

Evelyn Quarshie, Paul Dinh, Joan Ehrhardt, Robert Wahl, Mary Mobley, Glenn Copeland  
Michigan Department of Community Health

## Introduction

Cleft lip and cleft palate are birth defects that result from improper formation of the mouth and lip by about 10 weeks after conception. Together, these birth defects commonly are called “orofacial clefts”.

Figure 1: Cleft Palate



Figure 2: Cleft Lip



The Centers for Disease Control and Prevention (CDC) recently estimated there are 2,651 live births each year in the United States with cleft palate and 4,437 live births with cleft lip (with or without cleft palate).

Michigan statistics regarding orofacial clefts come from the Michigan Birth Defects Registry; a statewide population-based, passive system. In Michigan, from 1992 to 2010, the overall rate of orofacial clefts was 15.7 cases per 10,000 live births. From 2001 to 2010, a total of 1,981 infants were reported with an orofacial cleft, or 1 in 633 Michigan newborns. Children with oral clefts require specialized health care services during childhood. Families may benefit from additional financial and emotional support.

## Objective

- To assess the experience, needs, and utilization of services by families, parents and caregivers of children with orofacial clefts (OFC) in Michigan.
- To identify and address gaps in the information and support services provided to families of children with OFC.

## Methods

### Population:

- Parents of children with OFC, including isolated cleft palate and cleft lip (with or without cleft palate), born from 2009 through 2011.
- Identified from the Michigan Birth Defects Registry (MBDR).
- Inclusion criteria:** Children with OFC born in Michigan, not deceased, and not adopted.

### Survey:

- 420 families were invited in up to three mailings.
- Access to an Internet “Survey Monkey” iteration was provided in every mailing.
- Paper surveys were also provided in the second and third mailing.
- Participants were asked to complete the survey for their oldest child with OFC.

### Analysis:

- Results were analyzed using Statistical Analysis Software (SAS) version 9.2.
- Descriptive statistics were calculated as well as statistical significance where applicable.

## Results

### Demographics

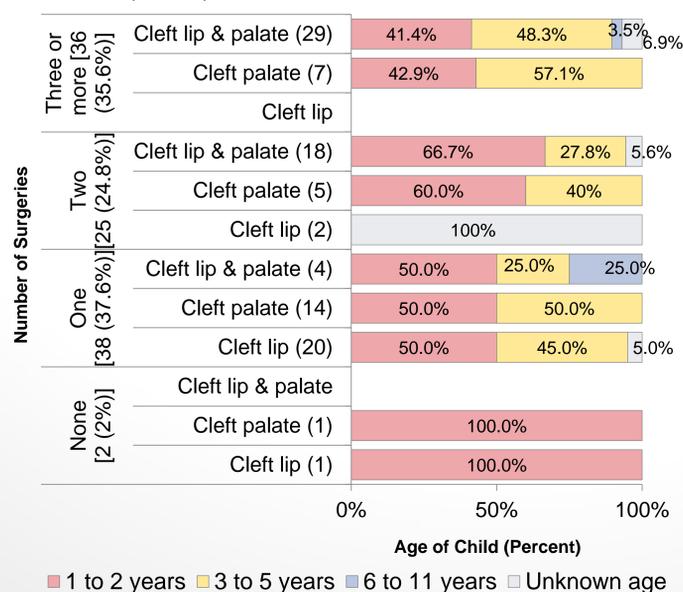
- Response rate: 34% (104 respondents; 82% online and 18% on paper).
- The majority of respondents were 25 years or older (92.9%), white (90.8%), and had more than a high school education (84.7%).
- Thirty-seven out of 83 MI counties were represented, with 55% in the Southeastern lower region.
- Children ranged in age from 1-11 years; the average age was 3 years.
- Cleft lip and palate was the most common type of OFC among respondents’ children (50.5%). About 23% had cleft lip only, and about 27% had cleft palate only.

Table 1: Family history of OFC and other children born with OFC (n=101).

	Family History					Total
	Maternal side	Paternal side	Both	No	Not sure	
Other children with OFC						
Yes	2 (2.0%)	2 (2.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	5 (5.0%)
No	10 (9.9%)	6 (5.9%)	2 (2.0%)	75 (74.3%)	3 (3.0%)	96 (95.1%)
Total	12 (11.9%)	8 (7.9%)	2 (2.0%)	76 (75.3%)	3 (3.0%)	101

- Having a family history and having other children born with OFC were significantly associated (Fisher’s exact test: p=0.0187).

Figure 3: Number of surgeries by type of OFC and age of child (n=101).



- Over 80% of respondents indicated that they received needed follow-up care and information on specialists. They felt that their child was getting needed care and did not currently need help finding information, services or support.
- Over half (54.4%) reported that a health professional did not talk with them about future expenses and planning how to pay for the medical care of their child with an oral cleft. However, the majority (84.4%) identified this as important.
- A third (33.3%) indicated that their health care provider did not provide a contact number to call with questions, although the majority felt it was important (96.7%).
- Nearly half (47.8%) indicated that they did not receive assistance with managing, planning and scheduling specialist appointments.

Table 2: Issues related to having a child with cleft, whether addressed by a health professional (HP) and perceived importance (n=99).

Issues	Addressed by HP			Importance
	Yes	No	Not sure	
Ways to cope with struggles	41.8%	43.8%	14.3%	88.9%
How having a child with cleft may affect family	40.4%	44.4%	15.2%	79.8%
Ways to contact other families/ support groups	35.7%	56.1%	8.2%	70.7%

Table 3: Family received emotional/social support and reported ability to cope with struggles (n=97).

Emotional/social support	Coping with struggles		
	Very well	Fair	Total
Yes	62 (63.9%)	12 (12.4%)	74 (76.3%)
No	5 (5.2%)	9 (9.3%)	14 (14.4%)
Not sure	3 (3.1%)	6 (6.2%)	9 (9.3%)
Total	70 (72.3%)	27 (27.8%)	97

- There was a statistically significant relationship between emotional/social support and ability to cope with struggles (Fisher’s exact test: p=3.458E-05).
- A greater percentage of respondents who met with a social worker or counselor (68.6%) reported that their emotional/social support needs were met (n=35).

## Discussion

- Most families (over 80%) provided positive feedback about accessing the follow-up care needed for their child and receiving information on needed specialists. Most did not currently need help finding any information, services, or support. However, several gaps were identified.
- Most children with cleft lip and palate had experienced at least two surgeries; more than a third had undergone 3 or more surgeries before age 3 (Figure 3).
- The association between family history and OFC (Table 1) underscores the importance of referral to genetics.
- Less than 50% of respondents indicated that a health professional had addressed certain issues surrounding the potential stress of raising a child with OFC that most families identified as important (Table 2).
- Results suggested an association between receiving emotional/social support and the caregiver’s ability to cope with struggles (Table 3). The majority of respondents who saw a social worker or counselor reported that their emotional and/or social support needs were met (68.6%).

## Public Health Impact

- New parents of children with OFC can benefit from receiving information and assistance beyond specialized medical care. Families identified needs related to care coordination, financial assistance, their ability to contact the health care provider with questions, coping with potential struggles, and contact with other families who had a child with an OFC or support groups.
- The MBDR has the opportunity to increase awareness among health care providers of family needs and available services.

## Acknowledgements

- We would like to thank the MBDR for their assistance in administering this survey.
- We acknowledge and thank the staff of the clinical care teams, support groups and parents for their assistance and contribution.

This publication was supported by Cooperative Agreement Number 5U50DD000615-05 from the CDC. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

