

Study of Cleft Lip and Cleft Palate in Tribal Areas of Gujarat

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Abstract: *Cleft of lip, hard and soft palate are the most common congenital abnormalities of the craniofacial structure. Worldwide incidence of cleft lip and palate is 1 in 600. It has some associations with genetics and nutrition deficiency. Making the disease more prevalent in tribal areas. This study is done to find out incidence, average age of presentation to health care worker and treatment, Outcome of surgery, Reason for delay in treatment etc in Tribal population of Gujarat. Comparison of tribal patients operated in tertiary center and primary centers. Impact of numerous camps for awareness and treatment of the disease.*

Keywords: Cleft lip, Cleft palate, Cleft disease, tribal area, Gujarat, Treatment of cleft lip, cleft palate, Smile train camps

1. Introduction

Cleft of lip, hard and soft palate are the most common congenital abnormalities of the craniofacial structure. Worldwide incidence of cleft lip and palate is 1 in 600. The overall worldwide prevalence of cleft lip with or without the cleft of palate is 9.92 per 10,000. The prevalence of cleft lip is 3.28 per 10,000, and that of the cleft lip and palate together is 6.64 per 10,000. Lowest incidence occurs in Native American tribes of Montana, USA, which is 1:2076. Indian sub-continent still remains one of the most populous areas of the world with an estimated population of 1.1 billion in India alone. Gujarat having population of 6 crore, the incidence of cleft lip and palate disease is 2500 per year. Inequalities exist, both in access to and qualities of cleft care with distinct differences among urban versus rural areas. Due to this inequality along with lack of awareness had lead to the accumulation of untreated clefts of the lip and palate leading to a significant health care problem in India. The term cleft lip and palate inadequately describes the potential complexities of the deformity which may involve nose, lips, alveolus or palate. As a consequence breathing, appearance, dentition, dental occlusion facial growth, speech and hearing can all be affected leading to psychosocial implications. It may not be the end of life but for children suffering from cleft problem, it goes beyond the obvious disfigurement of face to repeated infections, social stigma, and mental impairment that affect the speech, hearing, and dentition development or dentition as a whole. Such children are often misbehaved about their cleft related problems such as speech, teeth and lip appearance etc which results in lower level of confidence among such children. Research has shown that normal children are considered to be brighter having more positive social behaviour, socially more accepted than those children suffering from cleft diseases. These children suffer with emotional "burn out" in adolescence. Therefore, it has been suggested that these patients should also be included in national policies for integration of handicapped people, in agreement with programs of human rights, establishing a collaborative action between state and society. This would

assure their inclusion in the socioeconomic and cultural context and equal opportunities in society, without privileges or paternalism. Studies have shown association of clefts disease with haematological abnormalities such as anemia, eosinophilia and defects of the clotting mechanism. A common clinical observation among children with cleft palate is high prevalence of recurrent upper and lower respiratory tract infection. The various geographically difficult regions such as mountainous region of North-eastern Gujarat, rann of kachchhand the Southern region have diverse culture, and living standards. Due to insufficient, ineffective and disproportionate penetration of health care facilities the population at large have suffered a lot in terms of basic health care facilities. However certain NGOs and government agencies by means of various health projects have done excellent work but still lot of rural and tribal masses are deprived of quality and good health care. In addition, due to lack of awareness and illiteracy rate, the patients of cleft remain untreated or misguided by some quacks.

Tribes of Gujarat

There are twenty nine (29) notified Scheduled Tribes in the state, which are as follows:

- 1) Barda
- 2) Bavacha, Bamcha
- 3) Bharwad (in the Nesses of the forests of Alech, Barada and Gir)
- 4) Bhil, Bhil Garasia, Dholi Bhil, Dungri Bhil, DungriGarasia, Mewasi Bhil, Rawal Bhil, Tadvi Bhil, Bhagalia, Bhilala, Pawra, Valvi, Vasava, Vasave.
- 5) Charan (in the Nesses of the forests of Alech, Barada and Gir)
- 6) Chaudhari (in Surat and Valsad districts)
- 7) Chodhara
- 8) Dhanka, Tadvi, Tetaria, Valvi
- 9) Dhodia, Dhodi
- 10) DublaTalavia, Halpati
- 11) Gamit, Gamta, GavitMavchi, Padvi
- 12) Gond, Rajgond

