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The social impact on individuals with communication disorders associated with cleft lip and palate with and without hearing loss

As repercussões sociais em indivíduos com distúrbios da comunicação associados às fissuras labiopalatinas com e sem perda auditiva

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ABSTRACT

Purpose: To identify the social impact on individuals with communication disorders associated with cleft lip and palate with and without hearing loss. **Methods:** Participation by children and adolescents from 7 years to 15 years and 11 months old, of both genders, with cleft lip and palate or isolated cleft palate, with and without associated hearing loss. The survey consisted of 52 participants, divided into two groups: one consisting of 36 children and adolescents with cleft lip and palate without hearing loss and the other, 16 subjects with cleft lip and palate with associated hearing loss. **Results:** It was found that the socio-economic, family, educational and social effects are common to both groups. **Conclusion:** Children and adolescents with hearing loss associated with cleft lip and palate are not "disadvantaged" when referring to economic, family, school and social repercussions in relation to those who do not have hearing disorders. Both groups experience the worsening of living with the aesthetic and functional impairment caused by the anomaly and living in a society entirely concerned with the image and judging differences.

Keywords: Cleft palate; Hearing loss; Communication; Interpersonal relations; Social work

RESUMO

Objetivo: Identificar as repercussões sociais em indivíduos com distúrbios da comunicação associados às fissuras labiopalatinas com e sem perda auditiva. **Métodos:** Participaram crianças e adolescentes de 7 anos a 15 anos e 11 meses de idade, de ambos os gêneros, com fissuras de lábio e palato ou de palato isolado, com e sem perda auditiva associada. A pesquisa foi composta por 52 participantes, divididos em dois grupos: um constituído por 36 crianças e adolescentes com fissuras labiopalatinas e sem perda auditiva e outro, por 16 sujeitos com fissuras labiopalatinas e com perda auditiva associada. **Resultados:** Constatou-se que as repercussões socioeconômicas, familiares, educacionais e sociais são comuns aos grupos. **Conclusão:** As crianças e adolescentes com perda auditiva associada à fissura labiopalatina não estão em "desvantagem" no que se refere às repercussões econômicas, familiares, escolares e sociais, em relação às que não têm o distúrbio de audição. Ambos os grupos vivenciam o acirramento de conviver com o comprometimento estético e funcional causado pela anomalia e de viver em uma sociedade totalmente preocupada com a imagem e julgadora das diferenças.

Descritores: Fissura palatina; Perda auditiva; Comunicação; Relações interpessoais; Serviço social

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Study conducted at the Hospital for Rehabilitation of Craniofacial Anomalies, Universidade de São Paulo – USP – Bauru (SP), Brazil.

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INTRODUCTION

In the rehabilitation process of individuals with communication disorders associated with cleft lip and palate, the interdisciplinary team comprised of professionals in the areas of medicine, nursing, dentistry, speech therapy, nutrition, psychology, social work, physiotherapy, occupational therapy, and education exchange of information and knowledge. This is critical to the care of patients and their families, since one area directly affects the other, with regard to aesthetic, functional, psychological, and social rehabilitation.

Regarding the social impacts of a cleft lip and palate, these have already been addressed by the national literature. However, the possibility has not been explored that different social repercussions exist between people with and without hearing loss associated with the anomaly(1-4).

The social impact upon individuals with cleft lip and palate and/or hearing loss includes aspects related to the time of diagnosis and concerning the socio-economic, familial, scholastic, and social inclusion contexts, not to mention the expectations regarding treatment and resources to support the rehabilitation process.

A social worker, as a member of the interdisciplinary team for the healthcare and rehabilitation of cleft lip, palate, and the associated communication disorders, is the professional who is responsible for knowing the reality of the social repercussions for the patient and his family and, to this end, is an instrument for socio-economic study.

This instrument consists of five indicators: the number of family members, the occupation of these members, education, family income, and housing conditions. It extends to subjective issues involving expectations of diagnosis and treatment, family dynamics, school, profession, society, prejudices, rehabilitation support, community resources, and complementary services for rehabilitation in the city of origin(5,6).

Based upon the professional practice of social work in the hospital of reference for this study, the following question arose: is there a difference in social repercussions between individuals with a cleft lip and palate with hearing loss and those without?

