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Demographic Characteristics, Care, and Outcomes for Children With Oral Clefts in Three States Using Participants From the National Birth Defects Prevention Study

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Abstract

Objective—The primary objective of this study was to evaluate whether there were differences in the characteristics and outcomes of care for children with oral clefts (OCs) among population-based samples in three states.

Design—Data on the health status and on speech and esthetic outcomes were collected using structured telephone interviews conducted during 2005–2006 with mothers of children with OCs aged 2 to 7 in Arkansas, Iowa, and New York.

Participants—Mothers of children born with nonsyndromic OCs on or after January 1, 1998, and on or before December 31, 2003, in Arkansas, Iowa, or New York. Subjects were identified through their participation in the ongoing National Birth Defects Prevention Study.

Main Outcome Measures—Demographic characteristics, rating of cleft care, severity of condition, health status, esthetic outcomes, and speech problems were evaluated by state of residence.

Results—Children with OCs from Arkansas were from lower income families, and their parents were less likely to be married. Children with OCs from Arkansas were more likely to have special health care needs and to require mental health care. Few differences were found across states in type of cleft, severity of cleft, or outcomes of cleft care.

Conclusions—Combining results from population-based samples across multiple studies increases the variability of sample characteristics. Including multiple states can be an efficient way to learn more about the outcomes of medical care for less common conditions such as oral cleft.

Keywords

health status; oral clefts; outcomes; surgery; treatment

Although many studies have evaluated aspects of health status and of clinical and social outcomes for children with oral clefts (OCs), few of these have been population based. Most published studies have been limited to clinic-based or convenience samples, making generalizability of results questionable (Strauss et al., 1988). In addition, few studies have examined cleft care outcomes in multiple states. This study examined the demographic characteristics and outcomes of care for children with nonsyndromic OCs in Arkansas, Iowa, and New York.

One population-based study of the outcomes of care for children with OCs was conducted using patients and families identified by the Iowa Registry for Congenital and Inherited Disorders (Damiano et al., 2006). This study, which used telephone interviews with mothers of children born between 1990 and 2000, found several differences between children with cleft lip only (CL), cleft palate only (CP), and cleft lip with cleft palate (CLP). Mothers of children with CLP were most likely to rate the cleft as very severe. Mothers of children with a cleft lip had more esthetic concerns, and mothers of children with palatal involvement had more speech concerns. As a group, children with OC were reported to have a lower health status and were almost twice as likely to be identified as having a special health care need as children with a clubfoot or children statewide.

In 1996, the Centers for Disease Control and Prevention (CDC) established Centers of Excellence for Birth Defects Research and Prevention (CBDRP) in eight states. All CBDRP participate in the National Birth Defects Prevention Study (NBDPS), which is the largest case control study of birth defects in the United States. The NBDPS involves interviewing mothers of children with birth defects within 2 years following delivery. The NBDPS also provides a mechanism for the tracking and surveillance necessary for follow-up of population-based studies on the outcomes of care for birth defects as children age.

We present here results from a population-based study of children with OCs using data from three states participating in the NBDPS: Arkansas, Iowa, and New York. Descriptive results focus on demographic characteristics, cleft care, and outcomes of cleft care across the three states. Primary research questions for these analyses include the following: (1) Do children with OCs experience differences in cleft care, health status, and outcomes of the care they receive according to their state of residence? and (2) What factors are associated with each of three outcome measures: (i) how often the child has difficulty being understood when speaking, (ii) the mother's satisfaction with the child's facial appearance, and (iii) the mother's overall rating of the child's cleft-related care.

Methods

Study Population

Data for this study were obtained through telephone interviews with mothers of children born in Iowa or New York between January 1, 1998, and December 31, 2003, and with mothers of children born in Arkansas between January 1, 1999, and December 31, 2002, and diagnosed with one of three types of craniofacial malformation: a nonsyndromic oral cleft (i.e., cleft palate, cleft lip, or cleft lip with cleft palate), craniosynostosis, or microtia based on NBDPS case definitions. Only data on children with OCs were included in this analysis. Children were aged 2 through 7 at the time of the interview. Additional eligibility criteria were that the child (1) was currently living in Iowa, New York, or Arkansas with his or her birth mother, (2) did not have a diagnosis of craniosynostosis or microtia in addition to the OC, and (3) did not have bifid uvula only or submucosal cleft palate only, and that the birth mother had been interviewed for the NBDPS (with exception of New York births for 2003). The Iowa and Arkansas sites included children statewide. The New York site comprised 15 counties in the Western New York and Mid-Hudson areas of the state.