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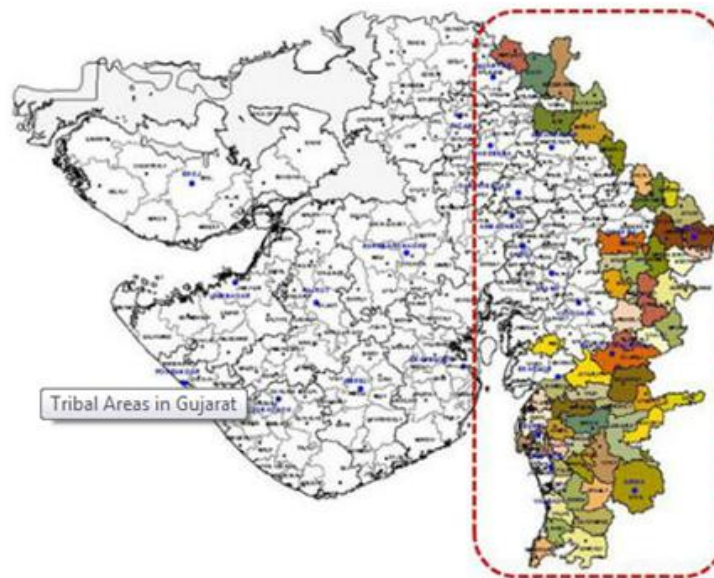
- 13) Kathodi, Katkari, DhorKathodi, DhorKatkari, Son Kathodi, Son Katkari
- 14) Kokna, Kokni, Kukna
- 15) KoliDhor, TokreKoli, Kolcha, Kongha
- 16) Kunbi (in the Dang Districts)
- 17) Naikda, Nayaka, CholivalaNayaka, KapadiaNayaka, MotaNayaka, Nana Nayaka,
- 18) Padhar
- 19) Pardhi, Advichincher, PhansePardhi (excluding Amreli, Bhavanagar, Jamnagar, Jungadh, Kutch, Rajkot and Surendranagar district)
- 20) Pateliya
- 21) Pomla
- 22) Rabari (in the Nesses of the forest of Alech, Barada and Gir)
- 23) Rathwa
- 24) Siddi, Siddi-Badshan (in Amreli, Bhavnagar, Jamnagar, Junagadh, Rajkot and Surendranagar Districts) (Muslim Tribes)
- 25) Varli
- 26) Vitolia, Kotwalia, Barodia

Most tribes belong to Hindu religion except the Siddi tribes which belonged to muslim religion.

The following are the scheduled areas of Gujarat:[5]

- 1) Bardoli, Mahuwa, Mandvi, Mangrol and Umrapadatalukas in Surat district
- 2) Nizar, Uchchhal, Dolvan, kukkarmunda, valod and vyaratalukas in Tapi district
- 3) Valia, Netrag and Jhagadiatalukas in Bharuch district
- 4) Vansda, Chikhali and Khergam in Navsari district
- 5) Dharampur, Kaprada and Umbergaontalukas in Valsad district
- 6) Ahawa, Subir and Vadhai in Dang district
- 7) Dediapada, Garudeswar, Nandod, Sagbara and Tilakvada in Narmada district
- 8) Chhotaudepur, pavijetpur, kvant and Nasvadi in chhotaudepur district
- 9) Dahod, DevgarhBariya, Dhanpur, Fatepura, Garbada, Limkheda, Sanjeli and Jalod in Dahod district
- 10) Dhodhamba and Jambughodatalukas in Panchmahal district
- 11) Kadana and Santrampuratalukas in Mahisagar district
- 12) Bhiloda and Megharajatalukas in Arravali district
- 13) Khedbrahma, Poshina and Vijaynagar in Sabarkantha district
- 14) Danta and Amirgadh in Banaskantha district





18% of the State's Area
(5884 Villages)

26 tribes (Including five
Particularly vulnerable
Tribal Groups)

