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Timeliness of Primary Cleft Surgical Repair for Children with Orofacial Clefts

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B.A. International Studies
The Ohio State University
2011

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An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
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Abstract

Timeliness of Primary Cleft Surgical Repair for Children with Orofacial Clefts

By Chelsea M. Rienks

Background: Information regarding use of team care for children with orofacial clefts (OFCs) and timeliness of primary surgical cleft repair in the United States is lacking. **Methods:** This statewide, population-based study included children born with OFCs between 1998 and 2007 in Florida. Eligible children were identified by the Florida Birth Defects Registry and linked with inpatient records beyond the first year of life. Descriptive results were reported both by overall and stratified by cleft type (cleft lip with cleft palate (CLP), cleft lip (CL) and cleft palate (CP)) and by isolated and non-isolated OFCs. We fit Poisson regression models to assess the associations between use of team care and timeliness of primary surgery (12 months for CL and 18 months for CLP and CP). **Results:** Analyses included 1,708 children with OFCs. The majority of children received team care (n= 1,577: 92.3%) and timely primary cleft surgery (n=1,633: 95.6%). Use of team care was not meaningfully associated with timelines of primary surgery, regardless of cleft type or isolated vs. non-isolated clefts. **Conclusion:** The majority of children are receiving team care and timely primary surgery. Although team care was not associated with timeliness of primary surgery, it likely improves care of children with OFCs in other ways.

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Chelsea M. Rienks

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Chapter 1: Literature Review:

Part I: Introduction:

Orofacial clefts (OFCs) include cleft lip alone (CL), cleft palate alone (CP), and cleft lip with cleft palate (CLP). In the United States, OFCs occur in 14.5 per 10,000 live births annually or approximately 1 in 690 births [1]. The distribution of clefts by infant gender is known to differ, as CLP and CL are more common among males (CLP 60%, CL 61%) and CP is more common among females (55%) [1]. Additionally, prevalence estimates are known to differ by maternal race and ethnicity [1]. While the prevalence estimates for OFCs are known and the literature examines how OFCs can affect a child's quality of life, it is not fully understood how team affects the timeliness of primary surgical repair.

Part II: Epidemiology of Orofacial Clefts

I. Terminology:

The majority of OFCs are considered malformations due to the abnormal embryologic tissue growth and fusion [2]. While it is possible for a secondary deformity to occur, the OFC itself is considered a malformation, regardless of the presence of secondary conditions [2]. In general, isolated OFC signifies either a CP without CL or the presence of a cleft without other major malformations or anomalies [2]. For purposes of this study, isolated OFC will be defined as having no other International Classification of Disease, 9th Edition, Clinical Modification (ICD-9-CM) codes for any major birth defect, but the presence of other minor birth defects may occur [2-4]. OFCs can be syndromic if the malformation occurs in conjunction with additional malformations in other areas of the body or developmental fields [2].

II. Classification:

Within OFCs, many variations exist in the type and severity of the OFC. For the purposes of this study, data will be classified as isolated and non-isolated CL, CP, and CLP. Cleft lip occurs in a complete or incomplete form as well as bilateral, unilateral, or central form [1, 5]. A complete CL refers to a cleft of the upper lip and alveolus terminating at the floor of the nose [5]. An incomplete CL may or may not affect the alveolus, and will not reach the floor of the nose [5]. Complete and incomplete CLs can be bilateral, unilateral, or central [1, 5].

Similar to CL, CP also occurs in a complete and incomplete form, as well bilaterally, unilaterally or centrally [1, 5]. A complete CP is a hole or separation in the primary and secondary palate, while an incomplete CP is limited to the secondary palate, but may be of the hard and soft or only soft palate [1, 5]. All combinations of complete and incomplete, bilateral, unilateral and central can occur in CLP [1, 5].

III. Prevalence Estimates in the United States:

OFC occurrence is measured by prevalence estimates. Incidence measures are unable to be calculated due to pregnancy losses, which prevent the quantification of the number of conceptions reaching the gestational age at which an OFC occurs [2]. As prevalence estimates of OFCs begin at time of delivery, not conception, this measure provides a more accurate measurement of OFC occurrence at birth [2].

In the United States, OFCs are one of the most common birth defects [1, 6]. Recent prevalence estimates indicate CL occurs in 3.1 per 10,000 live births, CLP in 5.6 per 10,000 live births, and CP in 5.9 per 10,000 live births annually [1]. The unadjusted prevalence estimates of OFCs are 14.5 per 10,000 live births annually in the United States or approximately 1 in 690 births [1].

Prevalence estimates differ slightly by infant sex. Males have a higher prevalence for CL, CLP, and overall OFCs (60%, 61%, and 54% respectively), while females have a higher prevalence for CP (55%) [1]. Maternal age also can influence the prevalence of OFCs with increased prevalence among mothers greater than 35 year of age compared to mothers less than 35 years of age [1]. The prevalence of CP alone increases most notably in mothers 40 years of age and older when compared to other cleft types (7.9 (CP), 7.0 (CLP) and 4.0 (CL) per 10,000 live births) [1]. Prevalence estimates also vary by maternal race and ethnicity. However, the differences are difficult to quantify due to small numbers of live births with OFC in certain minority racial and ethnic groups, such as non-Hispanic American Indians/Alaska Natives [1].

Part III: Quality of Life, Timeliness of Primary Surgery and Team Care:

I. Quality of Life:

OFCs are known to affect both the child and family's quality of life. Children with OFCs tend to report lower health status and are twice as likely to be identified as having a special health care need than children without an OFC [7]. From an early age, children with OFCs experience initial complications such as ear infections and problems feeding,

and they can experience long term adverse outcomes such as learning problems and impairment of speech and language [8-10].

