

# Perception of People towards Cleft Lip and Palate: A Cross-Sectional Study

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## Abstract

**Objective:** In this study, we assess the knowledge, awareness, and practices of the general population regarding Cleft lip and palate.

**Methodology:** In this descriptive cross-sectional survey-based study, we recruited 505 individuals from August 2020 to August 2021 visiting Fatima Memorial Hospital, Pakistan. A pre-validated questionnaire was used containing 36 questions to assess knowledge, awareness, and practices regarding cleft lip and palate, along with demographic data. For data analysis, Spearman's correlation test was used to analyze the impact of knowledge, awareness, and practices on predictor variables.

**Results:** Of the 505 participants, 194 (38.4%) were males and 311 (61.6%) were females who completed the survey. The majority of 413 (81.8) participants heard about cleft lip and palate. Most (82%) were able to describe cleft as a defect. Besides, Genetics (73.7%), Medicines (29.7%), and Alcohol (20.4%) were selected as the most common cause of cleft lip and palate. Most agreed with surgery is the best and first treatment. About 249 (49.3%) believed cleft lip and palate to be diagnosed antenatally. About 400 (79.2%) respondents agreed with treatment to be performed on adult patients. Knowledge had a significant relation with age and education along with practices with gender and education.

**Conclusion:** In general, the attitudes of the general population were positive towards cleft lip and palate along with adequate knowledge and awareness. Education is emphasized to be a major factor regarding knowledge about cleft lip and palate. Further knowledge and awareness of cleft lip and palate risk factors, causes, diagnosis, and treatment are required through various public healthcare campaigns.

**Keywords:** Cleft lip; Cleft palate; Knowledge; Awareness; Practices.

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## Introduction

Cleft lip and palate are among the commonest congenital abnormalities affecting the head and neck region [1]. A Cleft is a defect/opening that can affect the lip, alveolus, hard palate, and soft palate, either in combination or in isolation. Cleft lip and palate can occur either in combination with syndromes, in isolation, or as part of other associated deformities. Congenital heart diseases are most commonly associated with orofacial clefts and in this case, screening for heart anomalies should be done in a child born with orofacial clefts [2]. Children born with CLP may experience trouble with feeding, hearing, speech, and dentition along with its psychosocial effects of it which indeed can be corrected with proper surgery, psychological intervention, and speech therapy [3].

Incidence of Cleft Lip (CL), Cleft Palate (CP), and both (CLP) have been studied throughout the globe. In Pakistan, it has been found that cleft lip and/or cleft palate were present in 1.91 per 1000 births (1 per 523 births) [4]. Although, one of the most congenital anomalies in newborns, the prevalence of cleft lip and palate varies worldwide owing to different factors contributing to it. In terms of gender, cleft lip and palate in combination are more prevalent in males as compared to isolated cleft palate being dominated in females [5].

Exact etiological factors that lead to cleft lip and palate are currently being debated, but many factors do contribute to it. Pregnant females taking teratogenic drugs leading to a child being born with cleft lip and palate along with radiation exposure, maternal diabetes, maternal smoking, alcohol consumption, and family history are among the commonest causes associated with CLP [6]. It has been proven that early treatment of a child being born with a cleft lip and palate leads to normal growth and development along with normal speech, hearing, dentition, and feeding abilities [7,8]. Moreover, if the treatment for such children is not provided then all of these functions are affected to various degrees which not only has physical but psychological impacts as well. Early surgical treatment of CLP is the best choice for the child to have normal development and fewer chances of handicapped life.

When a child does not undergo surgical treatment, complications later on in life may develop [9]. Although treatment options are offered to adults who have CLP untreated during their childhood, speech, in particular, remains affected with the rest of the functions such as dentition, feeding, and hearing abilities positively enhanced. Knowledge and awareness of CLP are now considered to be prime concerns for parents due to its common occurrence. CLP is a preventable and treatable condition that can be very beneficial to restore normal life physically and psychologically for the affected child. Lack of knowledge about cleft lip and palate has been known to be the primary reason for negligence among the general population. Awareness levels of the parents have been known to have a profound role in developing an attitude to provide the patients with timely treatment. Additionally, family support also helps in overcoming psychological stress and provides positive reinforcement about knowledge, awareness, and practices regarding patients suffering from CLP [9].