Literacy rate of ST is
62.5% as compared to
78.0% of Gujarat

Concentrated in-
14 Eastern Districts
48 Talukas
15 Pockets
4 Clusters



Operative photo at a camp

Environmental Factors

Epidemiological and experimental evidences suggests that environmental risk factors such as maternal exposure to tobacco, tobacco smoke, alcohol, poor nutrition, viral infection, improper medications, and teratogens at the workplace and home in early pregnancy are some of the important etiological factors. The role of maternal nutrition and, multivitamins in particular, in orofacial clefts cases remains unclear. Furthermore, assessments of dietary intake or biochemical measures of nutritional status of OFC cases are challenging and often not available among the many impoverished populations suffering from the highest rates of orofacial clefts disease. The main environmental factors which

has been reported to possibly increasing the risk of orofacial clefts cases is tobacco smoking, alcohol consumption, solvents and agricultural chemicals. Certain types of anti-epileptic drugs have also been reported to increase the risk. It is, however, an established fact that the magnitude of the risk of recurrence of orofacial clefts to siblings increases after two or more affected siblings and is greater than that predicted by the familial aggregation of environmental risk factors. If measure of genetic susceptibility is not taken into account in epidemiological studies, measures of the relative risk of a disease associated with an environmental factor can be diluted considerably.

2. Aims of study

To study the cases of cleft lip and palate in tribal population of Gujarat:

- Age/sex distribution
- Region wise distribution
- Tribal distribution
- Diagnosis
- Family history
- Reason for treatment delay if present
- Surgery and Final outcome

3. Material and Methods

Source of data:

This is a prospective study of cleft lip and palate during the period from September 2015 to January 2018 in Civil Hospital, Asarwa, Ahmedabad attached to B.J. Medical college Ahmedabad and the camps carried out in rural and tribal areas during this period by department of burns and plastic surgery. Number of cases studied is 748.

Method of collection of Data:

- Demographic data collected including the age and sex.
- The geographic location where they stay and their birth place.
- The tribe they belong to is included.
- Hemoglobin, status of upper respiratory tract infection, cardiac and other anomalies are noted on presentation
- Reason for delay (if present) of surgery is noted.

Inclusion criteria

- All the patients, who presented between period of September 2105 to January 2018 with cleft disease to civil hospital or camps conducted during that period by department of burns and plastic surgery.

Exclusion criteria

- Rarer clefts (except group 7 and 0 tessier classification) are not included in the study.

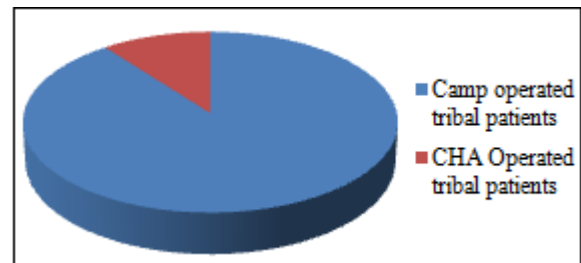
4. Observations and Discussion

In present study 386 operated cases and 110 non operative cases making total of 496 cases of cleft lip and palate. Total 16 camps were conducted and 192 patients were operated in camps. All the above cases were studied and following are the relevant observations and discussions.:

1) Tribal patients presenting to CHA and to CAMPS

Total Patients		Tribal Patients To Cha	
Operated	Non Operated	Operated	Non Operated
386	110	20	10

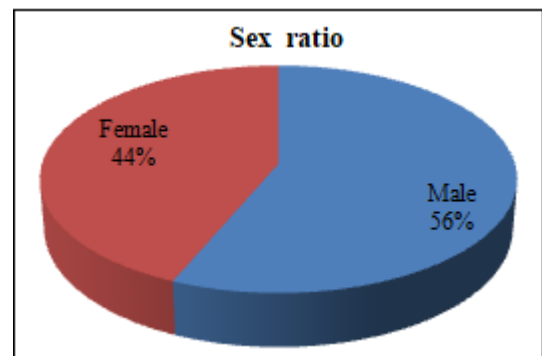
Total Patients		Tribal Patients in Camps	
Operated	Non Operated	Operated	Non Operated
386	110	172	58



In present study total of 386 patients were operated out of which 192 belonged to tribal areas of Gujarat. This constituted to 49.74 percentage of total operated population. The reason for such a large amount of tribal population operated is huge outreach activity, free of cost treatment and little more prevalence in tribal population than general group. Other thing is general population have access to many hospitals and centers where they can get operated, but this group don't have such. There is big difference in tribal population operated in CHA and at camps. Even in CHA the patient did not come directly, most of patients were brought by Healthcare workers, and others were complicated cases that cannot be operated in camps.

