Parent's opinions on the diagnosis of children under 2 years of age with urinary tract infection

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Background. Urinary tract infection (UTI) in childhood can be diagnosed in 5% of febrile infants. Renal scarring is associated with increasing numbers of UTI episodes, and the incidence of renal scarring rises with each urinary infection. High levels of awareness of childhood UTI are important among both professionals and parents. Whilst problems for professionals in making the diagnosis have been explored, few data exist concerning parental understanding and perspectives.

Objectives. The purpose of this study was to assess parental understanding of UTI in their child and identify any delay perceived in the diagnosis, along with identifying how helpful parents had found any information that they had been given.

Methods. Subjects were the parents of children aged <2 years being investigated in one outpatient department following proven UTI. A semi-structured questionnaire was given to parents at first attendance (quantitative data) and content analysis of qualitative data was carried out.

Results. Fifty-two out of 84 parents responded (response rate 64%), of whom 45 (86.5%) felt that they had been given a full explanation of the significance of UTI in childhood. Forty percent felt that clean catch was the easiest method of obtaining a urine sample from their child. Although the quantitative data were positive, several themes were identified in the qualitative data, relating to lack of awareness, delay in investigation by health professionals and issues regarding the information that had been imparted to parents. Parents would like more information about the illness that affects their child, and many would like this in leaflet form.

Conclusions. Parents perceive low awareness levels and delays in investigation of UTI in childhood amongst health professionals. Increasing awareness about the importance of UTI in childhood, its incidence and management should be generated amongst health professionals who deal with young children. Parents need and would like more information about the disease and how to identify it, with guidance on urine collection. Further research is needed into whether educational strategies for either parents or health professionals are effective in identifying UTI earlier, and what the best methods of implementing these would be.

Keywords. Children, diagnosis, general practice, urinary tract infection.

Introduction

Urinary tract infection (UTI) is a common bacterial infection in children, found in up to 5% of all febrile children under the age of 2 years presenting to emergency rooms1 and an incidence of 0.43/1000 patients per year in general practice.2 UTI symptoms in this age group can be non-specific, with fever, vomiting and diarrhoea being common presenting symptoms.3 These are common presentations of all viral infections in childhood, and thus misinterpretation and delay in diagnosis can occur. Despite the publication of guidelines on childhood UTI in 1991,4 GPs often do not investigate for UTI in febrile children for a number of reasons.1 It is thought that one of the predominant factors in failure to diagnose UTI is lack of professional awareness and practical difficulties in obtaining appropriate urine specimen for culture.5 Diagnosis and treatment of UTI...
in childhood is important; in particular, to prevent future renal scarring and renal failure and investigation is warranted to identify subgroups of children who are at increased risk of future morbidity.

After a first infection, ~50% of girls have a further infection in the following year. As the incidence of renal scarring rises with each urinary infection, parents need to be aware of early warning signs in order to identify a future infection, and also to understand the importance of identifying infections early so that treatment can be commenced without delay.

Few studies have explored parental understanding of the information given by health professionals at the time of diagnosis of the first episode of UTI and their sense of enablement to deal effectively with future episodes. Although professionals traditionally have identified practical difficulties in obtaining urine specimens, parental perceptions and experiences about difficulties may be at least of equal importance, and these require identification. Understanding these aspects may then be useful for developing educational interventions for the professionals and parents to enhance awareness and diagnosis of UTI.

To answer these questions, a study was performed to assess parental ideas about the initial management of their child during his or her first UTI, and their understanding of their child’s illness.

Methods

Patients were identified between 1998 and 2000. Children of ≤2 years were eligible if they had no previous history of renal pathology and had been referred to the out-patient department of the Department of Child Health Children’s Centre at University Hospital of Wales after a proven UTI. This department serves a population of ~300 000 in the Cardiff area as well as being a regional referral centre for paediatric nephrology. Patients were derived from many different practices serving a wide catchment area but were not demographically identified. All subjects were new referrals and were identified at their first visit to the clinic, and thus were close to the first diagnosis. The parents were a selected group, known to have experience of a child presenting and being diagnosed with UTI.

A questionnaire was given to parents of identified children following their attendance at the clinic. This was semi-structured, containing both fixed response and free text response questions in which participants were encouraged to add comments. This was designed to identify whether the parents felt that they had been given enough information about UTIs, from whom, in what format, how effectively this information had been received and whether this could be improved. The questionnaire was piloted in the clinic with 10 attendees and is included in Appendix 1.

