

“I’ve just taken you to see the man with the CD on his head”: the experience and management of recurrent sore throat in children

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Short Title: The experience and management of recurrent sore throat in children.

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Author contributions

CL trial manager (August 2004-August 2008) analysed and interpreted the data, drafted the manuscript and approved the final version. RB contributed to the design of the study, interviewed participants, interpreted data, revised the manuscript and approved the final version. KB trial manager (December 2001-August 2004) contributed to the design of the study, recruited participants, interpreted data, revised the manuscript and approved the final version.

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Abstract

Tonsillectomies for children with recurrent sore throat are common. There is a perception amongst medics that parents are eager for surgical intervention but the parent/child perspective is overlooked in the literature. This study aimed to identify parent/child experience of recurrent sore throat. The study was qualitative, using grounded theory approach to data collection/ analysis. Semi-structured, in-depth, interviews were conducted with 12 dyads of children (aged 4-16) and their parents, attending two Ear, Nose and Throat outpatient clinics held at a hospital in North East England, referred by their General Practitioner for recurrent sore throats. Analysis revealed recurrent sore throats significantly affected the families' quality of life. Families felt the need for antibiotics and tonsillectomies although parent and child were not always in agreement over their choice of treatment. Families felt empowered when the health care system showed some flexibility, such as allowing self re-referral, giving families greater choice in the way they managed the condition. Policy makers need to be aware of the consequences of recurrent sore throats in children and the needs of families in managing this chronic condition. More flexible approaches to health care, such as self re-referral and use of waiting list to review symptoms, may be needed if the number of tonsillectomies is to be reduced.

Background

Despite a policy drive towards reducing the number of tonsillectomies for children with recurrent sore throat (Scottish Intercollegiate Guidelines Network, 1999) it remains a common surgical procedure in the UK with some 51,000 tonsillectomies performed in England in the National Health Service in the year 2005/06. Around 58% of these were in children (aged 0-14 years) (www.hesonline.nhs.uk). There is a perception amongst medical professionals that parents of children with a recurrent sore throat are eager for surgical intervention (Fried, 1995) but the parent/child perspective is relatively overlooked in the medical literature. There are few studies reporting experiential, qualitative research in this field with most of this work focusing on post-operative pain either with parents alone (Gedaly-Duff and Ziebarth, 1994) or with children and their parents (Sutters et al., 2007, Idvall et al., 2005).

The cost of tonsillectomy together with the risk of adverse events associated with surgery (1/16000 to 1/35000) (Randall and Hoffer, 1998) have made it a prime candidate for randomised controlled trials (Paradise et al., 1984, Paradise et al., 1992, van Staaïj et al., 2004). In addition there is growing speculation that, without surgery, children will 'grow out' of their tonsillitis, that their symptoms could be managed with analgesics and antibiotics and surgery avoided. To date such trials have not provided a definitive answer and there remains uncertainty about the cost effectiveness of tonsillectomy (Burton et al., 2008), with studies ongoing (Bond et al., 2006).

Tonsillitis is common in children with differing levels of severity. Clearly unnecessary surgery should be avoided and there are guidelines associated with the

frequency of episodes of sore throat in the preceding years, sufficient to justify referral to secondary care:

- Sore throats are due to tonsillitis.
- Five or more episodes of sore throat per year.
- Symptoms for at least a year.
- The episodes of sore throat are disabling and prevent normal functioning (Scottish Intercollegiate Guidelines Network, 1999).

However quantitative research has revealed that symptoms can be unpleasant, disabling and may have a significant effect on children's education; in addition there is the possibility of social, emotional and financial impact on family members (Howel et al., 2002; Roos et al., 1995). If policies that aim to reduce the frequency of tonsillectomy for children with recurrent sore throat are to be developed, an understanding of the experience of illness and the social and educational impact of recurrent sore throats in children is clearly crucial.

Research exploring the impact of other chronic illnesses in children has highlighted negative consequences for parental employment, health and social relations (Westbom, 1992) as well as for children and their families in the areas of social and leisure pursuits, schooling, practical aspects of daily life and emotional effects (Nocon, 1991).

