

Ποιότητα ζωής παιδιών πασχόντων από υποτροπιάζουσα μέση ωτίτιδα

Recurrent acute otitis media - related quality of life

ΙΩΑΝΝΗΣ ΜΠΑΡΔΑΝΗΣ¹, ΔΗΜΗΤΡΙΟΣ ΜΠΑΤΖΑΚΑΚΗΣ²
¹ΩΡΛ Τμήμα Γ.Ν. - Κ.Υ. Ικαρίας, ²ΩΡΛ Τμήμα Γ.Ν. Λάρισας

Περίληψη

Σκοπός: Η αντικειμενικοποίηση της υποκειμενικής αντίληψης των γονέων παιδιών που πάσχουν από υποτροπιάζουσα μέση ωτίτιδα, σχετικά με την επίδραση της πάθησης στην ποιότητα ζωής τους.

Υλικό - Μέθοδος: Η μελέτη αυτή πραγματοποιήθηκε στο εξωτερικό ΩΡΛ ιατρείο ενός επαρχιακού νοσοκομείου που εξυπηρετεί 3 αιγαιοπελαγίτικα νησιά. Οι γονείς 108 παιδιών πασχόντων από υποτροπιάζουσα μέση ωτίτιδα απάντησαν σε ένα ερωτηματολόγιο βασισμένο στο OM-6 και OMO-22 που αφορά 6 παραμέτρους που επηρεάζονται από τη συγκεκριμένη νόσο. Αποτελέσματα: Η συναισθηματική κατάσταση των γονέων των παιδιών φαίνεται να είναι η πλέον επηρεαζόμενη παράμετρος της καθημερινής ζωής τους, ενώ ο λιγότερο επηρεαζόμενος τομέας είναι η ομιλία των παιδιών – πάντα σύμφωνα με τη γνώμη των γονέων.

Συμπεράσματα: Η πρώτη προτεραιότητα των γονέων, όσον αφορά την συγκεκριμένη νόσο, δε φαίνεται να ταυτίζεται με αυτή των γιατρών. Αυτός είναι ένας παράγοντας που πρέπει να λάβουμε υπ' όψιν μας, αν θέλουμε να καυχιόμαστε ότι ασκούμε ανθρωποκεντρική ποιοτική ιατρική.

Λέξεις κλειδιά: μέση ωτίτις, ποιότητα ζωής σχετιζόμενη με την υγεία.

Introduction

The list of articles and papers on otitis media is literally endless and keeps on augmenting. This is not surprising since otitis media persists in being the most common bacterial infection and indication for antimicrobial therapy of childhood^{1,2,3}.

At the same time myringotomy with or without grommet tube insertion – the simplest operation for COME and RAOM – is the most common surgical procedure performed on children in the U.S.^{4,5} as well as the most frequent surgical intervention performed by ear, nose and throat specialists⁶ worldwide. RAOM appears to be a problem for up to one third of children during the first years of their life⁷.

However, the vast majority of these articles refer to the diagnosis, pathophysiology, laboratory tests, treatment (medical or surgical), and research on otitis media.

All these are of great importance for doctors, audiologists, nurses and perhaps managers of hospitals and Insurance Companies - the annual cost of the medical and surgical treatment of otitis in the U.S. is estimated between \$3 billion and \$5 billion^{8,9,10}.

On the contrary they have less – if any – importance for the children themselves - and their parents. They care more about how their children feel, how much they suffer, generally how much their life is affected by their disease. It is absolutely logical that a parent cares less about the drop of his or her child's HL to 25 dB, than his or her absence from school. Since all these are rather subjective, certain instruments, based on questionnaires, have been developed in order to "measure" these immeasurable parameters.

Objective

To objectify the parents' perception of the subjective symptoms of their children and themselves, related to RAOM, as well as to measure their functional health status, in the rather – geographically – isolated population of three small islands in the Aegean Sea.

Setting

This survey took place in the outpatient practice of the ENT Department of the regional general Hospital of Icaria. This hospital and its departments offer first and second grade health services to the population of three rather isolated islands in the Aegean Sea (from a geographical point of view): Icaria, Fourni, Thymena.

