



myFace

Transforming Lives: The Impact of Prenatal Diagnostics on Postnatal Care

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Thursday, March 11, 2021

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Welcome and Introductions



Stephanie Paul
Executive Director
myFace



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Presentation



Thomas A. Imahiyerobo, MD, FAAP, FACS
Assistant Professor, Plastic Surgery
Columbia University Irving Medical Center
Director, Cleft and Craniofacial Surgery
Morgan Stanley Children's Hospital
New York, NY



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Aims

- Highlight CL/P Background Information
- Discuss Approach to Prenatal Diagnosis
- Review Key Concepts for Prenatal Counseling
- Emphasize the Impact on Post-Natal Care
- Introduce Concept of Community Building



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Cleft Lip and Palate Background



- Very Common → 1/700 live births
- More common in males and on the left side
- 67% CL/P (46% combined, 21% CL alone)
- 33% CP alone



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Cleft Lip and Palate Background



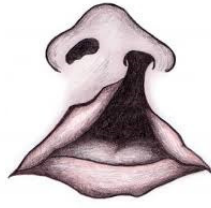
- Majority of Children will have Isolated CL/P
- 29% have additional Congenital Anomalies
- Some Children Will have a Craniofacial Syndrome



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Cleft Lip and Palate Etiology



- Multi-factorial process
- Environmental factors → Phenytonin, ETOH, Accutane, Corticosteroids and Tobacco
- Folic Acid supplementation protective against Cleft Lip
- Isolated Cleft Lip thought to be sporadic



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Cleft Lip Embryology



- Cleft Lip occurs during the 4–5th week of gestation
 - Failure of Fusion of Embryologic Facial Processes
- Cleft Palate occurs during the 6–8th week of gestation
 - Failure of Fusion of the embryologic Maxillary processes



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Prenatal Diagnosis

Thirty Years of Prenatal Cleft Diagnosis: What Have We Learned?

Jordan P. Steinberg, M.D.,
Ph.D.
Arun K. Gosain, M.D.
Chicago, Ill.

Summary: Prenatal ultrasound diagnosis of cleft lip with or without cleft palate has received little attention in the plastic surgery literature despite its initial description more than 30 years ago. With more families presenting in the prenatal period, it is critical for plastic surgeons to understand the techniques in use today for prenatal cleft diagnosis as well as their associated limitations. Moreover, it is incumbent on surgeons to understand the implications of the diagnosis as well as how to appropriately counsel affected families, including how to handle questions pertaining to termination. A comprehensive review was initiated to educate plastic surgeons with respect to these aims. The following points may be inferred: (1) Based on the rates of associated anomalies in low-risk screened populations, as opposed to the high-risk groups in previous reports, prenatally detected clefts do not appear intrinsically different from historically described cohorts; (2) in the absence of structural anomalies, chromosomal anomalies in prenatally detected cleft patients are rare; (3) ultrasound detection rates are highly variable across studies (10 percent to 90 percent); (4) reporting errors range from 10 percent to 60 percent and largely relate to characterization of the secondary palate; (5) accuracy is improving with the adoption of newer technologies, including three-dimensional ultrasound; and (6) prenatal diagnosis enables counseling and a sense of preparedness for the majority of affected families and only rarely results in termination for isolated clefts. (*Plast. Reconstr. Surg.* 136: 550, 2015.)

- Diagnosis Often Made During Anatomy Scan (16–22 wks.)
- Greater than 90% of Clefts can be detected Prenatally
- Detection Affected by: Anatomy, Imaging Modality
- Cleft Lip Easier to see on Ultrasound than Cleft Palate

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Common Prenatal Questions



- How Did the Cleft Occur?
- Why Did the Cleft Occur?
- What Do I do Next?
- What will my Child Look Like?
- How is My Child Going to Eat
- How is My Child Going to Speak
- What Surgeries will my Child Need

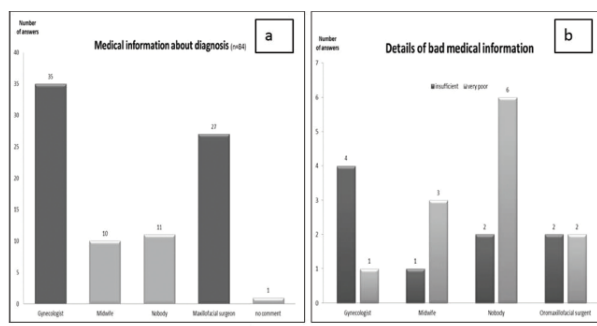
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Information vs Misinformation

Psychosocial and socioeconomically aspects of mothers having a child with cleft lip and/or palate (CL/P): a pilot-study during the first year of life

Konstanze Scheller¹, Jasmin Ulrich¹, Christian Scheller², Stephan Watzke³



J Clin Exp Dent. 2020;12(9):e864-9.