2) Sex in tribal population

Sex	Total population	Tribal population
Male	214	106
Female	172	86
Total	386	192



Out of total operated patients 214 were male constitutes 55 percentage and 172 were female constitutes 45 percentage of population. In tribal group 106 out of 192 were male which constitutes 56 percentage and 86 out of 192 were female which makes 44 percentage of female.

There was no significant difference between 2 population groups.

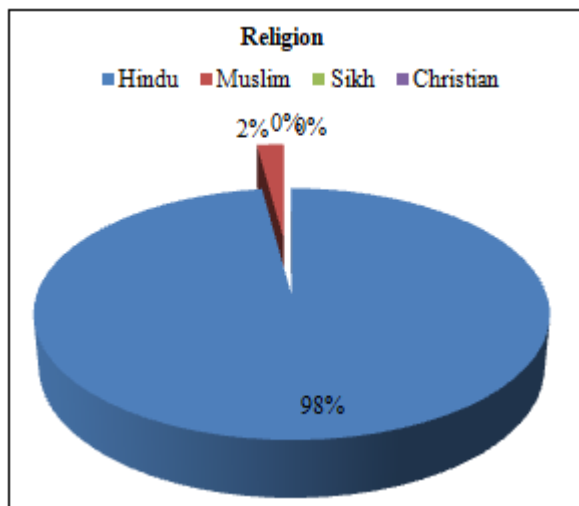
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125 Suppl 1:S1-14. doi: 10.1002/lary.24747. Epub 2014 May 27. Tollefson TT1, Shaye D, Durbin-Johnson B, Mehdezadeh O, Mahomva L, Chidzonga M.” Cleft lip cases were mostly left sided with equal gender distribution.

In other Indian study “A clinical and demographic profile of the cleft lip and palate in Sub-Himalayan India: A hospital-based study Indian J Plast Surg. 2012 Jan-Apr; 45(1): 115–120. Jyoti Dvivedi and Sanjay Dvivedi” where male to female ratio was 1.8:1.

3) Religion wise distribution

Religion	Total population	Tribal population
Hindu	272	188
Muslim	96	4
Sikh	6	0
Christian	12	0



As per demography of the state, Hindus form most of the population strata of State so incidence was more in this group followed by muslim religion. In tribal population most tribes belonged to hindu religion, so most patients coming to our study were hindu.

The above findings are comparable with “A clinical and demographic profile of the cleft lip and palate in Sub-Himalayan India: A hospital-based study Indian J Plast Surg. 2012 Jan-Apr; 45(1): 115–120. Jyoti Dvivedi and Sanjay Dvivedi” where Hindus constituted most of patients.

4) Total Camps and various operative data

Region wise Camps and dates	Unilateral Lip	Bilateral Lip	Palate	Misc.	Total Operated
Amreli Camp (Sept 15)	6	0	2	0	8
Dahod Camp (Sept 15)	13	2	0	0	15
Bhuj Camp (Oct 15)	8	1	0	0	9
Rajkot Camp (Nov 15)	11	2	4	0	17
Jamnagar Camp (Nov 15)	7	0	5	0	12
Palanpur Camp (Nov 15)	14	1	5	0	20

Shamlaji Camp (Nov 15)	5	0	6	1	12
Junagadh Camp (Dec 15)	5	1	4	0	10
Dahod Camp (Feb 16)	21	1	2	0	24
Bhuj Camp (May 16)	11	1	15	1	28
Shamlaji Camp (Jan 17)	10	0	6	0	16
Rajkot Camp (Jan 17)	4	0	3	0	7
Jamnagar Camp (Jan 17)	6	0	8	0	14
Bhuj Camp (Feb 17)	1	0	7	0	8
Dahod Camp (March 17)	9	1	6	0	16
Shamlaji Camp (Dec 17)	8	2	11	1	22

