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The Psychosocial Effects of Microtia on Family’s Decision Process

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Abstract

One in every 10,000 live births result in a facial anomaly called microtia, which affects the outer, visible part of the ear. This can have varying levels of severity, ranging from a smaller than average ear size (type one) to the complete absence of any external ear (type four). Families are presented with three options; surgery, hearing aids, or to allow the child to continue developing with no technological help. When families are presented with these options, the process tends to be stressful because of the added, unexpected decisions needed to be made on a family with a new member.

A literature review of the three options was conducted to better understand the options that are presented to families in the hospital. During each option psychological and social reasons were surveyed for, with the intent to understand why families choose to go that route. What were the factors that lead them to picking the option they did? What factors lead them to not pick the other two options? Who were crucial players in the decision making process?

There was not sufficient psychosocial research on this specific facial anomaly, which lead the literature review to broaden its scope to all facial anomalies, namely cleft lip/palate, because the assumption was made that the reasoning would be similar.

Research was conducted as a phenomenological study of one individual that was known to have type three grade of microtia. The individual was a young adult and the parents decide to not pursue surgical or hearing aid options. After interviews with the individual and their parents, a complete phenomenological analysis was conducted to reveal social and psychological patterns between responses. These responses were then filtered by category, one specific to the decision making process, emotions during, and emotions after the decision was made.

Between the literature review and the phenomenological study that was conducted, it is concluded that professional impressions play a major deciding role in swaying a family one route
or another, along with personal aesthetic reasoning. Even with aesthetic reasoning, professionals are what pushes a family toward one route. Professionals must be cautious in how the present information and how they counsel the family with their options because it is the deciding factor for a child’s lifetime.

Key Words: Microtia/ Atresia-Microtia, Clinical Audiology, Psychosocial Influencer, Phenomenological Analysis, Facial Anomalies
**Introduction:**

Microtia is a congenital facial anomaly that affects about 1 in every 10,000 live births in the United States. It affects the visible part of the ear, or the pinna, appearing as if it was crumpled or folded into itself. There are four degrees of severity, type one is the mildest and type four is the complete absence of the external ear. Depending of the type, the anomaly could affect the middle and/or inner functions that are crucial to identifying and processing sounds. This birth anomaly is not life threatening and due to many technological advances, is easy for families to get the required information to proceed with their child.

Three options are proposed to the families with a child diagnosed with microtia: the surgical option, the bone-anchored hearing aid option, and, of course, the option to not do either of the above options. Physicians worry about the auditory input of the child with the lack of an ear on, at least, one side which is why they encourage families to pursue one of the first two options. Current surgical technologies are minimal risk and quick healing rates, which tend to be attractive to families. Bone anchored hearing aid options are also attractive because they are quick in the process of obtaining and using.

Families are faced with the question of which decision they would like to pursue. This decision is made by the individuals in the family, outside influencing persons like physicians and friends, and their own biases toward a certain aesthetic. What this research began to investigate was the ‘why’ behind the process families undergo to decide. The research searched for themes of the social and psychological reasons families had for the route that they decided for their child.

**Surgery:**

There are a few different options that are presented to families when it comes to surgery. One of the options is basic repair of the outer ear, in which the surgeon uses a skin graft from the
scalp. The skin graft is shaped into a replica of the missing ear and stitched over the ear canal opening. If there is atresia, closure of the ear canal, an atresia surgery is performed to open the canal using skin from the graft. This option requires two to six surgeries depending on the case and child (Vanderbilt).

Atresia microtia repair has evolved as a surgical option in the last ten years, improving on healing time and number of surgeries for ease of process for the little ones that are receiving surgery (Bonilla). The graft, in the past, was harvested from the rib cage because the attributes of that type of skin was closest to the ear and healed rather quickly post-surgery (International Center for Atresia). It was discovered that skin even closer to the type in ears are found on the face (Bonilla 2015). A small amount is needed, and the face has many blood vessels that making healing even faster than the rib cage area.

Another, rather new option that is presented to families is the use of three-dimensional printing to recreate the missing ear(s). This option is typically only for auricular prosthesis, which is to say that it would only serve as an aesthetic solution, offering no hearing benefits (Weissler 2017). This is a popular option abroad, specifically in Asia (Weissler 2017), because it offers near perfectly looking ears to that of the child’s peers and ease in producing them, via the three-dimensional printer. This surgery option involves the process of attaching the prosthesis. In future research and practice, there is a high probability that the three-dimensional printer will be used in tandem with atresia microtia repair (Weissler 2017).

