



## Patient-centered outcomes research in appendicitis in children: Bridging the knowledge gap<sup>☆,☆☆</sup>



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### ABSTRACT

**Purpose:** Patient-centered outcomes research (PCOR) aims to give patients a better understanding of the treatment options to enable optimal decision-making. As nonoperative alternatives are now being evaluated in children for acute appendicitis, we surveyed patients and their families regarding their knowledge of appendicitis and evaluated whether providing basic medical information would affect their perception of the disease and allow them to more rationally consider the treatment alternatives.

**Methods:** Families of children aged 5–18 presenting to the Emergency Department with suspected appendicitis were recruited for a tablet-based interactive educational survey. One hundred subjects (caregivers and patients  $\geq 15$  years) were questioned before and after an education session about their understanding of appendicitis, including questions on three hypothetical treatment options: urgent appendectomy, antibiotics alone, or initial antibiotics followed by elective appendectomy. Subjects were clearly informed that urgent appendectomy is currently the standard of care.

**Results:** Only 14% of respondents correctly identified the mortality rate of appendicitis (17 deaths/year according to the 2010 US census) when compared with other extremely rare causes of death. Fifty-four and 31% thought it was more common than death from lightning (40/year) and hunting-associated deaths (44/year), respectively. Eighty-two percent of respondents believed it “likely” or “very likely” that the appendix would rupture if operation was at all delayed, and 81% believed that rupture of the appendix would rapidly lead to severe complications and death. In univariate analysis, this perception was significantly more prevalent for mothers (odds ratio, (OR) 5.19, confidence interval (CI) 1.33–21.15), and subjects who knew at least one friend or relative who had a negative experience with appendicitis (OR 5.53, CI 1.40–25.47). Following education, these perceptions changed significantly (53% still believed that immediate operation was necessary, and 47% believed perforation led to great morbidity and potential mortality,  $P < 0.001$ ). In a survey of potential appendicitis treatment options, urgent appendectomy was considered a “good” or “very good” option by 74% of subjects, compared with 68% for antibiotics only without appendectomy and 49% for initial antibiotic therapy followed by elective outpatient appendectomy.

**Conclusion:** There was a striking knowledge gap in the participant perception of appendicitis. Appropriate education can correct anecdotally supported misconceptions. Adequate education may empower patients to make better-informed decisions about their medical care and may be important for future studies in alternative treatments for appendicitis in children.

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Acute appendicitis is the most common surgical emergency in the pediatric population. In the United States over 300,000 appendectomies are performed each year, over 70,000 operations in patients younger

than 18 years [1]. The traditional emergency surgical management of appendicitis has been challenged. In a 2012 survey of members of the American Pediatric Surgical Association (APSA) [2], only 4% of 484 physicians polled considered non-perforated appendicitis to be an emergent procedure; most indicated that ‘urgent surgery within a day’ was a reasonable approach to treatment. This is a marked shift from the prevailing opinion only a decade ago, when a quarter of polled APSA members still viewed appendectomy as an emergent procedure [3]. Supporting this paradigm shift are several studies that demonstrated no increase in morbidity and mortality of appendicitis, and no increase

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in perforation, when appendectomy was postponed overnight [4–6]. This shift away from the emergent surgical nature of appendicitis has enabled the consideration of alternative management strategies for the treatment of acute appendicitis [7–9].

There has been extensive experience in the adult and pediatric literature with interval appendectomy for perforated appendicitis for those patients presenting with localized abscesses and minimal systemic symptoms [9,10]. A new concept has emerged suggesting that antibiotic therapy could be offered as primary treatment for acute appendicitis. Nonoperative treatment has been documented as an effective alternative when access to surgical care was limited as far back as the 1950s [7,11]. The concept of offering nonoperative therapy as an alternative to surgery was evaluated in a 2006 study by Styruud et al. [8] who randomized treatment among 252 men with acute appendicitis. The vast majority (86%) of the men treated with antibiotics only showed rapid clinical improvement. Patients who had no resolution of symptoms (14%) underwent appendectomy. Only 14% experienced recurrent appendicitis at 1 year follow-up.

While several studies have assessed these changing perspectives on the management of appendicitis within the medical community, very little is known about patient attitudes and expectations when a diagnosis of appendicitis is made. As alternatives to urgent appendectomy for appendicitis are now being evaluated in children, we surveyed patients and their families regarding their knowledge of appendicitis, and evaluated whether up-to-date medical information could affect their perception of the disease and enable them to accept treatment alternatives.