This qualitative study of parents and children was undertaken to inform the development of a randomised controlled trial (Bond et al., 2006) and to document the experience of recurrent sore throat and participants preferences for different treatment options.

Methods

The overall study design was qualitative using a grounded theory approach to data collection and analysis (Glaser and Strauss, 1967). Data were generated through in-depth interviews with dyads of children aged 4-16 and their parents.

Recruitment

A convenience sample was recruited from children and their parent or guardian attending one of two regular Ear, Nose and Throat (ENT) outpatient clinics held at a hospital in the North East of England. Children had been referred to these clinics by their General Practitioner (GP) for recurrent sore throats. One of the authors (KB) explained the study to all 16 children and parents/guardians attending the clinics and asked if they would be willing to be approached to participate in the study and to provide their contact details. A letter, signed by one of the authors/interviewer (RB), was sent to children and their parent/guardian, inviting them to participate in the study. A study information sheet was included with the letter providing details of the study team, why the children's help was required, how the interviews would proceed and how the information would be handled and ultimately reported. Parents were subsequently telephoned by RB to gain their consent to participate in the interviews. Out of the 16 families originally approached, 12 agreed to take part. Written consent was given by both the child and parent/guardian involved in each interview.

Interviews

The interviews took place in the family home, all of which were based in the North East of England. Data collection took place between July and August 2002.

Interviews lasted between 30 minutes and one and a half hours and their content was

recorded using a digital audio recorder. All interviews were carried out by RB who is a social scientist with expertise in qualitative methods. Semi-structured interviews were based on a flexible topic guide (available on request), which highlighted a number of issues considered to be relevant to the study. The topic guide was jointly developed by RB and KB in consultation with key informants and informed by the literature and focussed on the experience and social impact of recurrent sore throat from the perspective of the child.

Data management and analysis

Digital audio data were transcribed verbatim, by professional transcribers, as soon as possible after each interview. Typed transcripts were then reviewed by the interviewer for transcription errors and to respond to any queries regarding unclear or inaudible words. In accordance with grounded theory method data collection and analysis proceeded in an iterative fashion. Data management was carried out using the FRAMEWORK method (Ritchie and Spencer, 1994) which provided a simple, systematic but comprehensive way of ordering, coding and categorizing a large volume of contextual data. This method also enabled comparative analysis both within cases and between cases. Data analysis proceeded in several closely linked stages as follows: familiarization with the data by rereading transcripts; identification of recurrent topics; development of a topic index; use of index to code data on transcripts; elaboration of the topic index; coalescing of related topics into themes; abstraction of data from transcripts onto the matrices; further collapsing and refinement of categories; and finally interpretation of analysis into a narrative. Nvivo (QSR International, 2006) qualitative data management software was used in indexing and coding of data and themes. For ethical reasons children and their parents were

interviewed together however where possible data have been reported separately according to children's and parents' responses.

Ethical issues

Participation was entirely voluntary; however parents were approached and consented overall to the study allowing the potential for parents to coerce their children to become involved. In addition children and their parents were interviewed together; this method may have affected the comfort of respondents as there was limited privacy for both parties. Interview transcripts were anonymised and treated in the strictest confidence. All direct identifying information was removed from the transcripts by giving each child a unique code number which was used to attribute comments during analysis. The study received ethical approval from the Multi Research Ethics Committee.

Participants

The sample consisted of 12 parents and children (eight male and four female) aged between 4 and 16 years with recurrent sore throats who had recently been referred to ENT (see table 1). At the time of interview six of participants were on the hospital waiting list to have their tonsils removed, four were waiting to see if the frequency of their sore throats improved with time while two had already had their tonsils removed (one as an NHS patient and one privately). In all interviews the child's mother was present and on two occasions the father was also present. On one occasion the father was present in order to translate for both the mother and child.

Table 1 here

Findings

Results comprise an evaluation of the parent's and child's contribution to each interview following which data from the interviews are reported under the general themes of; physical and emotional effects of recurrent sore throat; impact of recurrent sore throat on education, social life and family; and management of this chronic condition. Anonymised quotations (children's highlighted in bold) are included in the text to illustrate points made.

