The Social Adjustment of Bearers of Craniofacial Abnormalities and the Humanist Praxis

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SUMMARY

Introduction: The impact of craniofacial anomalies in the life of people who are affected by it emerges the aesthetics and functional damages that, even repaired, can affect their whole for life.

Objective: To review the literature about the social and emotional impact to the bearer of craniofacial anomalies and their relatives, relating it with the principle of differences in an interdisciplinary way.

Method: The search was based on electronic database. It was utilized the following words: "craniofacial anomalies", "psychosocial impact", "bioethic" and "adjustment".

Results: The electronic search resulted in 47 studies. The current analysis denotes that the bearers of anomalies show adverse levels of anxiety, depression, social fear, self-esteem and quality of life when compared with normal individual. The facial appearance has a profound influence on social environments, interfering on social contact and on the development of personality. The psychological support is necessary during the development and rehabilitation of the craniofacial abnormalities, by sympathizing with their needs and with their parents in the process of feeling and experiencing such abnormalities.

Conclusions: The review aimed the association between the occurrences of this anomaly and psychosocial adjustment. These conditions suggest a larger attention to bearers of anomalies. The results show the need of psychosocial adjustment at the ethic responsibility perspective, from both health professionals and relatives. The philosophy of humanist praxis at the bioethic interface guides the need of professional involvement in a free, responsible and compromised way.

Key words: craniofacial abnormalities, cleft lip, psycosocial impact, bioethic.

INTRODUCTION

The craniofacial anomalies constitute a highly diverse and complex group that, in a whole, affects a significant ratio of people in the world. The generic denomination of craniofacial anomalies includes isolated and multiple anomalies of genetic etiology or not. Usually, the situation is mentioned in situations which the skull and/or face skeleton present contour alterations (1, 2). Among them, the orofacial fissures constitute the most known examples, and have significant impact on speech, voice, hearing, appearance and cognition, causing important psychological and functional disorders, and influencing, in long and adverse way, the health and the social integration of people who have such anomaly (2, 4-9).

The study of the orofacial fissures is of great importance once it is an anomaly of considerable frequency in the population. Data on the craniofacial anomalies in the Brazilian population come from *Estudo Colaborativo Latino-Americano de Malformações Congênitas* (ECLAMC), which carries through epidemiological monitoring of these conditions in voluntary maternity hospitals. According to the ECLAMC, the prevalence of labiopalatal fissures in the North-eastern and South of Brazil varies between 9, 72-11, 89/10 thousand, while in the Southeast, between 5, 39-9, 71/10 thousand. The palatal fissures vary from 2, 41-3, 08/10 thousand in the North-eastern and South regions, and from 3, 09-5, 01/10 thousand in the Southeast (1, 10).

The studies on impact of the or facial fissures in the lives of people who suffer from them, point out the aesthetic and functional damages that, even repaired, can happen in the whole life of the individual (11-13). Such conditions suggest a higher attention to the children and the adolescents with fissure, considering the factors that intervene with their global development and their insertion in the social environment, bearing in mind the deformity (14, 15).

Another important factor that justifies the study of the fissures is the necessity of longitudinal attention to people who have them, making families try a significant chronic stress of physical, emotional and social order during all rehabilitation. Therefore, the participation of the involved health professionals in this question involves not only technical and specific knowledge, but also the interface of the ethical responsibility, revealing moral and ethical principles based on the altered as main focus.

In general, literature (8) suggests that the individuals who have malformation present unfavorable levels of anxiety, depression, social phobia, self-esteem and quality of life compared to normal individuals, once the face appearance, according to some authors (5, 16), has a deep influence in social environments of people, being able to influence in the social contact, the development of personality and the educational progress.

METHOD

The source of information used in this review of literature was made of articles of electronic data bases MEDLINE, LILACS and Silo and list of references of identified articles. Also dissertations, theses and books, considered relevant for the accomplishment of this review, were consulted.

