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Nasoalveolar Molding: Prevalence of Cleft Centers Offering NAM and Who Seeks It

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Abstract

Introduction—Nasoalveolar molding (NAM) is a treatment option available for early cleft care. Despite the growing debate about NAM's efficacy, questions remain regarding its prevalence and demographic characteristics of families undergoing this technique prior to traditional cleft surgery.

Objectives—To determine the number of teams currently offering NAM, and to identify salient clinical and sociodemographic variables in infants and families who choose NAM compared with those who choose traditional cleft care across three well-established cleft centers.

Results—89% of US cleft teams contacted using phone surveys reveal that NAM is available at 39% of these centers. Chart reviews and phone correspondence with caregivers indicate that the average distance to the cleft center was 65.5 miles and caregiver age averaged 30.9 (SD=5.7) years. 85% of families who chose NAM received total or partial insurance coverage. No difference in caregiver education, income, or distance to the clinic between treatment groups was found. On average, infants receiving NAM and cleft surgery had larger clefts and had more clinic visits than infants receiving traditional cleft surgery. Infants who were first-born and those who did not have other siblings were more likely to receive NAM than infants who were residing with other siblings.

Conclusions—Currently over one-third of US cleft centers offer NAM. While the cleft size was larger in the NAM group, no treatment group differences in education, income, and distance to the clinic were found.

Keywords

Nasoalveolar molding; access to care; demographic variables; cleft care; social support; birth order; insurance

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According to a recent CDC report, cleft lip and palate (CLP) is the second most common birth defect (Canfield et al., 2006). Traditional cleft habilitation involves a lengthy process of evaluations and treatment by a multidisciplinary team of specialists. Clefts of the primary and secondary palate are repaired by about one year of age. The subsequent number of surgical interventions for individuals can vary from 2 or 3 to as many as 20 surgeries before the affected individual reaches early adulthood. Not surprisingly, treatment for CLP is costly. The medical costs of interventions average $15,000 each, and the cost of habilitation can average over $100,000 per individual (Snowden et al., 2003). This figure does not measure other impacts such as psychosocial sequelae (e.g., multiple doctor visits by patients and their caregivers, lost wages, etc.). Given current concerns regarding health costs and/or affordability in the US, it is vital to examine healthcare access as well as the benefits and disadvantages for families receiving cleft treatment protocols, like nasoalveolar molding (NAM), that are intended to reduce treatment costs.

Over the past decade, NAM, a relatively new technique, has emerged in cleft care. NAM is an early, pre-surgical intervention intended to reduce the severity of initial cleft deformity through the use of surgical tape, an intraoral molding plate, and nasal stents. Typically, NAM is initiated on newborns at approximately 1–2 months of age and is completed prior to the closure of the primary palate (lip) at approximately 5 months of age. The infants must undergo this treatment for about 3 months (unilateral cleft) or 5 months (bilateral cleft). During this time, caregivers make daily adjustments to the tape on the infant's face, as well as attend weekly clinic appointments with the infant. Both short (4 months-1 year) and long-term (4.5–9 years) studies indicate that NAM significantly improves nasal symmetry over surgery alone (Maull et al., 1999; Ezzat et al., 2007; Jaeger et al., 2007; Barillas et al., 2009). More specifically, NAM lengthens and widens the columella in bilateral clefts and improves nostril height and width in a pre-surgical phase of treatment (Pai et al., 2005; Lee et al., 2008; Nakamura et al., 2009; Chang et al., 2010).

However, the use of NAM is controversial, has polarized professionals in the field of craniofacial habilitation, and has challenged the established ACPA standards of care. According to NAM proponents, NAM reduces the severity of the cleft (e.g., nasal defect, cleft size) and thereby improves future surgical results, reduces the need for other surgeries like lip and nose revisions, and minimizes scarring. On the other hand, Berkowitz (2009) argues that NAM + GPP (gingivoperiosteoplasty) compromises future facial growth. Opponents also suggest that NAM places an extra emotional burden on the family system, which already must adapt to having a newborn with a birth defect. In other words, the described morphological benefits of NAM are not sufficient to counterbalance the burden imposed on caregivers. Although NAM may be offered at a growing number of cleft centers, it remains unclear how many centers actually provide NAM services and the potential burden of care NAM places on caregivers/families. This paucity of data poses a serious challenge to cleft care considering the pivotal role caregivers play in the treatment process. For example, NAM caregivers are responsible for: 1) attending weekly clinic visits for molding plate adjustments; 2) the daily care associated with cleaning and maintaining the appliance; and 3) the proper positioning and adherence of the surgical tape that holds the appliance in place. Infants with unilateral cleft lip require an average of 13–14 office visits, while infants with bilateral cleft lip require 20–22 visits, which can cost caregivers a significant amount of time and money. Some patients and their caregivers, for example, travel hours to craniofacial centers for appointments and all patients and their caregivers spend extended periods of time in waiting rooms (Levy-Bercowski et al., 2009). NAM opponents assert that NAM places an extra emotional burden on the family system since caregivers are already experiencing a critical period of adaptation to the arrival of a newborn with a birth defect (Bradbury and Hewison, 1994; Pope et al., 2005).

