



Patient Distress in Women with Recurrent Urinary Tract Infections: How Can Physicians Better Meet Patients Needs?

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Published online: 18 October 2018
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Abstract

Purpose of Review Recurrent urinary tract infections are a common condition that can impact patients' quality of life. The purpose of this review is to summarize and analyze the literature regarding the distress that these infections can cause to patients and provide guidance to clinicians on how to improve care of these patients.

Recent Findings The current literature on patient perspectives in urinary tract infections shows an emotional symptom experience that is not consistent with the typical symptoms expected by clinicians. The infections can impact all aspects of quality of life, including social, emotional, and financial domains.

Summary Women with recurrent urinary tract infections experience a significant amount of distress. They have a strong desire for validation of their experiences by their physicians. Clinicians can best serve these patients by understanding the true impact of their condition and creating treatment strategies that include shared decision making to meet patients' goals.

Keywords Urinary tract infection · Quality of life · Patient satisfaction

Introduction

Urinary tract infections (UTIs) are a very common problem affecting more than 50% of women during their lifetime [1]. Young women who develop a UTI are at high risk of developing a recurrence [2]. Post-menopausal women are also at increased risk of developing UTIs [3]. Although definitions vary, when these recurrences happen more than three times in 1 year, or twice in 6 months, a patient is usually considered to have a diagnosis of recurrent UTIs (rUTIs). A variety of antimicrobial and non-antimicrobial treatment options exist for rUTIs in

women and the recommended treatment for an individual patient depends on factors such as menopausal status, frequency of infections, individual risk factors, and patient preference. Despite the wide range of available treatments, many women suffer from rUTIs, with a detrimental impact on their quality of life [4]. Patients are often frustrated with the symptoms of rUTIs and their lack of progress in returning to their baseline healthy state. Women with rUTIs often develop self-care strategies and some seek health care providers for evaluation and treatment.

Although many methods of rUTI prevention have been studied, there is a shortage of high quality studies in the literature [5]. This lack of strong evidence to support any particular treatment can leave clinicians frustrated in helping these patients. While much work has focused on the epidemiology, risk factors, and treatment strategies of rUTIs, there has been little study on the impact of rUTIs on the quality of life of women. The purpose of this review is to evaluate the effects of rUTIs on patients' quality of life and emotional well-being and provide clinicians with a summary of these findings in order to better understand the patient's perspective on the distress that rUTIs can cause.

This article is part of the Topical Collection on *Lower Urinary Tract Symptoms & Voiding Dysfunction*

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Methods

We conducted a PubMed, Embase, and Google Scholar search in July 2018 to identify all English language publications related to UTIs or rUTIs and the patient perspective of women who have experienced UTIs. We included both original research and review articles. Keywords used for the search were “recurrent urinary tract infection,” “urinary tract infection,” “patient perspective,” “quality of life,” “psychological effects,” and “distress.” We limited the scope of this literature search to articles relevant to women with idiopathic urinary tract infections. We excluded articles on subgroups including pediatric populations and pregnancy, in order to focus on community-dwelling adult women of all ages. All relevant articles were reviewed, and the references of these articles were also reviewed for additional potentially relevant publications.

Results

Patient Perception of Symptoms: More Than Dysuria

Based on standard medical diagnoses for UTI, cystitis is a diagnosis based on the presence of urinary symptoms including frequency, urgency, suprapubic pain, and dysuria along with a urinalysis consistent with infection [6]. However, these clinical-specific symptoms may not represent an accurate reflection of what patients experience with a urinary infection. Malterud and Baerheim performed a qualitative analysis of women’s self-described experiences with UTIs [7]. The women described a variety of symptoms that create a more severe picture than using the term “dysuria” may represent. For example, women described a “terrible scorch” and “it feels like peeing barbed wire.” Symptom descriptions captured a diverse experience of urinary and bodily sensations from this population of women with UTIs in Norway.