The hypothesis was that children and adolescents with hearing loss associated with cleft lip and palate would present greater difficulties in aurioral communication and, consequently, in social relationships compared to those who do not have the associated hearing disorder.

This study aimed to identify the social impact upon individuals with communication disorders associated with cleft lip and palate with and without hearing loss.

The research is justified by the possibility of subsidizing the intervention of the rehabilitation team, given the demand for services coming from this group.

METHODS

The research was conducted at the Rehabilitation Hospital of Craniofacial Anomalies (HRAC), *Universidade de São Paulo* (USP) and approved by the Research Ethics Committee of the HRAC/USP under ruling No. 193.552. The parents and/or guardians signed an informed consent form.

The typology was transversal descriptive, with the intention of describing the prevalence of certain population characteristics, through a primary source, during a defined period of time(7).

Children and adolescents from 7 years to 15 years and 11 months old of both genders with clefts involving the palate (simultaneous cleft lip and palate or isolated cleft palate) with and without associated hearing loss and living in Bauru (SP) were selected. The characteristics of the participants are presented in Table 1.

The age range chosen for the research is justified due to its characterizing a school phase that is considered to be a period of new and diversified contacts beyond the already existing familial contacts.

Cracks involving the palate (simultaneous cleft lip and palate or isolated cleft palate) were selected because of the impairment of functional aspects (stemming from the fissure itself or from the velopharyngeal dysfunction), which result in communication disorders related to speech, language and hearing(8-17).

Table 1. Characteristics of the participants, according to gender and age

Categories	G1		G2		Total (G1 + G2)	
	n	%	n	%	n	%
Gender						
Feminine	14	39	12	75	26	50
Masculine	22	61	4	25	26	50
Total	36	100	16	100	52	100
Age group						
7 to 11 years and 11 months	13	36	7	44	20	38
12 to 15 years and 11 months	23	64	9	56	32	62
Total	36	100	16	100	52	100

With these types of cleft lips, palates, origins, and ages, regardless of hearing loss, 56 patients were identified, and, through analysis of the audiometric testing in the medical records of the participants, it was found that 17 had conductive hearing loss (considered for this study, unilateral or bilateral hearing loss, with a hearing threshold above 20 dB) and made use of Individual Sound Amplification Devices (ISAD).

Regarding the degree of hearing loss, the following parameters were used: light = loss with thresholds between 20 and 30 dB; moderate = loss with thresholds between 31 and 60 dB; severe = loss with thresholds between 61 and 90 dB; and deep = loss greater than 90 dB(10).

The exclusion criteria were as follows: patients admitted to the Unit of Specialized Care (USC) at the hospital; patients who had moved to another municipality; and those who terminated treatment in the hospital. Considering these criteria, four patients were excluded from this study, reducing the total to 52 participants who were then divided into two groups: Group 1 (G1), comprising 36 individuals with clefts involving the palate and without hearing loss, and Group 2 (G2), comprising 16 individuals with clefts involving the palate and associated hearing loss.

The data were collected through an interview based upon the Instrument of the Socio-economic Study for Social Work(5), which considers the socio-economic and cultural profile of the patients, as well as the family, school, and social relationships that reveal themselves in a supporting context, along with noting the use of additional community resources that are complementary to the rehabilitation process.

Due to the age range of the participants, the interview was conducted in the presence of their parents or guardians, lasting 30 to 60 minutes, according to the schedule of the patients in the hospital.

The data were divided into four thematic categories, according to the research objectives:

Category 1. Socio-economic configuration: socio-economic stratification and configuration of the strata regarding the economic situation, number of members, education, housing, and employment;

Category 2. Socio-familial aspects of the patients: family type, family relationship, health problems or disability in the family, and religion;

Category 3. Social aspects of the patients: school integration, scholastic relationship, social relationship, occurrence of discrimination/prejudice, site of the occurrence of discrimination/prejudice, support of the rehabilitation process, and source of the support for the rehabilitation process.

Category 4. Treatment and additional resources for the rehabilitation of the patients: the use of additional resources for rehabilitation, the existence of support resources for rehabilitation, the form of locomotion to the hospital, and expectations about treatment.

The data analysis was descriptive, considering the prevalence in each group separately (G1) and (G2) and in total (G1+G2).

RESULTS

Category 1. Socio-economic configuration

This characterization occurred based upon the different indicators in the socio-economic stratification of the research participants: lower bottom, upper bottom, lower medium, and medium.