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Information vs Misinformation

Psychosocial and socioeconomically aspects of mothers having a child with cleft lip and/or palate (CL/P): a pilot-study during the first year of life

Konstanze Scheller¹, Jasmin Ulrich¹, Christian Scheller², Stephan Watzke³

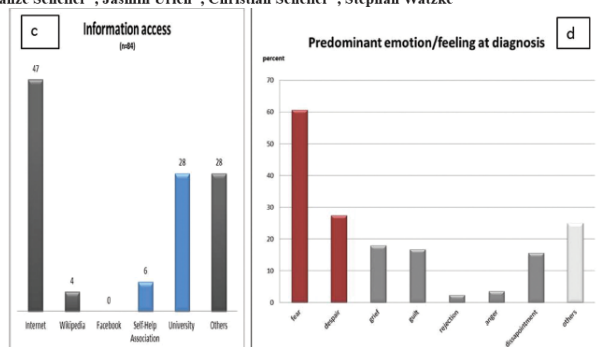


Fig. 2: First medical information. Most mothers were informed about the consequences of the diagnosis of a cleft lip and palate (CL/P) by a gynecologist or a maxillofacial surgeon (a). The "bad" information (b), the access of medical information after diagnosis (c) and the predominant feelings (red bar) and emotions (grey bar) at diagnosis were analyzed in detail (d).

J Clin Exp Dent. 2020;12(9):e864-9.

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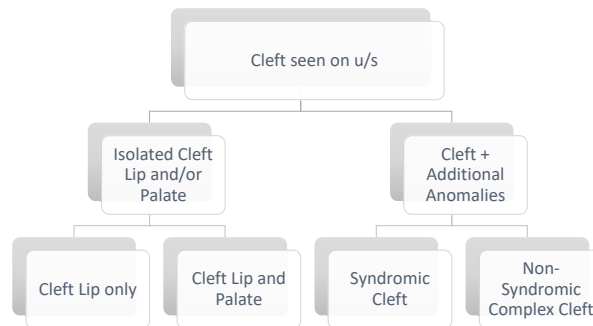


Prenatal Counseling Roadmap

- Comprehensive Prenatal Diagnostic Work-up
- Introduction to Comprehensive Cleft Care
 - Timeline, Multi-disciplinary care, Cleft resources
- Demystifying the Cleft
- Cleft Challenges and Preparation
- Building Cleft Community

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Comprehensive Diagnostic Work-up



- Prenatal Imaging → 2D/3D → Fetal MRI
- Prenatal Genetic Testing and Counseling
- Fetal Echo Cardiogram
- Maternal Fetal Medicine Consult

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A Comparison of Early Versus Late Prenatal Magnetic Resonance Imaging in the Diagnosis of Cleft Palate

Sherelle Laifer-Narin, MD,* Kathryn Schlechtweg, BS,† James Lee, MD,‡ Whitney Booker, MD,§
Russell Miller, MD,§ Rama S. Ayyala, MD,* and Thomas Imahiyerobo, MD‡

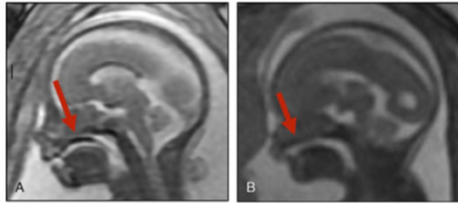


TABLE 1. Demographics

Characteristics	Value (%)
No. cases	61
Lost to follow-up	10
TOP without autopsy	9
No. cases included	42
Early GA (<24 wk)	20 (47.6)
Late GA (≥ 24 wk)	22 (52.4)
Cleft palate	24 (57.1)
Cleft lip	29 (69.1)
Micrognathia	14 (33.3)
Other anomalies	12 (28.6)
Average GA at time of MRI	26.2 wk

