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Prenatal Diagnosis of Orofacial Clefts: Association With Maternal Satisfaction, Team Care, and Treatment Outcomes

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Abstract

Objective—Prenatal diagnosis of an orofacial cleft is thought to allow mothers greater opportunity to become prepared for the special needs of an infant with a cleft and plan for the care of their child. Using a population-based sample, we determined which children were more likely to be diagnosed prenatally, and whether early diagnosis was associated with maternal satisfaction and treatment outcomes.

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Design—Interviews were completed with 235 (49% of eligible) mothers of children ages 2 to 7 with orofacial clefts initially enrolled in the National Birth Defects Prevention Study from the Arkansas, Iowa, and New York sites. Maternal satisfaction with information, support, and treatment outcomes was compared between women who received a prenatal diagnosis and those who did not.

Results—Of 235 infants with clefts, 46 (19.6%) were identified prenatally. One third of mothers were somewhat or not satisfied with information provided by medical staff. Satisfaction did not vary by timing of the diagnosis. Infants diagnosed prenatally were no more likely to have received care provided by a recognized multidisciplinary cleft team (76%) than were infants diagnosed at birth (78%). Speech problems and facial appearance as rated by the mother did not vary by timing of the diagnosis.

Conclusions—Timing of the cleft diagnosis did not alter maternal satisfaction with information, whether care was provided by a designated cleft team, or maternal perception of facial appearance or speech. Further research should determine whether prenatal diagnoses alter maternal anxiety or influence postnatal morbidity.

Keywords

aesthetics; NBDPS; team care; ultrasound

Twenty percent to 30% of pregnancies affected by an orofacial cleft are diagnosed prenatally, usually in the context of a routine ultrasound (Jones, 2002; Klein et al., 2006; Suresh et al., 2006). Recognition of clefts during ultrasound is limited by lack of attention to the face in the absence of risk factors, position of the fetus, maternal obesity, multiple pregnancies, reduced amniotic fluid, and skill of the sonographer (Klein et al., 2006). Cases of isolated cleft palate may be masked by acoustic shadows of facial bones (Pilu et al., 1986).

Parents often view ultrasound as a way of obtaining a first picture of their baby. Because they are not expecting the identification of a cleft, the moment they are first told of the diagnosis can be emotionally distressing (Strauss et al., 1995). Receiving this information prenatally is thought to allow parents a greater opportunity to adjust to the facial difference and prepare for the needs of the infant. Prenatal detection may allow better preparations for the unique neonatal feeding requirement of infants with clefts, allow early planning for surgical repair including location of a cleft team, and improve overall satisfaction with cleft care. It is not known whether mothers who learn of the orofacial cleft prenatally are more or less satisfied with the information and support they receive from health care personnel or whether they are better able to plan for access to cleft resources.

Using a population-based sample from three birth defect research centers, we determined what proportion of children with clefts are diagnosed prenatally, which children were most likely to be diagnosed prenatally, and whether mothers who learned of the cleft prenatally obtained more information prior to birth and were more satisfied with the information they were able to obtain than mothers who learned of the cleft at birth. We also studied whether children who were identified with a cleft prenatally were more likely to receive care from a

recognized multidisciplinary cleft team and whether a prenatal diagnosis was associated with facial and speech outcomes as perceived by the mother.

Methods

Study Population

Data for this study were obtained through telephone interviews with mothers of children born in Arkansas between January 1, 1999, and December 31, 2002, and mothers of children born in Iowa or New York between January 1, 1998, and December 31, 2003, and diagnosed with one of three types of craniofacial malformations: a nonsyndromic oral cleft (i.e., cleft palate, cleft lip, or cleft lip with cleft palate), craniosynostosis, or microtia based on National Birth Defects Prevention Study (NBDPS) case definitions. Only data on children with orofacial clefts are included in this analysis. The children were aged 2 through 7 years (mean, 4.5 ± 1.6 years) at the time of the interview. Further eligibility criteria included (1) child was currently living in Arkansas, Iowa, or New York with his or her birth mother, (2) child did not have a diagnosis of craniosynostosis or microtia in addition to the orofacial cleft, (3) child did not have bifid uvula only or submucosal cleft palate only, and (4) the birth mother had been interviewed for the NBDPS (with the exception of New York births for 2003). The Arkansas and Iowa sites include children from the entire state. The New York site comprises 15 counties in the Western New York and Mid-Hudson areas of the state.

