A Needs Assessment Survey for Parents of Children with Oral Cleft in Michigan

Results from the Orofacial Cleft Family Survey, 2013

A report prepared by

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MBDR MICHIGAN BIRTH DEFECTS REGISTRY

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Background Information

Cleft lip and cleft palate are birth defects that occur when a baby's lip or mouth do not form properly before birth. Together, these birth defects commonly are called "orofacial clefts" or "oral clefts" (OFCs). Affecting 1-2 per 1,000 newborns, together they are among the more common birth defects, and the most common affecting the face. These birth defects happen early during pregnancy, by 5 to 6 weeks after conception for cleft lip and by about 10 weeks after conception for cleft palate. A baby can have a cleft lip, a cleft palate, or both.[1] A cleft may affect one side of the lip and/or palate (unilateral) or both sides (bilateral) and may disrupt the formation of the nose and/or extend into the gum or upper jawbone. Children with orofacial clefts often have problems with feeding and talking. They might also have ear infections, hearing loss, and problems with their teeth.[1] They usually require one or more surgeries early in life, as well as special feeding techniques, orthodontic care and/or speech therapy. Severity varies with the degree of clefting and with the presence of other birth defects; in extreme cases, death may result.[1]

Figure 1: Cleft Palate[1]

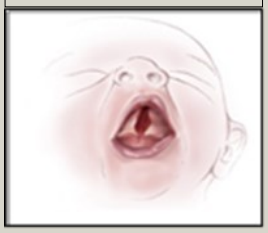


Figure 2: Cleft Lip[1]

The Centers for Disease Control and Prevention (CDC) recently estimated that each year 2,651 babies in the United States are born with a cleft palate, and 4,437 babies are born with a cleft lip (with or without a cleft palate).[1] In Michigan, from 1992 to 2010, the incidence of OFC was about 1 in 637 live births (15.7 cases per 10,000 live births) with an average number of 75 cases of cleft palate and 130 cases of cleft lip (with or without cleft palate) each year.

Previous research has identified that the causes of orofacial clefts are complex, involving both environmental and genetic factors.[2] According to the 2014 Surgeon General's Report, smoking in early pregnancy can cause orofacial clefts.[3] Studies have shown a protective effect with folic acid supplementation starting around the time of conception. However, this has not been proven conclusively.[4]

Purpose

The purpose of this study was to assess the experiences of families, parents and caregivers of children with OFCs in Michigan and their needs and utilization of services, in order to learn whether parents of children born with special health needs receive information and care that is available to them. Results of the study were used to identify gaps in the information, services and support that exist, and how they may be addressed by the Michigan Department of Health and Human Services (MDHHS).

Methods

Parents of children with OFCs, including isolated cleft palate and cleft lip (with or without cleft palate) born from 2009 through 2011, were identified from the Michigan Birth Defects Registry (MBDR). From this group, parents of children with OFCs, who were not deceased, adopted, nor born out of state, were invited to participate in this study. A total of 420 families were invited to take the survey, using up to 3 mailings, of which 111 were returned as undeliverable. Invitations provided a link for participants to complete the survey via 'Survey Monkey' online. A paper survey and a pre-addressed return envelope were also provided, following the first mailing, for those who preferred to complete the survey on paper. The first 75 people to complete the survey were offered a $10 gift card and all participants who completed the survey were entered into a drawing for a $50 gift card. Results received by the cut-off date were analyzed using Statistical Analysis Software (SAS) version 9.2 to assess the needs of families of children with clefts for care and services as well as barriers to accessing these services. Descriptive statistics of survey questions were calculated as well as statistical significance where applicable.

Results

Demographic Distribution

The response rate was 34% (104 participants completed the survey on time; 85 online and 19 on paper). Of respondents, the majority (92.9%) were 25 years or older and over half were 25-34 years of age (54.5%; Table 1). The majority were white (90.8%) and had more than a high school education (84.7%), with over 50% holding a college degree (Table 1). Thirty-seven of the 83 Michigan counties were represented on the survey (Figure 3), with about 55% from the SE lower peninsula region (Table 1).

Table 1: *Demographic distribution of survey respondents (n=104): Orofacial Cleft Family Survey, 2013*

Demographic Variable	Respondents (%)
Age	
<24	7 (7.1%)
25-34	54 (54.5%)
35+	38 (38.4%)
Total	99
Race	
White	89 (90.8%)
Black	<5 (<5%)
Other[1]	8 (8.2%)
Total	98
Education	
Grade school (1-8)	<5 (<5%)
Some high school	<5 (<5%)
High school diploma/GED	11 (11.2%)
Some college	27 (27.5%)
College degree	42 (42.9%)
Graduate degree	14 (14.3%)
Total	98
Region in MI	
Upper Peninsula	<5 (<5%)
NW Lower Peninsula	14 (14.4%)
NE Lower Peninsula	6 (6.2%)
SW Lower Peninsula	22 (22.7%)
SE Lower Peninsula	53 (54.6%)
Total	97

[1]Other encompasses those who do not define themselves as black or white and includes Native Americans and Asian/Pacific Islander.