The selection of the key words used in the review process was effected by means of consultation to the Decks (key words of subject in health science of BIREME). In the searches, the following key words in Portuguese and English languages were considered: "abnormalities craniofacial", "fend labial", "impact psychosocial", "altered", "bioethics" and "adjustment social". The logical operators "AND", "OR" and "AND NOT" were used for combination of the describers and terms used for tracking of publications.

Through this procedure of search 47 studies were identified, published until December of 2007, which approached the proposed theme. In the evaluation of articles, except for the ones of literature review, the ethical aspects were observed (mention to the approval in the committee of ethics, anonymity and term of free and clear consent).

DISCUSSION

Individual and Social Impact of characteristics of fissures

The concern the physical appearance generally affects a relatively great ratio of the population (17). Some concerns are related with the inherited characteristics, as well as the shape of the body and face traces and, moreover, with the changes in the appearance which may be desired or not, which occur during the course of life. Everywhere, most people make efforts to modify some of these aspects in search of the possibility of being seen better by oneself and by others, admitting that the physical appearance contributes for the impression of the others (17).

Considering the valuation in the current society of beauty and the perfect shape, one assumes that the concerns would be significantly higher or different for

those individuals who have malformations. Before such scene, having a malformation not only constitutes a daily and challenging experience of self-overcoming of the limitations, as well as of confrontation of the stigmatization and the exclusion that the society imposes concerning the educational and professional chances (7).

In the attempt to limit between what a deformation is, the authors (17) focused, in their researches, the relative concern to the differences in the visible image of the body for the others, as well as the problems experienced by people who have deformations, the identification of the factors that worsens or improves such difficulties, the variety of intervention mechanisms and, also, the numerous challenges faced by researchers in the area of the malformation. Still in terms of the word deformation, the same authors point that the language used is not appropriate to describe the visible differences in the appearance, once it predominates the use of a negative terminology (deformation, malformation, abnormality, defect, among others) for being derived from the vision of the treatment focused on the biomedical area, therefore centered in the problem and the pathology.

According to the authors (17) the negative terminology is useless and contributes to overexpose the difficulties experienced by the ones who need to look for help. Some writers and researchers have been working hard to deviate from the negative focus using a terminology based on the visible distinction, changing "deformation" to "difference" and their related problems. Such "differences" may be caused by a variety of congenital anomalies, injuries or even by surgical intervention.

The difficulties frequently reported by such individuals are related to the evaluation they make of their own corporal image, taking into account the affected area, severity and visibility, varying according to the innumerable individual and social characteristics (18). However, in spite of the complexity of the involved variables, there is a notable consensus in the report of such individuals in relation to the difficulties faced and the set of negative emotions involved, as anxiety, fear of the social evaluation, low self-esteem, favorable corporal image and social phobia (19-22). Other authors (23 - 26) agree on the relation of interdependence between appearance and self-esteem both in the population in general and in people with visible differences.

The authors (16) searched external characteristics, especially the attractiveness, as a generator of expectations on a person, influencing the behavior and the personality. The physical attractiveness is associated with positive characteristics, being seen as a determinative factor in social ability, once attractive individuals are seen as more qualified and socially popular than the non- attractive individuals. Although there is not an accurate definition of attractiveness available, the results of the studies show to the existing relation between faces considered as attractive and not attractive faces, suggesting that there can be an unconscious universal standard for the face attractiveness.

The authors (16) investigated the influence of the type of malformation concerning the attractiveness and the evaluation of damages in 208 children with craniofacial malformations, using questions and projections of slides with frontal and lateral images (one with smile and one as natural as possible) for the analysis of the impression of the eight evaluators.

It was possible to observe that the type and the severity of the malformation influenced in the judgment of the attractiveness of the face, once children with craniofacial abnormality associated to other malformation received significantly lower countings for the attractiveness and higher countings for the evaluation of damage than children with a craniofacial malformation without associated malformation. This study shows that deformation evokes both positive and negative answers: negative because the craniofacial malformation leads to rejection and positive because people learn to show greater sympathy for individuals with visible differences.

