

Study of Beliefs of Parents About The Etiology and Causes of Cleft Lip and Palate in Their Children

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Abstract

The purpose of the study was to investigate about the perceptions of parents regarding the etiology and causes of cleft lip and palate in their children and the impact of these beliefs on medical consultation. The study was conducted in **Civil Hospital Karachi** and **Jinnah Post Graduate Medical Center**. A questionnaire was used to collect the required data. The parents of patients under 10 year were investigated about the possible causes. Total 73 parents and grand parents were interviewed out of which 44 (60.3%) mothers belief on solar/lunar eclipse during pregnancy causing this, while 11 (15.1%) on some spiritual involvement. Fathers were also questioned and result were 30 (41.1%) solar lunar eclipse , while 23(31.5) spiritual involvement and the results of grand mothers beliefs were 58 (78.1%) solar/lunar eclipse while 6 (8.2%) punishment of false deeds. The majority of the parents consider solar/lunar eclipse as the main causing factor of the anomaly. Family history of disorder was found positive in 42 (57.5%) cases and 43 (58.9%) marriages were found to be consanguineous. 35 (47.9%) mothers and 56 (76.1%) of the fathers were found to have some sort of addiction.

Key Words: Cleft Lip & Palate, Etiology.

Introduction

Cleft lip and palate is one of the most common congenital anomaly of oro- facial structures. Cleft lip (*cheiloschisis*) and cleft palate (*palatoschisis*), which can also occur together as cleft lip and palate, are variations of a type of clefting congenital deformity caused by abnormal facial development during gestation. A cleft is a fissure or opening a gap. It is the non-fusion of the body's natural structures that form before birth. Cleft Lip & Cleft Palate may occur individually, but frequently both are found in association with each other and other congenital anomalies. 1 Isolated cleft lip and cleft lip with palate is

more common in males, while isolated cleft palate is more common in females.² World wide prevalence rate is 1 in 700 live births³. They are frequently associated with Congenital Heart Diseases. Problems are cosmetic, dental, speech, swallowing, hearing, facial growth, emotional. Cleft lip occurs when an epithelial bridge fails to unite. Clefts of primary palate occur anterior to incisive foramen while Clefts of secondary palate occur posterior to incisive foramen. Cleft Lip/Palate are an associated feature of over 300 Syndromes. Management of a child with a cleft lip (CL) or palate (CP) necessitates a team effort as these children have multiple problems. They require the skills of a plastic surgeon, speech-language pathologist, pediatric dentist, orthodontist, otolaryngologist, pediatrician, geneticist and an audiologist⁴. If the cleft does not affect the palate structure of the mouth it is referred to as cleft lip. Cleft lip is formed in the top of the lip as either a small gap or an indentation in the lip (partial or incomplete cleft) or it continues

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into the nose (complete cleft). Lip cleft can occur as a one sided (unilateral) or two sided (bilateral). It is due to the failure of fusion of the maxillary and medial nasal processes (formation of the primary palate) **Cleft palate** is a condition in which the two plates of the skull that form the hard palate (roof of the mouth) are not completely joined. The soft palate is in these cases cleft as well. In most cases, cleft lip is also present. Palate cleft can occur as complete (soft and hard palate, possibly including a gap in the jaw) or incomplete (a 'hole' in the roof of the mouth, usually as a cleft soft palate). When cleft palate occurs, the uvula is usually split. It occurs due to the failure of fusion of the lateral palatine processes, the nasal septum, and/or the median palatine processes (formation of the secondary palate). The hole in the roof of the mouth caused by a cleft connects the mouth directly to the nasal cavity. Prevalence in Pakistan is 1.91 per 1000 live births (1 in 523). 42% cases are isolated cleft lip, 24% cases are isolated cleft palate while 34% cases are combined anomalies.⁵ In Pakistan Every year more than 9000 children are born with clefts out of which 2000 get their Surgeries done. So each year the load of about 7000 Untreated Cleft Lip\Palate Patient add to the Population. After China, India & Indonesia, Pakistan is at the 4th place in the occurrence of this anomaly, followed by USA.

