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## Review article

# A systematic review of parents' experiences and information needs related to their child's urinary tract infection

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### ARTICLE INFO

#### Article history:

Received 23 October 2017

Received in revised form 18 January 2018

Accepted 22 January 2018

#### Keywords:

Urinary tract infection

Information needs

Parents

Pediatrics

Systematic review

### ABSTRACT

**Objective:** As a first step toward the development of an animated video and infographic to increase parents' knowledge of pediatric urinary tract infections (UTIs), we conducted a systematic review of their experiences and information needs.

**Methods:** We searched Ovid Medline, Ovid PsycINFO, CINAHL, and ProQuest Dissertations and Theses Global for studies published in 2000 or thereafter. We appraised quality using the Mixed Methods Appraisal Tool. We summarised the quantitative data narratively and the qualitative data thematically.

**Results:** We identified 1493 records and included four. Sample size ranged from 20 to 2726 parents. The children ranged from <1 to 12 years old and had experienced one to >10 UTIs. Parents were not always aware of UTI symptoms and generally received little information. Parents sought information online, and desired it via other means. Some parents were not confident in healthcare providers' (HCPs') knowledge of UTIs. Inadequate information about diagnostic tests sometimes resulted in fear and non-compliance.

**Conclusions:** From the limited literature, it appears that parents would like information about prevention, diagnosis, treatment, and prognosis, but do not always consider HCPs good information sources.

**Practice implications:** Care providers should communicate information in ways that suit parents' self-identified needs.

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<https://doi.org/10.1016/j.pec.2018.01.014>

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**1. Introduction**

Among infants and children, urinary tract infections (UTIs) are a common cause of acute illness. Although it is difficult to estimate how many infants and children will develop a UTI [1], the cumulative incidence during childhood is estimated between 5% and 12% [2,3]. Most children will recover without incident following the administration of adequate antimicrobial therapy [4]. A small proportion will experience long-term consequences, including chronic abdominal pain in childhood [5], and renal scarring resulting in hypertension and chronic renal insufficiency in adulthood [6]. To minimize the risk of long-term complications, it is important that UTIs are recognized early and treated quickly [7,8].

For parents, recognizing the onset of a UTI in their child is challenging because the symptoms arise insidiously and can differ from those that are common to adults [4]. For 0 to 24 month-old infants, the only and most accurate symptom is often a high and prolonged fever for which there is no other apparent cause [9,10]. Infants may also present with nonspecific symptoms, like vomiting, irritability, or jaundice [11,12]. In many children, even these common symptoms may be absent [9]. Due to widespread misconceptions about the symptoms of UTIs [13], parents may delay seeking medical care if overt signs (e.g., changes in urine odour), albeit clinically unfounded [14], are not present.

Common diagnostic procedures (e.g., urinalysis and urine culture) to test for pediatric UTIs require a urine sample, typically obtained in younger children via urethral catheterization or suprapubic aspiration [15]. These invasive and potentially painful procedures [16] may be distressing for parents and children, but are favoured above non-invasive options like urine collection bags because these are easily contaminated [15]. To minimize potential discomfort, a collection bag may be used first and further testing ordered only if the urinalysis is abnormal [15]. Follow-up imaging tests, including renal/bladder ultrasound and voiding cystourethrogram (x-ray of the bladder and urethra), may be used to identify renal abnormalities, with the former being recommended as a first step as it is less invasive [15].

To make educated choices about their child's care, parents must be fully informed of diagnostic and treatment options. Elements of family-centred care include involving parents in care decisions, incorporating their knowledge and preferences into the treatment plan, and communicating diagnostic and treatment information in understandable language [17]. TRanslating Emergency Knowledge for Kids (TREKK) (<http://trekk.ca>) is a Canadian knowledge mobilisation initiative led by researchers, clinicians, and consumers who aim to improve the uptake of high-quality pediatric emergency medicine knowledge. As part of ongoing work with TREKK, our author team (which includes experts in knowledge translation (SDS) and systematic review methodology (LH)) aims to develop an animated video and infographic that will increase parents' awareness and knowledge of pediatric UTIs. As a first step toward the development of these knowledge products, we conducted a systematic review of parents' self-reported experiences and information needs. The animated video and infographic

will be developed based on information gleaned from the findings of the systematic review, as well as interviews with the target audience (parents of a child who has experienced a UTI) about the type of information they need and would like to receive. The final versions of the video and infographic will be made available in Canadian emergency departments as a resource to parents of a child with a suspected or diagnosed UTI.

**2. Methods**

We undertook the systematic review in July 2017, following an a priori protocol (PROSPERO # CRD42017070012). We planned the review according to the rigorous standards laid out by Cochrane [18] and have reported our findings in adherence to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses standards [19].

*2.1. Experiences and information needs*

There is no universal operational definition of, or set of common concepts for patient (or parent) experiences [20]. For this systematic review, we operationalised experiences as unique to the individual [21]. Experiences could be physical, psychological, and/or emotional, and include events that happened to parents and their children, and the extent to which they felt that their needs were met [22]. Importantly, we defined parent experiences as distinct from satisfaction [20,21], which is the difference between expectations and experience [21]. We operationalised information needs as the type, quantity, and delivery mode of information that parents reported needing. Information needs could be influenced by parents' knowledge and the accuracy of this knowledge, and include information that addresses their perceived knowledge deficits.

*2.2. Search strategy*

We developed the search strategy (Appendix A) in collaboration with a research librarian (RF). The strategy combined subject headings and keywords for: UTIs, parents, and information needs. Between June 26 and 27, 2017 we searched the following online databases, which provided coverage of the health and biomedical sciences, behavioural sciences, psychology, and mental health literature: Ovid Medline In-Process & Other Non-Indexed Citations and Ovid Medline (1946 to present); Ovid PsycINFO (1987 to present); and CINAHL via EBSCOhost (1937 to present). We also searched ProQuest Dissertations and Theses Global (1861 to present).

We searched for records indexed from January 2000 onward to review the literature on current management of UTIs. Although antibiotic therapy has always been the most effective treatment for UTIs, until the mid-1990s there was little consensus as to which antibiotic should be used, how it should be administered, or for how long [6]. The ways in which parents seek out information have also changed since the turn of the century. Global Internet use has been increasing steadily over the past two decades, and in 2016

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