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Maternal Reports of Satisfaction with Care and Outcomes for Children with Microtia

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Sir:

Microtia is characterized by hypoplasia of the external ear and narrowing of the external ear canal. It often requires surgical correction and can present with additional comorbid conditions. To date, little published information is available about treatment outcomes for this defect and accompanying conditions.^{1,2} Tanzer¹ evaluated 43 ear reconstruction operations and reported few late postoperative complications, whereas Fraser and Watson² studied 17 patients and found recurrent restenosis, skin graft failures, and hearing, speech, and psychiatric problems. Given the improvements in treatment,³ we queried mothers of children with microtia to identify their satisfaction with care received, additional comorbid conditions, and access to healthcare services for their children.

Children with microtia and their mothers who resided in Arkansas, Iowa, or New York were identified from participants in the National Birth Defects Prevention Study, a population-based case-control study.⁴ Eligible children were delivered between January of 1998 and December of 2003 and were diagnosed with microtia but no additional major defects. Birth mothers of these children were asked to complete a computer-assisted telephone interview and results were summarized. The study protocol was approved by the institutional review boards in each state.

Thirty-six eligible children were identified (seven in Arkansas, 11 in Iowa, and 18 in New York), and birth mothers for 20 children (55.6 percent) (three in Arkansas, six in Iowa, and

11 in New York) completed interviews. Most mothers reported being “very happy” with the appearance of their child, although they indicated a need for improvement in patient-provider interactions for information and support received at the time of the diagnosis and for answers received regarding microtia and treatment options (Table 1). Overall, 75 percent of mothers reported that their child received care from an organized specialty care team, but only one-half of mothers in New York ($n = 6$) reported such care (data not shown). Because of the younger age of the sample, only three children (15.0 percent) received ear operations (excluding tympanostomy), although no postoperative complications were reported; one child (5.9 percent) reportedly needed surgery in the previous year but did not receive it. Using a scale of 0 (poor) to 10 (excellent), mothers reported a mean quality score of 8.3 for all medical care received (data not shown).

With regard to comorbid conditions, most children (90 percent) reportedly suffered hearing loss; however, only one child (5.6 percent) was fitted with a hearing aid (Table 1). Additional delays in development were also mentioned. Nearly all children (95 percent) reportedly had a primary care practitioner and each had healthcare coverage. Some children received additional care for behavioral or emotional problems (5 percent), speech therapy (60 percent), and learning problems (30 percent). In addition, most children (75 percent) were expected to need additional operations.

In summary, mothers of children with microtia were generally satisfied with the care provided, although a need for increased access to an organized specialty care team, improved interactions with healthcare professionals, and a lack of hearing aids were identified. Despite the modest number of participants, our study is the first population-based assessment to measure the baseline needs among parents of children with microtia. Continued follow-up of this sample might provide additional insights into postoperative care and outcomes experienced by these children.

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Table 1.

Maternal Reports of Satisfaction with Care Received, Comorbid Conditions, and Access to Care for Their Child

Interview Item	Maternal Responses	
	No.	%
Medical care		
Felt “very happy” about their child’s appearance	13	68.4 [*]
Very satisfied with the information received from healthcare professionals at the time of diagnosis	7	35.0
Very satisfied with the support and encouragement received from healthcare providers at the time of diagnosis	10	50.0
Received excellent answers for microtia and treatment options	4	21.1 [*]
Surgical care		
Care from an organized specialty care team (including at least a surgeon, hearing professional and a speech therapist)	15	75.0
Surgery to repair the child’s hearing condition (excluding tympanostomy)	3	15.0
Unable to receive ear surgery in the past year when needed	1	5.9 [†]
Hearing		
Child suffered hearing loss	18	90.0
Severity of hearing loss (compared with other children with microtia)	11	68.8 [‡]
Fitted with a hearing aid	1	5.6 [§]
Problems or developmental delays		
Physical delays	3	15.0
Mental or cognitive delays	2	10.0
Emotional or behavioral delays	4	20.0
Access to care		
Personal doctor or nurse for primary care	19	95.0
Healthcare coverage (health insurance, prepaid plans or governmental plans)	20	100.0
Received behavioral or emotional therapy in the past year	1	5.0
Received speech therapy in the past year	12	60.0
Received learning interventions in the past year	6	30.0
Perceived need for specialized therapy (physical, speech, or occupational) for at least a year	9	45.0
Perceived need for additional operations to affect their child’s appearance	15	75.0

^{*} Percentage based on 19 responses.

[†] Percentage based on 17 responses.

[‡] Percentage based on 16 responses.

[§] Percentage based on 18 responses.