A total of 582 children were identified in the three states as potentially eligible based on age and cleft diagnosis. Of these, 63 (11%) were determined to be ineligible for one of the following reasons: (1) child was not currently living with biological mother, (2) family moved out of state, or (3) child had a diagnosis of craniosynostosis or microtia in addition to orofacial cleft. Of the remaining 519 cases, mothers of 273 (53%) agreed to participate in the study. A total of 253 interviews were completed: 70 in Arkansas, 86 in Iowa, and 97 in New York for an overall completion rate of 49% of eligible cases.

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, with consultation from nationally recognized experts in the treatment of craniofacial anomalies. Questions included satisfaction with information provided about the condition at diagnosis (prenatally or at delivery), satisfaction with support and encouragement, and how well providers answered questions about the condition. Mothers were asked about the helpfulness of providers in addressing feeding difficulties of the infant. Interview items also addressed perceived severity of the cleft, satisfaction with facial appearance, and residual speech difficulties. Items addressing facial appearance and problems with speech 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 the child was with his or her facial appearance on a scale of 1 (“not very happy”) to 4 (“very happy”) and how happy they were with the child’s facial appearance. Five speech problem items addressed

how often (never, sometimes, usually, or always) the child experienced difficulty being understood when speaking. Mothers also rated their global impression of all the cleft-related care the child had received on a scale of 0 to 10, where 0 indicated “worst care possible” and 10 indicated “best care possible.”

Team care was evaluated by asking whether the child had been treated by “an organized cleft care team made up of at least a surgeon, dental professional, and a speech professional.” Questions also addressed number of cleft-related surgeries and surgical complications.

Prenatal diagnosis of the orofacial cleft was determined in the context of the NBDPS interview conducted with the mother up to the infant’s second birthday. Mothers were asked, “Did you have any ultrasounds which showed any abnormalities with the fetus, placenta, or fluid?” Positive responses were followed by “What was the abnormality?” Responses of “cleft,” “cleft lip,” and “orofacial cleft” were accepted as indications of prenatal diagnoses. Information on number of prior pregnancies and prenatal care also were obtained from the NBDPS interview with mothers.

Human subjects approval for the study protocol, informed consent procedures, and correspondence was received from institutional review boards at the University of Arkansas for Medical Sciences, the University of Iowa, and the New York State Department of Health. Subject recruitment for Arkansas was conducted by research staff at the Arkansas Center for Birth Defects Research and Prevention; whereas, the Iowa Registry for Congenital and Inherited Disorders recruited subjects from both Iowa and New York. Professional research staff at the University of Northern Iowa’s Center for Social and Behavioral Research conducted interviews for the Iowa and New York samples 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, 2006, and November 2, 2006.

Analyses compared responses of women who learned of the cleft prenatally with those of women who learned of the cleft at birth. Differences in satisfaction with facial appearance and residual speech difficulties were stratified by presence or absence of cleft palate.

Results

Of all 235 infants with clefts, 46 (19.6%) were identified by prenatal ultrasound. No infants with cleft palate only were identified prenatally. Excluding infants with cleft palate only, 46 of 162 (28.3%) were identified prenatally. Because cleft palate without accompanying cleft lip was never identified prenatally in this study, the remaining analyses are restricted to only infants with cleft lip or cleft lip and palate.

As shown in Table 1, a somewhat greater proportion of infants from New York than from Arkansas were diagnosed prenatally. Infants of mothers with family incomes greater than $60,000 per year were significantly more likely to have been diagnosed prenatally than were infants of mothers with family incomes less than $60,000. Almost all mothers of infants were white and married. Most mothers had private health insurance. Prenatal diagnosis was not associated with ethnicity, marital status, or type of insurance.

Almost all mothers (99%) reported receiving prenatal care, and two thirds had at least one prior pregnancy. Prenatal care and parity were not associated with the timing of cleft diagnosis. Similarly, timing of the diagnosis did not vary by type or severity of the cleft.

As shown in Table 2, most mothers expressed satisfaction with the information and support received from medical staff after the cleft was diagnosed, although a substantial minority expressed concerns. Satisfaction did not vary by timing of the diagnosis. About a third of mothers were somewhat or not satisfied with the information and encouragement provided by medical staff. Similarly, about one quarter felt that the explanations they received about the cleft and answers to questions about what to expect were only fair or poor. Mothers' ratings of information did not vary by timing of the diagnosis.

Most infants with clefts experienced difficulty feeding, as shown in Table 3. Mothers of infants who were diagnosed prenatally were more likely to rate medical staff as moderately or very helpful in making it easier for the infant to feed than were mothers of infants who were diagnosed at birth.