Category 2. Socio-familial aspects of the patients

With respect to social-familial aspects, considering the total sample, it was found that the prevailing family types were nuclear (56%), single parent (21%), extended (13%), reconstituted (6%), and others (4 %). This study considered "others" to include families consisting of grandparents who were the legal guardians of their grandchildren.

This category of analysis aimed to identify the level of the family relationships of the groups according to the perspective of the respondents. The data revealed a predominance of the family relationships were considered good for all of the groups together (G1+G2=77%) and for them separately (G1=66% and G2=86%), compared to the other relationship levels in all of the groups (G1+G2): very good (6%), regular (11%), and bad (6%). It is important to highlight that for G1, in 20% of the cases, the family relationship was considered regular, unlike the case of G2, which did not obtain any data at this relationship level.

The socio-familial context was analyzed to become familiar with the presence of health problems or other deficiencies in the family, considering the impact of living with a person affected by a chronic disease who requires special care. However, for most respondents, in the sum of the groups (G1+G2), there were no such cases in the family (60%), with the same results being reached when analyzed separately (G1=66% and G2=53%). Among families who had a member with an illness or disability (G1=34%; G2=47%; G1+G2=40%), the main situations cited were cleft lip and palate, cerebral palsy, physical disability, cardiovascular disease, and depression.

With regard to the religion of the research participants, the data showed a predominance of the Evangelical religion in G1 (54%), the Catholic religion in G2 (47%), and both in both groups combined (G1+G2=44%), followed by other religions with both groups combined (G1+G2): 4% were Spiritualists, 2% were Jehovah's Witnesses, and 6% declared themselves to have no religion.

Category 3. Social aspects of the patients

As for the social aspects of the patients, 100% were involved in school, and the scholastic relationship level was considered to be good for 56% in G1, 44% in G2, and 52% in both groups combined (G1+G2). The average level was 33% in

G1, 31% in G2, and 33% in G1 + G2. There were also reports of a poor level in the scholastic relationship for 11% in G1, 25% in G2, and 15% in G1 + G2. In this respect, an analysis was conducted on their school interaction level with peers and teachers, scholastic performance and achievement, acceptance by the school, contentment with the scholastic environment, and social inclusion.

The children's and adolescents' level of social relationships were analyzed based upon third-party contact – community, neighbors, church groups, friends, and others – beyond the family and school. A prevalence of social relationships that were considered good by the groups was determined (G1=80%; G2=75%; and G1+G2=79%) with a negation of any form of social isolation, conflict, or exclusion. The regular level reached the rate of 17% in G1, 13% in G2, and 15% in G1+G2. In these cases, the reports were of situations of little social life on the part of the children and adolescents.

Regarding the occurrence of situations of discrimination or prejudice, there was no report of such cases for 81% in G1, 62% in G2, and 75% in G1+G2. However, some participants reported having suffered harassment: 19% in G1, 38% in G2, and 25% in G1+G2. In these cases, the location of the occurrence of the discrimination or prejudicial situation was queried, and most stated "just in school" (G1=71%; G2=50%; and G1+G2=62%). Others have indicated the school and family as environments of violence: 29% in G1, 50% in G2, and 38% in G1+G2.

As to the form of harassment, the participants said it was verbal, through nicknames like "teeth," "porky," "wrinkle nose," "crooked mouth," "duck," "goose mouth," "Faustão" and "lispy." In addition, there were reports of isolation, exclusion, and devaluing of the intellectual/cognitive capacity of the child or adolescent.

The survey participants were also asked about the existence of a form of support in their lives, and most gave affirmative answers (G1=92%; G2=100%; and G1+G2=94%). The sources of support that were mentioned were school and family by 44% in G1, 56% in G2, and 48% in G1+G2; some referred only to school at rates of 44% in G1, 38% in G2, and 42% in G1+G2, and others considered only their family to be the source of support at rates of 12% in G1, 6% in G2, and 10% in G1+G2.

In relation to the family, the participants included support from family members other than their parents or guardians in the care related to rehabilitation.

In the scholastic context, a highlight was the support from teachers and students in the development of communication, performance, and interaction, as well as in providing encouragement about rehabilitation.

