International Journal of Science and Research (IJSR)
ISSN: 2319-7064
SJIF (2022): 7.942

Craniofacial Anomalies (CFA): A Stigma in India

Tamanna Borah[1], Dr. Krishnakali Bhattacharyya[2]

[1]M. Sc. Clinical Psychology, Department of Psychology, School of Allied Healthcare and Sciences, Jain Deemed-to-be University, Bengaluru, Karnataka, India

[2]Ph. D. (Psychology), M. Sc. (Psychology) &B. Ed& SLET

Abstract: ***Craniofacial Anomalies (CFA) is an umbrella term which consists of malformations and underdevelopment of the skull and facial bones in individuals. These abnormalities are birth defects as these facial and skull deformities are usually present from birth (congenital). CFA can range in severity from mild, moderate and severe. Some of the common CFA include: 1) CLEFT LIP AND PALATE-A separation in the lip and the palate. 2) CRANIOSYNOSTOSIS -Premature closure of the soft spots in an infant's skull. 3) HEMIFACIAL MICROSOMIA-A condition in which the tissues on one side of the face are underdeveloped. 4) VASCULAR MALFORMATION-An abnormal growth composed of blood vessels. 5) HAEMANGIOMA-A benign tumour that causes a red birthmark. The purpose of the paper is to create an understanding of what is CFA and its impact in an individual's life. This paper also throws light on the stigma surrounding CFA mainly in India. The objectives of the paper are: a) Understanding CFA through medical lenses. B) Understanding CFA from a psychological perspective. C) Understanding CFA in a holistic perception. D) To spread awareness of different policies, organizations, and treatments.***

Keywords: Craniofacial Anomalies, Types of Craniofacial Anomalies, Causes of Craniofacial Anomalies, Stigma in India, Management Plan, Treatment Plan, Advancement in India, Craniofacial Anomalies in Children, Craniofacial Anomalies in Adolescents, Perception Towards Craniofacial Anomalies, NGOS, Policies.

1. Introduction

1.1 What Are Craniofacial Anomalies?

The word craniofacial, referring to the skull or cranium, is derived from the word crania and facial, referring to the face. Anomaly is a medical term that means "irregularity" or "different from normal. " Craniofacial Anomalies (CFA) are a group of deformities that involve head and facial bone growth. These anomalies are congenital and vary in type and severity (present at birth).

It has been estimated that 1 in 700 children in India is born with a cleft lip/palate or other facial deformity (Survey by Indian health ministry in 2010-The approximate incidence of cleft lip and palate is 1.4 per 1, 000 live births in India) But more recent studies put the number at 1 in every 500 births (Journal of Indian Society of Periodontics and Preventive Dentistry 2012 vol.30 issue 3.)

Craniofacial peculiarities are another collection of face and facial bone deformations. Oddity is a therapy word that means "error" or "not the same as anticipated, " these abnormalities are present in (native) birth and exist in different types. Some of them are mild and some severe and require medical treatment. There are certain craniofacial oddities that may be severe in somewhere else in the flesh.

Craniofacial anomalies are deformities that affect a child's head and facial bones. These disorders are typically present at birth (congenital) and can range from mild to severe.

Common craniofacial anomalies include:

- CLEFT LIP AND PALATE-A separation in the lip and the palate
- CRANIOSYNOSTOSIS -Premature closure of the soft spots in an infant's skull
- HEMIFACIAL MICROSOMIA-A condition in which the tissues on one side of the face are underdeveloped
- VASCULAR MALFORMATION-An abnormal growth composed of blood vessels
- HAEMANGIOMA-A benign tumour that causes a red birthmark

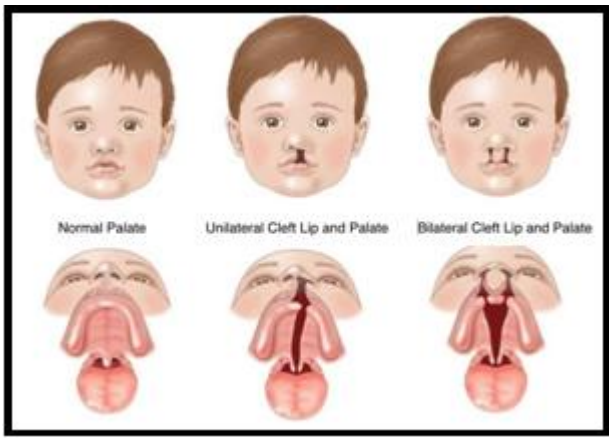

Figure 1: Craniofacial Anomalies

2. Types of Craniofacial Anomalies

Some of the most common types of craniofacial anomalies include the following:

Types	What Is It?	Symptoms
CLEFT LIP and (or) CLEFT Palate	• A separation that happens in the lip or the palate (roof of the mouth), or both. Cleft lip and cleft palate are the most common congenital craniofacial anomalies seen at	• A split in the lip and roof of the mouth (palate) that affects one or both sides of the face • A split in the lip that appears as only a small notch in the lip or extends from the lip through the upper gum and palate

	birth.	into the bottom of the nose • A split in the roof of the mouth that doesn't affect the appearance of the face • Difficulty with feedings • Difficulty swallowing, with potential for liquids or foods to come out the nose • Nasal speaking voice • Chronic ear infections
CRANIOSYNOSTOSIS	• A condition in which the sutures (soft spots) in the skull of an infant close too early. This causes problems with normal brain and skull growth. Premature closure of the sutures may also cause the pressure inside of the head to increase and the skull or facial bones to change from a normal, symmetrical appearance. • A condition in which the tissues on one side of the	• Full or bulging fontanelle (soft spot located on the top of the head) • Sleepiness (or less alert than usual) • Scalp veins may be very noticeable • Increased irritability • High-pitched cry • Poor feeding • Projectile vomiting • Increasing head circumference • Seizures • Bulging eyes and an inability of the child to look upward with the head facing forward • Developmental delays
Vascular Malformation	• A birthmark or growth present at birth, that is composed of blood vessels. It can cause functional or aesthetic problems. Vascular malformations may involve multiple body systems. There are several different types of malformations, and they are named according to which type of blood vessel is mostly affected. Vascular malformations are also known as lymphangiomas, arteriovenous malformations, and vascular gigantism.	• Seizures • Headache or pain in one area of the head • Muscle weakness or numbness in one part of the body • severe headache • Weakness, or paralysis • Vision loss • Difficulty speaking • Confusion or inability to understand others • Severe unsteadiness
Haemangioma	• A haemangioma is an abnormally growing blood vessel in the skin that may be present at birth (faint red mark) or appear in the first months after birth. A haemangioma is also known as a port wine stain, strawberry haemangioma, and salmon patch.	• During or after their formation, Haemangiomas do not usually trigger the diseases. However, if they become large or in a delicate region or if various • Haemangiomas exist, they may trigger certain diseases. Haemangiomas in the skin usually occur as purple spots or tiny scratches. Skin haemangiomas are sometimes referred to for their red deep appearance as strawberries. Most of this form happens on the throat or forehead.
Deformational Plagiocephaly.	• A misshapen (asymmetrical) shape of the head from repeated pressure to the same area of the head. Plagiocephaly literally means "oblique head" (from the Greek "plagio" for oblique and "cephale" for head).	• The flat spot may be either on one side of the head or on the back of the head.
Hemifacial Microsomia	• This mostly affects the ear, mouth, and jaw areas. Sometimes, both sides of the face can be affected and may involve the skull and the face. Hemifacial microsomia is also known as Goldenhar syndrome, or lateral facial dysplasia.	• The most visible signs of the condition are underdeveloped upper and lower jaws on one side of the face. It may appear that your child's mouth slants upward toward the affected side. • Often the forehead and cheek are flattened on the affected side and one eye socket is smaller than normal.

3. Causes of Craniofacial Anomalies

Most therapy specialists agree that there is no single variable causing such differences from the standard. Rather, there are numerous components that may add to their improvement, including the accompanying:

- Combination of qualities: A child can be inheritors to a combination of the gene (s). Or, again, the quality of the origination season could be adjusted. This results in a craniofacial characteristic.
- Environmental: It is not entirely understood how artificial exposures affect the advance of craniofacial variants of the standard. However, ecological exposure, especially in combination with hereditary abnormalities, can take up a task.
- Folic corrosive lack: The B-nutrient is a folic corrosive discovered in orange pressed, breakfast oats supported, fresh grain products, and red, red plants. Studies have shown that the risk of getting a child with certain inherent oddities is greater for women who do not carry appropriate folic corrosion during pregnancy or who

have a drinking daily ailment in folic corrosive. These include congenital fissure and fissure.