Besides the Medical & Scientific Causes of Cleft Lip/Palate, There exist some believes of Parents about many non-Medical causes of Cleft Lip/Palate. Our study is based to find ratio of the Parents Believing on such Scientific or Unscientific causes. Community believes on many cultural attributes towards the causation of disorder which are solar lunar eclipse, god's will, punishment of the sins committed in past life and black magic done by their enemies. These beliefs effect the psychosocial lives of patients and the families. Similar studies were taken place in

Nigeria and they found the prevalence of these non scientific beliefs in the society.⁶

Studies were also underwent in rural India and the results found to be 84% parents believe on "God's will" as the leading cause behind this condition⁷. Statistical data about the perception in Pakistani community was lacking on this topic.

It has been reported that the condition is surgically treatable with good prognosis and approximately 3% to 25% children treated will develop absolutely normal speech after primary surgery where as others require multiple interventions throughout the childhood and adolescence⁸. It has been reported that the leading cause of the CL/P is maternal smoking and alcohol abuse⁹.

While unnecessary use of drugs and nutritional deficiency during the gestation has also been reported. Studies have shown that supplementation therapy of vitamins and folate during pregnancy could have a protective effect on the congenital anomaly.¹⁰

Parents of clefted children avoid any particular antenatal care and after birth treatment in few cases as they regard it supernatural and beyond cure. They consider a divine power giving them a clefted child and in some cases blame themselves or each other for this and consider it punishment of their sins in past lives or regard it as "God's will"¹¹.

It is reported that parents want to know from the healthcare professionals about the disorder and its consequences, about the feeding of these babies and the causes of the cleft and they also want to be told that their child is not in pain due to this condition and this anomaly is not due to their fault.¹²

By public awareness programs these false beliefs can be corrected which can help the parents and children to get damage repaired and lead a healthy productive life.

Methodology

Aims of study

The aim of the study were to

1. Find out the ratio of the parents of clefted children who believe on un scientific or super natural causes of the anomaly
2. Find out the ratio of grand mothers believing on these causes
3. Obtain information from the mother about the pre natal causes that might had lead to anomaly
4. Inquire about the smoking and other addictions in mother and father of children with cleft
5. Find out how educational level of mother and father are related to their perception
6. Inquire about family history of the disease.

Study design

An exploratory-descriptive, quantitative research design was employed, which involved the use of individual interviews.

Inclusion and exclusion criteria

Parents of the children with cleft lip or cleft palate or combined cleft lip and palate not more than 10 years of age at the time of interview were included.

Sampling technique

Purposive sampling

Questionnaire

Interview was taken from parents, after informed consent via questionnaire.

Questions were regarding perception of Mother, Father and Grand Mother about the cause of this Anomaly.

Areas investigated are:

- Family History of Disease.
- Addiction of Father and Mother.
- Gestational Age.
- Nutritional Status.
- Drug History.
- Educational level of Parents.
- Brief physical Examination was done to

assess the Nature, Severity and extent of Anomaly.

Place of study

Civil Hospital Karachi
Jinnah Postgraduate Medical Center
Al Mustafa trust Hospital.

Sample size

A total of 73 parents of children with cleft lip and palate were investigated after informed consent via questionnaire.

Data analysis

Closed-ended questions were tabulated and analyzed using SPSS. version .14. results are shown with the help of charts , bar diagrams , multiple bar diagrams and pie charts.

RESULTS

A total of 73 parents were investigated at public sector, tertiary care hospital in Karachi. Out of 73 anomalies 47 were isolated cases comprising of 30 cleft lip and 17 cleft palate while other 26 cases having combined anomaly with clefted lip and

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Solar/Lunar eclipse	44	60.3	60.3	60.3
	Cousin marriage	2	2.7	2.7	63.0
	Punishment of false deeds	8	11.0	11.0	74.0
	God's will	11	15.1	15.1	89.0
	Genetics	5	6.8	6.8	95.9
	Black magic / supernatural	3	4.1	4.1	100.0
	Total	73	100.0	100.0	

palate. There were total 47 unilateral cases and 16 were right sided and 31 were left sided and another 26 cases were found to have bilateral involvement. Parents investigated were having 47(64.4%) male children and 36(35.6%) females. As reported earlier anomaly is more common in males with a ratio of 2:1. 13. 10 years of age were taken cut off for effected children; more than 85% cases were 1-4 years of age with mean of 3-4year age group.