Given the importance of the mother's role in preventing and possibly providing the right treatment for the child with CLP,

knowledge, and awareness of mothers should be of paramount importance. Alcohol consumption, lack of essential minerals, diabetes, and exposure to radiation during pregnancy has been known to be detrimental to the developing fetus, with Cleft lip and palate being one of the possible anomalies a newborn might be born with. Before a child is born, current modern enhancements offer the parents to view some developmental abnormalities beforehand, with Cleft lip and palate being one of them. Although it is possible to detect antenatally Cleft lip and palate, a fetus with an isolated cleft palate cannot be detected before birth [10]. With the right information, parents may be prepared beforehand for the child which may be born with this pathology and the additional needs the child may require [11]. Although CLP is a readily managed anomaly, some parents do opt for termination when being informed of the antenatal diagnosis. This is again mainly due to improper or lack of knowledge regarding CLP.

In this study, we aim to evaluate the general population's knowledge, awareness, and practices regarding patients being born with Cleft lip and palate. Moreover, the impact of age, gender, level of education, and occupation on knowledge, awareness, and practices is also being assessed.

## Methods and materials

In this cross-sectional survey-based study, we recruited a total of 505 participants using a convenience sampling method. The study was carried out from August 2020 to August 2021. The sample consisted of participants belonging to all age groups, visiting the Fatima Memorial Hospital, Pakistan for oral-health related concerns. A prevalidated questionnaire was used which consisted of 4 parts: 1) questions about demographic data, 2) questions about knowledge of Cleft lip and palate, 3) questions assessing awareness levels of cleft lip and palate, and 4) questions determining practices followed regarding cleft lip and palate. To ensure voluntary participation in this study, a consent statement was included and then the response was recorded.

Firstly, in our study, we evaluated the knowledge levels of the participants regarding cleft lip and palate through various questions such as understanding about cleft lip and palate, source of information on CLP, risk factors associated, etiological factors, the effect of gender, and complications which a child may develop if left untreated. Secondly, awareness levels were assessed by asking questions regarding treatment options available for cleft lip and palate patients, the right time for treatment, the correct initial treatment option, the possibility of antenatal diagnosis, doctors to consult, and the association of family history. Lastly, practices being followed were determined by asking questions regarding care required during pregnancy such as which foods and medicines should and should not be consumed, social habits e.g. smoking and alcohol, maternal diabetes, consulting a doctor for treatment, and the importance of adulthood treatment of Cleft lip and palate.

Participation in this study was primarily based on the general population belonging to all age groups who visited the respective hospital for concerns related to oral health. Those who were not able to read and write were excluded from this study. The data that was gathered from this survey was kept anonymous and confidential. The ethical approval was approved by the Fatima Memorial Hospital. For Data analysis, SPSS statistical software

version 25 was used. Descriptive statistics along with Spearman's correlation tests were used to analyze any significant relationship between age, gender, level of education, and occupation with levels of knowledge, awareness, and practices. A p-value of <0.05 was considered statistically significant.

## Results

In this study, we received a total of 570 filled questionnaires, out of which 65 were excluded based on being either incompletely filled or being of irrelevance. A total of 505 participant questionnaires were included in this study. The response rate was calculated to be 88.6%. A strong relation of 0.85 was found between the items used in this questionnaire using intraclass correlation. Descriptive statistics along with Spearman's correlation tests were used to analyze any significant relationship between age, gender, level of education, and occupation with levels of knowledge, awareness, and practices of the participants regarding cleft lip and palate.

Out of the 505 participants, 194 (38.4%) were males and 311 (61.6%) were females. The majority of 292 (57.8%) participants belonged to the age bracket of 18-30 years with a minority of 18 (3.6%) being in the 51-60 years age group. Predominantly, 166 (32.9%) participants had undergraduate education and 181 (35.8%) had a graduate education. Regarding the current occupation, 176 (34.9%) students, 155 (30.7%) healthcare professionals, and 62 (12.3%) businesses were the most commonly selected ones as shown in Table 1.

