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Timeliness of Services during the First Two Years of Life among Medicaid-Enrolled Children with Orofacial Clefts in North Carolina, 1995–2002

by

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Abstract

Background and Objectives: In 1993, the American Cleft Palate-Craniofacial Association (ACPA) developed parameters of care for patients with craniofacial conditions such as orofacial clefts (OFC). To date, no study has examined the timeliness of services according to these guidelines. The objectives of this study were to determine: 1) the proportion of children with OFC continuously enrolled in Medicaid who received primary cleft surgery within the ACPA guidelines; and 2) the proportion of children with OFC continuously enrolled in Medicaid who received selected specialized services during the first two years of life within the ACPA guidelines.

Methods: Data from North Carolina vital statistics, the North Carolina Birth Defects Monitoring Program, and Medicaid enrollment and paid claims were linked to identify resident children with OFC born between 1995 and 2002 who were continuously enrolled in Medicaid through age two. Proportions of children who received primary cleft surgery within six and 18 months of life by cleft type and presence of other birth defects were determined. Proportions of children who received specialized service such as speech and language therapy within the ACPA guidelines were also determined.

Results: About 78 percent of children with OFC had primary cleft surgical repair within 18 months of life. Of those children who received timely surgery, the mean age surgery occurred was five months. About 51 percent of children received speech and language therapy, 28 percent received audiology services, and 16 percent received dental care within the ACPA recommendations.

Conclusion: Most children with OFC who were continuously enrolled in Medicaid received primary cleft surgery within the ACPA recommendations; however, many children did not receive other necessary specialized services. Efforts to increase timely receipt of services for this population to improve their health outcomes are needed.

Background

Orofacial clefts (OFC) can impair the development of teeth, speech, hearing, feeding capabilities, and psychomotor and cognitive skills, thereby creating physical and emotional stress for infants, children, and their families. Services and treatment for children with OFC can vary depending on cleft severity, presence of associated syndromes and/or another birth defect, and the child's age and needs.[1,2] For example, a child who has cleft lip (CL) only (without cleft palate) may not need as many services compared to a child with cleft lip with cleft palate (CLP), an associated syndrome, or another birth defect.[1]

Despite these variations, some general recommendations exist for services and treatment for this population.[1–4] These recommendations were originally set forth by the American Cleft Palate-Craniofacial Association (ACPA) in 1993 and were amended in 2000 and late 2004.[2] Initial evaluations of infants with OFC are recommended within the first few days of life and subsequent evaluations should be scheduled at regular intervals.

Per the 2000 ACPA guidelines, speech and language, audiological (hearing), and dental services are recommended within the first year of life. Surgical closure of the CL should occur within the first six months of life and closure of the palate should occur within 18 months of life.[2] If a child is diagnosed with CLP, primary surgical repair should occur within 18 months of life. Otolaryngological (ear/nose/throat or ENT) services are recommended within the first six months of life. Psychological services are recommended periodically through adolescence.[2] Table 1 lists an abbreviated version of the 2000 ACPA recommended services and treatment and frequency of these services for children with OFC.[1,2]

As demonstrated, the ACPA recommends services and treatment throughout childhood and adulthood for children with OFC. Receipt of these services in a timely manner is essential to the medical and psychosocial well-being of children with OFC. Improving health outcomes of children with OFC is one of the Centers for Disease Control and Prevention's (CDC) priority research areas for this population.[5] Despite recommended services and treatments, no study has assessed the timeliness of services in accordance with nationally recommended services for children with OFC.

The primary objective of this study is to determine the percentage of children with OFC continuously enrolled in Medicaid who received primary cleft surgical repair within the first 18 months of life and the mean age at which cleft surgery occurred. These results were stratified by cleft type and presence of other birth defects. Another objective was to examine the percentage of children who received other specialized services within the ACPA recommendations by cleft type. It was hypothesized that the majority of children with isolated cleft palate (CP) and children with CLP would have their primary surgical repair within 18 months of life, and the majority of children with CL would have their primary surgery within the first six months of life. Lastly, it was hypothesized that the majority of children with OFC would receive specialized services within the ACPA recommendations.

