RESEARCH ARTICLE

Incidence and management of cleft lip and palate in Pakistan

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Abstract

Objectives: To compare the occurrence, distribution and management of clefts of lip and palate in local patients with the available data from India and China.

Methods: The retrospective study was conducted at the Interdisciplinary Research Centre in Biomedical Materials, COMSATS University Islamabad, Lahore Campus, Lahore, Pakistan, and comprised data related to a three-month period from January to March 2015 at two medical centres in Lahore. Data from Pakistani centres was analysed based on province, gender, age and clefts of lip and palate conditions and Spearman's correlation matrix.

Results: Of the 1574 cases, 1061(67.4%) were from Punjab, 361(23%) Khyber Pakhtunkhwa, 85(5%) Sindh and 67(4.2%) were from Azad Jammu and Kashmir. The incidence of clefts of lip and palate was higher in males than females. There was higher awareness of the need for timely management in new borns with clefts of lip and palate. Some patients seeking secondary treatment were also being surgically corrected. There is no national registry of children born with cleft defect, making it difficult to assess the full scale of the problem.

Conclusions: Based on available data, it is likely that there are many adults who have not been treated when younger.

Keywords: Cleft palate, Cleft lip, Alveolar defects, consanguineous marriages, Cleft repair. (JPMA 69: 632; 2019)

Introduction

Cleft of lip and palate (CLP) originates from failure in the fusion of oronasal processes within the first five to six weeks of gestation.[1,2] Clefts are classified as complete or incomplete, bilateral or unilateral and syndromic or non-syndromic.[2,3] Among the aetiological factors identified, excessive use of alcohol, smoking, low folic acid levels,[4,5] diabetes, genetics and consanguineous marriages contribute to this malformation.[6] Use of drugs like phenytoin, sodium valproate, benzodiazipines and corticosteroids during pregnancy[7] may also add to the chances. Difficulty in suckling in the early few months due to cleft leads to inadequate milk intake, fatigue, irritability, poor weight-gain and slow growth.[8] Extreme discomfort in eating at later stages of infancy, such as, escape of food into the nose, regurgitation causing coughing, choking and vomiting are also experienced.

Of all the congenital craniofacial malformations in the world, CLPs are among the top five. The incidence of cleft lip (CL) or cleft palate (CP) or both is 1 in 500 in the developing countries, and 1 in 700 live births in the UK and USA alone. The global burden is estimated to have a backlog of 4,000,000 CL and CP patients worldwide.[9]

The crude birth rate in Pakistan per 1000 population is 25.6, in China it is around 13, while in India it is 20.[10] As a rough estimate, 10,026 cleft cases were identified in 2015 in Pakistan. According to the data provided by Smile Train, 50,000 surgeries were performed to repair CL/CLP/CP from 2008 to 2015 in 25 centres in Pakistan and more than 8000 clefts were repaired in 2014 alone.[11]

In Pakistan, there have been very few studies on the specific incidence of CP malformations. In an isolated study conducted in 2013 in Karachi, CLP was reported as the most frequent birth defect. There was a delay in seeking care, and low follow-up after surgical repair and lack of involvement of speech therapists and orthodontists.[12] According to another small-scale study on the incidence of CLP from Peshawar was 1.91 per 1000 births (one per 523 births). CL was more frequent than isolated CP and combined CLP deformities. Boys were more commonly affected by CL and CLP, whereas isolated CP was predominantly found in females.[11] The study a small sample of 123 children. An overall estimate of the extent of congenital malformation of lip and palate has not been presented before and there is also a lack of information regarding the treatment and management of this malformation in Pakistan.[13]

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In Pakistan, organisations dedicated to cleft repair aim to follow the same treatment schedule as in practice in other developed countries. So, the defects are surgically repaired within the first three months of the infant's life. At about six to twelve months, the hard palate is covered with soft tissue around the cavity.[14] From eight to eleven years, the alveolar ridge is repaired using a bone graft. This procedure is important in achieving normal dentition. However, orthodontic treatments are not generally available even with world's best CLP organisations operating in Pakistan.

