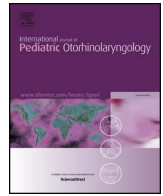




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Parental preferences for the first consultation for microtia

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ABSTRACT

Objectives: The aim of our study was to investigate subjective information concerning parental experiences and preferences with regard to the initial information that is provided right after the birth of a child with microtia. The analysis of these data is intended to help professionals improve the way in which such conversations are conducted. As a result, future parents may feel better informed and, hence, better fit to cope with challenges they may encounter having a child with microtia.

Methods: A self-administered questionnaire was sent to 106 parents and caretakers of children with microtia who visited the annual International Microtia and Atresia Conference in the Netherlands, May 2016.

Results: Eighty-seven questionnaires were returned (response rate 82%). Results revealed that 26% of the participants did not receive any information about the condition in the perinatal period. Participants who did receive information right after birth were informed by pediatricians and otolaryngologists in most of the cases. Plastic surgeons and maxillofacial surgeons were the less commonly serving specialties in this role. A majority of the participants experienced their informing consultation as either being “terrible”, or “bad”. Parents desired more information about all domains regarding microtia. Development, clothing and appearance, and psychology were believed to be the least important domains.

Conclusions: Parents are dissatisfied with several aspects of the initial information that is provided right after the birth of a child with microtia. We believe that there is a need for correct information and patient- and family centered care administered by multiple disciplines.

1. Introduction

Microtia is a congenital malformation of the external ear, varying from minimal structural abnormalities to a complete absence of the external ear (anotia) [1]. The prevalence of microtia at birth is reported to be 0.83–17.4 per 10,000 live births and is considered to be higher in Asians, Native Americans, Hispanics and Andeans [2]. Microtia is accompanied by aural atresia in 90% of the cases, which describes the congenital absence or stenosis of the external auditory canal with variable middle ear anomalies, causing a fixed, congenital hearing loss [3].

Males are more often affected than females, and most cases of microtia are unilateral with a preference for the right side [4,5]. Microtia can occur as an isolated condition, or in association with other congenital anomalies or syndromal disorders [1]. The impact of microtia can be of significant impact on the life of patients and their families [6].

Therefore, the need for correct information and support by multiple disciplines is of great importance.

Pre- and postnatal informing consultations often occur as the result of a child having a genetic condition, a syndrome or sequence, developmental delay, or a congenital defect, which can be a distressing experience for the parents of that child [7,8]. It is imperative that the informing clinician pays careful attention to how the initial information is given, since the parents' experience of the informing consultation can play a major role in the family's perception of the child and their long-term adjustment to the child's disability [9–11]. To our knowledge, no data is available on parental preferences for the postnatal informing process for children with microtia. We hypothesized that, due to the rarity of this condition, there is a paucity of information given to parents. The primary aim of our study was to investigate the experiences of parents and to evaluate which aspects of the informing consultation are important after the birth of a child with microtia. These data should

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help future health professionals to improve their informing consultations. As a result, future parents may feel better informed and, hence, better fit to cope with challenges they may encounter having a child with microtia.

2. Materials and methods

2.1. Ethical considerations

The Medical Research Involving Human Subjects Act did not apply to this study; therefore, official approval of this study by the University Medical Center Utrecht was not required under the act.

2.2. Study participants

Participants were invited to participate during the annual International Microtia and Atresia Conference in the Netherlands held in Kerkdriel, May 2016. Parents and caretakers who were willing to participate signed consent and contact details were collected. A self-administered questionnaire was e-mailed to all the potential participants from August 2016 to October 2016 (Appendix A).

2.3. Questionnaire

The questionnaire was developed by an expert panel, consisting of a pediatric plastic surgeon, a pediatric maxillofacial surgeon, an otolaryngologist, and an epidemiologist, who are all involved in the treatment of patients with microtia at the Wilhelmina Children's Hospital, the Netherlands. Input was also obtained from three mothers of children with microtia. The first part of the questionnaire consisted of questions about the experiences with the informing interview. The second part of the questionnaire consisted of 44 statements, which were categorized into 10 domains concerning microtia and atresia (1. Hearing, 2. Development, 3. Reconstructive surgery, 4. Maxillofacial surgery, 5. Clothing and appearance, 6. Genetics, 7. Psychology, 8. The medical team, 9. Financially, 10. Other). Participants were asked to rank the statements from 1 (not important) to 6 (very important), according to which subjects they believed should or should not be discussed in the informing consultation. Open ended sections of the questionnaire were used by respondents to describe items, that they had missed in the questionnaire and to leave additional remarks.

2.4. Statistical analysis

All experiences and preferences of the participants were exported to Statistical Package for the Social Sciences (IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corps, released 2012). Demographic characters and parental overall experiences with their informing consultation were extracted. An overall median score and IQR of all the questions was calculated. Median scores and IQR of all separate statements and ten domains were calculated as well.

3. Results

3.1. Study participants

106 parents and caretakers were sent the self-administered questionnaire, with a response rate of 82% (n = 87). Three cases were excluded due to incompleteness of the questionnaire (> 20% missing data). Sample characteristics of 84 included questionnaires are shown in Table 1.

3.2. Parental experiences with the informing consultation

Sixty-two (74%) of all parents and 12 (63%) parents of a child with a syndrome were informed about their child's diagnosis at the time of

Table 1
Characteristics of the study sample.

	Characteristics	n = 84	%
Relationship to child	Mother	56	67
	Father	24	29
	Grandparent	1	1
	Guardian	2	2
	Missing	1	1
Gender child	Boy	53	63
	Girl	31	37
Age child	0–2	21	25
	3–5	24	29
	6–8	16	19
	9–11	16	19
	12–14	4	5
	15–17	2	2
Ethnicity	Missing	1	1
	European	63	75
	North-American	2	2
	South-American	2	2
	Asian	10	12
	African	1	1
	Missing	6	7
Adopted	Yes	10	12
	No	74	88
Syndrome	Goldenhar	4	5
	OAV spectrum	9	11
	Treacher Collins	6	7
	None	59	70
	Missing	6	7
Affected ear	Right	42	50
	Left	27	32
	Both	15	18
Type of microtia	Lobular	15	18
	Small concha	4	5
	Concha	3	4
	Anotia	2	2
	Atypical	3	4
	Unknown	52	62
	Missing	5	6
Had an ear reconstruction?	Yes	18	21
	No	66	80
If yes, type	Rib cartilage	2	11
	Medpor	15	83
	Prosthesis	1	6
Age of first stage of ear reconstruction	3–5	7	39
	6–8	8	44
	9–11	2	11
	12–14	1	6
Number of surgeries	1–2	14	61
	3–5	7	30
	> 5	1	4
	Missing	1	4

birth (Figs. 1 and 2). Multidisciplinary teams consisted of pediatricians and otolaryngologists in all cases, with addition of a plastic surgeon in two cases, an audiologist in two cases, and a maxillofacial surgeon in one case. “Other” specialists were a neurologist, a cardiologist, a geneticist, or an audiologist.

Overall parental experience with the informing consultation are found in Fig. 3. Table 2 lists the rating per serving specialty.

3.3. Parental preferences

An overview of the median ratings of all statements of all domains is listed in Fig. 4. The median score of all statements was 5.8 (IQR 1). Six domains (hearing, reconstructive surgery, genetics, financially, and other) scored above average, one domain scored average (maxillofacial surgery), and three domains scored below average (development, clothing and appearance, psychology).

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