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Type of Oral Cleft and Mothers' Perceptions of Care, Health Status, and Outcomes for Preadolescent Children

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Abstract

Objective—To evaluate the outcomes of care for children by type of oral cleft.

Design—Data were collected through structured telephone interviews during 2003 in Iowa with mothers of 2- to 12-year-old children with oral clefts. Interviews with mothers of children with clubfoot and statewide data on Iowa children were used for comparison.

Participants—Participants included mothers of children in Iowa born between 1990 and 2000 with nonsyndromic oral clefts. Children were identified by the statewide Iowa Registry for Congenital and Inherited Disorders.

Main Outcome Measures—Rating of cleft care, severity of condition, health status, esthetic outcome, speech, and school performance were evaluated by type of oral cleft.

Results—Children with cleft lip and palate were most likely to have their clefts rated as very severe. Children with palatal involvement were reported to have a lower health status and were almost twice as likely to be identified as having a special health care need compared with either children with cleft lip or children statewide. Children with cleft lip had more esthetic concerns; children with palatal involvement had the most speech concerns.

Conclusions—Although mothers generally believed their children had received high-quality care, ratings of the children's current health status and outcomes of care varied significantly by type of cleft (cleft lip, cleft palate, and cleft lip and palate). Differences observed in this population-based study support the proposition that cleft type should be considered when examining outcomes of care for children with oral clefts.

Keywords

health status; oral clefts; outcomes

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It is generally accepted that in northern European populations the distribution of cases of cleft lip (CL), cleft lip and palate (CLP), and cleft palate (CP) is about 1:2:1 (Fogh-Anderson, 2002). Nonsyndromic oral clefts (OCs) represent 70% to 80% of all OCs (Milerad et al., 1997; Stoll et al., 2000). The remaining OCs occur in children who present with any of more than 400 different syndromes (e.g., Van der Woude syndrome), with the percentage of syndrome-related clefts being higher for children with CP than for children with CLP (NCBI, 2006). The causes of syndromes include single gene disorders, chromosome anomalies, teratogens, infection, and unrecognized effects, and a gradient of birth prevalence is seen highest with Asians, intermediate with Europeans, and lowest with Africans (Murray, 2002). For the OCs that present as nonsyndromic, there can be other significant health problems. Fifty percent of children with nonsyndromic OCs have been found to have other anomalies that are minor, prematurity related, or nonstructural (Wyszynski, 2002).

The distribution of the types of clefts found in nonsyndromic children is close to the 1:2:1 ratio (Wyszynski, 2002). Boys are more likely to have CL or CLP (2:1), and girls are more likely to have CP (Wyszynski, 1996). Children with nonsyndromic clefts are at increased risk for mild delays in some developmental areas (Nopoulos et al., 2002, 2005) and learning disabilities (Broder et al., 1998). They also have a lifetime risk for increased mortality across all causes, with suicide as a specific risk (Christensen et al., 2004).

Although many studies have evaluated various aspects of the health status and clinical and social outcomes for children with OCs, few population-based studies evaluating these issues have been conducted with a preadolescent population. Also, few studies have examined the potential relationships among these outcomes and cleft type in children with nonsyndromic clefts.

This study presents results from a population-based survey conducted in Iowa during a 10-year period with mothers of 2- to 12-year-old children who were born with nonsyndromic OCs. The primary research question for these analyses was whether children with different types of OCs (i.e., CL, CP, or CLP) experience differences in cleft care, health status, and clinical and social outcomes.

Methods

Ascertainment of children delivered with OCs in Iowa between January 1, 1990, and December 31, 2000, was conducted by the Iowa Registry for Congenital and Inherited Disorders (IRCID). The IRCID conducts active, population-based surveillance of pregnancy outcomes (elective terminations, stillbirths, and live births) diagnosed with birth defects among Iowa residents. For this project, live births with OCs diagnosed within the first year of life were identified, and medical records of these patients were reviewed by trained IRCID staff to identify live births diagnosed with nonsyndromic OCs. Nonsyndromic clefts included those with no evidence of additional noncleft structural birth defects, recognized etiology, or evidence of significant mental retardation. Cases are reviewed by a clinical geneticist, who in most instances also obtains physical exams and family histories. Records of patients with nonsyndromic OCs were then matched to State of Iowa death certificate data to identify the current vital status of these patients and to exclude from study those patients who were deceased.