Parent/child contributions to the data

Word count was used as a proxy for contribution to the interview by participants. Overall parents dominated the interviews taking on average 84% (range 44%-99%). Children's contributions ranged from 1% to 56% of the interview. Children dominated only one interview (56%); this was the oldest child (16 years) in the sample. While there were two other teenagers in the sample only one made a substantial contribution to the interview (31% versus 4%). For the younger children age did not appear to be related to contribution. These results, in relation to interviewing dyads, will have implications for the findings and will be examined in further detail in the discussion.

Effects of recurrent sore throat

Physical

There was a rich description of the physical symptoms that respondents associated with their own or their child's sore throat. While children naturally tended to use less mature language their descriptions were no less colourful than those given by their parents. Although some of the children found their symptoms difficult to articulate:

“Well it does hurt a little bit...it’s sore.”

(1, male, age 6)

This was not necessarily associated with the age of the child:

“It’s swollen and when I cough it’s dead loud and horrible and it croaks a little bit...it hurts when I cough in my throat... it hurts a little bit when I swallow...sometimes at night it stops my breathing...and I feel sick through the night too”

(4, male, age 5)

Most children mentioned sore throat symptoms which are associated with pain and difficulty eating. Children spoke of not being able to eat, not feeling hungry and finding it hard or impossible to swallow food. Most children said that it hurt or was painful having sore throats and one child talked of associated ear pain. About half of the children mentioned abnormalities of the tonsils such as being big and/or red and half of the children described abnormalities of the throat such as sore throat, dry throat and tickly throat. The use of the voice (difficult to talk, having a croaky voice or cough and a loss of voice) was also frequently mentioned. Other less frequently quoted symptoms included aches, temperatures, sickness, tiredness, general feelings of being unwell, and problems with breathing, snoring and bad breath (see box 1).

Box 1 here

Similarly all parents mentioned sore throat symptoms surrounding food (loss of appetite, poor eating and problems swallowing) but in contrast to the children’s responses all parents also discussed abnormalities of the tonsils, describing visible symptoms such as spots or pus on the tonsils. Pain was mentioned much less

frequently by the parents than by their children perhaps because parents tend to underestimate their children's pain (Chambers et al., 1998) but many talked about their child feeling "sore" in the throat. Again in contrast to their children the majority of parents listed changes in temperature as a symptom of sore throat. About half of the parents felt that energy levels and sleep patterns were affected and half said their children either felt sick or actually vomited. Just under half of the parents talked about a change in the voice. Parents mentioned all of the other less frequently disclosed symptoms which had been listed by the children however parents occasionally listed other less common symptoms such as prominent glands in the neck, cold sores, scarlet fever, pallor and anaemia (see box 2).

Box 2 here

Emotional

Although there was less data relating to emotional consequences of chronic sore throats, at least one of each parent/child dyad mentioned some emotional effect or alteration in personality which they associated with having chronic sore throats. The overriding theme was one of moodiness, general lethargy, withdrawal and clinginess.

"He's normally a happy go lucky child but when he's got tonsillitis he's really withdrawn in himself and he's, very, very, quiet, you know he's in pain"
(Mother of 5, male, age 14)

"It was kind of depressing at one point...I had worked so hard...for the drama and then it was all getting messed about with my tonsils"
(6, female, age 16)

More worrying emotional responses were bed wetting (which was only mentioned by parents and not children) and embarrassment and alienation because of smelly breath. It must be noted however that the children's responses may have been inhibited by the presence of others.

Impact of recurrent sore throat

Education

All of the children in this sample had had time off school either because they were sent home by their teachers or because they were kept off school by their parent(s) because they were either too ill or had related medical appointments to attend. All of the parents in this sample were concerned regarding the amount of schooling which had been missed by their child with this concern increasing during important school years. There were mixed views amongst children as to whether missing school was a positive or negative experience although many complained about having to catch up on missed work. On a number of occasions the school itself had cited concern regarding the child's attendance and on one occasion the education authority had become involved.

“Some of the teachers were having problems because I was missing some of the lessons”

(6, female, age 16)

Social Life

The social life of all of the children in this sample had been negatively affected by recurrent sore throats.