In addition, parents were asked to evaluate how easy it had been to obtain urine specimens from their child, if any particular method was preferred and whether they would know what to do if they suspected their child had a UTI in future. Specifically, parents were asked to remember back to the first time that their child had had a UTI and to comment on the time taken for diagnoses and treatment.

Parents were encouraged to comment on the information they had received and the care they had been given by health care professionals. Some (27) had received a leaflet about UTI in children, produced by KB, and their comments on the leaflet were sought.

Questionnaires were given to patients at the clinic and they were asked to return them by post. Reminders were sent after 1 month to non-respondents. Parents were assured that the responses would be analysed confidentially.

Analysis

The fixed response data were entered into SPSS version 11 for descriptive analysis.

Content analysis of the free text responses was undertaken, exploring for key themes in the data. As the responses were related closely to the direct questions about pre-defined areas, this analysis was analytic rather than descriptive, attempting to identify greater detail and interpretation in the patients’ views and experiences relating to the diagnosis of UTI. All data were anonymized, transcribed and collated under each question heading. Three researchers (DO, JVA and AE) examined these data for themes, and two researchers (DO and JVA) examined the data for specific examples of these and explored the data for evidence of patterns of responses between questions from individual respondents.

Results

Fixed response data

Eighty-one questionnaires were given out. Fifty-two were completed and returned (64.2%), three were returned unopened, and 26 were not returned. Two participants failed to enter any free text information in their questionnaires.

The fixed response data are summarized in Table 1. They indicated that most parents felt they had been given a helpful explanation of the importance of detecting UTI in infants. Approximately half the respondents had received a leaflet about UTI and collecting urine, and had found this useful. About half the respondents stated that they had had difficulty obtaining a specimen. Of the three methods (clean catch, bag and pad), parents were split between their preferred method, although slightly fewer favoured the pad collection method than the other two. Most respondents felt that they had been given sufficient information to enable them to collect urine from their child in future, and that they would specifically know what to do if their child were to suffer a repeat episode.

Most urine samples were requested at either the first or second visit to the primary health care team during an
illness episode, and usually before commencing antibiotic treatment for the child. However, a quarter of respondents indicated that they had either had to request samples to be taken themselves, or it had been done after admission to hospital.

**Qualitative data**

Content analysis of qualitative data identified some key themes.

- Delay in requesting urine samples (reluctance).
- Difficulties in collection.
- Information (leaflets).
- Empowering.
- Lack of awareness in health care professionals.
- Organizational problems.

Each of these is described below with a number of examples of the data related to each theme.

**Delay in requesting urine samples**

Some felt that there had been a delay between their child becoming unwell and a urine sample being requested.

“why does it take a GP so long to request water samples? I’ve learned more from the Internet than by my GP. (on the net it states if a baby is unwell more than 3 days then a water sample should be taken) so why did it take my GP nearly 3 weeks?” *(Questionnaire 29)*

One parent stated that it was taken

“after continual spells of high temperature—sixth visit.” *(Questionnaire 21)*

Others felt that they had had to insist themselves on the sample being taken in the first place.

“I suggested sending a sample myself which GP agreed to do.” *(Questionnaire 45)*

Although various respondents identified a delay in sending specimens, some also felt that there had been a reluctance to send them on the part of the GP.

“We had to insist, the GP would not have taken one.” *(Questionnaire 41)*

“. . . I returned to GPs insisting that something else was wrong with him.” *(Questionnaire 42)*

Also, in a number of cases, it was not the GPs but allied health professionals who thought of sending the sample in the first place.
“Several visits to GP then finally at baby clinic a nurse practitioner requested a sample.” (Questionnaire 30)

Not only was there was a perceived delay in sending a urine sample there was also a perceived delay in undergoing further investigations.

“The main cause of concern was the long waiting time between the first UTI and the hospital appointment.” (Questionnaire 3)

“Finding the cause after an ultrasound, took almost a year, from the day I first noticed my child was first unwell and after several UTIs. I feel that it was an unnecessary length of time.” (Questionnaire 10)

Difficulties in collection

Difficulties were voiced regarding urine collection, which was mainly around bag collection methods. Some felt that the bag collection produced unnecessary discomfort for their child whilst others felt that it was difficult to keep the bag in place.