For each living patient diagnosed with a nonsyndromic OC, an extensive search of available local, Internet, and commercial databases was conducted to find a current name, address, and telephone number of the patient's birth mother. Mothers who currently did not have custody of the patient (e.g., child was placed for adoption, child was in foster care, or mother was incarcerated) were excluded from the study. For the remaining eligible patients, the IRCID staff contacted a local physician of each patient (generally a pediatrician or family practitioner)

to inform the physician of our desire to contact the patient for study and subsequently the birth mother of the patient to invite her to participate in the study and to provide signed informed consent to have her contact information, including telephone number, released to the study interview team. Previous studies have indicated that the mother is overwhelmingly the person in the family with the most knowledge about a child's health. The University of Iowa Institutional Review Board approved all correspondence, consent forms, and study instruments.

Once signed informed consent was received, a 20-minute telephone interview was then conducted with the mother that included questions about the type and severity of the child's cleft, location and type of cleft care received thus far, access to care, health status, clinical outcomes (e.g., satisfaction with esthetics and speech), and social outcomes (e.g., school performance, parenting stress). The 15-question "Children With Special Health Care Needs" (CSHCN) screening instrument, the approach accepted by the U.S. Bureau of Maternal and Child Health for identifying children with special health care needs in a survey, was included in the interview (Bethell et al., 2002). A child is categorized as having a special health care need if he or she has a health condition that has lasted or is expected to last at least 12 months and has resulted in the child (1) needing or using prescription medication, (2) needing or using more services compared with other children, (3) having functional limitations, (4) needing or using specialized therapy, or (5) having a mental health problem requiring treatment for a health condition that has lasted or is expected to last for 12 months. Interviews were conducted between March and August 2003. Thus, children of all potential participants were between the ages of 2 and 12 years at the time of the survey.

The IRCID identified 937 children as having been born with OCs in Iowa between 1991 and 2000. A total of 482 children were excluded from the study for either not having OCs (e.g., submucous cleft, bifid uvula), having been diagnosed as syndromic, having moved out of state, being deceased, or not living with the birth mother. Of the remaining 455 children, 129 were unlocatable, whereas some phone or address information was found for 81 children but the families could not be contacted by phone. Of the 245 located families, 181 consented to participate in the study and 64 refused. A total of 151 mothers actually completed interviews; participation rates were 62% of the locatable families and 83% of the consenting families. Nonresponse analyses could not be completed because the IRCID was not able to release information to the researchers about families not willing to participate in the study and did not have current demographic characteristics for these families.

Data from interviews with mothers of children with idiopathic clubfoot (CF) were used as a comparison group in this study. Idiopathic CF was chosen as a comparison condition because its treatment requires multiple procedures early in life (as with CL, CP, and CLP) but it does not affect facial esthetics and speech. The population of children with CF was all children seen by the Department of Orthopedics at the University of Iowa Hospitals and Clinics between 1991 and 2000 who were between the ages of 2 and 12 years at the time of the interview. An expert chart review was conducted to ascertain that the final sample consisted only of children with idiopathic CF. A similar survey instrument and data collection process was used to collect information from the mothers of children with CF as was used in the survey of children with OCs. The response rate was 83% (85 of 103 identified in the hospital records).

In addition, statewide norms are available for some of the survey items. The Iowa Child and Family Household Health Survey, a statewide study of the health and well-being of children in Iowa conducted in 2000, obtained the statewide norms derived from the responses of 1041 Iowa children between the ages of 2 and 12 years. Specific information about the methodology used in that study can be found at <http://ppc.uiowa.edu/health/iowachild2000/index.html>.

Descriptive comparisons of results for children with CL, CP, and CLP were conducted, as were comparisons with the control group of children with CF and statewide norms, where available. Tests of statistical significance among children with CL, CP, and CLP (and children with CF, when appropriate) were conducted with chi-square tests for categorical data, Kruskal-Wallis tests for ordinal data, and *F*-tests for continuous data as indicated in the notes of Tables 1 through 7.