We identified 582 potentially eligible children whose mothers completed the NBDPS interview: 223 in New York, 226 in Iowa, and 133 in Arkansas. Multiple sources were used to verify eligibility and to obtain current contact information for each mother. These sources included death certificates to verify that both the child and the mother were living, surveillance system databases to verify cleft diagnosis, and telephone and internet databases to identify current contact information for each mother. Of 582 children identified, 65 (11%) (23 in New York, 33 in Iowa, and nine in Arkansas) were determined to be ineligible for one of the following reasons: (1) the child was not currently living with the biological mother, (2) the family had moved out of state, or (3) the child had a diagnosis of craniosynostosis or microtia in addition to OC; this left eligible samples of 200 in New York, 193 in Iowa, and 124 in Arkansas.

Mothers of the 517 eligible children were mailed an introductory packet that included information about the study and a request to complete the telephone interview. Mothers were also provided with a toll-free telephone number to call to agree to or refuse participation; those in New York were asked to provide signed, written consent to acknowledge their interest in participating. For mothers who did not respond to the introductory mailing, reminder calls were attempted at 2-week intervals for 6 weeks to encourage participation. Overall, interviews were completed with mothers of 253 (49%) children: 86 in Iowa (44%),

97 in New York (49%), and 70 in Arkansas (56%). Of the remainder, 152 refused participation (seven in Arkansas, 87 in Iowa, and 58 in New York), and 112 (47 in Arkansas, 20 in Iowa, and 45 in New York) were unable to be contacted by telephone or mail. Nonresponse bias tests indicated no statistically significant difference between respondents and nonrespondents on a variety of factors, including infant's sex, infant's gestational age, plurality, mother's race/ethnicity, mother's age, trimester prenatal care began, smoking during pregnancy, alcohol during pregnancy, and father's age.

Survey Instrument and Process

The survey interview was developed jointly by staff at the University of Iowa Public Policy Center, the Iowa Registry for Congenital and Inherited Disorders, the New York State Department of Health, the University of Arkansas for Medical Sciences, and the National Foundation for Facial Reconstruction (NFFR), with consultation provided by nationally recognized experts on the treatment of craniofacial anomalies. The interview addressed families' experiences with the child's diagnosis and with early treatments, locations of surgical care and methods of payment for surgical services, and satisfaction with treatments. Access to appropriate follow-up care (e.g., speech therapy, hearing tests, genetic testing, mental health care) was assessed through simple yes-or-no items. Mothers rated their child's current mental and physical health status using a five-level scale: excellent, very good, good, fair, or poor.

Children with special health care needs (CSHCN) were identified using the 15-item Child and Adolescent Health Measurement Initiative (CAHMI) CSHCN screening instrument (Bethell et al., 2002). Children were classified as having a special health care need if they had a health condition that had lasted or was expected to last for at least 12 months, and that had resulted in (1) use of or need for prescription medication, (2) use of or need for additional medical, educational, or other services compared with others of the same age, (3) functional limitations, (4) use of or need for specialized therapy, or (5) a mental health problem requiring treatment. A summative index of the mother's perception of the information and support she received from health professionals when the child's cleft was diagnosed was created by combining responses to ratings of how well the child's condition was explained and information provided (1 = excellent, 5 = poor), and satisfaction with answers to questions and supportiveness of staff (1 = very satisfied to 4 = not satisfied). In addition, those whose child had difficulty with feeding rated how helpful providers were with this problem (1 = very helpful to 4 = not very helpful). Each response was reverse-coded and was converted to a 0 to 100 metric. The mean of the four (or five) scales was taken as a general index of the mother's experience of support and information provided at the time of cleft diagnosis. Items addressing problems with speech and satisfaction with facial appearance were based on clinical measures and were developed in collaboration with expert clinicians at the University of Iowa Hospitals and Clinics and the University of Pittsburgh. Mothers rated their perception of how happy their child was with his or her facial appearance on a scale of 1 (not very happy) to 4 (very happy). Because most mothers (83%) indicated that they were very happy with their child's appearance, the rating was recoded for analysis into a binary variable so that 1 = very happy, and 0 = moderately happy to not very happy. The speech problem scale consisted of five items measuring how often (never,