Other works on self-perception of the face and psychosocial adjustment (27), in pre-adolescents and adolescents with craniofacial anomalies, showed positive correlation between these anomalies and the dissatisfaction with the aspect of the face and, also, that such self-perception differs from the perception of parents and relatives. The same authors observed that, in general way, the current studies relate less and less to differences between children with fissure and other children of the same age and development. From their point of view, this situation is due to the precocious intervention of multidisciplinary teams and to the programs of sensitization and education in this field.

For the evaluation of fissured 235 adolescents who have already received the aesthetic-functional correction and of 373 adolescents who do not have such fissure, of both genders, a French scale of self-esteem was applied, validated in Brazil, having 23 items with graduation of answers, that is, answers equivalent to the complete approval, approval, neutrality, incomplete disapproval and total disapproval (24).

After the calculation they obtained the maximum and minimum counting, respectively, of 115 and 23 points. Out of the fissured adolescents, 59% presented level of self-esteem below 67, in relation to 26.1% of the young

without fissure, what makes one conclude that the levels of self-esteem are different in the two studied groups. In the same study, the authors (24) observed the influence of gender in the level of self-esteem in the groups, being that adolescents who have fissure differed significantly from the ones who don't. It is believed that girls express greater dissatisfaction with the appearance than boys do. Such feeling would be justified by the evidence of that women experience greater social pressure to have an attractive appearance.

Other authors (28) evaluated, through a questionnaire, validated between Australian schools, the aspects of the self-concept of 23 adolescents aging between 12 and 16 years, having fissure and palate fissures, aided by the department of dentistry of a pediatric hospital in Australia. The subjects of the study had already received the treatments and were all in the same phase of the orthodontic treatment. Physical ability, physical appearance, relationship with parents, emotional stability, among others aspects were evaluated. Despite the obvious face differences, the patients considered themselves attractive when compared with not fissured patients and that the people around them shared such opinion. According to the authors, in contrast with a mechanism of defense to preserve self-esteem, this satisfaction with the physical appearance is a resultant phenomenon of the encouraging strategies used by parents and of the impact of the changes made possible by the surgical treatment.

In terms of the positive results, referring to the relationship with the parents, the authors (28) attribute to the action of the parents themselves, once they act aiming at preventing potential social problems, encouraging their children to social interactions. Also it is possible that the difficulty in forming new relations is what makes the adolescents invest more time in fortifying the relations in familiar environment; however, it can also indicate a protective relation that makes future emotional independence difficult. Such results show a wide association between fissures and the psychosocial adjustment.

In another study, the authors (23) compared groups of 65 fissured patients aging between 8 and 17 years in terms of behavior, anxiety and depression. The patients of the University Hospital were selected on the basis of the etiological types of fissure, without any associated alteration. The results indicated a relatively good global adjustment; however the individuals with palatine fissure showed greater problems with depression, anxiety and learning related to speech, if compared with patients who have labiopalatal fissures, who showed greater problems in relation to face appearance, emphasizing the importance of these sub-groups to be studied separately.

On the other hand, the authors (27) evaluated 70 subjects aging between 3 and 16 years in the Laboratory of the *Laboratório do Instituto de Psicologia Médica da Faculdade de Medicina de Lisboa*, having been 35 with fissures and 35 without, with complaints of behavior and learning difficulties. Among the variables analyzed (Development and Intelligence Coefficient, immaturity, aggressiveness, school adaptation, self-image) the categories of the social-affective and cognitive variables are distinguished, as well as their correlations. As for the analysis between groups significant difference in the changeable difficulty of language was verified, making one observe that this difficulty predominates in the group of the children with fissures. Also in the group of fissured patients, positive correlation between language difficulty and difficulty in interpersonal relations was found, what was not observed in the group of non-fissured patients.

