

Identify Different Challenges Throughout Child Development with Orofacial Clefts

Child
Development
with Orofacial
Clefts

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ABSTRACT

Objective: To Identify Different Challenges throughout Child Development with Orofacial Clefts.

Study Design: Cross-sectional study

Place and Duration of Study: This study was conducted at the Department of Pediatric surgery/Plastic surgery, Arif Memorial Teaching Hospital, Ferozepur Road Lahore from 15th April to 15th July, 2023.

Methods: A sample of 239 Children with OFC age 1-15 years was collected through purposive sampling technique. Sample of study was divided into two age groups including group A: 1-5 years and Group B: >5-15 years. PEEP (Portage Early Educational Plan) Guide was administered in Group A to determine developmental Delay in 5 domains of development (Cognition, Self Help, Socialization, Motor and Speech). CBA (Curriculum Based Assessment) and IQ (Slossen Intelligence Tests) applied in Group B to determine academic and learning & memory deficits. BRS (Behavior Rating Scale) was applied to determine behavioral issues in both groups. Demographic Questionnaire including Age, Gender, Family Size, Consanguineous, Education, income etc. was also administered.

Results: In Group A children with OFC 20-30% were found delayed in all domains of development (Cognition, Self Help, Socialization and Receptive Language). 97 % were delayed in expressive and receptive speech, 22.5 % shows delay in cognition and 33.5 % shows delay in socialization. Self help and motor component were relatively least affected with 11% and 8.9 % respectively. Behavior Issues were also noted in 31 %. In Group B Children with OFC 22.91 shows below average IQ level and 68.75 % shows above Average IQ level. 68.7% shows Academic and learning issues in both reading and writing component of different subjects according to CBA.

Conclusion: This study concludes that Children with OFC have developmental delay in all domains of development including cognition, socialization, self help, motor and not only in speech. Similarly Children with OFC also shows Difficulty in learning abilities

Key Words: OFC, Development Domains, Developmental Delay, Academic Learning, Social and Behavioral Issues

Citation of article: Abid MB, Afzal N, Zia W, Shiekh MA, Mahmood F, Ghous M. Identify Different Challenges throughout Child Development with Orofacial Clefts Med. Forum 2023;34(10):3-8. doi:10.60110/medforum.341001.

INTRODUCTION

Orofacial clefts (OFCs) affect 1 in 700 live births. One making them the most common craniofacial malformation and second only to structural heart defects among all birth defects.⁽¹⁾

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Received: August, 2023

Accepted: September, 2023

Printed: October, 2023

OFCs include cleft lip (CL), cleft lip and palate (CLP), and cleft palate (CP) only. Authors of numerous studies have reported that children with OFCs have worse neurodevelopmental and academic outcomes than unaffected peers.⁽²⁾ The underlying reasons for these deficits are unclear. Hypothesized mechanisms include functional consequences of oral cleft (e.g. feeding difficulty, Eustachian tube dysfunction, or speech impairment), treatment factors (e.g., frequent school absences), repeated anesthesia exposures, and social stigma (e.g., differential treatment based on appearance or speech and/or voice quality).^(3,4) Researchers also suggest that patients with OFCs may have structural brain differences and differences in outcome depending on cleft laterality, implying that a cleft might be a marker for aberrant brain development.^(5,6)

Cognitive dysfunction in children with OFC has been documented over time. Non syndromic clefts have been found to be associated with poor academic achievement, a lower verbal IQ, and deficits in rapid verbal labeling, verbal fluency, and short-term

memory.⁽⁷⁾ Among children with nonsyndromic OFC, the prevalence of learning disabilities, particularly specific reading disorders, has been estimated to be between 30% and 46%.⁽⁸⁾ Less attention has been placed on executive functioning skills (attention, organization, monitoring, planning, and initiation) or psychiatric disorders.^(9, 10)

Children with cleft lip and/or palate encounter different challenges throughout the course of their development. Both environmental and biological factors play a role, and can affect speech, academic performance, and behavior. Research has shown varying influences, including the type of cleft, gender, and age, affecting outcomes.^(11,12) It has been suggested that facial malformations may be associated with aberrant brain development. Interestingly, associations between nonsyndromic OFC and structural brain anomalies have been reported in children and adolescents with clefts. These midline brain anomalies have been associated with intellectual disability, developmental delay, and schizophrenia in previous studies. The relatively high incidence of central nervous system abnormalities among individuals with nonsyndromic OFC, being approximately 13 times higher compared to that in the general population, provides additional support for the hypothesis that cognitive and language deficits as well as other psychiatric disorders may be the result of underlying neurodevelopmental abnormalities. The craniofacial skeleton and the brain are derived from the same ectodermal tissues, and their development is closely linked during early morphogenesis.^(13,14)

