

## **Awareness, knowledge and attitudes of Saudi pregnant women towards cleft lip and palate.**

**Nujaim H Alnujaim<sup>1</sup>, Eman S Albedaei<sup>1</sup>, Leena S Alyahya<sup>1</sup>, Maha A Adosary<sup>1</sup>, Fahad F Alotaibi<sup>1</sup>, Mohammed H Alnujaim<sup>1</sup>, Saeed Mahmud<sup>2</sup>**

<sup>1</sup>College of Medicine, King Saud University, P.O. Box 7805 (92), Riyadh, 11472 Saudi Arabia.

<sup>2</sup>Department of Obstetrics and Gynecology, King Saud University, P.O. Box 7805 (92), Riyadh, 11472 Saudi Arabia.

### **Abstract**

**Objective:** Cleft lip and palate (CLP) is a common craniofacial deformity. Low awareness and knowledge and a negative attitude are known to increase social and emotional stress in this group of patients. In the present study, we assessed the knowledge, awareness, and attitude of Saudi pregnant women toward CLP.

**Methods:** A cross-sectional study using a validated questionnaire was conducted among 310 pregnant women attending the obstetrics and gynecology clinics in King Khalid University Hospital, Saudi Arabia. Level of awareness, mean cumulative knowledge score, and attitude scores were evaluated.

**Results:** Majority (81%) of the women reported that they had heard of cleft lip while (49.9%) heard of cleft palate. Nationality and highest level of education had significant effect on the awareness of CL, whereas occupation of the respondents was found significantly related to awareness of CP. Mean cumulative knowledge score was  $(14.2 \pm 6.6)$  and (52.5%) respondents exhibited high level of knowledge. Occupation and level of education of the women statistically affected the level of knowledge of CLP. Attitudes towards cleft lip and palate patients were generally positive. Knowledge of the participant was significantly associated with a positive attitude toward CLP.

**Conclusion:** There are variations in level of awareness, knowledge, and attitude in Saudi women. Mothers' knowledge about CLP might encourage better health related behavior in the children.

**Keywords:** Cleft lip and palate, Awareness, Knowledge, Attitude, Pregnant.

*Accepted November 06, 2017*

### **Introduction**

Cleft Lip and Palate (CLP) is a common craniofacial deformity and birth defect. It can arise as an isolated abnormality, as part of a syndrome, or along with other associated deformities [1-3]. A study by Hadadi et al. [4] reported that congenital heart diseases are the most common anomaly associated with orofacial clefts, and that routine screening should be considered.

The incidence of cleft lip (CL), cleft palate (CP), or a combination of both (CLP) has been studied worldwide. Globally, CLP occurs in approximately 1 in every 500-700 births per year [5]. Previous studies have reported that the incidence of CLP ranges from 1 to 2.2 per 1000 live births in European Caucasian population [6], whereas a study in

Brazil reported a prevalence of 0.19 per 1000 live births [7]. Another study in Saudi Arabia reported the incidence of CLP as 0.3 per 1000 live births [3]. Prevalence of CLP varies with geographic origin and ethnic groups; however, these are not the only determining factors.

High incidence of unoperated clefts has been reported in previous studies suggesting parents' low awareness and knowledge of the condition [8]. These, in extreme cases, could result in infanticide [9,10]. Because CLP is preventable to some extent and surgical correction can be largely achieved, deep understanding of the condition is required. A study in Nepal showed that lack of knowledge about CLP treatment was the most common reason for late presentation of the patients [11]. Poor knowledge of CLP

has also been reported in populations of many urban and rural areas of Africa [12-14] and Asia [8].

The attitude of individuals with CLP, their families, and community has a profound role in the development of patients [14]. Parental attitudes and expectations affect the social and emotional development of patients; a negative attitude has been linked with increased mental and social stress, leading to a lower quality of life. This can be overcome by positive attitude and support of family members, as well as adequate awareness and knowledge about the cause, management and treatment options.

Given the importance of mother's role in a child's development and the limited information regarding the level of awareness and knowledge in this group, the present study was undertaken among Saudi pregnant women to assess their knowledge, awareness and attitude toward CLP.

## **Materials and Methods**

### ***Study Design and Setting***

This quantitative observational cross-sectional study was conducted in Obstetrics and Gynecology clinics in King Khalid University Hospital (KKUH) in Riyadh, Saudi Arabia, from January 2017 to July 2017.