However, a more recent statistical study published by Smile Train in New York reports that China is believed to have the largest frequency of cleft births in the world. Several million individuals with CLP exist in China, and it is estimated that at least 30,000 new borns with CLP are born every year.[15] Similarly, in another neighbouring country of Pakistan, India, the distribution of CLP showed that there were 20.2%, 13.9% and 65.9% patients of CL, CP and CLP respectively. While the ratio for unilateral to bilateral cases was 2.49:1, in which 2.03:1 was the left-to-right ratio, the frequently performed surgeries involved primary repair of a unilateral CL which was 41.6%, followed by primary repair of CP which was 31.15%. Also, 1.58:1 was the male-to-female ratio, and the mean age was 7.91 years.

Pakistan also falls in the group of countries which do not have an established large-scale plan of treatment for congenital abnormalities, but with the help of some organisations, craniofacial and plastic surgeons in Pakistan have teamed up to treat patients. Secondary alveolar bone grafts and lip and nose surgeries are commonly done at adolescence.[16] Prior reports from Pakistan suggest that lack of access to healthcare varies within the country and leaves many unrepaired clefts well into late childhood.[17]

The current study was planned to evaluate the current status of the occurrence, distribution and management of CLP in patients distributed in different regions of Pakistan through an analysis of as many cases as possible, and to compare that data with the available data from India and China. Since there is no central registry where the incidence of congenital malformations can be noted at birth, estimates were made from the available data.

Subjects and Methods

The retrospective study was conducted at the Interdisciplinary Research Centre in Biomedical Materials, COMSATS University Islamabad, Lahore Campus, Pakistan, and comprised data related to a three-month period from January to March 2015 at two medical centres in Lahore. The patients were treated either in open camps in the respective areas of residence or were gathered and brought to the treatment centres in Lahore. The cases included were congenitally malformed Cl, CP or CLP only. Patients treated for traumatic injuries were excluded. The data from the two designated centres was carefully selected and plotted on the map of Pakistan to see the distribution. In addition, the statistical calculations were done for each separate variant like male-to-female ratio, CLP-to-CL incidence, gender-related anomalies, age of presentation, and treatment.

Statistical analysis was done using Spearman's correlation matrix and Chi-Square Fisher's Exact test. The Spearman's correlation matrix was performed to identify the problem of multicolinearity between the variables. The problem of multicolinearity exists if correlation value is higher than 0.90 or otherwise. All the values (-0.047 to 0.224) were below the maximum upper limit of 0.90 (Appendix) and thus the problem of multicolinearity did not exist.

All variables were examined for correlation to each other based on statistical significance with a confidence level of 95% to 99%. Results and postulations of Spearman's correlation matrix allowed us to move forward for further statistical analysis. Chi-Square Fisher's Exact test was applied to investigate the difference between study groups and significance between study group means for the subjected categories.

Results

Of the 1574 cases, 1061(67.4%) were from Punjab, 361(23%) Khyber Pakhtunkhwa, 85(5%) Sindh and 67(4.2%) were from Azad Jammu and Kashmir (AJK). The incidence of clefts of lip and palate was higher in males than females (Figure-1).

Age categories were checked for statistical difference and so was done with gender, and province to see if age, gender, and province had any influence on the decision to go for surgery (Table-1 Supplementary Data).

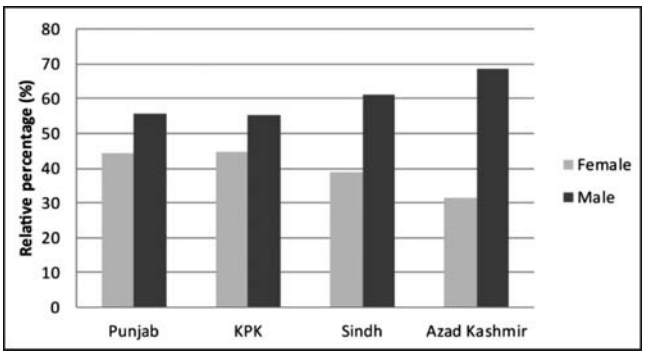

Figure-1: Gender distribution of cleft patients of different regions of Pakistan.

SUPPLEMENTARY DATA

Table-1: Chi-Square Test into whether age influences the incidence of surgical repairs, gender influences the incidence of surgical repairs, Province wise analysis of different clefts of lip and palate (CLP) conditions in Pakistan.