During this era of evidence-based outcomes, much attention in medicine has been given to new treatment advances in terms of technology, techniques, and medications. The focus of craniofacial habilitation transcends survival alone. Craniofacial teams typically focus on treatment that promotes thriving—treatment designed to enhance appearance, speech, and other factors associated with quality of life (QoL) (Broder and Wilson-Genderson, 2007). Recent health models suggest that in addition to patients' medical characteristics or status, treatment outcomes may be influenced by contextual and environmental factors which may be independent of clinical variables (e.g., width of the cleft) (Sischo and Broder, 2011). Further, clinical decision-making and outcomes such as QoL and satisfaction with care are often mediated by psychosocial factors. In pediatric health psychology, there is a robust literature that recognizes that demographic, contextual, and psychosocial factors impact decision-making, adherence, treatment effects, and QoL (Mellins et al., 2004; Patenaude and Kupst, 2005; Patrick et al., 2007).

As cleft care strives to optimize treatment outcomes, such data can take a long time to thoroughly evaluate and validate. To date, only one study has addressed the underlying assumption of NAM treatment—that the benefits of the treatment to the child in saved surgical costs outweigh other costs (Pfeifer et al., 2002). From a pragmatic perspective, treatment access and utilization are important issues at a time when health costs are one of the major political issues facing the US (DHHS, 2000).

In short, it is important to determine whether sociodemographic variables (e.g., income, proximity to clinic, caregiver education) are associated with early treatment decisions among caregivers having infants with cleft. It may be that birth order, education level, and income are predictive of treatment choice rather than variables like age of caregiver, number of caregivers in the home and/or proximity to the clinic. Such information may dispel or confirm biases associated with the type of patients/families who choose NAM. Our study will be the first to examine the prevalence of NAM across cleft teams and sociodemographic and clinical variables associated with early cleft care at three established cleft centers in the US. We expected that there would be systematic differences between the NAM and non-NAM groups across diverse variables (e.g., distance from clinic, payer status, size of cleft).

The purposes of this study were:

1. To identify the number of cleft teams that offer NAM to infants.
2. To examine health care utilization, access to care, and enabling resources in families whose infants with CLP undergo NAM compared to families whose infants with CLP do not undergo NAM.

METHODS

To carry out our first goal, a phone survey was completed by investigators from one of the study sites to ascertain the proportion of ACPA-sanctioned centers that offer NAM. One of the authors systematically called US centers listed in the recent ACPA directory as having evaluated more than 25 new patients annually. Descriptive statistics were used to identify the number of centers that do or do not offer NAM.

A review of the literature on decision-making and health utilization/access and early cleft care yielded a list of variables relevant for our chart review. To ascertain the relevant information (e.g., income, caregiver education), investigators from each site were required to contact the caregivers. We expected that there would be systematic differences between the NAM and non-NAM groups across diverse variables (e.g., distance from clinic, payer status, size of cleft). To obtain information about early cleft care, investigators from three well-established US cleft centers secured IRB approval (as this was a chart review, informed consent was not required). One center (Site 1) is located in a northeastern urban area and is a long-established site offering NAM. The other two renowned centers (Sites 2 and 3) are located in rural areas in the southeast—one is a private hospital and the other is state-owned. These two centers have introduced NAM within the past 24–30 months. At each center, one or two members of the cleft team were responsible for identifying consecutive cases over the past 18 months who have had NAM plus cleft surgery and those families whose infants had traditional care only. Inclusion criteria included all infants with non-syndromic unilateral or bilateral cleft who were consecutively evaluated at the three treatment sites within an 18-month period.

