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AWARENESS, AND ATTITUDES OF PARENTS TOWARD CLEFT LIP AND PALATE AMONG POPULATION IN SAUDI ARABIA

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Abstract

Background: cleft lip and palate (CLP) is a type of a congenital cranio-facial development malformation. The Previous studies show a widely prevalence of thismalformation Also show a lack of knowledge and awareness toward the parents, that results in a lot of complications in speech, nutrition, and hearing and even a psychological issue.

Objective: This observational study aimed to assess the awareness and attitudes of parents towards cleft lip and palate in subsets populations in Saudi Arabia.

Methods: In this study, a cross-sectional analytical study was conducted among the parents to investigate the awareness level and attitudes of parents towards cleft lip and palate (CLP) in subsets populations in Saudi Arabia. Before the beginning of the study, ethical approval for this study was obtained from the institutional review board (IRB). Also, the questionnaire was distributed through social media platforms such as Twitter, Telegram, and WhatsApp. The English language was used in both the text messages and the questionnaire. Participants were informed about the aim of the study as well as their participation in the questionnaire survey is voluntary and anonymous. The items of the questionnaire study are performed and sent to parents generally and parents accompanying infants with cleft lip and palate in Saudi Arabia.

Results: the total sample size were 461 participants. As regards awareness and attitude score revealed

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that 59% had neutral attitude, 21% had negative attitude and only 20% had positive attitude. Moreover, there was no significant association between participants' attitude scores with their sociodemographic characters (P>0.05).

Conclusion: The findings revealed a significant proportion displaying neutral or negative attitudes towards the condition. While there was no significant association between attitude scores and sociodemographic characteristics, it is crucial to continue educating and raising awareness among parents to improve their understanding and support for individuals with cleft lip and palate.

Keywords: Parent, orofacial cleft, cleft lip & palate

Introduction:

Cleft lip and palate are one of most important conditions in dentistry and community.The disease develops when orofacial structures do not close completely. Mostly, the condition is inherited. It is One of the most diverse orofacial abnormalities that affects one in every 700 births and accounts for 65% of head and neck anomalies [1].It is one of the most common orofacial malformations. When tissues fail to fuse properly or at the wrong [2]. time during the early phases of development .CL/P, whether syndromic or no syndromic. Congenitally malformed babies are frequently unexpectedly born, which can cause a range of emotions, including shock, worry, uncertainty, guilt, inadequacy, rejection, despair, and disappointment [3]. This studysought to assess the knowledge, awareness level and attitude of parents towards cleft lip and palate in subsets populations in Saudi Arabia. CL and CP can lead to avariety of issues, including ear irritation, trouble speaking, improper tooth and mouth development, and difficulties eating. To enhance patients' quality of life, adequate therapy is required [4].

In 2022, research has been completed the survey, and the total of 739 participants. The majority is aware of cleft lip (86.7%) and palate (63.2%). In general, attitude toward patients with CL/P was positive. Females had higher knowledge compared to males, 54.4% and 32.9%, respec-tively. Online resources were the main source ofinformation [5]. Published research has been completed the survey, A total of 100 mothers were included in this study. Half of the mothers (50%) had breastfeeding difficulties at the begin-ning of the child's life. A significant correlation was found between the child's defect and the feeding techniques used by the mothers. None ofthe cleft palate patients (0%) received breast feeding. Of all mothers, 51% had heardabout the special feeding bottle for CLP patients and only 13% from that subset have used it. A significant correlation was also found between mothers' level of education and their awareness of the existence of a specialized bottle (p-value 0.001) [6]. In 2023, cross-sectional survey-based study of the 505 participants, 194 (38.4%) weremales 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 describecleft 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

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significant relation with age and education along with practices with gender and education [7]. Prenatal orofacial cleft diagnosis is associated with a higher reporting of family conflicts ($p=0.04$, $r=0.32$). In case of non-syndromic clefts, families having children with CLP report more family conflicts compared to CL or CP ($p=0.02$, $\varepsilon^2=0.46$). Parental education and number of children within the household showed no significant impact on parental QoL [8].