Team care and outcomes of care by timing of the cleft diagnosis are presented in Table 4. Infants diagnosed prenatally were no more likely to have received care provided by a recognized multidisciplinary cleft team than were infants diagnosed at birth.

The two groups did not differ in number of surgeries, expectations for more surgeries, complications of surgery, or the mother's overall rating of the quality of cleft care. Some differences in aesthetics and residual speech problems were found. Mothers of infants diagnosed prenatally were significantly more likely to report being only moderately or not at all happy with the child's facial appearance at 2 to 7 years of age. When stratified by type of cleft, mothers of infants prenatally diagnosed with cleft lip and palate were significantly (p = .043) less satisfied with the child's appearance (36% moderately or not at all) than were mothers of infants diagnosed at birth (17%). Timing of the diagnosis was not significantly associated with satisfaction with appearance among mothers of infants with cleft lip only (20% moderately or not at all happy among prenatally diagnosed, 13% moderately or not at all happy among diagnosed at birth).

Mothers of infants diagnosed prenatally were somewhat more likely (p = .067) to report that the child had difficulty being understood at 2 to 7 years of age than were mothers of infants diagnosed at birth. When stratified by type of cleft, this relationship was seen more strongly among mothers of infants with cleft lip alone (p = .077) than among mothers of infants with cleft lip and palate (p = .373). On the whole, a greater number of infants with cleft lip and palate (60%) had difficulty being understood at 2 to 7 years than infants with cleft lip alone (29%).

A number of recurring themes were identified in response to the open-ended question "Thinking back to when the child's cleft was first diagnosed, can you think of anything else that would have been helpful for you at that time?" Foremost among these volunteered answers was a wish for more and better information. Mothers wished for more information about feeding challenges, prognosis, access to specialty care, and appropriate timing of surgery. In addition to more information, mothers would have liked more immediate

attention paid to linking them with peer support, a medical staff more knowledgeable about clefts, more sympathetic and supportive staff, and prenatal knowledge about the cleft.

Discussion

Consistent with the literature showing that cleft palate is difficult to detect prenatally (Matthews et al., 1998; Wayne et al., 2002; Rotten and Levaillant, 2004; Russell et al., 2008), no infants with a cleft palate without a cleft lip were identified prenatally in this study. Among all orofacial clefts, including palate only, 20% were identified prenatally. Among only those infants with involvement of the lip, 29% were identified prenatally. Detection rates of 20% to 30% are typical (Wayne et al., 2002; Rotten and Levaillant, 2004), though much higher detection can be achieved with expanded facial views (Wayne et al., 2002).

Most of the mothers in this study were white, married, and covered by private health insurance. Somewhat fewer (though not significantly so) infants were diagnosed prenatally in Arkansas than in New York. Access to prenatal diagnostic ultrasound is known to vary regionally (Gavin et al., 2004). Mothers of infants diagnosed early were significantly more likely to have family incomes greater than $60,000 per year.

This is the first population-based study of the importance of prenatal diagnosis on mothers' satisfaction with information they receive immediately following the discovery of a cleft. Contrary to expectations that a prenatal diagnosis might allow mothers the time to gather more and better information from medical staff about the cleft (Davalbhakta and Hall, 2000; Shaikh et al., 2001; Wayne et al., 2002), no differences were found between the satisfaction and support they reported and the satisfaction and support reported by mothers who learned of the cleft only following childbirth. With one exception, mothers who were prepared for the birth of an infant with an orofacial cleft were no more or less likely to benefit from early information and support from providers. An exception occurred with information about feeding. Mothers whose cleft pregnancies were identified prenatally were significantly more likely to report that providers helped them find ways to make it easier for the infant to feed. These women may have been better prepared to ask for help with feeding.

No evidence was found that women who learned of the cleft prenatally were more likely to receive care from a multidisciplinary cleft care team. Recognized cleft teams are ideally suited to advise and coach parents on the mechanics of feeding, need for special bottles, and early preparation for corrective surgery, speech and language therapy, and dental care (Davalbhakta and Hall, 2000). Despite perhaps greater opportunity to plan for the specialized care of the infant, mothers whose infants were identified prenatally with an orofacial cleft were no more likely to have received care from a cleft team than mothers whose infants were identified at birth.

