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KNOWLEDGE RELATED TO PATIENTS WITH CLEFT LIP AND PALATE AMONG PERIPHERAL HEALTH WORKERS IN INDIA - A CROSS SECTIONAL STUDY

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ABSTRACT

Introduction: The role of the primary care providers in India is to be a stable source of support for patients and to assist in coordinating care for the many physical and emotional conditions and creating awareness about conditions such as cleft lip and palate. **Aim:** To assess the knowledge related to cleft patients among peripheral health care workers. **Method:** A cross-sectional descriptive study with the aid of 15 self-administered questionnaire was conducted among 80 peripheral health care workers in Karnataka, India. Results were analysed by using Chi-square test and Mann-Whitney U test and Fisher's Exact test; P values < 0.05 were considered statistically significant. **Results:** The mean age of the subjects was 34.72 ± 4.22 years (age range: 16-42 years). The comparison of knowledge according to years of experience showed statistically significant difference between the groups with p value 0.003. **Conclusion:** There is a need for community health education and targeted programs to develop more positive attitudes towards disabled persons. Therefore, peripheral health workers should be trained to develop necessary knowledge and skills with recent updates. There is a need for health education to improve the knowledge and awareness towards such conditions.

KEYWORDS: Primary Health Care; Cleft Lip; Cleft Palate; Awareness.

INTRODUCTION

Facial conditions impose a greater burden on the personality: face is vital for identification of individual. Facial conditions cannot be concealed.[1] Both congenital and acquired facial conditions has profound psychosocial implications such as reduced quality of life, altered body image and poor self-esteem.[2] Cleft lip and palate are a common but significantly disfiguring congenital anomaly affecting facial structures resulting in oral, facial and craniofacial conditions.[3] Besides the multiple problems such as difficulty in child's feeding, speech, and hearing, they cause a major social stigma. Different degrees of parental guilt and shame are frequently encountered, primarily due to the perceived cause of the birth conditions. Many studies identified cultural and societal attitudes that deeply affect the way that communities treat children with clefts and other facial deformities. It is surprising to note the beliefs and perceptions about clefts have remained largely unchanged even today.[4] Lack of awareness is due to the absence, inaccessibility or inaccuracy of information, which is sometimes made harder by cultural taboos, myths and fear, which can stop people from taking preventative action or seeing doctors.[5] Adequate knowledge and awareness of cleft lip and palate (CLP) may help to counter the negative beliefs and attitudes toward the condition.[4] One of the most influential reasons that patients with cleft, particularly in rural parts of India, do not receive care is the lack of awareness. As a result, the total unmet cleft treatment need was estimated at 79,430 or 18.76% of the total Indian cleft population with orofacial cleft.[6] This is a result of social factors that prevent people from knowing about available cleft care options.[7]

The role of the primary care providers in India is to be a stable source of support for these patients and to assist in coordinating care for the many physical and emotional problems. Social health workers play a major role in creating awareness about such conditions. This team worked with the local coordinator and moved with a local person as a guide will be much more beneficial as they can reach the minds of rural community.[7] The Accredited Social Health Activist (ASHA) was introduced in India by the National Rural Health Mission (NRHM) in 2005. These peripheral health workers appointed in every village will counsel women on birth preparedness, importance of safe delivery, breast-feeding and complementary feeding, immunization and care of the young child. They will mobilize the community and facilitate them in accessing health and health related

services available at the primary health centers.[8] The Ministry of Health and Family Welfare, India launched the Rashtriya Bal Swasthya Karyakram (RBSK) program in 2013. Under this program, every health care worker is instructed to visit each home in her assigned village and screen every child for 30 identified health conditions, one of which is cleft lip and palate.[9] Programs such as Smile train in India merely provides infrastructure and facility for cleft surgery but lacks other components towards holistic care, is doomed to failure in the socio-economic realities of our region.[7] It is the duty of health care worker who finds a child with a cleft, to inform the family to receive free quality care that will be beneficial to the current and long-term health of their child in outreach programs. However, this system of cleft identification and linkage to care is not flawless either, and remains in the developmental process. There is a need to revise and update the knowledge of peripheral health workers from time to time.[10]

Therefore, this cross-sectional study was conducted to assess the knowledge among peripheral health workers related to cleft lip and palate patients.