A child's speech ability has also been linked to quality of life indicators [11]. Many children born with OFCs have speech difficulties and report feeling frustrated due to problems with being understood [11]. Studies using the Pediatric Quality of Life Inventory (PedsQL) indicate children with CL or CLP had significantly poorer scores than children without OFCs. Further, for children with OFCs, Peds QL scores improved as the severity of their speech problem decreased [12]. A child's speech ability additionally affects quality of life through development delays, receipt of lower letter grades, and increased days absent from school [10]. Additionally, OFCs have been linked with quality of life issues such as social stigma pertaining to appearance, speech ability, and overall oral health concerns [9, 13].

Due to these potential health outcomes, quality of life among children with OFCs and their families has been identified as a public health priority area for both research and intervention [14].

II. Timeliness of Primary Surgery:

To address the differences in quality of life between children with OFCs and those without OFCs, multiple studies have sought to identify what factors impact overall quality of life [15-17]. A few studies on timeliness of primary surgery suggest an improved quality of life as well as other positive outcomes for children with OFCs [15-17]. Timeliness of primary surgery is essential for starting the reconstruction process, to yield proper function of the lip and palate for improved development and speech

outcomes [17]. For children with CL, primary surgical repair serves to adhere the lip, repair the nasal deformity and properly align the gum line and floor of the nose [17]. For children with CP, primary surgical repair allows for closure of the palate, which assists with improving speech, facial growth and Eustachian tube function [17]. Both primary surgeries advance speech, language, dental, and psychosocial outcomes, which can lead to improved quality of life [17].

A crucial part of primary cleft surgery is the timing. In theory, the earlier a child can begin to recover the normal function of the craniofacial area, the greater the likelihood of better medical and academic outcomes [16]. However, the actual timing of primary surgery needs to account for balancing the possibility for abnormal craniofacial growth if the surgery occurs too early with the potential for speech or other medical and health complications if not repaired in a timely manner [16].

The American Cleft Palate-Craniofacial Association (ACPA), the nationally recognized professional organization for cleft and craniofacial anomalies in the United States, has developed guidelines for timely primary CL, CP and CLP surgical repair [15]. According to ACPA's Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate of Other Craniofacial Anomalies, primary surgical repair of a CL should occurs as early as is considered safe for the child and ideally prior to 12 months of life [15]. For children with CLP and CP, primary surgery should also occur as early as is considered safe for the child, and ideally prior to 18 months of life [15].

III. Team Care:

The purpose of a cleft team is to provide case management to ensure quality and continuity of care for the life of an individual with an OFC [15]. Cleft and craniofacial teams assist families by providing accurate information both pertaining to OFCs as well as health outcomes that may occur in the life of child with an OFC [13]. To be classified as a team, health care providers must meet eight basic criteria along with 30-35 additional criteria [18].

1. The cleft palate team (CPT) meets face-to-face for regularly scheduled meetings for treatment planning and case review, at least six times per year, with at least four specialties represented.
2. The CPT evaluated at least fifty new or recall patients with cleft lip/palate in the past year.
3. The CPT keeps a central and shared file on each patient.
4. The CPT has at least an actively involved surgeon, orthodontist and speech-language pathologist, who attend team meetings. At a minimum, patients evaluated by the CPT are seen by these specialties plus at least one additional team specialty that attends the CPT meetings.
5. The CPT assures that each child has a health evaluation by a primary care physician (pediatrician, family physician or general internist) in the community or on the team. The CPT uses the findings from the health evaluation to guide its treatment planning and team meeting deliberations.
6. Evaluations at the CPT include a screening hearing test and tympanogram. All patients with CP, or hearing concerns, or abnormal tympanograms or hearing

tests, are referred to an Otolaryngologist (E.N.T.) for examination, consultation, or treatment.

7. At least one surgeon on the CPT operated on ten or more patients for primary repairs of a cleft lip and/or cleft palate in the past year.
8. For patients requiring facial skeletal surgery, the CPT has or refers to a surgeon whose education, training and experience has adequately prepared him/her to provide facial skeletal surgery (bone graft, orthognathic surgery) and who has performed ten or more major maxillary or mandibular osteotomies in the past year (not necessarily on patients with cleft lip and/or cleft palate) [18].

Cleft and craniofacial teams are typically comprised of a variety of medical disciplines including, but not limited to: audiology, diagnostic medical imaging/radiology, genetic counseling, neurosurgery, oral and maxillofacial surgery, orthodontics, pediatrics, pediatric dentistry, plastic surgery, psychology and speech-language pathology [15]. Together, these teams are responsible for coordinating the implementation of treatment plans for children with OFCs and other craniofacial conditions [15, 19].

As outlined by the ACPA, a vital part of team care is the structured longitudinal evaluation and treatment of individuals with OFCs [15]. A crucial part of this care, is the timing of primary surgical repair depending on the factors present in each child [15]. A few studies have found that factors, such as maternal race/ethnicity, geographic location, payer status and cleft type, can influence a child's ability to receive timely primary surgical repair. The effect of receiving care from a team on timeliness of primary surgery has not been previously studied and thus is not well understood [16, 17].

Within the state of Florida the facilities in Appendix Table 1 are classified as offering cleft and craniofacial team care as defined by the ACPA and the Florida Cleft Palate-Craniofacial Association from 1998-2009 [20, 21].

Part IV: Current Literature and Study Justification:

At this time, no literature exists that assesses the relationship between timeliness of primary cleft surgery (outcome) and use of team care (exposure).

I. Team Care as an Exposure:

One previous study sought to demonstrate how team care could be associated with parental perception of better outcomes for children with OFCs [22]. This study used population based data from three states, linking maternal survey data from the National Birth Defects Prevention Study (NBDPS) with birth defects registries that identified infants with OFCs [22]. Maternal perception of child outcomes was assessed using qualitative methods [22].