Cleft lip and palate (CLP) is a significant concern in Saudi Arabia, affecting children's development and quality of life. Raising awareness and providing accurate information about CLP is crucial for improving outcomes, such as physical development, speech, hearing, and social well-being. However, parents in Saudi Arabia are often unaware of CLP, study in 2018 found that only 30% of pregnant women in Saudi Arabia knew that CLP is a birth defect that can be treated. Addressing this lack of information can help families access necessary care withoutfinancial burden. Cleft lip and palate (CLP) is a relatively common congenital cranio-facial developmental malformation [5]. It's estimated that 1 in 500 birth in China occurs with clift lip and/or palate Cleft Lip and Palate (CLP) is one of the most prevalent oro-facial deformities and visible birth defects that occurs in 1 out ofevery 500 to 1,000 live births worldwide [9]. Operation Smile is one such organization, with a 20-year history of such activity. The leadership has become increasingly aware that local culture principally religion, mythology, and superstition plays a major role in the way that society treats children with obviousfacial deformities [10].

Objectives:

This observational study aimed to assess the awareness level and attitudes of parents towards cleft lip and palate in subsets populations in Saudi Arabia

Materials and Methods:

Study design: This study used a structured questionnaire that the authors had created as partof an across-sectional study questionnaire survey.

Study setting: The study was conducted in the kingdom of Saudi Arabia. It is a desert country in the (Middle East) southwestern Asia and occupies most of the Arabian Peninsula. Participants, recruitment, and sampling procedure: The population participating in our study with an age range from 18-65 years old.Inclusion and Exclusion criteria: All pregnant women from the Saudi population who were 18 years and above and women who could provide informed consent were eligible to participate in the study. In this study, we included pregnant women in Saudi Arabia older than 18 years old and who agreed to participate in our study. Pregnant women younger than 18 years old, non-pregnant woman, medical or health field students, and health care provide excluded.

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Sample size: The sample size was estimated using the Qualtrics calculator with a confidencelevel of 95% and 5% margin of error; a sample size of 384 at least.

Method for data collection and instrument (Data collectionTechnique and tools):

The tools used were self-evaluated questionnaires developed by Google Form, first to measure the awareness levels of parents towards cleft lip and palate in Saudi population.
In addition, to measure the attitudes, there are three main sections. Started with demographic data in section one, Section two questions was to analyze the attitudes. The survey used two versions: Arabic, the native language for Saudis, and English version. The participants have the chance to choose which language they prefer.

Scoring system:

Scoring system of awareness and attitude:

There were 12 questions to measure the attitude toward cleft lip and palate.
"Yes" was measured by one value," No" and "I don't know" were calculated withzero value. The total scores of each section varied from 0-12 and were allocated into three levels as follows: low level:0-4 scores; moderate level: 5-8 scores; highlevel: 9-12 scores.

Analyzes and entry method:

software program for Windows (2016). Then, in order to perform a statistical analysis, the data was transferred to the SPSS application, version 20 (IBM SPSS Statistics for Windows, Version 20.0 Armonk, NY: IBM Corp.). Data was input using the Microsoft Excel application for Windows (2016) after being collected. The Statistical-Package of Social-Science Software (SPSS) application, version 20, wasthen used to import the data. being assessed statistically.

Results:

Table (1) shows that, the majority of respondents fall within the 20-30 age range, accounting for 44.0% of the total, followed by the 31-40 age group at 20.1%. The data also indicates that 90.1% of the respondents are of Saudi nationality, with the remaining 9.9% being non-Saudi. When it comes to location, the highest percentage of individuals are located in the East and South regions, at 27.9% and 26.2% respectively. In terms of education level, the majority hold a Bachelor's degree (62.8%), followed by secondary education (15.9%). Finally, the occupation data shows that students make up the largest percentage at 24.7%, followed by health staff at 16.3%.

