

# Management Challenges for Medically Complex Children with Cleft Lip and Palate

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## INTRODUCTION

Congenital facial clefting is one of the most common birth defects worldwide. Typically, cleft patients without other significant medical problems will undergo surgeries to repair their cleft defects within the first 12-18 months of life. There are numerous syndromes associated with cleft lip and/or palate as well as unique patients with multiple medical problems without an over-arching diagnosis.

This group of patients provides fundamental treatment challenges and require highly individualized treatment plans that take into account factors related to their long term prognoses. This is a previously unexplored area of study for cleft care at our institution and in general.

### AIM:

- Determine the prevalence of children in our Cleft Team population who also carry concomitant complex medical diagnoses
- Identify alterations in timing and nature of cleft-related surgeries and the problems that necessitate reprioritization of management strategies
- Understand the role of individualized protocol development for cleft patients with multiple medical problems to provide for their comprehensive care

## METHODS

A retrospective analysis at a tertiary care center. The target study population included patients with a diagnosis of cleft lip and/or palate with another diagnosis from the family of congenital anomalies ICD-9 codes 740.0-748.9 or 750.0-759.9 presenting to the Cleft Team from January 1, 2009 to December 31, 2014.

### Inclusion criteria:

- Patients presenting for cleft care with a history of multiple medical issues in addition to a diagnosis of cleft lip and/or palate
- Patients < 21 years of age

### Exclusion criteria:

- Patients whose other medical diagnoses do not require additional medical care, therapies, or follow-up
- Patients with incomplete records

## RESULTS

133 patients with complex medical conditions were identified with a variety of cleft conditions (Figure 1). The most common associated medical condition was developmental delay (Figure 2). A numerous variety of concomitant diagnoses were made by a combination of methods and included 37 named syndromes, 20 unique chromosomal abnormalities, and 17 unidentified constellations of anomalies.

- Average age at cleft lip repair: 7.29 months (SD 2.65)
- Average age at primary cleft palate repair: 23.13 months (SD 20.56)
- 38.06% had delayed or completely missed cleft-related surgeries
- 6.7% died prematurely related to their overall medical condition
- 81.2% of patients were cared for by 3 or more subspecialists outside of the Cleft Team, most commonly: ENT, Cardiology, Ophthalmology and Orthopedic Surgery

## CONCLUSIONS

Patients with congenital cleft conditions and concomitant complex medical presentations present unique situations for coordinated cleft team care. These patients have frequent delays in the timing of their cleft-related surgeries resulting from poor health condition, need for other surgery, or significant developmental delays. Limitations of this study include its retrospective design. There is a need for the development of a team-based, coordinated care model for patients with complex medical presentations. Having a clearer understanding of the challenges of caring for these patients will help us treat future patients and provide important information for other cleft teams nationally.

## REFERENCES

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Figure 1: Percentage of patients with a variety of cleft conditions

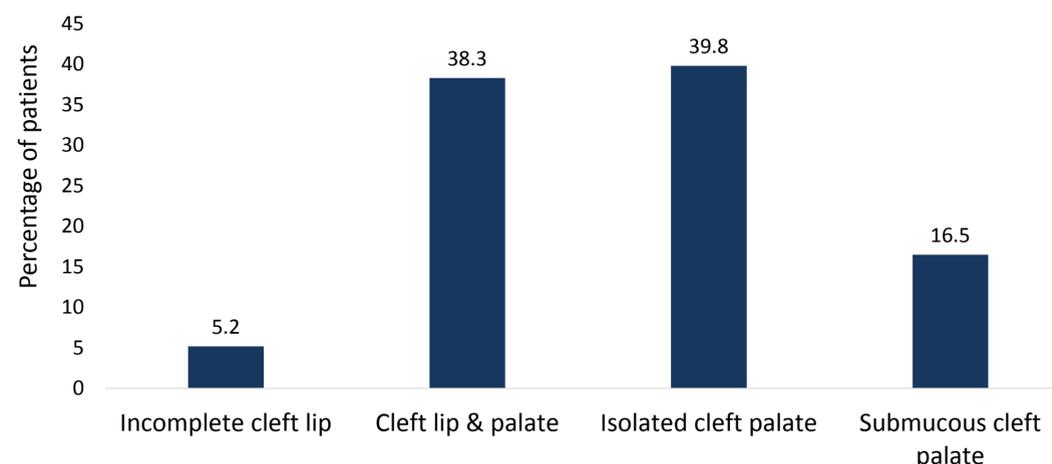


Figure 2: Percentage of patients with associated medical conditions

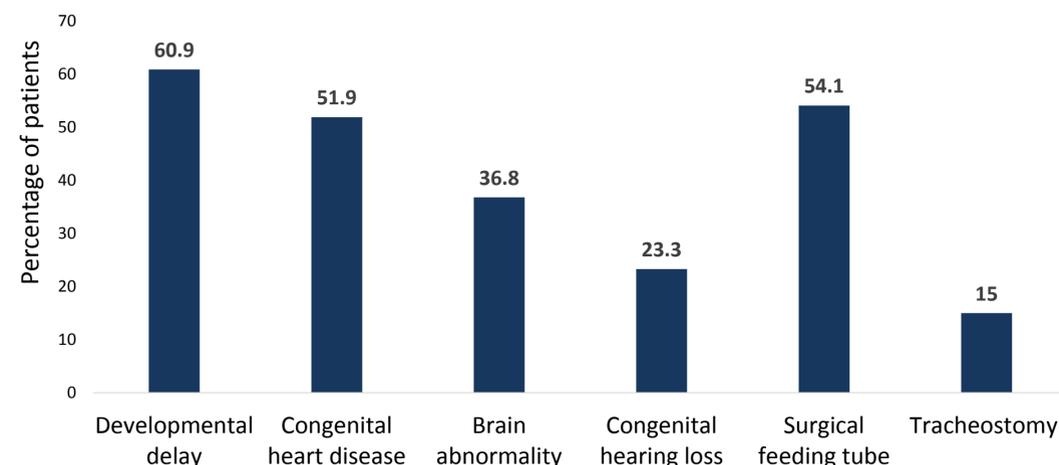


Figure 3: Reasons for cleft surgery delays