“I was given the bag which sticks onto them. This was very painful when removing so the next time I had to collect urine he would not let me put it on him because he knew it would hurt taking it off.” (Questionnaire 15)

“The bag would come unstuck and leak.” (Questionnaire 44)

Information

A number of themes were expressed relating to the information or the lack of it given to the parents. Although specific questions were asked about the information received in the initial questionnaire sent, parents were vocal about the information they had received in free text answers. This ranged from some being happy about what was received, with the majority requesting more, and also more detailed advice.

Parents expressed an opinion that there should be more information available to them.

“Any information would be helpful as if anyone is like me, once you leave the GP etc., you forget what they have told you.” (Questionnaire 15)

“When your child is ill, as parents you are also very distressed, leaflets could clarify and instigate questions.” (Questionnaire 25)

Some parents felt that leaflets they had received had been helpful both at the time and to prepare them for future episodes.

“Gave us a basic understanding what is happening to our child.” (Questionnaire 52)

Some felt that they had not been given enough information about UTIs in general.

“There should be more leaflets and more explanation about it.” (Questionnaire 5)

“. . . would have liked more information as the seriousness and importance of infection and future care to avoid recurrence.” (Questionnaire 31)

Others required more specific information relating to their child.

“I would like to be told the results of tests promptly and to be told whether my child has a UTI or not.” (Questionnaire 8)

Empowering

The parents in this study seemed to understand more about the diagnosis and felt in a better position to deal with future episodes of UTI in their children after the initial event. In some cases, leaflets and information were stated as being helpful in this aspect, with others suggesting that the experience had taught them what to do in future.

“Go to GP, request a sample to be submitted and demand antibiotics immediately before result comes back.” (Questionnaire 41)

The majority of respondents (71%) stated that if they suspected their child had another UTI they would collect a specimen and see their doctor immediately.

A number suggested that leaflet information made them more able to deal with infections in future, stating that leaflets made them

“able to notice infections easier and to treat quickly.” (Questionnaire 32)

Lack of awareness in health care professionals

A number of patients felt that their doctors showed a lack of information and awareness of UTIs in childhood, and suggested that further education of health professionals might be helpful.

“GPs to be more aware of UTIs in childhood.” (Questionnaire 45)

“please educate our GP re importance of a) testing for infection immediately, b) antibiotics before result comes back if suspects it is an infection.” (Questionnaire 19)

In some cases, parents felt let down by the health professionals

“I was disappointed that the possibility of a urine infection was not thought of sooner.” (Questionnaire 37)

“we had to go to the GP to ask to be referred . . . having heard from elsewhere that follow up investigations were important. They would not have sent us.” (Questionnaire 18)
Organizational problems
A number of parents expressed frustration at organizational aspects.
One parent expressed frustration that the local GP was not co-operative
“did not have any test sticks and do not have access to microscopy at weekend.” (Questionnaire 33)
Another stated problems with the hospital appointments.
“it would help if ‘... investigations ...’ were all done in the same OPD session.” (Questionnaire 26)
One even felt that she had had different information from different health care professionals.
“we spoke to 7 people all of whom were told the same story and who between them filled in 5 forms! ... different responses to the same queries at different times—approaches taken by staff should be standard.” (Questionnaire 7)

Discussion
Principal findings
Some parents in this study perceived delays in doctors considering UTI as a cause for fever in their children. Although collection of samples from these children can be difficult, parents in our study were very keen to try to do this if necessary, such as when the cause of fever is unclear. The majority of parents in this sample obtained an explanation about UTI from their GP and on the whole felt that they had understood this. They felt, however, that additional information was required and written information would be beneficial. These parents perceived a lack of awareness of the condition amongst health professionals. Following the first UTI, parents felt empowered to deal with future episodes.

Strengths and weakness of this research
We used analytical qualitative methods to try and minimize bias. We acknowledge that the group questioned was highly selective, in that only parents who had managed to obtain a urine sample (and from which a definite diagnosis of UTI was made) were included. This can also be seen as a strength of this research in that the group was therefore homogenous, and gives validity to the comments given in the questionnaires, as all parents had specific experiences to draw upon in making their responses.
It is noteworthy that the fixed data responses were all quite positive, whilst free text answers indicated more dissatisfaction and criticism from patients. Rather than a small number of negative comments skewing the data, the responses were widely spread amongst all respondents. This suggests that there were limitations in the fixed response questions, but that having highlighted certain aspects, many respondents felt strongly about these issues and were keen to offer further comments. As respondents were selected on basis of prior relevant experience, it is likely that the free text responses more accurately reflect the real views of the respondents.