sometimes, usually, or always) the child experienced difficulty being understood when speaking. Each item is reverse-coded so that a higher score indicates less difficulty. The mean of the five items was converted to a 0 to 100 metric for easier interpretation and comparison with other measures. Finally, mothers rated their global impression of the cleft-related care the child had received on a scale of 0 to 10, where 0 = worst care possible and 10 = best care possible.

Human subject approval for the study protocol, informed consent procedures, and correspondence were received from institutional review boards (IRBs) at the New York State Department of Health, the University of Iowa, and the University of Arkansas for Medical Sciences. Subject recruitment for both Iowa and New York was conducted by research staff at the Iowa Registry for Congenital and Inherited Disorders; the Arkansas Center for Birth Defects Research and Prevention recruited Arkansas subjects. Professional research staff at the University of Northern Iowa's Center for Social and Behavioral Research (CSBR) conducted interviews for the Iowa and New York samples over the period from August 18, 2005, through April 26, 2006, using a computer-assisted telephone interviewing (CATI) system. Research staff at the Arkansas Center for Birth Defects Research conducted the same interview with the Arkansas sample between April 21 and November 2, 2006.

Analysis

All analyses were conducted using Stata, version 9 (StataCorp, College Station, TX). Analyses focused on two main objectives: 1) description of differences between participating states, and 2) identification of factors associated with three key outcomes.

For the first main objective, describing differences between states—descriptive comparisons of results for children with oral clefts from Arkansas, Iowa, and New York were conducted. Differences between the three states were tested for statistical significance using Pearson chi-square tests, Kruskal-Wallis chi-square tests, and F-tests for differences in means as indicated in table notes.

For the second main objective identification of factors associated with three key outcomes (speech score, facial esthetics, and overall rating of cleft care), for each outcome, variables with which it was associated bivariate analysis at $p = .20$ or lower were used to develop a multivariate model. The starting (full) model for each outcome included the following as covariates: state, type of OC, child characteristics (age, sex, race), and mother characteristics (age, race, marital status, education). The most parsimonious model for each outcome was obtained using a backward stepwise procedure, eliminating one predictor at a time from the full model. State and cleft type were retained as covariates in the final models; individual child and mother characteristics were retained if they contributed to the model.

Before multivariate analyses were conducted, the four-level esthetic measure was dichotomized into 1 = very happy versus 0 = less than very happy. Similarly, the 0 to 10 overall rating of cleft care was collapsed into a three-level ordinal variable, where 0 through 7 = 1, 8 or 9 = 2, and 10 = 3. The speech scale score was transformed using the formula $\ln[(\text{score} - 1)/100 - (\text{score} - 1)]$.

Model 1—Speech score (children 3 and over)—Independent variables consisted of special health care needs, hearing loss, chronic physical condition, delayed emotional development, having received speech therapy within the last year, and having made a preventive visit in the last year. Child's global health rating and other developmental delays were not included because of collinearity. Because residuals from linear regressions on the 0 to 100 scale were neither homoskedastic nor normally distributed,¹ we reestimated the model using a logit-type transform of the speech score.² This approach successfully addressed both issues; however, coefficients should be interpreted in terms of the transformed score.

Model 2—Facial esthetics—Independent variables included delayed social development, unmet need for dental care, satisfaction with information and support at diagnosis, three or more children in the family, a sibling with an oral cleft, child enrolled in Medicaid or SCHIP, need for medical specialist within the last 12 months, and number of ambulatory visits over the last 12 months. Binary logistic regressions were used to determine the variables associated with whether the mother was “very happy” with the child's facial appearance. Finally, variables associated with mother's overall rating of cleft care were identified using ordinal logistic regression.

