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Original articles

Socio-economic classification and quality of life of family members of children and teenagers with hearing disability

Classificação socioeconômica e qualidade de vida de familiares de crianças e adolescentes com deficiência auditiva

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ABSTRACT

Purpose: to investigate the relation between socioeconomic classification and perceived quality of life of people who have a relative with hearing loss.

Methods: it is a quantitative and descriptive exploratory research developed with relatives of hearing impaired children and teenagers, users of Sistema Único de Saúde. The researchers applied Brazil Economic Classification Criteria, and Quality of Life WHOQOL-BREF surveys. All data were tabulated and statistically analyzed using the descriptive statistics and graphical analysis of the variables.

Results: twenty relatives of hearing impaired patients took part in the research. When the responses for the Brazil Economic Classification Criteria survey were descriptively analyzed, it was found that most of the participants belong to the B2 and C1 classes, corresponding to 35% each. The smaller part of the sample is in the C2 class, corresponding to 10%, and 20% are in the B1 class. It was perceived a better quality of life in the social field (69.1) and a worse quality of life in the environmental field (55.1).

Conclusion: the study showed that there was a relation between families' socioeconomic classification and perceived quality of life, because the lower the socioeconomic classification, the worse was the perceived quality of life in all areas except for the environmental field.

Keywords: Quality of Life; Hearing Loss; Unified Health System; Questionnaires; Income

RESUMO

Objetivo: investigar a relação da classificação socioeconômica e a percepção da qualidade de vida de pessoas que possuem um familiar com deficiência auditiva.

Métodos: trata-se de uma pesquisa exploratória de caráter quantitativo e descritivo desenvolvida com familiares de crianças e adolescentes com deficiência auditiva, inseridos no Sistema Único de Saúde. Foram utilizados na pesquisa o Critério de Classificação Econômica Brasil e o questionário de Qualidade de Vida WHOQOL-BREF. Todos os dados foram tabulados e submetidos à análise estatística. Foi realizada estatística descritiva e análise gráfica das variáveis.

Resultados: participaram da pesquisa 20 familiares de pacientes com deficiência auditiva. Ao analisar de forma descritiva as respostas do Critério de Classificação Econômica Brasil, percebeu-se que a maioria dos participantes pertence às classes B2 e C1, correspondentes a 35% cada. A menor parte da amostra encontra-se na classe C2, correspondente a 10%, e 20% está inscrita na classe B1. Percebeu-se melhor qualidade de vida no domínio social (69,1) e pior qualidade de vida no domínio ambiental (55,1).

Conclusão: o estudo mostrou que houve relação entre a classificação socioeconômica e a percepção da qualidade de vida dos familiares, pois quanto menor a classificação socioeconômica, pior foi a percepção de qualidade de vida em todos os domínios, exceto para o domínio ambiental.

Descritores: Qualidade de Vida; Perda Auditiva; Sistema Único de Saúde; Questionários; Renda

INTRODUCTION

Family is a social force that has influence on the development of the human behavior and personality. It is interdependent, in other words, the relationships established among family members influence each other and every change in this direction may have influence on each member individually or on the system as a whole[1].

Family relationships enable individuals to create concepts and achieve the integrity of the thought. It is through the exchanges performed between members of a family that the child constructs his maturity. Thus, for the child, the family environment may or may not, depending on its quality, construct the appropriate mental and language development[2].

Therefore, family plays a key role in the development and promotion of health of the child through the care provided in daily life[3], because it is the first social nucleus that the child is placed, constructing and strengthening his emotional bonds. Family would also offer physical, psychological, emotional and financial support to their children, as well as the support on the construction of the character at the moment of the choices that will bring consequences for both. Providing quality of life for children is the responsibility of the parents, when they give love, care and offer a favorable space of inclusion to their children, initiating a positive process of human development[2]. It is known that, in order to provide quality of life for children, in a first moment, their parents or guardians should have it, since one depends on the other.

Quality of life was defined by the World Health Organization (WHO) as "the perception of the individual regarding his position in life, in the context of culture and value systems in which he lives, and in relation to his goals, standards and concerns"[4]. The measure of quality of life has become a great ally when it comes to therapeutic intervention, services and intervention practices in health; besides being an important indicator due to the physical and psychosocial impact that disabilities or illnesses may cause in the lives of patients and their family members[5].

The economic and financial issue is often a factor that has a major influence on the families of patients who require targeted attention, since it is reported that the poorer the family, the more "disabled" the child is in terms of resources and alternatives to promote their development. This is due to social distance and location of the family in relation to the specialized services[3].