- Smoking—Women who smoke during pregnancy are more likely to have a baby with an orofacial cleft than women who do not smoke. [2-3]
- Diabetes—Women with diabetes diagnosed before pregnancy have an increased risk of having a child with a cleft lip with or without cleft palate, compared to women who did not have diabetes. [5]

Figure 2: A Child can be Inheritors to a Combination of the Gene or Can Have Environmental Affect

- Use of certain medicines—Women who used certain medicines to treat epilepsy, such as topiramate or valproic acid, during the first trimester (the first 3 months) of pregnancy have an increased risk of having a baby with cleft lip with or without cleft palate, compared to women who didn't take these medicines.
- Scientists believe that some instances of cleft lip and cleft palate may happen because of something that affected the mother during pregnancy, including taking certain medications, using tobacco or alcohol, vitamin deficiency and viral illness.
- Finally, in rare cases, a child's cleft lip and cleft palate may be related to a syndrome such as Van der Woude syndrome, Stickler syndrome, or Kabuki syndrome.

Figure 3: During the First Trimester (The First 3 Months) Of Pregnancy have an Increased Risk of Having A Baby with Cleft Lip With or Without Cleft Palate

4. The Craniofacial Anomaly Treatment Team

There may be many people involved in the management of craniofacial anomalies for your child because the skills of many different areas are needed to help with the problems that can occur. The following are some of the members of the craniofacial team:

- **PLASTIC/CRANIOFACIAL SURGEON**-a surgeon with specialized training in the diagnosis and treatment of skeletal abnormalities of the skull, facial bones, and soft tissue; will work closely with the orthodontists and other specialists to coordinate a surgical plan.
- **NEUROSURGEON**-a surgeon who specializes in the brain, spinal cord, and nerves; also coordinates all surgical interventions of head abnormalities with the craniofacial surgeons (i. e., craniosynostosis).
- **PEDIATRICIAN**-a physician who will follow your child as he/she grows and help coordinate the multiple specialists involved.
- **ORTHODONTIST**-a dentist who evaluates the position and alignment of your child's teeth and coordinates a treatment plan with the surgeon and other specialists.
- **PEDIATRIC DENTIST**-a dentist who evaluates and cares for your child's teeth.
- **SPEECH AND LANGUAGE SPECIALIST**-a professional who will perform a comprehensive speech evaluation to assess your child's communicative abilities and who will closely monitor your child throughout all developmental stages.
- **OTOLARYNGOLOGIST (EAR-NOSE-THROAT SPECIALIST)**-a physician who will assist in the evaluation and management of ear infections and hearing loss that may be side effects of your child's cleft abnormality.
- **AUDIOLOGIST (HEARING SPECIALIST)**-a professional who will assist in the evaluation and

management of any hearing difficulties your child may have.

- **OPHTHALMOLOGIST**-a physician who specializes in the structures, functionality, and diseases of the eye. An ophthalmologist evaluates and plans treatment of associated eye problems in coordination with other surgical interventions.
- **GENETIC COUNSELOR**-a professional who reviews the medical and family history, as well as examines your child to help in diagnosis. A genetic counsellor also counsels your family regarding risk for recurrence of craniofacial abnormalities in future pregnancies.
- **NURSE TEAM COORDINATOR**-a registered nurse who combines experience in paediatric nursing with specialization in the care of your child and acts as liaison between your family and the craniofacial team.
- **SOCIAL WORKER**-a professional who provides guidance and counselling for your child and your family in dealing with the social and emotional aspects of a craniofacial abnormality and assists your family with community resources and referrals (i. e., support groups).
- **PSYCHIATRIST**-a physician who assesses the psychosocial function and behavioural development of your child. The psychiatrist will assist the family in identifying therapy resources and coordinates referrals with the social services department.

4.1 Diagnosis and Treatment

Diagnosis of a craniofacial anomaly usually begins with a physical examination, as most of these conditions have distinct characteristics. Diagnosis may be based on skull measurements, physical exams, and family history. CT scans and/or X-ray imaging are usually not necessary, but they may be used to confirm a diagnosis. An infant or child with a craniofacial anomaly should be assessed by an expert craniofacial team which may draw on the expertise of several specialists, including a paediatric neurosurgeon, a craniofacial plastic surgeon, a paediatric dentist or an ENT, or other experts. These experts will determine whether treatment is necessary and whether they will recommend the best treatment plan. Some craniofacial anomalies resolve on their own with no treatment, others can be treated with non-surgical or minimally invasive procedures. Surgery is sometimes the only effective form of correcting a serious craniofacial anomaly. The best surgeons for these conditions are specially trained paediatric neurosurgeons with advanced skills and experience in craniofacial problems, working with an interdisciplinary team of other paediatric specialists.

A child or child diagnosed by a paediatrician with a craniofacial anomaly may be referred to a craniofacial program or to an experienced neurosurgeon with expertise in paediatric neurosurgery and craniofacial abnormality. The neurosurgeon, sometimes in consultation with a plastic surgeon or a reconstructive surgeon, will conduct an assessment and make recommendations on a course of treatment specifically tailored to each patient.

Figure 4: Diagnosis and Treatment

5. Craniofacial Anomalies in Different Stages of Life

5.1 Craniofacial Anomalies in Early Childhood

Darwin considered "experiments of nature a crucial method for clarifying human emotional expressions ' evolutionary origins. Children with craniofacial abnormalities are of particular concern because morphological malformations or associated facial defects or disabilities may make it more difficult to understand and interpret their messages correctly.

Children with craniofacial anomalies are at higher risk of developing issues with mental, cognitive, and social skills. Some children with oral clefts have decreased social competence, as shown by fewer friends and poor social interactions. Slifer et al. observed that 30% to 50% of children between the ages of 6 and 16 with cleft lip and/or palate were rated by their parents as 1.0 or more standard deviations below the average compared to noncleft peers on social adaptation and skill tests (sharing their mates in social activities, degree, and performance of social interaction). Unfortunately, this trend continued throughout adolescence and adulthood

Food and swallowing problems due to divisions and craniofacial anomalies are severely affected. The magnitude of cleating as well as other organizational, airway and neurological problems lead to the prospective problems with verbal eating techniques and airway security during eating. Oral motor dysfunction, coupled with a secondary to anatomical or physiological disturbance in the upper airway, could trigger severe breathing and swallowing disturbance to the needed alignment. Problems need to be identified quickly to tackle dietary and/or cardiovascular hazards.

Common Concerns for Children with Craniofacial Anomalies:

- Feeding: New-borns with clefts and other craniofacial anomalies frequently have difficulty with breastfeeding and standard bottle feeding.
- Hearing: Children born with craniofacial anomalies such as cleft palate has a much higher risk of hearing loss, in part due to inadequate Eustacian tube function. Many children with cleft and craniofacial conditions require tubes for drainage of the ear.
- Speech: Function of the palate is key to successful speech production. Children with cleft palate require palatal

surgery to correct the cleft and careful speech monitoring and sometimes therapy to achieve correct speech quality.

- Dental: Children with complete clefts, hemifacial microsomia and other jaw abnormalities frequently have dental problems which require expansion, orthodontic alignment (braces), and surgery to correct. Infants with excessively wide clefts may require early alignment of the gum lines before initial cleft lip repair.
- Genetics: Craniofacial anomalies are sometimes associated with known genetic (DNA) abnormalities. All new-borns, infants and children are clinically screened for the possibility of a genetic link. If certain patterns of facial features are noted, the individual may undergo blood test to determine if a genetic pattern is associated.
- Emotional Well-Being: Children with craniofacial differences frequently have concerns over appearance, scars, and social acceptance.

Figure 5: Craniofacial Anomalies in Early Childhood

5.2 Craniofacial Anomalies in Adolescents

Children with congenital craniofacial anomalies (CFAs) may find the developmental tasks of adolescence particularly challenging. At a time when adolescents and their peers are highly valued for self-esteem, social acceptance, and dating physical attractiveness (Hatfield and Sprecher, 1986; Harter, 1999), adolescents with CFAs may experience mild to profound differences in facial appearance.

