Article

Parental Knowledge of Appendicitis and Preference for Operative or Non-Operative Treatment at a United Kingdom Children’s Hospital

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**Abstract:** Appendicitis is a common cause of abdominal pain in children and the most common reason for children to undergo emergency abdominal surgery.To guide our research program in this field, we aimed to determine parental understanding about appendicitis and its treatment. We also wished to assess parental preference for non-operative or surgical treatment of children with uncomplicated appendicitis. We asked parents attending a children’s outpatient clinic to complete a brief questionnaire that was interspersed with educational content to rectify any knowledge gaps. Three hundred and ninety-six parents (of 414 approached) agreed to participate. There were gaps in parental knowledge including not knowing where the appendix is located (one third of respondents), not knowing what appendicitis is (40% of respondents) and underestimating the incidence of appendicitis. Parents typically overestimated risks of complications and dying of both uncomplicated and complicated appendicitis. There was no influence of gender, age or previous experience of appendicitis in these findings. When presented with the scenario of equal effectiveness of non-operative treatment and surgery for uncomplicated appendicitis, 59% of respondents expressed a preference for non-operative treatment over surgery and 21% a preference for surgery (20% no preference). These findings are important for clinicians and researchers when discussing appendicitis and treatment options with families and justify ongoing research into the comparative effectiveness of non-operative treatment and surgery.

**Keywords:** Appendicitis; children; parental knowledge; patient opinion; treatment preference

1. Introduction

Acute appendicitis is a common cause of abdominal pain in children and the most common reason for emergency admission to general surgical units. In the UK approximately 10,000 cases in children are treated annually [1]. It is most prevalent in those between the ages of 10 and 20 and the lifetime risk of developing appendicitis is approximately 8% [2]. Despite many decades of investigation there remain uncertainties regarding the optimum treatment of a number of aspects of appendicitis in children. These include the optimum method of diagnosis [3], the role of diagnostic imaging [4, 5], non-operative treatment compared to surgery [6-8], post-operative antibiotic type and duration [9] and the optimum way to treat complications following surgery such as deep surgical site infection and prolonged ileus[4]. Our program of research aims to investigate a number of these areas.

In paediatrics, parental/guardian (henceforth referred to simply as parents) involvement is crucial for the optimum care of children. Parents have the responsibility of making decisions about their children’s health and wellbeing. It is therefore essential that they are able to make informed and appropriate decisions about the health and welfare of their children. Parents also have influence over the decisions children make about their own healthcare [10, 11]. In order to make these decisions, parents require sufficient information and knowledge. to help them in their decision-making process. An understanding of parental knowledge is therefore important in guiding the provision of information. An understanding of parental knowledge and understanding is also important for researchers when designing clinical research studies involving children and their parents. Only by fully appreciating the knowledge, understanding and attitudes of parents can we design appropriate research studies that seek their involvement.

In order to inform our research program we sought to ascertain the current knowledge and understanding of parents with regard to appendicitis. In addition, given our current interest in the role of non-operative management of appendicitis as an alternative to surgery [6, 12, 13] we investigated parents’ attitudes towards non-operative treatment of acute appendicitis.

2. Materials and Methods

A questionnaire was developed that would enable us to ascertain the knowledge and understanding of parents with regard to appendicitis and its treatment, prior experience of the illness, and attitudes towards non-operative and operative treatment. The questionnaire was based on those used in a previous similar studies outside the UK [10-12] and questions were interspersed with short education sections to rectify any knowledge gaps. Having created a draft of the questionnaire we sought input from a group of young people and parents who provide patient and public involvement (PPI) into our research program. This enabled us to assess the questionnaire for content, readability, understanding, and through cognitive interviews with some of the group for measurement/observation error. Following this we modified questions that were unclear or ambiguous to ensure that responses provided accurately reflect the answers participants intended. This enabled us to ensure the questionnaire was as accessible as possible to the participants and used terms which were easy to understood (e.g. we used the terms ‘simple’ and ‘perforated/burst’ to describe uncomplicated and complicated appendicitis). The questionnaire was designed to be completed on an electronic tablet device using a commercially available survey platform (iSurvey) with a printed paper alternative available.

Parents (age 16 years or over) of children (age 16 years or younger) attending the general paediatric outpatient department of our hospital were approached by a single medical student (KM) and asked to complete the questionnaire whilst waiting for their child’s outpatient appointment. The age of 16 years was used since this is the upper age limit for children seen in our hospital’s outpatient department. Written consent to complete the study was taken. Respondents could complete the questionnaire either on electronic tablet or paper. The questionnaire (Appendix A) took approximately 10 minutes to complete.

A convenience sample of participants attending the outpatient department over a 2 month period starting October 2018 was used. We aimed to achieve minimum 200 responses.