Total Surgeries carried out in various camps are shown above, Total 238 surgeries were performed in camps out of which 172 belonged to tribal group. Total Unilateral lip were 139, Bilateral lip were 12, palate 24 and 3 miscellaneous surgery

5) Types of clefts and its incidence

Sex	Left side group 1 incomplete cleft lip	Left side group 1a cleft lip	Right side group 1 incomplete cleft lip	Right side group 1a cleft lip	Group 2 palate
Male	37	10	22	6	38
Female	20	8	26	4	30
Total	57	18	48	10	68

Sex	Bilateral group 1 and 1a	Left side group 3 cleft lip and palate	Right side group 3 cleft lip and palate	Bilateral Group 3 cleft lip and palate	Miscellaneous (Tessier 7 and group 1 plus 2 cleft lip and palate)
Male	3	47	22	22	7
Female	4	42	15	18	4
Total	7	89	37	40	11

Most common clefts include left side group 3 cleft lip and palate followed by group 2 palate and then left side group 1 cleft lip. Incidence wise left is more common than right 164 > 102, as per literature also the incidence of left side is more common than right side.

In a study of “Cleft lip-cleft palate in Zimbabwe: estimating the distribution of the surgical burden of disease using geographic information systems. Laryngoscope. 2015 Feb” Cleft lip cases were mostly left sided with equal gender distribution.

6) Region wise distribution operative data

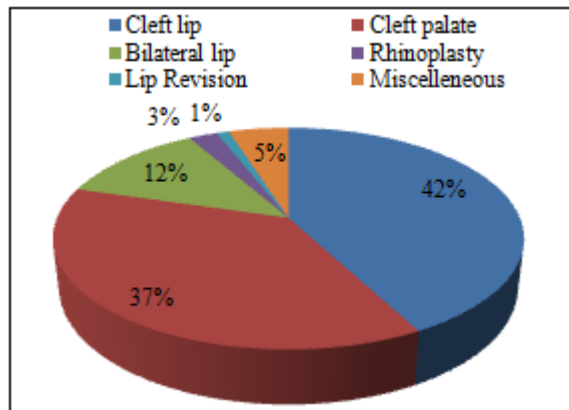
Region	Total Clefts	Region	Total Clefts
Ahmedabad	60	Dwarka	5
Bhavnagar	3	Aravalli	6
Amreli	15	Girsomnath	5
Junagadh	12	Dehgam	2
Dahod	58	Idar	1
Godhara	2	Patan	3
Banaskantha	23	Detroj	1
Kachchh	37	Bhiloda	4
Kheda	14	Meghraj	10
Gandhinagar	11	Himatnagar	2

Surendranagar	9	Vijaynagar	1
Rajkot	10	Bhuj	8
Porbandar	6	Anand	2
Morbi	6	Miscellaneous	39
Jamnagar	27		

Most patients came from ahmedabad, followed by dahod and then Jamnagar. We have conducted camps 2 times in Dahod which is reason for more of Dahod patients. Jamnagar refers most of its patients to CHA. Various patients from Rajasthan, Madhya Pradesh came to the Shamlaji camp which formed miscellaneous group.

7) Total Surgery performed

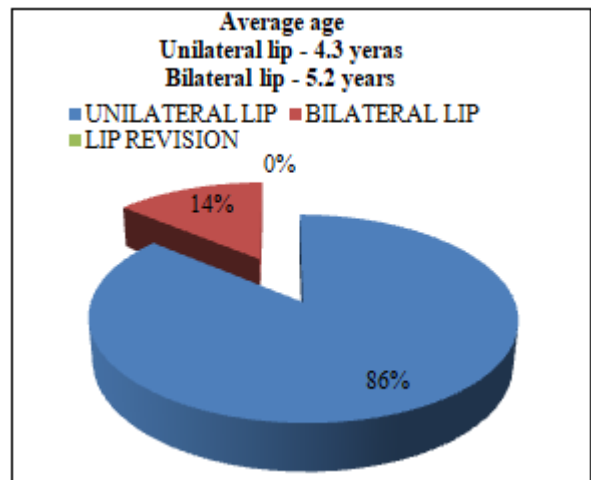
Cleft lip	163
Cleft palate	144
Bilateral lip	47
Rhinoplasty	9
Lip Revision	4
Miscellaneous	19