In infancy and early childhood <5 years invariable deficits (cognition, motor, communication and language) with definite delay in speech is present in children with OFC.^(15,16) When a child reaches school age, social skills, self-control, and other behavioral regulation come into play.⁽¹¹⁾ Parents and teachers have reported significantly higher behavior problems in children with clefts. The occurrence of reading difficulties and learning disabilities is high.^(8,16) The purpose of the study was to Identify Different Challenges throughout Child Development with Orofacial Clefts. Challenges are Development Delay, Communication/social, Behavioral, and Academic sequelae of Cleft in addition to speech delay.

METHODS

A Cross-sectional study was conducted at Department of Pediatric surgery/Plastic surgery, Arif Memorial Teaching Hospital, Ferozepur road Lahore. After taking Approval from institutional review board (IRB). A sample of 239 children with OFC was collected through purposive sampling technique. Sample size was collected through WHO calculator. Data was collected from parents of OFC children after taking written informed consent. Individuals with Oro Facial Clefts

placed in two age groups: Group A 1-5 years, Group B >5-15 years. Children having syndromic, dysmorphic, neurological deficits, Diagnosed neurodevelopment disorders, Hypoxic ischemic encephalopathy, Hearing Impairment and Craniofacial abnormalities other than OFC were excluded from the study.

Data collection methods, data instruments/ Questionnaires used, measurement tools: After approval from ethical board children reaching AMH for CL/CP surgery was enrolled for study. Each child will be assessed before surgery for speech, behavior and learning by SLP, Psychologist and Special needs educationist and occupational therapist. Their delays in their respective domains were identified, entertained in designated Performa and given scores to grade their gravity like mild, moderate and sever. Final results, discussion, conclusion and recommendations were included at the completion of study.

1. Demographic questionnaire:

Demographic questionnaire included child's name, age, gender, age at the time of diagnosis, severity of the disorder, mother's and father's age, education occupation, socio-economic status, monthly income, number of siblings, birth order etc.

2. Place and duration of study:

Arif Memorial Teaching Hospital, Lahore. Department of Paediatric Surgery, starting from 15th April to 15th July, 2023. (in three months)

3. Speech and Language Assessments

4. Developmental profile / CBA

5. Informal Behavioral Assessment

6. Occupational / fine motor assessments

7. IQ (SITS)

RESULTS

Data was analyzed using SPSS 25.0 Demographics was analyzed using frequency and percentages. Correlation and regression analysis was done to determine the relationship in children with oral clefts, having speech delays & delays in other developmental milestones, academic, learning and psychological issues. Out of 239 children with OFC, two groups were formed on the basis of tools used. In group A (age 1-5 years) portage (PEEP) & BRS tools applied and question were asked from the guardians during history. Delay in development domains and behavior issues were recorded. In group B (6-15 years) tools of CBA, IQ and BRS employed to determine academic learning, memory deficits and behavioral issues. Mean age of children and mothers are shown in histogram figure 1-4 respectively for both groups. In 1 to 5 years children: 191 out of 239 children with OFC developmental delay were noted. In Group A Chronological age was 31.24 months (SD= 14.48). For Cognition developmental age was 27.17 months (SD=14.64), For socialization Developmental age was 27.3247(SD=14.43), For Self-Help Developmental age was 29.99 months

(SD=14.66), For Speech and Language Expressive Developmental age was 14.80 months (SD=9.64), For Speech and Language Receptive Developmental age was 14.78 months (SD=9.74) and For Gross motor Developmental age was 30.38 months (SD=14.65).

In Table-2 Informal Behavioral Assessment between 1 to 5 years out of 191, 67.5 % shows normal behavior, 10.6% shows aggressive behavior, 5.2 % shows hyperactive behavior, 9.9 % shows inattentive behavior and 6.8 % shows mixed behavior.