Electronic responses were exported directly from the online survey platform into Microsoft Excel and paper responses were added manually. Prior to analysis we predetermined that we would describe the data descriptively but also plan subgroup analyses driven by our current research interests. These included impact of gender, age and prior knowledge of someone with appendicitis on survey responses, particularly understanding about appendicitis treatment and risks, and treatment preference. Statistical analyses were performed using IBM SPSS Statistics for Windows, version 28.1 (IBM Corp., Armonk, NY, USA). All responses were included in the analysis so long as at least one of the questionnaire questions had been answered (if demographic details section alone had been completed then the response was excluded).

The study was approved by the East Midlands Research Ethics Committee in September 2017 (ref 17/EM/0344) and the ethics committee of the University of Southampton Faculty of Medicine. No specific funding was used for the conduct of the study.

3. Results

3.1. Respondents

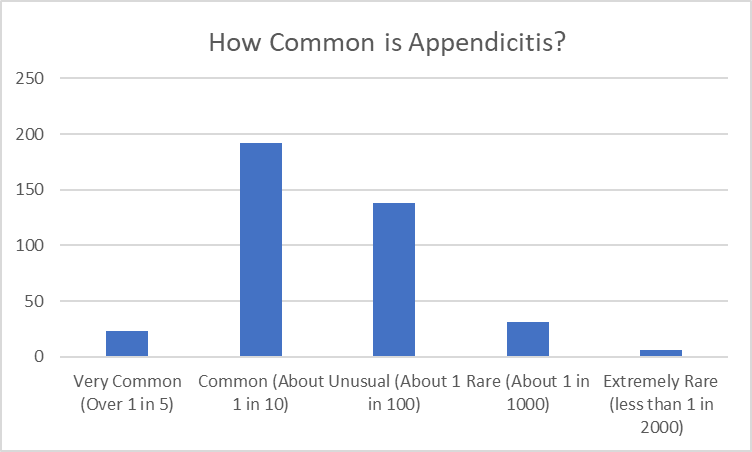
During the study period a total of 396 parents completed a questionnaire; all were included. A total of 18 individuals who were approached declined to participate. A full set of responses are provided in Supplementary material. Key findings are summarised here. Eighty-two respondents were male, 294 female (20 did not state). Age of respondent ranged from 16 years to >64 years and age of oldest child ranged from 1 month – 44 years. The highest level of education achieved by respondents was GCSE/O level (completion of secondary education to age 16) in 65, apprenticeship or similar in 35, A level (completion of education to age 18) in 93 and university degree or higher in 173 (30 unknown). The majority of respondents (253/387, 65%) knew someone who had been treated for acute appendicitis, whereas 33% (127/387) did not with the remaining 7 responding “don’t know”. Of those who did know someone who had been treated for appendicitis the relationship to them was as in Table 1.

**Table 1.** Relationship to respondent in those who knew someone who had had appendicitis.

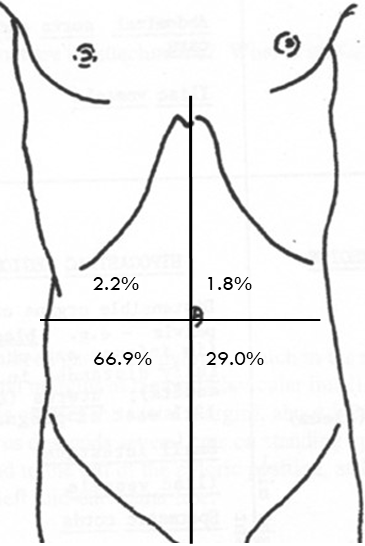
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| --- | --- |
| **Who?** | **Number of responses (n=251)** |
| Myself | 37 (14.7%) |
| My child | 13 (5.2%) |
| My parent/sibling | 51 (20.3%) |
| Other family member | 53 (21.1%) |
| A friend | 97 (38.6%) |

3.2. Knowledge and understanding of appendicitis

The most frequent response (49%) to the question about frequency of appendicitis was ‘Common – about 1 in10’ with the distribution shown in Figure 1 and most respondents (67%) were able to correctly identify the site of the appendix within the right lower quadrant although nearly one third chose the left lower quadrant (Figure 2). The most common keywords extracted from the free text descriptions regarding respondent understanding of appendicitis were inflammation and/or infection in 57%. All keywords extracted are shown in Supplementary Table S1. The experience of the individual who respondents knew who had had appendicitis was described as shown in Table 2.



**Figure 1.** Respondent understanding regarding frequency of developing appendicitis**.**

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**Figure 2.** Location of the appendix in the abdomen respondent understanding regarding frequency of developing appendicitis.