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Table (1): Sociodemographic characteristics of participants (n=473)

Parameter		**No.**	**Percent**
Age	less than 20	33	7.0
	20_30	208	44.0
	31_40	95	20.1
	41_50	89	18.8
	51_60	48	10.1
Nationality	Saudi	426	90.1
	Non-Saudi	47	9.9
Location	East	132	27.9
	Middle	122	25.8
	North	15	3.2
	South	124	26.2
	West	80	16.9
Education Level	uneducated	2	.4
	middle	7	1.5
	secondary	75	15.9
	Bachelor's	297	62.8
	diploma	58	12.3
	Master's	28	5.9
	Ph.D	6	1.3
Occupation	Health staff	77	16.3
	housewife	40	8.5
	Student	117	24.7
	military	3	.6
	Private sector	5	1.1
	Retired	36	7.6
	school	74	15.6
	other	121	25.6

Figure (1) shows the prevalence of cleft lip and palate among studied participants' children. Among the studied sample of the general population, there was 12 cases of cleft lip and/or palate, resembling 2%.

Figure (1): Prevalence of cleft lip and palate among studied participants' children

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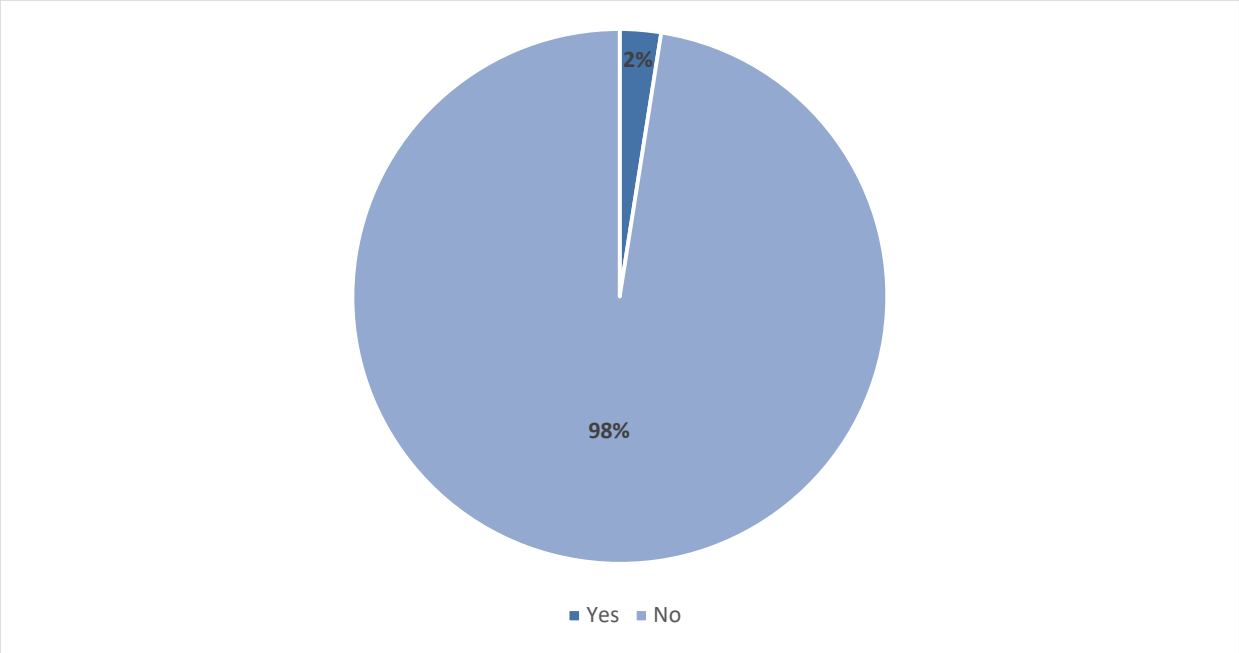