Model 3—Rating of all cleft care—Independent variables included mother's rating of the severity of child's cleft, having special health care needs, chronic physical condition, delays in emotional and cognitive development, satisfaction with support and information at diagnosis, speech score, rating of insurance coverage for cleft-related health care, worry about paying for child's cleft-related and other health care, and satisfaction with child's facial appearance.

Results

Demographic characteristics of children with OCs in the three states are presented in Table 1. Because of slightly different ages of inclusion, children about whom the interviews were conducted in Arkansas were significantly older than those in Iowa or New York, with the vast majority aged 5 to 7. Children from Arkansas were more likely to be living in a single-parent household and to be living in a lower income household. Children in all states were more likely to be white and male. Children in Iowa were most likely to be white. Overall, about 7% had a sibling with an OC.

Cleft-specific information and data about the medical care received by children are displayed in Table 2. A little more than 40% of children were born with a cleft lip and palate, almost one third with a cleft palate only, and a quarter with a cleft lip only. About one fifth (17%) reported their child's OC to be very severe, and a third not very severe. The OCs of remaining children were judged to be somewhat or moderately severe. No statistically

¹Breusch-Pagan/Cook-Weisberg test for heteroskedasticity: $\chi^2(1) = 16.60$; $p < .001$; Shapiro-Wilk test for normal data: adjusted $\chi^2(2) = 4.635$; $p < .001$.

² $\ln[(\text{speech score} - 1)/(100 - (\text{speech score} - 1))]$.

significant differences by state were noted in the relative frequencies of the three OC types or mothers' rating of cleft severity.

Two different measures of the children's overall health status are presented in Table 3: the global, single-item health rating, and the 15-item screening instrument for identifying children with special health care needs. No significant difference was observed in how mothers across the three states rated their children's global health status. Almost two thirds rated their children's health as excellent, and another quarter as very good. The proportion of children who met the criteria for being defined as having a special health care need was significantly higher in Arkansas (almost two thirds) as compared with the other two states (about half). Children with OCs in Iowa were significantly less likely to use or need specialized therapy than were children in Arkansas or New York. Significantly more children in Arkansas had a mental health problem that required treatment.

Three important outcomes of the care that children with OCs receive (satisfaction with care, child's esthetics, and child's speech) were evaluated in this study (Table 4). No statistically significant difference was noted in how mothers rated their satisfaction with their child's facial appearance (single item) or in how the child's speech was rated (five-item scale). Almost all parents reported that they were moderately or very happy with their child's appearance. Speech scores varied little across states. Satisfaction with cleft care provided to children differed by state. Although cleft care in all states was rated generally favorably, mothers in Arkansas were more likely to score their satisfaction at the high end of the scale (10), and those in New York were more likely to rate care at the low end of the scale (0 through 7).

Results for regression models with the three primary outcome measures (speech, esthetics, and rating of care) are shown in Tables 5 through 7. Age, special health care needs, delayed emotional development, and whether the child had received speech therapy within the last year were identified as being best related to speech score when speech outcomes were analyzed (Table 5).

As is shown in Table 6, mothers whose children had a cleft palate only were more likely to say they were very happy with the child's appearance, as were those who had another child with a cleft and those who had three or more children. Problems with peer relationships due to developmental delays were associated with less than very happy responses.

Lower overall ratings of the child's cleft care were associated with clefts involving the palate only, with the mother having a college degree or more education, and with the child's experiencing a cleft-related surgical complication (Table 7). Higher scores on the information and support at diagnosis measure and a positive response on the esthetic measure were associated with higher cleft care ratings. Worry over how the family would pay for the child's noncleft-related health care was associated with higher cleft care ratings.

Discussion

Results of this study indicate that combining population-based data from multiple states can bring together information that represents a broader set of parameters than is available from

a single state. In this study, certain demographic characteristics of children with OCs, as well as some of the results for care and outcomes measures, were significantly different by state, thus creating a more complete picture of issues for children with OCs when multistate data are combined.