Approximately 75% of children with OFCs were enrolled in team care, but this percent varied by cleft type [22]. Receipt of team care was not associated with maternal perception of better outcomes for children with OFCs [22]. However, the authors stated that using qualitative measures for maternal response to cleft team care may not have been the best measure to assess team care's effect on maternal perception of child outcomes, as it may not accurately reflect quality of care [22].

The authors also suggested team care may have been misclassified because children were only classified as receiving team care if they were receiving team care at the time the

maternal survey was conducted [22]. The authors also concluded that combining data from three states without measuring indicators that would affect the quality of care such as patient volume or staff experience did not account for possible differences in perceived outcomes by state in which children received care [22].

Further, the study was potentially limited by selection bias. Mothers who completed the survey had on average completed higher levels of education and were mostly non-Hispanic, white women, both of which were associated with use of team care and may have related to perceived quality of care [22].

II. Timeliness of Primary Surgery as an Outcome:

Another study sought to determine what factors were associated with receipt of timely primary cleft surgery for children with OFCs [17]. Population-based, state-wide birth defects data from the North Carolina Birth Defects Monitoring Program (NCBDMP) were linked to vital statistics, health services, and Medicaid enrollment records and paid claims data [17]. Team care use was evaluated to assess whether proximity to cleft craniofacial teams affected timeliness of primary surgery [17].

The authors reported that 78% of children with OFCs received timely primary surgery during the first two year of life. The authors found that receipt of maternal care coordination resulted in children being twice as likely to receive timely surgery compared to children of mothers without care coordination. Children living outside metropolitan areas in the state were 77% less likely than children living within metropolitan areas to receive timely surgery [17]. Maternal race was associated with timeliness of primary surgery: black, non-Hispanic children were 70% less likely and Hispanic children were

14% less likely than white, non-Hispanic children to receive timely surgery [17]. Although timeliness of primary surgery differed significantly by cleft type and by isolated vs. non-isolated OFC, overall, the majority (78%) of children received primary surgery prior to 18 months of life [17].

This study acknowledged limitations of the data, such as if children received care from non-Medicaid sources or for free. The outcome may have been misclassified because surgery would not have been recorded in the Medicaid paid claims. Other limitations included the inability to measure other factors such as service refusal and changing health and Medicaid policies [17].

While this study used population-based data, the sample was limited to children receiving Medicaid services and treatment. Therefore, it was representative of children receiving Medicaid and those children may have been more or less likely to receive timely primary surgery than children with no insurance, under insured children or those who were privately insured [17].

III: Study Justification:

Conducting a study that examines the association between timeliness of primary cleft surgery and use of team care for children with OFCs is justified because this association has not been studied. Further, the Centers for Disease Control and Prevention (CDC) sponsored an expert meeting where subject matter experts assisted in establishing these topics as a public health research priorities for OFCs [14]. This study will classify team care based on its availability at the location of primary surgical repair rather than maternal report to reduced recall bias. Selection bias will be minimized by the use of

statewide birth certificate, birth defects registry and hospital discharge data as opposed to a mother's willingness to complete a survey. The association between quality of life and team care will not be examined.

Chapter 2:

In the United States, Orofacial clefts (OFCs) occur in approximately 14.5 per 10,000 live births, rendering OFCs one of the most common birth defects in the United States [1, 6]. Orofacial clefts include: cleft lip alone (CL), cleft palate alone (CP) and cleft lip with cleft palate (CLP). Recent prevalence estimates indicate CP occurs in approximately 5.9 per 10,000 live births, CL occurs in 3.1 per 10,000 live births and CLP occurs in 5.6 per 10,000 live births [1]. The high prevalence of OFCs has helped reaffirm OFC research as a public health research priority [1, 14].

Specifically, quality of life for children with OFCs has been identified as an area where access to a team of specialists may improve outcomes [14]. It is hypothesized that the use of a cleft and craniofacial team yields a more organized, informed, and timely approach to manage and treat OFCs, and thus has the potential to improve long-term outcomes for individuals with OFCs [14, 17].

Timing of primary surgery has been established as both an indicator for efficacy of a cleft and craniofacial team as well as an indicator for quality of life and positive outcomes of the child [4, 6, 15, 16]. The American Cleft Palate-Craniofacial Association (ACPA) defines timely surgery as occurring within the first 12 months of life for CL and within the first 18 months of life for CP and CLP in the Parameters for Evaluation and Treatment of Patients with Cleft Lip/Palate or Other Craniofacial Anomalies [15]. ,

To date, studies have examined timeliness of primary surgery irrespective of use of team care [16, 17]. The primary objective of this study will be to examine the effect of using a cleft and craniofacial team on the timeliness of primary cleft surgical repair, using a population-based sample.

Methods

The study population was comprised of children with OFCs born between January 1, 1998, and December 31, 2007, identified by the Florida Birth Defects Registry (FBDR). The FBDR is a passive, statewide, population-based surveillance system that identifies infants with birth defects during the first year of life [23-25]. The FBDR files are a composite of Florida vital statistics data matched with newborn hospitalization records and post-birth hospitalizations data through age one [23-25]. Study data were derived from FBDR and linked to data from Florida's Agency for Health Care Administration (AHCA), after the first year of life. AHCA collects and reports on hospital inpatient ambulatory, outpatient, and emergency department discharge data from an array of facilities, including acute care hospitals, short-term psychiatric facilities, comprehensive rehabilitation facilities, ambulatory surgical centers, and cardiac catheterization laboratories [23-25].

For this study, eligible children's records from FBDR were linked with longitudinal hospital discharge data from January 1, 1998 through December 31, 2009 [3]. This allowed two years of follow-up to assess timeliness of primary cleft surgery. The study population included children with an International Classification of Disease, 9th revision; Clinical Modification (ICD-9-CM) code in the FBDR for OFCs (749.00–749.25) [4]. Isolated OFCs were defined as having no other ICD-9-CM code for any major birth

defect, but the presence of other minor birth defects was permitted. Non-isolated OFC were defined as the presence of any other ICD-9-CM code for a major, related birth defect in addition to OFC [2-4]. The presence of an ICD-9-CM code for single gene or chromosomal syndrome with OFC was also classified as non-isolated. This study was approved by the Institutional Review Boards at Emory University and the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities.