“You feel you are missing out sometimes when people go out to somewhere and you can’t because you’re bad [ill].”

(2, female, age 12)

None of the children would go out and play or be with friends during an episode of sore throat, either because they were not allowed to or because they did not feel able to. Many children had hobbies which they were unable to perform. Most of the children would rest or sleep and perform sedentary activities (such as watching TV, reading or drawing) during an episode of sore throat. Many of the children in this sample had missed out or caused the cancellation of family days out or special events due to their sore throat. Two participants had experienced disruption to their holiday as a result of their recurrent sore throat.

Family

Naturally any recurrent health complaint is likely to take its toll on the sufferer’s family. All of the parents in this sample were frustrated at the consequences of the recurrent nature of their child’s ill health. All of the working parents had, at some point, needed to take time off work to look after their child or to make visits to health professionals. On two occasions this was cited as the reason for leaving or losing jobs.

“I’ve lost jobs because of him having been off school...I don’t think that people believe you”

(Mother of 10, male, age 5).

Non-working parents were equally frustrated about being tied to the house or concerned about how they would cope if they went back to work.

“It’s terrible you have to stay in the house all week because you can’t go anywhere, she cannot go shopping and I’ve got to get my brother or her nana to come and sit with her.”

(Mother of 2, female, age 12)

Many of the parents used their extended family (aunties, uncles, grandparents, siblings) as an alternative source of care when taking time off work became difficult or they became ill. A lot of the parents said they experienced periods of tiredness because they had been kept awake during the night or had tried to sleep with their ill child. The social lives of families, including family holidays, days out and evenings out, were also affected by their child’s recurrent sore throats and some felt that their other children suffered from lack of attention as a consequence. Parents also had to deal with the associated emotional problems described above.

Management of recurrent sore throats

Throughout the interviews a number of themes arose regarding how the families managed the chronic problem of recurrent sore throats.

Requesting tonsillectomy

The overriding theme was the need to request or even demand the surgical removal of the child’s tonsils. There was a general feeling that parents might have to fight to get this treatment and that there was an increasing reluctance to remove tonsils in recent years which was understood to be largely because of costs. However parents were unconvinced that their children would simply “grow out of” recurrent sore throats and surgery was often thought to be the only long term solution.

“...that’s why we are trying to push to get his done because it’s recurring all the time and it’s not fair on the child and it’s not fair on his education”

(Mother of 5, male, age 14)

However it must be made clear that there were substantial differences within most dyads regarding their views on surgery. On only three occasions were parent(s) and child in agreement regarding their desire to have surgery. On two other occasions the child exhibited a strong desire for surgery while their parent(s) was less sure; these were the two oldest children in the sample.

“I was a bit disappointed actually because I just wanted to get rid of it straight away.”

(8, female, age 15)

In all other cases it was the parent(s) who desired surgery while the child was either “worried”, “scared”, “panicked”, or adamant that they did not want surgery.

“I’m worried ...just thinking that it will hurt”

(1, male, age 6)

“Playing” the surgical waiting list

For parents who were more cautious about surgery there was a strategy of “playing” the surgical waiting list. This involved joining the list for tonsillectomies but using the time to wait and see whether the symptoms improved. Once the child reached the top of the waiting list the parents would then choose whether or not to go ahead with the surgery. However if the decision was made not to have surgery at that time the parents suggested that they would be able to ask for their child to be put back on the bottom of the waiting list just in case their symptoms got worse again. This was viewed as the best use of the waiting time.

“Well, like the Consultant said, if for one reason you don’t want the operation, go on the waiting list again and if it starts re-occurring get it done eventually”

(Father of 7, male, age 7)

Self re-referring

Once families had been referred to secondary care but had agreed to wait and see if their child’s symptoms would improve with time there was a general agreement that they could then self re-refer. This gave parents the reassurance that they could seek direct help without having to “fight” their way through the referral system.

“I was really surprised she said that if he ever got that again ring us up direct and we will take him straight in and have them done, which I thought was good.”

(Mother of 4, male, age 5)

Having a tonsillectomy “just in case”

Even though symptoms were improving for some of the children, some of the parents thought that their child’s tonsils should be removed as a precaution against the sore throat re-occurring.