It is known that the process of healthcare has undergone numerous inflections, which requires professional health knowledge to enable group work, following interdisciplinarity. It also requires the appropriation of the concepts expressed in the guidelines of the Brazilian Unified Health System – UHS (In Portuguese: *Sistema* Único *de Saúde* - *SUS*) - Equity, Comprehensiveness and Universality[6].

Literature[7] highlights five aspects in which the low-income may influence the quality of life of families with children with disabilities, namely: (1) health related to hunger; consequences of malnutrition, malnutrition in pregnancy - unborn babies with low birth weight, premature babies and consequences of this situation and limited access to medical care; (2) delay in cognitive development by the lack of opportunity to attend good schools that stimulate knowledge and limited recreational opportunities for all family members; (3) physical environment - packed house and no infrastructure and unsafe neighborhoods; (4) emotional well-being - increased stress and adaptation to the child disability, difficult to provide benefits to children when there is no financial resources, and (5) low self-esteem of parents and children and family interaction - parents who disagree about what to say the their child, or they are unable to maintain an opinion.

Dialogical and social relations with family members are essential for the development of children. Family interactions facilitate the insertion of these children in the familiar communicative universe, which may increasingly develop their language skills[8]. In relation to hearing loss, the family relationship is also important to enable the linguistic, social and emotional development of children. However, it is known that the detection of hearing loss can be viewed as a shock for the family, making family relationships in conflict and disorder sources, intensifying when dealing with the difficulties faced by the family for possible communication problems with the child[9]. The family dynamic changed after the diagnosis of hearing loss requires the participation of the entire family in the rehabilitation process[10]. Thus, it is important to value the dyad between family and the person with hearing disability, their interrelations with others, as well as the economic, environmental and cultural context in which they are inserted[11].

Identify facilitators and/or harmful factors and intervene on all aspects related to welfare in everyday situation should be the commitment of therapist associated with the family. In this way, the therapist

may promote quality of life, strengthen self-esteem, the feeling of security, belonging and dignity. This is a role played by a speech therapist, a professional who is specialized and qualified to provide a facilitator environment for the development of human communication[12].

Then, this study aimed to investigate the relationship between the socioeconomic classification and the perception of quality of life that the family members who have a member with a hearing impairment.

METHODS

This is an exploratory study with quantitative and descriptive approach, which is part of a broader research project called "Speech Therapy Intervention with Family Members of Deaf Children", approved by the Ethics Committee of *Universidade Federal de Santa Maria (UFSM)* under the CAAE report No 26743114.9.0000.5346.

The sample was constituted by family members responsible for children and teenagers with hearing disability that were inserted in the Brazilian Unified Health System – UHS (In Portuguese: *Sistema* Único *de Saúde - SUS*) and subjects who were attended by the Speech and Hearing Service - SHS (In Portuguese: *Serviço de Atendimento Fonoaudiológico - SAF*), in the sector of Hearing Habilitation and Rehabilitation (HHR), an interagency body to the Clinical School of the Speech, Hearing and Language Sciences Major at the University where the research was carried out. The service is classified as medium complexity according to Ordinance No. 2.073/GM, established in 2004, which is about hearing health.

For the sample of this study, the following inclusion criteria were established: for family members – they should sign the Informed Consent Form (ICF); they should be normal hearing subjects; they should present some degree of kinship and they should be responsible for the children or teenagers with hearing disability. For children and teenagers – they should be under therapeutic care in the sector of Hearing Habilitation and Rehabilitation of SHS. Regarding the Exclusion Criteria: For family members – if they did not follow the children and teenagers regularly to speech therapy at SHS; if they had some self-declared hearing loss or other apparent impairment, such as cognitive deficits, syndromes, among others. For children and teenagers – if they were not regularly present at the speech care of HHR at SHS or if they were out of the Service.

Taking into account the criteria listed above, the sample consisted of all the families of children and teenagers who were treated at the sector of Hearing Habilitation and Rehabilitation at the time of the survey, comprising 20 subjects of both genders, aged from 22 to 70 years and level of education ranging from incomplete elementary school to incomplete higher education. The participants were invited by phone to make part of the sample, being scheduled a time when they already took the children and teenagers to HHR to answer the study instruments. Clarifications were given to family members about all the research procedures and the ethical principles were followed, by informing that no interest in participation or withdrawal of the research at any time would not interfere in the therapeutic process performed at SHS.