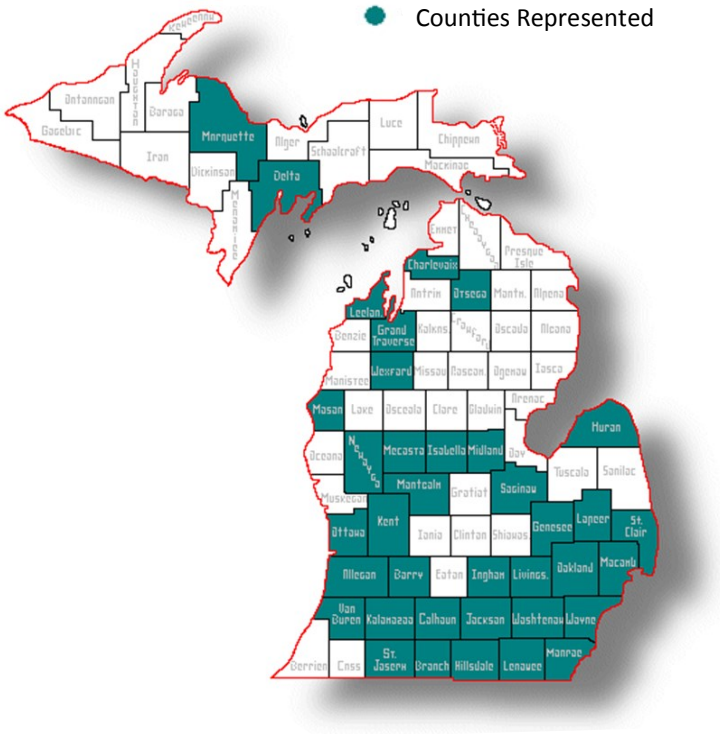


Figure 3: *County of respondents: Orofacial Cleft Family Survey, 2013*

Data from parents invited to take the survey were analyzed by selected demographic variables. Results were grouped by respondents, non-respondents and undeliverable surveys (due to a noncurrent address) and compared with the demographic characteristics of all those invited to participate in this study (Table 2). Invited parents, ages 25-34 years accounted for about 52% of the population (Table 2). Proportions were quite similar in the other groups except for the group with undeliverable and returned surveys where nearly half the parents (47.8%) were less than 25 years old (Table 2). Of those invited, the least represented were parents age 35 years and above (14.6%; Table 2). This pattern was observed in the other groups except for the respondents' group where the least represented were parents less than 25 years of age (7.1%, Table 2). Analysis revealed a significant difference between survey groups with respect to the age distribution ($p<.0001$; Table 2). Whites were the most represented of all those invited to participate (82.3%) while those in the race category "Other" were the least represented (7.7%;

Table 2). This pattern is seen in the other groups except for the respondents' group where the least represented were blacks, making up less than 5% of the survey respondents (Table 2). Results indicated a significant difference between survey groups by the race distribution (p=0.046; Table 2). By ethnicity, non-Hispanics (92.5%) were much more represented than Hispanics (7.7%) and the pattern was seen across all groups (Table 2). Of those invited, over 50% had male children born with an oral cleft (53.2%) while nearly half had female children with an oral cleft (46.8%; Table 2). A similar pattern is observed across all groups (Table 2). No significant differences exist between survey groups with respect to the distribution by ethnicity (p=0.2152) and sex of the child (0.7988; Table 2).

Table 2: *Demographic characteristics of all invited participants vs. survey groups: Orofacial Cleft Family Survey, 2013*

Variable	All invited	Survey groups			
		Respondents	Non-respondents	Undeliverable and Returned	p-value
Age	Number (%)		Number (%)		
<25	141 (33.8%)	7 (7.1%)	68 (33.7%)	53 (47.8%)	<.0001**
25-34	215 (51.6%)	54 (54.5%)	108 (53.5%)	47 (42.3%)	
35+	61 (14.6%)	38 (38.4%)	26 (12.9%)	11 (9.9%)	
Total	417[1]	99[1]	202	111	
Race					
White	343 (82.3%)	89 (90.8%)	164 (81.2%)	88 (79.3%)	0.046**
Black	42 (10.1%)	<5 (<5.0%)	21 (10.4%)	17 (15.2%)	
Other[2]	32 (7.7%)	8 (8.2%)	17 (8.4%)	6 (5.4%)	
Total	417[1]	98[1]	202	111	
Ethnicity					
Hispanic	31 (7.7%)	<5 (<5.0%)	16 (8.0%)	12 (10.8%)	0.2152
Non-Hispanic	384 (92.5%)	97 (97.0%)	185 (92.0%)	99 (89.2%)	
Total	415[1]	100[1]	201	111	
Sex of Child					
Male	222 (53.2%)	51 (50.5%)	110 (54.5%)	58 (52.3%)	0.7988
Female	195 (46.8%)	50 (49.5%)	92 (45.5%)	53 (47.8%)	
Total	417[1]	101	202	111	

[1]Missing data not included.

[2]Other encompasses those who do not define themselves as black or white and includes Native Americans and Asian/Pacific Islander.

**Statistically significant difference in distribution between survey groups (respondents, non-respondents and undeliverable and returned) at the 0.05 alpha level.

The demographics of the survey sample were compared with that of the MBDR OFC cases from 2009-2011, by age, race, ethnicity and sex of the child (Table 3). Parents, ages 25-34 years are the most represented among both the survey participants (54.5%) and the MBDR OFC cases overall (49.8%). The percentage of survey participants of less than 25 years was 7.1% compared with 34.9% for the MBDR, while the percentage of survey participants of 35 years old or greater was 38.4% compared with 15.3% for the MBDR (Table 3). The age distribution in this survey differed significantly from the MBDR cases ($p < .0001$). By race, white survey participants accounted for 90.8% compared with 83.9% for the MBDR cases. For blacks, survey participants accounted for less than 5% compared with 10.9% for the MBDR cases, and for the "other" race category, survey participants accounted for 8.2% compared with 5.1% for the MBDR cases (Table 3). No significant differences were found in the distribution of survey participants by ethnicity ($p=0.1952$) and sex of the infant ($p=0.5449$) compared with the MBDR OFC cases (Table 3).

Table 3: *Demographics comparison of MBDR OFC cases, 2009-2011 vs. survey participants, 2013*

Variable	MBDR[1]	Respondents	p-value
Maternal Age	Number of Cases (%)	Number of Participants (%)	
<25	167 (34.9%)	7 (7.1%)	<.0001**
25-34	238 (49.8%)	54 (54.5%)	
35+	73 (15.3%)	38 (38.4%)	
Total	478	99	
Maternal Race			
White	392 (83.9%)	89 (90.8%)	Too small to calculate
Black	51(10.9%)	<5 (<5.0%)	
Other[2]	24 (5.1%)	8 (8.2%)	
Total	467	98	
Maternal Ethnicity			
Hispanic	29 (6.1%)	<5 (<5.0%)	0.1952
Non-Hispanic	449 (93.9%)	97 (97.0%)	
Total	478	100	
Sex of Infant			
Male	254 (53.5%)	51 (50.5%)	0.5449
Female	221 (46.5%)	50 (49.5%)	
Total	475	101	

[1]MBDR OFC cases are based on resident occurrences. Data are current through May 2014.