Most surgeries performed were unilateral cleft lip repair followed by cleft palate repair

8) Cleft lip data Total Vs Tribal population

	Total Patients		Tribal Patients	
	Operated	Non Operated	Operated	Non Operated
Unilateral LIP	163	60	124	34
Bilateral LIP	47	10	20	7
LIP Revision	4	0	0	0

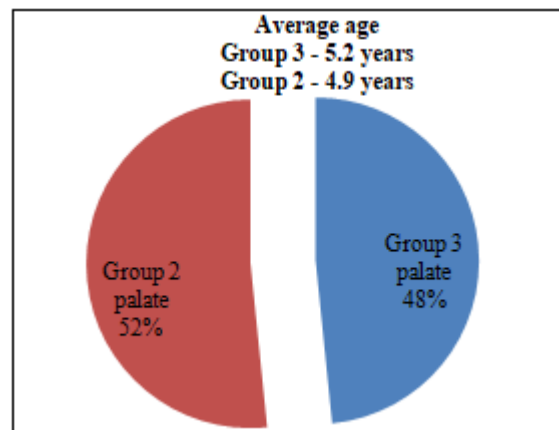


	Total Patients		Tribal Patients	
	Operated Average Age	Non Operated Average Age	Operated Average Age	Non Operated Average Age
Unilateral LIP	1.2 years	2.2 years	4.3 years	4.9 years
Bilateral LIP	2.8 years	3.8 years	5.2 years	5.8 years
LIP Revision	12	15 years	-	-

Average age of 1.2 years for unilateral cleft lip operative patients and 2.2 years in non operated patients in total population group and 4.3 years in operated unilateral lip and 4.9 years in non operated unilateral lip in tribal population, similarly 2.8 years and 3.8 years for operated and non operated bilateral lip patients in total patients group and 5.2 years and 5.8 years in non operated bilateral lip patients in tribal group.

9) Cleft palate data Total Vs Tribal population

	Total Patients		Tribal Patients	
	Operated	Non Operated	Operated	Non Operated
Group 3 palate	76	26	30	10
Group 2 palate	68	14	32	6
Total	144	40	62	16



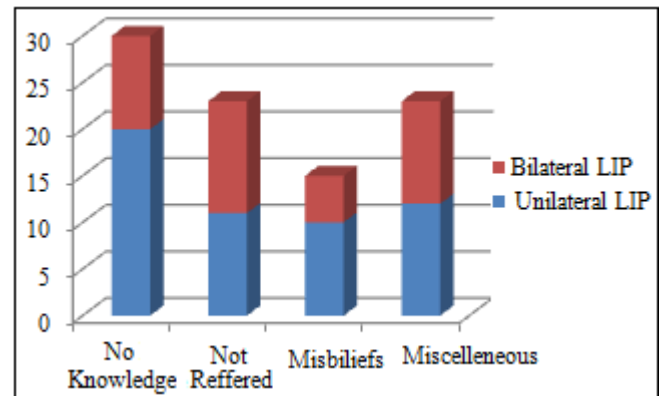
	Total Patients		Tribal Patients	
	Operated Average Age	Non Operated Average Age	Operated Average Age	Non Operated Average Age
Group 3 palate	4.8 years	5.3 years	5.2 years	5.5 years
Group 2 palate	3.5 years	3.8 years	4.9 years	5.2 years

Average age was 4.8 years for group 3 palate operated patients and 5.3 years in non operated patients in total population group and 5.2 years and 5.5 years in non operated palate patients in tribal group, similarly 3.5 years and 3.8 years for operated and non operated group 2 patients in total patients group and 4.9 years and 5.2 years in non operated group 2 palate patients in tribal group.