### ***Study Participants and Sampling Technique***

The study population included all pregnant women with confirmed pregnancies, who were attending the obstetrics and gynecology clinics in the KKUH. Convenience sampling technique was used to collect the data.

The number of participants was calculated statistically using the following variables: (50.5%) awareness of CLP was considered significant based on previous literature, (5%) sample error, and (95%) confidence level was considered. The final calculated sample size was 380. In total, 400 surveys were distributed, of which 90 were excluded, as they were incomplete or inappropriately filled. A total of 310 questionnaires were eligible for data analysis.

### ***Study Instrument***

The participants were surveyed by means of a self-administered questionnaire, which was closely adapted from previous studies in literature. The questionnaire consisted of three sections: 1) questions about general and demographic information of the respondents, 2) questions assessing the awareness and knowledge of CLP, and 3) questions determining the attitude regarding CLP by means of a standardized tool, the CLPQ survey.

A pilot study was conducted on a separate set of participants ( $N=30$ ) to assess suitability of the questionnaire prior to data collection. The survey was reviewed by experts in the field of cleft lip and palate to ensure scientific accuracy. Permission from the institutional review board of King Saud University was obtained before conducting the

study, and written informed consent was also obtained before participation.

### ***Cleft Lip and Palate Knowledge Assessment***

The participants' level of knowledge pertaining to diagnosis and prognosis of CLP was assessed by asking questions about the definition, risk factors, methods of management, professionals involved in the management, complications, and general knowledge of cleft lip/palate. Possible answers were "Yes", "No", and "I do not know" for each of the respective items. A total of *six risk factors* were included (family history, maternal smoking, maternal diabetes, Consanguinity, certain medication intake and folate deficiency). Common cleft lip/palate associated problems such as hearing loss, speech difficulties and facial deformity were asked to the participants. Knowledge of surgical and prosthetic management of cleft lip/palate was also assessed. The multidisciplinary nature of CLP management was assessed by asking the participants to choose the professional whom they think are involved in cleft lip/palate treatment. Finally, several questions about cleft lip/palate prognosis and diagnosis were included in the survey, such as the possibility to treat an adult with cleft lip/palate and prenatal diagnosis of CLP.

A total of 33 items were used to assess the level of knowledge of cleft lip/palate. A scoring system to estimate the level of knowledge was created specifically for this study and calculated as follows: each correct answer was given 1 point and points were neither given nor deducted for incorrect or "I don't know" answers, resulting in a maximum score of 33 and a minimum score of zero. Participants were classified into high level of knowledge and a low level of knowledge based on the mean score. Those who scored above the mean were classified as having a high level of knowledge and those who scored below the mean were classified as having a low level of knowledge.

### ***Reliability and Validity of the Cleft Lip/Palate Knowledge Assessment Tool***

The internal consistency using Cronbach's alpha had value of 0.904 ( $P<0.05$ ). Factor analysis showed that all the items were correlated with other items (at least of 0.50). The Kaiser-Meyer-Olkin measurement of sampling adequacy was 0.870, Bartlett's test of sphericity was 3992.899,  $P<0.05$ . Sampling adequacy values were greater than the recommended value of 0.6. By using eigenvalue of  $>1$ , the eight-factor extraction (of the thirty-three items) explained (59.526 %) of total variance and factor loading had a range of 0.308 to 0.667. The analysis of our data indicated that the knowledge assessment tool had good reliability and validity.

### ***Attitude Assessment Using the CLPQ Survey***

This survey, as introduction, briefly defined CLP in a non-technical language. This was followed by the core section, which assessed the attitude of participants toward CLP.

This survey was adapted from a questionnaire developed by Bebout and Arthur [15,16] for studying cross-cultural attitudes about speech disorders. The questionnaire comprised 12 statements, and a four-point scale was used to assess the extent to which the participants agreed or disagreed with each statement. These were described as “probably no”, “maybe no”, “maybe yes” and “probably yes”. Of the 12 statements, 3 were phrased (statement 2, 7 and 12) such that “probably yes” implied a favorable attitude to the statement, and 9 were phrased such that “probably no” indicated a favorable attitude to the statement. The completed questionnaires were analyzed by Bebout and Arthur’s scoring system [16]. Responses to each statement were scored from 1 to 4, where 1 implied a very unfavorable attitude and 4 indicated a very favorable attitude. A “probably Yes” was given a score of 1, “maybe Yes” was given a score of 2 “maybe No” was given a score of 3 “probably No” was given a score of 4. For all the statements except (2, 7 and 12) a mean score close to 4 indicate a favorable attitude or a response in favor of cleft lip and palate patients. For statements (2, 7 and 12) a mean score close to a 1 indicate a favorable attitude or a response in favor of CLP patients. The CLPQ survey has been found valid and reliable by a previous study [14]. The original 12 statements of the survey are attached in the appendix.

