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Review Article

Cross-cultural attitudes and perceptions towards cleft lip and palate deformities

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Abstract *Physical attractiveness is highly regarded in many societies. Cleft Lip and Palate (CLP) deformities have a global prevalence of up to 1 in 500 live births worldwide. Individuals with CLP face a myriad of problems in life including discrimination and prejudice. The cultural background of the different communities these individuals belong seems to have an impact on the type of treatment they receive. We compare and discuss the cultural attitudes, perceptions and approaches of CLP individuals, their families and peers in the Chinese, Africans and Indians. The perceived causes for CLP range from the Divine and evil spirits to astrology and diets. Traditional healers unique to each community are often involved in the management of the CLP, instead of Western medicine. Methods used by these healers vary as well. The motivations in seeking treatment include increasing the chances of getting a proper education and finding a spouse. There is a lack of well-controlled research and good evidence in our current knowledge of the relationships between CLP treatments and the influence of cultural perceptions. Presently, the evidences are more descriptive than quantitative. There is much potential for future research.*

Keywords: Cleft, cleft lip and palate, cultural attitudes, traditional healers, folk beliefs.

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INTRODUCTION

Research has shown that physically attractive people are often perceived as being more intelligent and are easily accepted by others. They are thought to have better social habits and this leads to more positive response from others, compared to their less attractive counterparts (Hunt *et al*, 2005).

Cleft Lip and Palate (CLP) is one of the most prevalent oro-facial deformities and visible birth defects that occurs in 1 out of every 500 to 1,000 live births worldwide (Cooper *et al*, 2006). People with CLP face a host of stressors in their lives. These include having to face discriminations and negative perceptions in social relationships, at school and at the workplace (Chan *et al*, 2006). There is a tendency towards social withdrawal and inhibitions in individuals with CLP in childhood, adolescence and even adulthood. These behaviors can become an impediment in developing meaningful social relationships (Berk *et al*, 2001). The attitudes of patients, their families and the community they live in, towards CLP are also crucial in the treatment outcomes and the social and emotional development of these patients (Chan *et al*, 2006).

However, explanatory models of CLP and reactions to the CLP child vary across cultures. Our perceptions, responses and interaction with others, as well as inter-personal attitudes, are shaped to a large extent by our cross-cultural variations and attitudes. Religious and cultural beliefs and demographical differences can have a huge impact in shaping these reactions and

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attitudes (Black *et al*, 2009). In this article, we attempt to compare cultural attitudes and perceptions of CLP deformities among the Chinese, Africans and Indians. The similarities and differences are discussed.

ATTITUDES TOWARDS CLP AMONGST THE CHINESE

The prevalence of syndromic or non-syndromic CLP is 1.30 in Chinese (Cooper *et al*, 2006). There is a scarcity of extensive research into the psychological profile of CLP individuals in a Chinese population. It has been found that the gender and educational level do not play an important role in the psychological status of the CLP individuals, whereas age and maturity do (Cheung *et al*, 2007). There are differences in the psychological profile in the adolescence and the adult age group of Chinese individuals studied. The Chinese adolescent group with CLP exhibited higher general self-esteem and lower social anxiety and distress compared to the adult CLP group. However, compared to the non-CLP adolescent patients, they were showed to have lower self-esteem and social confidence. These adolescents with CLP are thus likely to have more problems in developing a positive self-image and self–esteem compared to normal adolescents. They do, however, adjust better to their deformities compared to the adults (Cheung *et al*, 2007). Self-esteem plays an important role in the overall satisfaction with life and social anxiety of both the adolescent and adult Chinese CLP individuals (Cheung *et al*, 2007). The CLP individuals, however do not lack social skills when compared to their peers or unaffected siblings (Berk *et al*, 2001). It may be concluded that the increased social anxiety and lower self-esteem are thus hampering factors in the interactions of Chinese CLP individuals with others.

