Profile of Oral Cleft Cases Reported in the Philippine Oral Cleft Registry from May 2003 to December 2006

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ABSTRACT

The Philippine Oral Cleft Registry (POCR), an initiative of the Philippine Oral Cleft Registry Study Group (POCRSG), was launched in May 2003. The study group is composed of the Institute of Human Genetics (IHG) - National Institutes of Health, University of the Philippines Manila; the Philippine Association of Plastic, Reconstructive and Aesthetic Surgeons Inc. (PAPRAS); the Philippine Society of Otolaryngology - Head and Neck Surgery (PSO-HNS); Operation Smile Philippines Foundation Inc. (OSPF); and the Philippine Band of Mercy (PBM). The general objective of the POCRSG is to implement the POCR for patients with oral clefts (cleft lip and/or palate). The specific objectives are: 1) to establish the incidence of oral clefts in the Philippines; 2) to describe the different variants of oral clefts; 3) to identify the possible risk factors for oral clefts; and 4) to identify the regional distribution of patients with oral clefts. From May 2003 to December 2006, the POCR recorded a total of 2,324 cases representing a prevalence of 0.42 per 1000 livebirths [or 1:2367 livebirths] using an estimated birth rate of 1.5 million babies a year assuming full ascertainment. This observed rate is probably an underestimate of the true prevalence of oral clefts in the country. The POCRSG actively coordinates with both government and non-government organizations sponsoring oral cleft surgical missions to actively participate in the registry. By doing so, a more accurate prevalence can be established in the Philippines.

Key Words: cleft lip, cleft palate, The Philippine Oral Cleft Registry, Philippine Oral Cleft Registry Study Group

Introduction

Oral clefts are among the most common congenital anomalies. Various sources estimate global incidence of oral clefts at one for every 500-1000 live births, varying with race and gender.[1-6] Asians in particular, are at a higher risk for oral clefts.[7,8] The prevalence of oral cleft (cleft lip with or without cleft palate) in the Philippines was reported in 1997 to be 2 per 1000 livebirths using records from an 8 year period at a government hospital in Negros, the Corazon Locsin Montelibano Memorial Regional Hopistal.[9] Recurrence rates in siblings for non-syndromic clefts of the lip and palate were 23 per 1000 for cleft lip with or without cleft palate, and 14 per 1000 for cleft palate[9].

While timely surgical intervention around 6-18 months of age remains the primary treatment for oral clefts, a multidisciplinary approach involving a surgical, orthodontic and rehabilitation team is now recommended for treatment success. The lifetime cost for medical treatment, educational services, and loss of productivity averages more than US$100,000 in the United States.[10,11] So far, there is no cost benefit analysis on the advantages of early surgical correction versus a do – nothing alternative in the Philippine setting.

High prevalence and costly treatment shift management of oral clefts from acute treatment to possible primary prevention. Previous researches have expounded on the etiology, treatment, and prevention of oral clefts. The most relevant etiologic factors in the Philippine setting are micronutrient insufficiency and maternal exposure to tobacco smoke, alcohol, corticosteroids, exogenous estrogen, organic pollutants, and occupational chemicals.[12-14] A surveillance system under a registry provides data that can identify etiology, confirm hypotheses generated by past studies, and describe the proportion of and factors for successful management. These data can be used to develop health policies for disease management and/or primary prevention.

The need to establish a national registry for oral clefts was recognized by five (5) organizations (Appendix 1): the Institute of Human Genetics (IHG) of the National Institutes of Health, University of the Philippines Manila; the Philippine Association of Plastic, Reconstructive and Aesthetic Surgeons Inc. (PAPRAS); the Philippine Society of Otolaryngology - Head and Neck Surgery, Inc. (PSO-HNS); Operation Smile Philippines Foundation Inc. (OSPF); and the Philippine Band of Mercy (PBM). The inaugural meeting was on May 9, 2002 (Figure 1) with representatives from the following hospitals – AFP Medical Center, Cardinal Santos Medical Center, DLSU Medical Center, Dr. Victor R. Potenciano Memorial Medical Center, East Avenue Medical Center, FEU Medical Center, Jose Reyes Memorial Medical Center, Makati Medical Center, Manila Central University, Manila Doctors Hospital, Ospital ng Maynila, Our Lady of Lourdes Hospital, Philippine General Hospital, Quezon City General Hospital. Quirino Medical Center, , St. Luke's Medical Center, The Medical City, , UERM Medical Center, UST Hospital, Veterans Memorial Medical Center. After a