For data collection two questionnaires were used, the Brazilian Criteria of Economic Classification - BCEC (In Portuguese: *Critério de Classificação Econômica Brasil - CCEB*) and the WHOQOL-BREF. Both instruments were answered by family members in an airy and well-lit room of the SHS, while they waited for their children to be treated in speech therapy. For those family members with reserved educational level the researchers helped to fill the questionnaire.

The Brazilian Criteria of Economic Classification - BCEC (In Portuguese: *Critério de Classificação Econômica Brasil - CCEB*) was used to analyze the socio-economic issues, because it is a pricing classification system to the Brazilian public, not classifying the population in terms of social classes, but by dividing the market exclusively on economic classes, based on the ownership of assets and not based on family income. For all possessions there is a score and each class is defined by the sum of this score. This research used the 2012 BCEC version, which takes into account the data from the socioeconomic survey carried out by the Brazilian Association of Research Companies – BARC (In Portuguese: *Associação Brasileira de Empresa de Pesquisa - ABEP*) in 2010. Classes are defined by the BCEC, according to the family income, such as: A1 (R$ 12.926), A2 (R$ 8.418), B1 (R$ 4.418), B2 (R$ 2.565), C1 (R$ 1.541), C2 (R$ 1.024) D (R$ 714) e E (R$ 477)[13]. The interviewed subject had to answer on property ownership, family income and the level of education of the household head.

In order to identify the perception of the quality of life, the family members answered to the WHOQOL-BREF. It consists of 26 questions, where the questions 1 and 2 concern the overall quality of life and the remaining

24 comprise four areas classified as: Physical (corresponding to pain, discomfort, energy, fatigue, sleep, rest, activities of everyday life, dependence on medication or treatment, mobility and ability to work); Psychological (corresponding to positive feelings, thinking, learning, memory, concentration, self-esteem, body image, appearance, negative feelings, spirituality, religion and personal beliefs); Social Relations (corresponding to personal relationships, social support and sexual activity) and Environment (corresponding to aspects of physical security, protection, home environment, financial resources, social and health care/availability and quality opportunities to acquire new information and skills, participation in recreation opportunities and leisure and physical environment[14-16]. The interpretation of the responses followed the Likert scale, which correspond to values from 1 to 5 - the higher the score obtained the better quality of life the subject has.

All data were tabulated in Microsoft Excel 2010 software and they were submitted to statistical analysis. We used descriptive statistical analysis and graphical analysis for the correlation between the domains of quality of life and socioeconomic class. Thus, the positive correlation indicates that as a variable increases its value, the other correlated variable also increases

proportionally, and the negative correlation implies that the variables are inversely proportional, that is, as one increases the other decreases, or vice versa. For better visualization of the findings boxplots were used in the presentation of the results of graphical analysis.

RESULTS

For this research, 20 family members of patients with hearing disability agreed to participate. The descriptive analysis of the answers of the Brazilian Criteria of Economic Classification - BCEC (In Portuguese: *Critério de Classificação Econômica Brasil - CCEB*) showed that most of the participants belong to B2 and C1 classes, which correspond to 35% each. A reduced part of the sample is in the C2 class, which correspond to 10% and 20% is inserted in the B1 class.

Table 1 shows the results obtained from the application of the WHOQOL-BREF questionnaire. They were represented separately by the Physical Domain, Psychological, Social, Environmental and General variables. It was verified that the best perceptual quality of life has been attributed to the social domain, while the worst perception was related to the environmental domain.

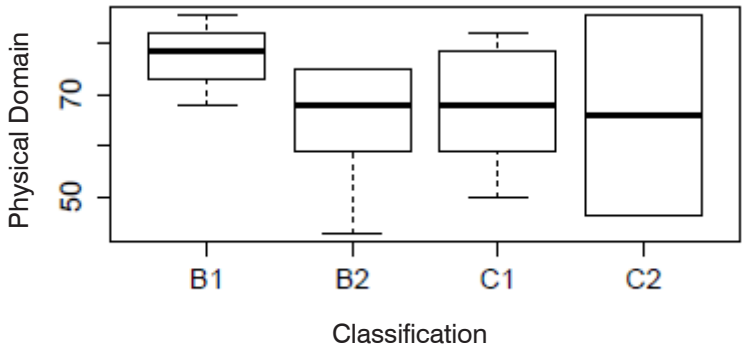
Table 1. Descriptive statistics of the domains scores of WHOQOL-BREF

Domains	Mean	Standard Deviation	Minimum	Maximum
	%	%	%	%
Physical	68,6	± 13,0	42,9	85,7
Psychological	64,8	± 12,6	45,8	87,5
Social	69,2	± 18,9	25,0	100,0
Environmental	55,2	± 15,3	28,1	78,1
General	64,4	± 10,1	37,1	82,9

Figure 1 shows an association between Physical Domain and Socio-economic Classification. A positive correlation was verified between the physical domain and thesocio-economic classification, which means that the worst perception of quality in the physical domain was related to the lowest socio-economic classification of the participants.

