who were not participants in this protocol (“MAPP-naïve”). We chose to perform MAPP focus groups to contextualize flare-related findings in the parent MAPP study and for practical reasons, i.e., to ensure a sufficient number of focus groups to achieve saturation in the time frame of the study. We chose to perform MAPP-naïve focus groups to avoid any possible influence that participation in the EP study might have on participants’ responses, as some EP questionnaires refer to the term “flare” and assess possible flare triggers. Focus groups were conducted from April through June of 2012. All participants provided informed consent and the focus group protocol was approved by the institutional review board at each participating site.

Study procedures

Each focus group consisted of a 1.5 hour moderator-directed discussion (for an example of the moderator’s guide, see Appendix Table 1) and all were facilitated by the same female moderator. Following the discussion, participants were asked to complete five brief questionnaires similar to those used in the EP study. These included a demographics survey,

a medical history survey, the IC Symptom Index and Problem Index [17], the female Genitourinary Pain Index [18], and a general symptom survey that included questions on whether or not participants were currently experiencing a “flare”, defined as urologic or pelvic pain symptoms that are “much worse than usual”, and the number of flares experienced in the past year [16]. All focus groups were recorded and transcribed verbatim by trained transcriptionists, and transcripts were checked for accuracy and de-identified.

Qualitative analysis

After review of all transcripts, we developed a comprehensive set of descriptive codes for qualitative analysis [19]. We developed most of these codes deductively from the moderator’s guide and a few codes inductively based on review of the transcripts. One primary rater coded all quotes, while a second rater coded approximately 20% of the quotes (mean kappa for agreement across all codes=0.91; median=1.00). We used Atlas-ti software (version 7) to facilitate the qualitative analysis.

RESULTS

Fifty seven (34 MAPP and 23 MAPP-naïve) patients participated in the eight focus groups (mean=7/group). Participants ranged in age from 19–77 years (mean=44), were mainly Caucasian (91.2%), and reported having experienced UCPPS symptoms for 1–45 years (mean=12, Table 1). Participants’ mean symptom ratings in the past two weeks were 4.0 (on a scale of 0–10) for severity of pelvic/bladder pain; 4.2 for urgency; and 4.5 for frequency. Approximately one quarter (26.3%) reported experiencing a flare at the time of the focus group and most (94.7%) reported having experienced a flare in the past year. Most (73.7%) also reported at least one non-urological condition frequently associated with UCPPS (e.g., irritable bowel syndrome (IBS)). MAPP and MAPP-naïve participants were similar in most respects, although MAPP-naïve participants reported more severe urologic and pelvic pain symptoms; this difference was independent of their flare status at the time of the focus group.

Flare description

Almost all participants, even the few with relatively constant severe symptoms, reported periods of time when their symptoms were worse. Most participants referred to these periods of time as “flares” or derivations thereof (e.g., “flare-ups”, “flare-outs”, or “flaring days”), whereas a smaller number referred to them as “bad days”, “bad bladder days”, “stay-in-bed days”, or “episodes”. These names did not vary by MAPP/MAPP-naïve status. Irrespective of the term used, symptom exacerbations encompassed a wide spectrum of experiences, ranging from small increases in symptoms that interfered with participants’ thoughts (“If I even think about it or notice it, I consider it a flare”) to large increases in symptoms that prevented them from carrying out their usual activities or incapacitated them (“When I consider myself having a flare, it’s when I’m in bed all day, and where I can’t move”). Most participants described flares on the more severe end of the spectrum, whereas fewer described mild flares unless specifically asked by the moderator. Two participants also mentioned “spasms”; one described them separately from flares and with milder symptoms (“A feeling like [squeezing] in my bladder” with increased urinary frequency), and the other

described them with more severe symptoms (“A Charlie horse, but it’s in your bladder” that caused the participant to drop to the floor).

Flares on the milder end of the spectrum, which participants sometimes referred to as “minor” or “moderate” flares (Table 2), were described as a slight increase in pain, pressure, discomfort, sensitivity, throbbing, or burning with urination, and/or a large increase in urinary frequency. These flares lasted for hours to weeks and could occur anywhere from once/month to once/three months. Their onset was typically gradual with symptoms increasing over the course of a day or from one day to the next. In contrast to these milder flares, severe flares, which participants sometimes referred to as “major” or “grand” flares, were characterized by a large spike in pelvic pain, bladder/urethral burning, burning with urination, and/or pressure, and were sometimes accompanied by large increases in urinary urgency and frequency, as well as non-pelvic symptoms (e.g., diarrhea). Severe flares frequently lasted for several days, although they could range from as short as a few minutes to as long as two years, with minor variation in symptoms over the course of these longer flares. Severe flares occurred daily to <once/year. Their onset was typically sudden and their recession gradual, although a few participants reported an hours- or days-long onset and a rapid recession. Finally, considering flare experiences from the same participant, some participants reported consistently similar flare experiences, whereas others reported a wide range of flare experiences from mild, short flares to severe, long flares.

Flare triggers

When asked what they believed triggered their flares, most participants felt they knew at least some of their triggers (e.g., stress and sexual activity; see Table 3 for a full list). These flare triggers varied both between participants and for the same participant. For instance, they could serve as triggers for some individuals, but had no effect or improved symptoms for others (e.g., sexual activity, alcohol, exercise). Their influence could also vary by category, brand, dose, and frequency or regularity of trigger, and over time with age. Finally, they could serve as either direct or indirect triggers. For instance, foods and beverages could trigger participants’ flares directly (the more common scenario) or they could trigger their IBS symptoms, which in turn triggered their UCPPS symptoms (the less common scenario). Most participants also reported that at least some of their flares occurred for unknown reasons, which was frustrating to them, and a few reported not knowing the cause(s) of any of their flares. No differences were observed in the range of flare triggers reported by MAPP or MAPP-naïve participants.

With respect to the latency period of perceived triggers, participants reported flare onset immediately after their trigger to as long as two days later, although most reported flare onset on the same day as their trigger. We could not identify any consistent pattern in timing of flare onset by category of trigger. When asked whether they engaged in trigger behaviors or consumed dietary triggers knowingly, participants frequently reported engaging in sexual activity knowingly as a trigger and occasionally reported engaging in stressful activities or consuming dietary triggers knowingly, either out of rebellion against the constraints of their condition or to maintain a semblance of their pre-UCPPS life. However, a more common experience was one associated with engaging in/consuming a trigger unknowingly and then

identifying the cause(s) of their flare through a detailed re-examination of their pre-flare exposures (“Most of the time I feel I can trace it back to something”). This recall process was occasionally associated with guilt, as some participants viewed their flares as their fault, which in turn led to consequences for both themselves and the people around them.