Methods

Study Design and Sample

We conducted a retrospective, cohort study of North Carolina resident children with OFC born between January 1, 1995, and December 31, 2002, who were continuously enrolled (11 or 12 months per year) in Medicaid during the first two years of life. Data sources included the North Carolina composite linked birth files, North Carolina Birth Defects Monitoring Program (NCBDMP) data, and Medicaid enrollment records and paid claims data. Children with OFC were ascertained by the NCBDMP using British Pediatric Association codes 749.000-749.290 (n=1,355). Infants who died within the first 12 months of life (n=103), who were born out of state, or who were adopted were excluded from the study. Records of all services received and paid for by Medicaid for calendar years 1995–2004 were extracted to allow for two years of health service utilization data for all children with OFC born during the study period.

The primary outcomes of interest were timely receipt of primary cleft surgery, ENT care, audiological services, speech and language therapy, dental services, and psychological and social services. To determine timeliness of services, service receipt dates were assessed. In this study, timeliness was defined using the 2000 ACPA recommendations through age two because these guidelines were most applicable to the study population. For children with OFC, timely primary cleft surgery was defined as surgery within the first 18 months of life. Timely CL surgery was defined as surgery within the first six months of life and timely CP with or without CL was defined as surgery within the first 18 months of life. Timely receipt of ENT care was within the first six months of life and once per year through age two. Timely audiological assessments, speech and language therapy, dental services, and psychological and social services, including screening evaluations, were within the first year of life and once per year through age two.[2]

To create these outcomes using the Medicaid paid claims, all past and current codes from the Physicians' *Current Procedural Terminology* (CPT) manual and diagnostic-related group codes for these services were employed. For dental services, the Medicaid paid claim pre-established category for dental claims and all past and current CPT and diagnostic-related group codes related to dental and orthodontic care were used. To ensure a comprehensive inclusion of procedural codes used during the study period, consultations occurred with several members of craniofacial centers and teams in the state. Any procedural codes for these services used by the craniofacial centers and teams and the Children's Developmental Services Agency (CDSA) for reimbursement of Medicaid in the state were also included.

Certain procedural codes were excluded because these were standard codes used for generic office visits, and the specific service rendered could not be determined. However, if the specific service rendered could be determined from the provider specialty code, these codes were used.

All analyses were conducted for children with OFC who were continuously enrolled in Medicaid during the first year of life (n=565) or from birth through the first two years of life (n=406). Among

Table 1. Summary of the 2000 American Cleft Palate-Craniofacial Association recommended services and treatment for children with orofacial clefts

Type of Service	Timing/Frequency
Primary cleft/lip surgical repair	Within 18 months of life
Audiological assessment	First assessment within first year of life and at least once per year thereafter
Speech and language pathology, including laryngeal function	At least once per year until age four
Otolaryngologic (ENT) care	Within first six months of life
Dental care, including primary care, routine maintenance, and orthodontic care	At least once per year throughout lifetime
Psychological and social services, including screening evaluations	Periodic through adolescence

Table 2. Selected characteristics of children with orofacial clefts by cleft type during the first year of life in North Carolina, 1995–2002[a]