Table 3 is For Occupational / fine motor assessments for 1 to 5 years children, in this among all cognition 67.5 % were age appropriate, 16.8 % mild delay, 6.3 % moderate delay and 9.4 % with severe delay. For Socialization 66.5% were age appropriate, 17.3 % mild delay, 8.4 % moderate delay and 7.9 % with severe delay for Self Help 89 % were age appropriate, 7.9 % mild delay, 2.6 % moderate delay and 0.5 % with severe delay. For Speech and Language Expressive 3.1 % were age appropriate, 12.6 % mild delay, 34.6 % moderate delay and 49.7 % with severe delay. For Speech and Language Receptive 3.1 % were age appropriate, 12.6 % mild delay, 35.6 % moderate delay and 48.7 % with severe delay. For Gross Motor 91.1 % were age appropriate and 8.9 % mild delay.

Table 4 is about IQ for 6 to 11 years, out of 48 Children with OFC 68.75% were above average, 8.34 % were average and remaining 22.91 % were below average. In group B out of 48 Children with OFC overall CBA result shows that 31.3 % were Age Appropriate, 14.6 % were Mild Delay, 33.3 % were Moderate Delay and 20.8 % were Severe Delay. In group B out of 48 Children with OFC **writing** CBA result shows that 27.1 % were Age Appropriate, 18.8% were Mild Delay, 33.3 % were Moderate Delay and 20.8 % were Severe Delay. In group B out of 48 Children with OFC **Reading** CBA result shows that 27.1 % were Age Appropriate, 16.7% were Mild Delay, 33.3 % were Moderate Delay and 22.9 % were Severe Delay.

Table 5 is about **Curriculum Based Assessment**, In this B out of 48 Children with OFC **Mathematics (Reading/solving)**CBA result shows that 27.1 % were Age Appropriate,16.7 % were Mild Delay, 33.3 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **English (Reading)** CBA result shows that 22.9 % were Age Appropriate,18.8 % were Mild Delay, 33.3 % were Moderate Delay and 25.0 % were Severe Delay. In group B out of 48 Children with OFC **Urdu (Reading)** CBA result shows that 22.9 % were Age Appropriate,16.7 % were Mild Delay, 37.5 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **Science (Reading)** CBA result shows that 27.1 % were Age Appropriate, 16.7 % were Mild Delay, 33.3 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **Mathematics**

(Writing) CBA result shows that 22.9 % were Age Appropriate,16.7 % were Mild Delay, 37.5 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **Urdu (Writing)** CBA result shows that 22.9 % were Age Appropriate,16.7 % were Mild Delay, 3 7.5 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **Science (Writing)** CBA result shows that 22.9 % were Age Appropriate, 16.7 % were Mild Delay, 37.5 % were Moderate Delay and 22.9 % were Severe Delay. In group B out of 48 Children with OFC **English (Writing)** CBA result shows that 18.8 % were Age Appropriate, 18.8 % were Mild Delay, 39.6 % were Moderate Delay and 22.9 % were Severe Delay.

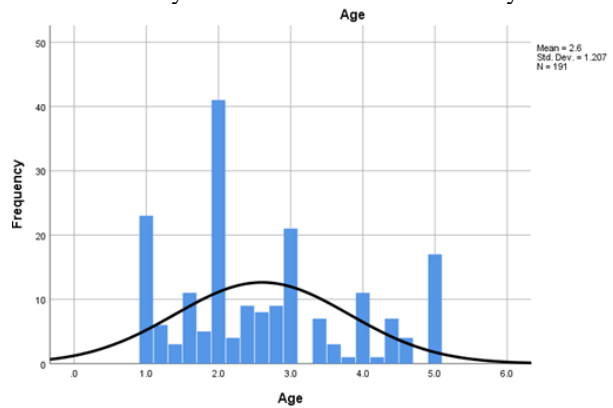


Figure 1: mean age of children in group A.

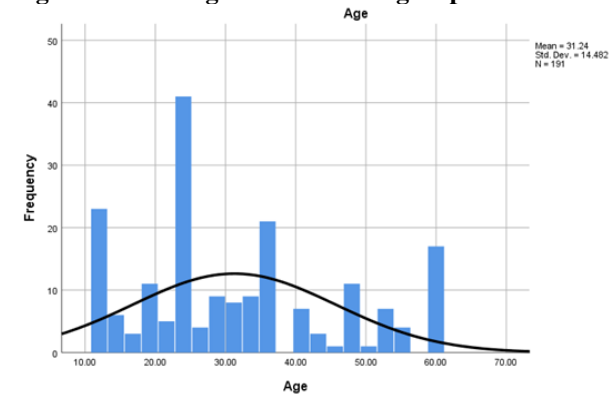


Figure 2: mean age of children's mothers in group A.