Flare treatments and self-management strategies

When participants knowingly engaged in/consumed flare triggers, they sometimes reported strategies to minimize or prevent their flares (Table 3), which were especially important for behaviors such as sexual activity to help maintain their romantic relationships. Participants also reported a variety of different ways in which they managed their flares once they had begun, typically starting with the least potent therapies and only progressing to more potent therapies (e.g., opiates/opioids, medications with greater side-effects, medical procedures, and emergency room visits) for more severe, recalcitrant flares (see Table 4 for a full list of treatments/self-management strategies). Participants also expressed an interest in ready or same-day access to non-emergency medical care during flares. Finally, beyond the immediate therapeutic effect of flare management strategies, a few participants reported that certain medications/therapies had reduced the overall severity and/or frequency of their flares (e.g., birth control, pentosan polysulfate sodium (Elmiron®, Janssen Pharmaceuticals), bladder instillations, hydrodistension, and physical therapy).

Immediate impact of flares

Irrespective of the severity of their symptoms, most participants reported some immediate impact of flares, including irritability, anxiety, and a reduced ability to concentrate (see Table 5 for a full list and representative quotes). Increased urinary frequency also forced many participants to remain close to a restroom, and could be disruptive and contributed further to anxiety for participants in jobs/situations with less flexibility. Additional influences of flares were determined largely by their severity and duration. For milder flares with less pain, participants were able to continue their regular activities and even reported that these activities provided good distraction from their symptoms. In contrast, for flares with more severe pain, participants reported having difficulty standing (“dropping to the floor” with pain) or even moving, which forced many to stay in bed or the restroom for the duration of their flare. Consequently, many participants had to cancel social plans; stop work, which could be disruptive even for brief flares if they occurred in structured situations (e.g., on a factory line); and a few had to go the emergency room during long flares. Finally, pain medications also contributed to the impact of flares, as some caused extreme drowsiness or dizziness.

Beyond the physical impact of severe flares, participants also reported a mental and emotional impact of these flares, particularly if they had not had a flare in a while and believed their condition to be improving. They reported going back into “fear mode”, feeling “demoralized”, and some reported having difficulty envisioning their future with cycling, severe pain. They also reported an emotional impact of flares on their spouses and family members that, in turn, made them feel badly and added to their level of stress.

Long-term impact of flares

For some participants, flares did not have a major reported long-term impact beyond such things as travel-related or general anxiety, and various changes to their daily routines for flare prevention (see Table 6 for representative quotes). These included eliminating certain foods/beverages from their diet, reducing their frequency of sexual activity, and generally reducing their degree of spontaneity. For other participants, however, these changes were more dramatic. For instance, some stopped or greatly reduced their travel, some eliminated a large number of foods from their diet, and some greatly reduced their frequency of sexual activity. Even participants who did not report a major impact of flares described a constant awareness or vigilance for things that might trigger a flare, and an attempt to control these factors. One participant even reported that the stress of worrying about a flare could trigger its occurrence.

While not stated explicitly, this degree of lifestyle change and vigilance appeared to influence participants' level of social interaction. For instance, they reported making fewer social plans out of concern that they might coincide with a future flare, and staying home more to relax and reduce their levels of stress. Major reductions in sexual activity also had an impact on participants' social interactions, as some participants, particularly younger ones, reported a lack of desire to initiate new sexual relationships, and some reported marital or relationship strain. With respect to their work and school life, a few participants who experienced frequent, severe flares reported losing their jobs because of flares, some went on disability leave or became self-employed to accommodate flares, and some had difficulty completing their education. Finally, participants reported that flares contributed to general anxiety, which a few addressed by carrying flare medications or self-care products with them at all times, and at their worst, a few participants reported that flares had "ruined" their lives.

During our discussion about the impact of flares on participants' lives, we attempted to distinguish the impact of flares from that of UCPPS in general. Some participants were able to distinguish the two clearly and their responses are described above:

"At its normal level, I can function. But because of the flares I can't make certain plans. Like, I can't be too [ambitious] ... I just live a much more quiet [simple] life."

For other participants, however, it was not possible to distinguish the impact of flares from that of their basic condition. In general, the reported impact of UCPPS was similar to that of flares, although it tended to be more closely related to urinary frequency and the desire to remain close to restrooms (e.g., avoiding activities with lesser access to restrooms) than to pain or the fear of pain during flares. They also mentioned additional broader consequences of flares or their condition, such as medication-related weight gain, becoming confined to their homes, losing touch with family members, getting divorced, and becoming depressed (see Table 6 for a full list and representative quotes). Finally, a recurrent theme for participants was that UCPPS is life-changing, and affects all aspects of their lives and everyone close to them.

DISCUSSION

In our focus groups of female UCPPS patients, we identified a wide spectrum of symptom exacerbations described by most participants as “flares”. These flares ranged from mild, uncomfortable symptoms that were short-lasting and interrupted participants’ thoughts to severe painful symptoms that could last for as long as two years and prevented them from working or leaving their homes. Along this spectrum of flares, participants also reported variability in pelvic pain and urologic symptoms involved (e.g., pain only, pain with urologic symptoms, and occasionally urologic symptoms only); non-pelvic or -urologic symptoms (e.g., diarrhea); and frequency of flares (e.g., daily to <once/year). Similar to findings from our previous survey, the most commonly reported flare experiences were painful flares that lasted for several days and were accompanied by urologic symptoms (reported by 87% of female participants in our previous survey [9]). These flares also tended to be most disruptive for participants, although sudden, short painful flares and flares limited to increased urinary frequency could also be disruptive, particularly in structured situations.

Beyond their immediate, disruptive impact, flares also had a longer-term and broader impact on participants’ lives, particularly those that occurred frequently and/or were painful and long-lasting. Participants who experienced these types of flares reported difficulties completing their education, quitting or losing their jobs, relationship strain, and anxiety. Although these consequences are similar to those reported for UCPPS in general in both our study and the literature [20–22, 13, 23–28], some participants attributed these consequences directly to flares, suggesting that one useful way to improve their quality of life would be to identify approaches to prevent or treat their flares, or to reduce the severity, duration, and/or frequency of their flares (e.g., through the longer-term effects of medications). Together with findings on the immediate impact of flares and those from our previous survey [9], these results also suggest that flare characteristics, such as symptom severity, duration, and frequency, as well as their degree of disruption or bother, should be taken into consideration in developing patient-centered outcome measures of flare burden.