During puberty, such differences from the standard facial structure the increase, as many teenagers may have outgrown earlier reconstructive surgery and are waiting for their final corrective surgery at the end of the teenage growth spurt (Munro, 1995).

Although the pressure to adapt intensifies and teenagers to CFAs cannot conceal their distinctions, they can create negative perceptions of themselves and separate themselves from peers. Typical teenage peers may themselves reject others who do not reach their beauty expectations, and the formation of partnerships may be particularly difficult (Reis and Hodgins 1995). The transfer to high school could pose additional challenges, with higher academic standards, a larger group of new peers and less opportunities to build positive relationships with teachers

Continuous medical care requirements can exclude teenagers with CFAs from normal peer-group activities and accentuate their disparities more (La Greca, 1990). Typical growth of May independence may be impaired when teenagers with CFAs do not have a suitable peer interaction and therefore continue to rely on their parents for companionship and affection as developmental activities are not completed, the risk of depression rises (Masten and Coatsworth, 1998). To date, no study has explored whether teenagers with CFAs are at increased risk of issues with psychosocial transition

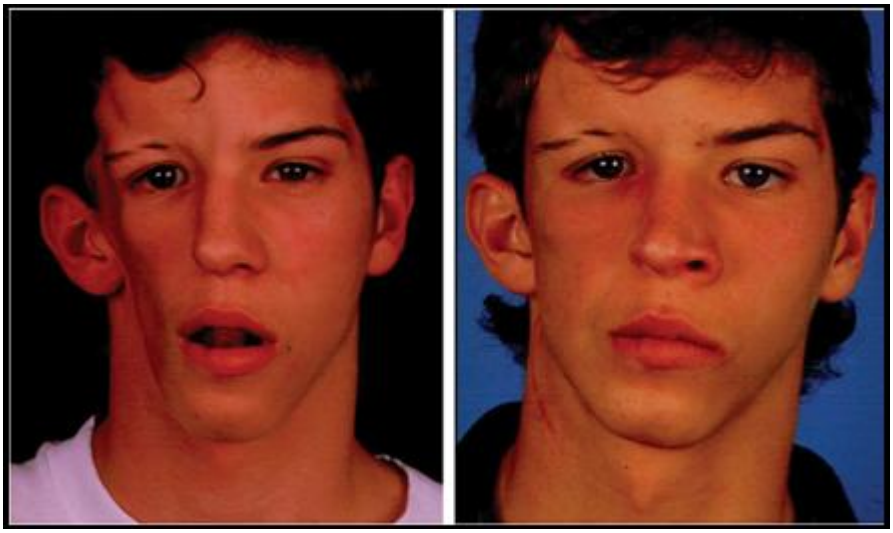

Figure 6: Craniofacial Anomalies in Adolescents

Case Study
Adolescents with Craniofacial Anomalies: Psychosocial Adjustment as a Function of Self-Concept
Dr. Monica J. Bilboul, Ph. D., Dr. Alice W. Pope, Ph. D., Dr. Heather T. Snyder, Ph. D.
First Published July 1, 2006, Research Article
https: //doi. org/10.1597/05-084.1

Abstract

Objective
To evaluate associations between self-concept and psychosocial adjustment among adolescents with craniofacial anomalies.

Design
Retrospective chart review.

Setting
Reconstructive plastic surgery department in urban medical centre.

Participants
Forty-nine adolescents with congenital craniofacial anomalies, aged 14 to 18 years, and their parents.

Main Outcome Measures
Psychosocial adjustment (internalizing problems and social competence), assessed by self-report and parent-report forms of the Child Behaviour Checklist; appearance self-concept and global self-worth, assessed by the Self-Perception Profile for Adolescents.

Results
Both appearance self-concept and global self-worth are correlated with psychosocial improvement; nevertheless, when the consequences of appearance self-concept were monitored, global self-worth stayed associated with change, whereas appearance self-concept was no longer associated with adjustment once global self-worth was regulated. The correlations between self-concept and transition are generally not moderated by demographic variables (ethnicity, socioeconomic status, and teenage gender).

Conclusions
Adolescent dissatisfaction with appearance is linked to psychosocial adjustment problems only when it is part of a negative overall view of the self.

6. Perception Towards Craniofacial Anomalies

6.1 Psychological Perception

The spectrum of craniofacial anomalies is very diverse, and the most common conditions include (but not limited to) cleft lip and/or palate, craniosynostosis (which may be associated with Crouzon Syndrome or Apart Syndrome), otomandibular anomalies (Treacher Collins Syndrome), CHARGE, holoprosencephaly, Stickler Syndrome, and foetal alcohol syndrome. Clinical features include a spectrum of craniofacial deformities, including cranium and cranial sutures, and skull and facial bone deformities, including maxillary, mandible, zygomatic arches, nose, eyes, ears, lips, and teeth.

Patients of abnormal facial appearance are often discriminated against by society. Throughout, people with unusual facial features are deemed less desirable and are often considered less educated, less intellectual, and less trustworthy. The facial appearance influences personal life, employability, and social interaction. Some work has shown that such disfiguring disorders can lead to different psychosocial issues, such as elevated levels of social depression and social isolation, and reduced quality of life.

Figure 8: Psychological Perception

CASE STUDY
Psychosocial Functioning in Adults with Congenital Craniofacial Conditions
Dr. R. M. Roberts Ph. D., Dr. J. L. Mathias, Ph. D.
First Published May 1, 2012

Abstract

Objective
To examine the psychosocial functioning of adults with congenital craniofacial conditions relative to normative data.

Design
Single sample cross-sectional design.

Setting
The Australian Craniofacial Unit, Women's and Children's Hospital, Adelaide, which is one of the main craniofacial treatment centres in Australia.

Participants
Adults (*N* = 93) with congenital craniofacial conditions (excluding cleft lip/palate) who were treated in the Australian Craniofacial Unit.

Main Outcome Measures
All participants completed self-report scales assessing health-related quality of life (SF-36); life satisfaction, anxiety, and depression (HADS); self-esteem (Rosenberg); appearance-related concerns; perceived social support; and social anxiety.

Results
Overall, participants were very similar in psychosocial function to the general population. However, adults with craniofacial conditions were less likely to be married and have children (females), were more likely to be receiving a disability pension, and reported more appearance-related concerns and less social support from friends. They also reported more limitations in both their social activities, due to physical or emotional problems, and usual role activities, because of emotional problems, as well as poorer mental health.

Conclusions
These results give cause to be very positive about the long-term outcomes of children who are undergoing treatment for craniofacial conditions, while also identifying specific areas that interventions could target.

6.2 Social Perception

An imperfect presence can open the door for bullying, abuse, or unwelcome questioning.

Social perceptions can also take the form of more subtle changes to regular verbal and nonverbal communication behaviours, such as facial expression (Bull, 1990). Such adverse social reactions stem from prejudice, where a person is subconsciously viewed negatively by strangers because of their imperfect appearance. Unfavourable social reactions can be viewed as a form of social unacceptability that can undermine individual self-esteem (Bernstein, 1976; Lefebvre and Munro, 1978; Macgregor, 1982; Bull and Rumsey, 1988; Bull, 1990).

Social rejection by outsiders is predicted and observed by people with CLP (Lefebvre and Munro, 1978; Rumsey and Bull, 1986). Fearful anticipation of these antisocial reactions in any disfigured individual will have an impact on how they function socially. These fears may lead to problems with psychosocial adjustment (Shaw, 1981, 1986) because unfavourable responses are recalled at the next encounter.

Figure 8: Social Perception

6.3 Developmental Perception

It is worth expatiating a life-cycle plan to kids with CLP to understand the origin and nature of psychosocial issues. Parents (especially mothers) are recorded to experience a sequence of emotional reactions, beginning with shock, rage, pain, doubt, anxiety, shame, scepticism, ambivalence, despair, and depression (Beaumont, 2006). For example, not all parents adapt and step forward with the same intensity or sequence of emotional reactions until they are reluctant to accept them (Black, Girotto, Chapman, & Oppenheimer, 2009).

