Gillette Children's Specialty Healthcare

A PEDIATRIC Perspective

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Treating Clefts in Older Children:

A Focus on Children Who Are Adopted Internationally

by Robert Wood, M.D.; Cheryl Cermin, D.D.S.; J. David Collier, D.D.S.; Kelly Nett Cordero, Ph.D.; and Cheryl Shell, C.P.N.P.

Each year, U.S. families adopt approximately 20,000 children from countries such as Guatemala, China, South Korea, Russia and Ethiopia. In 2008, Minnesota reported the highest proportion of international adoptions per capita of any state.

The International Adoption Medicine Program at the University of Minnesota estimates that 13 percent of its adoption-related referrals involve children who have mild to severe craniofacial anomalies. Clefts are the most common type of craniofacial anomaly; approximately 70 percent of children with clefts have them in both the lip and palate. Clefts are more prevalent in children of Asian, Latino or Native American descent.

This article will discuss treating clefts in children who are 18 months or older. It will highlight some of the problems — beyond cosmetic abnormalities — that clefts might cause, particularly when treatment is delayed. Such problems include feeding issues, ear infections, hearing loss, speech and language delays, and dental issues.

Planning Treatment for Children With Clefts

It is critical that a craniofacial team assess newly adopted children who have clefts — even if the children have received treatment in their countries of birth. At Gillette Children's Specialty Healthcare, a craniofacial team often includes craniofacial surgeons, plastic surgeons, nurses, otolaryngologists, orthodontists, dentists, audiologists, speech and language pathologists, feeding specialists, pediatricians, and primary-care providers.

Collaboratively, the team can develop a comprehensive treatment plan and address the potential problems that accompany clefts. More than 150 syndromes include cleft lip or palate in their differential diagnoses. Although clefts generally are isolated abnormalities, nearly 15 percent of all patients with cleft lip or palate present clinically with multiple concerns. Being aware of the potential problems associated with clefts can help primary-care providers and pediatricians assess growth and development (giving consideration to the cleft) and plan additional care.

Surgical Treatments

As the box on Page 2 shows, surgical treatment for children born with clefts in the U.S. typically starts at birth and concludes by 3 months (cleft lip) or 10 months (cleft palate). Some children might need subsequent surgery or other interventions.

Because international adoptions usually take place in late infancy or toddlerhood, however, internationally adopted children who have clefts typically begin surgical treatment at a later age.

The course of surgical treatment for those children depends upon the child's specific needs. Many have initial lip-repair surgery in the country of birth. Only rarely, however, do children experience cleft-palate repair before they are adopted internationally. Some children receive no treatment in their country of birth; they require cleft lip and cleft palate surgery when they arrive in the U.S.

Presurgical Treatment

Presurgical treatments for children who begin cleft repairs shortly after birth are less invasive than they are for children who begin repairs when they are older. Older children who have not undergone surgery for their clefts often develop a protuberance of the upper lip and alveolus (called the premaxilla).

Before repairing the lip, a surgeon must pull the child's alveolus into alignment as much as possible. When cleft-lip treatment begins immediately after birth, use of the Gillette OrthoCleft Retainer®, a presurgical orthopaedic device, can align the alveolus.

Pin-Retention Procedure

After children reach 3 to 4 months, however, the hard and soft tissues lose malleability, and the retainer does not create adequate force to move the alveolar

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segments. In such cases, craniofacial surgeons and orthodontists often perform a pin-retention procedure, fixing a device to the palate that forces repositioning of the segments and prepares the lip for cheiloplasty (a lip-augmentation procedure).

The objective is to create a dental arch similar to that found in children without clefts. Doing so optimizes the positioning of the premaxilla and allows the lip musculature to continue pulling the premaxilla into place after the lip is closed. An orthodontist — in a clinic setting — activates the device once every five to seven days during the two- to three-week period. After that, a surgeon removes the device and repairs the cleft lip.

Children having pin-retention procedures undergo general anesthesia. Although an overnight hospital stay is rarely necessary, patients often experience significant discomfort after the procedure. Therefore, providers prescribe a narcotic analgesic for patients to take home. Patients typically experience a setback in feeding and ingest a primarily liquid diet after surgery. Complications might include an infection at the pin sites and the unlikely scenario of damage to developing tooth buds.

Typical Course of Surgical Treatment for Children With Clefts

Treatment	
Presurgical orthopaedics	• Begin at 1 - 2 weeks • Continue through lip repair
Lip repair	• 3 to 4 months • Place pressure-equalizing tubes as needed, based on otolaryngology evaluation • Coordinate with lip or palate repairs
Palate repair	• 9 to 10 months • Lengthen palate (pharyngeal flap) as needed, based on speech evaluation
Lip and/or nasal revision	• As needed

Cleft-Palate Repair

Many children adopted with already repaired cleft lips will have palate-repair surgery within two to three weeks of their first exam in a U.S. craniofacial clinic. Repairing the palate helps to optimize speech development. It also decreases the likelihood of compensatory speech errors developing — or prevents such issues altogether.

Palate-repair surgery usually takes place six to eight weeks after lip-repair surgery. In older children, however, surgeons might repair the palate first and then the lip. The decision depends on each child's needs.

Four to six weeks after palate-repair surgery, children undergo speech evaluations and begin speech therapy, which continues as needed. After the initial services, the surgical schedule relaxes, giving children time to progress with their speech and language development. Future procedures might include conducting nasometry and nasendoscopy tests to check for excessive nasal resonance (hypernasality); revising the lip or nose surgically; creating a pharyngeal flap to improve speech production; or grafting bone to the gumline.