## 1. Methods

This prospective study was conducted in the emergency department of Hasbro Children's Hospital, a tertiary pediatric care center, from August 2013 to January 2014. We identified children ages 5–18 years with clinical suspicion for appendicitis, and approached their families/caregivers for participation in a computer tablet-based interactive educational survey. The educational presentation provided them with morbidity and mortality information on appendicitis, including statistics from Hasbro Children's Hospital [6,12,13] as well as information regarding current and emerging treatment options (see Appendix). Caregivers and patients older than 14 years were asked about their attitude toward appendicitis (based on their knowledge, concerns, and impressions) before and after the information session. They were also queried as to their willingness to consider each of three treatment options: urgent appendectomy, antibiotic therapy alone, or antibiotics followed by elective appendectomy. (Subjects were clearly informed that urgent appendectomy is currently the only acceptable treatment for acute appendicitis). Some questions were repeated at the end of the educational session. In order to better understand the basis of their "attitude" towards appendicitis, all subjects were asked if they had prior personal experience with appendicitis. Demographic data collected included age of patient/caregiver, gender, highest level of education, and ethnicity.

Statistical analysis of subgroups was performed using student t test for continuous variables and chi-square analysis for proportions. Subgroups assessed include: family role (mother, father, patient), past experience recollection (none, easy, complicated), ethnicity. Significance was established at a P value <0.05. Values are expressed as mean ± standard deviation (SD).

This study was approved by the institutional review board (IRB) of Hasbro Children's/Rhode Island Hospital. The content of the educational survey was reviewed for readability at the 8th grade level and approved by the IRB.

## 2. Results

One hundred subjects (80 parents, 20 patients > 15 years old) were recruited for the survey. Demographic data are noted in Table 1.

**Table 1**  
Demographic characteristics of the subjects.

		N
Subject	Child	20
	Mother	54
	Father	26
Ethnicity	Black/African-American	5
	White/Caucasian	70
	Hispanic/Latino	25
Level of education (parents)	High school or less	32
	At least some college	34
	Post-graduate education	14
Previous experience with appendicitis	None	37
	Good	33
	Bad	30

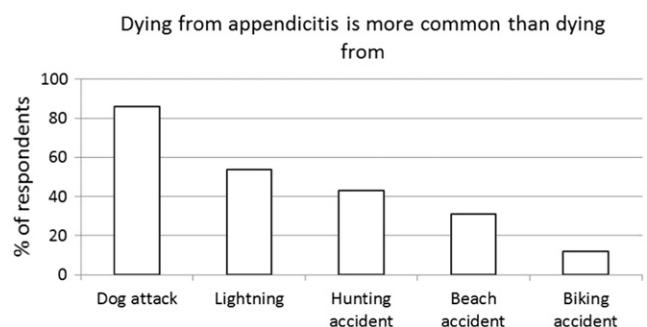
### 2.1. Current knowledge of the general public regarding appendicitis

According to the 2010 US census, 17 deaths/year are attributable to appendicitis [14]. When given a scale of magnitude comparing various risks of death, only 14% of respondents (5% of patients, 16% of parents) correctly identified the exceptionally low mortality risk of appendicitis (lower than death from dog attacks, 26/year, or lightning, 44/year). Fourteen percent of respondents thought appendicitis mortality was as common as beach-related or biking deaths, which are 10–50× more common (Fig. 1). Respondents who knew at least one friend or relative who had a relatively "easy" experience with appendicitis recovery believed the mortality of appendicitis to be significantly lower than those with no prior experience with appendicitis and those who knew at least one friend or relative who had a "complicated" experience with appendicitis recovery ( $P < 0.05$ ).

Eighty-two percent of respondents believed it "likely" or "very likely" that the appendix would rupture if not operated on immediately, and 81% believed that rupture of the appendix would rapidly lead to severe complications and death. In univariate analysis, this perception was significantly more prevalent for mothers compared with fathers, parents who had a high school education or less (compared with college education) and subjects who knew at least one friend or relative who had had a bad experience with appendicitis. In multivariate analysis, the perception that the appendix would rupture if not operated on immediately continued to be significantly more prevalent in mothers compared with fathers, and parents who had a high school education or less (Table 2). No significant difference in belief was demonstrated in subgroups by ethnicity or when comparing patient responses to parent responses.

### 2.2. The effect of basic medical information on perceptions of appendicitis

Following a short tablet-based educational session (see Appendix), these perceptions changed significantly. Fifty-three percent of respondents ultimately believed that the appendix would rupture if not



**Fig. 1.** Patients' and families' perception of the lethality of appendicitis (see text for details; according to the 2010 U.S. Census [14], 17 deaths/year are attributable to appendicitis – fewer than dog attacks).

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