PART A			Age (years)						Fisher's Exact
			1 and below	2-5 years	6-10 years	11-19 years	20 and above years	Total	Test Significant
Primary Lip Nose Unilateral	.00	Count	252	724	151	147	100	1374	0.00
		%within PrimaryLipNos U	18.3%	52.7%	11.0%	10.7%	7.3%	100.0%	
		% within Age	70.6%	91.5%	91.0%	98.0%	90.9%	87.3%	
	1.00	Count	105	67	15	3	10	200	
		% within PrimaryLipNos U	52.5%	33.5%	7.5%	1.5%	5.0%	100.0%	
		% within Age	29.4%	8.5%	9.0%	2.0%	9.1%	12.7%	
Total		Count	357	791	166	150	110	1574	
		% within PrimaryLipNosU	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Primary Lip Nose Bilateral	.00	Count	336	655	149	146	96	1382	0.00
		% within PrimaryLipNos B	24.3%	47.4%	10.8%	10.6%	6.9%	100.0%	
		% within Age	94.1%	82.8%	89.8%	97.3%	87.3%	87.8%	
	1.00	Count	21	136	17	4	14	192	
		% within PrimryLipNos B	10.9%	70.8%	8.9%	2.1%	7.3%	100.0%	
		% within Age	5.9%	17.2%	10.2%	2.7%	12.7%	12.2%	
Total	Count	357	791	166	150	110	1574		
		% within PrimryLipNos B	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Primary Cleft Palate	.00	Count	356	734	148	138	102	1478	0.000
		% within PrimryClipPlat	24.1%	49.7%	10.0%	9.3%	6.9%	100.0%	
		% within Age	99.7%	92.8%	89.2%	92.0%	92.7%	93.9%	
	1.00	Count	1	57	18	12	8	96	
		% within PrimryClipPlat	1.0%	59.4%	18.8%	12.5%	8.3%	100.0%	
		% within Age	0.3%	7.2%	10.8%	8.0%	7.3%	6.1%	
Total		Count	357	791	166	150	110	1574	
		% within PrimryClipPlat	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Fistula Repair	.00	Count	356	741	147	118	86	1448	0.000
		% within FistulaRepr	24.6%	51.2%	10.2%	8.1%	5.9%	100.0%	
		% within Age	99.7%	93.7%	88.6%	78.7%	78.2%	92.0%	
	1.00	Count	1	50	19	32	24	126	
		% within FistulaRepr	0.8%	39.7%	15.1%	25.4%	19.0%	100.0%	
		% within Age	0.3%	6.3%	11.4%	21.3%	21.8%	8.0%	
Total		Count	357	791	166	150	110	1574	
		% within FistulaRepr	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Lip Nose Revision	.00	Count	357	528	127	105	92	1209	0.000
		% within LipNoseRevision	29.5%	43.7%	10.5%	8.7%	7.6%	100.0%	
		% within Age	100.0%	66.8%	76.5%	70.0%	83.6%	76.8%	
	1.00	Count	0	263	39	45	18	365	
		% within LipNoseRevision	0.0%	72.1%	10.7%	12.3%	4.9%	100.0%	
		% within Age	0.0%	33.2%	23.5%	30.0%	16.4%	23.2%	
Total		Count	357	791	166	150	110	1574	
		% within LipNoseRevsion	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Secondary Cleft Plate	.00	Count	354	750	147	149	102	1502	0.000
		% within SecondryCP	23.6%	49.9%	9.8%	9.9%	6.8%	100.0%	
		% within Age	99.2%	94.8%	88.6%	99.3%	92.7%	95.4%	
	1.00	Count	3	41	19	1	8	72	
		% within SecondryCP	4.2%	56.9%	26.4%	1.4%	11.1%	100.0%	
		% within Age	0.8%	5.2%	11.4%	0.7%	7.3%	4.6%	

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Total		Count	357	791	166	150	110	1574	
		% within SecdryCP	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	
Alveolar Bone Graft	.00	Count	357	790	156	136	96	1535	0.000
		% within AlveolarBoneGraft	23.3%	51.5%	10.2%	8.9%	6.3%	100.0%	
		% within Age	100.0%	99.9%	94.0%	90.7%	87.3%	97.5%	
	1.00	Count	0	1	10	14	14	39	
		% within AlveolarBoneGraft	0.0%	2.6%	25.6%	35.9%	35.9%	100.0%	
		% within Age	0.0%	0.1%	6.0%	9.3%	12.7%	2.5%	
Total		Count	357	791	166	150	110	1574	
		% within AlveolarBoneGraft	22.7%	50.3%	10.5%	9.5%	7.0%	100.0%	
		% within Age	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	