Category 4. Treatment and additional resources for the rehabilitation of the patients

With regard to the use of additional resources for rehabilitation, 100% of the participants, in all groups, confirmed receiving other health services in their city of origin. Among the services mentioned were consultations and routine exams in the Family Health Strategies, Basic Health Units, medical specialty clinics, and the ER, these being for integral care.

While all of the survey participants were residents of the same county where their hospital was located, as part of the interview they were asked about their form of transportation to the institution. Most reported that they relied on their own resources (97% in G1, 100% in G2, and 98% in G1+G2). In these cases, the rationale was residing near the hospital or having one's own car, at the option of the patient and family. On the other hand, only one participant from G1 (3%) claimed to use the benefit of the Municipal/Disabilities Pass: Law No. 3540/93*.

As to expectations regarding hospital treatment, most participants were only in favor of complementary treatment (72% in G1, 88% in G2, and 77% in G1+G2). There were reports of auxiliary speech, dental, neurological, ENT, and psychological assistance. Some participants claimed to have expectations of complementary and surgical treatment, 25% in G1, 12% in G2, and 21% in G1+G2, recognizing the need for follow-up with the specialties mentioned above. They said, however, that they found themselves waiting for surgery, including secondary bone grafting, plastic surgery for nasal correction, ear reconstruction, and protruding-ear correction, among other microsurgeries. The expectation of only surgical treatment stood out in only one case, in G1 (3%). This one participant said he was only waiting for the surgical procedure for the secondary bone graft, foregoing the complementary treatment. In this case, the family received guidance regarding the institutional routines and the importance of complementary accompaniment for successful rehabilitation.

DISCUSSION

In the characterization of the participants, a predominance of males was found in the group without hearing loss and of females in the group with hearing loss, and, in both, the majority were adolescents. These results do not differ from findings in the literature, because simultaneous cleft lips and palates are more common in males, while isolated cleft palates, which tend to cause hearing impairment more often, are more prevalent in females(9,11). Although this was not the case with the study participants, it is noteworthy that isolated hearing loss not due to cleft lip and palate is predominant in males(8).

Adolescence is an important age group and its members deserve attention from the family, school, and rehabilitation team, since it is marked by curiosities, biological and emotional changes, and a greater appreciation of one's body image(2,4),

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*Law No. 3540 of March 11, 1993, granting free public transport for people with disabilities.

factors that affect self-esteem and psychosocial development.

The age group from 7 years old to 11 years and 11 months old is also considered relevant. Although it appeared less frequently in this study, its members require family support with regard to school integration, since this is a phase that usually involves insecurity and difficulties with social interaction(2).

The socio-economic profile (Category 1 of Table 2) showed that in both groups, the majority were members of the bottom social strata, mostly the upper bottom. This reality reflects the norm for patients enrolled in the reference hospital of the study, in which the majority (74%) belong to the bottom social strata, and 50% are members of the upper bottom social stratum, specifically(1,6). This scenario also coincides with that of Brazilian society, in which 63% of the population belongs to the lower social classes(18).

The lower socio-economic classes are characterized not only by insufficient income, but also by the combination of economic, familial, educational, social, and cultural aspects that add to the lack of opportunities to access basic needs and social rights(4,18).

For a better understanding of the characteristics of the different social strata of the research subjects, in Category 1 (Table 3), the indicators that compose the socio-economic stratification (economic situation, number of members, education, housing situation/condition, and the occupation of the responsible adult) show, in an approximate manner, the reality experienced by the patients and families in the socio-economic and cultural contexts. There is also emphasis on the social-familial, scholastic, and social aspects, as well as those related to support resources for rehabilitation and expectations with regard to treatment, as already evidenced by the literature(5,6) and demonstrated in the other categories.

Category 2, the social-familial aspects, in general demonstrated the predominance of the nuclear family typology with a good relationship among its members. They belonged to the Christian Evangelical religions in the group without hearing loss and Catholic religion in the group with hearing loss. Overall, there were no reports on the occurrence of other health problems or disability in the family. It appears that the traditional family (nuclear) model went through a process of transformation in society, affecting the daily lives of Brazilian families in different types or family models(1,19).

Through these data, it was possible to verify that, although the nuclear typology has predominated among the study participants, it was observed that families have created particular forms of organization and are no longer limited to that consisting of father, mother, and children of the same parents, but to a distinct form resulting from modern times.