Characteristics	CL[b] N=108 (%)	CP[b] N=210 (%)	CLP[b] N=247 (%)	All OFC[b] N=565 (%)	P-value
MATERNAL					
Age					
≤ 20 years old	42 (38.9)	48 (22.9)	83 (33.6)	173 (30.6)	0.01*
21-24 years old	32 (29.6)	63 (30.0)	71 (28.7)	166 (29.4)	
25-29 years old	22 (20.4)	56 (26.7)	63 (25.5)	141 (25.0)	
≥ 30 years old	12 (11.1)	43 (20.5)	30 (12.2)	85 (15.0)	
Education					
< High School	44 (40.7)	80 (38.1)	123 (49.8)	247 (43.7)	0.04*
High School	49 (45.4)	85 (40.5)	79 (32.0)	213 (37.7)	
> High School	15 (13.9)	45 (21.4)	45 (18.2)	105 (18.6)	
Race					
White/Non-Hispanic	70 (64.8)	124 (59.1)	154 (62.4)	348 (61.6)	0.62
Black/Non-Hispanic	23 (21.3)	51 (24.3)	52 (21.1)	126 (22.3)	
Hispanic	9 (8.3)	26 (12.4)	34 (13.8)	69 (12.2)	
Other[c]	6 (5.6)	9 (4.3)	7 (2.8)	22 (3.9)	
Number of Living Children					
0	49 (45.4)	84 (40.0)	116 (47.0)	249 (44.1)	0.11
1	38 (35.2)	66 (31.4)	61 (24.7)	165 (29.2)	
≥ 2	21 (19.4)	60 (28.6)	70 (28.3)	151 (26.7)	
Marital Status					
Married	43 (39.8)	105 (50.0)	111 (44.9)	259 (45.8)	0.21
Not married	65 (60.2)	105 (50.0)	136 (55.1)	306 (54.2)	
Initiation of Prenatal Care during 1st Trimester					
Yes	77 (71.3)	169 (80.5)	189 (76.5)	435 (77.0)	0.20
No	31 (28.7)	41 (19.5)	56 (22.7)	128 (22.7)	
CHILD					
Birthweight					
< 2,500 grams	10 (9.3)	31 (14.8)	41 (16.6)	82 (14.5)	0.19
≥ 2,500 grams	98 (90.7)	179 (85.2)	206 (83.4)	483 (85.5)	
Preterm Birth					
< 37 weeks	11 (10.2)	29 (13.8)	45 (18.2)	85 (15.0)	0.12
≥ 37 weeks	97 (89.8)	181 (86.2)	202 (81.8)	480 (85.0)	
Gender					
Female	45 (41.7)	110 (52.4)	93 (37.7)	248 (43.9)	0.01*
Male	63 (58.3)	100 (47.6)	154 (62.4)	317 (56.1)	
Presence of Other Anomalies[d]					
Isolated	87 (80.6)	107 (51.0)	174 (70.5)	368 (65.1)	<0.00*
Multiple	21 (19.4)	103 (49.1)	73 (29.6)	197 (34.9)	

Table 2. Selected characteristics of children with orofacial clefts by cleft type during the first year of life in North Carolina, 1995–2002[a]

Characteristics	CL[b] N=108 (%)	CP[b] N=210 (%)	CLP[b] N=247 (%)	All OFC[b] N=565 (%)	P-value
SYSTEM					
Source of Prenatal Care					
Health department	60 (55.6)	139 (66.2)	151 (61.1)	350 (62.0)	0.17
Other	48 (44.4)	71 (33.8)	96 (38.9)	215 (38.1)	
Receipt of Maternity Care Coordination Services					
Yes	51 (47.2)	92 (43.8)	109 (44.1)	252 (44.6)	0.83
No	57 (52.8)	118 (56.2)	138 (55.9)	313 (55.4)	
Receipt of WIC					
Yes	81 (75.0)	139 (66.2)	167 (67.6)	387 (68.5)	0.26
No	27 (25.0)	71 (33.8)	80 (32.4)	178 (31.5)	
Birth Hospital Level of Care					
Level III	45 (41.7)	92 (43.8)	104 (42.1)	241 (42.7)	0.91
Community/Other	63 (58.3)	118 (56.2)	143 (57.9)	324 (57.4)	
Perinatal Care Region					
Northwestern	30 (27.8)	58 (27.6)	55 (22.3)	143 (25.3)	0.44
Southwestern	18 (16.7)	26 (12.4)	52 (21.1)	96 (17.0)	
Northeastern	18 (16.7)	37 (17.6)	37 (15.0)	92 (16.3)	
Southeastern	15 (13.9)	23 (11.0)	36 (14.6)	74 (13.1)	
Eastern	18 (16.7)	41 (19.5)	40 (16.2)	99 (17.5)	
Western	9 (8.3)	25 (11.9)	27 (10.9)	61 (10.8)	