PART B			**Gender**			**Fisher's Exact**
			F	**M**	**Total**	**Test Significant**
Primary Cleft Palate	.00	Count	606	872	1478	0.358
		% within PrimryCP	41.0%	59.0%	100.0%	
		% within Gender	94.2%	93.7%	93.9%	
	1.00	Count	37	59	96	
		% within PrimryCP	38.5%	61.5%	100.0%	
		% within Gender	5.8%	6.3%	6.1%	
Total		Count	643	931	1574	
		% within PrimryCP	40.9%	59.1%	100.0%	
		% within Gender	100.0%	100.0%	100.0%	
Fistula Repair	.00	Count	591	857	1448	0.496
		% within FistulaRepr	40.8%	59.2%	100.0%	
		% within Gender	91.9%	92.1%	92.0%	
	1.00	Count	52	74	126	
		% within FistulaRepr	41.3%	58.7%	100.0%	
		% within Gender	8.1%	7.9%	8.0%	
Total		Count	643	931	1574	
		% within FistulaRepr	40.9%	59.1%	100.0%	
		% within Gender	100.0%	100.0%	100.0%	
Lip Nose Revision	.00	Count	466	743	1209	0.000
		% within LipNoseRivion	38.5%	61.5%	100.0%	
		% within Gender	72.5%	79.8%	76.8%	
	1.00	Count	177	188	365	
		% within LipNoseRivision	48.5%	51.5%	100.0%	
		% within Gender	27.5%	20.2%	23.2%	
Total		Count	643	931	1574	
		% within LipNoseRivision	40.9%	59.1%	100.0%	
		% within Gender	100.0%	100.0%	100.0%	
Secondary Cleft Plate	.00	Count	604	898	1502	0.013
		% within SecdryCP	40.2%	59.8%	100.0%	
		% within Gender	93.9%	96.5%	95.4%	
	1.00	Count	39	33	72	
		% within SecondryCP	54.2%	45.8%	100.0%	
		% within Gender	6.1%	3.5%	4.6%	
Total		Count	643	931	1574	
		% within SecondryCP	40.9%	59.1%	100.0%	
		% within Gender	100.0%	100.0%	100.0%	
Alveolar Bone Graft	.00	Count	625	910	1535	0.300
		% within AlveolarBoneGr	40.7%	59.3%	100.0%	
		% within Gender	97.2%	97.7%	97.5%	
	1.00	Count	18	21	39	
		% within AlveolarBoneGr	46.2%	53.8%	100.0%	
		% within Gender	2.8%	2.3%	2.5%	
Total		Count	643	931	1574	
		% within AlveolarBoneGr	40.9%	59.1%	100.0%	
		% within Gender	100.0%	100.0%	100.0%	