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Figure 1. The Philippine Oral Cleft Study Group during the inaugural meeting (May 9, 2002). Seated from left to right: Carmencita David-Padilla, Mel Cruz, Corazon Buenviaje, Florencio Lucero, Teresita Tongson, Eutrapio Guevarra, Gretchen Navarro-Locsin. Standing from left: Mary Anne Chiong, Eva Cutiongco-de la Paz, Lourdes Angliongto, Joseph Sia, Hector Santos, Natividad Arceo, Atoy Manalo, Lawrence Loh, Joseph Raymond Tapang, Marlou Padua, Sheila Pangalangan , Placido Calimag, Jose Suan, Cesar Villafuerte, Jr , Elias Reala.

series of meetings, the Philippine Oral Cleft Registry Study Group (POCRSG) was formalized with the signing of the Memorandum of Agreement on May 21, 2003, to formally launch the Philippine Oral Cleft Registry (POCR). The general objective of the POCRSG is to implement the POCR for patients with oral clefts (cleft lip and/or palate). The specific objectives are: 1) to establish the incidence of oral clefts in the Philippines; 2) to describe the different variants of oral clefts; 3) to identify the possible risk factors for oral clefts; and 4) to identify the regional distribution of the patients with oral clefts.

Through the network of organizations, the POCRSG aims to cover all cases of oral clefts in the country, both from community-based surgical missions and from hospitals. Cases reported by the OSPF and PBM come from community surgical outreach missions for oral clefts throughout the country. The PAPRAS and PSO-HNS cover both in-hospital cases and provide free services in the medical missions organized by OSPF and PBM. The IHG serves as the base of the registry where registry reports are submitted, consolidated and generated into reports.

Methods

Case Definition

All of the following criteria must be met for a case to be included in the POCR: 1) The mother's residence at the time of delivery must be in the Philippines; 2) The patient must have a structural defect in the lip and/or palate diagnosed by plastic or ENT surgeons affiliated with the collaborating organizations or hospitals; 3) The patient must be registered in any of the participating hospitals or community based missions on or after March 1, 2003.

The form was finalized by the 5 institutions. The manner of reporting of the oral cleft was agreed upon by representatives of PAPRAS and PSO-HNS.

Registry Forms

The registry form includes the following information:

- *Notifier's/ Interviewer's Data.*
- *Informant's Data.*
- *General Data for all patients.*
- *Patient's Information*. This part is accomplished by the surgeon who provided the evaluation or surgical management. The hospital and surgeon's name are identified. The diagnosis is established and the classification of cleft lip and/or palate is further specified using ICD-10 code.
- *Maternal History.* This part includes problems during pregnancy such as exposure to radiation, drugs, and chemicals; presence of infection; intake of vitamins; presence of metabolic illness (such as diabetes and thyroid disease); smoking; exposure to cigarette smoke, alcohol, medicines, illicit drugs and substances, and vitamins during pregnancy.
- *Family History of Oral Cleft.*
- *ENT Data.* This section describes history of illness, presence of other anomalies and ENT findings, otoscopic and audiologic findings.

Data Collection and Management

The POCRSG used passive surveillance. Reports were submitted by hospitals or medical professionals through completion of the Oral Cleft Registry Form. Forms were reviewed for completeness by trained personnel prior to encoding. Forms with incomplete data were returned to the physician in charge for completion. Completed forms were encoded. Quality control procedures for defining the diagnosis, abstracting information, and coding defects helped ensure completeness and accuracy (Appendix 2). Duplicate entries were double checked manually from the electronic database.

