



Socio-Cultural Dimensions of Cleft Lip and Palate in India

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ABSTRACT

This theme paper outlines the unique socio-cultural facets of cleft lip and palate in India. The triumvirate perspectives of magico-religious, medical and human rights models are invoked to highlight the phenomenology of nomenclature, characteristics, etiology, and management of persons with such orofacial differences. The need to supplement the prevailing, pervading and predominantly medical approach to cleft lip and palate in the country with studies espousing the 'person-in-environment' social perspective is advocated. By invoking a life span perspective blended with rights based approaches, the related problems or issues emerging and impacting on the quality of life of these persons across age levels are highlighted. It is argued that the experience of negative thoughts and feelings among these persons are more due to the unpredictability of other peoples' reactions than owing to their primary condition. Amelioration of their well being is recommended by fostering socio-cultural and attitudinal change programs through propaganda and public education as a needed agenda for social action.

Key words: Orofacial – Rights Based – Stereotypes – Self Perception

INTRODUCTION

Cleft Lip and Palate (CLP) is a congenital malformation of the face and oral cavity that occurs during pregnancy (Kummer, 2008). While it may be identified at birth or thereafter, the management of CLP is a lifelong process. It requires multiple surgical and other intervention procedures to deal with issues, such as, facial abnormalities, difficulties in feeding, speech impairments, abnormal resonance and hearing difficulties (Baker, Owens, Stern, & Willmot, 2008; Kapp-Simon, 2004; Kummer, 2008). According to the International Peri-natal Database of Typical Oral Clefts (IPDTC; 2011), the overall prevalence of cleft lip with or without cleft palate was 9.92 per 10,000. The prevalence of cleft lip was 3.28 per 10,000 and that of cleft lip and palate was 6.64 per 10,000. In Indian sub-continent, out of the estimated 24.5 million births per year, the birth prevalence of clefts is somewhere between 27000 and 33000 clefts per year (Mossey & Little, 2009).

TERMINOLOGY

There are three models of naming, identification, understanding its etiology and management of CLP. These perspectives have implications for unraveling the socio-cultural status and understanding their psychosocial functioning. If one follows the archaic, traditional or unscientific **magico-religious models**, both, in the East as well as West, then one is inclined to believe that the condition is the consequence of a curse or blessings by preternatural forces for the alleged good or bad deeds committed by the victim in their past birth (Bhattacharya, Khanna & Kohli, 2009). Going by this approach, culture based causal attributions can be grouped by category as environmental, self-blame, supernatural, chance, unknown, or others, and by the type of locus of control as external, internal, or unknown (El-Shazly et al., 2010). Common sense and laypersons name the condition as 'harelip'. The term is now considered inaccurate, insensitive and intolerable, brings to attention the cleft lip's resemblance to the mouth of a rabbit. The Hindu Karmic theory holds that the orofacial anomaly is characterized by 'monkey' like facies, and even possibly, the animal's temperamental characteristics owing to their allegiance or inheritance of the simian clan. Therefore, lay persons, especially in Hindu context, are moved by a sentiment of fear or reverence underlined in this approach. They even tend to name such affected children as either 'Anjaneya' or 'Hanumantha'. Following the same outlook, proponents of this approach would recommend prayers, appeasement to gods and rituals as the only cure available for persons afflicted by this condition (Ross, 2007; Weatherly-White, Eiserman, Beddoe & Vanderberg, 2005; Oritz-Monasterio & Serrano, 1971).

Contrasting the above, **medical models** (Miller, Vandome & McBrewster, 2010) insist on biological causes. They advocate surgical interventions, speech and language remediation for those affected by the condition. The International Classification of Diseases (ICD-10, 2007) typically follows the medical model. It uses a broad term 'orofacial cleft' (OFC) to cover a wide range of disorders affecting the lips and oral cavity. Generally, distinctions are made between cleft lip (CL; ICD-10: Q36.-), cleft lip and palate (CLP; ICD-10: Q37.-) and cleft palate (CP; ICD-10: Q35.-). Additionally, OFCs may be left- or right sided (unilateral), or both sided (bilateral).