[2]Other encompasses those who do not define themselves as black or white and includes Native Americans and Asian/Pacific Islander.

**Statistically significant difference in distribution between the two groups at the 0.05 alpha level.

Diagnosis and Follow-up Care

Participants were asked if they had a child born with an oral cleft. Three respondents indicated on the survey that their child had no cleft. Additionally, three individuals who did not participate in this study contacted the MBDR program to report that they had no child with an oral cleft.

From the survey, about 21% of respondents had a family history of cleft. Of these, 11.5% indicated that the history of cleft was on the child's mother's side, 7.7% indicated it was on the child's father's side and 1.9% indicated it was on both sides of the family. Five percent of respondents indicated having other children born with a cleft. The association between family history and having other children born with clefts was studied. Analysis suggested a statistically significant relationship between the two variables (p=0.0187; Table 4).

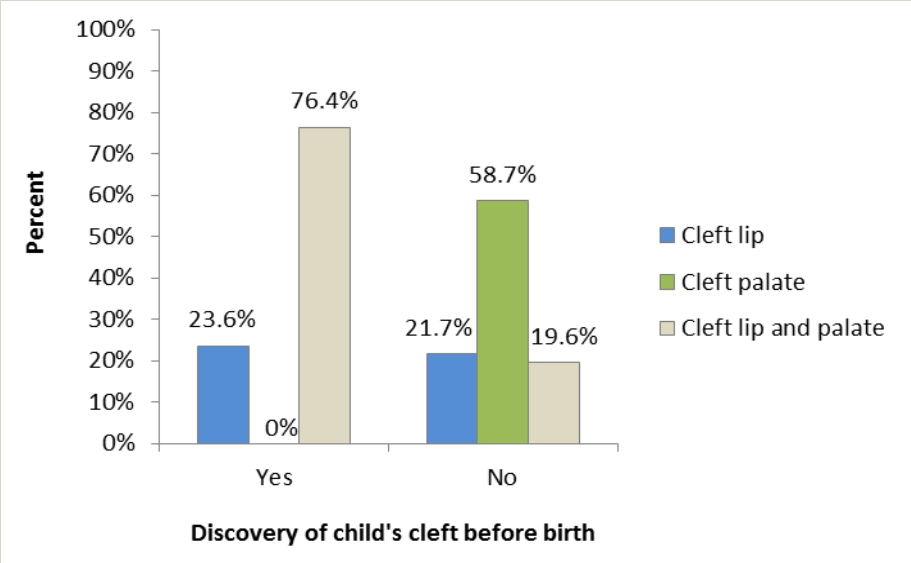
Table 4: *Family history and other children born with an oral cleft (n=101):Orofacial Cleft Family Survey, 2013*

Other children born with cleft	Family History					
	Mother's side	Father's side	Both sides	No	Not sure	Total
Yes	2 (2.0%)	2 (2.0%)	0 (0.0%)	1 (1.0%)	0 (0.0%)	5 (5.0%)
No	10 (9.9%)	6 (5.94%)	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

At the time of this survey, the ages of the children with OFC ranged from 1-11 years with the average being 3 years. Survey results showed that cleft lip with cleft palate was the most common type of cleft among the respondents' children (50.5%). About 23% of the respondents' children had cleft lip only and about 27% had cleft palate only.

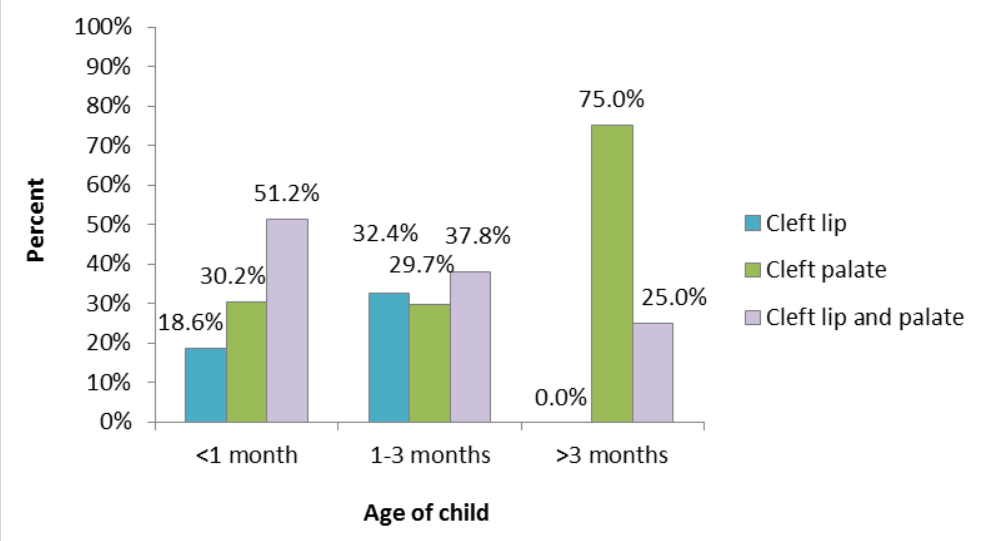
From this survey, prenatal diagnosis versus postnatal diagnosis of OFC was almost an even distribution. About 55% of respondents reported that they found out about their child's oral cleft before birth. Of these, cleft lip and palate was the most predominant type of cleft (76.4%; Figure 4). Nearly half the respondents (45.5%) indicated that they discovered that their child had an oral cleft after birth. Of these, the majority (58.7%) had cleft palate only (Figure 4).