Information regarding date of primary surgery, facility location, and procedure type was provided from AHCA data. To determine if a child received timely primary surgery, all surgical codes during the study period (1998-2009) were examined. A craniofacial surgical specialist determined and verified the ICD-9-CM surgical codes indicative of primary surgery. Using date of birth and date of primary surgery, surgical codes present within 12 months of life for CL were considered timely and those within 18 months of life for CLP and CP were considered timely [16, 17]. In consultation with cleft and craniofacial surgeons, it was decided to limit the follow-up period to two years after the date of birth for identification of dates of primary surgery. Surgical codes present past the cut off for timely surgery, but within two years of birth were considered not timely. Children without a date of primary surgery within the first two years of life were excluded, because it was assumed they received surgery elsewhere, or did not receive primary cleft surgery.

The exposure of interest, receipt of team care from an established cleft and craniofacial team in Florida, was based on the provider list from the APCA and the Florida Cleft Palate-Craniofacial Association, which identifies hospitals or clinics that provide cleft

and craniofacial team care in Florida (Appendix Table 1). To determine whether a child received team care, facility codes were matched with lists of facilities offering team care at time of primary surgery during the study period. Children receiving primary surgical repair at a facility offering team care were classified as receiving team care. Children receiving primary surgery at facilities not listed as offering team care were classified as not receiving team care.

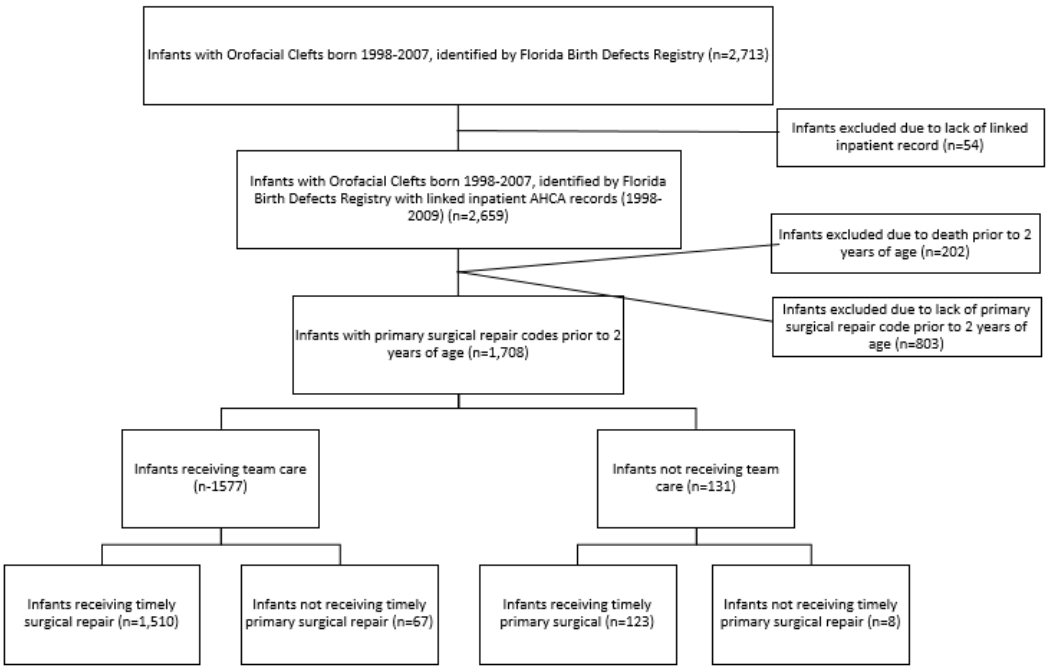
Maternal and child demographic characteristics were based on the FBDR data. Infant's date of birth, date of death, maternal age, maternal race/ethnicity, maternal education, receipt and initiation of prenatal care, and other information was abstracted from the birth certificate and fetal and child death certificates. Adopted children, prospective adoptees, and children whose mothers delivered out-of-state were excluded from this analysis because the FBDR did not capture their information. Covariates of interest included: maternal race/ethnicity, maternal age, maternal education, maternal nativity, marital status, adequacy of prenatal care (Kotelchuck Index), plurality, gender of child, gestational age, birth weight, and principal payer at time of primary surgery.

Descriptive analysis examining demographic characteristics of mothers and children with OFCs were performed, stratified by team care and cleft type. Further descriptive analyses were conducted to assess differences in maternal and child characteristics by timeliness of primary surgery and cleft type. Distribution of the median month of primary surgery was assessed by cleft type and presence of other birth defects.

Poisson regression models were fit to assess the relationship between team care and timeliness of primary surgery. Unadjusted models were fit for all OFCs and stratified on

cleft type. All variables of interest were included in each model. For adjusted models, covariates were selected a priori based on prior studies. [2-4]. All analyses were performed using SAS version 9.3 (SAS Institute Inc. Cary, NC).

Figure 1: Flow Chart of Inclusion and Exclusion Criteria and Study Sample for Team Care and Timeliness of Primary Cleft Surgery for Children Born with Orofacial Clefts in Florida, 1998-2007



Results

The FBDR included 2,659 children born with OFCs between 1998 and 2007 and these children were linked to AHCA data through 2009 (Figure 1). Of these, 202 children were excluded because of death during the time frame for timely surgical repair. An additional 803 children were excluded from analysis due to lack of linked AHCA surgical code for primary cleft surgical repair before 2 years of age The remaining 1,708 children were included in the study sample with the cleft type distribution being 56.1% CLP (n=951), 15.5% CL (n=265), and 28.9% CP (n=492).