The results obtained in this work lead to conclude that many unknown factors still exist that can contribute so that differences in the performance between the studied groups are not verified, with exception of the changeable difficulty of language. This seems obvious, if the precocious or simultaneous beginning of the anatomic-functional reconstruction process is observed in relation to the beginning of the development of speech. The fact of children being very stimulated by parents, according to their own report, together with the fact of most of the evaluated children already have completed most of the reconstruction of the face and the rehabilitation of speech, could have intervened with the results (27).

Evaluating the quality of life of 130 patients, with age between 18 and 30 years, taken care of in a reference hospital in Brazil, the author (29) found above-average indices of quality of life of the group in terms of social relations and psychological aspect, suggesting that the good capacity of adjustment of the patient with fissure and the overcoming of the possible difficulties are resultant of an efficient rehabilitative process which enables him/her to a life with quality.

Psychological factors

When a baby is conceived, it already belongs to a familiar network that encloses father, mother and extension of its family and, as part of this group, which group it will be inserted to and its interactions are already established. According to the authors (30), when a child is generated the bond with the new being occurs, even before birth that is composed of imaginary idea which is full one of hope. The bond is essential in the human condition and essential to the development of the child, having its meaning in the "living together" atmosphere, not only to be seen as a

moral, religious and cultural question, but also as a vital question.

When the news of malformation is anticipated either by image diagnosis or at birth, can cause conflicts and instability in the family. The parents suffer a great emotional shock, once the idealized child will be substituted by the real child who was born with a congenital defect (31, 32). The most common standards are the reactions of negation, rejection, feelings of guilt, depression and sadness, which are gradually substituted by the acceptance and reorganization, attenuating the anxiety and contributing for the cooperation of the parents in relation to the treatment. Consequently, the psychological support is specially relevant in the diagnosis of fetal abnormality and soon after the birth of the child in order to assist parents in the understanding of their feelings and the personal reorganization in order to accept the real child and its potentialities, looking for ways of adapting it to the society and aiming at its global rehabilitation (4,30,32-34). The parents represent the main point of all the treatment, having to receive correct information, to perceive and realize the importance of their participative position in the treatment.

The children with fissure only realize that they are different when they are 4-5 years old, and such difference may contribute in the behavior, the personality and the socialization of the affected ones. When the child gets in contact with other children the prejudice and the valuation of the stigmas of the illness may occur, making them introverted, with immature or aggressive behavior (35). Before the child enters the school there is not much difficulty of adaptation in terms of its consequent difficulties of the fissure once it was more present in the familiar environment. If there was acceptance of the family, there were not psychological problems until this moment. In school, on the other hand, the child feels excluded of the activities that demand well-articulated speech and, not being able to correspond to these social yearnings, feels limited, inferior and excluded of these activities, and it may even abandon school.

Another factor that can contribute for the development of negative behaviors, as shame of speaking, is related to the necessity of several surgical interventions and speech therapy for a long period of time, once it interferes in an adverse way with the routine of life of the ones who have fissures and their family members.

Adolescents can have psychological disorders if when they look at themselves on the mirror they do not create an adequate "myself" and are ashamed of the face they have. The young adults feel higher difficulty for an interpersonal relationship. These patients can present psychological problems as depression, easy irritability, frustration, reduction of self-esteem, isolation and suicide, however depending on the personality of the affected patient and the acceptance of the family, the authors (35) relate that these adolescents may not present psychological disorders.

In general, the revised studies showed a wide association between the occurrence of malformation and the psychosocial adjustment, once the people who have malformation present unfavorable levels of anxiety, depression, social phobia, self-esteem and quality of life compared to the normal individuals, once face appearance has a deep influence in social environments of people, intervening with the social contact, the development of the personality and the educational performance. Consequently, the psychological support becomes necessary throughout the growth and development of children who has it and, also, during the long process of rehabilitation, searching the understanding of the necessities of children and their parents in the process of deeply feeling and living the craniofacial malformation (20,36,37).