Among participants reported having children with cleft lip and palate, cleft lip was the most prevalent at 66.7%, followed by a combination of cleft lip and cleft palate at 16.7%, and cleft palate alone at 16.7%. Additionally, it is noteworthy that 33.3% of respondents consider cleft palate to be part of their family's medical history. The timing of diagnosis is also varied, with 66.7% of cases being identified during or immediately after birth, 25% during pregnancy through advanced imaging techniques, and 8.3% after childbirth due to an accident. Furthermore, the survey highlights the prevalence of smoking among parents, with 41.7% having at least one smoking parent and 8.3% having both parents as smokers. When it comes to the emotional response of parents, 50% accepted their child's situation, while the other 50% struggled to accept it. The survey also delves into the perceived causes of cleft lip and cleft palate, with genetics being the leading cause according to 33.3% of respondents, followed by medication during pregnancy and poor maternal psychological state at 33.3% and 16.7% respectively.

Table (2): Determinants of cleft lip and palate among reported cases (n=12).

Parameter		**No.**	**Percent**
Child's specific injury	My child has cleft palate	2	16.7
	My child has cleft lip	8	66.7
	My child has both cleft lip and cleft palate	2	16.7
Cleft palate considered to be elements of the family's medical history	Yes	4	33.3
	no	4	33.3
	I'm not sure about that.	4	33.3
Time of diagnosis	During/immediately after birth (congenital disease)	8	66.7

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	During pregnancy through advanced imaging techniques (congenital disease)	3	25.0
	After childbirth due to an accident (acquired disease)	1	8.3
Parents smoking status	Yes (one of the parents is a smoker)	5	41.7
	Yes (we are both smokers)	1	8.3
	No (we both do not belong to the category of smokers)	5	41.7
	No (one of the parents is a non-smoker)	1	8.3
What is your first reaction when your child suffers from a cleft lip or cleft palate?	Yes, I accepted my child's situation	6	50.0
	I could not accept my child's situation	6	50.0
In your opinion, what is the biggest and main cause of cleft lip - cleft palate or (both)?	Exposure to some industrial or radiation areas	1	8.3
	Genetics	4	33.3
	Taking medications during pregnancy	4	33.3
	Taking birth control or stabilizers	1	8.3
	Poor psychological state of the mother	2	16.7

In table (3), the majority of children with cleft lip and cleft palate require medical care for speech problems, with 92.2% of respondents indicating this need. Additionally, 66.2% of respondents reported that children with these conditions have difficulty building friendships, highlighting the social challenges they may face. It is important to note that 79.4% of respondents acknowledged that cleft lip and cleft palate can cause developmental problems such as breathing, swallowing, and speaking disorders, emphasizing the multifaceted nature of these conditions. Furthermore, the data indicates that factors such as family history, maternal nutrition during pregnancy, and exposure to cigarette smoke can influence the occurrence of cleft lip and cleft palate, underscoring the complex interplay of genetic and environmental factors. Overall, the data underscores the need for comprehensive medical care, support, and understanding for children with cleft lip and cleft palate, as well as the importance of addressing the various challenges they may encounter.

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Table (3): Participants' awareness and attitude towards cleft lip and palate (n=461).

