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Main Article

Otitis media with effusion: what parents want to know

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Abstract

Introduction: Otitis media with effusion is a common condition of childhood. The development of an information leaflet for parents of children with the condition, and its impact on clinical management, have not previously been examined.

Patients and methods: Eighteen doctors and 38 parents assessed the content of an information leaflet on otitis media with effusion, by applying two rounds of the modified Delphi technique. A qualitative assessment of content items was also performed.

Results: From the 23-item list used in the first assessment round, four items had a low doctor–parent agreement and seven were excluded. Differences were also noticed in comments on the value of such leaflets, with parents being more positive about the value of leaflet distribution.

Conclusion: During the consultation, doctors may not tell parents what they want to know, especially regarding daily care of their child. An information leaflet, developed using the Delphi technique, can help reduce this discrepancy and increase parents' satisfaction.

Key words: Otitis Media With Effusion; Pamphlets; Delphi Technique

Introduction

Otitis media is a common childhood problem and is responsible for the majority of paediatric otolaryngology consultations. Up to 90 per cent of children are expected to have suffered the condition by the time they enter primary school.[1]

A great number of books, scientific articles and presentations, plus exhaustive internet resources, are available for clinicians and parents, providing information on the pathophysiology, presentation, complications and treatment of the condition. Much of this information refers to exceptional cases, is obsolete or is not of great interest to parents.

Therefore, the development of an information leaflet on otitis media with effusion (OME) could be useful in everyday clinical practice. The modified Delphi technique could be used as a means of gaining consensus on the content of such a leaflet. The leaflet was especially intended to provide information about OME to parents of children with the condition. The leaflet's purpose was to inform parents, in a simple, clear and quick manner, and to answer the majority of their questions, thus helping the clinician to perform a more thorough and efficient consultation.

Materials and methods

Medline and Google internet searches were performed using key words and terms, including otitis media, Delphi technique, and information leaflet or booklet. No study was identified which evaluated the content of an information leaflet for parents of children with OME, by using the Delphi technique. In order to reduce the number of rounds required in the Delphi method, a list of 23 OME-related facts was generated by the first two authors of the study (IMV and JH), with contributions from two parents. The list was then distributed to 18 doctors (three experienced paediatric otolaryngologists, two general head and neck surgeons, two otolaryngology residents, three paediatric residents, five paediatricians and three general practitioners) and to 17 parents of 10 children with OME who had visited one ENT out-patient clinic. The 23 items were related to the diagnosis, treatment, pathophysiology and prevention of OME. The 23 items were chosen on the basis of probably being of greatest interest to the parents, and being simple enough to be understood by the majority of non-medical subjects. Doctors and parents were asked to comment on the content of the leaflet, the clarity of the items and their necessity. Necessity was examined by one