PART C			Province					Fisher's Exact
			1.00	2.00	3.00	4.00	Total	Test Significant
Primary Lip Nose Unilateral	.00	Count	920	334	58	70	1382	0.068
		% within PrimryLipNosU	66.6%	24.2%	4.2%	5.1%	100.0%	
		% within Province	86.7%	92.5%	86.6%	82.4%	87.8%	
	1.00	Count	141	27	9	15	192	
		% within PrimryLipNosU	73.4%	14.1%	4.7%	7.8%	100.0%	
		% within Province	13.3%	7.5%	13.4%	17.6%	12.2%	
Total		Count	1061	361	67	85	1574	
		% within PrimryLipNosU	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	
Primary Lip Nose Bilateral	.00	Count	1012	321	67	78	1478	0.470
		% within Primary Lip Nose B	68.5%	21.7%	4.5%	5.3%	100.0%	
		% within Province	95.4%	88.9%	100.0%	91.8%	93.9%	
	1.00	Count	49	40	0	7	96	
		% within Primary Lip Nose B	51.0%	41.7%	0.0%	7.3%	100.0%	
		% within Province	4.6%	11.1%	0.0%	8.2%	6.1%	
Total		Count	1061	361	67	85	1574	
		% within Primary Lip Nose B	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	
Fistula Repair	.00	Count	983	337	51	77	1448	0.016
		% within FistulaRepr	67.9%	23.3%	3.5%	5.3%	100.0%	
		% within Province	92.6%	93.4%	76.1%	90.6%	92.0%	
	1.00	Count	78	24	16	8	126	
		% within FistulaRepr	61.9%	19.0%	12.7%	6.3%	100.0%	
		% within Province	7.4%	6.6%	23.9%	9.4%	8.0%	
Total		Count	1061	361	67	85	1574	
		% within FistulaRepr	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	
Lip Nose Revision	.00	Count	823	265	49	72	1209	0.433
		% within LipNoseRevision	68.1%	21.9%	4.1%	6.0%	100.0%	
		% within Province	77.6%	73.4%	73.1%	84.7%	76.8%	
	1.00	Count	238	96	18	13	365	
		% within LipNoseRevision	65.2%	26.3%	4.9%	3.6%	100.0%	
		% within Province	22.4%	26.6%	26.9%	15.3%	23.2%	
Total		Count	1061	361	67	85	1574	
		% within LipNoseRevision	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	
Secondary Clip Palate	.00	Count	1021	345	51	85	1502	0.030
		% within SecondryCP	68.0%	23.0%	3.4%	5.7%	100.0%	
		% within Province	96.2%	95.6%	76.1%	100.0%	95.4%	
	1.00	Count	40	16	16	0	72	
		% within SecondryCP	55.6%	22.2%	22.2%	0.0%	100.0%	
		% within Province	3.8%	4.4%	23.9%	0.0%	4.6%	
Total		Count	1061	361	67	85	1574	
		% within SecondryCP	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	
Alveolar Bone Graft	.00	Count	1027	356	67	85	1535	0.001
		% within AlveolarBoneGr	66.9%	23.2%	4.4%	5.5%	100.0%	
		% within Province	96.8%	98.6%	100.0%	100.0%	97.5%	
	1.00	Count	34	5	0	0	39	
		% within AlveolarBoneGr	87.2%	12.8%	0.0%	0.0%	100.0%	
		% within Province	3.2%	1.4%	0.0%	0.0%	2.5%	
Total		Count	1061	361	67	85	1574	
		% within AlveolarBoneGr	67.4%	22.9%	4.3%	5.4%	100.0%	
		% within Province	100.0%	100.0%	100.0%	100.0%	100.0%	