Results

A description of the children with OCs in Iowa is presented in Table 1. Although there was some variation, there were no statistically significant differences in the age of the children by type of cleft. Children with CP were least likely to be Caucasian, though the population was still overwhelmingly white and more likely to live in smaller households. Children with all types of OCs lived in households with incomes higher than those in all statewide households of families with 2- to 12-year-old children. Children with CL were in families with the highest income.

Cleft Care and Severity of Cleft

Mothers of children with CLP were most likely to report that their children were being treated by an organized cleft team, defined in the question as a team made up of at least a surgeon, a dental professional, and a speech professional (Table 2). Children with CLP also had the most surgeries and were most likely to have additional surgeries. The three groups did not differ in terms of their satisfaction with cleft-related care, with 80% to 90% of mothers rating their children's care as excellent or very good.

Mothers were asked to rate the severity of their children's OCs or CF as compared with other children with the same condition (Table 3). Children with CLP were the most likely to have the condition of their cleft rated as moderately severe or very severe (29% very severe). However, mothers of children with CF were significantly more likely to rate their children's CF conditions as very severe in comparison with other children with CF (42% very severe) than were mothers of children with any type of OC.

Child's Health Status

The overall health status of the child was determined in two ways: (1) using a standard global health scale (excellent to poor) and (2) using the CSHCN screening instrument (Table 4). Children with CL were rated in better health than were children with CP or CLP and, along with children with CF, were rated in better health than were children statewide. Children with CP and CLP were rated in significantly lower health than were children statewide. When the CSHCN screening instrument was used, children with CL and CF were least likely to be defined as having a special health care need; however, children with all types of OCs were more likely to be defined as having a special health care need than were children statewide. Children with CP and CLP were most likely to meet the definition of having a special health care need because of (1) needing more services compared with other children their age, (2) needing or using specialized therapy, and (3) requiring mental health services. Children with CP were most likely to have functional limitations and have mental health problems requiring treatment.

Two clinically related outcomes were evaluated from the mothers' perspective: esthetics (Table 5) and speech (Table 6). Mothers of children with OCs that involved the lip had more esthetic concerns than those whose children had only CP (Table 5). Maternal ratings of their own satisfaction with their children's facial appearance were higher than their perceptions of their children's satisfaction with the facial esthetic outcomes. Satisfaction with the posttreatment

appearance of feet for children with CF was generally lower as compared with the satisfaction with the facial appearance of children with OCs.

Mothers' perceptions of children's speech outcomes are presented in Table 6. Over half (56%) of all children with OCs were perceived to be frustrated because of problems with being understood. In general, however, children with CL were least likely to have speech difficulties. Children with CP were most likely to avoid talking because of problems with being understood; however, children with CLP were slightly more likely than children with CP to have trouble with being understood.

Social Outcomes–School Performance

The mothers' perspectives on different aspects of their children's school performance are shown in Table 7. According to the school engagement scale from the National Survey of American Families (NSAF) (Macomber and Moore, 1999), children with CP were rated by their mothers as significantly more likely to be highly engaged in school than were children in any of the other cleft groups or all children in Iowa. Regarding the type of cleft, there were no statistically significant differences in children's educational aspirations, school performance ratings, and rates of extracurricular activities. All study groups were less likely to participate in extracurricular activities than were children statewide; however, this difference was not statistically significantly different at the $p < .05$ level.

Discussion

This study presents one of the few population-based studies of the health status and clinical and social outcomes for children with OCs. Because the results pertain to 2- to 12-year-olds, these are shorter-term results following the complete treatment for some children and partial treatment for others. As one of the few studies comparing children by type of cleft, these analyses provide documentation for some findings that may be considered intuitive by those in the field while raising issues in other areas.

For example, children with CLP received the most surgeries and were most likely to have their clefts rated as severe and to be treated by an organized cleft team. Also, as might be expected, children with CL were rated in the best overall health of all children and were less likely to be considered to have a special health care need than were children with CP or CLP. The quality of the care for children with all types of OCs was considered excellent or very good by nearly 90% of all mothers, with little unmet need for surgical care.