[a] All children with OFC who were continuously enrolled in Medicaid during the first year of life (n=565).
[b] CL = cleft lip only; CP = cleft palate only; CLP = cleft lip with cleft palate; OFC = orofacial clefts
[c] Other includes Native American, Asian/Pacific Islander and other Non-white
[d] Isolated anomaly = orofacial cleft diagnosis only; multiple anomalies = orofacial cleft + other birth defect diagnosis
[*] $P < 0.05$

the 565 children with OFC who were continuously enrolled in Medicaid during the first year of life, six children had missing data for one or more of the variables analyzed. Because this represented only 1.1 percent of the entire dataset, missing data had very little effect on the results. Consequently, these children were not deleted from the dataset; however, they were deleted in the analyses.

This study was approved by the University of North Carolina at Chapel Hill Public Health Institutional Review Board (IRB), the North Carolina Division of Public Health IRB, and the North Carolina Division of Medical Assistance.

Statistical Analyses

Relationships between maternal, child, and system characteristics and cleft type were assessed using Pearson chi-square if cell sizes were greater than five or Fisher's exact tests if cell sizes were less than five. All analyses were conducted using SAS software, version 9.1.

Results

Sample Population Characteristics

For children with OFC continuously enrolled in Medicaid during the first year of life (n=565), the distributions of maternal, child, and system characteristics among the cleft types were similar except for maternal age, maternal education, child's gender, and presence of other anomalies (Table 2). Children with CLP were significantly more likely to be male and were more common among mothers with less than a high school education. About 65 percent of the study population had isolated clefts, and multiple anomalies were significantly more common among children with CP. The percentages of mothers receiving maternity care coordination (MCC) services, WIC, and prenatal care at a health department were higher among study participants than among all mothers giving birth in North Carolina during this time period.

Timeliness of Primary Cleft Surgery and Specialized Services

As shown in Table 3, about 78 percent of children with OFC received primary cleft surgical repair within the first 18 months of life. Among those who received timely primary cleft surgery, the mean age at which surgery occurred was five months. About 88 percent of children with CL received primary surgery within the first six months of life and 58 percent of children with CP received primary surgery within 18 months of life. The average age that primary cleft surgery occurred was similar for children with CL with or without CP, about three months. Children with isolated clefts were more likely to receive surgery within 18 months of life than children with multiple anomalies (84% vs. 69%).

During the first year of life, speech and language therapy was the most commonly used service (51.2%) followed by audiology services (28.3%) and ENT care (20.0%). Children with CL had the lowest percentage of receipt of these specialized services (Table 4). Except for speech and language therapy, much less than half of the children with OFC received timely services according to the ACPA recommendations (Table 5).

Table 3. Timely receipt and average age primary cleft surgery occurred among children with orofacial clefts during the first two years of life in North Carolina, 1995–2002[a]

	Received within ACPA Recommendations[b]			Average Age in Months That Surgery Occurred (Range)
	N	Yes N (%)	No N (%)	
Cleft Type				
Cleft lip	75	66 (88.0)	9 (12.0)	3 (1, 5)
Cleft palate	150	87 (58.0)	63 (42.0)	10 (0, 17)
Cleft lip with cleft palate	183	164 (89.6)	19 (10.4)	4 (0, 16)
All orofacial clefts	406	317 (78.1)	89 (21.9)	5 (0, 17)
Presence of Other Anomalies[c]				
Isolated	260	217 (83.5)	43 (16.5)	5 (0, 17)
Multiple	146	100 (68.5)	46 (31.5)	6 (1, 16)

[a] All children with OFC who were continuously enrolled in Medicaid during the first two years of life (n=406).
[b] The American Cleft Palate-Craniofacial Association (ACPA) recommends primary cleft repair within the first six months of life for children with cleft lip and within 18 months of life for children with cleft palate with or without cleft lip.
[c] Isolated anomaly = orofacial cleft diagnosis only; multiple anomalies = orofacial cleft + other birth defect diagnosis

Discussion

Results from this study show that most Medicaid children with OFC received primary cleft surgical repair within the ACPA recommendations. These results substantiated our hypothesis. In contrast, most children did not receive other recommended specialized services during the first two years of life.