**Statistical Analysis**

Data were analyzed using the Statistical Package for Social Sciences (SPSS) version 23 (SPSS Inc., Chicago, Illinois, USA). Results were expressed as numbers and percentages for categorical data, and mean, standard deviation, and range for continuous data (Tables 1-5). Association between two variables was done using the Pearson correlation test (Table 5) Test of significance between two variables was done using the Chi-square test for categorical variables (Tables 2 and 3). P-values ≤ 0.05 were considered statistically significant.

**Results**

**Characteristics of the Respondents**

In total, 310 pregnant women were recruited to the study. Majority of the women were of age 25-34 years (57.4%). Women of Saudi nationality comprised (93.2%) of the participants, whereas (6.8%) of the women were of non-Saudi nationality. Characteristics of the participants are summarized in Table 1.

**Awareness of Cleft Lip/Palate**

In total, (81%) women reported that they had heard of Cleft lip, whereas (49.4%) women had heard of Cleft Palate and (63.2%) women had seen a person with Cleft lip/palate before.

Table 2 shows the association between awareness of Cleft lip/palate and participants characteristics. Nationality and level of education had significant effect on the awareness

of Cleft lip (p=0.021 and p=0.006, respectively), whereas age groups, occupation, and number of current/previous pregnancies were not significantly related. In terms of awareness of Cleft palate, only the occupation of the respondents was found significantly related (p=0.038).

**Knowledge of Cleft Lip/Palate**

**Understanding of cleft lip/palate:** A group of pregnant women (27.1%) described CLP as “Opening of the lip and hard palate”. On the other hand, (18.7%) as described it as a “Congenital facial deformity”. While most of the respondents (41.9%) agreed that CLP is both a “Congenital facial deformity” and “Opening of the lip and hard palate”.

**Risk factors of cleft lip/palate:** Family history as a major contributing factor in cleft lip and palate was only identified by (14.9%) while the majority rejected family history (20.6%) or did not identify it as a risk factor (30.0%). Maternal smoking, diabetes and consanguinity were identified as risk factors by (28.1%), (28.7%), and

*Table 1. Characteristics of the participants*

	N	%
<b>Age groups</b>		
<18 years old	5	1.6
18-24 years old	63	20.3
25-34 years old	178	57.4
35-44 years old	57	18.4
45-54 years old	5	1.6
55-64 years old	2	0.6
<b>Nationality</b>		
Saudi	289	93.2
Non-Saudi	21	6.8
<b>Occupation</b>		
Housewife	151	48.7
Student	48	15.5
Teacher	56	18.1
Health related employee	16	5.2
Other	39	12.6
<b>Highest level of education achieved</b>		
Illiterate	2	0.6
Elementary	6	1.9
Intermediate	6	1.9
Secondary	74	23.9
Some post-secondary	20	6.5
College (Bachelors)	181	58.4
Higher education (Masters or PhD)	21	6.8
<b>Number of current and previous pregnancy</b>		
First time pregnancy	107	34.5
Three previous children or less (including current pregnancy)	128	41.3
More than three previous children (including current pregnancy)	75	24.2

**Table 2.** Association between participant’s characteristics and awareness of cleft lip and cleft palate

Characteristics	Awareness of cleft lip	Awareness of cleft palate
	P value	P value
Age groups	0.326	0.551
Nationality	0.021*	0.535
Occupation	0.463	0.038*
Highest level of education achieved	0.006*	0.583
Number of current and previous pregnancy	0.646	0.372