The Philosophy of Humanist Praxis

The necessity of the involvement of professionals in a free, responsible and committed way, no matter they deal with health or education, in the relationship between patients who live deeply the craniofacial malformation and their family members is of basic importance for the success of the treatment and of the social adjustment of these patients. The interface of bioethics, in a contribution of theorization of ethical responsibility, can contribute with professionals in this process. In summary, some definitions and reflections become necessary in order to place professionals in the context of alterity, which is the main focus of their performance together with these patients.

Bioethics is defined as systematic study of human behavior in the area of life science and health care, when such behavior is examined based on values and on moral principles, thus becoming a sector of applied ethics. It is an intellectual movement that appeared in the last few decades in the United States and that promotes the philosophical reflection regarding moral, social and legal problems, considered by the development of the contemporary technological civilization (38). It can still be defined as the systematic study of the moral dimensions, including vision, behavior, and moral norms of life sciences and health care, using a variety of ethical methodologies in an interdisciplinary context.

Bioethics surrounds the recognition of human beings as people and their dignity must be inalienable and

imprescriptible, once 'being' is to recognize themselves in 'alterity', where the others are me (39). Therefore, the bioethics guides the attitude of professionals in this context of conflicts, covering philosophical ideas, in order to clarify and to recommend the study of the philosophy of the humanist praxis in the individual and social scenery.

According to one of the most important authors on contemporary moral reflection, alterity (of the Latin *alter*= the other) implies in placing the other in the place of the being, and in such a way, the other is no longer an object for the subject (40). The alterity clarifies the fact of that beyond the totality the other is found. The other is the referential landmark to discern if we act well or badly bioethically (41).

In its proposal, instead of the individual acting with the other in the way that he/she would like to be treated (Law of Gold and of categorical imperative), the author considers that it is the discovery of the other that imposes the adequate behavior. It is not me in front of the other, but the other continuously in front of me. The author develops a reflection on the relation between the *I* with the *OTHER*, where being to the other means the ethical responsibility for it, in a disinterested social relation with the other. In this communication we are besides the other, not facing it. To become related with another one does not mean thematize it, to take it as knowledge object or to communicate knowledge to it. The understanding of the other is thus a hermeneutics, where the other happens in the concrete of the totality, is present in a cultural conjuncture and from it receives its light, as a text of its context (40).

Alterity can be seen as basic criterion in the ethical responsibility where the understood person as relation, opening and communicability, represents the base of the alterity. Therefore, the person is the foundation of all practical bioethics. Alterity, which throughout the history of the philosophy, received different meanings as to be another one, to be of the other, recognition of the others. However, in the recent history of the ethics, alterity was guarded in the person notion, without extracting all the consequences to ethical act (41).

Alterity is an instrument of reflection of bioethics. It makes the ethical requirements of the person to be seen as protagonist and subject, restitutes to the person its moral abilities, sensitizing the recognition of the ethical problems in the scope of health and of life in a reciprocal way; the other is also me, reciprocal responsibility.

The other shows another one in its face; expression of the being through words. The language becomes only the space of meeting between the I with the other; the language becomes the place of meeting with the other. The other that is expressed in the face transmits, in some way, its proper plastic essence as one to be that it opened the window where its figure was already drawn. The face speaks. The manifestation of the face is the first speech.

The expression that the face introduces in the world crosses the form that delimits it, the face speaks and invites thus to a relation in parallel with a power that is exerted. The new dimension confides in the sensible appearance of the face. The ethical essence of the relation - 'I' and 'the other' - we are evidenced by the linking with the face, source of all the direction (42). It is in this direction of face, as the author describes, which reveals all relationship of the patient with the professionals, where the alterity must then be revealed as ethical principle. The face in the aesthetic and psychological direction exerts an immeasurable influence in this process, in such a way that individuals with malformation present anxiety, depression, social phobia, low self-esteem when compared to normal individuals, intervening, consequently, in the social contact and even in the development of the personality (40).