METHODOLOGY

A questionnaire-based cross-sectional survey was carried out among 80 peripheral health workers. Details of the peripheral health workers were collected from registry of respective Government hospitals of Karnataka, India. 100 questionnaires were prepared out of which 80 were filled through direct personal interview. 20 participants from different hospitals, who did not take interest in participation and who partially filled the questionnaire were excluded from the study. Ethical approval was obtained from the Institutional Ethical Board from Bapuji Dental College and Hospital, Davangere (Ref.No. BDC/Exam/016/2018-19). Informed consent was taken from all the study participants prior to the study. Participation in the study was voluntary and confidentiality of data was maintained. The questionnaire used in the study consisted of two parts. The first part included the demographic data and the second one included the knowledge, attitude related questions regarding patients with cleft.

The survey sought information on the following items: 1) The participant's demographic data: age, qualification, years of experience 2) Knowledge.

Questionnaire Validity

A 15-item anonymous questionnaire was developed through review of the literature which was pilot tested on 10 participants from two government hospitals and peer reviewed among the investigators. 15 questions were knowledge based. The sample size was selected based on the previous studies and keeping the power of the study as 80%. The Cronbach's alpha value for the questionnaire was found to be 0.8. Construct validity of the questionnaire was assessed using Spearman's correlation coefficient between individual parameter/construct and overall score of the construct.

STATISTICAL ANALYSIS

Data were analysed using the Statistical Package for Social Sciences (SPSS) version 23 (SPSS Inc., Chicago, Illinois, USA). Association between 2 variables was done using chi-square test and Mann-Whitney U test and Fisher's Exact test; P values < 0.05 were considered statistically significant. Those questionnaires that which showed statistically significant results were analysed in the discussion part.

RESULTS

Mean age of study participants was 34.72 ± 4.22 years. Of the 80 participants 64 were having education qualification of SSLC (Secondary school leaving certificate) and 16 participants were having education qualification of PUC (Pre-University Course) qualification. 48 peripheral health workers were having less than 5 years of experience; 24 peripheral health workers were having more than 5 years of experience and 8 peripheral health workers were having more than 10 years of experience. (Table 1)

Table 2 shows comparison of knowledge according to years of experience showed statistically significant difference between the groups with p value 0.003. There is statistically significant difference between Group A and Group C with p value of 0.003. There is statistically significant difference between Group B and Group C with p value of <0.001.

Table 3 shows association between response to individual questions on knowledge and years of experience. Statistically significant difference was noted wrt to individual questions on knowledge and years of experience.

Table 4 shows association between response to individual questions on attitude and educational qualification. There is no statistically significant difference between response to individual questions on attitude and educational qualification.

Table 1: Demographic Details.

Age (Mean +/- SD)	**34.7250 +/- 4.22439**
Qualification	SSLC (Secondary school leaving certificate) – 80% PUC (Pre-University Course) – 20%
Experience	Group A - Less than 5 years– 60% Group B - More than 5 years – 30% Group C - Above 10 years – 10%

Table 2: Comparison of knowledge according to years of experience.

Years of experience	N	Mean (SD)	Range	Median (Q1-Q3)	Kruskal-Wallis Test		Mann-Whitney U Test (p-value)	
					Chi-Square value	p-value	Group A vs Group C	Group B vs Group C
Group A	48	6.50 (1.60)	5 - 8	6.50(5 – 8)	11.77	0.003*	0.004*	<0.001*
Group B	24	8.83 (0.92)	7 - 10	9(9 – 9)				
Group C	8	8.46 (1.37)	6 - 10	9(7 – 10)				

*p<0.05 Statistically Significant, p>0.05 Non-Significant, NS

Table 3: Association between response to individual questions on Knowledge and Years of experience.