In a qualitative analysis of postings by patients with rUTIs on a web forum, Flower et al. also found that women describe symptoms that are outside of the usual clinical definition [8•]. In this study, women describe systemic symptoms and pain throughout the body, rather than localized to the bladder or pelvis. Women also posted that many of their symptoms are more disabling than what would typically be presented in textbooks. One woman described that she does not get “simply cystitis” but rather a “vile infection” that causes symptoms such as “shaking and shivering, terrible diarrhea, waves of nausea,” and weight loss. Another study on the use of acupuncture to treat recurrent cystitis included qualitative symptom description after treatment [9]. The symptom relief was described as a “happiness” in the bladder. Overall, these studies show that the symptoms experienced by women who have

rUTIs are often self-described in a more severe, bodily, and emotional way than is typically recognized by clinicians.

Effect of rUTIs on Quality of Life and Other Aspects of Health

Acute lower UTI is generally regarded by clinicians as a benign reason for a visit to the physician, perhaps due to its ubiquity. However, this notion has been challenged by researchers who have evaluated the effects of UTIs on quality of life from the patient’s perspective. Ellis and Verma performed a study of 47 women with a diagnosed UTI and 71 controls comparing responses to the RAND 36-Item Health Survey (SF-36). They found significant differences in all domains of the SF-36 with women in the UTI group scoring lower for indices including physical functioning, emotional health, and emotional well-being. The authors challenged the general notion of UTIs as a benign disease, as women with UTIs report that UTIs have a significant detrimental impact on their physical and emotional health as well [10].

Wagenlehner et al. studied women with rUTIs through a web-based survey in five European countries to determine the effects on quality of life. They found that rUTIs are a longstanding condition with over 40% of the women surveyed suffering from recurrent infections for more than 10 years. Antibiotic treatments were costly, and women commonly had to change antibiotic treatment due to lack of efficacy (39–53%). Women used a mean of 3.09 sick days, representing a high indirect cost of UTIs. Women who were not acutely infected but had an infection within the past 4 weeks demonstrated lower scores than the general US population on mental health indices [11]. This highlights the negative cost of UTIs on economics, work productivity, and mental health.

Renard et al. studied the effects of rUTIs on quality of life and the impact of prophylaxis in a 6-month observational study of 575 patients. Using the Hospital Anxiety and Depression (HAD) scale, they found that 61.9% of patients had some degree of depression at baseline. Ninety-five percent of patients received some form of prophylaxis during the 6-month period, and at the end of the study the mean number of UTIs decreased by 59.3%. The total HAD score decreased by 32.1%, representing a statistically significant reduction in anxiety and depression. These findings suggest that rUTIs are associated with higher levels of anxiety and depression which can potentially be decreased with effective treatment and alleviation of symptoms [12•].

Challenges Faced by Clinicians

As clinicians, treatment of patients with rUTIs can be frustrating due to the variability in results of common treatments and lack of a specific treatment algorithm. Long-term antibiotic

prophylaxis is known to be effective in reducing the risk of rUTIs but carries risks of side effects, adverse reactions, and antimicrobial resistance [13]. Non-antibiotic prophylaxis, such as methenamine and D-mannose have demonstrated good results in rUTI prevention with very few adverse reactions, however the evidence to support their use is not robust [14, 15]. Similarly, the use of cranberry products has shown mixed results in the literature, but with adverse events being an extremely rare occurrence [16]. Use of vaginal estrogen can be beneficial for rUTI prevention, but only in postmenopausal patients [17].

To evaluate the physician's perspective on rUTIs, Flower et al. performed an investigation of General Practitioners (GPs) in the UK on their views about the treatment of rUTIs. While most of the physicians appreciated the significant impact that the condition can have on patients' quality of life, there were challenges reported in regard to how to manage these patients. GPs felt pressure to prescribe antibiotics for each infection despite not believing that they were always necessary. They also had mixed views on the value of referral which could lead to unnecessary testing that does not change the patient's treatment course [18]. While acute UTIs are effectively treated with a short course of antibiotics, rUTIs are challenging clinical dilemmas for physicians because the evaluation is often low yield and treatments have variable efficacy.

Physicians may also find it difficult to understand the severity and impact of urinary symptoms on their patients. In one study, patients were asked to complete the Urogenital Distress Inventory (UDI-6) prior to a visit with their urologist. Urologists were then asked to complete the form after interviewing the patient without reviewing the patient's self-reported score. The results demonstrated poor concordance between patient and physician responses to the questionnaire, with physicians underestimating the bother 25–37% of the time [19].