Although a national population-based approach is the gold standard when one is trying to generalize to the United States as a whole, this is particularly difficult for low-prevalence conditions such as birth defects. The use of multistate data from participants in the NBDPS is a compromise approach that can improve our understanding of issues related to these low-prevalence birth defects, but it does not overcome methodologic issues entirely. Comparison of these results versus those of previously published studies is difficult because the samples vary considerably. Even comparing the Iowa results versus those of previous studies in Iowa of children with OCs is difficult because the ages of the populations are different. This is particularly important because a previous Iowa study of the health-related quality of life of children with OCs found differences in outcomes by age (Damiano et al., 2007).

For the current analyses, inclusion of children from Arkansas brought older children with a greater number of surgeries for their OCs because Arkansas did not include in its sample births after 2002. This may or may not have been related to greater satisfaction with the cleft care received. Arkansas children came from households with lower incomes. Iowa added a primarily white, middle-income population to these analyses, and New York added a higher income population with some Hispanic/Latino children.

In addition to state-related results, outcomes analyses found that factors other than state were significantly associated with the three primary outcomes. The lack of a cleft lip as important in the mother's perception of the child's esthetic outcome is intuitive and is supported by the findings of previous studies (Strauss et al., 1988; Broder et al., 1992, 1994; Damiano et al., 2006). The indication that the type of cleft did not influence the mother's perception of the child's speech outcomes, however, is not expected, given previous research in which cleft type, especially the presence of a cleft palate, has been found to influence cleft outcome measures (Scherer et al., 1999; Millard and Richman, 2001; Snyder and Scherer, 2004; Montagnoli et al., 2005; Schuster et al., 2006). Whether the child had received speech therapy within the last year may be an indicator of the severity of the child's speech problems as a factor in the lower rating of the child's speech. Rating of all cleft care was positively influenced by a supportive health care system, as well as perhaps by emotional support on a daily basis of a mother who is more pleased with the appearance of her child. Lower ratings by higher educated mothers may have been related to greater expectations for the care that their child received or to enhanced perception of lower outcomes.

Future analyses should include an evaluation of how much of the variance in outcomes can be attributed to the state in which children live. This could be particularly important for outcomes of care where factors such as being cared for by an organized cleft team or family income would be hypothesized to be related to positive outcomes. In addition, the relationship of cleft type (lip only, palate only, or both lip and palate) versus outcomes should be examined in multiple states.

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TABLE 1

Demographics of Children With Oral Clefts by State

Variable	Arkansas (n = 70)	Iowa (n = 86)	New York (n = 97)	Total (N = 253)
Child, age group [*] ($p = .001$)				
2–4 y	28.6%	54.7%	56.7%	48.2%
5–7 y	71.4%	45.4%	43.3%	51.8%
Mean age, y [†] (SD)	5.2 (1.3)	4.2 (1.7)	4.3 (1.6)	4.5 (1.6)
Child, female	45.7%	38.4%	38.1%	40.3%
Child, Hispanic/Latino(a) ancestry	0%	0%	6.2%	2.4%
Child, Caucasian [*] ($p = .003$)	87.1%	98.8%	84.5%	90.1%
Mother's marital status				
Married or in marriage-like relationship [*] ($p = .019$)	77.1%	93.0%	85.6%	85.8%
"Single parent"	22.9%	7.0%	14.4%	14.2%
Mean household size (SD)	4.4 (1.3)	4.4 (1.0)	4.3 (1.4)	4.4 (1.2)
Other child in family with same condition	4.3%	10.5%	5.2%	6.7%
Yearly household income [‡] ($p = .002$)				
Under \$20,000	26.2%	11.3%	9.5%	14.7%
\$20,001–\$40,000	27.9%	15.0%	19.1%	20.0%
\$40,001–\$60,000	16.4%	31.3%	17.9%	22.2%
\$60,001–\$80,000	11.5%	18.8%	17.9%	16.4%
Over \$80,000	18.0%	23.8%	35.7%	26.7%
Median income level category ($p = .032$) [§]	\$35,001–40,000	\$50,001–55,000	\$60,001–65,000	\$50,001–55,000

^{*} Pearson χ^2 test.

[†] F-test for difference in means.

[‡] Kruskal-Wallis test.

[§] χ^2 for difference in median.