		Years of experience			Total	Fisher's Exact test
		Less than 5 years	More than 5 years	Above 10 years		p-value
Source of information?	**Hospitals**	22	16	0	38	<0.001*
		45.8%	66.7%	0.0%	47.5%	
	Health Camps	26	8	0	34	
		54.2%	33.3%	0.0%	42.5%	
	Mass media	0	0	8	8	
		0.0%	0.0%	100.0%	10.0%	
Do you know which faculty of dentistry deals with PNAM?	**Pediatric dentist**	24	8	0	32	<0.001*
		50.0%	33.3%	0.0%	40.0%	
	Orthodontist	0	4	4	8	
		0.0%	16.7%	50.0%	10.0%	
	Oral maxillofacial surgeons	24	12	4	40	
		50.0%	50.0%	50.0%	50.0%	
Once diagnosed whom do you think should be consulted first among the array of multispecialists involved?	**Pediatrician**	0	4	0	4	0.02*
		0.0%	16.7%	0.0%	5.0%	
	Plastic surgeon	16	4	4	24	
		33.3%	16.7%	50.0%	30.0%	
	Feeding specialist	32	16	4	52	
		66.7%	66.7%	50.0%	65.0%	
Have u heard about SMILE TRAIN?	**Yes**	22	20	0	42	<0.001*
		45.8%	83.3%	0.0%	52.5%	
	No	26	4	8	38	
		54.2%	16.7%	100.0%	47.5%	
What kind of problems a child with cleft lip and palate will face according to you	**Speech and esthetics**	8	0	8	16	<0.001*
		16.7%	0.0%	100.0%	20.0%	
	Feeding difficulty	40	24	0	64	
		83.3%	100.0%	0.0%	80.0%	
Have u ever taken any initiative to refer any cleft lip and palate patients to hospitals near you for treatment?	**Yes**	36	20	0	56	<0.001*
		75.0%	83.3%	0.0%	70.0%	
	No	12	4	8	24	
		25.0%	16.7%	100.0%	30.0%	

*p<0.05 Statistically Significant, p>0.05 Non Significant, NS

Table 4: Association between response to individual questions on knowledge and educational qualification.

		Educational qualification		Total	Chi Square test	
		SSLC (Secondary school leaving certificate)	PUC (Pre-University Course)		Chi Square value	p-value
Ever participated in awareness program on cleft lip and palate?	**Yes**	60	16	76	-	0.58(NS)
		93.8%	100.0%	95.0%		
	No	4	0	4		
		6.3%	0.0%	5.0%		
What kind of problems a child with cleft lip and palate will face	**Speech and esthetics**	12	4	16	-	0.73(NS)
		18.8%	25.0%	20.0%		

according to you	**Feeding difficulty**	52	12	64		
		81.3%	75.0%	80.0%		
Have u ever taken any initiative to refer any cleft lip and palate patients to hospitals near you for treatment?	**Yes**	44	12	56	-	0.77(NS)
		68.8%	75.0%	70.0%		
	No	20	4	24		
		31.3%	25.0%	30.0%		

*p<0.05 Statistically Significant, p>0.05 Non Significant, NS

DISCUSSION

According to the World Health Report 2008, *Primary Health Care, Now More than Ever*, the mission of "health for all", delivers quality primary health care services by universal coverage to improve health equity, people-centred service delivery, public policy reforms to promote and protect community health, and leadership reforms to make health authorities more reliable. Peripheral Health Workers are the major work force who satisfy the above goals of community health.[11]

The peripheral health workers play a vital role in facilitating the provision of care for patients with cleft, who often have numerous health care needs, including feeding difficulties, speech disorders, chronic ear infections, and dental and orthodontic problems. The emotional issues of patients with these deformities and their families are significant and include disrupted parent and child bonding, body image disturbances, and impaired socialization.[12]

In the present study, we assessed the knowledge and attitude of peripheral health workers towards cleft lip and palate patients.

Comparison of knowledge according to years of experience showed statistically significant difference between the groups with p value 0.003. There is statistically significant difference between Group A and Group C with p value of 0.003 and with Group B and Group C with p value of <0.001. This showed an association between the years of experience and the knowledge. Inadequate knowledge significantly affects the standard of care. Years of professional experience are the predictors of knowledge.[13] Results showed a stronger association between the years of experience and knowledge among peripheral health workers.

