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Knowledge and awareness of individuals in Türkiye about cleft lip and palate

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ABSTRACT

Aim: Cleft lip/palate (CL/P) is one of the most common craniofacial congenital anomalies. The aim of this study was to evaluate the level of knowledge and perception of individuals in a large sample group in Türkiye about CL/P.

Materials and Methods: A cross-sectional 11-items questionnaire study was performed and was sent to individuals living in Türkiye using Google Forms.

Results: A total of 886 participants responded the questionnaire. The rate of Nasoalveolar Molding (NAM)/feeding plate knowledge was significantly higher in female (P<0.001). More than half of the participants who had knowledge about NAM/feeding plate stated that they get information about CL/P from health employers (P<0.001). The results revealed that gender, age, job, knowledge of diagnosis of CL/P before birth, and sources of information about CL/P, were statistically significant independent determinants of NAM/Feeding Plate knowledge (P<0.05).

Conclusions: The knowledge and awareness about CL/P is moderate among participants. Informative seminars should be organized to increase the awareness of the general population about CL/P, and reliable information should be uploaded to the Internet by the professional associations.

Keywords: Cleft lip and palate; nasoalveolar molding; newborn; public awareness

INTRODUCTION

Cleft lip/palate (CL/P), one of the most heterogeneous orofacial malformations and representing a major public health burden worldwide, occurs in approximately 1 out of every 700 births and accounts for 65% of head and neck anomalies (1-3). CL/P, which be syndromic or non-syndromic, occurs in the early stages of growth due to unsuccessful or inappropriate fusion of tissues (4,5). Craniofacial clefts occur if the fusion of the facial structures on the right and left sides to the midline does not occur properly due to environmental or genetic factors during the development of facial structures between the fourth and twelfth weeks of pregnancy (6, 7).

Due to maxillary hypoplasia and mouth breathing in patients with CL/P, conditions that may adversely affect the quality of life such as further reduction of salivary secretion, more serious periodontal problems and more orofacial and dental disorders can be seen (8). Also, individuals with cleft lip and palate may have severe speech, feeding, hearing, and social and mental developmental disorders (5, 9). Although if the severity of the problems varies, multidisciplinary treatments including craniofacial surgery, dental and orthognathic treatment, speech and hearing intervention, and educational, social

and psychological evaluations are often required in patients with CL/P. The aim of medical and psychosocial interventions is to restore the function and aesthetics of the mouth, support normal speech and hearing development, maintain good oral hygiene and improve quality of life (10).

The presence of CL/P creates significant physical and psychological burdens for the affected child, their family, the society and the health system (11). Psychological and emotional distress can significantly affect children with CL/P and their families, and psychological difficulties such as depression, low self-esteem and social anxiety may be more common in children with CL/P compared to children without CL/P (11-15). At the first stage, providing nutrition and improving facial aesthetics in individuals born with CL/P are important for improving the physical and psychological condition of both the infants with CL/P and their family. Nutritional problems in individuals born with CL/P can be eliminated with passive feeding plates, and it is also possible to extend the columella and bringing the cleft segments closer together by adding active regulators to these plates in order to improve facial aesthetics (7).

Considering the importance of early treatment approaches in patients with CL/P, this study aimed to evaluate the level of knowledge and perception of individuals in a large sample group in Türkiye about CL/P and the applications to be made in individuals with CL/P.

MATERIALS AND METHODS

In this study, a questionnaire consisting of 11 questions was created as a data collection tool in order to evaluate awareness about cleft lip and palate in Türkiye. Five of the questions in this survey were used to measure demographic characteristics including gender, recent education status, age, job and salary, and the other six questions were used to measure information about CL/P and NAM/feeding plate. The questionnaire application was carried out online and the participants were asked to confirm that they participated in the study voluntarily in the survey forms. The study was approved by the Clinical Research Ethics Committee of Ordu University (No: 2021/262).