It is interesting that mothers who learned of the cleft before birth were more likely to recognize speech deficits in their 2- to 7-year-old and were somewhat less happy with the child's current facial appearance. These perceptions were not due to differences in cleft severity or involvement of the palate. In fact, timing of the diagnosis was significantly

associated with mothers' happiness with facial appearance among children with cleft lip alone but not among children with cleft lip and palate. Mothers who are forewarned of a cleft may have higher expectations for surgical repair than mothers who learn of the cleft at birth.

To better understand the value to the mother of information provided following diagnosis, it may be important to consider the context in which information is provided. When clefts are identified prenatally, information about the condition is typically delivered by an obstetrician following a diagnostic ultrasound. This situation allows opportunity for the woman to discuss the implications of the diagnosis with obstetrical, neonatal, pediatric, and surgical staff. In contrast, recognition of the cleft at birth occurs in the context of heightened emotion when there is most likely the expectation of a healthy, perfectly formed newborn. Due to the limited time for staff to explain the cleft and answer questions from the family and due to the immediate demands of the newborn, birth may not be ideal opportunity to inquire about the condition. It is therefore reasonable that knowledge about the cleft obtained prenatally may be more complete and satisfying to the mother than knowledge obtained unexpectedly at birth.

Although the moment of childbirth itself may be an inopportune time to learn details about the cleft, information obtained later from the pediatrician at the birthing center may be of great value to the mother. Pediatricians are likely familiar with the feeding challenges of an infant with a cleft and should be able to inform the mother about progression to surgical repair and the possible need for speech, language, and dental care in the future. It is therefore possible that quality information and support can be available to the mother both following early prenatal diagnosis and after delivery during the childbirth hospital stay.

An important minority of mothers whose infants were diagnosed prenatally and mothers whose infants were diagnosed at birth were dissatisfied with the content and the manner in which information was provided. Consistent with other research (Strauss et al., 1995; Matthews et al., 1998; Byrnes et al., 2003), recurring themes of disappointment included desire for more information, wish for more discussions with other parents of children with clefts, and desire for more knowledgeable and sympathetic medical staff.

This study has addressed only a very limited context in which timing of the diagnosis of an orofacial cleft may be important. Although there were few benefits of prenatal diagnosis on the quality of information received by mothers, advanced knowledge of a cleft birth might be of great value in other areas. Because birth of an infant with a cleft lip or palate may be emotionally distressing to parents, advanced knowledge gained through prenatal diagnosis is thought to allow the family an opportunity to learn about clefts and become prepared for the event. Parents may be counseled about how the immediate needs of their newborn will differ from infants born without an orofacial cleft. Parents will have time to prepare by talking with health care providers, family members, and tapping multiple resources to learn more about orofacial clefts. Informed parents may modify their plans for care of their newborn and infant. Knowing their infant may have increased medical and nutritional needs may lead to changes in parental employment or changes in child care plans. Ideally, prenatal diagnosis would trigger referral to a cleft team who could counsel parents on the causes and effects of

clefts, explain feeding techniques and roles of team members, and discuss planned corrective surgical procedures. Team care was not more common among infants diagnosed prenatally in this study.

Research on the outcomes of prenatal diagnosis conducted with clinic samples has confirmed a number of benefits of early knowledge. In contrast, some question remains as to whether early knowledge of a cleft pregnancy may generate greater maternal anxiety during a presumably joyful period (Matthews et al., 1998; Klein et al., 2006), whether prenatal information is of any value because the problem cannot be corrected prenatally (Matthews et al., 1998), and whether prenatal diagnosis might encourage termination of the pregnancy in the absence of other malformations (Klein et al., 2006). No population-based studies have compared these more detailed preparations and outcomes among mothers forewarned of the cleft birth to preparations and outcomes among mothers who learn of the cleft at delivery (Collett and Speltz, 2006).

This research has identified few advantages to early prenatal diagnosis of orofacial clefts. Expected preparatory information gathering was not found. Further research on population-based samples is required to determine whether infant-related factors such as growth and postnatal infant morbidity or maternal-related factors such as anxiety, postbirth family support, and postbirth career plans are influenced by early knowledge that the infant has a cleft. Research is also needed to help inform counseling policies and procedures (Skari et al., 2006) and to train ultrasound technicians, obstetricians, and pediatricians in the type of information and manner of delivery most beneficial to parents when they learn that their infant has an orofacial cleft.

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References

Byrnes AL, Berk NW, Cooper ME, Marazita ML. Parental evaluation of informing interviews for cleft lip and/or palate. Pediatrics. 2003; 112:308–313. [PubMed: 12897279]

Collett BR, Speltz ML. Social-emotional development of infants and young children with orofacial clefts. Infants Young Child. 2006; 19:262–291.