These new family types have developed over time as a result of social, political, economic, and emotional changes,

Table 2. Characteristics of the participants according to socio-economic stratification

Socio-economic stratification	G1		G2		(G1 + G2)	
	n	%	n	%	n	%
Lower bottom (LB)	7	19	4	25	11	21
Upper bottom (UB)	24	67	8	50	32	62
Subtotal (lower levels)	31	86	12	75	43	83
Lower middle (LM)	5	14	3	19	8	15
Middle (M)	-	-	1	6	1	2
Subtotal (middle levels)	5	14	4	25	9	17
Total	36	100	16	100	52	100

Table 3. Prevalence of social indicators in the socio-economic setting

Indicators (Tiers)	Average income (Minimum salary)			Members (Number of individuals)			Education (Responsible)			Housing			Occupation (Responsible)		
	Category	nº	%	Category	nº	%	Category	nº	%	Category	nº	%	Category	nº	%
LB	0 to ½ MW	2	18.5	3 to 4	6	54	E2 I	4	36.5	IU	2	18.5	TA PGS	4	36.5
	½ to 2 MW	7	63	5 to 6	2	18.5	E1 I	2	18.5	IR	3	27	NW	4	36.5
UB	2 to 4 MW	18	56	3 to 4	21	66	CS	19	60	IR	5	16	TA PGS	24	75
	4 to 9 MW	9	28	5 to 6	7	22	E2 I	4	13	PG	12	38	SE NE	6	19
LW	9 to 15 MW	1	12.5	3 to 4	6	75	CU	4	50	PO	2	25	SW AST	4	50
	4 to 9 MW	7	87.5	5 to 6	2	25	CS	2	25	PG	3	37.5	TA PGS	3	37.5
M	15 to 30 MW	1	100	5 to 6	1	100	E2 C	1	100	PG	1	100	B	1	100

Note: MW = minimum wage; LB = lower bottom; UB = upper bottom; LM = lower middle; M = middle; E2 I = elementary 2 incomplete; E1 I = elementary 1 incomplete; SS = completed secondary school; CU = completed university; E2 C = elementary 2 complete; IU = issued and unsatisfactory; IR = issued and regular; PR = proper and regular; PG = proper and good; PO = proper and optimal; SW PGS = salaried workers production, goods, and services; NW = not working; SE NE = self-employed, no employee; SW AST = salaried workers administrative, scientific, and technical; B = businesspeople as well as the advancement of technology, thus bringing new configurations to society(19).

Given this reality, it is necessary to analyze the family through new parameters in the daily professional practice, since the changes in its organization and form of constitution present different demands upon health and rehabilitation professionals(5).

Regardless of their typology, it is known that the family is a reference field for individuals, that it is essential to establish relationships of affection, and that it contributes to human and social development(2,3).

In the case of the study population, even when presenting an anomaly, there is a context in the family environment that is common to that of other families in society. Thus, for the analysis of family relationships, the study participants reflected on their family dynamics, the interaction between the members, conviviality, affection, attitudes of the responsible members toward the patient, the presence or absence of addictions to psychoactive substances, and games, among other things, in the family environment, as well as the existence or absence of family conflicts.

Part of the familial social reality that plays a key role in understanding the behaviors, habits, and attitudes of the patients and their families is religion, which is comprised of a belief in the existence of supernatural forces that are considered creators of the universe and expressed by means of their own doctrines and rituals, generally involving ethical principles(19).

Although the data show differences between the religions followed by the groups, they represent the reality of Brazilian life, which shows a prevalence of Christian religions over others(4,5). It is also worth mentioning the advancement of the Evangelical Protestant religion, which has been expanding and conquering new spaces throughout Brazil and the world.

After the family, school is the second most important social environment in the formation of a person's identity, since the psychosocial identity presupposes the social reality to which the individual belongs and reveals his living conditions, family background, customs, religion, and the way he is involved in this reality(2).

Thus, in Category 3, the scholastic reality showed that all of the participants were members of an educational system, and the participants of both groups rated the relationship with their classmates and teachers as ranging from normal to good; in some cases, it was reported as bad but without any significant differences between the groups. There were reports of difficulties with social interaction, school performance, and shame regarding one's own speech, voice, and aesthetics.