Source of information is another important factor to grade the level of knowledge that is acquired. There was statistically significant difference between years of experience and the source through which information is collected. 54.2% participants with less than 5 years of experience procured information through health camps. 66.7% participants with more than 5 years of experience procured information through hospitals. All participants with above 10 years of experience procured information through mass media. Mode of acquiring information was different among different groups. Many social media tools are available for health care professionals (HCPs), including videos, blogs, microblogs, wikis, media-sharing sites, and virtual reality. These tools can be used to improve or enhance professional education, patient care, patient education, and public health programs.[14] Participants with above 10 years of experience showed greater level of knowledge as the source of acquiring knowledge was mass media.

66.7% of the participants with both less than 5 year and more than 5-year experience, opted for feeding specialists as the first among the array of multispecialists involved. 50% of the participants above 10 years of experience opted for plastic surgeon as the first among the array of multispecialists. But one of the first consultations for a patient with cleft is with the feeding specialist, who assists families with managing the special feeding needs. Later consultations will be with plastic surgeon, otolaryngologist, and oral surgeon.[15] Participants experience did not count in making decisions in such scenario.

83% of participants with more than 5-year experience have heard about Smile training program. All the participants with more than 10 experience have never heard about Smile training program. Smile Train Project in India, with a goal of reaching the unmet needs of patients with cleft, with unwavering commitment of the Indian plastic surgeon, provides all facilities essential for surgery, But the lack of creating awareness about the cleft condition and the treatment approach will lead to failure of such programs in India. Therefore, outreach programs are meticulously planned with a trained social worker as its leader. The program was launched in India in the year 2000, started organizing outreach program to reach out to these cleft patients with peripheral health workers as their leaders.[7] But majority of the experienced peripheral health workers are still not aware of this program.

Majority of the participants with less than 5 years and more than 5 years of experience refer feeding difficulty as the most commonly encountered problem, where participants above 10 years of experience refer speech and aesthetics as the most commonly encountered problem. Feeding difficulty is one of the most difficult problem encountered among CLP children.[16] These difficulties can be addressed by various feeding techniques, feeding aids and easily managed. Management of speech and aesthetics in cleft lip and palate patients needs special speech training and multiple surgeries.[15] Therefore, participants above 10 years of

experience referred speech and aesthetics as the most commonly encountered problem.

83.3 % of the participants with more than 5-year experience took initiative to refer patients to nearby hospitals. Participants with more than 10 years of experience never took an initiative to refer the patients to nearby hospital. This shows poor knowledge among peripheral health workers towards patients with cleft lip and palate.

There was no statistically significant difference between educational qualification and knowledge. Similar responses were noted between SSLC and PUC groups. The SSLC is obtained on passing the grade 10 public examination, which is commonly referred to as 'class 10 board examinations' in India. PUC is an Intermediate Course (which is known as 10+2) of two years' duration, refers to Class 11th and Class 12th and called as 1st PUC and 2nd PUC respectively in the PU Colleges or Junior Colleges and are conducted by state education institutions or boards in India. It is considered as a degree bridge course to prepare students for university education.[17] There is no statistically significant difference between both qualifications, as it is an intermediary course to enter university.

Poor knowledge about CLP has been reported in rural and urban Asian and African populations. There is a need for community health education and targeted programs to develop more positive attitudes towards disabled persons.[5,18] Therefore, peripheral health workers should be trained to develop necessary knowledge and skills with recent updates. The block level meetings should be utilized for the feedback, enhancing knowledge & solving the problem faced by the peripheral health workers. The health talks, training sessions will further improve the knowledge about CLP, probably because such sessions are specifically targeted to CLP.

CONCLUSION

Management of cleft lip and palate requires a multidisciplinary team approach where Peripheral Health Workers have their essential role in identifying condition, creating awareness at the community level, educating and motivating them to utilize health care facility. Peripheral health workers showed a poor knowledge towards management of patients with cleft. There is need for health talks and training sessions will further improve the knowledge about CLP among peripheral health workers.

Conflict of interest

The authors declare no conflict of interest

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