\* Association is significant

**Table 3.** Relationship of participant’s characteristics and cleft lip/palate knowledge mean score

Participants characteristics	Low knowledge score N (%) N=147	High Knowledge score N (%) N=163	P values
<b>Age groups</b>			0.108
<18 years old	1 (0.7)	1 (0.6)	
18-24 years old	36 (24.5)	27 (16.6)	
25-34 years old	83 (56.5)	95 (58.3)	
35-44 years old	23 (15.6)	34 (20.9)	
45-54 years old	1 (0.7)	4 (2.5)	
55-64 years old	0	2 (1.2)	
<b>Nationality</b>			0.498
Saudi	139 (94.6)	150 (92.0)	
Non-Saudi	8 (5.4)	13 (7.9)	
<b>Occupation</b>			0.023*
Housewife	80 (54.4)	71 (43.6)	
Student	25 (17.0)	23 (14.1)	
Teacher	24 (16.3)	32 (19.6)	
Health related employee	2 (1.4)	14 (8.6)	
Other	16 (10.9)	23 (14.1)	
<b>Highest level of education achieved</b>			0.002*
Illiterate	1 (0.7)	1 (0.6)	
Elementary	3 (2.0)	3 (1.8)	
Intermediate	3 (2.0)	3 (1.8)	
Secondary	49 (33.3)	25 (15.3)	
Some post-secondary	9 (6.1)	11 (6.7)	
College (Bachelors)	79 (53.7)	102 (62.6)	
Higher education (Master and PhD)	3 (2.0)	18 (11.0)	
<b>Number of current and previous pregnancy</b>			0.599
First time pregnancy	51 (34.7)	56 (34.4)	
Three previous children or less (including current pregnancy)	64 (43.5)	64 (39.3)	
More than three previous children (including current pregnancy)	32 (21.8)	43 (26.4)	

(12.9%) participants, respectively. Moreover, the effect of drug intake and folic acid deficiency, as a risk factors, was agreed by (38.4%) and (45.5%) participants, respectively. The role of supernatural (*witchcraft*) in CLP was answered as “Yes” by (9%), “No” by (46.1%) and “I do not know” by (44.5%) respondents.

**Complications of cleft lip/palate:** Majority of the participants agreed feeding difficulties (74.5%), speech difficulties (63.9%), facial deformity (76.1%) and psychological distress (66.5%) as complications of Cleft

lip/palate. Less than half the respondents identified abnormal dental development as a complication (46.8%), whereas recurrent middle ear infections and hearing loss was agreed only by (15.6%) participants.

**Methods of Treating Cleft Lip/Palate:**

Surgery as treatment option for Cleft Lip and palate was identified by most of the participants (86.1%). On the other hand, Prosthesis as a treatment modality was identified by only (11.3%).

**Table 4.** Attitudes towards cleft lip and palate patients

Cleft lip and palate attitude statements	Mean	Standard deviation	Range
1. Have trouble making friends and/or getting married.	2.25	0.88	1-4
2. Go to a doctor or other professionals.	3.63	0.68	1-4
3. Jokes acceptable if a person with CLP is not listening	3.65	0.83	1-4
4. Job problems	2.65	1.02	1-4
5. Punished by God/fate	3.44	0.94	1-4
6. Less intelligent	3.25	0.90	1-4
7. Go to non-doctor.	1.54	0.94	1-4
8. Could speak more clearly if they tried harder	2.20	0.82	1-4
9. Hide at home	3.82	0.59	1-4
10. Teasing or making fun of a person with CLP is acceptable	3.75	0.69	1-4
11. Emotionally disturbed	2.64	0.96	1-4
12. Should get help with speech problems.	3.42	0.87	1-4

**Table 5.** Correlation between cleft lip and palate knowledge and attitudes mean scores

Cleft lip and palate attitude statements	Correlation coefficient	P value
1. Have trouble making friends and/or getting married.	-0.180	0.001*
2. Go to a doctor or other professionals.	0.098	0.087
3. Jokes acceptable if a person with CLP is not listening	-0.023	0.691
4. Job problems	-0.210	<0.001*
5. Punished by God/fate	-0.041	0.471
6. Less intelligent	0.111	0.052
7. Go to nondoctor.	-0.044	0.444
8. Could speak more clearly if they tried harder	0.030	0.601
9. Hide at home	-0.056	0.327
10. Teasing or making fun of a person with CLP is acceptable	-0.042	0.462
11. Emotionally disturbed	-0.136	0.017*
12. Should get help with speech problems.	0.127	0.025*

\* Significant correlation between knowledge mean score and attitude mean score

#### **Knowledge of Professionals Involved in the Management of Cleft Lip/Palate:**

Plastic/maxillofacial surgeon was agreed as a professional by majority of the participants (82.9%). Less than half the respondents identified pediatrician (47.1%), followed by speech pathologist (43.2%), otolaryngologist (40.6%), dentist (38.4%), psychologist (35.8%) and social workers (29.4%). Furthermore, audiologist was agreed by (15.5%) participants, obstetrician/gynecologist by (11.3%).