All internalize and outsource inward-directed emotional reactions (blame or doubt on others) and/or outward (guilt, self-doubt, anxiety, or depression) are reported in parents that appear to influence even their interactions with these infants and children (Hohlfeld, 2011; Murray et al.2008; El-Sheikh, 2005; Hall, 2003). The first bonding and attachment

in the mother-infant dyad happens by reciprocal social smile in the baby by around three months. Typical infants smile at normal or regular faces but withdraw such reactions to grotesque or disfigured faces (Kagen et al.1966). When bizarre faces were shown to typical children at nine months age, it was seen that they reacted with anxiety (Richardson, 1969). Developmental psychology attests that children's drawings are first about the human face followed by sketching of the hands or legs (Goodenough, 1926). Nursery children are shown to discriminate between 'attractive' and 'unattractive' faces as shown by the 4-year-old test item on Indian Scales of Intelligence (Venkatesan, 2002). Unattractive children are categorized as violent or antisocial, whereas physically attractive children are rated as wiser by adults (Goffman, 1963). It has been shown that causal attributions created by baby parents with CLP affect childcare activities, albeit briefly (Stock & Rumsey, 2015; Dabit et al., 2014; Grollemund et al., 2010; Nelson, O'Leary, & Weinman, 2009). Attachment is a mechanism that is equal. The relation between the perceiver and the observed is likely to be affected (White, Eiserman, Meddoe & Vanderberg, 2005; Coy, Spertz & Jones, 2005).

6.4 Self & Other Perception

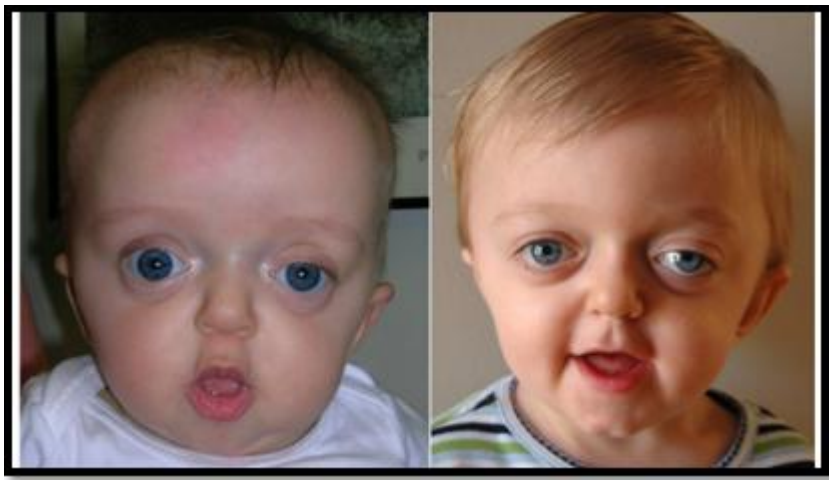

Figure 9: Developmental Perception

Charles Horton Cooley in 1902 (McIntyre, 2006) stated that the self of an individual grows out of society's interpersonal reactions and the perception of others (Shaffer, 2005). People shape their self-concepts based on their understanding of how others perceive them. Hence, the term used is 'looking glass self'. The looking-glass self begins at an early age and continues throughout the person's life since one will never stop modifying their self unless all social interactions are ceased. In the context of persons with CLP, wherein the society reflects negative images, depressing feedbacks, damaging facial stigmata, flawed stereotypes, unhelpful prejudices, and/or such other faulty judgments, the victim is likely to get into the vicious cycle of hopelessness and pessimism. The whole process is reciprocal. Impressions are made by attributing positive personality characteristics to people with good looks and negative qualities to persons with deformities and disfigurements (Kwart, Foulsham & Kingstone, 2012; Springer et al.2012). The problem with stereotypes is that it will implicitly or explicitly influence the self and other perceptions of both, the affected as well as people around them. Naming or labelling itself has the unique power to influence a person. Many times, such implicitly conveyed expectations from others will itself prompt the person to behave in a manner that fulfilsother expectations! When a mother keeps telling in front of her child that s/he is a fussy eater; indeed, the child turns out to be one. This phenomenon is called 'self-fulfilling prophecy'. Also called 'Pygmalion Effect' or 'Rosenthal Effect', if a teacher expects enhanced performance from her pupils, then the student's performance will be enhanced. The reverse is also true. It is a kind of observer expectancy effect that works in many persons with CLP. 'When people say you are dumb, you feel dumb'. This aphorism is best exemplified in the lives or circumstances of children with CLP. When a child is repeatedly told that she cannot do it, or that she needs help, or even that she better not tries all by herself, the child will then never give a try. It cripples their willingness to act and results in what is termed as 'spoiled identity' (Berger & Dalton, 2011; Marlene & Gregory, 2003)

7. Parent Coping and Parent-Child Relationships

In the scenario for parents, having a child with craniofacial anomalies raises anxieties about the cause of the condition concern about the reactions of peers and others to their child, for instance, if the child will be teased and questions about the developmental implications of the disorder. parents' concerns evolve over time. Initial worries focus on the pragmatics of feeding, timing of lip repair surgery, and possible embarrassment upon introducing the new-born child to others. Parents must cope with the stress of having a child with a facial anomaly, which may lead to feelings of guilt, anxiety, anger, and depression (Canam, 1987; Black et al., 2009; Chuacharoen et al., 2009). In fact, research indicates that often parents of children with chronic conditions like CLP experience five stages of reactions: shock, denial, sadness and anger, adaptation, and reorganization (Drotar et al., 1975). Beyond coping with the reality of having a child who is not "normal, " parents must also endure the added care associated with CLP and other chronic conditions, which is reportedly associated with parental stress (Pope and Speltz, 1997; Hentinen and

Kyngas, 1998; Meleski, 2002; Pelchat et al., 2007). Parents must devote significant time and energy organizing daily life activities as well as providing special care that includes attending frequent appointments with various medical specialists and finding and negotiating services (Pelchat et al., 2007), all of which are thought to elevate stress levels. Indeed, the care for an individual with CLP is substantial because ongoing evaluations and treatment, including hospitalizations, begin during infancy and extend over a long period of time, often into young adulthood (Snowden et al., 2003). The impact of having a child with cleft not only affects the parents but the entire family unit, and the existence of a chronic condition, such as cleft, has the potential to profoundly disrupt the family system (Hentinen and Kyngas, 1998). In fact, one study found that divorce rates are higher in families having children with craniofacial anomalies compared with a control group (St. John et al., 2003). Other evidence, however, suggests that families of children with chronic conditions fare the same (Herzer et al., 2010) if not better than (Rodrigues and Patterson, 2007) their healthy counterparts. Nevertheless, it is clear that caring for a child with a chronic condition can have a significant impact on family structure and functioning (Locker et al., 2002; St. John et al., 2003). This effect may be influenced by the type of cleft (Kramer et al., 2007); familial characteristics such as age of the child, number of children, family income (Herzer et al., 2010), and social support; contextual factors such as family values; and cultural issues such as their worldview (Patterson, 2002).

Family and parental adjustment to the stress associated with having a child with cleft often depends on various psychosocial factors such as social support and coping, the latter of which refers to behavioural and mental efforts to handle a stressful situation (Ben-Zur, 2009). Research suggests that coping modes are related to caregivers' (CGs') affect: problem-focused coping (i. e., coping intended to address the problem) is associated with positive affect while avoidance coping (i. e., coping intended to ignore or avoid the problem) is associated with negative affect (Ben-Zur, 2009). The paediatric chronic condition literature has examined the effect of these coping strategies on various outcomes. For example, a recent study used a resilience model and suggested that parents of children with cleft who used problem-focused coping and had high levels of social support reported less family impact and more positive adjustment to their child's condition than those who used avoidance-oriented coping strategies and had lower levels of social support (Baker et al., 2009). Indeed, how families and parents cope with their child's condition impacts their stress level (Pope et al., 2005).

In addition to family impact and parental stress, the paediatric cleft literature has also explored the effect of cleft on parent-child interactions and bonding. Some evidence suggests that having a child with a cleft may have a detrimental effect on parent-child interactions. For example, compared with controls, Murray et al. (2008) found that mothers of children with a cleft had less maternal sensitivity toward their children at 2 months of age; additionally, mothers whose children had late surgical repairs were less positively involved and looked at their children less than controls did. Yet other research indicates that "children with clefts and their mothers are doing as well as families without cleft with regard to emotional development and mother-child relationships" (Habersaat et al., 2013, p.711).