	Yes	No
Children with cleft lip and cleft palate require medical care for speech problems	425 92.2%	36 7.8%
Children with cleft lip and cleft palate could speak clearly if they tried	245 53.1%	216 46.9%
Children with cleft lip and cleft palate have difficulty building friendships	305 66.2%	156 33.8%
Children with cleft lip and cleft lip cannot control their expressions	181 39.3%	280 60.7%
Children with cleft lip and cleft palate have difficulty finding a suitable job	245 53.1%	216 46.9%
Children with cleft lip and cleft palate have a weak intelligence level	50 10.8%	411 89.2%
Parents who have children with cleft lip and cleft palate tend to hide their children from society	214 46.4%	247 53.6%
A cleft is a birth defect in which there is an abnormal opening or division in the lip or palate	424 92.0%	37 8.0%
Cleft lip more common in male children	242 52.5%	219 47.5%
Know complications of cleft lip or cleft palate	284 61.6%	177 38.4%
The possibility of cleft lip in children being affected only by family history	155 33.6%	306 66.4%
Cleft lip and cleft palate cause developmental problems such as breathing, swallowing, and speaking disorders	366 79.4%	95 20.6%
After having a child with a cleft lip, there is a chance of having another child with a cleft lip	229 49.7%	232 50.3%
Using medications without a doctor's prescription is one of the reasons for cleft lip in children	280 60.7%	181 39.3%
Mother's nutrition, such as folic acid, vitamin B12, vitamin A, zinc, and calcium during pregnancy affect the child's cleft lip	238 51.6%	223 48.4%
Exposure to cigarette smoke during pregnancy linked to the occurrence of cleft lip and cleft palate	260 56.4%	201 43.6%

Figure (2) gives an insight on the awareness and attitude of the studied participants towards cleft lip and palate. The studied sample of the general population had 20% only with positive attitudes, while 59% had neutral attitudes and 21% had negative attitudes.

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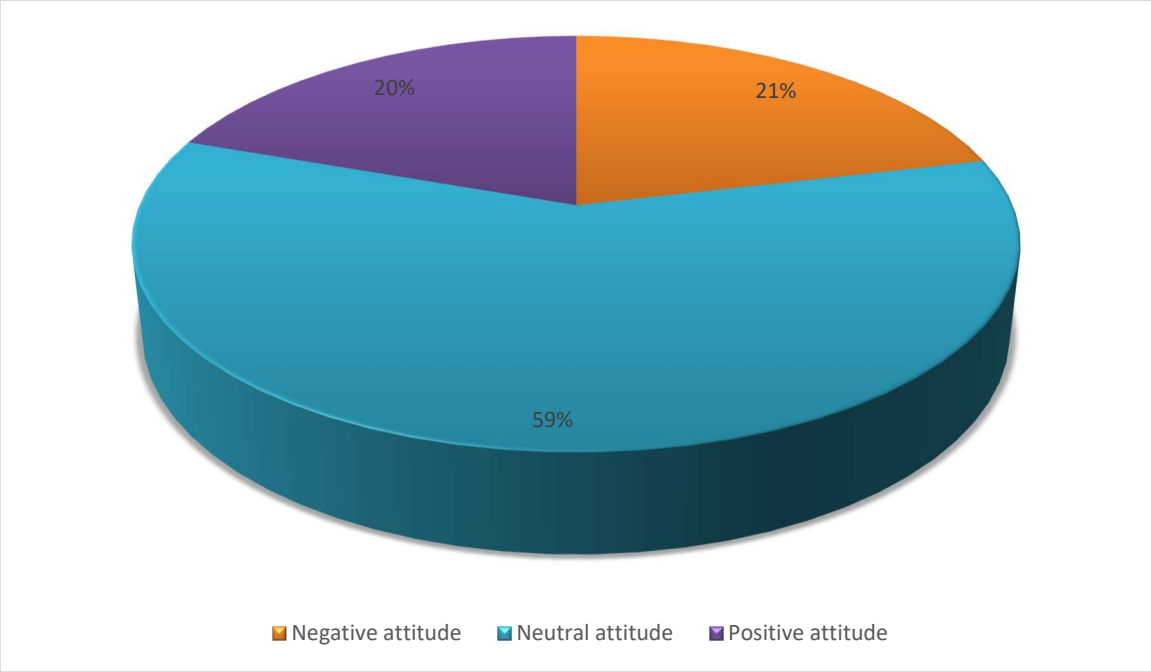
Figure (2): Participants' attitude scores towards cleft lip and palate (n= 461)



As illustrated in table (4), there was no significant association between participants' awareness and attitude score with their sociodemographic characters (P>0.05).