Beyond the surgical options for the outer part of the ear, there is another form of surgery which is the atresia/microtia repair. Atresia refers to the closing of the ear canal that leads to the middle and the inner ear parts. This surgery attempts to open the canal on top of reconstructing the outer ear so that natural hearing would be an option to the patient (Bonilla 2016). This
surgery, however preferred, requires certain criteria for the patient to meet before being approved for the procedure.

The first criteria would be an MRI of the middle ear bones to see if all are present and not ossified due to premature development (International Center for Atresia). The MRI would also look at the tympanic membrane, which separates the ear canal from the middle ear bones. These bones and membrane are essential to hearing through the outer ear, because it transfers sound waves into the inner ear. With any of these bones missing the chain would be broken; if the bones were ossified (hardened), the chain would be stiff and not perform the correct function of hearing, rendering the surgery pointless. The opening of the ear canal would only work if the MRI reveals healthy and normal bones and tympanic membrane (International Center for Atresia).

CAM, or combined atresia microtia surgery, is a lengthy process that has high rates of infection and fracture rate, of facial bones, of 5.2% (International Center for Atresia). This would be the second criteria of the patient, that they would be healthy and able to endure a long process of surgeries and healthy afterwards (International Center for Atresia). The patient must also consent to knowing and understanding the risks and surgical process through healing before being allowed to proceed.Patients must meet both above criteria, as well as obtaining approval from a physician before beginning the surgery process (International Center for Atresia).

**Psychosocial Influencers:**

After knowing the different options open to a family, the next part of the decision is a personal one. One reasons families pursue surgery is because of social reasons. Research shows that self-esteem tends to be lower in children with hearing impairments, and it compounded when combined with the visibility of the hearing loss (Theunissen 2014). The low levels of self-
esteem are typically due to lower language and communication use during daily activities (Theunissen 2014). This can be very isolating to children as they develop through school. School not only plays a key role in academic growth but is the child’s main platform of social interaction. Social interaction is shown to be as equally vital to development as food and water, which is why the setbacks on development due to hearing loss are significant. Typically, students with hearing loss are separated, for at least part of the day, into special education classroom settings. Pulling out isolates a child from most of their peers, which in recent years, schools have attempted to combat “pull out” sessions to avoid lower social interaction.

On top of the school situation, students with hearing loss experience higher levels of parental stress in the home. Parents have more responsibility to bolster their child’s learning experience, more medical appointments to stay on top of, and learning a completely new way of living (Boron 2010). This can be especially hard on new parents who had expectations of a different life with their new child. This research is true of children with bilateral hearing loss, but microtia usually affects the child unilaterally. The social interactions of children usually vary with unilateral hearing loss (Boron 2010), and they are often overlooked in the classroom which makes them prone to experiencing isolation at school.

Parents acknowledge the risk that their child is at when having unilateral or bilateral hearing loss, which drives them toward surgery. Children need good access to hearing to learn and develop normally, which attracts families to the surgery option. Surgery can open the child’s hearing, naturally, and can help bolster their learning. Once hearing is accessed, social development of self-esteem and friendships made are easier to access as well (Boron 2010). This helps prepare the child for their future to succeed in the world.
Another reason families look to surgery is aesthetic, which is more common. The child without a visible ear could be exposed to ridicule at school by peers and the family could be subject to “looks” or questions by bystanders in their daily lives. Often the stress alone of having to *always* deal with staring, questions, and potential bullying is a path parents wish to avoid at all costs (Mandelbaum 2017). Success of a parent of a child with hearing loss is dependent on the social support that they receive and their own external locus of control. Social support lowers negative stress levels from 62% to 43%, when given to mothers in this situation (Mandelbaum 2017). It is said that “degree of child’s hearing loss is the least salient predictor” (Mandelbaum 2017). The research is saying that how severe the loss doesn’t change opinions of the public toward the family, hearing loss is looked at the same by the public. This can cause tremendous strain on the family as they try to deal with hearing loss alone.

Success has been seen in parents with a higher external locus of control (Calderon 1999), which is to say that they see the situation as one that they cannot change but can control from now on. Parents with this mentality show higher levels of problem solving, they are more active in searching for social support, and they seek the services required to meet the needs of their children (Calderon 1999). They tend to be more involved in the process of helping their child to success.