#### **General Knowledge of Cleft Lip/Palate:**

Only (25.8%) knew that CLP can be diagnosed before a child is born. Also (24.8%) stated that CLP is a preventable deformity. When asked "At what age should a child with CLP commence treatment?" maximum respondents (43.2%) were not able to identify the correct answer. A successful treatment of an adult patient with CLP was agreed by (48.4%) of the participants. When asked to choose the correct statement, (42.69%) answered "Cleft lip or Cleft palate can be an isolated deformity", (10.0%) answered "Cleft lip and palate always occur together".

#### **Differences in Cleft Lip/Palate Knowledge as a Function of Participants Baseline Characteristics**

Table 3 summarizes the mean knowledge score of the respondents. The mean total knowledge score was (14.2 ± 6.6) with (52.5%) having high knowledge. It was observed that individuals with a college degree and in the age group of 24-34 were more likely to exhibit high knowledge of CLP (62.6%) and (58.2%), respectively. On the other hand, a housewife was more likely to exhibit a low level of knowledge of CLP (54.4%; P=0.023).

Occupation and level of education of the women statistically affected the level of knowledge of Cleft lip and palate (p=0.023, p=0.002, respectively). There was no significant relation between level of knowledge and age group, nationality, or number of current and previous pregnancies (p<0.05).

#### **Attitudes of Respondents Toward Cleft lip/Palate**

Overall, the mean attitude score was maximum for statement 9 (3.82 ± 0.59), whereas minimum was for statement 8 (1.54 ± 0.94) (Table 4).

### **Correlation between Knowledge of Participants and Attitudes Scores**

Table 5 summarizes the relation between knowledge and attitude scores. Significant negative correlation between knowledge and attitude scores was seen for *statements 1, 4 and 11* ( $r=-0.180, p=0.001$ ;  $r=-0.210, p \leq 0.001$ ;  $r=-0.136, p=0.017$ , respectively), and significant positive correlation was seen for *statement 12* ( $r=0.127, p=0.025$ ).

### **Health Information Sources used by Participants**

Analysis of the source of knowledge of CLP revealed that majority of the respondents (34.8%) mentioned Internet as the source of knowledge, followed by family/friend (23.9%), broadcast media (18.4%), printed media (16.5%), health professionals (8.7%), other sources (8.7%), and public health campaign (8.1%).

### **Discussion**

In the present study, we assessed the awareness, knowledge, and attitudes of pregnant Saudi women toward CLP. Variations in the levels of awareness and knowledge of the participants were observed.

Nationality and level of education of the participating women were found significantly related to their awareness of CL, but not to the awareness of CP; conversely, occupation of the participants was found significantly associated with awareness of CP but not to awareness of CL (Table 2). Moreover, majority of the respondents (81%) in this study had heard about Cleft lip, nearly half (49.4%) had heard of Cleft palate before, and (63.2%) had seen a person with CLP. The results are in contrast to a previous study by Middleton et al [17] in which more than half (54.8%) the respondents had not heard of Cleft lip/palate and CLP-related awareness of the general public was found less than adequate, suggesting the need for public awareness and information programs. The high proportion of awareness in our study could be attributed to the location of the study, as university hospitals have many teaching programs to spread awareness. Several studies have reported a significant defect in the awareness of CLP and its influence on parents and their children. A Nigerian study reported that half of the women (50.5%) had seen or heard about CLP and that many respondents had neither read an article on CLP nor participated in any public enlightenment program. Also, the more educated was the respondent, the more aware and knowledgeable they were about CLP [18]. Similarly, in our study, the level of awareness increased with the education of the respondent.

In terms of understanding the presented condition, most of our sample correctly defined CLP as a congenital facial deformity with an opening of the lips and hard palate. In addition, most have understood that Cleft lip and cleft palate can be a separate deformity. Our current study is consistent with Owotade et al. [18] results, where (63.4%) of the questioned pregnant Nigerian female

defined CLP as “*opening of the lip*” and “*defect of the lip*”. On the other hand, Middleton et al. [17] results on the general population, (18.4%) could not define CLP and (45%) provided incorrect definitions, as well as (61.3%) stated that a cleft lip always includes a cleft palate. This difference in understanding might be due to the different form of questions asked to the participants.