The permanent inhabitants of these islands are about 11,000 (summer population estimated about 30,000), 90% of which are Greek natives and the rest 10% economic immigrants, mainly from Albania and the former Soviet Union. The setting has several disadvantages, mainly having to do with the geographical location of the islands and

TABLE 1. RAOM QUESTIONNAIRE

Would you please help us understand the impact of your child's otitis media upon you and your child?
(put a tick in the appropriate box)

- A. How much does your child suffer physically? (ear pain, ear drainage, fever)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []
- B. How much is your child's hearing affected? (keeps asking "what", turns up television volume, doesn't respond to verbal commands)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []
- C. How much is your child's speech affected? (delayed speech, doesn't speak clearly)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []
- D. How much is your child stressed emotionally? (irritable, sad, restless child)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []
- E. How much is your child's activity limited? (playing, sleeping, attending school)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []
- F. How much do you worry about your child's disease? (how inconvenienced do you feel, how often do you think of or talk about it, or take off from work because of it)
 very much [] a lot [] moderately [] a little [] slightly [] not at all []

Is there anything else you would like to comment on?

.....

.....

TABLE 2. SCORING SCALE

Quality	Score
very much	1
a lot	2
moderately	3
a little	4
slightly	5
not at all	6

the transportation facilities between the three islands. The major advantage of the setting is that all otorhinolaryngological patients of these islands refer to this specific practice, since there are no other private or public ENT practices in the territory.

This single fact guarantees that the results of this survey are not affected by factors such as socioeconomic, cultural, or racial status factors, well-documented in the literature to be of influence in OM^{11,12}. Up to now - and as far as we know - no similar study has been conducted in the Greek islands.

Method

We developed a questionnaire in Greek based on OM-6¹³ and OMO-22¹⁰, regarding the parents' perception of six groups of symptoms of RAOM of children and their parents that have already been validated^{10,13} to measure HRQoL:

- physical suffering of the child,
- influence of hearing loss on the child on its everyday life,
- speech impairment of the child,
- emotional distress of the child,
- limitation of activity of the child, and
- emotional distress and worries of the child's parents (table 1).

Additionally to these six guided questions, a more indefinite question was asked.

This questionnaire was suggested to every parent that accompanied a child suffering from RAOM, aged below 10 years, who visited the above described ENT practice. The scoring format of the parents' answers consisted of a 6-point scale for each group of symptoms, ranging from 1, for "very much", up to 6, for "not at all" (table 2).

The mere inclusion criterion for a child, accompanied by at least one of its parents and aged below 10 years, was the presence of RAOM as derived from its medical history ➔

TABLE 3. MEAN SCORE

Group of symptoms	Score
Physical suffering of the child	1.83
Influence of hearing loss of the child on its everyday life	3.89
Speech impairment of the child	4.39
Emotional distress of the child	2.44
Limitation of activity of the child	2.17
Emotional distress and worries of the child's parents	1.28
Total	16

(at least three attacks of AOM during the last six months), no matter what the result of otoscopy, audiometry, tympanometry might have been and no matter what medical or surgical intervention the child might have already undergone, or was undergoing at the time of examination.

Parents whose mother language was not the Greek language were also included in the survey and answered the questionnaire simply by our explaining it more thoroughly to them. It just took a little more time. In this way the chil-

dren excluded from the survey were those not accompanied by at least one of their parents and those over 10 years.

Results

The survey took place starting Autumn 2003, until Autumn 2006. One hundred and eight (108) children with RAOM and consequently 108 parents, who fulfilled the inclusion criteria, were included in the survey and answered the questionnaire.

No parent refused to answer it. According to the chosen scoring format, the maximum possible total score was 36 (best possible HRQoL, or in other words no decline in the child's and its family's HRQoL) and the minimum possible total score was 6 (worst possible HRQoL, or in other words 100% decline in the child's and its family's HRQoL).

The mean total score of the participants was 16, which represents a decline in the child's and its family's HRQoL up to 66.6%. The maximum possible score, for each group of symptoms individually, was 6 (best possible HRQoL) and the minimum 1 (worst possible HRQoL). The mean score for each group of symptoms, individually, is shown on Table 3.

According to these scores, the aspect most affected by RAOM is the emotional distress and worries of the parents - mean score 1.28, which represents a decline in HRQoL

of 94.4%. The aspect least affected is the speech impairment of the child - mean score 4.39, which represents a decline in HRQoL of 32.2%. Only two parents answered the last question of the questionnaire ("Is there anything else you would like to comment on?") and the answers were rather identical: "I never thought the ear could cause so much trouble".