In a similar study in an urogynecology clinic the King's Health Questionnaire (KHQ) was completed by patients prior to attending their visit. The form was then completed by the physician independently after the visit. Interestingly, they found that physicians underestimated the impact of lower urinary tract symptoms on physical limitations and emotions and overestimated their impact on social and personal limitations. The authors concluded that the assessment of quality of life from a physician's perspective may lack validity [20]. Taken together, these findings demonstrate that physicians underestimate the degree of bother of urinary symptoms and their negative impact on physical, emotional, and social health. Therefore, in order to achieve improved patient satisfaction, physicians need a deeper understanding of the patient perspective on rUTIs.

Patients' Views on rUTI Treatment

It is difficult for physicians to truly understand patients' individual views on the treatment of their urinary tract infections.

In the Flowers et al. study of web forum postings, women articulated a wide range of feelings regarding how their recurrent infections were managed in the past. Several women expressed frustration that doctors would ask or advise them on hygiene practices to prevent UTIs [8]. For example, women were told to wipe from front to back, which they had been doing, and the instructions felt condescending and inappropriate. However, in another qualitative analysis of women's experiences with UTI treatment, many considered hygiene to be a cause of their infections [21••]. In both studies, women felt the need for their physicians to validate their symptoms and experiences [8••, 21••]. These findings may indicate that women with rUTIs have a variable base of knowledge and experiences, and may benefit from an assessment of their knowledge prior to educational counseling.

Patients communicated a wide variation of views on the use of antibiotics for management of their infections. Women described short-term relief, frustration with antibiotic resistance over time, as well as happiness when the antibiotics provided relief of their symptoms [8••]. Patients also varied in their opinions regarding immediate versus delayed treatment with antibiotics, with some patients being frustrated by the delay, and others pleased to avoid any unwanted side effects [21••]. In a study of patients using prophylactic antibiotics for intermittent self-catheterization, patients were used to taking prophylaxis and it became part of their normal routine. However, there was a varied amount of worry regarding bacterial resistance [22]. Despite strong evidence supporting the use of long-term low-dose antibiotic prophylaxis, patients express variable experiences regarding their efficacy in preventing rUTIs, as well as concerns of bacterial resistance and potential side effects.

In these qualitative studies, patients desired alternative forms of prophylaxis besides antibiotics. Many were interested in "natural" or "alternative" forms of treatment [8••, 21••]. Despite this, many physicians are underprepared to advise patients on the variety of alternative treatments due to limited compelling evidence as well as concerns regarding safety [18]. Due to their desire for cure, patients may seek out alternative or natural treatments, with or without the guidance of their physician. Therefore, in order to better meet patients' needs, physicians should be open to discussing non-antimicrobial treatments.

Discussion

Patients Quest for the Answer and a Cure

At the root of the patients' concerns on urinary tract infections is the common patient's desire to know what is causing their rUTIs and to alleviate the distress that recurrent UTIs cause in their lives. Primary care providers and/or specialists may not,

in most cases, be able to answer the question of root cause, because there is often not a specific etiology, but rather a vulnerability to symptomatic UTIs. Therefore patient-centered counseling and education that is directed toward patient concerns is paramount. It is particularly frustrating for patients to leave a provider appointment without a clear understanding of their condition and the evaluation and treatment plan.

Patient Education Tool on Evaluation and Prevention Options

In order to attempt to address this gap between providers and patients, we propose the use of a patient-education tool that visually summarizes the possible diagnostic testing and treatment options for patients with rUTIs (Fig. 1). By using a patient education tool that outlines the diagnostic evaluation and treatment options, patients may gain a better understanding of their options for evaluation and prevention of rUTIs. Together, the provider and patient can develop a plan of care that incorporates their specific risk factors, concerns, preferences, and condition severity. This educational tool is a visual aid to facilitate communication and shared decision-making. Further studies of the utility of such a visual tool can be performed, and patient feedback can be incorporated.