Consanguinity of Marriage

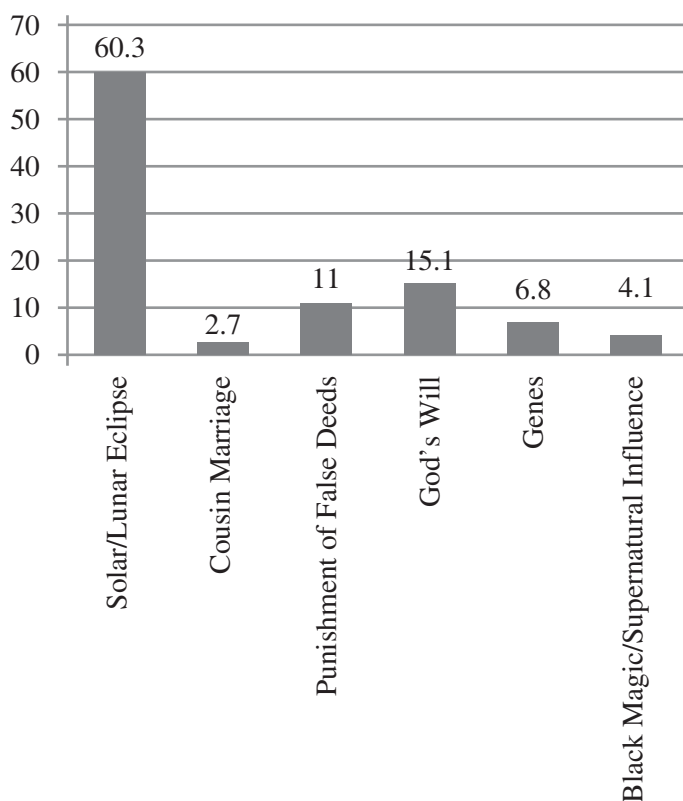
Type of pre marital relation between father and mother were found to be 59% consanguineous and rest non-consanguineous.

Perception of Mothers

Mothers were questioned about their beliefs on etiology of cleft lip and palate in their children and the results were:

What do you (Mother) think is the cause of this disorder in your child?

Table .1

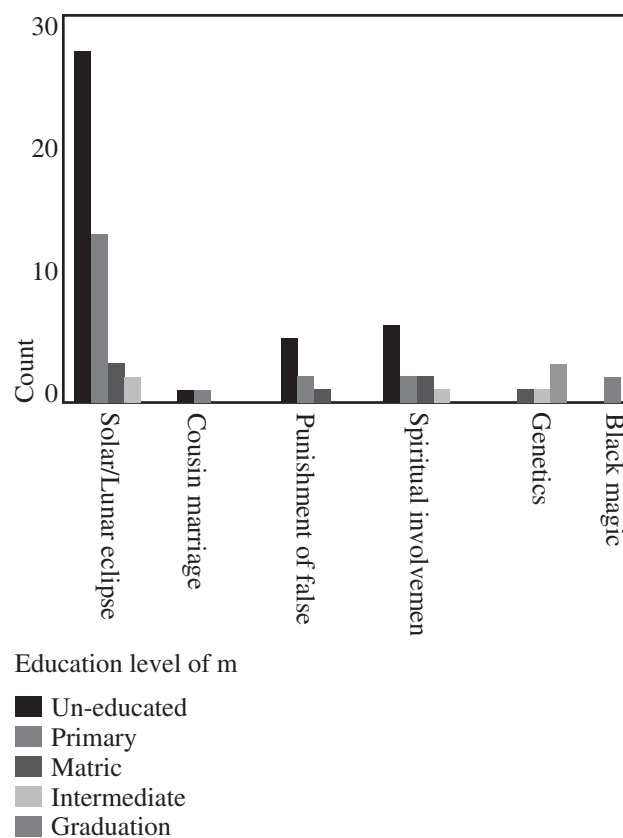


Family History

Family history of anomaly was found positive in 42-57.5% cases. 19 (26%) of total 73 mothers of effected children took folate and/or multivitamins during gestation 12(16%) took some other medications and 31(42.5%) did not took any medication and