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TABLE I

DELPHI TECHNIQUE RESULTS

List item	1st round scores		2nd round score
	Doctors	Parents	Average
1 Otitis media with effusion means the presence of fluid in the middle ear (behind the eardrum).	94	71	64
2 It is a very common condition in childhood. Up to 90% of children are expected to have suffered from this by the time they enter primary school.	53	76	74
3 It is not related either to wax or to the possible wetting of the ear during a shower or swimming.	28	88	91
4 It might be the result of acute otitis media.	59	29	
5 Allergies, adenoid hypertrophy and craniofacial anomalies contribute to it.	53	79	82
6 Often, we cannot find the exact cause, and it is believed to be the result of a not properly working eustachian tube. The eustachian tube is a natural passage between the middle ear and the back of the throat.	23	56	
7 The eustachian tube is smaller and more horizontal in children than in adults. Therefore, it can be more easily blocked by conditions such as large adenoids and infections. Until the eustachian tube changes in size and angle, children are more susceptible to otitis media.	70	26	24
8 Hearing loss is the most usual presenting symptom, whereas mild pain, clumsiness and irritability in infants are rarer presentations.	47	47	
9 A tympanogram and audiogram are helpful in diagnosis and treatment but cannot replace the examination by your physician.	42	79	79
10 Your doctor is going to check the status of the eardrum and to consult you if a treatment is needed.	44	35	
11 In the majority of cases, regular follow up is all that is needed.	92	65	64
12 Balloons blow ups, nose baths with natural saline, or the use of antibiotics, anticongestives or other medications are rarely helpful and should not be used without a doctor's advise.	89	65	58
13 Talk clearly and more loudly than usual (but you don't have to shout). Talk directly face to face. Cut out background noise when you talk to your child (for example, turn off the TV or radio).	92	82	79
14 Discuss the problem with the teacher if your child is at school or nursery. Sitting near to the teacher may help.	39	88	89
15 Don't let anybody smoke in the same home as your child.	67	59	58
16 Glue ear can resolve by itself, but the problem may return for a while after a cold or ear infection.	83	74	77
17 Therapy is not always needed, except in cases where the fluid causes a decrease of hearing for more than 3 months.	83	68	65
18 In such a case, the child is at risk for speech, language and learning problems, and tympanostomy tubes insertion is the preferred initial procedure.	69	85	86
19 Tympanostomy tubes are tiny pipes inserted in the eardrum. General anaesthesia is required for tubes insertion but the procedure is generally well accepted, with relatively rare complications like perforation of the eardrum.	78	35	33
20 After a few months, the tubes will fall out on their own. In rare cases, a child may need to repeat the operation.	56	59	
21 In some cases, like snoring and sleep apnoea, an adenoidectomy may also be required. This is the extraction of adenoids, which are small clumps of glandular tissue similar to tonsils, which are attached at the back of the nose cavity.	47	18	
22 Glue ear rarely persists in children over the age of eight.	58	47	
23 Anxiety and rushed treatment aren't necessary, since most otitis media with effusion cases have a self-limited nature.	56	76	80

Note that items 4, 6, 8, 10, 20, 21 and 22 were excluded from the second round.

multiple choice question containing three possible answers: (a) very important, (b) important (i.e. good to know), and (c) less important (i.e. good to know but can omitted from the leaflet). Answer (a) was rated with 100 points, (b) with 50 points and (c) with no points. The mean score for each item was calculated by dividing the total points by the number of participants (doctors and parents). Items scoring less than 60 points in both groups were excluded from the second, revised list, which was distributed to 33 parents of 20 children.

Both lists were provided to parents, either immediately after OME was diagnosed, as part of the consultation process, or at the end of the consultation (as a summary).

Results and analysis

A total of 58 subjects participated in the study (18 doctors and 40 parents). Of these, two parents (of foreign origin) were excluded from the study due to their inability to read and understand the items.

The parents' and doctors' qualitative assessment of the first list of items differed, although both made positive and negative comments. Most of the doctors questioned the need for such a list, since they already explained the majority of the items to parents during the consultation. Moreover, the doctors feared that the abstract style of information presentation might confuse some parents, trigger more questions and prolong the consultation. On the other hand, the majority of the parents felt that

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such a leaflet (received from the doctor) would be useful, mostly because such written information would increase their trust in the doctor's statements and may reduce the need for additional information (and thus allay anxiety). Both parents and doctors commented, positively, that the information was presented in a relatively simple and clear fashion, and that it could increase compliance by increasing the reliability of doctors' input.

The results of the Delphi rounds, regarding the leaflet content, are presented in Table I. Items 3 and 14 were considered much more important by parents than by doctors (by a difference of more than 40 points), whereas items 7 and 19 were scored more highly by doctors. Items 4, 6, 8, 10, 20, 21 and 22, which mostly related to aetiology and surgical treatment, scored less than 60 in both groups and were thus excluded from the second list. (Since item 6, explaining the eustachian tube, was omitted, item 7 was modified in the second round to include this explanation.)