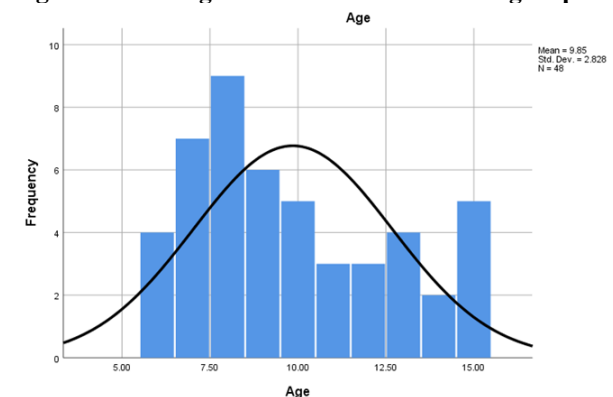


Figure 3: mean age of children in group B.

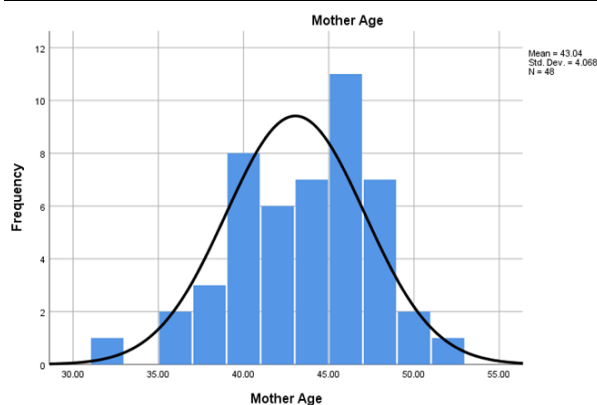


Figure-4 mean age of children’s mothers in group B.

Table 1: Characteristics of Developmental profile (PEEP) children between 1 to 5 years

Developmental profile (PEEP) for Years 1 to 5	Mean	Std. Deviation
Chronological Age	31.2440	14.48154
Cognition	27.1797	14.64841

Socialization	27.3247	14.43649
Self Help	29.9956	14.66509
Motor	30.3826	14.65805
Speech and Language Expressive	14.8065	9.64620
Speech and Language Receptive	14.7880	9.74935

Table 2: Informal Behavioral Assessment between 1 to 5 years

Informal Behavioral Assessment for Years 1 to 5		Frequency	Percent
Behavior	Age Appropriate	165	69.0
	Aggressive	24	10.0
	Hyperactive	17	7.1
	Inattentive	20	8.4
	Mixed	13	5.4

Table No.3: Occupational / fine motor assessments for 1 to 5 years children

Occupational / fine motor assessments for Years 1 to 5		Frequency	Percent
Cognition	Age Appropriate	129	67.5
	Mild Delay	32	16.8
	Moderate Delay	12	6.3
	Severe Delay	18	9.4
Socialization	Age Appropriate	127	66.5
	Mild Delay	33	17.3
	Moderate Delay	16	8.4
	Severe Delay	15	7.9
Self Help	Age Appropriate	170	89.0
	Mild Delay	15	7.9
	Moderate Delay	5	2.6
	Severe Delay	1	0.5
Speech and Language (Expressive)	Age Appropriate	6	3.1
	Mild delay	24	12.6
	Moderate delay	66	34.6
	Severe delay	95	49.7
Speech and Language (Receptive)	Age Appropriate	7	3.7
	Mild delay	24	12.6
	Moderate delay	68	35.6
	Severe delay	92	48.2
Motor	Age Appropriate	174	91.1
	Mild Delay	17	8.9

Table No.4: IQ assessments for 6 to 11 years

IQ assessments		Frequency	Percent
IQ	Above Average	33	68.75
	Average	4	8.34
	Below Average	11	22.91
CBA overall	Age Appropriate	15	31.3
	Mild Delay	7	14.6
	Moderate Delay	16	33.3
	Severe Delay	10	20.8
CBA writing	Age Appropriate	13	27.1
	Mild Delay	9	18.8