Results and Discussion

Of the 2,529 cases reported from May 2003 to December 2006, 205 cases were dropped from the roster of cases from community missions due to incomplete information on the type of cleft diagnosis. Thus, only 2,324 forms were encoded

into the registry. Table 1 shows the number of cases reported by each collaborating organization.

Among the 2,324 cases reported, 60.11 % were males, 39.67 % were females and a few (0.22 %) had no gender specified. There is a consistently observed male predominance in all of the reported cases across the organizations, with an overall female to male ratio of 1:1.5 (Table 2). This slight male predominance has been reported by others.[8, 16]

Among the oral cleft cases reported, the combination of cleft palate with cleft lip accounted for the most number of cases (Table 3).

Tables 4, 5 and 6 show the different variants of the cleft palate with cleft lip, cleft palate only and cleft lip only, respectively.

Based on geographical location, majority of the cases whether mission-based or hospital-based were from the island of Luzon (Table 7). The top two regions of origin of cases are the National Capital Region (NCR) and CALABARZON Region accounting for 30.6 % and 20.0 %, respectively (Table 8 and 9). Data from national statistics reveal that these 2 regions have the highest contribution of livebirths in the country.[17] In the Visayas, there is an equal share of cases between Central Visayas and Eastern Visayas (Table 10). The island group of Mindanao had the lowest (Table 11).

Data gathered from registries assist in launching several public health policies for early diagnosis and management of oral clefts. Continued surveillance through a registry will allow evaluation of existing programs and the promotion of new public health projects that will adequately deal with the preventable causes of oral clefts. There are several successful models for oral cleft/birth defects registries. In other countries, oral cleft registries are part of a birth defects registry with varying coverage or scope. The Iowa Registry for Congenital and Inherited Disorders, for example, identifies and monitors birth defects exclusively in the State of Iowa.[18] The Danish Medical Birth Registry, on the other hand, was established for surveillance and research to monitor the health of the newborns and of the quality of the antenatal and delivery care services covering the whole country of Denmark. The registry is limited to congenital anomalies including oral-facial clefts diagnosed in hospitals in the child's first year of life.[19] Another registry of larger coverage is the Estudio Colaborativo Latino Americano de Malformaciones Congenitas (ECLAMC), initially limited to the city of Buenos Aires and Argentina now covering all the 10 countries of South America, Costa Rica and the Dominican Republic. It is a clinical and epidemiological investigation of risk factors in the etiology of congenital anomalies in Latin-American hospitals, using a case-control methodological approach. It is a voluntary agreement among professionals lacking institutional base as well as designated budgets.[20] The POCR specifically addresses oral clefts only. Another Birth Defects Surveillance Program (BDSP) in the Philippines is currently taking charge of reporting other forms of birth defects. The POCR includes patients with oral clefts at all ages whereas the BDSP is only for newborns. It is envisioned that in the future, when the BDSP is of national coverage, all patients with oral clefts will be identified during the newborn period. The BDSP is also based in the Institute of Human Genetics, National Institutes of Health, University of the Philippines Manila.

Since there are other groups or organizations that are doing oral cleft missions in the country, the observed rate is probably an underestimate of the true prevalence of oral clefts in the country. The POCRSG is actively coordinating with both government and non-government organizations sponsoring oral cleft surgical missions, to participate in the registry. By doing so, a more accurate prevalence can be established in the Philippines.

Data generated from the registry forms may help us identify the possible risk factors for oral clefts and further understand the different variants of cleft.

Limitations of the POCR include the following: 1) the registry does not capture fetal deaths and stillbirths with oral clefts; 2) the registry relies on passive surveillance and does not include undiagnosed cases or cases that have not been seen by a physician; 3) the registry constitutes data reported by four organizations only and the patients of doctors who were not affiliated with the collaborating organizations were not included.

