Undercared-for Chronic Suffering

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Off-Label Drug Uses

Amitriptyline: Interstitial Cystitis (Painful Bladder Syndrome)

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This Hospital Pharmacy feature is extracted from Off-Label Drug Facts, a publication available from Wolters Kluwer Health. Off-Label Drug Facts is a practitioner-oriented resource for information about specific drug uses that are unapproved by the US Food and Drug Administration. This new guide to the literature enables the health care professional or clinician to quickly identify published studies on off-label uses and determine if a specific use is rational in a patient care scenario. References direct the reader to the full literature for more comprehensive information before patient care decisions are made. Direct questions or comments regarding Off-Label Drug Uses to jgeneral@ku.edu.

BACKGROUND

Interstitial cystitis/bladder pain syndrome is a chronic condition characterized by an unpleasant suprapubic sensation of the urinary bladder (pain, pressure, discomfort) accompanied by lower urinary tract symptoms of more than 6 weeks’ duration that are not due to infection or other causes. Interstitial cystitis/bladder pain syndrome is more prevalent in women but can affect men as well. Etiology is poorly defined and therefore hampers classification and treatment; current treatments are not uniformly effective. Mast cell degranulation within the bladder wall, possibly related to histamine release, has been proposed as a contributing factor in the inflammatory process. Amityriptyline acts via the blockade of acetylcholine receptors, inhibition of reuptake of released serotonin and norepinephrine, and blockade of histamine $H_1$ receptors.

PATIENT POPULATION

Adults with signs and symptoms of interstitial cystitis/bladder pain syndrome.

DOSAGE AND DURATION

Ten to 25 mg daily titrated weekly over several weeks, to a target dose of 75 to 100 mg as tolerated for up to 23 months.

Guidelines

American Urological Association

American Urological Association (AUA) guidelines on the diagnosis and management of interstitial cystitis/bladder pain syndrome present a tiered approach to treatment based on expert opinion and an evidence-based review of published data. First-line treatment, which includes education regarding normal bladder function and self-care practices/behavioral modifications that can improve symptoms, is recommended for all patients. Second-line therapy includes multimodal pain management, physical therapy, and oral (amityriptyline, cinetidine, hydroxyzine, or pentoxyphine hydrochloride) or intravesical (dimethylsulfoxide, heparin, or lidocaine) agents that have demonstrated limited efficacy in a subset of patients and an uncertain risk-to-benefit ratio.
“This experience cannot be unique to me.”
medically unexplained syndromes
medically unexplained symptoms
somatic symptom disorders
(formerly somatic disorders, formerly somatoform disorders)
somatic symptoms
functional syndromes (formerly functional somatic syndromes)
functional symptoms
bodily distress syndrome
idiopathic (or cryptogenic) disorders
undercared-for chronic suffering
Conditions or symptoms that are difficult to diagnose, measure, and/or treat under the traditional medical paradigm.

Long, expensive, and often confusing/conflicting journeys to diagnosis.

Patients feel misunderstood, unimportant, and/or delegitimized.
Qualitative Systematic Review Aims

- What are the experiences of patients, clinicians, and/or caregivers with UfCS?
- What elements of patient support can mitigate:
  - frustrating patient-clinician conversations;
  - difficulties with self-management and treatment; and
  - patients’ feeling misunderstood, unimportant, and/or delegitimized?
Qualitative SR Methods

• Systematic review of English-language qualitative studies <5 years in 5 databases

• Used keywords related to conditions/symptoms we expected to be associated with UfCS (e.g., fibromyalgia, chronic pain, medically unexplained symptoms, etc.)

• Qualitatively/thematically analyzed results sections of included studies
Findings: Major Themes and Subthemes

1. Patient challenges that create the unique experience of UfCS
   a) Invisibility and uncertainty
   b) Lack of legitimacy and believability
   c) Thorny interactions with clinicians and social expectations
Findings: Selected Quotes

“Almost all participants thought that a diagnosis would be beneficial to them. Not only did they think that diagnoses facilitated treatment, but … [they] believed that a diagnosis would reduce their anxiety derived from uncertainty regarding the pain’s cause.”

