



ORIGINAL RESEARCH PAPER

Dentistry

BARRIERS AND ATTITUDES TOWARDS PRENATAL DIAGNOSIS OF OROFACIAL CLEFTS AMONG PARENTS OF AFFECTED CHILDREN ATTENDING REHABILITATION CARE IN BANGALORE-A CROSS SECTIONAL STUDY

KEY WORDS:

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ABSTRACT

Aim: the present study was conducted to assess the barriers and attitudes towards prenatal diagnosis of Oro facial clefts.

Methodology: The present cross sectional study was carried out among 240 smile train beneficiaries in Bangalore city. A pretested, structured, self-administered questionnaire was administered which consisted of general information, barriers and attitude based questions. Results were subjected to statistical analysis **Results:** Cost of the scan, lack of time, importance of the test was a major barrier assessed. The respondents agreed that, that they would not have more children if they were diagnosed at a risk of having a defective child prenatally.(53%)., that they would undergo prenatal diagnosis in their future pregnancy(70%). 40% agreed that it is good to know prenatally about cleft anomalies.

Conclusion: The benefits of utilisation of prenatal diagnosis should be emphasised

INTRODUCTION

Oro-facial cleft (OFC) remains a prominent health issue in developed and developing countries alike. It is the commonest craniofacial birth defect in human's¹. Facial deformity, especially around the mouth, is rated as the least attractive of all deformities². Children who have a cleft lip and palate often experience feeding, speech and swallowing problems as well as poorer dental health.

Advancement in ultrasonography has led to the prenatal diagnosis of a higher percentage of oro facial anomalies. The detection of Orofacial clefts is being routinely included in ultrasound screening practices in some countries and providing reproductive choices to pregnant women. The availability of this advanced technology in the Indian subcontinent can offer reproductive choices to pregnant women who were hitherto unexposed to the prenatal diagnosis of clefts⁴. Potential advantages of a prenatal cleft diagnosis include psychological preparation, an opportunity for parent education, planned neonatal care and preparation for feeding, an opportunity for the investigation of other anomalies and possible chromosome studies, as well as increased reproductive choices for the parents, including termination of pregnancy⁵. The Utilisation of prenatal diagnosis depends on public attitudes and barriers to use the prenatal diagnostic methods. Hence, the present study was conducted to assess barriers and attitudes towards prenatal diagnosis of Orofacial clefts.

METHODOLOGY

The present study was a cross sectional study carried out among 240 smile train beneficiaries in Bangalore city for a period of three months from July 2013 to august 2013 among the parents of children affected with Orofacial clefts attending smile train rehabilitation centre in Bangalore. A total of 285 parents were invited to participate, out of which 240 parents consented. Inclusion criteria were those willing to participate in the study. Exclusion criteria were those children with syndromic Orofacial clefts, mother's age over 35 years. Ethical clearance for the study was obtained from institutional review board. Written informed consent was obtained from the participants prior to the study.

A standardized interviewer administered, closed ended questionnaire was used for the study; the investigator himself collected required information. The Proforma consisted of three parts. The first part included the demographic data like age, sex, religion, family history, place of delivery of the child, education of the mother. Socioeconomic Status: (SES) was assessed using kuppaswamy scale 2012. Type of defect was recorded Cleft Lip (Unilateral or Bilateral), Cleft Palate, Or Both, any other. The second part of the questionnaire consisted of barriers to undergo prenatal diagnosis. Six

questions were used to assess barriers to undergo prenatal diagnosis. The questions framed consisted of financial barriers, physical barriers, attitudinal and familial barriers.

The third part of the questionnaire consisted of questions regarding attitude towards prenatal diagnosis. The responses to questions was obtained using 5 point Likert scale ranging from strongly disagree to strongly agree with the scores from 0 -40.

PILOT STUDY

A self-designed questionnaire was prepared and a pilot study was carried out among 30 parents. Validity of the questionnaire was assessed. Face validity was checked by asking experts to scrutinize the questions, while content validity was checked by ensuring that the questions covered all the areas according to initial objective. Reliability of the questionnaire was checked and subjected to statistical analysis and Cronbach's was obtained as 0.84

Statistical analysis

All the statistical analysis was done using SPSS version 20. chi-square test was applied to denote the association between socioeconomic status and barriers towards prenatal diagnosis

RESULTS

Among 240 parents, interviewed majority of the respondents had male child(69%) with the defect and Children with unilateral cleft lip with cleft palate were about more than half (51%) and followed by unilateral cleft lip (29%), bilateral cleft lip with cleft palate(13%), had bilateral cleft lip (7%). The mean age of the participants were (25.6+3.5)

Based on kuppaswamy socioeconomic scale 2012 the participants belonged to middle/lower middle (47%), lower/upper lower class (33%), and (21%) in upper middle class. Mothers of these affected children had education of primary school (30%), high school (31%), pre-university (32%), had graduation. (6%). participants in the study had family history of Orofacial clefts (20%) and had their siblings affected with the defect (12%). Majority of the respondents of children were born in hospital (63%), among these (72%) mothers had prenatal check-ups done but only few had undergone ultrasound scan during their pregnancy(24%).

The barriers assessed in the present study are illustrated in table 2. Attitude towards prenatal diagnosis, which was assessed on a five point Likert scale is illustrated in table 3. The association between respondents socioeconomic status and barriers is illustrated in table 4.