Figure 10: Parent and Child Coping Relationship

8. Down Syndrome & Craniofacial Abnormalities

Down's syndrome is a genetic disorder arising from a chromosomal abnormality attributed to trisomy of chromosome 21 in whole or in large part. It is the most known congenital, autosomal disorder associated with physical and mental development that has been disrupted. Down's syndrome patients have numerous characteristic physical findings (Desai, 1997). Craniofacial presentations are among the most common results. Aberrations have been reported in both craniofacial systems (Regezi and Sciubba, 1999, Shafer et al., 1983). Facial indications identified in Down's Syndrome involve distorted nasal bridge, slanting eyes with epicanthic folds, ocular hypotelorism, and strabismus. Oral aberrations include inept eyes, macroglossia, fissured tongue and broad high arched palate (Desai, 1997, Gorlin et al., 2001, Regezi and Sciubba, 1999). Craniofacial radiographic observations of Down's syndrome include brachycephaly, calvaria thinning, incomplete ossification along the sutures, impaired suture closing, missing and poorly developed air sinuses, reduced infraorbitalsinuses. These classically described features vary significantly between individuals despite the widely recognized typical characteristics of Down's syndrome (Levinson et al., 1955). Even though people with Down syndrome might act and look similar, each person has different abilities. People with Down syndrome usually have an IQ (a measure of intelligence) in the mildly-to-moderately low range and are slower to speak than other children.

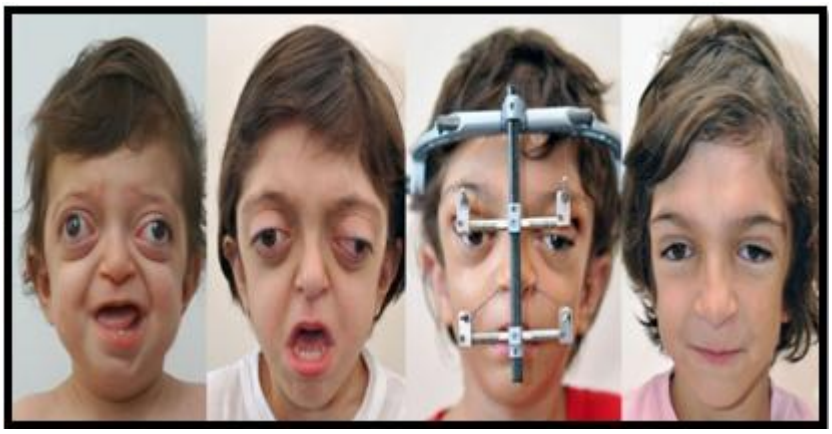

Figure 11: Down Syndrome and CFA

Some common physical features of Down syndrome include:

- A flattened face, especially the bridge of the nose
- Almond-shaped eyes that slant up
- A short neck
- Small ears
- A tongue that tends to stick out of the mouth
- Tiny white spots on the iris (coloured part) of the eye
- Small hands and feet
- A single line across the palm of the hand (palmar crease)
- Small pinkie fingers that sometimes curve toward the thumb
- Poor muscle tone or loose joints
- Shorter in height as children and adults.

9. Social Stigma

As such, shame and social discrimination are associated with cleft and CF. There are also gaps between urban and rural areas and between rich and poor in terms of access to and quality of care. Most of these children and adults come from poor backgrounds and can hardly manage a cleft operation. Many of them are still ignorant of the risk of cleft being handled. It is claimed that there is a backlog of one million cases in India and that the systems in place are not adequate. Nevertheless, questions about the well-being of children born with a cleft lip and/or palate have prompted studies in different fields (Hunt et al., 2006).

The incidence of behavioural and social problems in infants and children born with clefts suggests that these children are at risk for social-interactive difficulties (Collett and Speltz, 2006), as well as for difficulties with communication and cognitive competencies (Field and Vega-lahr, 1984).

Prejudice control is an important aspect for people living with visible genetic differences to achieve positive self-esteem. Individuals with craniofacial differences face social prejudice and discrimination at a particularly high rate. Social bias targets (such as those with craniofacial conditions) are often at risk of experiencing social and psychological stress, which may have a negative impact on their quality of life. Individuals with apparent facial variations therefore need to recognize and incorporate successful emotional well-being coping strategies.

The level of social stigma alone does not disclose the impact on human well-being. According to Crocker and Major [1989], the impact of social stigmatization on self-esteem is said to be a major indicator of emotional well-being and mental health; yet "despite strong empirical support for such inference, empiric proof that leaders of stigmatized communities have less self-esteem than non-stigmatized people is strikingly sparse" [Crocker and Major, 1989;]

Figure 12: Social Stigma

9.1 Common Myths-Misconceptions-Stigma-Stereotypes Superstitions

Surgery to repair CLP is usually carried out within first two years life, or at least, before the child starts school. More surgery is often carried out when the child is about nine years old, during teenage years and sometimes also later. Therefore, many of these children are likely to have a visible scar. Some of them may have an irregular nose and teeth, and therefore, wear braces before their peers. Some children with CLP are likely to feel self-conscious about looking different. This may affect their class participation and leave them sensitive to comments from others. The lower expectations of others about these children may in turn affect their own self-evaluation about themselves (Hunt et al., 2006; 2007).

Among the common myths, misconceptions, prejudice, superstition, stereotypes, flawed opinion, and attitude (Mednick et al., 2013; Naram et al., 2013; Shaw, 2010; Langlois et al.2000) for or against persons with CLP are:

- The birth of such persons is possibly the consequence of a curse or blessing received for their own deeds in a previous birth.
- They are to be deemed as 'different' from their unaffected peers, or that they belong to a 'lesser' or 'unfortunate' category.
- If a few such individuals succeed in their lives, they must be regarded as 'superhuman' to have overcome several odds in their personal lives.
- The unaffected persons must maintain a discrete silence, avoid talking, commenting, discussing on or about the so-called personal calamity being suffered by the affected individual.
- Civility and good manners demand that the problems or issues related to CLP are better left to the individuals themselves to address or resolve than to make it public.
- Wherever possible, the unaffected persons must consider themselves fortunate, and therefore, must be under a continual obligation to help persons affected with CLP.
- Such affected children may be viewed as 'holy innocents endowed with special grace and are meant to inspire others to value life'.
- Children with CLP have low intelligence and learning difficulties.
- Persons with CLP, including such children, are frequently depressed, high strung, anxious, and/or have temperamental difficulties or personality problems.
- If a pregnant woman is frightened by devil, handles sharp objects during an eclipse, eats rabbit meat and/or prays Lord Hanuman, her infant could be born with cleft.
- Fasting, self-purification ceremonies, charity, community service, tying of blessed amulets or talismans can prevent the birth of the next child with CLP if she already has delivered one.
- Seeing the face of a person with CLP spells bad luck or disaster; Studies indicate that children or adults with CLP are in no way less or more in intelligence owing to their primary condition. It is possible that some such children missed opportunities for early speech-language stimulation, suffered social discrimination and/or minimal exclusion by peers (Priester & Goorhuis-Brower, 2008). Therefore, it appears that by end of two years, there is a measured developmental delay seen in such children compared to their unaffected peers (Kapp-Simon & Krueckeburg, 2000). Each child with CLP must be seen as an individual and such issues must be considered sensitively. It is often assumed that their levels of distress are directly linked to the degree of disfigurement.

10. Craniofacial Surgery

Craniofacial surgery is a surgical subspecialty that deals with congenital and acquired deformations of the head, skull, face, neck, jaws, and associated structures. Even though craniofacial treatment sometimes even encompasses bone manipulation, craniofacial surgery is not specific to tissue; craniofacial surgeons deal with bone, skin, nerve, muscle, teeth, as well as other related physiology.

Craniofacial surgeon typically treated defects include craniosynostosis (isolated and syndromic), rare craniofacial clefts, acute and chronic sequellae of facial fractures, cleft lip, and palate, micrognathia, Treacher Collins syndrome, Apert's syndrome, Crouzon's syndrome, craniofacial microsomia, microtia and other congenital ear anomalies, among many others.

Craniofacial surgery training includes a Craniofacial surgery residency to be done. These fellowships are accessible for people living in oral or maxillofacial surgery, cosmetic or reconstructive surgery, and ENT surgery. Those who have undergone oral or maxillofacial surgery internship may be either single or dual-degree surgeons with no variations. For craniofacial surgery, there is no table.