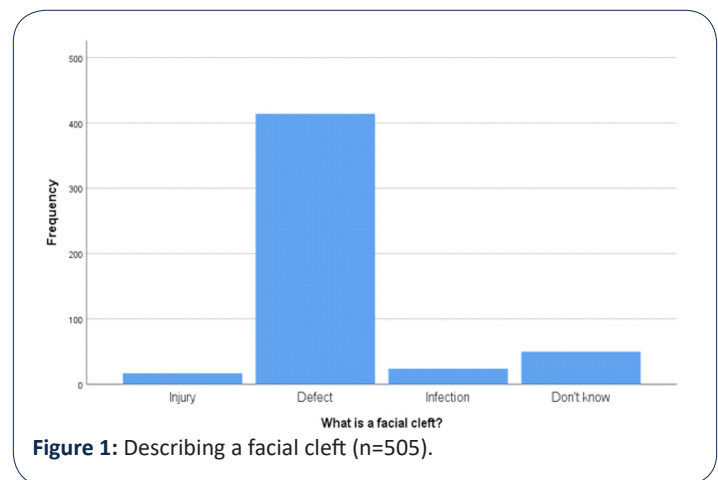
**Table 1:** Clinicopathological characteristics of PEACs in comparison with MCC.

	Variables	N	%
Age	Below 18 years	39	7.7
	18-30 years	292	57.8
	31-40 years	99	19.6
	41-50 years	37	7.3
	51-60 years	18	3.6
	Above 60 years	20	4.0
Gender	Male	194	38.4
	Female	311	61.6
Education	Undergraduate	166	32.9
	Graduate	181	35.8
	Postgraduate	130	25.7
	Below graduate	28	5.5
Occupation	Student	176	34.9
	Business	62	12.3
	Healthcare Professional	155	30.7
	Engineer	29	5.7
	Teacher	32	6.3
	Unemployed	21	4.2
	Others	30	5.9

Regarding knowledge, the majority of 413 (81.8%) participants had heard previously about cleft lip and palate, with healthcare professionals being the most common source of information for 151 (29.9%) participants along with friends and family and social media. A few 45 (8.9%) participants had never heard about cleft lip and palate. When describing a facial cleft, 82% (414 out of 505) participants believed that a cleft is a defect with a few 9.9% (50 out of 505) not able to describe it, as shown in figure 1. Regarding

the etiology, most of the 372 (73.7%) participants believed that genetics caused cleft lip and palate, along with some selecting medicines (29.7%), autoimmune (20.4%), and alcohol (20.4%) as additional causes. Regarding risk factors about a child being born with cleft lip and palate, predominantly, 51.9% (262 out of 505) believed maternal smoking, maternal diabetes, family history, medicines, and radiation as possible risk factors. A majority of 56.4% (285 out of 505) respondents said that child born with cleft lip and palate faces difficulties in speech, hearing, and feeding. The majority of 412 (81.6%) participants answered cleft lip and palate occur both in males and females. More than half of 270 (53.5%) participants believed cleft lip and palate do not always occur together. About 202 (40%) answered that cleft lip and palate accompany other abnormalities as well with 27.1% (137 out of 505) disagreeing with it.

Regarding awareness, the majority of 384 (76%) participants said cleft lip and palate are not contagious. Most of the 297 (58.8%) participants had never come across a patient suffering from cleft lip and palate. 396 (78.4%) participants agreed that treatment options are available for cleft lip and palate patients. About 61.6% (311 out of 505) participants responded "No" to cleft lip and palate being a burden to the parents with some 23% (116 out of 505) considering it a burden. 250 (49.5%) participants believed enough doctors are available to treat such patients, with the majority 80.4% (406 out of 505) agreeing on surgery was the best and first choice of treatment (73.3%). Regarding the best time for treatment, 73.3% (370 out of 505) participants believed infancy was the best time to start the treatment. A majority of 249 (49.3%) participants believed that cleft lip and palate can be diagnosed before birth. A majority of 167 (33.1%) respondents said pediatricians should be the first doctor to consult when a child is born with cleft lip and palate. Predominantly, 230 (45.5%) participants answered "Yes" to if one child or parent has CLP, it increases the risk of another child also having it.