DISCUSSION

The rationale of this study was to include parents of affected children to assess their attitudes and barriers towards prenatal diagnosis. In the present study Among the barriers which was assessed , felt necessity was the major barrier noted which was similar to the study conducted by Ohagwu.c.c et al , where the felt need of the procedure was rated as a barrier by most of the participants⁹. Similarly, study conducted by Scupholme et al had reported patient felt requirement of scan as one of the barriers to prenatal diagnosis.

Cost of the scan, long waiting period's i.e. Lack of time, long distances from service points are other barriers rated high in the present study, which was similar to the study conducted by Ohagwu.c.c et al.⁹

In the present study more, than half of the participants agreed that their reproductive plans have been changed that they will not have children any more, which was not in coherence with the study conducted by Andrews-casal et al In Texas and Boston in which the majority of mothers and fathers indicated that their reproductive plans had not changed because of the birth of their child with cleft lip with or without cleft palate¹⁰.

Half of the participants disagreed that undergoing Prenatal diagnosis reduce anxiety, which is similar to the study conducted by green et al that informed choice is associated with increased anxiety³². However, in contrary to the study conducted by Davalbhakta and hall stated that a correct diagnosis could help decrease the level of shock¹¹.

More than half the participants had positive attitude towards knowing that their child had cleft lip or palate before their birth. This is similar to study conducted by Celine Rey Bellet et al were mothers thought that this was probably done in best interest to avoid upsetting them, and insisted that the prenatal diagnosis should be given to avoid the shock of discovery at birth and the feeling of being bet rayed by their obstetrician³. Van den berg et al reported that informed choice was associated with less decisional conflict for continuing or termination of pregnancy¹³.

The participants had neutral attitude towards benefits of prenatal diagnosis, as it will help to provide better health care and psychological predisposition to receive a malformed child. A study conducted by skotko as revealed that women who think that the major benefits of prenatal diagnosis is for better health control are more likely to continue pregnancy in case of fetal anomaly¹².

In the present study 68% agreed that they would terminate pregnancy, 20% strongly agreed for termination of pregnancy if child is diagnosed with cleft lip/cleft lip and palate. The present study is in contradictory with the study conducted by Diego F. Wyszynskil et al none of the respondents would terminate a pregnancy because the ultrasound reveals an oral cleft. Similarly, very few (6.1%) would terminate the pregnancy if there were an early diagnosis of Down syndrome. The differences observed in this study to the present study might be explained by a combination of a variety of factors: (1) religious, since close to 90% of the respondents themselves practicing members of the Catholic faith;(2) legal, since abortion is legally restricted in Argentina and the conditions in which they are performed are extremely poor; (3) social, because abortion produces stigma and isolation; (4) financial, since abortions are largely illegal, women have to pay in full out of their Own pocket; but in the present study majority of the participants belong to Hindu faith and the study was conducted in India where medical termination of pregnancy act states that a pregnancy may be terminated by a registered medical practitioner, -(a) where the length of the pregnancy does not exceed twelve weeks if such medical practitioner .

CONCLUSION

The benefit of utilization of prenatal diagnosis within 12 weeks of gestation among all pregnant women needs to be emphasized. Pre marital Counselling should be done to all couples to educate te importance of prenatal diagnosis as in the present study it was noted that participants felt that it was not important to undergo prenatal diagnosis. Efforts should be directed to reduce the cost of prenatal ultrasound to relieve financial burden associated .The diagnosis of Orofacial clefts must be revealed to the parents as it helps the parents and family members to be prepared psychological , an opportunity for parent education on planned neonatal care and preparation for feeding, information on available surgical and other rehabilitative care to the child, an opportunity for the investigation of other anomalies and possible chromosome studies, as well as increased reproductive choices for the parents, including termination of pregnancy

Table 1. Distribution of affected children based on type of defect

Type of Defect	N	%
Unilateral Cleft Lip	70	29%
Bilateral CL	16	7%
Unilateral CLCP	122	51%
BCLCP	32	13%
Total	240	100%

Table2 Distribution based on barriers assessed

	N	%
Cost of the scan was too high	112	25%
Did not think it was necessary	126	29%
Too far distance of the diagnostic centre	54	12%
Scared of the procedure	19	4%
Family people did not allow me	36	8%
Lack of time	94	21%

*multiple answers by a single respondent

Table3 Distribution based on attitude towards prenatal diagnosis.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Prenatal diagnosis for cleft lip/palate is valuable and beneficial to all pregnant women	0%	1%	30%	68%	1%
Knowing the child had cleft lip/palate before its birth reduces anxiety	0%	50%	31%	18%	0%
Would not have more children if you are diagnosed as at risk of having a child with cleft lip /palate	0%	5%	14%	53%	29%
Would have prenatal screening in their future pregnancy	0%	1%	13%	70%	17%
That it is good to know that the child had cleft lip/palate before it was born	0%	33%	28%	40%	0%
Psychological and better predisposition to receive a child with cleft lip/palate before it was born	0%	24%	63%	13%	0%

Would terminate pregnancy if known that child had cleft lip/palate prenatally	0%	11%	0%	68%	20%
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Table4: Barriers to prenatal diagnosis in relation to socioeconomic status

	Upper Middle		Middle/Low er Middle		Lower/Upp er Lower		P- value
	N	%	N	%	N	%	
Cost of the scan was	13	19%	41	24%	58	29%	<0.001
Did not think it was	45	22%	53	31%	28	42%	
Too far distance of	2	3%	14	7%	38	22%	
Scared of the proceed	0	0%	18	9%	1	1%	
Family people did no	7	10%	3	1%	26	15%	
Lack of time	17	25%	63	31%	14	8%	
Total	84	100%	192	100%	165	100%	

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