Over riding the above models, the contemporary post-millennium **human rights model**, as they are called, uses a 'person-in-environment' social perspective (Fougeyrollas & Beaugard, 2001). According to this viewpoint, human disabilities (if OFCs can be called one!) are not so much the making or misfortune of an affected gene, a faulty chromosome, or by gestational insults. It is not even owing to the retaliatory machinations of divine forces for errors committed in ones past life. Rather, it is alleged as the intended or unintended consequence of several barriers imposed by the larger social system on the affected persons. The argument is that society is created and operated in a way that does not take into account the genuine differences among people (Ormerod, 2005; Braddock & Parish, 2001). Going by their tenor, instead of disease based classifications, positivistic health oriented classifications are invoked, such as,

International Classification of Functioning, Disability and Health: Children and Youth Version (ICF-CY; WHO, 2007) for persons with CLP (Neumann & Romonath, 2012).

ANOMALY-IMPAIRMENT-DISABILITY-HANDICAP CONTINUUM

In view of the changing models and perspectives on or about persons with differences, discussions are initiated and sustained on the issue whether CLP can be deemed as a mere facial anomaly, disfigurement, impairment, disability or handicap (Hunt, Burden, Hepper & Johnston, 2005; Harper & Peterson, 2001). An anomaly is simply a deviation from what is standard, normal or expected. It is an oddity, peculiarity or incongruity restricted to the face in case of CLP. While this is so, impairment is any structural loss, disability is functional incapacity and handicap is social disadvantage experienced by a person (Venkatesan, 2004; p. 20).

There is indeed an element of structural disfigurement to qualify CLP as impairment. There is also a facet of functional incapacitation as shown by what is called 'cleft palate speech' which is characterized by atypical consonant productions, abnormal nasal resonance, abnormal airflow, altered laryngeal voice quality and nasal/facial grimaces (Nagarajan, Savitha & Subramaniyan, 2009). If one were to espouse the human rights perspective, then CLP is less of an impairment and disability, especially after surgery, treatments and speech therapy and more of a social handicap.

SOCIAL DIMENSIONS

Facial appearance is the core of interpersonal relations and attractions. Despite lofty maxims like 'beauty is skin deep', there are also popular proverbs like 'face is the index of mind'! Culture and society extols human beauty by outer appearance and complexion. Even a small pimple on the face is wished away. A scar or mole is to be eliminated. The teeth are expected to be in perfect shape. The over importance given to outer physical appearance needs no elaboration given the growing propaganda and profits reaped in the contemporary cosmetic industry. It is also evidenced by the several cultural events that celebrate good looks through beauty pageants. It is shown in the increasing visits to beauty parlors. There is ever growing number and popularity for products that claim to enhance physical attraction. Simultaneously, the celebration of fashion in the media combined with albeit subtle disgracing of 'not-so-good looks' as rustic or comical is evident everywhere (Reid, Stoughton & Robin, 2006). Terms of reference conveying intended or unintended labels about persons with disabilities in general and CLP included is ubiquitous even in art and theatre (Saman, Gross, Ovchinsky, & Wood-Smith, 2012; Dajani, 2001).

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 effect 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 demands 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 a 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 & Krueckeberg, 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 in

any given individual. It is actually that they experience greater feelings of anxiety due to the unpredictability of other peoples' reactions more than owing to their primary condition.

DEVELOPMENTAL PERSPECTIVE

A life cycle approach to understanding the origins and development of psychosocial issues in children with CLP is worth expatiating. As in children with any other disabilities, parents (especially mothers) are reported to undergo a series of emotional reactions beginning from shock, disappointment, hurt, doubt, shame, guilt, denial, ambivalence, despair and depression (Beaumont, 2006). Of course, not all parents respond or progress with the same intensity or sequence of these emotional reactions before coming to a sense of reluctant acceptance (Black, Giroto, Chapman, & Oppenheimer, 2009). Both, internalizing and externalizing emotional reactions directed inward (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 boys are rated as aggressive and antisocial, whereas physically attractive children are rated by adults as being more intelligent (Goffman, 1963).