**Table 2.** Rated experience of appendicitis in those who knew someone who had had appendicitis.

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| **Experience of symptoms and treatment** | **Number of responses (n=251)** |
| Very easy | 6 (2.3%) |
| Easy | 47 (18.7%) |
| Neither easy or difficult | 75 (29.8%) |
| Difficult | 87 (34.7%) |
| Very difficult | 36 (14.3%) |

3.3. Understanding of treatment and risks of appendicitis

The most frequent response provided about current usual treatment for appendicitis was surgery (348/387; 90%) with just under 9% (34/387) responding antibiotics alone and 1% pain relief and bed rest. When asked how likely it was that if a child with appendicitis would suffer from a burst appendix if they did not have surgery straight away, over three quarters responded either likely or very likely (Table 3). Over 90% of respondents thought it ‘likely’ or ‘very likely’ that a child would become ‘very sick or even die’ as soon as their appendix burst. Only 9% thought it ‘unlikely’ or ‘very unlikely’.

Serious complications were thought to occur with a frequency of 1 in 4 or more frequent following simple appendicitis by 30% of respondents and following perforated appendicitis by 73%. Death was thought to occur at a frequency of 1 in 4 or more frequent by 6% of respondents and following perforated appendicitis by 31%. Prior knowledge of someone with appendicitis did not influence understanding of risk of serious complication of death from simple or complicated appendicitis.

There were no statistically significant relationships between respondents who knew someone who had previously had appendicitis and the frequency with which they thought appendicitis occurred, nor the perceived frequency of significant complications or death from either simple or complicated appendicitis. However, those who knew someone who had previously had appendicitis more frequently identified the correct incidence (‘about 1 in 10’) of appendicitis (52% vs 40%; Supplementary Figure S1).

**Table 3.** Perceived likelihood of a child with appendicitis suffering from a burst appendix if they did not proceed to surgery straight away

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| **Likelihood** | **Number of Responses (n=386)** |
| Very Likely | 95 (24.6%) |
| Likely | 223 (57.8%) |
| Unlikely | 56 (14,5%) |
| Very Unlikely | 12 (3.1%) |

3.4. Opinions regarding different treatments for appendicitis

Three hundred and six of 380 respondents (81%) indicated that they would probably or definitely consider their child being treated with antibiotics alone if they were to develop simple appendicitis compared to 44% (167/377) who would probably or definitely consider surgery. Overall, there was a preference for antibiotics over surgery for 59% (223/375), a preference for surgery over antibiotics for 21% (78/275) and no preference for 20% (78/375). No significant associations were identified between age or gender of respondent, or previous experience (knowing someone) with appendicitis, and treatment preference. However, there was a significant (p=0.004) association between highest educational attainment and treatment preference such that a greater level of education was associated with a preference for non-operative treatment.

4. Discussion

In this study we aimed to document parental understanding about appendicitis, its risks and treatment, and to determine attitudes to operative and non-operative treatment of uncomplicated appendicitis. The rationale for the study was to inform the design of our ongoing research program and in particular to guide provision of information to parents in discussions and information leaflets. Whilst previous similar work in this field has been undertaken, to our knowledge this is the first such study to be completed in the UK. This is important as there may be different knowledge and attitudes based on culture. Overall, we identified some knowledge gaps in understanding about appendicitis, some misunderstandings about the risks of appendicitis, and that whilst both non-operative treatment with antibiotics and surgery are accepted treatments, there appears to be a preference for non-operative treatment if both are equally effective.

Two thirds of respondents (67%) were able to correctly identify the location of the appendix in the right lower quadrant of the abdomen and just over half of respondents (57%) including the keywords infection and or inflammation in their responses about their understanding of what appendicitis is. These findings indicate some gaps in parental knowledge that clinicians and researchers may wish to take into account when providing written and/or verbal information. Additionally, these findings may have clinical implications – a lack of awareness regarding the correct location of the appendix may mean that parents of a child with worsening right lower quadrant pain are unaware of the possibility of appendicitis and therefore do not present to hospital. Improving this knowledge, for example via a public health intervention, may reduce late presentations of appendicitis. Despite this, the majority of respondents (90%) were aware that the typical treatment of appendicitis is appendicectomy.

When considering respondents’ awareness of risks of appendicitis, three-quarters believed it was likely or very likely that the appendix would burst if surgery was not performed immediately and 90% believed it was likely or very likely that a child would become very sick and may even die were the appendix to burst. Similarly, when considering the risks of serious complications and death, we found parents typically over-estimate the frequency with which serious complications or death occur following both simple and perforated appendicitis although more so for perforated disease. Knowing that parents typically overestimate the risks associated with appendicitis provides a useful understanding of the context for clinicians and researchers when having discussions with families about treatment and research. Clinicians may find it helpful to reassure parents that risks may be present yet not perhaps as high as anticipated. Researchers may find it useful to address these risks during discussions about research particularly if parents consider that involvement in research may increase the risks to their child.