“If he didn’t need it done, my wife says, ‘Oh I might get it done anyway, just in case’.”

(Father of 7, male age 7)

Using the experience of others

As a result of the lack of evidence relating to the best treatment for recurrent sore throats parents relied heavily on their own or others experience.

“His brother had his taken out and he’s been brilliant since he got his done – it was the best thing I could have done for him.”

(Mother of 5, male, age 14)

The majority of parents had either had their own tonsils removed or knew of someone else who had had their tonsils removed with great success and used this knowledge to decide on the best course of treatment for their child. However two parents had also heard about tonsillectomy operations “going wrong” which left them scared and worried. However after raising these concerns with the consultant the parents felt that the risks were small enough for them to still request the operation. None of the parents or children related experiences of others successfully “growing out” of sore throats.

Requesting prescriptions for antibiotics

Another popular strategy in coping with recurrent sore throat was one of requesting repeat prescriptions for antibiotics from the GP. Often this was dependent on seeing the “right” GP in the practice or visiting an out of hours service. However many parents preferred not to see the GP but to request prescriptions over the telephone. This allowed parents to receive the desired outcome from a trip to the GP without having to actually attend an appointment. It appeared to be a solution for some GPs as well as parents.

“It started a few year ago...he was just constantly sore throats obviously all the time...so we were obviously down the Doctors but the last few month I was just actually phoning the Doctor up and asking for a prescription over the phone because they knew what is was and they were well Doctor always just used to say, right we know what’s the matter with him...and just give him a prescription over the phone for the last few month.”

(Mother of 3, male, age 10)

Attending school with sore throat

Most of the parents at one time or another had sent their child to school while they were ill. This was often in response to increasing levels of absence from school (for the child) and work (for the parents). This strategy sometimes resulted in the child being sent home from school by their teacher however this allowed the parent to transfer the responsibility for the child's absence to the teacher or school.

“If I had my way she would be at school with a sore throat. I have been guilty of sending her to school because I know that she comes home.”

(Mother of 2, female, age 12)

Discussion

While recurrent sore throats are far from life threatening, this chronic condition can significantly affect children and their families' quality of life (Howel et al., 2002). Treatment in the form of antibiotics or surgical removal of the tonsils is available although the efficacy of such treatments is not proven. Therefore government policy is to discourage such treatment.

This qualitative study has revealed that recurrent sore throat in children can significantly affect families' quality of life. The effect of this chronic condition was not only physical but emotional and affected children's' education and social lives as well as the rest of the family. These findings echo the impact that other chronic condition, such as asthma, physical and mental disabilities, have on children and their parents (Westbom, 1992, Nocon 1991).

Inevitably, children and their families still feel the need for antibiotics and tonsillectomies although parent and child are not always in agreement over their preferred choice of treatment. It was interesting to find that families of children with recurrent sore throat felt empowered when the health care system showed some flexibility, such as allowing self re-referral which gave families greater choice in the way they managed the condition.

Not surprisingly therefore, in our pragmatic randomised controlled trial with parallel non-randomised cohort we found that the majority of participants expressed a preferred method of treatment. Of the participants who were not in 'equipoise' there was a strong preference for surgical removal of the tonsil. Participants reporting that

progress at school had been impeded were more likely to seek surgical treatment of sore throat (Lock et al., in press).

There are a number of caveats that should be made about these data. The study used a convenience sample; the selection of families was based on ease of availability and accessibility rather than using a purposive sample guided by theory. However the sample broadly reflected the normal range of children seen in ENT outpatient clinics. However, it did not cover the whole range of ages for both boys and girls with fewer younger girls than might have been expected from normal referral patterns. The interviews provided a rich description of the condition from the perspective of children and their parents and provided an insight into their treatment preferences.