Regarding practices, 459 (90.9%) participants strongly agreed that a healthy diet is important during pregnancy for newborns' health. A majority of 422 (83.5%) respondents believed that smoking cessation is important during pregnancy along with the cessation of alcohol (83%). For pregnant women with diabetes, the majority of 378 (74.9) said their blood sugar levels should be controlled. Furthermore, unnecessary medicines should also not be given to expecting mothers (90.5%). The majority of 91.5% (462 out of 505) participants believed immediate doctor consultation for a child with CLP. Predominantly, 311 (61.6%) did not

attend an informative seminar on CLP. The majority of 90.9% (459 out of 505) participants believed gynecologist consultation to be important for pregnant females. Regarding vitamins and mineral intake, 464 (91.9%) participants agreed to be part of a healthy diet during pregnancy. Regarding adult CLP treatment, 79.2% of participants think they should be offered treatment, but speech (62.6%) was the most commonly selected option which could not be corrected during adult CLP treatment as shown in Figure 2.

Spearman’s correlation test was used to analyze any significant relationship between age, gender, education, and occupation with knowledge, awareness, and practices regarding cleft lip and palate. A significant relation was found between Knowledge with age (p-value=0.01) and Education (p-value=0.001) and Practices with gender (p-value=0.01) and education (p-value=0.049) as shown in table 2. No significant relation was found among the other remaining variables.

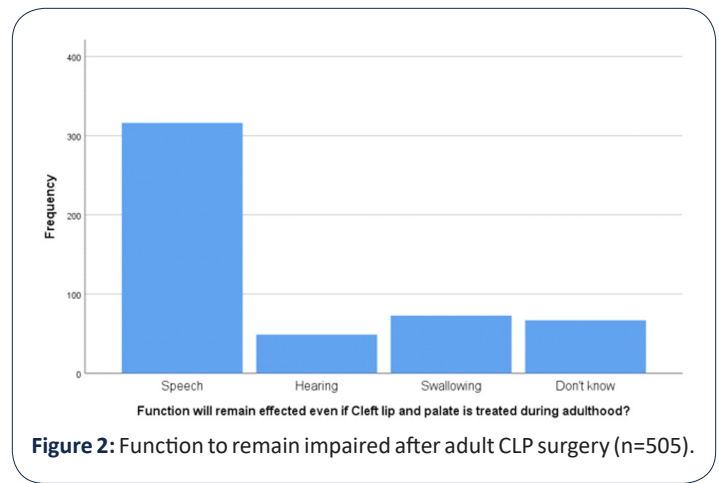


Figure 2: Function to remain impaired after adult CLP surgery (n=505).

Table 2: Correlation of knowledge, awareness, and practices with predictor variables.

Parameters	Correlations	Age	Gender	Education	Occupation	Knowledge	Awareness	Practice
Age	Correlation	1	-0.139	0.409	0.372	0.109	-0.055	-0.063
	Sig. (2-tailed)		0.002	0	0	0.014	0.216	0.156
Gender	Correlation	-0.139	1	-0.017	0.087	0.027	-0.004	-0.108
	Sig. (2-tailed)	0.002		0.711	0.05	0.542	0.928	0.015
Education	Correlation	0.51	-0.115	1		0.039	0.086	0.044
	Sig. (2-tailed)	0	0.022		0	0.44	0.85	0.382
Occupation	Correlation	0.372	0.087	0.542	1	0.061	0.03	-0.02
	Sig. (2-tailed)	0	0.05	0		0.17	0.499	0.652
Knowledge	Correlation	0.109	0.027	0.148	0.061	1	0.289	0.092
	Sig. (2-tailed)	0.014	0.542	0.001	0.17		0	0.039
Awareness	Correlation	-0.055	-0.004	0.059	0.03	0.289	1	0.391
	Sig. (2-tailed)	0.216	0.982	0.183	0.499	0		0
Practice	Correlation	-0.063	-0.108	0.088	-0.02	0.092	0.391	1
	Sig. (2-tailed)	0.156	0.015	0.049	0.652	0.039	0	

## Discussion

In this study, we assessed the knowledge, awareness, and practices of the general population regarding cleft lip and palate. To some extent, CLP is preventable, and if a child is born with it, timely surgical treatment can return the child to normalcy and satisfactory quality of life [12]. So, adequate knowledge, awareness, and practice regarding CLP are of paramount importance. Furthermore, an increased positive perception of CLP will be indeed beneficial for the child with CLP to promote a better quality of life.