The results of the second round are also shown in Table I. This revised list was distributed to 12 parents who had already participated in the first round and to 21 new parents who visited the ENT out-patient clinic. In this round, nine items scored greater than 70 (see Table I).

Discussion

In the current era of managed health services, research which aims to improve patients' satisfaction and compliance with treatment and to reduce unnecessary use of health resources is very useful. Informative leaflets on the prevention, diagnosis and treatment of various diseases and conditions, produced by health care trusts and other official organisations, have been shown to increase patients' satisfaction, knowledge and compliance.[2–6] However, the actual effectiveness and cost-effectiveness of such leaflets have been questioned.[7,8] Their usefulness has been recognised within preventive medicine (e.g. providing clear, reliable information on pneumococcal vaccines in order to increase vaccination rates).[4] However, their effectiveness is much less certain within the context of clinical consultations for specific diseases (e.g. otitis media with effusion (OME)).

Qualitative assessment of the OME information leaflet showed that it had the potential to increase doctors' reliability and parents' satisfaction. This can be of great importance in private practice, where an increase in patients' satisfaction is more important than a reduction in consultation time. The impact of such leaflets on the management of chronic conditions remains to be quantified. However, developing their content, using the modified Delphi technique, can lead to some useful conclusions. Our findings show that the information doctors provide about a disease is not always the information patients (or their parents, in paediatric cases) want. The modified Delphi technique can improve doctors' understanding of patients' information needs. This can be especially useful for junior doctors, who have limited experience of interacting with patients.

The modified Delphi technique has already been used in the field of medical education, in the development of a psoriasis curriculum for medical students, and it has been shown to be useful in identifying important points within a chronic disease curriculum from the patient perspective.[9] Since 'there is scope for more use of patient representation on boards and much greater input from patients in teaching and assessment' and 'patients will need to be more involved in education as well as in development of services',[10] the application of the modified Delphi technique in the present study can be seen as a useful example of addressing such trends.

However, many methodological issues can arise from such applications of the technique, which remain to be clarified. These issues include: the number of Delphi rounds involved; whether the leaflet is provided during or after the consultation; and the numbers of doctors and patients (or parents) who should be involved. In this study, the second round was applied more to emphasise parents' opinions than to reduce the number of leaflet items. All of the items in the second list were included in the final information leaflet, but higher-scoring items were printed in bold characters. Thus, in this case, the second Delphi round can be regarded as a way of making the leaflet more 'consumer friendly', by indicating which items parents thought were more important.

Kubba[11] has previously studied the impact on information leaflets of: the grade of existing evidence; the use of specific formulas (such as the Simple Measure of Gobbledegook formula) to test readability; and the use of pre-existing development guidelines. (However, in that particular study, the aim of the leaflet was to 'help parents make an informed decision regarding surgery' (i.e. tympanostomy tubes insertion).) The readability of the leaflet is of great concern, since 'poor reading skills are surprisingly common in the general population and [amongst] otolaryngology patients in particular'.[12] The Delphi technique can prove useful on this point, by helping to choose the most 'patient friendly' sentences.

- **Patients need to be more involved in medical education as well as in the development of health services**
- **Information leaflets can be an effective way to increase patients' knowledge about disease**
- **The Delphi technique is a useful method for identifying important points within a chronic disease curriculum, from the patient's perspective**
- **The information doctors provide on a disease is not always what the patients (or their parents in paediatric cases) want to know**
- **Use of the Delphi technique in the production of an information leaflet on otitis media with effusion can help reduce this discrepancy and increase the parents' satisfaction**

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Conclusion

Use of the modified Delphi technique showed that doctors and patients differed in their evaluation of the importance of medical information. Such differences could potentially result in less satisfactory consultations and reduced compliance. Several methodological issues require further discussion and research. Nevertheless, in this study, use of the modified Delphi technique in the production of an information leaflet on otitis media with effusion can be regarded as an attempt to increase patient input in medical education and in health services development.

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