Figure 4: *Percentage of respondents who found out about their child's oral cleft before birth by type of cleft (n=101): Orofacial Cleft Family Survey, 2013*



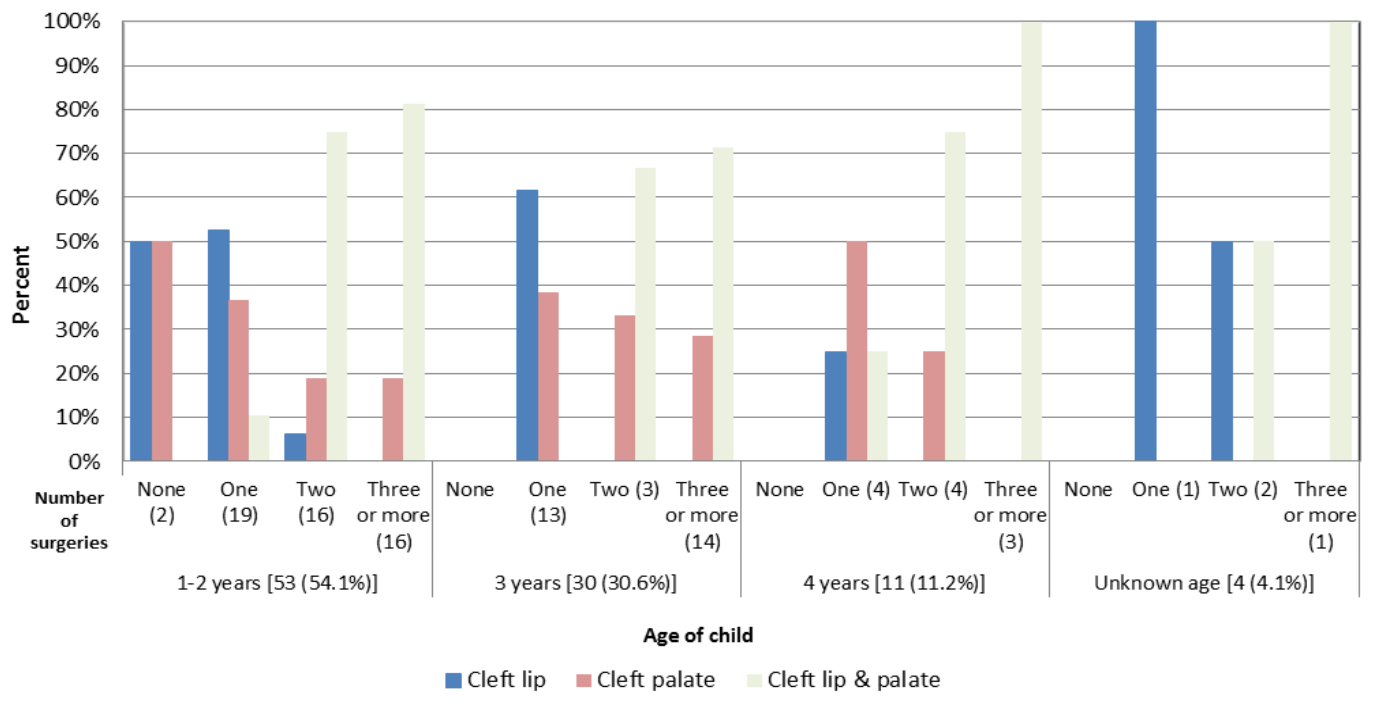
Overall, about 43% of respondents first met with a cleft specialist when their child was less than 1 month of age, about 37% when their child was 1 to 3 months of age and about 4% when their child was over 3 months of age. Figure 5 shows the age group distribution of children when the parent or care giver first met with a cleft specialist, stratified by the type of cleft. For children seen less than 1 month of age, over half (51.2%) had cleft lip and palate (Figure 5). For children seen at 1 to 3 months of age, most (37.8%) had cleft lip and palate (Figure 5). For children seen older than 3 months, most (75%) had cleft palate only (Figure 5). There was no statistical difference between the age distribution of the children when the parent first met with a cleft specialist and the type of cleft (p=0.2496).

Figure 5: *Percentage of respondents who met with a cleft specialist by age of child (at initial meeting) and type of cleft (n=84): Orofacial Cleft Family Survey, 2013*



The number of surgeries for children born from 2009 through 2011 (n=98) was analyzed by the age of the child and type of cleft. For older children born in 2009, who were about 4 years old (n=11), most (72.7%, n=8) had one or two surgeries. Of those with one surgery half (50.0%; n=4) had cleft palate only and of those with two surgeries, the majority (75.0%; n=4) had cleft lip and palate (Figure 6). For children born in 2010, who were about 3 years old (n=30), nearly half (46.7%; n=14) had three or more surgeries. Of these, the majority (71.4%) had cleft lip and palate (Figure 6). For younger children born in 2011 who were 1-2 years old (n=53), most (35.8%; n=19) had only one surgery. Of these, over half (52.6%) had cleft lip only (Figure 6). Results indicated that children who were 3 years or older had at least one surgery. Children with cleft lip and palate had more surgeries compared to children with cleft lip alone or cleft palate alone. The surgery experience of other children born with cleft who were 5 to 11 years old (n=3) was also assessed. Results indicated that the majority (66.7%) had three or more surgeries and had cleft palate only (data not shown).