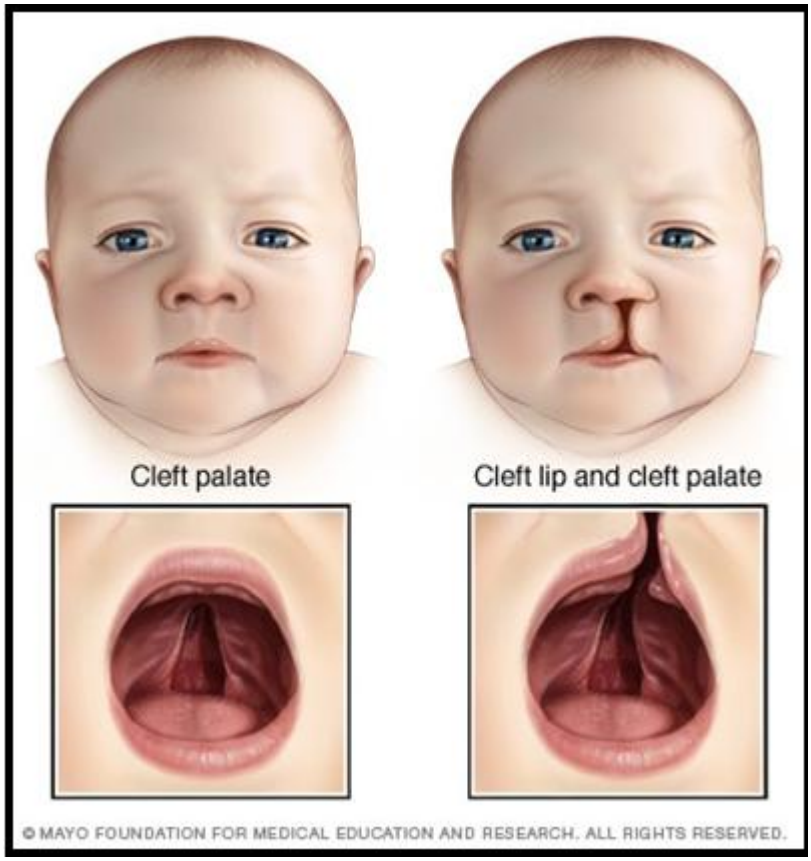

Figure 13: Craniofacial Surgery

10.1 Recent Advancements in India

Dedicated surgeons have made impressive progress in establishing craniofacial surgery services in India, reports a special feature in the September the Journal of Craniofacial Surgery. The journal, edited by Mutaz B. Habal, MD, is published by Lippincott Williams & Wilkins, a part of Wolters Kluwer Health.

But they still face daunting challenges in meeting the demand for surgery in patients with craniofacial deformities, cleft palate, and head and neck tumours. "Our special issue presents frontline reports from surgeons striving to make craniofacial surgery more widely available in India, " comments Editor-in-Chief Mutaz B. Habal, MD.

The special section includes contributions from surgeons engaged in building craniofacial surgery services and training programs across India. Dr. Ramesh K. Sharma shares his experience in establishing a craniofacial surgery department at the Post Graduate Institute of Medical Education and Research in Chandigarh.

Since opening in 1995, the service has performed about 1, 000 major craniofacial procedures, including surgery for infants with congenital skull and facial deformities, cancer resections, and reconstructive surgery in trauma patients. But with a population of 100 million spread across five states, the service can't keep up with the demand. Dr. Sharma makes recommendations for extending craniofacial surgery capabilities at other Indian teaching hospitals.

Dr. Vaibhav Khanna of Vivekananda Polyclinic & Institute of Medical Sciences and Dr. Divya Narain Upadhyaya of King George Medical University, Lucknow, discuss the future of craniofacial surgery in India. They emphasize the need to develop Indian training programs, presenting two alternative models: Dr. Khanna's charity hospital and Dr. Upadhyaya's government-supported university hospital.

Both units provide access to cleft palate and craniofacial surgery to largely impoverished populations, as well as training opportunities for the next generation of surgeons. While intensive effort and increased funding will be essential, the authors conclude, "Craniofacial services and training are now being made available to this part of the developing world. "

Dr. Hemen Jaju of The Gujarat Cancer and Research Institute, Ahmedabad, presents his experience with another category of complex, highly technical procedures: surgery for tumours of the skull base. At least 3, 500 skulls base tumours occur in India each year--typically diagnosed at an advanced stage.

The Gujarat unit, along with a handful of others, strives to provide a chance of long-term survival for patients with tumours that would otherwise be untreatable. Dr. Jaju's recommendations for raising the level of skull base surgery in India include creating a national database and consolidated centres of excellence.

Surgeon-in-training Cameron C. Y. Lee and colleagues highlights the experience at Operation Smile's Cleft Comprehensive Care Clinic in Guwahati. The clinic is

shifting from a "mission-based" approach--focusing on cleft palate repair procedures performed by visiting surgeons--to a more comprehensive, developmental approach.

To meet the standard of care in more-developed countries entails long-term follow-up from multiple specialists, including nose and throat surgery, speech pathology, and particularly dentistry. The authors highlight the importance of "cultivating host country independence"--establishing a permanent staff of specialists to provide ongoing care after cleft palate surgery.

"These articles highlight the efforts of dedicated professionals seeking to extend the availability and quality of craniofacial surgery services to the world's second most populous country, " Dr. Habal adds. "Their efforts reflect our specialty's commitment not only to develop increasingly refined and advanced surgical techniques, but also to increasing access to needed care for people all over the world. "

11. Craniofacial Anomalies Treatment in India

Plastic and reconstructive surgery is not just about corrective skin and tissue-related deformities. One of its latest branches, craniofacial surgery, has gone to the level of re-contouring and re-construction of skull, face, and jaws. But dealing with congenital and acquired deformities of skull is much more complicated and difficult than liposuction, removing wrinkles, earlobe re-construction and for that matter breast enhancement and penile reconstruction. In fact, craniofacial treatment involves equal participation of neurosurgery and plastic surgery apart from dental surgery and expert post-operative care. A craniofacial surgeon deal with bone, skin, muscle, and teeth, etc. The best part is that Lucknow is the only place in north India after PGI Chandigarh and Delhi to have expertise and facilities for craniofacial surgery. Today, the city is not only catering to domestic needs of the state and the country but now patients are also coming from neighbouring countries, providing an opportunity to the state government to develop and market it for medical tourism. Craniofacial surgery deals with abnormal shape of the head, shortening of the lower jawbone, depressed cheek bones, deformities of the forehead, increased distance between the eyes leading to a grotesque appearance of the face and facial asymmetry among other things. The problem can be both since birth and accidents. Another cause of deformity could be tumours and infections leading to necrosis of skin or bone. On an average 10-15 patients having craniofacial problem report per week in the department of plastic surgery, Chhatrapati Shahuji Maharaj Medical University (CSMMU), only place with expertise in government sector. "We have experts but are not able to work at the optimum level because of limited facilities, particularly post-operative intensive care, which is the most important aspect of the entire surgery, " said Prof AK Singh, head of the plastic surgery department, CSMMU. Rajiv Agarwal, associate professor and former fellow of the International Craniofacial Institute, USA, stressed on developing craniofacial surgery training centres in India keeping in mind the requirement of the country. "Training centres in developed countries have strict eligibility criteria making it out of bound for the average surgeon, " he said. Prof Singh said that a little help from government can make CSMMU a centre of excellence in the field and to promote it for medical tourism. Craniofacial surgery is of 10-12 hours and needs multi-speciality approach, he said. "It also requires counselling of the patient who has to be psychologically prepared for the surgery, " said Dr Agarwal who has dealt with number of cases. "The impact of surgery is both physical and psychological. It provides a person a presentable look and appearance, thus infusing confidence and self-esteem, an important factor to lead a normal andsuccessful life in the society, " he added. Private sector in Lucknow does not have the problem of facilities for post-operative care. "We are second to none, " said Dr Vaibhav Khanna, who led a team of doctors which successfully dealt with a challenging case of mandibular and cheek reconstruction recently on a patient, Sediqa Yassin Anwari, who had come from Kabul, Afghanistan. The patient was operated a year ago in Delhi, but results were unsatisfactory, hence she came to Lucknow. The surgery here was done in a private hospital by a team comprising surgeons Dr Ramesh Kohli and Dr Surajeet Bhattacharya and anaesthetist's Dr Priya Motwani and Dr Aadesh Srivastava. COST As craniofacial surgery is sophisticated and complicated besides it requires joint expertise of super-specialists like craniofacial surgeon, neurosurgeon, neuroanaesthetist, paediatrician and intensive care, the cost is usually high in the private sector. On an average, the cost in a private set-up may easily be in the range of Rs 2-4 lakh. But, in CSMMU, the same can be accomplished in less amount because one doesn't have to pay to surgeons. Hence, the cost is generally Rs 15, 000-20, 000. It excludes cost of implants or devices that may be required in the surgery. The cost of implants/devices depends on the quality.