In addition to flare characteristics, the unpredictability of flares also contributed to their negative impact. This unpredictability made it difficult for participants to carry out their day-to-day activities, as well as to plan for and realize longer-term goals. A recurrent theme for participants was thus the need for control over their symptoms, consistent with findings from a previous focus group study of goal achievement among female patients [29]. In our focus groups, the need for control frequently manifested as thorough self-reflection and the development of detailed narratives to explain their flares. While this process appeared to allow some participants to avoid or minimize their flares (e.g., ibuprofen before sexual activity) and provided others with a sense of control and a helpful coping mechanism, it was not clear for many other participants to what extent their personal hypotheses about flare triggers had a physiologic basis or were helpful in controlling symptom variation. This retrospective flare trigger identification process also led many participants to lead highly restrictive lifestyles. Another way in which participants gained a sense of control over their symptoms was by carrying flare medications with them at all times or when they traveled, or by having ready access to health professionals. Either way, having a sense of control over some aspect of their flares seemed to be an important coping mechanism for participants.

Therefore, helping patients understand how to assess their triggers correctly and giving them meaningful reassurance that they have access to treatment during flares (e.g., by discussing a flare strategy with patients) may help them lead more active and satisfying lives.

In addition to control, another cross-cutting theme identified in the focus groups was reduced social engagement. While several studies have noted lesser social functioning or support in patients than in healthy women [22, 23, 30–32], few have described the causes or consequences of this reduced functioning [26]. We found that, during flares, participants reported cancelling family and social activities, missing work or school, and preferring to stay home to be close to a bathroom. When not experiencing a flare, they also reported avoiding making social and travel plans out of fear that a flare might occur and because of non-flare related urinary frequency; avoiding activities that involved food prepared by others to reduce accidental exposure to flare triggers; reducing their physical activity, including playing team sports; avoiding romantic relationships; and staying at home and “withdrawing” from life to avoid the stress of interacting with other people and life in general. Some participants also reported losing friends because of cancellations, and losing family and/or spouses because of the difficulties of interacting with patients with chronic, debilitating conditions and because of diminished levels of sexual activity. Many were not happy with their reduced degree of social interaction, and reported that lying in bed or sitting at home contributed further to their depressed mood. Therefore, finding ways in which to increase patients’ degree of social engagement – for instance, by in-person or online support groups, by better flare trigger identification to avoid unnecessary social restrictions, or by lay health advisors/companions – may serve to reduce the negative impact of UCPPS on patients’ lives and to relieve some of the burden on their family members and spouses.

A few further novel observations also deserve mention. With respect to flare symptoms, non-pelvic symptoms, such as diarrhea and exacerbated IBS or fibromyalgia symptoms, have not, to our knowledge, been described and could be explored further for their possible insight into systemic processes. Newly-reported flare triggers, including dehydration, brands of toilet paper, brands of water or water of varying pH, PAP smears, forgetting to take medications, skipping meals, and emotions, could also be incorporated into future research efforts. Finally, additional reported consequences of flares and UCPPS (e.g., staining toilets by urine colored by urinary tract analgesic agents, weight gain from reduced physical activity and the side effects of medications, and poor posture from chronic pain) may warrant further research attention to help improve patient quality of life.

As a final consideration, our results illustrate a range of experiences reported by participants during a directed group discussion and should be interpreted as such. They cannot be used to quantify participants’ experiences or to represent experiences of participants with different characteristics than those who participated in our focus groups - primarily patients from specialized urologic and gynecologic centers. Having said that, a recent comparison of patients from these same types of centers to a community based sample of symptomatic women found generally similar levels of symptoms [33], suggesting that our findings may generalize to patients not receiving specialty care. Differences between MAPP and MAPP-

naïve participants likely reflect differences in patients' interest and ability to participate in a complex and demanding study, such as MAPP.

In summary, we identified a wide spectrum of flare experiences and major immediate and long-term impact of flares, particularly those that occur frequently, and are painful, long-lasting, and unpredictable. Therefore, we suggest that patient-centered outcome measures of flare burden should include flare characteristics, such as frequency, severity, duration, and predictability; and that future research should focus on approaches to prevent flares (e.g., by trigger identification and therapy); to reduce their frequency, severity, and/or duration; and to reduce flare-related anxiety (e.g., by on-hand medications, same-day medical appointments, mindfulness meditation/stress reduction). Our findings also suggest that patients' quality of life may be improved by engaging them socially.

ACKNOWLEDGMENTS

We thank the research coordinators at each focus group site (Mary Eno, Vivien Gardner, Megan Halvorson, Nuwanthi Heendeniya, Ginny Leone, Ratna Pakpahan, and Suzanne Smith) for recruiting participants and coordinating the focus groups; Sam Silver for re-coding the focus group transcripts; and, most importantly, the participants for their participation.

Information contained in this manuscript was presented as an abstract at the Annual American Urological Association meeting in Orlando, FL in 2014. This study was funded by MAPP Research Network grants, NIH DK082370, DK082344, DK082345, DK082315, and DK082316.