Davalbhakta A, Hall PN. The impact of antenatal diagnosis on the effectiveness and timing of counselling for cleft lip and palate. Br J Plast Surg. 2000; 53:298–301. [PubMed: 10876253]

Gavin NI, Adams EK, Hartmann KE, Benedict MB, Chireau M. Racial and ethnic disparities in the use of pregnancy-related health care among Medicaid pregnant women. Matern Child Health J. 2004; 8:113–126. [PubMed: 15499869]

Jones MC. Prenatal diagnosis of cleft lip and palate: detection rates, accuracy of ultrasonography, associated anomalies, and strategies for counseling. Cleft Palate Craniofac J. 2002; 39:169–173. [PubMed: 11879073]

Klein T, Pope AW, Getahun E, Thompson J. Mothers' reflections on raising a child with a craniofacial anomaly. Cleft Palate Craniofac J. 2006; 43:590–597. [PubMed: 16986992]

Matthews MS, Cohen M, Viglione M, Brown AS. Prenatal counseling for cleft lip and palate. Plast Reconstr Surg. 1998; 101:1–5. [PubMed: 9427909]

Pilu G, Reece EA, Romero R, Bovicelli L, Hobbins JC. Prenatal diagnosis of craniofacial malformations with ultrasonography. Am J Obstet Gynecol. 1986; 155:45–50. [PubMed: 3524242]

Rotten D, Levaillant JM. Two- and three-dimensional sonographic assessment of the fetal face. 1. A systematic analysis of the normal face. Ultrasound Obstet Gynecol. 2004; 23:224–231. [PubMed: 15027008]

Russell KA, Allen VM, MacDonald ME, Smith K, Dodds L. A population-based evaluation of antenatal diagnosis of orofacial clefts. Cleft Palate Craniofac J. 2008; 45:148–153. [PubMed: 18333649]

Shaikh D, Mercer NS, Sohan K, Kyle P, Soothill P. Prenatal diagnosis of cleft lip and palate. Br J Plast Surg. 2001; 54:288–289. [PubMed: 11355980]

Skari H, Malt UF, Bjornland K, Egeland T, Haugen G, Skreden M, Dalholt BM, Bjornstad OA, Emblem R. Prenatal diagnosis of congenital malformations and parental psychological distress—a prospective longitudinal cohort study. Prenat Diagn. 2006; 26:1001–1009. [PubMed: 16958144]

Strauss RP, Sharp MC, Lorch SC, Kachalia B. Physicians and the communication of “bad news”: parent experiences of being informed of their child’s cleft lip and/or palate. Pediatrics. 1995; 96:82–89. [PubMed: 7596729]

Suresh S, Vijayalakshmi R, Indrani S, Devaki G, Bhavani K. The premaxillary triangle: clue to the diagnosis of cleft lip and palate. J Ultrasound Med. 2006; 25:237–242. [PubMed: 16439788]

Wayne C, Cook K, Sairam S, Hollis B, Thilaganathan B. Sensitivity and accuracy of routine antenatal ultrasound screening for isolated facial clefts. Br J Radiol. 2002; 75:584–589. [PubMed: 12145131]

TABLE 1

Timing of Cleft Diagnosis by Characteristics of Mother and Type and Severity of the Cleft

	Cleft Diagnosis Prenatally (n = 46)*	Cleft Diagnosis at Birth (n = 116)*	p Value
State of residence†			
AR	9 (19.6)	37 (31.9)	.151
IA	17 (37.0)	45 (38.8)	
NY	20 (43.5)	34 (29.3)	
Family income†			
< 20K	5 (11.9)	16 (15.5)	.045
20–40K	4 (9.5)	26 (25.2)	
40–60K	7 (16.7)	25 (24.3)	
60–80K	11 (26.2)	16 (15.5)	
>80K	15 (35.7)	20 (19.4)	
Age, mean (SD)	33.4 (6.4)	32.2 (6.0)	.281
Ethnicity†			
White	41 (93.2)	108 (93.9)	.656
Black	1 (2.3)	5 (4.9)	
Hispanic	1 (2.3)	2 (1.7)	
Asian	0 (0.0)	0 (0.0)	
American Indian	1 (2.3)	0 (0.0)	
Marital status†			
Married or living together	43 (93.5)	101 (87.1)	.242
Unmarried	3 (6.5)	15 (12.9)	
Insurance†			
Public	9 (19.6)	28 (24.1)	.779
Private	33 (71.7)	74 (63.8)	
Uninsured	1 (2.2)	5 (4.3)	
Other	3 (6.5)	9 (7.8)	
Number of prior pregnancies†			
0	15 (32.6)	36 (31.0)	.846
1 or more	31 (67.4)	80 (69.0)	
Prenatal care (first 2 trimesters)†			
Yes	45 (100.0)	107 (99.1)	.517
No	0 (0.0)	1 (1.0)	
Type of cleft†			
Lip	15 (32.6)	46 (39.7)	.404
Lip and palate	31 (67.4)	70 (60.3)	
Severity of cleft†			
Very	9 (13.0)	18 (15.7)	.404
Moderately	13 (28.3)	40 (34.8)	