The interpersonal dynamics and mutual relationships play an important role in the psychological outcomes of the ethnic Chinese. There is a stronger emphasis placed on interpersonal relationships in the Chinese culture compared to the Western culture, the latter being characterized by a more individualistic orientation in the definition of the self (Berk *et al*, 2001). In the Chinese culture, however, the locus of influence and control lies outside that of the single individual and is placed within the interpersonal and social network. In comparison, the Western individual is more person-focused, with the locus of control and influence lying within the person (Wen, 2008). It has been demonstrated that the subjective well-being of the ethnic Chinese is more easily influenced by the feedback from other people. How well the person felt was linked to what others thought of them. Furthermore, interpersonal focus is more prominent in the Chinese culture compared to the West (Cheung *et al*, 2007; Ho *et al*, 2003). This stronger concern about maintaining social harmony might result in adverse coping behavior in the face of negative social interactions (Lai, 1995). Thus, support and acceptance from family members and friends are particularly important to the Chinese CLP patients. In the Chinese populations, there is a higher tendency of the parents to become over-protective of their children, especially those with any deformities (Coy *et al*, 2002). Parents of CLP individuals are more accepting of the possibility of CLP children being emotionally disturbed (Chan *et al*, 2006). However, the reason may be due to the knowledge and understanding of CLP deformities in their children, rather than any bias in attitude. The expression of anxiety and its adjustments are different in Chinese populations compared to other cultures where there is greater social acceptance of the physical deformities (Berk *et al*, 2001). There is a general cultural bias and a less positive attitude towards individuals with physical disabilities in the Chinese (Chan *et al*, 2006). It has also been noted that CLP is perceived as an anomaly rather than a symptom. CLP is commonly regarded as a disfigurement and a malformation in itself and not because the individual is suffering from an organic disease. The actual cause of the CLP is often ignored or rejected. They may also have false expectations about the efficacy of therapy and believe that success is guaranteed as long as their CLP children tried hard (Bebout & Arthur, 1997). This has an influence on the coping strategies used, as the Chinese are less likely to focus their attention on any new information regarding the deformities and develop coping mechanisms to overcome or adjust to them.

There is a large proportion of the Chinese culture that is still deeply entrenched in the teachings of Buddhism. The Buddhists believe that a handicap or deformity is an act of karma or fate. Thus, there is greater passivity and a fatalistic outlook of their disorder compared to the West (Cheng, 1990). This would have implications for their desire and motivation to seek treatment and even the satisfaction after any treatment recieved. There may be concerns about upsetting the spiritual dimensions of their life after receiving treatment for their deformities as these are perceived to be an act of fate.

Chinese mothers who have given birth to a child with CLP may feel trapped under the 'One-Child policy' in China. The negative feelings may translate into a strain in the relationship between mother and child. This situation is not helped by the financial disincentives that would follow if a family was to have more than one child (Black *et al*, 2009). The mother may be blamed for the inability to have a 'normal' child for the family and there may be implications regarding the prevalence of perinatal depression. The folk beliefs and perceptions of the Chinese culture contribute towards the blame on the mother whenever a CLP child is born. For example, there is a belief that the pregnant mother in China cannot eat rabbit meat for fear of giving birth to a baby with a 'hare lip' (Cheng, 1990). Another example is that the pregnant mother should not use a scissor at all until delivery, especially when sitting on the bed, otherwise this may result in a cleft in the baby. In China, sex selection abortion occurs due to the desire to have a male heir to the family name (Zhu *et al*, 2009). If there are associated deformities, including CLP, late abortions are also known to happen (Han *et al*, 2009). It is perhaps not too speculative to suggest that if the foetus is found to be deformed and of the female gender, there would be an increased possibility of an abortion as a consequence. This may in turn have health implications on the women, especially in case of late abortions. Furthermore, individuals with deformities may be viewed as cursed and become obstracized by the society. Hospitalization may also be viewed negatively as going to a place to die rather than to receive treatment (Cheng, 1990). These attitudes and beliefs can all add to the difficulties the CLP person faces in society in general and in receiving treatment.

ATTITUDES TOWARDS CLP IN AFRICA The incidence of CLP in Africa is lower compared to the West or Asia. It is about 0.7 per 1,000 live births (Pham & Tollefson, 2007). Just as in other communities, cultural and religious factors influence the concepts, perceptions and attitudes towards the causation of disease, the utilization of health services and the labels, explanations for and treatments of the diseases. Myths and folk beliefs frequently accompany the birth of a child with deformities (Olasoji *et al*, 2007). There is a higher prevalence of such attitudes in rural and less educated areas.