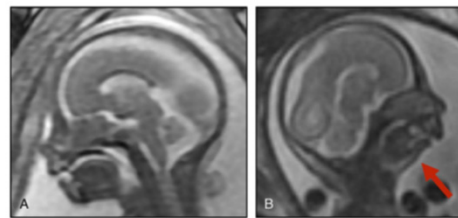


TABLE 2. Cleft Palate MRI Diagnostic Statistics

	Overall (95% CI), n = 42	Early GA (95% CI), n = 20	Late GA (95% CI), n = 22
Sensitivity	91.7% (80.6–102.7%)	100%	86.7% (69.5–103.9%)
Specificity	100%	100%	100%
NPV	90.0% (76.9–103.2%)	100%	77.8% (50.6–104.9%)
PPV	100%	100%	100%

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Comprehensive Diagnostic Work-up

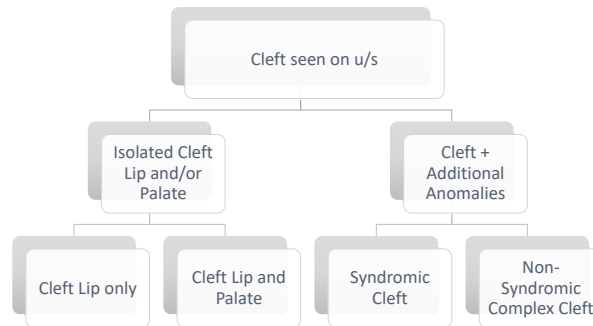


- Prenatal Imaging → 2D/3D → Fetal MRI
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Comprehensive Diagnostic Work-up



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Coordination of the Fetal Medicine Institute and the Cleft and Craniofacial Center: Application to Early Management of Infants With Cleft Lip and Palate

Kenneth L. Fan, MD,* Cara K. Black, BA,* Esperanza Mantilla-Rivas, MD,¹ Dorothy I. Bulas, MD,² Eva Rubio, MD,³ Anna R. Blask, MD,³ Chelsea Robinson, BS,⁵ and Albert K. Oh, MD¹

Background/Purpose: The primary objective of this study is to describe the authors' experience at the Children's National Health System with the coordination of the Fetal Medicine Institute and the Cleft and Craniofacial Center. This collaboration highlights the accuracy and completeness of prenatal diagnosis of cleft abnormalities with expedient postnatal management.

Methods: With Institutional Review Board approval, the authors retrospectively reviewed 74 patients referred for potential orofacial cleft and 44 met the inclusion criteria. Follow-up fetal ultrasonography is typically performed and three-dimensional imaging was performed when feasible. If questionable anomalies or facial findings are present on these studies, the authors proceed with fetal magnetic resonance imaging. A thorough consultation is held with the cleft team, resulting in a comprehensive plan of care. Postnatal examination confirmed the correct prenatal diagnosis in nearly all patients.

Results: Sensitivity and specificity for isolated unilateral cleft lip were 89% and 100%, respectively; for unilateral cleft lip and palate, sensitivity and specificity were 82% and 90%, respectively; for bilateral cleft lip and palate, sensitivity and specificity were 97% and 90%, respectively. Initial postnatal evaluation by the cleft surgeon occurred at an average age of 21 days after birth. All patients who were candidates for presurgical orthodontia were treated at an appropriate young age (mean: 66.5 days).

Conclusions: Coordinated prenatal evaluation of patients with cleft lip/palate by multidisciplinary centers plays an important role in the care of these complex patients. The results of the authors' study demonstrated high sensitivity and specificity for the prenatal diagnosis of cleft lip/palate, leading to timely postnatal evaluation and treatment.

(*J Craniofac Surg* 2019;30: 2061–2064)

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Compressive Cleft Care

Cleft Lip/Palate Treatment Timeline



NOTE: Treatment timeline provided includes approximate time frames and may vary by patient.