In North Carolina, seven craniofacial teams and centers exist and are located in certain geographic locations throughout the state.[6] However, there are none in the southeastern and western perinatal care regions of the state (Figure 1), which may have influenced our results.

Differences in services and treatment between and within craniofacial centers and teams may affect timeliness of services.[7] For example, some craniofacial teams may provide no direct clinical treatment, but only evaluation and quality assurance. In comparison, craniofacial centers usually provide more services and treatment. Differences may also exist in the number and types of services the centers and teams offer such as some centers and teams offer dental and orthodontic care whereas some may not. Craniofacial centers and teams vary in their capacity to treat patients with clefts and/or other craniofacial conditions as well.[6,7] Despite the ACPA recommendations, differences can exist between the plastic and oral and maxillofacial surgeons regarding treatment options with pre- and post-surgical orthodontic appliances and with presurgical orthopedics like nasal moldings in infancy.

Our results may also be affected by parental perception of need and cleft severity. Orofacial clefts, especially CL, are readily apparent at birth. Compared to other more severe birth defects, this type of birth defect can be readily and sometimes easily treated, especially CL alone. Consequently, parents usually see and understand the need to medically repair the cleft. Parents may place a higher priority on repairing the cleft rather than obtaining specialized services like dental, speech, language, and audiology services that children might need.[8–12]

Low dental service use may be due to parents not recognizing the need for dental care for their children with OFC.[13] Additionally, most children do not see a dentist during infancy.[14,15] However, it is important for children with OFC to see a dentist in the first year of life due to the need of specialized oral health services and higher risk of a variety of oral health conditions such as dental caries and periodontal disease.[14,16–18] This is a need that is clearly not being met and was recently recognized as such by the American Academy of Pediatric Dentistry.[19] Low dental use could also be explained by low or no reimbursement from Medicaid for specialized dental and orthodontic care of children with OFC and/or the low number of dentists specialized to treat children with OFC.[17,19–21]

Our results may also be influenced by how specialized services are being billed by the service provider. For example, children enrolled in Medicaid may have received services and treatment, but had another payor source and/or went to hospitals where services and treatment were free. At St. Jude Children's Research Hospital in Memphis, Tennessee, and Children's Hospital of the King's Daughters in Norfolk, Virginia, children with OFC can receive services and treatment for free. State-financed and private sources of care such as the Shriners Hospitals for Children also exist that can pay for services and treatment for children with OFC.[22] The extent to which this occurred and its effect on our results are unknown.

During well-child care visits, hearing screening and dental services are supposed to be rendered, along with vision and medical check-ups and referrals for treatment. Hence, hearing screening and dental services may be captured under the Medicaid well-child care paid claims. Yet, such services could not be specifically identified from these paid claims and thus were not included in the analysis.[1,23–26] Consequently, this may have led to an underestimation of children with OFC receiving timely dental and hearing care.

Some other potential limitations are exclusion of generic procedural codes for office visits and inadvertently omitting other related procedural codes. Some craniofacial centers and teams in

North Carolina used generic CPT codes for specific services such as ENT services and pediatric and general dentistry. These codes were excluded from the analysis because the specific services rendered at these visits were unable to be determined. In addition, it is possible that other relevant current procedural terminology and diagnostic-related group codes were inadvertently omitted from the analysis. Some children could have received specialized services, but were not captured in these results, which may have biased the results.