Yoruba, Hausa/Fulani and the Ibo are the majority of the more than 250 ethnic groups in Nigeria, which has a population of almost 90 million (Olasoji *et al*, 2007) There is a belief among Yoruba parents in Africa that CLP is caused by supernatural forces such as evil spirits or ancestral spirits. In this African group, being inflicted by evil sources is regarded as a family shame and it lowers the family's position in that society. This is in line with the prevailing ideas about the aetiology of CLP. In another African society, the Hausa/Fulani of northern Nigeria, they may consider CLP to be the act of spiritual or divine intervention rather than being inflicted by negative factors, such as retribution from past sins or crimes. This belief in fact lessened any feeling of shame about CLP. The Hausa/Fulani group is predominantly Muslims and Islamic beliefs that tend to be more fatalistic and maintain spiritual explanation for a disability might have an impact (Strauss, 1985). The child with CLP may be left untreated for fear of 'interfering with God's will'. However, the CLP child may be referred to traditional healers for help before going to hospital. This is because traditional healers are highly revered in that society (Dagher & Ross, 2004) and believed to be able to treat disease with supernatural causes. They have for generations been using rituals in combination with herbal and animal remedies for treatments of disease where modern medicine has failed to find a cure (Dagher & Ross, 2004). The cleansing rituals performed by these healers are

considered important in the overall management of CLP as many regard the cause of CLP to be possession of the mother during pregnancy and/or of the child after delivery. Interestingly, the traditional healers have been found to refer these patients to the hospital for treatment eventually. This is the case especially when the patients needed surgery or antibiotics (Dagher & Ross, 2004). Other causes of CLP in the opinions of the parents of African CLP children include worms within the abdomen when women are denied food during pregnancy, pregnant women laughing at a patient with CLP and pregnant women going out during an eclipse. Thus, there appears to be a tendency to attribute the cause of CLP to a sense of retribution from higher orders, as well as astrological and spiritual origins (Olasoji *et al*, 2007).
Even amongst the traditional healers themselves, there are a myriad of ideas and beliefs regarding the aetiology and treatment of CLP. There is a belief that ancestral spirits have expressed their thirst for blood and *utshwala* (a kind of Zulu sorghum beer) through the baby's sickness. Others consider it as a reminder that a sacrifice is overdue and thus the child is punished with having CLP. There is also a belief linked to the high esteem the people have of their ancestors. The CLP is explained as angry ancestors causing the baby to have CLP due to the family carrying out the traditional family ritual ceremony erroneously and not following the customs. Other causes are related to evil sprits, curses and witchcraft inflicting the ailment on the child at birth. There can also be curses from ordinary people. Any person can 'become a witch' and practice witchcraft due to the pregnant mother having offended them, for example, over financial matters. The person believes that he can place a curse on the child and cause him/her to have CLP. Food was also a factor cited as a cause of CLP. Eating poisoned rabbit meat is also a possible reason. Other animal related causes include the mother being close by to a skunk. Perhaps the more medically oriented idea is the perception that the CLP is caused by the mother having attempted an abortion unsuccessfully and thus the baby's face has been disfigured. In some African cultures, abortion and witchcraft are thought to be linked and thus the mother is stigmatized as a witch (Dagher & Ross, 2004). In a more positive light, in some cases the CLP child is believed to have been bestowed with supernatural powers that are predestined to be of good use for the family and the community.
As for the treatment of CLP, herbal remedies and rituals are used. The choice may differ between practitioners. Psychological support is most commonly given to the patients and their parents by the traditional healers. In addition, the CLP individual may be asked by the healers to contribute to charity so as to increase their merit before the spiritual world and serve as penance for their past sins. Such penances may include fasting, going on a pilgrimage or bathing in a sacred river. Even more interestingly, the traditional healers may refer to their sacred texts and from there, decide on the best medical treatment to be sought (Dagher and Ross, 2004). Even when using herbal remedies as a treatment for CLP, if the practitioner is unsure he will still consult the ancestral spirits. The latters may communicate with the healers through their dreams, and guide them towards the type of herbs to use. A practice closer to current Western medical treatment is the use of the hoof of piglet, calf or sheep as a dummy for the CLP child to suck on as a way to improve the shape of the musculature and the speech. This may be akin to the orthodontics interventions in the CLP child in dentistry. The idea of cleansing and spiritual healing of the CLP child seems to be prevalent as well. The purpose is to 'remove impurities and restore balance'. This may involve the *chirumiko* (cupping horn), whereby a cut is made on the forehead of the CLP child and the blood is allowed to gather in the horn as a way of 'removing the impurities and restoring balance' (see **Table 1**). There is also reluctance among the healers to advocate for modern surgery as it may interfere with the wishes of the ancestors, spirits or disrupt the supernatural powers. As previously mentioned, there is perhaps a deeply seated and more fatalistic concern about incurring the wrath of interfering "God-Will" in giving the individual CLP. As most of the aetiology of CLP is explained by 'divine intervention', it is also believed that it may alter the role the CLP child is destined to play in the community he/she is in.