In our study, females were more aware of CLP as compared to males. Furthermore, the majority of the participants were in general aware of CLP. This is not surprising as the study was carried out in locations where people mainly belong to good socioeconomic status. Poor knowledge about CLP has been reported in previous studies in rural and urban Asia [13,14]. In general, high knowledge levels were reported in our study (81.8%), these results contrast with previously carried out studies [15] where more than half of participants did not hear about CLP, suggesting the need to implement public health sessions to increase knowledge about CLP.

A study by Owotade et al, concludes that more than 50% of the females were unaware of CLP and that a similar percentage didn't participate in any public health program to enhance CLP knowledge. Moreover, the more educated an individual was, the better the knowledge about CLP [16]. Similar trends were also reported in our study.

In terms of describing what a facial cleft looks like, most of the participants in our sample described it as a “defect” of the lip and palate. Furthermore, many understood that cleft lip and palate can present as isolated deformities. Results of our study as consistent with Owatade et al, the majority selected CLP as a defect [16]. On the other hand, Middleton et al concluded that the general population was not able to define a cleft (18.4%) [15]. Possible reasons for this could be lack of proper education, poor socioeconomic status, and the way the questions might be asked of the participants.

Regarding the cause of CLP, mostly the participants were aware of it because of genetics, consumption of medicines, and alcohol. Literature states, increased levels of cortisol, which is a corticosteroid, released during stress could increase the risk of the de-

velopment of orofacial clefts [5]. Few participants (20%) in our study select corticosteroids as a potential cause of CLP but further research is mandated to figure out the possible relation. Moreover, diabetes, alcohol consumption, and family history were possible risk factors for CLP. Kozma et al concur that uncontrolled diabetes during pregnancy leads to increased chances of orofacial cleft along with alcohol being a possible risk factor too [17]. Some studies report self-perceived causes of CLP including exposure to an eclipse, and black magic [18]. No relevancy has been stated of these causes in the medical sciences, these are just self-perceived causes with no supporting evidence.

A child being born with CLP may face difficulties with speech, hearing, feeding, and dentition along with the psychosocial impact of it. Most of the participants in this study were aware of these problems. These results correspond with a similar study carried out by Nujaim et al [19]. Surgery is the best treatment for a child with CLP. This statement was agreed upon in our study along with previous studies in the literature [15]. This surgical treatment is most commonly offered by plastic and maxillofacial surgeons. Some aspects of the treatment mandate the involvement of physicians from other specialties. So, in general, the treatment of CLP is offered in a multi-disciplinary approach with a team of doctors. Most of the participants in our study were not aware of the approach, and selected doctors of individual specialties.

Being born with cleft lip and palate in children has been associated with a deficiency of folic acid in pregnant females [20]. This has been emphasized in our study, where many participants agree on taking multivitamins as part of their diet during pregnancy.

A recent trend has been of encouragement of pregnant females to visit their gynecologist to keep their and yet to be born child's health to the best [21]. Due to this, knowledge of CLP is primarily disseminated by doctors, as seen in our study. Furthermore, the diagnosis of CLP can be made before the birth of the child. If it is present, this gives the parents an adequate amount of time and counseling about the increased requirements of the child being born with CLP.

Adults being untreated CLP during their childhood meet with increased risks along with being unable to restore certain functions to normalcy. In our study, speech was the most commonly selected function to be impaired even after the treatment of CLP during adulthood. This is supported by previous studies which not only conclude impairment of speech even after treatment but the imperfect nasolabial appearance was also found [22]. But offering treatment to adults remains beneficial to a great extent with significant improvements in quality of life.

We evaluated the knowledge, awareness, and practices of the general population regarding cleft lip and palate comprehensively using validated tools. In this study despite the mentioned strengths, we were met with a few limitations. Firstly, the sample consisted of individuals mostly from the urban population with good socioeconomic status. Lastly, the inclusion of pregnant females could be further beneficial to increase the scope of this study.

## Conclusion

In conclusion, the general population which was surveyed showed adequate knowledge and awareness of cleft lip and pal-

ate with a supportive and positive attitude. Education plays an important part in understanding CLP as a condition that is to an extent preventable and treatable to near normalcy. To further increase knowledge about CLP, awareness programs through public healthcare programs regarding risk factors, diagnosis, causes, and multidisciplinary treatment can be beneficial.

## Declarations

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**Conflict of Interest:** None.

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