Crude data showed that 92.3% of children received team care and 95.6% of children received timely primary surgical cleft repair. Of those receiving team care, 95.8% had timely primary surgical cleft repair and among those not receiving team care, 93.9% of children received timely primary surgical cleft repair.

Regardless of cleft type, children with a public insurance payer at the time of primary surgery were less likely to use team care than children with a private payer, although differences were small for CLP and CP (CLP: 92.0% and 93.8%, CL: 85.3% and 94.0%, CP: 93.3% and 94.2%, public and private payer respectively) (Table 1). Black, non-Hispanic mothers were slightly less likely to use team care than white, non-Hispanic mothers for children with CLP and CL (87.5% vs. 94.5% (CLP)) and (82.1% vs. 89.5% (CL)). This difference was not observed for CP. Mothers who did complete a high school education were less likely to use team care for children with CL compared to mothers with some college education (83.3% vs. 93.5%). Infants who were born low birth weight

with CL were less likely to use team care than infants born normal weight (81.5% and 90.2% respectively).

Children of Hispanic mothers were less likely to receive timely primary surgery compared to white, non-Hispanic children for all cleft types, most notably for CP (88.9% and 94.2% respectively) (Appendix Table). Children with CP whose mothers were less than 20 years of age were less likely to receive timely primary surgery than children of mothers of all other ages, but most notably compared to mothers 25-29 years of age (85.1% and 96.2% respectively).

The median time in months to primary surgery was less for children with team care, than children without team care for CLP (isolated: 4.2 vs 5.9 months, non-isolated:5.7 vs 7.8 months) (Table 2). For children with isolated CL, time to surgery was similar for those receiving team care and those who did not (4.0 vs 4.4 months), but for those with non-isolated CL, the median time to surgery was almost 6 months earlier for those with team care. However, this difference may be driven by the small number of children with non-isolated CL who did not use team care. For children with isolated and non-isolated CP, the median time until primary surgery was similar for those receiving and not receiving team care.

No association was observed between use of team care and timeliness of primary surgery for all OFCs or when stratified by cleft type for unadjusted estimates (Table 3). The results were similar for adjusted Poisson regression estimates.

Tables:

Table 1. Characteristics of Children Born in Florida 1998-2007 with Orofacial Clefts from the Florida Birth Defects Registry with Linked Longitudinal Discharge Data by Team Care Use. (n=1708)

	Team Care[a]					
	CLP (n=951)		CL (n=265)		CP (n=492)	
Maternal Characteristics:	Yes (n=881)	No (n=70)	Yes (n=237)	No (n=28)	Yes (n=459)	No (n=33)
Maternal Age						
<20	123 (91.1)	12 (8.3)	13 (NR)	NR	45 (NR)	NR
20-24	230 (92.4)	19 (7.6)	57 (90.5)	6 (9.5)	115 (92.7)	9 (7.3)
25-29	242 (93.1)	18 (6.9)	70 (88.6)	9 (11.4)	124 (93.9)	8 (6.1)
30-34	177 (91.2)	17 (8.8)	61 (89.7)	7 (10.3)	106 (93.0)	8 (7.0)
35-39	89 (NR)	NR	25 (NR)	NR	59 (NR)	NR
≥ 40	20 (NR)	NR	11 (NR)	NR	10 (NR)	NR
Maternal Race/Ethnicity						
White, Non-Hispanic	532 (94.5)	31 (5.5)	145 (89.5)	17 (10.5)	285 (92.5)	23 (7.5)
Black, Non-Hispanic	105 (87.5)	15 (12.5)	23 (82.1)	5 (17.9)	59 (92.2)	5 (7.8)
Hispanic	219 (92.0)	19 (8.0)	58 (NR)	NR	96 (NR)	NR
Asian/Pacific Islander/American Indian/Alaska Native	23	NR	9 (NR)	NR	16 (NR)	NR
Other	NR	NR	NR	NR	NR	NR
Maternal Education						
12th grade or less, did not graduate	212 (91.8)	19 (8.2)	40 (83.3)	8 (16.7)	97 (94.2)	6 (5.8)
High school/equivalent	317 (94.1)	20 (5.9)	65 (86.7)	10 (13.3)	156 (93.4)	11 (6.6)
At least some college or university	349 (92.3)	29 (7.7)	130 (93.5)	9 (6.5)	205 (93.6)	14 (6.4)
Missing	NR	NR	NR	NR	NR	NR
Maternal Nativity						
Domestic Born	680 (93.5)	47 (6.5)	179 (89.5)	21 (10.5)	364 (92.9)	28 (7.1)
Foreign Born	200 (90.1)	22 (9.9)	58 (89.2)	7 (10.8)	94 (94.9)	5 (5.1)
Missing	NR	NR	NR	NR	NR	NR
Maternal Marital Status						
Married	511 (92.6)	41 (7.4)	150 (89.8)	17 (10.2)	266 (94.0)	17 (6.0)
Single	370 (92.7)	29 (7.3)	87 (88.8)	11 (11.2)	193 (92.3)	16 (7.7)
System Characteristics:						
Adequacy of Prenatal Care[b]						
Adequate/Adequate plus	664 (93.0)	50 (7.0)	170 (89.9)	19 (10.1)	333 (94.1)	21 (5.9)
Intermediate	79 (94.0)	5 (6.0)	21 (NR)	NR	44 (89.8)	5 (10.2)
Inadequate	97 (93.3)	7 (6.7)	22 (NR)	NR	49 (NR)	NR
Missing	41 (83.7)	8 (16.3)	24 (NR)	NR	33 (NR)	NR
Principal Payer at Primary Surgery[c]						
Public	551 (92.0)	48 (8.0)	110 (85.3)	19 (14.7)	264 (93.3)	19 (6.7)
Private Insurance	323 (93.6)	22 (6.4)	126 (94.0)	8 (6.0)	194 (94.2)	12 (5.8)
Self-Pay/uninsured	7 (NR)	NR	NR	NR	NR	NR