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**Craniofacial
Surgery**

AMAZING
THINGS
ARE
HAPPENING
HERE

FOR KIDS

 **Morgan Stanley**
Children's Hospital of NewYork-Presbyterian
Columbia University Medical Center



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Cleft and Craniofacial Team

The Multidisciplinary Cleft and Craniofacial Team

Many specialists are needed to provide the expert consultation and skillful care required to diminish the problems of craniofacial disfiguration. The following healthcare professionals work as a team to provide your child with the best possible care:

- audiologists (hearing specialists)
- genetic counselors
- neurosurgeons
- nurse coordinators
- occupational and physical therapists
- ophthalmologists
- oral and maxillofacial surgeons
- orthodontists
- otolaryngologists (ear-nose-throat specialists)
- pediatric dentists
- pediatricians
- plastic and craniofacial surgeons
- social workers
- speech and language specialists



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Cleft Lip and Palate Challenges

A study into weight gain in infants with cleft lip/palate

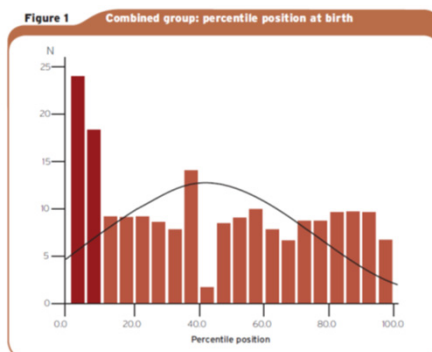


Table 2 Mean percentiles of study group compared with general population

	Number	Mean percentile at birth (SD)	P Value
Combined group	197	42.7 (31.2)	0.002*
ICL	41	50.7 (27.6)	0.866
UCLP	43	44.1 (32.8)	0.244
BCLP	18	40.3 (28.3)	0.166
ICP	85	38.6 (38.6)	0.002*
Non-syndromic	145	45.4 (30.6)	0.073
ICL	38	51.5 (26.1)	0.726
UCLP	38	44.1 (33.4)	0.290
BCLP	15	45.9 (27.2)	0.566
ICP	54	41.8 (32.4)	0.070
Syndromic	43	33.3 (31.7)	0.002*
ICL	3	41.0 (49.5)	0.783
UCLP	5	43.4 (31.0)	0.659
BCLP	3	12.6 (15.9)	0.055
ICP	31	32.9 (31.7)	0.006*

(P value calculated using One sample t-test, *significant at 0.05 level)

paediatric nursing July 2008 vol 20 no 6



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Treatment of Cleft Lip and Palate



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Specialized Bottles for CLP



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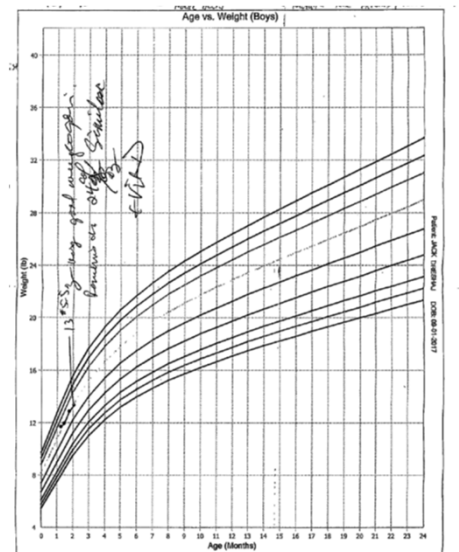


Dr. Brown Specialty Feeder



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Monitored Feeding Program



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Incidence of Gastroesophageal Reflux Disease in Children With Cleft Lip and Palate and an Evaluation of Its Impact on Weight Gain

Ishani D. Premaratne, BA, Nicholas Brownstone, MD,
Philip Lotfi, MD, and Thomas A. Imahiyerobo, MD, FACS, FAAP

