

Investigating the Family and Child's Experience of Microtia and Hearing Loss

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Background

Microtia is the underdeveloped ear or ears. Various management options include hearing aids/devices and/or ear reconstruction. Little is known about the experiences of children and their families with microtia. This PhD study set to explore these experiences.

Aims

1. To investigate children and young people's experiences of microtia
2. To explore parent/carer experiences of their child's microtia

Methods

An inductive qualitative method was used informed by Grounded Theory.

Participants were invited to take part in focus groups (for parents of children with microtia) and individual interviews for children and young people.

These took place online using Microsoft Teams or in person. The interviews and focus groups were semi-structured with questions exploring home and school life, identity and challenges.

Purposive sampling was utilised to account for varied patient demographics.



Acknowledgements

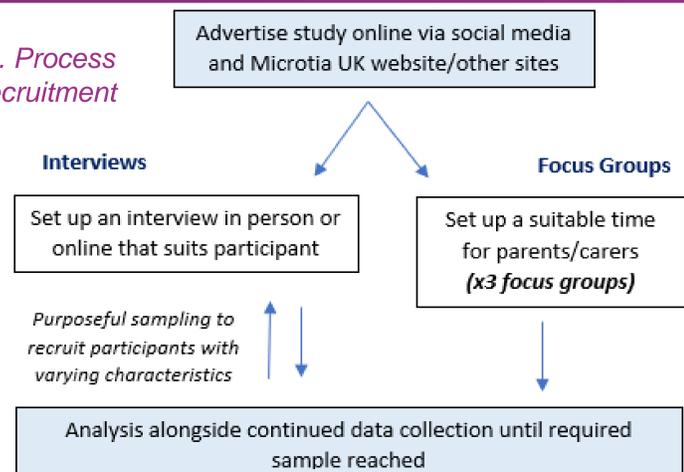
Thank you to Microtia UK charity for funding this PhD and to its members for joining the study and PPIE activities.



Results

10 parents of children with microtia and 11 children/young people with microtia took part in semi-structured interviews. Data was analysed using a constant comparative approach in line with Grounded Theory methods. Parents and children held very similar views on the experience of microtia. Support and the lack of clarity varied amongst the participants, with many requiring further information on the nature of microtia and next steps. Overcoming barriers and not allowing microtia to dictate futures was highlighted by participants.

Fig 1. Process for recruitment



“The most important thing I think is instilling confidence in children, because I know for me when I was little just being able to have something or someone show me other people with my disability, and being able to read their stories, or being able to have knowledge of what I’m growing up with, I think that would have helped.” (Young Adult Participant Quote)

Conclusion

The experience of living with microtia varies amongst individuals and families. Identities for most individuals does not encompass microtia, however, there are challenges unique to those with the condition. The next stage of the PhD is to create a toolkit based on participant preference that is aimed at young children before starting secondary school.