Aesthetic reasons toward pursuing surgery offer a solution that relieves the stress of parenting a child with hearing loss *and* it being noticed by outsiders. Families often see this as a strong reason to protect their child from ridicule which can be hindering to their success just as much as the hearing loss itself.
**Bone Anchored Hearing Aids (BAHA):**

Another option that families have when having a child with microtia is a hearing aid route. Bone anchored hearing aids are a bit different than regular hearing aids because they don’t go through the ear canal. Individuals who have middle or outer ear hearing losses and/or single sided deafness are great candidates for bone anchored hearing aids, or BAHAs (Ears: Ear Associates).

BAHAs utilize bone conduction, the process of bypassing the outer and middle ear, which sends sound waves through the bone by the ear directly into the inner ear (Ears: Ears Associates). This is helpful to individuals with conductive hearing loss. Individuals who have BAHAs have a small rectangle device that sits right behind the affected ear. A small surgery is performed to insert a screw behind the ear receiving the device so the receiver can screw into the skull of the individual. The receiver sends the impulses through the screw and into the skull bones (Ears: Ear Associates).

This option does also require a surgery, but a lot smaller than atresia surgery. The surgery is approximately an hour and they can return to daily life activities immediately afterwards (Asma 2013). The healing process is about seven to ten days; however, the hearing aid will not be activated for two weeks to allow the bone to grow around the screw (Asma 2013). Common complications are inflammation and/or infection at the sight of the screw which are the only risks presented to families (Asma 2013).

**Psychosocial Influencers:**

As a family is presented with the option of hearing aids, similarly to choosing atresia repair surgery it is heavily influenced by the physician’s recommendations and the personal feelings of the family toward the options presented. BAHAs offer significant assistance to the academic learning of the student. However, aesthetic reasons are not present when deciding to
get BAHAs, because the ear is not reconstructed only amplified hearing is provided through a device behind the affected ear (Asma 2013). A research article does indicate that the improvement of psychosocial outcomes seen in the child is correlated with treatment of the hearing loss (Mandelbaum 2017).

**No Medical Treatment:**
Families’ third option with a child who has microtia is to do nothing. There are many reasons families decide to not pursue surgery or bone anchored hearing aids, some of which are the costs of treatment and/or the personal choices made by the family. Many physicians, however, do not encourage this option because it puts the child at risk for lower receptive and expressive vocabulary (Theunissen, S.C.P.M, et al 2014). However, many families do choose this option because of the variability unilateral hearing loss can have and they are not noticing any concerns with their child.

A phenomenological study was conducted of an individual that is consistent with this case. The individual was born with unilateral microtia, type three, on the right side. The parents of this child understood the options that they had and decided to not pursue either option. Today the child has high academic success, graduating valedictorian of their high school, and an honors student at their university.

Phenomenological studies involve interviews, observations and analysis of the qualitative data collected during data collection. An interview was conducted with the parents of this individual as well as an interview with the individual. Observations were also collected of the individual in group settings and in one-on-one settings. The analysis of the data was a process of surveying for common themes surrounding life with microtia and the decision-making process the parents went through. The key of phenomenological study analysis is the look for “essential
pieces”, social interaction and their meanings, and to go beyond the words to search for deeper psychosocial influences. The analysis of the data collected is shown below.