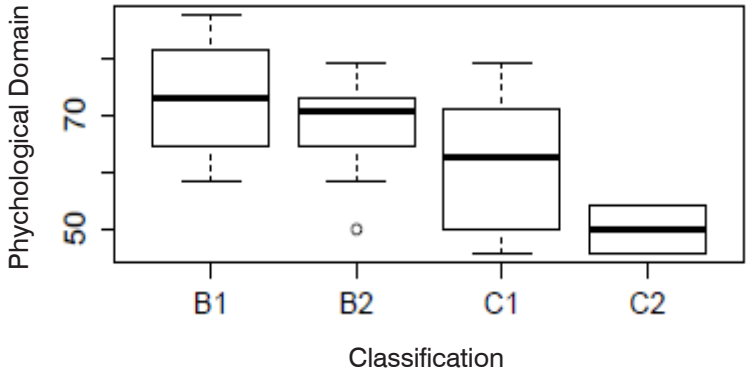
In Figure 2, it is possible to verify a positive relationship between the psychological domain and the Socio-Economic Classification, because as the psychological area decreases, the average economic status also decreases in all classifications.

Figure 3 presents a similar relationship between Social and Socio-Economic Classification. It seems that as the social domain decreases the average economic status also decreases.



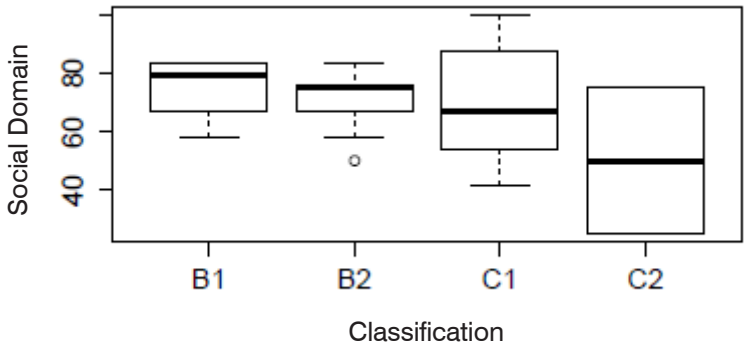
Caption: Socio-economic stratum related to the average household income: B1 (R $ 4,418), B2 (R $ 2,565), C1 (R $ 1,541), C2 (R $ 1,024).

Figure 1. Bloxpot of the correlation between the Physical Domain and the Socio-economic Profile



Caption: Socio-economic stratum related to the average household income: B1 (R $ 4,418), B2 (R $ 2,565), C1 (R $ 1,541), C2 (R $ 1,024).

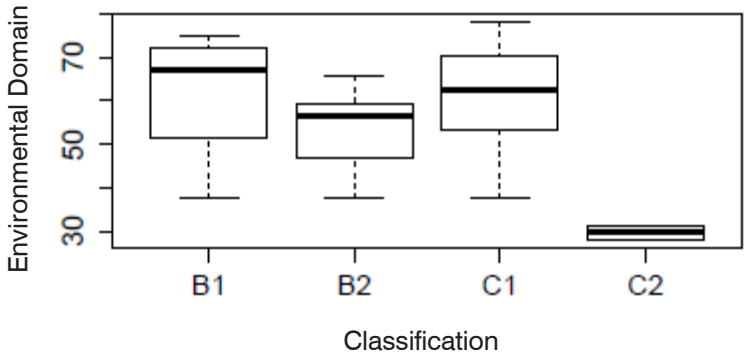
Figure 2. Bloxpot of the correlation between the Phychological Domain and the Socio-economic Profile



Caption: Socio-economic stratum related to the average household income: B1 (R $ 4,418), B2 (R $ 2,565), C1 (R $ 1,541), C2 (R $ 1,024).

Figure 3. Bloxpot of the correlation between the Social Domain and the Socio-economic Profile

By analyzing Figure 4, there was no relationship between the Environmental Domain and Socio-Economic Classification, since there is variation in the perception of quality of life when related to the socio-economic classification; except in the C2 class that it is possible to verify an evident decline in the perception of quality of life in the domain. Participants who meet the characteristics of C2 class, the one with the lowest Socio-Economic Classification, presented the lowest perception of quality in the environmental domain.