Table 1. Total number of oral cleft cases reported by each collaborating organization from May 2003 to December 2006

Organization	Number of cases	Per cent
OSPF	265	11.4
PAPRAS	159	6.8
PBM	1530	65.9
PSO-HNS	171	7.4
Other organizations	50	2.1
Organization not specified	149	6.4
Total	**2324**	**100.0**

Table 2. Gender distribution of reported oral cleft cases reported by each collaborating organization from May 2003 to December 2006 (N=2,324)

Organization	Gender		Ratio	
	Female	Male	Not specified	F:M
OSPF	103	161	1	1:1.6
PAPRAS	64	93	2	1:1.5
PBM	597	931	2	1:1.6
PSO-HNS	75	96	0	1:1.3
Other organization	20	30	0	1:1.5
No specified organization	63	86	0	1:1.4
Total	**922**	**1397**	**5**	**1:1.5**

Table 3. Frequency distribution of oral cleft cases reported by all collaborating organizations from May 2003 to December 2006

Diagnosis	Number of cases	Per cent
Cleft palate with cleft lip	1319	56.8
Cleft lip only	588	25.3
Cleft palate only	417	17.9
Total	**2324**	**100**

Table 4. Variants of combined cleft palate with cleft lip cases reported by all collaborating organizations from May 2003 to December 2006

Variant	Number of cases	Percent
Cleft Hard Palate Bilateral with Cleft Lip Bilateral	30	2.3
Cleft Hard Palate Bilateral with Cleft Lip Unilateral	19	1.4
Cleft Hard Palate Unilateral with Cleft Lip Bilateral	8	0.6
Cleft Hard Palate Unilateral with Cleft Lip Unilateral	56	4.2
Cleft Hard Palate Unilateral with Cleft Lip Medial	1	0.1
Cleft Soft Palate with Cleft Lip Bilateral	8	0.6
Cleft Soft Palate with Cleft Lip Unilateral	30	2.3
Cleft Soft Palate with Cleft Lip Medial	1	0.1
Cleft Soft Palate Bilateral with Cleft Lip Bilateral	1	0.1
Cleft Soft Palate Bilateral with Cleft Lip Unilateral	1	0.1
Cleft Soft Palate Unspecified with Cleft Lip Unilateral	3	0.2
Cleft Hard Palate with Soft Palate Bilateral with Cleft Lip Bilateral	380	28.8
Cleft Hard Palate with Soft Palate Bilateral with Cleft Lip Unilateral	199	15.1
Cleft Hard Palate with Soft Palate Bilateral with Cleft Lip Medial	1	0.1
Cleft Hard Palate with Soft Palate Unilateral with Cleft Lip Bilateral	36	2.7
Cleft Hard Palate with Soft Palate Unilateral with Cleft Lip Unilateral	433	32.8
Cleft Hard Palate with Soft Palate Unilateral with Cleft Lip Medial	62	4.7
Cleft Hard Palate with Soft Palate Midline with Cleft Lip Bilateral	3	0.2
Cleft Hard Palate with Soft Palate Midline with Cleft Lip Unilateral	5	0.4
Cleft Hard Palate with Soft Palate Unspecified with Cleft Lip Bilateral	8	0.6
Cleft Hard Palate with Soft Palate Unspecified with Cleft Lip Unilateral	10	0.8
Cleft Uvula with Cleft Lip Bilateral	2	0.1
Cleft Uvula with Cleft Lip Unilateral	9	0.7
Cleft Palate Unspecified Bilateral with Cleft Lip Bilateral	4	0.3
Cleft Palate Unspecified Bilateral with Cleft Lip Unilateral	1	0.1
Cleft Palate Unspecified Unilateral with Cleft Lip Unilateral	7	0.5
Submucuous Cleft with Cleft Lip Unilateral	1	0.1

Table 5. Variants of cleft palate only cases reported by all collaborating organizations from May 2003 to December 2006

