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Parental perceptions and understanding of information provision, management options and factors influencing the decision-making process in the treatment of children with glue ear



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ABSTRACT

Objectives: Otitis media with effusion (OME) is a common cause of hearing loss and possible developmental delay in children, and there are a range of 'preference sensitive' treatment options. We aimed to evaluate the attitudes and beliefs of parents of affected children to treatment options including watchfulwaiting, hearing aids, grommets, and, oral steroids with the intention of developing our understanding of decision-making and the factors influencing it, sources of parental information, and satisfaction with information provision.

Design: We recruited a convenience sample of twelve parents of eleven children with OME at a single ENT department of a teaching hospital into a qualitative research study. The children of the parents interviewed had already been recruited into the Oral Steroids for the Resolution of Otitis Media with effusion In Children (OSTRICH) study. Semi structured interviews were audio recorded, transcribed and then coded using an inductive, thematic approach.

Results: Parents were satisfied with the verbal provision of information during the treatment consultation, although many were keen to receive supplementary printed information. Discussion with family and friends helped the decision-making process, whereas insufficient information and a paternalistic approach were viewed as obstacles. Parents were particularly influenced by the following: the immediacy of the treatment option effect, perceived efficacy, perceived risks and adverse effects, social implications (especially with hearing aids) and past personal and informant experience.

Conclusions: Parents appreciate clinicians tailoring information provision to parents' information needs and preferred format. Clinicians should also elicit parental attitudes towards the different management options for OME and the factors influencing their decisions, in order to optimise shared-decision making and ultimately provide a better standard of clinical care.

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1. Introduction

Otitis media with effusion (OME), also known as 'glue ear', is a condition resulting from fluid accumulation in the middle ear, in the absence of acute inflammation [17]. OME is a disease mainly of

infancy and early childhood, with up to 80% of children being affected by the age of 4 years [16]. OME is the commonest cause of acquired hearing loss during childhood and has the potential to adversely affect IQ, language and behavioural development, as well as reading, extending into late teens [2]; [11]. The overall prognosis is generally good with about 50% of cases resolving within three months and 95% within a year without treatment [17].

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http://dx.doi.org/10.1016/j.ijporl.2016.07.021 0165-5876/© 2016 Elsevier Ireland Ltd. All rights reserved. The National Institute for Health and Care Excellence (NICE) recommends an active observation period of three months

(watchful waiting) before surgery to insert ventilation tubes (grommets) is considered [12]. Hearing aids are another option where surgery is not preferred or contraindicated [12]. While oral steroids have been found to be beneficial in some small, randomised control trials [17], effectiveness has not yet been evaluated in a rigorous, adequately powered trial of cost effectiveness. Previous research in parental decision-making in OME has not explored responses to all of the available treatment modalities simultaneously.

There has been a gradual shift away from paternalistic doctorpatient relationships with a move towards shared decisionmaking between patients and physicians [6]. Shared decision making has been found to lessen decisional conflict [9]. This is particularly pertinent when there are multiple treatment options [10], such as in OME. In paediatrics, parents may not be involved in the decision-making process as much as they would wish to be [1]. In order to improve and facilitate the decision-making process in paediatric consultations, we need to better understand how parents decide when it comes to choosing treatments on behalf of their children [10], especially when there is considerable 'preference sensitive' variation in care [21], and which factors and sources of information influence their decisions.

The aim of this study was to explore parental experiences, understanding, and perceptions of the decision-making process regarding management options for children suffering from OME. This includes parental experiences and perceptions of information provision about treatment options, their views about the actual treatment options themselves (including oral steroids), and their views about the decision-making process.

2. Methods

This was a qualitative study, involving semi-structured interviews with parents of children with OME who attended an Ear, Nose and Throat (ENT) outpatient clinic and had been recruited as part of the Oral STeroids for Resolution of otitis media with effusion In CHildren (OSTRICH) Study. OSTRICH is a multi-centre, doubleblinded, randomised controlled trial to investigate the efficacy, safety and cost-effectiveness of a short course of oral steroids in improving hearing loss in children with [20].

The trial protocol including the qualitative interview study was reviewed and approved by Wales Research Ethics Committee (REC) 3 (approval number: 13/WA/0004). All hospital sites received Research and Development approval from the respective NHS Health Boards and Trusts in Wales and England.

2.1. Sample

As part of the OSTRICH study, child participants were recruited through convenience sampling from ENT clinics across a number of UK hospitals. Participation in the OSTRICH study was subject to various inclusion/exclusion criteria (Table 1).

For this present study, we decided to recruit the parents of children through convenience sampling at a single site, a hospital in South Wales, UK. Parents of children enrolled as part of the OS-TRICH study were approached about participating in an optional semi-structured interview. No financial or other incentives were offered to the study participants, and eligible candidates were informed that participation was entirely voluntary and that the care of their child would not be affected by their decision.

2.2. Procedures

The study involved semi-structured interviews, with the aim of investigating the parents' views about how they make decisions with regards to treatment options for OME. This included their views on the sources of information they used and satisfaction with information provision. We also sought to measure the parents' attitudes and beliefs towards conventional treatment modalities for OME (watchful waiting, grommets and hearing aids), as well as treatment with oral steroids (the intervention offered in the OS-TRICH trial).

We developed a semi-structured interview schedule based on previous research findings, the aims of the study, and through discussion with members of the broader OSTRICH study team. The interview schedule (see Text, Supplemental Digital Content 1) consisted of 17 open questions and a number of follow-up prompts. A semi-structured approach was used because it allows collection of detailed information in a conversational style, whilst allowing for a profound exploration of different topics and better understanding of the answers provided [7]. Taking into account the flexible nature of this qualitative approach, the interview schedule was revised throughout the study, to allow exploration of emerging topics from the participants' accounts. The interviews took place immediately after participant enrolment into the trial and were conducted in a private room by one member of the study team (VG). Prior to the interview, participants were briefed as to the nature and purpose of the study and a participant information leaflet was provided. In addition, written informed consent was obtained from all parents who agreed to participate.

Interviews were audio-recorded and then transcribed by VG. Any participant identifiable information was removed from the transcripts at this point.

Analysis was conducted using an inductive thematic approach [3] and began concordantly with data collection. VG and NF met regularly to discuss emerging themes and develop a coding framework, which was then also discussed at meetings of the broader OSTRICH Study Management Team. A coding framework document describing each theme in detail was developed in order to aid the consistency of coding. Line-by-line coding was conducted by VG and JK using the NVivo qualitative research software [14]. Any disagreements were resolved through discussion and new themes were developed in consultation with the team.

3. Results

11 child participants were recruited and interviews were conducted with 12 parents between June 2014 and January 2015. The interviews lasted between 5 and 15 min. Participant demographics are detailed on Table 2 below.

The decision to stop interviews after 11 interviews (with 12 participants) was made due to time constraints. However, analysis of the data at this point had indicated data saturation: no novel themes emerged from the last two interviews.

From the study data, we were able to determine a number of key themes that influence parental decision-making, including the sources of information parents use and satisfaction with information provision. Moreover, we were able to identify factors that are important to parents when considering different treatment options for OME, such as immediacy of effect, perceived efficacy and risks of treatments, as well as past experience.

3.1. How do parents make decisions?

3.1.1. Sources of information

Parents reported getting most of their information about OME from the clinicians they had consulted with. This included General Practitioners (GPs), ENT doctors, nurses, audiologists and health visitors and was through a combination of discussion and provision of written information.

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