REFERENCES

1. Hanno P, Dmochowski R. Status of international consensus on interstitial cystitis/bladder pain syndrome/painful bladder syndrome: 2008 snapshot. *Neurourology and urodynamics*. 2009; 28(4): 274–286. [PubMed: 19260081]
2. Clemens JQ, Link CL, Eggers PW, Kusek JW, Nyberg LM Jr, McKinlay JB, Investigators BS. Prevalence of painful bladder symptoms and effect on quality of life in black, Hispanic and white men and women. *The Journal of urology*. 2007; 177(4):1390–1394. [PubMed: 17382739]
3. Berry SH, Elliott MN, Suttrop M, Bogart LM, Stoto MA, Eggers P, Nyberg L, Clemens JQ. Prevalence of symptoms of bladder pain syndrome/interstitial cystitis among adult females in the United States. *The Journal of urology*. 2011; 186(2):540–544. [PubMed: 21683389]
4. Hanno PM, Burks DA, Clemens JQ, Dmochowski RR, Erickson D, Fitzgerald MP, Forrest JB, Gordon B, Gray M, Mayer RD, Newman D, Nyberg L Jr, Payne CK, Wessellmann U, Faraday MM. E. Interstitial Cystitis Guidelines Panel of the American Urological Association, I. Research. AUA guideline for the diagnosis and treatment of interstitial cystitis/bladder pain syndrome. *The Journal of urology*. 2011; 185(6):2162–2170. [PubMed: 21497847]
5. Whitmore KE. Self-care regimens for patients with interstitial cystitis. *The Urologic clinics of North America*. 1994; 21(1):121–130. [PubMed: 8284835]
6. Nickel JC, Shoskes DA, Irvine-Bird K. Prevalence and impact of bacteriuria and/or urinary tract infection in interstitial cystitis/painful bladder syndrome. *Urology*. 2010; 76(4):799–803. [PubMed: 20573386]
7. Jeong HJ. Effects of a Short Course of Oral Prednisolone in Patients with Bladder Pain Syndrome with Fluctuating, Worsening Pain despite Low-Dose Triple Therapy. *International neurourology journal*. 2012; 16(4):175–180. [PubMed: 23346483]
8. Sutcliffe S, Colditz GA, Pakpahan R, Bradley CS, Goodman MS, Andriole GL, Lai HH. Changes in symptoms during urologic chronic pelvic pain syndrome symptom flares: Findings from one site of the MAPP Research Network. *Neurourology and urodynamics*. (In press).
9. Sutcliffe S, Colditz GA, Goodman MS, Pakpahan R, Vetter J, Ness TJ, Andriole GL, Lai HH. Urologic chronic pelvic pain syndrome symptom flares: characterization of the full spectrum of

- flares at two sites of the MAPP Research Network. *BJU Int.* 2014; 114(6):916–925. [PubMed: 24730356]
10. Interstitial Cystitis Association Web survey. How do you define an IC flare? 2009 Available at: <http://www.ichelp.org/Page.aspx?pid=525>.
 11. Webster DC, Brennan T. Self-care strategies used for acute attack of interstitial cystitis. *Urologic nursing.* 1995; 15(3):86–93. [PubMed: 7481892]
 12. Bassaly R, Downes K, Hart S. Dietary consumption triggers in interstitial cystitis/bladder pain syndrome patients. *Female pelvic medicine & reconstructive surgery.* 2011; 17(1):36–39. [PubMed: 22453670]
 13. Koziol JA. Epidemiology of interstitial cystitis. *The Urologic clinics of North America.* 1994; 21(1):7–20. [PubMed: 8284848]
 14. Shorter B, Lesser M, Moldwin RM, Kushner L. Effect of comestibles on symptoms of interstitial cystitis. *The Journal of urology.* 2007; 178(1):145–152. [PubMed: 17499305]
 15. Bade JJ, Peeters JM, Mensink HJ. Is the diet of patients with interstitial cystitis related to their disease? *European urology.* 1997; 32(2):179–183. [PubMed: 9286650]
 16. Landis JR, Williams DA, Lucia MS, Clauw DJ, Naliboff BD, Robinson NA, van Bokhoven A, Sutcliffe S, Schaeffer AJ, Rodriguez LV, Mayer EA, Lai HH, Krieger JN, Kreder KJ, Afari N, Andriole GL, Bradley CS, Griffith JW, Klumpp DJ, Hong BA, Lutgendorf SK, Buchwald D, Yang CC, Mackey S, Pontari MA, Hanno P, Kusek JW, Mullins C, Clemens JQ. The MAPP research network: design, patient characterization and operations. *BMC Urol.* 2014; 14(1):58. [PubMed: 25085119]
 17. O'Leary MP, Sant GR, Fowler FJ Jr, Whitmore KE, Spolarich-Kroll J. The interstitial cystitis symptom index and problem index. *Urology.* 1997; 49 Suppl(5A):58–63. [PubMed: 9146003]
 18. Clemens JQ, Calhoun EA, Litwin MS, McNaughton-Collins M, Kusek JW, Crowley EM, Landis JR. Validation of a modified National Institutes of Health chronic prostatitis symptom index to assess genitourinary pain in both men and women. *Urology.* 2009; 74(5):983–987. quiz 987 e981-983. doi:S0090-4295(09)02200-6 [pii] 10.1016/j.urology.2009.06.078. [PubMed: 19800663]
 19. Bernard, HR. Research methods in anthropology: qualitative and quantitative approaches. Oxford, UK: AltaMira Press; 2006.
 20. Beckett MK, Elliott MN, Clemens JQ, Ewing B, Berry SH. Consequences of interstitial cystitis/bladder pain symptoms on women's work participation and income: results from a national household sample. *The Journal of urology.* 2014; 191(1):83–88. [PubMed: 23872030]
 21. Bogart LM, Suttorp MJ, Elliott MN, Clemens JQ, Berry SH. Prevalence and correlates of sexual dysfunction among women with bladder pain syndrome/interstitial cystitis. *Urology.* 2011; 77(3):576–580. [PubMed: 21215432]
 22. Slade D, Ratner V, Chalker R. A collaborative approach to managing interstitial cystitis. *Urology.* 1997; 49 Suppl(5A):10–13. [PubMed: 9145998]
 23. Simon LJ, Landis JR, Erickson DR, Nyberg LM. The Interstitial Cystitis Data Base Study: concepts and preliminary baseline descriptive statistics. *Urology.* 1997; 49 Suppl(5A):64–75. [PubMed: 9146004]
 24. Held, PJ.; Hanno, PM.; Wein, AJ.; Pauly, MV.; Cahn, MA. Epidemiology of interstitial cystitis. In: Hanno, et al., editors. *Interstitial cystitis.* New York: Springer-Verlag; 1990. p. 29-48.
 25. Clemens JQ, Brown SO, Calhoun EA. Mental health diagnoses in patients with interstitial cystitis/painful bladder syndrome and chronic prostatitis/chronic pelvic pain syndrome: a case/control study. *The Journal of urology.* 2008; 180(4):1378–1382. [PubMed: 18707716]
 26. Hatchett L, Fitzgerald MP, Potts J, Winder A, Mickelberg K, Barrell T, Kusek JW. N. Urologic Pelvic Pain Collaborative Research. Life impact of urologic pain syndromes. *Journal of health psychology.* 2009; 14(6):741–750. [PubMed: 19687111]
 27. Webster DC, Brennan T. Use and effectiveness of sexual self-care strategies for interstitial cystitis. *Urologic nursing.* 1995; 15(1):14–22. [PubMed: 7792618]
 28. Webster D. Comparing patients' and nurses' views of interstitial cystitis: a pilot study. *Urologic nursing.* 1990; 10(3):10–15. [PubMed: 2399466]