Interviewing dyads presents its own problems as they are jointly created accounts presenting neither the parent's nor the child's version of events. Certainly the percentage contribution of the children to the interviews was much lower than that of the parents. Both contributions may have been inhibited by the presence of others. The presence of parents is likely to affect the accounts given by children as they are tempered by the presence of adults. Similarly parents are perhaps unlikely to express their deepest fears of the risks of surgery in front of young children. Although young people may have the cognitive skills to form opinions, the adult status of the researcher may cause problems in eliciting, collecting and interpreting their thoughts. In addition it was parents who took the lead in volunteering and consenting to the study and it is difficult to establish how far this was in collaboration with the child.

Policy makers need to be aware of the consequences of recurrent sore throats in children and the needs and desires of families in managing this chronic condition. More flexible approaches to health care, such as self re-referral and use of waiting list to review symptoms, may be needed if the number of tonsillectomies is to be reduced.

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Table 1 Characteristics of the sample

Interview Number	Gender	Child's Age	Parent(s) Present	Tonsillectomy
1	Male	6	Mother	On waiting list
2	Female	12	Mother	On waiting list
3	Male	10	Mother	Yes (National Health Service)
4	Male	5	Mother	Wait and see
5	Male	14	Mother	On waiting list
6	Female	16	Mother	Wait and see
7	Male	7	Mother & Father	On waiting list
8	Female	15	Mother	Wait and see
9	Male	4	Mother & Father*	Yes (Privately)
10	Male	5	Mother	On waiting list
11	Female	10	Mother	On waiting list
12	Male	10	Mother	Wait and see

* Father present to translate for mother and child.

Box 1 Children's descriptions of symptoms associated with chronic sore throat

	1	2	3	4	5	6	7	8	9	10	11	12
Big tonsils		✓		✓		✓		✓				
Red tonsils						✓		✓				
Sore throat	✓		✓					✓		✓		
Dry throat		✓										
Tickling in throat						✓						
Neck aches/sore neck	✓									✓		
Headaches								✓			✓	
Difficult to talk	✓		✓			✓						
Croaky voice				✓								
Loss of voice						✓						
Loud cough				✓								
Can't eat	✓		✓								✓	
Not hungry	✓							✓		✓		
Can't swallow				✓				✓	✓		✓	
Being/feeling sick		✓		✓						✓		
Tired	✓					✓						
Snoring	✓											
Stops me breathing				✓								
Hard to breathe						✓						
It hurts	✓		✓	✓								
Painful						✓		✓	✓	✓		
Ear pain											✓	
Get hot				✓							✓	
Temperature								✓	✓			
Don't feel well				✓								
Feel run down								✓				
Bad breath											✓	

Box 2 Parents' descriptions of symptoms associated with chronic sore throat

	1	2	3	4	5	6	7	8	9	10	11	12
Very large [swollen] tonsils	✓	✓		✓		✓		✓		✓		
Red tonsils	✓	✓				✓					✓	
Little white deposits [on tonsils]	✓											
Yellow poisey colour [in back of throat]			✓									
Yellow spots [in back of throat]				✓								
White spots [in the mouth]									✓			
Sore throat	✓	✓		✓	✓	✓	✓			✓	✓	
Feeling "something" in throat				✓								
Prominent glands in the neck	✓					✓						
Swollen [puffed up] face		✓			✓							
Headache/aches	✓			✓								
"Thick" voice/croaky voice	✓									✓		
Hoarse/barking cough				✓								
Cough									✓		✓	
Loss of appetite/poor eating	✓	✓	✓	✓	✓		✓		✓	✓	✓	
Problems swallowing	✓	✓	✓				✓		✓			
Feeling sick/vomiting		✓		✓			✓	✓	✓	✓		
Lack of energy/need to sleep/drained	✓	✓		✓			✓				✓	
Problems sleeping							✓					
Snoring	✓						✓					
Problems breathing		✓		✓								
In pain					✓							
Stomach pains			✓							✓		
Problems with ears/ear infections		✓				✓				✓		
High temperature/sweating/fever/shivering	✓	✓	✓	✓			✓	✓	✓	✓		
Red blotches [rash] on face/arms		✓		✓								
General feeling of being unwell										✓		
Bad breath	✓						✓		✓		✓	
Sneezing/sniffing	✓											
Scarlet fever				✓								
Cold sores							✓					
Pallor							✓			✓		
Anaemia										✓		