Variant	Number of cases	Percent
Cleft hard palate, unilateral, left	4	1.0
Cleft hard palate, unilateral right	6	1.4
Cleft hard palate, unilateral, unspecified	2	0.5
Cleft hard palate, bilateral	19	4.6
Cleft soft palate, unspecified	132	31.6
Cleft soft palate, bilateral	12	2.9
Cleft soft palate w/ sub mucous cleft	1	0.2
Cleft uvula	11	2.6
Submucous cleft	4	1.0
Cleft hard palate with cleft soft palate, unilateral, left	31	7.4
Cleft hard palate with cleft soft palate, unilateral, right	16	3.8
Cleft hard palate with cleft soft palate, unilateral, unspecified	17	4.1
Cleft hard palate with cleft soft palate, unspecified	2	0.5
Cleft hard palate with cleft soft palate, bilateral	145	34.8
Cleft hard palate with soft palate, midline	8	1.9
Cleft palate, unspecified, unilateral left	0	0.0
Cleft palate, unspecified, unilateral right	0	0.0
Cleft palate, unspecified, bilateral	5	1.2
Cleft palate, unspecified, medial	2	0.5

Table 6. Variants of cleft lip only cases reported by all collaborating organizations from May 2003 to December 2006

Variant	Number of cases	Per cent
Cleft lip, unilateral, unspecified	118	20.1
Cleft lip, unilateral, left	244	41.5
Cleft lip, unilateral, right	130	22.1
Cleft lip, bilateral	92	15.6
Cleft lip, medial	3	0.5
Cleft lip medial and cleft lip unilateral, left	1	0.2

Table 7. Distribution of cases reported by the collaborating organizations from May 2003 to December 2006 according to major island groups and site of operation

Region	Total cases	Per cent	Mission-based[a]	Hospital-based[b]	Others[c]
Luzon	2071	89.1	1587	314	170
Visayas	103	4.4	90	8	5
Mindanao	61	2.6	44	2	15
No specified region	89	3.9	74	6	9
Total	2324		1795	330	199

[a]OPSF and PBM; [b]PAPRAS and PSO-HNS; [c]Others and Unknown

Table 8. Regional distribution of cases reported by the collaborating organizations from May 2003 to December 2006

Rank	Region		Number of cases	Per cent
1	NCR	National Capital Region	713	30.6
2	IV A	CALABARZON[a]	464	20.0
3	I	Ilocos Region	249	10.7
4	III	Central Luzon	218	9.4
5	II	Cagayan Valley	138	5.9
6	IV B	MIMAROPA[b]	122	5.2
7	V	Bicol Region	100	4.3
8	CAR	Cordillera Administrative Region	67	2.9
9	VII	Central Visayas	47	2.0
10	VI	Western Visayas	46	2.0
11	X	Northern Mindanao	22	1.0
12	XII	SOCSARGEN[c]	19	0.8
13	XI	Davao Region	14	0.6
14	VIII	Eastern Visayas	10	0.4
15	XIII	CARAGA[d]	4	0.2
16	ARMM	Autonomous Region of Muslim Mindanao	2	0.1
17	IX	Zamboanga Peninsula	0	0.0
		No specified region of origin	89	3.9

[a]Cavite, Laguna, Batangas, Rizal, and Quezon
[b]Occidental Mindoro, Oriental Mindoro, Marinduque, Romblon, and Palawan
[c]South Cotabato, Cotabato, Sultan Kudarat, Sarangani, and General Santos City
[d]Agusan del Norte, Agusan del Sur, Dinagat Islands, Surigao del Norte and Surigao del Sur

Table 9. Regional distribution of cases reported by the collaborating organizations from May 2003 to December 2006 in Luzon

Region #	Region Name	Total cases	Mission-based[a]	Hospital-based[b]	Others[c]
I	Ilocos Region	249	184	11	54
II	Cagayan Valley	138	120	3	15
III	Central Luzon	218	171	38	9
IV-A	CALABARZON	464	342	99	23
IV-B	MIMAROPA	122	119	2	1
V	Bicol Region	100	94	5	1
NCR	National Capital Region	713	492	154	67
CAR	Cordillera Autonomous Region	67	65	2	0
Total		2071	1587	314	170