Using the G*Power (version 3.1.9.2; Axel Buchner, Universität Düsseldorf, Düsseldorf, Germany) program, the total sample size required to detect a medium effect with 95% power and 0.50 effect size was 80 individuals for this study. The questionnaires were sent to 2300 people via e-mail using Google Forms©. A short informative letter describing the purpose of the study was written in the introduction part of the questionnaire and no information was requested from the participants that could reveal their identities. The answers of 886 participants who participated in the survey and filled out the entire form were evaluated.

Statistical analysis of all data obtained in this study was performed using SPSS software (SPSS for Windows version 20.0; SPSS Inc, Chicago, Illinois). Descriptive statistics were performed for evaluated all parameters. Pearson chi-square and Fisher's exact tests were used to compare the responses of individuals according to their knowledge of NAM/ feeding plate, ages and jobs. Multiple linear regression analyses were performed to adjust for the effects of potential confounding factors and to identify independent determinants for knowledge of NAM/feeding plate. Statistical significance was accepted at $P<0.05$.

RESULTS

A total of 886 participants responded the questionnaire by filling out the entire form, and the proportion of female participants (58.9%) was higher than that of males (41.1%). Of the participants, 71% reported that their last education level was bachelor and a very low percentage was primary school (1.6%). More than half of the participants were officer other than healthcare professionals, and the ratio of housewives/job seekers, students-university and health employer was 8.1%, 21.1% and 14.3%, respectively. When evaluated according to their salary, it was seen that most of the participants had a

salary below 10000 TL. According to age distribution, the rate of participants aged 55 and over (4.5%) was lower than other age groups. The demographic characteristics of the subjects participating in this study are shown in Table 1.

Table 1. Demographic characteristics of subjects participating in this study (n=886).

		N	%
Gender	Female	522	58.9
	Male	364	41.0
Recent Educational Status	Primary School	14	1.5
	Secondary School	15	1.6
	High School	138	15.5
	Bachelor	629	70.9
	Master or PhD	90	10.1
Job	Housewife/Job Seeking	72	8.1
	Officer (Other than healthcare professional)	500	56.4
	Student-University	187	21.1
	Health Employer	127	14.3
Salary (TL)	<3000	315	35.5
	3000-5999	248	27.9
	6000-9999	262	29.5
	10000-14999	41	4.6
	15000 and over	20	2.2
Age (years)	18-24	268	30.2
	25-34	298	33.6
	35-44	174	19.6
	45-54	106	11.9
	55 and over	40	4.5

Comparison of participants' responses according to their knowledge of NAM/Feeding plate in newborns CL/P is shown in Table 2. In both male and female participants, the number of those who did not know about NAM/feeding plate was higher than those who did. The rate of those with NAM/Feeding plate knowledge was significantly higher in female, participants aged 25-34, health employers, and participants with a salary of 15000 TL and over compared to other groups (P<0.001). Participants with and without a diagnosis of CL/P had similar rates of NAM/feeding plate knowledge, and participants who knew and did not know someone with CL/P had no significant difference in their knowledge of NAM/feeding plate. Those who answered "yes" to the questions of "Can CL/P be diagnosed before birth?" and "Do you know that CL/P subjects should seek medical attention for speech problems?" had significantly higher knowledge of NAM/feeding plate than those who answered "no" or “don't know” (P<0.001). More than half of the participants who had knowledge about NAM/feeding plate stated that they get information about CL/P from health employers (P<0.001).

Table 2. Comparison of responses of individuals according to their knowledge NAM/Feeding plate in newborns CL/P.