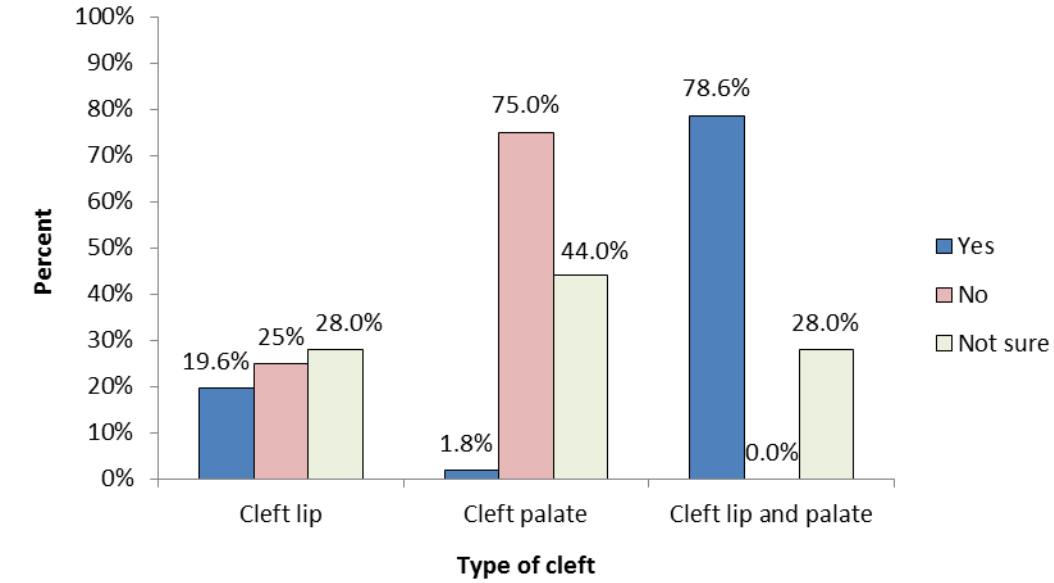
Figure 6: *Number of surgeries by age of child and type of cleft for children born 2009-2011 (n=98): Orofacial Cleft Family Survey, 2013*



When asked if more surgery was needed to revise their child's oral cleft, over half the respondents (55.5%) reported more surgery was needed, 19.8% indicated the surgical repair of their child's cleft was complete and nearly a quarter (24.8%) indicated not sure. Analysis of the data revealed that most children with cleft lip and palate (78.6%) required more surgery than children with cleft lip only (19.6%) or cleft palate only (1.8%; Figure 7). Most children with cleft palate only had their cleft repair completed (75.0%; Figure 7). No child with a cleft lip and palate was reported to have a complete

repair (Figure 7). For those who were not sure if their child required more surgery, 44% of the children had cleft palate only (Figure 7).

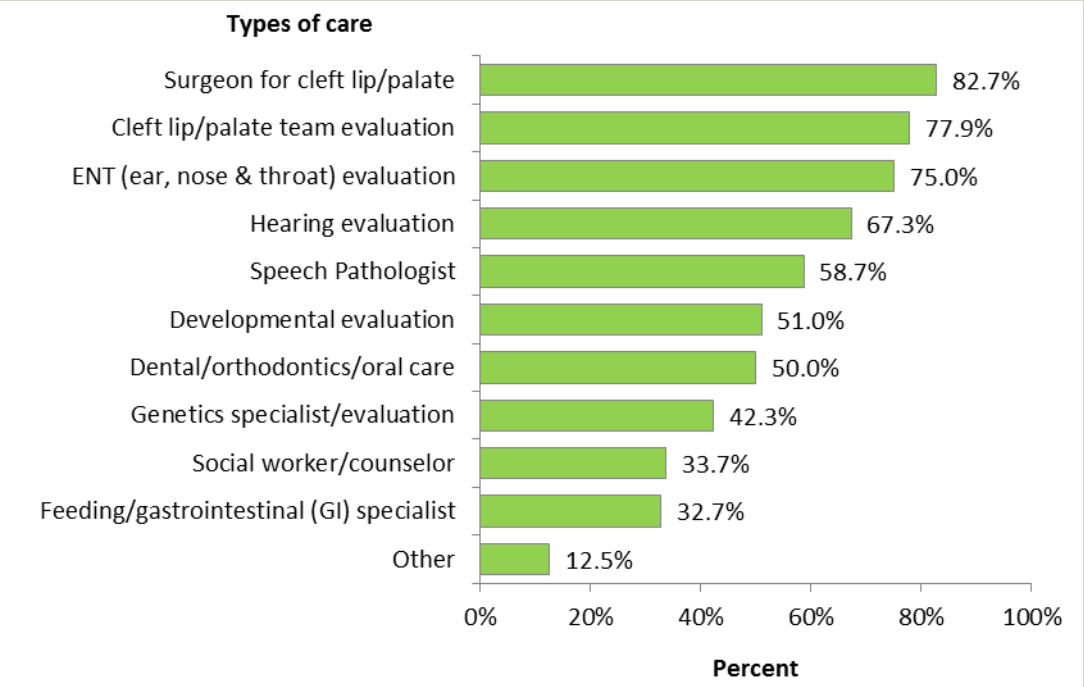
Figure 7: *Percentage* of *children needing more surgery to revise oral cleft (n=101): Orofacial Cleft Family Survey, 2013*



While 89.1% of respondents indicated that, besides surgery, their child currently receives, or had received in the past, follow-up specialty care, 10.9% indicated their child did not receive any follow-up care related to his/her cleft.

The top three types of care families reported receiving included surgeon for cleft lip/palate (82.7%), cleft lip/palate team evaluation (77.9%) and ENT (ear, nose, & throat) evaluation or care (75.0%) (Figure 8). A small percentage of respondents (12.5%) indicated receiving other types of care which included cardiologist, OT and PT Therapy, eye specialist and sleep specialist (Figure 8). Of note, a respondent indicated on the survey "There is a strong correlation between cleft patients and sleep apnea."

Figure 8: *Types of care received by percentage of children (n=89): Orofacial Cleft Family Survey, 2013*



Although 84.2% of respondents reported they were given information about specialists needed for their child's care, 15.9% did not receive this type of information. Of these, 6.9% selected "other" and reported receiving information about specialists through their own research efforts. Referral to specialists by health professional was assessed by the type of care or evaluation respondents actually received. Results revealed that referral to services was lowest among those who saw "other" specialists (76.9%) and highest among those who had a developmental evaluation (88.5%; data not shown). For those who indicated they received no information about specialists, genetics evaluation ranked highest for care received (9.1%); none of these respondents saw a feeding/ GI specialist or a social worker/counselor (data not shown).

Respondents reported they did not get much help with the care coordination for their child with an oral cleft. Nearly half (47.8%) indicated receiving no help and about 12% indicated getting some help, but not enough. Only 38.9% of respondents reported getting assistance with managing, planning, and scheduling specialist appointments for their child (data not shown).