[a]OPSF and PBM; [b]PAPRAS and PSO-HNS; [c]Others and Unknown

Table 10. Regional distribution of cases reported by the collaborating organizations from May 2003 to December 2006 in Visayas

Region #	Region Name	Number of cases	Mission-based[a]	Hospital-based[b]	Others[c]
VI	Western Visayas	46	40	4	2
VII	Central Visayas	47	45	1	1
VIII	Eastern Visayas	10	5	3	2
TOTAL		103	90	8	5

[a]OPSF and PBM; [b]PAPRAS and PSO-HNS; [c]Others and Unknown

Table 11. Regional distribution of cases reported by the collaborating organizations from May 2003 to December 2006 in Mindanao

Region #	Region Name	Number of cases	Mission-based[a]	Hospital-based[b]	Others[c]
IX	Zamboanga Peninsula	0	0	0	0
X	Northern Mindanao	22	6	1	15
XI	Davao Region	14	14	0	0
XII	SOCSARGEN	19	19	0	0
XIII	CARAGA	4	3	1	0
ARMM	Autonomous Region of Muslim Mindanao	2	2	0	0
Total		61	44	2	15

[a]OPSF and PBM; [b]PAPRAS and PSO-HNS; [c]Others and Unknown

Conclusion and Recommendations

The POCR needs commitment and cooperation from all sectors to establish a more accurate prevalence of oral cleft cases in the Philippines. These sectors include health workers attending the delivery of newborns with oral cleft, specialists in charge of the surgical management of the patients, government and non government agencies sponsoring surgical missions. The prevalence computed from the dataset in this paper [0.42 per 1000 livebirths or 1: 2367 livebirths] is most probably an underestimate. Vigilance in reporting will be critical for more accurate statistics that will be the basis for the formulation of health policies for managing affected patients.

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APPENDIX 1
The Philippine Oral Cleft Registry Study Group

1. The Institute of Human Genetics - National Institutes of Health - University of the Philippines Manila is a center dedicated to making genetic testing available and accessible to Filipinos all over the country. Four major services relevant to the understanding and management of genetic disorders common to Filipinos are offered: basic and clinical researchers; expert diagnosis and management of genetic disorders; technical services for the diagnosis of genetic disorders, for carrier detection and for newborn screening; and training and materials on the clinical applications of genetics. The specialized units of the institute include the Cytogenetics Unit, Newborn Screening Unit, Molecular Genetics Unit, Biochemical Genetics Unit, Clinical Genetics Unit and the Research Unit.

2. The Philippine Association of Plastic, Reconstructive and Aesthetic Surgeons, Inc. (PAPRAS) is the professional organization of Plastic Surgeons in the Philippines. As a component society of the Philipine College of Surgeons, the members of PAPRAS are committed to the highest level of excellence in the practice of Plastic Surgery (http://www.papras.org/).

3. The Philippine Society of Otolaryngology - Head and Neck Surgery (PSO-HNS) is a nationally recognized association of certified specialists of Otolaryngology-Head and Neck Surgery engaging in the relentless pursuit of excellence of service, training, research and public information to all people in the Philippines (http://www.psohns.org.ph/v2/about.html).

4. The Operation Smile Philippines Foundation, Inc. (OSPF) is the local affiliate of Operation Smile International (OSI). Today OSI is the leading international humanitarian organization dedicated to providing free reconstructive surgery to indigent children and young adults with cleft lips, cleft palates and other facial deformities. In the last 21 years, of the 60,000 or so treated around the world, around 14,000 of them are in the Philippines, making this country the largest beneficiary (http://www.opsmilephilippines.com/index.html).

5. The Philippine Band of Mercy (PBM) is a private non-stock, non-profit foundation established in 1937 providing free medical and surgical services to underprivileged children born with cleft lip / palate deformities (http://www.philbandofmercy.org/index.htm).

APPENDIX 2

Flow of Operations for the Philippine Oral Cleft Registry Project