

A Forgotten Disability: A Parental Survey on Patients in West Virginia with Cleft Lip and Palate

Lesley Cottrell, PhD and Paige Rutter, BA

Purpose

- ⤴ West Virginia (WV) has twice the national average of children diagnosed with cleft lip or palate.
- ⤴ Additionally, WV has higher rates of maternal smoking and drug abuse, which can affect children born with cleft lip or palate.
- ⤴ It is important that people with a cleft have access to the care needed soon after diagnosis so that treatments can be received for better outcomes and less complications later in life.
- ⤴ The purpose of this study is to determine when and where treatments for children with cleft lip or palate are received and what barriers are noted with regard to quality services and service utilization, as well as general demographics of the child and descriptors of the diagnosis.

Background

- ⤴ There are different forms of cleft lip and palate. A cleft lip can be unilateral or bilateral, with or without cleft palate. Cleft palate can also occur on their own and involve the hard or soft palate of the mouth.
- ⤴ The cleft lip is formed at approximately five weeks gestation while a cleft palate is generally formed by the ninth week. Both cleft lip and palate can be diagnosed prenatally, however, palates are generally not detected until after the child is born as they are hard to diagnose on an ultrasound. If there is an associated condition (i.e., Trisomy 13) then a blood test may be indicative of an abnormality such as a cleft lip or palate.
- ⤴ Treatments to cleft lip and palate span many years. Treatments include cleft lip repair, cleft palate repair, speech evaluation and bone grafting. Access to these treatments is essential, but often times problematic for patients.
- ⤴ Our hypothesis is that in a rural setting such as WV, people with cleft lip and palate will have to travel a large distance to receive treatment, which may prolong treatment.

Objective

1. To determine if there are any connecting demographic factors that may suggest indications causing cleft lip and palate.
2. To determine if members of the craniofacial team were readily available to patients in WV with cleft lip and palate.
3. To determine if surgeries were performed within the recommended time frame.
4. To determine what interactions parents had with the hospital staff and the craniofacial team directly after the birth.

Methods

A survey composed of demographic, descriptive and qualitative questions was created. The survey was distributed using the WV Birth Score Registry. Surveys were returned in postage paid envelopes and then entered into a computer database. Data was analyzed using geospatial analyses and illustrative

mapping to demonstrate the location of common services for this sample, the distance from their homes to services and common physical barriers that may be noted as a result of living in a rural, mountainous setting.

Results

- ⤴ Diagnosis of cleft lip, cleft palate or both. Children diagnosed with cleft lip were 33.33 percent, children diagnosed with cleft palate were 50 percent and children diagnosed with both were 16.67 percent.
- ⤴ Severity of cleft lip or palate at birth. Children diagnosed with a mild cleft were 50 percent, children diagnosed with a moderate cleft were 33.33 percent.
- ⤴ Outline of the counties of West Virginia noting where craniofacial teams are located and one location of a dentist from the data we collected.

Conclusions

Through this survey, we were able to determine that on average people with cleft will travel approximately 17.3 miles to the hospital and approximately 93.4 miles to be seen by their craniofacial team. Distance traveled to a dentist was much less at approximately 13.4 miles, since there are many dentists located throughout the state. Some families may travel an excess of 160 miles to reach their craniofacial team. This can be problematic if transportation is limited or if finances are tight for families.

Timeline of cleft surgeries:

- Cleft lip repair occurs between 2 and 3 months. Average for our study was approximately 3 months.
- Cleft palate repair occurs between 6 to 12 months. Average for our study was approximately 10.5 months.
- Speech evaluations occur between 12 to 14 months of age. Average for our study was 18.5 months.

Analysis of qualitative data revealed the majority of parents are satisfied with their child's care, but suggest that the hospital care could be improved. Mothers noted that most hospitals were not equipped for people with a cleft and staff was not properly trained in feeding techniques.

Babies with a cleft require special Haberman bottles that can be manually squeezed since they are not able to suck properly. It would be important for all hospitals to keep these on hand for any babies that are born with a cleft at those hospitals. Mothers also reported that hospitals were not equipped with proper arm restraints for people with a cleft that require surgery.

References

Burstein, F.D., Martin, J., Nahai, F.R., etc., Seminars in Plastic Surgery. The Management of Cleft Lip and Palate: Pathways of Treatment and Longitudinal Assessment. 2005 Nov; 19(4) 275-285. West Virginia Health Statistics Center. Cleft Palate and/or Lip Birth Defects, 1990-1999; No. 9.