This study represents children with OFC who were enrolled in Medicaid, a subpopulation of children in the state. Thus, these results may not be representative of all children with OFC receiving services and treatment. Receipt and timeliness of services can vary by type of health insurance due to different referral policies and reimbursement rates.[27,28] Restricting the study sample to those children continuously enrolled in Medicaid provided a more homogeneous population and reduced the potential for confounding by socioeconomic status. Medicaid paid claims also include information on services and treatment received outside of North Carolina that were reimbursed by Medicaid, which provided a more comprehensive analysis of timeliness of services.[29]

Despite these limitations, this study had several strengths, including the use of a population-based birth defects registry to verify birth defect diagnoses. This study demonstrates how useful existing surveillance systems can be in analyzing timeliness of services for children with OFC and children with other birth defects.

This study provides unprecedented data on the proportion of children with OFC receiving primary cleft surgery and specialized services. This is the first study to examine the timeliness of services, such as primary cleft surgery and speech and language therapy, per the ACPA recommendations and by cleft type and presence of other anomalies. These data can identify populations in need of services to better target resources and better understand barriers to accessing services. This is particularly important as children with OFC are at increased risk for learning disabilities and hearing loss. Timely receipt of speech and language therapy and audiology services is critical to helping children with OFC reach their full potential. Understanding the nature of receipt of timely services among children with OFC is also important for health planning efforts and service delivery by public agencies such as federal, state, and local Title V Children with Special Health Care Needs programs.[30]

One of the reasons for the shortage of health care professionals specifically trained to treat children with OFC is low reimbursement rates. In addition, third party payers have refused to pay for oral health services even if they are associated with the OFC.[19,31] Having both insurance and access to medical and specialized services for children

Table 4. Receipt of specialized services among children with orofacial clefts by cleft type during the first year of life in North Carolina, 1995–2002

Service	CL[a] N=108 (%)	CP[a] N=210 (%)	CLP[a] N=247 (%)	All OFC[a] N=565 (%)
ENT care	5 (4.6)	46 (21.9)	62 (25.1)	113 (20.0)
Audiological assessment	16 (14.8)	69 (32.9)	75 (30.4)	160 (28.3)
Speech and language therapy	30 (27.8)	108 (51.4)	151 (61.1)	289 (51.2)
Dental	13 (12.0)	30 (14.3)	47 (19.0)	90 (15.9)
Psychological and social services	13 (12.0)	28 (13.3)	29 (11.7)	70 (12.4)

[a] CL = cleft lip only; CP = cleft palate only; CLP = cleft lip with cleft palate; OFC = orofacial clefts

Table 5. Timeliness and receipt of specialized services among children with orofacial clefts during the first two years of life in North Carolina, 1995–2002

Service	Received within first two years of life (N=406) Yes N (%)	Timely[a] (N=565) Yes N (%)	Received in Year 1 and Year 2 (N=406) Yes N (%)
ENT care	101 (24.9)	44 (7.8)	44 (10.8)
Audiological assessment	118 (29.1)	160 (28.3)	50 (12.3)
Speech and language therapy	198 (48.8)	289 (51.2)	134 (33.0)
Dental	67 (16.5)	90 (15.9)	21 (5.2)
Psychological and social services	51 (12.6)	70 (12.4)	51 (12.6)

[a] Timely services (within the first year of life) as defined by the 2000 ACPA: ENT care recommended within the first six months of life. Audiological assessment, speech and language therapy, dental services, and psychological and social services, including screening evaluations, recommended within first 12 months of life.

with OFC are imperative to their overall health and psychosocial well-being and ability to fully function in life.