Caption: Socio-economic stratum related to the average household income: B1 (R $ 4,418), B2 (R $ 2,565), C1 (R $ 1,541), C2 (R $ 1,024).

Figure 4. Bloxpot of the correlation between the Environmental Domain and the Socio-economic Profile

DISCUSSION

This study investigated the relationship of socio-economic classification and perception of quality of life of family members who have a member with hearing disability. The results showed that there was a correlation between socioeconomic classification and perception of quality of life of the participants.

The dominant classes in the study were the B2 and C1. The household income analyzed ranged from 1,541 reais to 2,565 reais, being considered relatively low for families who have a member with a hearing disability, based on the number of members in the income division. This finding might be explained as the care activity of a disabled person often leads caregivers and family members to reduce the workday or leave the paid work, especially when the situation of children and teenagers requires full dedication for a determining factor[17]. This compromises family income even more, as there is one family member less to contribute financially to the family income.

It is understood that unfavorable economic conditions may be related to a limitation in access to food and social care, which may restrict the access to health and education, compromising significantly the quality of life[18]. When related to health, socio-economic inequalities are directly associated with the premise "the worse the social position is, the worse the health is consequently"[15], with people of lower socioeconomic classes, greater biomedical, environmental, behavioral and psychosocial risks that are directly associated with to social conditions and the disease[19].

The socio-economic classification of the participants in this study is in agreement with other studies in the literature. Among them, there is a study that ranked the socioeconomic profile of mothers assisted in a Newborn Hearing Screening Program - NHS[20]. The income of these mothers was relatively low, and most of them, 72.8% lived on less than one minimum wage and 67.5% had a family income between one and three minimum wages. The study did not use the Brazilian Criteria of Economic Classification - BCEC (In Portuguese: *Critério de Classificação Econômica Brasil - CCEB*), being not possible to characterize the participants in classes, however, it showed that such a financial situation made these more mothers exposed to social risks such precarious conditions of housing, food and hygiene[20].

Another study described some demographic and socioeconomic aspects of mothers of newborns and infants who were assisted in a Newborn Hearing Screening Service (NHS). Regarding the socio-economic aspects, this study found that 38.6% had no personal income and 60.6% had family income between one to three minimum wages. The study found that the population studied was in conditions that are considered unfavorable to the health and the overall development of newborns and infants, as both the demographic profile and the socioeconomic classified mothers to a category considered under risk[21].

Although this study focused on the analysis of the socio-economic aspects of family members of children and tenagers with hearing disability, it is possible to establish a relationship with the aforementioned studies on the NHS because it is clear that, from birth, children with hearing disability experience major difficulties in their family context. This may compromise the entire development, as well as weaken the relationship and interaction between family and person with hearing disabilty.

With regard to the domains of quality of life, the social domain presented, in this study, better perception of quality of life and the environmental domain had the lowest perception. A better perception in the social domain may be related to the fact that, when contemplating questions regarding personal relationships, sexual activity and emotional support, family members, most of whom are in characteristically healthy young age, claim to have an emotional life, stable sexual and social even considering their responsibilities to their family member with hearing disability. This result, however, differ from those ones presented in a study that analyzed the quality of life of caregivers of children and teenagers with speech and language disorders, compared with caregivers of children without disorders[22]. For the group of caregivers of children and teenagers with disorders, the best domains were the physical and the psychological ones, respectively. On the other hand, the worst perception were the social relations and environmental domains. When comparing with both caregivers, the authors noticed that the group needed no care for subjects with language disorders and speech presented poorer quality of life, with a significant difference in physical, psychological and social relations domains[22]. This finding shows the importance of giving more attention to aspects of health and quality of life of caregivers. In other words, the patient should not be the only one to be focused in speech therapy care.

The best perception of quality of life in the social domain, found in this study, is also justified by the increase of social relationships that families build in search of understanding hearing disability and, in a way, these relationships are strengthened, since it is known that social support is considered as the "process involving interactions with others and that facilitates the confrontation of stress and other aversive stimuli"[23]. Parents and family members, when they feel welcomed by the service system where they live or by other people who make part of them, they end up being facilitators of therapeutic interventions, since such relationships potentialize the desire of participating and promoting their therapeutic development[24,25].