29. Payne C, Allee T. Goal achievement provides new insights into interstitial cystitis/painful bladder syndrome symptoms and outcomes. *Neurourology and urodynamics*. 2009; 28(1):13–17. [PubMed: 19089894]
30. Michael YL, Kawachi I, Stampfer MJ, Colditz GA, Curhan GC. Quality of life among women with interstitial cystitis. *The Journal of urology*. 2000; 164(2):423–427. [PubMed: 10893601]
31. Rothrock NE, Lutgendorf SK, Hoffman A, Kreder KJ. Depressive symptoms and quality of life in patients with interstitial cystitis. *The Journal of urology*. 2002; 167(4):1763–1767. [PubMed: 11912405]
32. Nickel JC, Tripp DA, Pontari M, Moldwin R, Mayer R, Carr LK, Doggweiler R, Yang CC, Mishra N, Nordling J. Psychosocial phenotyping in women with interstitial cystitis/painful bladder syndrome: a case control study. *The Journal of urology*. 2010; 183(1):167–172. [PubMed: 19913812]
33. Konkle KS, Berry SH, Elliott MN, Hilton L, Suttrop MJ, Clauw DJ, Clemens JQ. Comparison of an interstitial cystitis/bladder pain syndrome clinical cohort with symptomatic community women from the RAND Interstitial Cystitis Epidemiology study. *The Journal of urology*. 2012; 187(2): 508–512. [PubMed: 22177158]

Table 1

Characteristics of female urologic chronic pelvic pain syndrome focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

	All groups	MAPP	MAPP-naïve	P-value
N	57	34	23	
Age (years, mean (range))	43.7 (19.0, 77.0)	44.6 (20.0, 77.0)	42.3 (19.0, 69.0)	0.61
Caucasian (%)	91.2	88.2	95.7	0.33
Duration of symptoms (years, mean (range))	11.8 (1.0, 45.0)	12.0 (2.0, 45.0)	11.5 (1.0, 34.0)	0.85
Severity of symptoms in the past two weeks (on a scale of 0–10, mean (range)):				
Pelvic/bladder pain, pressure, or discomfort	4.0 (0.0, 10.0)	3.2 (0.0, 9.0)	5.2 (1.0, 10.0)	0.002
Urgency	4.2 (0.0, 10.0)	3.1 (0.0, 8.0)	5.7 (1.0, 10.0)	<0.001
Frequency	4.5 (0.0, 10.0)	3.8 (0.0, 8.0)	5.5 (1.0, 10.0)	0.006
Overall urologic or pelvic pain symptoms	4.4 (1.0, 10.0)	3.5 (1.0, 9.0)	5.8 (1.0, 10.0)	<0.001
Overall non-urologic pain symptoms	3.5 (0.0, 10.0)	3.1 (0.0, 8.0)	4.3 (0.0, 10.0)	0.085
Genitourinary pain index (on a scale of 0–46, mean (range))	25.0 (7.0, 44.0)	22.3 (8.0, 40.0)	29.4 (7.0, 44.0)	0.005
Interstitial cystitis symptom index (on a scale of 0–20, mean (range))	10.0 (2.0, 20.0)	9.5 (2.0, 19.0)	10.8 (4.0, 20.0)	0.25
Interstitial cystitis problem index (on a scale of 0–16, mean (range))	8.2 (1.0, 16.0)	7.2 (1.0, 14.0)	9.7 (1.0, 16.0)	0.022
Currently experiencing a flare (%)	26.3	20.6	34.8	0.19
Flare history in the past year (%):				
0 flares	5.3	5.9	4.3	0.97
1–4 flares	33.3	32.4	34.8	
5–9 flares	33.3	35.3	30.4	
10 or more flares	28.1	26.5	30.4	
Self-reported co-morbid conditions (%):				
Fibromyalgia	24.6	26.5	21.7	0.83
Irritable bowel syndrome	45.6	50.0	39.1	0.50
Chronic fatigue syndrome	14.0	8.8	21.7	0.15
Depression disorder	33.3	29.4	39.1	0.38
Anxiety disorder	40.4	35.3	47.8	0.28
Any of the above	73.7	73.5	73.9	0.75

Table 2

Spectrum of symptom exacerbations reported by female urologic chronic pelvic pain syndrome (UCPPS) focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

	Mild/moderate symptom exacerbations	Severe symptom exacerbations
Illustrative quotes	<p>"P: The pain will stay or maybe get a little worse. M: And how long does that last? P: Hours." "a couple of days of just being a little more uncomfortable all the time"</p>	<p>"I could be fine and just be standing there and it drops me to my knees the pain is so severe. And then I'm fine. I mean it lasts maybe three minutes and then I'm completely fine." "I get them usually at night and I just go sit on the toilet, pillow in the sink. I try to drink more water, but never emptying your bladder and it just burns and burns and the pain is just awful."</p>
Symptom exacerbation names	"mild", "moderate", "minor", "mini", "light", "tiny", or "little" flare	"severe", "major", "grand", "big", "huge", "bad", or "serious" flare
Symptoms, symptom severity, and symptom descriptors:		
Sensitivity	"a little more sensitive"	"particularly sensitive"
Pressure	"dull pressure"; "constant pressure"	"a lot of pressure"; feels like "carrying cantaloupes"
Discomfort	"a little more uncomfortable"	Not mentioned
Pelvic pain:		
Level	"a little bit of pain"; "just noticeable but there" 1–4 on a scale of 0–10	"crippling pain all the time"; pain "through the roof" 6 through 15 on a scale of 0–10
Description	"ache and pain"	"burning hot core of throbbing pain"; "intense searing pain"
UTI-like feelings	"very dull UTI coming on"	"searing UTI pain"
Pain related to urination	"burning in the urethra" during voiding	"feels like I'm urinating razor blades"
Urgency	Not mentioned	"intense urgency"
Frequency	"a lot" of frequency; 30 times per day	"constant feeling of having to always go to the bathroom"; "every 10 to 15 minutes"
Other symptoms	Feeling of not completely emptying their bladder	Feeling of not completely emptying their bladder "trying to pee and dripping" Blood in urine Pelvic floor symptoms Kidney pain; back pain Headache Fever-like feeling, sweaty, hot flashes Achy and flu-like feeling; feeling "deathly ill" Sick; cannot keep any food down; feeling nauseous Diarrhea Yeast infections Irritable bowel syndrome symptoms Fibromyalgia symptoms Fatigue
Flare duration	Hours to weeks	Minutes to two years
Flare frequency	Every four weeks to every 2–3 months	Daily to once/year or less
Timing of flare onset	Gradual	Typically sudden
Timing of flare recession	Not mentioned	Typically gradual