These data also provide opportunities for craniofacial centers and teams, birth defects surveillance programs, hospitals, and local, state, and national programs and organizations to work collaboratively on increasing access to care for children with OFC. Service coordination for children with OFC is an entitlement under the United States Individuals with Disabilities Education Act and a mandate under Title V. State-based care coordination programs for children with OFC in North Carolina include the Early Intervention/Infant-Toddler Program and the Child Service Coordination Program. National organizations such as the ACPA, Cleft Palate Foundation, and Family Voices provide opportunities for birth defects programs and craniofacial teams to collaborate and partner together to improve the lives of children with OFC. Members of these organizations and programs can help create and evaluate referral systems to help families of children with OFC obtain the resources and services they need. They can also inform and ensure families that their children are eligible for certain services and that families have the information they need to make informed decisions about their child's care.

Because the billing codes used in this study may have resulted in an underestimation of the services that children with OFC receive, future research should closely examine the billing practices and services covered for Medicaid and other insurers in order to determine the best list of codes to use for assessing services received by children with OFC. Additional research should also include the location of services received to determine if there are geographical barriers to accessing care for this population, such as distance to craniofacial centers or teams. Future research should also include an assessment of health outcomes of children with OFC to determine appropriate benefit packages and efficient payment mechanisms for both private and public health insurance systems.[30]

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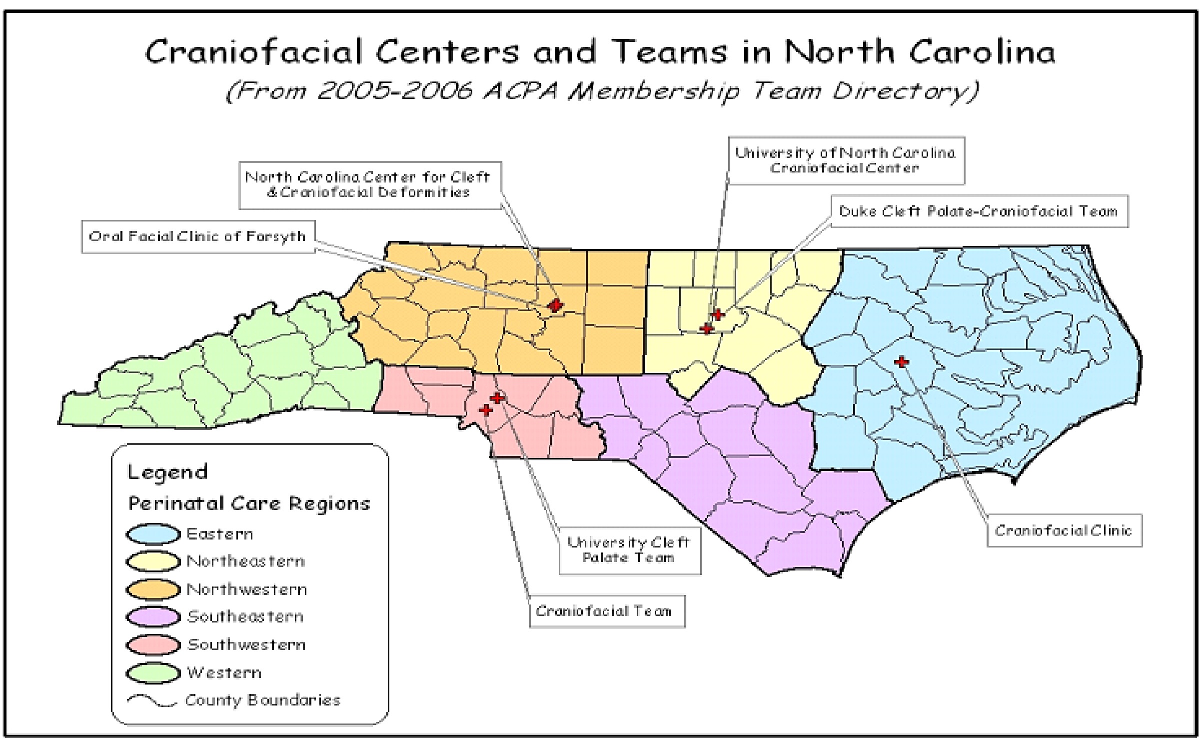
Figure 1



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