The social domain also presented a higher percentage in the perception of quality of life in a study of 66 families members of people with special care in the south of the capital of São Paulo[24]. The domain involving social relations was also justified by the questions referred the interpersonal relations and the support that they receive from friends and family members.

Regarding the environmental domain, it is known that this domain includes issues related to physical security, environmental situation at home, financial, health and social care (availability and quality, opportunities for acquiring new information, participation in recreation opportunities and leisure and transportation). Economic and social factors may be determinants of health, due to their direct influence on the environment, since economic development and urbanization may present some increase on the living standard of the family member. The greatest decline in the environmental domain, also observed in this study, was also reported in a study of 96 caregivers of adults and children with hearing disability in Vale do Itajaí, Santa Catarina, whose worsening was observed in the quality of life regarding psychological and environmental domains. The authors reported a worsening in the environmental domain due to the chaotic situation of the Brazilian economy and the cost of living that is going higher and higher, associated with unemployment, lack of access to basic services and violence that result in the recognition of a low quality of life in the environmental aspect[26]. Another study of caregivers of patients inserted in a speech therapy service of *Universidade Federal de Minas Gerais*[27] showed that low monthly income resulted in low scores in the environmental domain.

Furthermore, the disbelief with their own safety and with the safety of the family itself may result in negative consequences to the life and health of the family. They can experience situations of stress, distress and fatigue, which might influence the perception of quality of life as well as possible interference in the perception of psychological integrity[28]. The low level of family income and the lower score regarding the environmental domain, when compared to other aspects of quality of life, denote scarcity of financial resources, not enabling the payment of a professional caregiver for the child or teenager, which would allow the mother to dedicate herself to work or do some leisure activities, relaxation and intellectual enrichment, as it was observed no significant limitation on the ability to enjoy life and achieve satisfaction[29].

A graphical analysis of Figures 1, 2, 3 and 4 allows to point out a positive correlation between physical, psychological and social domains and socioeconomic classification. It is known that the quality of life depends

on a variety of factors. Among these, there are the interpersonal and environmental interactions,

In a study of caregivers of children diagnosed with cerebral palsy, in outpatient care, there was a significant relationship between the answers to the psychological domain when related the answers of economy class[30]. Confirming also with results found in a study carried out in Iran with mothers of children with neurological disorders. They found that the lower the household income, the more likely diagnosis of depression and anxiety of mothers who are caregivers[31].

Authors state that the quality of life includes elements related to physical, emotional and relationship aspects, linked to well-being[31,32]. The analysis of the quality of life by a subjective bias takes into account the individual perception of the subjects face their own expectations, by considering the cultural diversity of society and differences in social classes identified in the same society. As a result, it evaluates how people feel or what they think of their lives as well as how they realize the value of the material components recognized as social basis of the quality of life[33,34]. This correlation becomes important as a way to reflect on the quality of life of family members of people with hearing disabilty, since it is not just the hearing loss of the children that interferes with daily life of the family, but also other factors that may sometimes be potentiated after the difficulty confronted with the diagnosis[35].

In the present study the socio-economic differentiation of the analyzed sample suffered direct influence of the factors related to WHOQOL, both the physical, with respect to pain, energy and fatigue, sleep and rest; and psychological, related to positive feelings, thinking, learning, memory, concentration, self-esteem, body image and appearance and negative feelings; as the social, concerning personal relationships, social support and sexual activity[36]. In this regard, the lower the socioeconomic classification of the family is, the worse was the perception of quality of life in these domains, bringing into focus the economic limitation that might bring impact on many ways, which might also compromise the quality of life of the family members who have a member with hearing loss in their living.

It is evident, therefore, that in families of children with developmental disorders and in which there are difficulties of interaction and language, the quality of life of their caregivers may be affected. With the understanding that this aspect might influence the lives of children with speech and language difficulties, actions and health care aimed at this group are needed, as established by the Brazilian Unified Health System over the full care of the subject, including, in this sense, their caregivers[37].

CONCLUSION

The study showed that there was a relationship between socio-economic classification and perception of quality of life of the family members, as it was verified that the lower the socioeconomic classification is, the worse the perception of quality of life was in all domains except for the environmental sphere.

The research allowed the reflexition on the socio-economic issues of the families of patients with hearing disabilities, which allows to broaden the perspective of people regarding the relationship between low economic income and the worsening of quality of life of these subjects. Such reflections can contribute to the creation or implementation of public policies in the hearing health care, to better serve this population, maximizing the well-being through contextualized interventions to the socio-economic reality that is presented.

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