What might not be expected is that about 50% of children with CP and CLP were identified as having a special health care need, even though all were categorized as having nonsyndromic OCs by the IRCID. Many of these children were categorized as having a special health care need because of a greater need for services and/or because of mental health problems or a need for specialized therapy. This is consistent with what is known about the CP population and reflects the expected interaction between the oral-structural deficit caused by a palatal cleft and the speech learning process during the first years of life. Children with clefts may not have their palatal clefts repaired until well after the speech learning process has begun. Palatal clefts are commonly repaired at age 12 to 18 months or later. Prespeech babbling, necessary for the development of normal speech sounds, usually begins at 6 to 9 months. It is not surprising that there is a greater need for speech therapy in the CP population than in the noncleft population.

According to the NSAF school engagement scale, children with CP were reported to be most engaged in school, and mothers of children with CP also had the highest educational aspirations for their children. The school performance of children with CLP was rated the highest, and

they were most likely to participate in extracurricular activities, yet children with all three types of OCs were less likely to participate than were children statewide.

By definition, the use of maternal interviews for this data collection means that these results are the mothers' perceptions, which is one important yet specific outcome of cleft care. The relativity of comparisons one receives from maternal interviews is evident by the fact that the severity of the CF condition for children in the control group was more likely to be rated very severe (42%) as compared with children with any type of OCs. Furthermore, satisfaction with the posttreatment appearance of feet for children with CF was generally lower than the satisfaction of the esthetics for children with OCs (even though some children with OCs are still in treatment and may need secondary lip repair in the future). Mothers were also more likely to believe that they themselves were more pleased with the esthetic outcome of the cleft care than were their children. Mothers thought that speech was more of an issue for a cleft involving the palate; however, over half (56%) of all children with OCs were perceived to be frustrated because of problems being understood, including more than one in five children with an isolated CL.

As with all studies, the results should be generalized and interpreted carefully. As mentioned, maternal interviews were used and may provide different information than would have been obtained from other data sources such as chart reviews, clinical evaluations, or administrative data. For this study, a difference could have occurred because the maternal identification was used to classify the type of cleft (i.e., CL, CLP, CP). Chart reviews might classify some children differently. These analyses are also descriptive and do not control for demographic characteristics as might be done in multivariate analyses; however, because type of cleft was of most interest and the demographic characteristics of the children in the three groups were very similar, these analyses were deemed appropriate.

In summary, this is one of the few population-based studies of children with OCs that focuses on differences in health status and other outcomes by type of cleft. Children with CL were generally considered to have a less severe condition and fewer speech problems but more esthetic concerns. A cleft team treated about two thirds of children, with the overall quality of care considered positive. Future studies will focus on psychosocial and quality-of-life issues as well as any differences in the care provided by cleft teams.

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TABLE 1

Demographics by Type of Cleft With Clubfoot Comparison and Statewide

Variable	Cleft Lip (n = 41)	Cleft Palate (n = 43)	Cleft Lip and Palate (n = 67)	Clubfoot (n = 85)	Statewide
Child age group in years					
2 to 4	29.3%	39.5%	35.8%	24.7%	30.9%
5 to 7	29.3%	18.6%	26.9%	29.4%	23.9%
8 to 12	41.5%	41.9%	37.3%	45.9%	45.2%
Mean age in years (SD)	6.9 (3.0)	6.1 (3.1)	6.4 (3.2)	7.0 (3.0)	6.9 (3.2)
Girl	41.5%	41.9%	37.3%	24.7%	48.4%
Child Hispanic/Latino(a) ancestry	2.4%	9.3%	9.0%	1.2%	3.9%
Child Caucasian*	100%	97.7%	92.5%	100.0%	91.8%
Mother's marital status					
Married	82.9%	74.4%	76.1%	90.5%	80.6%
In marriage-like relationship	14.6%	16.3%	11.9%	3.6%	6.7%
Divorced, widowed, separated	2.4%	4.7%	9.0%	4.8%	8.8%
Never married	0.0%	4.7%	3.0%	1.2%	4.0%
Mean number in household (SD)	4.6 (1.1)	4.6 (1.2)	4.1 (1.0)	4.6 (1.2)	4.6 (1.3)
Other child in family with same condition***	2.4%	2.3%	11.9%	3.7%	NA [†]
Yearly household income					
Under \$10,000	2.7%	2.4%	7.9%	2.7%	8.2%
\$10,000 to \$20,000	5.4%	14.6%	9.5%	1.4%	8.5%
\$20,000 to \$35,000	5.4%	14.6%	7.9%	16.4%	17.7%
\$35,000 to \$50,000	13.5%	22.0%	31.8%	17.8%	26.8%
\$50,000 to \$75,000	37.8%	22.0%	20.6%	31.5%	23.4%
Over \$75,000	35.1%	24.4%	22.2%	30.1%	15.3%
Median income level category	\$50,000 to \$75,000	\$35,000 to \$50,000	\$35,000 to \$50,000	\$50,000 to \$75,000	\$35,000 to \$50,000