Cleft lip and palate predispose to a variety of complications due to disruption of the normal anatomical relations [19,20]. Participant understanding of CLP was demonstrated in their ability to correctly state the common complications of CLP including speech and feeding difficulties, facial deformities, psychological distress and abnormal dental development. There were few respondents who stated recurrent middle ear infections and consequent hearing loss as a complication. This is because most are not familiar with Eustachian tube dysfunction caused by poor palate muscle insertion [20]. Our results are consistent with Middleton et al [17] results where only (6.3%) of the public correctly identified dental, cosmetic, and hearing problems as possible complications.

Previous studies have reported several risk factors for CLP incidence such as twin pregnancies, maternal antibiotic use, severe morning sickness and smoking [21]. In the present study, majority of the participants were not aware of most of the risk factors including a previous family history of CLP and consanguinity. However, they ruled out the involvement of witchcraft as opposed to the general opinion published previously on African population where the role of ancestral spirits and witchcraft was a popular belief [22].

Surgery is the definitive treatment of CLP. This was agreed by our current and previous samples in other studies [17]. However, prosthesis has an established role in the management of Cleft palate in terms of speech production. There are three types of prosthesis: palatal obturator, palatal lift, and speech bulb obturator. The palatal obturator is used to cover the defects of the hard palate. The palatal lift and the speech bulb obturator are used for velopharyngeal incompetence, and velopharyngeal insufficiency respectively. There are several indications for prosthesis use in cleft palate including failure or contraindication to surgery, a wide cleft with insufficient local tissue to cover the defect or a neuromuscular deficit of soft palate and pharynx [23]. The current study showed that only (11.3%) of pregnant women could state prosthesis as a way of managing a cleft palate. Similarly, only (3.5%) of Middleton et al. [17] population included prosthetics as management modality.

Plastic and maxillofacial surgeons perform the reconstructive surgical treatment for cleft lip/palate and are commonly associated with CLP treatment. However, several complications of CLP emerge necessitating the intervention of physicians from other specialties [20]. This multidisciplinary approach for CLP management is

vague to the public as is seen in the current study where almost less than half of professionals involved in CLP treatment were identified. Obstetrician / Gynecologist have a tremendous role in diagnosing CLP prenatally, delivering the news, and educating parents about the disease [20]. However, only (11.3%) stated an obstetrician as professional and (25.8%) knew the possibility of CLP prenatal diagnosis. The current findings are consistent with Middleton et al [17] where (17.8%) and (0.7%) identified a speech pathologist and prosthodontist as part of CLP management team.

Cleft lip and palate (CLP) are linked to folic acid deficiency, therefore folic acid supplements taken during and before pregnancy may potentially decrease the risk of CLP occurrence and recurrence [24]. This was not familiar to our current and Middleton et al [17] sample where most have stated that CLP cannot be prevented.

Low knowledge of CLP has been reported by Owotade et al. [18] study on pregnant Nigerian population, where only (19.8%) of the sample scored above (50%) of the total score of (20). In our study, the mean knowledge score was average ( $14.2 \pm 6.6$ ), with more than half the sample scoring above the mean. This difference in total knowledge score might be attributed to different questionnaires employed in each study. The geographic areas could in part affect the level of knowledge as Saudi Arabian government is keen on educating the public about common diseases. This is demonstrated by Saudi Ministry of Health (MOH) dental department efforts on social media to spread the awareness. Although, up to our knowledge there are no organized health campaigns about CLP despite how common it is in the area [3]. Health campaigns organized on the national level would better serve to spread the awareness to a wider population. The result of the current study can be used to guide the construction of such campaigns by focusing on the deficient areas in the knowledge of public as our sample consisted mostly of educated pregnant females; we assume the general Saudi public has a similar deficiency in the areas of knowledge demonstrated in the study.

Regarding the sources of knowledge, internet was found to be the most common source of knowledge (34.8%) in our study population. A previous study that assessed the use of social media among parents of infants with CLP found the most common reason for accessing social media by CLP patients was to educate themselves about the diagnosis and treatment (87%), followed companionship and support (56%) [25].