The author deals with the responsibility for the other, clarifying that when the face of the other emerges in my world, since the other looks at me, I am responsible for them, and then proximity is established, the human will to make some thing for the other is previous to the dialogue. The *I* before the other is infinitely responsible. The other provokes this ethical movement of responsibility in the conscience (40). It is in the face-the-face relation, between the I and the other that proximity establishes, whose primordial direction is the responsibility of the I for the other, without reciprocity requirement, once if such requirement existed, it would not be an uninterested relation anymore.

The other that is expressed then is an individual with craniofacial anomaly that suffers from personal dissatisfaction, with their self-esteem harmed by the labial fissure. The social and psychological impacts could be brightened up with a more solidary and critical vision of their reality, where the professional feels responsible for this being that is another one, beyond *I*.

The responsibility can still be seen as appropriate tool for analyses of moral customs in public health. The applied ethics attribute responsibility to the individuals based on the idea that each human act has been carried through by a moral agent, responsible for their decisions and consequences (43). From this interface, the psychosocial adjustment of these patients can happen in worthier and more ethical way before itself and professionals, reflecting the humanization of relations and the praxis of care in all society.

The complexity of the intellectual representations of the being in the scope of human sciences, increased by the clarifying-comprehensive vision of clinical psychology and the technical data obtained, makes the biological, philosophical and symbolic dimensions of human life in all their mediation. That is, the bioethics means an interdisciplinary interlacement inside intellectual perspectives of man within biomedical humanities in a deep social conscience involved with philosophical, sanitary, psychological, legal, economic and political aspects of their existence in the world, leading to a moral reflexiveness in the context of sciences of the life (44).

The contribution of the psychosomatic medicine and the entrance of psychology in the context of health were of extreme importance in recent years to rescue the human being for beyond their physicist-biological dimension and pointing out it in a bigger context of sense and meaning, in their psychic, social and spiritual dimensions (45).

In humanistic psychology the essence of the concept of the other in the care relation is observed. Taking care of a person is to help it with their growth and self-accomplishment; it is a process, a relation that we call therapeutical relation. Taking care, therefore, involves a deep respect for the alterity of the other, to help the other to take care of themselves, through an established alliance between the involved ones in the relation. In this direction, the moral aspect is a basic and inevitable element in the relations (46).

Any human action which has some consequence on people and their environment must imply the recognition of values and an evaluation of how these could be affected. The first of these values is the person, with the peculiarities that are inherent to their nature, also their material, psychic and spiritual necessities (47).

The responsibility and the ethical commitment of the health professionals of health involved in this process are of great relevance, since the alterity that is inserted in the relationship with these patients, in a determinative and positive way, minimizes the suffering, the exclusion and the constraints that can be caused by the absence of ethical attitudes of these professionals.

Final Considerations

The studies revised on the impact of the craniofacial abnormality in the life of the people suffering from it, point a wide association between the occurrence of this malformation, their aesthetic and functional damages and the psychosocial adjustment, demonstrated through the detention of favorable levels of anxiety, depression, social phobia, self-esteem and quality of life of the patients.

The face appearance has a deep influence in social environments of people, intervening with the social contact, the development of the personality and the educational performance. In this way, the deformity can be considered in their bigger context of feeling and meaning, in their psychic, social and spiritual dimensions.

Such conditions suggest a bigger attention to patients having fissure, specially children and adolescents, considering the factors that intervene with their global development and their insertion in the social environment. For so, the psychological support becomes necessary throughout the growth and development of the patients and, also, during the long process of rehabilitation, searching the understanding of their necessities, of the familiar parents and in the process to feel and to live deeply the craniofacial malformation.

The psychosocial adjustment of these patients can happen in worthier and more ethical way before themselves and the professionals, reflecting the humanization of relations and the care praxis in all society.

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