Caring for Children with Craniofacial Differences: The Team Approach

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Overview

• Craniofacial conditions
• The importance of team care
• How to choose a team
• 25 years of care coordination – a personal perspective
Craniofacial Differences

- Cleft lip/palate
- Pierre Robin sequence
- Craniosynostosis
  - single suture
  - complex
- Craniofacial dysplasias
  - hemifacial microsomia
  - Treacher Collins
Cleft Lip and Palate
Unilateral cleft lip

incomplete unilateral cleft lip

complete unilateral cleft lip
Bilateral cleft lip

Incomplete cleft lip

Complete cleft lip
Cleft Palate
Cleft Palate

Isolated cleft palate

Submucous cleft palate
Pierre Robin sequence
Pierre Robin sequence

- Defined by triad of small jaw, retro-displaced tongue (glossoptosis), and breathing issues

- Majority of children have “U” shaped cleft palate

- Can be related to a craniofacial syndrome or non-syndromic
Craniosynostosis

Premature closure of one or more of the sutures leading to an abnormal skull shape
Metopic craniosynostosis
Craniofacial Syndromes

- Apert
- Pfeiffer
- Crouzon
- Saethre-Chotzen
- Carpenter
- Muenke
Craniofacial Dysplasias

- Treacher Collins syndrome
- Hemifacial microsomnia/microtia
- Hypertelorism
- Frontonasal encephaloceles
- Pediatric skull tumors
Hemifacial Microsomia
Treacher Collins Syndrome
Many Differences, Many Similarities

- Despite the many visible differences among these children, they all share the need for the services of multiple health care providers.
Potential Areas of Concern

- Surgery
- Airway
- Feeding
- Hearing
- Speech/Language
- Cognition
- Psychosocial
- Dentition
Surgery

- Craniofacial surgery deals with restoring, to the extent possible, the normal anatomy of the craniofacial unit.
- Other types of surgery may be required.
- Surgeries are often staged and may continue though adolescence into adult life.
Airway

- Children with certain craniofacial differences may have difficulty with breathing.
- Specialized evaluation of airway early in life may be indicated.
- Children may require different levels of intervention to maintain a good airway, from positioning to tracheostomy.
Feeding

• Differences in anatomic structures may contribute to feeding difficulties.
• Neurologic impairment may affect a child’s ability to suck, chew, and/or swallow.
• Children may require placement of feeding tubes.
• Specialized evaluation and therapy are often indicated.
Hearing

- Children may present with hearing loss, whether transient or persistent.
- Hearing loss may be caused by conductive or sensorineural issues.
- Regular contact with the audiologist is required.
- Established care with the otolaryngologist is required.
Speech and Language

- Speech refers to the actual production of sounds and words.
  - Speech errors may be caused by structural problems, neurologic problems, developmental delay or any combination

- Language refers to the ability to understand speech (receptive language) or use speech (expressive language).
Speech and Language

• Speech and language evaluations should begin early in life and be continued on a regular basis.
Cognition

• Cognition is a term which includes thinking, knowing, remembering, judging and problem solving.

• These are higher-level functions of the brain and encompass language, imagination, perception and planning.

• Developmental and neuropsychological evaluations should be included in the team evaluation.
Psychosocial

• Self esteem in children is always a concern and requires monitoring.
• Family dynamics are affected and these effects should also be monitored.
• Multiple stressors facing a family may include surgery, hospitalization, financial issues, marital and sibling relationships.
Dentition

• Dental development may be affected by craniofacial differences.
• Establishment of dental care at an early age is needed to promote good dental hygiene.
• Regular dental evaluation by the pediatric dentist and orthodontist at the appropriate time needs to be part of the treatment plan.
The need for team care

Key points

• facilitation of parent/professional collaboration
• sharing of unbiased and complete information with parents
• provision of emotional and financial support
• sensitivity to cultural differences
• encouragement of parent-to-parent support
• incorporation of developmental needs into health care plans
• comprehensive social, emotional, and cognitive services
• interdisciplinary approach to care
Why Team Care?

There are many health care professionals who are qualified to perform a particular surgery or therapy.
Why Team Care?

• Children with craniofacial differences often require complex and lengthy care over a period of time from many different specialists.

• All children with craniofacial differences deserve coordination of services among the various specialists.
Why Team Care?

• The main role of the interdisciplinary team is:
  – to provide coordinated and integrated management for you and your child
  – to assure quality and continuity of care and long-term follow up for you and your child.
Choosing the right team
What to look for in a team

• The number of different specialists on the team
• Qualifications of the individual team members
• Experience of the team
• Location of the team
• Team communication
What to look for in a team

• The number of different specialists
  – The more specialists, the more likely every aspect of treatment will be considered during team evaluation.
  – If specific services are not available, the team is responsible for making appropriate referrals and providing necessary communication to families and professionals.
  – Not every child requires every specialist. Despite this, it is helpful to undergo complete team evaluation to monitor change over time.
What to look for in a team

• Qualifications of the team members
  – All team members should be fully trained and appropriately licensed and certified.
  – This is important for quality of care and also may impact your insurance coverage.
  – Team members should stay current with recent developments.
What to look for in a team

• Team experience
  – Teams take responsibility for ensuring their members have experience in evaluation and treatment of children with craniofacial conditions.
  – Parents may inquire how often the team meets and how many patients are followed at each meeting and overall in the program.
What to look for in a team

- Location of the team.
  - Families will work with teams in an ongoing manner. Consider travel time and costs when choosing a team.
  - Teams will see you from once a year to once every few months, and this will change as your child grows and develops.
  - Routine treatments such as speech therapy, dental care or pediatric care may be received in your local community by providers who should be in regular contact with your team.
What to look for in a team

- Communication **with** the team and **within** the team.

- **With** the team:
  - Treatment recommendations should be discussed in person and also provided in writing.
  - You should feel open and comfortable talking with team members.
  - The clinic coordinator may be your point person for facilitating discussions.
What to look for in a team

• Communication with the team and within the team.

• Within the team:
  – The team should meet on a regular basis.
  – It is critical that team members meet face to face after evaluation– this allows for open discussion and planning for coordinated and integrated treatments.
VCU Center for Craniofacial Care

- Pediatric Plastic/Craniofacial Surgery
- Pediatric Neurosurgery
- Pediatric Otolaryngology
- Oral Maxillofacial Surgery
- Speech Therapy
- Pediatric Dentistry
- Orthodontics
- Interventional Radiology
- Pediatric Dermatology
- Pediatric Surgery
- Clinic Coordinator
- Genetics
- Pediatric Ophthalmology
- Clinical Anthropology
- Psychology
- Audiology
A 25 year perspective of a craniofacial coordinator
Perspectives

• Privilege of working with children and families for over 25 years

• Unique opportunity to watch many children grow from infancy to adulthood

• Able to share some of the experiences, both positive and negative, of our families
Perspectives

• Role of the clinic coordinator
  – Facilitate team function and communication
  – Education of public and professional community
  – Research and program development
Perspectives

• Role of the clinic coordinator

- Provide feeding consultation
- Provide speech, language and developmental expertise
- Serve as resource/referral source
- Serve as a family advocate
- Provide emotional support
The wearer of many hats
Some common parent concerns

• “My child has too many doctors and too many opinions—how do I know what to do?”
Some common parent concerns

• “We have our own specialists; I don’t need to see the team.”
Some common parent concerns

• “My child had his/her surgery and everything is going great – why do I need to continue seeing the team?”
Key Points for Families

• The coordinated team approach is the standard of care for all children with craniofacial differences.

• Treatment is not a “one shot deal”.