The data first were analyzed for descriptive purposes without regard to site or NAM status. Analyses were then performed to compare the sites without regard to NAM grouping status. Lastly, analyses were completed comparing the NAM and non-NAM infants without regard to site. Based on the distributions of data in the univariate analyses and the relatively small sample size compared to the number of groups formed, it was not appropriate to analyze by site and NAM status simultaneously (i.e., two-way analysis). Comparison of categorical variables was completed using cross tabulation and Fisher’s Exact test. Comparison of numeric variables was done by t-test for the two NAM groups or by one-way ANOVA with Tukey’s HSD post hoc comparison for site groups. Bivariate statistics (Chi-square/Fisher’s Exact for nominal or Unpaired t-tests for continuous variables) were used to evaluate distributional differences between those families whose infants received NAM and cleft surgery and those families whose infants underwent traditional care only.

RESULTS

Teams Offering NAM

Of the 207 US teams listed in the 2007–2008 ACPA Membership Team Directory, 132 teams (64%) met our inclusion criteria of treating more than 25 new patients annually. Of these 132 teams that were contacted, 117 teams (89%) were reachable. The remaining 15 teams were unreachable (i.e. voice-mail, staff on disability or maternity leave, closed due to inclement weather conditions, or non-working numbers). Of the 117 teams contacted, 43 teams (37%) reported that they offered NAM, and 74 teams reported that they did not offer NAM. This result far exceeds estimates of 10–15% as expressed by the Americleft Chairperson (Long, 2010).

Infants/Families Across Sites

A total of 83 families had infants who completed treatment at one of the three cleft centers —Site 1 (n=36), Site 2 (n=19), and Site 3 (n=28). Over an 18 month study period (September 2009–January 2010), 39 infants received a NAM device (47%) and cleft surgery; while 44 (53%) infants underwent traditional care (cleft surgery only).

Table 1 presents the description of the families across the three centers that underwent cleft care during the study period regardless of treatment group. Across the three sites, caregivers were on average young (M=30.9 years old). Caregivers from Site 1 (northern/urban) were significantly older on average (33.6 years) than the caregivers from the other two sites (28.9 years and 28.8 years), respectively. No differences across sites were found on the number of clinic visits or the distance (averaged 65.5 miles) from the clinic. The caregiver education and income level were also higher at Site 1 than the other two southern rural sites ($p<0.01$).

Approximately 26 of the 36 caregivers (72.2%) from the northern/urban site at least completed college compared to 5 of 19 (26.3%) and 12 of 28 (42.9%) from Sites 2 and 3, respectively. However, it is noted that a range of income and education levels were observed across sites. For example, twenty-eight percent of the families had an income of less than \$25,000/year, while 33% earned more than \$100,000/year. Caregivers were mostly female (n=79, 95%) and the majority of infants had two caregivers in the home (66%) with the primary caregiver being predominantly non-Hispanic white (71%). With regards to private insurance and Medicaid, one of the southern sites had significantly less private insurance with 8 of 19 (42.1%) and higher proportion covered by Medicaid (63.2%) compared to the other two sites which reported 51 of 64 (79.7%) with private insurance and 16 of 64 (25%) with Medicaid. The majority of infants studied had unilateral clefts (n=62, 74.7%). Of those infants who received NAM, 64% were fully covered by insurance, 21% (n=8) were partially covered, and 15% (n=6) were not covered at all by third party payers. Thus, treatment was partially or fully covered by insurance in 85% of the infants.

NAM and Non-NAM Comparisons

Table 2 compares the families whose infants received NAM and cleft surgery with those who had traditional cleft care only. The number of clinic visits for patients receiving NAM (M=14) was significantly higher than the number of clinic visits for non-NAM subjects (M=3.14) ($p<0.01$) across the three sites. The size of the cleft for infants with unilateral cleft who received NAM averaged 9.0 mm, which was significantly larger than the average cleft size of 4.0 mm for infants undergoing traditional care only ($p<0.01$). The average size of the bilateral clefts (combining the left and right sides) was 13.9 for the NAM group and 8.8 for the non-NAM group. While the direction was larger for the NAM group, significance was not obtained.

The majority of the infants are first or second born (n=61/83, 73%). However, there is a significant difference by birth order—if the infant with cleft is first or second in the birth order, they are more likely to have NAM. Conversely, caregivers residing in households having other children more often choose traditional care for their infants ($p<0.05$).