rest 11(15.1%) don't remember any such history. 9 out of 73 mothers(12.3%) mothers were found to be addicted to smoking cigarette/beenhi and another 26 (35.6%) mothers used to have paan, chaalia and ghutka. 39(53.4%) Mothers were completely uneducated and 20 mothers (27.4%) attended primary schools while other 14(19.2%) attended secondary and above education. It was found that mothers who are more educated used to think more scientifically than uneducated ones , results are depicted in figure 1.

Fig.1 Education level of mothers vs. beliefs



what do you think is the cause of this disorder in your child?

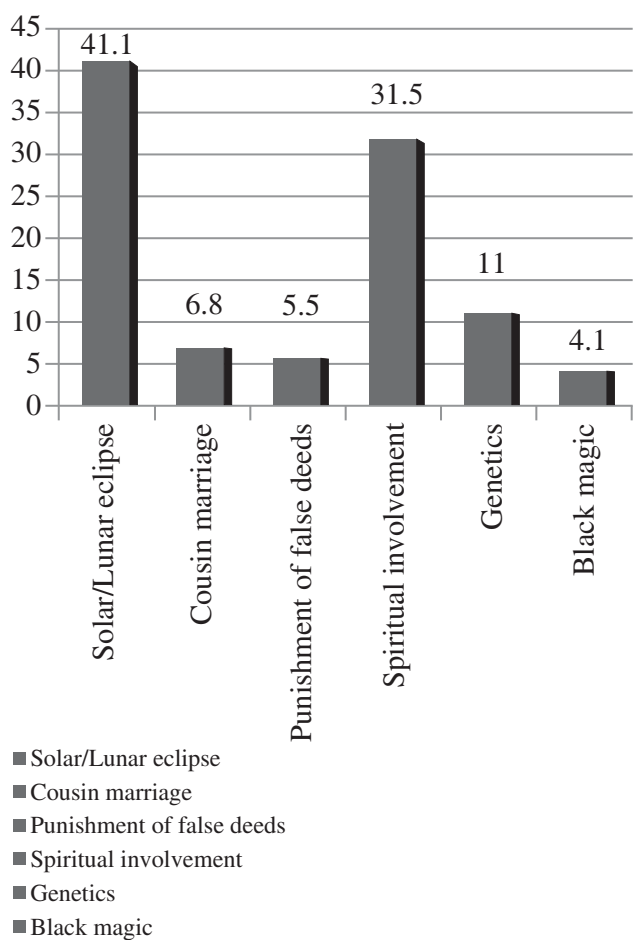
Perception of Fathers

Fathers were investigated regarding their believes on the etiology of anomaly and the results were found to be :

Being a father, what do you think is the actual cause of this disorder?

Table 2.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Solar/Lunar eclipse	30	41.1	41.1	41.1
	Cousin marriage	5	6.8	6.8	47.9
	Punishment of false deeds	4	5.5	5.5	53.4
	Spiritual involvement	23	31.5	31.5	84.9
	Genetics	8	11.0	11.0	95.9
	Black magic	3	4.1	4.1	100.0
	Total	73	100.0	100.0	



increasing level of education were also found in fathers this comparison is depicted in figure.2

Socio Economic Groups

Most of the families investigated were belong to lower socio economic group 45 (61.6%) and lower middle socioeconomic group 23 (31.5%) while only 5 (6.8%) belong to middle class or well to do families. It can be ascertained from the result that as financial status of family effects antenatal and post natal care, uses of folates or multivitamins and awareness about hazard of smoking , it may be indirectly related to high incidence of congenital anomalies.