Table 1 Treatment options for African traditional healers

Psychological support
Give to charity as penance for past sins and wrongdoings
Going on a fast, pilgrimage or bathing in a sacred driver to cleanse away sins
Use the hoofs of animals as aids to close the clefts
Blood letting from CLP patients to 'restore balance and remove impurities'

ATTITUDES TOWARDS CLP IN INDIA The incidence of CLP in India was found to be 1.09 in every 1,000 live births (Reddy *et al*, 2010). This is comparable to the incidence in other Asian countries such as China and Japan and higher than in Africa. However, it is still lower than the figures in the West. There is a predominance of males in CLP individuals in India. Another unique feature of the CLP incidence in India is that a large proportion of it arises from consanguineous relationships (Reddy *et al*, 2010).

There is an inverse proportion between the level of education of the individual on one hand, and the tendency to attribute the casuation of CLP to spiritual causes or to hold folk explanatory models for it. As in many traditional societies, the literature shows that there is a difficulty in interviewing the mothers about their attitudes towards and perceptions of CLP. Often during the clinical interview it is the father who is doing all the answering and when in doubt, he will turn to another male relative rather than the mother (Weatherley-White *et al*, 2005). In one study among the rural Gujarat community consisting of mainly manual labourers, with Hindu being the predominant religion, 84% of them believed that CLP is due to the "act of fate" There was also a belief that CLP was a punishment due to a previous sinful act. Other perceived causations included a solar eclipse occurring during pregnancy and starvation in the village during pregnancy (Weatherley-White *et al*, 2005). Another study (el-Shazly *et al*, 2010), was done amongst the rural parts of Gujarati in Mumbai, India. It was an area where there was high poverty rates, unemployment and illiteracy. The study populations consisted of patients whose parents have not largely accepted Western methods of cleft treatment as the norm. It was found that almost all parents in this cohort of India blamed the birth of a CLP child on a curse or an act of evil spirits and similarly, retribution for past sins. This may be related to the Hindu beliefs about reincarnation. On reviewing the available literature, it is not clear whether the CLP is believed to be caused by the mother looking at certain animals or consuming the wrong food during pregnancy.

Given the ideas the families have about CLP, it is understandable that the CLP child would experience strained relationships with family members and poor exposure to the outside world. There is a tendency for the CLP child in India to have limited social interaction due to the family's shame and concern. There are always raised anxieties and unique concerns when exposing the child to a new environment such as a new school (el-Shazly *et al*, 2010; Weatherley-White *et al*, 2005). There are also families who choose to isolate their children, perhaps as a way of protecting them. Some extreme examples include parents abandoning the child and leaving them to be raised by the grandparents.

Many of the parents and family members in India are receptive to the idea of treatment for CLP. The idea that the CLP child, after repair surgery, may have a better self-esteem, more confidence and better acceptance by peers appealed to the Indian families studied (Weatherley-White *et al*, 2005). Interestingly, the predominant concern was the possible improvement in marriage prospects amongst the female CLP individuals. In this society, the family bears the responsibility of ensuring that the female child is married, and gainfully done so. The female child with CLP is thus considered an even greater liability and economic burden (Weatherley-White *et al*, 2005) to the family until she is married, as it may be more difficult to find an acceptive family for her, given her CLP. There are also many incidences of the CLP child being refused entry into schools. Thus, there is also hope that there will be a better chance of a proper school education after the CLP repair through surgery. However, there are also concerns about upsetting the supernatural forces, given that CLP is understood to be a 'Will of God' or evil spirits.

DISCUSSION The Chinese, African and the Indian communities each have their unique cultural and religious beliefs impacting on the perceptions of and attitudes towards CLP and its treatment. However, there are some striking similarities that these cultures share as well.

The sense of interpersonal relationships seems to be very important in the Chinese society but, with regards to CLP, this is not so well studied in the Africans and Indians. In China, this may result in a collective negative or positive opinion shared by the community where the CLP person lives. Differing opinions only shared by a minority may not be expressed openly for fear of disrupting the group dynamics of the people in China.

The Chinese parents are found to be over-protective and perhaps even accommodative to their children. Such feelings may be further escalated by the 'One-Child' policy in mainland China. The parent, especially the mother, may blame herself for causing the CLP in the child. The parents might try to make up for it by bestowing excessive amounts of material affections and protection on the child. Such behaviours may have a negative impact on the mental and social development of the child. This is in addition to the fact that CLP adolescents have been found to have decreased levels of self-esteem and heightened social anxiety (Cheung *et al*, 2007). Such factors are also examined by a few studies looking at the psychosocial aspects of CLP individuals in India and Africa. The Indian studies have shown that marriage especially for the female CLP child was one of the biggest concerns for the parents interviewed. The main motivation for seeking surgical treatment was to help the child to find a life partner. This is an interesting finding as the Indians practice arranged marriage as well. Perhaps there should be further studies in these areas.