	Answer	Knowledge NAM/Feeding plate		*P*
		Yes	No	
Gender	Female	90	432	<0.001#
	Male	32	332	
Recent Educational Status	Primary School	0	14	<0.001¥
	Secondary School	0	15	
	High School	11	127	
	Bachelor	84	545	
	Master or PhD	27	63	
Age (years)	18-24	40	228	<0.001¥
	25-34	63	235	
	35-44	11	163	
	45-54	5	101	
	55 and over	3	37	
Job	Housewife/Job Seeking	2	70	<0.001¥
	Officer (Other than healthcare professional)	19	481	
	Student-University	33	154	
	Health Employer	68	59	
Salary (TL)	<3000	40	275	<0.001#
	3000-5999	23	225	
	6000-9999	42	220	
	10000-14999	8	33	
	15000 and over	9	11	
Have you been diagnosed with CL/P?	Yes	1	6	1.000¥
	No	121	758	
Do you know someone with CL/P?	Yes	25	132	0.388#
	No	97	632	
Can CL/P be diagnosed before birth?	Yes	88	222	<0.001#
	No	15	67	
	Don't Know	19	475	
Do you know CL/P subjects should seek medical attention	Yes	121	700	0.001¥
	No	1	64	
Which source did you get your information about cleft lip and palate?	I do not have any information.	4	419	<0.001¥
	Internet, Social media or TV.	16	235	
	Health Employer.	75	72	
	Health Employer + Internet, Social media or TV.	27	37	

#Pearson chi-square test results; ¥Fischer's Exact test results.

The comparison of the responses given by the participants according to their age periods is shown in Table 3. The distribution of male and female individuals according to age periods was similar. However, according to age periods, the recent educational status, jobs and salaries showed significant differences (P<0.001). The answers to the questions "Have you been diagnosed with CL/P?", "Do you know that CL/P subjects should seek medical attention for speech problems?" and "Which source did you get your information about CL/P?" did not differ significantly by age period. On the other hand, the rates of other questions asked about CL/P and NAM/feeding plate knowledge differed significantly according to age periods (P<0.05).

Table 3. Comparison of responses of individuals according to their age periods.

	Answer	Age Periods (years)					*P*
		18-24	25-34	35-44	45-54	55 and over	
Gender	Female	156	186	102	62	16	0.112#
	Male	112	112	72	44	24	
Recent Educational Status	Primary School	0	0	6	4	4	<0.001¥
	Secondary School	0	1	4	8	2	
	High School	27	18	50	30	13	
	Bachelor	240	216	95	60	18	
	Master or PhD	1	63	19	4	3	
Job	Housewife/Job Seeking	6	17	30	17	2	<0.001¥
	Officer (Other than healthcare professional)	60	207	120	78	35	
	Student-University	177	10	0	0	0	
	Health Employer	25	64	24	11	3	
Salary (TL)	<3000	218	45	25	16	11	<0.001¥
	3000-5999	31	77	77	46	17	
	6000-9999	18	152	53	31	8	
	10000-14999	1	15	14	7	4	
	15000 and over*	0	9	5	6	0	
Have you been diagnosed with CL/P?	Yes	5	0	1	1	0	0.148¥
	No	263	298	173	105	40	
Do you know someone with CL/P?	Yes	40	44	43	19	11	0.020#
	No	228	254	131	87	29	
Can CL/P be diagnosed before birth?	Yes	70	117	68	42	13	0.025#
	No	26	26	15	8	7	
	Don't Know	172	155	91	56	20	
Do you know CL/P subjects should seek medical attention for speech	Yes	249	280	158	99	35	0.509¥
	No	19	18	16	7	5	
Do you know about NAM/Feeding Plate in	Yes	40	63	11	5	3	<0.001¥
	No	228	235	163	101	37	
Which source did you get your information about cleft lip and palate?	I do not have any information.	127	143	81	50	22	0.088¥
	Internet, Social media or TV.	78	71	55	33	14	
	Health Employer.	42	66	25	12	2	
	Health Employer + Internet, Social media or TV.	21	18	13	11	1	

#Pearson chi-square test results; ¥Fischer's Exact test results.

When the answers of the participants according to the job were compared, there were significant differences in the distribution of the answers to the questions asked about all other demographic characteristics in the study (P<0.001). While the distribution of answers to the questions "Have you been diagnosed with CL/P?" and "Do you know someone with CL/P?" by occupation did not differ significantly, the proportions of answers to other questions about CL/P and NAM/feeding plate showed significant differences (P<0.05) (Table 4).