Causal attributions made by parents of babies with CLP have been shown to influence child rearing-caring practices, albeit temporarily (Stock & Rumsey, 2015; Dabit et al., 2014; Grollemund et al., 2010; Nelson, O'Leary, & Weinman, 2009). Attachment is a reciprocal process. Hence, it is likely to affect the bonding between the perceiver and perceived (White, Eiserman, Meddoo & Vanderberg, 2005; Coy, Spertz & Jones, 2002).

SELF & OTHER 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 labeling 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 fulfills others 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 actually 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 try 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).

INDIAN EXPERIENCE

While the above may be deemed as transcultural problems and issues in persons with CLP, the uniquely Indian experience needs to be highlighted. As indicated, the child with an orofacial deformity is often deemed as a preternatural blessing. It often leads to delaying if not denial of medical consultation or treatments. It may be out of sheer ignorance, lack of affordability, difficulties in commuting, gender bias, or an instance of child neglect.

Some key areas pertaining to the lives and circumstances of these persons are related to schooling and education, vocation, livelihood or employment and marriage. Children with CLP run twice the risk of being out of school, denied or self ejected. Their supposedly poor academic performance maybe attributed to their condition. Teachers may fail to appreciate what these children are saying. The peer group may be simply curious about the child's facial difference, or they may be openly pejorative (Richman, McCoy, Conard & Nopoulos, 2012). There are reports to suggest that nearly half of the population of children with CLP do not go beyond elementary education. The reasons given for their non-attendance at school are shame, being hidden by the family, rejection by teachers, bullying by peers, speech and/or communication problems, illness and socio-economic reasons (Reddy et al. 2010; Ankola, Nagesh, Hegde & Karibasappa, 2005).

On one side, there are work, livelihood, employment and/or vocational issues of un-operated adult persons with CLP, such as, workplace stigma, on-the-job discriminations, behind-their-back comments or them being made the butt of jokes (DeSouza, Devare, & Ganshani, 2009). On the other side, there are serious sociological issues related to getting affected children to undergo surgery even if they are made available at affordable cost along with monetary incentives. Singh (2009) observed that parents could not afford to miss out on their livelihood for more than a week even to avail free surgery and treatments under the Smile Train Program. Women with CLP are reportedly more affected with

unemployment or under employment than men with similar problems. The end result is their poor quality of life (Patrick et al. 2007; Marcusson, Akerlind & Paulin, 2001) as well as negative impacts on their physical, personal and emotional well being (Sagheri, Ravens-Sieberer, Braumann, & von Mackensen, 2009). There is evidence to show that children and adolescents with CLP suffer from specific social psychological issues arising from stigma experiences, anxiety-depression, dissatisfaction with facial appearance, shyness, withdrawal and internalizing problems (Snyder & Pope, 2010; Brand et al., 2009; Snyder, Biliboul & Pope, 2005). Marriage for un-operated adults with CLP can be quite a challenging prospect. The rates of marriage may increase after surgery. This is only the tip of the iceberg. Demands for dowry, need to reconcile for a partner from a lower SES and/or educational backgrounds, delaying the marriage are some of the common psycho-social obstacles reported in the domain of marriages by these persons.

SUMMARY AND CONCLUSIONS

In sum, socio-cultural dimensions appear to have a complex inter relationship vis-à-vis persons with CLP. Results from the available body of western literature as well as the sparsely available details on the subject in our country have thus far failed to provide a coherent picture. The reasons for this may be because various investigators have used different measures, non-representative and/or small samples. It may be also that studies lack control groups or that there are not many longitudinal studies using the life span perspective by accommodating cultural differences.

It was the intention and attempt of this paper to highlight that it is important not only to understand the medical aspects of CLP; but also, the psychosocial and cultural implications thereof. The term 'psychosocial' refers to a 'person-in-environment' social perspective. By doing so, it at once dissolves the several the incorrect knowledge or faulty attitudinal barriers which contemporary society holds for or against these persons, and which in turn, damages their inner self concept and verve for life. The paper invites attention towards the paucity of research using the right based paradigm on psychosocial aspects of CLP particularly in our country.

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