Children and adolescents who display an anomaly react with difficulties in the face of adversity and their need for acceptance by their peers differs because of the way they deal with the stresses of life. It is precisely in these phases of affective and emotional ordeal that each individual's personality characteristics surface, including the weaknesses and difficulties involved in social inclusion(1,4).

Thus, the school is a world of personal and existential circumstances that require humanization on the part of the educator in direct involvement with children and adolescents(3). This attitude ends up demanding performance far beyond the pedagogical and methodological positioning of school practice.

As to the social relationships of the research participants with neighbors and the community, results were considered to be good in both groups, and most participants denied having suffered situations of prejudice or social discrimination. For those who experienced harassment, references were to the school and family environments.

The literature reveals prejudice to be prior knowledge which is independent of any interpersonal attention, preventing opportunities for dialogue and contributing to the denial of the alterity of the person who is subjected to the discriminatory act(20).

This situation gives rise to an unequal level, which is so exacerbated that it is as if the other were a kind of collective denial of the social order, and he comes to be seen not as someone who does belongs to the same species, but as a different "thing"(20).

On the other hand, the groups have reported relying on the support of these very same sources, namely families and schools, in the rehabilitation process. This reality reveals the existing contradiction, because while family and school reveal themselves as the focus of the occurrence of prejudices, they are also foundations of support regarding the rehabilitation process.

The situations in which people with cleft lips and palates are subjects must be addressed with the support of the community. Rehabilitation based on community support is a process in which the persons with disabilities, their families, and their communities are the main agents for their social training(2).

Based on the data in Category 4, with regard to resources that are complementary to the rehabilitation process, all of the participants claimed to know and rely on the health services of the public and private network in their municipality for other treatments.

It is noteworthy that, for patients with cleft lips and palates, speech therapy and dental monitoring, which are complementary to rehabilitation, are performed in the hospital. In relation to children and adolescents who have hearing loss, the additional speech therapy is provided by a Speech Therapy Clinic at the *Universidade de São Paulo* (USP), located on the same campus as the hospital.

Patients also rely upon the benefits provided by the Association for the Social Promotion of Cleft Lip (PROFIS)**, a social service organization without government subsidy, the main objective of which is the promotion of the welfare and citizenship of patients and families of the hospital in general,

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**PROFIS is the first association for parents and patients with cleft lips and palates, based in Bauru, Brazil. It was founded in 1975 to provide social assistance to HRAC patients in order to ensure access and care continuity for patients coming from all regions of Brazil.

including the lounge, nursery, lockers and sanitation, patient/caregiver housing, and accommodation for drivers, in addition to offering training courses and specialization in dentistry to students in the area.

For care provided in the hospital, both groups reported relying on their own resources for locomotion. The expectations of patients and families focused on complementary treatment, such as speech-language therapies, dentistry, psychology, and other specialties. These individuals demonstrated having knowledge of the need for accompaniment in their city for improvement in the development of communication, rehabilitation, and the quality of life.

It is worth mentioning that in societies where social inequalities greatly hinder equal access to goods and services, and when family resources are not sufficient to satisfy needs, social support networks have a significant value(20). This applies to the families of the study subjects belonging to the lower classes who, based on the data presented in Category 4, have a social support network consisting of family, friends, neighbors, religious institutions, and community services, the latter being a right which is not always available to patients from other cities/regions.

The expectations regarding treatment were taken into consideration when planning for therapeutic procedures in the rehabilitation process at the hospital. To investigate the perceptions and expectations of the patients is to promote maximum growth and changes in the doctor-patient relationship, valuing the human being and rescuing disability as a starting point for the emancipation of the same(2,20).

Given the above, the demands brought by patients with communication disorders associated with cleft lip and palate present challenges for the rehabilitation team. Their confrontation starts with knowledge close to the familial, cultural, and social reality of that group in order to decipher the expressions of the social questions that surround it, and is extended to intervention, with their participation, in the development of strategies for the prevention and transformation of the scenario of inequality and social exclusion.

CONCLUSION

Children and adolescents with hearing loss associated with cleft lips and palates are not disadvantaged in relation to their economic, familial, scholastic, and social realities in relation to those who do not have hearing disorders. Both groups experience the negative effects of living with the aesthetic and functional impairment caused by the anomaly and of living in a society that is completely engrossed in image and judgment of those who appear different.

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