**Phenomenological Interview Analysis:**

<table>
<thead>
<tr>
<th>Facts</th>
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<tbody>
<tr>
<td>● Absent EAC</td>
</tr>
<tr>
<td>● Incus and malleus present; no stapes? (not visible)</td>
</tr>
<tr>
<td>● Atresia</td>
</tr>
<tr>
<td>● Unsure if tympanic membrane present</td>
</tr>
<tr>
<td>● Moderate to severe HL (right side)</td>
</tr>
<tr>
<td>○ Not sensorineural due to atresia</td>
</tr>
<tr>
<td>● Reason? 12 weeks pregnant fever while in Vegas</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Parent observations (influencing decision)</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Feel child responds fairly well to sounds</td>
</tr>
<tr>
<td>● Early talker</td>
</tr>
<tr>
<td>● Surgeon was a jerk (“that means I haven’t done enough surgeries if I haven’t cut a facial nerve yet)</td>
</tr>
<tr>
<td>● No effect on speech</td>
</tr>
<tr>
<td>● Well informed about the decisions they could make</td>
</tr>
<tr>
<td>● Constantly checking if he would react to sounds</td>
</tr>
<tr>
<td>● First kid= proactive about reading</td>
</tr>
<tr>
<td>● Day care showed no change in functionality amongst peers</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td>● M-sweaty passed out, worrying about disabled child (praying for none)</td>
</tr>
<tr>
<td>○ Skin tag on right cheek, freaked out</td>
</tr>
<tr>
<td>○ Crying (bc “retarded” child)</td>
</tr>
<tr>
<td>■ Ran away from hospital room</td>
</tr>
<tr>
<td>○ Dad said “not a big deal, pull yourself together)</td>
</tr>
<tr>
<td>○ Fight with wife, called child “a freak!”</td>
</tr>
<tr>
<td>■ “Leave and don’t come back until your attitude is changed” from wife</td>
</tr>
<tr>
<td>○ Regret of saying that to child and wife</td>
</tr>
<tr>
<td>○ Gratitude for the child that was healthy and they had</td>
</tr>
<tr>
<td>○ Acted like it wasn’t a thing and teamed up with wife</td>
</tr>
<tr>
<td>○ Upset that 5-year-old children would laugh (strong negative emotion towards kids)</td>
</tr>
<tr>
<td>● D- husband held self together so well she didn't know it was as bad</td>
</tr>
<tr>
<td>○ “Seriously, it's just an ear!”</td>
</tr>
<tr>
<td>■ Other people (friend of family) had a stillborn</td>
</tr>
<tr>
<td>○ Yelled at husband for reaction and lack of support</td>
</tr>
<tr>
<td>○ Teamed up with husband and treated it like it wasn’t a big deal</td>
</tr>
<tr>
<td>○ Wished people who starred would just ask</td>
</tr>
</tbody>
</table>
Parent observations (after decision)

- D-6 mo at volleyball tournament were staring
- M- 6 years old (1st grade) at baseball game kids were laughing and pointing
- M- 5 years old child was pointing and asking about a midget and was informed that that isn't nice because it would make you feel bad about your ear
  - First time parents pointed it out to child
- Made it a joke= doctors would forget and would make it into a joke
- Schwan's guy had same thing and made child feel like they weren’t alone
- Acted like it was normal
  - Didn't want a special seat at school (maybe only in kindergarten)

Child influences

- Personality= confident to talk to people
  - Make up stories when people asked to make it funny (perpetuating into adulthood)
- “Do you want to fix your ear?”
  - “No why?”
- Active in sports and with friends and didn’t want surgery and miss out on activities

*Parent’s names were changed to single letters, “D” and “M”, to ensure privacy of family’s story*

**Interview Analysis Conclusion:**

After analyzing the interview data and organizing the information chronologically and by type (before, during and after decision) a few themes were discovered.

**Theme one: The emotional stress experienced by the parents is the key factor in deciding which route to proceed.**

During the interview with the parents, despite the constant information and support received by the physicians, the decision was still an emotional decision. When “D” lost support of “M” because of the emotional trauma experienced in the surprise of the birth, tensions between the parents rose. This tension slowed the decision-making process and hindered the social supports parents individually need when faced with a situation like this.
Theme two: Past research of “external locus of control” on parents dealing with hearing loss is supported in this study.

Two different reactions to the situation were recorded by the parents. “M” experienced a crippling trauma of being born with a child without an ear, seeming to blame oneself for the outcome. This was perpetuated because during the pregnancy this was a real fear of “M” for their first child. This is consistent with an “internal locus of control” that medical issues were the fault of a bad parents.

“D” experienced an opposing feeling, one of understanding that this was out of their control. It was recorded in the interview, “I was just happy that I was born with a baby who was healthy and beautiful, so what if they don’t have an ear” (“D”, personal communication, September 16, 2017). The experience of shows an “external locus of control” acknowledged by “D”, this was a situation out of their choice control and the best thing they could do was look forward to how to help their child. “D” experienced a healthier response to the situation comparatively to “M”.

Theme three: Social support is key and is supported by past research.

