

The management of Otitis Media with Effusion in children with Cleft Palate – Qualitative Study

Initial Interview Topic Guide - Parents

Note: The following topic guide is indicative. Interviews will only be loosely structured moving between topics in response to what the parent is saying.

A. Parents/Carers will be asked to tell the story of their child's cleft

- I'd like to start by asking you to tell me about your child's cleft and associated glue ear.
- When did you first notice a problem with your child's ears? – what alerted you?

B. Discussion of the treatment received

- What treatments the child received for glue ear (eg one or more grommets operation)
- What other help they received to deal with symptoms (eg hearing aids)
- What choices were made available to you?
- How were decisions made about treatments (eg involvement of child and/or parent in decisions)
- What information was available to choose between treatments?
- Why did you choose the treatment you did?
- What would you advise another parent about treatment choices?

C. Views about parent's satisfaction with the treatment their child received

- Experiences of surgery: hospitalisation, general anaesthetic, post operative care, absence from school.
- If grommets fitted, have they fallen out, when?
- Experience of hearing aids: how they were used, how they do/do not help with hearing (eg parents, siblings, teachers, friends)
- What was helpful about surgery and/or hearing aids
- What problems were associated with surgery and/or hearing aids
- What would you advise another parent about treatment?

D. Views about parent's expectations from treatment and ideal outcomes

- What did you hope the treatment would do to help your child?
- What effect would a treatment have to be useful?
- What did you expect from the treatment?
- Which aspects are important in terms of determining the success/failure of treatment?
- What would you tell another parent about what to expect from treatment?

E. Discussion about the impact of glue ear and its management on the family's day-to-day routines

- What impact did/has glue ear had on the family's routines?

- What impact did it have on other children in the house?
- What impact did it have on other adults in the house?
- Can you rate the impact of your child's illness on the family's routines on a scale of 1 to 5 where 1 is a low impact and 5 the highest.
- What impact did it have on family expenditure?
- Were additional appointments needed at audiology for example, due to the treatment received – adjustment/changing of hearing aids? – if so what impact did this have?

F. Discussion about the impact of glue ear and its management on the child's day-to-day activities

- What impact did/has glue ear have on your child's routines?
- What impact did it have on your child's school performance and progression?
- What impact did it have on your child's relationships at home as well as at school?

G. Discussion about willingness to partake in a trial comparing grommets and hearing aids

- Would you be willing to allow your child to take part in a trial comparing two common treatments for glue ear (Grommets and hearing aids)?
- Would you be likely to participate if it meant that your child was randomly allocated to one of the treatments?
- What kind of information would you need to help you make this decision?

H. Views about any recommendations for other parents

- What is your main recommendation?
- What outcome of treatment has/would have had the most impact on you?

Final Interview Topic Guide - Parents

Note: The following topic guide is indicative. Interviews will only be loosely structured moving between topics in response to what the parent is saying.

Topic guide for with parents

1. Thank the participant for agreeing to be interviewed
2. Brief outline of the purpose of the research – want to focus today on talking about your child’s glue ear – realise there are other things that relate to having a cleft but for the purpose of this project is to focus on glue ear
3. Reassurance about anonymity, confidentiality, and non impact on service delivery – remind participant that you will only repeat what they have said to a member of their treatment team if they or others are thought to be at significant risk of harm
4. Check it is still OK to record the conversation (even though written consent will have been received)
5. Ask about any concerns before starting
6. Have they got any questions?
7. Make clear = OK to stop at any point or refuse to answer questions during interview – no right or wrong answers

A. Tell story of child’s glue ear

- To start, can you tell me about your child’s glue ear.
- When did you first notice a problem with your child’s ears? What alerted you?
- How aware were you that glue ear was common among children with cleft palate?
- What problems did your child experience?
 - Pain, hearing, discomfort, bunged up, restriction of activities, time off school, social interactions, communication difficulties

B. Discuss treatment received

- What choices were made available to you? What options were you given?

- How were decisions made about treatments?
- What about taking no action – was that given as an option?
- How did this compare to other decisions you've had to make about your child's health?
- What information was available to you about different treatments?
- Why did you choose the treatment you did?
- How involved was your GP?
- How old was your child when he/she received the treatment?
- How long did it take to get treatment?
- What would you advise another parent about treatment choices?

C. Views about satisfaction with the treatment their child received

- Grommets: Can you tell me about the surgery – what was it like?
 - Hospitalisation, anaesthetic, post op care, school absence
- If grommets fitted, have they fallen out, when?
- How often did have to go for check-ups?
- Did it make things better or worse?
- Hearing aids: Can you tell me about getting a hearing aid?
 - How did your child get on with a hearing aid?
 - Did it make things better or worse?
- How often did you have to go to the hearing aid service?
- Both: What was helpful about surgery and/or hearing aids?
- What problems were associated with surgery and/or hearing aids?
- What changes have you noticed in your child following treatment?
- What things didn't change?
 - Number of ear infections, ear discharge

D. Views about expectations from treatment and ideal outcomes

- What did you hope the treatment would do to help your child?
- ON IPAD – If a child has treatment for glue ear, as a parent what would you be looking for in terms of results from that treatment? What things would you look to change or improve?
- **ASK PARENTS TO RANK IN IMPORTANCE**
- Why did these results matter to you?
- What were the drawbacks of any treatment your child has had?
- What are the long-term problems that might be a concern for you with your child's hearing?

E. Discuss impact of glue ear and its management on family's day-to-day routines

- What impact did/has glue ear had on the family's routines?

- What impact did it have on other children in the house?
- What impact did it have on other adults in the house?
- What impact did it have on family finances?
- Were additional appointments needed - at audiology for example, due to the treatment received – adjustment/changing of hearing aids? If so, what impact did this have?
 - Time off work?

F. Discuss impact of glue ear and its management on child’s day-to-day activities

- What impact has glue ear had on your child’s routines?
- What impact did it have on your child’s school performance?
- What impact did it have on your child at home? At school?
 - Time off school?

G. Views about any recommendations for other parents

- If you knew another parent who was considering treatment for their child’s glue ear, what would you recommend?

H. Discuss willingness to have child involved in a trial

*I want to end by getting your advice on another study we hope to carry out in the future. We are not asking you to take part in this research but would value your views because it would involve children with glue ear. The study would be what is known as a clinical trial. **EXPLAIN THIS.***

At the moment it’s not clear what treatment is best for glue ear. We would like to do a trial comparing two different treatments. The best way to do a fair test between two types of treatments is for there to be an equal chance of children receiving treatment A and B. This could be done by a computer programme or by rolling a dice - if an even number comes up the child receives treatment A, if an odd number comes up they receive treatment B.

So if a parent agreed to let their child be part of this type of trial it wouldn’t be a doctor who decided what treatment they received or the parent and the child would have an equal chance of receiving treatment A or B. What they did receive would be down to chance. Does this make sense?

- Would you have let your child take part if you knew they would get a treatment depending on chance?
 - Why?
 - Is there anything that would change your view?
 - What would you want to know before you decided?
 - How would you want to find out about the study?
 - If there was some sort of pill your child could take and researchers wanted to test that how would you feel?

End question

- Is there something else that you want to say about your experiences of the treatment for glue ear received by your child that we haven't covered already?