TABLE 2

Type of Cleft and Treatment Issues by State

	Arkansas (n=70)	Iowa (n=86)	New York (n=97)	Total (N=253)
Type of oral cleft				
Cleft lip	20.0%	31.4%	25.8%	26.1%
Cleft palate	34.3%	27.9%	30.9%	30.8%
Cleft lip + cleft palate	45.7%	40.7%	43.3%	43.1%
Severity of oral cleft (mother's rating)				
Not very severe	33.3%	38.1%	34.0%	35.2%
Somewhat severe	11.6%	11.9%	14.9%	13.0%
Moderately severe	34.8%	36.9%	33.0%	34.8%
Very severe	20.3%	13.1%	18.1%	17.0%
Number of cleft-related surgeries [*] ($p = .029$)				
1	41.2%	51.2%	48.4%	47.4%
2	20.6%	31.0%	32.6%	28.7%
3	23.5%	15.5%	12.6%	16.6%
4 or more	14.7%	2.4%	6.3%	7.3%
Unmet need for surgery last 12 months	4.3%	2.3%	2.1%	2.8%
Planning more cleft-related surgery in the future	47.8%	57.8%	61.5%	56.4%

^{*} Pearson χ^2 test.

TABLE 3**Child's Overall Health Status by State**

	Arkansas (n=70)	Iowa (n=86)	New York (n=97)	Total (N=253)
General health rating (by mother)				
Excellent	62.9%	65.1%	58.8%	62.1%
Very good	22.9%	24.4%	29.9%	26.1%
Good	10.0%	7.0%	5.2%	7.1%
Fair or poor	4.3%	3.5%	6.2%	4.7%
Meets screening criteria for special health care needs (CSHCN) [*]				
(<i>p</i> = .024)	65.7%	44.2%	50.5%	52.6%
CSHCN screener components [†]				
Uses or needs prescription medication	25.7%	15.1%	19.6%	19.8%
Uses or needs more services than others	41.4%	30.2%	29.9%	33.2%
Has functional limitations	12.9%	9.3%	11.3%	11.1%
Uses or needs specialized therapy [*] (<i>p</i> = .030)	42.9%	25.6%	42.3%	36.8%
Has mental health problem requiring treatment [*] (<i>p</i> = .002)	15.7%	2.3%	4.1%	6.7%

^{*} Pearson χ^2 test.

[†] Columns do not add to 100% because children can qualify as having an SHCN in more than one category.

TABLE 4

Selected Outcomes of Cleft Care by State

	Arkansas (n=70)	Iowa (n=86)	New York (n=97)	Total (N=253)
How happy is mother with child's facial appearance?				
Not at all happy	0.0%	3.5%	1.0%	1.6%
Somewhat happy	1.5%	2.3%	3.1%	2.4%
Moderately happy	14.7%	7.0%	14.6%	12.0%
Very happy	83.8%	87.2%	81.3%	84.0%
Speech outcome scale, mean (SD)	78.9 (22.5)	80.3 (20.2)	80.3 (19.5)	79.9 (20.5)
Mother's rating of all child's cleft-related care *				
0-7	7.1%	8.1%	18.8%	11.9%
8-9	32.9%	50.0%	33.3%	38.9%
10	60.0%	41.9%	47.9%	49.2%

* Kruskal-Wallis $\chi^2(2) = 5.02$; $p = .081$.

TABLE 5

Ordinary Least Squares Regression, Variables Associated With Speech Score, Ages 3 Through 7^{*†}

Parameter	Coefficient (SE)	p
State		
Iowa (0–1; Ref: New York)	–0.404 (0.268)	.133
Arkansas (0–1; Ref: New York)	–0.334 (0.275)	.227
Oral cleft type		
Cleft lip only (0–1; Ref: CLP)	0.411 (0.282)	.146
Cleft palate only (0–1; Ref: CLP)	–0.429 (0.261)	.102
Child age, y (3–7)	0.178 (0.083)	.033
Child meets special health care need screening criteria (0–1)	–0.610 (0.264)	.022
Delay in emotional development (0–1)	–0.811 (0.384)	.036
Received speech therapy in last 12 months (0–1)	–1.366 (0.266)	.000
Preventive care visit with personal doctor in last 12 months (0–1)	–0.648 (0.350)	.066
Constant	3.33	
Observations	207	
R ² (adjusted)	0.342	
F(9, 197)	12.89	
Probability >F	0.000	

* The 0–100 speech score was transformed using the formula $\ln[(\text{score} - 1)/100 - (\text{score} - 1)]$, resulting in a scale ranging from (–1.45) to (+4.59). The regression coefficient is interpreted as the change in the logit-transformed score associated with a unit change in the independent variable.