Child Characteristics:						
Gender						
Male	551 (92.0)	48 (8.0)	152 (90.5)	16 (9.5)	194 (95.1)	10 (4.9)
Female	330 (93.8)	22 (6.3)	85 (87.6)	12 (12.4)	265 (92.0)	23 (8.0)
Gestational Age						
Very preterm birth (20-31 weeks)	25 (NR)	NR	7 (NR)	NR	13 (NR)	NR
Preterm birth (32-36 weeks)	120 (94.5)	7 (5.5)	33 (NR)	NR	65 (NR)	NR
Term (37-44 weeks)	735 (92.3)	61 (7.7.)	197 (88.3)	26 (11.7)	381 (92.7)	30 (7.3)
Missing	NR	NR	NR	NR	NR	NR
Birth Weight						
Very low birth weight (1250-1500g)	24 (NR)	NR	NR	NR	9 (NR)	NR
Low birth weight (1500-2500g)	108 (93.9)	7 (6.1)	22 (81.5)	5 (18.5)	73 (NR)	NR
Normal birth weight (2500-6000g)	749 (92.5)	61 (7.5)	212 (90.2)	23 (9.8)	376 (92.6)	30 (7.4)
Missing	NR	NR	NR	NR	NR	NR
Plurality						
Singleton	859 (92.8)	67 (7.2)	225 (88.9)	28 (11.1)	439 (93.2)	32 (6.8)
Multiples	22 (NR)	NR	12 (NR)	NR	20 (NR)	NR
Timeliness of Primary Surgery[d]						
Yes	852 (92.8)	66 (7.2)	228 (89.8)	26 (10.2)	430 (93.3)	31 (6.7)
No	29 (NR)	NR	9 (NR)	NR	29 (NR)	NR

Abbrivations: CL: cleft lip, CLP: cleft lip and cleft palate, CP: cleft palate, NR: not reported due to cell counts ≤ 5

[a] Children receiving primary surgical repair at a facuilty with availabile team care was categorized as receiving team care.

[b]Adequacy of Prenatal Care Utilization (APNCU) Index is a measure of the adequacy of both initiation of and the receipt of prenatal care services; adequacy is classified as "inadequate", "intermediate", and "adequate/adequate plus".

[c] Private insurance included employer-based insurance (including military coverage, Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) and Tricare). Public Insurance included Medicare, Medicaid, and other state and local government insurance in Florida, such as state's Children's Health Insurance Program (CHIP), KidCare. Self or under-insured was defined as no

[d] Timely primary surgery was classified as primary surgery prior to 12 months of age for children with CL and primary surgery prior to 18 months of age for children with CLP and CP.

Table 2. Distribution of Time of Primary Surgery (in months) for Children Born in Florida 1998-2007 by Orofacial Cleft Type and Team Care[a] Use from the Florida Birth Defects Registry with Linked Longitudinal Discharge Data. (n=1708)

	Team Care					
	Yes			No		
Cleft Types	n	Median	IQR	n	Median	IQR
CLP						
Isolated[b]	612	4.2	2.8-7.3	52	5.9	3.3-10.8
Non-Isolated[c]	269	5.7	3.2-10.0	18	7.8	4.5-11.8
CL						
Isolated[b]	215	4.0	2.7-6.0	26	4.4	3.3-7.5
Non-Isolated[c]	22	5.0	3.4-8.3	NR	11.3	8.4-14.2
CP						
Isolated[b]	323	10.5	7.9-12.9	26	9.9	7.8-11.6
Non-Isolated[c]	136	11.6	8.2-14.4	7	11.4	6.9-14.1

Abbreviations: CL: cleft lip, CLP: cleft lip and cleft palate, CP: cleft palate, IQR: inter quartile range (25%-75%), NR: not reported due to cell counts < 5

[a] Children receiving primary surgical repair at a facuilty with availabile team care was categorized as receiving team care.

[b] Isolated = no *International Classification of Disease, 9th Revision; Clinical Modification* (ICD-9-CM) code for any other major birth defect present in the Florida Birth Defects Registry; could include minor birth defects or other birth defects related to orofacial clefts.

[c] Non-isolated = ICD-9-CM codes for other major birth defects present in the Florida Birth Defects Registry,

Table 3. Adjusted[a] Estimates of Prevalence Ratios for Association of Team Care[b] and Timeliness[c] of Primary Surgery for Florida-Born Children with Orofacial Clefts, 1998-2007, overall and stratified by cleft type.

	All OFCs		CLP		CL		CP	
Teamcare[b]	uPR (95% CI)	aPR (95% CI)	uPR (95% CI)	aPR (95% CI)	uPR (95% CI)	aPR (95% CI)	uPR (95% CI)	aPR (95% CI)
Yes	1.0	1.0	1.0	1.0	1.0	1.0	1.0	1.0
No	0.98 (0.93, 1.03)	0.97 (0.91, 1.03)	0.97 (0.91, 1.04)	0.96 (0.90, 1.03)	0.97 (0.86, 1.08)	0.99 (0.86, 1.13)	1.00 (0.88, 1.14)	0.97 (0.84, 1.11)

Abbreviations: aPR: adjusted prevalance ratios, CL: cleft lip, CLP: cleft lip and cleft palate, CP: cleft palate, CI: confidence intervals, OFCs: orofacial clefts, uPR: unadjuste

[a] All OFCs adjusted for maternal characteristics: age, race/ethnicity, education, marital status, nativity, system characteristics: adequacy of prenatal care, payer at time of primary surgery, child characterisitcs: gender, gestational age, birth weight, plurality, cleft type, presence of other birth defects.
CLP, CL and CLP stratified by cleft type and adjusted for: maternal characteristics: age, race/ethnicity, education, marital status, nativity, system characteristics: adequacy of prenatal care, payer at time of primary surgery, child characterisitcs: gender, gestational age, birth weight, plurality, presence of other birth defects.