[†] NA = not applicable.

* Pearson chi-square test, $p = .02$.

** F -test for difference in means, $p = .04$.

*** Pearson chi-square test, $p = .063$.

**** Kruskal-Wallis tests were used to compare among the five groups, $p = .04$.

TABLE 2
Treatment for Cleft Lip, Cleft Palate, and Cleft Lip and Palate

	Cleft Lip (n = 41)	Cleft Palate (n = 43)	Cleft Lip and Palate (n = 67)	Total
Cared for by cleft team *	63.4%	58.1%	86.6%	72.2%
Mean no. of surgeries (SD) **	1.4 (0.7)	1.3 (0.7)	3.3 (1.6)	2.2 (1.5)
Range	1 to 4	1 to 4	1 to 8	1 to 8
Unmet need for surgery in past 12 months ***	2.4%	0%	0%	0.7%
Planning more surgery ****	53.7%	9.3%	83.6%	54.3%
Rating of all oral cleft-related care				
Excellent	82.9%	62.8%	71.6%	72.2%
Very good	9.8%	20.9%	17.9%	16.6%
Good	7.3%	9.3%	10.5%	9.3%
Fair or poor	0.0%	7.0%	0.0%	2.0%

* Pearson chi-square test, $p = .006$.

** F -test for difference in means.

*** $p = .000$.

**** Kruskal-Wallis test, $p = .108$.

TABLE 3

Mothers' Rating of Severity of Cleft and Clubfoot*

	% Cleft Lip (n = 41)	% Cleft Palate (n = 43)	% Cleft Lip and Palate (n = 67)	Clubfoot (n = 85)
Not very severe	52.5	33.3	13.6	3.9
Somewhat severe	20.0	16.7	19.7	12.8
Moderately severe	27.5	41.7	37.9	41.0
Very severe	0.0	8.3	28.8	42.3
Total number	40	36	66	78

* Kruskal-Wallis test across the four groups, $p = .0001$.

Children's Overall Health Status

TABLE 4

Variable	% Cleft Lip (n = 41)	% Cleft Palate (n = 43)	% Cleft Lip and Palate (n = 67)	% Clubfoot (n = 85)	% Statewide [†]
General health rating (by mother) *					
Excellent	75.6	46.9	59.7	72.0	67.7
Very good	19.5	30.2	31.3	24.4	24.2
Good	2.4	23.3	9.0	4.7	7.1
Fair or poor	2.4	0.0	0.0	0.0	1.1
Percentage with special health care needs **	22.0	51.2	49.3	20.7	16.4
CSHCN screener components [‡]					
Needs/uses prescription medication **	14.6	20.9	16.4	9.8	11.7
Needs/uses more services than others	12.2	39.5	34.3	8.5	6.9
Has functional limitations **	2.4	14.0	7.5	6.1	2.8
Needs or uses specialized therapy **	2.4	23.3	29.9	7.3	2.6
Mental health problem requiring treatment	2.4	16.3	13.4	8.5	4.4

[†] Statewide percentages are shown for descriptive comparison.
[‡] Columns may not add to 100% because children can qualify as having a special health care need in more than one category.
* Kruskal-Wallis test across the four groups.
** Pearson chi-square test, $p = .000$.