Table (4): Participants' attitude scores in association with their sociodemographic characters (n=461).

		Awareness and attitude score			**Total (N=461)**	**P value**
		Positive attitude	Neutral attitude	Negative attitude		
Age	less than 20	11	18	3	32	**0.036**
		2.4%	3.9%	0.7%	7.0%	
	20_30	42	128	33	203	
		9.1%	27.8%	7.2%	44.1%	
	31_40	16	50	25	91	
		3.5%	10.9%	5.4%	19.8%	
	41_50	12	48	27	87	
		2.6%	10.4%	5.9%	18.9%	
	51_60	9	28	10	47	
		2.0%	6.1%	2.2%	10.2%	
Nationality	Saudi	82	244	90	416	**0.804**
		17.8%	53.0%	19.6%	90.4%	
	Non-Saudi	8	28	8	44	
		1.7%	6.1%	1.7%	9.6%	
Location	East	26	78	24	128	**0.252**

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		5.7%	17.0%	5.2%	27.8%	
	Middle	20	76	21	117	
		4.3%	16.5%	4.6%	25.4%	
	North	4	6	3	13	
		0.9%	1.3%	0.7%	2.8%	
	South	30	61	31	122	
		6.5%	13.3%	6.7%	26.5%	
	West	10	51	19	80	
		2.2%	11.1%	4.1%	17.4%	
Education Level	Illiterate	3	3	1	7	**0.435**
		0.7%	0.7%	0.2%	1.5%	
	Secondary	16	38	19	73	
		3.5%	8.3%	4.1%	15.9%	
	Bachelor	53	177	61	291	
		11.5%	38.5%	13.3%	63.3%	
	Diploma	10	34	13	57	
		2.2%	7.4%	2.8%	12.4%	
	Master	0	5	0	5	
		0.0%	1.1%	0.0%	1.1%	
	Doctoral	8	15	4	27	
		1.7%	3.3%	0.9%	5.9%	
Occupation	Healthcare worker	18	45	13	76	**0.208**
		3.9%	9.8%	2.8%	16.5%	
	Housewife	5	20	12	37	
		1.1%	4.3%	2.6%	8.0%	
	Student	31	63	20	114	
		6.7%	13.7%	4.3%	24.8%	
		1	2	0	3	
		0.2%	0.4%	0.0%	0.7%	
	Retired	0	2	3	5	
		0.0%	0.4%	0.7%	1.1%	
	Teacher	5	22	6	33	
		1.1%	4.8%	1.3%	7.2%	
		13	42	18	73	
		2.8%	9.1%	3.9%	15.9%	
	Other	17	76	26	119	
		3.7%	16.5%	5.7%	25.9%	

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Discussion:

Cleft lip and palate (CLP) is one of the most prominent hereditary diseases affecting newborns. Clefts occur in the early stages of human embryonic development and are categorized as “non-syndromic” if the malformation appears to be an isolated defect or “syndromic” if the malformation is a part of a larger disorder in a known pathologic pattern. The former represents approximately 70% of facial congenital malformations [13]. The etiology of CLP is thought to be multifactorial, resulting from a combination of genetic and environmental factors [14]. Advanced maternal age, smoking, alcohol consumption, and deficiency in folic acid and B6 and B12 vitamins during pregnancy are associated with an increased risk of CLP [15,16]. A number of genes and molecular pathways have been linked to the etiology of clefting. An understanding of the molecular mechanisms of cleft formation is therefore important in supporting decision-making and counselling [17]. The prevalence of CLP varies according to race, geographic location, environmental exposure, and social and economic conditions with the highest prevalence found among Asians and Native Americans (1/500), while the lowest prevalence observed among Africans (1/2500). Caucasians have an intermediate prevalence of 1 in 1,000. Variable levels of CLP knowledge have been reported in different countries in various urban and rural areas [18,19]. In fact, previous studies elucidated the importance of parents’ education toward the successful management of CLP. This might include comprehensive information and treatment options explanations [20,21]. An obvious association between parents’ awareness/knowledge and high incidence of unrepaired cleft cases was reported, which may result, in extreme cases, in death [22]. Schwarz and Khadka observed that one of the most important reasons for late presentation of CLP patients is the lack of sufficient knowledge [23]. Also, late surgical procedures can lead to poor outcomes and have a potential impact on the child's and family's quality of life (QoL) [24]. Therefore, adequate levels of knowledge about the anomaly, cause and treatment options can have a significant impact on the social, health, and psychological support of CLP patients. thus, we aimed in this study to assess knowledge, awareness level and attitudes of parents towards cleft lip and palate in subsets populations in Saudi Arabia.