Cleft patients with a visible facial deformity usually suffer from social discrimination [26]. Several studies have shown that CLP patients are at increased risk for psychological distress and social inhibition [27,28]. Abnormal speech pattern may hinder their personal relationships and contribute further to their social isolation [29]. Generally, the participants indicated a favorable attitude toward CLP. They have strongly disagreed with the opinion that children with CLP should be hidden from the public. In

addition, most have agreed that no one should make jokes, tease or make fun of CLP patients. In a previous Indian study (84%) of the respondents attributed cleft lip and palate to “*God’s will*”, whereas (10%) of the respondents thought it was because of sins that were committed in past lives [12]. The current study participants were against the opinion of cleft patients being punished by god or fate.

Most of CLP patients, even after surgical repair, have delayed speech production and “*cleft palate speech*” which includes phenomena such as abnormal nasal resonance and airflow with hyper- and hyponasality and altered laryngeal voice quality [30]. The current samples have disagreed that CLP patients should seek help regarding their speech problems. On the other hand, most (63.9%) have identified speech difficulty as a complication of CLP. This contradiction may point toward an under estimation of the impact of speech difficulties these patients may have. It could be an issue of not being familiar with the speech pattern of cleft patients.

Knowledge of the participant was significantly associated with a positive attitude toward CLP. This was indicated by examining that the participants did not associate CLP with trouble in making friends or getting married, job problems, or emotional stress. In contrast to Chan et al [14] study, which reported that the study groups generally associated CLP with difficulty in making friends?

This is the first study in Saudi Arabia to discuss public views about cleft lip and palate. In comparison to previous studies, we have comprehensively assessed the awareness, knowledge and attitudes towards cleft lip and palate using validated tools. We have also surveyed a pool of pregnant mothers who could potentially have a child with CLP, thus the results of this study are promising. Despite the above strengths of the study, there are some limitations. Given that the present study was conducted within a single university hospital, participants’ level of education and the quality of hospital care may differ from that of other hospitals, precluding the generalization of our results. Finally, this study relied on convenience sampling and is thus not representative of the general population.

## Conclusion

In conclusion, the pregnant women surveyed in KKHU have shown an adequate awareness and knowledge of CLP with a positive attitude towards the condition. The more educated was the respondent, the more aware and knowledgeable they were about CLP. Several areas in CLP knowledge might be better improved through health campaigns including risk factors of orofacial clefts, role of prosthesis, multidisciplinary management of CLP and the impact of CLP complications.

## Acknowledgement

We would like to thank each of Asmaa Alrusaies, Laila Mathkour, Raneem Al-ghamdi, Aya Aldayel, Hanin Bashaikh and Fadah Alanazi from the college of medicine , King Saud University for their help in data collection.