The context of current literature
We were unable to find any other studies exploring parental views of the first UTI in their child. It is therefore difficult to compare these results with others. However, in marked contrast to the recently published study by Liaw et al.,10 the majority of parents in our study found obtaining a clean catch was the easiest method of obtaining a sample.
Van der Voort et al.1 identified that 94% of GPs would find guidelines helpful on when to send a urine sample for culture for a child under 2 years. If the delays perceived by many parents in our sample are confirmed in further research, it would seem reasonable to disseminate existing guidelines widely and increase awareness of UTI amongst GPs and other health professionals working with young children. In the same study, it was found that “GPs frequently do not investigate UTI in febrile children due to practical difficulties, lack of awareness and financial costs”. Our study shows, however, that 46% of parents did not report any difficulty in obtaining a sample, and all reported willingness to send another should it be necessary.
Parents in this study appreciated information and leaflets regarding diagnosis and urine collection. It might be worthwhile giving them more information about UTI in children and urine collection in a standardized way, including the information in the parent-held child health record, for example. With over half of the respondents getting an explanation of the cause of illness in their child from their GP, it would be sensible if the primary health care team was prepared to discuss the diagnosis and implications of the condition with parents.

Further research
These data arise from a selected sample using questionnaire methods and require corroboration in further qualitative studies. However, if confirmed, further research is indicated to elucidate why there still seems to be a delay in identifying UTI as a cause of fever in childhood amongst health professionals, and whether specifically educating parents, health professionals or both would result in earlier identification of UTI as a possible cause. Further work is also necessary to identify the best way of doing this. Information for parents could include the value of obtaining samples early in illness episodes. Strategies to professionals might include trying to change the emphasis in diagnosis from ‘opt in’ to ‘opt out’, i.e. in a child with a fever of unapparent cause, a negative urine specimen is necessary before the cause is attributed to non-specific (and often ‘viral’) aetiologies.
In the long term, it would be valuable to study whether earlier identification and treatment of susceptible children is achieved and whether this would have any effect on morbidity rates from renal causes.

Conclusions

This study outlines parental perception about the first episode of UTI in their child, and suggests that more work needs to be done to increase awareness of UTI in childhood amongst health professionals.

Parents in this study perceived delays in diagnosis and lack of awareness and investigation of UTI in childhood amongst health professionals. Increasing awareness about UTI in childhood, its incidence and management should be disseminated amongst health professionals, but efforts directed at parents may be an effective way of bringing about consideration and diagnosis of childhood UTI in primary health care practice.

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References


Appendix 1

Childhood urinary infection questionnaire for parents

1. How old was your child when they had their first urine infection?
2. How many urine infections has your child had?
3. Have you received a full explanation about the importance of urine infection?
   Yes
   No
   If yes, who gave the explanation?
4. Have you been given a Urine infection leaflet for parents?
   Yes
   No
   If yes where from, how useful was it? Please comment on the leaflet.
5. Have you received a full explanation about how to collect urine from your child?
   If yes who gave the explanation?
6. Have you experienced difficulties in collecting urine from your child?
   Please comment.
7. Which method(s) of urine collection have you used? (Please tick all that apply)
   Clean catch method (holding a container under a stream of urine)
   Bag collection method (attaching a bag to child)
   Pad collection method (inserting a pad in nappy)
   Other (please specify)
   If you have used more than one method, please indicate which method you found the easiest.
   Clean catch
   Bag collection
   Pad collection
   Other (please specify)
8. Overall, do you feel that the information given was sufficient for you to increase your knowledge and awareness of urine infection?
   Yes
   No
Enable you to collect urine from your child?
Yes       No
Please add any comments you have.

9. If you have received information leaflets, do you have any suggestions regarding these?
If you have not received information leaflets, do you feel written information would have been helpful?
Yes       No
What would have been of most benefit to you?

Please answer the following questions about the first time your child had a urine infection.

10. From the time your child became unwell, when was a urine sample first requested?

11. Was a urine sample taken before antibiotics were started?
Yes       No

12. How long did you wait from collecting your child’s urine to receiving the result?
1 day       2 days
3 days       If more than 3 days please specify how long
Never told result

13. From the time your child became unwell, on which visit to the doctor were antibiotics started?
First visit   Second
Third         If after third please specify

14. Can you suggest any improvements to the care you received?

15. Do you feel that you would know what to do if your child has a further urine infection?
Yes       No
Please explain what you would do.

16. Do you have any further comments to make?