



Adults' experiences of living with Microtia

Report Summary

In recognition of a pressing need to advance research pertaining to the psychosocial impact of living with Microtia. The charity Microtia UK approached the Centre for Appearance Research (CAR) at the University of the West of England, to conduct research exploring the experiences of adults living with the condition. Funding was awarded to CAR by Microtia UK in February 2018 and was subsidised by funds from the Vocational Training Charitable Trust Foundation (VTCT Foundation).

In order to better understand the experiences of adults living with Microtia, a qualitative research project was designed. Recruitment to the research was facilitated by Microtia UK. Between February and June 2018, 15 semi-structured interviews were conducted with adults aged 20 to 62 years.

Data was subjected to an inductive thematic analysis. Four main themes were identified in the data 1) Microtia as an invisible difference 2) Discovering Microtia 3) Surgery for Microtia 4) Living well with Microtia. Some of these themes had related subthemes.

Microtia was considered an **invisible difference** for many participants, who chose to conceal their ears with hair, therefore revealing they had Microtia was a significant experience for many. Challenges encountered included anxiety disclosing their condition to others (particularly romantic partners) and managing the workplace environment. **Discovering** they had Microtia was reported by many

as a significant point in their lives, particularly as many had grown up not knowing what had caused their small ear(s). Some participants reported difficulties as an adult in deciding whether to undergo ear reconstruction, and if they did, adjusting to their new ear post-**surgery**. Despite the challenges, on the whole adults in this study reported **living well** with Microtia, demonstrating resilience and ways of managing the challenges it presented. This appeared to be strengthened following the discovery that their condition was called Microtia, which enabled them to become more informed about it and seek treatment and support, such as finding Microtia UK. The charity was identified as a valuable source of support to participants. However, some felt that that parents can struggle to make decisions for reconstruction on behalf of their child, and that posts from anxious parents on this topic sometimes overshadowed the Microtia UK Facebook support page. Therefore they suggested a separate web space for adults.

To the best of our knowledge, this is the first qualitative study to focus specifically on the psychosocial impact of living with Microtia in adults. Whilst participants felt Microtia had not negatively impacted their lives, and some decided to have their ear(s) reconstructed, most still chose to conceal their ears and expressed anxiety in accidentally or decisively revealing them to others. This indicates that psychosocial support in managing these challenges could be beneficial for some. Additionally, the complexities around making decisions to undergo reconstructive surgery indicates that psychosocial evaluation and support before and after surgery may be required. Future research, should explore parents' experiences of decision making about reconstruction of their child's ear, especially as this research highlights this may be particularly challenging for parents.