A small number of previous similar studies have investigated knowledge about appendicitis and its treatment, as well as attitudes towards non-operative treatment of appendicitis, with mixed observations [14-18]. To our knowledge no previous investigation has been undertaken in the UK, the majority arising from the USA. Kadera and colleagues identified similar knowledge gaps to those we have identified, similar misunderstandings regarding risks of appendicitis and also a preference for non-operative over surgical treatment. Their study involved 129 adults at a single hospital in the USA. In a single centre study involving parents from the USA responding in relation to appendicitis in their child, similar knowledge gaps existed to those we encountered [15]. In a larger study from the USA Hanson and colleagues surveyed over 1700 individuals [16] of whom nearly 80% expressed a preference for laparoscopic appendicectomy for their child were they to develop uncomplicated appendicitis. Their sample had a strong medical influence since the survey was advertised at a medical school campus and through contacts of the investigative team. In a smaller subsample (n=220) recruited at public (as opposed to medical) venues, non-operative treatment was viewed more favourably. Althans and colleagues surveyed 255 medical students in a single medical school in the USA and presented them with realistic risks regarding efficacy of non-operative treatment and adverse events related to both surgery and antibiotic therapy. They reasoned that medical students were in a unique position of being potential patients with greater medical knowledge than the general public and possibly less bias than practicing physicians. Two thirds of respondents expressed a preference for surgical treatment and 24% a preference for non-operative treatment [18].

Outside of the USA, Bom and colleagues reported findings of a study conducted by an independent market research agency in The Netherlands [17]. They hoped to remove the influence of pre-existing medical knowledge through this independent methodology and found that a similar proportion of adults expressed a preference for either non-operative treatment (49%) or surgery (44%). In a recently reported study similar to ours, Ensor and colleagues surveyed 311 parents attending an outpatient clinic at a specialist children’s hospital in Australia [19]. They also found that parents typically overestimated the risk of dying from perforated appendicitis, and similar proportions preferring non-operative (52%) or surgical treatment (48%).

There are some limitations to our study which should be considered when interpreting our findings. Although we had a relatively large sample size, there was an imbalance between male and female respondents which may have influenced our results overall. This is a consequence of our approach of using a convenience sample rather than purposively sampling to achieve equal gender distribution. However, in subgroup analyses for each key metric there were no statistically significant differences between male and female respondents. A further limitation is that the study was completed in a single hospital. It is possible that there may be geographic variation in knowledge and understanding about appendicitis that we have not been able to detect. Despite these limitations we believe our large sample size provides an extremely useful overview of UK parents knowledge, understanding and opinion. A limitation regarding the question about non-operative treatment is that we set the context of these questions as being that non-operative treatment and surgery are equally effective (although we did not further define effectiveness). This suggestion was made by our PPI group given that providing adequate estimates of comparative effectiveness of these two treatment modalities based on current evidence is unclear and research is ongoing. Despite this our findings support ongoing investigation of the comparative effectiveness of non-operative treatment and surgery. Whether a preference for non-operative treatment remains once comparative data are available remains to be seen. As with any survey, hypothetical choices made by parents may differ from choices they may make if their child were to actually develop appendicitis, yet our observations in treating patients and through our research confirm significant interest in non-operative treatment [13, 20]. We also note that this work was undertaken prior to the SARS-CoV-2 pandemic, a period during which there was much greater use of non-operative treatment than had previously been the case, certainly within the UK [21]. Whether attitudes have changed as a result in uncertain.

5. Conclusions

In conclusion we have found that knowledge gaps exist in parental understanding of appendicitis and its treatment, and that parents, in general, overestimate risks of appendicitis. These findings are similar to others reported outside the UK. Our data suggest that there is significant interest in non-operative treatment and a preference for it over surgery if they are equally effective. This knowledge is useful when discussing appendicitis and its treatment with families and when designing future research in this field.

**Supplementary Materials:** The following supporting information can be downloaded at: www.mdpi.com/xxx/s1, Table S1: Keywords extracted from free text responses of respondents understanding of appendicitis.

**Author Contributions:** Conceptualization, KM and NJH; methodology, KM and NJH; formal analysis, KM and NJH; data curation, KM; writing—original draft preparation, KM; writing—review and editing, NJH; supervision, NJH; project administration, KM. All authors have read and agreed to the published version of the manuscript.

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**Institutional Review Board Statement:** The study was approved by the UK National Research Ethics Service (ref 17/EM/0344) and the ethics committee of the University of Southampton Faculty of Medicine.

**Informed Consent Statement:** Informed consent was obtained from all subjects involved in the study.

**Data Availability Statement:** Anonymized data will be made available by the study team on reasonable request so long as accompanied by a protocol outlining proposed use of the data and confirmation of ethical approval from the requesting institution. A fully executed data sharing agreement will also be required.

**Conflicts of Interest:** The authors declare no conflict of interest.

**Appendix A**

Full questionnaire administered to participants

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