No other differences in sociodemographic variables were found between treatment groups—including distance to the clinic, income and Medicaid status. Furthermore, no statistical difference between treatment groups was found regarding the number of caregivers residing at home. With regards to ethnicity, there was no statistical difference between treatment groups. However, a possible trend was observed at the $p<0.08$ level with African Americans and Latinos more often receiving traditional care. However, due to the small numbers, this trend is only speculative. In summary, given the nature of NAM, it is not surprising to find differences in the number of visits to the clinic. However, the absence of difference based on distance, income, and type of payer is noteworthy.

DISCUSSION

The results from the chart reviews revealed some interesting information regarding sociodemographic comparisons between the two treatment groups. Both cleft size and the number of clinic visits were significantly larger in the NAM group than non-NAM group. Given the goals of NAM, it is logical that the extent of the defect may in part determine treatment choice, both in terms of the teams' recommendations and/or caregivers' responses to the size of the cleft. Surprisingly, distance from clinic, caregiver age, and income were not associated with treatment choice. However, the infant birth order and the presence of other children in the family were associated with treatment group. In short, multiple children in the family and having the affected child not be first in the birth order are linked to having traditional care. Such issues may relate to social support. Contextual factors, like quality of the support system, have been found to affect treatment adherence, health care utilization, and quality of life issues in families with chronic conditions (Horwitz et al., 1985; Wallander and Varni, 1989; Drotar, 1997; Janicke et al., 2001). However, the data collected in this study merely capture size, not quality, of the family system. Another study limitation is the lack of diverse ethnic representation in the sample. Despite a slight directional tendency for African Americans and Latinos to select traditional care, it remains unclear and merely speculative whether elective treatment or service utilization is linked to ethnicity, a factor often associated with access to care (DHHS, 2000). Since a potential relationship between ethnicity and socioeconomic status may also exist (Butani et al., 2008), further investigation is needed in this area.

A follow-up study to determine the number of subsequent procedures completed over time at individual sites across treatment groups may be revealing. In addition, it would be helpful to know if the number of elective procedures is decreasing as a result of the economy, unemployment rates, and/or the costs of care. On the other hand, the number of infants receiving NAM may be increasing in response to increased insurance coverage of NAM and prevalence of centers offering such care. Another way to ascertain prevalence and frequency of NAM at centers is to include this information in the ACPA directories under team services. Such a change would be congruent with the 2009 alteration to the ACPA’s Parameters of Care that now includes infant orthopedics like NAM (ACPA, 1993).

Based on anecdotal information from the site directors, caregivers are informed about NAM prior to their initial discussions with the plastic surgeons at the participating sites. Cleftline, a toll-free service as well as a website through the Cleft Palate Foundation, is one such mechanism that has enabled caregivers to become aware of NAM therapy through its information about clefts and craniofacial care. Although we were unable to ascertain specific hits for NAM information, it is clear that Cleftline is a well-utilized service for caregivers and health providers, as it averaged 19,522 daily hits in 2010 (Gregson, 2011). Additionally, those active on Cleftline can recount numerous discussions from parents and professionals regarding NAM. While we were able to detect treatment group differences regarding specific variables, a prospective study to replicate these findings is recommended. It may be important to obtain a larger sample to examine differences across groups, as well as expand the scope of information. For example, measuring stress, coping, and quality of the support system may reveal significant issues associated with treatment choice. Further, we need longitudinal studies to look at satisfaction with early cleft care over time. Although we may not be able to definitely state whether there are fewer surgeries in the NAM group, systematic collection of prospective data is imperative to evaluate those outcomes over time. Data examining contextual and psychosocial factors are suggested to determine if time-intensive therapies, like NAM, are detrimental to family cohesion and, if so, whether adjunct support services are indicated. Conversely, it is possible that such substantial caregiver involvement may empower parents, thereby increasing and strengthening family bonding. Both qualitative and quantitative analyses are recommended to address such issues (Strauss and Broder, 1991; Nelson, 2009).

In short, focusing on clinical factors alone is a limited approach to analyzing decision-making. Long-term outcomes and satisfaction with treatment are multidimensional and often mediated by multiple factors (Evers et al., 2003; Ganzini et al., 2003; Brod et al., 2007). Thus, congruent with current health models (Sischo and Broder, 2011), use of multilevel and multivariate analyses in a prospective study is recommended to increase our understanding of decision-making and responses to early cleft care.