Training in craniofacial surgery usually consists of a year-long fellowship after a residency in plastic surgery. Besides, plastic surgeons can go for training in the speciality abroad as no centre in India has training facility for the craniofacial surgery. The CSMMU, however, can boast of having specialist in this field. The World Craniofacial Foundation (WCF) has picked up the plastic surgery department of CSMMU for training and assistance in developing the expertise. Head, plastic surgery department, Prof AK Singh is in the medical advisory WCF board and department has faculty members who have been trained abroad

11.1NGOs In India

Mission Smile: Mission Smile **(formerly known as Operation Smile India)** is a Govt. registered and FCRA approved Medical Charitable Trust dedicated to providing free life changing cleft care and surgery for children and adults born with cleft lip, cleft palate, and other facial deformities.

Operation Smile: Operation Smile also called as Operation MUSKAAN is an initiative of the Ministry of Home Affairs (MHA) to rescue/rehabilitate missing children. It is a dedicated campaign for a month where several activities are taken up by the State Police personnel to trace and rescue the missing children and reunite them with their families.

The "Operation MUSKAAN-III" was taken up during July 2017 throughout the country as a follow up of the earlier campaigns to rescue/rehabilitate the missing children.

Activities taken up as part of operation smile

- All children residing in shelter homes, platforms, bus stands, roads, religious places, etc. are to be screened by trained police personnel.
- Before the operation, the Police personnel from each State are properly trained in methodology to extract information from such children tactfully without they are getting intimidated, as well as in various provisions of Protection of Children from Sexual Offences (POCSO) Act, Juvenile Justice (Care and Protection of Children) JJ Act, Protection of Child Right Act, relevant sections of Cr. PC& IPC and Advisories issued by MHA etc.
- To know the magnitude of the problem, data with full details of number of cases of missing children will be maintained and shared at intra-State and Inter-state level. Information about Child Welfare Committees (CWCs) would be prepared and shared among all rescue teams and stakeholders.
- During the operation, the particulars of such identified children will be uploaded on the 'Missing child' portal of the Ministry of Women and Child Development by the respective State Police.
- Rehabilitation measures whenever needed are to be taken up in coordination with the other line Departments like Department of Women & Child Development, Police, Labour, etc so that scope of re-victimization is eliminated.
- Public awareness to be increased by way of national campaign, advertisement on national media, etc.

11.2 Policies Covering Cleft Care in India

The Government of India has the Rights of Persons with Disabilities Act 2016 which classifies physical disabilities of various parts of the body, but unfortunately cleft lip and palate is not considered a disability. If somebody has a cleft, they may not be able to speak normally, eat; thus, a sufficient reason to be included under the Act if we define 'Disability' in true sense.

The Rastriya Bal Swasthya Karyakram (RBSK) is a new initiative aimed at screening over 27 crore children from 0 to 18 years for 4 Ds-Defects at birth, Diseases, Deficiencies and Development Delays including disabilities. Children diagnosed with illnesses shall receive follow up including surgeries at tertiary level, free-of-cost under the National Health Mission that includes cleft lip and palate.

As per the information received under the RTI from the Union Ministry of Health and Family Welfare, the scheme is being implemented with a total number of 11, 420 RBSK mobile health teams across the country and a total of 24, 547 children with cleft lip and palate are identified only in the financial year 2016-17. But this is just the beginning. The figure of cleft children further calls for a triggered effort to prioritize the issue, identifying scope at both the Government as well as non-profit institutions to bridge the gap that exists between supply and demand and help people with cleft lead a second chance in their lives.

12. Management

Management of children with cleft lip and palate should go through a multidisciplinary team who will provide the optimal treatment (Bill, 2006). The managing team should provide comprehensive diagnosis, planning, and treatment. The cleft team usually includes orthodontist, maxillofacial surgeon, plastic surgeon, prosthodontist, speech therapist, audiologist (ENT specialist), psychologist, and paediatrician. Goals of treatment of the child with a cleft lip and palate should include the repairing the birth defect (lip, palate, and nose), achieving normal speech, language, hearing, functional occlusion, and good dental health. It should also optimize the psychosocial and developmental outcomes. However, protocols for the management of CLP patients vary from centre to centre. According to the Eurocleft project between 1996 and 2000, there were 194 different surgical approaches followed for treatment of unilateral cleft alone. Management is dome according to specific time periods. Ultrasound examination may detect clefts of the lip and alveolus unlike cleft palate, which is difficult to diagnose through routine screening. Additional examinations and tests can confirm the presence of deformity. These include cephalic presentation of the child, low body mass index of the mother, and examination preferably around the 20th gestational week. Moreover, information about family history should be addressed so that provisions for postnatal measures in adequately equipped hospitals can be made in with improvement in ultrasound technology.

In case of cleft identification, genetic counselling the family including amniocentesis should be performed. For this purpose, a complete pregnancy progress and family history should be addressed. Exposure to any teratogenic factors, the presence of family members with cleft or other birth defects, developmental problems, and genetic syndromes are all important parameter to explore during counselling. In cases where clefts are diagnosed prenatally, the cleft team will be involved in the management so that the family can learn about the nature of the deformity and its care and treatment strategies. Psychological and emotional support of the family is very essential procedure at this time due to the very negative effect once the diagnosis was confirmed. The most

immediate problem caused by orofacial clefting is likely to be difficulty with feeding. The anatomical characteristics of cleft lip and palate greatly hinder infants' ability to feed. Poor intraoral suction may produce choking, emission of milk through the nose, and excessive air intake. The feeding process can also be extremely stressful for the parents of such infants who often struggle to find effective feeding method. Early referral to the infant-feeding specialist or nurses associated with cleft teams can facilitate to solve this problem. Those children need special teat and bottles that allow milk to be delivered to the back of throat where it can be swallowed. In addition, we may use special dental plates (palatal prosthesis) to seal the cleft side. Such prosthesis could be effective in increasing the volume of fluid intake, decreasing time of feeding, and promoting adequate growth and gain in infants with cleft lip and palate Some babies may not have the energy to suck from a teat, and here a cup and spoon method may be helpful.

13. Literature Review

In the study ***Hearing impairment and ear anomalies in craniofacial microsomia: a systematic review: International Journal of Oral and Maxillofacial Surgery***by **Rooijers, W., Tio, P. A. E., van der Schroeff, M. P., Padwa, B. L., Dunaway, D. J., Forrest, C. R& Caron, C. J. J. M. (2022),** the purpose of this systematic review was to assess the incidence of hearing impairment and ear abnormalities in individuals with craniofacial microsomia by reviewing the literature. There were 62 records totalling 5122 patients. Ear abnormalities were seen in 52–100% of individuals. Microtia, pre-auricular tags, and external auditory canal atresia were the most often observed external ear abnormalities. Ossicular abnormalities were the most often reported middle ear malformations, whereas oval window anomalies, cochlear anomalies, and semi-circular canal anomalies were the most reported inner ear malformations.