Table 2 Common perceived causes of CLP in the different communities

Chinese	Africans	Indians
Eating rabbit meat during pregnancy (Cheng, 1990)	Eating poisoned rabbit meat (Dagher & Ross, 2004)	
Will of God/Act of Fate (Cheng, 1990)	Will of God (Olasoji *et al*, 2007)	Will of God (el-Shazly *et al*, 2010)
Punishment for past sins/wrongdoings (Cheng, 1990)	Punishment for past sins/wrongdoings (Dagher & Ross, 2004)	Punishments for past sins/wrongdoings (Weatherley-White *et al*, 2005)
	Work of evil spirits, from being cursed (Olasoji *et al*, 2007)	
	Worms within the abdomen when denied food during pregnancy (Olasoji *et al*, 2007)	Starvation during pregnancy (Weatherley-White *et al*, 2005)
	Going out during a solar eclipse during pregnancy (Olasoji *et al*, 2007)	Staring at a solar eclipse during pregnancy (el- Shazly *et al*, 2010)
Use of scissors during pregnancy (Author's personal communication)	Handling a scissors or other sharp objects (Ross, 2007)	

With regards to the aetiologies of CLP, there are many similarities as well as differences among the Chinese, Indians and Africans (**Table 2**). There is a general regard across the three different systems of cultures that the mother is usually responsible for causing of the CLP deformities. The causation can range from the diet or starvation during pregnancy to the fact that the pregnant mother looked at a solar eclipse or stared at a rabbit. This may be a reflection of the predominant male domination that seems to be a common aspect in these three cultures. Interestingly, diet during pregnancy seems to be a common belief in the causal attribution of CLP in the Chinese and Africans but not among the Indians. Religious explanations for the causation of CLP are common in all the three cultures as well. Given that many of the Chinese and Indians are Buddhists, Hindus or Muslims, there might be a sense of passive acceptance and fatalism with regards to the CLP, when it is broadly considered an act of the Divine. With regards to the Africans, there may be a tendency to attribute CLP to evil forces, ancestors interventions and witchcraft. This is not so prevalent, though it is likely to

exist, in the Chinese and Indian communities. This perhaps explains why the Africans seek the help of traditional healers; a fact that was not noted in the Chinese and Indians in the existing literature. While it was considered acceptable to consult traditional healers, seeking modern surgical treatment is sometimes perceived as dangerous because of the risk of incurring the wrath of God, ancestors or spirits. This is seen in all the 3 communities and it is possibly a hampering factor to the CLP individual receiving treatment. Even if the individuals themselves are keen for treatment, they may face opposition from their families or communities. Given the societal pressure to maintain harmony in these communities, especially for the Chinese, the treatment may thus be delayed or not happen altogether.
School entry was difficult for the Indian CLP patients, though this was not studied in the Chinese and the Africans. A few studies on the Chinese noted that the employers might hold a more negative view of the CLP patients, at least initially (Chan *et al*, 2006).

CONCLUSION This literature review suffers from several limitations. First of all, the studies we have included vary in their aims. Hence, we could only reach a few inferred conclusions when comparing the different societies in their explanations and treatments of CLP individuals. The available literature on perceptions of CLP in different cultures is more qualitative and descriptive than quantitative and thus there is no best evidence for current practice available. We have yet to fully understand the folk beliefs of the different cultures with regards to CLP. This makes it difficult for Western medicine practitioners to offer a holistic management of the many implications of CLP in these communities. Furthermore, it would be interesting to search through a few more similarities and differences, among these three cultures, with regards to explanatory models and their influence on treatment choices. For example, while it was not known if the Chinese seek the help of traditional healers for CLP deformities, just like in Africa, it is the authors' opinion that this is highly possible. Comparative studies on treatment outcomes in different societies are lacking. Thus, there is potential for research to increase the existing knowledge of CLP individuals in different cultures. A better understanding of CLP patients with respect to their different cultural backgrounds can improve future efforts to help these patients. Perhaps even more importantly, there will be a greater sensitivity in handling the psychological needs of these patients and their families, apart from attaining medical success in treatment.

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