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TABLE 1

Descriptive Data Across Sites

Variable	n (%) (N=83)
Gender of Primary Caregiver	
Female	79 (95.2)
Male	4 (4.8)
Race/Ethnicity of Caregiver	
Non-Hispanic White	59 (71.1)
Non-Hispanic Black	8 (9.6)
Hispanic	5 (6)
Asian	8 (9.6)
Other	3 (3.6)
Education of Caregiver[**]	
<High School	5 (6)
High School Diploma	23 (27.7)
Some College	12 (14.5)
College Degree	24 (28.9)
Some Graduate School	2 (2.4)
Professional/Graduate Degree	17 (20.5)
Family Income[**]	
0–25,000	23 (27.7)
26,000–50,000	20 (24.1)
51,000–100,000	13(15.7)
>100,000	27 (32.5)
Other Children	
0	31 (37.3)
1	26 (31.3)
2 or more	26 (31.3)
Birth Order of Affected Child	
1st	33 (39.8)
2nd	28 (33.7)
3rd or more	22 (26.5)
Private Insurance[**]	
Yes	59 (71.1)
No	24 (28.9)
Medicaid[**]	
Yes	28 (33.7)
No	55 (66.3)
Was NAM Covered (N=39)	

Variable	**n (%) (N=83)**
Yes	25 (64.1)
Partially	8 (20.5)
No	6 (15.4)
Type of Cleft	
Bilateral	21 (25.3)
Unilateral	62 (74.7)
Age of Caregiver (YRS) **	
M (SD)	30.9 (5.8)

[*] $p<0.05$;

[**] $p<0.01$

TABLE 2

Descriptive Data Across Treatment Groups

Variable	**NAM (N=39)**	**NON-NAM (N=44)**
	n (%)[1]	**n (%)**[1]
Gender of Primary Caregiver		
Female	39 (49.4)	40 (50.6)
Male	0 (0)	4 (100)
Number of Caregivers in the Home		
1	5 (45.5)	6 (54.6)
2	28 (50.9)	27 (49.1)
3+	6 (35.3)	11 (64.7)
Race/Ethnicity of Caregiver		
Non-Hispanic White	31 (52.5)	28 (47.5)
Non-Hispanic Black	1 (12.5)	7 (87.5)
Hispanic	2 (40)	3 (60)
Asian	5 (62.5)	3 (37.5)
Other	0 (0)	3 (100)
Education of Caregiver		
<High School	3 (60)	2 (40)
High School Diploma	11 (47.8)	12 (52.2)
Some College	3 (25)	9 (75)
College Degree	12 (50)	12 (50)
Some Graduate School	2 (100)	0 (0)
Professional/Graduate Degree	8 (47.1)	9 (52.9)
Family Income		
0–25,000	10 (43.5)	13 (56.5)
26,000–50,000	9 (45)	11 (55)
51,000–75,000	6 (46.2)	7 (53.8)
>100,000	14 (51.9)	13 (48.2)
Other Children *		
0	19 (61.3)	12 (38.7)
1	11 (42.3)	15 (57.7)
2 or more	9 (34.6)	17 (65.4)
Birth Order of Affected Child *		
1st	19 (57.6)	14 (42.4)
2nd	15 (53.6)	13 (46.4)
3rd or more	5 (22.7)	17 (77.3)
Private Insurance		
Yes	28 (47.5)	31 (52.5)

Variable	**NAM (N=39)**	**NON-NAM (N=44)**
	n (%)[1]	**n (%)[1]**
No	11 (45.8)	13 (54.2)
Medicaid		
Yes	12 (42.9)	16 (57.1)
No	27 (49.1)	28 (50.9)
Type of Cleft		
Bilateral	9 (42.9)	12 (57.1)
Unilateral	30 (48.4)	32 (51.6)
Size of Cleft (MM)	**M(SD)**	**M(SD)**
Bilateral Cleft (Lft + Rt Combined Average) (SD)	13.9 (5.3)	8.8 (6)
Unilateral Average (SD) **	9.0 (5.5)	4 (4.3)
Number of Clinic Visits **		
M (SD)	14 (5.3)	3.14 (1.7)
Distance From Clinic (MI)		
M (SD)	77.7 (198.9)	54.6 (46.2)
Age of Caregiver (YRS)		
M (SD)	31.0 (5.8)	30.9 (5.8)

[1] Percentages reported are within each subcategory.

* $p<0.05$;

** $p<0.01$