From the survey, clinics that had the most frequently seen children for out-patient cleft care included University of Michigan Craniofacial Anomalies Program (28.9%), DeVos Children's Hospital (Grand Rapids) Oral Cleft Program (21.2%) and Children's Hospital of Michigan (Detroit Medical Center) Craniofacial Clinic (19.2%). Overall, most out-patient cleft care is/was received at individual specialists with separate appointments on a regular basis (36.7%), at a craniofacial clinic seeing many different specialists (cleft team) in one day (30.0%) or at individual specialists on an as-needed basis (24.4%; data not shown).

Thirty percent of respondents indicated that they were not provided with information (for example, information about the medical, emotional or social needs of children with clefts or information about the causes of clefts) when their child was born (Table 5). A third (33.3%) also reported that no health care provider gave them a contact number to call with questions or concerns after leaving the birthing center (Table 5). However, over 95% of respondents felt it important for new parents to be provided with such information. Only 44.4% of respondents reported that a professional talked with them about future expenses and planning how to pay for the medical care of their child with an oral cleft. The majority (84.4%), however, felt that such information for new parents was important (Table 5).

Table 5: *Helpful resources for parents of children with cleft, whether these resources were provided by a health professional (HP) and perceived importance (n=90): Orofacial Cleft Family Survey, 2013*

Resources/Information	Did HP provide?			Important for HP to provide
	Yes	No	Not sure	Total
Information about children with special needs/causes of clefts	64.4%	30.0%	5.6%	99.0%
Contact number to call with questions/ concerns	54.4%	33.3%	12.2%	96.7%
Information about expenses and paying for medical care	44.4%	54.4%	1.1%	84.4%

Approximately 15% of respondents reported that before leaving the birthing hospital, they were not given or offered a special feeder for their child with an oral cleft (Table 6). In addition, over a quarter (28.9%) indicated they were not given information on how to get a special feeder (or additional ones) for their child with an oral cleft before leaving the birthing hospital (Table 6).

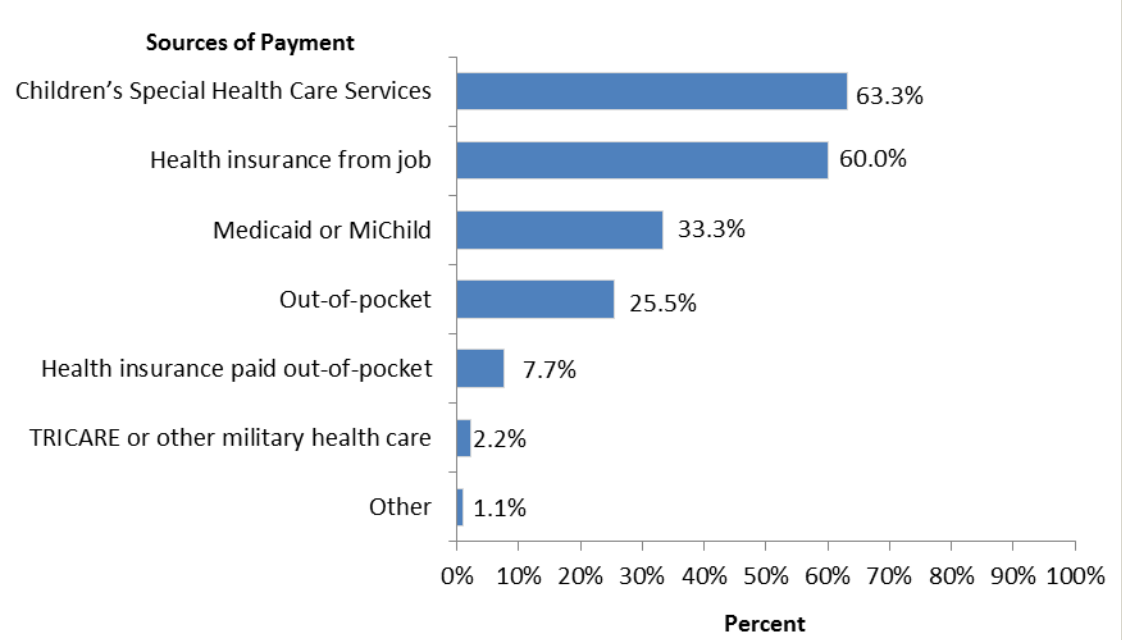
Table 6: *Percentage of respondents who received special feeding resources provided by a health professional (HP; n=90): Orofacial Cleft Family Survey, 2013*

Special feeding resources	Did HP provide?			
	Yes	No	Not sure	Not applicable
Special feeder for child with oral cleft	76.7%	14.4%	0.0%	8.9%
Information on how to get a special feeder	60.0%	28.9%	4.4%	6.7%

When asked how the medical expenses for their child with an oral cleft were paid, the majority of respondents selected Children's Special Health Care Services (54.8%) or health insurance from their job (51.9%). The answer option least selected was "other" (1.9%), specified as Shriners Hospital.

Figure 9 shows the source of payment indicated by those who reported that, besides surgery, their child was currently receiving or had received in the past, the follow-up care related to their cleft. Results showed that the majority had their follow-up medical expenses paid for by Children's Special Health Care Services (63.3%) or through a health insurance from their place of employment (60.0%; Figure 9). About 26% of respondents indicated that they paid for the medical expenses of their child out-of-pocket (Figure 9).

Figure 9: *Source of payment for medical expenses for those who received follow-up care (n=90): Orofacial Cleft Family Survey, 2013*



Overall, the top three services or types of support respondents reported receiving were Early On® (44.4%), Supplemental Nutrition Program for Women, Infants & Children (WIC; 30.8%) and Aid (19.2%) such as Aid to Families with Dependent Children (AFDC), Welfare, Public Assistance, General Assistance, Food Stamps, or SSI. About 27% of respondents indicated that they received none of these services.