M=moderator; P=participant; UTI=urinary tract infection

Table 3

Flare triggers^a reported by female urologic chronic pelvic pain syndrome (UCPPS) focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

Reported flare triggers	Examples of triggers	Examples of variation by category, brand, dose, frequency, or regularity of trigger	Preventive or therapeutic measures taken before or after triggers
Stress		Extreme stress over a short period of time or lesser stress over a long period of time	
Sexual activity		Sexual activity with one man but not another	Before: Phenazopyridine HCl (Pyridium®); After: ibuprofen, condom pops, washing up, and urinating
Menstrual cycle			Continuous birth control (i.e., without placebo pills)
Caffeinated foods and beverages	Coffee, tea, caffeinated soda, decaffeinated coffee, chocolate	Instant but not ground coffee; regular but not low acidity coffee; >1 but not one cup of coffee; consuming Starbucks® coffee two days in a row but not once; coffee but not tea; coffee but not caffeinated soda; coffee or soda but not chocolate; tea but not coffee; tea but not soda; soda but not coffee	
Alcoholic beverages	Champagne, wine, beer	Champagne but not wine or beer; beer but not wine	Pyridium, additional water intake
Other foods and beverages	Tomatoes or tomato sauce, citrus fruits and juices, pineapple, strawberries, multivitamins and vitamin C, vinegar, other acidic foods or products, spicy foods, soy, flour, bread, corn syrup, red meat, nuts, and dairy foods	Brand or pH of water; large but not small quantities of soy products	Prelief (Ak Pharma)
UTIs			
Delaying urination or urinating			
Dehydration			
Changes in season or weather			
Allergies	Pet allergies, flower allergies		Antihistamines
Jarring or bumpy movements	Long and/or bumpy car and bus rides, leg bouncing	Bus but not car rides	
Certain medications	Theraflu® (Novartis), sinus medications, anti-depressants, acetaminophen and hydrocodone (Vicodin®), acetaminophen (Tylenol®)		
Clothing	Bathing suits, jeans		
Chemicals	Laundry detergents, pool chemicals		
Toilet paper		Brand of toilet paper	
Certain physical activities	Running; pushing or lifting heavy objects; squatting; certain Tai-Chi exercises		
Standing for long periods of time			
PAP smears			

Reported flare triggers	Examples of triggers	Examples of variation by category, brand, dose, frequency, or regularity of trigger	Preventive or therapeutic measures taken before or after triggers
Fatigue			
Forgetting to take medications			
Skipping meals			
Emotions	Anger, sadness		

UTI=urinary tract infection

^a Patient-reported triggers are listed in the approximate order of frequency with which they were brought up in the focus groups, with those discussed with the greatest frequency listed first and those discussed with the least frequency listed last.

Table 4

Flare treatment and self-management strategies reported by female urologic chronic pelvic pain syndrome (UCPPS) focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

Flare treatment or self-management strategy	Examples
Medications	Non-steroidal anti-inflammatory drugs, urinary tract analgesic agents, UCPPS medications, opiates/opioids, fibromyalgia medications, muscle relaxants, antibiotics, antihistamines, intravenous medications, and topical gels
Medical procedures	Bladder instillations and hydrodistension
Emergency room or healthcare provider visit	
Herbal or dietary therapies and supplements	Aloe vera supplements, Proleve, herbal teas (e.g., Cat's Claw and peppermint tea), D-mannose powder, and baking soda water
Diet modification	Drinking more water or drinking less water, avoiding dietary triggers, being more careful about their diet, eating "better", eating different foods, going on a Cheerios diet, or stopping eating
Heat-based therapies	Heating pads, hot baths with or without baking soda, hot showers, hot washcloths, sitting in front of a heater or on heated car seats, and staying warm
Cold-based therapies	Ice packs and condom pops
Sitting on the toilet	
Resting, sitting, lying down, or sleeping	
Other strategies	Removing tight clothing, underwear, or pads; sitting on a hard floor; standing and moving around; distracting themselves (e.g., turning up their Interstim (a neuromodulation device), taking a scalding hot shower, continuing to work); tightening their pelvic floor muscles; having stomach or back rubs; and having a bowel movement

Table 5

Immediate impact of flares reported by female urologic chronic pelvic pain syndrome (UCPPS) focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