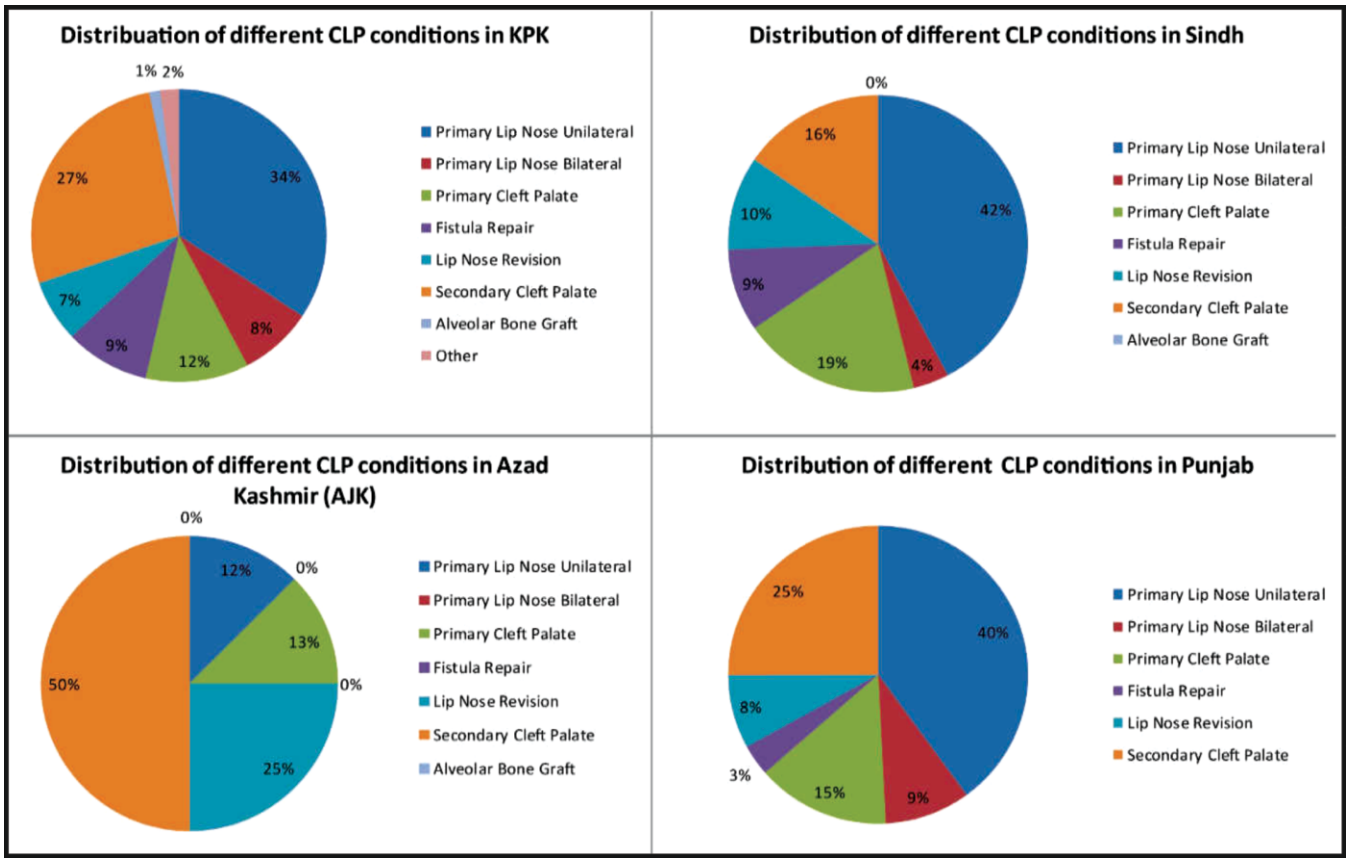

Figure-2: Distribution of CLP conditions in regions of Pakistan.

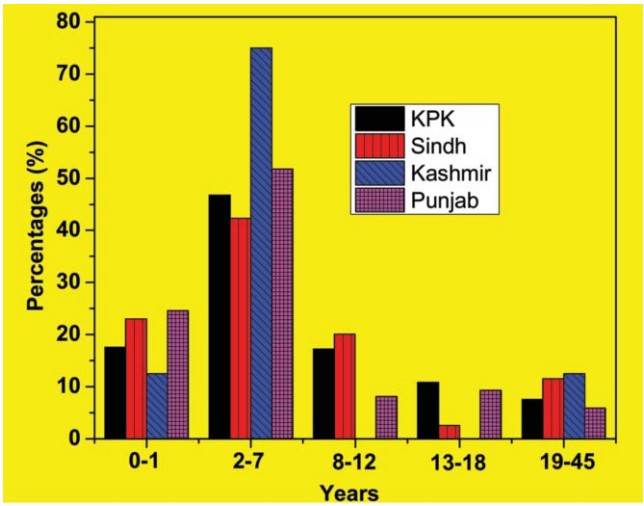

Figure-3: Age groups of patients from different regions of Pakistan.

Distribution of different cleft conditions across the different provinces and comparable data from India and China was also analysed (Table-1).

Province-wise presenting condition and outcome was also assessed (Figure-2).

The data was again split into respective provinces to which the patients belonged to see the pattern in terms of presenting age (Figure-3). The statistical results are given in Table-1 supplementary data.

Discussion

The study was conducted to provide information regarding the prevalence, incidence and treatment of CLP in Pakistan in comparison with neighbouring countries. The total number of babies born with cleft defect in the world is more than 170,000 per year. According to World Bank data, the crude birth rate in Pakistan is 29 per 1000 population and the incidence CLP/CP births is 1 in 523 in Pakistan[13] which is higher than China and India. The total number of children born in Pakistan per annum is calculated to be more than 4.5 million and the estimated number of CLP births in Pakistan per annum is over 22500.

There are only a few studies conducted so far regarding CLP in Pakistan and in the absence of a national registry, these of necessity discuss small datasets or data confined

to a specific small area.[9,18] Accordingly, it is difficult to find out the exact picture of the problem in the whole country. Several techniques are currently in use by plastic, reconstructive surgeons.[19,20] Some use acellular dermis to close the fistula in combination with oral mucosal grafts. Other studies used acellular matrix to close alveolar cleft in combination with bone graft.[21] Both reported a better outcome compared to the regular grafts not using acellular dermis. The data collected although from a single organisation contains information on a larger population distributed countrywide. It was found that the incidence of 1/500 is higher in Pakistan and neighbouring India and China compared to the developed countries where 1/700 newborns are affected with CLP.[22,23]