Partnership Between Providers and Patients: Starts with a Deeper Understanding of the Patient Perspective and Meeting Patient’s Needs on Recurrent UTIs

Recurrent UTIs are a common condition that can cause a devastating impact on women’s quality of life. Patients often view their symptoms and UTI episodes in an emotional context that physicians may not fully appreciate. The recurrent episodes are associated with depression, anxiety, and negative impacts on many domains of quality of life including emotional, social, and financial. Future studies can address this gap in the literature and focus on the development of a standardized questionnaire to provide a patient-reported, objective evaluation of the impact of rUTIs on quality of life.

With increased knowledge of the patient perspective, physicians can improve the care of patients who are suffering from rUTIs by addressing patient’s needs and concerns to the best of their ability, with the ultimate goal of improving their quality of life. While common treatments such as antibiotic prophylaxis can be effective, there are adverse effects associated with antibiotics that can cause patients to have conflicted views on treatment. Patients desire to have their symptoms acknowledged and validated by their physician, without judgment, and for their concerns to be taken seriously.

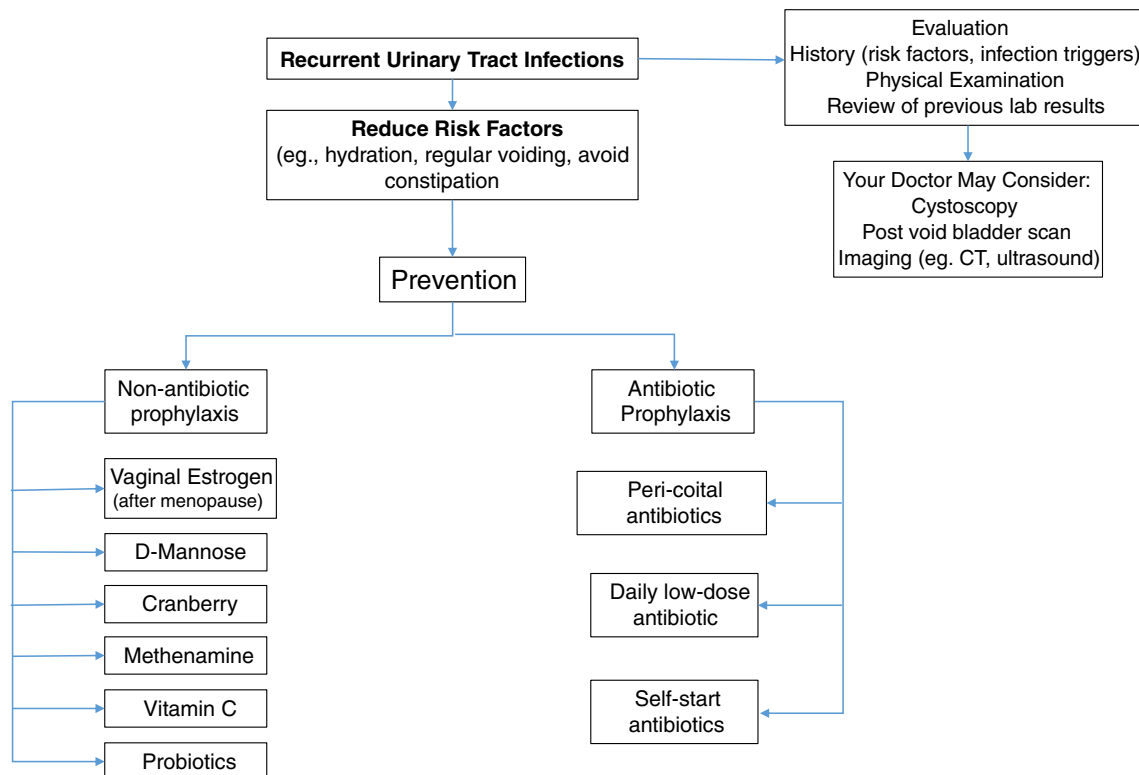


Fig. 1 Patient handout on rUTIs

Conclusions

Women with rUTIs have a high level of distress associated with their condition. They suffer a variety of devastating symptoms that impact their social, emotional, and physical health. There is a desire amongst patients to have their symptoms and concerns validated by their physician. By understanding the patient perspective, physicians can improve the counseling of patients with rUTIs and develop individualized patient-centered treatment strategies.

Compliance with Ethical Standards

Conflict of Interest Dena Moskowitz and Una Lee each declare no potential conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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