Table 4. Comparison of responses of individuals according to job.

	Answer	Job				*P*
		Housewife/ Job Seeking	Officer	Student	Health Employer	
Gender	Female	70	235	119	98	<0.001¥
	Male	2	265	68	29	
Recent Educational Status	Primary School	6	8	0	0	<0.001¥
	Secondary School	8	7	0	0	
	High School	41	75	15	7	
	Bachelor	17	352	172	88	
	Master or PhD	0	58	0	32	
Salary (TL)	<3000	46	79	174	16	<0.001¥
	3000-5999	20	176	7	45	
	6000-9999	6	202	5	49	
	10000-14999	0	32	0	9	
	15000 and over	0	11	1	8	
Age (years)	18-24	6	60	177	25	<0.001¥
	25-34	17	207	10	64	
	35-44	30	120	0	24	
	45-54	17	78	0	11	
	55 and over	2	35	0	3	
Have you been diagnosed with CL/P?	Yes	2	3	2	0	0.168¥
	No	70	497	185	127	
Do you know someone with CL/P?	Yes	11	96	28	22	0.567#
	No	61	404	159	105	
Can CL/P be diagnosed before birth?	Yes	16	160	45	89	<0.001#
	No	9	36	23	14	
	Don't Know	47	304	119	24	
Do you know CL/P subjects should seek medical attention for speech problems?	Yes	66	454	176	125	0.024¥
	No	6	46	11	2	
Do you know about NAM/Feeding Plate in newborns with CL/P?	Yes	2	19	33	68	<0.001¥
	No	70	481	154	59	
Which source did you get your information about cleft lip and palate?	I do not have any information.	34	283	87	19	<0.001¥
	Internet, Social media or TV.	33	151	56	11	
	Health Employer.	2	44	24	77	
	Health Employer + Internet, Social media or TV.	3	21	20	20	

#Pearson chi-square test results; ¥Fischer's Exact test results.

Results of the multiple linear regression analysis of the NAM/Feeding Plate information in CL/P newborns, according to the parameters are presented in Table 5. The results revealed that gender, age, job, knowledge of diagnosis of CL/P before birth, and sources of information about CL/P, were statistically significant independent determinants of NAM/Feeding Plate knowledge (P<0.05).

Table 5. Multivariate linear regression analysis of the Nasoalveolar Molding/Feeding Plate in CL/P newborns, according to the parameters

Parameter		Coefficient (β)	Standard Error	95% CI	*P*
Gender	Male	-0.537	0.272	0.343-0.997	0.049
	Female*				
Age (years)	18-24	0.619	0.160	1.358-2.540	<0.001
	25-34				
	35-44				
	45-54				
	55 and over*				
Recent Educational Status	Primary School	0.111	3.057	0.156-1.270	0.971
	Secondary School				
	High School				
	Bachelor				
	Master or PhD*				
Job	Housewife/Job Seeking	-1.379	0.138	0.192-0.330	<0.001
	Officer (Other than healthcare professional)				
	Student-University				
	Health Employer*				
Salary (TL)	<3000	-0.166	0.113	0.679-1.056	0.140
	3000-5999				
	6000-9999				
	10000-14999				
	15000 and over*				
Have you been diagnosed with CL/P?	Yes	1.258	1.213	0.326-37.932	0.300
	No*				
Do you know someone with CL/P?	Yes	0.574	0.307	0.973-3.242	0.061
	No*				
Can CL/P be diagnosed before birth?	Yes	0.845	0.140	1.770-3.063	<0.001
	No*				
Do you know CL/P subjects should seek medical attention for speech problems?	Yes	1.595	1.033	0.650-37.326	0.123
	No*				
	No*				
Which source did you get your information about cleft lip and palate?	I do not have any information.	-1.534	0.127	0.168-0.277	<0.001
	Internet, Social media or TV.				
	Health Employer.				
	Health Employer + Internet, Social media or TV.*				

*Reference parameter, TL; Turkish Liras, CI; Confidence Interval.