As regard the studied population awareness and attitude score, it was revealed that 59% had neutral attitude, 21% had negative attitude and only 20% had positive attitude. On the other hand, a cross-sectional study by Middleton *et al*. found that 18.4% of mothers could not define CLP properly. In contrast, two studies conducted on pregnant women in Nigeria and Saudi Arabia reported a high percentage of a proper definition of CLP [25,26]. moreover, a study conducted by Mushriq Abid et.al [2021] revealed that the majority of the mothers did not show a great deal of knowledge and awareness of most of the risk factors, such as family history, consanguinity, diabetes, and smoking. This disagrees with previous studies that reported the important role of exogenous risk factors such as mothers’ illness, medication intake, and smoking in the aetiology of CLP [27,28,29]. The difference could be attributed to the difference in the questionnaire perception, cultural background and educational and health programs in each country. Another study by Jones and Brown (2017) [30] evaluated the knowledge of parents towards cleft lip and palate in London and reported that 75% of parents had misconceptions about the causes and treatment of the condition. This study emphasizes the importance of providing accurate information to parents to dispel myths and misconceptions. Moreover, a study by Patel et al.

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(2019) [31] compared the knowledge and attitudes of parents towards cleft lip and palate in the United States and India. The researchers found that parents in the United States were more likely to have accurate knowledge about the condition and were more accepting of children with cleft lip and palate compared to parents in India. This suggests that cultural factors may play a role in shaping attitudes towards these conditions. Similar to our study results, a study conducted by Al-Harbi et al. (2017) [32] aimed to assess the awareness and knowledge of parents towards cleft lip and palate in Saudi Arabia. The results showed that only 45% of parents were aware of cleft lip and palate, and only 30% had adequate knowledge about the condition. This lack of awareness and knowledge could potentially lead to delays in seeking treatment and support for affected children. Another study by Al-Johar et al. (2019) [33] focused on the attitudes of parents towards cleft lip and palate in Saudi Arabia. The study found that 60% of parents had negative attitudes towards children with cleft lip and palate, citing concerns about social stigma and discrimination. This negative attitude could have a detrimental impact on the emotional well-being of affected children and their families. In a more recent study by Al-Mahmood et al. (2021) [34], researchers investigated the overall perception of parents towards cleft lip and palate in Saudi Arabia. The study revealed that only 25% of parents had a positive perception of the condition, with the majority expressing feelings of fear and uncertainty.

Conclusion:

In conclusion, this study highlighted the importance of assessing the awareness, and attitudes of parents towards cleft lip and palate in subsets of populations in Saudi Arabia. The findings revealed a significant proportion displaying neutral or negative awareness and attitudes towards the condition. While there was no significant association between attitude scores and sociodemographic characteristics, it is crucial to continue educating and raising awareness among parents to improve their understanding and support for individuals with cleft lip and palate. Further efforts are needed to promote positive attitudes and enhance the quality of life for those affected by this condition in the Saudi Arabian context.

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Conflict of interests

The authors declare that there are no conflicts of interest.

Informed consent:

Written informed consent was obtained from all individual participants included in the study.

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Data and materials availability

All data associated with this study are present in the paper.

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