Participants were asked to identify barriers to providing the first surgical repair or follow-up cleft care needed for their child. Of note, 79% of respondents indicated they had no barriers. Barriers that were reported included having no transportation to get to the clinic or doctor's office (1.9%). Over 6% of respondents indicated having other barriers which included the following:

- "Currently going through insurance issues,"
- "Wanted to transfer from birth hospital and was very difficult," and
- "Wish I had better information about different doctors to make a better informed decision."

Over 3% of participants reported having other challenges in providing the follow-up cleft care needed for their child including:

- "Despite calling the clinic two times, we were never contacted for follow up care."

Overall, respondents felt that their child born with an oral cleft was getting the care he or she needed (92.3%). A small percentage of respondents (2.3%) felt that their child was not getting the care needed and explanations reported for this included the following:

- "Worried about dental/orthodontic work down the road,"
- "We live in Port Huron, where there are other children born with clefts... very disappointed in the lack of local health care specialist that can help," and
- "We now are but we have had a frustrating 2 years."

Emotional/Social Support

The following section provides a summary of findings related to emotional or social support for families. The most important source of emotional or social support identified by respondents was family (78.0%). Other sources of support identified included parent or family support groups (5.0%), friends' (5.0%), craniofacial organization (2.0%) and a health care provider or counselor (1.0%). Two percent of respondents indicated that they had no support.

Overall, 76.5% of respondents reported that they had received the emotional or social support they needed while 14.3% indicated they had not. Explanations provided by those who had not received the emotional/social support needed included:

- "Family doesn't always understand because no one has had a cleft kid. Can feel like you're on an island at times,"
- "Family has been supportive but would have liked other support about the emotional aspects of surgery,"
- "I do wish there were more outlets to speak to families effects by clefts. Although family support is great, I would love to speak to parents that have been through the same thing as me," and
- "We have the support of our family but leaving the hospital we felt very alone and weren't sure where to begin. Luckily a nurse that was taking care of us at the hospital knew of a family who had a child with a cleft and gave her our name. She contacted us, which was a big help. We felt the hospital really dropped the ball with any information or guidance on the cleft."

According to our survey, 71.2% of respondents indicated they were coping very well with having a child with special health care needs, and 28.3% indicated they were coping fairly well. Families were asked a variety of questions about coping with the additional stresses related to having a child with an oral cleft and the perceived importance of health professionals addressing these issues.

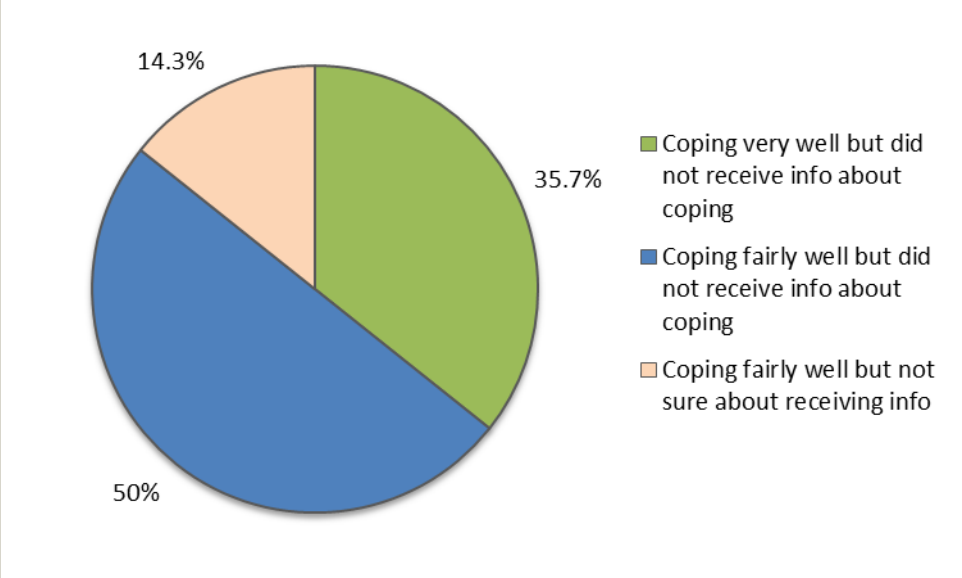
As shown in Table 7, less than 50% of respondents felt that a health professional addressed three important issues— ways to cope with their struggles as they care for a child, how having a child with special health care needs like an oral cleft may affect their family, and information about ways to contact other families or parent support groups. However, over 70% of respondents felt it was important for a health professional to address these issues (Table 7).

Table 7: *Issues related to having a child with cleft, whether these issues were addressed by a health professional (HP) and perceived importance (n=99): Orofacial Cleft Family Survey, 2013*

Issues	Did HP address?			Important for HP to address
	Yes	No	Not sure	Total
Ways to cope with struggles caring for a child with cleft	41.8%	43.8%	14.3%	88.9%
How having a child with special needs 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%

Responses for those who reported that they did not receive the needed emotional or social support were assessed by how well they were coping with the struggles of caring for a child with an oral cleft and whether they were given information on coping by a health professional. Only 35.7% of those indicating they had not received the needed support reported coping very well. Moreover, these respondents indicated that no health professional talked with them about ways to cope with struggles they may have as they care for their child with a cleft (Figure 10). Most respondents indicated they were coping fairly well (64.3%). Half the respondents reported coping fairly well but did not receive any information about coping strategies and about 14% reported coping fairly well but were not sure or did not recall receiving information about ways to cope with their struggles (Figure 10).

Figure 10: *Percentage of respondents who did not receive the needed support by how well they were coping and whether they received information about coping (n=14): Orofacial Cleft Family Survey, 2013*



The relationship between having the needed emotional or social support and the ability to cope with struggles caring for a child with an oral cleft was assessed (Table 8). Results indicated a statistically significant relationship (p<.0001). Furthermore, results indicated that a greater percentage of respondents who saw a social worker/counselor (68.6%) had their emotional or social support needs met.