Immediate impact	Illustrative quotes
Irritability	• “I’m probably a total bitch to everyone that sees me.”
Anxiety	• “I become very anxious, if I have to teach a class and I have the symptoms, because I know that I can’t stop in the middle and run out to the restroom.”
Reduced ability to concentrate	• “And I can’t focus on my finals. And I usually end up getting bad grades because I’m so focused on I need to get out of here.”
Difficulty wearing certain types of clothing	• “I’ve noticed that a lot of times it’s made worse by like physical conditions. Like tight clothes, pads”
Lack of desire to engage in sexual activity	• “There’s definitely we’re not having sex tonight, so it interferes in that way.”
Desire or need to be close to a bathroom	• “I sit at home all day. I’m scared to leave the house. I don’t know how bad it’s going to get, if it’s going to get worse.”
Difficulty standing or moving, forcing participants to rest or stay in bed or the restroom	• “But when I’m in a flare-up I can’t walk across campus. I can get everywhere on campus within ten to 15 minutes, but that is a really long time when you are in so much pain you can barely get out of bed in the morning.
Cancelling social events	• “There are things like I’ve had to miss out on though. Like friends’ birthdays and stuff where I’ve been like, I can’t go. I cannot physically go.”
Stopping or missing work or school	• “If it gets really, really bad, I do have to stop work, because I just can’t be working and constantly in the bathroom, and bent over in pain.”
Going to the emergency room	• “And then if Vicodin’s not working then I add on all these other things ... and then the times when those haven’t worked, I’ve gone to the ER.”
Going on family and medical leave	• “I was in a trial for medication and it flared me, and I was sick for two years. I was on FMLA at that point.”
Drowsiness or dizziness from pain medications	• “I get all like light-headed and like you know, like dizzy and like high-feeling from the Vicodin ... So I have to like really plan like if I think I’m going to have a flare, I need to like plan for school.”
Emotional impact of flares on patients	<p>• “I also have that feeling of helplessness, hopelessness and feeling like is this ever going to get better, is there ever going to be a day when I don’t have to deal with this and at its worst, I’ve just started to think, is this something I can live with the rest of my life? ... but I know that it’s happened before and I’ve survived and I’ve moved on, but when it happens again that intensely, it’s just completely discouraging. Because sometimes I’ll think for months on end, I’ll be pretty stable in my symptoms and I think I’m better, but then when that major flare-up hits, it makes me realize that that’s not the case ... so very demoralizing.”</p> <p>• “P: We all have our moderate tone that we live on, but when things really kind of [freak] out, and it flares, you’re like, oh, my god, is this it? Am I going to pull out of this one? ... Then you’re dealing with some forms of depression, and then you have anxiety ...</p> <p>M: So let me see a show of hands around the table for how many people feel that this resonates with them, that they are... so almost everybody.”</p>
Emotional impact of flares on patients’ spouses and family members	<p>• “the kids know ... that I’m crabby and that I’m depressed. And so everyone in my family [has] to walk around on eggshells.”</p> <p>• “So for me that’s the worst part, the anxiety and feeling bad, because I know my husband will feel so bad for me and then I’ll feel guilty.”</p>

M=moderator; P=participant

Table 6

Longer-term impact of flares and urologic chronic pelvic pain syndrome (UCPPS) in general for female focus group participants, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

Longer-term changes associated with flares		
Domains of change	Minor changes	Major changes
Travel	<ul style="list-style-type: none"> • “When it comes to traveling, I always have a little bit of concern of whether or not I might have a flare-up and I try to take all the things that I think I could possibly use or take.” 	<ul style="list-style-type: none"> • “[my doctor] told me to take an overnight bag in case I couldn't make it. This is the first time that I've actually driven up to ... by myself in probably about five years.”
Clothing	<ul style="list-style-type: none"> • “I completely changed all my underwear to the breathable stuff, started wearing looser clothing.” 	<ul style="list-style-type: none"> • “it's like I do laundry for four people and my underclothes have to have this whole special process, so it's just incredibly inconvenient.”
Diet	<ul style="list-style-type: none"> • “I try to avoid a lot of sugar and processed foods, and I rarely eat out anyway.” 	<ul style="list-style-type: none"> • “my life is extremely rigidly controlled. I don't eat any flour ... I don't eat anything with corn syrup. I don't do any dairy in any way, shape, or form. And when I mean flour, I don't even do tomato soup, because the third ingredient is whole wheat flour”.
Physical activity	<ul style="list-style-type: none"> • “Well, you know, I used to exercise a lot, and now, I don't. Now I go for nice, like, strolls in the woods.” 	<ul style="list-style-type: none"> • “I can no longer play softball. I can no longer run. [They] told me I couldn't even go for long walks.”
Sexual activity	<ul style="list-style-type: none"> • “frequency of sex is definitely different” 	<ul style="list-style-type: none"> • “I've been married to my husband for 11 years. And, you know, once it started it was like that was it ... It's, like, having a relationship with someone that you love so much, and you can't be sexual with them, because it's that painful.”
Reduced spontaneity	<ul style="list-style-type: none"> • “that's what I miss most, I think, being able to just get in the car and go and not have to worry.” 	<ul style="list-style-type: none"> • “it does make everything so much more of a challenge. You just have to come prepared with the foods you can have, if you can have that. It's just a lot of work and concern.”
Vigilance for flare triggers	<ul style="list-style-type: none"> • “I'm not, like, constantly worrying about it, but anywhere I go to eat, the first thing I do is, like, scan the menu for, okay, what I cannot eat for sure, ... I know, like, kind of what makes me flare, so I try to avoid all that stuff. But, I mean, yeah, you're pretty much, like, I don't want to say constant fear of being in a flare, but I mean, it's pretty much most of your day.” 	<ul style="list-style-type: none"> • “This affects me every hour of the day. It's like what I'm eating, what I'm drinking, how much sleep did I get, how do I feel, am I stressed out, do I need to just hang out for a little while, a couple nights?”
Impact of flare-related changes and other impact of flares		
Reduced social interaction	<ul style="list-style-type: none"> • “As far as relations, I don't have a lot of people around me that... well, I don't want to have anybody around me worrying about me or anything, but I also keep people out, because I don't want to be stressed. Like, I can't have somebody wanting something from me or, you know, other people's needs. So it's made me a little bit of a recluse.” • “I hate going out to eat, and I hate going to people's houses, because no matter how many times I'll try to explain it, my mom doesn't get the diet that I, you know, sometimes have to be on more than other times.” • “I used to always go with my friends, but now I cancel. I had to cancel all the time. Couple of my friends just dropped me. They don't even ask me to do anything. I lost a lot of friends.” 	
Romantic relationship avoidance and strain	<ul style="list-style-type: none"> • “I won't date because I don't want anybody near me. I'm scared that it'll hurt if I try and do anything, so I don't.” • “And he doesn't want to hurt me and it's a real difficult situation ... thank God we love each other so much, but it has been an issue. It'll continue to be an issue, I think.” 	
Reduced career or educational advancement	<ul style="list-style-type: none"> • “thinking about going back to school, which I would like to be a nurse anesthetist, but thinking of my career and being in the OR and not being able to leave, thinking about career changes because of it.” • “it has made me, for sure, stay at a certain level of poverty, because there's no way I can work eight hours. And I'm self-employed because of that too. I stay self-employed, because I have to have a job where if I don't feel good, you know, I can't lose everything.” • “I haven't been able to work for over a year. I'm only 20 years old - I should be able to do that. I haven't been in college for two years.” 	
“Ruined life”	<ul style="list-style-type: none"> • “P1: It ruins your life.” 	

P2: It has ruined my life."