	Cleft Diagnosis Prenatally (n = 46)*	Cleft Diagnosis at Birth (n = 116)*	p Value
Somewhat	8 (17.4)	15 (13.0)	
Not very	16 (34.8)	42 (36.5)	

*Categories may not sum to total due to missing data.

†Information presented as n (%).

TABLE 2

Support From Medical Staff After Diagnosis of Cleft by Timing of Diagnosis

	Cleft Diagnosis Prenatally (n = 46)	Cleft Diagnosis at Birth (n = 116)	p Value
How well staff explained cleft			
n (% fair or poor)	11 (25.8)	34 (29.6)	.621
n (% good or excellent)	32 (74.2)	81 (70.4)	
Satisfaction with information from staff about cleft			
n (% somewhat or not satisfied)	15 (33.3)	36 (31.0)	.778
n (% moderately or very satisfied)	30 (66.7)	80 (69.0)	
Satisfaction with support or encouragement from staff			
n (% somewhat or not satisfied)	14 (31.1)	23 (20.0)	.134
n (% moderately or very satisfied)	31 (68.9)	92 (80.0)	
How well staff answered questions about what to expect			
n (% fair or poor)	9 (20.4)	27 (23.3)	.703
n (% good or excellent)	35 (79.6)	89 (76.7)	

TABLE 3

Feeding Problems and Help With Feeding Problems by Timing of Cleft Diagnosis

	Cleft Diagnosis Prenatally (n = 46)	Cleft Diagnosis at Birth (n = 116)	p Value
Trouble with feeding because of cleft			
n (% yes)	32 (69.6)	74 (63.8)	.486
n (% no)	14 (30.4)	42 (36.2)	
Helpfulness of staff in finding ways to make it easier for child to eat			
n (% moderately or very)	27 (87.1)	51 (68.9)	.052
n (% somewhat or not)	4 (12.9)	23 (31.1)	

TABLE 4

Team Care and Outcomes of Care by Timing of Cleft Diagnosis*

	Cleft Diagnosis Prenatally (n = 46)	Cleft Diagnosis at Birth (n = 116)	p Value
Team care			
Yes	35 (76.1)	90 (77.6)	.838
No	11 (23.9)	26 (22.4)	
Number of surgeries			
1	13 (28.3)	37 (32.7)	.660
2	17 (37.0)	41 (36.3)	
3	10 (21.7)	27 (23.9)	
4 or more	6 (13.0)	8 (7.1)	
More surgeries planned			
Yes	35 (79.6)	83 (74.1)	.476
No	9 (20.4)	29 (25.9)	
Surgery complications			
Yes	4 (8.7)	8 (7.0)	.715
No	42 (91.3)	106 (93.0)	
Rating of cleft care, low (0) to high (10)			
0–7	6 (13.0)	9 (7.8)	.251
8	11 (23.9)	19 (16.4)	
9	11 (23.9)	23 (19.8)	
10	18 (39.1)	65 (56.0)	
Satisfaction with facial appearance			
Child happy with appearance (not at all to moderately)	9 (28.1)	17 (18.9)	.273
Mother happy with appearance (not at all to moderately)	14 (30.4)	18 (15.5)	.032
Speech problems			
Frustrated when speaks (sometimes, usually, or always)	24 (53.3)	47 (41.2)	.167
Avoids talking (sometimes, usually, or always)	5 (11.1)	19 (16.7)	.378
Difficulty being understood by acquaintances (sometimes, usually, or always)	20 (44.4)	42 (36.8)	.376
Difficulty being understood by nonacquaintances (sometimes, usually, or always)	27 (60.0)	57 (50.0)	.255
Difficulty being understood overall (sometimes, usually, or always)	27 (60.0)	50 (43.9)	.067