The parents expressed a unique response by their town to the situation. They both decided that they were not going to “make a big deal” out of the situation, nor were they going to use it as a crutch for the child. They “acted like nothing was wrong” and did so around their friends and family. “Because of the way we acted,” “D” commented, “no one else in the town acted differently either” (“D”, personal communication, September 16, 2017). On top of the attitude of the parents, social support was received at daycare and church settings because of the
continual awareness of the learning of the child. Each social group treated the parents like regular parents and would continual inform them of changes, if any, of the child’s development. The social support helped change “M”’s perspective as the child grew and developed typically, to the point where it was not noticeable by the age of five to the family.

**Theme four: Physicians involved in the process play the keystone role in the psychosocial decision parents’ face.**

When inquiring about the decision-making process, the parents clearly indicated the reason why they choose to not pursue any medical treatment. “D” recounted, “the surgeon had said something that instantly made my decision for me. He had said ‘there is a potential that I could hit the facial nerve that would cause paralysis and drooping in your child’s face. I have yet to hit one which means, I guess I haven't done enough surgeries yet!’ This immediately made me defensive, even though I was sure he wasn’t trying to scare us. But I didn’t want my baby to be the one he messed up on.” (“D”, personal communication, September 16, 2017).

Up until the comment made by the physician, both the parents were open to surgery options because the information was presented to them well. Both commented on how much they felt they understood the risks and the benefits of their options. But because of a physician’s *socioemotional* typed comment, not a medical comment, the parents completely stopped pursuing medical treatment. This shows the key role providers have in the social and emotional process of family’s decision-making process.

**Theme five: Child’s personality plays a role in the success socially and academically.**

After the decision was made by the parents to not do anything, to continue to monitor the child’s hearing development especially when in school. No concerns were brought to their
attention. However, the child had a personality that didn’t seem to notice or care what other peers thought of the “missing ear”. “M” remembered that at one of the child’s very first baseball games the other team was making fun of the child, which made “M” very upset. However, the child didn’t seem to notice the comments at all.

Later, when the child was older the parents offered a suggestion of possibly getting the ear “fixed”. The individual immediately shot the idea down, expressing confusion on why it would be a concern. This led the parents to not bring the question up again. The unnoticing personality of the individual is consistent to present day, noted in the interview with only the individual.

**Other Facial Anomalies Psychosocial Influencers:**

A literature review was performed on all facial anomalies’ psychosocial effects on the family. The research suggests that there is an adverse effect on social integration and academic performance (Fitzsimons 2017). Children with craniofacial microsomia are three times more likely to perform at risk and to show a negative impact in “multiple developmental stages”, according to Fitzsimons (Fitzsimons 2017). A study on cleft lip and palate revealed that academic performance, assessed specifically in language, is significantly affected compared to the peers of these individuals (Fitzsimons 2017).

Furthermore, the research also suggests that the social interaction of these students is greatly affected because of “cuteness” (Talley 2015). Infants that were affected by cleft lip or palate were rated “less cute”, significantly less cute when they were being rated by men (Talley 2015). The American Journal of Sociology says that society “makes surgeries seem necessary” (Talley 2015) because of the “jarring and offensive” effects of facial distortions that lead to social death (Talley 2015).
If all of this is applied to the research found in this study, families would choose surgery because of the aesthetic reasons as well as academic reasons when presented with a child with microtia. These personal influencers should hold the majority of the weight in the decision-making process with families.

**Conclusion:**
Many factors contribute to the decision and success of the child with hearing loss due to microtia like personality and parental attitudes as well as social support. This is not within the control of the provider or even the family in the situation. The two important themes were how the decision was made by the family; emotionally, and who influenced the decision; the surgeon. Thus, leads me to the conclusion that decisions this early in a family’s life is heavily dependent on the emotional influencers, mostly positive in this study, and who is delivering the negative.

All options come with research for the improvement of academic outcomes and the risks that a child would face when born with microtia. As well as academic reasons, providers provide information about the social development of the child. The information, although important, do not make the decision. Individual emotional reasons such as aesthetics and potential low academic performance are secondary to the emotional emphasis providers put on different options. Providers have a clear role in providing quality information to a family facing hearing loss from birth, however it is the emotional information they convey that decides the route families pursue. As providers consult their families who face this decision, it is best practice to provide information that is conscious of the emotional state of the family and free from their own emotional opinions.
References:


https://www.journals.uchicago.edu/doi/abs/10.1086/681079.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3983202/.