Discussion

Nowadays, the interest in HRQoL of children suffering from OM is growing and a number of instruments are used to "measure" it. The OM-6¹³ appears to be the best¹⁴ - and perhaps the most commonly used one. OM-6 is a questionnaire originally introduced by R. Rosenfeld and colleagues¹³, in 1997, and has been validated in a cohort study of 186 children, aged 6 months to 12 years, suffering from COME and RAOM. It has been used to evaluate the impact of tympanostomy tube insertion on child HRQoL⁴. It has been translated from English into Dutch, as well, and used in the ENT Department of the University Hospital of Maastricht, also to evaluate the change in HRQoL of children aged between 12 and 36 months, before and after tympanostomy tube insertion⁷.

In this study the parents' bias, which affect their responses and consequently the scoring in OM-6, are also investigated. OM-6 has been used to check the change in HRQoL after pneumococcal vaccination¹⁵. In this study an improvement in HRQoL after vaccination was present in both pneumococcal vaccine and control vaccine groups, although there was no difference between the two groups after vaccination. This rather confusing result, according to the authors, is due to parents' overestimation of their children's AOM frequency before enrollment in the trial. OMO-22 - the other questionnaire we have taken into account in developing a Greek questionnaire - is an expanded version of OM-6¹⁰.

The expansion refers to individual variables to allow for analysis of each specific variable. According to our opinion the major difference between the two questionnaires is that OM-6 refers to six domains (physical suffering, hearing loss, speech impairment, emotional distress, activity limitations, caregiver concerns) regarding the quality of life of a child with OM and its parents, whereas OMO-22 refers to five domains (physical, emotional, hearing loss, speech and social symptoms).

For those familiar with OM-6 and OMO-22, it is obvious that the questions we have included in the Greek questionnaire is a combination of the questions of both instruments. The questionnaire we have developed differs from OM-6 and OMO-22 in the scoring format. The differences are two: firstly, OM-6 and OMO-22 use a 7-point response scale to score each individual group of symptoms, while we use a 6-point scale. We did this because we believe it is less complicated for the participants, as well as less time-consuming, without affecting the final result. Secondly, the "way" of scoring: in our scoring higher score

stands for higher quality of life and lower score for lower quality of life in contrast to OM-6 and OMO-22 in which higher score in each individual group of symptoms stands for lower quality of life and vice versa.

We believe that the "way" of scoring we have adopted is more easily perceived by human mind, since 'high' corresponds better to 'high' than to 'low'. Besides, this type of scoring has been used in OM-6 to score the global measure of ear-related quality of life, using a 10-point visual analog scale where the higher the score, the higher the quality of life. This difference in scoring in the very same questionnaire (OM-6) was actually confusing at first glance.

As far as it has to do with our results, they seem to agree with up-to-date literature. According to J. Lee and colleagues¹⁶ the global quality of life of patients with OM over 5 years of age is worse than that of healthy children of similar age, with moderate correlation between OM frequency, as well as effusion duration, and physical suffering and caregiver concerns. CN Brouwer and colleagues¹⁴ conclude that RAOM or COM have a substantial and negative effect on various domains of functional health status and HRQoL of children.

Conclusion

The first priority of the parents with regard to this specific disease does not necessarily coincide with the one of the doctors. The first priority of the participants in this study seem to be the emotional distress and worries of the parents themselves, the second being the physical suffering of the child. This is a factor that we - the doctors - have to reconsider, if we want to boast that we exercise human-centered quality medicine.

Summary

Recurrent acute otitis media - related quality of life

I. Bardanis, D. Batzakakis

Objective: To objectify the subjective parents' perception of the influence of RAOM on everyday life of their children and themselves.

Setting: The outpatient practice of an ENT Department of a regional Hospital that serves 3 islands in the Aegean Sea.

Method: The parents that accompanied 108 children suffering from RAOM answered a certain questionnaire, based on OM-6 and OMO-22, regarding six parameters affected by the specific disease.

Results: The parents' emotional status seems to be mostly influenced by their children's disease in this group, whereas the speech of their children proves to be the least influenced, according to their perception.

Conclusion: The first priority of the parents with regard to this specific disease does not necessarily coincide with

the one of the doctors. This is a factor that we – the doctors – have to reconsider, if we want to boast that we exercise human centered quality medicine.

Key words: *otitis media, health related quality of life.*

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Abbreviations used

RAOM: Recurrent Acute Otitis Media; OM-6: Otitis Media – 6 (6-item quality of life survey); OMO-22: Otitis Media Outcome – 22 (22-item questionnaire); COME: Chronic Otitis Media with Effusion; HL: Hearing Level; dB: decibel; ENT: Ear, Nose, Throat; OM: Otitis Media; HRQoL: Health Related Quality of Life; AOM: Acute Otitis Media; COM: Chronic Otitis Media.

