How Do Patients Describe Their Symptoms of Interstitial Cystitis/Painful Bladder Syndrome (IC/PBS)? Qualitative Interviews With Patients to Support the Development of a Patient-Reported Symptom-Based Screener for IC/PBS

Lucy Abraham,1 Rob Arbuckle,2 Nicola Bonner,1 Tim Crook,1 Louise Humphrey,1 Ian Mills,1 Rob Moldwin,2 Jörgen Nordling,4 David Schofield,1 Tara Symonds,1 Joop P. van de Meurpe1

Fletcher Ltd, UK; 2 Mapi Values, UK; 3 Hofstra University School of Medicine, Hempstead & Pelvic Pain Center, The Arthur Smith Institute for Urology, New Hyde Park, NY, USA; 4 University of Copenhagen, Denmark; 5 Erasmus Medical Centre, Rotterdam, The Netherlands

BACKGROUND
- The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) require cystoscopic features of interstitial cystitis (IC) as a diagnostic criterion. These features include glomerulations and/or Hunner’s lesion.
- These criteria were meant to define a population for research purposes only, and exclude significant numbers of patients with clinical symptoms of IC/Painful Bladder Syndrome (PBS).2
- Patient-reported, symptom-based assessments may be more appropriate for identifying IC/PBS patients.
- Existing IC/PBS symptom measures have poor specificity, likely due to inadequate content validity.

OBJECTIVE
- The objective of this study was to conduct qualitative interviews with IC/PBS patients to identify key IC/PBS symptoms and the language patients use to describe them, in order to develop a new symptom-based IC/PBS screening tool for use in a clinical trial setting.
- Interviews were also conducted with overactive bladder (OAB) patients, a condition often confused with IC, to improve content validity and specificity of the new measure.

METHODS
Study Sample
- 44 patients (age 22–72) with a confirmed diagnosis of IC/PBS were interviewed in the USA (n = 20), France (n = 12), and Germany (n = 12).
- 10 US patients with a confirmed diagnosis of OAB (age 31–69) were also interviewed.

Study Design
- Interviews began with open-ended questions about the patients’ experience of IC/PBS (or OAB), followed by creative tasks which included patients making a collage representing their condition, and finished with focussed discussion on topics of interest, such as questions about specific symptoms and impact on quality of life.

Analysis
- Verbatim transcripts were translated into English (where necessary), and qualitatively analyzed using Atlas Ti software and grounded theory methods.

RESULTS
- Key symptoms identified by IC/PBS patients were the urge to urinate, urination frequency, and bladder pain.
- The symptoms and their sub-concepts are summarized in Figure 1.

CONCLUSIONS
- Utilizing an extensive interview process and a geographically and culturally diverse sample, we elicited key symptoms that differentiate IC/PBS from OAB patients.
- These data will be used to generate items for a new symptom screening measure, with input from IC/PBS experts.
- Efforts to optimize the sensitivity and specificity of the new symptom measure are critical to accurately identify patients with IC/PBS.

REFERENCES

DISCLOSURE
This study was funded by Pfizer, Inc.