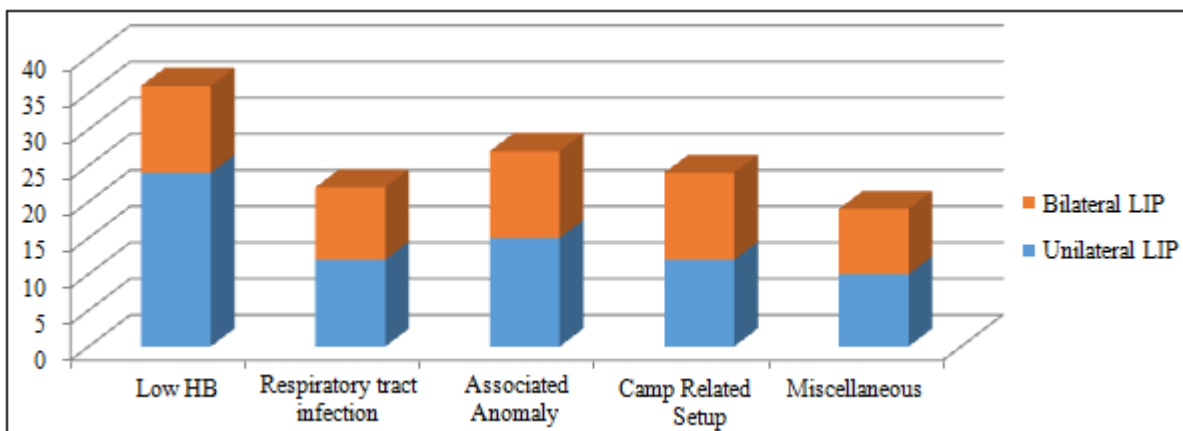
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10) Reason for late presentation and postponement of surgery in Cleft lip patient

Reason of Late Presentaion in Total Population	Unilateral LIP	Bilateral LIP
No Knowledge	30	20
Not Reffered	32	24
Misbiliefs	11	12
Miscelleneous	34	10
Reason of Late Presentaion in Tribal Population	Unilateral LIP	Bilateral LIP
No Knowledge	20	10
Not Reffered	11	12
Misbiliefs	10	05
Miscelleneous	12	11



Reason for Postponement of Surgery in Total Population	Unilateral LIP	Bilateral LIP
Low HB	22	23
Respiratory Tract Infection	34	11
Associated Anomaly	10	15
Miscellaneous	15	10
Reason for Postponement of Surgery in Tribal Population	Unilateral LIP	Bilateral LIP
Low HB	24	12
Respiratory Tract Infection	12	10
Associated Anomaly	15	12
Camp Related Setup	12	12
Miscellaneous	10	9



Complicated cases (anaesthesia wise as well as surgery wise) are operated in the tertiary center. Low Hb was predominant

cause of postponement of surgery in tribal population while URTI was cause in total population.

11) Follow up for staged reconstruction

Total patients with group 3 cleft lip and palate	Lip patients coming for palate reconstruction	At ideal age	Late presentation
130	76	56	20
Total patients with group 3 cleft lip and palate	For alveolar bone grafting Primary / Secondary	At ideal age 5 to 12 years	Late presentation
130	12	2	10

Out of 130 group 3 patients 76 came for follow up reconstruction of palate, 56 at ideal age and 20 late presentation. Late presentation is considered 2 years beyond date of lip reconstruction.

More than half of patients turned out to follow up staged reconstruction due to repeated outreach activity in form of camps though few were late but they came for staged reconstruction due to work at root level by Health workers.

This was similar to study carried out in Zimbabwe "Cleft lip-cleft palate in Zimbabwe: estimating the distribution of the surgical burden of disease using geographic information systems. *Laryngoscope*. 2015 Feb; 125Suppl 1:S1-14. doi: 10.1002/lary.24747. Epub 2014 May 27. Tollefson TT1, Shaye D, Durbin-Johnson B, Mehdezadeh O, Mahomva L, Chidzonga M." **The age of children with isolated cleft palate decreased by 0.8 years per surgical trip (P=.01)**, suggesting the prevalence of unrepaired cleft palate is decreasing due to local and visiting surgeons. The catchment area extended to a less populous area, but clustered around Harare and Bulawayo.