	Moderate Delay	16	33.3
	Severe Delay	10	20.8
CBA reading	Age Appropriate	13	27.1
	Mild Delay	8	16.7
	Moderate Delay	16	33.3
	Severe Delay	11	22.9

Table No.5: Curriculum Based Assessment between 6 to 11 years

Curriculum Based Assessment		Frequency	Percent
Curriculum Based Assessment Mathematics (Reading/solving)	Age Appropriate	13	27.1
	Mild Delay	8	16.7
	Moderate Delay	16	33.3
	Severe Delay	11	22.9
Curriculum Based Assessment English (Reading)	Age Appropriate	11	22.9
	Mild Delay	9	18.8
	Moderate Delay	16	33.3
	Severe Delay	12	25.0
Curriculum Based Assessment Urdu (Reading)	Age Appropriate	11	22.9
	Mild Delay	8	16.7
	Moderate Delay	18	37.5
	Severe Delay	11	22.9
Curriculum Based Assessment Science (Reading)	Age Appropriate	13	27.1
	Mild Delay	8	16.7
	Moderate Delay	16	33.3
	Severe Delay	11	22.9
Curriculum Based Assessment Mathematics (Writing)	Age Appropriate	11	22.9
	Mild Delay	8	16.7
	Moderate Delay	18	37.5
	Severe Delay	11	22.9
Curriculum Based Assessment English (Writing)	Age Appropriate	9	18.8
	Mild Delay	9	18.8
	Moderate Delay	19	39.6
	Severe Delay	11	22.9
Curriculum Based Assessment Urdu (Writing)	Age Appropriate	11	22.9
	Mild Delay	8	16.7
	Moderate Delay	18	37.5
	Severe Delay	11	22.9
Curriculum Based Assessment Science (Writing)	Age Appropriate	11	22.9
	Mild Delay	8	16.7
	Moderate Delay	18	37.5
	Severe Delay	11	22.9

DISCUSSION

In children with OFC speech delay and disorders are the major concerns of the parents as well as the surgeons and allied professionals. So after surgical repair of OFC and other anatomical defects, speech therapy, correction of other surgical defects, orthodontics maxillofacial, hearing impairment all are focused but other domains of development cognition, socialization, fine motor skills, learning, academic and behavior sequelae of the cleft are not addressed in most centers where cleft repair are done. Literature and studies of last 3 decades have shown that 20-30% of children with OFC have delay in all domains of development and also have academic and psychosocial sequelae of the cleft. This much 20-30 percentage of the children are left behind compared to their peers with OFC with normal development. So this study to

identify different challenges throughout child development with orofacial clefts with development delay, communication/social, behavioral, and academic sequelae of cleft in addition to speech delay.

Results were almost same as found in previous study findings. And it showed developmental delay in 20-30 % in all domains of development (cognition, socialization, self-help, motor and language) including speech delay in all patients. Academic, learning and memory deficits were also found in 20-30 % with reading and writing difficulties up to 72 %. Break up percentage were also calculated in all domains of development and academic subjects. Psychosocial issues were also addressed and were common in both groups up to 32 % including hyperactivity, aggression, inattentiveness, dissatisfaction, low self-esteem and mixed pattern.

20- 30 % of the children with OFC had developmental delays psychosocial, academic and learning issues in addition to speech delay. All children with OFC coming for surgical repair should be screened and assessed timely and intervene with multidisciplinary team rehabilitation in cognition, language, academic, psychosocial domains in addition to speech therapy so that developmental delay and other deficits of learning and behavior be prevented.

CONCLUSION

In age group of 1 to 5 years, 20-30 % (irrespective of the cleft type) have developmental delay in addition to Speech which is 95-100% in all Children. They have few behavioral issues. In group B Similar percentage was found in context of academic learning and memory Deficits with more pronounced behavioral issues. In age group of 6 to 11 years with OFC 22.91 shows below average IQ level and 68.75 % shows above Average IQ level.68.7% shows Academic and learning issues in both reading and writing component of different subjects according to CBA.

Author's Contribution:

Concept & Design of Study: M Bilal Abid
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Conflict of Interest: The study has no conflict of interest to declare by any author.

Source of Funding: None

Ethical Approval: No.IRB 2023/093 dated 13.04.2023

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