† Covariates in full model were state, cleft type, child's age, sex and race, mother's age, race, marital status, and whether she had a college degree. Independent variables included hearing loss, developmental delays, having received speech therapy within the last year, and having made a preventive visit over the last year.

TABLE 6

Logistic Regression, Variables Associated With Esthetic Outcome—Mother's Satisfaction With Child's Facial Appearance^{*,†‡}

Parameter	Odds Ratio [†] (SE)	p
State		
Iowa (0–1; Ref: New York)	1.610 (0.703)	.275
Arkansas (0–1; Ref: New York)	1.368 (0.620)	.489
Oral cleft type		
CL (0–1; Ref: CLP)	1.668 (0.719)	.235
CP (0–1; Ref: CLP)	4.419 (2.381)	.006
Problem with peer interactions due to delays (0–1)	0.205 (0.102)	.001
Three or more children in the household (0–1)	3.095 (1.439)	.015
Observations	248	
Likelihood ratio χ^2 (6)	24.42	
Probability > χ^2	0.000	

* 1 = Very happy with child's facial appearance, 0 = "moderately happy" to "not very happy" with child's facial appearance.

† Covariates in initial model included state, cleft type, child's age, sex and race, mother's age, race, marital status, and whether she had a college degree. Independent variables included delay in social development, unmet need for dental care, satisfaction with information and support at diagnosis, three or more children in the family, a sibling with an oral cleft, child enrolled in Medicaid or SCHIP, need for medical specialist in last 12 months, number of ambulatory visits in last 12 months.

‡ Factor change in the odds of "very happy" associated with a unit increase in x . For example, the odds of a mother being very happy with the child's appearance are more than three times higher among those with three or more children at home than among those with one or two children, holding other variables constant.

TABLE 7

Ordinal Logistic Regression, Variables Associated With Mother's Overall Rating of Cleft Care^{*,†,‡,§}

Parameter	Odds Ratio ^{†‡} (SE)	p
State		
Iowa (0–1; Ref: New York)	0.961 (0.299)	.897
Arkansas (0–1; Ref: New York)	1.912 (0.685)	.071
Oral cleft type		
CL (0–1; Ref: CLP)	0.977 (0.331)	.945
CP (0–1; Ref: CLP)	0.517 (0.168)	.042
Mother has college degree or more education (0–1)	0.506 (0.141)	.014
Information and support at diagnosis score (0–100)	1.034 (0.005)	.000
Child had complications with a cleft-related surgery (0–1)	0.305 (0.142)	.011
Mother worried about paying for <u>non</u> cleft-related care (0–1)	2.671 (0.876)	.003
Mother “very happy” with child’s facial appearance (0–1)	5.003 (1.856)	.000
Observations	241	
Likelihood ratio χ^2 (9)	79.99	
Probability $>\chi^2$	0.000	

* 0–10 overall rating recoded to (0 – 7 = 1) (8 – 9 = 2) (10 = 3).

† Covariates in initial model were state, cleft type, child’s age, sex and race, mother’s age, race, current marital status, and whether she had a college degree. Independent variables included mother’s rating of severity of the child’s cleft, having special health care needs, chronic physical condition, delays in emotional and cognitive development, satisfaction with support and information at diagnosis, speech score, rating of insurance coverage for cleft-related health care, worry about paying for the child’s cleft-related and other health care, and satisfaction with child’s facial appearance.

‡ Factor change in the odds of a higher versus a lower value of y associated with a unit increase in x . For example, the odds of a higher care rating are 0.506 times smaller for mothers with a college degree than for those with less than a college degree. The odds of a higher versus a lower care rating are five times higher for mothers who are very happy with their child’s appearance than for those who are less than very happy.

§ Brant test indicated that the model did not violate the proportional odds assumption.