This is a hospital based study, the patients who came to us in CHA and camps were included, whole population was not screened, also patients going to other center and camps were not accounted. So this study cannot predict exact incidence and prevalence of anomaly in a group. The demographic data provided above also cannot be considered exact.

5. Summary

- In present study there were total 496 cases out of which operated cases were 386 and non operated were 110. Tribal population constituted 302 patients out of which 192 were operated.
- After filling details in proforma, master chart was prepared. A detailed analysis was done and various observations were derived, discussed and concluded.
- The total tribal population that present to civil hospital Ahmedabad was 20 operative and 10 non operative in compared to as a part of outreach activity (camps) was operative 172 and 100 non operative.
- Male: Female ratio for clefts in tribal population is 1.2:1 .
- Region wise distribution includes following, Maximum tribal population came from Dahod region due to increased number of camps conducted there, followed by Jamnagar region that is draining center of South Gujarat.

- The total tribal population operated was 192 out of which camp operated were 172.
- Incidence of cleft lip in tribal population was 190 and that of cleft palate was 112
- Total operated cases were 144 out of 192 cases for cleft lip. And 62 out of 192 cases for cleft palate including patients coming for staged procedure.
- Total Patient presented at appropriate age for cleft lip was 64 patients out of 144 operated patients and 85 patients out of.
- Total Patient presented at appropriate age for Group 2 cleft palate were 36 out of 62 patients
- Reason for late presentation in total population was "not referred" compared to tribal population where "no knowledge" was the reason
- Reason for postponement of surgery in total population was "respiratory infection" as compared to tribal population where "low Hb" was the reason.
- Patients who came for staged reconstruction at appropriate age were 56 patients out of 76 patients.
- This is a hospital based study, the patients who came to us in CHA and camps were included, whole population was not screened, also patients going to other center and camps were not accounted. So this study cannot predict exact incidence and prevalence of anomaly in a group.

6. Conclusions

- Most of tribal population was operated in camps (90 percentage) in contrast to Civil Hospital Ahmedabad (10 percentage) .
- Male: Female ratio was 1.2:1, There was no significant difference.
- Maximum patients were Hindu by religion. Most tribes belong to Hindu so maximum patients were Hindu.
- In present study I have concluded that left sided group 3 cleft lip and palate is most common type of cleft found in tribal population, it is also most common form in total population.
- Average age of presentation for unilateral cleft lip was 4.3 years in operated unilateral lip and 4.9 years in non operated unilateral lip in tribal population, 5.2 years and 5.8 years in operated and non operated bilateral lip patients respectively, and 5.2 years and 5.5 years in operated and non operated group 3 palate patients in tribal group, 4.9 years and 5.2 years in operated and non operated group 2 palate patients in tribal group.
- Most common reason for late presentation was no knowledge and distant treatment centers in tribal population.
- Approximately 65 percentage of population came for staged reconstruction back due to significant outreach activity out of which 80 percentage came at appropriate age and others were late presentation.
- Regionwise most tribal population belonged to Dahod.
- Most common reason for postponement of surgery in tribal population was low Hb level.

- Due to increased number of camps, more cases are screened and operated every year and thus number of undiagnosed and untreated clefts decreases. Thus more number of such camps should be conducted.

List of Abbreviations

GA: General Anesthesia
OPD: Out Patient Department
CNC: Cranial Neural Crest
FNP: Frontonasal prominence
CL: Cleft lip
CP: Cleft Palate
CLP: Cleft lip palate
CL/P:Cleft lip/palate
OME: Otitis Media with Effusion
VPI: Velopharyngeal incompetence
NAM: Naso alveolar Molding
UCLP: Unilateral cleft lip palate
BCLP: Bilateral cleft lip
PSO: Pre Surgical Orthopaedics
CS: Cleft Side
NCS: Non Cleft Side
CHA: Civil Hospital Ahmedabad
Hb: Hemoglobin

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