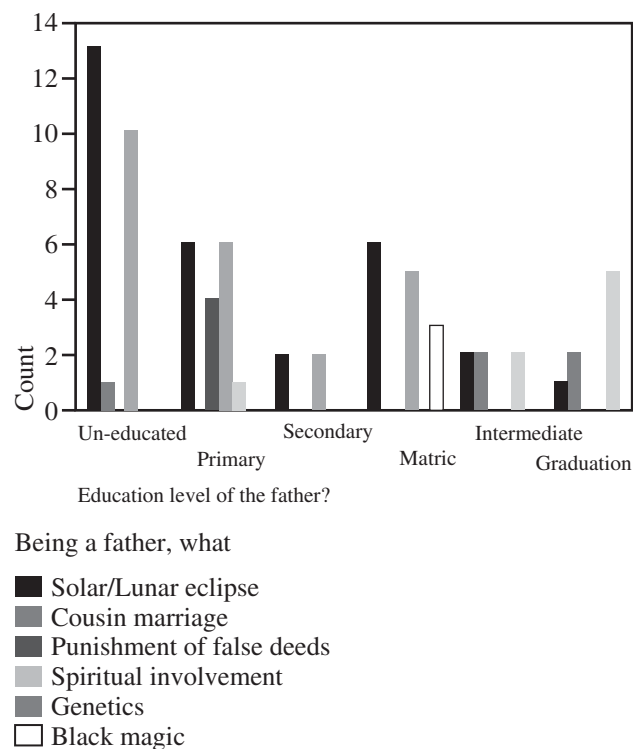


Fig .2 Education level of father vs. beliefs

30(41.1%) out of 73 fathers were found to be smokers while another 26(37.6%) used to take paan, chalia ghutka or maenpuri. 24 (32.9%) fathers were completely un educated while 17(23.3%) and 32(44.8%) attended primary and secondary or above educations. Same trend of more scientific beliefs with

Perception of Grand Mothers

Grand mothers were also inquired where present or asked from mother or father about grand mother's perception on etiology of CL/P and the results found are depicted in Table.3.

Being a grand mother, what do you think is the cause of this disorder in your grand child?

Table .3

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Solar/Lunar eclipse	57	78.1	78.1	78.1
	Punishment of false deeds	6	8.2	8.2	86.3
	God's will	6	8.2	8.2	94.5
	Black magic / supernatural	4	5.5	5.5	100.0
	Total	73	100.0	100.0	

Discussion

- Our study provides statistical data about the perception of community especially parents of children with cleft lip and palate.
- According to results majority of the parents consider solar/lunar eclipse , God's will and supernatural causes
- Similar study was done in Nigeria and the results were God's will, supernatural causes and self blame in order of occurrence.¹⁴
- According to a study in India they found 84% due to God's will and 10% sins committed , as a social perception.¹⁵
- Although scientific studies proved the genetic and environmental causes behind the anomaly.
- It is also evident through our study that more of the Grand mothers beliefs on such scientific causes followed by mothers and then fathers, so awareness is increasing with time.
- Due to these false beliefs a feeling of self guilt is found in some mothers and fathers which has its psychological consequences.

Recommendations

- It is observed that more educated parents used to think more scientifically.
- Mass education programs should be

started to educate community about true causes.

- Mothers should be educated about smoking as a leading cause in anomaly.
- Stress should be given to nutritional adequacy during pregnancy.
- Use of folates/ multivitamins should be encouraged by mothers.
- Parents of patients should be counseled about availability of surgical treatments.
- Psychological counseling of self blaming parents.
- Public sector arrangements should be increased to surgically correct the condition.
- More emphasis should be laid on rural population.

Conclusion

Our study provide statistical prove of the non scientific beliefs found in parents of the patients of cleft lip and palate, it is a avoidable condition and we can help population by working on the recommendation made above.

Limitations

Questionnaire based interviews were taken from 73 parents of children with cleft lip or palte or both. In some cases both parents were not available so we had to rely on one parent, we asked the available one about the perception of other. In the same way grand mothers were present only in few cases so we took her view directly but in other cases mother or father were asked to tell grand mothers view on the anomaly. Study duration was short so could not got the desired number of sample size. Some information inquired was from past history of mother or father and there may be a recall bias. Study on perception of parents on cleft lip or palate were not taken place in Pakistan so we can't compare our study with other studies with in our local dynamics. These were few limitations in our study design and conduction.

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