However, when comparing with China taking Hong Kong, for example, out of the cleft population studied, 20% of children had an isolated CL, 33% had CLP and 45% had CP alone. Out of all the children studied, boys were more commonly affected with CLP (66%) while CP was more common in girls (62%).[24] Shenyang in Northern China has one of the highest reported prevalence rates of oral clefts in the world with 1.76 per 1000.[16] Shanxi province in China has been identified with a frequency of orofacial clefts of 3.27 per 1000 births. A survey of 7812 patients funded for surgery by Smile Train Programme identified that different types of clefts appeared in the highest proportion in CLP and lowest proportion in CP. Interestingly, there was a pair of twins among the patients but only one of the twins was found affected with the cleft while the other was perfectly normal.[25]

Similarly, an Indian study measured CLP burden in the Patan district of Gujarat. The overall CL patients contributed 69.4%. The incidence of cleft deformity was 0.73 per 1,000 births and its prevalence was 0.1 per 1,000 people. The incidence of CL was 0.7 per 1,000 births.[23] Another multifactorial comparison study in Nagpur found that the prevalence of CLP was 66% and of CP was 27%, suggesting a positive connection between CLP and factors such as nutritional insufficiency, anaemia, and self-prescription of medicine.[26]

A high ratio of consanguineous marriages, lack of formal prenatal counselling, monthly examinations, and any regular laboratory testing during pregnancy, maternal malnutrition and a low use of supplements are thought to be some of the aetiological factors associated with the high ratio of CP in Pakistan.[13] The male-to-female ratio that is more males than females is also in accordance with the other developing countries. This higher male-to-female CLP occurrence is also prevalent in all the four regions studied here and the data is consistent with other Asian countries like China, India, Philippines etc.[23,26] A wide difference between male and female incidence in AJK can be due to the smaller sample size for this region.

As the data suggests, there is a statistically significant difference among all the age groups in different defect categories. This suggests that the treatment timeline is determined early in the developmental stages of a child with CP. The relatively lower number of adults receiving CLP repair surgeries may be due to several reasons - lack of awareness, low follow-up of patients for secondary repair or simply lack of resources.

The results explain that there is a significant statistical difference for when surgeries for revision of lip nose clefts and secondary cleft palates are undertaken. Both treatments are usually taken at later stages when the growth spurt has been crossed and the person is considered adult. Data suggests that the feedback, advocacy, support and tolerance are the same for all patients regardless of gender.

There was a significant statistical difference among all the province categories for primary CP, fistula repair, secondary CP, and alveolar bone graft defects. The number of patients was higher in Punjab and Khyber Pakhtunkhwa than in Sindh and AJK.

This study is limited to the data provided by a centre run by Smile Train located in Lahore city with two hospitals. A centralised registry is not available yet and the National Database and Registration Authority of Pakistan (NADRA) does not register such abnormalities. It will be useful to add a column reporting the type of congenital abnormality in the hospital registry at the time of childbirth. Another solution could be that provincial centres should be established where computerised information about congenital malformations could be entered at the time of the birth of a child.

This information may be useful in devising realistic healthcare plans which can assist the affected public.

Another purpose of the study was to assess the types of treatments provided for CLP repair so that better and improved methods could be developed to heal the suffering of patients. An advanced and current technique which may be applicable in the cleft repair is a wide range of biomaterials to assist in the repair of CLP beyond the initial repair of the soft tissues as well as to reduce the misery of repeated surgical interventions.

The data for Baluchistan could not be obtained due to a lack of access to the data due to political turmoil in that province. The total population of Baluchistan is less than 8 million compared to 101 million of Punjab. This mapping,

however, does not clearly depict the true distribution of CLP since the data was obtained from a single organisation. However, the distribution of estimates can be predicted because this organisation is active in the rest of Pakistan. The patients' access to treatment was maintained through a regular transportation of cleft patients with their attendants to the centres for cleft surgeries from widespread areas of the country, also evident from the map. A complete set of data from every province was not available, since there is no centralised birth registry reporting congenital abnormalities.

There is a need for a more extensive registry of the nature of the patients, their long-term follow up and the introduction of materials that could assist beyond the initial repair of the soft palate.

Conclusions

The incidence of cleft defects was essentially the same as in developing countries. Among the different Pakistan provinces, the trends were the same whether related to age, gender or type of cleft.

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