Abstract: Patients with cleft lip and/or palate have higher rates of failure to thrive (FTT), decreased growth, and more often experience feeding difficulties as compared with the general pediatric population (*J Child Health Care*. 2014;18:72-83). Although insufficient nursing, excessive air intake, and incorrect feeding methods have been established in the literature, the role of gastroesophageal reflux disease (GERD) as a contributing factor in cleft patients has not been thoroughly examined. Presently, there is a paucity of literature analyzing the incidence and effect of GERD on this unique population. Furthermore, no studies have evaluated the effect of GERD therapy on improvement of weight gain and FTT in cleft patients. The purpose of this retrospective review was to identify the incidence of GERD in the orofacial cleft population and to see if appropriate treatment was effective in improving weight gain. Fifty patients with cleft lip, cleft lip and palate, and isolated cleft palate were identified from a single surgeon's experience at a large academic medical center from 2015 to 2019. The data show that a significantly higher percentage of patients with cleft lip and/or palate have clinical evidence of GERD, which required treatment as compared with published reports of less than 1% in the noncleft population. The data also suggest that the patients diagnosed with GERD who received pharmacologic treatment showed improved weight gain as compared with those who did not. Given our findings, the diagnosis of GERD should be considered in orofacial cleft patients exhibiting signs of feeding difficulty or those with FTT. The early diagnosis and treatment of GERD in patients with orofacial clefts may improve weight gain.

Key Words: cleft lip and palate, gastroesophageal reflux disease, failure to thrive
(*Ann Plast Surg* 2020;85: S141-S142)



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Three-Dimensional Assessment of Facial Appearance Following Surgical Repair of Unilateral Cleft Lip and Palate

The Cleft Palate-Craniofacial Journal 51(4) pp. 462-471 July 2014



FIGURE 1 Construction of 3D facial model: mesh framework merging right and left side.

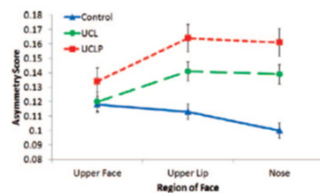
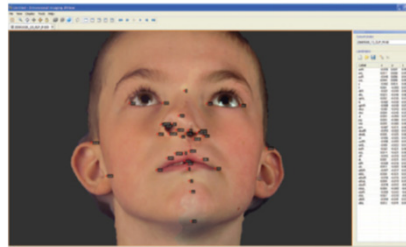


FIGURE 6 Square root asymmetry scores for landmarks across different facial regions.

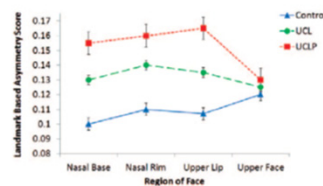


FIGURE 7 Landmark-based asymmetry scores for different facial components.



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Pre-surgical Nasal Molding



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Pre-surgical Nasal Molding



Table 1. Nasal Symmetry Comparisons

	Surgery-Along Control Group (%)	Surgery with NAM Group (%)
Nasal ala projection length*†	93.0 ± 1.7	96.5 ± 2.3
Nostril dome height*†	86.8 ± 7.5	96.4 ± 5.9
Columellar deviation†	96.6 ± 2.7	98.1 ± 3.2
Superoinferior alar groove position*†	91.4 ± 6.5	96.9 ± 2.0
Mediolateral nasal dome position*†	82.3 ± 9.3	91.1 ± 6.1
Nasal bridge deviation†	92.0 ± 2.4	97.9 ± 1.7

NAM, nasolabial molding.

*Linear measurement.

†Angular measurement.

‡Statistically significant difference.

(*Plast. Reconstr. Surg.* 123: 1002, 2009.)



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Comparative Study of Nasoalveolar Molding Methods: Nasal Elevator Plus DynaCleft® Versus NAM-Grayson in Patients With Complete Unilateral Cleft Lip and Palate

Luis Monasterio, M.D., Alison Ford, M.D., Carolina Gutiérrez, D.D.S, María Eugenia Tastets, R.N., Jacqueline García, R.N.

Cleft Palate-Craniofacial Journal, September 2013, Vol. 50 No. 5



TABLE 5 Statistical Analysis (Student's *t* Test and Mann-Whitney *U* test) of Variable Differences Between Both Groups

Difference Between Nasal Elevator and DynaCleft® and NAM-Grayson		Z Value	Bilateral Probability Value*
Cleft width, mm	Initial	-0.299	.779
	Post	-1.091	.289
	Total difference	0.66	.513
Columellar angle, degrees	Initial	-1.070	.289
	Post	-0.447	.659
	Total difference	0.98	.333

* $P > .05$.