[c] Children receiving primary surgical repair at a facility with available team care was categorized as receiving team care.

[b] Timely primary surgery was classified as primary surgery prior to 12 months of age for children with CL and primary surgery prior to 18 months of age for children with

Discussion

In this study, the majority of children received both team care and timely primary surgery. Use of team care was similar by payer status at time of primary surgery. However, use of team care was lower for children with CL. Associations between use of team care and timeliness of primary surgical repair for children with OFCs within this study population were not meaningfully or statistically different. However, for children with CLP and non-isolated CL, team care was associated with a shorter median time to surgery within the recommended timeframe.

The distribution of cleft type by maternal age for data from the FBDR was representative of the national distribution, with the majority of cleft births occurring among women ages 20-34 [1]. The distribution of infant gender by cleft type was also representative with roughly 60-64% of CLP and CL occurring among male infants and 40-45% of CP occurring among female infants [1]. For these data, the distribution of cleft type by maternal race and ethnicity was also similar with white, non-Hispanic mothers and Hispanic mothers comprising 52-62% of CLP, CL and CP births [1].

Compared to children with Medicaid coverage in North Carolina from 1995-2002, overall, children born in Florida during the study period were more likely to receive timely primary surgery (NC: 78.1% vs. FL: 95.6% respectively) [17], but timely surgery was similar between the two studies for children with CLP (NC: 89.6% vs. FL: 96.5%) and CL (NC: 88.0% vs. FL: 95.9%) [17]. The main difference occurred among children with CP. In the Florida study, 93.7% of children with CP received timely primary surgery compared to 58.0% in the North Carolina study [17]. The North Carolina study was

limited to children continuously enrolled in Medicaid for 2 years, while this study included all children born with OFCs, regardless of insurance payer status. This may lead to a higher prevalence of timely surgery in our results because children with public insurance were less likely to receive timely surgery than children with private insurance in Florida

This study was subject to limitations both from the data and study design. FBDR is limited because it is a passive surveillance system utilizing ICD-9-CM codes for diagnosis and classification of children with OFCs, as opposed to clinically verifying cases. Further, only AHCA data for hospitalizations occurring in the state of Florida can be linked to FBDR so only children with primary cleft surgical repair in Florida included in this study.

Receipt of team care was based on the assumption that children receiving primary surgery in a hospital or clinic where team care was available, did receive team care. Children who received primary surgery at a facility with team care may not have received team care, and this potential misclassification of the exposure, may bias the results, if it is also associated with timeliness of primary surgery. Children receiving surgical repair at a non-recognized team care facility, may have received team care.

Use of ICD-9-CM codes to identify primary surgery was a limitation because of potential data entry errors as well as discrepancies across care providers in the coding of surgeries. A clinician was consulted to provide a comprehensive list of possible codes for primary surgical cleft repair. However, the choice of alternative codes may have resulted in

children seeming not to have had a primary surgical code within the first two years of life.

Children without a primary surgical code were, excluded from this study to minimize misclassification. However, this exclusion may have led to selection bias if children receiving timely surgery outside of Florida were more likely to have or to not have had team care than those included. Specifically, if children without a surgical code within the two-year period actually did not receive timely surgery, and did not use team care, our results would be bias if the effect of team care on timely surgery towards the null. Finally, small numbers limited results for stratified analysis and limited the study precision.

This study is the first to examine the association between use of team care and timeliness of primary surgery for children with OFCs. The main strength of this study was the data source. FBDR is a population-based, statewide registry that is linked to longitudinal hospital discharge data and utilizes multiple sources for ascertainment of birth defects [23-25]. Although ascertainment varies by birth defects, the overall ascertainment of birth defects for this registry is approximately 88%, high for a passive surveillance system [23-25]. The selection of data from the state of Florida strengthens the generalizability of these results due to the large number of births per year and the diversity of Florida residents. In 2010, Florida had the fourth largest number of live births in the U.S. [26]. Further, Florida had the largest number of births to black mothers and the third largest number of births to Hispanic mothers [26].

Conclusion

In this study, most children received timely surgery and used team care. There was no observed association with team care and timeliness of primary surgery. However, for CL and CLP, team care was associated with a shorter time to primary surgery, which may have benefits beyond having timely care.

Appendix Tables:

Appendix Table 1: APCA and the Florida Cleft Palate-Craniofacial Association Classification of Cleft and Craniofacial Teams in Florida, 1998-2009

North Florida	Central Florida	South Florida	North West Florida
Jacksonville Cleft Palate Team (University of Florida)	Florida Otolaryngology Group (Winter Park)	Joe DiMaggio Children's Hospital Cleft and Craniofacial Center (Hollywood)	CMS Cleft Palate Team (Pensacola)
Nemours Children's Clinic (Jacksonville)	St. Joseph's Craniofacial Center (Tampa)	CMS Craniofacial Team (West Palm Beach)	CMS Panama City
University of Florida Craniofacial Team (Gainesville)	Cleft Palate Team (Rockledge)	South Florida Regional CL/CP and CF Anomalies Center (Miami)	
	Cleft Palate Team (Lakeland)	The Craniofacial Center Miami's Children's Hospital	
	St. Petersburg Cleft Palate Team	Cleft Palate Team (Ft. Meyers)	
	CMS Cleft Palate Team (Sarasota)	Cleft and Craniofacial Center of the Cleveland Clinic (Ft. Lauderdale)	

Appendix Table 2. Characteristics of Children Born in Florida 1998-2007 with Orofacial Clefts from the Florida Birth Defects Registry with Linked Longitudinal Discharge Data by Timeliness of Primary Surgery[a]. (n=1708)

