Clinical Practice Guideline by Infectious Diseases Society of America (IDSA): 2025 Guideline on Management and Treatment of Complicated Urinary Tract Infections: Patient Perspectives

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Chronic UTI symptoms and knowledge gaps

The evidence base for our guidelines is drawn from the general population of patients with cUTI who are healthy enough to enter a clinical trial. In this population, treatment is expected to relieve the symptoms of the acute infection and prevent recurrence. However, a subset of the cUTI population suffers from chronic urinary symptoms. Recommendations about diagnosis or treatment of chronic UTI are outside of the scope of our cUTI guidelines. However, the guidelines panelists acknowledge that patients who suffer from acute, recurrent, or chronic UTI symptoms should be heard. Several large patient advocacy groups support people who suffer from recurrent UTI or the inadequately defined entity of chronic UTI. We invited three representatives from these groups to participate in our patient advisory group. All three of our patient representatives for these cUTI guidelines believe that the chronic UTI symptoms they experience are related to insufficient antibiotic treatment of earlier episodes of UTI. Although the medical community for the most part does not accept the concept of chronic UTI as an ongoing

infection that requires long-term antibiotic suppression, we believe in listening to patients' lived experiences. The issues that concerned our three patients most were:

- Chronic UTI sufferers experience debilitating symptoms that negatively impact
 their quality of life and can greatly reduce their ability to function. A Twitter-based
 survey distributed through a UTI research society likewise reported that UTIs can
 drastically impact physical and mental well-being.³⁵
- They believe that chronic UTI is caused by insufficient antibiotic treatment upon initial acute infection (wrong choice, wrong route of delivery, and/or wrong duration).
- They believe in longer courses of antibiotic therapy for subsequent bouts of acute UTI.
- They believe that healthcare providers should listen to the patient's perspective on UTI symptoms.

Patients' values and preferences about treatment duration of cUTI from the perspective of patients who suffer chronic UTI symptoms

There is little direct evidence addressing antibiotic duration in cUTI and patient well-being. Consultation with patient representatives participating in this guideline revealed a disconnect between stewardship goals (shorter is better) and their desire to avoid chronic urinary symptoms (longer is better). Several of our patient representatives suffer from chronic UTI symptoms, and their experience may be representative of a subpopulation that is most severely affected by UTI. Our recommendations may be less applicable to this subpopulation. In light of the high value our patient representatives place on avoidance of recurrent infection, we considered recurrence of infection to be a critical outcome for our analyses.

Clinical cure (with relief of symptoms) was the most important outcome from the patient representatives' perspectives, and the duration of antibiotics chosen should be sufficient to achieve clinical cure. They did not feel that a negative urine culture was necessarily a goal, and they lacked confidence in the accuracy of urine cultures at predicting urinary symptoms. They also valued avoiding recurrence of symptomatic infection and readmission to hospital. Patients expressed that if an individual patient has experienced clinical recurrence of cUTI after a shorter duration of therapy, consideration should be given to treating the recurrence with a longer course of antibiotics.

Patient-suggested research topics

Our patient advisors proposed several research topics related to chronic UTI symptoms. These included exploring whether interstitial cystitis has an infectious component, comparing whether longer courses of antibiotics for acute UTIs can prevent long-term urinary symptoms, and a

study of the prevalence of chronic UTI symptoms in the United States. Our patient advisors with chronic UTI symptoms suggested that long-term UTI symptoms be an outcome measured in clinical trials of duration of treatment of the initial episode of UTI. The guidelines panel broadly agrees that more research is needed regarding the impact of chronic UTI symptoms and how these patients can be optimally evaluated and treated.