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Unilateral Cleft Lip



32



Unilateral Cleft Lip



33

Unilateral Cleft Lip



34



Unilateral Cleft Lip



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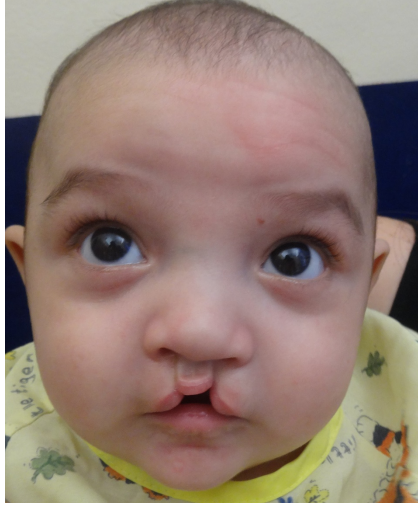
Unilateral Cleft Lip



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Bilateral Cleft Lip



37

Bilateral Cleft Lip



38



Bilateral Cleft Lip



39

Bilateral Cleft Lip



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Bilateral Cleft Lip



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Impact on Postnatal Care

Prenatal Counseling's Effect on Rates of Neonatal Intensive Care Admission for Feeding Problems Cleft Lip/Palate Infants

by Bradley A. Hubbard, MD, C. Lynette Baker, RN & Arshad R. Muzaffar, MD

Abstract

Prenatal counseling and feeding instruction is standard at our institution for parents of cleft lip and palate patients. We studied this intervention's effect on Neonatal Intensive Care Unit (NICU) admission solely for feeding. Ten percent (2/20) of patients whose parents received counseling were admitted to the NICU for feeding issues alone compared to 21% (5/24) of the non-counseling group. Prenatal counseling and feeding instruction appears to decrease NICU admission, duration and health care costs.

Table 1
Association between prenatal counseling and NICU admission for patients with unilateral cleft lip and palate. The effect of prenatal counseling on admission to the NICU for feeding issues alone was compared.
**p-values are based on the Fisher's exact test (two-side).*

	Admission for Comorbidity	Admission for Feeding	No Admission	P-value*
Counseling	3	2	8	0.61
No Counseling	6	3	6	

Table 2
Association between prenatal counseling and NICU admission for patients with bilateral cleft lip and palate: the effect of prenatal counseling on admission to the NICU for feeding issues alone was compared.
**p-values are based on the Fisher's exact test (two-side).*

	Admission for Comorbidity	Admission for Feeding	No Admission	P-value*
Counseling	3	0	4	0.18
No Counseling	5	2	1	

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Impact on Postnatal Care

Postpartum Depression in Mothers of Infants With Cleft Lip and/or Palate

Alexis L. Johns, PhD, ABPP,* Jennifer A. Hershfield, PhD,¹
Netsanet Mulugeta Seifu, RN, MSN,*
and Karla A. Haynes, RN, MPH*

Abstract: This study describes postpartum depression rates and risk factors for mothers with infants with cleft lip and/or palate as postpartum depression has been associated with a range of negative maternal and child outcomes. A retrospective chart review from August 2009 to May 2015 included medical diagnoses, demographics, receipt of prenatal diagnosis, and the Edinburgh Postnatal Depression Scale (EPDS). Mothers (N = 206) had infants (59.2% male; mean age in weeks 5.1 ± 6.9) with isolated cleft lip (18%), cleft palate (22.8%), or cleft lip and palate (59.2%). Mothers ranged from 16 to 45 years old (mean age 29 ± 6.2) and half had received a prenatal diagnosis. Patients mostly had public insurance (57.8%) and represented diverse ethnicities. Based on the EPDS, 11.7% of mothers met the depression cutoff of 10 or higher. The majority endorsed self-blame (68.9%), difficulty coping (59.2%), and feeling anxious (57.3%). Mothers of infants with cleft lip or cleft lip and palate who did not receive a prenatal diagnosis had higher total EPDS scores, anxiety, and incidence of feeling scared. Higher EPDS scores were predicted by not having a prenatal diagnosis and by older maternal age. Mothers of infants with a cleft had similar rates of postpartum depression as the general population; however, those who were older and who did not receive a prenatal diagnosis endorsed more symptoms. Prenatal diagnosis may contribute to positive maternal postpartum adjustment. Providers should incorporate screening for risk factors into their evaluation and treatment planning. *The Journal of Craniofacial Surgery* • Volume 29, Number 4, June 2018