## References

1. Peterson LJ, Ellis E, Hupp JR, et al. Management of patients with orofacial clefts: In: Contemporary Oral and Maxillofacial Surgery. 4th ed Mosby, Missouri 2003; 623-645.
2. Mzezewa S, Hamese K, Mashego T. Neonatal cleft lip repair in babies with breastfeeding difficulties at Polokwane Mankweng Hospital Complex. SAJCH 2014; 8: 157.
3. Sabbagh HJ, Mossey PA, Innes NPT. Prevalence of orofacial clefts in Saudi Arabia and neighboring countries: A systematic review. Saudi Dent J 2012; 24: 3-10.
4. Hadadi A, Al Wohaibi D, Almtrok N, et al. Congenital anomalies associated with syndromic and non-syndromic cleft lip and palate. JPRAS Open 2017; 14: 5-15.
5. World Health Organization. Global registry and database on craniofacial anomalies. In: organization, W.H. (Ed.) Report of a WHO Registry Meeting on Craniofacial Anomalies. Geneva, Switzerland. 2013.
6. Meštrović MM, Bagatin M. An epidemiological study of orofacial clefts in Croatia 1988-1998. J Craniomaxillofac Surg 2005; 33: 85-90.
7. Loffredo LDCM, Freitas JADS, Grigolli AAG. Prevalência de fissuras orais de 1975 a 1994. Rev Saúde Pública 2001; 35: 571-575.
8. Kwari DY, Chinda JY, Olaso Ji HO, et al. Cleft lip and palate surgery in children: Anesthetic considerations. Afr J Pediatr Surg 2010; 7: 174.
9. Akinmoladun VI, Owotade FJ, Afolabi AO. Bilateral transverse facial cleft as an isolated deformity: Case report. Ann Afr Med 2007; 6: 39.
10. Mzezewa S, Muchemwa FC. Reaction to the birth of a child with cleft lip or cleft palate in Zimbabwe. Trop Doct 2010; 40: 138-140.
11. Schwarz R, Bhai Khadka S. Reasons for late presentation of cleft deformity in Nepal. Cleft Palate Craniofac J 2004; 41: 199-201.
12. White WRCA, Eisenman W, Beddoes M, et al. Perceptions, expectations and reactions to cleft lip and palate surgery in native populations: A pilot study in rural India. Cleft Palate Craniofac J 2005; 42: 560-564.
13. El-Shazly M, Bakry R, Tohamy A, et al. Attitudes toward children with clefts in rural Muslim and Hindu societies. Ann Plast Surg 2010; 64: 780-783.
14. Chan RKK, McPherson B, Whitehill TL. Chinese attitudes toward cleft lip and palate: Effects of personal contact. Cleft Palate Craniofac J 2006; 43: 731-739.
15. Bebout L, Arthur B. Cross-cultural attitudes toward speech disorders. J Speech Lang Hear Res 1992; 35: 45-52.
16. Bebout L, Arthur B. Attitudes toward speech disorders: Sampling the views of Cantonese-speaking Americans. J Commun Disord 1997; 30: 205-229.
17. Middleton GF, Lass NJ, Starr P, et al. Survey of public awareness and knowledge of cleft palate. Cleft Palate J 1986; 23: 58-62.
18. Owotade FJ, Ogundipe OK, Ugboko VI, et al. Awareness, knowledge and attitude on cleft lip and palate among antenatal clinic attendees of tertiary hospitals in Nigeria. Nig J Clin Pract 2014; 17: 6-9.
19. Shkoukani MA, Chen M, Vong A. Cleft lip - A comprehensive review. Front Pediatr 2013; 1: 53.
20. Shaye D, Liu C, Tollefson T. Cleft lip and palate. Facial Plast Surg Clin North Am 2015; 23: 357-372.
21. Sabbagh HJ, Alamoudi NM, Abdulhameed FD, et al. Environmental risk factors in the etiology of non-syndromic orofacial clefts in the Western Region of Saudi Arabia. Cleft Palate Craniofac J 2016; 53: 435-443.
22. Dagher D, Ross E. Approaches of South African traditional healers regarding the treatment of cleft lip and palate. Cleft Palate Craniofac J 2004; 41: 461-469.
23. Dhakshaini MR, Pushpavathi M, Mirna G, et al. Prosthodontic management in conjunction with speech therapy in cleft lip and palate: A review and case report. J Int Oral Health 2015; 7: 106-111.
24. Houston M. Taking folic acid at start of pregnancy seems to lower risk of cleft lip and palate. BMJ 2012; 345: e4614-e4614.
25. Khouri JS, McCheyne MJ, Morrison CS. Cleft: The use of social media amongst parents of infants with clefts. Cleft Palate Craniofac J 2017.
26. Glener AD, Allori AC, Shammass RL. A Population-based exploration of the social implications associated with cleft lip and/or palate. Plast Reconstr Surg Glob Open 2017; 5: e1373.
27. Murray L, Artech A, Bingley C, et al. The effect of cleft lip on socio-emotional functioning in school-aged children. J Child Psychol Psychiatry 2009; 51: 94-103.
28. Endriga M, Kapp-Simon K. Psychological issues in craniofacial care: State of the art. Cleft Palate Craniofac J 1999; 36: 3-11.
29. Richman L, McCoy T, Conrad A, et al. Neuropsychological, behavioral and academic sequelae of cleft: Early developmental, school age and adolescent/young adult outcomes. Cleft Palate Craniofac J 2012; 49: 387-396.



30. Sell DA, Harding A, Grunwell P. Speech assessment for children with cleft palate and/or velopharyngeal dysfunction. *Int J Disord Communication* 1999; 34: 17-33.

**Correspondence to:**

Nujaim H Alnujaim,  
College of Medicine,  
King Saud University,  
PO Box 7805 (92),  
Riyadh, 11472,  
Saudi Arabia.  
Tel: +966506688244;  
E-mail: Nujaimhs@gmail.com