Additional impact of flares and UCPS in general

Weight gain from medications and less physical activity, and other side effects of medications	<ul style="list-style-type: none"> • "I started retaining a lot of water when I was doing the drug therapy and so bad I gained 40 pounds in just water weight." • "Part of my depression is because I've gained so much weight. I'll be looking back at pictures when I was in high school, and I was like 120–130 pounds, and ... they're like, 'Well, make sure you keep your physical activity.' Well, what physical activity do you want me to do?" • "My antidepressant messed up my liver. So it's like okay, I don't have a perfect liver right now or a perfect kidney, but yet I won't die from this."
Poor posture	<ul style="list-style-type: none"> • "It affects your posture ... I don't stand up straight anymore."
Urinary tract anal-gesic agent staining	<ul style="list-style-type: none"> • "With the Pyridium I've stained somebody's toilet. And they're, like, 'Why is my toilet like an orangey-yellow color?' And I'm, like, 'I'm sorry, I'll come over and bleach it, but that was my urine.'
Home confinement	<ul style="list-style-type: none"> • "And I enjoyed being with people. Now I'm stuck in my house all day long, and it's really a horrible feeling." • "You're tired of looking at the four walls. You can't look at them walls, yeah. They start closing in on you."
Losing touch with family members	<ul style="list-style-type: none"> • "there are certain people - even people that are close to me like my father and my sister, in particular, they don't want to hear anything about it. They were with me for the first few years that were real bad and then they said, 'We can't take it anymore.' I guess sometimes you have to pick and choose. And sometimes those you think would be understanding won't necessarily be."
Getting a divorce	<ul style="list-style-type: none"> • "I am going through a divorce, so I see it actually really affected our marriage, my husband couldn't stand it, couldn't deal with a chronic illness."
Concerns for the future	<ul style="list-style-type: none"> • "But I've always been just really frightened of like, is my body going to be able to handle pregnancy? And then, yeah, if I ever want to be a mother, like, what if I'm a crappy mother because I feel bad? What if I just like - what if I'm in pain and how is that going to transmit to my family? It already affects my parents and my friends and my partners, you know, severely. But children, it's like - it's terrifying to think that that's going to cripple me."
Depression	<ul style="list-style-type: none"> • "After I was officially diagnosed and I got really depressed about it and I thought my life is over."
Life-changing influence	<ul style="list-style-type: none"> • "[It affects] everybody in your family. It affects my mother, because she can't help me. It affects every relationship I've ever had, because they don't understand it. It affects your work. It affects every single person in one way or another, which is just one more added pressure and stress to you, because you can't explain it."

P=participant

Appendix Table 1

Urologic chronic pelvic pain syndrome symptom variability focus group discussion outline, Multidisciplinary Approach to the Study of Chronic Pelvic Pain (MAPP) Research Network

INTRODUCTIONS	Let's go around the room and tell us your first name and how long you've been living with chronic pelvic pain?
TYPICAL SYMPTOMS	Can you tell me what your symptoms are like on a typical day for you? ^a <i>Probe:</i> If no typical day: Can you tell me what your symptoms were like yesterday or on a good day?
VARIATION IN SYMPTOMS	Are most days the same or are there times when your symptoms are much worse than usual? What do you call it when this happens? Do you ever think of it as a "flare"? <i>Probe:</i> If no: how would you define a flare? <i>Probe:</i> Do you have any other names for flares?
DESCRIPTION OF VARIATION	Can you tell me what it's like to have a flare/(whatever they call it)? <i>Probe:</i> Can you tell me what your symptoms are like when you have a flare? For instance, what your pain or urinary habits are like when you have a flare. <i>Probe:</i> How big of a change is that from your usual symptoms? <i>Probe:</i> What changes, if any, do you see in bowel habits, mood, or other symptoms? <i>Probe:</i> Do your symptoms change quickly or is it a gradual change? <i>Probe:</i> How long does it usually take for a change from usual symptoms to what you call a "flare"? <i>Probe:</i> Do your symptoms go away quickly or slowly? How long does that take? <i>Probe:</i> How often do you have flares? <i>Probe:</i> Would you say every day, every week, every month, or less frequently? <i>Probe:</i> How long do they usually last - hours, days, weeks, or what? <i>Probe:</i> If no one mentions flares that last only minutes or hours: Have you ever had flares that last only minutes or hours? <i>Probe:</i> What are your symptoms like during flares that last for minutes or hours? <i>Probe:</i> Do these shorter flares bother you? How do they bother you? Do they cause you to stop what you are doing at the time?
PREDICTABLE	How predictable are flares? Are there certain things that you think cause them or are related to them? What are things that trigger them or predict that they will happen? <i>Probe:</i> Do you think that it's your fault when you have a flare - that you could have prevented it - or do you think they just happen for no reason?
RELIEF	What helps relieve your symptoms during flares?
BEST AND WORST FLARE	Think about the worst flare you've ever had and the least bothersome flare you've ever had. What made the worst flare so bad? What made the least bothersome flare not so bad?
EFFECTS ON LIFE	When you're having a flare, how does this affect your life? <i>Probes:</i> For example, how does it affect your work, your family, your social activities, your relationships, your sex life, or any other aspects of your life that you'd like to tell me about? <i>Probe:</i> Do you have to stay at home, stay in bed, be near a bathroom, or any other special things when you are having a flare? <i>Probe:</i> Do you take medications for it - either different ones or more than usual? <i>Probe:</i> How does that affect your activities when you are having a flare? What about very short flares?
EFFECTS OF FLUCTUATION	How does the fact that your symptoms fluctuate over time or that you have flares affect your life? <i>Probe:</i> Are there things that you avoid doing or committing to because your symptoms might be worse at times? <i>Probe:</i> Does having flares affect your schooling, work or family life or did it in the past?
OTHER ASPECTS OF FLARES	Is there anything else that you'd like to tell me about flares - anything I haven't asked about?
MOST BOTHERSOME FEATURE OF CHRONIC PELVIC PAIN	This discussion has focused mainly on flares, but now let's talk more broadly about chronic pelvic pain. If you could tell someone without chronic pelvic pain about the one most bothersome aspect of your condition, what would it be, or if doctors and researchers could work on only one aspect of chronic pelvic pain, what would you like it to be? Why is that the most important one for you?

^a Our procedure was to first ask the question and encourage general discussion, and then to follow up with specific probes as needed to address additional aspects of the topic.