Findings: Major Themes and Subthemes

2. Impacts of UfCS on patients’ lives
   a) Lack of social validation
   b) Negative emotional wellbeing
   c) Day-to-day struggles
   d) Communication work to make ailments visible to others

3. Communication strategies patients take on
Findings: Selected Quotes

“[S]ome felt that their symptoms [fatigue, pain, headaches, sleep disruption, and other symptoms] were perceived as exaggerated or ‘whiny’ to others….Alternatively, some participants expressed how they themselves had questioned the nature and severity of their symptoms, at least temporarily, during the illness process. Many participants expressed frustration in conveying that their symptoms were qualitatively and quantitatively different from the aches, pains, and tiredness of everyday life” [8].

Findings: Selected Quotes

“Other patients described how they learned to adjust their verbal and nonverbal behaviors (e.g., not displaying a cheerful demeanor) when interacting with PCPs in order to increase the believability of their pain symptoms”

Qualitative prospective experiences study

1. How do patients’ experiences shape their interactions with healthcare?
2. What practices help patients feel heard in clinical visits?
Methods

• Patients and clinicians in the family medicine and gastroenterology practices at Mayo Clinic consented to record their visit

• Conditions where we expected patients would experience UfCS

• Follow-up interview within one month of their visit
Results
The UfCS Journey

Seeking answers
Seeking answers

In the context of multiple known conditions: “[Symptom, constipation] gotten significantly worse within the last year. Everybody – you know, they’re like ‘well, what are you eating? Are you exercising? Have you taken this laxative? If you just take miralax it’ll be ok’ … I’ve done miralax. Done citucel. You know I eat a lot of cooked vegetables. I know to drink a lot of water. I’ve done all that. What am I supposed to do now?”
The UfCS Journey

Seeking answers

Demonstrating worthiness
The UfCS Journey

Seeking answers

Gatekeeping

Demonstrating worthiness
Gatekeeping

“I didn’t find that out [how far away appointment availability was] when I was actually in here with [clinician]. It wasn’t until I was out at the appointment desk when they started telling me what the first available was. Knowing the system, if I continued to have these horrible problems that I did, I knew that I would be back on the phone talking to her again. Because, as bad as things were, I knew there was no way I could live with that kind of pain for another two months.”
The UfCS Journey

Seeking answers

Gatekeeping

Demonstrating worthiness

Biases
Biases

“I’ve had lots of doctors – every time I saw them, ‘let’s talk about weight loss surgery’ But I might be here because I am throwing up. Please don’t talk to me about weight loss surgery. So it’s a sensitive area. I’ve done the research. I am not dumb. Um, that was the first time she brought it up to me was in that session. I’m not blaming her. It’s a sensitive area for me because I’ve had a lot of providers where they don’t focus on me. They focus on the one thing. The obvious thing. ‘Oh you’re fat so if you lose the weight, this will solve everything.’”
The UfCS Journey

- Seeking answers
- Gatekeeping
- Demonstrating worthiness
- Biases
- Rhetorical work
Rhetorical work

“A lot of times when I’m coming in, I’m coming in because I’m in pain. And I really try to stay away from narcotics or even asking for narcotics, mostly because of the fact that, you know, my pain is legitimate, so I don’t wanna give them a reason to quickly rule out that I’m there for a reason I’m not there for. I normally say things – because I do coach I know a lot of the biomechanics of how certain things happen, and so I generally know what part of my anatomy is hurting, so I can articulate where the pain is. I can tell them whether it’s sharp or if it’s something deep and throbbing. ...I use that kind of language.”
The UfCS Journey

- Seeking answers
- Gatekeeping
- Rhetorical work
- Demonstrating worthiness
- Biases
- Delaying/forgoing care
Delaying/forgoing care

“I got really anti-medicine in general, like Western medicine. I just decided all doctors were, you know – I mean if I had like sepsis or you know I needed my appendix taken out, then ok, I’ll go to the doctor – but other than that I was just like taking care of stuff on my own. My pain level was nuts, but I just – you know – when I got into my 30s it got really bad but I kind of like passed it off.”
The UfCS Journey

- Seeking answers
- Gatekeeping
- Rhetorical work
- Putting life on hold
- Delaying/forgoing care
- Demonstrating worthiness
- Biases
Communication Practices

• Affirming practices do matter
  • Verbal/non-verbal communication
    • Eye contact, posture
    • Words of solidarity
    • Conversational space
  • Legitimizing vs delegitimizing experience
    • Longest interval to delay care when delegitimized was 18 years
“But you don’t look sick.”