In the study ***Craniofacial morphology in Apert syndrome: A systematic review and meta-analysis. Scientific Reports*** by **Alam, M. K., Alfawzan, A. A., Srivastava, K. C., Shrivastava, D., Ganji, K. K., &Manay, S. M. (2022),** the goal of this study was to see if there was a link craniofacial features obstructive sleep apnea in children and adolescents. In terms of technique, the research objectives were fulfilled by searching seven databases. For this analysis, clinical trials that involved patients younger than 18 years old with or without OSA and examined skeletal, soft craniofacial, or dental arch morphology were considered. The risk of bias was considered, as well as the certainty of the evidence. When there was a lot of methodological and clinical heterogeneity, a meta-analysis was done. All of the protocols outlined by the Preferred Reported Items for Systematic Reviews guideline were followed in this study. At the end, the selection procedure, nine studies were found, five of which did not show any differences. When comparing an OSA group to an asymptomatic control group, four investigations found variations in craniofacial characteristics. Children with OSA have been found to have mandibular retrognathia, reduced antero-posterior (AP) linear dimensions of the bony nasopharynx (decreased pharyngeal diameters at the levels of the adenoids), a longer facial profile, and a shorter inter-canine breadth. A meta-analysis was conducted using research with identical methodological approaches, and no differences were found in any of the cephalometric angles studied (SNA, SNB, ANB, NSBa, U1-L1, U1-SN). As a result, even though some limitations were recognised, all of the included studies were deemed to have a low risk of bias.

In the study ***Impact of environmental chemicals on craniofacial skeletal development: Insights from investigations using zebrafish embryos. Environmental Pollution*** by **Huang, W., Wu, T., Au, W. W., & Wu, K. (2021),** gives an update on the adverse effects of environmental contaminants on craniofacial skeletal development in zebrafish embryos, including metallic elements, nanoparticles, persistent organic pollutants, pesticides, and pharmaceutical formulations. The information gathered will aid in the induction of craniofacial skeletal deformities as well as the creation of improved preventative techniques. Several research including human populations and experimental animals have revealed that genetic and environmental factors play important roles in the onset and progression of these abnormalities. Environmental factors that cause craniofacial malformations, including as teratogens and toxin combinations, are receiving more attention. The usage of the zebrafish (Danio rerio) in experimental studies has been on the rise.

In the study, ***Fetal markers for the detection of infants with craniofacial malformation. In Seminars in Fetal and Neonatal Medicine*** by **Wiechers, C., & Kagan, K. O. (2021),** discusses about how Facial clefts and Robin sequence (RS) are similar in terms of when they are diagnosed during pregnancy, their link to genetic illnesses, and how they are treated after the first diagnosis. If a facial cleft or RS is suspected, a complete physical examination of the foetus should be performed to rule out any other defects. Genetic testing, such as a microarray or an exome analysis, may also be required. This counselling should include interdisciplinary counselling, which should include prenatal and postnatal experts with sufficient experience in the management of such infants. Parents should be made aware of disease-specific therapy choices as well as postnatal outcomes. The delivery should take place in a centre that has experience with craniofacial deformities and where specialists are prepared to deal with potentially life-threatening airway blockage right after birth.

In the study, ***Dental anomalies in craniofacial microsomia: A systematic review. Orthodontics & craniofacial research*** by**Elsten, E. E., Caron, C. J., Dunaway, D. J., Padwa, B. L., Forrest, C., &Koudstaal, M. J. (2020),** indicates the purpose of this research is to give an overview of the prevalence and types of dental abnormalities in craniofacial microsomia patients. Four retrospective cohort studies, four prospective cohort studies, four case control studies, and one case series were included in the total of 13 papers. The research revealed information on dental agenesis, delayed dental development, tooth size anomalies, tooth morphology, and other dental anomalies, according to a summary of the findings.

In the study ***Craniofacial Malformations And Their Association With Brain Development: The Importance Of A Multidisciplinary Approach For Treatment,*** byOrnoy. A (2020), indicates a modest number of craniofacial deformities have been discussed in this review along with concomitant dental defects and a brief overview of craniofacial development, the paper goes on to discuss oral clefts, craniofacial microsomia, teratogens that can interfere with craniofacial development and cause various malformations, genetically determined craniosynostoses syndromes, and a few other relatively common syndromes that affect other organs in addition to the craniofacial complex. Dentists play a major role in the diagnosis and comprehensive treatment of congenital abnormalities, thus understanding them is crucial.

In the ***study Down syndrome as a cause of abnormalities in the craniofacial region: A systematic literature review. Advances in Clinical and Experimental Medicine: Official Organ Wroclaw Medical University***by **Kaczorowska, N., Kaczorowski, K., Laskowska, J., &Mikulewicz, M. (2019),** indicates the irregularities and traits present in trisomy 21, which have a significant impact on the stomatognathic system's function, are described in this article. False macroglossia, muscular hypotonia, and gothic palate are three of the most common conditions. Articulation, respiration, food intake, and swallowing are all affected by these disorders. Based on the current literature analysis, we looked at the morphological characteristics of the craniofacial region in children with DS. MEDLINE (through PubMed), Scopus, Infona, and Dentistry & Oral Sciences Source were used to conduct the research. The researchers looked at 199 pieces of literature, including 18 studies about children and adults with Down syndrome.

In the study ***Fat grafting in managing craniofacial deformities. Plastic and Reconstructive Surgery,*** by**Denadai, R., Raposo-Amaral, C. A., &Raposo-Amaral, C. E. (2019)** discusses key principles and procedures for craniofacial fat grafting, as well as a SOBRAPAR Hospital strategy for establishing craniofacial contour symmetry as soon as possible without sacrificing function. The successful correction of craniofacial contour malformations remains a key issue in plastic surgery, according to the paper. The treatment plan and surgical approach used to address bone and/or soft tissue deformities were decided by the specific diagnosis, patient age at presentation, and functional state, according to the findings of the study. In skeletally immature patients, bone restoration is reserved primarily for those with functional difficulties.

In the study***, Masses of developmental and genetic origin affecting the paediatric craniofacial skeleton. Insights into imaging*** by**Stefanelli, S., Mundada, P., Rougemont, A. L., Lenoir, V., Scolozzi, P., Merlini, L., & Becker, M. (2018),** outlines a comprehensive strategy to evaluating children with masses or mass-like lesions affecting the craniofacial bone that are of developmental or hereditary origin. The different roles of computed tomography (CT), cone beam CT (CBCT), magnetic resonance imaging (MRI) with diffusion-weighted imaging (DWI) sequences, and ultrasonography (US) in pre-therapeutic assessment, complex treatment planning, and post-therapy surveillance are discussed. The most important imaging findings and clinical symptoms are discussed.

In the study ***Genetic studies of craniofacial anomalies: clinical implications and applications. Orthodontics & craniofacial research***by **Hart, T. C., & Hart, P. S. (2009),** the goal of the study was to provide an overview of the significance of genetic research in promoting translational studies of craniofacial illnesses of dental relevance. Background material is provided to demonstrate the factors influencing genetic research investigations of Mendelian illnesses. There is a review of genetic studies on amelogenesis imperfecta, dentinogenetic imperfecta, hereditary gingival fibromatosis, and Papillon Lefèvre syndrome. The findings are provided to demonstrate how clinical and fundamental research translational applications might improve clinical treatment**.** Specific genes and mutations responsible for amelogenesis imperfecta, dentinogenetic imperfecta, hereditary gingival fibromatosis, and Papillon Lefèvre syndrome have been found via clinical and fundamental scientific research. These discoveries are allowing researchers to better understand how certain genetic changes disrupt normal dental tissue growth and development. The identification of the genetic basis of these problems is allowing clinicians and researchers to gain a better understanding of the genesis and clinical repercussions of these important dental illnesses. Results from genetic studies of dental illnesses can be used to establish diagnostic genetic tests and therapeutic intervention techniques aimed at the underlying disease aetiology, this researchhas been expanding our understanding of how oral tissues form in health and disease. To assist the identification and treatment of persons with genetic illnesses, the dentistry community must examine how to incorporate these findings into efficient disease preventive models. Many dental problems have a hereditary foundation, according to clinical and scientific studies. The findings of these research can be used to enhance illness diagnosis, categorization, and therapy. To assist the identification and treatment of persons with genetic illnesses, the dentistry community must examine how to incorporate these findings into efficient disease preventive models.

14. Conclusion

The Government of India has the 2016 Act on the Rights of Persons with Disabilities, which classifies physical disabilities in different parts of the body, however sadly cleft lips and palate are not deemed to be disabilities.3500 children are born with cleft lips, palate a year in India. Social stigma associated with cleft lip palate or craniofacial defects is a major obstacle to modern treatment; financial constraints and low levels of education are other reasons.

As many of the children with CLP and their parents experience discrimination from a societal perspective, as society's view of CLP revolves around religious affluence, especially in rural areas, and henceforth it becomes difficult to do so.

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