	Timeliness of Primary Surgery					
	CLP (n=951)		CL (n=265)		CP (n=493)	
Maternal Characteristics:	Yes (n=918)	No (n=33)	Yes (n=254)	No (n=11)	Yes (n=461)	No (n=31)
Maternal Age						
<20	130 (96.3)	5 (3.7)	14 (NR)	NR	40 (85.1)	7 (14.9)
20-24	241 (96.8)	8 (3.2)	59 (NR)	NR	113 (91.1)	11 (8.9)
25-29	252 (96.9)	8 (3.1)	75 (NR)	NR	127 (96.2)	5 (3.8)
30-34	189 (97.4)	5 (2.6)	68 (NR)	NR	109 (95.6)	5 (4.4)
35-39	85 (92.4)	7 (7.6)	27 (NR)	NR	60 (NR)	NR
≥ 40	21 (NR)	NR	11 (NR)	NR	12 (NR)	NR
Maternal Race/Ethnicity						
White, Non-Hispanic	549 (97.5)	14 (2.5)	156 (96.3)	6 (3.7)	290 (94.2)	18 (5.8)
Black, Non-Hispanic	115 (95.8)	5 (4.2)	26 (NR)	NR	62 (NR)	NR
Hispanic	225 (94.5)	13 (5.5)	59 (NR)	NR	88 (88.9)	11 (11.1)
Asian/Pacific Islander/American Indian/Alaska Native	25 (NR)	NR	11 (NR)	NR	17 (NR)	NR
Other	NR	NR	2 (NR)	NR	NR	NR
Maternal Education						
12th grade or less, did not graduate	222 (96.1)	9 (3.9)	46 (NR)	NR	94 (91.3)	9 (8.7)
High school/equivalent	327 (97.0)	10 (3.0)	69 (92.0)	6 (8.0)	153 (91.6)	14 (8.4)
At least some college or university	364 (96.3)	14 (3.7)	136 (NR)	NR	211 (96.3)	8 (3.7)
Missing	5 (NR)	NR	NR	NR	NR	NR
Maternal Nativity						
Domestic Born	707 (97.2)	20 (2.8)	191 (95.5)	9 (4.5)	369 (94.1)	23 (5.9)
Foreign Born	209 (94.1)	13 (5.9)	63 (NR)	NR	91 (91.9)	8 (8.1)
Missing	NR	NR	NR	NR	NR	NR
Maternal Marital Status						
Married	531 (96.2)	21 (3.8)	161 (96.4)	6 (3.6)	268 (94.7)	15 (5.3)
Single	387 (97.0)	12 (3.0)	93 (94.4)	5 (5.1)	193 (92.3)	16 (7.7)
System Characteristics:						
Adequacy of Prenatal Care[b]						
Adequate/Adequate plus	687 (96.2)	27 (3.8)	180 (95.2)	9 (4.8)	335 (94.6)	19 (5.4)
Intermediate	81 (NR)	NR	23 (NR)	NR	46 (NR)	NR
Inadequate	102 (NR)	NR	25 (NR)	NR	46 (86.8)	7 (13.2)
Missing	48 (NR)	NR	26 (NR)	NR	34 (NR)	NR
Principal Payer at Primary Surgery[c]						
Public	572 (95.7)	26 (4.3)	121 (93.8)	8 (6.2)	261 (92.2)	22 (7.8)
Private Insurance	338 (98.0)	7 (2.0)	131 (NR)	NR	197 (95.6)	9 (4.4)
Self-Pay/uninsured	8 (NR)	NR	NR	NR	NR	NR

Child Characteristics:						
Gender						
Male	583 (97.3)	16 (2.7)	162 (96.4)	6 (3.6)	191 (93.6)	13 (6.4)
Female	335 (92.5)	17 (4.8)	92 (94.8)	5 (5.2)	270 (93.8)	18 (6.3)
Gestational Age						
Very preterm birth (20-31 weeks)	25 (78.1)	7 (21.9)	7 (NR)	NR	11 (NR)	NR
Preterm birth (32-36 weeks)	121 (95.3)	6 (4.7)	34 (NR)	NR	62 (91.2)	6 (8.8)
Term (37-44 weeks)	770 (96.7)	26 (3.3)	213 (95.5)	10 (4.5)	388 (94.4)	23 (5.6)
Missing	NR	NR	0.0%	NR	NR	NR
Birth Weight						
Very low birth weight (1250-1500g)	22 (NR)	NR	NR	NR	8 (NR)	NR
Low birth weight (1500-2500g)	106 (92.2)	9 (7.8)	24 (NR)	NR	70 (93.3)	5 (6.7)
Normal birth weight (2500-6000g)	790 (97.5)	20 (2.5)	227 (96.6)	8 (3.4)	382 (94.1)	24 (5.9)
Missing	NR	NR	NR	NR	NR	NR
Plurality						
Singleton	894 (96.5)	32 (3.5)	242 (95.7)	11 (4.3)	440 (93.4)	31 (6.6)
Multiples	24 (NR)	NR	12 (NR)	NR	21 (NR)	NR
Team Care[d]						
Yes	859 (96.7)	29 (3.3)	228 (96.2)	9 (3.8)	430 (93.5)	30 (6.5)
No	67 (NR)	NR	26 (NR)	NR	31 (NR)	NR

Abbrivations: CL: cleft lip, CLP: cleft lip and cleft palate, CP: cleft palate, NR: not reported due to cell counts < 5

[a] Timely primary surgery was classified as primary surgery prior to 12 months of age for children with CL and primary surgery prior to 18 months of age for children with CLP and CP.

[b] Adequacy of Prenatal Care Utilization (APNCU) Index is a measure of the adequacy of both initiation of and the receipt of prenatal care services; adequacy is classified as "inadequate", "intermediate", and "adequate/adequate plus".

[c] Private insurance included employer-based insurance (including military coverage, Civilian Health and Medical Program of

[d] Children receiving primary surgical repair at a facuilty with availabile team care was categorized as receiving team care.

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