

## Towards A Multicultural Approach in Occidental Health Care: The Example of Orofacial Clefts

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Latest studies concerning the psychological impact of orofacial cleft showed that, with the improvements in surgery and with adequate multidisciplinary support, clefts were no more associated with major psychological problems. However, the growth of humanitarian craniofacial care, as well as the increase of populations' migration, raises new concerns about cultural influences in the perception and satisfaction with surgical interventions, and treatment success, suggesting that medical acts alone are not the only answer to such malformation. Moreover, at a time of world migrations and mixed ethnicities, physicians and surgeons are exposed in their practice to a multiplicity of cultures that understands and conceptualizes "health" and "illness" differently. These differences in the perception of illness and care could lead to a gap of understanding between physicians and patients, which could impact patients' adherence to treatment, healing processes and further utilization of health care systems. Therefore, it is now crucial to assess and implement models of health care integrating cultural aspects.

Orofacial cleft is a frequent craniofacial anomaly, with an incidence of 2 per 1000 newborns in occidental countries [1]. Cleft formation occurs between the 4th and the 12th week of gestation [2], but may vary according to cleft types (cleft lip and/or palate and/or maxillary, uni- or bilateral), and is usually detected around the fifth month of gestation, during the morphologic ultrasound, or at childbirth.

While there is a very consequent literature dedicated to the origins of orofacial cleft [3], as well as to medical treatments [4] and functional aspects [5] in occidental countries, recent literature concerning psychological and social aspects of such medical problem seems to have decreased over the past decade. All over, researchers did not highlight psychological pathologies or major psychosocial problems related with the experience of having an orofacial cleft, probably leading to a slow erosion of interest and financial support in this topic. Although problems linked to facial appearance, self-esteem or bullying were found in adolescents and adults that were operated in the late 80's and 90's [6], many studies showed no or few differences between children with or without an orofacial cleft in attachment [7,8], child adjustment [9,10], parent-infant interactions [11], or social issues [12], among others.

These overall good results may be related to the fact that orofacial clefts are now a well-know and common problem which can be dealt with in a relatively short period after the childbirth. Moreover, it is often not related, at least in occidental countries, to problems that may endanger or significantly alter the infant's life. Another possibility explaining that few differences were found between individuals with and without clefts over the past years can be related to the implementation of multidisciplinary care in many hospitals, involving not only surgeons and nurses, but also psychologists, child psychiatrists, speech therapists, orthodontists, etc., and following the individual and his/her family from cleft announcement up to adulthood. This medical support may help parents cope with the situation as well as respond to concerns as soon as they come [11,13].

However, a number of recent studies on the perception of orofacial

clefts in different countries (e.g. Benin, Cambodia, India, Egypt, etc.) revealed that cultural beliefs have a very strong influence in causal attributions for orofacial cleft children [14,15], and therefore, in the way medical care was perceived. Indeed, culture is known as having an important role when it comes to medical care, as it deeply influences perceptions of disease and perceptions of treatment [16]. Corporal integrity, health and illness are concepts whose interpretation varies among cultures leading to different social perceptions of medical acts. If cultural factors are not taken into account, medical care may quickly become deleterious, losing its first objective of "repairing" and "treating". For instance, during the war in Somalia, occidental medical teams reported hostile reactions of young militiamen following a limb amputation. Indeed, for Somalian fighters, amputation represented a bodily injury detrimental to human dignity and preferred to die, rather than to survive mutilated [17]. From an occidental medical point of view, the amputation was reasonable, but for Somalian militiamen, it was socially intolerable. This example shows the importance of social and cultural perceptions of medical care and how it can affect not only patient's health but also his/her life in the community.

Many authors highlighted how cultural beliefs could impact the perception and recognition of mental and physical symptoms, and consequently, health care utilization and patients' adherence to treatment [18-21]. For instance, a literature review provided evidence that ethnic minorities reported less satisfaction with the health care system, received less information from their physicians and were less encouraged to participate in medical decision making [22]. This last point is especially important as one way to fill cultural gaps and misunderstandings would be for the practitioners to let patients expose his point of view concerning treatments. In patients with orofacial clefts, studies evidenced how cultural beliefs about clefts may influence perception of the disease and therefore treatment [23]. For instance, a study on different communities found that, in Peruvians, more than 28% of participants reported blaming themselves for the cleft, suggesting that, in such communities, additional psychosocial support might be necessary [14]. On another hand, the Hindu religion believes that the cleft is caused by sins committed in a past life, causing shame to the child's family. Therefore the family will hide the child, keeping him/her away from medical care and treatment [24]. In opposition, in a sample from Mariana Islands, authors emphasized that children born with an orofacial cleft were considered as gifts from God and should be

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protected and sheltered [25]. In this last case, we could seriously wonder how cleft repair would be perceived and even if it would be beneficial for the child's quality of life in his/her community. In the same line, a recent study in Benin showed that Christian mothers thought that the cleft was a God's trial and therefore, repairing it would go against God's will [11,13]. The same results were evidenced in Nigerian families whose members were reluctant to "interfere with God's will", leading to a large number of adults with unrepaired clefts [26]. In such circumstances, medical act in itself should be re-considered, as should be the definition of malformation, and the fact that surgery is maybe not always the only answer to such malformation. Indeed, in such community, repairing the cleft without any other cultural considerations could lead to the rejection of the patients from this community. This is especially important in cultures where social bounds are related to survival.

These examples show how the lack of cross-cultural understanding and communication between patients and practitioners may be detrimental to the healing process and to patients' quality of life and satisfaction with the health care system. Especially in orofacial clefts, cultural beliefs about what causes clefts have an important role, as for now, the scientific community has no clear explanation concerning the origins of cleft formation, even if it is thought that it may result from a complex interaction between different environmental and genetic factors. However, if recent studies explored perceptions of the cleft across culture, studies investigating the perceptions of the medial act, of the follow-up, as well as the quality of life of the patients back into his/her community in relation with cultural aspects are clearly missing. Moreover, if these cultural questions concerned, in a first step, only occidental humanitarian surgeons confronted to foreign cultures, world population's migrations brought new cultural mixing in many countries that needs to take account for its differences. For instance, one of the few studies assessing the implementation of cultural aspects in care showed that the consideration and integration of cultural aspects in care systems was related to a better patients adherence to treatment in a Latino population [27]. Another study in Nigerian Yoruba patients, where clefts are considered as the result of an evil spirit's interference, suggested that integrating traditional healers in the treatment process could help families [26]. Indeed, the authors showed that many Yoruba families first went to a traditional healer in order to overcome the bad spells causing the cleft, and that the healer would eventually advise them to go to a hospital, underlying the need of a closer collaboration between modern and traditional medical practitioners. However, if studies highlighted the importance of considering culture in medical care, very few intervention studies assessed models for implementing cultural aspects in medical care, and only few medical schools provide classes concerning cultural aspects of care. Therefore, it is important, when it comes to health care, to understand that what seems a good treatment regarding occidental medical sciences is not always the best response to disease in other cultures, and that multidisciplinary care teams need to consider not only how to treat the disease, but also how to integrate personal social and cultural aspect in the way of treating the disease. In the words of the philosopher and practitioner, Georges Canguilhem: "Patients are not interested in the function of such or such organ threatened by illness, but in their "pace of life", this means the relationships and integration to their environment" [28].

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