TABLE 5

Mothers' Perspective on Esthetic Outcomes

	% Cleft Lip (n = 41)	% Cleft Palate (n = 43)	% Cleft Lip and Palate (n = 67)	% Clubfoot (n = 85) [†]
How often is child unhappy with facial appearance (appearance of foot)? [*]				
Never	60.5	100.0	51.7	74.0
Sometimes	39.5	0.0	36.7	22.1
Usually	0.0	0.0	6.7	3.9
Always	0.0	0.0	5.0	0.0
How happy is child with facial appearance (appearance of foot)? ^{**}				
Not at all	0.0	0.0	5.3	1.5
Somewhat	7.9	0.0	12.3	14.5
Moderately	21.1	10.0	28.1	26.1
Very	71.1	90.0	54.4	58.0
How happy is mother with child's facial appearance (appearance of child's foot)? [*]				
Not at all	0.0	0.0	0.0	2.4
Somewhat	2.4	2.3	7.5	11.0
Moderately	14.6	0.0	14.9	25.6
Very	82.9	97.7	77.6	61.0

[†] Question concerned the esthetic appearance of child's foot posttreatment.

^{*} Kruskal-Wallis test across the four groups, $p = .001$.

^{**} Kruskal-Wallis test across the four groups, $p = .0007$.

TABLE 6

Mothers' Perspective on Speech Outcomes

How Often Does Child ... [†]	% Cleft Lip (n = 41)	% Cleft Palate (n = 43)	% Cleft Lip and Palate (n = 67)	% Total
Appear frustrated because of problems with being understood? [*]				
Never	75.6	45.2	50.0	55.7
Sometimes	22.0	40.5	39.4	34.9
Usually	0	7.1	7.6	5.4
Always	2.4	7.1	3.0	4.0
Avoid talking because of problems with being understood? ^{**}				
Never	95.1	76.7	83.3	84.7
Sometimes	4.9	18.6	12.1	12.0
Usually	0	0	4.6	2.0
Always	0	4.7	0	1.3
Have difficulty with being understood by people who see him or her every day? ^{***}				
Never	78.1	58.1	53.9	61.7
Sometimes	19.5	37.2	38.5	32.9
Usually	2.4	4.7	7.7	5.4
Always	0.0	0.0	0.0	0.0
Have difficulty with being understood by people who do not see him or her often? ^{****}				
Never	70.7	39.5	34.9	46.0
Sometimes	22.0	44.2	45.5	38.7
Usually	7.3	11.6	10.6	10.0
Always	0.0	4.7	9.1	5.3
Have difficulty with being understood overall? ^{*****}				
Never	75.6	41.9	34.9	48.0
Sometimes	22.0	51.2	51.5	43.3
Usually	2.4	7.0	13.6	8.7
Always	0.0	0.0	0.0	0.0
Total number	41	43	66	150

[†]Kruskal-Wallis test across the three groups.

*
 $p = .007$.

**
 $p = .058$.

 $p = .036$.

 $p = .001$.

 $p = .000$.

TABLE 7

Children's School Performance

	% Cleft Lip (n = 41)	% Cleft Palate (n = 43)	% Cleft Lip and Palate (n = 67)	% Clubfoot (n = 85)	% Statewide [†]
School engagement scale [*]					
Low engagement	17.1	4.7	7.5	13.4	12.1
Medium engagement	26.8	18.6	26.9	39.0	47.6
High engagement	56.1	76.7	65.7	47.6	40.4
Parent rating of school performance					
Excellent	32.1	40.0	46.3	29.3	36.3
Very good	39.3	28.0	24.4	31.0	36.3
Good	25.0	16.0	24.4	27.6	20.1
Fair	0.0	12.0	4.9	10.3	5.6
Poor	3.6	4.0	0.0	1.7	1.8
How far parent would like to see child go in school					
No high school diploma	0.0	0.0	0.0	0.0	0.1
Get high school diploma	0.0	8.0	7.3	7.0	5.4
Graduate technical school	0.0	0.0	0.0	1.8	0.6
Two-year college degree	10.7	4.0	9.8	1.8	4.5
Attend four-year college	14.3	16.0	2.4	8.8	10.3
Four-year college degree	60.7	44.0	61.0	54.4	62.5
More than four-year degree	14.3	28.0	19.5	24.6	16.7
Child participates in extracurricular activities (e.g., band, scouts, chorus, lessons, sports, church group)					
	69.4	60.0	70.6	60.6	80.6

[†] Statewide percentages are shown for descriptive comparison.

^{*} Kruskal-Wallis test across the four groups, $p = .0091$.