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Impact on Postnatal Care

The impact of having a baby with cleft lip and palate on parents and on parent-baby relationship: the first French prospective multicentre study

Bruno Grollemund^{1*}, Caroline Dissaux², Pascale Gavelle³, Carla Pérez Martínez⁴, Jimmy Mullaert⁵, Toni Alfaïate⁶, Antoine Guedeney⁷ and CLIP team (Cleft Lip & palate Infant Parent)

Abstract

Background: The objective of this prospective, multidisciplinary and multicenter study was to explore the effect of a cleft lip, associated or not with a cleft palate, on parents, on parent-infant relationship, and on the baby's relational development. It also highlighted how the type of cleft and the timing of the surgery could impact this effect.

Method: 158 infants, with Cleft lip with or without Palate, and their parents participated in this multicenter prospective cohort. Clinical evaluations were performed at 4 and 12 months postpartum. The impact on the parents and on the parent-infant relationship was evaluated by the Parenting Stress Index (PSI), the Edinburgh Post-partum Depression Scale (EPDS) and the Impact-on-Family Scale (IOFS). The relational development of the infant was assessed using the Alarm Distress Baby Scale (ADBB). The main criteria used to compare the infants were the severity of cleft and the time of surgery.

Results: The timing of surgery, the type of malformation or the care structure had no effect on social withdrawal behaviors of the child at 4 and 12 months postpartum (ADBB). Furthermore, early intervention significantly decreased maternal stress assessed with the PSI at 4 months. Parents for whom it had been possible to give a prenatal diagnosis were much better prepared to accept the waiting time between birth and the first surgical intervention (IOFS). Higher postpartum depression scores (EPDS) were found for both parents compared to the general population.

Conclusion: A joint assessment of the mental health of both infants and parents is required in the follow-up of cleft lip and palate. Even if most families are remarkably resilient faced with this major cause of stress, a significant proportion of them could require help to deal with the situation, especially during this first year of follow-up. An assessment of the child's social withdrawal behaviour and of the parental stress and depression appears useful, in order to adapt care to infant and parent's needs.

Grollemund et al. *BMC Pediatrics* (2020) 20:230

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Building Cleft Support System



children's craniofacial association
www.ccakids.org



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Building Cleft Support System



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Building Cleft Support System



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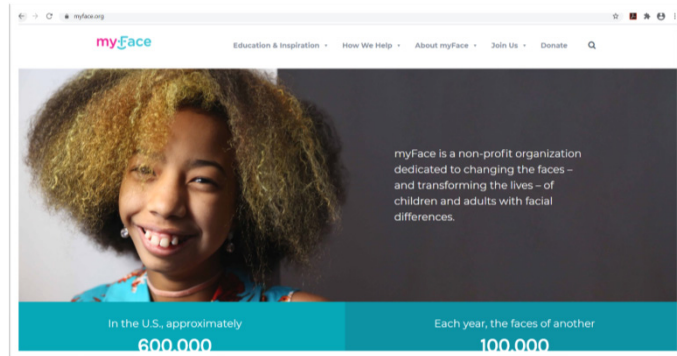
Building Cleft Support System



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Building Cleft Support System



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Landon Stack



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A Family Journey

- Our story
- The tough questions and issues
- Finding the team
- Going on the journey



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Question & Answer

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Closing Remarks

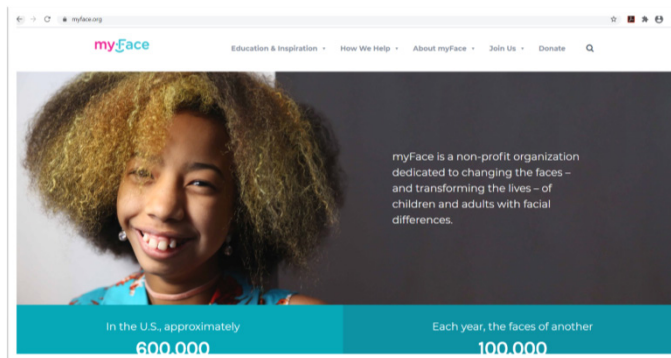


Stephanie Paul
Executive Director
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visit [myFace.org](https://myface.org)



Or email us at
info@myface.org



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Thank You