DISCUSSION

CL/P are among the most common congenital anomalies in head and face region. For this purpose, it is of great importance to redirect newborns with CL/P to proper clinical services. The aim of this study was to evaluate the knowledge and awareness of CL/P with a large sample size in the general population in Türkiye.

In our study, 17.2% of the individuals who participated in the survey know someone with CL/P, while 83.8% of them know someone with CL/P. Alawi et al. (11) conducted a recent study with 739 participants in Oman, 50% of the individuals participating in the study stated that they know individuals with CL/P. In our study, it is seen that the profession is an important factor in the level of knowledge about individuals with CL/P. It has been observed that healthcare professionals have knowledge about NAM applications in newborns with CL/P, that can be defined before birth, speech problems can be seen in individuals with CL/P. Alawi et al. also reported that, healthcare workers have a higher level of knowledge (83.3%) about CL/P consistent with our study.

While 47.7% of the individuals participating in our study did not have information about CL/P, the remaining 52.3% said that there was information about CL/P. Those who know about CL/P reported that they learned this information from the Internet, social media, TV or healthcare professionals. Studies have also reported that the Internet is an important source for obtaining information about CL/P, however it has been found that the information about CL/P on the Internet is of low quality.

Presurgical orthopedic treatment, which is a crucial part of the multidisciplinary management of CL/P, has many important advantages such as facilitating feeding, narrowing the cleft width, and being effective in improving the results of surgical repair of CL/P (16, 17). Nasoalveolar molding (NAM), a form of presurgical orthopedic treatment, is a method used for preoperative repositioning of the premaxilla and lengthening of the columella in patients with CL/P (18). NAM, which is based on the fact that the cartilaginous tissues of the infants are softer due to the high level of estrogen transferred from the mother and the ability to shape these tissues is greater until the baby is approximately 3-4 months old, provides some benefits such as decreasing the width of the cleft, restoration of the alveolus, improving nasal shape and symmetry for surgeons and patients with CL/P by reducing the severity of cleft repair (7, 18, 19). It has been reported in previous studies (20, 21)(17, 20, 21) that one of the most important reasons for the late presentation of CL/P patients is the lack of sufficient information and that late surgical procedures may have a potential negative impact on the quality of life of the child and his family. In order to improve the health and psychological and social support of CL/P patients, it is important to have enough information about the causes of this anomaly and treatment options (17, 22).

While 13.8% of the individuals participating in this study have information about the NAM/Feeding plate applications, applied in newborns with CL/P, 86.2% of them have no information about these applications. Abid et al. (17) performed a study on 145 mothers with unilateral or bilateral cleft lip and palate, 70.57% of mothers reported that NAM/Feeding plate applications were beneficial. One-hundred twenty-two infants of 145 mothers participating in this study used the NAM appliance. Also, Kurt Demirsoy et al. (23) designed a study to determine the awareness and knowledge of pediatricians about NAM in newborns CL/P, the authors reported that pediatricians do not have adequate knowledge about NAM. In this study, the general public's knowledge about NAM in CL/P newborns was inadequate.

CONCLUSIONS

It has been observed that the Turkish population has moderate knowledge about CL/P. The awareness of healthcare professionals about CL/P was found

to be higher than other professionals. Informative seminars and TV programs should be organized to increase the awareness of the general population on CL/P, and reliable information should be uploaded to the Internet by the professional associations.

This study has some limitations. This study was performed 886 individuals from different occupational groups. Large sample size studies should be organized with more participants.

Ethics

Ethics Committee Approval: The study was approved by the Ordu University Clinical Research Ethics Committee with approval number: 2021/262 and date: 03/12/2021.

Informed Consent: For this type of this study, the informed consent is not required.

Authorship Contributions

Concept: G.T., S.K.B., Data Collection or Processing: A.U.U, Analysis or Interpretation: S.K.B., Writing: G.T., A.U.U.

Conflict of Interest:

The authors declared no conflict of interest.

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