Speech and Language Development

In surveys, parents who are adopting children (even those without clefts) from outside the U.S. report that language development of the adopted child is their primary concern. One study of children adopted from China at 6 to 25 months of age found that 94.5 percent of the sample developed skills within or above the typical range for English-speakers after two years of English exposure. Earlier adoption was linked to stronger skills. Some studies show that if surgery for cleft conditions is delayed, speech outcomes are less favorable and articulation-error patterns are more difficult to correct. Anecdotal reports, however, show that if children learn a new language — especially one with a different speech sound system — after a palate repair, negative consequences might be less severe.

When evaluating language development in children whose cleft-repair surgeries were delayed, it is important to keep in mind all factors related to cleft palate, including possible velopharyngeal concerns. A speech evaluation four to six weeks after palate repair can help families assess and encourage their child's emerging speech and language skills.

Children who have clefts only in the lip generally develop normal or near-normal speech. After cleft-palate repair, many children have speech therapy and eventually develop normal speech.

Some children with cleft palates, however, develop speech more slowly and/or less accurately than other children do. When a cleft palate is present, the ability of the velopharyngeal port to close properly is sometimes altered — even after repair. That can make it more difficult or impossible to separate the oral and nasal cavities during speech. Such an increase in oral-nasal coupling can allow excessive amounts of air to escape through the nose during speech production, resulting in the perception of hypernasality and/or nasal emissions.

About 20 to 30 percent of children who have cleft palates will have velopharyngeal incompetence or

hypernasal speech after surgery and might require a pharyngeal-flap procedure at age 4 or 5. The procedure involves raising a flap of tissue from the posterior pharynx and inserting it into the soft palate.

In addition to velopharyngeal dysfunction, missing teeth and dental-alignment issues are frequently present in children with clefts. Such issues can contribute to articulation errors, including use of nasal phonemes (such as *m*, *n*, and *ng*) in place of pressure, or "stop," phonemes (such as *p*, *b*, *t*, *d*, *k* and *g*). For example, the word *button* could sound like *munon*. Alternately, a child might replace the stop phonemes with sounds, generated from the back of the mouth or the throat, called pharyngeal or glottal stops. Those stops are similar to the sound produced in the word *uh-oh*. Before surgery and speech therapy, children who have cleft palates might have difficulty producing some consonant sounds.

Ear Infections and Hearing Loss

Infants with clefts — particularly cleft palates — have a higher incidence of hearing problems than infants who do not have clefts. The muscles responsible for opening the Eustachian tube do not function well in children with cleft palates. That can result in fluid building up frequently in the middle ear, otitis media, and ear infections, all of which can lead to fluctuating hearing loss.

Primary-care providers, pediatricians and/or audiologists should check children's hearing during the initial health exam, and routinely thereafter, to monitor middle-ear problems that could alter the development of normal hearing and speech. If hearing is impaired by fluid build-up or unequal pressure, it might be necessary for the otolaryngologist to insert pressure-equalizing tubes. Surgeons can coordinate that procedure with cleft repairs to minimize a child's exposure to anesthesia.

Nutrition

At the time of adoption, children with clefts typically fall into the lower percentiles for weight and height measurements. And because they are typically older at the time of adoption, children with clefts have often devised their own methods of adapted feeding. Living conditions and social interactions in their country of birth often influence their eating habits.

In the U.S., feeding specialists are often part of the cleft-care team. For families who are traveling outside the U.S. to complete an adoption, feeding specialists might advise taking along a variety of feeding tools, including specialized cleft bottles and nipples, bowls, toddler spoons and soft-tip, non-spill (sippy) cups. Most children will be able to eat and/or drink with such devices.

Upon adoption, children often experience many new food tastes and textures. Most adapt well to their new diet, gain a significant amount of weight in the first one to two months after adoption, and experience rapid catch-up growth. When monitoring the weight and height of such children, primary-care providers and pediatricians should consider the cleft anomaly. Such providers might have to deviate from the standard growth charts to track the children's progress.

Dental Problems

In the cleft area, teeth often erupt in a crooked position. Radiographs are often necessary to determine the exact position of the teeth. Because dental problems affect speech, chewing and appearance, they frequently require orthodontic treatment. Children adopted from outside the U.S. often have multiple oral problems, including decay; abscesses; bacterial, viral and fungal infections; and malocclusions. Such problems are often caused in part by abnormalities in tooth development, which make it more difficult to properly clean the teeth.

Due to the scarring effects of the previous surgeries, the maxilla — in most cases — does not grow at the same rate as the mandible. Children, therefore, might require early orthodontic intervention to expand the maxilla in width as well as stimulate the forward growth of the upper jaw. This intervention can begin as early as 3 to 4 years of age but typically is performed at 6 to 7 years of age. Such interventions prepare the dental arch for the eventual bone-graft procedure.

Preadoption Consultations

Gillette conducts preadoption consultations upon request. Many families bring photos, medical information and reports from the country of birth. We cannot rule out diagnoses based on such information, but we might be able to provide information concerning:

- Surgical repair of the cleft lip and/or palate
- Dental and orthodontic management techniques related to cleft lip and/or palate
- Feeding skills and strategies for children with cleft lip and/or palate
- Issues related to learning a new language in internationally adopted children who have a diagnosis of cleft lip and/or palate

We always recommend that, within a week of arriving in the U.S., internationally adopted children see a pediatrician for a general health exam, any needed blood work, a nutritional assessment and immunizations.

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Robert Wood, M.D., is a craniofacial surgeon and medical director of the Center for Craniofacial Services at Gillette Children's Specialty Healthcare. He treats patients who have various craniofacial anomalies, including cleft lip and/or palate. Wood received his medical degree from the University of Minnesota Medical School and completed a general surgery residency at Hennepin County Medical Center in Minneapolis. At Emory University in Atlanta, he trained in plastic surgery. Wood completed a fellowship in craniofacial surgery at New York University Medical Center.

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