Table 8: *Received social support needed and ability to cope with struggles (n=97): Orofacial Cleft Family Survey, 2013*

Received needed emotional/ social support	Ability to cope 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

Although 90.7% of respondents indicated their family did not need help finding any information, services, or support, about 9% indicated needing help. These, among others included:

"Financial assistance for future surgery."

"How often should she be seen post-surgery? What kinds of support services are available?"

"We are hoping to get a referral to a different cleft clinic for services and support."

"Local family support."

Respondents were asked if they would like to be contacted by someone from the Birth Defects Follow-up program. About 25% were unsure at the time, 5.2% indicated they would contact the program and 8.5% asked to be contacted.

Finally, nearly a quarter of the respondents (22.2%) provided additional information they thought was important for the Birth Defects program to know. A partial list includes:

- "Finding out before child is born helps prepare you, I think versus the surprise of when they are born."
- "Healthcare providers need to be equipped with information to pass along to families after the birth of a child with a cleft lip or palate."
- "I think the phone system that was available for parents to connect with other parents was greatly appreciated since we did not have to pay to talk to other parents. I am not sure if that phone system is still available for those new moms that could really benefit from it."
- "My daughter was not diagnosed with a cleft palate until she was 6 months old."
- "There is a group called MiCleft that helped with support when I really needed it."

Discussion

Clefting is more likely to occur in a newborn who has a family history of primary relatives (parents, siblings) with clefts.[5] Researchers have observed that the history of oral clefts in the family is strongly associated with new occurrences of oral clefts.[6] Results from our survey reflected this. This underscores the importance of referral to genetics. Less than half the respondents were seen by a genetics specialist. From the survey, it appears more may have been referred, but probably did not make the appointment. We did not assess whether or not individuals in this cohort had additional birth defects or genetic syndromes associated with oral clefts. However, some families chose to share that information with us.

It has been found that about 50% of children with clefts have clefts that involve both the lip and palate. Another 25% have clefts that involve only the lip and the remaining 25% have clefts that only affect the palate.[7] Survey respondent proportions were quite similar.

Babies with cleft lip and palate will have multiple surgeries during their infancy, childhood and adolescence. Depending upon the severity of the case, these surgeries can include the initial repair of the lip and nose (in the first 6 months of life), the palate repair (by 12-18 months of age) and repair of the cleft in the gum line (between 7 and 9 years of age).[5] Thus, families will typically experience the stress of additional medical appointments, procedures, therapies and bills throughout the childhood years. At the minimum, one surgery is needed to repair the lip and a separate surgery is needed to repair the palate. However, several surgeries are needed to make the lip appear as normal as possible. And sometimes additional surgeries involving the palate are needed to improve speech.[7]

Results indicated that children with cleft lip and palate tended to have more surgeries than children with cleft lip alone or cleft palate alone.

Previous research shows that having more support from friends and family is associated with less negative family impact, lower psychological distress and better adjustment.[8] Survey results suggested an association between having the needed emotional/social support and the ability to cope with struggles. Seeing a social worker or counselor also appeared to have a positive impact on having a respondent's emotional or social support needs met.

Public Health Impact

Although most families provided positive feedback regarding the needed follow-up care for their child, information on specialists, services, support, or feeling that their child was getting care, several gaps were identified.

Results clearly indicated the need for health care professionals to provide new parents with information and resources related to care coordination such as managing, planning and scheduling appointments with specialists, financial assistance, coping with potential struggles, a number to call with questions or contact with other families who had a child with an OFC or support groups. New parents of children with OFC can benefit from receiving information and assistance beyond specialized medical care.

The MBDR has the opportunity to increase awareness among health care providers of family needs and available services.

References

1. Centers for Disease Control and Prevention. Facts about Cleft Lip and Cleft Palate. Retrieved April 8, 2014 from the World Wide Web at http://www.cdc.gov/ncbddd/birthdefects/cleftlip.html.

2. Schutte B.C, Murray J.C. The Many Faces and Factors of Orofacial Clefts. Human Molecular Genetics: 1999; Vol. 8, No. 10 Review 1853-1859.

3. U.S. Department of Health and Human Services. The Health Consequences of Smoking: 50 Years of Progress. A Report of the Surgeon General. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, 2014. Printed with corrections, January 2014.

4. Butali A1, Little J, Chevrier C, Cordier S, Steegers-Theunissen R, Jugessur A, Oladugba B, Mossey PA. Folic acid supplementation use and the MTHFR C677T polymorphism in orofacial clefts etiology: An individual participant data pooled-analysis. Birth Defects Res A Clin Mol Teratol. 2013 Aug;97(8):509-14. doi: 10.1002/bdra.23133. Epub 2013 May 13.5.

5. Pediatric Plastic Surgery. University of Missouri Children's Hospital. Cleft lip & Palate. Retrieved April 8, 2014 from the World Wide Web at http://smilesforkids.missouri.edu/common-conditions/cleft-lip-palate/.

6. Leitel I.C.G, Sérgio K. Oral clefts, consanguinity, parental tobacco and alcohol use: a case-control study in Rio de Janeiro, Brazil. *Brazilian Oral Research*: Jan./Mar. 2009 São Paulo; Vol.23, No.1.

7. University of Iowa Children's Hospital. Cleft Palate: Frequently asked questions. Retrieved April 8, 2014 from the World Wide Web at http://www.uichildrens.org/cleft-palate-faqs/.

8. Sarah R. Baker, Jan Owens, Melanie Stern, Derrick Willmot, (2009). Coping Strategies and Social Support in the Family Impact of Cleft Lip and Palate and Parents' Adjustment and Psychological Distress. *The Cleft Palate-Craniofacial Journal*: May 2009; Vol. 46, No. 3, 229-236.

Suggested Citation:

Quarshie E, Dinh P, Ehrhardt J, Wahl R, McKane P, Mobley M, Copeland G. *A Needs Assessment Survey for Parents of Children with Oral Cleft in Michigan*. Lansing, MI: Michigan Department of Health and Human Services, Lifecourse Epidemiology and Genomics Division. September 2015.